

PaCC Position Statement: Social Care for Children and Young People with SEND 0-25

August 2022



This position statement has been written by the Parent Carers' Council in Brighton and Hove to put a spotlight on the acute difficulties children and young people and their families are facing around social care provision for children and young people with special educational needs and disabilities age 0-25 years.

Our aim is to bring the wide range of issues together in one document, to highlight the real crisis families are facing, and provide a strong basis from which to co-produce improvements in provision for children and young people with SEND (Special Educational Needs and Disability) and their families.

Introduction

Social care in Brighton and Hove for children and young people 0-25 with SEND is in urgent need of investment in direct payments and short breaks, a review of provision and processes, and a strategic approach to managing the current and ongoing challenges, to ensure children and young people and their families receive the support from social care that they need and are entitled to.

Many families are at breaking point due to a lack of respite from their caring responsibilities and children and young people are unable to access the activities their non-disabled peers enjoy. This has only been made worse by the pandemic.

The Disabled Children's Partnership state in their Left in Lockdown report: *COVID-19 has merely shone a light on the existing inequalities that already existed in disabled children's health and care services.* <https://disabledchildrenspartnership.org.uk/leftinlockdown/>. This echoes ongoing feedback PaCC receive from families of children with SEND in Brighton and Hove who tell us that the problems we are facing were there before covid.

PaCC recognise the importance of working in coproduction with officers for the benefit of the SEND community. We acknowledge the value of our positive working relationship with the Local Authority, and highlight successful co-production in other areas of work, including improvements to the home to school transport service, development of the proposed increase in school provision for autistic children and young people, and more broadly within the SEND strategy. PaCC remain committed to working in co-production with officers - in both Children Families and Learning, and Adult Social Care - on the issues detailed in this position statement, to ensure similar improvements in social care provision for children and young people (0-25) with disabilities and their families.

In this position statement, we refer to the legal framework, combined with direct feedback from parent carers alongside data from the compass data base, to highlight the urgent need to review and improve social care provision in Brighton and Hove.

Some of these areas for improvement are included in Brighton and Hove strategies, including the SEND strategy, but PaCC feel it is essential to draw together the range of concerns in this document to enable a joined up and strategic approach to the issues around social care, as well as to highlight the serious impact on families.

PaCC recognise ongoing pressures on officers regarding capacity in Brighton and Hove City Council (BHCC), and PaCC is aware some of the issues reflect the national challenges around budgets and recruitment. However, it is essential that we reflect the grave concerns held by the SEND community and flag the heightened sense that the current position is unsustainable.

A. Social Care provision – legal framework

An understanding of the legal framework is essential context for this position statement, so we have provided a summary for any readers without legal expertise. More detail is included in Appendix 1.

Social services departments of local authorities are legally responsible for arranging support for disabled children, their siblings, and their carers. The legal duties of social services to disabled children and their families include:

- maintaining a register of disabled children
- providing information about services which may be available
- assessing the needs of disabled children and their carers
- providing a range of services to meet these needs.

Social services departments have a general duty under Section 17 (10) of the Children Act 1989 to safeguard and promote the interests of ‘children in need,’ and to promote their upbringing by their families. The law recognises disabled children as being in need.

(Contact “Services and support from your Local Authority” <https://contact.org.uk/wp-content/uploads/2021/03/Services-and-support-from-your-local-authority.pdf>)

Definition of disability under the Equality Act 2010

“A person has a disability for the purposes of the Act if he or she has a physical or mental impairment, and the impairment has a substantial and long-term adverse effect on his or her ability to carry out normal day-to-day activities” ([Disability: Equality Act 2010 - Guidance on matters to be taken into account in determining questions relating to the definition of disability \(HTML\)](#)). This guidance includes reference to ADHD and autism.

Short breaks and respite provision

The legal responsibilities around short breaks draw on several pieces of legislation, which are summarised in Appendix 1. This provides the legal framework for families needing social care support to maintain family life and achieve a good quality of life and is essential

context for the parent carer feedback and PaCC's recommendations within this position statement.

This entire framework is relevant and important, but we highlight here two key points from the appendix: The local authority is required to give [disabled] children the opportunity to lead lives which are as normal as possible, and ensure disabled young people aged between 13 and 25 have access to sufficient educational and recreational leisure-time activities which are for the improvement of their wellbeing. They must also consider the needs of carers who would be unable to continue to provide care unless breaks from caring were given to them, or would be able to provide care for their disabled child more effectively if breaks from caring were given to them.

The 2011 guidance states that "Short breaks should not just be there for those at crisis".

B. Brighton and Hove Parent Carer Feedback

We hear repeatedly from parent carers that they are in crisis. They report that they need to be at breaking point to receive support from social care, and many in crisis are unable to access either an assessment or short breaks because their child does not fit the eligibility criteria.

"you have to be in crisis before having access and you continuously have to go back and fight for it and keep getting turned down"

"You don't get provision unless you go into crisis. When he was younger, we could not leave the house. Kept going to panel could not get anything. We've now had a family break down, now a single parent"

Below is PaCC's report on the focus group on the recommissioning of short breaks by Brighton and Hove, which also reflects feedback we received pre-pandemic and on an ongoing basis.

More recent feedback has shown many families facing feeling desperate over the summer holidays due to lack of access to either short breaks or universal short breaks provision and has brought to a head the urgent need to address this essential support for children and young people and their families.

This feedback highlights the vast disparities of the real lives of parent carers and their families in Brighton and Hove to what is intended by the broader legislative framework outlined in Appendix 1. PaCC flags significant concerns regarding the level of short break provision offered in Brighton and Hove.

Focus group on Recommissioning Respite/Short Breaks by BHCC

In Spring 2022, an online focus group was organised at the request of Brighton and Hove City Council (BHCC) and the Clinical Commissioning Group for parent carers of Children and Young People to provide feedback to officers to inform the recommissioning of Short Breaks provision for Children and Young People 0-25 with SEND in Brighton and Hove, specifically providers Extratime and Barnados Link Plus. The PaCConnect was also used as an opportunity to collect feedback about broader need for social care, including families currently deemed ineligible under Brighton and Hove guidelines.

The event was well attended by parent carers, demonstrating the high importance of this issue to families. Additionally, a number of parent carers fed back to PaCC via email/telephone. Two commissioners from the local authority health and SEND team attended. The PaCC Chair, Vice Chair, and PaCC reps were also in attendance.

Parent Carers attending the focus group included:

- Families in receipt of short breaks or respite
- Families not in receipt but with a need for short breaks or respite

General feedback:

- **Acute Mental Health issues:** parent carers report their CYP (Children and Young People) are isolated, depressed and having suicidal thoughts, with the whole family also isolated and close to or at crisis point. Families who have tipped into crisis fear they have no choice but to seek full time residential care for their disabled CYP.

"I am a disabled single parent with a disabled child and do not qualify for disabled services and would just like to share how desperate parents are."

"Without support with respite when they are younger, in the absence of support, the family will be so exhausted and must do full time residential care."

- **Financial insecurity:** the cost-of-living crisis is significantly affecting families with CYP with SEND, e.g., see <https://contact.org.uk/help-for-families/campaigns-and-research/out-of-energy>. There is a lack of suitable holiday and after school provision for children and young people with disabilities, particularly as they get older. An increasing number of parent carers report employment is impossible due to the lack of appropriate provision – including universal short breaks - in the city. Pressures on families from all sides, including exhaustion through lack of respite, leave many parent carers unable to work.

"It's the uncertainty of it. It's going to get worse with the cost-of-living crisis. People are going to need more work"

- **Inequalities:** parent carers report the vast inequality of opportunity for families with CYP with SEND in contrast to the abundance of opportunity for families not impacted by SEND e.g., access to holiday schemes. This lack of opportunity significantly

impacts siblings, as parent carers are unable to spend quality time with siblings due to their caring responsibilities. PaCC highlight that these inequalities significantly impact the physical and mental health of all family members and long-term outcomes for CYP are poor.

"We need a resource that can be easily accessed to provide after school and holiday club provision to support working families. The systems in place make you feel like you would be better off on benefits. Also, what is on offer for non-disabled children is vast in comparison."

- **Eligibility for short breaks and respite:** a significant number of parent carers of CYP with a high level of need do not come under the current Brighton and Hove eligibility criteria for short breaks/respite. Many of the CYP are neurodivergent, some with Pathological Demand Avoidance which can have a huge impact on everyday life. Families reported being confined to the house, unable to support siblings and that their own health is impacted. Parent carers were at absolute breaking point and in clear need of respite.

"...trying desperately to get help, with supporting letters from Family Support Worker. Doesn't have Learning Disability, and so can't meet threshold."

"Considered putting my child into care because I was so desperate"

Feedback on processes:

- **Social care information and processes:** parent carers fed back that information regarding accessing social care assessments and process can be poor. Parent carers also reported a poor communication culture – parent/carer blaming by professionals is a common and ongoing theme.

"Information is wildly inconsistent from the Specialist Community Disability Team"

"I was torn between reaching out for support and not being judged"

- **Thresholds for eligible families:** families report too frequently that no support is offered unless the family is in crisis. Thresholds are confusing, and signposting to other BHCC support teams where families are not eligible is sometimes very poor and has led to safeguarding issues for some neurodivergent CYP.
- **PA recruitment:** PAs are opting to work in other sectors as the pay is better.

"You can stack shelves for more money an hour, yet PAs can't get that with all the responsibilities involved working with vulnerable children and adults."

- **Transition to adulthood:** timescales around assessments and planning remain poor. For eligible families, transition planning does not start until a young person is 18+, despite national guidance stating this should start in Year 8/9. Also, CYP without a severe LD (often high risk neurodivergent young people), have been moved from the children's disability service to adult social care at age 18, with no handover and therefore fall through the gaps between SCDS (Specialist Community Disability

Service) and HASC (Health & Adult Social Care). Once in adult social care, there is virtually no service, with long waiting times and lack of communication.

“No transition planning but they didn’t start until son was 18. Capacity is such an issue.”

“I know so many friends who are parent carers who realise they can no longer work; I fear for our family's future if I have to give up work.”

- **Panel:** parent carers report that the social care panel decision-making process is dominated by budget and not need. Parent carers report that the panel’s default position is to turn down any offer of support at first - only persistent but realistic desperation of a family in crisis results in panel offering social care support. Parent carers report a lack of transparency.

“You must accept your first panel will be declined and have to think I have to go to 2nd and 3rd.”

“The decision about whether you can get into the SCDS should be made more transparent, and you should be able to challenge it formally.”

- **Residential respite** at Drove Rd, Tudor House, and Beech House: beds are blocked for families needing respite by CYP living permanently on site, this problem has existed for many years and not been addressed. This means too many young people are forced to leave the city, living far away from their families, which remains unacceptable and costly.

“Started at Tudor house, bed blocking so took ages to get a bed there.”

“We had huge challenges at home and had reached crisis (police involved, social worker, safeguarding around siblings), but there was no provision for overnight respite due to challenging behaviours. Building up relationships is really important, so needs to come before crisis point reached.”

Feedback on Extratime and Barnardos

- **Services are exemplary:** but there remains significant unmet need as both providers do not have the financial resources to offer more provision.
- **Fear of the future:** parent carers worry what about the future Brighton and Hove short breaks and respite offer. if these highly trusted providers are no longer contracted in the city. NB: both Easter and Summer provision from Extratime has been significantly impacted and reduced with huge impact on families and causing ongoing anxieties.
- **Feedback prior to the summer holidays:** that families face crisis in the summer holidays, as holiday short breaks provision is inadequate.

“How will we survive with just three days support?”, “Our mental health is ignored, it is unworkable to function as a family with such little support”. “I can’t work in the summer holidays.”

C. Families accessing / needing social care according to data on the Compass Register

This data taken from the Compass database (the children's disability register held by Amaze) and highlights the level of unmet need for social care in the city, directly reflecting the feedback from parent carers at the focus group.

For example. 116 families need, but do not receive, direct payments - greater than the number who do. 83 families need, but do not receive, residential short breaks, compared with the 12 families who do.

NB. This data is self-reported by families and does not include 100% of families in the city. Therefore, the actual numbers of families receiving or needing a service are likely to be higher than those show here.

Under 18

SERVICE	Receiving	Needed	Receiving - more needed	Total
SCDS social worker	55	31	1	87
Outreach team	12	25	0	37
Direct Payments/PBs	103	116	13	232
Link Plus,	14	10	1	25
Other social worker	91	15	4	110
Residential short breaks	12	83	3	98

18+

SERVICE	Receiving	Needed	Receiving - more needed	Total
Social Care Worker/Manager	65	29	2	96
Community support at home	9	5	0	14
Support through Care Team	7	8	0	15
DPs or PBs	45	16	5	66
Residential Short Breaks	6	20	1	27

D. PaCC recommendations

1. Complete a holistic review of Social Care children and young people with SEND:

Based on both recent and historic data and feedback, PaCC takes a strong position that there is an urgent need for a review of all 0-25 social care provision and processes in Brighton and Hove to include a review eligibility criteria and identification of unmet need in the city. Further this needs to include addressing the PA recruitment crisis as well as transition to adulthood.

This review will need to be led by a designated officer at Brighton and Hove County Council, with strong links to the SEND strategy, Learning Disability Strategy, and adult social care. It must be fully co-produced with parent carers and providers, underpinned by the legal framework and best practice therein, and should include the following:

- **Increased investment** in children's social care for front line services including direct payments and short breaks. PaCC note that social care budgets have remained static. This should include a review of the level of unmet need in the city, highlighted in this position statement.
- Apply an **Early Intervention family support model**, providing respite before families reach crisis, to invest to save and reduce the need for high-cost packages at a later stage.
- Review and co-produce Brighton and Hove's **short breaks and respite policy** (ref SEND Strategy), including a focus on eligibility criteria, adhering to national legislation, adopting best practice, and responding to local need.
- **Extend eligibility for respite and short breaks to neurodivergent CYP** without a learning disability and their families, where a need for respite has been identified. This will require additional funding to cover increased levels of direct payments and/or short breaks
- **Direct payments:** review processes, including interface between social workers and support agencies (Possability People, People Plus), and achieve consistent information. e.g.: a booklet of comprehensive information for all families, services, and educational settings.
- Review of **PA recruitment**, in collaboration with relevant organisations such as Possability People, to identify and address factors impacting recruitment such as rates of pay, recruitment processes, training, peer support etc.
- Review **residential short breaks** to improve consistency, breadth, and amount of provision for eligible children and young people, and identification of gaps in provision for those with high level need who are currently outside eligibility criteria.
- Review information regarding access to social care and the role and remit of social care panels.
- Review and improve **social care assessment processes**, ensuring they are in line with statutory changes and updates and are clearly communicated to families.

- Promote and improve access to **Carer's assessments** and ensure clear information about the difference between Needs and Carer's assessments.
 - Review **transition to adulthood** processes for both those eligible for specialist children's disability service and those who are not (including autistic young people), to bring into line with statutory requirements. This will require strong joint working between SCDS and adult social care.
 - Review suitability and availability of **universal short breaks** offer for children and young people with SEND, to ensure strong city-wide provision for those not eligible for short breaks.
 - Update the SEND community around the strategic development of an **extended day** for children and young people, as agreed by councillors as part of the package of plans for the integrated special school hubs.
(<https://democracy.brighton-hove.gov.uk/documents/s117888/Special%20Educational%20Needs%20and%20Disability%20SEND%20-%20Reorganisation%20of%20Special%20Schools%20and%20Pupil%20Referr.pdf>)
 - **Review provision for children in need with SEND** who do not currently qualify for support from SCDS and ensure robust joint working between the relevant teams to avoid children and young people falling between gaps between services, and ensuring they get appropriate support from social care.
 - **Communication and information:** ensure clear and transparent information for families, referrers, and other agencies, regarding eligibility, social care processes and clear signposting to other relevant services.
 - **Training for all social care staff about SEND** to ensure an appropriate response to the challenges faced by families and help avoid erroneous safeguarding concerns raised due to lack of SEND understanding, reducing parent carer blame and improving parent carer support.
 - **Staff capacity** at BHCC: PaCC highlights the need for increased investment in staff teams, including at strategic level, to address the significant issues in social care.
 - Use appointment to the role of Designated Social Work Officer to ensure strong **strategic overview and joint working** between health, social care, and education.
2. **Build and maintain trust and transparency regarding social care through improved communications:** BHCC and the integrated care system should develop a communication strategy to ensure that parent carers can identify that their views have been taken into account following consultations and engagement events. It is noted that confidence within the SEND community is lower when information from providers is unavailable, e.g follow up from a focus group. Parent Carers also note insufficient updates regarding the citywide strategies relating to SEND social care.
3. Take immediate action to **look strategically at the current acute challenges facing social care** provision, including difficulties recruiting staff, to identify ways to mitigate the impact on families.

4. Take forward social care recommendations as outlined in citywide strategies as a priority. The SEND community must be notified of the timeline for this activity.

PaCC look forward to working with relevant officers in Children's Services, Adult social care, and the Specialist children's disability service to address the challenges and find solutions to improve respite and social care provision for disabled children and young people and their families.

This position statement precedes BHCC/CCG comms and/or a BHCC/CCG report relaying next steps following the recommissioning parent carer consultation focus group.

On behalf of the PaCC community, PaCC welcome a joint reply from BHCC/CCG to share with parent carers.

PaCC welcome any communication on any of the issues contained in this document. You can contact us by emailing **admin@paccbrighton.org.uk**

The Parent Carers' Council (PaCC) is a parent-led forum which represents parent carers with children and young people with any kind of physical disability, learning disability, complex or long-term medical/health condition, mental health issue or special educational need. The group was formed to enable parent carers to work closely together to help improve services and support. It aims to help parents get more directly involved in the strategic delivery of services for disabled children in Brighton & Hove and now has over 525 signed up members. This position statement was developed through consultation with our Steering Group members and our partner groups: Barnado's Link Plus, Brighton Pebbles, Extratime, mASCot, T21, Amaze Face 2 Face and Children's Hearing Services Working Group (CHSWG).

Appendix 1

A reminder of the legal framework

(Source Contact 2022 <https://contact.org.uk/wp-content/uploads/2021/03/Short-breaks-1.pdf>)

The Chronically Sick and Disabled Persons Act 1970

Creates a right for disabled children to receive social care services, including short breaks, when they are assessed to be necessary to meet their needs. Under this Act, the duty to provide services is to the individual disabled child and does not extend to other members of the family. Examples of these services are:

- practical assistance in the home, like help with personal care of your child, eg help with getting in/out of bed. This could also be home-based short break
- outings or other recreational facilities outside the home.

The Children Act 1989

Schedule 2, paragraph 6 (1) of the Children Act 1989 requires local authorities to: *‘assist individuals who provide care for such children to continue to do so, or to do so more effectively, by giving them breaks from caring’*. It also requires them to:

- minimise the effect on disabled children within their area of their disabilities
- give such children the opportunity to lead lives which are as normal as possible. Local authorities are required to ensure disabled young people aged between 13 and 25 have access to sufficient educational and recreational leisure-time activities which are for the improvement of their wellbeing
- promote disabled children being brought up by their families, including the right to permanent and or temporary residential accommodation, if your child needs it.

It forms the legal basis for residential short breaks. If your child needs this service, then it should be provided. Importantly, the Act allows social services to provide help which will benefit other family members, like siblings and other carers. To comply with the law, local authorities must not only offer short breaks to families in or near crisis, but also support families to allow effective caring to continue by providing appropriate services for them.

Government guidance **Short breaks for carers of disabled children 2011** states that

“Local authorities must:

- provide a range of short breaks services;
- give families the choice to access short breaks services using a direct payment;
- publish a statement of their short breaks services on their website;
- keep their short breaks statement under review;
- state in their short breaks service statement the range of short breaks services available, the criteria by which eligibility for services will be assessed, and how the range of services is designed to meet the needs of families with disabled children in their area;
- consult parents as part of the review of the statement;
- consider the legal implications of the eligibility criteria they apply to short breaks services; and
- not apply any eligibility criteria mechanistically without consideration of a particular family’s needs”

This guidance also states that: “1.2 Short breaks should be used to enhance the ability of parents to care for their disabled child and any other children they may have. In performing its duty under the Short Breaks Regulations, the local authority will need to consider a broad spectrum of families and family circumstances – families should not have to reach crisis point before they receive a short break.”

Breaks for Carers of Disabled Children Regulations 2011

These regulations require local authorities to set out a range of short break services to help parents of disabled children have time away from their caring responsibilities. The regulations say that local authorities must take into account:

- the needs of carers who would be unable to continue to provide care unless breaks from caring were given to them, and
- the needs of carers who would be able to provide care for their disabled child more effectively if breaks from caring were given to them to allow them to:
 - undertake education, training or any regular leisure activity
 - meet the needs of other children in the family more effectively, or
 - carry out day to day tasks which they must perform in order to run their household.

The range of services must include:

- daytime care in the homes of disabled children or elsewhere
- overnight care in the homes of disabled children or elsewhere
- educational or leisure activities for disabled children outside their homes or elsewhere
- services available to assist carers in the evenings, at weekends and during the school holidays.

Children and Families Act 2014

The Special educational needs and disability code of practice 0-25 (which accompanies the Children and Families Act) says that local authorities need to take the views of parents, children and young people into account so that services, like short breaks services, meet their needs. One way the Act says they must do this is via local parent carer forums. Parent carer forums are groups of parents and carers of disabled children in each local authority area. Their aim is to make sure the services in their area meet the needs of disabled children and their families.

The Care Act 2014

The guidance says Councils must:

- Plan services thinking about wellbeing and what is important to people who use them
- Think about services having the right staff and enough money to give good support

Under the Care Act, Statutory guidance to support implementation of the Adult Autism Strategy and Care and Support Statutory Guidance (Page 306) states that “local authorities are required to:

- Carry out a child’s needs assessment where it appears to them that the person under 18 is likely to have care and support needs after turning 18. Young people with autism are identified by the Care and Support statutory guidance as a group whose members may not have received support as a child but who may have care and support needs in adulthood. This duty applies to all young people with autism, not just those with an EHC plan.”