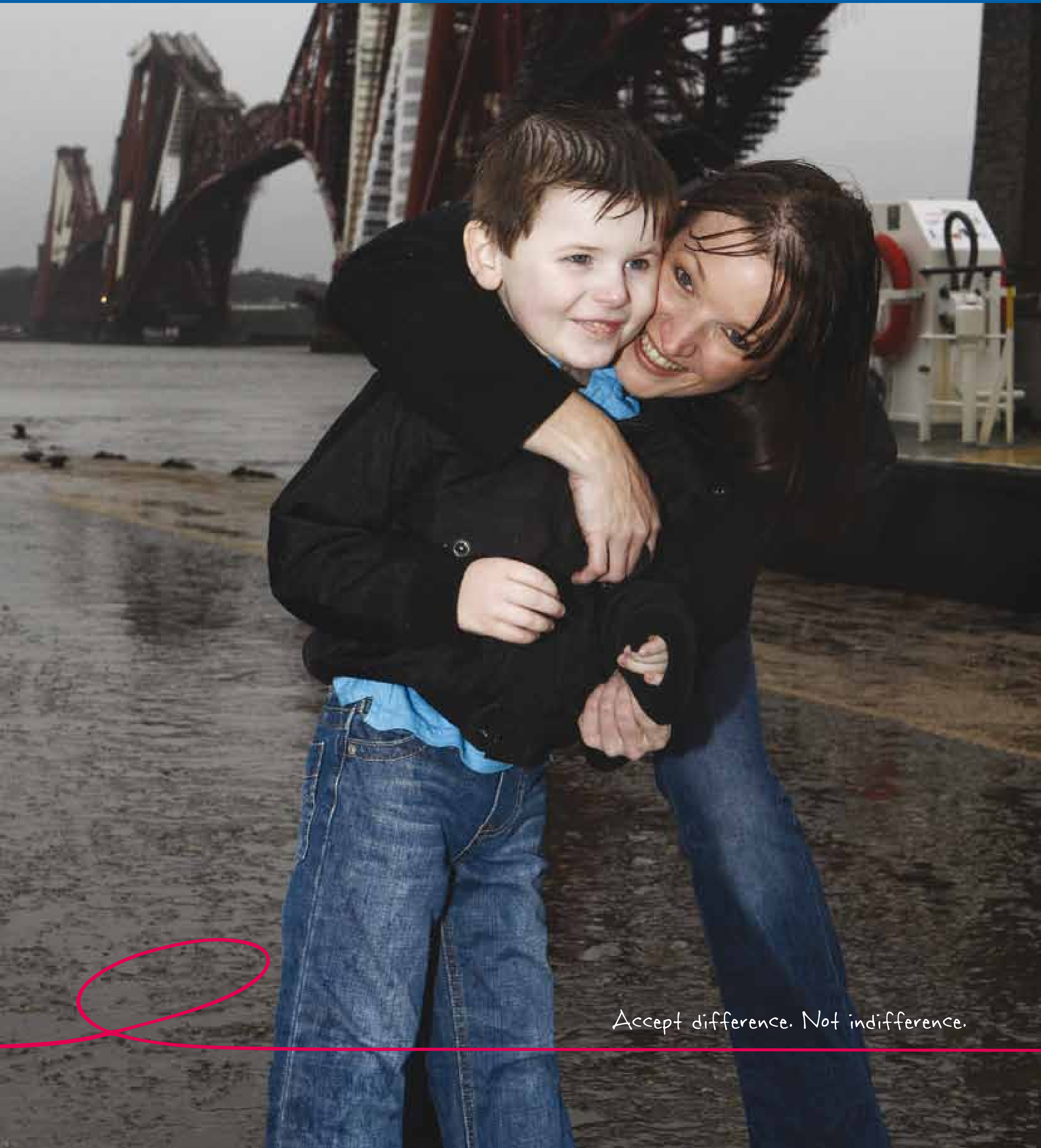
We Exist

A Bill for Autism, A Bill for Scotland

The National
Autistic Society
Scotland


Accept difference. Not indifference.

Acknowledgements

Thanks to all those people who filled in the survey that was used to inform this report, including adults with autism and their parents and carers, and representatives from local authorities, NHS boards, fellow autism organisations throughout the whole of Scotland, and teachers and schools.

This report has been written by Beth Reid, Robert MacBean and Raemond Charles of The National Autistic Society.

Thanks also to Ryan McRobert for helping to compile and publish the survey online and to the people who helped to produce this report, including James Christie, James Cusack, Malcolm Mill, Carol Evans, Amanda Batten and Matthew Downie.

The photographs used in this report are of people with autism or Asperger syndrome. The photographs on the cover, pages 6 and 24 were taken by Mark Ferguson. The photographs on pages 21 and 23 were taken by Steve Hickey. The photographs on pages 4 and 11 were taken by Marie Paterson. The photographs on pages 15 and 18 were taken by Ewen Weatherspoon.

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A case for change

The National Autistic Society Scotland has brought together over 100 organisations and key people from across Scotland who believe that change is needed at a legislative and strategic level to make sure that children and adults with autism[1] in Scotland get the support and services they need. As more people are identified with autism, and as people with autism grow older and their families are no longer able to care for them, a strategic approach to delivering services becomes even more imperative.

According to our survey conducted across the whole of Scotland, **95% of those who responded believe it is necessary to create a legal duty on local councils and health boards to improve services for people with autism**. This includes 93% of the professionals working with people with autism who replied. A similar proportion also **believe there needs to be a national Scottish autism strategy**, which would support the implementation of legislation.[2]

In addition, local agencies want more support. In 2008, when asked about what support would help them meet the needs of adults with autism, **95% of local authorities said that they felt that the Government could do more to assist them**. Every Community Health Partnership (CHP) surveyed also agreed with this.[3]

A wake-up call is required to better meet the needs of people with autism. For too long they have fallen through the gaps between services. The need for a strategic, long-term approach to developing services for people with autism has now been recognised in other parts of the United Kingdom.

The passing of the Autism Act 2009 in Westminster is a major achievement. The Autism Act will give the new Department of Health Adult Autism Strategy in England real legal force.

In Wales and Northern Ireland the assemblies have both developed autism spectrum disorder (ASD) strategic action plans with actions planned on three year cycles. These should lead to real improvements in care and support, but without any national ASD strategy people with autism in Scotland are unlikely to see similar change.

Many people with autism have higher levels of support needs because they have not been given appropriate support. Work by the National Audit Office has identified the hidden costs of not meeting the needs of people with autism. This works out at around £2.3 billion for Scotland each year.[4]

Around 50,000 people of all ages and backgrounds are asking for their needs to be recognised. It is time now for change in Scotland.

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[1] 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.

[2] The survey was available online, with paper copies available on request to NAS Scotland; 424 people completed the survey online, and 19 completed it in hard copy. The survey ran from 8 October to 4 November 2009. Respondents included people on the autism spectrum, parents and professionals, and the majority responded on behalf of an adult or a child with autism. Of those who had a diagnosis 38% had a diagnosis of autism, while 58% had a diagnosis of Asperger syndrome or high-functioning autism. Results are published here for the first time and referenced as Scottish autism services survey, 2009.

[3] Daly, J. (2008). *I Exist: the message from adults with autism in Scotland.* London: The National Autistic Society

[4] National Audit Office (2009). *Supporting people with autism through adulthood.* London: The Stationery Office. For adults with autism, 59% of these costs are accounted for by services, 36% by lost employment, and the remainder by family expenses.

Autism in Scotland

Autism spectrum disorder (ASD) is a lifelong developmental disability which affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them. Asperger syndrome is a form of autism. All people with autism have difficulties within three areas of everyday life: communication, social interaction and social imagination.

Some people with autism are able to live relatively independent lives but others may have accompanying learning disabilities and need specialist support throughout their lives. People with autism may also experience over- or under-sensitivity to sounds, touch, tastes, smells, light or colours.

There are an estimated 50,000 people in Scotland with autism – that is 1 in 100.[5] Along with their parents, families and carers, autism touches the lives of over 200,000 people in Scotland every day.

The reality for people with autism in Scotland: an overview

Autism is often referred to as an 'invisible disability'. 80% of people who have heard about autism are unaware how common it is and 49% do not know that it is a life-long condition.[6] The invisible nature of autism is reflected in local service provision. All over Scotland children or adults with autism have difficulty accessing proper care and support.

To help us get a better picture of service provision across Scotland, we surveyed people with autism and their families; 443 people completed the survey and we have used the findings to inform this report.[7]

Survey: key findings

- 95% told us more services were needed locally for people with an autism spectrum disorder.
- 48% rated their overall experience of services to help them with their autism as poor or very poor.
- Almost a quarter (23%) have had to go outside their own local authority to get the right services.
- A third have had to go to a tribunal to get the right support.
- 42% rate care professionals' understanding of autism as poor or very poor.
- Key gaps people identified in support are social support, advocacy, self-directed support, employment support or training, and short breaks/respite.

We discovered that people with autism in Scotland are not getting the help they need and many experience misunderstanding, social isolation, unemployment, worsening mental health, financial hardship and reduced life chances.

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[5] Green, H. et al (2005). *Mental health of children and young people in Great Britain.* London: Office of National Statistics; Baird, G. et al (2006). Prevalence of disorders of the autism spectrum in a population cohort of children in south Thames: the Special Needs and Autism Project (SNAP). *The Lancet,* **368** (9531), pp210-5; Brugha, T. et al (2009). *Autism spectrum disorders in adults living in households throughout England: report from the adult psychiatric morbidity survey 2007.* Leeds: NHS Information Centre

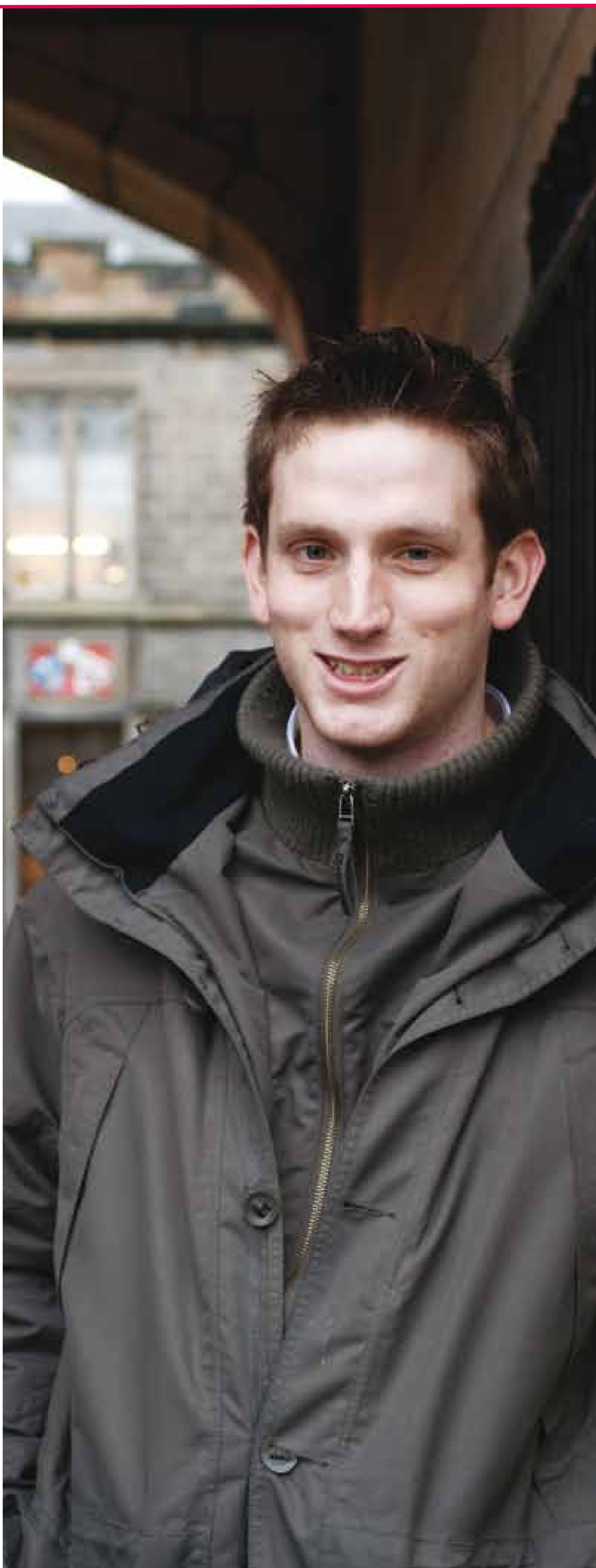
[6] The National Autistic Society (2007). *Think differently – act positively: public perceptions of autism in Scotland.* London: The National Autistic Society

[7] Scottish autism services survey, 2009

- Children with autism are three times more likely to have mental health problems than other children.[8]
- Only 13% of adults with autism are in full-time employment.[9]
- Over half of adults with autism have experienced bullying or harassment since they were 18.[10]

The next part of this report looks in detail at some specific aspects of providing support for people with autism to see how it is working in practice.

> "I remember how my parents fought desperately to ensure that my local education authority gave me an education to meet my needs... Every time a person with autism misses services that other people with autism have received due to a postcode lottery, Scotland potentially loses another individual who could have contributed to Scottish society." James Cusack



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[8] Green et al (2005). *Mental health of children and young people in Great Britain*

[9] Daly (2008). *I Exist*

[10] Daly (2008). *I Exist*

Supporting people with autism

Diagnosis

"Our son has been excluded from services because he did not have a diagnosis until aged 14 ([and he's] still not received a written diagnosis) but [we are] told by [the] psychiatrist that there is no doubt [that he has autism]!" Tom, Midlothian.

Getting a diagnosis is often a critical milestone for people with autism. For some it may be a relief, explaining years of feeling 'different' and providing a gateway to identifying support; for others it feels more of a shock. Scottish Government guidance is clear that a diagnosis should not be a requirement for getting support,[11] but too often not having a diagnosis creates a barrier. 60% of local authorities agree that having a diagnosis means someone is more likely to get support.[12]

Getting a diagnosis, however, can be a daunting process and take a long time as there are few people with the expertise to diagnose autism.[13] A third of people have waited more than two years for a diagnosis of autism, and some people told us they have been waiting over ten years to get a diagnosis. 25% of people have had to go outside their local authority to get a diagnosis.[14]

Both parents of children and adults find it difficult to get a diagnosis, but evidence suggests it is particularly hard for adults. The Autism Services Directory provided by NAS Scotland identifies just 12 services in Scotland providing adult diagnosis.

One man said he'd been told he *"can't have dual diagnoses so will be waiting forever"* for an autism diagnosis.[15]

Follow-up support after diagnosis is critically important so that people can understand the information they have been given, work out what it means for them and their families and begin to get the support that they and their families need and are entitled to. Yet 57% of people were unhappy with the support they received after diagnosis, and 20% received no support at all.[16]

"I was not told of my son's diagnosis and only found one had been made when a passing reference was made to it being in his notes, but I have never had his diagnosis explained or offered support. I have had to do all my own research and seek my own support, inform school, etc." Debbie, Fraserburgh.

Education: the right start in life?

Children with autism need support at school to help them gain the most from their education. Their disability means that they find the social aspects of school particularly challenging and are likely to need help to communicate with and understand the people around them.

Getting the right support for pupils with autism at school can be extremely challenging. Over half (52%) of those who have attended school in the last five years say that they did not get enough support.[17] In one survey 43% of parents said it took over a

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[11] Scottish Government (2008). *Commissioning services for people on the autism spectrum: policy and practice guidance.* Edinburgh: Scottish Government

[12] Daly (2008). *I Exist*

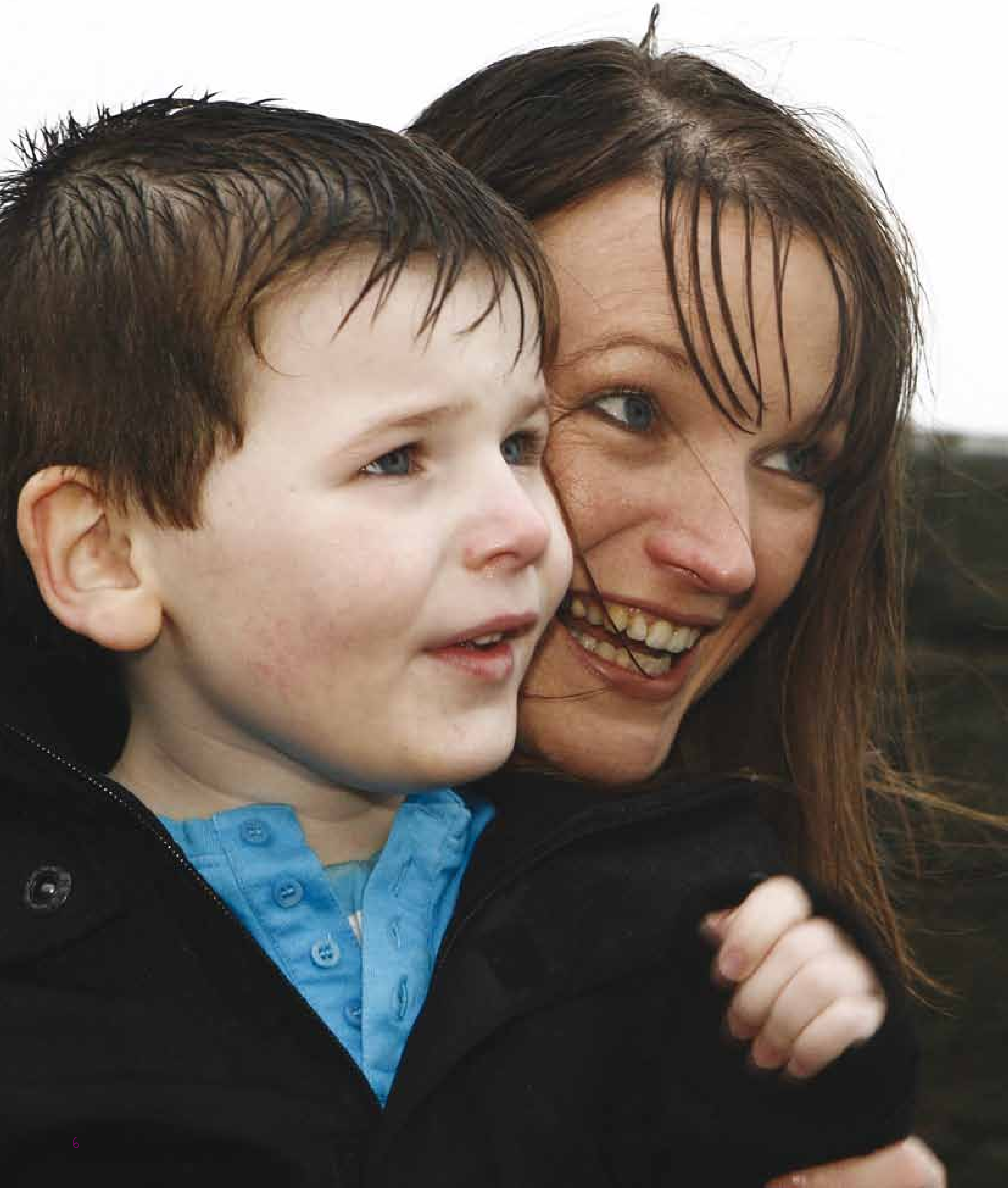
[13] Daly (2008). *I Exist*

[14] Scottish autism services survey, 2009

[15] Scottish autism services survey, 2009

[16] Scottish autism services survey, 2009

[17] Scottish autism services survey, 2009



Gillian Naysmith: a case study

Gillian Naysmith is mother to Jaymi, age 8, and Sam, age 4. Sam has a diagnosis of autism and global developmental delay. They live in Dunfermline.

"Transition from stage to stage in Sam's life has been difficult so far. On leaving the child development centre nobody told me that some of the multi-disciplinary-team services would stop and that I would have to physically go to Sam's paediatrician or GP or health visitor to have him re-referred in order for therapy to continue. We then had to be put back on the waiting list which took around ten months – a lot of wasted time when they say that early intervention is the best thing possible to help our children."

"I am now in a position where I am having to decide what to do with regard to Sam's schooling – everyone in Sam's care must have an opinion... Those who have decided to share their opinion have all given me completely different advice, not all of it based on his cognitive ability... So confusing. As a mum, I am looking for advice from the people who should know what the best options are for my son."

"Some of the services are reasonably easy to access but waiting lists are so incredibly long to see anyone even for an assessment. I also find that when we have to have review meetings for Sam, we can never get everyone involved in Sam's care there, no matter how far in advance it is planned. Therefore a full picture of his needs and care is never really achieved at these meetings. So our needs are never fully met in that respect."

"Transitional periods from one step to the next should be much smoother and people affected by autism should effectively get all the help they require and living life with this difficult enough condition should be made more easy to cope with because help will be available and disruption could effectively be minimal."

year to get any support.[18] Even where children get some support, frequently it is not enough to meet all of their needs. In particular, many children do not receive speech and language therapy.[19]

In the UK, 27% of children with autism have been excluded from school.[20] Of those who had experienced exclusion in our survey, 23% were excluded informally, for example missing out on school trips.[21] In our experience, exclusion frequently results from children not being given appropriate support.

As a result, education tribunals are disproportionately likely to concern children with autism. Just under half of all appeals dealt with by the Additional Support Needs Tribunal concern children or young people with an ASD[22] even though these children make up only 12% of those with identified additional support needs.[23]

Furthermore, many parents feel they have little choice over the kind of school their child attends, with 46% believing that their child is not in the kind of school that would best support them. Over half of parents feel that a lack of appropriate placements limits choice, especially at secondary level. 17% of children have to travel over 11 miles to attend school.[24]

One reason for the lack of support may be a failure to identify children's needs. We have already seen that it can take a long time to get a diagnosis of autism, and 24% of parents say that not having a diagnosis delays support.[25] One in 100 people are on the autism spectrum. This equates to around 6,800 children in Scottish schools. Figures from the Scottish Government identify 4,900 pupils with additional support needs in Scottish schools as being on the autism spectrum.[26] This suggests that the needs of over a quarter of pupils with autism in schools (nearly 2,000 children) are not being recognised.

> "As a mum, I am looking for advice from the people who should know what the best options are for my son." Gillian Naysmith

A delay in putting support in place has a detrimental effect on children's well-being. Two-thirds of parents say it has had a negative effect on children's behaviour and self-esteem, and over a third say it has affected their child's mental health.[27]

In 2006 Her Majesty's Inspectorate of Education (HMIE) found in a survey of education authorities that *"several authorities were unable to quantify the numbers of pupils with ASD or the number who had been formally diagnosed"*.[28] Of the six education authorities HMIE inspected, policy development and planning were judged to be effective in only two.

The survey found that education authorities and schools needed to track pupils' progress and attainment more effectively to ensure that children with autism are progressing well. It also found that *"The majority of teachers and non-teaching staff in*

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[18] Batten, A. and Daly, J. (2006). *make school make sense: autism and education in Scotland – the reality for families today.* London: The National Autistic Society

[19] Batten, A. and Daly, J. (2006). *make school make sense*

[20] Green et al (2005). *Mental health of children and young people in Great Britain*

[21] Scottish autism services survey, 2009

[22] Additional Support Needs Tribunals for Scotland (2009). *Annual report of the president of Additional Support Needs for Scotland, 2008-9.* Glasgow: Additional Support Needs Tribunal for Scotland

[23] Scottish Government (2009). *Pupils in Scotland 2008.* www.scotland.gov.uk/Resource/Doc/266539/0079763.pdf

[24] Batten, A. and Daly, J. (2006). *make school make sense*

[25] Batten, A. and Daly, J. (2006). *make school make sense*

[26] Scottish Government (2009). *Pupils in Scotland 2008*

[27] Batten, A. and Daly, J. (2006). *make school make sense*

[28] Her Majesty's Inspectorate of Education (2006). *Education for pupils with autism spectrum disorders.* Livingston: HMIE

mainstream schools did not have a sufficiently good working knowledge of ASD", particularly those in secondary schools.

HMIE made the following recommendations:

- education authorities should ensure that they hold complete information on the numbers of pupils with an autism spectrum disorder to ensure that they develop a coherent strategy for meeting a range of needs
- the Scottish Executive, education authorities and other agencies should work together to coordinate support for pupils with an autism spectrum disorder, where there is a need. Education authorities should work with health boards to develop clear procedures for early identification of children with an autism spectrum disorder
- education authorities and agencies should work together to develop plans, share strategies and commit resources to ensure that pupils with an autism spectrum disorder receive appropriate support in line with their needs.

> "Transition from stage to stage in Sam's life has been difficult so far."
>
> Gillian Naysmith

To support better policy making in schools the Scottish Government launched the Autism Toolbox to advise schools on how to meet the needs of pupils with autism. We strongly welcome this and hope that it will make a significant difference to the levels of support that children with autism receive at school. However, we agree with HMIE that strategic planning is essential to make sure that provision for children with autism is adequate at local level, and we believe that it should be a requirement on every local authority to ensure it happens.

Moving to adulthood

The transition to adulthood is a crucial time for young people. The planning of a transition, for example from school to college or work, can have long-lasting consequences for someone with autism. Done well, it can set people up effectively for the future, but poorly planned transitions contribute to later exclusion from local services and life opportunities. This can and often does have a devastating effect on the individual.

People with autism need to undertake a lot of preparation and planning to help them cope with even minor changes, especially as they may find it difficult to imagine different alternatives. Where a change as significant as leaving school is concerned, the need for effective preparation and planning is even greater. Moving to a new environment, often with less structure, and reduced or different forms of support, is very difficult. Building new relationships can be a frightening prospect for some people with autism.

All too often young people with autism do not receive the support that they need as they become adults. Frequently, information on children and young people is not passed on to local authority adult services teams.[29] Many young people with autism aren't provided with a transition plan and many of the key authorities, such as health, social work or housing, aren't involved as they should be.

For young people with autism to make the transition to adulthood successfully, agencies need to co-operate, working together with the young person and their family, to share information, and identify and plan how to provide appropriate support at an early stage. The Scottish Intercollegiate Guidelines Network (SIGN) recommends that particularly

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[29] Daly (2008). *I Exist*

James Cusack: a case study

James Cusack, 24, lives in Aberdeen and is currently completing his doctorate, studying human action detection in autism at the University of Aberdeen. James was diagnosed with Asperger syndrome when he was 13.

"I enjoy a fairly typical and average existence. I play football, go out and drink with friends and I am engaged to my girlfriend of five years who I now live with. Academically, I enjoy a fairly obsessional interest in autism, which doesn't take over my life but probably frustrates my girlfriend a bit. Perhaps my case study can prove that success is possible. You don't need only cases of failure, but cases which show change can help others succeed."

"On a daily basis autism still affects me. I still have a poor sleeping pattern. Every night I have to work hard to try and get to switch off and get to sleep, and every morning I struggle to wake up due to my tiredness. My organisation is problematic. Working out how to sequence actions is difficult whilst for most people this seems to be easy. Linked to this is my one-dimensional and almost obsessional approach to life. I can become fixated on topics and have no awareness of time passing."

"For me this is autism in action. I attended a base at secondary school throughout my adolescence, which is especially designed to support people with autism. It was there where I learnt strategies to ensure that these issues whilst still problematic did not become debilitating. These strategies may seem obvious and perhaps not particularly significant but they are the difference between daily success and daily failure. Consequently, these strategies are the difference between me being unemployed with no social life on incapacity [benefit] and being in the position I am now."

"I remember how my parents fought desperately to ensure that my local education authority gave me an education to meet my needs. Initially, they were told no; when they pushed further the LEA agreed to offer education. This changed my life and the evidence really does show that without this I would have been in residential care on benefits at considerable cost to the tax payer for the rest of my life, instead of in the fortunate position I am today."

"in regard to periods of transition, there should be multiagency life long planning".[30] Trying to find placements or get funding at the last minute means that placements are more likely to break down and may ultimately lead to people needing a higher level of support in the long term.

SIGN states that *"Professionals should be aware that difficulties with transition may arise because the high level of support being provided prior to a transition was unrecognised. Reassessing support needs and planning ahead prior to a transition may allow appropriate new support to be put in place"*.[31] In our survey just 5% of those aged 15–25 told us that they didn't need support to make this transition, yet over half (53%) had not received any support.[32]

Support for living: health and social care

"Autistic adults are misunderstood and their needs are often ignored. We have struggled (and still are) to get any help, advice or support for my husband. The assumption is that he's coped for 53 years, so he must be ok! Well, he's not. He hasn't coped – it's been a long hard struggle!" Anon.

According to the NAS report *I Exist*,[33] just over half of adults with autism are currently receiving some form of service from their local authority or health board, but over half of all adults know they do not have enough support to meet their needs. A higher proportion of people with Asperger syndrome or high-functioning autism feel they do not have enough support to meet their needs.

The majority of people with autism need support to live independently. Half of parents and carers told us that their adult child needs 24-hour support, and another 37% that their adult child needs some level of daily support.

Nevertheless half of the adults with autism tell us they have experienced problems in receiving support. There are a number of reasons for this. Many local adult services are organised into separate mental health and learning disability teams. Although some people with autism have an accompanying learning disability and/or mental health needs, autism itself is a developmental disability, not a learning disability or mental health condition, which means that people with autism may not be able to access these services, or the service may not be able to support their autism-related needs. Learning disability services for example are only provided to those with an IQ below 70. This structure discriminates against adults with autism who do not have a learning disability.

This is a leading cause of inequality for people with an ASD who need support.

- 52% of adults with high-functioning autism or Asperger syndrome say the gap in provision is a significant barrier to accessing support.
- Only 40% of local authorities and no CHPs have a process to manage this gap in provision.[34]

Another reason people struggle to get support is because many people are not receiving assessments of their needs. Around half do not have access to a social worker, and a similar proportion have not had an assessment since they were 18, despite a duty on local authorities to assess any adult believed to be in need of community care services. This rises to

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[30] Scottish Intercollegiate Guidelines Network (2007). *Assessment, diagnosis and clinical interventions for children and young people with autistic spectrum disorders: a national clinical guideline,* p27. Edinburgh: SIGN

[31] Scottish Intercollegiate Guidelines Network (2007). *Assessment, diagnosis and clinical interventions for children and young people with autistic spectrum disorders,* p26

[32] Scottish autism services survey, 2009

[33] Daly (2008). *I Exist*

[34] Daly (2008). *I Exist*

62% among those with high-functioning autism or Asperger syndrome.[35]

Frequently the professionals who carry out assessments do not have training in autism and cannot make an informed decision about the needs of people with autism. 54% of parents and carers of adults with autism believe a lack of professional understanding has been a barrier to receiving services.

Other professionals also lack specific training. GPs are a key gateway to getting support, but only 39% of adults feel that GPs' knowledge of autism is good or very good. Social workers, care managers and psychiatrists have also been singled out for their lack of training.[36] Local authorities admit that there are significant gaps in the training of their frontline staff, but only 45% have an autism training strategy in place to resolve this.

> "With this Autism Bill, Scottish government has an opportunity to help not only people with autism but Scotland to succeed."
>
> James Cusack

In 2008 the NAS report *I Exist* found that local authorities believe that more information would help with long-term planning.[37] Nevertheless, the majority of local authorities and CHPs in Scotland are not accurately recording adults with autism: 60% of local authorities and 92% of CHPs keep no record of the number of adults with autism in their area.

This finding was reinforced in 2009 when local authority data was collected for the first time on the number of adults with autism and a learning disability as part of the Scottish Government's project eSAY.[38] Information is currently missing about many of the people covered, including adults with an autism diagnosis. It also only covers those adults known to learning disability services and there are wide variations between the authorities that have reported. Many local authorities were unable to respond fully, and four local authorities did not provide any information.

The problems caused by not meeting basic needs are severe:

- around 55% of adults with autism find it hard or very hard to make friends, but 80% say that if they had more support they would feel less isolated
- 31% of adults with autism have developed severe mental health problems
- 57% of parents and carers say that a lack of timely support has resulted in their son or daughter having higher support needs
- 70% of those adults who said they received insufficient support believed their general health would improve if they had more support.[39]

It is not just unmet need and reduced life chances that should be concerning the Scottish Government and local authorities. According to the National Audit Office, if local authorities identify and support just 4% of adults with Asperger syndrome, services will become cost-neutral over time. **The more people who are identified and supported, the greater are the savings that can be made.**[40]

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[35] Daly (2008). *I Exist*

[36] Daly (2008). *I Exist. See also* Royal College of Psychiatrists (2006). *Psychiatric services for adolescents and adults with Asperger syndrome and other autistic spectrum disorders.* London: Royal College of Psychiatrists

[37] Daly (2008). *I Exist*

[38] Scottish Consortium for Learning Disability (2009). eSAY project

[39] Daly (2008). *I Exist*

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

Elkie Kammer: a case study

Elkie Kammer, 46, lives in Inverness and works with children with developmental disorders. She has been diagnosed with Asperger syndrome.

“I am very musical and love the harmonies in nature, but many other sounds are causing me a lot of pain and [have become] obstacles in my daily functioning.”

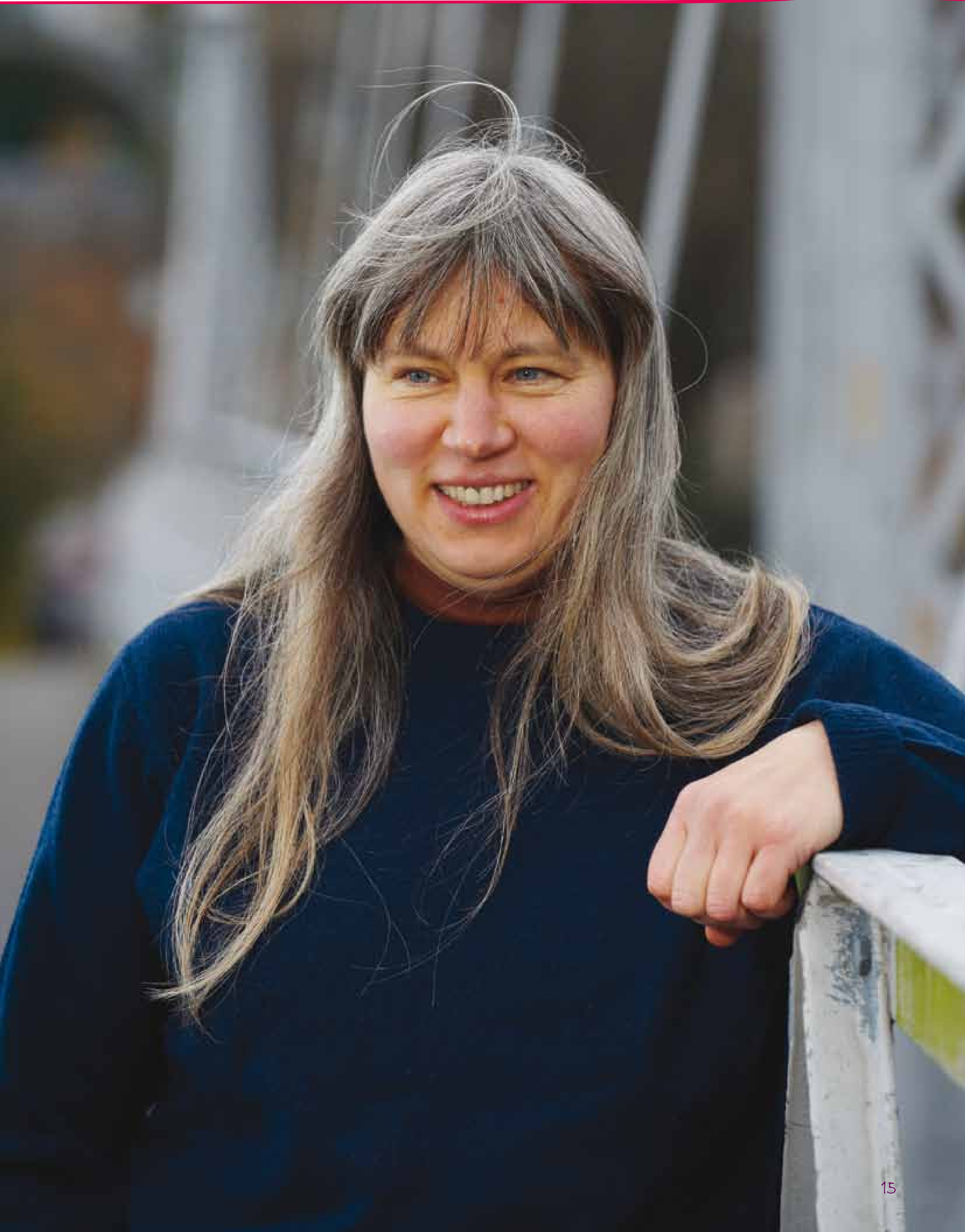
“Accommodation is one area which, until recently, was often a nightmare due to the noise of flatmates, neighbours, road traffic or central heating pumps – sounds that most people easily tolerate or are not even aware of. Self-harm was often the only way I could cope with the auditory pain and frustration.”

“At work, electronic noise, background music or too many people talking at once would cause me so much stress that I had to change jobs very frequently (misunderstandings with colleagues being the other reason for this). Yet it only takes a few adjustments and a positive attitude towards difference, as my present employment shows, to allow me to contribute in a meaningful and healthy way.”

“Going shopping, using public transport, sitting in the doctor's waiting room or crossing the road at pedestrian traffic lights, all have become more and more noisy, making ordinary life difficult for me.”

“If you are blind or deaf, services have a legal duty to respond to your needs. If you are hypersensitive in your vision or hearing, no adjustments are made. This is one of the reasons why we need a Scottish Autism Bill. Another reason concerns diagnostic services for adults.”

“Throughout the centuries, people with ASD have made unique and valuable contributions to society, from new inventions to artistic expression, but our modern society has to be prepared to make adjustments to allow us to fulfil our potential. This is where the Scottish Autism Bill can make a big difference.”



An opportunity to contribute: employment

Although not everyone with autism is able to work, the majority want to,[41] and many people with autism have a wide range of skills to offer the workplace. Employment can give people with autism a sense of self-esteem, reduce social isolation, and enable them to not rely on benefits or family for financial support.

> "If you are blind or deaf, services have a legal duty to respond to your needs. If you are hypersensitive in your vision or hearing, no adjustments are made."
>
> Elkie Kammer

People with autism have many skills to offer employers, such as a strong ability to focus on detailed or repetitive work, and high levels of accuracy.

> "My daughter requires support to get back into the work market and this is not available! She has excellent computer art skills – she has now been unemployed since 2002 – not of her own choice or mine but NO real help or support is there. Tragic!!!"
>
> Kay, Brookfield.

Given the right support people with autism can and do make a contribution to society. An evaluation of one specialist employment service showed how it was able to successfully place 67% of its clients in appropriate work environments, and found that the total saving to the UK Government for all those clients who were employed would be the equivalent of just under half a million pounds in less than three years.[42]

People with autism frequently do not receive the right support. As a result, only 13% of adults with autism in Scotland are in full-time employment.[43] Even those who are well qualified do not make the expected progress in their careers. Research by the Autism Resource Centre[44] in Glasgow has found that qualification levels are not reflected in the types of jobs people with autism could get: 43% of graduates or postgraduates never achieve any sort of managerial position and 31% of those with a Higher National Certificate or Higher National Diploma, degree or postgraduate qualification are unemployed. Almost half of the people with autism the Autism Resource Centre surveyed have experienced "career regression" and are consistently failing to achieve the average earnings of their peers.

> "I was not informed of ANY support, merely that I have this condition. The clinical psychologist said she would pass my details on to the local disability employment unit but I never heard anything from them." Anon.

The Scottish Autism Services Network (SASN) has consistently highlighted the lack of data on employment and ASDs, hiding the problems people with autism face with employment. The Scottish Government's 2003 report *Working for a change?*[45] contains some helpful recommendations, but does

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[41] Redman, S. et al (2009). *Don't write me off.* London: The National Autistic Society

[42] Alcock, J. and Howlin, P. (2003). *An evaluation of Prospects Supported Employment Service for individuals with Asperger syndrome.* London: Department for Work and Pensions

[43] Daly (2008). *I Exist*

[44] Autism Resource Centre (2007). Autism spectrum disorder and employability questionnaire

[45] Scottish Government (2003). *Working for a change? The same as you? National implementation group report of the short-life working group on employment.* Edinburgh: Scottish Executive

not fully address the employment and support needs of people with autism. Research commissioned by the Scottish Executive in 2005 found that stakeholders felt that employment of people with autism and/or learning disabilities was *"not yet on the corporate agenda"*, despite the Scottish Government's strategy arising from the report *Same As You*[46] and the *Working for a Change?* strategy.

The Scottish Executive research also found that few services existed to support people with autism into employment: *"A main barrier to employment was felt to be the lack of leadership and not having a consistent framework to commission 'supported employment' and audit performance."*[47]

Social support: autism-specific services

"Before my diagnosis I used to get put into psychiatric hospital for respite care but now I have nowhere as I now 'don't fit into the system anywhere'." Anon.

For those who have more complex needs an autism-specific service tailored to their individual requirement is essential. 25% of local authorities do not have any autism-specific services and have to rely instead on generic services.[48]

The Scottish Government has identified that where 'low level' preventative services are present there is a reduced need for expensive crisis services.[49] For people with autism this often means social support, such as befriending or social skills development.

These relatively inexpensive services can be a lifeline to many people who feel very isolated. But they are some of the services with the biggest gaps between demand and delivery.

	Would like	Actually receive
Social skills	51%	14%
Befriending	41%	8%
Social groups	42%	20%

Over half of adults with autism say they find it hard or very hard to make friends, yet 80% think that with more social support they would be less isolated.[50]

Impact on families

Very often, it is families who are providing the support people with autism need and which statutory services are failing to provide:

- two in five (41%) of adults with autism currently live with their parents
- over half (52%) are financially dependent on their families
- of those people who live in their own house or flat, 38% say that the majority of the support they receive is provided by their family.[51]

Parents and carers are picking up the tab for supporting people with autism, often with very little support themselves. Only 22% of carers had received any support from social work departments in their caring role.[52] In the long term, this won't work. Parents cannot support their adult children into old age, and 82% of parents and carers are worried about their son or daughter's future when they are no longer able to support them.

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[46] Scottish Government (2000). *The same as you? A review of services for people with a learning disability.* Edinburgh: Scottish Executive

[47] Ridley, J. et al (2005). *"Go for it!" Supporting people with learning disabilities and/or autism spectrum disorder in employment,* p37. Edinburgh: Scottish Executive Social Research

[48] Daly (2008). *I Exist*

[49] Scottish Government (2008). *Commissioning services for people on the autism spectrum,* p3. Edinburgh: Scottish Government; National Audit Office (2009). *Supporting people with autism through adulthood*

[50] Daly (2008). *I Exist*

[51] Daly (2008). *I Exist*

[52] Broach, S. et al (2003). *Autism: rights in reality – executive summary,* p3. London: The National Autistic Society

"If I don't push all the time nothing happens – I just want to be a parent not a project manager and quasi-therapist."
Marjorie, Banchory.

A lifelong condition

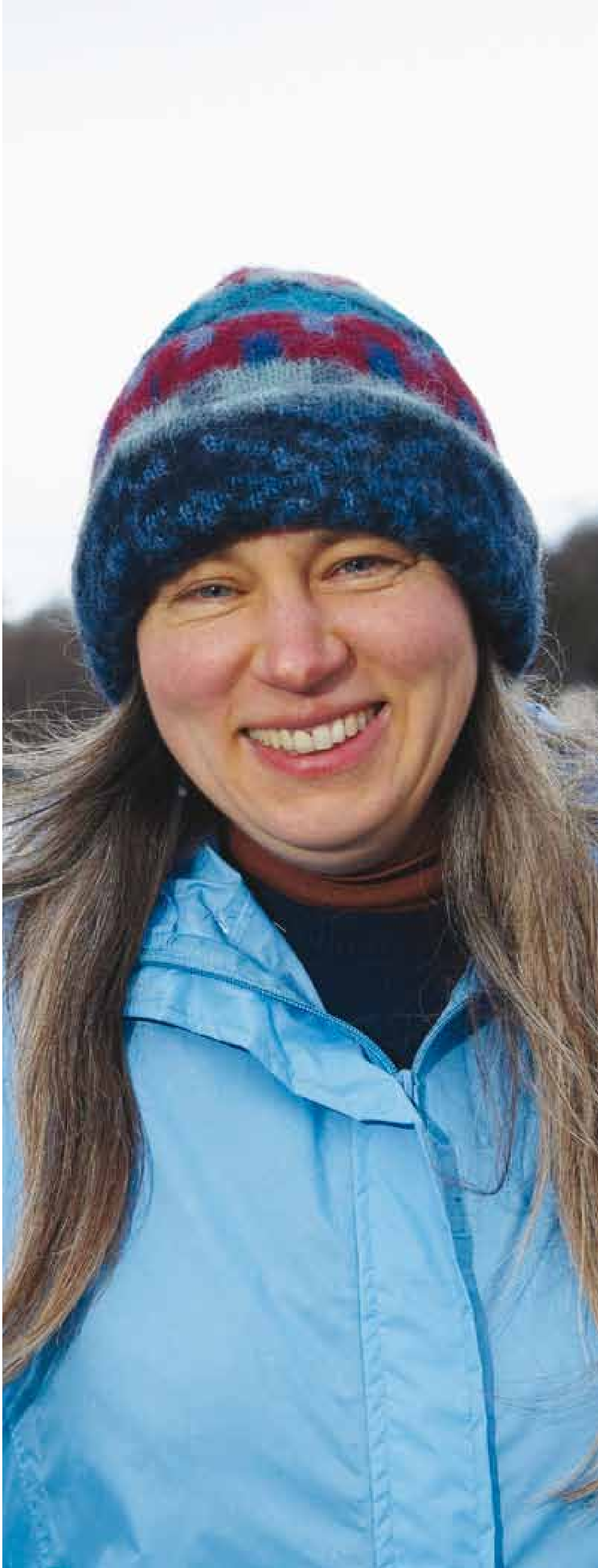
In our survey[53] we asked what services were needed. Fewer than 1% told us there were enough services available locally overall and 95% said that although there are some services more are needed. Nearly three in five (58%) have had to use services provided by a local authority which is not their own.

The need for adequate support is not only directed at many of the obvious services such as education and social care, it is reflected across many services that people with autism would like to use.

People with autism will come into contact with the police or criminal justice services, as victims of hate crimes or bullying, or because their behaviour has been misinterpreted by others. Many police forces do not have officers trained in understanding autism.

Housing needs are a very important issue for many families raising a child or children with autism. Support with housing is key to helping adults with autism live more independently. We have welcomed Glasgow City Council's Housing and Autism Spectrum Disorder Action Plan as an example of good practice and think it should be emulated by other strategic housing authorities.

Other areas of good practice that should be extended include advocacy support. Four out of five in our survey don't feel able to get the services they need by themselves, and a third said they have had to use a tribunal at some time.



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52 Scottish autism services survey, 2009

A new strategic approach for Scotland

Across the different areas described so far it is clear that over and over again in numerous aspects of life, people with autism cannot get the services and support they need to be able to live everyday lives. Fundamentally this comes down to a failure by a range of local agencies to recognise and meet the needs of people with autism. This situation cannot continue.

There are examples of good practice where people do receive the services they need,[54] but this only serves to underline the injustice of the postcode lottery of provision and the gaps in support elsewhere. Autism touches all aspects of people's lives, and a wide range of services must be provided.

The Scottish Government must act to make sure that people with autism get support before they reach crisis point. A new national approach is required to tackle these issues head on and gain the momentum required for excellence in meeting the needs of people with autism in Scotland.

In order to deliver effective services and support there are five strategic factors that local agencies need to address:

- identifying who has autism in the local area and what their needs are
- planning to ensure the right services are available to meet these needs
- delivery of good quality services
- the skills required by professionals working with these people
- local leadership to ensure change happens.

Identification

Effective data collection is the precursor to effective planning and the basis for building collaboration across agencies. The top priority for people affected by autism to improve services locally is for local authorities and health boards to know what people with autism in their area need.[55] Without this it is not possible to take a strategic approach to service delivery for people with autism.

The Scottish Government's commissioning guidance states: *"Following the national audit of services for people with autism spectrum disorder in 2003, localities should have robust systems for the collection and dissemination of information about the needs of people with autism spectrum disorder."*[56] Clearly they do not.

Data collection needs legal force to make it happen universally. Such a duty on local authorities will also help to deliver the *Same As You?* strategy[57] and help them to comply with the *Guidelines on Commissioning Services for People on the Autism Spectrum.*

Service planning

Local service planning has frequently failed to take into account the particular needs of people with autism because of the absence of data and the lack of understanding of autism. As a result many people with autism fall through the gap between services, and do not receive the support they need.

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[54] See for example The National Autistic Society (2009). *Supporting adults with autism: a good practice guide for NHS and local authorities.* London: The National Autistic Society

[55] Scottish autism services survey, 2009

[56] See for example The National Autistic Society (2009). *Supporting adults with autism: a good practice guide for NHS and local authorities.* London: The National Autistic Society

[57] Scottish Government (2000). *The same as you? A review of services for people with a learning disability*

People with autism face discrimination because of the way local services are structured and organised between learning disability and mental health teams. As autism often fits neither with one team nor the other, people often fall through the gaps in the system. A multidisciplinary approach is needed which requires support from both social care and health services.

In 2007 the authors of the SIGN guideline warned that *"there is a danger that a piecemeal approach is taken to the delivery of services to individuals* [with ASD] *over the course of their lifetime"*.[58]

Poor and inconsistent planning, combined with the problems of identifying people with autism, are resulting in poor service delivery and a failure to address national outcomes properly.

Training

Effective training can have a significant impact on improving existing service delivery.[59]

The Scottish Executive funded the Social Work Training Project to address the lack of basic awareness of autism, targeted at children's and adult's services, managers of day services, people working with learning disabilities, community care assessors and ancillary staff.

Basic awareness training was given in 31 local authorities and 28 established steering groups. This resulted in a 22% average increase of autism-specific knowledge; 4,000 staff were trained, around 4% of the total staff who could benefit. The Scottish Executive aimed to continue this work by establishing multi-disciplinary steering groups in each local authority to advance training, although there were then difficulties in maintaining the momentum of steering groups and funding.

The SIGN guidelines[60] state: *"Despite the increasing awareness of, and interest in, the nature of ASD, there are considerable gaps in training for adults and children with ASD. This results in a lack of skills, knowledge and expertise across all general and specialist groups."* SASN was set up in 2006 to build the capacity of the care workforce, but there are still major gaps in training for professionals.

Local authorities and CHPs reported that the ongoing training for key professionals such as support workers, care managers, psychiatrists and clinical psychologists is insufficient. For example, only 6% of staff in CHPs felt GPs receive sufficient ongoing training; 79% of local authorities and 88% of CHPs want to see more autism training in professional development.[61]

Those who deliver autism-specific services and those who work with people with autism in more generic services across Scotland need to receive training and continuing professional development to improve service delivery.

Local leadership

A strategic and multi-agency approach is essential to tackle the needs of people with autism. It takes time for good services to be developed and strong local leadership, clearly identified and positioned within health and social care services, to make them happen.

Only a third of local authorities in Scotland have a named individual or group that is responsible for delivering services across the local area.[62] Partnership

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[58] Scottish Intercollegiate Guidelines Network (2007). *Assessment, diagnosis and clinical interventions for children and young people with autistic spectrum disorders,* p27

[59] Broach, S. et al (2004). *Autism: improving understanding.* London: The National Autistic Society

[60] Scottish Intercollegiate Guidelines Network (2007). *Assessment, diagnosis and clinical interventions for children and young people with autistic spectrum disorders,* p25

[61] Daly (2008). *I Exist*

[62] Research by The National Autistic Society Scotland (2008). Unpublished

in Practice agreements are supposed to clarify arrangements between councils and health boards.

It is vital that these partnership agreements work effectively, but there can be uncertainty over who is responsible for delivering services.[63]

Some areas have developed the role of local autism co-ordinator, following the recommendation of the 2001 Needs Assessment Report.[64] In 2007 the Scottish Autism Services Network found wide variation in the way these roles were carried out, with many co-ordinators struggling to develop a strategic role, focusing instead on specific areas of service development. Some areas had not even identified a co-ordinating role. The report concluded: *"Current responsibility for delivery of services to individuals with ASD varies across the country and from service to service. Clear identification of where responsibility for those individuals on the spectrum lies, given their diverse needs, requires to be made. Following this, clear joint service plans and training requirements need to be developed for all mainstream services."*[65] Furthermore, NAS research has shown that only 63% of co-ordinators work with people across the whole of the autism spectrum.[66]

The following year, the Scottish Government found a worrying lack of clarity over which bodies were responsible for delivering services for people with autism. In its guidance it recommended that a local ASD co-ordinator, focusing on strategic leadership across local agencies, be given responsibility for the implementation, monitoring, quality assurance and reporting of service delivery.[67]

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[63] Daly (2008). *I Exist*

[64] Public Health Institute of Scotland (2001). *Autistic spectrum disorders: needs assessment report.* Edinburgh: Scottish Executive

[65] Scottish Autism Services Network (2007). *Report on ASD coordinators.* www.scottishautismnetwork.org.uk/about/networkgroups/ASDcoordinatorsreport.doc

[66] Daly (2008). *I Exist*

[67] Scottish Government (2008). *Commissioning services for people on the autism spectrum,* p1, p8

A Scottish Autism Bill to deliver a national autism strategy

"We must have some concrete legislation in place in Scotland so that the children and adults with an ASD and their families can be provided with the recognition, acceptance, support and understanding that they need and deserve." Charlotte, Fife.

To effectively deliver a national strategy for autism and give it real force, we have identified the key duties that need to be placed on local authorities and health boards.

- There needs to be a duty to identify and record numbers of children and adults with autism.
- People with autism must be able to get appropriate assessment of their needs.
- Each local area must plan for services that meet the needs of people with autism, their families and carers adequately.
- The appropriate training of staff is essential to deliver appropriate and high quality services.
- Local areas must establish cross-agency leadership arrangements to develop joint working.
- There should be a duty to engage with and consult people who have autism. This will help to meet the aspiration that people should be fully involved in helping to plan the services they receive. It would be a significant step forward for Scotland if the right for people with autism to be consulted is included at all levels.

All these duties will also help local authorities meet their legal obligation under the Disability Equality Duty to promote equality and demonstrate the involvement of people with disabilities.

Support autism, support Scotland: delivering key national outcomes

The aspirations set out by the Scottish Government in *Scotland Performs*[68] are directly relevant to meeting the needs of people with autism but they need to become a reality.

Many people with autism have higher levels of support needs as a result of a failure to provide appropriate support. Research has identified the hidden costs of not meeting the needs of people with autism.[69] This works out at around £2.3 billion for Scotland each year.

Getting it right will help reduce these costs and deliver on six of the Scottish Government's national outcomes:

- ✓ Our public services are high quality, continually improving, efficient and responsive to local people's needs.
- ✓ We have improved the life chances for children, young people and families at risk.
- ✓ We have tackled significant inequalities in Scottish society.
- ✓ Our children have the best start in life and are ready to succeed.

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[68] Scottish Government (2008). National outcomes. http://www.scotland.gov.uk/About/scotPerforms

[69] Knapp, M., Romeo, R., and Beecham, J. (2007). *The economic consequences of autism in the UK.* London: Foundation for People with Learning Disabilities. Of the cost for adults, 59% is accounted for by services, 36% by lost employment for the individual with autism, and the remainder by family expenses.

- ✓ We realise our full economic potential with more and better employment opportunities for our people.
- ✓ Our young people are successful learners, confident individuals, effective contributors and responsible citizens.[70]

Improving support and services for people with autism in Scotland will count toward the Scottish Government's national indicators that measure progress towards meeting national outcomes.

- ✓ Improve people's perceptions of the quality of public services delivered.
- ✓ Increase the proportion of school leavers in positive and sustained destinations.
- ✓ Decrease the proportion of individuals living in poverty.
- ✓ Improve the quality of healthcare experience.
- ✓ Increase the average score of adults on the Warwick–Edinburgh Mental Wellbeing scale by 2011.
- ✓ Increase the proportion of adults making one or more visits to the outdoors per week.

The Scottish Government's report on the future of social work, *Changing Lives,*[71] highlights the need to shift to preventative work from crisis management. It links this to achieving national outcomes for health, and to the objective of leading longer, healthier lives.

The Scottish Government is committed to investing in infrastructure that transforms public services. It believes public services have a positive impact on wider society and the economy, and that there should be a new user focus on planning and better partnership working.

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[70] Scottish Government (2008). National outcomes. www.scotland.gov.uk/About/scotPerforms/outcomes

[71] Scottish Government (2006). *Changing lives: report of the 21st century social work review.* Edinburgh: Scottish Government

Audit Scotland has challenged the Scottish Government and the Scottish Parliament to consider how to improve evidence-based priorities, improve the links between spending, activity, performance and outcomes, and identify areas where spending now can deliver future efficiencies.[72] In addition it calls for the barriers to joined-up and effective service delivery to be addressed and for far more to be done across service boundaries to place the needs of users first.

A national autism strategy, backed with the legislative power of a Scottish Autism Bill, will meet both the needs of people with autism and the needs of Scotland to be a more successful country in which everyone flourishes.

"We need a Scottish Autism Bill because legally all the services will have to be in place to make every stage of development easier [on all those affected by autism]. Change is one of the hardest things for a person affected by autism to deal with – the changes should be easier to cope with if the right help and services are in place." Gillian, Dunfermline.

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[72] Audit Scotland (2009). *Scotland's public finances – preparing for the future.* Edinburgh: Audit Scotland

Coalition partners

We would like to thank all of the coalition partners, individuals and organisations from throughout Scotland who have come together to pledge their support for a Scottish Autism Bill.

Ian Angus	Aberdeenshire Local Authority
Anne Applyby	Kenmay School, Aberdeenshire
Rory Archibald	Special Scotland
Lucy Baillie	NAS South Queensferry and District Branch
Luke Beardon	Sheffield Hallum University
Shaben Begum	Scottish Independent Advocacy Alliance
Jackie Bell	Vericore Limited, Dundee
Gillian Bennett	Bridge of Don Academy
Dave Bleasdale	Turning Point Scotland, Dumfries
Vivienne Bon	VK Astronomy Technology Centre
Evelyn Bonnar	Inverurie Academy, Aberdeenshire
Kerry Brook	Autism Rights Group Highland
Fiona Brown	Renfrewshire Local Authority
Dr Lynn Bunton	Royal Aberdeen Childrens Hospital, NHS Grampian
James Christie	Supporter
Pamela Cornwallis	NHS Grampian
Manuela Costa	Camphill School, Aberdeen
Catherine Coursey	Gordon Primary School, Aberdeen
Valerie Culley	Inspire Partnerships Through Life, Aberdeen
James Cusack	Supporter
Vanessa Dallas-Rose	Dundee Carers centre
Angela Davey	University of Abertay, Dundee
Lizzy Dixon	Young People's Department, Royal Cornhill Hospital
Brian Docherty	NAS West Dunbartonshire
Susan Dolan	Strathclyde Autistic Society
Howard Elliot	Scotland Care UK
Lynne Ethertington	Moray District Council
Charlotte Farmer	PHAD Fife
Ian Findlay	Aberdeenshire Local Authority
Ian Finlayson	GP, NHS Grampian
Lizzie Finlayson	GP, NHS Grampian
Dithe Fisher	Summerhill Education Centre, Aberdeen
Penny Forsyth	Dundee Educational Psychology Service, Dundee City Council
Glenda Fraser	Meldrum Academy, Aberdeenshire
Rev. Dr Bruce K Gardner	Berwickshire
Liz Gault	Banff & Buchan College
Pauline Gerrard	Aberdeen Council of Voluntary Organisations
Norman Gray	NAS Dundee Branch
Nikki Gray	Aberdeenshire Local Authority
Andrew Gray	Supporter
Rachel Grieve	Forfar, Angus
Paulla Hall	NAS Isle of Man Branch
Donna Hardie	Gordon Rural Action Carers Support, Huntly
Jackie Harland	Bridge of Don Academy
Renee Hepburn	Respite Carer for Autism, Fife
Jane Hook MBE	Buddies Playscheme, Glasgow
Susan Howie	NAS North Ayrshire Branch
Laura Hubbard	Balnacraig Residential School
Robert G Hubbard OBE, Med (Cantab), FRSA	The Priors Court Foundation, Berkshire
Richard Ibbotson	Scotland Autism Initiatives
Morag Irvine	Assessment & Information Services, Social Work Services, Inverclyde Council
Iain Jamieson	Outf!t-Moray
Michelle Keenan	Lothian Autistic Society
John Kitson	Scout Association
Sally Lakeman	Leonard Cheshire Disability
Pam Leslie	Dundee City Council
Jackie Macdonald	Falkirk Parent Support Group
John Macdonald	Former CE, Scottish Society for Autism
Ross Macfadyen	NAS Scotland
Eila MacQueen	Archaeology Scotland
Cllr Dr Christopher Mason	Glasgow City Council
David McDiarmid	NAS Inverness Branch
Dorothy McElroy	Ardgowan Hospice
Liz McGeachy	Careers Scotland, Dundee
Laura McGregor	Banff Primary School
Barbara McGuire	Dundee Carers centre
Gail McKeitch	NAS Ellon Branch
Elaine McKelvie	South Lanarkshire Branch
Paul McLafferty	Strathclyde Fire & Rescue
Daphne McWilliam	Bridge of Don Academy
Dorothy Miles	Target Training, Aberdeen
Malcolm Mill	Supporter
Peter Moran	Keppie Design, Glasgow
Catherine Murray	Aberdeenshire Local Authority
Kirstie Mutch	Gilcomstoun Primary School, Aberdeen
Sian Nash	Grampian Autistic Society
Jon and Hillary Newey	Supporters
Linda Noon	Autism Unit, Harris Academy, Dundee
Maria Parker	Dyce Academy, Aberdeen
Catriona Patterson-Craib	Autism in Moray
Emma Powell	Aberdeen City Council
Margaret Preston	AAA Parent Support Group Aberdeen
Derek Purvis	Borders Autism & Aspergers Support Group
Dr Jackie Ravet	University of Aberdeen
Faye Rodwell	Threshold South Lanarkshire/Crossreach
Nigel Rooke	Glasgow City Council, Autism Resource Centre
Cathy Scott	Fife Action on Autism
Sally Sheehan	Aberdeenshire Local Authority
Frances Simpson	The Samaritans, Head Office, Dundee
Anne Slee	Moray District Council
Colin Smith	Hope for Autism
Fiona Smith-Dodd	Royal Aberdeen Childrens Hospital, NHS Grampian
Chris Stewart	Aberdeen City CHP
Susan Strachan	NHS Grampian
Meg Taylor	University of Aberdeen
Irene Thomson	Meldrum Academy, Aberdeenshire
Robin Walker	Supporter
Moira Wares	Kingspark School, Dundee
John Welsh	Angus Council, Social Work and Health
Dr Justin Williams	Aberdeen Medical School
Tom Wilson	Beechwood School
Seonaid Workman	Dundee
Mandy Yilmaz	University of Dundee
Ian Yuill	Cornerstone

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

Over 50,000 people in Scotland have autism. Together with their families they make up over 200,000 people whose lives are touched by autism every single day.

Despite this, autism is still relatively unknown and misunderstood. Which means that many of these 200,000 people get nothing like the level of help, support and understanding they need.

Together, we are going to change this.

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Autistic Society
Scotland

The National Autistic Society is a company limited by guarantee
Registered in England No. 1205298
Registered in Scotland No. SC039427
Registered Office: 393 City Road London EC1V 1NG
Registered in England as a charity No. 269425
ISBN 978-1-905722-59-4 NAS 903