

SUBMISSION FROM ELIZABETH LAURIE

1. I am the parent of a 36 year old who was diagnosed with asperger's syndrome when he was 23. My husband and I endeavoured to find appropriate help for our son for over 20 years until his diagnosis. The delay in diagnosis obviously impacted badly on his years of learning and ability to cope at school or in finding appropriate work.
2. It is important to address the fact that autism is a lifelong disability, and in our case was accompanied by challenging behaviour, and the longer difficulties fail to be addressed the more problematic a person's life will become. Diagnosis and suitable support for each individual needs to be available as early as possible. Therapeutic and supportive packages, while appearing costly in the first instance are a lot less expensive than remedial packages later in life. This also requires accurate recording and the formulation of information regarding numbers of people with autism, which should assist local councils to facilitate future planning.
3. Training for all those working with people with autism is crucial. Although there are many highly qualified individuals working, or coming into contact with this group, not everyone is able to understand autism or indeed the differences from one to another within the spectrum. This training needs to be available to everyone from the daily, or, on the ground workers, to social workers, mental health officers, psychologists and psychiatrists who may work with adults as well as those in educational services for younger people.
4. There must be guidance for multi-disciplinary working/integrated services/or indeed joined-up working within health services, local councils and education. Speaking from the experience of having a son detained in psychiatric hospital for almost four years I would state that it took the health service seven months to even acknowledge that any other agency or person may be able to assist. Despite one meeting at that point, it again became an on-going struggle for further appropriate support or input.
5. We require support for parents who struggle for years to gain assistance and who may have to support sons or daughters for as long as they are able. Even within hospital we paid for autism specific support for our son for almost four years and requested frequent visits from an appropriately trained psychologist. During this time the total cost of the support, seeking assistance from solicitors and similar costly methods of gaining an end to our son being held in an unsuitable environment, would have been enough to buy our son an extremely reasonable flat. The fact also that not all parents can afford to help financially and not all parents feel able or articulate enough in the difficult struggle for help, are issues which must be considered.
6. Scotland should be able to care for its own individuals with autism. We have been offered places from the north of England to the south of England as well as Wales. Why are we so lacking in suitable places or

placements within Scotland? Also we discovered that we appear to be such a “tight knit” community in Scotland within psychiatry, that if we wish impartial representation, it may be necessary to go to England or Wales to find it. There requires to be legislation or further legislation, regarding the sharing of confidential documentation within our professional circles.

7. All stages of life for someone with autism which requires a transition/change of any kind can be problematic and in particular moving to adult services. The immense difficulties from the stages of junior school to senior school and from there to work must be catered for or the consequences may take further years of work.
8. I would further comment that we have been through the mental health tribunal system, more than once, have been greatly opposed by our local council and health board and the cost of all of this must have been immense. However, currently we have an appropriate care package at home in a suitable environment, with a professional team who also visit. We now work as a team with the health board and local council. This has been in place for over two years without any signs of challenging behaviour. Once again, however, this is a lifelong disability and, in our case will require lifelong vigilance, but nevertheless it can be done **in Scotland**, hopefully without battling for 30 years as we have done to achieve it.
9. We parents desperately require the legislation to support us, as do those with this lifelong disability.

Elizabeth Laurie
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