

## **SUBMISSION FROM THE NATIONAL AUTISTIC SOCIETY SCOTLAND**

1. The National Autistic Society (Scotland) is part of the UK's leading charity for people affected by autism<sup>1</sup>. Founded in 1962, by a group of parents who were passionate about ensuring a better future for their children, we currently have over 20,000 members, 105 branches and provide:
  - Information, advice, advocacy, training and support for individuals and their families
  - Information and training for health, education and other professionals working with people with autism and their families
  - Specialist residential, supported living, outreach and day services for adults
  - Specialist schools and education outreach services for children
  - Out-of-school services for children and young people
  - Employment training and support and social programmes for adults with autism.
2. A local charity with a national presence, we campaign and lobby for lasting positive change for those affected by autism in England, Wales, Scotland and Northern Ireland.

### **The case for change**

3. NAS Scotland fully supports the proposal for an Autism (Scotland) Bill.
4. In 2010 we produced our report *We Exist: A Bill for Autism, a Bill for Scotland* which put forward the case for change with regard to autism services in Scotland. The report highlighted the results of a survey with 424 respondents across Scotland. It concluded 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.
5. This is despite the Public Health Institute for Scotland (PHIS) Needs Assessment (2001) which, although significant in moving things forward in some areas such as the SIGN guidelines for diagnosis, has not had much impact regarding other recommendations, such as developing global standards for lifelong services for people with autism and the systematic development of services. Almost a decade on, 95% of respondents to *We Exist* told us more and better services were needed for people with autism. Almost all local authorities and community health partnerships also said the Government should do more to help them meet the needs of people on the spectrum.

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<sup>1</sup> In this paper we generally refer to 'people with autism' which includes adults and children with autism, an autism spectrum disorder or Asperger Syndrome.

6. We recognise that the Scottish government has recently issued *Towards an Autism Strategy for Scotland*. However, we do not believe that the proposals they set out are robust enough to address the real challenges facing people with autism in Scotland.
7. Therefore NAS Scotland believes that legislation in this area is absolutely necessary to ensure that action is taken so that both children and adults with autism across Scotland are properly supported to fulfil their potential.

### **Key findings from *We Exist***

8. The PHIS Needs Assessment and associated initiatives, such as guidance for service commissioners set out clear directions for change. However, our research found that, a decade on, this has not been enough to deliver change on the ground—
  - 95% of people told us more appropriate services were needed locally for people with an ASD
  - 48% rated their overall experience of services as poor or very poor
  - 42% rate care professionals' understanding of autism as poor or very poor.
9. The key gaps identified by the survey were social support, advocacy, self-directed support, employment and training and short breaks or respite care.

### **National Audit Office - autism currently costs Scotland £2.3bn a year**

10. In 2009 the National Audit Office produced *Supporting people with autism through adulthood*, a best-value report looking at multi-disciplinary services. This report identified that autism currently costs the public purse £27bn a year in the UK.
11. This suggests that around £2.3bn per annum is spent on supporting and caring for people with autism in Scotland.
12. Many of the costs identified could be significantly reduced; for example, lost income from unemployment, lost tax revenues, costly out-of-area placements, benefits support and inappropriate care packages or mental health care as a crisis intervention policy. Although not included in the figure of £2.3bn, it would also be reasonable to presume that other avoidable costs are accrued as a result of people with autism experiencing homelessness and being unnecessarily caught up in the criminal justice system.
13. We therefore believe that the introduction of legislation, which would lead to improved services for people with autism in Scotland, could also save significant amounts of money.

## Identification of autism in Scotland

14. The Scottish Government's commissioning guidance for services for adults with autism states that there should be "robust systems for the collection and dissemination of information about the needs of people with autism". NAS Scotland believes that this is essential to ensure that the needs of people with autism are properly planned for and met in a local area.
15. However, in 2008 we found that 60% of local authorities and 92% of community health partnerships did not systematically record the number of adults with autism in their area.
16. Moreover, the Scottish Consortium on Learning Disability eSay report for 2009 reveals that only 2,270 adults with autism are known to learning disability services across Scotland. Based on current prevalence research, we would expect there to be around 40,000 adults with autism in Scotland, and it is clear that the overwhelming majority of the adult population with autism in Scotland remains invisible and ignored.
17. Without robust data collection, local authorities and health boards can't efficiently or effectively plan services. Instead people with autism will continue to access services when they are in a crisis, and at greater cost than when they are appropriately supported.
18. *Towards an Autism Strategy for Scotland* will not address this situation because it contains no recommendations relating to comprehensive data collection nor addressing the needs of the many thousands of adults who remain undiagnosed yet continue to struggle with their condition.
19. We therefore believe that the introduction of statutory duties around data collection and planning as set out in the Autism (Scotland) Bill is necessary to make sure that local authorities and health boards collect appropriate data for planning purposes.

## Service planning

20. The current structure of services is a key barrier for people with autism as they try to access support. Services tend to be provided via specific teams which are categorised into client groups. Consequently, people with autism will usually come into contact with the learning disability team and/or the mental health team. However, as autism is a developmental disability and not a learning disability nor a mental health problem, many people with autism, and particularly those with Asperger Syndrome or high-functioning autism find themselves "falling through the gap" between learning disability teams and mental health services, as both refuse to take responsibility for them.
21. As a direct result of this, adults with autism are not getting the help they need and many face isolation. We estimate that round 40% of adults

currently live with their parents and over half are financially dependent on their families.

22. Moreover, our research suggests that almost a third of adults with autism have developed severe mental health problems, as a result of a lack of support. It suggests that many undiagnosed adults with autism are experiencing difficulty with regard to criminal justice, housing, unemployment and with deteriorating mental health. Similarly, Green et al (2005) suggests that children with autism are three times more likely to have mental health problems than other children. In the absence of appropriate services these people are currently being supported through crisis based interventions and at great cost to the public purse. This situation persists, despite knowing that appropriate and timely support makes a real difference to the outcomes of people's lives and also produces economic benefits.
23. NAS Scotland believes that shaping the range of services available to provide appropriate support, and therefore better outcomes, requires Government to take a strategic approach to the allocation of resources. This is particularly important given the current state of local authority budgets.
24. We therefore support the proposed Autism (Scotland) Bill and the statutory duties it places on the Minister. The Bill would ensure, in law, that an autism strategy is produced and reviewed with robust consultation from ALL stakeholders, along with a duty to issue guidance on service provision to local authorities and NHS bodies. In contrast, *Towards an Autism Strategy for Scotland* contains no such safeguards with regard to long term actions that will improve outcomes for people who live with autism.

*Example - the autism alert card and police training*

25. The National Autistic Society and their partners produced a low cost alert card and provided training for Strathclyde Police. Officers subsequently found a young woman with autism in distress on a busy road. The training and the woman's card allowed the officers to deal with her in a highly effective manner. Senior officers later said that in the past it was not unusual for these incidents to escalate with the possibility of the woman being temporarily hospitalised. They commended the card and the training and cited them as major factors that influenced this successful outcome.
26. It is noticeable that investment in one service (the police) can lead to savings in another (the NHS). Autism affects every part of an individual's life but, despite a definite will to collaborate, many agencies do not have the means to share data and good practice. The jurisdiction of some agencies, such as the police and the NHS, span many local authorities and these systemic and geographical limitations suggest a strong need for nationwide statutory guidance from national government with regard to the coordination of autism services.

## **Training**

27. In *We Exist* 42% of people rated care professionals' understanding of autism as either poor or very poor.
28. Successfully meeting the needs of people with autism requires service providers to have an appropriate level of understanding of autism. This is reinforced in the 2007 SIGN guidance on ASD. This guidance cites multi-level training as a vital component that will improve service delivery and achieve satisfying outcomes for people with autism.
29. Unfortunately, attempts to establish multi-disciplinary steering groups to advance training in each local authority have petered out. Other initiatives have been tried such as Scottish Autism Services Network, set up in 2006 to build capacity of the care workforce, but major gaps in training for professionals persist. *We Exist* shows that only 6% of staff in CHPs felt GPs receive sufficient ongoing training and 79% of local authorities want to see more autism training in professional development.
30. We therefore support the Autism (Scotland) Bill and its emphasis on a training framework and a duty on the Minister to issue guidance on training, as we think that this will help ensure better training and awareness of autism in Scotland leading to better support for people with autism in Scotland, delivering better outcomes for them and savings to the public purse.

## **Local leadership - postcode lottery across Scotland and across services**

31. At present, autism services are patchy, with obvious gaps in support both across the country and within local authority areas.
32. 'Partnership In Practice' (PiPs) agreements were previously recommended by the Scottish Government as a means of co-ordinating services delivered by local authorities and health boards.
33. To assess the impact PiPs have had on service planning, we used Freedom of Information requests to all 32 local authorities. Only 36% of respondent local authorities had a form of autism provision included in their PiP. A similar picture emerges regarding local area coordinators (LAC). Only 12 local authorities in Scotland (37.5%) are providing full access to LACs to individuals in their area with autism. Only ten of the 12 local authorities could provide figures for the amount of autism casework each LAC carried out. On average, across the respondent local authorities, only 20% of a LAC's casework load was supporting individuals with autism.
34. The failure to implement PiPs or any other guidance and co-ordination has continued to perpetuate inequalities regarding access to autism

services across Scotland. To address this issue of local implementation we support the Bill's proposal for Ministers to produce statutory guidance to local authorities and health boards on the planning of services to help achieve consistently better outcomes across the country.

35. Although there has been a significant improvement in the identification of children and young people with an ASD, there is little sign that adult services across Scotland are preparing to receive these young people when they make the transition to adult life. Transition is notoriously difficult for young people with autism. *Towards an Autism Strategy for Scotland* does not address this issue adequately. We support the Bill's proposal for the Minister to issue guidance on transitions to address this key issue.

## **Conclusion**

36. The Autism (Scotland) Bill has been widely welcomed by our members and the people with autism that are supported by our organisation. The Bill addresses what we see as the critical factors that will develop appropriate support for people with autism. This support has been too absent for too long.
37. A national strategy backed up by statutory guidance will help to ensure that change will happen. The experience of the last ten years can largely be described as a plethora of voluntary guidance and best practice advice and the proposals put forward by the Government in *Towards an Autism Strategy for Scotland* do not go far enough from this position to be truly life changing.
38. There are too many people with autism facing exclusion, inequality and broken lives. We now need legislation in Scotland to change this situation. We need an Autism (Scotland) Bill.

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