

# Speech

25th May 2005

## **Introductory Speech by Nigel Williams, Northern Ireland Commissioner for Children and Young People at the PAPA “Side by Side with Parents” Celebration on Wednesday 25th May 2005 at Hillsborough Castle**

Thank you for that welcome and I am delighted to be here. Right from the announcement of my appointment as Commissioner in June 2003, the needs of children with a disability, and especially a learning disability have been at the top of my agenda. Within that broad grouping, I have been especially concerned about how we as a society are responding to children on the autistic spectrum.

Children with autism have never been far from the news over recent years, whether it is debate about possible causes of the condition, or disagreement about the best therapeutic approach to adopt in responding. In my remarks this morning I want to focus if I may on two areas.

- First, I want to explain what NICCY has been doing over the last 18 months which will lay the foundations for our future action in this area; and
- Second, I want to comment briefly on the importance of the partnership between parents (and their children), the voluntary sector – organisations like PAPA; and the government in all its guises from the Departments of Education and Health at Stormont to individual education and library boards and health and social services trusts around Northern Ireland.

First then, what has NICCY been up to? We have been through a rigorous and open process of deciding what the priority issues relating to children’s lives that we should concentrate on in our work over the next three years. I am glad to say that with Ministerial approval of the NICCY Corporate Plan received last week, I can now publicly confirm the direction we are taking.

But let me remind you how we got to here. When first appointed I announced a major research project, undertaken by a team from Queen’s University, to compare the state of children’s rights in Northern Ireland against the international standard, highlighted in my legislation, of the UN Convention on the Rights of the Child. In essence, that convention is a set of promises by our government, and other governments around the world, to their citizens aged under 18. I wanted the Queen’s research to answer the question as to whether the Government were keeping their promises.

I published the research last October. It showed a very wide range of issues where the promises to our children were either not being met or only partly met. The whole area of learning disability was one of those areas of deficit. I therefore proposed in October, 14 different priority areas that I and my staff should focus on for our 3 year plan.

But I wanted to hear what the public thought about these proposals so I launched a major SHOUT! Consultation, with megaphones being sent to most homes across Northern Ireland and all sorts of events, especially with young people. For example, I visited a special school and listened to the principal and parents. I met with a group of young people with attention deficit disorder, some of whom also had Aspergers’ Syndrome. I met with a group of young people convened by Mencap. These are just three examples from a long list of consultation events.

We had over 1600 responses to our consultation and we made a number of changes to our proposed plans as a result. For example, we decided that 3 of our priority areas for action

were so fundamental and influenced all the others that we should highlight them as the underpinning priorities – they are ensuring young people have a say; making children and their parents aware of their rights under the Convention on the Rights of the Child; and thirdly ensuring that public bodies implement the Convention.

I can confirm this morning that the two priority areas relating to disability and special educational needs were very strongly supported through our consultation, and form part of our plans.

You may also be interested to learn that we did decide to add one priority area to our plan – and this was largely influenced by strong feelings from young people in the consultation – that area is responding to Risk taking behaviour i.e. alcohol, drugs, smoking, early sexual experimentation.

So we now move on to the next stage of our work – action to produce change in each of these priority areas. Well, it's not quite right to say it is the next stage – that might give the impression we have been twiddling our thumbs while our corporate plan was being developed and approved! As Linda Kerr – NICCY's Head of Legal and complaints - who is here this morning can tell you that is far from the truth. Linda's section have dealt with over 200 complaints since NICCY was established and the biggest single issue of complaint has been services for children and young people with autism. Linda's team has a good track record in getting resolution to the individual problems that are brought to them.

However, some issues require further research and pressure on Government to sort out. One example where we have made progress already is Speech and Language Therapy. I was so concerned about the huge differences that seemed to exist in the delivery of the SLT service across Northern Ireland that I asked my research team to undertake a survey of all health and social services trusts. That survey, which we published on the NICCY website in March, confirmed our fears about the length of some waiting lists and the delays being experienced, especially for young children awaiting their first appointment.

I am glad to say that having highlighted the issue we are beginning to see some positive developments in addressing the problems. I will not be letting this issue go. I promise you, the report we produced will not lie on a shelf and gather dust. I will be meeting each Health Board and its associated trusts next month to see what action they are taking in the light of the problems they face. So watch this space!

The second major area I wanted to mention this morning was the importance of partnership in dealing with issues like autism. I think this theme of partnership is especially relevant on a day when we are celebrating the work PAPA has been doing with parents, and we are having that celebration in a building that is at the heart of Government in Northern Ireland.

My background is unusual in that I started my working life after university as a Civil Servant, then after 8 years moved on to set up and run my own business for 4 years, before moving on again to work in the voluntary sector for 15 years, the last 8 spent in establishing and developing a small children's charity. Now I am back with my salary paid by the government, but spending most of my time challenging civil servants about how we can do things better.

I of all people recognise the vital importance of a constructive relationship between government, the voluntary sector, and families.

I think the history of parents responding to autism in Northern Ireland has been one where for many years parents struggled to be heard. They knew their children needed more and better help than they were getting, but it seemed like Government was struggling to understand that and respond.

I think the establishment of PAPA was a watershed in bringing together parents into a grouping where alongside professionals, as the name suggests, they could have a more

effective voice. PAPA also gave a chance to learn together, to look at best practice and new ideas for helping children on the autistic spectrum. Indeed PAPA has developed some very innovative resources for parents and their children – some of which you will hear more about later.

I don't think the establishment of PAPA somehow meant that the fight for proper treatment of children with autism was won – far from it, I suspect that it has allowed a much better recognition of the extent of the challenge, of the number of children involved, and of the depths of the needs that should be met. Over recent years we have seen other organisations and groups come into being too – some to fight for a particular type of therapy, and others to support particular groups of children. The fight for proper services goes on – and indeed there are a number of cases before the courts at present raising a range of issues in relation to individual children.

But what about the future? How should the relationship between parents, the voluntary sector, and government develop.

I think the important thing is that each party plays its full role, doing what they do best.

Parents are the primary care givers to their children. Parents are the ones who often recognise when something is not right, or can see when their child needs help. Parents are the best advocates for their children's needs.

But parents need support and parents need listened to. I see PAPA's primary role as providing that support to parents. PAPA provides a place where you can know that you are not alone, and that there is hope for your child. That peer to peer support is invaluable, and cannot be replaced by any government service. I think PAPA also has an important role in lobbying for change, in highlighting new approaches to dealing with autism, and in pioneering new types of service.

But, and hear I sound a note of caution, I don't think PAPA's primary role should be in "service delivery" - that is in providing the day to day professional support in education, in speech and language therapy, and in other areas of help to children with autism. That is the Government's role. That is why we pay our taxes.

Government needs to ensure that all children enjoy the rights to education and health which are spelt out in the promises they have made in the UN Convention. Government may want to pioneer new approaches in conjunction with agencies like PAPA – that can only be good. But PAPA should resist any pressure from government to become a basic service provider potentially on the cheap, because of the commitment and passion of its staff and volunteers.

That is my vision of this partnership. I see my own role, and that of NICCY, as helping parents and the voluntary sector to keep the Government honest in honouring its promises to children. We will do that through dealing with individual cases. We will do that in arguing for policy change. We will do that through research like our Speech and Language Therapy Report that shows the need for improved service delivery. NICCY is an additional partner in this process where the children and young people must come first.

Thank you for listening and I wish you well with the rest of your celebration.