

SUBMISSION FROM HOPE FOR AUTISM

1. As a third sector organisation representing over 200 families who live with a child or young adult with an autistic spectrum disorder (ASD) living in North Lanarkshire, please accept this short statement as written evidence on our behalf as advocates and as informed service providers to this group.
2. The six key areas which the Bill would address are shown to be of an inconsistent nature in families experiences. Therefore a national strategy and authority to such would be of great benefit. Particularly the provision of diagnostic services; the identification of children with an ASD locally and proper assessment would benefit from statutory guidance and inform a robust care pathway.
3. Most families who use our service report of a fragmented pathway to diagnosis. Experiences vary from parents being denied diagnostic assessments; labelling behavioural issues as being poor parenting, to waiting lists of over 14 months forcing selective criteria for children to be assessed and families subsequently resulting in distrust of professionals. These types of barriers such as outdated aetiological attitudes have had impacts such as family break ups, mental ill-health and informed wrong education placements which have major impacts on the young person with an ASD, often resulting in expensive crisis intervention requirements.
4. In terms of the planning and provision of services, currently there is a culture within North Lanarkshire of social inclusion but, by the very nature of ASD, individuals on the spectrum find huge difficulty in adhering to such an ideology but with a desire for such. Equality by its very definition does not mean treating everyone the same but rather addressing individual needs in a holistic way and this particular group would benefit by having local authorities addressing this with proper guidance.
5. The existing guidance available is good but lacks authority as it does not work for many families at present. Examples of this being—
 - Some head teachers in school not knowing they have an Autism Toolbox at their disposal
 - Current criteria for accessing parental interventions training as per SIGN 98, highlights gaps for families with older children
 - Inconsistent application of recommended interventions by statutory agencies.
6. Examples of good practice have several things in common in our experience. They usually begin with early identification of a possible need for diagnostic referral with an appointed person for the family to be reassured and supported by throughout. This person liaises with

education, the diagnostic service and other statutory agencies. This has allowed supports to be planned such as adaptation of curriculum.

7. This type of good practice informs accurate prevalence and planning needs. Diagnosis, support and training as early as possible helps families contextualise their child's behaviour, to access services such as our own as quickly as possible and to implement proper interventions which research has shown benefits all. Additionally, a multi agency approach to awareness raising through training and leadership works well when people 'buy into it'. Statutory guidance on accessing this training would mean this approach worked well more often and reached the right people.

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