

Thursday, 18 January 2007

The Joint Committee met at 11.30 a.m.

Members Present:

Deputy B. Andrews,  	Senator P. Coghlan, *  
Deputy S. Crowe,  	Senator M. Finucane, +  
Deputy J. Curran,  	Senator J. Hanafin, *  
Deputy J. Ellis, *  	
Deputy D. English,  	
Deputy O. Enright,  	
Deputy P. Hogan, +  	
Deputy N. O’Keeffe, *  	
Deputy J. O’Sullivan,  	
Deputy M. Ring, +  	

* In the absence of Deputies T. McEllistrim and M. Hoctor and Senators U. Burke and L. Fitzgerald, respectively.

+ In the absence of Deputy Ring and English, respectively, and Senator P. Coghlan, for part of meeting.

DEPUTY M. MOYNIHAN IN THE CHAIR.  

► **Business of Joint Committee.**

Clerk to the Committee: In the absence of the Chairman, I call for the nomination of a temporary Chairman.

Deputy N. O’Keeffe:   I propose that Deputy Andrews act as temporary Chairman.

Clerk to the Committee: In the absence of other nominations, I ask Deputy Andrews to take the Chair.

Deputy Andrews took the Chair.

Acting Chairman (Deputy Andrews):   Apologies have been received from Senator Ulick Burke. As there are housekeeping matters to be dealt with before we meet our guests, I suggest we go into private session. Is that agreed? Agreed.

The joint committee went into private session at 11.40 a.m. and resumed in public session at 11.45 a.m.

► **Parents and Professionals and Autism, Northern Ireland: Presentation.**

Acting Chairman: 📄 🗣️ The joint committee is in public session. I welcome Ms Arlene Cassidy, chief executive of Parents and Professionals and Autism, PAPA, in Northern Ireland. I will hand over to the Chairman who has joined proceedings.

Deputy M. Moynihan took the Chair.

Chairman: 📄 🗣️ I thank Deputy Andrews for commencing the meeting and apologise for being late. I welcome Ms Cassidy.

Before the presentation commences, I draw the attention of witnesses to the fact that while members of the committee have absolute privilege, the same privilege does not apply to witnesses appearing before it. Members are reminded of the long-standing parliamentary practice to the effect that they should not comment on, criticise or make charges against a person outside the House or an official by name or in such a way as to make him or her identifiable. I call on Ms Cassidy to commence her presentation on behalf of Parents and Professionals and Autism.

Ms Arlene Cassidy: I am grateful to the Oireachtas Joint Committee on Education and Science and its Chairman, Deputy Michael Moynihan, for giving Autism Northern Ireland, Autism NI, and Parents and Professionals and Autism, PAPA, an opportunity to be heard on the matter proposed, namely, early intervention for children with autism. I have provided some personal background information for the committee. The speech I will read is contained in the packs provided for committee members with what we hope is other useful information. I have made some minor changes to the speech, as I discovered a couple of typographical errors when I read it last night. I will point them out as I go along.

Before moving to the issue before us, I wish to clarify the rationale behind Autism NI's request to be heard. In so doing, I hope I can also set the issue of early intervention within a wider policy and strategic and legislative context. The history of autism provision in Northern Ireland proves it is critical to root services in a cohesive future-orientated strategy that will guide services instead of services guiding strategy.

I acknowledge the encouragement of the late Michael Ferguson, MLA, who was one of the cross-party Northern Ireland Assembly autism ambassadors. In response to our expression of interest in developing partnerships and sharing information on an all-Ireland basis we were introduced to Deputy Crowe and the possibilities of approaching this committee. To complete my introduction to the issue before us, it is important to explain the ethos of Autism NI and why we believe early intervention is such a strategic and pivotal issue for the State.

Autism NI-PAPA has been the only independent voice for the Northern Ireland autism community since the establishment of the organisation in 1990 as a parent-led, partnership-focused agent provocateur for the development of expertise, resources and

services for individuals with an autistic spectrum disorder, ASD. Using evidence based research and developing a network of parent and professional partnerships, Autism NI has contributed significantly to the enhancement of professional expertise regarding autism and the empowerment of parents by designing and delivering models of best practice. The organisation set itself apart from the growing number of service providing ASD groups and services by retaining its resistance to taking on a traditional service providing role, preferring instead to develop effective partnerships with established statutory and voluntary providers. This role was powerfully illustrated in the repeated recorded references to our work in the Northern Ireland task group on autism report published in 2001 by the Department of Education in Northern Ireland.

The years 2001 and 2002 and the task group on autism report marked a watershed for those with autism in Northern Ireland. Equipped with the evidence of need, prevalence rates and recommendations from this landmark service evaluation, Autism NI activated an accelerating political lobby within the Northern Ireland Assembly to effect policy, strategy and legislative change. The task group report bravely acknowledged failings across the education, health and social care sectors, enabling us to switch our focus from proving to meeting need. Our political lobby began based on three key messages, the first of which is that we need an autism-specific service structure with ring-fenced funding within a Northern Ireland autism strategy contained in the Northern Ireland Autism Act.

At a reception in Parliament Buildings Stormont in June 2002 MLAs listened to parents and professionals and members of Autism NI-PAPA as they were urged to ensure the task group report findings were resourced and implemented. In March and September 2002 two debates on autism were held and both motions in support of ASD services were passed unanimously. By November 2002, after a year long lobby within the Northern Ireland Assembly, a cross-party network of autism ambassadors was established. These Members of the Legislative Assembly in Northern Ireland were also the education, health and social services spokespersons for their parties.

A range of local and regional events have taken place since, culminating most recently in the following programme of activity. Members will be pleased to hear I will not go through each one but they are provided for the purpose of record. It is difficult to pick out the highlights but I will refer to some of them.

In January 2006 there was a gathering of Northern Ireland MLAs. They made a written pledge to initiate a commitment to see through autism legislation. This was not done in the Assembly chamber but in a reception setting. In March we launched our partnership with the Welsh autism society, Autism Cymru. Politicians from various parties, parents and representatives of the statutory sector were in attendance. The lobby that took place at that event in Whitehall caused the Secretary of State, Peter Hain, to ask for a meeting with a delegation from Autism Northern Ireland.

The next little milestone in our political lobby was an event in the Northern Ireland Assembly, that is, the launch of the document entitled, *The Blueprint for Change*. It is really a response to a question we have been asked: if there is to be legislation on autism,

what should it contain? Most recently, there was a debate on autism and a motion was passed unanimously calling upon the Assembly to consider the Northern Ireland autism legislation as its first item of business. I have copies of the debate in the Assembly buildings last week for members of the committee.

The Celtic Nations Autism Partnership is to be launched at the end of this month. It is a growing organisation and its membership currently comprises representatives from Northern Ireland, Scotland and Wales. In 2007 we seek to develop links with the United States. In February I am going to meet colleagues in the Autism Society of America regarding the recent Combating Autism Act. We are seeking to deepen our links with the Swedish autism society. Sweden has protections pertaining to autism enshrined in legislation. We also seek to develop links with Canada, Denmark and New Zealand which either have their own ASD strategies or are developing them.

As the number, variety and levels of partnerships for autism grow and as the policy and legislative scene is being set for a more strategic approach to meeting the acknowledged and well documented need, there is a great opportunity for developing a co-ordinated, cohesive, effective and efficient practice across Ireland and the United Kingdom. Thanks to EU-funded and Irish-led projects such as the European Autism Information System, one can have an impact across Europe. Kathy Sinnott, MEP, is involved in this work. Developing services without a strategy could be described as putting the cart before the horse. Future development needs to be rooted in a cohesive, future-orientated strategy that would guide services, rather than having services that would guide strategy.

Let me use this philosophy to illustrate the potential of early-years ASD services underpinned by evidence-based research operating within the Northern Ireland early-years strategy. I assume we are all convinced by the extensive body of research worldwide supporting the critical significance of early intervention in addressing skill deficits experienced by children with autism. The Autism Northern Ireland early-years strategy is guided by this research, in addition to a significant body of Northern Ireland research on foot of collaboration between Professor Roy McConkey, University of Ulster, and Autism Northern Ireland. The strategy embodies the principles of statutory and voluntary partnerships to develop a service framework that addresses the key three stages of identification, assessment and diagnosis, and post-diagnostic support. These are all based on the key three principles of parent training and empowerment, professional training, and child-focused, home-based intervention. We need to be practical and examine what service models exist and see what this voluntary agency has developed within a partnership model.

The service models that operate within this context are detailed in the leaflet distributed to members of the committee. When parents sense there is a problem regarding their child's social development and communication they can use the rainbow kit. The kit is presented in a backpack, to be attractive and portable, and contains bright, colourful booklets written by parents for parents on issues such as play and communication. The pack also contains toys, resources, and trays to which tasks can be attached, such as shape and colour matching exercises. There are similar tasks whose importance educated people

would be capable of recognising. They are in the pack for ready access. We have examined this kit in our research collaboration with the University of Ulster.

The rainbow kit is a practical, tangible resource that can be given to parents as they struggle with the uncertainties of an impending assessment on their children. We provide a backpack of activities, jigs, resources and booklets for parents to use with professional support to address their children's key deficit areas. The name of a professional trained in the use of the kit is supplied with each kit. The professional's role is to support and guide parents in the use of the various items and why they need to be taught. Research has shown the outcome to be an alleviation of parental stress at a time of great uncertainty and powerlessness. In addition, Autism Northern Ireland provides a free autism information pack, an example of which is included in the kit.

Other supports include a helpline, training resources, a GP leaflet and our branch network. We regard assessment and diagnosis as the meat in the sandwich, linking identification to intervention. It must be a statutory provision. Access to specialist multi-disciplinary autism assessment and diagnostic teams is critical in helping families and professionals to apply scarce resources appropriately. The voluntary sector has a role in this respect, for example, the Northern Ireland diagnostic special interest group is a professional body comprising paediatricians and psychologists. The group provides peer support and advice on practice standards. It has recently linked up with the Western Australia diagnosticians forum to extend that peer support.

Parents can help their children through home intervention, parent training and professional training. Home intervention offers a home-based early intervention therapy service, linked to early years education provision. Personnel must be trained in a full range of key educational and therapeutic strategies to work alongside, and empower, parents. Our access workshops provide a six week programme in which families can debate core issues in a mutually supportive atmosphere.

With regard to parent training, again we have a practical model, access workshops which provide a six-week programme for families to debate core issues in a mutually supportive atmosphere. Group members have the option of joining, and also a NI local parent support group, at the end of the series of meetings. A help-line is also offered as well as a range of training provided by the Autism NI training department. We also run siblings' groups and we have begun to deliver workshops for grandparents.

An example of professional training is the keyhole pre-school training programme, delivered as part of a partnership of voluntary organisations such as Autism NI, PAPA, the Early Years organisation and Barnardos. The programme is designed to train early years professionals in pre-school settings. Along with the transition liaison service, it provides a bridge to facilitate a child's move from home intervention to an education setting. This strategy is still being rolled out across Northern Ireland. Two of the four health and social services boards have invested in the complete service programme with the two remaining boards piloting various elements.

Our partnership with the national autism societies of Wales and Scotland has facilitated an exchange and sharing of information and knowledge. This early years strategy for autism is one example of what Autism NI can contribute to the wider autism community. My presentation is an extension of this. This is the potential of strategic partnerships which will hopefully help us not to waste time re-inventing the wheel.

As we consider the potential impact of the All-Ireland Centre of Excellence for Autism at Middletown, I appeal to members, and their colleagues in Northern Ireland, to commission a thorough audit of ASD strategy and practice. This would ensure the very best from the voluntary sector and voluntary statutory partnerships in the North and South is recognised, supported and integrated where possible. I, therefore, encourage members to actively support a cross-Border initiative to address the all-Ireland identification and sharing of best practice across all sectors. This has to be led by the key autism society in each jurisdiction to ensure effective representation of the voluntary sector in any strategy.

I particularly appeal to members to consider not only our work in the field of early intervention but also to be aware of our establishment by the Northern Ireland Department of Health, Social Services and Public Safety as a specialist autism training provider and our pivotal role and experience in the provision of family support and parent empowerment. In the absence of autism strategic planning in Northern Ireland, the role of Autism NI has also included that of being a strategic driver for policy and practice development. For example, we secured a British Government research grant to develop training standards linked to the Scottish autism training strategy. The presentation intends to give the committee the evidence of the vital role fulfilled by the voluntary sector. It is a role that can be easily forgotten and whose work can be obliterated by the bureaucratic urgency that can result from governmental decisions to develop services without an integrated strategic context.

Additional information is available on our website. I thank the committee for its valuable time and its consideration of the issues submitted to it.

Chairman: 🗣️ Thank you very much, Ms Cassidy.

Deputy Enright: 🗣️ I thank Ms Cassidy for her presentation. At what stage is the Middletown project? The 2001 task force report on autism contained no reference to Middletown or any all-Ireland centre. Some groups were concerned that we were providing a Rolls Royce service in Middletown for only a small number of people who could get there. The services for children in this State were quite limited in comparison. Some did not want their children to spend a week seeing how a fantastic service operated if they could not access the same service when they returned home. However, I am aware the idea was to show parents an example of best practice. Can Ms Cassidy tell us how the project is progressing?

Ms Cassidy appeared to say that autism in Northern Ireland was dealt with separately from other disabilities. That was the case in this State until approximately two years ago,

when it was brought under the control of the HSE and the Department of Education and Science. Some 12 autism units exist, linked to different schools, but separate facilities are not provided and they are mainstreamed with other disabilities. What are Ms Cassidy's views on that? Is the service still separate in Northern Ireland? There are arguments for and against but the parents of children with autism whom I meet feel the demands are so great and that their children have so many other difficulties that autism needs separate attention.

I did not hear anything about applied behavioural analysis. The delegation is probably aware that it is a big issue for us at the moment. Do schools operate that approach in Northern Ireland? What State assistance or intervention is available? There are only 12 schools in this State and another 12 which are currently seeking funding. Some parents use home tuition grants to operate the approach themselves, which creates financial difficulties. What are Ms Cassidy's views on that?

At what age does early intervention start and who is responsible for it? Is the health service involved in diagnosis? We have a problem that probably also exists in Northern Ireland. The Department of Education and Science only steps in when children are aged approximately five. The HSE intervenes earlier but children seem to fall between the two, which is a difficult problem to address.

Chairman:   We will hear from a number of members and return to Ms Cassidy for her replies.

Deputy Crowe:   I welcome Ms Cassidy to the committee. As she said, I met the group in July and the joint committee can learn much from her presentation. It is also important to engage in dialogue with different groups, particularly PAPA. I have spoken to parents and see no difference between a child with autism in Derry and a child with autism in Dublin. Equally I see no difference between a child with autism in Cork and one in Cardiff or Edinburgh. Families are crying out for resources but also want dialogue, not only among groups but among individuals and families. Ms Cassidy said her own group had opened up discussions with groups in Scotland and Wales and we should have such a discussion among the people on the island of Ireland.

The need for a centre of excellence was identified early on in the negotiation of the Good Friday Agreement and funding was agreed by both Governments for such a centre at Middletown. Like other people at the meeting today I am concerned at the delay in its roll-out. It was raised in a recent discussion of the Assembly and all sorts of reasons were given. Anybody with a child with autism will be seeking answers and new ways of approaching the child's impairment and moving on. I am conscious that next week there will be the culmination of one family's court case, where the €5 million cost is the extent to which that family felt it was not getting the best response from the Department of Education and Science. The family felt it necessary to take such action, but we all want to see a situation come about where families would not be forced to take court action.

It is important that we share information. There may be a difficulty with this and an issue that strikes me with regard to autism is that we do not know the exact number of autistic children out there. A recent edition of *Lancet* indicated that one child in 1,000 was previously affected by autism, but now the number is one from every 100. Other studies argued that autism affects 3.4 from every 1,000 children between the age of three and ten years.

All the experts agree that early diagnosis and intervention is important, but there are difficulties in this regard. I have seen figures from the North on the roll-out of that assessment. Perhaps Ms Cassidy might speak on that, as I believe the period for diagnosis is approximately 30 or 35 months. How are other groups, from Wales and Scotland for example, coping with regard to assessment? The assessment period is fairly short in Wales.

With regard to the Middletown question, Ms Cassidy has mentioned the audit and assessment. Is PAPA satisfied with the progress of the jointly-funded all-Ireland centre of excellence for children with autism? I have been told the Department of Education and Science has already spent €2.6 million, but what is holding up the process and how can such issues be rectified? Is there an update on efforts to develop this all-Ireland partnership, particularly with the voluntary sector? Has there been outreach with different groups? There is a problem in the Six Counties with long waiting times, up to and beyond 35 months. In Wales, the waiting time is ten months, so there is clearly a worry in this respect.

Autism occurs more frequently in males than females, with the ratio of 4:1. Does the witness know of any other research relating to this? There are between 1,200 and 2,000 children and young adults with autism in Ireland, with an increasing rate of 100 new cases every year. We seem to be getting better at identifying children with autism every year, but if the assessment is that long and early intervention is so important, it will create a significant worry for families.

Within a three-year period, the identified number of school-age children with autistic spectrum disorders in the Six Counties increased from 1,000 to 3,000, which I assume is down to better assessment. Perhaps the witness will indicate how she sees dialogue and interaction with parents and voluntary groups developing in the future.

Deputy Andrews:   I welcome Ms Cassidy and have some questions on which Deputy Crowe may have touched. He gave figures on the prevalence of autism in children but I recall that Kathy Sinnott said before this committee that in her view, given the direction of the pattern, in time one child in seven will be diagnosed with autism. This is a dramatic figure. Is research funding being provided to examine the issue of prevalence? I have noted the research issues in which Parents and Professionals and Autism, PAPA, have been involved.

Regarding early diagnosis, international comparisons on the average age at which a diagnosis is made are very beneficial. In the Republic of Ireland it could be 24 months,

while in other places it might be 18 months. This would provide a way of setting early diagnosis benchmarks based on international standards. What are the benefits of early diagnosis in terms of treatment and intervention?

Deputy O’Sullivan: I apologise for being late; I think I ended up on the same train as the Chairman because the other one broke down. I missed the presentation but have had a quick look at the details.

I wish to return to a point Deputy Crowe was making as I entered the room on the importance of learning from each other and co-operating wherever we can. There has been huge development in autism research and it is growing all the time increasing our knowledge of the condition and the best forms of intervention. I receive many e-mails with detailed information on the ongoing research. It is important that we learn what we can from each other and implement what we learn.

Deputy English and I, with a number of other representatives of this Parliament, recently attended a joint North-South meeting on educational disadvantage which was also attended by politicians from Northern Ireland and individuals involved in the education and library boards. It proved beneficial because we learned about some of the good things happening in Northern Ireland and they learned about some of the good things happening here. The more we do this across the various sectors the better.

The proposals made in the blueprint for change are geared towards early identification and setting specific timeframes for the diagnosis of autism and the development of a care plan. This is in line with what has been discussed at this committee, particularly with regard to the Education for Persons with Special Educational Needs Act 2004. The difficulty lies in having all of this implemented and getting the various personnel in place to make the diagnosis and provide support. Are the same difficulties experienced in Northern Ireland in terms of ensuring expertise in the various forms of assessment? Is it necessary to conduct a detailed assessment to determine the condition and needs of a child? I have heard descriptions, ranging from the making of a diagnosis after a couple of hours to an observation of the behaviour of a child in the family home lasting five days.

I understand Deputy Enright has asked whether the applied behavioural analysis, ABA, system is used widely in Northern Ireland. There is growing demand from parents here for this form of intervention for children with autism. I visited an ABA school recently and was very impressed with how the children were treated. They seem to respond and make progress in such a one-to-one setting. One of the difficulties here is that people who may have expertise in that area are not necessarily trained in education. There is an ongoing evolving situation where groups of parents have come together to set up an ABA school and have been using home tuition grant funding — which I am not sure is available in Northern Ireland — to pay for the staff working in those schools. They are now being told that such funding will be withdrawn, that their children should be in mainstream schools and that their children, whether in ABA schools or at home, should have people who are trained in education. Is it the view of PAPA that people need to be trained both in autism and in education? Is it more important to have a sound

understanding of how to work with children with autism, or is it more important to have the formal training of a primary teacher? I realise at least some of PAPA's emphasis is on pre-school rather than school children, but it all overlaps in the case of children with autism because their developmental progress can be very different from that of children who are not in the autistic spectrum.

Those are my main questions. I am sorry if they have been asked already. I stress that all of us here — this may be PAPA's experience — are constantly on a learning curve on autism. Deputy Crowe stated the statistics on the growing number of children diagnosed and the implications of that in terms of both diagnosis and service. I do not know if there is anything in what Ms Cassidy stated already about providing the resources and funding to address the obvious growing need.

Ms Cassidy: Several themes were raised. From the debate I have particularly drawn out Middletown, the ABA, early intervention, prevalence and diagnosis, and where autism sits with regard to provision in the North — is it separate or is it integrated with mainstream services.

To start with Middletown, the up-to-date position is that the chief executive was appointed a couple of weeks ago. It has been said to us that there will be a consultation exercise but the blueprint seems to be fairly well established in terms of the four main focuses of Middletown. My information is that the first departmental director — for want of a better word — who will be appointed will be responsible for the issues of research and training. Speaking for Autism NI and PAPA, that is where our concern lies because we have quite a history of association with research and training for autism in Northern Ireland. The fact that we have not yet been engaged in the debate to avoid duplication and to move forward sharing expertise causes us some concern, and we have raised that with the Minister for Education in Northern Ireland, Maria Eagle MP, on the couple of occasions that she has been good enough to grant us a meeting.

I am sure everyone here shares our concerns that Middletown does not sit as an ivory tower. It must be related to real services and there must be an effective interface with local services. However, I applaud the announcement of Middletown because it has set itself as a centre of excellence for autism in Ireland. I really believe that in 2002 there were many in the Northern Ireland autism community who were encouraged by the focus and profile that it would give within services to a long ignored condition.

I could say more but my time is limited. Those are the main issues we have regarding Middletown.

We hope that Middletown will be the first of a number of regional centres, which will take the spotlight away from it. Where specialist assessment is required on a more local-regional basis, we look to the model which is about to be rolled out in the United States and which is funded under the combating autism legislation. Centres of excellences for autism are being developed in the US. These are also being developed as centres of

research and service provision. We are looking to this model in terms of the impact it will have on the development of Middletown.