

# PARENT CARERS TOGETHER



## **Bournemouth Christchurch Poole**

the voice of parent carers of young people with  
special educational needs and disabilities

# Short Breaks Report - What Parents have told us

## Summary of Legislation

Local Authorities have a legal duty to provide breaks for carers and disabled children which are called 'short breaks.' The legislation that applies to short breaks is as follows:

1. The Chronically Sick and Disabled Persons Act 1970 which 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. This act applies to the child and not to other members of the family.
2. The Children Act 1989 schedule 2 para 6 of which requires LAs to: 'assist individuals who provide care for such children to continue to do so more effectively, by giving them breaks from caring'. In practice this means that LAs must not only offer breaks to families in or near crisis but also support families to allow effective caring to continue by providing appropriate services for them.
3. Breaks for Carers of Disabled Children Regulations – 2011 – these regulations require LAs to set out a range of services to help parents of disabled children have time away from their caring responsibilities. The range of services must include day time or overnight care in the home or elsewhere, educational or leisure activities for disabled children outside their homes or elsewhere and services to assist carers in the evenings, at weekends and during the school holidays.
4. Children and Families Act 2014 – SEND Code of Practice which says that LAs must take the views of parents, children and young people into account so that services, like short break services, meet their needs.

See Appendix 1 for more information on legislation

BCP Council's Short Breaks Statement can be found [here](#):

## Background

---

*Parent carers Together is the collective voice for SEND families across Bournemouth, Christchurch & Poole.*

*Parent Carers Together has been the strategic voice of parents and carers working in partnership with BCP Council and Dorset NHS since 2019. It is funded through a direct DfE grant (administered by Contact) and BCP Council.*

*We know from parent carer feedback that short breaks and respite are a vital service for many families; the lack of such opportunities can leave parent carers in desperate situations. The lack of suitable Short Breaks was also referenced in the Ofsted/CQC Inspection of June 2021 when parents described attempting to access Short Breaks advertised as inclusive and SEND friendly only to find on arrival that there was a lack of staff training or capacity within the teams to meet the children's specific needs. The report also referenced the lack of awareness among parents and carers regarding personal budgets and direct payments, thus limiting the take up and access to these. This results in parents not being able to build support and respite packages for themselves, consequently more families fall into crises before they can access any meaningful support.*

Parent Carers Together have done a substantial amount of work to engage with families about local Short Breaks provision.

*We held feedback sessions in October 2020 and in April 2023. We were also involved in the sessions facilitated by Oxford Brookes University in June and July 2022. [See Appendix 2]*

*Short breaks are an opportunity for children and young people with special educational needs & disabilities to have fun, enjoy new experiences and spend time away from their families.*

---

## Some messages were consistent across all the sessions:

- Short Breaks are valued by parents and carers supporting a child with complex needs and are seen as important in improving the quality of family life
- Short Breaks should offer quality outcomes for children and young people in addition to providing a break from caring for parents and carers, with a particular focus on preparing for adulthood
- The experience of requesting support should be transparent, positive and without judgement, recognising the impact on family life of caring for a child with complex needs and understanding how this results in a need for support
- Support should be person centred and able to respond to individual needs
- Staff should be well-trained and consistent
- Regular, effective and timely communications between providers, commissioners and families is essential
- Short Breaks offer should be able to respond to local demand

- There was also some other messages about the importance of support being available to parents and carers of younger children (under 5) with complex needs and supporting families who are offered direct payments to find the support needed.

## Parental Quotes:

---

‘Not much available till the age of 5 .. and not sure what support would be available’

‘Haven’t registered as everything seems to be in Poole – travel is difficult as using public transport’

‘Leaving them with people they don’t know would cause anxiety’

\*Short breaks has been great. We have used them several times a year. They are organised very well. All the staff has been very professional and helpful. It has allowed us to have a much-needed break. Our child has enjoyed all the activities.

---

## Summary from 2022 consultation:

- Information about short breaks was confusing and parent carers were unclear about the eligibility criteria to access different types of breaks. Much seemed to depend on word of mouth or on who you spoke to.
- Overall, parent carers felt that there were too few short breaks available, especially in certain areas and for certain groups.
- The after school and holiday short breaks offer originated in Poole and parent carers felt there was still not enough coverage in Bournemouth or, especially, in Christchurch. This was a particular issue given the costs and time of travel, increased financial pressures on families and the fact that many activities were quite brief.
- There was a gap in terms of provision for older young people aged 19-25 who could not access the current short breaks programme and, in any case, had different needs and interests.
- Children with more complex needs, such as behaviour which challenges, or special medication or nutritional requirements and those who require 1:1 support are not well catered for. Providers often lacked the staff, skills or confidence to cope with their needs, and sometimes parents had to provide one to one support themselves meaning that they did not get a break.
- Lack of transport is a real barrier to accessing breaks.
- There was a real appetite for further engagement and co- production to improve the short breaks offer going forward.

## Key Messages from 2023 Short Breaks Panels

*'Not much for teens ... Diverse Abilities have had funding cut from BCP, so they have been struggling to give places to our children ... completely unacceptable and disappointing from a parents and young persons ... community feel completely let down ... this is a disappointing decision and will have a detrimental impact on vulnerable children and their families'*

*'For families with more than one child, the cost is prohibitive'*

Specifically in relation to Lemur Landings 'too expensive' Timings: Tues evenings 'starts and ends too late' Suggestion: Maybe hold this once a month and find alternative activities

*'Christchurch area has been neglected'*

Booking form 'annoying as I have to complete a separate form for each child – would be easier to do one form for the whole family'

*'The family activities are too pricey'*

*'The family activities all seem to be on the same day – could they be spread out a bit more'*

*'Activities not accessible for children less physically or cognitively capable'*

*'Swimming activity was double booked by venue – but no apology or refund offered'*

*I know many parents in BCP who have had to quit their jobs in order to look after their child in the school holidays due to the lack of suitable short breaks providing enough support for their child'*

*'Good consultation on their private members FB page-Short Breaks staff wanted to ideas for out of area excursions. Is Legoland, zoo, etc.'*

*'Staff are amazing ... very professional'*

## Solutions

How to improve

- BCP Council should listen to parent carers feedback drawn together in this document and act on it, adapting the current short breaks offer in response to these consultations.
- Explore 'traffic light' system for categorising different levels of need being met by different activities i.e., Red: caters for medically complex needs (e.g., peg feeding/medication administration etc) and offers 121. Amber: some needs which need to be met. Green: minimal support required.
- Families need clear information regarding both Personal Budgets and Direct Payments, plus information on who to contact for help with both.
- All staff involved with families accessing Short Breaks need to receive the same training and be able to provide the same information about the application forms, the allocation of budgets, the provision (specialist or universal) and the appeals/ complaints procedure.
- Provide parents with more information about budgets and whether there are any hidden extras such as mileage, cancellation fees, etc.

- Provide clear information on what they can spend their budgets on, whether it's personal assistants, activities, etc.
  - Provide information on organisations that can help parents with information about employing a personal assistant.
- Provide a list of short break providers and how to access it to all parent carers in BCP consistently through schools, including a list or information about where to find other universal services in their areas.
- Provide parents with more information and contact details on who they can turn to if they have issues or concerns.
- Families need better information about what is available – suggestion was 'could short breaks information be cascaded via Health Visitors, Portage, School Nurses, Family Liaison Officers etc – so that parents don't have to rely on word of mouth'

## So, what happens next

Although the focus groups were about short breaks, we also heard about families who are in urgent need of specialist respite services, including overnight provision. The compounding effect of a lack of adequate services in both short breaks and respite services for a family with a disabled child with complex needs can be extremely negative.

Parent Carers Together look forward to collaborating with relevant Officers in Children's Services, Adult Social Care, PfA Team, the Children's Specialist Disability Service, representatives from Short Breaks Service and other Providers, Commissioners, and Health Services to address the challenges and find solutions to improve Short Breaks, respite and social care provision for children and young people and their families.

We will be looking for parent carers who would like to be part of this work. Please watch this space for further developments or [get in touch](#) if you'd like to register your interest in becoming more involved in this work. We'd love to hear from you.

Finally, Short Breaks cannot be viewed in isolation. The situation of the child or young person's immediate family – financially, socially, geographically and in other ways – is often very relevant to what kind of Short Break provision will best support the child or young person and enable the family to continue to be a key factor in his or her support. It is also important that the family is made aware of all the kinds of support to which they are entitled, such as via carer assessments, support groups and benefits.

When a system that is meant to support children and young people with SEND results in increased stress for families already living with additional stresses, changes need to be made. As always, Parent Carers Together would recommend listening to parents themselves about how to provide the best service possible.

## Appendices

## Appendix 1

A reminder of the legislation

### **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, e.g., 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 mechanically 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 children 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:
  - o undertake education, training or any regular leisure activity
  - o meet the needs of other children in the family more effectively, or
  - o 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 wo may have care and support needs in adulthood. This duty applies to all young people with autism, not just those with an EHC plan.”

Appendix 2

## **Bournemouth, Christchurch and Poole**

### **Parent/Carer Feedback - Short Breaks for Disabled Children**

#### **June and July 2022**

The Institute of Public Care, part of Oxford Brookes University, facilitated two sessions for parents/carers as part of the development of a Market Position Statement for Bournemouth, Christchurch and Poole on Short Breaks for Disabled Children. All information has been anonymised and is part of a wider engagement exercise which will support Bournemouth, Christchurch and Poole in developing the market for providers of short breaks for disabled children.

We would like to thank the parents and carers who participated in the sessions for their valuable contribution and their time.

#### **29 June – Session one**

Introductory comments on parent/carers experiences

- Information hard to access
- Breaks that had been experienced were not felt to be fully inclusive
- Opportunities for schools to be used for activities – this would support children/young people who attend the school as a consistent environment but should also be on offer to children not attending that school. This was felt to be true of mainstream and special schools.
- Felt to be a gap for older young people, post-16 and 19-24 opportunities were seen as a particular gap.

Positives - What’s worked well?

- Trampolining and gym summer sessions are popular and children enjoy them. Children also enjoyed bubbles, farm visit and wild animal session.
- The farm venue was good and also offered craft activities.
- The wild animal session was mainly positive.

What could be better?



- Greater support to help children to know exactly what would happen at the event prior to attending. Often the lead up to the event can be problematic, especially for those children/young people who need to know exactly what will happen, location of fire escapes, toilets, travel arrangements etc. This is particularly true if the activity is a one-off event.
- Providers/venues should be able to include children with allergies and respond to their needs.
- It would be good for children to get the opportunity to meet up with their disabled friends or make new friends from other schools
- Some people are not engaged as there is confusion about what they are entitled to. There was a general sense amongst parents that they do not know what they are entitled to in terms of breaks, even if they are in receipt of Disability Living Allowance.
- Children in special schools have a better offer of what is available than those children with SEND who attend mainstream school provision.
- General sense that there is little creativity in the current commissions 'easiest, cheapest' e.g., trampolining which some children very much enjoy and others do not.
- The wild animal session was positive, although held in a youth club which was not ideal – children not interested in the animals were playing in sports hall which then became noisy.
- Families report that 'if there's no diagnosis, then you are not entitled to short break provision'. Also report a lack of trained one-to-one staff for children with highly complex needs which leads to parents either needing to pay for own one-to-one staff or feeling compelled to stay at the activity and therefore not achieving the stated outcome of having a break for themselves (e.g., to do housework/breaks/work/care for siblings).
- Information provision – information shared via word-of-mouth in parent/carer group or via trusted colleagues. Online and in person information is helpful but some websites inaccessible to parents with their own access needs. EHCP help/support feels similarly inaccessible. After-school activities are offered in mainstream for some children but not fully accessible.
- A 'SEND provision map' provided by one school simply details the extra support in school and does not consider opportunities/contacts outside school.
- Geographical differences – parents reported that far more in Poole, far less in Bournemouth and even less in Christchurch. Parents happy to suggest venues in Bournemouth and Christchurch. e.g., SnowTracks.
- Suggested that there are a number of venues/activities which could accommodate:
  - All ages
  - Whole families
- The programme for short breaks not felt to vary much from year to year. There are reactive options such as those offered a few years ago by Harbour Challenge (especially for young people aged 14 plus) e.g kayaking/den building/archery/animal tracking.

- Transport – even delays in buses can have an impact on some young people. Are there opportunities to capitalise on known home-school transport contract/structures/staff in holidays for short breaks. Separate contract negotiation?

#### Ideas for the future

##### For older young people

- Specific activity clubs which would appeal to children and young people e.g., Lego, trains, art
- Events need to be regular for children with anxiety otherwise it's too much effort to prepare them
- More activities which would allow young people to feel more independent – meeting up with their friends to go bowling or go to an inclusive cinema show Build in independence skill development, such as travel training
- Opportunities – Brockley in Poole Park.

##### For younger children

- Cooking
- Arts (e.g., anime, drawing and music but is not very sporty)
- A computer gaming club
- Whole family activities – cooking, film nights, outdoor picnics
- Gardening – making use of parks
- Mini beasts
- Sensory walk
- Crabbing/rock pooling/sea safety
- Interest groups e.g. Lego/drawing/gaming/model trains

##### Venues and support

- Make better use of venues there are lots of underused buildings and community assets – Slades Park and Butcher's Coppice were mentioned as examples
- Could have 'pop-up' activities – making them accessible to more people. Need to be very local if they are short and utilise existing public sector venues as pop-ups
- Encourage more mainstream activities/venues to include more children
- Conversation with health to see if they could support venues to cater for more complex medical needs

##### Timings

- More half day or full day events which would provide a real break
- Consistency of activities over the summer

#### **6 July – Session Two**

#### Positives:

- Diverse Abilities have a range of services– sensory offer valued e.g., slime-making and also more affordable.
- Victoria School (special school) – offer was good but has now stopped owing to difficulties recruiting staff.
- There is a gap in provision for older children (12 plus?) and a large gap for 19-24 year olds so activities for this age range are welcome. The Exchange information project was useful and covered all geographical areas – this is confirmed as still running.
- Young Carers project more helpful than short breaks for those children who access it. The provision they offer links to employability skills etc and there could be some learning there.

#### What could be better?

- For those children/young people with complex needs, the costs of most provision prohibitive, even if in receipt of direct payments. For very young children, it is difficult to know if any provide one-to-one support. Again, one-to-one support costs can be prohibitive.
- Information - email notification about short breaks is received.
- Linwood offer is good but parents reported that they tend to prioritise their own students for places. Positive when the children know the Teaching Assistants supporting the children who attend both school and holiday provision. There have been some barriers to children with very complex needs attending e.g., staff skills and logistical issues in meeting the needs of some children e.g., tube-feeding.
- Langside school (run by Diverse Abilities) equally have good provision but it is limited to their students.
- One-to-one support is required for many children and the parents need to be able to leave them safely otherwise it does not constitute a break for the parents/carers. Provision better for children with learning difficulties or autism, the offer is much more limited where there are complex physical or medical needs. Still feeling the impact of COVID on provision.
- There are gaps for older children (12 plus?) who want to access the same activities as their peers and feel included e.g., cricket basketball or wheelchair versions of these.
- Issues identified with the administration of medicines/controlled drugs during activities, particularly controlled medicines which need to be locked away. Many providers not equipped for this.

Direct payments: Too many exceptions to how they could be used for some families. Communications seemed to state what they could not be used for rather than what they could be used for. One parent was not made aware that she could access direct payments until her child was four years old.

Overnight breaks: there was a desire for overnight breaks but eligibility is limited/can be waiting lists/not fully transparent about waiting lists or eligibility. Often access support run by charities e.g Lily's Place/Julia's House. It is believed that the choice is overnight breaks or direct payments – not both.

Respite and care are separate but often seen as interchangeable by Local Authorities (not parents generally). Parents can only relax if they trust the staff and need to feel that their children's needs are met.

Eligibility: Not all children eligible for a social worker so the offer is uneven. Communication can be patchy if children not eligible for a social worker and especially if they don't have access to the internet.

Ideas for the future:

Suggested a traffic light system for providers to explain their offer to make communication easier e.g.

Red- caters for medically complex needs (e.g. peg feeding/medication administration etc)

Amber – some needs which need to be met

Green – minimal support required

- 'Coping With Chaos' scheme – this is a valued whole family offer but currently parents attend with young people so not a real break . Could it be combined with a playworker to give parents/carers more of a break?
- Providers to be more transparent about what they can and cannot offer (and funding?).
- Mix needs to be broader – sensory activities welcomed. e.g crabbing/skate park but only if more support provided to be accessible. Weekend sessions such as 'Squidge and Pop' (bubbles etc) offered by a very experienced worker are valued.
- Music and performing arts, which mixes children with and without SEND has been welcomed. Extra support for children with SEND and more innovative to mix all children/yp. Activate Arts and Dorset Community Foundation also could/have provided activities in the past but not currently funded.
- Short one-off activities may not be worth the effort to sort the logistics, especially if the parent/carer has to attend too.
- Transport is a major barrier to accessibility. Dorset Community Transport are a good charity. In the past more organisations had mini-buses. Pop-up activities could help bring activities nearer.

---

### *Contact Us*

*Parent Carers Together (BCP) CIC*

*Company Number: 14691196*

*[louise@parentcarerstogether.org.uk](mailto:louise@parentcarerstogether.org.uk)*

---