

Response ID ANON-EXGA-GCWH-E

Submitted to SEND Review: Right support, right place, right time
Submitted on 2022-07-22 17:28:16

Introduction

Who is this for?

Instructions

About you

a) Welcome - what is your name?

Name:
James Cooper

b) Would you like to provide your email address?

Email:
james.cooper@togetherforshortlives.org.uk

c) Are you happy for the Department for Education to use your email address to contact you to clarify points in your response, if necessary?

Yes

d) Would you like us to keep your responses confidential?

No

Reason for confidentiality:

e) Can we publish your response?

Yes, publish my response

f) Which of the following best describes the capacity in which you are responding to this consultation?

On behalf of a charity/ voluntary or community organisation

If Other, please give details:

g) What is your role within your organisation?

What is your role within your organisation:
Head of Public Affairs and Policy

Not Answered

h) What is the name of your organisation?

Organisation Name:
Together for Short Lives

Not Answered

Chapter 2: A single national SEND and alternative provision system

1 What key factors should be considered, when developing national standards to ensure they deliver improved outcomes and experiences for children and young people with SEND and their families? This includes how this applies across education, health and care in a 0-25 system.

Q1:

Together for Short Lives is a UK-wide children's palliative care charity. We are keen to make sure that the SEND system in England brings about a joined-up approach to assessments, plans and services for all disabled children and young people. This includes children and young people with life-limiting and life-threatening conditions, some of whom will have a complex needs across education, health and social care.

Together for Short Lives is a steering group member of the Disabled Children's Partnership (DCP) and we support its response. We are also a member of

the Complex Needs Coalition, a grouping of 14 charities, representing children with complex disabilities, including deafblindness, multi-sensory impairment (MSI), and life-threatening and life-limiting conditions. Many of these charities represent children and young people with rare conditions or rare syndromes.

The Children and Families Act, the associated regulations and the Code of Practice provide a national framework for assessing and meeting needs, including individually-owed duties and rights of appeal. The first and overriding consideration must be to ensure that any national standards do not undermine existing statutory rights and protections. Any standards should, therefore, focus on system level support, such as: expectations for the levels of service provided in local offers; what should be ordinarily available in:

- Schools
- support from social care
- community health services.

While we welcome the concept of national standards, the green paper does not explain how they would interact with the current legislative framework. There are a number of areas where we call on the government go further:

- For standards to be effective, services need to be equitably and sustainably funded and resourced. Many of the challenges children and families are currently facing are due to under resourcing rather than the framework which the Children and Families Act and other legislation provides.
- The government should clarify how commissioners and providers are accountable for meeting the standards; there is a relatively robust legal framework of rights, but we do not feel that the system is held to account for meeting them.
- For low incidence groups, high cost groups such as children and young people with complex disabilities, the government should make sure that standards are met consistently across England. There is currently too much unwarranted local variation.
- For many, the ability to access to education and attain academic qualifications will be an important outcome. But these may be just two of many outcomes that the system should help them to achieve. The SEND system should ultimately aim to ensure that disabled children and young people can lives as fulfilling lives as possible; these outcomes will be unique to individual children and young people, and may include the ability to make and maintain relationships, take part in leisure activities and to live independently.

2 How should we develop the proposal for new local SEND partnerships to oversee the effective development of local inclusion plans whilst avoiding placing unnecessary burdens or duplicating current partnerships?

Q10:

Whilst we see potential benefits in new local SEND partnerships and local inclusion plans, the government needs to clearly set out how that will sit with existing statutory bodies such as Health and Wellbeing Boards and integrated care systems, to avoid them simply adding bureaucracy and to provide clear accountabilities.

We ask the government to take action to:

- make sure that the partnerships do not duplicate functions of other, exiting bodies or partnerships
- consult with a wide range of stakeholders, including parents, to understand what is missing from current partnerships and structures in order for these to be developed
- clarify who will sit on these partnerships and what their role and authority will be
- make sure that partnerships represent disabled children and young people and their families, including those with complex needs
- clarify the scope and purpose of inclusion plans, including how they relate to local offers
- make sure that local inclusion plans include the full breadth of services and support children may need, including palliative care;
- make sure that inclusion applies across both mainstream and specialist settings.

3 What factors would enable local authorities to successfully commission provision for low-incidence high-cost need, and further education, across local authority boundaries?

Q3:

We call on the government to make sure that local authorities, the NHS and education providers work at regional and sub-regional levels with statutory and voluntary sector providers (for example, through integrated care systems and NHS strategic clinical networks for Children and Young People) to create the economies of scale to commission and provide low-incidence, high cost services. We call on the government to take a joined-up approach by making sure that relevant NHS England specialised commissioning specifications correlate with national SEND standards to support this approach. We ask the government and the National SEND Delivery Board to:

- provide service specifications for these services and hold regions and systems to account for implementing them

- make sure that commissioners and providers have the resources to implement them; this should include action to increase the number of professionals with the skills and experience needed to care for and support children and young people with complex disabilities
- make sure that regions and systems have access to robust prevalence data which enables them to understand the demand for these services
- make sure that families understand why sub-regional or regional commissioning is taking place and communicate what this means for them
- make sure that children, young people and families can exercise choice and control and receive services as close to their homes as possible.

4 What components of the EHCP should we consider reviewing or amending as we move to a standardised and digitised version?

Q4:

We welcome the proposal to standardise EHCPs; there is currently too much unwarranted variation in the content of these plans. We ask the government to:

- introduce a simplified and shorter format of the EHCP
- make sure education, health and social care providers provide timely information to inform EHCPs – and are provided with the resources to do so
- make sure the standardised template is co-produced with families and professionals from education, health and social care, the voluntary sector and other key stakeholders.
- make sure EHCPs must consider the child holistically and not simply their educational needs.
- Make sure EHCPs are able to articulate the needs of disabled children, including those with complex and/or low incidence needs.

5 How can parents and local authorities most effectively work together to produce a tailored list of placements that is appropriate for their child, and gives parents confidence in the EHCP process?

Q5:

We do not agree with this proposal.

A better assessment of population need should lead to improved commissioning of provision and therefore enable local authorities to provide more accurate advice to parents on suitable placements. However, there should be no change to the current position where parents can request a placement of their choice.

We are concerned that the list would allow local authorities to limit parental choice and reduce cost at the expense of meeting the needs of children, particularly those with complex needs. This is of particular concern with current SEND support struggling to meet need. We agree that parents need information and advice on options available, but the needs of the child must be the priority, not the capacity of provision.

It is crucial that this list is akin to a guide or starting point of what is available locally, not the entirety of placement choice. These lists could usefully set out where there are gaps in support in local areas

6 To what extent do you agree or disagree with our overall approach to strengthen redress, including through national standards and mandatory mediation?

Strongly disagree

Q15:

It is vital that redress is strengthened, but we do not agree with the principle of mandatory mediation. Mediation should be about dispute resolution, not redress. The proposal to make mediation mandatory introduces an additional barrier before parents or young people can achieve redress at the tribunal. In addition, on a practical level, we are doubtful that there would be sufficient capacity in the system to deliver mediation in all cases.

We are even more concerned about the suggestion that the government might introduce an independent review mechanism, especially if this is the same panel as had an earlier role in the decision-making process. We feel that the tribunal is already an existing independent review mechanism that can make the binding legal judgements required to overturn previous local authority decisions. We see no reason to put in additional quasi-judicial stages.

7 Do you consider the current remedies available to the SEND Tribunal for disabled children who have been discriminated against by schools effective in putting children and young people's education back on track? Please give a reason for your answer with examples, if possible.

Q16:

We are concerned that there is too little understanding of the tribunal's role in this respect, nor sufficient options for redress that that tribunal can impose.

Chapter 3: Excellent provision from early years to adulthood

8 What steps should be taken to strengthen early years practice with regard to conducting the two-year-old progress check and integration with the Healthy Child Programme review?

Q8:

OFSTED and the Care Quality Commission (CQC) have found in their programme of local area SEND reviews that difficulties in securing input from relevant specialists has hampered its effectiveness. This has meant that important opportunities for effective early intervention for children with SEND have been lost. We call on the government to provide local areas with the resources to carry out the two-year-old check as an integrated review with input from relevant specialists. Ministers should also hold them to account for doing so.

9 To what extent do you agree or disagree that we should introduce a new mandatory SENCo NPQ to replace the NASENCo?

Agree

Q18:

We are concerned that the green paper focusses is too heavily on SENCOs. There needs to be more on training for all education professionals if the government's vision for SEND is to be realised. The green paper appears to move away from the emphasis in the current code of practice on "all teachers being teachers of SEND" with the onus being placed heavily on the SENDCo alone.

10 To what extent do you agree or disagree that we should strengthen the mandatory SENCo training requirement by requiring that headteachers must be satisfied that the SENCo is in the process of obtaining the relevant qualification when taking on the role?

Strongly agree

Q19:

11 To what extent do you agree or disagree that both specialist and mixed MATs should be allowed to coexist in the fully trust-led future? This would allow current local authority maintained special schools and alternative provision settings to join either type of MAT.

Neither agree nor disagree

Q20:

12 What more can be done by employers, providers and government to ensure that those young people with SEND can access, participate in and be supported to achieve an apprenticeship, including through access routes like Traineeships?

Q12:

Chapter 4: A reformed and integrated role for alternative provision

13 To what extent do you agree or disagree that this new vision for alternative provision will result in improved outcomes for children and young people?

Neither agree nor disagree

Q22:

14 What needs to be in place in order to distribute existing funding more effectively to alternative provision schools, to ensure they have the financial stability required to deliver our vision for more early intervention and re-integration?

Q14:

15 To what extent do you agree or disagree that introducing a bespoke alternative provision performance framework, based on these 5 outcomes, will improve the quality of alternative provision?

Neither agree nor disagree

Q24:

16 To what extent do you agree or disagree that a statutory framework for pupil movements will improve oversight and transparency of placements into and out of alternative provision?

Neither agree nor disagree

Q25:

Chapter 5: System roles, accountabilities and funding reform

17 What are the key metrics we should capture and use to measure local and national performance? Please explain why you have selected these.

Q17:

We are concerned that the drafting in the green paper suggests a heavy focus on financial control, rather than the impact on children and families' lives. We call on the government to measure the extent to which:

- the outcomes specified in children and young people's EHCPs are met
- system partners, including the NHS, local authorities and education providers, meet their legal requirements, including deadlines for providing information for assessments, completing assessments and drafting plans
- children and young people receive the support they are assessed as needing in a timely manner
- children, young people and parents are satisfied with the way that the system is operating.

18 How can we best develop a national framework for funding bands and tariffs to achieve our objectives and mitigate unintended consequences and risks?

Q27:

We do not support this proposal. We feel it is possible to set national funding bands in a way that is responsive to individual needs and compliant with the legal framework.

Chapter 6: Delivering change for children and families

19 How can the National SEND Delivery Board work most effectively with local partnerships to ensure the proposals are implemented successfully?

Q19:

We ask the board to work with the government to take the actions we set out in our response to questions three and four.

20 What will make the biggest difference to successful implementation of these proposals? What do you see as the barriers to and enablers of success?

Q20:

Education, health and social care services are funded inequitably and unsustainably. There are also too few education, health and care professionals with the skills and experience to assess needs, plan and deliver the services that disabled children and young people need. If these barriers are not overcome, the government will not be able to achieve the SEND vision to which it aspires.

21 What support do local systems and delivery partners need to successfully transition and deliver the new national system?

Q30:

- National specifications for SEND services.
- To be held to account for implementing them.
- To be given the resources to implement them; this should include action to increase the number of professionals with the skills and experience needed to care for and support children and young people with complex disabilities
- Access to robust prevalence data which enables them to understand the demand for these services.

22 Is there anything else you would like to say about the proposals in the green paper?

Q22:

The success of the SEND reforms should be judged on whether they lead to a more joined up system of assessments, plans and services for children with the most complex needs and their families across education, health and care. As vital as educational attainment and routes to employment are, the ultimate test of the SEND system should be whether it helps disabled children and young people lead as fulfilled lives as possible and achieve the outcomes that are important to them.

We welcome ministers' decision to publish the long-overdue SEND review and their ambition for a more clear, consistent and better quality SEND system. They acknowledge the way in which the current SEND system is failing, including for families of children and young people with complex life-limiting and life-threatening conditions. The maze of education, health and care services they need to navigate further reduces the precious, limited time that they have with their children.

The existing law related to disabled children and their families stems from over 10 different Acts of Parliament, regulations and guidance which have developed over the past 50 years. It is difficult for parents to navigate; and it leads to different services and agencies shifting responsibility between themselves, and with families falling between the gaps.

At both national and local level, responsibility for the support that disabled children need – including those with life-limiting conditions – sits with a range of organisations. All too often, the needs of disabled children and their families are not the priority within those services; and no-one sees it as their responsibility to ensure that services join-up and meet the needs of families.

We call on the government to:

- set out a vision for what an integrated system is for all disabled children, not just those with a special educational need; this should include making sure all seriously ill children in England have the right to an integrated assessment, plan and personal budget
- commission a review of health and social care law, to simplify and strengthen rights and entitlements for disabled children and their families, including seriously ill children
- work with parents to clarify existing legal rights and entitlements
- make disabled children a priority across government, at both national and local level.

One of the areas that we are concerned has been overlooked in the green paper is transition. For disabled children with complex needs there a number of key transition points including early years to primary school, primary to secondary and then transition from school to adult life.

We do not feel that sufficient consideration has been given to the transition from primary to secondary education. Many children with complex needs access mainstream support for their primary education before moving to specialist provision for secondary onwards. Many children transition to mainstream secondary settings before needing to move to specialist provision due to the support not being available.

While the SEND system should apply to the age of 25, we are concerned that this is not the reality. Many children have their EHCPs removed once they complete A-levels or similar qualifications. This creates a significant cliff edge of support, with many young people then unable to transition successfully to higher education.

Enquiries