

## **Parent's Autism Lobby**

Written evidence to the Committee for Health, Social Services and Public Safety re Autism Bill

PAL would like to briefly give written evidence to the bill.

### **Section 1:**

#### ***Amendment to the Disability Discrimination Act 1995 (c. 50)***

PAL acknowledges that within DHSSPS, generally Autism is recognised as a disability (under the mental health or learning disability budgets) and that services are provided on a needs basis not a diagnosis basis. However the needs of individuals with Autism are much wider than DHSSPS's remit and other government departments do use the descriptions within DDA to allocate resources and provide funding.

*Currently individuals have difficulty accessing DLA because Autism is not listed in the DDA*

### **Section 2:**

#### ***The Autism Strategy***

PAL recognises that DHSSPS has an Autism Strategy and that DENI are working towards an Autism Strategy, however Northern Ireland needs a Cross-Departmental Autism Strategy such as in place in Wales because Autism Needs implicate on many government departments.

*Currently there is a lack of coordination between departments so that there is duplication of some aspects, and gaps in other services. Training is patchy and parents and individuals have to fight for recognition repeatedly, rather than the diagnosis being made and information shared between departments to allow a simple system for individuals with Autism (which by diagnosis recognises communication difficulties). Currently individuals with Autism (or their parents) are having to deal with each department in isolation.*

### **Section 3:**

#### ***Content of the Autism Strategy***

PAL recognises that DHSSPS has made progress in reducing waiting lists for initial diagnosis. A holistic approach is needed however, looking at cradle to grave services for this life-long condition. Quality diagnosis should be followed by early intervention and a package of support provided for the family. Additional resources should be ready for those who need them particularly at periods of transition. Supported employment and supported housing should be available when required. Autism

related questions should be on the DLA form, many of the issues faced by individuals with ASD and their families are ignored in the form and questions on the form are irrelevant to them. The Department of Policing and Justice should be aware of the risks individuals with ASD have of being misinterpreted by the system and have systems in place for interviewing individuals with ASD in a suitable environment with advocates to support their difficulties in communication skills.

*The current situation is that many report cases of “watchful waiting” where individuals are seen then simply moved to another waiting list, one that is not target driven. Furthermore it is apparent that methods of best practice identified a decade ago and in practice until recently are being abandoned and diluted methods are being used because they are faster and help meet targets. This Target driven system does not deliver the quality of diagnosis, nor is it followed up with adequate services. There is not a cohesive link between departments, each to a large extent, are self-focused, with a silo mentality. Supported employment is not always available and supported housing is judged on DDA criteria which does not include Autism.*

**Conclusion:**

In conclusion PAL with the 1000 families it represents draw attention to the urgent need for joined up government to deal with the rapidly increasing number of individuals with ASD, mindful that children diagnosed with ASD grow into Adults with ASD.

A cohesive Strategy will not only stop wasteful duplication of some services, but through appropriate interventions and support greatly reduce future costs on society as individuals and families are empowered to support themselves and boost the NI economy.