

Date: 9/4/07

Autism and The National Autistic Society

1. The National Autistic Society (NAS) is the leading charity for people with autistic spectrum disorders in the UK. It has a membership of over 12,000, a network of 60 branches, and 80 partner organisations in the autism field.
2. In Wales, NAS Cymru has five branches and links to a range of independent parent support groups for autism. NAS Cymru is the leading provider of information, advice, services and support for people with autism, their families and carers, in Wales and exists to champion the rights and interests of all people with autism and to ensure that they and their families receive quality services, appropriate to their needs.
3. **Autistic spectrum disorders (ASD) are a group of lifelong developmental disorders that affect the way a person communicates and relates to people around them. People with autistic spectrum disorders experience difficulties with social interaction, social communication and imagination known as the 'triad of impairments'<sup>1</sup>. Whilst people with ASD share common impairments, each individual is unique, with different life experiences, genetic inheritance and personalities.**
4. In preparing its response to this policy review, NAS Cymru has consulted with NAS branches, independent parent groups and individual parents whose children have an ASD.
5. The NAS welcomes the opportunity to comment on the Education and Lifelong Learning Committee's review of Special Education Needs.
6. Since the consultation process has opened, NAS Cymru has tried to inform parents and carers, as well as practitioners as widely as possible about this review. However, we would draw your attention to the fact that many people we have spoken were unaware that a review of this was taking place (including teachers and SENCO's) and were concerned that they had not been made aware of this. This point was also raised at the last meeting of the National Assembly for Wales Cross Party Autism Group.

Prevalence

7. The scientific consensus is that autistic spectrum disorders can be identified in 1 in 166 children under eight years old<sup>2</sup>. The number of older children and adults affected by autism is not

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<sup>1</sup> 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

<sup>2</sup> Medical Research Council, Review of Autism research: Causes and Epidemiology, MRC, November 2001

known. However, the NAS prevalence estimate for autistic spectrum disorders in the total population is 1 in 110<sup>3</sup>. Moreover, in a recent survey by the NAS, primary school teachers reported a prevalence rate of 1 in 86 pupils in school<sup>4</sup>. This indicates that all services should expect to come into contact with young people on the spectrum. As such, autism must be treated as a common disability, with clear implications for mainstream policy and practice.

8. The National Assembly for Wales has a responsibility to ensure that society, and in particular key professional groups such as teachers, police officers and medical professionals, is sufficiently informed about autism to meet the needs of people with ASD.

### **Question 1- What are the advantages and disadvantages of the current assessment process?**

9. NAS Cymru believes that the current assessment process is far from perfect and can be an extremely lengthy and frustrating experience for parents, children and professionals alike. However, it does provide an opportunity for a formal assessment of a child's educational needs and allows support to be put in place to address these needs. Parents highly value the safeguards that statements provide in terms of clearly identifying their child's needs and ensuring appropriate provision, support and placement is put in place.

#### **Advantages**

- The assessment process provides an opportunity to access support for a child over and above what a normal school would be able to offer within existing resources
- The assessment process establishes clear processes and actions which are in theory uniform across LEA boundaries and provides a mechanism to identify and respond to the needs of a child with special educational needs with the inclusion of the parents in a multi-agency approach.
- Under the current system, a parent's right to appeal against the LEA's decision is enshrined in law. This is an extremely important factor for most parents, who feel without the ability to challenge their LEA, they would not have received adequate support for their child
- The process sets in place time limits, enshrined in law, which should ensure that assessment of and provision for the child is undertaken within a specified time. This allows all involved, but particularly parents; to have a clear understanding of how long the process should take
- The process ensures that the child receives an initial assessment by relevant professionals that establishes what the child's needs actually are
- Allows for the provision of additional support from relevant professionals, are more likely to appreciate the needs of the child outside the schools budget

#### **Disadvantages**

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<sup>3</sup> How many people have autism spectrum disorders? (2003) NAS: London

<sup>4</sup> Barnard et al, (2002). *Autism in Schools: crisis or challenge?*, London: National Autistic Society, p.5

- At present, the assessment process is much too lengthy- parents regularly tell us of having to fight for a statement from anything from a few months to several years. Some parents also tell us of huge backlogs in some LEA areas. This is of no benefit to the child
- It is also often extremely costly to parents and their child/children, not just financially, but emotionally
- Can cause strained relations between the parents and the school and LEA, which may impinge on ensuring the child is the focus of the process
- Many parents are not aware that their child is being supported through school action and action plus and what this means to their child, as there is no formal requirement for the school to advise the parent
- It is difficult for parents to access. Many parents are not made aware of how to initiate the assessment process, whilst others will be dissuaded from doing so by the school or LEA. NAS Cymru often hears that parents have been told by an LEA **‘we don’t do assessments or statementing’** or that **‘your child won’t get a statement, as they have Asperger Syndrome’**.
- The focus of identification and assessment of whether a child requires additional support is often too strongly around the child’s educational needs. It is important to include provision around other areas which not only impact on education, but also the child’s own development and life chances. The SEN Code of Practise includes “behaviour, emotional and social development”<sup>5</sup> in it’s description of areas included in SEN
- There is diversity in criteria from area to area as to who will receive an assessment and subsequent statement, despite guidance LEA SEN policies vary across Wales. There is no standard cut off point for what provision of support will be available from LEA to LEA. An example of this would be in Bridgend, where parents tell us the LEA will not statutorily assess a child unless they are in need of or in, a special school.
- Our experience has shown that SEN officers do not seem to have proper training in the law. They are faced with making key decisions regarding the children’ s educational support needs, which in turn have legal implications. They may only be given minimal training, whilst parents rely on their knowledge and trust what they are doing. On going training to keep SEN officers updated with changes in the law and other key issues, is also ad hoc.
- There is also a lack of understanding amongst schools as to what is expected of them under the law and what is guidance (the SEN Code of Practise for Wales).
- The policies and practise in how to meet the needs of children with ASD and what type of placement, varies between LEA’s in Wales. For instance, some LEA’s will not recognise that children with Asperger Syndrome (AS) require additional support in school, despite the fact that many children with AS have particular social needs. These might include problems understanding instructions and understanding what is expected of them, interacting with other children and particular problems at break time and lunchtime.

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<sup>5</sup> SEN Code of Practise for Wales, 2002

## **Question 2- Should statements of special educational needs be scrapped- why or why not?**

10. NAS Cymru strongly believes that statements should not be scrapped in Wales. The SEN Code of Practice for Wales states that “children with SEN should be offered full access to a broad, balanced and relevant education”. However, in our experience, many parents feel that without obtaining a statement for their child, they would not have been able to access the appropriate support they now have. For too many, they are still fighting for support and the further reduction or scrapping of statementing, threatens to leave parents without any recourse to challenge LEA decisions.
11. Many parents have told us their experiences of the LEA trying to hold off providing support for as long as they can through the process and by threatening legal action, is the only way the LEA will consider offering additional support.

**“If you go through legal channels, they give you more, if you go to tribunal, they give you even more”**

*Parent from South Wales*

12. For many parents, once they get to the stage of involving a legal representative or going to tribunal the LEA will often back down at the last minute, with an increased offer (although often still not as much as parent would like, it provides a compromise between what is needed and what can be reasonably provided). No parent should have put themselves and their children through this financial and emotional strain. An average tribunal will cost a family around £4000.
13. If parents do take a case to tribunal, there can also be a difficulty in getting LEA’s to enforce tribunal orders. The SENTW currently has no powers to monitor or enforce their decision. For a high percentage of the tribunal cases the NAS supports, as a result of the LEA’s inaction on a tribunal decision, we advise parents to write to LEA’s with a 5 day letter, asking for provision to be provided, otherwise they will be seeking legal advice.. If an LEA do not reply to this, we will refer them to a solicitor (There is also a shortage of Education solicitors in Wales and often parents will be referred to other areas).
14. The legal safeguards in place around statementing remain imperative. Particularly when too many families still have to fight to get appropriate provision for their child. Reports published by three autism charities<sup>6</sup> in 2003 brought home the devastating impact of this battle on many families.

**“The fact that I have been able to keep my son in some sort of education, has been down to his statementing”**

*Parent from South Wales whose son, at the age of 11 years old is on his fifth school, having not been able to find enough support through his previous schools without being excluded*

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<sup>6</sup> The National Autistic Society, PACE (Parents Autism Campaign for Education) and PEACH (Parents for the Early Intervention of Autism)

15. If statementing were scrapped much more responsibility would fall on the individual teacher and school involved, which would take teachers away from teaching and make it difficult for schools to make decisions as to how to best channel resources. This would also mean that parents would need to dispute directly with school rather than LEA which is often more difficult. Where schools are responsible for the allocation of SEN money, they must be accountable for delegated funds, to ensure that they are spent according to the needs of each child.
16. As levels of awareness in schools are still patchy, the experiences of children with SEN in schools would be dependent on the knowledge and commitment of the professionals within that school.
17. In the research by the Audit Commission in 2001, 70% of the lowest statementing authorities reported that they are maintaining more statements for children with autism, even though the rate of statementing for other children with SEN is falling. The research suggests that this reflects a high level of anxiety amongst parents of children with autism, associated with their perception of low levels of autism awareness in their local schools.
18. In Wales according to Estyn, “the number of pupils with communication difficulties has risen steadily in recent years...in part, the increased numbers of children with autistic spectrum disorder accounts for this rise”<sup>7</sup>. This can be explained by the increased awareness of autistic spectrum disorders in Wales and improved diagnosis (although for many parents getting a diagnosis is still extremely difficult in Wales).
19. Levels of awareness of autism amongst professionals including both health and education professionals is still patchy in Wales, therefore highlighting the importance of getting an assessment from professionals that understand the condition.
20. The National Autism Plan for Children<sup>8</sup> recommends multi-agency programmes of ASD awareness training on a continuous basis for all professionals working with children, enabling teachers to recognise the alerting signals of a possible developmental disorder, to support children with ASD and to know when to seek specialist advice.<sup>5</sup> Until such measures are put into place, it is likely that children displaying autistic traits are unlikely to be diagnosed and receive appropriate support, unless a formal assessment of need has taken place.
21. It is also imperative that autism awareness is widespread amongst all who come into contact with children with an ASD at school. Without such awareness and in some cases (such as class teacher and LSA) in-depth training and support mechanisms need to be available. As *one parent from north Wales* told us:

**“My son has autism. He has a one to one worker, who is a local mum, she isn’t qualified, but is paid. She is there to help when required and provides support through break time and throughout the day. But she does not have any training; she is reading up on autism in her own time”**

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<sup>7</sup> Support for Children with Special Educational Needs: An Estyn Overview, October 2003

<sup>8</sup> The National Autism Plan for Children (NAPC), published by NAS in collaboration with the Royal College of Paediatrics and Child Health and the Royal College of Psychiatrists, 2002

22. In the period between 2002/2003, 16% of cases submitted to the SENTW against LEA's were where ASD is the primary SEN referred to at the point of appeal, which the SENTW Annual Report 2002/2003 notes "once again, a marked increase in cases concerning autism"<sup>9</sup>. In the most SENTW report for the period 2003/2004, this figure has risen to 22%<sup>10</sup> and of the 9 appeals submitted; only 1 was dismissed<sup>11</sup>.
23. The comparatively high level of appeals both submitted to and upheld by SENTW against LEA's in Wales, would indicate that some parents and LEA's cannot agree on the appropriate levels of provision for their child and the right to appeal to tribunal is an important mechanism in assisting in this process.
24. The annual review allows for the systematic monitoring of progress and accountability for children with statements
25. The NAS is concerned at the possible implications of scrapping statementing and the extent to which this policy review would result in the further delegation of SEN resources to schools. Such a policy direction is based on a limited research base, and we would welcome the opportunity to work with the National Assembly for Wales in monitoring more closely the impact of delegated funding on parental satisfaction with their child's provision.

**“Without his statement, my son would not have been able to access his secondary place in a mainstream school with an Asperger Syndrome unit”**

*Parent from North Wales*

26. Many children with ASD will need a statement because their needs are so complex; they will not be met by money delegated to the school.
27. Money currently allocated to schools for the provision of SEN is currently not ring fenced and very little guidance is given to schools as to how monies should be used/allocated. Parents have told NAS Cymru that children with ASD and particularly Asperger Syndrome do not take priority in schools for provision of additional support through delegated funds.
28. There is no systematic monitoring of progress and accountability for children without statements. NAS Cymru believes that until a formal monitoring and assessment process is available to all pupils with SEN in schools, statementing is still necessary.
29. Building parental trust and confidence in mainstream provision as a crucial prerequisite for its success. The NAS believes that attempts to implement a reduced-statementing policy before, rather than as a result of, an increased measurement of satisfaction amongst parents is likely to result in conflict and polarisation, rather than trust and collaboration.

**Question 3- If the statementing process were abolished, what should be put in its place?**

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<sup>9</sup> SENTW Annual Report 2002/2003

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<sup>11</sup> SENTW Annual report 2003/2004

30. NAS Cymru would be concerned about any move away from the statementing process that did not include safeguards for children and parents. It is imperative that adequate mechanisms are in place to ensure that children are able to access timely and appropriate support.
31. Ideally, NAS Cymru believes that there should be a formal assessment for every child who has a disability, as without this, it is difficult to build picture of the child's educational needs. Such a multi-disciplinary assessment (although not necessarily leading to a statement) would allow the identification of the child's individual requirements, without which, it is difficult to ascertain what the child's needs are.
32. Any change from the current assessment and statementing process would have to be replaced with a process enshrined in law.

**Question 4- Is information on the statutory assessment process easily accessible and understandable?- If possible, please give examples of good practise.**

33. The current SEN Code of Practise for Wales clearly outlines everyone who has responsibility under law to SEN has to 'pay regard' to the SEN Code of Practise and explains the SEN process. However, parents are often unaware of this resource, which can advise on how the process should work and the legal obligations of the LEA.
34. The Code of Practise toolkit produced to accompany the Code of Practice in England also provides some useful information and advice for parents.
35. A recent Advisory Centre for Education (ACE) survey indicated that most of the 22 local education authorities in Wales did not publish "vital information required by law on their websites about extra help for children with SEN"<sup>12</sup>. The survey also identifies the levels of jargon still used by LEA's in communication with parents as an issue and the use of out of date information. Information, if present, is often only restricted to statementing, on LEA websites.

One parent told us:

***"There is no mention of school action and school action plus on our local LEA website"***

*Parent from South East Wales*

36. Although this issue has been brought the attention of Estyn, the NAS believes that it is imperative local education authorities make information around support readily available to parents both through their websites and through written material.

**Question 5- Is support for parents/carers of children and young people currently undergoing statutory assessment readily available?- If possible, please give examples of good practise**

37. In our experience, information available for parents and carers from LEA's is limited. Although NAS Cymru welcomes the National Assembly for Wales' SEN guide for parents, we would suggest that this leaflet is not currently made widely available to parents. Every parent whose child is identified as having SEN, should receive such a leaflet. Local Education Authorities

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<sup>12</sup> ACE Bulletin, October 2004

may also want to consider providing their own leaflets. Brighton and Hove LEA are an example of an LEA who produce a clear and comprehensive local advice guide for parents.

38. In some LEA areas, when correspondence is exchanged between an LEA and parent, information is provided to the parent about their local SNAP parent support group. Such groups can provide extremely valuable support and information and guide parents through the statutory assessment process- although experiences do vary between each parent and each local area.
39. The National Autistic Society's **Advocacy for Education Service** provides advice and advocacy on special educational needs provision and entitlements for families whose children have an autistic spectrum disorder to help guide them through this complex and difficult process. The Advocacy for Education Service can even provide free legal representation for families who are faced with SENTW. The effort parents face in obtaining an appropriate education for their child is revealed by the fact that many parents return to the NAS Advocacy for Education service for advice at each stage in the process and often return even following tribunal.
40. NAS Cymru also run workshops for parents in Wales advising on their rights and our Help! Programme for parents of children recently diagnosed with an ASD also includes information on educational support and legislation. The NAS can also provide fact sheets advising parents of their rights, as well as information packs for teachers and LSA's

**Question 6- Is support for children and young people with a statement of special educational needs appropriate and timely?- If possible, please give examples**

**“Our experience of the annual review process has been good, although different to most I think. We tend to get everyone involved including the educational psychologist around the table to discuss my son's progress”**

*Parent from South East Wales*

41. If the LEA do not fulfil what is agreed as a result of the assessment they will be breaking the law and you can take them to court. However, it is clear from our Advocacy for Education Service and individual parents we have spoken to that in some areas, LEA's are not providing the full levels of support indicated on the statement. An example of this would be when a statement includes the provision of speech and language therapy. Due to the lack of access to speech and language therapists in Wales, many children, who have been recognised as needing such provision to progress, are not able to access such support in a timely fashion.
42. Even when support is identified in the statement, in some cases, children are still not receiving this. This is particularly true of Speech and Language Therapy, due to the lack of accessibility to trained professionals in Wales
43. Our evidence would suggest that a statement does not automatically guarantee that the support identified will be provided by the LEA. Indeed, many parents end up having to police their LEA



in trying to obtain such support. This can take the form of anything from refusing to leave meetings until a LEA has agreed to provide the service required, or even threatening, and in some cases applying for judicial review against their LEA.

**Question 7- Is support for children and young people with special educational needs, but without a statement, appropriate and timely? (for example ‘school action’ and ‘school action plus’)- if possible, please give examples.**

44. In our experience, where support is being provided to a child by the school, parents knowledge of what support is being provided and what this means is patchy. In particular parents feel their children do not receive appropriate support quickly enough.
45. An example of this would be a parent in Bridgend, told us how the graded response system had not worked at all for her son, who is 7 years old and has a diagnosis of autism, **“I can’t say this worked at all for my son. It is a very reactive system and I think with autism they need to be proactive”**. Although, after a battle, her son is now in an autistic unit, although still without a statutory assessment, he is still not getting the communication support he needs. Instead the family are paying for a home based intervention, which has helped him in school. She confirmed that **“I have never had his educational needs assessed properly, so how can they be met?”**.
46. The only way to trigger the legal process is to request a statutory assessment, there is nothing in law to protect children with SEN supported through school action and school action plus, which can lead to problems for parents in obtaining additional support for their child.
47. Many schools are still unaware of what school action and school action plus means and what is required of them under the law and the Code of Practise guidance
48. Parents should be an important part of the decision making process about what additional support their child needs. Although school action and action plus are not protected by law, it should be good practise that a parent receives written confirmation of what support their child is receiving from school and what this means.
49. There is also no systematic monitoring of progress and accountability for children without statements at present. Such measures should be introduced to ensure that the progress of children with SEN, but without a statement is monitored.
50. It is also important to note that many children should be formally assessed much sooner. Often parents will have go to the LEA several times to request a formal assessment, before this is agreed. This is particularly relevant for children diagnosed with Asperger Syndrome, where their literacy and speech may be fairly well developed and often appear to ‘just be getting on in school, without the need for additional support’. Many of these children may have social and behavioural problems that would benefit from early intervention.
51. In the NAS’ Autism in Schools report, schools told us they had difficulty accessing funding for additional support because the child’s needs were not defined as ‘exceptional’

**Question 8- With regards to Statutory Assessment, can you give examples of good practise in joint working between local education and health authorities?**

52. The most recent Audit Commission report ‘SEN: A Mainstream issue’ states that ‘a lack of systematic monitoring by schools and LEA’s makes it difficult to recognise good practise- or to challenge poor practise’<sup>13</sup>. The NAS believe that it is imperative that where good practise is displayed it can be shared within and between LEA areas.

**Question 9- Is information and support for parents/ carers of children and young people currently undergoing statutory assessment readily available through the medium of welsh? – If possible please give examples of good practise**

53. Information and support for parents and carers through the medium of Welsh is patchy. The NAS does offer its ‘Advocacy for Education Service’ through the medium of Welsh via Language Line at present. This is partly due to cost implications and also issues around staff recruitment.

54. In respect of statutory agencies, it seems that most correspondence and contact occurs through the medium of English. In discussions with a first language welsh speaking parent in Gwynedd, we were told:

**“Although Gwynedd has a Welsh Language policy, in practise most of the contact is using English, information in welsh is just not available”**

*Parent in north Wales*

**Question 10- What improvement to the statutory assessment process would you like to see implemented as soon as possible?**

55. Better information provision to parents of children with SEN about how school action and school action plus works as well as the statutory assessment process. Such information should be made available to parents when their child has been identified as having SEN in school. This should also be readily available from LEA’s.

56. Time taken to make an assessment. One of the key characteristics of success set down in the SEN Code of Practise is that “assessments are timely”<sup>14</sup>. It is clear that a process that should take 26 weeks, let alone when this goes on longer than this (as in many cases) is neither of benefit to anyone involved, not least the child.

57. Reduction of cost implications to parents wishing to challenge the system (independent reports etc).

58. Timely and appropriate responses to the request to a formal assessment by parents

59. Better information sharing between schools and local educational authorities to parents of children on school plus and school action plus.

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<sup>13</sup> Audit Commission report quoted in Support for Children with Special Educational Needs: An Estyn Overview, October 2003

<sup>14</sup> SEN Code of Practise for Wales, 2002

60. All children with SEN, should have an Individual Education Plans, which parents and children are aware of and are reviewed three times per year.
61. The exact level of provision should be included in the statement. For example what support a child will receive, who is responsible for providing this support, how often the support will be and when. Flexible times should only be included when the child is in a special school e.g. accessing on different days depending on timetable (although even in such cases, the statement should at least state how many hours per week the support is for). The SEN Code of Practise clearly states that “statements of SEN are clear and detailed”<sup>15</sup> and case law exists that all statements should be ‘quantified and specified’, therefore NAS Cymru would like to see this provision more strictly adhered to by LEAs.
62. Greater recognition of social support needs within the assessment process. Examples of this would be the need to recognise the additional support some children may require at break times and lunch times. There is also a need to provide opportunities to learn social skills through circle time or buddying. When a statement is present and social support is identified as a need, this should be explicitly referred to.
63. Post 16- the statement can stay with the child post 16 as long as still in full time mainstream school education. But from 16-19 the LEA do not have to continue statementing. Greater support should be given to pupils leaving school post 16 with SEN. NAS Cymru hope that the Equality of Opportunity Committee’s recommendations around service provision for young disabled people will include such provision.
64. Greater work to be undertaken to ensure the views of the child are taken into account in the provision of support and finding a suitable placement, where the child will able to receive the support they need to develop educationally and socially and will provide them with the skills to live their lives as fully as possible. As Estyn note “common weaknesses in SEN services include a failure to consult users regularly”<sup>16</sup>.
65. Pupils should have support or training to help them participate in their Individual Education Plans.
66. LEA’s to provide up to date and digestible information about the statementing process and how to obtain independent advice and support from organisations such as the NAS, SNAP Cymru and IPSE.
67. The NAS also believes in the importance of better data collation on SEN to inform need and future policy direction and the planning and delivery of services in Wales. An example of this would be the lack of information regarding the prevalence of ASD in Wales and the levels of support required by children with ASD.
68. It is imperative that greater awareness raising and training around Autistic Spectrum Disorders is provided across the agencies in Wales. From health visitors to care workers, social workers, teachers and support staff, it is important to ensure that these professionals can not only act as

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<sup>15</sup> Special Educational Needs Code of Practise for Wales, 2002

<sup>16</sup> Estyn Annual Report 2003/2004

problem noticers, but also better identify and respond to the needs of children and young people with ASD

69. LEA staff to receive training in writing SEN statements, SEN law and the SEN process

70. Schools to be made more aware of their obligations under the law and what is expected of them through the SEN Code of Practise. In particular administration teams, who manage much of the paperwork around annual reviews for instance and contact with parents, need to understand the SEN process. They should at least have a basic awareness of the key documents involved and the schools obligations.

**The NAS believes that early intervention, partnership, raising expectations and removing barriers to learning, intended to ensure that all children with SEN get the support they need to reach their full potential are imperative. We look forward to the working with the National Assembly for Wales, as work on this policy review progresses.**

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