

## **SUBMISSION FROM DUNDEE PARENT GROUP**

1. People on the autistic spectrum suffer from a lifelong condition and require lifelong support. While education is of prime importance it should not detract from the needs of those at diagnosis, or post-education as they move into the worlds of employment, relationships and independent living. It is a continuum involving all agencies as sufferers proceed through life and support services should reflect this.
2. It is a developmental disability and not a learning one yet current support services do not reflect this. The support offered can be inappropriate and not recognise the difference in the needs between the two. For this reason it is appropriate to have a separate bill which recognises the developmental aspect rather than the learning one. It can sit alongside other legislation affecting disability quite comfortably and not detract from them.
3. Diagnosis is important in that it gives the carer and the sufferer, where old enough to understand, peace of mind and reassurance. It opens up pathways for the future. For many at present obtaining a diagnosis is a difficulty due firstly to the lack of awareness amongst those on the spectrum as to how to obtain a diagnosis and then to the reluctance of the professionals involved to commit themselves. There is a marked disparity throughout the country in the provision for a service to conduct the diagnosis especially in the area of adulthood. This disparity is reinforced by the contrast offered by Autism Resource Centre (ARC) in Glasgow and Edinburgh with what is available elsewhere. All health areas should have the equivalent of that service.
4. Education would appear to be the least problematic area given the provision within the Education (Additional Support for Learning) Act 2009 and Getting It Right For Every Child yet they do not go far enough in acting on the particular needs of the child having an autistic spectrum disorder (ASD), and concentrate on the school aspect and relate little to further education (FE). A bill would give the provision in schools a stronger footing and ensure the uniform provision of services between and within authorities. The specialist provision of autistic units must present an attractive target for local authorities seeking to reduce their budget and the Bill would be one means of safeguarding this provision.
5. The transition from school to FE, employment and adulthood is a fraught occasion since the support so helpful in schools appears to disappear and it is difficult to obtain a clear picture of the pathways ahead. If there was a key worker allocated to the sufferer at this stage to help manage the way ahead then and at other decision making stages life would be easier and more cost effective regarding support. The worker would know the particular needs of the individual and be able to tailor resources to meet these. At the same time the individual on the spectrum would get to know the worker, trust them and hopefully communicate with them.

6. Persons on the spectrum present a very valuable employment resource if properly managed but there are too many barriers for many to move into employment. The barriers begin with the process of finding and getting employment and continue within it. Failure in this area results in benefit claims and the move into psychological and psychiatric difficulties. Training and sympathetic management would overcome this problem but the current support services are geared to learning difficulties and target different aspects of employment. The employability of a person on the spectrum is witnessed by the number who work quite successfully in the voluntary/charity sectors.
7. Services currently are disjointed, not there at short notice when required and short of the support level expected. They generally lack an understanding of the real needs of a person on the Spectrum especially at the level of higher order functioning. For example one problem in independent living is managing money. For many the problem addressed by the services is the physical handling of money but the real need is for the understanding of the value of money and the rationalisation of purchasing so as not to waste money. Similarly in transport the problem is not getting on and off the bus but rather planning out the logistics of getting to and from a place. These types of issues differentiate the difficulties of autistic persons from those with learning difficulties alone. All persons have a right to independent living if desired but the current arrangements do not serve the needs of the autistic person to make this viable.
8. ASD sufferers are more likely than most groups to experience the justice system due to their inability to fully appreciate the consequences of their actions or in the way they react to a situation. A considerable sum of money and time is spent in processing a relatively minor misdemeanour even up to court level. If there was a national uptake by police forces of the Strathclyde initiative regarding the training for all force members by DVD of how to manage an autistic incident and the provision of autism alert identity cards to sufferers then a large savings could result from a small outlay.
9. In summary there is evidence of good practice and outcomes throughout the country but they are often confined to specific areas. The provisions in the Bill and strategy would remove the current "post-code lottery" vision of services and guarantee a uniformity of meaningful support across the country. Although there would be some initial costs in setting up some of these systems the savings in the longer term in areas such as employment; benefit and health and justice would far outweigh these. In many cases all that would be required might be awareness training and a redirection on existing provision at negligible cost.
10. Although the consultation process has been quite effective as witnessed by the level of responses at various stages we feel that the voice of the majority on the ASD spectrum cannot be heard because of the nature of their condition and written evidence would not be forthcoming from them. This is especially true of the middle and lower order functioning groups

within the spectrum. This might be rectified by representatives of the committee meeting groups to talk about the main issues.

11. The need for a bill is referred to throughout the submission but in essence it would ensure equality for all throughout Scotland. Without a bill there might be a “pick and choose” approach to which elements are progressed.

Sally Haslam  
Norman Gray  
Anne Chien  
Adele Donald  
Irene Ewen  
Li Zheng

Dundee Parent Group  
8 October 2010