

Legislative proposals for additional learning needs

Consultation response form

Your name: Caroline Brocklehurst

Organisation (if applicable): Teenage Cancer Trust

e-mail/telephone number:

c.brocklehurst@teenagecancertrust.org

020 7612 0724

Your address:

Teenage Cancer Trust

3rd Floor

93 Newman Street

London

W1T 3EZ

Responses should be returned by **25 July 2014** to:

Additional Needs Branch
Support for Learners Division
Department for Education and Skills
Welsh Government
Cathays Park
Cardiff
CF10 3NQ

or completed electronically and sent to:

e-mail: SENReforms@wales.gsi.gov.uk

Question 1 – New terminology

- a) Do you agree that a new term, 'additional learning needs', (ALN) should focus on children and young people who need additional and/or different support with learning to allow them to benefit as fully as possible from the education or training available to them?

Agree	<input checked="" type="checkbox"/>	Disagree	<input type="checkbox"/>	Neither agree nor disagree	<input type="checkbox"/>
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Supporting comments

We welcome the move by the Welsh Government to adopt a new term of

Additional Learning Needs (ALN) in these legislative proposals. This provides an opportunity to review the scope of provision for children and young people in Wales who may require additional support during their time in education up to the age of 25.

It will be important for a clear definition of ALN to be set out which includes children and young people with disabilities, including young people with cancer. Guidance must be provided for children and young people, their families and education professionals on how disabled young people will be included and impacted by the proposed change.

Cancer is a specifically defined disability under the Equality Act 2010, and its treatments and late effects can have a huge impact on a young person's experience of education. However, many young people with cancer, their families and their schools are not aware of their protected status, or its implications on their entitlement to support, and consequently are not accessing the support they need. This is why it's important any new definition clearly includes and explains how disability fits into ALN. Furthermore, the explanation of the additional and/or different support that will be available for those identified as having ALN should also be clear in its application to young people with disabilities such as cancer.

Clarification will also be needed on how provision for those with ALN will interact with other pieces of legislation, including the Welsh Government's guidance on children with medical needs. It will be important to provide details on how young people with medical conditions, such as cancer, will be included and evaluated with the new terminology. The legislation must also reference the medical needs guidance, which is not currently mentioned in the White Paper.

The Scottish Government, in the Education (Additional Support for Learning) (Scotland) Act 2004, replaced the term Special Education Needs (SEN) with Additional Support Needs. At the same time, the definition was also expanded to enable the provision of extra support to include a broader range of children and young people, including those who care for disabled siblings, those being bullied, or those with a disability or health need for example.

We note that the Welsh Government's 2012 consultation paper¹ on proposals to reform SEN put forward the concept of Additional Needs. It also listed a range of young people who may fall within this, including pupils with a disability and pupils with medical needs. We would strongly suggest that when adopting the new term of ALN, the Welsh Government use this opportunity to expand the scope of support outside of the current SEN boundaries and thresholds, and to use a definition more in line with previous Welsh proposals or similar to those used in Scotland.

¹ Welsh Government (2012), *Consultation Document: Forward in partnership for children and young people with additional needs*: <http://wales.gov.uk/docs/dcells/consultation/120710senconsultationen.pdf>

The Department for Education in England has recently revised its SEN provision to create a new Code of Practice for Special Educational Needs and Disabilities (SEND). The Code and accompanying legislation applies from 0-25 years old and set out to incorporate both those children and young people currently classed as having SEN, and those young people identified as having LDD. The explicit inclusion of 'disability' within the new SEND terminology in England will help disabled children and young people to recognise that the guidance and provision might apply to them. We would therefore suggest that the Welsh Government consider this approach, and ensure that the relevance of new legislation for young people with disabilities, including cancer, is made clear whatever terminology is chosen.

- b) Do you agree that the new system should apply to children and young people from birth up to the age of 25? If so, what implications should we consider for the professionals involved in assessing and providing that support?

Agree	<input checked="" type="checkbox"/>	Disagree	<input type="checkbox"/>	Neither agree nor disagree	<input type="checkbox"/>
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Supporting comments

We welcome the plans to extend the new system to all children and young people up to the age of 25. Young people with cancer may have to retake school years, defer entry to university, or may wish to change their subject choices as a result of their illness. As a result, they may still be in secondary and further education beyond the mandatory leaving age of 16 and 18, and should not be at greater risk of missing out on provision than their younger peers.

Question 2 – Individual development plans (IDP)

- a) Do you agree that all children and young people with ALN should be entitled to an IDP which sets out their agreed additional learning provision?

Agree	<input checked="" type="checkbox"/>	Disagree	<input type="checkbox"/>	Neither agree nor disagree	<input type="checkbox"/>
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- b) Do you agree that IDPs should replace statutory assessment and statements of SEN, assessments for learners over 16 (under section 140 of the Learning and Skills Act 2000) and non-statutory plans including individual education plans under School Action and School Action Plus?

Agree	<input checked="" type="checkbox"/>	Disagree	<input type="checkbox"/>	Neither agree nor disagree	<input type="checkbox"/>
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Supporting comments

We welcome the plans to extend IDPs to all children and young people with ALN. Currently significant numbers of young people with cancer who have additional needs, yet do not meet the threshold for a SEN statement, are outside of the scope of the additional support available in Wales. Providing IDPs to all children and young people with ALN may address this, and as noted in our response to Question 1a we strongly recommend that disability is explicitly included and referenced within the definition of ALN.

It will also be important to have a holistic approach to what is included as 'agreed additional learning provision'. For example, we would advocate including provision of psychosocial support and recognising the impact of medical conditions and disabilities on the wellbeing of young people.

Furthermore, it's vital that future legislation makes clear the link between IDPs and Health Care Plans for young people with medical conditions, or that HCPs are integrated into IDPs.

- c) Do you agree that local authorities should be ultimately responsible for preparing an IDP for children and young people aged 0–25 with ALN and for ensuring that agreed provision set out in the IDP is delivered and reviewed?

Agree	<input checked="" type="checkbox"/>	Disagree	<input type="checkbox"/>	Neither agree nor disagree	<input type="checkbox"/>
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Supporting comments

We welcome the call for one body, such as local authorities, to be ultimately responsible for ensuring that all stakeholders meet their responsibilities for young people with ALN. Young people with cancer are likely to receive some form of educational support from a wide variety of health professionals which can be confusing, and so a central coordinating role would be a positive step. However, it is critically important that this role is clearly defined to ensure it is successful in practice, and that the lines of accountability between local authorities and other bodies are clear and transparent.

Question 3 – A new code of practice

- a) Do you agree that a new code of practice on ALN should include mandatory requirements in accordance with which local authorities, schools, further education institutions, local health boards and the tribunal must act?

Agree	<input checked="" type="checkbox"/>	Disagree	<input type="checkbox"/>	Neither agree nor disagree	<input type="checkbox"/>
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Supporting comments

The new code of practice should include mandatory minimum requirements for all bodies that will play a role in supporting children and young people with additional needs. This should include timelines for putting support in place.

These requirements should be reviewed and monitored regularly, in order to ensure a national standard is adhered to, and data should be collected and published on all aspects of the new system. A process for addressing inequitable services must be laid out, and this must be accessible to young people and their families.

The code could also include case studies of best practice which reflect the range of children and young people who will be included within its scope, such as young people with cancer. We would be very happy to provide guidance and case studies relating to effective provision and support for teenagers and young adults with cancer.

- b) Do you agree that the code of practice should set out guidance for any other bodies, such as third sector organisations or other providers of education and training?

Agree	<input checked="" type="checkbox"/>	Disagree	<input type="checkbox"/>	Neither agree nor disagree	<input type="checkbox"/>
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Question 4 – Securing provision

Do you agree that further education institutions should be included alongside schools, maintained nurseries and pupil referral units, as institutions that must use their ‘best endeavours’ to secure the additional learning provision called for in an IDP?

Agree	<input type="checkbox"/>	Disagree	<input type="checkbox"/>	Neither agree nor disagree	<input type="checkbox"/>
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Supporting comments

Question 5 – Securing specialist provision for young people

Do you agree that local authorities should be responsible for securing specialist education provision for post-16 learners outside of the further education sector where the IDP indicates that this is necessary to meet a young person’s ALN?

Agree	<input type="checkbox"/>	Disagree	<input type="checkbox"/>	Neither agree nor disagree	<input type="checkbox"/>
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Supporting comments

Question 6 – Placement at independent schools

Do you agree that local authorities should be prohibited from placing a child or young person at an independent school which has not been registered to provide the type of additional learning provision identified in their IDP?

Agree	<input type="checkbox"/>	Disagree	<input type="checkbox"/>	Neither agree nor disagree	<input type="checkbox"/>
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Supporting comments

Question 7 – A multi-agency approach to planning and delivery

- a) Do you agree that local authorities, local health boards and further education institutions should be required to cooperate and share information in assessing, planning and delivering support to meet ALN?

Agree	<input type="checkbox"/>	Disagree	<input type="checkbox"/>	Neither agree nor disagree	<input type="checkbox"/>
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Supporting comments

- b) As well as using the code of practice to provide guidance, are there any other ways in which you think multi-agency partnership working could be strengthened?

Supporting comments

Question 8 – Supporting looked after children

Do you agree that IDPs should be able to replace or function as personal education plans for children and young people who are looked after by a local authority?

Agree	<input type="checkbox"/>	Disagree	<input type="checkbox"/>	Neither agree nor disagree	<input type="checkbox"/>
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Supporting comments

Question 9 – Resolving disputes at an early stage

- a) Do you agree that local authorities should be required to put in place disagreement resolution arrangements?

Agree	<input type="checkbox"/>	Disagree	<input type="checkbox"/>	Neither agree nor disagree	<input type="checkbox"/>
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Supporting comments

- b) Do you agree that there should be a requirement to use the appropriate local complaints processes prior to appeal to tribunal?

Agree	<input type="checkbox"/>	Disagree	<input type="checkbox"/>	Neither agree nor disagree	<input type="checkbox"/>
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Supporting comments

Question 10 – Extending the right of appeal

Do you agree with our proposals in relation to extending rights of appeal to tribunal (see proposals 19, 20 and 21)?

Agree	<input type="checkbox"/>	Disagree	<input type="checkbox"/>	Neither agree nor disagree	<input type="checkbox"/>
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Supporting comments

Question 11

We have asked a number of specific questions. If you have any related issues which we have not specifically addressed, please use this space to report them.

Introduction to Teenage Cancer Trust

Teenage Cancer Trust is the only UK charity dedicated to improving the quality of life and outcomes for young people with cancer. We fund and build specialist units in NHS hospitals and provide dedicated staff, bringing young people together so they can be treated by teenage cancer experts in the best place for them.

Cancer is the most common cause of non-accidental death in young people, and five-year survival rates remain lower in teenagers than in children². Through our own research and working with our partners in the NHS, across the UK governments, and organisations both nationally and internationally, we strive to improve outcomes for young people.

Our Education and Advocacy team deliver a pioneering education programme throughout the UK. The programme is delivered in schools, colleges and universities for free, and aims to remove the stigma of cancer and demystify the disease by including discussions on the signs and symptoms of cancer, its treatment, healthy living and the emotional support issues surrounding the disease.

Overarching comment

Teenage Cancer Trust have been supporting and advocating for young people with cancer for over 20 years, and, as world leaders in the field of teenage and young adult cancer care, we welcome the opportunity to comment on this consultation.

We applaud the Welsh Government for reviewing their provision and support for young people with additional needs, as cancer, its treatments and late effects can have a huge impact on a young person's experience of education. We particularly support moves towards an approach for all young people aged 0-25, and plans to offer ICPs to all young people with ALN. However, we feel that it will be important for future legislation to include clear definitions and accessible explanations of which children and young people will or will not fall

² Cancer Research UK (2013), *Cancer Stats Report: Teenage and young adult cancer*

under the remit of ALN. It will also be vital to lay out clear lines of accountability for the different bodies who may be involved in providing or coordinating this support.

Around 2,500 young people are diagnosed with cancer each year across the UK. In Wales approximately 114 new patients will be diagnosed annually, while around the same number again will continue to receive care for cancer or relapse³.

Young people have told us how the impact of cancer on their education is a concern for themselves and their family, and how retaining the normality of education as much as possible becomes a priority, often from the point of diagnosis⁴⁵.

Cancer is a specifically defined disability under the Equality Act 2010, yet we know that many young people, their families and their schools are not aware of this status, or its implications on their entitlement to support, and many young people with cancer are not currently accessing the SEND support they need. Despite this, their cancer, its treatments and late effects can have a huge impact on a young person's experience of education.

Treatment for cancer may involve young people being absent from education for significant periods of time, and attendance can continue to be irregular up to 3 years after diagnosis⁶. Some young people with cancer will return to school or further education while continuing with treatment, while others may complete their treatment and return to school once in remission. For these young people their need for additional support in education does not end once they have completed their treatment. For example, for young people returning to school following cancer treatment on-going cognitive effects can include a reduction in memory, information retention and organisational ability. Physical consequences might include amputation and chronic, on-going fatigue. While some of these effects are immediately visible to teachers and other pupils, others, such as fatigue, are less visible or less well known, and all are likely to require additional support long after treatment for cancer may have concluded.

80% of teenagers and young adults with cancer now survive for five years or more, and so the numbers seeking to return to or remain in education are only set to increase⁷. It is therefore vital that young people with cancer in Wales

³ Cancer Research UK (2013), *Cancer Stats Report: Teenage and young adult cancer*

⁴ Teenage Cancer Trust (2012), *Young Voices Report*

⁵ Decker et al, Information needs of adolescents with cancer, *Journal of Paediatric Oncology Nursing* (2004) 21, 6 327-334.

⁶ Pini et al, What effect does a cancer diagnosis have on the educational engagement and school life of teenagers? A systematic review, *Psycho-Oncology* (2012) 21, 7 685-694

⁷ Cancer Research UK (2013), *Cancer Stats Report: Teenage and young adult cancer*

have access to appropriate support within education for their additional needs at the time of their diagnosis, during their treatment, and post-treatment.

Responses to consultations may be made public, on the internet or in a report. If you would prefer your response to remain anonymous, please tick here: