

SUBMISSION FROM ELLON AUTISM NETWORK

1. The Ellon Autism Network is submitting the following points of evidence to support the need for legislation to address the needs of people who have autism spectrum disorder. Members of this multi agency group include representatives from the pre-school, primary school and secondary school sectors and community learning and development.

Early intervention

2. Research has shown very clearly how the early social and emotional experience of very young children affects their future growth and potential. This is particularly so for a young child with autism. Delay in diagnosis, or acknowledgment that significant developmental problem exists – and therefore needs intervention, results in vital time being lost before the child engages with statutory services.
3. Disparate services in North East Scotland has meant that some children are not given the support they need at the earliest stage to help them develop language, communication and social skills

Family support

4. There is no legislation presently in place which places a duty on the statutory services to provide specific support to families who have a child diagnosed with autism. Generic legislation provides for “children in need”, but this can be interpreted in different ways, often constrained by budgets. Families who might otherwise not be seen to be “in need” are therefore are not brought into contact with support services until situations reach crisis point.

Leisure and social opportunities

5. Children and young people on the autistic spectrum who have associated specific needs such as sensory difficulties, behaviours and anxiety are frequently unable to access mainstream activities. Although policies of “open to all” and “inclusion” may theoretically exist, in reality children and young people are excluded due to lack of trained support staff and increased staff: child ratios to enable the necessary level of support to be provided.

Diagnosis

6. At present in Scotland there is no definitive structure or process for diagnosis but it very much depends on the area you reside in, the experience of the professionals within your area and their readiness to diagnose. This leads too many individuals not being recognised, not being put forward for diagnosis or being wrongly diagnosed. Some children struggle to cope in school, and think they are stupid because they don't know that they have a developmental disorder. In turn this

leads to isolation, exclusion and an increased likelihood for psychological health problems. Parents may know that there is something wrong but unless they push for a diagnosis then they are unlikely to know how to help their child, get the correct advice and support (including financial).

7. We believe the prescribed diagnosis should be through a multi- agency approach. This means that the diagnosis is more likely to be accurate and there is a far less chance of someone receiving a mis-diagnosis which can cost both local authorities and the individual both financially and not address the individual's needs. Is it time to have a uniform prescriptive format for the diagnosis process to end the postcode lottery of service being delivered? Accurate diagnosis would save councils money as planning of services would be more efficient as accurate numbers would mean that money could be apportioned to where it was most needed rather than the common practise at present of "plugging the gap" with short term inefficient and often second class provisions. How can a council and Scotland's government support and help people with autism if they have no accurate way of knowing how many people are affected, their ages and their needs?

Inclusion

8. We are fully supportive of the Government's policy of Inclusion however the nature of the condition itself impacts on social interaction and communication and this needs to be addressed if people with autistic spectrum disorders (ASDs) are to be fully included.
9. Inclusion seems to be the buzz word however it needs to be properly quantified eg meaningful inclusion ie an individual needs to be able to cope and flourish within the situation they are put. All too often Inclusion seems to mean simply putting a child into mainstream at any price. Some children are simply unable to cope with mainstream settings. If a child in school is hypersensitive to sound putting them in a noisy assembly where they spend the whole time rocking and covering their ears is surely cruelty.
10. Inclusion is about more than being "physically" in a class
11. Individuals with an ASD will not learn social skills and communication skills simply by being put in amongst mainstream pupils
12. Much money appears to have been spent by regions on training at for example Strathclyde or Aberdeen University in post graduate work. How is this being used in schools across Scotland? Facilities that have been set up and developed in recent years e.g. Communication bases, mainstream integration of children on the autistic spectrum (MICAS) bases and specialist accommodation are being closed, and all pupils 'put' into mainstream. It is important to support pupils with ASD in

mainstream but this is not enough. We need specialist intervention - and pupils have a right to access it

Training and practice

13. The group are concerned that the number of Support for Learners (SfL) Auxiliaries has started to be reduced across the authority. We believe that their continued role is essential in the classroom. Any cost savings will only be short term due to the problems which will inevitably emerge once this support has been withdrawn.
14. It is important to have specialist-trained staff who can influence what happens within schools. (There are staff with post graduate certificates, diplomas and beyond - but their views are not being heard above the call for inclusion).
15. What has happened re the Scottish Government's recommended training in autism structure which laid out levels of training for all professionals to standardise the whole thing? Costs cut if staff with training already were utilised to use and advise others on same. Teacher training needs more specific ASD training especially if more and more children will be in mainstream and cost cutting exercises mean less front line staff such as direct SfL support. How can teachers cope with specific programmes to tackle identified needs on a daily basis as well the teaching of the rest of the class to a high standard especially if they have had only basic ASD training? Surely initial good quality training should be compulsory and this would indeed prove cost effective long term. Pupil exclusion, home tutoring and specific units needed to deal with the consequence of not supporting pupils with ASD including increase in mental health issues cost the government dearly.
16. Many individuals with ASD require specific and specialist intervention in order to help them to access mainstream -this includes communication skills, emotional literacy skills, specifically differentiated subject work (not usually simplification), help with sensory issues, daily schedules or plans, time to de-stress and focus on deep interest topic, respite and a cognitive behavioural therapy type approach to identifying and dealing with "hot" spots.
17. Most teachers do not have specialist knowledge of ASD (other than, for example, a twilight session). Class teachers cannot be expected to spend major amounts of time with one pupil and more use could be made of specialist trained teachers in both subject work and guidance.

Transition and beyond

18. We question the recording of "positive destinations" for school leavers. Some young people leave special or mainstream schools to go on to college or work placements. Although College may only be for a one year course, or may not prove to be suitable after only a short time,

recording that transition as a “success” does not create a true picture of the move into adult life.

19. In the Ellon area a significant number of young people with severe autism are leaving education to move into adult services. Social work provision has not been increased in recent years with the result that existing provision is already beyond capacity. It also caters for a wide age range of a variety of needs. Legislation would help to ensure that local authorities are required to provide autism specific facilities/provision. This is necessary, in our view, to avoid young people entering into a situation which could exacerbate anxieties, behaviours and contribute to poor mental health.
20. Many people with ASD are eager and able to do some sort of work, however if they are not given a chance then surely this is discrimination? In studies it has been proven with initial social and work support the chances of an individual being able to participate in society, a workplace and independent living is vastly increased.
21. Pupils leaving school, college or university with no support such as supported employment means both social exclusion and a huge financial burden to the government in benefits. Giving the correct support would financially benefit the government and promote inclusion within communities.

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