

SUBMISSION FROM THE ACADEMY OF MEDICAL ROYAL COLLEGES AND FACULTIES IN SCOTLAND

1. The Academy of Medical Royal Colleges and Faculties in Scotland thank the Scottish Parliament for the opportunity to comment on the Consultation: Autism (Scotland) Bill: Call for Evidence. We have asked our member for Paediatrics and Child Health to collate this consultation on our behalf. The response includes comments from members from the Royal College of Radiologists, The Royal College of Psychiatrists, The Royal College of Paediatrics and Child Health, Royal College of General Practitioners and our Lay Member.

Would people with autism in Scotland benefit from a national strategic approach?

2. We would support the development of a national strategic approach for people with autism in Scotland. We would suggest, however, that the term autistic spectrum disorder (ASD) is used to ensure that all people including those with Asperger's syndrome are included.
3. Up to date prevalence figures for ASD within Scotland indicate that there are large numbers of people who have this diagnosis. The development of the national SIGN guidelines has been welcomed by users, carers and professionals in the field. There is variation in provision for this group of patients across the country and development of a national strategic approach would help to identify and manage variation in service delivery. It would also bring Scotland in line with the rest of the UK and international community.

Is a Scottish autism strategy act needed to meet a national ASD effective?

4. Statutory measures tend to carry more weight but resources would be needed to follow the statutory measures in order to implement the strategy.

Are the duties proposed appropriate to enabling a national ASD Strategy for Scotland?

5. The document is helpful. We appreciate, however, that this is guidance only and will need to be followed with resources. There is a real difficulty in prioritising vulnerable groups, ASD is one such group but there are others.

Are the duties proposed appropriate to guide local agencies to take a strategic approach to autism services in their area?

6. There are difficulties in areas where local authorities and health board boundaries are non coterminous. There are challenges for larger health

boards, particularly NHS Greater Glasgow & Clyde which is served by several local authorities. Centralisation within large health boards can make it more difficult to develop local links and respond to local needs. Children, young people and their families value local input and it will be important to ensure that this is not lost within particularly NHS Greater Glasgow & Clyde, the largest health board in the UK.

7. From a practical point of view, for example, it would be very useful if patients who have significant autistic traits and indeed other patients who have behaviour issues are identified to radiology and oncology departments, so that appropriate arrangements can be made to facilitate their examinations/treatments.
8. There are also problems faced by rural or highland health boards because of geographical spread and transport issues.

Other any comments you wish to make about this proposal?

9. It is important to continue to recognise the good work that is occurring across Scotland within statutory and voluntary services. The emphasis should be building on this good work.
10. There is a place for this legislation as ASD is amongst the most prevalent serious neurodevelopmental disorders in childhood and affect around 1%. Key to the disorder is impairment in communication, social understanding with restricted and repetitive behaviours especially in stressful situations such as transitions. It is one of the most stressful conditions for parents.
11. There are a number of good quality guidelines for health and education/social work services and therefore clear frameworks for services to work to. Research has shown benefit from psycho-educational interventions, some carefully targeted medications and supports for families and affected young people. Affected children and their families benefit from appropriate changes to receiving environments. Legislation that demands that services take this evidence into account in their strategic planning to meet the substantial needs of this population would be welcome and most likely to also be cost effective.
12. The faculty welcomes the proposal to develop a strategy for Autism in Scotland and agree that Scotland has lagged behind other parts of the UK in this respect.
13. We would particularly welcome scrutiny of appropriate services for those adults who have high functioning autism/Asberger's Syndrome as these are a group of individuals who struggle to find services and do not "fit" into either learning disability services or mental health services. A decision from

central government as to who should take responsibility for such individuals would be most welcome and would, hopefully, put an end to the shuttling of such referrals between services which is not helpful to the adult or their families.

14. There is, however, also a concern expressed among some groups of medical professionals that the increasing trend to legislate in areas that are clearly about clinical judgment, diagnosis and treatment would adversely affect doctor/patient relationship and would be unhelpful.
15. We hope, therefore, that the consultation will be wide and take in views of as many relevant groups as possible.

Executive Secretariat
6 October 2010