

The Parent Carers' Council on Disability

The Parent Carers' Council on Disability was established in 2005. This Council came about from a number of parents with children and young people with disabilities. As parents we did not make a difference in what the child's disability was for e.g. if it was learning disability, physical disability or sensory disability or a prolonged condition which impacted on daily living. As a group of parents we felt we were the experts in our child and young person's life. Our vision was to seek new and distinctive ways of working with the different multi-agencies and professionals that came into contact with the lives of our children and young people. We wanted to make a difference to the lives of children with disabilities and their families. We also wanted to have our own voice as we felt we were let down by the volunteering and statutory agencies. We, as a group, felt that the best people to plan for their child and young person is their parent/carer as we have first hand experience of our child's condition.

Our families go through a grieving process. We go through stages of denial, shock, anger, guilt, overwhelming anxiety, sadness and even depression before we are able to accept the reality of our child's disability – this is a continuous process.

The Parent Carers' Council on Disability is involved in:-

- Regional ASD Work.
- Looked after Children (LAC).
- Northern Ireland Social Care Council
- Regulation & Quality Improvement Authority
- Social Care Institute for Excellence
- Carers' Reference Group (Southern Trust)
- Wraparound & Children's Services Planning
- Training
- Department of Health Social Services & Public Safety
- Health & Social Care Board
- Public Health Agency Health & Social Services
- Education & Library Board
- Guidelines & Audit Implementation Network (Adults with a Learning Disability in Hospital)
- Patient Client Council
- Department of Health & Social Security (DLA Branch, Castle Court, Belfast)

As you can see from the above our involvement is expansive. As parents we feel it is important to be involved in the planning and development of services. This is only

a small part of the work carried out by the Parent Carers' Council on Disability. If you would like more information please do not hesitate to contact Mrs Mary Duffin, Chairperson.

The 1995 Disability Discrimination Act (DDA) defines disability as a "*physical or mental impairment which has a substantial and long term adverse effect on a person's ability to carry out normal day to day activities*". This is the legal definition of disability and is applicable to all public bodies. It is the opinion of the Parent Carers' Council on Disability that this Act covers both Autism and Aspergers.

The Parent Carers' Council on Disability would like to know:-

- What does the Autism Bill offer to families on the ground on a daily basis that we have not already got?
- Will the Bill provide a better quality of services for families for e.g. respite, speech & language, occupational therapists, better schooling?
- Will there be better support for families?
- Will there be better access to services?
- How many other Autism Groups were spoken to?
- How many other disability groups views were sought?
- How much is this Bill going to cost and at what cost to existing families in the disability world?

The Parent Carers' Council on Disability welcomed the Regional Autism Spectrum Disorder Network (RASDN). As a Council we also support the work to date that RASDN has done. We are delighted that parents and service users are involved in this work. We as a Council feel that not all the members of the Health Committee have read all the information and material on RASDN. Had they done so they would not be supporting for another Autism Strategy. Given the current economical climate we feel that at this moment in time it would be a waste of resources which could be spent to help and provide services for all families with disabilities. Parents have raised concerns about dual diagnosis and do not understand how a Bill could help them. Some of these families have children and young people with Down Syndrome, Epilepsy, Cerebral Palsy and Mental Health problems, Autism is not the primary diagnosis but the Autism has a major effect on their lives. What does the Bill entail for these families? Would it not be better if we had a Bill for all disability instead of putting our children and young people into silos? A child or young person should be seen first as a person and their diagnosis second. If there was more Person Centred Planning, more working together, families would feel much better and more equipped to deal with their everyday situation. We also feel that if voluntaries would work more together and listen to families, life for families would be much better. We would also like to remind you that one size does not fit all. When you look at Autism from beginning to end it is a very long, diverse journey. No two children/young person with Autism are the same so we think it is time that we all work together in the good and the better for the children and young people. We

would also like to see the end of the internal battles in the ASD world as it is not good for families.

As a Council we feel the way forward is working in partnership, providing information, giving families choices, equality and to be involved in the planning and decision making of their child/young person's life. We as a Council will continue with this ethos. We hope that you will now have a better insight and understanding of the emotional rollercoaster of life that we are on.

On behalf of the Parent Carers' Council on Disability we would like to thank you for giving us this opportunity to express our thoughts on this Bill.