

Parents' Education as Autism Therapists (PEAT)

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Comments on the Draft Autism Bill for Northern Ireland

In principle, PEAT agrees there is a need for legislation to protect the rights and interests of persons diagnosed with Autistic Spectrum Disorders (ASD) and their families or carers. PEAT is aware that the HSC already has an ASD strategy which came following the review of HSC Autism provision chaired by Lord Ken Maginnis (Maginnis, K.(2008) *Independent Review of Autism Services*). However, PEAT was not consulted concerning this review and again we raised our concerns in relation to the "AUTISM SPECTRUM DISORDER (ASD), STRATEGIC ACTION PLAN, 2008/09 – 2010/11" (see Annex I). Indeed PEAT, in collaboration with Queen's University Belfast and the University of Ulster, published a research report "Meeting the needs of families living with children diagnosed with ASD" in 2007 which focused on families in Northern Ireland (Annex II). This report, although made readily available was ignored by the Maginnis review.

The priority for ASD in Northern Ireland should be effective treatment and intervention. The Health Committee should consider a truly independent review of ASD services which would be open, transparent and take account of international best practice. As a starting point, the Health Committee should look at recent happenings in the USA and Canada in relation to ASD provision. For example, Ontario will be expanding services for children with autism-spectrum disorders starting next spring. The province will spend \$25 million a year to provide **Applied Behaviour Analysis** services and supports in community agencies and centres, schools and homes (Canadian Press, 14, 12, 2010). In the USA, to date 31 States have passed autism insurance legislation which will require health insurance policies to cover the diagnosis and treatment of autism spectrum disorders, and require health insurance companies to pay for evidence-based early intervention, widely recognised as **Applied Behaviour Analysis**.

Applied Behaviour Analysis intervention is not a statutory right for children with ASD in Northern Ireland and families must pay privately for such intervention, which is therefore not regulated. Given the investment and legislation in the USA and Canada, obviously there is a strong economic argument for effective intervention based on ABA. Indeed there have been several cost-based analyses reported on the use of early intervention based on ABA and all conclude that there would be significant cost savings in the long term. For example, Motiwala et al (2006) reported that the use of early intensive ABA would reduce the total costs of care for autistic individuals and increase the gains in dependency-free life (Annex III). Chasson et al. (2007) reported estimated cost savings in the region of \$2.09 billion for the State of Texas alone if early intensive ABA was funded for the existing children with ASD, as opposed to existing (eclectic) special education provision (Annex IV). There are a number of reports concerning the cost of provision over the lifetime of a child diagnosed. For example, Knapp et al. (2007) reported on the cost of ASD in the UK. The aggregate national costs of supporting children with ASD were estimated to be £2.7 billion each year. Most of this cost is accounted for by services used. For adults, the aggregate costs for adults amount to £25 billion each year. Of this total, 59% is accounted for by services, 36% by lost employment for the individual with ASD, and the remainder by family expenses (Annex V).

If the proposed Autism Bill will ensure that effective treatment and intervention for children and adults with ASD will be delivered in Northern Ireland, then it will have the full support of PEAT.

Yours sincerely

Dr Tony Byrne

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On behalf of the PEAT Charity