Consultation Response Booklet

Every School A Good School

The Way Forward for Special Educational Needs (SEN) and Inclusion

The closing date for this consultation is: 31 October 2009
Extended to 30th January 2010

Your comments must reach us by this date.

August 2009
Every School A Good School

The Way Forward for Special Educational Needs (SEN) and Inclusion

Name
Shirelle Stewart

Address National Autistic Society Northern Ireland 59 Malone Road Belfast

Deleted: ¶

Telephone 028 90236235

E-mail Shirelle.stewart@nas.org.uk

Organisation on whose behalf you are replying (if applicable)

National Autistic Society Northern Ireland

Does your response represent the collective view of your organisation (if appropriate)?

Yes these are the views of the National Autistic Society Northern Ireland

Your position within that organisation (if appropriate)

Communications Officer

Responses can be sent by email or post

E-mail: seninclusion@deni.gov.uk

Post: The Review of SEN and Inclusion Team
Room G18
Department of Education
Rathgael House
43 Balloo Road
Bangor
BT19 7PR

This consultation response booklet should be read alongside 'Every School A Good School: The Way Forward for Special Educational Needs (SEN) and Inclusion' in order to understand the context of the policy proposals.

The proposals are shown in bold throughout the consultation document; Annex A of that document provides a summary table of the proposals and their identified benefits.

We welcome views on all aspects of these policy proposals. You are asked to consider each of the consultation points. Space is provided to allow additional comment on each of the questions posed.

Opportunity is provided at the end of this response booklet for any additional comments you would care to make. If, however, you have a particular interest **in one area and do not wish to comment on the whole document, feel free to complete only those sections that are of interest to you.**

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Introduction

Autism and the National Autistic Society Northern Ireland

The National Autistic Society (NAS) Northern Ireland is the charity working throughout Northern Ireland for people affected by autism. In Northern Ireland we provide information, advice and support and campaign and lobby for lasting positive change for those affected by autism.

We have nine NAS branches in Northern Ireland, providing local sources of information and support.

NAS Northern Ireland delivers a number of services including:

- Our ***help!*** Programme which provides parents and carers of school-age children, young people and adults with post-diagnostic information, advice and support
- Our befriending scheme which trains and supports volunteer befrienders to spend a few hours a week with an adult or child with autism or Aspergers syndrome or a family member
- Parent to parent confidential telephone support service, provided by trained parent volunteers who have personal experience of autism and want to support other parents
- Our telephone based Advocacy for education service, which provides information, advice and support on education provision and entitlements to help guide families through education law
- Our outreach service offers individualised support for young people and adults across Northern Ireland with a diagnosis on the autism spectrum. The service aims to promote independence, self confidence and an overall quality of life for people with ASDs
- Our social groups are for over 16's with high functioning autism or Aspergers syndrome and meet once a month for social activities.

What is an autism spectrum disorder?

Autism is a lifelong developmental disability that affects the way a person communicates with, and relates to, other people. It also affects how they make sense of the world around them. It is a spectrum condition, which means that, while all people with autism share three main areas of difficulty, their condition will affect them in different ways. The three main areas of difficulty (sometimes known as the 'triad of impairments'[1]) are:

- Difficulty with social interaction. This includes recognising and understanding other people's feelings and managing their own. Not understanding how to interact with other people can make it hard to form friendships.
- Difficulty with social communication. This includes using and understanding verbal and non-verbal language, such as gestures, facial expressions and tone of voice.
- Difficulty with social imagination. This includes the ability to understand and predict other people's intentions and behaviour and to imagine situations

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[1] Wing, L. and Gould, J. (1979) Severe impairments of social interaction and associated abnormalities in children: epidemiology and classification. Journal of Autism and Developmental Disorders, Vol. 9(1), pp. 11-29

outside of their own routine. This can be accompanied by a narrow repetitive range of activities.

Some people with autism are able to live relatively independent lives but others may need a lifetime of specialist care. People with autism may also experience some form of sensory sensitivity or under-sensitivity, for example to sounds, touch, tastes, smells, light or colours.

Asperger syndrome is a form of autism. People with Asperger syndrome are often of average or above average intelligence. They have fewer problems with speech but may still have difficulties with understanding and processing language. People with Asperger syndrome may not necessarily have learning disabilities but often have accompanying learning difficulties, including dyslexia.

We use the term autism here to cover all people on the autism spectrum, including autism, Asperger syndrome and other diagnostic terms used for autism spectrum conditions. Over 17,000 people in Northern Ireland have autism if you count their families autism touches the lives of over 68,000 people. Despite this, autism is still relatively unknown and misunderstood. That means that many people affected by autism and their families get nothing like the level of help, support and understanding they need.

General Comments on the Department of Education's Consultation Every School a Good School: The Way forward for Special Educational Needs and Inclusion.

The National Autistic Society Northern Ireland welcomes the opportunity to respond to the Department of Education's Consultation Every School a Good School: the way forward for Special Educational Needs and Inclusion.

The National Autistic Society is committed to supporting the special needs arising from autism. Hence our comments are focussed on how the proposals affect children and young people with an autistic spectrum disorder and the implications for their parents.

Using the Booklet to Respond

The National Autistic Society Northern Ireland would suggest that the booklet that the Department of Education has devised for this consultation response is not user friendly. We would suggest that in future consultations the use of plain English is employed and that the format of agree/disagree etc is not used. The Agree/disagree tick box is misleading as consultees may agree with some aspects of the proposals but not others. For busy parents who have many demands on their time including looking after a child or several children with SEN this format is unhelpful. We would strongly suggest that when analysing the responses that the Department does not just count the numbers of ticks but takes full account of the comments and any responses/letters that are sent to the Department on this issue. Many of the parents that we have been in contact with feel very strongly about the Review of Special Educational Needs and the potential impact on their children. The National Autistic Society hopes that the

Department will give full consideration to their Reponses in whatever format they are submitted.

The National Autistic Society Northern Ireland acknowledges the work that has been put into the Review proposals by the Department of Education and welcomes the profile that has been created for Special Educational Needs. However, the National Autistic Society Northern Ireland is concerned that under these new proposals the needs of children with autism will not be adequately met. We are concerned that there will be a dilution in terms of legal redress under the new system and a lack of opportunity for parental involvement. Lines of accountability are unclear and there is the potential for inconsistent provision across the sector. The Department of Education refers to these proposals as being "high level" and here lies part of the problem. It is extremely difficult to support proposals which contain very little detail. This lack of detail has produced concerns amongst professionals, the voluntary and community sector and amongst parents of SEN children.

The National Autistic Society Northern Ireland has in the course of research for its response met with parents of children with autism, Trade Union representatives, practitioners, and other voluntary and community organisations some of which are detailed below.

Met with parents of children with autism through our own consultation event on the 8th October 2009
Contacted parents through our branch network
Attended three of the Department of Educations consultation events
Met with the SEN Forum hosted by the Children's Law Centre
Met with INTO (Irish National Teachers Organisation)
Met with the Children's Commissioner
Met with various other Voluntary Organisations working on this issue

Underlying Assumptions

The proposals contained within the Department of Education's consultation document are based on assumptions about the present system and its shortcomings:

- It is resource-intensive
- It is slow to provide support from the moment of identification of a child's needs
- It removes too much responsibility from the school
- It has resulted in inconsistencies across the five Education and Library Boards
- It has resulted in too many statements being issued
- It is perceived as bureaucratic by parents

The National Autistic Society Northern Ireland would question some of the assumptions outlined in the Department of Education's proposals, for example we would suggest that the number of statements issued may be a reflection of need as opposed to "too many being issued". We would also question whether or not there is any evidence to suggest that these new proposals will reduce bureaucracy?

The National Autistic Society Northern Ireland would question whether or not it is essential to completely overhaul the present system and replace it with one where

there is no evidence to suggest that it will bring about significant improvement. The National Autistic Society Northern Ireland believes that the Department of Education has the power already to address some of the deficiencies in the existing system.
It is vital that the aim of these proposals is to improve the educational outcomes for children with Special Educational Needs, rather than cutting resources. The support that children with Special Educational Needs need in order to access an education may be resource intensive, however it is essential that their right to an education is upheld. A reduction in the number of statements or CSPs will not dissipate the need. In an analysis of the economic costs of autism in the UK Martin Knapp concluded [2]"If early intervention could successfully change some aspects of behaviour that are cost-raising, both in childhood and subsequently, it may allow cost savings to be made and quality of life improvements to be achieved. Children with autism need specialised autism specific support if the best outcomes are to be achieved. Below a parent of a child with autism outlines her experience of the complexity of the condition and the need to provide specialised, well resourced support. It is a lack of resources which prevents the employment of a 1:1 assistant in this case.

> *"My son is generally in good health. His language is reasonably good and he has a good vocabulary. However, he repeats the same things over and over again and insists that you listen intently. He has reasonably good relationships with family members but his unpredictable behaviour makes it difficult for him to sleep over with all but the closest family. He is very sociable but often approaches strangers. He seems to persevere with school more than enjoy it. He refuses to go to school at least twice a week and does not talk about his activities unless pressed. School have identified him as an excellent candidate for 1:1 support which they are unable to provide. His work is cut down so I believe that he is not accessing the full curriculum*
>
> *He is a frustrated child. He does not understand why certain behaviours are not acceptable or are inappropriate. He has regular tantrums when things do not go his way. His behaviour is very unpredictable and going out always has the possibility of being cancelled if he puts himself or one of his siblings in physical danger. He tries very hard to follow rules but is regularly disappointed when he doesn't manage it.*
>
> *Our main concern is that without support and assistance, he will never achieve his potential whatever that might be and that his mental state will continue to deteriorate as his peers move further and further away educationally."*

The National Autistic Society Northern Ireland would strongly recommend that the Department of Education focuses its attention on improving the deficits in the current system rather than introducing these radical changes to the system which lacks empirical evidence to suggest improved outcomes.

The National Autistic Society Northern Ireland strongly recommends:

- **That the Department of Education abandons these proposals and instead concentrates on reforming those parts of the current system which are not working effectively.**

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[2] Martin Knapp, Renée Romeo and Jennifer Beecham (2009) Economic cost of autism in the UK, *Autism* 13: 317-337
http://www2.lse.ac.uk/ERD/pressAndInformationOffice/newsAndEvents/archives/2009/05/MartinKnappAutism.aspx

Consultation Point 1 - **Inclusion**

(Reference: paragraphs 3.1 to 3.8)

1 Do you agree with the introduction of an inclusive framework based on the wider concept of additional educational need (AEN)?

The proposals outlined are aimed at reinforcing the principle of inclusion. The National Autistic Society Northern Ireland supports the principle of inclusion. It is important to note that the principle of inclusion should not be confused with the terms 'integration' or 'mainstreaming' which describe a situation where the child is placed in mainstream education and expected to adapt to the curriculum and classroom environment. For inclusion to take place, educational provision must be adapted according to the pupil's individual needs.

Inclusion is about the quality of a child's experience; how a child develops his or her skills, participates in the life of the school and learns and plays with children from a range of backgrounds. Many children with autism can be supported to play a full role in mainstream schools; however, some children will be able to have a more inclusive experience in a specialist setting.

Whatever the setting, educational provision for children with autism needs to be appropriately resourced. All mainstream schools should expect to teach children on the autism spectrum, and have the understanding, resources, training and specialist support to meet their needs. Where training and resource needs are not met, the principle of inclusion is undermined.

Because autism is a spectrum disorder, individual children will require different levels of provision. Parents are confident in their child’s schooling when they are able to choose the placement they feel is best suited to their child’s needs. The child's needs should be the starting point for identifying what type of school they should attend and the support they need in that setting. The policy of inclusion should never be used as a rationale for cutting specialist provision, as long as that provision continues to be necessary for any child with autism.

An inclusive environment should also ensure that children with autism have access to the “wider curriculum” Often children with autism are restricted in the opportunities they have for accessing extra-curricular activities. Schools and school authorities need to be proactive and take account of the social difficulties experienced by children with autism to ensure that access to the extra-curricular activities is achieved.

Case Study of School in Fermanagh

A recent example of the issue of Inclusion was brought to the attention of the National Autistic Society Northern Ireland by parents in Fermanagh. The case involves a Primary School P1and P2 composite class which includes three children with a diagnosis of autism. There is only one classroom assistant for the three children. The children have been excluded from going on school outings because of “their behaviour”. One mum was told that her son could not go on the school trip because he was “too hard to mind” One classroom assistant is clearly not enough to meet the needs of these children and as a result they are being excluded from school activities.

Additional Educational Needs (AEN)

Under the Department of Education’s proposals the overarching concept of Additional Educational Needs has been introduced. These will include:

- Children with SEN
- Children who have English as a second language
- Looked after children, young carers or those from the Traveller Community
- Those suffering from bullying or who have been recently bereaved

The National Autistic Society Northern Ireland recognises and fully supports the importance of providing for all needs and recognises that the groups above are not mutually exclusive. Children with autism are more likely than their peers to be bullied or to be looked after children. However, the National Autistic Society and the parents we support do not understand the logic behind the change, and the amalgamation of SEN into the concept of AEN.

The needs of children with SEN and disabilities are very different from those needs which will now come under the wider concept of AEN. Autism is a complex, lifelong disability that requires expert provision and support. We do not feel that this “wide umbrella” model acknowledges the differing and individual needs of different conditions and barriers to learning and that under this model the needs of children and young people with autism will not be given the attention they need. Previously SEN and AEN were budgeted for separately. These proposals will merge budgets and it will be unclear as to what the spend is on children with SEN. In these proposals there is no mention of children with disabilities and it is unclear as to what the implications for these children will be. SEN and disability have statutory protection; these proposals do not recognise this. There is concern that resources for these groups will be diluted. Parents already feel there is a lack of support for their children. They are genuinely concerned that the needs arising from autism will be submerged in the new proposals.

Consultation Point 2 **-** **<u>Key Principles of the Proposed Policy Framework</u>**

(Reference: paragraphs 4.1 to 4.6)

2 Do you agree with the key principles on which the policy proposals are based?

The National Autistic Society Northern Ireland finds it extremely difficult to respond to the question “do you agree with the key principles on which the policy proposals are based”. This section not only contains the principles but also sets out the policy proposals that are dealt with further on in the consultation. There is too much information within this one consultation point to either agree or disagree.

Principles
Many of the principles contained within the consultation document are highly aspirational in nature but unfortunately there is a lack of detail with regard to how they will be realised. The National Autistic Society does not disagree with the principles outlined but we do have major concerns with the Department's proposals for realising the principles. Many of the key principles underlining this new framework should already have been applied to the current framework.

Proposals
There is no evidence contained in the Consultation document to back up the Departments view that these proposals will bring about a significant improvement in meeting the needs of SEN children or that the changes will provide "good value" either in a financial or outcomes sense. The Department of Education states "that these policy proposals are based on best practice already evident in a number of our schools", the document however does not outline or include in the annex of the document this evidence. The National Autistic Society Northern Ireland has outlined its views on each of the proposed changes outlined in point 4.3 a-l in the relevant sections further in the consultation response.

Consultation Point 3 **-** **Early Identification and Intervention**

(Reference: paragraphs 5.1 to 5.5)

3 ***Do you agree with the proposals relating to Early Identification and Intervention?***

The National Autistic Society Northern Ireland agrees that Early Identification and Intervention are of the utmost importance in meeting the needs of SEN children. Early identification of ASDs and early intervention are important for ensuring that the needs of a child with autism are met. The sooner ASDs are identified the sooner support mechanisms can be created for the child in question. In 2003, the National Initiative for Autism: Screening and Assessment (NIASA) identified that "The benefits of the early identification of ASD are recognised by parents and professionals alike."[3]

There may well be economic benefits to early identification. Knapp et al. (2009) highlight that there is "a need for a much better understanding of the cost and cost-effectiveness of various interventions and supports for children and adults to ensure that decision makers have a stronger evidence base when deciding how to allocate resources."[4] The authors note that early intervention could lead to a lower need to rely on more expensive interventions later on in life. This approach would not only be more cost effective, but would also increase the quality of life for children with autism whose needs will be addressed and support provided at an earlier stage: "interventions that could divert people from care pathways that are not only expensive, but also damaging in terms of the quality of life impacts for those

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[3] NIASA. "National Autism Plan for Children" (2003). (NAS:London).

[4] Knapp et al. (2009). "The Economic Costs of Autism". Autism Volume 13(3) pp. 317-336, at p. 333.

individuals and their families, would need to be evaluated for both effectiveness and cost-effectiveness."[5]

Although the National Autistic Society Northern Ireland agrees with the need for early identification and intervention we do not agree with the Departments proposals for achieving this. Under the new proposals it will be the responsibility of the individual schools to determine in the first instance the range, type and level of support to be offered to SEN children. Clarity is needed as to whether or not this will include children with complex needs such as autistic spectrum disorders. The National Autistic Society would have great concerns that schools would not be able to deliver this without significant resources in terms of skills and adequately trained staff. Children with autism need autism specific interventions and supports and well trained professionals. Apart from the initial identified training budget there is no guarantee that sufficient funding will be available for continued training.

For children with autism early identification and intervention must be multi-agency and must not be restricted to support in the school environment especially for children who need a 24 hour curriculum. Any thorough early intervention with children with autism should involve speech and language therapists, occupational therapy and probably an educational psychologist. Teachers are not trained to perform these roles and it places enormous pressure on teachers and schools.

Personal Learning Plans (PLPs) will replace IEPs and become part of the early intervention process. The National Autistic Society Northern Ireland needs clarity as to what the status of a PLP will be, how it will differ from an IEP, how it will be maintained, how often it will be reviewed etc? There needs to be consistency across all schools regarding the production, maintenance and review of PLPs.

The National Autistic Society would question how the Department of Education will ensure consistency across all schools in Northern Ireland when they cannot achieve consistency across the current five education and library boards. Clarification is also needed with regards to the process for those children who have already had a diagnosis and their needs identified prior to starting school.

The National Autistic Society also seeks clarity as to how funds will be delegated to meet individual identified need. How will funding be allocated to schools to deliver the support needed to children and an early stage. Clarity is also needed as to how schools are to be held to account for allocated funds.

Consultation Point 4 - <u>**Pre-School Settings**</u>

(Reference: paragraphs 6.1 to 6.3)

4 Do you agree with the proposals relating to pre-school settings?

The National Autistic Society would support the inclusion of preschool providers in accessing the full range of pupil support services provided by the ELBs/ESA. We

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[5] *Ibid.* at pp. 331-332.

would also support the introduction of early intervention officers, however again more detail is needed with regards to their role and qualifications.

***Consultation point 5* - <u>Primary and Post Primary</u>**

(Reference: paragraphs 7.1 to 7.5)

5 *Do you agree with the proposals relating to primary and post primary?*

Collaborative working is a positive concept as is the sharing of expertise and knowledge it is also however reliant on adequate resources.

***Consultation Point 6* - <u>Training and Development</u>**

(Reference: paragraphs 8.1 to 8.5)

6 *Do you agree with the proposals relating to training and development?*

The Department of Education's policy proposals recognize the need for training if effective SEN provision is to be provided. Existing evidence suggests that currently there is awareness of ASD in schools, but the availability of appropriately trained staff (both teaching and classroom assistants) is patchy and often insufficient to meet needs effectively. The proposals suggest that as a starting point awareness training elements are introduced in initial teacher education courses and there is the provision of some form of continued professional development for teachers already in post. The National Autistic Society Northern Ireland welcomes the acknowledgement of the need for major training provision in the school workforce. We would however emphasise the need for autism specific training. The NAS feels that the proposals do not give a clear indication of the extent of training required. Will the initial teacher training be generic or specific to individual conditions? Will schools have a statutory duty to ensure that teachers receive training in specific conditions? What guarantee can be given that the funding proposed will be adequate to meet these new training requirements? Calls from parents to our Education helpline are often on the issue of what parents feel is a lack of understanding of ASD and the provision of specialist support. Below is a quote from a Parent outlining her experience of how a school has addressed the issue of autism.

> *"A number of incidents have happened since the start of term. The school has dealt with these simply as incidents of bad behaviour. I feel that the problems are due to sensory issues which have not yet been understood or addressed. My son is beginning to say that he "hates school" and I am beginning to lose confidence in the school. I am starting to consider educating him at home"*

The quote below outlines the difference that appropriate specialised support can make to a child with autism.

> *My son's educational needs are best met in a highly structured environment. The support he has received so far illustrates that his needs require a predictable,*

understanding environment. For reasons of health and safety and to enable my son to develop, he will require constant 1:1 adult support and supervision. The benefits of having support from adults with a good knowledge of autism spectrum disorders has been proven and is very obvious to us as parents.

The National Autistic Society Northern Ireland has grave concerns over whether or not there will be the adequate funding to sustain training beyond the initial budget for capacity building. It is imperative that no changes are implemented until training is delivered.

The National Autistic Society Northern Ireland strongly recommends:

- **That the proposals contained within this document and changes to the system are not implemented until full training has been carried out and funding secured for ongoing training.**

Consultation Point 7 **-** **<u>Learning Support Coordinators</u>**

(Reference: paragraphs 9.1 to 9.4)

7 Do you agree with the proposals relating to Learning Support Coordinators?

Learning Support Co-coordinators

Under the new proposals SENCOs (special educational needs co-coordinators) will have greater responsibility and an enhanced career framework. They will be renamed Learning Support Co-coordinators and will become part of the senior management team and have access to greater training. The National Autistic Society Northern Ireland welcomes these proposals. In order to ensure that the proposals deliver they must be backed up with appropriate training and resource investment. Will the necessary resources be made available to ensure both the expansion and the additional responsibilities of this role? How will the Department ensure that the training and resources available to SENCO's/LSC's is consistent across all schools regardless of location i.e. the rural/urban environment?

The National Autistic Society Northern Ireland would like further clarification on proposals for SENCOs/LSC's to carry out "low level diagnostic work". It would be totally inappropriate for SENCOs to be responsible for diagnosing an Autistic Spectrum Disorder. A diagnosis of an Autistic Spectrum Disorder and the provision of support require a multi-disciplinary assessment from qualified professionals. SENCO's should have responsibility to "flag up" concerns and refer children for assessment rather than carry out diagnostic testing.

Consultation Point 8 **–** **<u>Co-ordinated Support Plans</u>**

(Reference: paragraphs 10.1 to 10.6)

8 Do you agree with the proposals relating to Coordinated Support Plans (CSP)?

Co-ordinated Support Plans (CSPs)

Under this new system statements will be replaced by co-ordinated support plans. Co-ordinated support plans will be for children with “complex needs” who face “multiple barriers to learning” which cannot be wholly met within the school environment. There is no clear guidance within the document as to what constitutes complex and it is unclear as to what the exact mechanism is for obtaining a CSP. This must be addressed. The National Autistic Society Northern Ireland is concerned that the majority of children with Asperger syndrome or High Functioning Autism will not qualify for a CSP under this narrow definition despite requiring a range of support. Many children with autism only cope in mainstream school with a high level of support which in the past has been outlined in their statement. Reducing the number of statements will not dissipate the need but may increase the difficulties.

When a similar system was introduced in Scotland the number of new statements fell dramatically. The National Autistic Society Northern Ireland is concerned that without a CSP those children with autism whose needs are not being met will lose their legal right to support, and the right to challenge a failure to provide this support. Autism is a complex disability and the needs arising from the condition will have significant individual differences. It is difficult to understand how a child with autism will access the specialist support they will need without a CSP.

The Department of Education appears to want to follow the Scottish model of “Co-ordinated Support Plans” –defined in section 2 of the Education (Additional Support for Learning) Scotland Act 2004. The intent in Scotland was to reduce the number of pupils with a “Record of Need” (the CSP’s predecessor in Scotland) which stood at about 2% of the population to1% of the population having a CSP. A “Report on the implementation of the Education (Additional Support for Learning) (Scotland) Act 2004 published by the [6]HM Inspector of Education in Scotland stated that “in most schools, head teachers and classroom teachers felt that the number of children and young people with CSPs was too low”

Here in Northern Ireland under these proposals there is also the potential reduction in legally enforceable rights to provision. There is no guarantee that CSPs will have the same emphasis on provision. Also many children that currently qualify for a statement may not under these new proposals qualify for a CSP hence a reduction in their legally enforceable rights.

Research into autism including the Department of Education’s report from the Task Group on autism 2002 has stated that early identification and intervention are essential in achieving the best outcomes for children with autism. However the Department of Education’s proposals in relation to CSPs seem to mitigate against early intervention. Under the new policy proposals Co-ordinated support plans will only be given to a small number of children, who are seen to have complex needs and multiple barriers to learning. It would appear that it will be up to the Multi-Agency Group (MG) which is comprised of representatives from ELBs/ESA and HSC Trusts to decide if a CSP is to be awarded but the proposals state that a CSP will only be

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[6] Report on the implementation of the Education (Additional Support for Learning) (Scotland) Act 2004 produced for HMIE by RR Donnelley November 2007

awarded when the MG feels that all resources within the school environment have been exhausted and that the support plans that have been put in place have not worked. This mechanism may result in long delays for those children who may need and qualify for a CSP.

The National Autistic Society Northern Ireland strongly recommends:

- **That Statements are retained and that they are properly resourced**

Review of CSPs

Under the present system statements are reviewed on an annual basis. It is proposed that this annual review will be scrapped. The Department of Education has stated that parents report that they are pointless. This is not the experience of the National Autistic Society Northern Ireland which works with parents and guides them through the statementing process. Parents when properly informed feel that the annual review is a very useful opportunity for everyone involved to review whether the support provided to the child in their statement is meeting that child's needs. The Department of Education's own research briefing [7]"Parental Attitudes to the Statutory Assessment and Statementing Procedures on Special Educational Needs" stated that 80% of parents indicated that they were satisfied with the statutory assessment procedure and 76% indicated that a review was needed annually, even if their child's needs remained unchanged. The National Autistic Society would therefore question the justification for scrapping the annual review. The Annual Review is another mechanism for parents to input their knowledge and experience of their child's needs. Regularly reviewing the effectiveness of support and allocation of resources in a holistic child centered way should not be discouraged. A child's needs will change over time therefore it is sensible to review support and it should mean a more efficient use of resources.

The proposals state that CSPs will be reviewed at trigger points such as transitions or on parental request, however leaving the regularity of the review process in the hands of parents may in practice be discriminatory against those who have less capacity to advocate for their child. The NAS NI believes that it is more appropriate for the providers of education to hold the responsibility to regularly review the effectiveness of the support they are providing, rather than place this responsibility on the parent. Schools and Trusts are well placed to bring together the relevant professionals necessary to hold a review.

The National Autistic Society Northern Ireland strongly recommends:

- **Statements are retained**
- **The annual review is retained**

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[7] Department of Education Research Briefing Parental Attitudes to the statutory assessment and statementing procedures on Special Educational Needs. September 2005
www.deni.gov.uk/factsfigures/

***Consultation Point 9* - <u>Transition Points</u>**

(Reference: paragraphs 11.1 to 11.7)

9 Do you agree with the proposals relating to transition points?

Transition

Most young people look forward to leaving school and starting the next phase of their life with great excitement. However, the transition from school to adulthood can be a particularly difficult time for young people with autism. People with autism struggle to make sense of, and communicate with, the world around them. In order to cope they tend to rely on structure, routine and rules to help them manage what can feel like an overwhelming mass of sounds, events and information. Disruption to these routines or rules can lead to high levels of anxiety and distress. People with autism find social situations difficult and may struggle to make new friends. Individuals may find it difficult to adapt the ‘rules’ they have learnt in one context to new relationships and situations. They may also become distressed when other people break their rules or make it difficult for them to follow a familiar set routine. Consequently, people with autism may need to undertake a lot of preparation and planning to help them cope with even minor changes. Where a change as significant as leaving school is concerned, the need for effective preparation and planning is even greater.

Young people with autism will have become familiar with their school environment and may be used to receiving support there in a certain way. Moving to a new environment, often with less structure and reduced or different forms of support, will take getting used to, and having to build new relationships can be a frightening prospect.

Some young people will have complex needs which require specialised support and placements but, whatever the level of need, people with autism will need to be prepared for any change to make sure that it happens smoothly and results in positive outcomes. It can be very hard for young people with autism to take in several options at one time, and it is therefore good practice to introduce options gradually.

A person-centred approach

All young people have the right to be involved in decisions about their future.
Very often preparation and ongoing work will need to be undertaken to enable the young person to understand what transition means and what options are available to them.

Autism is a spectrum condition and people with autism need very individual support and individually-tailored opportunities. They may also need different levels of support to understand choices and express their views in meaningful ways, so that they can participate in the transition planning process. They may need help to visualise choices, which can be offered by using pictures, photographs and visits to help the individual understand and become familiar with a new environment. Some may need support with communication using tools such as the Picture Exchange Communication System (PECS) or Makaton.

Person-centred approaches aim to create and offer services that meet the individual needs and aspirations of young people with autism – as opposed to matching young people to services on the basis of availability. They provide a useful framework for involving not just the person with autism but also their family and wider support network. The input of family and other significant people, such as advocates who help young people with autism to express their views, can be invaluable in building up a picture of the support needed by an individual to achieve their aspirations. The transition process should be person-centred, taking into account the wishes of the individual and their family. Putting together individual packages of support like this will take time and effort, but in the long term placements are more likely to succeed. The National Autistic Society welcomes the expansion of the transition service to all children with SEN.

The National Autistic Society Northern Ireland strongly recommends:

- **That a person-centred approach is adopted to transitions**

***Consultation Point 10* - <u>Developing Effective Partnerships</u>**

(Reference: paragraphs 12.1 to 12.30)

10 Do you agree with the proposals relating to the development of effective partnerships:

(a) Within school and pre-school settings? (paragraphs 12.3 to 12.5)

The National Autistic Society Northern Ireland broadly agrees.

***(b)* Across educational settings & learning communities? (paragraphs 12.6 to 12.7)**

The sharing of good practice and partnership working is a positive development and should be encouraged through proper resourcing. However learning communities are still in the early stages of development and still "bedding down" so more time is perhaps needed before they are fully functional.

10 Do you agree with the proposals relating to the development of effective partnerships:

(c) Between mainstream and special schools? (paragraph 12.8)

The National Autistic Society Northern Ireland supports the sharing of expertise, information and advice. We believe that special schools contain a wealth of skills and expertise, and that they have an important role to play. Special schools play a key role in educating children with more complex needs, and working in partnership with mainstream schools to support greater inclusion. We would support effective partnerships between mainstream and special schools and further proposals need to be developed to support joint working between the sectors as it is currently underdeveloped.

The National Autistic Society Northern Ireland recommends that:

- **Further proposals are developed by the Department to support special schools to work with and support the mainstream. This will involve identifying ways to address the barriers to joint working**

10 Do you agree with the proposals relating to the development of effective partnerships:

(d) Between Education and Health and Social Care (e.g. Education and Skills Authority and proposed Regional Health Boards)? (paragraphs 12.9 to 12.17)

Partnership working between Education and Health and Social Care is a weakness within the current system. Under the new proposals there is no statutory obligation on the part of Health and Social Care to provide what is outlined in the CSP as again it is reliant on resources. This is a major weakness. Children with autism will often require the services of occupational therapists because of sensory issues or need the input of speech and language therapists etc. If under these arrangements there is not a legal obligation to meet that need then this partnership is unlikely to succeed. The proposals do not inspire confidence that the situation will improve.

The National Autistic Society Northern Ireland recommends:

- **That there should be a statutory obligation on Health and Social Care to provide provision outlined in a CSP.**

10 Do you agree with the proposals relating to the development of effective partnerships:

(e) **Between the Department of Education (DE) and the Department of Employment and Learning (DEL)? (paragraph 12.18)**

This is another important partnership which is vital to help realise the best outcomes for young people with autism. It is essential that all these partnerships work together and not in isolation. The transition process needs to be strengthened through strong partnership working. However there are not enough opportunities for young people after they leave the school setting and this needs to be examined. Recent research by the National Autistic Society entitled Don’t write me off found that only 15% of people with autism across the UK were in full time employment. The National Autistic Society Northern Ireland is calling on the Department of Employment and Learning to produce an employment strategy for people with autism. This would raise awareness of autism amongst employers and ensure that the right support is in place to enable people with autism to access employment and get the support they need to remain in the workplace. Partnership at a departmental level is to be commended but it must translate into joint working on the ground.

The National Autistic Society Northern Ireland recommends that:

- All transition plans include young people's employment goals and outline the work support programmes available to them
- That young people with autism have appropriate meaningful work experience in Year 11 or 12

10 Do you agree with the proposals relating to the development of effective partnerships:

(f) Through the establishment of Multi-disciplinary Groups? (paragraphs 12.19 to 12.25)

It is proposed that multi-disciplinary groups will be developed and staffed by a small number of Education Skills Authority (ESA) staff, health staff, education professionals such as teachers and SENCOs/LSCs; these groups will have responsibility for evaluating children's needs and determining the next step. Referrals are to be made from schools. It is unclear as to whether or not these groups have any legal responsibilities or whether or not they hold their own budgets. Detail is needed on whether or not MGs have a role in challenging schools.

It is unclear as to how parents will input into this group. In the proposals there is no indication of parental involvement. We would also suggest that parents as well as schools should have the right to refer their child to the Multi-Disciplinary Groups and the right to view all documents that are produced by this group on the needs of their children

Also assessments need to be done by professionals who have knowledge of autism and who work with the child over a period of time

10 Do you agree with the proposals relating to the development of effective partnerships:

(g) With parents and carers

In the case of autism, parents have a significant role to play and contribution to make to the arrangements which are made for the special educational needs of their children. They are best placed to understand and to communicate the individual needs which their children have. Experience gives them insights into their child's impairments, abilities, sensory issues, behavior etc. Parents therefore have the experience to make a very relevant and practical input into their children's education and the type of support they need. The Department of Education's existing code of practice allows for partnerships and for ways of involving the child, the new proposals do not appear to give this a similar prominence. Collaboration between schools and between professional services is emphasised in the consultation document. There is less recognition given of the benefit and indeed for the involvement of parents in the process. This is a major omission in the document. For example there is no clear pathway for parents to be involved if the Multi-disciplinary groups are assessing the needs of their child. Under the present system parents of statemented children are involved at a number of different levels and intervals, through parental evidence and consultation when a statement is being produced, at the annual review and at transition points. The new policy proposals will mean that there be substantially less children qualifying for a CSP. As stated earlier we believe that is extremely important that annual reviews are maintained and the responsibility for organizing them should rest with professionals. We do not agree with the Departments proposals to only review CSPs at key stages or when parents request a review. The responsibility for reviews should not be placed upon parents.

Parent G's experience of the present system has been positive. Appropriate support has been obtained through having information about the system and through a good partnership between ELB and parent

"Thank you for your help in reviewing our proposed statement. We managed to arrange a meeting with staff in the ELB and agreed that mainstream education was the most appropriate environment for our son. The ELB has also agreed to provide him with 20 hours adult assistance per week."

Parent F valued the opportunity to discuss her son's progress at an Annual Review Meeting. However, she was disappointed when relevant reports were not made available prior to the meeting

"I have always valued the opportunity to be involved in my son's care and education. I have appreciated the information I have received about his needs and progress. I was disappointed by the absence of some reports before the meeting. These should have been made available and were very necessary, especially since a major change in my son's school placement was being proposed. I would have found it easier to agree if I had had a fuller picture of his present needs"

10 Do you agree with the proposals relating to the development of effective partnerships:

(h) With children and young people? (paragraph 12.29)

The National Autistic Society welcomes proposals relating to the effective partnership with the child and young person.

10 Do you agree with the proposals relating to the development of effective partnerships:

(i) With voluntary organisations? (paragraph 12.30)

The National Autistic Society welcomes proposals to involve and work in partnership with the voluntary sector. The voluntary sector has a lot of expertise which could be utilised by the education sector. However cognisance needs to taken of the increased financial pressures faced by this sector in the current financial climate.

***Consultation Point 11* - <u>Outworking of the Proposed Model</u>**

(Reference: paragraphs 13.1 to 13.9)

11 Do you agree with the replacement of the sequential stages of 1-5 of the current CoP by the proposed 3 strand model (Within School, Within School plus External Support, Co-ordinated Support Plans)?

The National Autistic Society Northern Ireland is not convinced that reducing the number of the sequential stages of 1-5 of the current CoP to the proposed 3strand model will overcome the present delays in the system which we believe are due to a lack of resources and specialist staff. If schools do not put in place the correct interventions quickly at the “within school” phase then a child’s needs may not get met. Autism is a complex disability which often requires specialist input, however under this model there could be long delays while teachers carry out assessments and interventions before external support is accessed. Although at first glance it looks like this may reduce waiting times in reality it may mean that children with autism wait much longer for the specialist support they need.

***Consultation Point 12* - <u>Resolution and Appeal Mechanisms</u>**

(Reference: paragraph 14.1)

12 Do you agree that the current informal appeal, dispute avoidance and resolution and formal appeal arrangements (SENDIST) for children with SEN should remain unchanged?

The National Autistic Society Northern Ireland is unsure as to how the appeals mechanism will work. At present DARS does not appear to be used to its full capacity. This could be for a number of reasons i.e. it is not well advertised and it is not viewed by parents as independent given that it is facilitated by Education and Library Board officers. Under the policy proposals there is no firm detail as to who will have the legal duty to provide for children with SEN. It is unclear as to whether that will lie with the Education and Skills Authority, the Multi-disciplinary Groups or schools given that budgets would be devolved. Clarification is required on any possible changes to the current grounds of appeal given the proposed changes from 5 stages to 3. The National Autistic Society is also concerned that these proposals put huge pressures on schools and teachers. At present the Boards act as a “buffer” between school and the child/parent if there is a disagreement about how and what provision is made. It is unclear from these proposals as to what will happen if there is a dispute between parents and schools or parents and MGs etc. If the current mechanisms remain in place and apply only to those who have a CSP then the majority of children with SEN who previously had a statement would have no rights of appeal.

Consultation point 13 - Funding

(Reference: paragraphs 15.1 to 15.5)

13 Do you agree with the proposals relating to funding?

The National Autistic Society is concerned that the funding will not be available to provide the ongoing training and provision of services etc that these proposals are based on. The preface to the Consultation document states on page 6 of the Executive Summary "In the recent budget, the DE has acquired funding for the ***commencement*** of finalised proposals. It should be noted, however, that full policy proposals can only be implemented as, and when, the resources become available in both education and social care sectors."

An initial £24million will be made available for capacity building in the 2010-2011 year, this is to be used for necessary training, however it is unclear how much additional funding will be made available overall. The Department of Education will have to bid for resources under the Comprehensive Spending Review and there is the potential for a decrease in available funds because of the present economic climate.

To commence such a radical review of a system without the necessary funding is unwise and puts at risk our ability to meet the needs of the most vulnerable children in our society.

The National Autistic Society Northern Ireland strongly recommends:

- **That these proposals do not proceed without secure long term funding**

Distribution of Funding

It is unclear how funds will be distributed to schools and without appropriate funding the proposals for early identification and meeting of need can not be implemented. There is a real risk that children with SEN who do not have a CSP will face discrimination during the school admissions process. Unless funding 'follows the child', each child with SEN that a school enrolls will stretch the AEN funding further, thereby providing a disincentive for schools to accept children with SEN without a CSP. It is also unclear as to what mechanisms will be employed to ensure that schools spend their resources on Special Education Needs. The NAS Northern Ireland believes that clear accountability is essential to parent confidence in the system, and parent-school relationships.

The National Autistic Society Northern Ireland strongly recommends:

- **That Special Educational Needs funding should be ring fenced and clear accounting mechanisms put in place to monitor how these funds are utilized.**
- **These accounts should be publically available**

- **The way in which funding is delegated to schools is calculated in a way that will not risk increasing discrimination in school admissions against children with ASD who do not have a CSP**

Consultation Point 14 **- Monitoring, Review, Evaluation & Accountability**

(Reference: paragraphs 16.1 to 16.5)

14 Do you agree with the proposals relating to monitoring, review, evaluation & accountability?

The National Autistic Society Northern Ireland has concerns as to how the Department of Education will monitor the progress of schools in the provision and effectiveness of early intervention for children with autism. We are extremely concerned with the proposal that funding released to schools for SEN will not be ring fenced. Funding for SEN should be ring fenced and clear, robust accountability mechanisms put in place to ensure that funding will be used to meet the needs of individual children with SEN. It is difficult to see how consistency of provision is going to be managed across the whole of the school sector when it could not be guaranteed across five education and library boards.

Consultation Point 15 **– Roles and Responsibilities**

(Reference: paragraphs 17.1 to 17.19)

15 Do you agree with the proposals relating to the roles and responsibilities for:

(a) The Department of Education (DE)? (paragraphs 17.1 to 17.2)

The National Autistic Society Northern Ireland is not convinced that the production of guidance and quality indicators for schools, support and outreach services will be enough to ensure that effective interventions are being put in place for children with autism. The National Autistic Society's advocacy for education service frequently comes across cases whereby the current code of practice is not being adhered to. We would however welcome the production of a communication strategy to enable parents to have more faith in the system. A communication strategy would be very helpful in the current system.

15 ***Do you agree with the proposals relating to the roles and responsibilities for:***

(b) The proposed Education and Skills Authority (ESA)? (paragraph 17.3)

At the time of writing this submission there is political uncertainty regarding the future of ESA and the timescales originally proposed are no longer possible.
It is also unclear from these proposals how ESA will operate. Clarity is needed as to what the relationship will be between ESA, The MGs, Schools and parents. It is also unclear as to who will have which powers, duties or where accountability rests in terms of legal redress.

15 Do you agree with the proposals relating to the roles and responsibilities for:

(c) The Department of Health, Social Services and Public Safety (DHSSPS)? (paragraphs 17.4 to 17.6)

The National Autistic Society Northern Ireland is concerned that the proposals relating to Health and Social Care and the provision of services are subject to "available resources". The National Autistic Society Northern Ireland strongly disagrees with this statement as the provision of services should be based on need.

15 Do you agree with the proposals relating to the roles and responsibilities for:

(d) Multi-disciplinary Groups (MGs)? (paragraphs 17.7 to 17.8)

The National Autistic Society Northern Ireland feels that more information is required as to the role, remit and accountability of these groups. It is unclear as to who will take the lead within these groups and as stated previously there is no clarity as to what involvement if any that parents can have with these groups. Clarity is also needed as to how parents would access reports and information which this group would produce on their child.

15 Do you agree with the proposals relating to the roles and responsibilities for:

(e) Mainstream schools and other educational establishments? (paragraphs 17.9 to 17.16)

The National Autistic Society agrees that schools should take responsibility for the educational outcomes of children with SEN and that this should be monitored and measured and all available strategies should be utilised. We also support increased capacity and training but we have major concerns around the resources available to enable this to happen. We also have concerns regarding the level of responsibility being placed on schools and the accountability mechanisms being put in place. I would refer you to consultation point 8 on CSPs and Consultation Point 3 on early Identification and Intervention which provides further detail on our position regarding schools responsibilities in these areas

15 Do you agree with the proposals relating to the roles and responsibilities for:

(f) The Education and Training Inspectorate (ETI)? (paragraphs 17.17 to 17.18)

The National Autistic Society Northern Ireland broadly agrees but feels this is reliant on adequate resources being available.

***Consultation Point 16 -* <u>Proposed Phased Introduction of the Policy</u>**

(Reference: paragraphs 18.1 to 18.7)

16 Do you agree with the proposed phased introduction of the policy?

Proposed phased introduction of the policy

The National Autistic Society Northern Ireland does not agree with the proposed phased introduction of the policy. The timescales outlined for these changes are completely unrealistic and don't take account of this consultation process. Training and funding should be secured before any of these proposals are implemented. It is recognised in the document that the full policy proposals can only be implemented when necessary resources become available to both the education and health and social care sectors. This is not acceptable here needs to be major clarification on many fundamental points and confirmed funding and resourcing before these proposals are implemented.

The National Autistic Society Northern Ireland believes that whatever system is in place, including the current one it should incorporate the following

- There should be legal redress on an individual level
- There should be a fair and adequate system of funding
- There should be adequately trained professionals with access to specialist expertise
- There should be partnership working between professionals and parents
- There should be strong accountability and transparency

For more information contact Shirelle Stewart at the National Autistic Society Northern Ireland 57A Botanic Avenue Belfast BT4 1JL Tel: 028 90236 235 Mobile: 07789941239 Email: Shirelle.stewart@nas.org.uk