

Questions for Children and Young People

Question 7: In the future, what do you think is the best way to ask children and young people what they think about our plans for children's social care?

At The Challenging Behaviour Foundation (CBF) we support children and young people with severe learning disabilities and behaviour that challenge, as well as their families. The children we represent often have communication difficulties, and many are nonverbal and are unable to read and write, therefore their views cannot be gathered through an online consultation. But their views on social care are just as important. The Challenging Behaviour Foundation has demonstrated it is possible to gather the perspectives of people with severe or profound and multiple learning disabilities in multiple projects.

Our *Stop Look and Listen* project worked with the Tizard Centre to develop new and creative ways to improve how we listen to these individuals and support them to make choices and indicate preferences. Children were able to indicate what they enjoyed and did not enjoy and who or what supported them to do the things they enjoyed. Family carers, advocates and staff who knew the children well were key to successful engagement with the children.

Other projects including a report for the Office of the Dental Commissioner and for NHSE (Seldom Heard) have demonstrated that it is possible to consult young people with severe or profound and multiple disabilities on strategic issues.

The *Stop Look and Listen* report is available here: <https://www.challengingbehaviour.org.uk/what-we-do/projects-and-research/valuing-individuals-and-their-families/seldom-heard/>

NHSE has the Seldom Heard report, and the report for the Office of the Dental Commissioner.

There are many other examples of good practice in engaging the views of people with complex communication challenges, such as:

- Doukas et al (2017). *Supporting people with profound and multiple learning disabilities: core and essential service standards*. Available at: <http://www.pmlmlink.org.uk/wp-content/uploads/2017/11/Standards-PMLD-h-web.pdf>
- Mencap and BILD's 'Involve me' project: <https://www.mencap.org.uk/advice-and-support/profound-and-multiple-learning-disabilities-pmld/pmld-involve-me>
- Mansell, J. (2010). *Raising our sights: services for adults with profound intellectual and multiple disabilities*. Tizard Learning Disability Review. Available at: <https://www.pmlmlink.org.uk/wp-content/uploads/2020/09/Raising-our-sights.pdf>
- Goldbart, J., & Caton, S. (2010). *Communication and people with the most complex needs: What works and why this is essential*. Available at: https://e-space.mmu.ac.uk/198309/1/Mencap%20Comms_guide_dec_10.pdf

Chapter 1 - Our vision & making reform work for everyone

Question 1: Overall, to what extent do you agree these six pillars are the right ones on which to base our reforms for children’s social care?

Agree

If desired, please briefly explain your answer

The CBF believe that the pillars of reform identified are focused on the important issues, but that the actions and commitments within the pillars may fail to deliver the changes needed for children with learning disabilities.

Pillar 1 of ‘Family Help’ describes “the right support at the right time”. For children with learning disabilities who display behaviour seen as challenging and their families, it is vital that the ‘right time’ is as early as possible, not just at crisis point when consideration is being given to a residential placement. It is widely evidenced that early intervention improves the wellbeing of young people and their families and is most effective at earlier ages, as advised in the SEND Code of Practice and NICE guidelines. Yet, access to these services is poor, with recent research finding 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 (Sapiets et al. 2022). Local areas lack sufficient funding to make early intervention for children with learning disability a reality. Dame Christine Lenehan, Director of the Council for Disabled Children describes how “Local authorities’ cupboards are bare so they often wait until families are at breaking point before intervening”. Ringfenced funding should be allocated to a programme of family help tailored for families of children with learning disabilities, which includes investing in and building on family carer knowledge and skills, including around behaviour. Without dedicated funding and investment in early intervention we will continue to see the unnecessary institutionalisation of children with learning disabilities in social care placements when they could have been cared for by loving families at a lower cost to the state.

For further information see article by Dame Christine Lenehan, Council for Disabled Children:
<https://www.thetimes.co.uk/article/the-way-we-care-for-disabled-children-is-a-betrayal-vnlj3k2ft>

See Recommendation 5.4 in the *SEND Code of Practice: 0 to 25 years*:
<https://www.gov.uk/government/publications/send-code-of-practice-0-to-25>

See Recommendation 1.4.2 in the *NICE Guideline Learning disabilities and behaviour that challenges: service design and delivery*: <https://www.nice.org.uk/guidance/ng93>

The ‘right support’ for children with learning disabilities must include services that are specialised to their needs. Universal forms of support and early intervention often do not provide an understanding of the needs of children with learning disabilities including the causes of challenging behaviour and Positive Behaviour Support principles. This was a key finding of the CBF’s local area work on the Getting It Right Project; parents said they found generic parenting courses unhelpful for supporting the needs of a child with a learning disability including delayed communication, sleep problems and challenging behaviour.

On the other hand, specialised services, for instance, evidence-based parenting programmes like Early Positive Approaches to Support (E-PATs) or Positive Behaviour Support training give parents the tools and knowledge they need and improve the wellbeing of parents and carers.

For Pillar 1 of reform to work for everyone, it must pay particular attention to the needs of disabled children. This is supported in recent recommendations issued by the Panel in phase 2 of the national review into Hesley Group homes which highlight the need to build on 'what works' from research evidence and local best practice to meet the particular needs of children with learning disabilities and complex needs. The report describes that "Current provision at the local level is often patchy and in residential settings is incredibly varied and expensive. We need the certainty of a range of provision from early intervention through to specialist residential care that will address the needs of children with disabilities and complex health needs in the right place at the right time. There is no 'one' package that meets the individual needs of every child with disabilities and complex health needs" (p.5, Child Safeguarding Practice Review Panel, 2023). It forms a major recommendation that improvements to the quality and range of provision available in the community and schools must be a priority for the government's pathfinder programmes in children's social care and SEND (p.29, Child Safeguarding Practice Review Panel, 2023).

Work to join up funding and strategy within Family Help must include supporting children with disabilities and their families to access support across the multiple systems of health, education and social care. It must not be assumed that learning disabled children's needs are 'covered' by forthcoming SEND and Alternative Provision Improvement Plan, rather social care reform must be made to work in conjunction with it.

Pillar 2 outlines a new Child Protection Lead Practitioner role, which will have a strong understanding of different forms of abuse and neglect. We support this focus, and recommend that this role must include specialist expertise in issues of child protection specific to disabled children. For instance, the risks associated with living in residential homes at great distances from their family, such as closed cultures and organisational abuse. They should also have training in policies and guidance around restrictive practices. The development of national training standards around the use of force could ensure a sufficient level of understanding for this. These are amongst many other issues highlighted in phase 1 report into the Hesley Group residential homes (Child Safeguarding Practice Review Panel, 2022).

Many children with severe learning disabilities and complex needs in care live in residential homes far away from their families. To achieve Pillar 4 and prioritise loving relationships for this group, individuals and families must be supported to enable communication and involvement. The Challenging Behaviour Foundation's *Keeping in Touch with Home* report outlines good practice examples and a checklist for settings, as recommended in the phase 2 report of the national review into Hesley Group settings.

The *Keeping in Touch with Home* report is available here:

<https://www.challengingbehaviour.org.uk/information-and-guidance/early-intervention/>

Work towards Pillar 6, to make better use of evidence and data, must specifically address the learning from the Child Safeguarding Practice Review Panel about how best to safeguard children with disabilities in residential settings. Their recent reports describe massive failings in quality and regulatory oversight and recommend a "major overhaul" to the quality standards of all settings where children are living away from home (Child Safeguarding Practice Review Panel, 2023). This work is necessary to address the 'closed cultures' which enable disabled children to be vulnerable to abuse and harm when placed at large distances from family.

Question 2: What more can be done by government, local authorities and service providers to make sure that disabled children and young people can access the right types of help and support?

Early intervention for children with learning disabilities and behaviour that challenges should be easily accessible in all areas of the country and as early as possible to equip families with specialist knowledge and prevent them reaching crisis point. Local authorities should invest in evidence-based early intervention provision such as Early Positive Approaches to Support (E-PAtS), focusing on strategic implementation and monitoring outcomes. The *Investing in Early Intervention* report highlights that the benefits of early intervention are recognised and embedded in policies, yet targeted early intervention support is not available to the majority of families. Recent research 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 (Sapiets et al. 2022). The report details best practice case studies which demonstrate that intervening early has the potential to change the trajectory of development and decrease the inequality in outcomes between children with learning disabilities and their peers. It also demonstrates large savings that can be made by local authorities when intervening to avoid costly 52-week residential placements and inpatient admissions. The importance of early intervention is supported by the findings of the national review of Hesley residential settings; the children and young people were known to services from an early age, and so early intensive support to meet their needs could have been provided (p.18 and p.64, Child Safeguarding Practice Review Panel, 2022).

The *Investing in Early Intervention* report is available here: <https://cerebra.org.uk/wp-content/uploads/2022/05/EARLY-INTERVENTION-REPORT-A4-FINAL.pdf>

Good community crisis support is another key intervention to prevent placement breakdown and avoid inpatient admission. NHS England made a Long-Term Plan commitment to have a 24/7 intensive or crisis support team in every area (the deadline for this plan is now less than a year away) yet have not provided any updates regarding the progress of this goal (NHS England, 2019). The development of this community support should be monitored and reported to enable accountability and transparency. A current research study by the University of Warwick is mapping community behaviour support services available for families of children with learning disabilities. This type of service has the potential to provide early information and support to children as behaviour problems emerge, but such support and services are not universally available. Delivery of early support and of these NHSE commitments is vital to improving the accessibility of support and the wellbeing of disabled children and their families in the long-term.

The MELD research study: <https://warwick.ac.uk/fac/soc/cedar/meldstudy/projectfindings/>

In contrast to the policy aim families of disabled children report that they are experiencing extremely long waiting times to access services across health, education and social care. The recent *Failed and Forgotten* report by the Council for Disabled Children found that 1 in 5 disabled children and their families are experiencing delays with more than 10 health services. They report the detrimental effects this is having on the child with unmet needs (for 7 in 10 their health has deteriorated and they are more anxious due to the lack of support available) as well as their parents (87% reporting an impact on their mental health) and siblings (69% experiencing anxiety and 67% experiencing isolation). In addition, more than half of disabled children that require support or advice for self-harming, self-injurious or high-risk behaviour reported waiting more than a year to access a service. Such levels of delay are not just a risk to a disabled child's quality of life, but a risk to life. In order to ensure children and families can access

the right type of support, these waiting times must be reduced. More investment is required in services and the training and retention of skilled professionals in order to address these issues.

The *Failed and Forgotten* report is available here: <https://disabledchildrenspartnership.org.uk/our-campaigns/failedandforgotten-read-our-new-report/>

Recent research has shown that the burden of seeking out support can add to the distress and trauma that family carers already face when navigating social care systems (Baker et al., 2021). This is also recognised as 'Challenge 2' in the green paper *SEND Review: Right support Right place Right time* (2022). It found that navigating local authorities and service providers can be bureaucratic and adversarial, rather than collaborative. Changes, including policy reform, must ensure all points of support that engage with families are empathetic and trauma-informed.

It must be a priority to address the current *Working Together to Safeguard Children* guidance which channels parents and carers of children with learning disabilities down a child protection pathway even if there are no child protection concerns.

Research has shown that many families who approach social service agencies for support in caring for their disabled child are inappropriately assessed on child protection pathways, or have safeguarding concerns raised (Clements & Aiello, 2021). The independent review which informed this strategy describes families of disabled children experiencing 'one size fits all' assessments which are intrusive and not tailored enough to the needs of families (The independent review of children's social care, 2022). The effect is an institutional culture of 'parent blame'. Local authorities should have a distinct assessment pathway to support parents and carers who have a disabled child, separate from assessments for child protection (unless there is evidence the child is at risk). This will improve parents experience of engaging with services, enhancing wellbeing and encourage parents to seek support when it is beneficial to the child and family unit.

To ensure that disabled children and young people can access the right types of help and support, local authorities and services must value the expertise of family members when making decisions about a child's care. The lived experience of family carers means they know their child best, including how best to meet their needs. Key messages from family carers about how best to support their children with learning disabilities and behaviours that challenge can be seen in the graphic 'A Vision for our Children', as featured in the Phase 2 report on Hesley Group residential homes. It is recommended in guidance as best practice to involve and collaborate with families or carers in all discussions and decision making (including in *SEND code of practice: 0 to 25 years*, *SEND Review: Right support Right place Right time*, *Mansell Report 2007*, *NICE Guideline Looked-after children and young people*). Yet, many parents have reported to the CBF's family helpline that this is not the case in reality. Going forward, reform must be co-produced and informed with the views of children and family carers at the centre.

The CBF graphic 'A Vision for our Children' can be found here: <https://www.challengingbehaviour.org.uk/what-we-do/strategic-influencing/early-intervention/>

The CBF welcomes the strengthening of National Minimum Standards for residential care. However, this action should be accompanied by high priority work to provide community support to prevent children leaving their homes in the community, and to help them return after a stay at a residential setting. This

should include an emphasis on bespoke and creative commissioning to create care packages that can meet complex needs. The demand for this work is demonstrated by the thematic review of the safe and wellbeing reviews (NHS England, 2023) which found 41% of people in inpatient settings could have had their needs met in the community, and the most common reason was lack of suitable accommodation. The lack of local supported living options and resistance to bespoke, personalised solutions is a huge barrier which increases the vulnerability of children. This is evidenced by the findings of the phase 1 report into the Hesley Group homes which found some children could have had their needs met in the community, yet children were placed a mean of 95.16 miles from their home authority (Child Safeguarding Practice Review Panel, 2022). NICE guidance promotes a 'whole life' approach to service design and recommends that when exploring residential placements lead commissioners must include practitioners with clinical expertise in learning disability and any specific challenging behaviours. This would address the issue that many families who contact the CBF helpline describe - that commissioners look to find somewhere to "put" their child, rather than having the skills to commission local packages of support tailored to individual need.

See NICE Guideline *Learning disabilities and behaviour that challenges: service design and delivery*: <https://www.nice.org.uk/guidance/ng93>

Another key finding of the Child Safeguarding Practice Review Panel's phase 2 report is that children's views and feelings were not routinely sought, with few having access to an independent advocate. They recommend that *"all children with disabilities and complex health needs in residential settings should have access to independently commissioned, non-instructed advocacy from advocates with specialist training to actively safeguard the children and respond to their communication and other needs"* (Child Safeguarding Practice Review Panel, 2023). Independent advocacy is also important to support disabled children undergoing section 47 enquiries. Disabled children with behaviour disorders and speech and language difficulties are at the greatest risk of abuse, yet the most vulnerable are less likely to receive an advocacy service (Miller and Brown, 2014). In addition, disabled children face a reluctance to be believed, minimisation of the impact of abuse and mistakes attributing indicators of abuse to a child's impairment (Miller and Brown, 2014). The increased provision of specialist independent advocacy should be one of a full range of measures undertaken to enable children to express their views, wishes and feelings (a statutory right under Section 7 of the Children's Homes (England) Regulations 2015).

Chapter 2 - Family Help

Question 1: To what extent are you supportive of the proposal for a system that brings together targeted early help and child in need, into a single, Family Help Service in local areas?

Fully supportive

If desired, please briefly explain your answer

The CBF are fully supportive of the proposal as long as each area provides specific support for families of disabled children. This includes specialised support for children with severe learning disabilities and challenging behaviour. This view is shared by the findings of the Independent Review of Children's Social Care 2022 that "whilst disabled children will benefit from the overall improvements to Family Help [...]"

their needs can also differ from other children supported by social care and so require specific consideration” (p.59).

Question 2: Looking at the features of early help listed below, in your opinion or experience, what are the top 3 features that make it a supportive service for families?

1. The service is designed together with the input of children and families
2. Being able to access the right type of support
3. Strong relationship with one key worker/lead individual for every family

Chapter 5 – The Care Experience

Question 1: Overall, to what extent do you agree that the 6 key missions the right ones to address the challenges in the system?

Agree

If desired, please briefly explain your answer

The CBF agree strongly with Mission 2’s focus on the right homes being available locally. It is a nationwide issue for children with severe learning disabilities that there are very few placements which can meet their needs, let alone placed local to their family and community. We would welcome a particular focus on disabled children placed in residential homes at great distances from their family and local authority. However, this focus should not overshadow or replace efforts to meet children and young people’s needs in their family homes before a residential setting is considered.

The CBF strongly agree with the need to ensure a strong and skilled workforce in children’s homes. This is a particular issue for disabled children and especially children with severe learning disabilities and challenging behaviour. The *Failed and Forgotten* report found that a third of parents said that their child did not receive support at their settings from staff who were fully trained to understand and adapt provision accordingly. In addition, 70% of families experienced a delay in the provision of personal assistants due to the current workforce issues regarding availability of staff. Similarly, the *CQC State of Care in England 2021-2022* report describes a shortage of learning disability nurses. As a result, the workforce census and in-depth cases studies should have a strong focus on the deficit in workers who support learning disabled children.

Additionally, strategies must recognise the need to develop a ‘culturally intelligent’ workforce. Phase 2 of the national review into Hesley Group settings found that the staff supporting children with a learning disability failed to respect or affirm their cultural background, marginalising the needs of these children (Safeguarding Children Practice Review Panel, 2023). Staff training and provision must better meet the needs of Black and minoritised children with disabilities, recognising and affirming their cultural identities and keeping them well connected to their local communities. This is particularly important given the ethnic disproportionality of children with SEND.

Question 5: Do you have any additional suggestions on improving planning, commissioning and boosting the available number of places to live for children in care?

The CBF strongly support the focus on improving the way that children’s residential homes are matched, built, and run. For the group of children with severe learning disabilities and challenging behaviour, living close to home, with specialist care, and with sufficient and expertly trained workforce are the most important areas in need of improvement.

The risks of institutionalisation and organisational abuse are higher in large-group homes where personalisation and individualized care are more difficult to maintain. The development of new placements and stable homes should focus on smaller-scale localised solutions which can be personalised to meet a child’s needs. This is embedded in commissioning guidance: *Building the right home* (NHS England Transforming Care Programme, 2016) states “housing with occupancy of six or more people can quickly become institutionalised. New campus sites should not be created” (p.12). *The service model for commissioners of health and social care services* (NHS England, 2015) states “Commissioners should co-produce local housing solutions leading to security of tenure, that enable people to live as independently as possible, rather than in institutionalised settings” (p.19).

Yet, this non statutory guidance is disregarded and the commissioning of children and young people in large residential schools, inpatient units and group homes continues..

Under current guidance, young people with learning disabilities in a residential school placement are given 28-day notice periods to leave a service. Our experience supporting families has shown that residential homes have issued a 28-day notice period when challenging behaviour increases or a relationship with family members has broken down. This leaves families in a very difficult position to find alternative provision in a very short time, and are faced with inadequate options such as an inpatient unit or an unregulated placement. The contracts should be reformed to mandate longer notice periods and additional support and input to allow a suitable alternative to be located and a supportive transition plan put in place.

Instances of ‘revenge evictions’ are not unique to CBF’s helpline, but have been reported in adult social care here: https://www.theguardian.com/society/2023/apr/22/care-homes-in-england-using-revenge-evictions-to-stifle-complaints-from-residents?CMP=share_btn_link

And documented in research: Emmer De Albuquerque Green, C., & Manthorpe, J. (2023). ‘Angry, relieved, forever traumatised’: A report into the experiences of families of care home residents who were served a ‘notice to quit’. NIHR Policy Research Unit in Health and Social Care Workforce, The Policy Institute, King's College London. <https://doi.org/10.18742/pub01-113>

The CBF helpline has heard that this is an issue affecting children and young people with learning disabilities in residential school placements. The current regulations that permit 'revenge evictions' should be reviewed to better protect children in care.

Chapter 7: System Enablers

Question 1: Beyond the proposals set out in this chapter, what would help ensure we have a children’s social care system that continues to share and apply best practice, so that it learns from and improves itself?

The CBF supports the focus on better use of evidence and data, including funding for local authorities based on an up-to-date assessment of needs and resources. But we have concerns that the *Failed and Forgotten* report by the Disabled Children’s Partnership shows that reliable and up-to-date data is often not available. The findings suggest that many local authorities are failing to meet the legal requirement from Section 2 of the Children’s Act 1989 to “open and maintain a register of disabled children within their area”. If this is the case, many local authorities do not have an accurate picture of the needs of the children and families in their area. They will then be unable to fulfil recommendation 3.28 of the *SEND code of practice: 0 to 25 years* with states “To inform commissioning decisions, partners should draw on the wide range of local data sets”, including the register of disabled children. Without this data, local authorities will not be able to effectively assess whether they are providing the right types of help and support. Low-incidence needs such as those of children with severe learning disabilities and complex needs are particularly difficult to plan for from national data sets. There must be additional incentives or accountability for local authorities to proactively maintain this register. The availability of specialist services is already described as a ‘postcode lottery’, this must be addressed with robust data collection and analysis.

The *Failed and Forgotten* report is available here: <https://disabledchildrenspartnership.org.uk/our-campaigns/failedandforgotten-read-our-new-report/>

The Children’s Social Care Dashboard should agree key datasets for learning disabled children, then track and monitor them. It is particularly important to monitor factors that increase the vulnerability of disabled children such as distance from their family or local authority, whether their needs can be met in the community, and the availability of placements locally and nationally. This data will also enable monitoring and accountability of the NHS Long Term Plan to reduce inpatient provision to less than half of 2015 levels by 2024.

One current gap in available data is a complete lack of national data collection on the availability of crisis support. Without monitoring the availability of local services, it will be very difficult to have accountability for, let alone achieve, the NHS England made a Long-Term Plan commitment to have a 24/7 intensive or crisis support team in every area.

Another gap recognised in Phase 2 of the national review is “data and intelligence to support the analysis of the distinct needs of specific groups of children, including on the basis of ethnicity and gender” (p.54, Child Safeguarding Practice Review Panel, 2023). If this data was collected, it would enable better practice in commissioning and matching of children for residential placements and care staff who can best support their needs.

The CBF welcome engagement with practitioners, leaders and those with lived experience to hear their feedback on reform. Participation from stakeholders (especially individuals who use services) is most effective when it is present from the beginning of development and has limited impact if it is gathered in the final stages of development. Co-production processes should be used to involve the views of key people with lived experience from the initial stages of development, to use their expertise from navigating education, health and social care systems.

Important learning about the wellbeing and financial benefits of investing in early intervention are often overlooked. Research has shown that this kind of support early on can prevent breakdown in placements and admission to inpatient hospitals so that people with learning disabilities can live a more fulfilling life in their community close to their families. In addition, *Investing in Early Intervention* makes the economic case. A financial review of the iPBS in Bristol calculated that over four years it produced savings of £1.8 million. And Ealing Intensive Therapeutic and Short Breaks Service (ITSBS) found that even when accounting for additional costs of children remaining locally, the service is significantly cheaper than placing children in residential school. This learning should be utilised to inform local authority investment in children with SEND and encourage a more proactive intervention-based approach to support.

The *Investing in Early Intervention* report is available here: <https://cerebra.org.uk/wp-content/uploads/2022/05/EARLY-INTERVENTION-REPORT-A4-FINAL.pdf>

Chapter 8: Delivery

Question 1: In your opinion, how can we ensure the delivery of reform is successful?

A major barrier to the delivery of reform is securing sufficient investment to deliver this full programme of work. This is on top of recent cuts in services. The *Failed and Forgotten* report describes that in this current financial year, 50% of local authorities have a real-term cut in services for disabled children and 87% of local authorities plan to cut at least one of four services during the current financial year. Figures show that this occurs after successive cuts to budgets in previous years, with 97% of local authorities cutting one of the budgets for disabled children in 2019/20. Without additional funding, reform will not succeed.

The *Failed and Forgotten* report is available here: <https://disabledchildrenspartnership.org.uk/our-campaigns/failedandforgotten-read-our-new-report/>

The proposed strategy to strengthen the inspection and regulatory powers of Ofsted must focus on improving oversight of safeguarding risks in all settings, including those with 'good' or 'outstanding' ratings. It must be recognised that the current inspection and regulatory powers of Ofsted have been insufficient to identify and mitigate cultures of abuse including institutional abuse, such as in Hesley Group settings in Doncaster (which had an Ofsted rating of 'good'). This concern also arises with the new CQC single assessment framework, as it increases its reliance on data to determine inspection frequency. New approaches to quality assurance and regulation must be able to penetrate the 'closed cultures' that can develop in residential settings, which should be regarded as potential "high risk" environments for disabled children. This risk of abuse is heightened while regulators lack an accurate understanding of the experiences of children and are unresponsive to intelligence they have received.