

Autism Debate: 9th January 2007

Autism

Madam Speaker: The Business Committee has allowed two hours for the debate. The Member proposing the motion will have 15 minutes to speak, with 15 minutes allowed for the winding-up speech. All other Members will have a maximum of 10 minutes to speak.

Mr D Bradley: I beg to move

That this Assembly recognises the need for, and supports the introduction of, legislation which would guarantee the future security and rights of those on the autistic spectrum and would combat the tragic social injustice being perpetuated through lack of planning and funding, at a time when the number of individuals with autism is increasing dramatically.

Go raibh maith agat, a Cheann Comhairle. Tá an-áthas orm an rún seo a mholadh inniu.

I am pleased to propose the motion and am happy to accept the amendment that has been tabled.

Over the past number of years, there has been an awakening in Northern Ireland to the prevalence and challenges of autism, not only in the minds of the health professionals, teachers and parents who deal with autism daily, but in the mind of the wider public. The increase in awareness of autism is largely due to autism advocacy groups and the excellent work that they do in, and for, the community.

My former colleagues John Fee and Joe Byrne sponsored the first debates on autism in the Northern Ireland Assembly, which were held shortly after the Department of Education published the task group's report on autism. Mr Fee's motion called on the then Minister of Education and the then Minister of Health, Social Services and Public Safety to instigate a comprehensive review of services provided to adults and children with Asperger's syndrome, and the training of professionals specialising in their treatment.

Mr Byrne's motion called on the then Minister of Health, Social Services and Public Safety to introduce a training programme for health visitors, school nurses, Key Stage 1 teachers 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 children with autism.

Reviewing previous motions is an interesting exercise because progress has been made in some areas. For example, the Northern Ireland Commissioner for Children

and Young People (NICCY) commissioned a review of services for children with Asperger's syndrome, the provision of training has progressed and education services have developed their autistic spectrum disorder (ASD) support services.

However, more must be done. It is now four years since those motions were debated. According to a report published in 'The Lancet', the number of individuals with a form of ASD in Northern Ireland tripled between 2001 to 2004 — and rates are still rising.

Experts assert that early diagnosis and early intervention are the keys to starting to help children and parents to cope with autism. However, as many Members know, diagnosis can take up to three years and more, which means that the window of opportunity that early intervention affords is lost. Those with ASD, their parents and carers and society in general will personally bear the cost of such missed opportunities in years to come.

Early diagnosis and intervention would greatly increase the chances of individuals being able to continue their education, enter employment and live independently in the future.

We are advised that to carry out these diagnoses it is essential to have trained educational psychologists who are experienced in dealing with ASD, yet there are far too few professionals trained or available to carry out these assessments. Often, when one professional retires, that post remains unfilled for an indefinite period.

We understand also that special support in classroom work, through the use of classroom assistants, can be vital to help a child with an ASD adjust to school life and to learn in a progressive manner. However, education budget cuts have ripped the heart out of special needs units and stunted the recruitment of special needs assistants.

Even when assistants are appointed, the level of training often falls short of what is required. According to a survey, 74% of front-line workers in health and education feel that they are poorly trained and do not fully understand ASD. In addition, there is no requirement for trainee or practising teachers to undertake any training, and 70% of schools are not satisfied with the level of training in ASD that their teachers have. Many of the 25% of children with autism who have been excluded from school are excluded due to a lack of understanding and awareness on the part of the school.

There are more appeals to the Special Educational Needs and Disability Tribunal about schooling for children with autism than for children with any other type of special educational need. Of the parents who have appealed to the tribunal, 79% won their case. That shows that provision is far from adequate.

The situation post-school is no better. Only 5% of individuals with ASD are in employment or higher education, and only 3% of adults at the higher end of the autistic spectrum live independently.

Even though some progress has been made, there is no cohesive strategy for ASD in Northern Ireland. Families who move between health and social services boards encounter significant disparities in services. That is ridiculous when one considers the small population and geographical area that those boards operate in. The Western Health and Social Services Board has a cradle-to-grave strategy; the Southern Board has a strategy for those under the age of 18; the Northern Board is working on an initial framework; and the Eastern Board has no strategy. There is little cross-board strategic cohesion.

The recent initiative to create an ASD service framework and service standards is a positive move forward. However, it is not rooted in any strategy. To develop a framework without a strategy could be described as putting the cart before the horse. The negative experience of the Bamford Review of Mental Health and Learning Disability (Northern Ireland) has underlined to the ASD community in Northern Ireland the fact that any changes must be rooted in a cohesive, future-orientated strategy that guides ASD services, rather than services guiding strategy.

The all-Wales autism strategy is to be launched in January or February 2007, and there is a similar aim in Scotland. Autism Northern Ireland has formed a strategic Celtic Nations Autism Partnership with Scotland and Wales. The partnership involves the sharing of good practice and training in ASD, and also seeks to exert political pressure to make legislative changes for ASD in the respective member nations. The official launch of the partnership will take place in Cardiff on 30 January 2007, and I hope that Members of this House will attend.

Worldwide, the United States, Sweden, Canada, New Zealand and Australia have implemented, or are in the process of implementing, legislation relating to ASD. Those countries recognise the complex nature of ASD, and we have a chance to be the first region in the United Kingdom to seize the initiative and make positive changes for people living with ASD.

Despite many initiatives and high-profile awareness-raising activities, the desperate plight of people with ASD remains unresolved. There is a huge demand for consolidated efforts to provide appropriate services for the large number of individuals with an ASD. In the interim, the impact on the economy and on health cannot be estimated, but it is of sufficient magnitude to warrant Government direction and leadership.

The bottom-up strategy has influenced practice, but not policy. The policy shift must come from the top down, and that is why legislation is required that will ensure that, in line with Autism Northern Ireland's blueprint for change, the rights of people

with autism and their families are catered for in the areas of health, education, training and criminal justice.

Government ownership of the ASD issue is the unavoidable way forward. We have the capacity to easily create an authoritative strategy for autism, and the four key charities in Northern Ireland, Wales, Scotland and England have considerable expertise and knowledge that could be effectively utilised by the Government to achieve such a strategy. Close co-operation with organisations in the Republic of Ireland would also be to the benefit of all.

The identity in legislation of ASD — as separate from other disorders and disabilities — will be a major step forward. There is also an opportunity to follow the example set by Sweden, where a significant impact on services, health and the economy has been made by the inclusion of ASD in the Swedish 1993 code of statutes, resulting in the practical initiation and implementation of appropriate support.

In the meantime, it would be helpful to have a cross-party group in Stormont that would ensure that today's motion impacts on Government policy. That group could develop links with colleagues in Scotland and Wales through the Celtic Nations Autism Partnership that could be used as a resource and a linkage to the Welsh Assembly and the Scottish Parliament on matters regarding ASD. The group could also liaise with groups in the Republic of Ireland.

I welcome the fact that Autism Northern Ireland is to make a presentation this month to the Dáil Éireann Education and Science Committee. Such co-operation benefits all, North and South.

I agree that we have been waiting too long for the development of the cross-border centre of excellence for autism at Middletown, County Armagh, as stated in the amendment. When up and running, that centre will provide a range of services, including learning support, educational assessment and training, and a training and advisory service for parents, teachers and other professionals, including support staff. Those are necessary and valuable services, and I hope that the Assembly will join me in urging the two Governments to expedite the development of the centre without further delay.

Finally, I pay tribute to the late Michael Ferguson MLA, who was a fellow autism ambassador and a strong advocate of the rights of people with autism. He is missed by those for whom he worked with the utmost diligence and dedication, and we remember his work today.

I commend the motion, as amended, to the House, and I ask Members to give it their full support. Go raibh míle maith agat.

2.15 pm

Mr McElduff: Go raibh maith agat, a Cheann Comhairle. Tá áthas orm an leasú seo a mholadh don rún, agus ba mhaith liom mo bhuíochas a ghabháil le Dominic as ucht tacaíocht a thabhairt don leasú.

I beg to move the following amendment: at end insert:

“; and further calls for the immediate funding and implementation of the long overdue centre of excellence for autism at Middletown, Co. Armagh.”

I commend the proposer of the motion, and I hope that the amendment in the name of John O'Dowd and myself simply adds value to it.

The amendment highlights the delay in establishing the long awaited and overdue centre of excellence for autism at Middletown, County Armagh. Quite rightly, Dominic Bradley invoked the name of Michael Ferguson, who was a great champion of this project. I welcome reference to him in the debate.

It is worth noting that the decision to establish a national centre of excellence was taken early in the lifetime of the last functioning Assembly. It was a decision that was jointly taken by the two Ministers with responsibility for education on the island at the time: Martin McGuinness in the North and Michael Woods, the Minister for Education and Science in the rest of Ireland. Unfortunately, the project appears to have been bedevilled for some years by legal arguments over land and property acquisition. That resulted in an unacceptable delay for several years. Site refurbishment was necessary as well. Neither the money nor the budget was the issue, as the money was ring-fenced when the decision was taken. The project gave strong expression to education as an area of co-operation, North and South, under the Good Friday Agreement.

Just this morning, I spoke to senior officials in the Department of Education to receive a further update on the all-Ireland centre of excellence for autism at Middletown. I was told that a limited company had been set up to oversee the development of the centre, that the process is under way to appoint a chief executive officer, and that I should expect an early announcement. Let us move speedily towards the development of this project and the setting up of a management board.

We are told that some operations will commence in mid-2007, and the amendment sends an urgent message to both sponsoring Departments to fully implement this centre, which has been talked about for many years now. People want to see it fully operational and offering the necessary support to children, parents, carers and teachers. That must happen without delay.

The motion calls for legislation to guarantee the future security and rights of those on the autistic spectrum. That complements Autism NI's campaign for a specific

autism Act and a programme of care in the North for ASD as well as a local autism strategy. Sinn Féin fully supports that.

The motion also pinpoints the lack of planning and funding, or perhaps the absence of a cohesive strategy. Dominic Bradley, the proposer of the motion, highlighted the different approaches among health boards and education and library boards in the North. That does not inspire confidence. Often, parents say that the education and health boards are not working with the necessary collaboration or cohesion.

Of course, there is mention of the increasing prevalence of ASD. I think it was 'The Lancet' report that said that, previously, one child in every 1,000 was affected by autism; now it is one in every 100 — although I have also seen the figure of 166. Whether 100 or 166, there is what can be described as a tidal wave. It requires greater political will, greater investment, joined-up approaches and co-ordination between Departments.

It is also appropriate to highlight the pressure on parents and carers of a child who is on the autistic spectrum. A few years ago, I organised a seminar in the town of Fintona, County Tyrone, in the Ecclesville Centre, called "A forum for carers".

I was struck by a young mother's comment that she used to be mild-mannered but that she was now aggressive, because every day of every week she has to fight agencies and Departments for services. That was her experience of trying to get the necessary support for her son.

Last week, 'The Irish Times' ran a compelling series of articles on autism by Adrienne Murphy. She asked:

"Can there be anything more frustrating than having to stand by while your child disintegrates before your very eyes?"

That is especially frustrating when that child is being denied access to early intervention and diagnosis, and to therapies that could make a difference.

Many parents believe that Governments are deliberately disputing therapies such as applied behavioural analysis (ABA) because of resource implications. In other words, they dispute the validity of those scientifically proven therapies because it costs a great deal of money to provide those therapies. Parents talk about how their children blossom when they undertake intensive one-to-one programmes, such as ABA, but such programmes are often not recognised or resourced, and parents sometimes have to borrow thousands of pounds to pay for the tuition themselves.

About two years ago, I spoke to an educationalist about the development of an ABA unit in a primary school in County Tyrone, and he simply said: "What unit?" until I used the appropriate term, which was, I think: "additionally resourced unit". He did

not like the idea of an autism unit or an ABA unit inside a school, and I had to use correct terminology to even get a response from him.

Furthermore, if an argument is made for resources to be directed towards an individual child, the education providers will have people in court as soon as they open their mouths. The providers say that it may lead to a tribunal and that anything that is said will be taken down in evidence and used against them. Unfortunately, if someone is advocating for resources for a parent or a child, the relationship becomes adversarial almost straight away.

To return to the 'The Irish Times' articles, Adrienne Murphy's son Caoimh attends Achieve ABA, which is based in St Colmcille's School in Donaghmede in Dublin. He had late-onset autism and, as far as she is concerned, he is now in an appropriate place, and she is immensely relieved about that. She sees a tremendous difference in her son's behaviour before ABA and after ABA.

I am the first to acknowledge that I am not competent to determine which therapies are appropriate, but an open and honest debate on all the available therapies is needed. If resource implications are the blockage, education providers must be honest and admit that. Adrienne Murphy talked about her memories of her son Caoimh in the time before he:

"pulled the shutters down on the world and retreated deeply and almost unreachably into his own mind."

There is tremendous pressure on parents and carers, and education and health providers must listen closely to parents. The parental instinct is usually right, and it deserves greater weight when decisions are made on what support should be offered.

I take this opportunity to commend all those groups that are raising awareness, supporting parents, lobbying and campaigning — groups such as Irish Autism Action, the Irish Autism Alliance, Autism NI (PAPA), the Irish Society for Autism, and the National Autistic Society (NAS). I commend the NAS 'Make School Make Sense' campaign, which emphasises the need for the right school, the right approach and the right training, and which aims to provide proper education for children — the education that they deserve. It is a matter of ensuring that children with autism have the appropriate opportunities to manage their lives and to lead, if at all possible, independent lives.

Go raibh míle maith agat, a Cheann Comhairle.

Mrs I Robinson: I rise to support the motion, and I congratulate the proposer for affording us the opportunity to debate this important subject. My party does not support the amendment, as Middletown in County Armagh could not, because of its

location, cater for the majority of the population of Northern Ireland who may need to take advantage of a centre of excellence. My party would support a centre at that location without difficulty: however, a regional centre should be located where it advantages the greatest number of autism sufferers. The issue should not be a political football.

As has already been indicated, autistic spectrum disorder is a persistent condition that appears in childhood and affects crucial areas of a person's development, including communication, social interaction and creativity. Recent studies have estimated that autism affects 3-4 out of every 1,000 children who are aged between three and 10 years. Although autism varies widely in its symptoms and severity, early diagnosis and treatment can help autistic people to live independent and productive lives.

The motion focuses on legislation. Clearly, the Assembly must be mindful of the funding implications of matters to which it would commit itself through any new legislation. It is important to have an accurate idea of the likely resources involved. I will refer to examples of international autism legislation. In the United States, President Bush signed the landmark Combating Autism Act of 2006 just before Christmas. I want to deal with the Swedish situation first, however.

Since 1995, autistic people in Sweden have been protected by the Act concerning Support and Service for Persons with Certain Functional Impairments, known as the LSS law. As well as those who have autistic spectrum disorder, the act also applies to people who are mentally incapacitated, have permanent brain damage sustained through external force or physical illness, and those who have some other lasting impairment that is not due to the normal ageing process.

The law ensures good living conditions for those concerned, assistance in their daily living, and influence over the support and services that they receive. An individual makes a request for support and services, and their needs are then evaluated. Individuals must meet specified criteria. Those who are deemed eligible are entitled to various forms of support, such as advice and personal support from experts such as social workers, psychologists, physiotherapists, pre-school advisers, speech therapists, occupational therapists and dieticians. Advice and support should be complementary to, and not a replacement for, rehabilitation and social services.

Individuals who have serious physical impairments and have not reached the age of 65 may be entitled to help from one or more personal assistants. That includes help with meals, personal hygiene, dressing and undressing, and communicating with others. Those who do not receive personal assistance may be entitled to companion service — a service that is personalised and tailored to meet the individual's needs, so that he or she can have an active social life.

In order to reduce social isolation, assist participation in leisure activities, and provide advice in daily situations, individuals in Sweden can get help from a “contact person” who can make it easier for them to live independently. Sometimes, a “support family” can provide back-up. Respite is provided in the home, both as a regular service and in unexpected situations. Short stays away from home permit individuals to have the opportunity for recreation and a change of environment while providing relief for relatives. A stay can be arranged in a short-term home with another family or in a camp, for example.

Children who are over the age of 12 years are entitled to supervision before and after school, and during holidays. Children and young people who cannot live with their parents may be entitled to live with another family or in a residence that provides special services. That should be a complement to the parental home, both for children who live with their parents part of the time and for those who cannot live at home at all.

Specialised residential accommodation varies, but includes group housing and service housing. An individual may also be entitled to a specially adapted home. Individuals of working age who are not gainfully employed or studying are entitled to assistance with participation in daily activities.

2.30 pm

In the US, the ink is barely dry on the Combating Autism Act of 2006, which had the support of all major US autism advocacy groups and authorised more than £1 billion of funding over the next five years to combat autism through research, screening, early detection and early intervention. Spending on autism will increase by at least 50% and will include provisions relating to the diagnosis and treatment of persons with ASD and will intensify biomedical research on autism, including possible environmental causes.

Little is understood about the causes and mechanisms of autism. Many studies have been carried out into researching possible genetic and environmental causes of autism, and scientists are learning more about the disorder and how its effects can be lessened or eliminated. More work must be done to pinpoint the true causes of autism and come up with a cure.

The US legislation also includes provisions designed to improve and co-ordinate the US Government’s response to autism. That legislation instructs the Centers for Disease Control and Prevention (CDC) to expand and update efforts to monitor incidence and prevalence of autism around the country, and to educate parents and healthcare providers about the early warning signs of autism and the need for early and regular screenings.

The US legislation demands extra autism-related research, including investigating possible environmental causes of autism. There remains much that we do not know about the biological pathways and origins of the disorder, and further investigation into all possible causes of autism is needed.

We should leave no stone unturned in our efforts to understand autism, whether that means exploring possible environmental factors; paternal age; genetic factors, or any others that may hold answers. Perhaps further enquiry will show that it is not a single factor but a combination of factors that are responsible. For example, a child may have a genetic predisposition, which is triggered by an external, environmental factor that causes autism.

The Combating Autism Act of 2006 strengthens the Interagency Autism Coordinating Committee (IACC), comprising relevant Government officials; experts; parents and families of those suffering from autism. The committee's far-reaching mandate will be to compose and annually report on a strategic plan for autism provision and how improvements can be made. Public participation, particularly among the parents and families of those affected by autism, was deemed necessary to emphasise the human side of autism research and to ensure that resources are used wisely.

The growing number of people in Northern Ireland who are diagnosed with ASD deserve the same level of provision as others around the world. I am sure that everyone in the Chamber would agree with that. It is important that we learn from the experience of others and are not dragging behind in delivering a first-class service in Northern Ireland.

Every child is precious, but children with special needs require extra attention and services to help with their quality of life. We have much to do in comparison to the US and Sweden, but let us hope that when we get our Executive up and running, we can tackle this matter head on and treat it with the seriousness that it deserves.

Rev Dr Robert Coulter: I begin by declaring an interest as a board member of Dunfane Special School in Ballymena and chairman of the interim board for the amalgamation of the three special schools in Ballymena. I am also the grandfather of an autistic child, of whom I am immensely proud.

Mr Storey: Would the Member join me in commending Dunfane Special School in Ballymena? There are many other examples of good provision, but, having experienced the excellent provision that Dunfane Special School has provided in our constituency, would he join me in wishing it well, especially in light of the difficulties that it faces in dealing with autism?

Rev Dr Robert Coulter: I thank the Member for the intervention and I fully support his sentiments.

Dunfane Special School has done a marvellous job under very difficult circumstances. The school needs all the support that we can give it.

From the point of view of those who are, tragically, affected by autism, I am pleased that today's motion has been tabled. However, I am disappointed that an amendment to it has been accepted so easily, because I think that it takes away from the original motion. It deflects our sentiments away from the people to whom they should be directed; it takes away the humanity of the original motion and leaves us with a political football that should be dealt with at another time.

The issue of autism should be discussed in the context of real people with real names, individualities and identities. It is not simply a matter of statistics or politics, although statistics are important in helping us to focus on the scale of the problem. For instance, more people in Northern Ireland suffer from ASD than the combined total of people who have Parkinson's disease, multiple sclerosis and Down's syndrome.

In Northern Ireland, clarity about autism is required. We need definitive research into the causes and treatment of autism; we need to recognise the need for family respite care; and we need to initiate a policy for the treatment and support of people suffering from autism after they pass the age of 19. I hope that this simple outline will supply the headings of an action plan to deal with what is increasingly being recognised as a widespread problem. In 2006, the medical journal 'The Lancet' estimated that autism affected one in 100 children.

There is no Province-wide approach to the problems posed by autism. Members have already mentioned the difficulties that people face when they move from one board area to another. Families with children suffering from autism who move between education and library board areas encounter significant differences between the services available. That is a ludicrous and unacceptable situation in a Province of some 1.7 million people. We need to move on from this situation to become a leader and an example of best practice in the UK. Members have already mentioned that countries such as the United States of America, Sweden, New Zealand, Canada and Australia are proposing legislation on ASD that recognises the complex nature of the causes and treatment of autism.

The all-Wales autism strategy is due to be published this month or next month. Autism Northern Ireland has already formed a strategic Celtic Nations Autism Partnership with Scotland and Wales, and we compliment it on its initiative. I have the honour of being my party's autism ambassador, and, in March 2006, I joined 50 other people from the Province at the Great Britain launch of a campaign for a Northern Ireland-specific autism Act. This network of party ambassadors was established in 2002 and has initiated strategic partnerships within Northern Ireland and with Wales, Scotland and Sweden. We took our petition for an autism Act directly to the Secretary of State for Northern Ireland and for Wales, Peter Hain, at the Welsh

Office. Mr Hain was left in no doubt that there was massive cross-party support for this measure.

That meeting was, indeed, a notable first, because representatives of all five main political parties in Northern Ireland met and agreed a strategy. We focused our lobbying on the early diagnosis and treatment of autism. We revealed that, according to figures that my party had obtained from Lord Rooker in 2005, around 700 children in Northern Ireland were waiting for this vital primary assessment.

In the Northern Board area 117 children were waiting; 188 were waiting in the Western Board area; 128 in the Southern Board area; and 253 in the Eastern Board area. The model for legislation for a Northern Ireland PAPA Act — as it has become known — already exists. That model is in the Autism Northern Ireland (PAPA) document ‘The Blueprint for Change’.

The Government need to recognise ASD as a complex, lifelong developmental disability in its own right. It is neither a learning problem nor a mental-health disorder. A Northern Ireland policy on the issue, which would be the precursor of an Act, should raise public awareness of autism, create a dedicated programme of care for autism sufferers and create a funding mechanism to underpin a distinct and separate programme of care for them.

It is critical that all staff who work with young children are aware of the features of autism. It is also important that a quick response mechanism is put in place that ensures not only early detection but early treatment. Referral routes need to be established for children and adults, and each diagnosis should result in the appointment of a health professional to supervise and support those cases. Multi-agency and multidisciplinary teams that comprise ASD healthcare specialists who have received specific training are essential. That should result in a needs-led care plan that is based on best practice.

I should reinforce the need for proper clinical and scientific research into ASD. Genetic research is particularly important. I was delighted at last year’s announcement that a Bristol-based team is to research the genetic causes of autism and other chronic childhood conditions. It intends to build a biobank — or DNA database — that contains the genetic profile of some 14,000 children. Given that Autism Northern Ireland has estimated that one adult in 86 in Northern Ireland suffers from ASD, Northern Ireland scientists should either establish their own database or aim to participate in the Bristol study.

Finally, I ask that carers be remembered. It is difficult being the parent of an autistic child. Respite care for families of autism sufferers, as well as families of those who have other chronic disorders such as Alzheimer’s disease, is a critical part of the overall care package. It is amazing what a difference a week — or even a weekend — away from the responsibility of looking after a child with ASD can make. That can

be a relief for siblings, who can find it difficult to communicate with their autistic brothers or sisters.

We should never lose sight of the fact that when a chronic disease affects people it affects more than the patients themselves. It affects their carers and their families. We need a whole-family approach to the problem if we are to create the climate in which to optimise treatment.

I support the motion.

Mr McCarthy: It gives me great pleasure to voice my support for the motion and, indeed, for the future of those in Northern Ireland who live with autism.

You, Madam Speaker, were the Alliance Party's ambassador for autism for a number of years. You supported the efforts of so many people, including parents, to secure better deals for individuals who suffer as a result of autism spectrum disorder. When your talents were required to carry out the duties of Speaker of the Assembly, you very kindly handed over your role of ambassador for autism to me, and I am privileged to carry on the work that you started.

I, like everyone else here today, pledge my support for a better future for all people who have autism. I acknowledge the work that Autism Northern Ireland has done under the dynamic leadership of Arlene Cassidy and her staff. Indeed, other groups are advancing the needs of those who deal with ASD in Northern Ireland.

2.45 pm

The need for advancement for people with ASD has never been greater; we are told that the number of sufferers is increasing at an alarming rate. In Northern Ireland, up to 200 babies born each year are later diagnosed with autism. This is a staggering figure. While this is the case, every help and assistance must be provided to those individuals and their carers.

At present, the Departments relevant to the needs of ASD sufferers are grossly underfunded. It is a shame that families are having to wait for up to three years for their child to be assessed. It is also disgusting that, at the end of 2006, there is no Northern Ireland strategy for autism; there is no ring-fenced funding; and there is no legislative protection for the condition to guard against vested interests.

On 30 June 2006 'The Blueprint for Change' report was launched in the Long Gallery. All Members who attended gave their full support. The report stated that:

"the Blueprint does not seek to replicate existing legislation; but rather addresses the unique issues facing individuals with ASD and their carers that existing legislation did not reach".

Autism NI has found that there is a huge differential between health boards in Northern Ireland for people with ASD. There ought to be the same facilities and provisions for everyone, regardless of the board area in which one lives.

Working with other parts of the UK has led to real progress. The all-Wales autism strategy is shortly to be launched, and Scotland is also working in that direction. Indeed, other parts of the world are in the process of implementing legislation for ASD. We have a chance to be the first in these islands to make positive changes for ASD sufferers.

In conclusion, today while the Transitional Assembly has no power, let us commit our parties to do in the near future what is required to ensure that all ASD sufferers get a better deal. Dominic Bradley has invited me, and I would be delighted to accept, to be part of an all-party group of the Assembly to deal specifically with ASD. Similar groups have dealt with other areas of complaint and we have had some success, so that is an important development on the way forward. I hope that other parties will join in to advance the needs of autism sufferers.

Dr McCrea: For too long, people with ASD have been forgotten citizens. Their unique condition is referred to as a hidden disability. In its mission statement, Autism NI focuses on the need for:

“people within the autistic spectrum and their carers [to] have access to appropriate services, enabling people with autism to be valued members of their community”.

Yet it is apparent that despite the many initiatives and the high-profile awareness-raising activities, the desperate plight of a person with ASD remains largely unresolved. Autism NI joined with its Welsh neighbour, Autism Cymru, to produce the report ‘Government and Autism: Opportunities and Solutions’, which concluded that:

“Ownership by Government of the ASD ‘issue’ is the unavoidable way forward”.

Therein lies the importance of today’s motion. We need to move towards a solution where people with autism feel both respected and supported. The report of the education Task Group on Autism published in 2002 recognised that autism was underreported and an underdeveloped aspect of special needs.

Even then the task group found that much progress still had to be made before it would be possible to say that all children and young people with ASD were being identified and their needs being fully met. The report recognised that a demand exists for more prompt access to diagnostic services at an early age and that those services should be followed immediately by effective home- and school-based intervention.

The report also highlighted the fact that there was:

“an ‘autistic spectrum wave’ rising through the school system”.

That has led to a large increase in the number of pupils and trainees being diagnosed with ASD, resulting in a large increase in demand for appropriate services and educational provision.

Help and support for people with ASD is a right. It is a way in which to level the playing field and to enable those with autism to make the same choices and lead the same lives as all other citizens. However, in order to ensure that the rights of those on the autistic spectrum are fully recognised, there must be planned development in all service areas. New resources must underpin that development in order to drive up the level of service that every family receives.

Children with autism require services that are provided by members of many different professions, working in a variety of agencies. Autistic children’s need for such services continues into their adult life, because autism is not a condition that disappears with maturity.

Although the strategies for catering for the needs of individuals with ASD are primarily educational, there are implications for the Department of Health, Social Services and Public Safety (DHSSPS) and the Department for Employment and Learning (DEL). Our health and social services boards and trusts are at different stages in current provision. The Southern Health and Social Services Board (SHSSB) is well advanced, having released its children’s autism strategy 2005-10. I welcome the fact that work on the development of a service framework for ASD by the Northern Health and Social Services Board (NHSSB) continues apace.

There has been significant progress in some areas, and that must be recognised, but a great deal still needs to be done so that people with autism, and their families and carers, can access services to which they should be entitled.

Short-break and respite services are an essential part of family support, representing a major area of unmet need for families that autism affects, yet parents’ greatest concern is the lack of reliable respite care. In truth, that service is often not delivered until families are at breaking point. Many have described to me how much more difficult life becomes when, as happens too often, their respite is delayed, curtailed or cancelled because of staff shortages or transport problems. The impact of the Government’s failure to improve services is real and present, and the failure to deliver appropriate services consistently and at the right time causes families huge distress and anguish.

Let us be truthful: current funding levels for services for children with autism and their families are set too low. The allocation of resources has not kept pace with the growing numbers of children with autism. Prevalence rates for autism in Northern Ireland have tripled over the past three years, with almost 4,000 school-age children

now with ASD. Waiting lists for diagnosis top 35 months. So much for the Government talking about how quickly problems can be diagnosed.

About 20% to 25% of children with ASD have also been diagnosed with epilepsy, and a significant proportion of children diagnosed with ASD also have an associated learning disability. As such, autism must be treated as a common disability with clear implications for health, education and social services. For too long, however, children and their families have struggled to access good-quality, co-ordinated services.

Autism, as a spectrum condition, is different from all other disabilities and does not fit neatly into the existing structures of mental health or learning disability — a point that Autism NI was keen to stress to the Bamford Review of Mental Health and Learning Disability, which concluded that the needs of all those with ASD, and their carers, should be the subject of a separate and overarching autism paper. However, unless new funding is prioritised, the Bamford Review's recommendations in the six key areas for service development may never be fully recognised. There are funding implications for those recommendations for the Assembly today.

As Members know, autism is a complex and stressful condition, not only for those affected, but also for their families and carers. A family left alone to face the stressful challenge of raising a child with autism is, from the very beginning, the victim of despair and exhaustion because of the misconceptions surrounding autism, which include the lack of specialised services available in the local area, but mainly because of the impossibility of planning for the child's future.

Sadly, there is no known cure for autism. However, children with ASD have huge potential. Appropriate services and early years education can greatly improve later functioning and help those affected to live their lives with as much dignity and independence as possible. That is what we should aim for. Each child has the right to a specifically tailored programme of help, and each parent should have the right to sleep at night knowing that the proper provision will be in place quickly for his child.

Much of the awareness in highlighting this condition has been generated by Autism NI. I pay tribute to its members, and, in particular, to the members that I know in the mid Ulster and Ballyclare groups. Their commitment and enthusiasm has been unstinting and acts as a source of active encouragement and support to others.

There are other models of excellence. For example, my colleague from Strangford mentioned Sweden, where ASD has been clearly identified as a condition and afforded appropriate primary and secondary legislation since 1993. In the United States, a five-year programme to support people living with autism has been announced recently, and that should encourage us in Northern Ireland to provide something better for those who need it most.

The significant increase in the number of children identified with ASD will require an improvement in our provision to meet that need. We may even require a spectrum of provision to meet a spectrum of need. While there is no cure, there is always potential for positive progress.

I support the motion.

Mr B Bell: I support the motion. I am aware that the prestigious medical journal 'The Lancet' estimated in 2006 that one in every 100 people suffers from Autism Spectrum Disorder. I am also aware that Autism NI has estimated that the problem in Northern Ireland is significantly worse than that figure of one in 100. It is estimated that 4,000 school-age children suffer from ASD, and the Assembly must address the issue.

Once a disorder is as well defined and documented as ASD, it is unthinkable that in any civilised society legislative provision is not put in place with underpinning public funding available to deal with the problem.

It is also unthinkable that in a Province of 1.7 million people, different regimes for dealing with autism exist across the education and library boards. That situation cannot pertain following the review of public administration, when massive reductions in bureaucracy are envisaged. The situation will be the same regardless of which type of review we agree to.

3.00 pm

I was pleased to hear that there has already been a significant amount of self-help. Dr Coulter demonstrated the ways in which autism ambassadors have been developed in the political parties here, and how a blueprint for change already provides the structure for any future Northern Ireland autism Act. I was moved by the way in which Dr Coulter reminded us that autism is a whole-family disorder, and of the need for respite care for families and carers. I was also moved by the sincerity with which he spoke of his pride in his grandson, whom I know, and who suffers from ASD.

The legislative path that this Assembly needs to follow is already laid out in some detail. I do not propose to revisit the particular aspects of any possible Act, but simply to say that the sooner we can legislate on this matter the better. We should never forget how many measures like this are sitting in the pipeline, waiting for action by this Assembly. It must give a greater sense of urgency to our efforts to find a way forward to a political settlement as soon as possible. Every day without a settlement is another day without an autism Act and another day that ASD sufferers and their families have to do without adequate levels of support.

(Mr Deputy Speaker [Mr Molloy] in the Chair)

Regarding the lack of planning and funding for services for those on the autistic spectrum, I want to point out that, according to Dr Larry Martel of Down and Lisburn Trust, a specialist in the field of attention deficit hyperactivity disorder (ADHD), some experts have said that 20% of children with Asperger's syndrome, recognised as part of the autistic spectrum, also show aspects of ADHD. In Dr Martel's opinion, around 10% of his patients display Asperger's traits.

There are approximately 1,000 children diagnosed with ADHD in the Down and Lisburn Trust area alone. It is my certain knowledge through personal experience that families of children diagnosed with ADHD are in an identical position with a lack of funding and services for support post-diagnosis. That being the case, I request that any autism legislation should also include planning and funding for the promotion of awareness of ADHD, and support services and research into the social implications and problems surrounding the condition.

In reply to a question for written answer from Lord Maginnis in 2005, Lord Rooker revealed that over 700 children in Northern Ireland were waiting for vital primary assessment of ASD. Those are sobering figures; they are a reproach to this Assembly, and they imply that action should have already been taken.

Autism often involves considerable financial sacrifice for the families affected. That is a primary reason why the disorder requires specific legislation. It is not simply a matter of the disruption of family life; it is also a matter of cost.

Autism costs can include medical treatments and equipment and home adaptation. At present, family carers are subsidising the care budget. Legislation will ensure greater equity in the allocation of resources. There are hidden costs of autism — divorce and family splits can occur because of the enormous pressures that autism can impose on a family. That has cost implications for the state, as carers can be prevented from normal employment, which has an indirect impact through the loss of earnings and tax revenue.

One other cost aspect that needs to be considered is that although early autism intervention — both medical and educational — is expensive, there may be a recruitment factor later because intervention enables those on the autism disorder spectrum to lead a more normal life. Crisis intervention is by its nature more expensive than well-structured, well-planned early intervention that is amenable to unit cost savings. Correct diagnosis of autism at an early age can lead to savings by avoiding misdiagnosis such as schizophrenia and the resulting incorrect treatment that often occurs.

There should be special emphasis on the more able children with autism. The link to autism has given us great individuals in history. Some people reckon that Mozart, Beethoven, and Bartók suffered from autism. Thomas Jefferson, the founding father of the United States and Isaac Newton, who discovered gravity, Al Gore, the former

vice-President of the United States, and Bill Gates, the richest man in the world, along with George Bernard Shaw and the painter Van Gough are among the famous people who are said to have suffered in some degree from autism. History is littered with great men who may have suffered; and great talent could be lost to our society by a failure to identify intelligent sufferers of autism at an early age.

We owe it to the future of humanity to identify intelligent sufferers of autism as early as possible, since society could be immeasurably enriched by their contribution. The fact that so many great men and women have been sufferers should remove all stigma from the disorder. It is important that we treat this subject with the care and attention that it deserves and that the Assembly puts an autism Act on the statute book at the earliest possible opportunity. That is why I strongly support the original motion.

Ms Ruane: Go raibh maith agat, a LeasCheann Comhairle. Cuirim fáilte roimh an díospóireacht seo, nó is díospóireacht an-tábhachtach í. Is bunéileamh iad an t-oideachas agus an comhionannas deise, rochtana agus soláthair. Is ceart bunúsach é an cumas a bheith ag foghlaimoirí a lánacmhainneacht a bheith acu trí rochtain a bheith acu ar leibhéal an churaclaim, ar na hinstiúidí agus ar na cineálacha teagaisc agus foghlama is oiriúnaí chun a leithéid a thabhairt i gcrann. Ba chóir do dhaoine aonair a bheith ábalta a leithéid a dhéanamh ag aois ar bith agus ag staid ar bith ina saol. Iarrann a leithéid de sholáthar infheistíocht chuí inbhuanaithe san acmhainn is saibhre againn — ár muintir féin.

Equality of opportunity, access and provision are basic entitlements. Learners have a fundamental right to achieve their full potential by having access to the curriculum levels, institutions, forms of teaching, learning and healthcare best suited to deliver success. Individuals should be able to do so at any age or stage of their lives. Such provision calls for adequately sustained investment in our richest resource — our people.

Over the past few weeks, Barry McElduff and I, along with colleagues from other parties in the Subgroup on Schools Admission Policy, have been discussing the post-primary arrangements to replace the 11-plus. The subgroup invited representatives from various bodies with an interest in education and children to present evidence. They all spoke with such conviction and passion about education and the support that our children need. The majority of witnesses said that the current system is failing a significant number of children. In particular, our education system is failing children with autism and those awaiting diagnosis.

Any educationalist or health expert will say that early intervention is the key to dealing with autism. The diagnostic process in the North of Ireland takes far too long. There are not enough educational psychologists, which severely disadvantages children with special needs and those with ASD.

That is particularly frustrating for parents who know instinctively, long before anyone else, that their child needs specialist help, and that the earlier the intervention, the better. They also live daily with the effects of late intervention: a child crying before going to bed; not wanting to go to school; and, in some cases, being bullied and their self-esteem severely affected. Many Members are also parents and know how heartbreaking it is when our children's self-esteem is affected. We dread them saying that they do not want to go to school.

ASD is a lifelong, complex developmental disability. Adequate funding is needed to ensure a personalised, tailor-made package, so that parents, carers and people with autism can avail themselves of much-needed services. A personalised package would allow people with autism and Asperger's syndrome greater control over their lives and offer them better alternatives. Crucially, it will give children hope and access to support and appropriate intervention.

Like Barry McElduff, I pay tribute to groups that are working to highlight needs and change the services that are currently available throughout the island of Ireland. Sinn Féin believes that there needs to be a joined-up approach, North and South. The all-Ireland centre of excellence for autism, which was mentioned earlier, should have been up and running long before now, offering support and training to people living and working with autism across the island.

Autism recognises no borders. The centre of excellence, which has been hailed as a dynamic concept, will provide exemplars of education intervention; a lead for the training of parents and professionals; a research facility; and an outreach support service complementing current and developing service provision.

Consider the professionals who would potentially be involved in the centre: a learning support and assessment division; an assessment centre with educational psychologists; speech and language therapists; occupational and behavioural therapists; teachers; classroom assistants; and visiting professionals. There would be a learning support centre, with teachers; classroom assistants; educational psychologists; speech and language therapists and music therapists. There would be a training, advisory and research division, with ASD advisers and trainers, and a research and information service. There would also be care staff and administration and other support staff.

When this initiative was advanced by Martin McGuinness and his counterpart in the South, Michael Woods, it was hailed as a ground-breaking initiative, and everyone living and working with autism could see the enormous potential of the facility. Unfortunately, under British direct rule, the project has been caught up in bureaucratic wrangling.

My late colleague, Michael Ferguson, refused to let successive direct-rule Ministers off the hook, and we are now seeing signals that the wait is over. I have no doubt

that, in true Tyrone style, my party's education spokesperson, Barry McElduff, will take the ball and run with it. I, as equality spokesperson, will assist him.

3.15 pm

There is much work to be done. In 2005, campaigners and autism support groups from across Ireland travelled to the European Parliament in Brussels at the invitation of Mary Lou McDonald. A total of 24 delegates representing 10 autism non-governmental organisations (NGOs) from all over the island made the trip, and they told stories of state neglect on both sides of the border; lack of support; and woefully inadequate provision of essential services. The Irish Government and the British Government are failing the families who are caring for children and adults with autism. The situation here is not acceptable and needs to be changed.

The British Government has a fundamental responsibility to ensure support and provision of services, yet in this state there is no adequate and specific facility for autism. There is no cohesive strategy. We may sit here, talk and have a wonderful debate, but we all know what needs to be done: sit down, form a power-sharing Government, establish a North/South Ministerial Council and stop making excuses. Let us move forward and get the arrangements up and running, so that we can help those who need help.

This involves us as political parties in the North of Ireland. There should be Ministers from the DUP, my party and all the parties here running health and education, equality, OFMDFM and our justice system — and those are the Departments that must work with families who need support on the whole issue of autism. It is not acceptable that we continue to let the British Government dictate the pace.

Furthermore, we have human rights and equality legislation, and we need to use it. I know from my experience as a human rights worker prior to being a politician that the only way to realise change is by fighting from a rights-based perspective. I commend Disability Action's new centre for human rights and I look forward to the centre taking test cases that will change people's lives for ever.

Finally, I commend the people who deserve our respect the most: those who have had to fight for their children — who should not have had to fight, but whose circumstances dictated that they must. They are men and women, family members, brothers and sisters, but invariably they are mothers. I work with many families whose children have special needs, and nine out of 10 of the people who come to my constituency office are the mothers.

Billy Bell talked about the historic men; I want to talk about the brave and powerful women who have done so much and who have taken on the system and come up against a terrible brick wall that they had to break down. I commend them — and fair

play to them. Sinn Féin will join with them in their fight, but the best way that we can do that is to get the institutions up and running, work together and stop this nonsense. Go raibh maith agat.

Mrs Hanna: I welcome the motion from my party colleague, and I support the amendment.

As elected representatives we are becoming more aware of the autism spectrum disorder, a developmental disability. However, there is still a general lack of understanding on the part of the public. That is by the very fact that it can be a hidden condition and is such a varied condition. However, that is improving through the well-organised campaign mounted by Autism Northern Ireland, which is a charity made up of parents, professionals, other support groups, and friends and acquaintances, as well as constituents.

The dire need for the implementation of a well-co-ordinated strategy has been brought home to me. Furthermore, awareness needs to be raised with regard to the dilemmas and issues facing parents and carers of people with autism. We are learning more about this complex and challenging disorder from other places, particularly regarding legislation and the need for a clear strategic direction; we must continue to learn.

Today is our opportunity to move the issue forward, and so I make a plea, particularly to the DUP and Sinn Féin, to make a move; get on with it and let the rest of us get back to work.

Some Members: Hear, hear.

Mrs Hanna: Although the number of people with autism has tripled and is still rising, there is no cohesive strategy. Some services are in place, but they are patchy and must be better co-ordinated. The length of the waiting lists for diagnosis is unacceptable. More paediatricians, educational psychologists and many other professionals are needed. A mechanism must then be put in place to enable health and education professionals to respond quickly in order to create a clear referral route for children and adults and to provide straightforward support, direction and service for parents and carers. Together, those measures will form a proper, comprehensive care plan.

It is essential that the diagnostic team receive specialist training in the assessment and diagnosis of autism. Appropriate accredited training must be available to other healthcare providers, particularly so that they can recognise other possible healthcare needs related to autism. Training must also be provided for parents and carers to empower them to do the best for their children.

The education system must provide a service that supports people with ASD to realise their potential and that provides them with the appropriate social skills and life-skills training.

Parents of children with autism experience undeniable stress. All parents want the best for their children, and rightly so. I have met many parents who are at their wits' end as to how to help their children. All parents have experienced a feeling of helplessness when their children have been ill, but most know that a specific treatment will remedy the illness.

However, some parents worry that they may have an autistic child, because, for one reason or another, the child does not respond to affection or appears to be in a world of his or her own — it is hard to imagine how helpless those parents feel. Parents know that there should be help for their child but that professional support is needed to unlock that child's potential. Those parents are all too aware that the days, weeks, months and, sadly, years, waiting for help may represent lost opportunities.

That situation must not be allowed to continue. Let us get the Assembly back, so that we can roll out a strategy — with any necessary legislation — to protect people with autism and to ensure that the structured support is in place through to adulthood. Every person has a right to a comprehensive service.

Mr McGlone: It should be noted, a LeasCheann Comhairle, that 80% to 90% of individuals diagnosed with ASD will develop mental-health problems. Only 5% of people with ASD are in employment or higher education. As a former Minister for Employment and Learning, Carmel has experience in that field and knows that, set in the context of Government initiatives intended to encourage people into the workplace, that is an extremely low figure.

Moreover, as Carmel mentioned earlier, 74% of front-line workers in health and education consider themselves to be poorly trained and not to understand ASD fully. Thank you, a LeasCheann Comhairle.

Mrs Hanna: I thank the Member for his intervention, which highlights that a co-ordinated strategy for autism is essential. Training for health professionals, carers and parents is required so that other conditions related to autism can be recognised. A comprehensive service is not only required but is the right of every person with autism, the parents, carers and extended family.

Some Members: Hear, hear.

Mr Berry: I support today's important motion and welcome the debate. However, it is unfortunate that the amendment takes the focus away from the motion and from the message that Members are trying to send out.

We must have a Northern Ireland centre of excellence, rather than one that is cross-border and politically motivated. Such a centre of excellence was hailed by Sinn Féin and others. It was promised but never delivered. Therefore the amendment is politically motivated and for that reason should not have been tabled.

Although autism was first identified in 1943, it is still a relatively unknown disability. Autistic spectrum disorder is estimated to touch the lives of over 500,000 families throughout the beloved United Kingdom. People with autism are not physically disabled as a person with cerebral palsy might be. They do not require wheelchairs, and they look just like those without the disability. Due to the invisible nature of autism, it can be harder to create awareness and understanding of the condition. The motion will help to do that, even at the level of Government.

A carer commented that, because autistic children look normal, others assume that they are naughty or that parents are not controlling them as they should. Strangers refer to that perceived failing frequently, and it causes concern, anxiety and stress for parents when they socialise, and many of us should take that on board.

I support the call for legislation that will ensure that the rights of people with autism, and their families, are upheld, and that services are provided continually to meet their needs. We must combat the disgraceful social injustice that exists due to the lack of funding and planning of services across Northern Ireland.

Local provision for children with autism is often limited. Teacher training in autism is inadequate, and children and their families struggle to access the entitlements that are their right. It is vital that the good practice that exists in some areas in the United Kingdom is extended to schools in all areas so that all children with autism get the education that they deserve. Postcodes must not determine provision.

I, like others, commend Autism NI. They have carried out tremendous work and continue to lobby hard throughout Northern Ireland for their members and for people in general who suffer as a result of autism. Dr McCrea quoted the mission statement for Autism NI. That should be the mission statement for the Assembly. This House must ensure that there is access to the appropriate services for people with autism and carers. Members must help to achieve an autistic spectrum disorder programme of care, an autistic spectrum disorder strategy for Northern Ireland and, as has been mentioned earlier, a Northern Ireland autism Act.

In the United States, the needs of autism sufferers and their carers have been debated on Capitol Hill. Due to the efforts of Cure Autism Now, and other groups, Congress passed legislation six years ago to boost research funding for autism. Last summer, the Senate passed follow-up legislation called the Combating Autism Act of 2006, which not only calls for a doubling of funds for autism research, but also for autism screening, surveillance and early intervention programmes in all 50 States. It is important to state that they still have a long way to go, and some groups are

concerned that funding has not yet been provided. However, that is, at least, the first step in the process, and we, in Northern Ireland, must take note of it.

Funding is required to provide support for schools, and it would involve working directly with teachers and classroom assistants. For many years, there have been concerns in this area. Although classroom assistants have been trained in autism, parents feel that teachers, on occasions, brush off children with autism and leave them for the classroom assistants to deal with. That matter must be dealt with.

It is vitally important that teachers work in partnership with classroom assistants in the preparation of materials to support children with autism.

3.30 pm

Individual support for each child is required, and it is imperative that parents, teaching staff and other services are trained in how to support children with autism. One hears so much about joined-up government, but when one looks at the provision of such support services, it seems that joined-up government is far from the agenda. The Southern Education and Library Board provides an autism advisory and intervention service, and I welcome such a partnership approach that helps everyone involved to support and help young people who have autistic spectrum disorder.

It has been said that the earlier an autism diagnosis is made, the better the person's chances are of receiving appropriate help and support. However, we have heard many statistics in the course of the debate that show that there is a long way to go before the needs of the people who are affected by autism are met.

The Government must hear the clear message that more funding and better planning are required to deliver the necessary resources for people who have autistic spectrum disorder and their carers. An urgent joined-up-government approach is needed to tackle the issue. I support the motion.

Mr Dawson: In common with many Members, I have had occasion to meet parents, grandparents and other family members who have gone into great detail in outlining the personal and often heartbreaking reality that an Assembly motion could never express. There are children in all sections of the community who are on the autism spectrum. Therefore, I am disappointed, but not surprised, that some Members have sought to politicise the motion and score political points on the back of children in real need.

All parents, regardless of the community from which they come, want to know that the needs of their children are being adequately met, and that their children will be allowed to perform to the best of their ability. They want to know that their children will not be disadvantaged compared with other children because they are on the autism spectrum.

I will concentrate on autism in the classroom, because it is there that the shortcomings of the system, as summarised in the motion, are graphically demonstrated. I have consulted professionals in the education sector, and some key themes have emerged. First, there is a need for flexibility of approach. As Members know, autism is different from other difficulties that may affect children. It is defined as a spectrum because it differs from child to child, and because it is global and pervasive in relation to the child's experience.

All aspects of the life of the individual are affected, and children with autism are found in every type of school in Northern Ireland. Therefore, there is no one-size-fits-all approach for the education sector. In order to meet the children's needs, boards and schools must be adaptive and flexible in their approach to the situation. The concept of 10 hours of classroom assistance in blocks of time is nonsensical to a child on the autism spectrum. The child requires a minimum of 10 hours of assistance spread across 20 hours of teaching time. Therefore, the classroom assistants should be available throughout the teaching day and teaching week. That flexibility does not exist in any of the boards in Northern Ireland.

Secondly, thorough and specific assessments are essential if we are to allow for the correct planning and package to be made available for the child and the family. Early assessment has already been mentioned, and it will reassure the parents and allow for the specific needs of the child to be met. It is essential that assessment occurs as early as possible so that action can be taken as early as possible. However, that runs counter to established educational practice, which results in up to 18 months lapsing before a statement can be issued for a child.

That 18 months is lost time — it is time during which the child is not receiving appropriate help, could be developing further problems, and could be falling behind in achievement.

The third key theme is the training required for parents and teachers, and support staff in the education board structures. Training delivery needs to be tiered so that it is appropriate in individual cases. Once again, flexibility of approach is important. Without necessary training, relationship issues will inevitably develop within the school.

Like others, I have had to deal with difficult situations in the classroom. One situation involved a young person on the autistic spectrum who was being disciplined by a school for going down a corridor the wrong way to get to the classroom for a lesson at the scheduled time. The child was being disciplined because a teacher felt that it was being disobedient and disrupting school life. However, the child was not being disruptive or disobedient. It was simply that the lesson time created an absolute for the child that the one-way system in the school did not. Training of staff in the school would prevent such an incident. Indeed, perhaps such a child would need a classroom assistant to accompany him or her from class to class to ensure

that the difficulty did not arise. That takes us back to the need for flexibility of approach.

The fourth key theme is multidisciplinary working. Children on the spectrum require a wide range of professionals, some of who have been mentioned.

Mr Shannon: Is the Member aware that 50% of carers are in ill health and are being driven to the brink of despair? One supreme example is the case of Alison and Ryan Davies across the water. Alison, who was the mother of Ryan, an autistic child, was driven to take the ultimate step and committed suicide.

Mr Dawson: I thank the Member for that intervention. I am aware of examples of where people have been driven to despair, not only in that case, but in other cases too. Multidisciplinary working can assist families, because this is a complex issue, and a seamless approach and support to the child is needed.

Let me ask the House a very simple and straightforward question. Who in the government system is responsible for the delivery of that seamless provision to the child? The stock answer is that they are all responsible, or, that the organisation itself is responsible — which means that no one is responsible, and the inevitable result is that the child will suffer.

It should not be up to parents to have to pick their way through the maze of bureaucracy, the quagmire of no funding, or the constant argument about the needs of the child. The child's needs should be met as a matter of right.

That takes us to the further key theme of regularity of contact. Professionals are under so much pressure that running for the needs of the child must be done by the school, the parent, or both. That is never in the best interests of the child. There are gaps in service delivery, and that leads to children not receiving a quality education. It can also mean that parents are forced to seek private intervention, which can lead to confusion in delivery, and may not be best practice. However, who could fault parents who see a gap in the delivery to their children and seek a way to plug that gap. Sadly, too often the gaps in service lead to court cases, which develop as parents rightly demand the delivery of existing legal obligations for their children. Perhaps Members will feel that the service I have described this afternoon is a long way from best practice. Sadly, it is.

I have sought to elaborate on the motion using my knowledge of what is going on in education. However, that is but one area of Government. The motion covers a much wider canvas, which, I am sorry to say, is no less shambolic than education.

It is for these reasons that I support the motion.

Mr P Ramsey: Thank you, Mr Deputy Speaker, for calling me to speak in the debate. I realise that there are time pressures as so many Members wish to speak.

I welcome Dominic Bradley's suggestion to set up an all-party working group to deal with autism. Given the number of parents who have expressed interest in today's debate, we should, at the very least, activate such a group to give some reassurance and comfort to those parents. The working group should focus on the three key priorities that have been identified: to develop a Northern Ireland strategy for autism; to ring-fence funding for autism; and to initiate Northern Ireland legislation on autism.

I commend all Members on their contributions. Like this morning's debate, this afternoon's debate has been good. All Members honourably shared their concerns from their constituency perspectives, describing the work that they regularly do on this issue, particularly with parents of statemented children.

At a recent public meeting in Derry, I listened to testimonials from parents of young adults with autism. As other Members have done, I have supported parents in tribunals and meetings with health boards and trusts. Listening to so many different people describe their experiences of the same underfunded, fragmented service was not nice. I could share with Members the frustrations of all those who have been forced to put up with an inadequate service. Experiences ranged from problems with speech and language therapy to difficulties with education boards. There has been practically no co-operation between health boards and education boards.

After that meeting, I found it hard to look parents in the eye, knowing that they would have to fight for services for their children — services to which their children are entitled. No parent should have to waste time fighting and campaigning for a service that should already be in place. No parent should have to give up their time to meet health and social service council subgroups to ensure that the needs of their child are being met, as is the case in the Sperrin Lakeland Trust.

Destined is a self-advocacy group for young adults with autism in the Foyle area, and it does sterling work for people with autism. Members including Raymond McCartney, Mary Bradley and Willie Hay will be aware of Destined's advocacy work, and I am sure that they have been canvassed by or have met the group.

It is vital that all people with autism, and their families, receive quality services appropriate to their needs. Caring for a child with autism spectrum disorder can be strenuous, and we know that many parents experience great worry and stress. They cannot get peace to sleep because they are so worried, as Dr McCrea mentioned. The quality of the current service for autistic children, from diagnosis to treatment, is below par. As a result, parents are suffering unduly.

With increasing numbers of children being diagnosed with autism, it is important that action be taken to tackle and properly fund the needs of those with autism. Although there has been a great increase in awareness of autism, the Government have failed to implement any meaningful changes to the provision of services and therapies for those with autism.

Direct rule and, in particular, direct-rule Ministers, have failed people with autism and their families. For years, services have been underfunded, badly managed and poorly planned. A devolved Government can provide the opportunity to change that — an opportunity that must not be wasted.

A new Programme for Government could introduce legislation to protect and guarantee a future for those with autism and to give their parents the peace of mind that they want. We can ensure that the needs of everyone with autism are met and that they can access a service that is well resourced, well funded and flexible enough to respond to the needs of each individual.

Parents of children with autism have three demands: first, that every child with autism should have local access to a diverse range of mainstream and specialist educational provision; secondly, that all teachers should expect to teach a child with autism and must receive appropriate training to best support such children's needs; thirdly, that all schools should be autism-friendly and promote and provide a positive environment now and in the future. Those should be target areas for an all-party working group to challenge permanent secretaries of Government Departments to deliver for the parents of autistic children.

3.45 pm

Mrs Foster: Like other Members, I am pleased to take part in the debate, and to wholly endorse and congratulate Autism NI and others who work in the field of autism for the way in which they have promoted and worked on a comprehensive autism strategy for Northern Ireland. I pay tribute to the autism ambassadors in the different political parties, not least in my own party.

When I talk about a comprehensive autism strategy for Northern Ireland, I mean just that: a strategy that takes in all aspects of the condition, is holistic in dealing with all of the service providers, and most importantly for me, coming from the west, is that it covers Northern Ireland in its entirety.

Yesterday's debates highlighted the difficulties faced by rural dwellers. Unfortunately, I must continue with that theme today. Often, where someone lives determines the level of service that he or she receives. I want to stress to the House that that is fundamentally unfair and must be dealt with. Why should someone's address determine the quality of service that he or she receives? Following on from the previous Member's remarks about the Sperrin Lakeland Trust, I must point out

that there are major problems in the west of the country with regard to occupational therapy, speech and language therapy, and paediatrics. Those are the basic building blocks of any service and must be improved.

The option has often been presented to access professionals from outside the trust area. However, that is not a solution. It serves only to demoralise the existing staff, who are trying to do whatever they can for people.

Mrs D Kelly: I am sure that the Member, along with many others, has been lobbied by graduates from the physiotherapy service. It is an absolute scandal that young graduates must seek employment not only across the water in England, but as far away as Australia, and that after being educated in our own fine establishments, and despite there being huge waiting lists at child development clinics, there are no jobs for them. Where does the money go that comes from the Department to the boards and trusts?

Mrs Foster: I sincerely thank the Member for her point of information. That is an issue that must be examined soon because money is being put into the trusts and boards. I hope that the autism strategy will be able to identify the gaps in the current service.

There has been a dramatic increase in the number of people who are on the autistic spectrum. Nowhere is that more evident than in my own constituency. When I was growing up and still at school — which, I must say, Mr Deputy Speaker, was not that terribly long ago — autism was a relatively rare phenomenon. It is not so now, however. Indeed, between 2001 and 2004, the number of individuals who were diagnosed as having ASD tripled. The number is now higher than the combined totals of sufferers of multiple sclerosis, Parkinson's disease, and, indeed, Down's syndrome, yet there is still no cohesive autism strategy in Northern Ireland.

Early intervention for ASD sufferers is crucial to giving them the best start in life. Members have heard much about that today. It also helps to identify and address the needs of those who are carers of ASD sufferers. It is no surprise to those of us who have been involved with families of autistic children that the level of stress for those people is highest among all the major disabilities. It must be pointed out that the way that autism has been addressed by Government — or rather not addressed by Government — has been one of the major sources of worry and concern for those carers. Families have told me that the wait for diagnosis, intervention and support is frustrating and soul-destroying.

Parents ask me questions such as, "When will my child be assessed?", "When will my child get meaningful speech and language therapy?", "Will there be a teacher at my chosen primary school who will be able to effectively teach my child?", "Will there be a classroom assistant who is trained to deal with autism?", and, "If I choose a home programme for my child, will I be able to get funding to support me?". Indeed,

there are many other questions that families who are living with autism must face every day.

Autism for those families is a way of life. It cannot be designated as either a health or education issue and put into a tidy box, as has heretofore been attempted. That is not the way that people with autism live their lives and is, therefore, not the way that they can be catered for — in some sort of artificial dichotomy.

I am happy to endorse calls for a cross-departmental autism strategy but, as Members know, that is not where it will end; behind every good strategy is the finance to see it implemented, therefore funding must follow the functions.

There are huge gaps in staffing and resourcing for autism services, and we know that different Departments deliver different services. As my colleague George Dawson pointed out, funding gets lost in the muddle.

In June 2006, I tabled a motion to Fermanagh District Council on the autism strategy. The Education Minister, Maria Eagle, wrote to the council about the proposals for a Northern Ireland autism Act, and stated that provision for individuals with autism was covered by the relevant education and health legislation that is already in place. Clearly, that is not so. I implore the Government to listen to organisations such as Autism NI and NAS, who are specialists in that field; to listen to the carers of those with autism, who, by necessity, have become very effective advocates for their children; and to listen to the voice — that I hope will be united — of the political parties today to focus on an autism strategy and to move to a cross-departmental comprehensive strategy for the whole of Northern Ireland. That strategy should bring about effective services in sensible timescales with fully trained staff, so that the growth in the number of people with ASD, or families living with it, is matched with the necessary quality and availability of services. I support the motion.

Mr O’Dowd: Go raibh maith agat, a LeasCheann Comhairle.

Sinn Féin welcomes the motion, from which the amendment takes nothing away. I welcome the fact that the proposer of the motion has accepted the amendment, which is simple and non-political — despite the narrow, blinkered views that we have heard from across the Chamber. The amendment simply states that this Assembly:

“further calls for the immediate funding and implementation of the long overdue centre of excellence for autism at Middletown, Co. Armagh.”

We cannot be taken seriously by families affected by autism, those with autism, and the lobby groups, if we politicians cannot implement a decision that was taken four years ago. How can they take us seriously when the Assembly, which has no powers, discusses a motion that seeks more funding and a strategy, given that the

decision taken four years ago by an Assembly and by a Minister who had power has not been implemented?

I will outline what the centre at Middletown is all about. The Department of Education's brief states:

"The centre will strive to achieve excellence in its provision. It will provide a model of best practice in assessing the educational needs of children and young people with an Autistic Spectrum Disorder and in establishing working partnerships with those involved in providing and operating services at a local level."

Those working partnerships will apply to the support groups, the families, Autism NI and other autism charities.

"The centre will provide:-

a lead for, and offer exemplars of educational intervention;

a lead for the training of parents and professionals;

a research facility; and

an outreach support service complementing current and developing service provision."

If calling for such a centre is being political, then Sinn Féin is being political. However, that centre is needed. Middletown is only the start. No one is saying that if Middletown were established, we would walk away from the autism debate and the need for an autism strategy. Middletown is a centre of excellence, but I would like to see satellites or other centres of excellence across Ireland, from Ballymena to Bandon.

If anyone can object to an outreach support service that complements current provision, or to the development of service provisions, or to a research facility, they have not explained that objection. This is not a political question. Sinn Féin is saying that we must be serious. If the North/South Ministerial Council meeting of April 2002 announced the Middletown centre, and it has not been built, why should we be taken seriously when we debate funding and a strategy for autism in an Assembly that has no powers?

I support the call for an all-party working group that was made by the proposer of the motion. That is an excellent idea. I am sure that he would support the call for the most important all-party working group to be set up in the Assembly, namely the Executive.

If we had an Executive with functioning Ministers for health and education, the demands that we are making could be brought to fruition with greater ease.

Mrs Foster: Same speech, different day.

Mr O'Dowd: Yes, it is a case of "same speech, different day", unfortunately. It will not be a different day tomorrow for people who have family members with autism — it will be the same day. It is time that we as politicians grasped the nettle and moved forward. Sanctimonious, pompous speeches in this Chamber will not make one iota of difference to people's lives.

The need for an Executive is clear. We can no longer proceed with such demanding debates without putting measures into action. Our party has supported the ongoing campaign for the rights and needs of people with autism. I welcome the kind comments that have been made about my deceased party colleague Mickey Ferguson, who would have revelled in today's debate. He would have enjoyed participating and pushing the matter forward.

As has already been said, we have taken the issue of autism to Europe and facilitated links between autism groups in the North with groups in the Twenty-six counties and in the rest of Europe. That action has allowed autism groups here and in the South to co-ordinate and to seek funding on an all-Ireland basis. The debate has concentrated on education, but we must also refer to health matters. The need for better services and support is not solely the education system's responsibility. Children with ASD need access to the kind of health and community services that can impact positively on their standard of living and allow them as much independence as possible.

Primary healthcare providers must be aware of the impact of ASD and understand the complex communication and social issues that accompany the condition. We must ensure that primary healthcare providers have the right training in, and understanding of, ASD to allow them to provide the full range of necessary care.

Mention was made of a postcode lottery to determine the delivery of autism care in the four health boards. A centre of excellence, as is to be provided at Middletown, will serve as an exemplar of educational intervention and provide a lead for the training of parents and professionals. It will ensure that the future make-up of the health boards, while providing an education, will provide a single, world-class service to people with autism and their families. That is where the thought processes and the new ideas must be crunched down, where the training must be given and where those new ideas must be brought out into the community. A building in Middletown is fair enough, but unless it can provide a service to the whole community it will have failed in its objective. However, the centre at Middletown meets the criteria, and I am sure that its objectives will be achieved.

Reference was made earlier to how autism affects people throughout their lives. For example, training is required for those in the criminal-justice system who are likely to come into contact with those with ASD. Appropriate detention, custody and

interview accommodation should be provided, and appropriate intervention strategies must be put in place. I was shocked when I saw the figures for those with ASD who end up in jail as a result of not being properly cared for in their formative years. Intervention should have taken place when they were in primary school but did not. Those people have gone through life and, through no fault of their own, have ended up in conflict with the criminal-justice system. Who has committed the real crime? Did the individual let down society, or did society let down the individual?

We need to change our approach to autism and autism care. We need to implement a strategy and move forward. As I have said, our amendment is not about narrow politics. The criteria for the centre of excellence speak for themselves. Middletown must only be the start — we must have satellite centres or independent centres from Ballymena to Bandon. However, we need to tackle the problem urgently. Go raibh maith agat, a Leas Cheann Comhairle.

4.00 pm

Mr Dallat: Parents, children and carers who are affected by autism have had a slow and tortuous struggle for equality. That struggle has been compounded by disappointment after disappointment. Those disappointments have gone well beyond the tolerance of the most patient people who are affected by the condition.

The gravest disappointments in the delivery of Government services are in the education and health sectors. For children who live with autism, that is a double whammy and is therefore doubly unacceptable in a modern society that claims — indeed, guarantees — equality for all its citizens. Many of the groups that welcomed the Good Friday Agreement were affected by inequality. One of those groups was people affected by autism. One can imagine how disappointed they are that the advances that should have been made have not been made.

In moving the motion, my colleague Dominic Bradley referred to a report in ‘The Lancet’. That report stated that the problem has tripled in the past three years. He called for early diagnosis of children who are affected, and he complained, rightly, that diagnosis takes up to three years. He criticised cuts in expenditure, which compound the problem. He also pointed out that only 5% of autistic people are employed once they leave school and only 3% live independently. That is a shame and is therefore a good reason to seek unanimity in the Assembly today. Unfortunately, that is not to be. Sadly, this is the second time today that Members have been divided on serious issues. That does not go down well.

The SDLP accepted the amendment without hesitation, because the all-Ireland centre of excellence for autism in Middletown was always a part of the strategy: simply because it was not included in the motion does not mean that the party excludes it. Earlier, I wondered whether some Members thought that Midleton in County Cork, where the splendid whiskey is made, was being referred to. However, I

assure them that the centre is in Middletown in County Armagh, unless, of course, the border has been shifted. *[Laughter.]*

My colleague also paid tribute to Michael Ferguson, and Barry McElduff acknowledged that. Iris Robinson made a well-informed speech that was particularly enlightening on international developments. She emphasised the progress that has been made in Sweden and in the United States. I wonder why Middletown, which is so much closer to home, is a problem.

I was much impressed by Robert Coulter's speech. Having declared an interest in different organisations, he spoke with great pride about his grandson. Anyone who heard him could not help but be moved and encouraged to do everything humanly possible to help.

Several Members made the same points. Kieran McCarthy made a valuable contribution, emphasising the need to ring-fence funding. However, he underlined the fact that Members have no power, which is all the more reason why a new Assembly should be up and running. Rev McCrea made an excellent contribution; he is obviously well-informed about the problems that are involved. He pointed out that autism does not disappear; it is a lifelong condition. He also stated the need for families to have respite. I know from my own experience that that is a major issue. Families that are affected by autism really do need a break; however, that is not to say that they do not love their autistic children.

Billy Bell, in his usual manner, gave an interesting address in which he emphasised the need for legislation. He pointed out that autism affects the entire family and stressed the need for a greater sense of urgency. He highlighted the fact that there are 700 people on the waiting list for assessment, and, as Dominic Bradley mentioned, that it takes up to three years to get a diagnosis. That is a disgrace. He also referred to other costs associated with autism that are not thought about — family break-ups, divorce, and so forth, brought about by pressures on families.

Caitríona Ruane emphasised the need for equality of opportunity in early intervention. Carmel Hanna rightly pointed out the lack of public understanding of autism and said that any new strategy must have a clear direction. She appealed to the DUP and Sinn Féin — as do I — to ensure that the Assembly delivers on what has been debated today. Mrs Hanna also spoke about the response to clear referral routes, which do not yet exist, and the importance of properly trained diagnostic teams to identify not only autism but other related problems.

Patsy McGlone made a timely and important intervention on the difficulties that must be faced. Unsurprisingly, Paul Berry told Members that he was not happy with the amendment, but he made a positive contribution and emphasised the need for access, a programme of care, the development of a clear strategy, and so forth.

George Dawson spoke about the classroom environment. He emphasised the fact that no size fits all, and he highlighted the lack of flexibility. He also spoke about the need for early assessment.

Pat Ramsey reminded Members of the need to set up an all-party group on autism, which everybody will support. Arlene Foster emphasised the need for a comprehensive strategy. She highlighted an important point, which is the remoteness of rural areas. She emphasised that not so long ago she was at school. However, Members had no need to hear that — it was quite superfluous.

Mr A Maginness: John is an old flatterer.

[Laughter.]

Mrs Hanna: John might not like not so much of the “old”.

[Laughter.]

Mr Dallat: Flattery may get the amendment pushed through.

Mr A Maginness: He has no chance.

Mr Dallat: My learned colleague Alban Maginness says that I have no chance.

Arlene Foster raised important issues about assessment, teaching, classroom assistants and home programmes.

The debate was excellent. I am sorry that the amendment that the SDLP accepted caused problems — it was not intended to do so. John O’Dowd’s summing up for the amendment was largely political, if I may so. I hope that any new Assembly will not follow that kind of policy and that Members will embrace the needs of people who are less well off than we are, represent them and leave the political baggage behind.

Question, That the amendment be made, put and negatived.

Main Question put and agreed to.

Resolved:

That this Assembly recognises the need for, and supports the introduction of, legislation which would guarantee the future security and rights of those on the autistic spectrum and would combat the tragic social injustice being perpetuated through lack of planning and funding, at a time when the number of individuals with autism is increasing dramatically.

Adjourned at 4.09 pm.

<http://www.niassembly.gov.uk/transitional/plenary/070109.htm>