

SUBMISSION FROM ANGUS AUTISTIC SPECTRUM DISORDER PARENTS GROUP

Introduction

1. Angus Carers Centre facilitates the Angus Autistic Spectrum Disorder Parents Group. At its meeting on 15 September 2010, members of this group drew together the following written response to the Autism (Scotland) Bill which is currently in the consultation phase.

Autism diagnostic services

2. The group felt that there were advantages and disadvantages to the diagnostic experience. The advantages were that the professionals involved in relation to support after the diagnosis, eg pathway training where parents find out about the diagnosis and the opportunities for extended family was beneficial. Helpful to the process is involvement in speech and language or with physical disability, eg occupational therapy. However the diagnosis can be lengthy or difficult to obtain and parents feel they are not supported enough after diagnosis. The impact on the family, including siblings and extended family members can lead to family stress. There is a significant difference in siblings living with an autistic spectrum disorder (ASD) brother or sister. The actual diagnosis can lead to other support provided for people with autistic traits to go unrecognised. The group feel that their child's diagnosis was not reviewed often enough. The diagnostic services provided could work better together by integrating services because sometimes it is not always the same doctor or there is an apparent lack of communication between services. Early intervention with children is extremely beneficial and helps the development and this then supports and informs the parent with their child's needs and interests.

Identification of persons with autism

3. The group felt that again there were disadvantages and advantages to the identification of children with autism. Some parents like their child to be known as autistic; others do not. It is beneficial to be identified as ASD to get the right support in place for families, yet ASD can be labelling and discriminatory. There needs to be more an inclusive approach that is more accepting of the diagnosis which if not addressed can lead to other issues such as discrimination and prejudice. The disadvantages are that services are stretched due to more people being diagnosed. The group felt that the knowledge of the diagnosis to the child can be beneficial but that the situation is complex in relation to how a child or parent feels about others knowing, eg the need to be identified balanced against the isolation that might occur if not identified. There is a lack of general public awareness of ASD with a feeling that there is a need for a more tolerant society. All

services connected to education and mainstream activities should be ASD aware and recognise the need for planning strategies and the resources required. It is important to have early planning for transition stages (including the child's knowledge of the diagnosis) in life of the child with ASD. Recognition and identification will lead to more mainstream activities, partnership working with families, better provision, and the support needed for inclusion.

How services should support young people with autism when they leave school

4. Services should recognise that transition stages do not exist in isolation and should be part of a process that involves nursery, primary and secondary towards adulthood and its associated transitions. It is felt that early identification of the support required could lead to less financial implications. This should take account of the ethos of lifelong learning for all and the recognition of the ambitions of the Curriculum for Excellence and its consideration of people with ASD. The transition of leaving school should be planned for well in advance. This includes awareness and support for colleges, employers, employment services, and the voluntary sector. Extra help and an advocacy role should be taken into consideration to prepare for adult life. Social services such as housing, care managers and respite need to take account of the additional needs and the planning provision. The impact on parent/carer/family also needs to be taken into consideration as this could result in an added burden to services. This can be a stressful time for parents and persons with ASD. There is an expectation that families will continue to provide for their children after they leave school and this may not be sustainable. The transition also includes a move from children's to adult's services and this can have an adverse impact on the family and the young person. The overall impact both financially and emotionally needs to be taken into consideration and recognised by all services involved in this transition.

How the needs of people with autism should be assessed

5. At present the group feels that the Education (Additional Support for Learning) (Scotland) Act 2004 is not specific enough to people with ASD and that people with ASD are not being addressed. It is felt that early support is required because the present situation of no support will cost more in the long run. Most members of the group believed that the Individual Educational Plan (IEP) can have little or no effect, providing little stimulation or development that can lead to more problems. The IEP needs to be ASD specific with a greater recognition of specific needs. This should also include supported environments and the sensitivity of the individual. The assessment process takes far too long in some cases and this is a stressful process and could involve more consultation with the family and

their concept of the situation. The assessment process needs to include all family members including siblings and their relationship with service providers.

How other services should be planned

6. The group felt that there should be a multi-agency approach with one to one annual reviews similar to people with physical disabilities. Services should plan together for ASD that is spectrum wide and is inclusive. The awareness of mental health is a very important factor and that early intervention and recognition is paramount in relation to future planning and the mental well being of the child and family. Trained staff in other services including people who come in contact with ASD persons should be trained (lollypop person, taxi service to school /college, mainstream activities run by local authorities). Sometimes there is no service, eg clubs, social activities that ASD can fit into because of specific needs. It is thought that overall there is a lack of recognition of the relationship of services to the whole family. Services should be listening to all people that care for the child.

Training for people who work with people who have autism

7. Parents felt that teachers should train in enhanced provisions and that teacher training should have more focus on ASD. This should include all staff in schools including classroom/playground/catering assistants. This needs to lead to more awareness in the community, including school boards, out of school clubs, services attached to schools e.g. transport services. Recognition of persons with ASD in waiting areas in doctors, dentists, hospitals, public toilets, Also awareness by the Police and legal services. It was felt that accessing other services e.g. Housing where people could benefit from ASD awareness training.

How local services should work together

8. The group felt that there is a greater need for people/services to work better together. Sometimes the local services are inadequate for children with ASD. The GP is not always involved and there seems to be a lack of agencies working in partnership. It was strongly felt that education services and NHS should work better together. There seems to be a lack of consistency in approach to persons with ASD. The group have had some good experience of practice that could be used by other local services.

Conclusion

9. The group conclude that an ASD specific approach is paramount and that good practice should be shared across services. With reference to an Autism (Scotland) Bill a strategy would be beneficial that supports and

recognises that ASD is such a complex spectrum wide diagnosis that needs a thorough approach.

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