



Southern Health & Social Services Council

*Response to
SHSSB Children's Autism Strategy
2005 - 2010*

August 2005

SHSSB Children's Autism Strategy 2005-2010

A response from the Southern Health & Social Services Council

1. The Southern Health & Social Services Council (SHSSC) was set up by the Government to represent the view and opinions of the public and to comment upon the public's behalf about changes to existing services and the introduction of new services.
2. This response is made independently from the decision makers and providers of services and aims to reflect a broad public perspective.
3. Before commenting on the consultation document, the SHSSC would like to make a number of general comments.
4. In relation to the consultation workshops, it was unfortunate that there was no Education & Library Board representation at the events even though an SELB representative was on the working group. Families experience need across a range of services and look at their child's development as a continuum. It is very frustrating for parents when it appears that service providers are not working in a 'joined up' fashion. Autism is obviously an area where educational input at all ages and stages will be important and is related to the child's health needs.
5. The consultation workshops demonstrated the high level of need experienced by families. It is apparent that existing levels of funding will not be able to provide the range of services requested, therefore, the service appears to be largely aspirational.

6. In spite of improvements in sharing information and signposting services, parents still appear to be having difficulties in getting information about services and resources. Staff training and attitudes are probably an important factor in this but there are also structural issues. Practical measures such as a more co-ordinated system across HSSBs and ELBs to support parents in moving from one area to another would assist families.
7. The consultation document appeared to be easy to read and generally accessible. In particular, the quotes from parents were helpful in highlighting the day to day issues that families have to deal with.
8. The range of services set out in the document is helpful and provides a Board wide view.
9. The document does reflect the needs the children and young people with Autism and the SHCCS is supportive of the recommendations. However, the recommendations are very general and for some of the recommendations, there is no detail provided as to how these will be taken forward. The SHSSC would like to make a number of observations.
10. Respite services are a crucial source of family support and in maintaining everyday life for parents and siblings. Whilst families and community networks can contribute to a family's respite opportunities, there may be training and other implications if the full benefit is to be gained from these resources. The strategy could identify how the building and development of any additional community capacity will be supported. This might be particularly helpful as the strategy does recommend that the development of a full range of respite services be taken forward, but does not specify how or when this will be done.

11. Increased awareness in health workers generally is important and could facilitate early diagnosis and support to families.
12. There is a need for further education for teachers in relation to Autism and including parental support.
13. Given the concern amongst parents in relation to the MMR vaccine, an early screening programme may help with early diagnosis and clarify any link with MMR. For example, routine screening at one year would flag up any early concerns about a child and would provide a baseline to measure any changes post-MMR.
14. Transition planning for families is very important particularly in children and young people with a desire for independence but no sense of danger to self. The provision of a range of supported housing arrangements may be an option for some families. Facilities such as the Camphill Communities provide a safe living and working environment. Given the SHSSB estimate of a cohort of 800 cases in the 0-19 year age range, forward planning for the post 19 age group would appear to be urgent.
15. Workforce planning and training needs to be factored in to ensure that if key staff members retire or move on, the service is not unduly weakened.
16. In conclusion, the SHSSC welcomes the strategy and its recommendations. In particular, we congratulate the SHSSB on its commitment to multi-agency working and partnership with parents.

S Cunningham

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