Submission to Green Paper: Children And Young People With Special Educational Needs And Disabilities - Call For Views

from the Joint Epilepsy Council (JEC)
Name: Sharon Wood
Organisation (if applicable): Joint Epilepsy Council
Address: Joint Epilepsy Council, PO Box 186, LEEDS, LS20 8WY
Please mark an X in the box below that best describes you as a respondent.

- [ ] Parent/Carer
- [ ] Child/Young Person
- [X] National Voluntary Organisation
- [ ] Children’s Service
- [ ] Local voluntary Organisation
- [ ] School/College
- [ ] Local Authority
- [ ] Headteacher/Teacher
- [ ] SENCO
- [ ] Governor
- [ ] Other (please specify)

Please Specify:
The Joint Epilepsy Council is an umbrella body comprised of 23 charitable and other organisation epilepsy groups.
Q1) Are the SEN and Disability statutory frameworks - including the SEN statementing process - helping children and young people to get what they need? If not, what changes could help?

Yes  X No  Not Sure

Comments:
In the case of children with epilepsy, the current system is not working well at all. There is a long history of children with epilepsy not realising their potential in mainstream schools. In the past, epilepsy was poorly understood but we now have the knowledge to support many of these children much more successfully and without major resource implications.

It is remarkable that the following extract from the key Warnock Report into special education of 1978 remains as valid today as it was at the time. The actions proposed by Warnock still need implementation.

“11.43 …. We consider that every effort should be made to inform staff in schools and colleges about the facts of epilepsy, how it may be controlled by drugs, what the side effects of these drugs may be and how to manage seizures should they occur, in order to create the right attitudes to children with epilepsy. Lack of full knowledge may cause a child’s activities to be unduly restricted and if the school does not know about the existence of the condition the child may run unnecessary risks. This is an instance where mutual confidence and understanding between parents, doctors and teachers is particularly important.

11.44 Even where satisfactory control of seizures by anticonvulsants is achieved, many children with epilepsy may have serious problems in concentration and behaviour, which affect their learning….Their particular difficulties are not always recognised by schools and colleges, and better arrangements for reviewing their progress are needed….if these children are to be helped to develop their potential to the full.”

A large part of the problem for children with epilepsy is the lack of recognition that epilepsy is a condition that may cause special educational needs. The Department views epilepsy as a purely medical condition, similar to asthma and diabetes. In the case of asthma and diabetes, as long as appropriate medication is used, there are few children who experience serious educational challenges as a result of that condition. This is not the case for epilepsy where there are substantial and known challenges experienced by the child. Not all children with epilepsy need a Statement or School Action/School Action Plus interventions but where they do, recognition that epilepsy is the cause of the SEN is needed otherwise intervention strategies tend to fail because they concentrate on the symptoms rather than the root cause.
Q2) How can we identify children's special educational needs earlier, and make sure that they get the support they need as quickly as possible?

Comments:
In the case of epilepsy, individual assessment of each child’s needs is required at an early stage. This will help enormously to overcome the problems.

The importance of school/teacher awareness: It is the experience of the NCYPE Champions for Childhood Epilepsy Campaign education pilot work that even in well run, successful and inclusive schools there is little appreciation of the impact that epilepsy and/or epilepsy medication can have on learning. Without this basic understanding it is difficult to know how teachers can ensure they adequately meet the needs of these students. A bright student with epilepsy may be performing at a reasonable level and therefore not come to the attention of the school SENCO yet that child may be significantly underachieving in relation to their individual potential.

Former Prince of Wales’s Chair of Childhood Epilepsy, Professor Brian Neville said in his ‘Code of Practice’ "children with epilepsy, should have their problems identified early and assessed where indicated and that any intervention should be prompt and carried out on a multi-agency basis. The only method of achieving better care is for teachers, medical and allied professionals and parents to work together."

Without question good regular communication between home, school and health is an essential element of good practice in meeting the educational needs of children with epilepsy.

Q3) How can we improve the processes for special educational needs and disability - in schools, in assessments, and across all services - so that professionals can spend more of their time with children and their families?

Comments:
The provision of a school nurse in secondary schools – as has been promised for Wales by Cheryl Gillan MP, Secretary of State for Wales - could make a lot of difference.

The introduction of a more standardised system for addressing special medical needs, as proposed by the GMB, might be a good starting point for ensuring that all schools take a responsible proactive approach to understanding the impact any medical condition and/or medication can have on learning.
Q4) How can we ensure all schools and colleges have high expectations for children and young people with special educational needs and disabilities, including their future potential and contribution to society?

Comments:
It is known that about half of the children with epilepsy are seriously underperforming in relation to their intellectual capacity. If the performance of all children with SEN were to be benchmarked against their intellectual capacity, we would have an easy tool to establish who was doing well and who needed further support. It would be obvious that schools who performed poorly against this measure had a problem.

The problem for children with epilepsy has been in translating our modern knowledge into practice in our schools. This could change with appropriate support from the Department. Training and information for education staff is readily available.

Apart from the benefits to the child, improved support will assist, in concert with the improvements required in NHS services, in driving down the high unemployment rate and consequent benefit dependency of people with epilepsy.

About 60,000 young people under 18 in the UK have epilepsy in the UK
Half of these children are estimated to be under-achieving academically in relation to their intellectual level
Approximately 40,000 children with epilepsy are in mainstream schools

Inappropriate ‘allowances’ made out of kindness for students with epilepsy may also be an issue. Children with epilepsy deserve to have their needs fully understood. For example, a reduced rate of educational progress could be due to a change in medication and/or seizure pattern and should therefore not be dismissed as ‘poor behaviour’ or excused as ‘doing his/her best’ without first understanding what is going on for that student so that appropriate strategies can be employed.

Q5) How can we improve the choices of schools and services available to parents and improve opportunities for them to be involved in decisions that affect their family?
Comments:
By ensuring that all schools and service providers recognise their responsibility to understand the needs of children with epilepsy (and other medical conditions) and that such provision will be subject to Ofsted inspection. Over one million children in mainstream education have a health condition. Schools and teachers will struggle to understand often complex educational needs additional to the medical management requirements for so many conditions. Epilepsy, however, is a particularly complex and varied condition and without a regulated system there is no measure of how well any given school fully understands and therefore meets needs. A regulated system would allow parents to make more informed judgements about the quality of provision.

Q6) How can we improve the transition from school to adult life for young people with special educational needs and disabilities and the support provided for their families throughout?

Comments:
For students with profound learning difficulties, developing ‘life skills’ may be the single most important aspect of their education. Yet such progress is not taken into account when assessing the value of an educational placement, only ‘academic’ progress counts. This particularly disadvantages young people with epilepsy post 16 (or post 19 if they have a statement) for whom further years of intensive education can make all the difference to the level of independent living they are able to achieve.

Q7) Ideas and examples of what's working well
We would like to include ideas and examples of what's working well. If you have an example we could include please respond setting out your response as detailed below.

Summary: 150 words

Ideas

- What is it? (brief description)
- Who is it for?
- How would it work?

Or;

Examples: 150 words
Where is it? The NCYPE, the Champions for Childhood Epilepsy Campaign education pilot worked with schools in Surrey and West Sussex.

What was done, by whom, how and when? In 2009/10 in collaboration with 21 participating schools, the campaign developed an effective, affordable and sustainable model of good practice that can be adopted by schools across the UK. Schools nominated a staff member to be their School Epilepsy Champion and receive a full day of training in epilepsy and education. They return to school to share their learning with colleagues and review current practice in line with the training and the campaign’s Education Action Plan. School policy is then amended/developed to reflect improved practice and sustain it in the longer term. The School Epilepsy Champion becomes a ‘resource’ for the whole school, raising awareness and maintaining close links with the NCYPE. They receiving up-dates, advise colleagues and can identify further training needs within the school. More detailed information about this work can be found in the NCYPE’s Education Pilot Report at: http://www.ncype.org.uk/dmdocuments/EpilepsyChampionsPilotReport.pdf

The NCYPE Champions for Childhood Epilepsy Campaign are currently developing distance learning materials to support campaign up-take.

What resources were required? The good practice model can be developed by any participating school at minimal cost – one full day of training (around £45)

How was the work funded? The campaign was funded by donors

A bit about you: 100 words

Tell us a little about yourself and your role

I joined the NCYPE to lead their Champions for Childhood Epilepsy Campaign. My background is in theatre nursing, school nursing, politics and campaigning. I have been a school governor for over 15 years.

As the NCYPE’s Campaign Coordinator I have worked in collaboration with 21 local schools on an education pilot to ‘test’ the campaign’s education action plan. A detailed report of that very successful work can be found at: http://www.ncype.org.uk/dmdocuments/EpilepsyChampionsPilotReport.pdf

I am currently preparing resources to support the national promotion of the campaign model to schools across the UK.

Permission to use:

Please confirm a contact name from whom permission has been granted to use the example in the Green Paper

Alison Cornell – Campaigns Coordinator, National Centre for Young People with Epilepsy
Q8) Please use this space for any other comments you would like to make.

Comments:

Q9) Please let us have your views on responding to this consultation (e.g. the number and type of questions, was it easy to find, understand, complete etc.)

Comments:
Thank you for taking the time to let us have your views. We do not intend to acknowledge individual responses unless you place an ‘X’ in the box below.

**Please acknowledge this reply X**

Here at the Department for Education we carry out our research on many different topics and consultations. As your views are valuable to us, would it be alright if we were to contact you again from time to time either for research or to send through consultation documents?

<table>
<thead>
<tr>
<th>X Yes</th>
<th>No</th>
</tr>
</thead>
</table>

All DfE public consultations are required to conform to the following criteria within the Government Code of Practice on Consultation:

**Criterion 1:** Formal consultation should take place at a stage when there is scope to influence the policy outcome.

**Criterion 2:** Consultations should normally last for at least 12 weeks with consideration given to longer timescales where feasible and sensible.

**Criterion 3:** Consultation documents should be clear about the consultation process, what is being proposed, the scope to influence and the expected costs and benefits of the proposals.

**Criterion 4:** Consultation exercises should be designed to be accessible to, and clearly targeted at, those people the exercise is intended to reach.

**Criterion 5:** Keeping the burden of consultation to a minimum is essential if consultations are to be effective and if consultees’ buy-in to the process is to be obtained.

**Criterion 6:** Consultation responses should be analysed carefully and clear feedback should be provided to participants following the consultation.

**Criterion 7:** Officials running consultations should seek guidance in how to run an effective consultation exercise and share what they have learned from the experience.

If you have any comments on how DfE consultations are conducted, please contact Donna Harrison, DfE Consultation Co-ordinator, tel: 01928 794304 / email: donna.harrison@education.gsi.gov.uk

**Thank you for taking time to respond to this consultation.**

Completed questionnaires and other responses should be sent to the address shown below by 15 October 2010

Send by post to:

SEN and Disability Frameworks Team
Special Educational Needs and Disability Division
Department for Education
Sanctuary Buildings
Great Smith Street
London
SW1P 3BT
Send by e-mail to: send.callforviews@education.gsi.gov.uk