



Northern Ireland Assembly

Tuesday 23 April 2002 (continued)

Mrs Courtney mentioned the number of hospitals in her constituency that, at different times, have experienced difficulties with the provision of equipment and services. She too acknowledged the vital role that organisations such as "Friends of Hospitals" provide in meeting the needs of the area that she represents.

Rev Robert Coulter has given the reasons why the Ulster Unionist Party cannot support the amendment. We would like "Friends of Hospitals" to be able to operate with total freedom to meet the needs of the hospitals that they represent, and, in collecting for their hospital, contribute to the needs of that hospital and help it to develop the services required in their area.

Ms Ramsey:

Will the Member give way?

Mr Hamilton:

No. Therefore, we urge Members to reject the amendment, because it does not provide fully for that. This has been a timely debate, and it is a worthy motion. The proposer highlighted its success in other parts of the UK. The Department should consider seriously the motion. I, therefore, urge Members to reject the amendment and support the motion.

Question put, That the amendment be made.

The Assembly divided: Ayes 28; Noes 36.

Ayes

Alex Attwood, P J Bradley, Joe Byrne, Annie Courtney, John Dallat, Bairbre de Brún, Pat Doherty, Mark Durkan, David Ervine, Sean Farren, Tommy Gallagher, Carmel Hanna, Billy Hutchinson, John Kelly, Patricia Lewsley, Alban Maginness, Alex Maskey, Alasdair McDonnell, Gerry McHugh, Eugene McMenamin, Pat McNamee, Monica McWilliams, Conor Murphy, Mick Murphy, Mary Nelis, Eamonn O'Neill, Sue Ramsey, John Tierney.

Noes

Ian Adamson, Billy Armstrong, Roy Beggs, Billy Bell, Paul Berry, Esmond Birnie, Mervyn Carrick, Wilson Clyde, Fred Cobain, Robert Coulter, Ivan Davis, Nigel Dodds, Oliver Gibson, John Gorman, Tom Hamilton, David Hilditch, Derek Hussey, Roger Hutchinson, Gardiner Kane, Danny Kennedy, David McClarty, William McCrea, Alan McFarland, Michael McGimpsey, Maurice Morrow, Dermot Nesbitt, Ian Paisley Jnr, Edwin Poots, Iris Robinson, Mark Robinson, George Savage, David Trimble, Peter Weir, Jim Wells, Jim Wilson, Sammy Wilson.

Question accordingly negatived.

Main Question put and agreed to.

Resolved:

That this Assembly calls upon the Minister and the Department of Health, Social Services and Public Safety to set up urgently a separate funding network for the provision of matching funds for items and/or projects identified by local groups commonly known as "Friends of Hospitals".

Screening System for Early Diagnosis of Autism

11.30 am

Mr Byrne:

I beg to move

That this Assembly calls on the Minister of Health, Social Services and Public Safety to introduce a screening system for all pre-school children to assist in the early diagnosis of autism and to make adequate provision for the needs of autistic children.

In the past year, the plight of autistic children and their parents has been brought into sharp focus through events that attracted the attention of the media. In Britain, the fears surrounding a possible link between autism and the measles, mumps and rubella (MMR) vaccination reopened issues relating to the causes of autism, provoking considerable controversy and disagreement among healthcare professionals and Government Ministers. In the Republic, the Supreme Court decision in the Sinott case, and the publication of a special task force report on autism, raised public awareness of the provision of educational services for autistic children. In recent weeks, the announcement by Ministers McGuinness and Woods of the first all-Ireland centre of excellence for autism education marked a step in the right direction and brought a long overdue recognition of the increasing level of concern about autism and autistic spectrum disorders on the island of Ireland.

The purpose of the motion and the subsequent debate is neither to come to conclusions on the causes of autism, nor is it to agree on a single approach to the education of children with autism. The purpose of the debate is to increase Members' and Ministers' awareness of autism and to agree on what all parents and professionals who work in the field of autism already know: the earlier that formal diagnosis is made of children who suffer from autism, the earlier effective educational methods can be employed to ensure those children have the opportunity to lead normal lives.

Our Department of Health, Social Services and Public Safety and our Department of Education have responsibility for the diagnosis of autism and appropriate interventions, such as speech and language therapy. However, owing to the mix of Departments and professionals involved, there has been an ad-hoc development of autistic services in Northern Ireland. Voluntary organisations such as Parents' Education as Autism Therapists (PEAT) and Parents and Professionals & Autism (PAPA) have been left to bear the brunt of promoting the needs of autistic children and their carers.

An important piece of recent research, which represented a major step forward, was the Northern Ireland scoping research into the diagnosis of autism. Although advances were made in the 1990s in the early diagnosis of autism compared with the situation in the 1980s, the report's recommendations were not fully implemented at trust and health board level. Today, individual trusts have different referral paths, and there is a wide range of differences between the level of services offered by the North's health trusts and boards. Only the Down Lisburn Trust, the Homefirst Community Trust, and Newry and Mourne Trust offer formal diagnosis services. They have been innovative and proactive with their respective health boards. Other trusts have lagged behind. Some are even in denial and refuse to accept the reality of the illness, or disability.

It is generally recognised that the early diagnosis of autism, which leads to early treatment and intervention, can have huge benefits and make a significant difference to the quality of life for autistic children and their parents.

A major piece of work is currently being conducted by a task force that consists of the Department of Health, Social Services and Public Safety, the Department of Education and voluntary groups. It is essential that its report contain proposals from the Department of Health recommending the introduction of a screening programme for all pre-school children. That is vital - according to the National Initiative for Autism: Screening and Assessment (NIASA), almost 50% of children are not diagnosed as autistic until they are 16 years old. Many parents and children in Northern Ireland are living with the consequences of autism and a failure to diagnose their children's illness at an early stage; some of those parents are here today.

I shall elaborate on the nature of this illness, the effect that it has on children and their parents and why early diagnosis and intervention is vital to its treatment. Autism is an illness of which I was aware, but, like many, I never appreciated fully the effect that it has on children and their families until a mother in my constituency contacted me to express her concerns about her child, who has not yet been formally diagnosed as suffering from autism. She also expressed her fears about the level of education services available. Her child was born healthy, without complications and with no history of serious illness in the family. After 19 months, the parents became increasingly concerned that their child was not developing normal communication and social skills. Despite the fact that two years have elapsed since their concerns surfaced, their child has not yet been formally diagnosed as suffering from autism, even though the child is displaying all the symptoms of the illness and is approaching school age. The mother was told authoritatively in a private consultation that her child was autistic, but the health authorities have not yet recognised that.

The symptoms of autism include a difficulty in acquiring, using and understanding speech, and using other forms of communication, including gestures and facial expressions. Children who are autistic can often relate well to their parents and carers, but not to other children. Autistic children also have a highly restricted range of behaviours and interests, may have repetitive body movements and a preference for routine, and may have a preoccupation with certain objects and activities. Those three characteristics are known as the "triad of impairments", and they are familiar to many families in the North who live with them 24 hours a day, seven days a week.

Autistic children often represent a considerable challenge to those who care for, train, educate and support them. Children who suffer from autism need constant care and attention. In many cases, parents, like the mother who asked for my help and, indeed, that of the Assembly, have had to give up their employment to care full-time for their children. That has put considerable pressure on many families, who feel that they have been abandoned by the authorities, especially by the Health Department.

Autism will not go away, and the Minister of Health must take it seriously. Autism-UK stated that during the 1990s the rate of children being diagnosed with autistic spectrum disorders rose significantly. For example, some areas of Britain and Northern Ireland are recording rates as high as one in 200 children; overall the illness affects four times more males than females.

Once formal diagnosis has been made, early intervention is essential. Specialist education is critical. Delivered in a structured environment it can minimise behavioural difficulties and enhance an individual's skills and life experiences. The two most effective methods are TEACCH (treatment and education of autistic and related communication handicapped children) and ABA (applied behaviour analysis). The latter, which entails intensive behavioural intervention, shows an autistic child how to learn academic and behavioural skills. ABA programmes, which can involve intensive learning of up to 40 hours a week with a trained professional, can be tailored to suit the individual needs of a child. Properly designed and delivered, ABA programmes contain most, if not all, of the necessary components for the effective treatment of children with autism. However, in Northern Ireland, the majority of parents who choose that teaching method must finance the programme themselves. They must deal with hostile attitudes towards the inclusion of ABA in the statementing process, despite the fact that research findings have shown that up to 40% of children with autism can benefit from ABA to the extent of being indistinguishable from normal children.

Due to varying resources and recognition of the gravity of autistic disorders by different trusts and health boards in Northern Ireland, there is glaring inequality in access to diagnosis, intervention and educational services. That must not continue. Why should parents and children who live in Tyrone and Fermanagh, for example, be denied the same access to, and standards of, services that are available in areas where the health trusts have the foresight and commitment to deal with autism?

11.45 am

That contrasts sharply with recent developments in the Republic of Ireland, where a more centrally planned, consistent approach to autism has been adopted.

Mr Deputy Speaker:

Will the Member please draw his remarks to a close.

Mr Byrne:

In March 2002 two new units were opened in the Republic to deal with autistic children.

The lack of clear direction and commitment of resources for autism by the health authorities has been marked. The Minister must take the issue seriously and take the lead on it, as her counterpart in education has done. Under the new equality legislation, the Minister and the Department of Health, Social Services and Public Safety have a public duty to ensure that all parents have equal access to the same level of diagnosis and intervention services. We eagerly await the publication of the task force report, which is due at the end of this month.

Autistic children and their parents do not have the luxury of time. They urgently require a screening programme for all pre-school children and equal access to services for autistic children throughout Northern Ireland.

Mr Deputy Speaker:

The Business Committee has allocated one hour for the debate, so I must ask Members to restrict their speeches to five minutes.

I have received one amendment to the motion, which is published in the Marshalled List of amendments.

Mr J Kelly:

Go raibh maith agat, a LeasCheann Comhairle.

I beg to move the following amendment: Delete all after "to" and insert:

"introduce a training programme for Health Visitors, School Nurses, Keystage 1 and Nursery School Teachers to facilitate the early detection of autism and to make adequate provision in collaboration with the Department of Education to meet the needs of autistic children."

I thank Mr Byrne for bringing to the Assembly an issue that vexes parents and society, because autistic children are special.

Ms Ramsey and I tabled the amendment because there is no widely acceptable, credible tool for universal mass screening. We believe that the use of any such mass-screening tool could create more problems than it solves, by creating false positives and negatives. In other words, children may be diagnosed as autistic when they are not, and autism may remain undetected in others.

There are also serious resource implications to consider. The cost of providing a mass-screening tool may impact on resources for treating autism. By training health visitors, school nurses, and Key Stage 1 and nursery teachers we can establish a framework for individual assessment that will be much more effective in detecting the spectrum of autism.

The key issue, which was missed by the well-intentioned motion, is that we must allocate more resources and support to meet the needs of autistic children, and their parents and carers.

It was in that context that Sinn Féin tabled the amendment. I thank Mr Byrne for bringing this difficult and vexing issue

to the House. However, the amendment will much more effectively provide for those difficulties that are suffered by autistic children and their parents.

Rev Robert Coulter:

I congratulate Mr Byrne for bringing this motion before the House. It is fitting that the Assembly should debate the matter today. However, I support the amendment, because it reaches beyond the original proposition and adds much more strength to what we are aiming at.

Early intervention is essential in the diagnosis of autism. The sooner that therapy begins, the better chance there is of a child's speech and behaviour progressing. Professionals are understandably reluctant to label a child autistic. However, many children reach the age of six or seven - sometimes even adulthood - before being fully diagnosed. Health boards and trusts should work closely with education boards to ensure that parents and teachers have an early route for those children who reach school without being diagnosed. Health visitors, nurses and doctors should also receive specialist training in the symptoms to look out for, as in the majority of cases an autistic child is diagnosed as a result of an initial diagnosis of hearing or speech problems.

As well as early diagnosis being essential for a child's development, financial and practical help is also available once a diagnosis of special needs has been made. Pre-school teachers, special nursery places, and occupational and speech therapy can then be availed of, as well as financial help for struggling parents who are often forced out of work because they must look after a child with learning difficulties. The disability living allowance (DLA) also needs to be re-examined. Many cases exist of parents of autistic children being turned down for that benefit. They have to undergo the trauma of an appeal to prove that their child needs help. A diagnosis of autism should be enough for DLA to be granted.

My views come not only from my interest in autism as a member of the Health Committee - they are expressed from the heart of a grandfather of an autistic boy. My grandson, who has just turned seven, was diagnosed with autism at the age of two and a half when he was referred to a speech therapist. He still has no speech. However, he was one of the lucky ones who benefited from early therapy, a nursery school place and a place at a special school where the staff were experienced in dealing with autistic spectrum disorder. His parents have also been greatly helped by Parents and Professionals & Autism (PAPA). I pay tribute to the work of that organisation.

Many autistic children in Northern Ireland have gone undetected and will continue to do so until we channel funds and personnel into that vital work. Some dictionaries describe autism as being "divorced from reality". It is time that MLAs woke up to reality and realised that autism is on the increase. We must be vigilant and help the health professionals. It is not only the need for early diagnosis that is essential. We must also implement a thorough programme of research that is aimed at finding the root causes of autism.

There has already been considerable debate within the community about the alleged links between autism and the MMR vaccine. I wish to emphasise that I am not opposed to the vaccination of children. However, Northern Ireland is a democratic society, and one of the foundation stones of any democracy is freedom of choice. Parents must have the freedom to choose whether they want their children to be vaccinated with the single MMR jab or to receive those vaccinations separately. The MMR vaccine's reputation has become tarnished because of its alleged links with autism.

One of the tragedies of autism is that, as yet, there is no known cure. Early diagnosis is therefore essential, as is an in-depth research programme into the causes of autism. It is also vital that a full independent inquiry be carried out into the safety of the MMR jab. I support the amendment.

Mrs I Robinson:

I support the motion, and I thank Mr Byrne for tabling it. I shall include in my comments the needs of autistic adults, because they too require proper attention and adequate provision from the Department of Health, Social Services and Public Safety. Public awareness of autistic spectrum disorder and the Government's duty to target and fund measures against the illness must increase and must reflect better direction. We must all understand exactly what autism is, and how it affects both individuals and those who care for them.

Autism is a disability that disrupts the development of social and communication skills. It is believed that approximately 70% of those who suffer from autistic spectrum disorder also have learning difficulties. Whatever their level of ability, which varies widely - some have incredible special talents - they all share a common difficulty in making sense of the world in comparison with other children of a similar age and background. The common denominator is a clear difficulty with social relationships. The individual's ability to join in social activities is clearly impaired, as is his or her capacity to understand the feelings of others. Most sufferers of autistic spectrum disorder experience great difficulty in acquiring, using and understanding speech; they also have problems with facial expressions and gestures. Typical behaviour and characteristics of autism include: resistance to normal teaching methods; sustained, odd play; lack of eye contact; apparent insensitivity to pain; a stand-offish manner; crying and tantrums for no apparent reason; and resistance to any change in routine.

Research suggests that there is no single cause for autism, but that it is a physical problem affecting those parts of the brain that integrate language and information processed from the senses. The condition is of physical, not emotional, origin and can be identified by the age of three in most children. Unfortunately, there is no known cure for autism, but with appropriate education and support services, sufferers can be helped to live with as much dignity and independence as possible. We in Northern Ireland can help to deliver that through the Assembly.

The significance of the central aim of the motion, namely early intervention, cannot be underestimated. Coupled with specialist education, early intervention is vital if children with autism are to develop their full potential in life. Early diagnosis of the disability is the first crucial step towards helping them to lead full lives. The later a child is diagnosed, the more he or she has had time to feel different and isolated from others, and the greater the trauma and worry for the family.

Over the years, several constituents whose children are autistic have contacted me. The effect that autistic spectrum disorder has had on the child and the family unit is shocking. For the family, it is hard to cope with a child who cannot mix socially and is indifferent to other children. Inappropriate social behaviour, tantrums and disruptive actions can cause much distress and worry within the family, so support and direction from those who know and care about autistic issues are essential. Isolation does not affect only the sufferers of autism; in many circumstances, their families experience it also.

I am often asked: "To whom do we turn? What help can we get?" There are groups and individuals who are making a serious attempt to help autistic spectrum disorder sufferers and their families to come to terms with the condition and to provide a decent life for them. Autism is a lifelong illness; the sooner it is diagnosed and cared for, the better for the child and his or her family.

The hard work and dedication of groups such as PAPA and Barnardo's, which encourage and initiate training and research into the subject to facilitate better diagnosis and early intervention, cannot be praised highly enough. I support the motion.

12.00

Ms McWilliams:

This is a timely motion, given the recent public debate. The Committee for Health, Social Services and Public Safety debated the link between the measles, mumps and rubella (MMR) vaccine and autism when it became a crisis in the

community. For that reason, it is important to debate autism exclusively.

There are several reasons why Joe Byrne's motion is useful. It is strong because of the great public concern about the incidence of autism in children, and, until we find out how extensive that is, it will be very difficult to allocate resources to deal with it. Indeed, as other Members said, the earlier that autism is diagnosed, the earlier help can be given not just to the child, but to carers and supporters of families with autistic children.

Debate on autism has also been taking place in Britain. It is interesting that the Minister of State for Health, Jacqui Smith, has said that she will look positively at a national screening programme if it facilitates understanding of the syndrome. Others have talked about the spectrum of disorders. If officials in Britain are giving serious thought to a national screening programme, we must do likewise in Northern Ireland.

According to research conducted in the United States and recently published in the Journal of the American Medical Association, there has been a fourfold increase in autism. The research suggests that autism has not suddenly become more widespread because of a recent occurrence, but rather that it is now detected more often. If that is the case, it is due to screening.

If the detection of the condition is on the increase, not only are health professionals being better trained, but screening has been introduced to determine the extent of autism. The message from the United States and Britain is that we would do well to consider introducing a screening programme here.

It is also important to urge people who are concerned about the link between MMR and autism to follow advice and opt for the triple jab, rather than single vaccines, given the dangers that can arise as a result of delays in individual inoculations. Single jabs would increase the risk of disease and would also have huge resource implications. It may lead to people not having their children vaccinated, because single vaccines take much longer to administer than triple jabs. Triple jabs save resources.

If we advise that the link to autism is not proven, and promote the triple jab, we must not leave it at that. We must respond to those who are concerned and confused about the links between MMR and autism. As was suggested in the Health Committee and elsewhere, a national screening programme is the only way to allay the fears of those who write to us: the parents of autistic children, and other parents who demand the introduction of single vaccines in their GP practices. We must answer them; the best response is to continue to advise parents to choose the triple vaccine, and to introduce a screening programme for autistic spectrum disorders alongside it.

I welcome, as did Rev Robert Coulter, the announcement of the new centre, which is supported by parents and professionals in the field of autism. For many years, we have known that self-help and support groups have much to offer. They work alongside professionals and the task forces that deal with autism, bringing together all their knowledge and expertise. That inter-agency approach is extremely important.

However, the amendment in its own right is not to be ignored. If screening is introduced, it will be necessary to have the training in place.

Mrs Courtney:

I congratulate my Colleague Joe Byrne on tabling the motion and for mentioning the bodies that are available to help parents whose children have been diagnosed as autistic.

PAPA was formed in 1989 by a group of concerned parents and professionals. It is a registered charity in Northern Ireland, whose aim is to promote the needs of those with autistic spectrum disorders and their carers. A central office was established in 1992, and a western regional office in 1999. PAPA was first established with a staff of three. It was given a recurring budget of £40,000 per annum for three years. There are now between seven and nine staff.

Unfortunately, however, its central funding remains the same. The service could not survive without volunteers.

In my own area, the Foyle Community Trust in the Western Health and Social Services Board used to allocate some funds, but was unable to help in the last financial year. I have spoken to health professionals, and the consensus is that two problems stand out as critical to care. The first, mentioned by every Member who has spoken, is early diagnosis. The second is increased central funding. It was said yesterday that to underline the dire need for increased funding in the Foyle area for autistic spectrum disorders, we have simply to look at the number of doctors who can treat or diagnose patients with autism or associated disorders in the area. At present, there is only one part-time doctor who is qualified to diagnose patients with the condition. The waiting time for this doctor stands at 10 to 11 months. That is unacceptable.

The crucial point seems to be that until a child or individual is diagnosed, the family and the child are in a state of limbo. Once diagnosis has taken place progress can be made, but an 11-month waiting list is perceived as being simply not good enough. Yesterday, the Foyle Community Trust manager for learning disability services said that it provides a service for any child with a severe learning disability. However, medium and milder cases do not receive care. A child who is just above or below the set requirements will miss out because the funding is not there.

PAPA provides parents and carers with leaflets that give valuable information; however, as specialist education and structured support can assist in maximising a child's skills and in minimising any behavioural problems, the right education and care programmes are essential. For example, all children - not just autistic children - throw tantrums. Unless professionals are trained to recognise symptoms of the condition, sufferers can be left undiagnosed until adulthood.

I therefore support the motion, but a serious attempt to address the problem must be made by education and library boards so that it can be recognised by all health professionals. Central funding must also be addressed so that children can avail of specialist help and parents are not left to cope with the problem alone. The educational needs of autistic children are paramount also.

I support the motion.

Rev Dr William McCrea:

There is a requirement to address the challenge of screening, diagnosis and early intervention for children with autism. Why does this need exist? The answer is simple: for too long, early diagnosis has been a struggle for many people to achieve.

Screening leading to diagnosis should in turn lead smoothly to intervention by the appropriate health authority. However, many parents, particularly those with young children of pre-school age, have spoken to me - and I am sure to many others in the House - about falling into a black hole immediately after diagnosis, and the Assembly seeks to fill that void. Many parents, indeed several from my constituency, believe that the present system has failed them and that they have been left with no other recourse than to seek alternative expensive private consultations. They hope that their child's condition will be diagnosed properly, that his or her abilities will be assessed, and that that will lead to a genuine consideration of the child's future health and education needs.

Like other Members, I can produce many letters from parents expressing their distress at what they see as a failure in the system. It saddens me that they think that the system that was designed to offer them support and guidance when they are most needed has failed. There is a strong consensus among professionals about that, and Joanne Douglas of the Spectrum Diagnostic Assessment and Theory Centre of Queen's University, Belfast said:

"Early intervention is beneficial for children with autism, partly because it is thought that they need intensive support to reach their optimal learning, and partly because early intervention is known to help reduce challenging behaviour."

No doubt, it will be argued that the current guidelines do not recommend universal screening for pre-school children with autism on the basis that there are no suitable screening instruments. However, if an autistic spectrum disorder is not identified at an early age, it follows that the extent of the need for provision will not be recognised either - that is a

catch-22 situation.

There is a clear consensus that early identification must be achieved through the increased professional awareness of all community staff who have contact with young children and their families, particularly GPs, health visitors and educational psychologists. The consequences of not diagnosing autism at an early stage are worth bearing in mind. A survey conducted last year by the National Autistic Society said that only 43% of children at the less able end of the spectrum were diagnosed before the age of five, despite

"Having urgent needs that could have been addressed through early intervention."

Approximately 18% of people at the lower end of the spectrum did not receive a proper diagnosis until the age of 16 or beyond, yet evidence suggests that autism is becoming more prevalent, and I have statistics from other parts of the United Kingdom that show that. When I tried to ascertain the number of cases of autism in each health board area in Northern Ireland, I was disappointed to be informed by the Department of Health, Social Services and Public Safety that those statistics were unavailable. Does that not therefore acknowledge that if the information is unavailable, the appropriate provision for children is also unavailable?

Another survey conducted by the National Autistic Society showed that only 38% of adults with an autistic spectrum disorder admitted to having had a community care assessment. For many, slipping through the net until adulthood brought further complications, and those left to struggle without support more often than not spiralled into mental decline. That is a disappointing scenario, given that people with Asperger's syndrome have several occupational strengths that make them excellent workers.

In recognising the need to care for children with autistic spectrum disorders, it follows that we must have professional care that can be delivered by those who are specifically trained to support individuals with those disorders. Only then will children benefit from the support of staff who have appropriate knowledge and experience of teaching children with an autistic spectrum disorder, and specialist training must be provided for teaching and support staff who work with autistic children. I support the motion.

12.15 pm

The Minister of Health, Social Services and Public Safety (Ms de Brún):

Go raibh maith agat, a LeasCheann Comhairle. Tá mé buíoch den Uasal Byrne as an deis a chur ar fáil domh plé a dhéanamh ar scagthástáil le haghaidh uathachais a thabhairt isteach do pháistí réamhscoile agus ar sheirbhísí a chur ar fáil le riar ar a riachtanais. Tá a fhios agam go bhfuil an-suim ag mórán Comhaltaí san ábhar.

Is féidir uathachas a aithint ar chomharthaí luatha lagaithe i sóisialú agus i gcumarsáid agus ar an iompraíocht athchleachtach. Cuimsíonn an speictream mí-eagair uathaigh páistí atá faoi lagú trom intleachta agus páistí eile atá ar ard-fheidhmiú, ar a dtugtar Siondróm Asperger.

I am grateful that Mr Byrne has provided an opportunity to discuss the introduction of autism screening for pre-school children and the provision of services to meet their needs. Autism is of considerable interest to many Members. It is defined by early signs of impairments, socialisation and communication difficulties and repetitive behaviour. Autistic spectrum disorders affect children of varying intellectual ability and impairment - from the severely impaired to those with high-functioning autism, termed Asperger's Syndrome. Approximately one third of children with autism appear to lose skills in their second year, but the significance of the cause and life course of the disorder is unclear.

As stated again and again during the debate, the consensus among experts on autistic spectrum disorders is that early diagnosis and support are of great importance if the best outcome is to be achieved. Autism can manifest itself before the age of two and can be identified in some children at that early age. However, some children may not be diagnosed early because of the variability in the onset and severity of the condition. Several tests can be used to screen for different types of autism, including CHAT, the checklist for autism in toddlers, and DISCO, the diagnostic interview for social and communication disorders. Those tests can be useful in certain cases, but no one test is reliable for all autistic

spectrum disorders.

Missing genuine difficulties or raising unnecessary worries are serious problems. For that reason, several studies in diagnostic screening procedures have been carried out. In March 2001, the Department of Health in London commissioned the Medical Research Council (MRC) to provide it with a clear picture of what scientific research has revealed about the epidemiology and causes of autism. The MRC report of December 2001 states that

"To date, there is no screening instrument that would identify all and only those children with ASDs".

'Health for All Children' is the periodic report of the joint working party on child health surveillance. The current draft of the fourth edition states that

"Formal screening for learning disabilities, developmental delay and cerebral palsy are not currently recommended".

Reference was made in the debate to the National Initiative for Autism: Screening and Assessment (NIASA). For the past 15 months, it has been examining screening, diagnosis and early interventions for autism. Its view is that there is no adequate screening tool for autism. Therefore, it could not recommend the introduction of screening.

Figures on the prevalence of autism vary according to the criteria applied. Therefore, I must treat with caution some of the figures that were referred to today. Those supplied by health and social services boards in September 2001 show that 732 children were known to trusts as having been diagnosed with an autistic spectrum disorder. Although there has been some increase in prevalence - the exact levels and causes of which require further research - there is no definitive evidence of an increasing incidence of autism in children. The increased professional awareness and higher public profile referred to in the debate may be contributing factors to the rise in public awareness of the condition, which may in turn lead to an illusion or suggestion of a higher prevalence rate when that is not the case.

The child health surveillance programme monitors the development of babies and pre-school children and is the primary means of early identification of impairments in development. However, some children may not be identified early because of the variability in the onset and severity of the condition. Given that autism affects communication and behaviour, it is difficult to identify the condition before children reach the age of two, when impairments begin to become noticeable.

However, behavioural communication impairments may not become apparent until a child has started school. The school health service, therefore, has a key role in identifying developmental disorders in school-age children, and it can refer children to a range of professionals, including speech therapists and child or educational psychologists. In that regard, education professionals work closely with their counterparts in health and social services.

If a child is identified as having autistic tendencies by a health visitor or other healthcare professional, he or she will be referred to relevant clinicians for formal diagnosis. That will trigger a referral to the appropriate health and social services and support, including that provided by voluntary organisations such as PAPA. I take this opportunity to add my praise and thanks to that of others for the work of the voluntary organisations, as well as those working in the service.

The Department sponsored a diagnostic scoping study that was carried out by PAPA and the University of Ulster between June 1997 and December 1998. The purpose of the study was to evaluate the effectiveness of diagnostic provision for people with autistic spectrum disorders and their families, and to make recommendations for the enhancement of service provision. The key principle is that diagnosis should take place as early as possible in the child's life to sustain the family's adaptation to the outcome of the diagnosis and to maximise and enhance the child's developmental potential. The report on the study was issued to health and social services boards to inform service development.

Healthcare professionals' awareness of autism and autistic spectrum disorders has increased significantly in recent years and continues to do so. We are committed to developing that understanding further. The improved understanding is resulting in better diagnosis, which, in turn, is informing service development. For its part, PAPA has been instrumental in rolling out the treatment and education of autistic and related communication handicapped children (TEACCH) education programme. It has also provided important awareness training for professional healthcare

staff. Health visitors and school nurses receive autism awareness training through a one-year postgraduate course at the University of Ulster. Training is not currently provided in the early detection of autism. However, as part of the standard five-year review, a group that is made up of community nurses, nurse managers and representatives from the University of Ulster and the Department of Health, Social Services and Public Safety, is examining the content of the curriculum. The issues raised during the debate will be fed into that review.

Iris Robinson asked about autistic adults. Service provision is made through the community learning disability services.

With regard to the weight of research evidence on the safety of the measles, mumps and rubella (MMR) vaccine, the World Health Organization, the Medical Research Council, the Medicine Safety Committee and the Joint Committee on Vaccination and Immunisation have all stated that there is no link between the MMR vaccine and autism. I have seen no credible evidence to the contrary. The Medicine Safety Committee and the Joint Committee on Vaccination and Immunisation also advised recently that the MMR vaccine is safer than giving the vaccines separately. Our Chief Medical Officer wrote to GPs and other healthcare professionals in February to update advice on handling parental concerns. The purpose of the letter was to update professionals on the most recent studies on the MMR vaccine and to assure them that the Department and independent medical experts remain convinced that the vaccine is both safe and the most effective way to protect children from measles, mumps and rubella.

Mr Byrne raised a point about applied behaviour analysis, which is one of many interventions that have been suggested as beneficial for people with autism. Various elements of behavioural therapy are already being used by healthcare professionals in that field. Although it is recognised that behavioural therapy can be beneficial, the particular intervention used is determined by a clinical judgement based on the assessed needs of the child. I am not aware of the case that Mr Byrne mentioned, so he may wish to write to me about that.

The Department of Education's task force on autism took evidence from boards and trusts, rather than formally involve the Department. The report will be out for debate, and I look forward to that. I reiterate that healthcare professionals accept the need for early diagnosis and intervention, as has been stressed here.

Annie Courtney asked about support for PAPA. In the last three financial years, departmental support for PAPA has totalled £239,000. The Department has provided the project funding for the diagnostic scoping study, and will consider any funding proposals submitted by PAPA. Of course, these will go alongside other proposals.

Mr Deputy Speaker:

Minister, I must ask you to conclude your remarks soon.

Ms de Brún:

The health and social services boards are reporting on developments in services for children with autism, and these are being progressed on a board basis. One of my Department's priorities for action requires boards and trusts to continue to develop therapy provision to reduce waiting times for children's and adults' services. We will continue to monitor developments in screening, and review current arrangements in the light of positive developments. Officials are involved in discussions with PAPA about how additional awareness training for healthcare professionals might be provided. The care and development of children with autism is a shared responsibility across a number of Departments, and a holistic approach will offer a better and brighter future for these children, which is an absolute commitment on all our parts.

Ms Ramsey:

Go raibh maith agat, a LeasCheann Comhairle. I thank and commend Joe Byrne for tabling this motion. John Kelly and I proposed our amendment because there is no widely accepted, credible tool for universal mass screening. Other Members pointed out that autism has been brought to the fore lately, and that the issue has been raised with political parties. With that in mind, I commend PAPA and other groups for placing autism not only at the top of the political agenda, but at the top of the general agenda.

I welcome yesterday's announcement by the Minister of Education that videos will be developed and produced for the parents of children with autism and dyslexia, and that a CD-ROM will be provided for their teachers. He also said that the Centre for Cross Border Studies would engage a special education teacher on secondment to organise and facilitate a jointly funded programme designed to promote dialogue and co-operation among professionals in the field, which is key.

People want a statement. It is on record that the four reports that the task group has commissioned highlight the need for the training of classroom teachers to identify children who may have an autistic spectrum disorder or dyslexia, to address their difficulties, and to meet their needs. The reports also point out the importance of the involvement of parents in the assessment of their children's difficulties, and the training of parents in suitable approaches to meeting their children's needs, so that a continuity of care and learning approach can be provided throughout the child's day. That ties in with our amendment. We are calling for early intervention. Health visitors, nursery schoolteachers and school nurses should be involved in early intervention. Key to our amendment is that by providing this crucial training and development of health visitors, school nurses, Key Stage 1 teachers and nursery teachers, we would create a framework of individual assessment that would be much more effective in detecting autism.

It is also vital to provide resources to meet the needs of people with autism and their families - that is what people want, it is what parents want, and what the groups are telling us is needed. The key requirement is early intervention, and I agree with Bob Coulter, who has first-hand knowledge of autism, that the amendment goes further than the original motion. We do not need, and cannot allow, children to fall out of the loop by creating false positives or negatives. The recent cases of inaccurate screening for breast cancer and of misdiagnosed breast cancer in Hammersmith Hospital should make us all cautious. There is no universally, accepted issue about mass screening.

12.30 pm

Several Members have spoken about a joined-up approach, which is key. We need a joined-up approach from the Department of Education and the Department of Health, Social Services and Public Safety. That is exactly what our amendment is about. There is no point saying that we need this and that, when the motion calls for only one Department to provide what is needed. The Department of Education and the Department of Health, Social Services and Public Safety must get together; one has as much responsibility as the other.

I agree wholeheartedly with Annie Courtney that the professionals need to be trained to identify the problems. That is the key point of our amendment. I commend Joe Byrne for tabling the motion, and I do not want to take away from that. However, our amendment takes it a small step further. It puts the onus not only on the Department of Health, Social Services and Public Safety, but on the Department of Education, which is crucial. I urge Members to support the amendment.