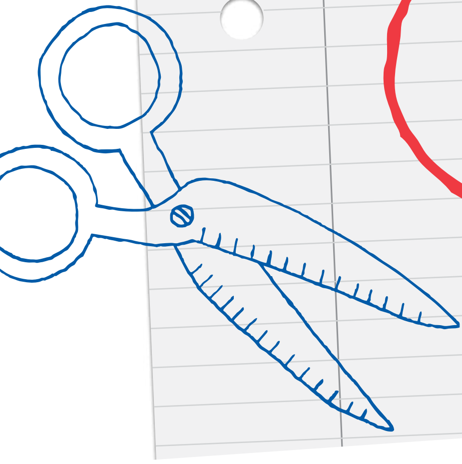
The National
Autistic Society
Northern Ireland

A* for Autism

Make every school a good school



Accept difference. Not indifference.

Acknowledgements
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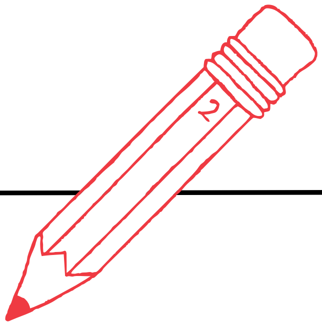

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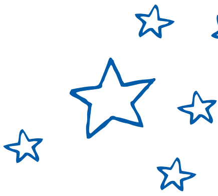


What is autism?

Autism is a lifelong developmental disability that affects how a person communicates and relates to other people. It also affects how they make sense of the world around them. It is a spectrum condition, which means it affects people in different ways. But everyone with autism shares three main areas of difficulty.

Social interaction: children with autism can have difficulties recognising and understanding their own and other people's feelings. They may sometimes find it hard to manage stress and frustration. At school they may not always understand the 'social rules' and how to act appropriately with their peers. This can make it hard to form friendships and many experience bullying as a result of these difficulties.

Social communication: children with autism may have difficulties understanding both verbal and non-verbal language, such as people's gestures, facial expressions and tone of voice. They may need support with understanding and how to express themselves.

Social imagination: This affects children's ability to imagine situations outside of their normal daily routine, to plan ahead and to cope with change or stress. They generally like set routines, familiar people and environments and may find unexpected changes to the school timetable, for example, hard to cope with. Unstructured time during the school day – such as break times, lunch times and moving between lessons – can be particularly difficult. They may also struggle to understand and predict other people's intentions.

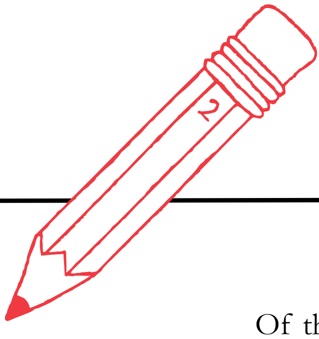
Children with autism may also be over- or under-sensitive to stimuli such as sound, taste, smell, light or colour. If children are over-sensitive this can make busy, brightly-lit or noisy environments such as classrooms, playgrounds and dinner halls difficult to cope with.

Some children with autism have a learning disability or specific learning difficulties, such as dyslexia, but can make good progress with the right support. Many are academically able, but will still need some support to cope with school life and realise their potential.

It is estimated that 1 in 100 people in Northern Ireland has autism. It is a lifelong condition: children with autism grow up to be adults with autism, and a good education can equip them with the skills and confidence they need in life. It is imperative that, no matter were a child lives in Northern Ireland or what type of school they go to, our education system can identify, understand and respond to their needs.

The National Autistic Society Northern Ireland

The National Autistic Society's Education Rights Service provides information, advice and support to around 2,000 callers every year, including support for families taking cases to tribunal. In Northern Ireland we employ family support workers who support and help parents with a range of issues related to autism. We have a range of parent support groups which meet monthly, as well as social groups for adults with autism, youth groups for teenagers and various activity groups for children with autism.



Introduction

An A* education

Education is a fundamental part of every child's life. It gives children the opportunity to learn about the world they live in, and how they can play a part in that world. It should be a time when children feel safe and happy, confident about building relationships and friendships, and able to make the most of their abilities and talents. It should help them to develop independence and prepare them for a bright and happy future.

Parents of children with autism tell us that they want an education system that:

- is ambitious and believes their children can achieve
- gives their children similar opportunities to other children
- understands and supports their children's needs
- allows their children to develop friendships and life skills
- allows their children to enjoy good mental health
- prepares their children for life.

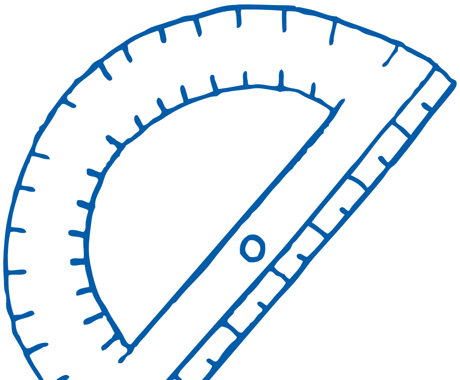
These parents want every school in Northern Ireland to be a good school, delivering an A* education for their children with autism. But the reality for many children with autism in Northern Ireland is far from A*.

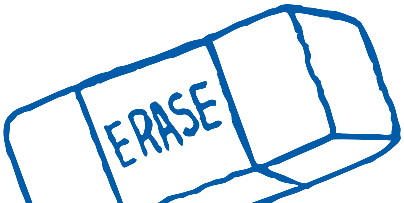
Of the families we surveyed:

- more than one in four young people with autism (27%) said they don't feel happy at school
- one in five young people with autism (20%) don't feel safe
- one in three children with autism (33%) have only one friend, or no friends at all, even though 80% say they want to have friends
- a quarter of young people with autism say that one of the worst things about school is being picked on, with almost one third saying that one of the worst things about school is teachers not understanding them
- just half of parents (51%) feel their child with autism is making good educational progress
- almost one in three parents feels that the education their child receives is not adequate to their needs
- less than half of parents (48%) are satisfied with the support their child receives at school.

This report highlights how children with autism in Northern Ireland are not getting a good enough education, and identifies the solutions that are needed to fix the problem.

The proposed reforms to the Special Educational Needs (SEN) system in Northern Ireland will shape the future of a generation of children with SEN. This could be the Northern Ireland Assembly's chance to make every school a good school for children with autism.





Children need an A* Education that sets them up for life.

Without the right support from school, the educational progress, social skills, self-esteem and health of children with autism will suffer. With support, they can achieve their full potential, paving the way for a happy, fulfilled adult life.

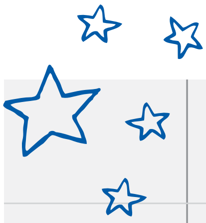
Parents need an A* system that works with them, not against them.

Parents will always want what is right for their children. But too many parents of children with autism have had to fight to get the right support for their child. Parents' voices need to be heard and they need to be at the heart of any reform to the SEN system.

We need the Northern Ireland Assembly to listen and to act.

The Assembly must listen and act on what parents and children have to say. This report is based on the real views of parents and children with autism in Northern Ireland. We need the Assembly to pass this test and to ensure they do not fail children with autism.

We are ambitious for children with autism and their families. Let's get it right.



Methodology

The research for this report was carried out between October 2011 and March 2012. We carried out the research using a survey methodology.

A: Workshop with parents

A one-off workshop took place with parents of children and young people with autism aged nineteen or younger to highlight the main areas of concern with the education placement of their children. These areas of concern were the mainstay of the surveys.

B: Survey of parents of young people with autism

The National Autistic Society Northern Ireland (NASNI) designed a survey, which elicited largely quantitative responses and offered the opportunity for lengthier qualitative responses to selected questions. The aim was to find out more about the experiences of parents and carers relating to their children's education.

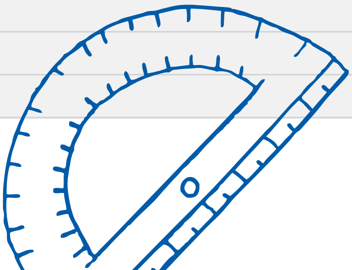
The questionnaire was advertised on The National Autistic Society (NAS) website, through NASNI membership, through other voluntary organisations and through social networking sites. Any parent with a child or young person with autism under the age of 19 was invited to complete the questionnaire.

A total of 151 parents and carers of young people with autism started the survey by the deadline. Only those responses from parents or carers of those under the age of nineteen were analysed. A link to the young person's questionnaire was included in case anyone had erroneously started the wrong questionnaire.

C: Survey of young people with autism

The young people's survey was advertised on the NAS website, through NASNI members and other voluntary organisations and on social networking sites, as well as through NASNI member support groups and Teen Scene groups inviting any young person with autism aged under 19 to take part. A link was also provided from the parents' survey. 66 young people with autism completed the survey.

Analysis: There were no incentives for respondents to complete the survey. The introduction to each survey explained the purpose of the research and set out confidentiality procedures. Responses were anonymised and analysed using a software package to produce aggregated tabulated results.



1: The right support at the right time

Children with autism need to have their special educational needs identified as quickly as possible. This is the crucial first step towards getting them the right support. When a child's needs are identified early on, and accurately, the right support can be put in place to prevent the development of even more serious difficulties later.

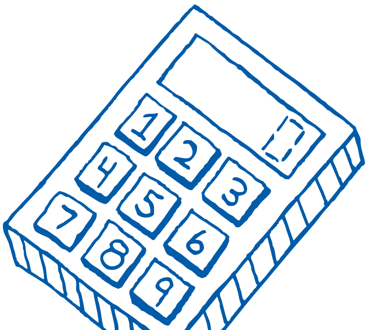
Unfortunately, getting support for a child with autism in Northern Ireland is not always easy or straightforward. Many parents have to fight every step of the way to get the support that their child needs. When we asked parents if it had been easy to get support for their child with autism, nearly two in three respondents to our survey said it had not been easy.

> "Getting support in the first place would be a huge bonus. Why does everything have to be such an uphill struggle? I feel because my child looks 'normal' he is expected to act as such. I am sorry I have nothing positive to say on this." Parent

Over half (52%) of parents who took part in our survey had to wait over a year from when concerns were first raised about their child to actually getting appropriate support; nearly one quarter (22%) have waited over two years, whilst one in ten children have waited more than three years.

> "It was only in January 2011 that a diagnosis of Asperger's was given, some eight years after a problem was first identified by my daughter's P2 teacher. Needless to say, our daughter's experience of school has been a very unhappy one which caused her a great deal of distress, so much so that she finally dropped out of school in April 2011. I am sure that if our daughter's difficulties had been taken seriously by teaching staff and educational psychologists alike and proper intervention and support put in place, she would still be in school today, receiving the education that she so rightly deserves. Our daughter has never had the right to an equal or fair educational opportunity." Parent

Children with a diagnosis of Asperger syndrome or high-functioning autism in our research are more likely to have waited longer to get the right support. The needs of these children are often not understood and are sometimes overlooked. A number of parents of children with autism feel that if a child at school acts out their difficulties through their behaviour they are more likely to get help than a child who is quieter or tries to mask their difficulties – when both are in equal need of support.



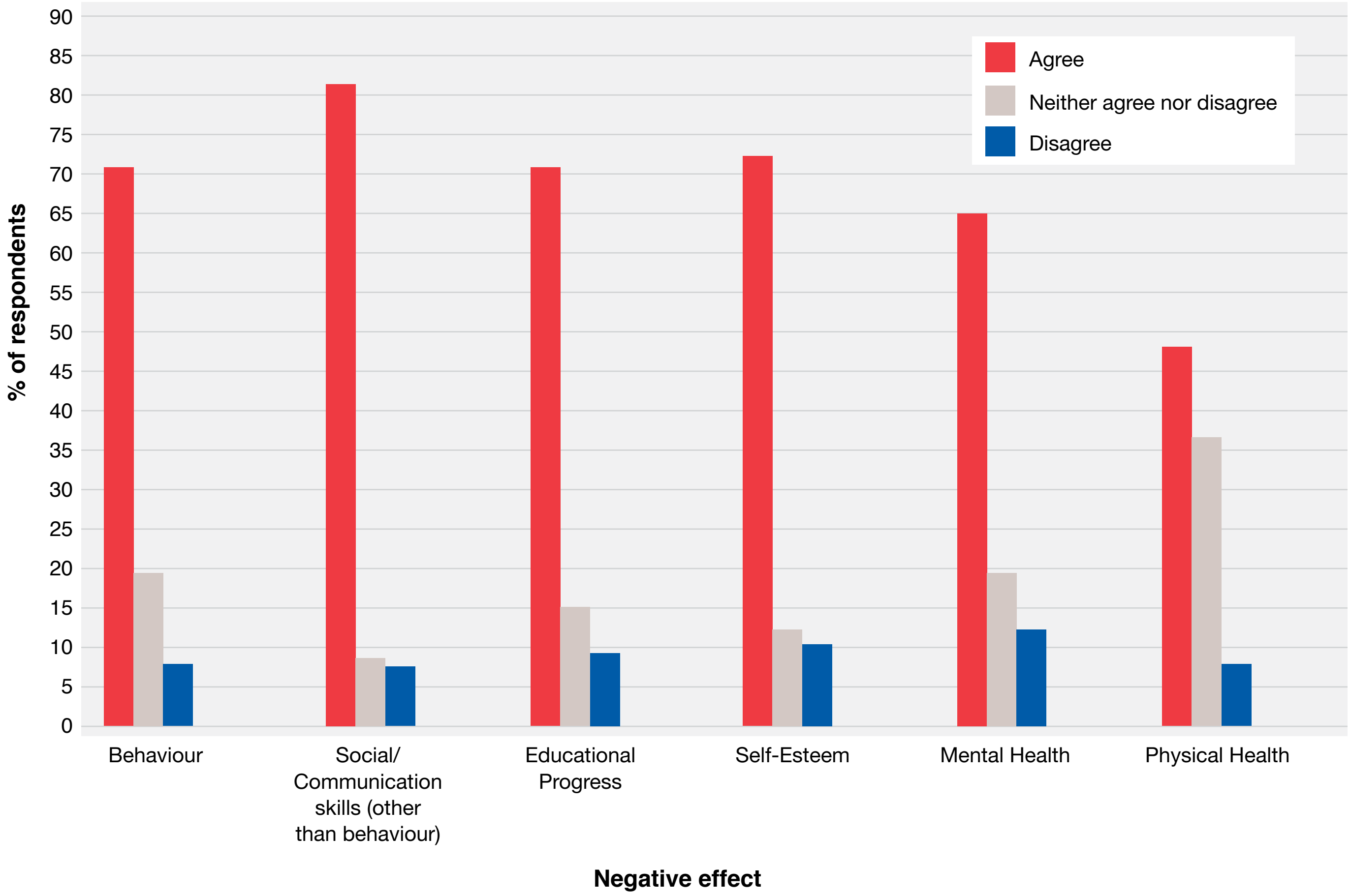
"If you have a child on the autistic spectrum you very much learn to sink or swim. You have to be very proactive and at times militant with the system to get help. If you sit back and wait for the system to work, you will have lost your child and all hope with them."
Parent

"My child was diagnosed over the summer before she was due to start secondary school. I made an appointment with the SENCO who was very nice and understanding; she told me I wouldn't need a statement as they would provide my daughter with what she needed. We are now in the middle of our second year and my daughter gets very little help, if any – their reason being that 'she is doing well and holding her own'." Parent

The consequences of getting it wrong

A lack of timely support can have a profound impact on a child's educational progress, their social and communication skills and behaviour, as well as their mental and physical well-being.

Figure 1: Lack of timely support: has it had a negative effect on your child?



Nearly three quarters (71%) of parents in our survey told us that their child's educational progress has suffered because of a lack of timely support (see figure 1).

Critically for children with autism, over 80% of parents say that a lack of support has harmed their children's social and communication skills. Social and communication skills help all of us to learn, and to cope with day-to-day life. Yet they are also the things that all people with autism experience difficulty with. It is essential that children with autism get appropriate support to help them develop and learn these skills. When a child finds it difficult to communicate verbally, they may have no other way to express themselves other than through their behaviour. Over 70% of parents say their child's behaviour has suffered as a result of a lack of support.

> "A combination of a lack of support and the time taken to diagnose my son's condition has had a negative impact on his progress." Parent

A child who has problems with social interaction may also struggle to make friends and to take part in everyday school life. He or she can become isolated and a target for bullying and therefore may be more prone to develop mental health difficulties.

Shockingly, 65% of the parents who responded to our survey said that a lack of support has affected their child's mental health, and over 45% said it has harmed their child's physical health. Some children refuse to go to school altogether because it becomes such a detrimental experience.

> "My son became so mentally ill he took to cutting himself last year... he was unable to explain what was wrong and this is why this behaviour happened. It was a scary time with no support. If he had got help sooner and quicker I am sure this would never have happened." Parent

> "By the time my child received his statement and classroom assistant he was so disturbed at school he was unable to attend and now has home education. His statement was started at the end of P2, at the end of P4 it was pushed on, at the end of P5 he was still coping in mainstream, by P6 he was showing signs of distress and unable to cope. In April 2006 he finally received his statement but it was too late – he has never used his classroom assistant as he had to be withdrawn from school due to a near mental breakdown." Parent

Recent research by The National Autistic Society Northern Ireland for our *You Need To Know* campaign[1] found that education plays an extremely important role in the mental health of children with autism. Difficulties at school can affect children's self-esteem – they can become anxious and upset if the right support is not in place. A supportive educational setting which works in partnership with mental health services can be crucial in maintaining emotional well-being and preventing mental health problems from developing or escalating.

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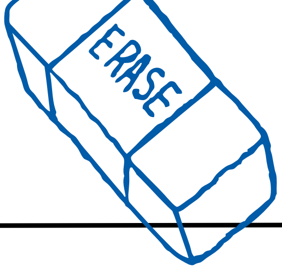
[1] The National Autistic Society. (2011). *You Need To Know*. Belfast: The National Autistic Society



Exclusions and suspensions

Many children with autism miss out on parts of both their formal and informal education. When asked about times of absence from school for any reason other than ill health or family circumstances, almost 1 in 5 parents (18%) said they had been asked to take their child home early or at lunchtime for a reason other than sickness, with over 14% of parents reporting that this had happened on more than three occasions. Almost 10% of parents reported that their child had missed between half a term and one school year. Another 5% reported that their child had missed school for one year or more. There were various reasons for these absences, ranging from anxiety and nerves to bullying by other pupils and teachers for reasons caused by their autism.

"My daughter would self-harm because she was so unhappy at school. The school just wanted her out of the way – they said she was upsetting the other children." Parent

On many occasions, parents had been asked to take their child out of school because the school would not or could not cope with the child's behaviour. These informal requests are illegal and are often caused by the failure of the school to put support plans in place for the child with autism, especially at break and lunchtimes. Training in how autism affects children could have, on many occasions, aided the school in understanding and dealing with the child's distress or disruptive behaviour.

"We have had so many temporary exclusions I have lost count. Every day you wait for the phone to ring expecting to have to go to school for some reason... that's just how it is." Parent

"In my son's previous school there was a two-week period when we were asked to collect him five times because he was so upset at the places they were taking him to. They hadn't prepared him for the outings and he was very frightened as a result. He then started refusing to go into school." Parent

2: Better autism training in schools

Nearly nine out of ten (88%) parents of young people with autism agree that, more than anything else, knowledge of autism helps their children's needs to be met. We know there are many professionals who are very well equipped to support children with autism. Some have undertaken specialist training and undertaken research, often in their own time, so they can support children with autism more effectively. These teachers, classroom assistants, Special Educational Needs Co-ordinators (SENCOs), principals and others are greatly valued by parents of children with autism.

> "I appreciate that we were very fortunate in the schools. We had chosen them for our older children because of their great reputation for pastoral care and they were both quite small establishments. It was always about good communication – but we did know we could trust the schools, which makes a huge difference. We recommended both schools to other parents, and think that in looking for suitable schools, parents should listen carefully to what other parents are saying." Parent

> "I find the staff in the unit more aware of his needs than the mainstream staff, who constantly try to make him fit in with the norm and push him beyond his capabilities." Parent

> "I have found every person I have spoken with in both the education and medical authorities to be an extremely helpful, caring, dedicated professional who was genuinely concerned for the needs of my child and I am very grateful for that." Parent

Unfortunately, our research indicates that expertise across all schools and sometimes within individual schools remains patchy. Often, teachers are let down by a system that doesn't give them the training, knowledge or resources that they need to help children with autism thrive at school.

> "His assistant has no training or experience with autism and told me she is learning on the job from my son. This is causing my son to get anxious as she tries to force him to try new things, which he hates as he likes his day structured. There are problems on an almost daily basis. I have to go in and speak to the SENCO frequently too." Parent

> "Autism training is not mandatory and therefore the level of understanding is limited – whilst it is said that there is sufficient online training, it is an unreal expectation to expect an already overworked teacher to start training online after a busy day in the classroom." Parent

For parents, good training and teaching practice is of great concern. Almost one in five parents (19%) are dissatisfied with their child's teacher's understanding of how to support children with autism. There was greater satisfaction with primary school teachers' understanding of autism, with just over half of parents in primary school being satisfied. But only 29% of parents in secondary education were satisfied with class or form teachers' understanding of autism, dropping to 12.4% for satisfaction with subject teachers.

Many parents expressed their frustration at having to constantly visit the school to explain autism and the difficulties that their child was experiencing because of their condition. Autism is a hidden disability and without a good understanding of it, a child's needs may be overlooked, or teachers may be unsure what adjustments they should make to support their pupils.

Young people themselves are dissatisfied with the lack of understanding of autism. More than two fifths of young people who responded to our survey (42%) feel that teachers do not know enough about autism, with another third (30%) being unsure whether they do or not. This is particularly worrying because when we asked young people what the worst thing about school is, the most common answer (33%) was "when teachers don't understand me". This lack of knowledge has a direct impact on the lives of young people with autism.

Bullying in school

Sadly, over 41% of parents who replied to our survey said their child had been bullied, with over a quarter (23%) not sure if they had been or not. Children with autism are at particular risk of being bullied. They have difficulty interpreting and understanding social situations and knowing how to interact in different environments. They also find it hard to predict and understand other people's behaviour. This makes it difficult for them to understand the intentions of others and can make them an easy target for bullies.

Children with autism can be socially naive when offered friendship from someone whose real intention is to get them to take part in inappropriate activities. Some children will also do things that their peers suggest which ends up getting them in trouble. Some of the behavioural characteristics of children with autism, such as formal speech, unusual behaviour and obsessive interests, coupled with social naïvety, can make them very vulnerable to bullying.

> "My child suffered extreme bullying and the teachers' attitudes were that it was boys being boys. They only took the matter seriously when my son talked of taking his own life because of the bullies." Parent

> "Throughout primary school he was constantly teased as he was always alone and walking the edge of the playground. The others knew he didn't get their humour and disliked misbehaving. He also had things stolen on a daily basis and the others would laugh at him." Parent

Making adjustments for children with autism

Many children with autism need certain adjustments to be made in the classroom or to the school day to enable them to cope. Reasonable adjustments and adaptations are required by law and necessary to meet a child with autism's needs, but in many cases they are simply not being made. Many parents still do not know or are not informed about whether adjustments are being made, or what those adjustments are (see figure 2).

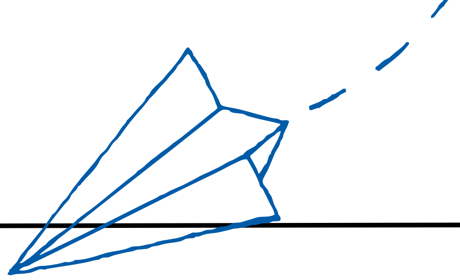
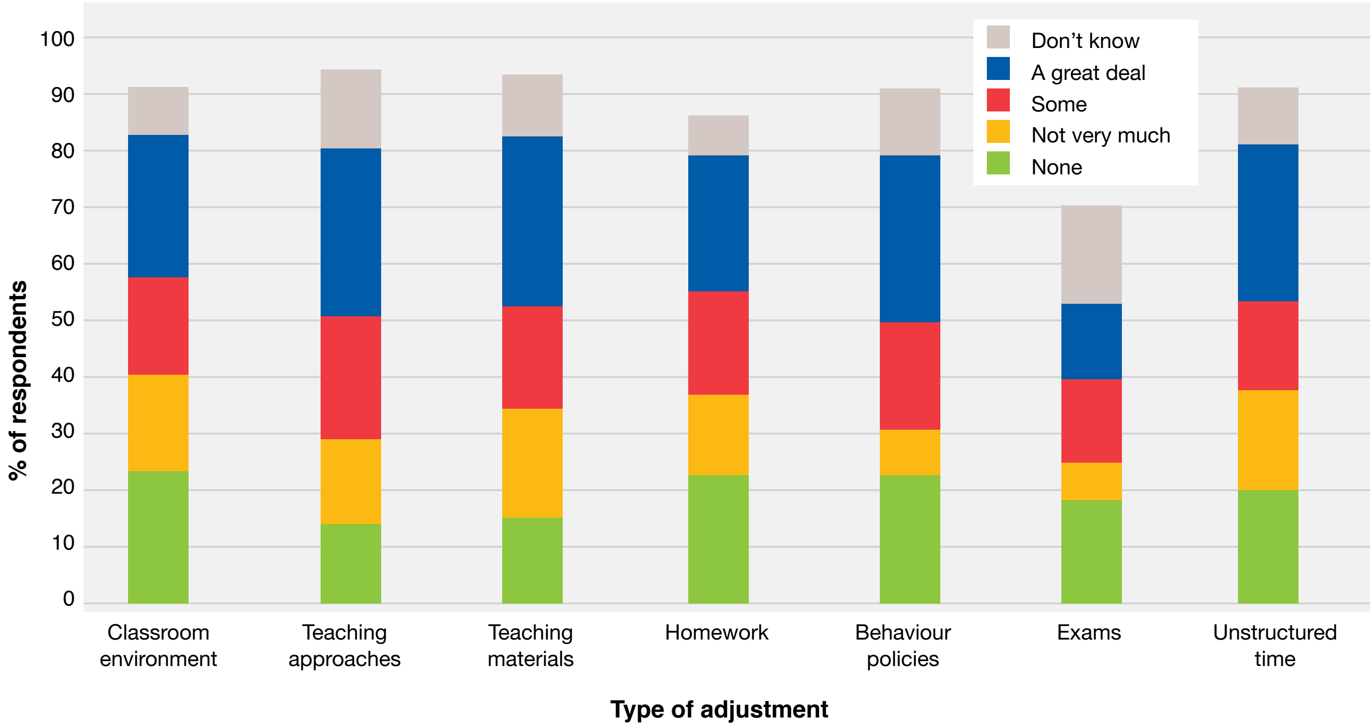


Figure 2: Is the school making adjustments or adaptations?



One of the most commonly-missed adjustments is in relation to the classroom environment. Simple adjustments within the classroom can be easily made in order to manage a child's sensory sensitivity. These could include an individual work station, or giving the child a 'time out' card to hold up if they feel anxious or stressed.

Often, no adjustments are made in relation to homework and unstructured time, such as breaks and lunchtimes, which children with autism can find difficult. Again, some of the adjustments required are relatively easy to make, such as providing a quiet bench in the playground or allowing the child to go to the library at lunch. Introducing a 'buddy scheme', where another child helps to support the child with autism, is another example of an adjustment that may help a child to integrate with others. These ideas are often inexpensive but they can make a real difference to a child with autism.

> "Better understanding of my difficulties and not being punished for needing more time to finish my work."
> School student with autism

> "More things in place like a quiet room or someone to help me when I am upset." School student with autism

Many children with autism experience some form of sensory difficulty which can impact on their ability to learn and to cope in different environments. It is essential that sensory assessments are carried out by well-trained occupational therapists to ensure that a child's sensory difficulties are highlighted and advice can be offered to the school on what adjustments will help the child to cope in the school environment.

Transitions

A transition plan is a plan for the future of a child who has a statement of special educational needs. It should take place following the annual review after the child's 14th birthday. It is a very important plan as it outlines a young person's wishes for all aspects of life, from education to housing, employment, transport and health. This plan should include input from support workers, teachers, doctors, educational psychologists, parents and the child themselves. It is there to highlight areas where support and services may or may not be needed in the future. It also allows for smooth transitioning from the final school years into adult life and the change of services provided. Unfortunately, almost two thirds (63%) of our parents with children aged 14 or over do not have a transition plan in place, with another 17% not knowing whether they do or not. Several parents were very reticent about what that might mean and felt scared and unsure of what to expect.

"We got a letter from the Transitions Service the September after he left school asking for feedback – I had to write and tell them that was the first I'd heard of them." Parent

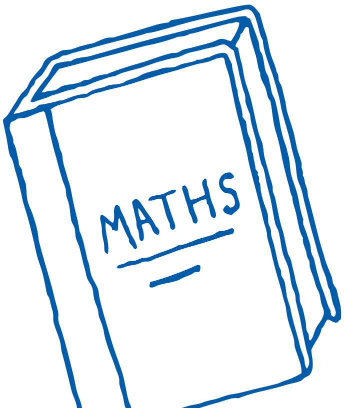
Others who had a transition plan in place also voiced their frustration about the lack of input from the child and family. They felt either left out of the process or that it had been decided before they were consulted.

"I don't think that my child and myself got to make many of the decisions as the school and other agencies had come up with a plan for him." Parent

"At times, so many people were involved it was hard to know what the next step was." Parent

The benefits of getting it right

Everyone recognises that dedicated and capable school staff make a big difference during a child's time at school and later in life. With approximately 7,000 children with autism in the school system in Northern Ireland[2], teachers need the right training to feel confident about supporting these children, so that schools can meet their legal obligations.



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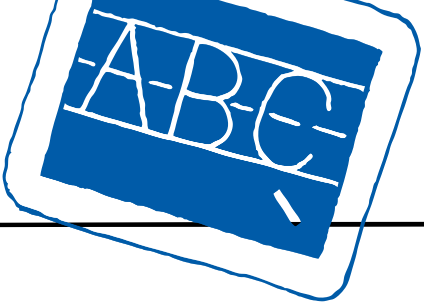
[2] Hansard. (2011). *Department of Education Briefing to the Education Committee at the NI Assembly*. Belfast: Hansard



> "My child has super support in an autism-base attached to a mainstream school – the staff and their expertise is exemplary. I feel very fortunate to have a place there. It was a struggle to find and be offered a place, but worth the fight." Parent

When autism training works, families feel the benefit of it. Some of the parents who responded to our survey spoke about well-trained teachers in special schools or autism-specific units, where their child was well supported.

There are training resources on autism already available, which teachers can access online. One example is the SEN resource file, which is available online and in every school and aims to ensure that all schools are equipped with the necessary knowledge and skills to successfully manage the needs of most pupils with SEN and/or a disability. A similar SEN resource file for early years is under production.

Accessing online training is a positive first step, but it is not mandatory for teachers or classroom assistants to access this training or to disseminate their learning amongst colleagues. They are often not given the time or support to access this training anyway. But any teacher and classroom assistant who works regularly with children with autism should be undertaking appropriate training and getting support to do so.

Putting training into practice

Autism awareness training is just the first step towards creating an understanding and supportive environment for children with autism. Teachers and classroom assistants need to know how to teach children with autism; they need to know about modifying language to make it more concise and literal. This is a simple and effective strategy which will not only benefit children with autism but also others with communication difficulties.

Teachers and classroom assistants need time and support to enable them to put their training into practice. Autism is a complex disability and every child with autism is different. Any training that is undertaken needs to emphasise this and focus on how teachers and classroom assistants can adapt strategies and approaches based on their knowledge and observations of each child. Clear action plans and objectives which are outcome-focussed should be in place.

Good communication between home and school is essential to ensure that strategies and approaches to behaviour and learning are consistent. Parents know their child best and can offer a lot of information and advice on what adjustments may help. The relationship between parents and the school needs to be cultivated and the best outcomes can be achieved when parents feel listened to and informed about their child's progress.

Effective leadership

Head teachers have a really important role to play in supporting children with autism within their school. They identify areas for development and set the tone and attitude of the school towards children with autism. Just half of parents are satisfied with their head teacher's understanding of how to support their child with autism.

Special Educational Needs Co-ordinators (SENCOs) advise on the provision for children with special educational needs, including autism. Nearly 45% of parents were happy with their SENCO's understanding of autism but a fifth (21%) were not. SENCOs often have teaching duties as well as their SENCO role and can struggle to understand and meet the needs of all children with SEN. All SENCOs need to be well trained on how to meet the needs of children with autism. They must have influence, for example, through representation on the senior management team, so that they can proactively ensure that all staff throughout the school are well trained and that strategies are being put in place to meet the needs of children with autism.

Access to autism expertise

While improved training for teachers and school leaders is critical, it is not possible for every teacher to be an expert in autism: access to high quality external expertise and specialist support will still be necessary. Yet often these resources are limited and have long waiting lists. Teachers need to know that additional support is available and how they can access it. Parents need to be confident that it will be available if needed for their child.

> "We were promised that the specialist autism service would assess my child in school and give specific advice to teachers. This has never been implemented and probably never will." Parent

However, when schools get it right, the outcomes for children with autism improve substantially. The child is happy and can develop and learn. Parents report that their child's progress becomes positive and a good working relationship is established between the parents and the school.

> "We are privileged to be in an excellent autism unit in a primary school, with amazing teachers. They have attached speech and language at the school – the teachers have years of experience, we've learnt so much." Parent

3: The right school for every child

Choosing the right school for any child is a big decision and parents want and expect a choice of local schools to meet their child's individual needs. Parents need better information and advice about the options available to them and what they should be able to expect for their child. Almost half (49%) of parents did not feel that they had enough information when choosing an educational placement for their child.

In Northern Ireland there is limited choice in terms of what type of school a child with autism will attend. Children with autism are educated in either a mainstream school, a specialist autism unit attached to a mainstream school, a learning support unit or a generic special school. There are no autism-specific schools in Northern Ireland. Parents also tell us it is extremely difficult to get their child into an autism-specific unit.

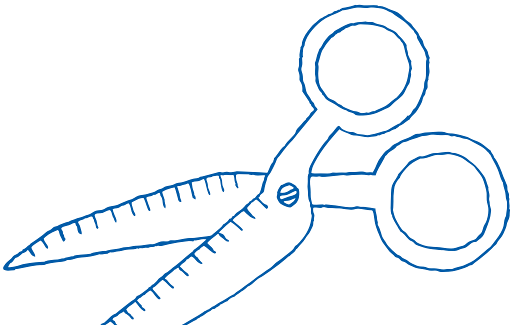
In our research we wanted to find out where children with autism go to school and where parents would like them to go to school.

We found that the majority of respondents (62%) said their child attended mainstream schools or an autism unit in a mainstream school, especially those who had been diagnosed as having Asperger syndrome or high-functioning autism. Those who have autism and additional learning difficulties are most likely to be in a special school environment.

Figure 3 shows that parents want a range of provision. What is also apparent is that the majority of parents want some kind of autism-specific provision – 51% of parents say their preference would be either an autism-specific school or an autism unit attached to a mainstream school or a dual placement where their child can be supported by autism-trained staff. The majority of parents (80%) whose children have Asperger syndrome or high-functioning autism wish their child to attend either mainstream school or an autism-specific unit attached to a mainstream school. In contrast, the majority of parents (60%) whose child has autism and an accompanying learning disability want their children to attend an autism-specific special school.

"I wish there were more schools in Northern Ireland just for kids with autism." Young person with autism

"More units for autism within mainstream schools would be the best thing to happen. At such a difficult stage for a child with all the stress of moving to a big school, this would protect and help them for a few more years, plus give the correct teaching and life skills needed for these children to have a successful and fulfilling education." Parent



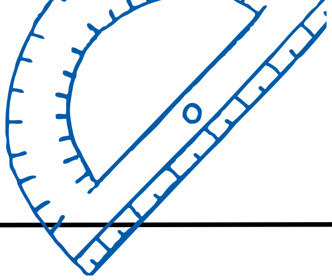
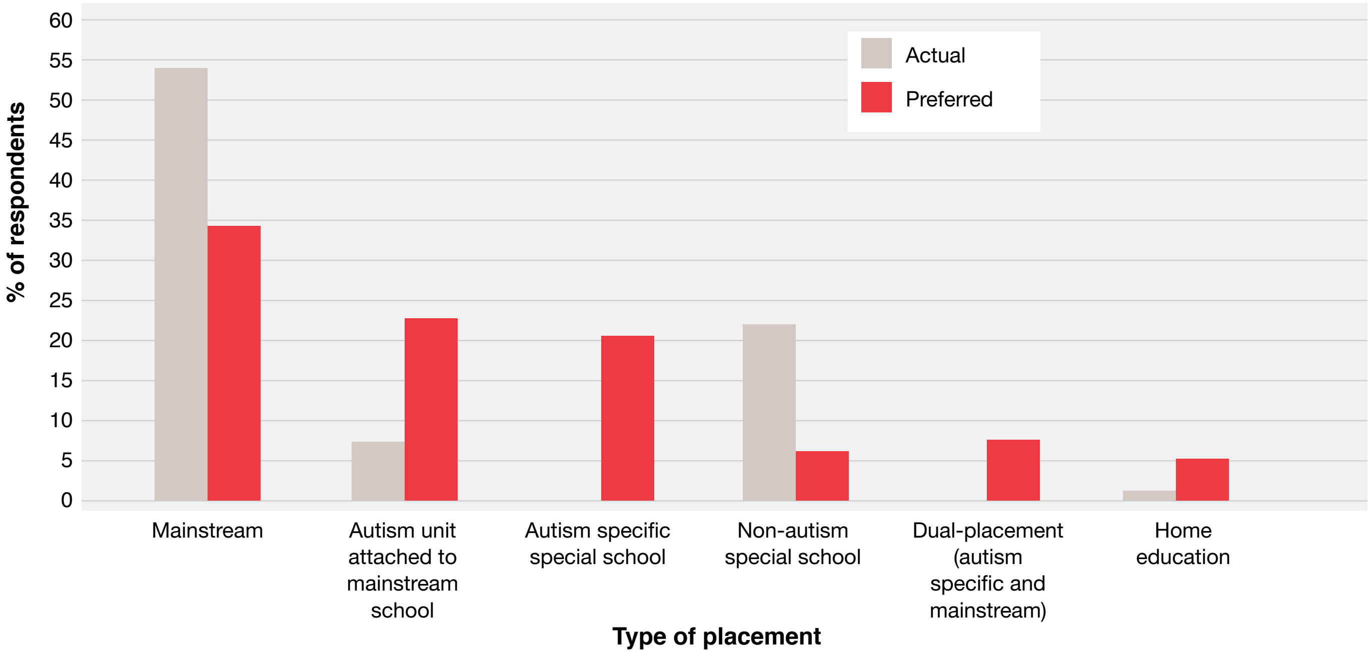


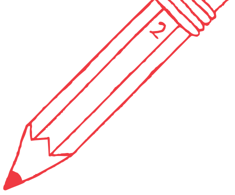
Figure 3 : Actual versus preferred school placement



"What works well in my child's school is that it caters for children with all abilities: inclusion and integration at its best. There are special provision units at the school so the specialist expertise is there. All the teachers care and have training and experience with children with special educational needs. The whole school is very open to helping each individual child regardless of special needs. They develop the whole child as well and my son has been given a great opportunity to learn natural social behaviours by just having friends in school. The whole ethos of the school is based on inclusion, integration and equality for everyone. No one is excluded but everyone is helped." Parent

"There needs to be more specialised schools for this type of pupil – they find it hard to cope with large classes because of their social problems. More teachers need to be trained and educated to be able to cope with these children so they can be recognised, especially in mainstream schools, and given the help and structure they need. Too many slip through the net... teachers need to take more of an interest to help them if problems arise." Parent

Children with autism have a wide range of abilities and need access to a wide variety of curricula to suit their needs. Every area of Northern Ireland needs to have education provision that understands autism, both mainstream and more specialized provision.



4: Conflict in the system

Parents want to know that their child will get a good education without them having to fight for it. Unfortunately many parents have to fight every step of the way to get the right support for their child.

As children's most ardent advocates, parents should be at the heart of their child's education. But many parents responding to our survey felt that professionals did not listen to them or take their concerns seriously. Parents want professionals to work in partnership with them and to recognise that their knowledge of their own child is extremely valuable. Professionals need to listen to them when they have concerns and communicate with them so they feel fully involved. Parents of children with autism particularly value this, as many of those children need support to apply what they learn in school to other areas of their life.

Confronting the system

Parents often have to fight to get a statement, just so their child can get the support they need. We asked parents to tell us about their experiences with the statementing process. They told us that the whole statementing process is long and complicated. 47% of parents say they don't find the system straightforward to navigate – five times more than those who do find it straightforward to navigate. Just one in ten parents found the process straightforward and less than 14% found their Education and Library Board (ELB) helpful and supportive.

Without help, support and information about the whole statementing process, parents either had no idea of what was expected or had to fight constantly to ensure that their child's needs were met. The problems highlighted by parents include:

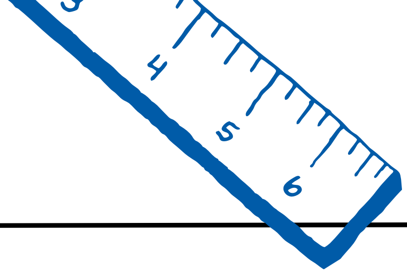
> "Length of time it takes. Parents are not aware of the process, they are not informed enough of how the process progresses or what half of it means."

> "I found it very hard to find out the necessary information to negotiate the statementing process, and felt I had to push constantly. I also found the disconnect between the medical and educational authorities surprising and had to work out how to ensure all information was passed appropriately."

> "Too long, lack of transparency, lack of support for parents, too many additional forms and information needed, duplication of information, lack of communication from board and school."

> "There are also problems if the Education and Library Boards in which a child lives is different to where they want to go to school, with parents having to fight not one but two ELBs to ensure that their children's needs are met."

Without the help that is needed to ensure suitable education provision and support for their children, parents are often forced to confront their ELB about its failings. One in ten parents in our survey had to go so far as appealing to the Special Educational Needs and



Disability Tribunal (SENDIST). The most common reasons for appealing to SENDIST were the refusal of the ELB to carry out a statutory assessment or re-assessment and the contents of the statement itself.

Many parents also felt that by appealing to the SENDIST they became labelled by their ELB as a difficult parent.

> "I had to meet with the head of SEN in my area to try and discuss issues with my child's education but nothing was resolved to my satisfaction. I was labelled a 'difficult' parent and accused of making my issues too personal to the teacher involved, so a no win situation." Parent

> "We have found that the ELB are very defensive when talking to us and tend to speak in jargon which can be misinterpreted by parents." Parent

Just less than 15% of parents said they had used a mediation service to talk to their ELB about support for their child's special educational needs. Some parents felt that the mediation service had helped them understand and navigate the system better. As with the rest of the process, many parents do not know about their rights for appeal. Others found the appeal process stressful and incomprehensible.

> "I went to tribunal but the outcome wasn't understood by any one. We asked them to clarify the outcome but they refused to do so. So I had no other choice but to go to high court." Parent

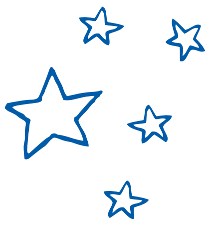
> "Again I wasn't aware that you could appeal and to be honest they don't provide you with enough information for you to actually realise that your child isn't getting all the help that they possibly can be provided with." Parent

> "We withdrew our request as the process was very stressful. It was over a refusal to carry out an assessment. It is not parent-friendly, even to professionals." Parent

Just over half of parents (55%) said that they would be confident in challenging the school if they were unhappy with the support for their child's special educational needs. However, almost half (45%) would not be confident in doing so. Parents want regular communication and consultation with their child's school but feel that if they complain, things will get worse for their child.

> "If you challenge the school, the teachers become very defensive and say they are limited by the resources. The trouble is that trust breaks down very quickly on both sides." Parent

> "I did challenge the school, it got me nowhere." Parent



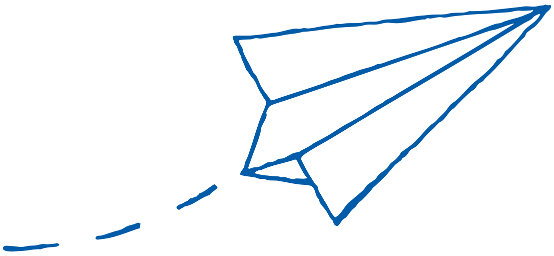
5: Reforming the system?

At present there is a lot of uncertainty with regards to SEN provision in Northern Ireland. There are currently nearly 65,000 children on the SEN register with almost 14,000 having a statement of Special Educational Needs. The majority of these children are in mainstream education.

At the time of this report going to print, the Minister for Education announced his plans on how to proceed with the reform of the SEN system. The consultation, entitled *Every School a Good School: The way forward for Special Educational Needs (SEN) and Inclusion* was originally launched in August 2009 with the consultation period being extended until January 2010 due to the concerns raised by parents of children with SEN and the voluntary and community sector, alongside a number of political representatives. There were over 2,900 responses to the consultation.

In a briefing to the Education Committee on 18 January 2012, highlighting the way forward in SEN reforms, Minister for Education John O'Dowd stated that the Department of Education had a long way to go before they finalised their plans for reform. However, he gave strong indications as to what changes he had in mind. These include:

- the replacement of statements with Co-ordinated Support Plans (CSPs) for those children who have 'multiple and/or complex needs'
- the current timeframe of 26 weeks for the statutory process being reduced to 20 weeks, with five steps being reduced to two steps
- a change in the statutory process for the annual review of statements, with a review only taking place if the parent or school requests it
- parents having the same rights of appeal to the Special Educational Needs and Disability Tribunal (SENDIST) with regard to CSPs as currently exists for statements
- greater use of the informal Dispute Avoidance and Resolution Service (DARS) with plans to make it more independent from the Department for Education and the Education and Library Boards
- the introduction of Personal Learning Plans (PLPs) to replace Individual Educational Plans (IEPs), backed up by a statutory duty on school governors to ensure that every child with SEN has a plan
- the introduction of a stronger statutory obligation on school governors for CSPs
- a proposal to change the name of the SENCO to the Learning Support Co-ordinator (LSC) to emphasise the concept of the school supporting the learner in reaching their full potential. The LSC will have responsibility for the co-ordination of teaching and learning in the school for pupils with SEN and/or a disability. They will also have a voice on the senior management board of the school.



6: Making SEN reforms work for children with autism

The Department of Education has said that it wants to change the statutory process for statements to raise standards in SEN provision and to reduce bureaucracy. When we asked parents to tell us about their experiences of the current statutory process, their responses highlighted the length of time it took to get a statement and the "daunting and stressful" process. Parents talked about inconsistencies across Education and Library Boards and about their child being unable to see an educational psychologist because the school "had used their quota for that year". So changes are needed and bureaucracy is an issue that needs to be addressed.

> "An extremely stressful time for the whole family." Parent

> "Takes too long! Too few children actually get seen by the educational psychologist – they only take educational needs into account, not things like changes, bullying, interaction with peers." Parent

> "I found it quite intense at the time – there were so many appointments, we were running all the time. Once the process was finished, the extra help seemed to fall away very fast and I felt like I had been sucked up and spat out by a whirlwind." Parent

But parents also told us that although they found the system bureaucratic, time-consuming and extremely stressful, they had very definite reasons for ensuring their child got a statement. The main reason for getting a statement was to get additional support for their child (44%); however, 22% of parents said it was to get the school they felt their child needed and 29% said it was to give their child stronger rights. Parents felt very strongly that they needed a statement to get the right school, the right support and to give them enforceable rights should their child not get that support.

So will the Government's proposals make the difference these families so desperately need?

1. Qualification for assessment

What is the Minister proposing?

The Minister for Education proposes that statements should be replaced by Co-ordinated Support Plans (CSPs). The five-step proposal for getting a statement would be reduced to two steps for a CSP: stage one at school level and stage two at Education and Library Board / Education Skills Authority level. Only those children with the 'most complex and/or multiple needs' would qualify for a CSP. The Minister also proposes reducing the maximum time limit for a statutory assessment from 26 to 20 weeks.

The Minister has stated that 'most complex/ multiple needs' will be defined in legislation and through case law. Children in special schools or learning support centres will, it is thought, transition automatically on to CSPs. Children in mainstream school will be re-assessed to determine if they qualify for a CSP. The Minister estimates that the number of children in receipt of a CSP will be reduced by about half, although the Department of Education has stated that there is no target with regards to reducing the number of statements.

How does this proposal measure up?

Nearly 70% of parents who responded to our survey said that their child had a statement of Special Educational Needs. 14% of parents were still waiting for support for their child's special educational needs through the statutory process.

Many children with autism can only cope in mainstream school because of the high level of support outlined in their statement. Reducing the number of children qualifying for a CSP will not dissipate need. We are particularly concerned about those children with autism in mainstream education who fall just below the threshold to qualify for a CSP – how will their needs be adequately assessed and met?

Autism is a complex disability and the needs arising from the condition will have significant individual differences. If a child with autism does not qualify for a CSP it must be made explicit how they will access the specialist and individual support they may need. Parents need clear and enforceable rights to ensure that they can challenge the system if their child is not getting the support they need.

2. Changing the statutory process

What is the Minister proposing?

The Department of Education has suggested that the statutory process will be reduced from five stages to two stages. Currently the statementing process has five stages with stage 1 to 3 being school-based. Stage 1 is when a teacher identifies and registers a child's special educational needs and consults the SENCO. At stage 2 the SENCO takes the lead for collecting, recording information and co-ordinating provision with teachers; and at stage 3 a specialist educational psychologist from outside the school will get involved. At stages 4 and 5 the Education and Library Board shares responsibility and a decision is taken as to whether it is appropriate to undertake a statutory assessment. At stage 5 the Board considers the need for a statement.

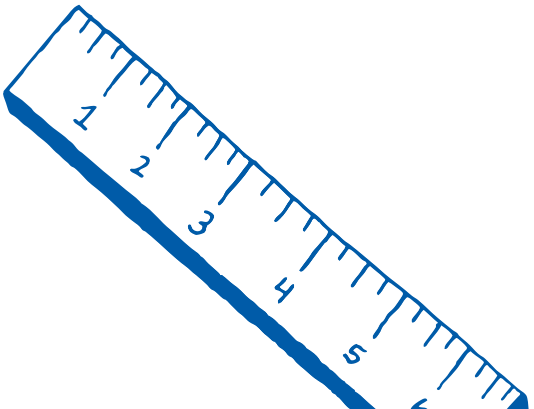
How does this proposal measure up?

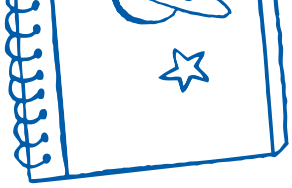
A benefit of the current five stage process, although bureaucratic, is that it allows professionals to build a good picture of the complex needs of an individual child with autism and to access the specialist assessments and reports that provide thorough knowledge about the child's needs.

In the Minister's proposals there is very little detail about what is involved at level one/school stage. A child with autism may be academically able but have many difficulties in terms of their social and communication skills which will impact upon their educational progress. For a thorough assessment of their needs to take place, a number of professionals need to be involved, including most likely an educational psychologist, speech and language therapist and an occupational therapist to assess a child's sensory difficulties. It is unclear how a thorough assessment would take place. Teachers are unlikely to be the appropriate professionals to undertake assessments of children with autism, especially if they are working in isolation. There is a real danger that children who on the surface appear to be coping will not have their needs understood and not have appropriate support put in place.

At present there is not enough capacity, resources or specialist knowledge and training in many schools to provide appropriate support for children with autism. The new proposals appear to put enormous pressures on schools, teachers and SENCOs and may lead to major inconsistencies across the education system. Under the proposals it is unclear as to how funding will be allocated to meet individual assessed needs and how schools will be accountable for the spending of SEN funds.

The Minister has also suggested that the annual review will be abolished and only take place if the school or parent requests it. The annual review is a useful tool for monitoring progress and discussing concerns or amending current provision. If it is no longer a statutory obligation then parents need to be proactively informed of their right to request one if needed.





3. Introduction of Personal Learning Plans (PLPs)

What is the Minister proposing?

Under the new proposals, Individual Education plans (IEPs) will be replaced by Personal Learning Plans (PLPs). The Minister has proposed that a statutory duty will be placed upon school Governors to ensure that every child with SEN has a PLP and that they are reviewed regularly and have a stronger emphasis on outcomes.

How does this measure up?

We strongly welcome the proposal to put statutory duties on school governors around PLPs and urge the Department of Education to make sure they take this forward. All children with autism should have an action plan which is outcome-focussed, is regularly updated, sets appropriate objectives, and which is adhered to. A good school will develop a child's confidence, their social skills, their skills for independent living and in many cases for employment. PLPs need to be robust plans that are properly implemented and evaluated. We would welcome the opportunity to work with the Department of Education to develop the new model for PLPs. We are particularly keen to ensure that there are adequate measures in place so that parents are involved with the development of PLPs and are confident that any support outlined in a PLP will be provided. A PLP must encompass clear enforceable rights for children and their parents.

7: Our recommendations

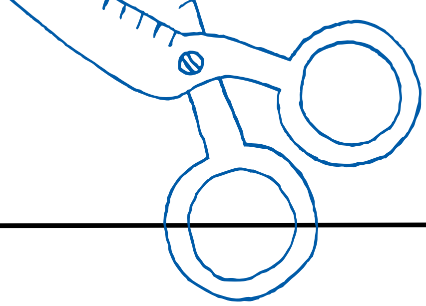
It is a worrying time for parents of children with SEN as there is a lack of detail about some of the new proposals. This report has outlined the very real problems that parents of children with autism face in accessing the right support for their child. The system is bureaucratic and often confrontational and there is a clear need for change. But parents have also told us that the statementing process is the vital tool which enables them to access support. Parents need enforceable rights so they can challenge the system if it fails to deliver. We have a number of recommendations about how the Department of Education can use these reforms to reduce bureaucracy and improve delivery.

We hope that the Minister will listen to the concerns of parents of children with autism and ensure that they get the A* education they are entitled to.

The right support, at the right time

To ensure that children with autism can access an A* education that sets them up for life, the Northern Ireland Assembly should:

- set out a clear guideline to health and education professionals that a diagnosis on the autism spectrum should act as a trigger for a thorough assessment of a child's educational needs
- develop clear pathways so that autism (and other special educational needs) is identified promptly and appropriate support can be put in place



– these pathways should be set out in a clear Code of Practice and should look at the level of support needed, regardless of whether the child has a CSP

- put protocols in place between health and education services to ensure that schools can access external support (including speech and language therapy, occupational therapy and child and adolescent mental health services) for children with autism as appropriate – such support should not be dependent on whether the child has a CSP
- give all teachers who regularly work with children with autism the scheduled time to undertake training in autism
- develop a coherent strategy for a range of educational provision for children with autism in Northern Ireland, in particular autism-specific specialist provision.

A system that works for parents, not against them

To ensure that the system becomes less adversarial and that it becomes an A* system that works with parents and not against them, the Northern Ireland Assembly should:

- make sure that any revision of the SEN system retains clear and enforceable rights for children and their parents, regardless of whether or not they qualify for a CSP
- ensure each Education and Library Board/ Education Skills Authority and each school publishes details of how funding for SEN is allocated and spent to increase transparency
- make sure that parents and children with autism are involved in the development and review of their PLPs
- develop training for school governors in SEN, including autism, and ensure that each school's Board of Governors undertakes this training
- develop clear mechanisms for parents to complain to school governors when they do not feel the PLP is satisfactory
- retain the right to appeal where a child's needs are not being met. PLPs could be used as evidence within the tribunal.
- make sure that children's progress is measured against the objectives in PLPs and that this information is used by the Education and Training Inspectorate when evaluating a school's performance

- allow parents to log complaints to the Education and Training Inspectorate, where they believe that the support in their child's PLP is not being provided. The Education and Training Inspectorate should inspect those schools where there is sufficient evidence that the support set out in PLPs is not being provided.
- give SENCOs representation on school senior management teams.

The proposed reforms to the Special Educational Needs system in Northern Ireland will shape the future of a generation of children with SEN. This could be the Northern Ireland Assembly's chance to make every school a good school for children with autism. We need the Northern Ireland Assembly to listen to parents when they tell us the system could do better. Parents should not have to fight to secure the support that their child needs. The Assembly should act to ensure that every child with autism gets an A* education.

- **Children need an A* education that sets them up for life.**
- **Parents need an A* system that works with them, not against them.**
- **The Northern Ireland Assembly needs to listen and act on what parents and children have to say.**

We are ambitious for children with autism and their families. Let's work together to make sure that every school is a good school for children with autism in Northern Ireland.

Notes

The National
Autistic Society
Northern Ireland

A* for Autism

Make every school a good school

Children need an A* education that sets them up for life.

Parents need an A* system that works with them, not against them.

The Northern Ireland Assembly needs to listen and act on what parents and children have to say.

Let's work together to make sure that every school is a good school for children with autism in Northern Ireland.

The National Autistic Society Northern Ireland
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Autism Helpline: 0808 800 4104
Fax: 02890 688 518
Email: northern.ireland@nas.org.uk

The National Autistic Society is a company limited by guarantee registered in England (No.1205298) and a charity registered in England and Wales (269425) and in Scotland (SC039427), registered office:
393 City Road, London EC1V 1NG 555 300312

The National Autistic Society Northern Ireland is part of the UK's leading charity for people affected by autism.

Over 17,000 people in Northern Ireland have autism. Together with their families they make up over 68,000 people whose lives are touched by autism every single day.

Despite this, autism is still relatively unknown and misunderstood. Which means that many of these 68,000 people get nothing like the level of help, support and understanding they need.

Together, we are going to change this.