

SEND response questions

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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.

(Please refer to Chapter 2, paragraphs 4-6 for further details).

(up to 250 words)

Individual needs must be met in line with current legislation. Children with severe learning disabilities often have multiple complex needs that span several diagnostic criteria and therefore would span multiple standards. New national standards must avoid a one size fits all approach within diagnostic categories. Watering down children's rights to have their individual needs met by introducing national standards would be unacceptable.

Children who display behaviours that challenge are more likely to be excluded and experience a range of poor outcomes.

In our 2022 report, '*Investing in early intervention*', we recommend that if national standards are introduced, they include early support for parents and frontline workers with behaviour, communication, sensory processing, and skills building. These are pivotal skills that contribute to all later developmental outcomes. These skills, if not developed early on, increase the risk of later problems for children with learning disabilities (including challenging behaviour and mental health difficulties).

Multiple family carers we consulted considered the problems they encountered in the SEND system as downstream of inadequate assessment. We therefore urge that, in line with [NICE guidelines](#) on prevention and intervention in behaviours that challenge, the national standards include a guarantee of multidisciplinary EHC assessments, to provide a holistic view on behaviours that challenge.

Additionally, standards should outline how parents are informed of their rights. Co-produced EHCP guidance should be provided for families on the new EHCP template. The process for mediation, and where to go to attain support through this process should also be covered in the standards.

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?

(Please refer to Chapter 2: paragraphs 6-12 for further details).

(up to 250 words)

In order to deliver the transformation required system change must be co-produced with children, young people and parents with lived experience.

New local SEND partnerships should include parents with lived experience of learning disabilities alongside relevant professionals from across health, education and social care and ensure that the views of children and young people inform their work.

The new SEND partnerships should work closely with the local Integrated Care Board to ensure efficient use of resources and avoid duplication.

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

(Please refer to chapter 2: paragraph 10 for further details).

(up to 250 words)

Family carers we consulted described a lack of cross-boundary collaboration among local authorities, which hindered the provision of effective support to young people and their families.

Provision for low-incidence high-cost needs should focus on pooling expertise across local authority boundaries and making this available to children in their local area rather than focussing on new residential schools serving multiple local authorities. The use of such services denies children with SEND the right to a family life.

Low-incidence high-cost needs can be met locally. Service models such as the Intensive Therapeutic and Short Breaks Service in Ealing have proven to be effective and demonstrate good value for money. The service brings together an MDT led by clinical psychology and short breaks services. The introduction of this service significantly reduced the number of children placed in out of area residential schools at high cost. Children showed a significant reduction in challenging behaviour and the annual cost of intensive support and follow-up for 7 young people was circa £110,000 – less than the average cost of just one residential placement. This service was originally developed as a pilot project utilising time limited Aiming Him funding. Additional funding will be required to enable commissioners to invest in new service models.

A model of regional services such as [Autism and Intellectual Disability Intensive Intervention Team \(AID-ITT\)](#) to support children and young people with the most complex needs working across boundaries would support children to remain in the community and avoid unnecessary inpatient admissions.

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

(Please refer to chapter 2 paragraphs 15 - 23 for further details).

(up to 250 words)

EHCPs should involve assessments of behaviour for all children with learning disabilities whose behaviour challenges (in line with NICE guidance), rather than relying merely on diagnostic categories. There is currently wide variation in assessing and recording behaviours that challenge and the services and support required in order to achieve good outcomes.

A family carer in our focus group detailed the inaccessibility of speech and language therapists/occupational therapists for short breaks within the home. The EHCP template should assess the needs of children in the home environment as well as at school and ask to specify when services need to be made available at home or short breaks to provide a 24 hour curriculum for children who need holistic joined up support.

Bespoke solutions for supporting children and young people with complex needs are often needed, not all children fit into existing provision. There is resistance in the system to engaging in creative options that require flexible funding and co-production and do not neatly map onto EHC plans.

After participating in a digital EHCP trial, one family carer concluded they may be helpful if all stakeholders can make amendments in one place, rather than emailing back and forth and making individual phone calls. However, reasonable adjustments must be made under the Equality Act 2010 for parents who have a disability themselves. Adjustments should also be made for parents who face digital exclusion due to lack of access to technology, internet or do not have a good level of IT skills.

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?

(Please refer to chapter 2: paragraphs 24-28 for further details).

(up to 250 words)

We oppose the introduction of a tailored list of placements. Rather than give parents confidence in the EHCP process, we feel this will fetter parental choice and further reduce confidence in the SEND system.

Family carers in our focus group reported receiving inappropriate informal school recommendations from local authorities (LAs), raising concern about the proposal for a tailored list. For example, one family carer said their caseworker suggested a mainstream placement for their non-verbal son because 'he looked like he might talk'. Family carers linked inappropriate recommendations from LAs with a desire to limit more expensive specialist school placements, particularly when budgets are already overstretched.

Better LA funding to invest in local schools for those with SEND was seen as an important step in ensuring a tailored list does not exclude appropriate schools for budgetary reasons.

Another concern related to judgements about complex needs. For example, the combination of severe learning disability with other conditions, e.g., autism, epilepsy, post-traumatic stress disorder and sensory processing disorder, creates a complicated set of needs that are not easily interpreted to produce an 'appropriate' list of schools. LA's should work in partnership with families to find or create bespoke solutions.

Another family carer was concerned that choosing from a tailored list would designate their choice as 'parental preference,' making them ineligible for school transport assistance from the LA. Since tailored lists would reflect judgements about need, parents should not lose their entitlement to school transport on the basis that their choice constitutes preference beyond need.

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

(Please refer to chapter 2 paragraphs 29-32 for further details).

Strongly agree Agree Neither agree nor disagree Disagree **Strongly disagree**

If you selected disagree or strongly disagree, please tell us why, specifying the components you disagree with and alternatives or exceptions, particularly to mandatory mediation.

(up to 250 words)

Family carers in our focus group agreed that mandatory mediation could be additional barrier: "***You don't try to fix the system by creating more barriers for us" (family carer)***

The current system is reflective of one in which local authorities often attempt to avoid meeting their legal obligations to disabled children necessitating challenge. Mandatory mediation could merely postpone inevitable tribunal action as it will draw in cases in which parents and local authority are diametrically opposed and mediation is unlikely to succeed. Parents highlighted that delays can cause significant harm to children. Concern was expressed when disputes centre on seeking appropriate provision for a child who has been excluded from school due to challenging behaviour associated with their severe learning disability. Further delays within the system would leave children without education at a crucial time in their development, contribute to social exclusion and place them and their family at risk of harm.

Whilst opposed to mandatory mediation, our focus group did describe ways to improve it. Mediation is sometimes experienced as an unhelpful 'tick-box exercise' with national helplines that lack local knowledge. Family carers suggested that national standards should stipulate a manager from the relevant service must meet with parents before they are put in contact with the national mediation line to try resolving the situation informally. Additionally, local authorities should allocate sufficient budget to fund organisations that can provide support during mediation.

Reasonable adjustments must be made under the Equality Act 2010 for parents who have a disability themselves.

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.

(Please refer to chapter 2: paragraphs 33-34 for further details).

(up to 250 words)

No. Far too many children with learning disabilities are excluded from school due to reasons related to challenging behaviour that arises due to the child's disability and unmet needs. Currently there is a lack of understanding at Tribunals about the assessment and support that children with learning disabilities can be provided with to avoid disability discrimination and provide an equal opportunity to access education in the future.

There is a lack of investment in skilled local services and an over-reliance on out of area residential school placements and inpatient beds. Without investment in these services disability discrimination will continue.

Our 2022 report, 'Investing in early intervention' identifies 1,360 children with learning disabilities and autism in residential schools and 190 placed in inpatient units.

In a 2019 report, '*The detention of young people with learning disabilities and/or autism inpatient settings for children with learning disabilities and autism*', the Joint Committee on Human Rights recognised that inpatient detention is often inappropriate and causes suffering and does long term damage.

The number of children with learning disabilities and autism being placed in residential schools (often a long way from their family) and in inpatient units therefore indicates that current remedies available to the SEND Tribunal are insufficient for providing the necessary local support to put disabled children back on track.

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?

(Please refer to chapter 3: paragraphs 3-5 for further details)

(up to 250 words)

Inequalities in outcomes for children with learning disabilities emerge very early in child development. For example, children with learning disabilities are more likely to have behavioural and emotional problems from a very young age. The Foundation for People with Learning Disabilities explains that 36% of children and adolescents with learning disabilities have a diagnosable psychiatric disorder, compared with 8% of those without a learning disability.

The two-year-old progress check should seek to improve the identification of children with developmental delay and behavioural and emotional problems, to ensure that families receive timely targeted early intervention. Our 2022 report, '*Investing in early intervention*', provides a set of case studies on effective early intervention in action. This includes Early Positive Approaches to Support (E-PAtS). Commissioners should invest in support such as E-PAtS so that health visitors have tailored support to refer families to.

Such support is not currently available. A UK study of over 600 families found that less than 30% of families in the UK who have a child with a learning disability had access to targeted early intervention support in the preceding 12 months.

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

(please refer to chapter 3: paragraphs 21-24)

Strongly agree **Agree** Neither agree nor disagree Disagree Strongly disagree

If you selected disagree or strongly disagree, please tell us why.

(up to 250 words)

Family carers in our focus group emphasised the need for a high standard of recruitment and evidence-backed training for caseworkers in addition to SENCos. This enables better communication between stakeholders and appropriate planning and provision to meet the needs of children with learning disabilities and behaviours that challenge. The introduction of a mandatory SENCo NPQ is welcome. The new NPQ should include information on functional assessment of behaviour and positive behaviour support (PBS).

The PBS approach is vital for developing an understanding of challenging behaviour based on an assessment of the social and physical environment and broader context within which it occurs. The framework incorporates stakeholder perspectives and uses these insights to develop, implement and evaluate the effectiveness of a personalised and enduring system of support. The PBS approach therefore significantly enhances the quality-of-life outcomes for the focal person as well as other stakeholders, making it a crucial part of training for Special Educational Needs Co-ordinators.

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?

(please refer to chapter 3: paragraphs 21-24 for further details).

Strongly agree **Agree** Neither agree nor disagree Disagree Strongly disagree

If you selected disagree or strongly disagree, please tell us why.

We believe that headteachers should be required to check that a SENCo is in the process of obtaining the relevant qualification before appointing them to the role, as this will help to ensure that those co-ordinating SEND provision have a suitable level of training to effectively communicate with stakeholders including parents and to help in planning appropriate support for students with SEND. This will be particularly important if our recommendation is followed that a new mandatory SENCo NPQ includes thorough training and assessment on

Positive Behavioural Support, which is a crucial approach for understanding and responding to challenging behaviour.

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?

(please refer to chapter 3: paragraphs 44 – 51 for further details).

(up to 250 words)

Providers should be commissioned that can support young people with severe learning disabilities to achieve apprenticeships.

We led a pilot project called the Sustainable Hub of Innovative Employment for People with Complex Needs (SHIEC) which was successful in supporting people with complex needs to gain employment. Approaches such as job carving – breaking jobs down into smaller tasks as a way of finding elements of the job that are compatible with the person's abilities could equally be applied to apprenticeships.

Providers can work with individuals and their parents to develop vocational profiles. These profiles build an understanding of what skills the individual has and the support that would be needed for them to carry out a role, e.g., hand-over-hand support or how best to communicate with them.

It is also important to provide training on how employers can support individuals with complex needs into work as well as offering information for family carers on how to support people with learning disabilities into work.

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?

(please refer to chapter 4: paragraphs 8 - 11 for further details).

Strongly agree Agree Neither agree nor disagree **Disagree** Strongly disagree

If you selected disagree or strongly disagree, please tell us why.

(up to 250 words)

Improved outcomes for children and young people with severe learning disabilities and behaviour that challenges will only be achieved when there is sufficient investment in short breaks services, CAMHS-LD and intensive support teams and in skilling up the education workforce to better understand the causes of challenging behaviour and Positive Behaviour Support.

There is insufficient expertise within the alternative provision sector in understanding and responding to challenging behaviour. Children's social care is underfunded leading to significant delays and barriers to accessing short breaks causing a detrimental impact on parents mental health.

Without investment in community services and support and joined up working across the system children with learning disabilities and their families will continue to be failed.

Investment is needed to support families taking a whole family approach to supporting the family.

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?

(please refer to chapter 4: paragraphs 12 – 15 for further details)

Strongly agree Agree Neither agree nor disagree **Disagree** Strongly disagree

If you selected disagree or strongly disagree, please tell us why.

(up to 250 words)

We believe that there are additional outcomes that should be included in the performance framework for bespoke alternative provision. Firstly, improving child wellbeing should be included to encourage practices that can advance the holistic development of children with SEND, which go beyond their educational success.

Secondly, reducing behaviours that challenge should be incorporated into the framework given the link to poor outcomes and exclusions. In our report, '[Paving the Way](#)', Professor Eric Emerson of Lancaster University explains that "there is strong evidence that some of the key factors causing challenging behaviour can be changed, and when changed can lead to marked reductions in challenging behaviour". Improving wellbeing and reducing challenging behaviour should be an integral outcome of bespoke alternative provision.

Finally, supporting children to remain educated in the local area, with or close to their family, is an important outcome. We know that school placements that are distant from home can cause further socio-emotional difficulties for children with learning disabilities and behaviours that challenge, as well as difficulties maintaining contact with family (particularly for those children who are non-verbal and communicate with augmentative communication). Providing local forms of support and provision should therefore be a key priority in bespoke alternative provision.

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.

(please refer to chapter 5: paragraph 14 – 20 for further details).

(up to 250 words)

We believe the following data metrics should be captured::

- o High-quality, standardised data on restrictive practices in schools - A 2021 report by the EHRC, '[Restraint in schools inquiry](#)', found that school data collection on restrictive practices is inconsistent and they recommend national standards for recording/reporting.
- o School exclusion data
- o Tracking the availability of community team e.g. CAMHS, CAMHS-LD, Intensive Support teams etc, as well as how many are fulfilling the targets set out in the NHS Long Term Plan for 24-hour, seven-day access.
- o children and young people with learning disabilities and or autism placed in inpatient units (Building the Right Support)
- o Children and adults with LDs/autism at risk of inpatient care (DSR data)
- o No of children placed in residential school/college placements and their distance from family home
- o Access to short breaks for families of disabled children
- o Access to early help (reconfigured as Family Help) for families of disabled children
- o % young people with learning disabilities (aged 14+) who've had an annual health check
- o Early years - take-up of entitlements by young children with SEND; especially take-up of extended entitlement (which is even lower).

Key points to bear in mind:

1. Include locally-determined indicators - co-produced to reflect local priorities - as well as a core set of nationally-prescribed ones.
2. Ensure metrics include early years, post-16 and post-19 measures
3. Explore variation in access to services & outcomes for children and young people from Black, Asian and ethnic minority communities

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

(please refer to chapter 5: paragraph 27- 32 for further details).

(up to 250 words)

Family carers in our focus group expressed concern that funding bands and tariffs would impose rigid thresholds that fail to account for the complexity of need and was a worrying move away from a personalised child-centred approach. Speaking of their son, one participant said, '*I know he won't fall into a box.*' Our family carers worry that bands and tariffs might leave their children in a funding category that harmfully limits their entitlement to resources. Some risks were described as downstream from inadequate assessment. One family carer explained that it is difficult to receive an assessment that understands the complexity of his needs. When assessments already face these challenges in capturing

presentations, the imposition of a banding system further inhibits the process of directing necessary resources to meet complex needs.

Participants also described a mismatch between what the local authority caseworker thought of their child's needs and what they were seeing themselves. Family carers in the focus group sought independent assessments from educational psychologists that they felt better captured these needs in order to secure the provision their child needed. A key concern was that the people conducting assessments were the same people whose budgets would be affected by the level of that need and the reports were not sufficiently detailed/specific regarding the child's needs or provision required.

Family carers lacked confidence about the fundamental premise of bands and tariffs, but also believed that the perverse incentives and inadequacies of assessment would need to be addressed to mitigate the risks.

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?

(please refer to chapter 6: paragraph 6 – 7 for further details).

(up to 250 words)

Children and young people with SEND and parents must be key stakeholders in the SEND delivery board.

It is vital that the National SEND Delivery Board establishes clear lines of accountability and metrics so that outcomes are effectively monitored by the .

The board would also have a key role to play in monitoring that local partnerships are effectively 'joined-up' and do not attempt to shift responsibility for provision and funding assessments. Too often, disputes over who funds provision between agencies stalls needed actions for children with SEND, leaving them without adequate support or excluded from education altogether.

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?

(please refer to chapter 6: paragraphs 8 – 14 for further details).

(up to 250 words)

In our focus group with family carers, one barrier identified for the successful implementation of proposals was the inflexibility of local authority funding. This prevents creative use of funding to produce tailored solutions for families with children with learning disabilities. A lack of willingness to co-produce solutions with parents and a lack of collaboration across local authority boundaries as well as between Health, Education and Social Care further

inhibits effective planning and provision. The group advocated greater use of pooled budgets to encourage collaboration across systems to provide holistic, coherent support. When appropriate working in partnership with parents to find bespoke CYP and family centred solutions such as EOTAS would enable all children to achieve good outcomes.

Another barrier identified for successful reform was insufficient staff training, which was described as turning caseworkers into administrators, unable to think beyond their box-ticking procedures to deliver truly person-centred planning. The focus group emphasised that there is insufficient funding for the SEND system, leading to organisational strain as schools and alternative placements lack the necessary resources and staff to achieve successful outcomes. This environment was said to create perverse incentives, as overstretched local authorities and services seek to remove themselves from fulfilling costly obligations or those that might depress outcome measures. Pursuing these incentives can leave children and young people with learning disabilities without adequate support and push families into legal battles, whilst the real experiences of students are obscured by providers manipulating service environments, access, and outputs to obtain positive outcome ratings.

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

(please refer to chapter 6: paragraphs 8 – 14 for further details).

(up to 250 words)

Local systems and delivery partners will need be given support to help them understand what good practice looks like for children and young people with learning disabilities whose behaviour challenges, as well as how to commission such provision, and what constitutes adequate transitional funding across systems partners. The Challenging Behaviour Foundation has put together a collection of resources for commissioners working with children with learning disabilities whose behaviour challenges available [here](#)

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

(up to 250 words)

We are disappointed by the inadequate coverage of social care in the SEND Review. The Independent Review of Social Care paid insufficient attention to issues facing disabled children and their families, whilst stating that it would pay due regard to the SEND Review to consider the 'main questions' for these groups. The gap in addressing this vital issue must be addressed as neither review has sufficiently addressed social care for children with SEND.

One social care issue raised by a family carer in our focus group related to the exclusive ability of organisations to take advantage of the Health and Care Worker visa. They felt that this visa programme should also be accessible for family carers looking to recruit a personal assistant, for example, to help support their child at home.

We know that national and local social care policies in England create a default position for those assessing disabled children that assumes parental failings. As a result, families are subjected to humiliating and intimidating inspections of their house and lone interviews of

each family member. A separate pathway for disabled children is urgently needed in national guidance to avoid this policy of parent blame.