

## **SUBMISSION FROM AUTISM RIGHTS GROUP HIGHLAND (ARGH)**

1. Autism Rights Group Highland (ARGH) is run by and for autistic adults; we joined together to form a group with the aim of improving the lives of autistic people. We were the first group of our kind in the UK and are still the only one in Scotland: independent from any other body we are self-governing, a group controlled entirely by autistic people to promote the rights of autistic people.
2. ARGH fully supports the Autism (Scotland) Bill: it is imperative that any autistic spectrum condition (ASC) strategy is backed by legislation. As a nation, we can no longer allow those responsible for providing/planning services to get away with being “seen to be doing” by writing policy that is never adhered to, or that is so “woolly” that there is no real benefit to be gained from it. To try to rely on a non statutory strategy would be an injustice to all autistic people in Scotland and would not affect the necessary changes that are needed to promote well being and equality for autistic people.
3. Currently autistic people and those around them rely upon personality not policy for their wellbeing and access to supports. The service/support received relies upon the individual staff member that we are lucky (or unlucky) enough to come into direct contact with. This has to change; we need the equity of provision and fairness that this Bill will ensure.
4. We need a strategic approach, joined up thinking and working: not just on paper but in practice, even if this has to at first be enforced. Sharing of good practice is essential but care must be taken that any change in current service provision ensures that good examples are championed and replicated, rather than (as some fear) cut, because other areas cannot or will not replicate them.
5. We would like to raise our concerns that the Bill refers to “guidance”; we feel that this is not strong enough. It would be more appropriate to use language that is less advisory in nature and more explicit, for example using the terms obligation or requirement. It is our experience that anything of this nature that is not explicit in its meaning or that does not demand compliance will not be taken seriously in the spirit in which it is meant and does not reach fruition.
6. The term “stakeholders” is used throughout the Bill, those referred to will be crucial in ensuring that the Bill and strategy meet the need of those they intend to assist. Yet, in Section 4 (Interpretation) the definition of “appropriate stakeholders” is given and omitted are autistic people themselves. Section 4(1)(a) mentions “organisations representing persons with autistic spectrum condition” but this is inadequate. Autistic people themselves must be included as key stakeholders. This is enshrined in legislation, for example the Disability Equality duty says—

*“Remember that the duty specifically requires the involvement of disabled people, including organisations run by disabled people. The involvement of nondisabled people or organisations working in the field of disability which are not controlled by disabled people will not satisfy this legal requirement.”*

7. Also, the United Nations Convention on the Rights of Persons with Disabilities, article 4.3. states—

*“In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations.”*

8. In order to comply with the convention you need to ensure that organisations run and controlled by autistic people are invited, as organisations, to appoint their own representatives.
9. We do not want to be represented by “representative groups” that are actually in reality non-representative. We deserve to have our voices heard, not drowned out by non autistic voices that have no possibility of truly understanding our needs as we do.
10. Similarly it is important that the voices of parents/carers are heard and their views are sought on issues affecting them as caregivers/supporters. This should again be achieved by means of appropriate representative selection, drawn from their own representative groups. It should also be acknowledged that there are autistic people who are also parents of autistic (and non autistic) children / adults and they also have their own unique perspective to add.

### **The six key areas covered by the Bill**

*Section 2(5)(a) - The provision of relevant services for the purpose of diagnosing autistic spectrum conditions*

11. Currently there is an inconsistency of service in this area, the delay or denial of diagnosis and understanding can lead to mental ill health. Autistic people have the right to discover that they are autistic; not broken or defective but different as soon as possible. Years of not knowing why we are different can have severe adverse effects.
12. It is everyone’s right to forge their own self identity. Misdiagnosis with mental health conditions and the inappropriate prescribing of psychiatric medications is an ongoing problem which can only be addressed with the increase in the number of skilled practitioners available and access to the appropriate diagnostic and assessment services.

*Section 2(5)(b) - The identification of persons with such conditions.*

13. Where there is a lack of diagnostic services the identification of autistic people cannot happen. Services are more often than not accessed through diagnosis and services (especially for adults) are refused without diagnosis.

*Section 2(5)(c) - The assessment of the needs of persons with such conditions for relevant services.*

14. Needs assessments are crucial, even when diagnosis is given there can be a lack of assessment of need and people are left with just a diagnosis and nothing else.
15. An assessment of need should be done as soon as the person is identified in order that if there is a long wait for diagnosis or a non ASC diagnosis is made the person is dealt with appropriately and their needs addressed.
16. People should be assessed by an understanding and skilled practitioners who accept that they are working with an autistic person, not a broken "typical" person. Acceptance of autism as a difference, whilst still understanding and addressing any impairment/needs arising for that individual is important. It is important that assessments are carried out in the appropriate settings, for example cooking skills should be assessed in the setting that the person usually prepares meals: assessing a person out of context or in an artificial setting is irrelevant.

*Section 2(5)(d) - Planning in relation to the provision of relevant services to persons with autistic spectrum conditions as they move from being children to adults.*

17. Often when an autistic person becomes an adult they find that the service that they have been receiving (however limited) will stop and there is nothing to replace it. Even those of us that do well in education find that with no support we cannot utilise our qualifications. This is equally true for further/higher education. Many find themselves with excellent qualifications but are left behind their equally (and less) qualified peers. Finding a job/housing etc without support is impossible for some and they can flounder; autistic people often do not have the same support systems or relationships that many non-autistic people enjoy and this can leave us vulnerable.

*Section 2(5)(e) - Other planning in relation to the provision of relevant services to persons with autistic spectrum conditions,*

18. Planning of services should involve autistic people and build upon identified areas of good practice (not closure of services to achieve parity). Reduction of "waste": if referrals to inappropriate services and the giving of inappropriate "treatment" was stopped and replaced with support / solutions that we wanted and worked well for us there would be cost savings. For example, mental health services spend time and money trying to "normalise" and "cure" rather than offering appropriate

support, this is not acceptable. It must be accepted that we cannot be judged by psychiatry against their “typical” model.

19. Accessibility to mainstream services is limited partly because of attitudinal barriers, for example the refusal to accept a persons’ needs or requests for reasonable adjustments because they have been wrongly categorised as “wants” rather than “needs”.
20. There is an overreliance on large corporate charities with SLA’s that can be easily dismissed. Locally some years ago such a service was removed leaving a huge and possibly dangerous gap in provision. The plan for the future was an in-house service which has still to appear. In-house provision is important and should, whenever possible, be ingrained into mainstream services. With correct and flexible needs assessments this would protect service provision and save money.

*Section 2(5)(f) - The training of staff who provide relevant services to persons with such conditions*

21. The use of large corporate charities with rigid training packages is undesirable; training should come from autistic people and autistic led groups. It should be the duty of the local authority to contact these groups as a first step and enable them, through training, to deliver training from an autistic perspective. Autistic people should be involved in all aspects of the planning and delivery of training. Practical, non-judgemental understanding of equality which rejects the concept of normalisation is needed. Autistic people must not be treated as a problem to be solved; it is important that difficulties are approached with a no blame attitude. Staff should be empowered to be confident and use approaches that will benefit everyone including autistic people; they must understand the use of supportive not punitive support structures.

*Section 2(5)(g) - Local arrangements for leadership in relation to the provision of relevant services to persons with such conditions*

22. This is important: it should be well managed and monitored independently. Autistic people should no longer have to accept approaches that do things “to” us or “for” us; we need to be included, this means having our voices heard at leadership level. All those involved as stakeholders (by that I mean my accepted idea of stakeholders not those listed in the current draft), should be included in this process, with autistic people and their elected representatives at the heart.

**What’s missing?**

23. There are gaps that must also be considered—
24. Access to independent advocacy for all autistic people, regardless of perceived “functioning level”. This must include autistic people with the most complex communication difficulties.

25. Appropriate environments; awareness of differing environmental needs which will impact on all areas of a person life, e.g. 'unusual' sensory perceptual experiences that may involve hypo- and hypersensitivity which will effect the cognitive processes.
26. Access to communication tools / adaptations to enable everyone to have a voice, for example staff having a duty to adapt to differing styles of communication on an individual basis.
27. This includes access to assistive technologies, communication through IT (as advocated by Autreach IT).

K Brook  
Chairperson  
7 October 2010