Policy Paper: Improving disabled children’s social care (England)

What is social care and why it’s failing disabled children
Good quality social care[1] enables disabled children to thrive and families to sustain their parenting and caring roles. Timely, high-quality support can prevent a child’s needs from escalating and families reaching crisis point. Social care in England is failing disabled children and young people.

Families report negative and even bruising experiences after seeking help from children’s social care services. For too long disabled children’s social care has been primarily linked to safeguarding processes with families forced to undergo intrusive social care assessments such as asking to see a child’s bedroom.

Families are often denied support when social workers find no evidence of neglect or abuse. Parents describe a culture of parent blame when they seek help and in the most extreme cases parents are accused of fabricating or inducing their children’s condition without justification.

Others see hard won social care direct payments clawed back by local authorities because they are unable to find suitably trained personal assistants to work with their child

The current system for disabled children is “bafflingly complex”, according to leading disabled children’s rights barrister Steve Broach KC. The Law Commission describes routes to accessing support for parent carers of disabled children “unnecessarily complicated”.

We welcome the Law Commission’s Final Report: Disabled Children’s Social Care and support its recommendations for legal reform which will simplify

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[1] Social care for disabled children can include short break services, care in the home, holiday play schemes, some aids and adaptations and direct payments.

the complicated patchwork of outdated legislation and local eligibility criteria that prevent families of disabled children getting the support they need and are entitled to.

The complexity of the law governing social care for disabled children, coupled with deep cuts to local authority funding, has led to an unacceptable variation in the amount and quality of support local authorities provide to families of disabled children.

Disabled children's social care needs urgent reform in terms of the law, workforce and funding to ensure families get the support their disabled child needs to thrive.

Contact's social care asks

Contact social care asks align with Law Commission's 40 recommendations for reforming disabled children's social care law set out in its Final Report .

We call on the Government to accept in full the Law Commission's recommendations for comprehensive legal reform and to set out its plans for implementing the reforms without delay.

Our 3 key social care asks:

1. **Law reform - to create a separate assessment pathway for disabled children with explicit legal duties to assess and meet the social care needs of disabled children and to end the culture of parent blame.**
2. **National eligibility criteria for disabled children's social care support.**
3. **Address the £573 shortfall in funding for disabled children's services and double funding for the Short Breaks Innovation Fund.**

Other measures necessary to improve social care for disabled children:

- **More flexibility for direct payments, allowing parent carers to use them to pay a family member to care for their child or pay for an**

activity. A legal requirement for direct payments to be 'sufficient' to meet a disabled child's social care needs, not just 'reasonable'.

- **Expand and improve training for the disabled children's social care workforce.**
- **Increased access to advice on rights and entitlements help families navigate the social care system and secure support.**
- **A strengthened system of accountability to ensure local authorities comply with their social care legal obligations to disabled children.**
- **Improved joint commissioning of support through better coproduction with families.**

Detailed explanation on Contact's Social Care asks for disabled children

4. Ask 1. Assessment:

Law reform to create a separate assessment pathway for disabled children with explicit legal duties to assess and meet the social care needs of disabled children and end the culture of parent blame.

- Families of disabled children have a legal right to ask for and receive social care support when they need it.
- Under s.17 of the Children Act 1989, disabled children are automatically considered a Child in Need and entitled to an assessment of need, even if they are not 'at risk' of abuse or neglect.
- Disabled children and their families have distinct assessment and support needs, yet they are typically funneled through assessments designed for safeguarding or child protection (Section 47 assessments) when there is no evidence of or suspicion of neglect or abuse.
- Parents of disabled children often experience 'parent blame' in their interactions with social care services and describe the assessments as "brutal", "humiliating" and "intrusive". See Institutionalising Parent Blame

- The Working Together to Safeguard Children guidance fails to stipulate a separate assessment regime for disabled children (who may be a Child in Need but not ‘at risk’) compounding the ‘one size fits all’ child protection approach.
- Disabled children subject to section 27 social care assessments can have stigmatising alerts flagged on family medical records, even when an assessment finds no child protection concerns.
- False accusations of Fabricated and Induced Illness are often used by local authorities to deflect blame and are devastating for families.
- On in four families who sought help from social care are told their disabled child did not meet the threshold for a social care assessment. DCP, Failed and Forgotten report

“I have withdrawn from disability social care for my son, I have never known something both so UNHELPFUL and INTRUSIVE in my life. We were consistently just a check box exercise for the social worker, every 6 weeks she would come to our home, offer no support, demand to see my son's bedroom and then leave. We went on holiday recently, and although we scored 10/10 across the board for parenting during the initial disability social care assessment and there are NO safeguarding concerns, they told us we shouldn't really leave the country without having had a welfare check on the children. A welfare check? Why? I felt like we weren't allowed to take our own children on holiday. The support they offer is not worth the intrusiveness. I felt like we were fighting to keep our kids every 6 weeks. It made me so anxious.”

What we would like to see:

- A separate assessment process led by disabled children’s social workers to reflect disabled children’s distinct care and support needs through reform of the Children Act.
- A clear legal duty to assess the social care needs of disabled children underpinned by statutory guidance that does not assume or require parental failings, neglect or abuse to trigger support for a disabled child in need.
- New statutory guidance setting out the social care assessment process and legal entitlements of disabled children.

- Social care assessments under the Children Act 1989 carried out at the same time as EHC Plan assessments to ensure a child’s social care support needs and provision are included in the legally binding plans.
- Reintroduction of local authority disabled children’s social workers with the knowledge and skills to conduct disability-informed assessments of children and their families and identify appropriate support.
- A legal requirement for assessors to have expertise in disability.

Ask 2. Support: Establish transparent national eligibility criteria for disabled children’s social care support.

- Even where a families’ needs are assessed, they are frequently told they are ineligible for support struggle to access support they need (Independent review of children’s social care, 2022).
- The frequency with which local authorities deny disabled children support after assessments indicates that the system is not working. Thresholds for help under Section 17 and Early Help are too high.
- The Disabled Children’s Partnership Failed and Forgotten report in 2023 found just one in seven families had the correct level of support from social care
- Eligibility criteria for children’s social care support is set by individual local authorities and vary around the country leading to a post code lottery.
- Local authorities rarely make eligibility criteria publicly available on Local Offer websites, so families have no idea if they are entitled to support.
- Generic children’s social care departments often lack proper training in disability and an understanding of the challenges faced by families with disabled children, leading to inadequate or no support.
- Lack of timely and suitable early support for children and their families can lead to escalating needs and crisis, sometimes resulting in children being admitted to residential or mental health/ psychiatric inpatient care.

- Disabled children are also more likely to be re-referred to children's social care than other children (Troncoso, 2017).
- Typically, if social workers find no evidence of neglect, abuse or imminent family collapse, they get little or no support.

A parent of two autistic teenagers said her children was repeatedly told her family did not meet the criteria for a disability social work despite escalating needs and undergoing several Section 17 assessments over the years. Eventually the local authority agreed to for help only to have the support withdrawn a month later. The pressure was so great, the mother experienced a mental health crisis and was admitted to hospital for two months.

What we would like to see:

- An end to the post code lottery in social care support for disabled children through introduction of national eligibility criteria akin to the adult social care under the Care Act 2014. This would benefit disabled children and their families by providing support and safeguarding and promoting children's welfare and keep disabled children out of the care system.
- An express legal duty to meet the needs of disabled children based on national eligibility criteria, coproduced with families, children and organisations representing families with disabled children. This must be set out in new statutory guidance specific to disabled children.
- A named disability social worker for every family with a disabled child to ensure they get useful, timely support.
- A requirement for local authorities to publish children's social care eligibility criteria on Local Offer websites.
- Access to advocacy, including legal aid, and support for families navigating the existing system and waiting for support to be agreed.
- Investment in disabled children's social care and short breaks so local authorities have sufficient funds to provide support to families in need financial constraints (see Ask 4).

Ask 3. Funding

Address the £573 shortfall in funding for disabled children's services and double funding for the Short Breaks Innovation Fund.

- Disabled children's social care is underfunded. Cash-strapped local authorities protect their budgets by setting too high thresholds for eligibility for support, often only offering support when a family with a disabled child is in crisis.
- Analysis commissioned by Scope and the Disabled Children's Partnership found a £573 million and growing funding gap in disabled children's social care (The Gap Widens, 2021).
- Failure to fund social are support and short breaks for disabled children early often leads to more costly support, including crisis support as they get older.
- Evidence emerging from the £30 million short breaks innovation fund shows improved health and wellbeing outcomes for disabled children in the 20 participating 20 local authorities.

What we would like to see:

- Prioritisation of funding for disabled children to close the £573 million funding gap in disabled children's social care.
- Further investment in short breaks for all local authorities, expanding and building on the success of the £30m short breaks innovation fund.

Ask 4. Direct Payments

More flexibility for direct payments– allowing parent carers to use them to pay a family member to care for their child or pay for an activity.

- Direct payments often do not meet the full cost of care, forcing parents top up carers' pay out of their own pockets and are not always reviewed.
- Local authorities are only required to provide direct payments that are 'reasonable' rather than 'adequate' to cover a child's

care costs, leaving families to pay the difference from their pockets.

- Local authorities frequently claw back direct payments because families cannot find suitable paid carers to work with their child or young person due to the crisis in the social care workforce.
- While direct payments offer welcome flexibility to some families, they are excessively bureaucratic, shunting additional pressure on parents on top of their existing caring responsibilities.
- Many families wish to use direct payments to pay family members to care for their child, but local authorities rarely use their discretion to approve this arrangement.

A parent told us it took 'many months' for direct payments to be approved for her nonverbal autistic teenager. Her son has behaviour that challenges and is at high risk of hospital admission. The local authority paid a lump son into their account almost a year after they applied for. The family struggled to find a care worker to work with him and were forced to hand back the money to the council.

What we would like to see:

- Increased flexibilities for direct payments to enable parents to train and pay family members to care for their disabled child in the absence of reliable, quality paid carers.
- A legal requirement for direct payments be 'sufficient' to reflect the full cost of paying for care for a disabled child (rather than just 'reasonable' funding)
- And end to local authorities clawing back direct payment funds from families struggling to find and employ carers or PAs.

Ask 5. Workforce:

Expand and improve the quality of the disabled children's social care workforce.

- 70% of disabled children and young people needing a personal assistant face delays due to the lack of availability of the workforce (Failed and Forgotten, DCP, March 2023)
- Workforce statistics obtained by the DCP (Failed and Forgotten, DCP, March 2023) found 3/4 local authorities dedicated 10% or less of the children's social care workforce to disabled children.
- A critical shortage in care workers in the UK is pushing parents of disabled children out of work and into poverty because they are unable to find Personal Assistants to support their children.
- The rise in use of direct payments has impoverished the social care 'market' with overreliance on generic private care agencies using staff on zero-hour contracts leading to a decline in the quality social care provision for disabled children.
- Families are affected by a shortage of children's early help practitioners, attracted by higher wages in the retail sector (Institute for Government children's social care tracker, 2023)

"We were assessed, and they agreed we needed extra help: a personal assistant (PA) for 10 hours a week. They advertised, as did I, but the recruitment issues mean we still don't have a PA. When asked if the LA could support us in other ways while we waited, they said: 'We do child in need meetings. The PA is your issue to source' which are equally pointless. They visit my children every 3 months to make sure they are okay but as for support, nothing. I've been thinking about withdrawing because of the lack of support and added stress."

– Parent of two autistic nonverbal children.

What we would like to see:

- Significant investment in, and expansion of, the social care workforce for disabled children, including the third sector and local authority workforce.
- An attractive career pathway for care and support staff, PAs, enablers and outreach workers for disabled children with qualifications and other incentives to enable them to progress and develop their skills.
- Better training to enable care and support staff who work with children to provide empathetic and confident care for a range of disabilities while promoting the social model of disability.

Ask 6. Advice and advocacy

Increase access to independent advice to help families navigate the social care system and secure support

- The current system for disabled children is unduly complex. The Law Commission has described routes to accessing support for parent carers of disabled children “unnecessarily complicated”.
- Charities like Contact receive thousands of enquiries from families every year in need of help to navigate the system to get support. Social care one of the top three reasons parents call the Contact helpline.
- The Law Commission’s review of disabled children’s social care is likely to take 5 to 7 years to realise leaving thousands of families missing out on vital support for their children.
- Parent carers do not have a blanket entitlement to independent advocacy. Local authorities having complete discretion on when to offer advocacy to parents and operate high eligibility thresholds.

What we would like to see:

- Immediate investment in independent and trusted social care advice and advocacy for families of disabled children that reflects actual demand among families.
- A requirement for local authorities to commission independent social care accessible advocacy for all parent carers of disabled children without eligibility criteria that excludes most parents/families.

Ask 7. Accountability

Strengthen the system of accountability to ensure local authority social care departments comply with their legal obligations.

- Children with special educational needs and disabilities (SEND) have rights to social care assessments and support under the Children Act 1989 and the Children and Families Act 2014
- Local authorities routinely fail to comply with their legal duties towards disabled children with SEND with no negative consequences for non-compliance.
- Routes of redress for families wishing to challenge local authority social care decisions relating to their child are unsatisfactory and lengthy.
- Outside of the SEND tribunal process, parent carers or disabled young people must discuss any issues with social care provision with the local authority and take their complaint to the local ombudsman if they remain unhappy.
- Under ‘extended appeals’, SEND tribunal can make recommendations on a child or young person’s social care needs, but these are non-binding on local authorities.

A parent felt they had no choice but to ‘go the legal route’ and fund a pre-action letter after waiting a year to get her son assessed for social care provision. They self-funded the initial costs then got legal aid. After the

assessment, which showed her son was entitled to provision, the director of children's services said there wasn't any provision. Care in their area is provided through a 'local supporters scheme' but the young people who work on the scheme for minimum wage are not allowed to do personal care and it has been difficult to find a suitable match for their child.

What we would like to see:

- Non-compliance with the law on supporting children and young people with SEND made unacceptable and unaffordable for local authorities including for social care services.
- CQC reports that take full account of local authorities' compliance with legal duties toward children with SEND.
- CQC prevented from rating organisations "good" or "outstanding" if they do not comply with the law.
- Improved monitoring and oversight of systemic duties through the EHC Plan process and commissioning of social care services for disabled children.
- Simpler and quicker complaint routes so families do not have to wait unacceptably long periods for social care issues to be resolved.
- SEND tribunals given powers to compel local authorities to deliver social care support set out in EHC Plans.
- More funding for the Local Government and Social Care Ombudsman (LGSCO) to enable it to provide speedier responses to families who need to challenge social care decisions.
- Increased funding for advice services and easier access to legal aid to help parent carers and young people navigate the complex lengthy social care processes and challenge decisions if needed.

Ask 8. Commissioning

Improve joint commissioning through better coproduction with families.

- Alongside the increase in direct payments, there has been a corresponding decline in local authority-run provided services, including cuts to vital overnight respite care for disabled children.
- Some respite centres closed during covid and never reopened, and some are under threat including the Getaway, a respite care centre in Derbyshire.
- Service closures mean social care staff disperse, and their experience is lost in the area.
- Families lack a real choice in provision with a balanced ‘mixed economy’ of direct payments and high quality commissioned and directly provided services for those who do not wish to employ care staff themselves.
- Integrated support services need to be codesigned and commissioned with families of disabled children to ensure local services meet their needs.

What we would like to see:

- Protection and expansion of ‘in-house’ local authority ‘provided’ and commissioned support alongside flexible direct payments, so families have choice and to ensure there are enough support workers with the right skills and training to work with disabled children..
- A halt to cuts to respite services for disabled children with the most complex needs.
- High quality ‘provided’ social care support services designed and commissioned in coproduction with local families.

About Contact

Contact supports more than 291,000 families of disabled children in the UK to navigate health, social care and education services. We provide trusted information advice, and support through our national helpline, website, workshops, London and nation offices and 1:1 support. We support 152 parent carer forums that make up the National Network of Parent Carer Forums to ensure voices of parent carers of disabled children are heard by strategic decision makers. Contact chairs the Disabled Children's Partnership, a coalition of more than 110 charities supporting disabled children and their families.

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