

SUBMISSION FROM ARCHIVE

1. ARChive is a Glasgow coalition of adults affected by Asperger Syndrome and autism.
2. We are writing to express our full support for the Autism (Scotland) Bill. We feel most strongly that the Autism (Scotland) Bill, by its commitment to keeping the terms of any autism strategy under review by the Scottish Government, by seeking the participation of appropriate stakeholders in the preparation and revision of the strategy and – most importantly of all – by providing a statutory duty for NHS and local authorities to have regard to official guidance in providing services, will best deliver the change that we feel is necessary to fully support everyone in Scotland who has an autism spectrum disorder (ASD) and their families.
3. All of us have experienced a range of common problems that we know – from speaking to our peers in the ASD community – are not peculiar to ourselves (depressingly so). Some people have experienced difficulty in accessing diagnosis in their area. Others, while having no difficulty in obtaining diagnosis, have suffered as a result of inadequate post-diagnostic support, which is often piecemeal, postcode-restricted, non-existent or confined to a limited range of services that do not cater for the full range of needs that exist among adults, children and the families who struggle to support them. Access to diagnosis, while important, is only half the battle and the real challenge, we feel, lies in being able to obtain appropriate support after diagnosis to accomplish even the most basic tasks of daily life – things that most other people take for granted – as well as to allow us to fulfil our potential in education and employment.
4. While we acknowledge the good practice that does exist, including among services that we use or have used in the past, we are also aware of the limitations of existing services, in terms of scope, capacity to deliver, and the absence of genuine across-the-board partnership working between services. All of these are barriers to us receiving the breadth of support that we need to build a sustainable independent lifestyle.
5. We have also experienced ineffective services, largely so because of a lack of autism-specific knowledge and practice among the social care, social services, NHS and education workforces. A lack of autism awareness among practitioners is a source of great frustration and distress for those of us on the receiving end of even the best designed services and has the potential to cause real harm in the case of services on which we are dependent and which do not adequately train their staff to be able to understand and cater for the very specific needs of people on the autism spectrum.
6. As adults with Asperger Syndrome we continue to fall between gaps in services within the NHS and social work services. Most commonly, mental health services that will not treat or support us because we do

not have a specific mental illness or learning disability services that will not support those of us who need high levels of support with daily living because we do not have a learning disability. This can result in people receiving inappropriate services or no services at all.

7. We share, in common, a range of problems that we feel that the Autism (Scotland) Bill could effectively help to address. These include problems in obtaining effective joined-up services staffed by professionals who have received a level of autism training appropriate to their role.
8. We would also recommend more comprehensive and widespread training for staff in other public authorities, including employability professionals such as staff at Jobcentre Plus/Department of Work and Pensions and others engaged in supporting people in employment. While we acknowledge that this is not a devolved area of policy, success in employment is crucial to the wealth and wellbeing of adults on the autism spectrum (and also their dependents) and its absence has a direct impact on the need for other services.
9. We feel that there is a lack of appreciation of how difficult it is for adults with ASD to function in society without the necessary support and understanding and the recognition that ASD is much more than a mere personality variance within the general population that can be readily catered for to the fullest extent within existing services. The lack of support can really damage an individual's ability to fully participate in society and the workplace and often leads to mental health difficulties which draw not only on societal resources – benefits, medication, etc – but often lead to the loss of the individual to the workforce and the tax income accruing from that. This is in addition to the phenomenal degree of suffering often endured by individuals, their partners and their families. A lack of support can destroy relationships, break-up families and lead to estrangement and extreme social isolation, with all of the consequent health problems arising from this for individuals with ASD.
10. We have all experienced difficulties in relation to health and social work services, employment and housing in ways which have often exacerbated existing health problems, many of which could have been avoided had there been greater awareness and understanding of our condition and the difficulties that it causes and – where necessary – a legal requirement to deliver a model of service more appropriate to our needs. In our experience, leaving the planning and delivery of services to the discretion of individual statutory service providers clearly does not work, which is why we support the Autism (Scotland) Bill and its belief that statute is necessary.
11. We also wish to register our disapproval that we have been asked to consider two draft papers with apparently competing aims simultaneously (ie the Autism (Scotland) Bill and the autism strategy). This shows a lack of consideration for the difficulties that people with autism have in processing information, extracting meaning, and

providing an appropriate response, or our consequent difficulties in dealing with paperwork, form-filling and meeting deadlines. These documents are difficult enough for us to consider without the unnecessary complication of having to deal with both at the same time and the decision to hold overlapping consultations risks promoting cynicism about the government's intentions in these matters as well as a barrier to adults with autism participating in the call for evidence. The chosen method of submitting evidence – ie in writing – is in itself a barrier for many people.

12. A number of people from within our group have previously contacted their MSPs to make our concerns about autism services known to them and hope that the passing of the Autism (Scotland) Bill would assist in creating a framework within which our concerns can be addressed in a meaningful way.

ARChive
7 October 2010