



## Parent Carers' Council (PaCC) report on Brighton & Hove Short Breaks and Activities - January 2024

*'A short break is a fun and enriching time for children and young people with SEND, and offers their families the time to work and a chance to rest from caring duties and spend time with siblings.'*

Brighton & Hove City Council is looking into increasing the availability of good quality short breaks and activities. A revised short breaks offer will start in March 2024, the offer will be delivered by different providers across the city-

PaCC organised an online survey in to understand what short breaks and activities parent carers need. The information gathered in this report will be shared with Brighton & Hove City Council (BHCC) to inform them when making decisions about the short breaks and activities offer.

Brighton and Hove City Council are committed to working in co-production with PaCC and we thank Georgina Clarke Green for making families, children and young people with Special Educational Needs and Disability (SEND) at the centre of this review of provision across all areas of need.

PaCC thank families for their feedback, we will ensure the details within this extensive report are recognised by BHCC, with families seeing an improved offer.

### Summary report:

PaCC note that the results of this survey are consistent with the PaCC Position statement shared in August 2022 [PaCC-position-statement-Social-Care-Oct-2022-Final.pdf](https://paccbrighton.org.uk/PaCC-position-statement-Social-Care-Oct-2022-Final.pdf) ([paccbrighton.org.uk](https://paccbrighton.org.uk))

### The key findings of the survey include:

**Parent carers acknowledge ongoing austerity measures;** however, they are explicit that the SEND offer in the city is inequitable compared to children and young people (CYP) without SEND. Parent carers have provided many innovative ideas in the longer report to help shape services going forward with value for money in mind.

**Parent Carers continue to report immense difficulties in accessing short breaks,** families report fatigue, burnout, and crisis at home as a direct result of difficult to navigate social care processes. Parent carers ask that an improved offer across all areas of need includes focus on developing the Local Offer as per the statutory requirement.

**Access to the Specialist Community Disability Team,** remains a challenge for families whose CYP do not have a Learning Disability (LD) ; clear social care pathways for the non-LD cohort are not in place and families frequently report services are not joined up. Families are spiralling dangerously ever downward, with whole families experiencing significant

safeguarding risks. PaCC supports community concerns that the legal criteria to support this cohort is yet to be implemented in a clear way.

**Families are positive about support and provision that is working well for them**, and many organisations within the city are named to reflect in the survey findings to this. Alongside the positive reflections families are extremely concerned about Extratime and Barnardos ceasing their provision, and reassurances are needed that specialist providers are commissioned alongside capacity within in-house provision being increased and developed. Families fear they will have to give up work if services are not replaced. There are concerns that short term contracts with providers and issues unresolved around contract values / financial viability are impeding market development.

**Families highly value support provided by Tudor House and Drove Rd**, but lack of capacity to offer what is needed remains a long-standing issue, there are concerns about a blanket core offer policy. Bed blocking is cited as a problem for young people (YP) moving towards adult services where transition planning is delayed, this problem is also reported at Beech House. Families ask that housing for adults with SEND is looked at in parallel to in-house residential respite.

**Residential respite for CYP with Social Emotional and Mental Health (SEMH)** is asked for by families needing this support.

**Families highlight the legal framework of provision** being tailored to individual family's needs, and blanket policies around core offers to cease.

**Family based care is seen as added value to a short break offer**, this care is reliable, offers good support for families and improved outcomes for CYP are observed.

**Families with CYP with Neurodivergent, Social Emotional and Mental Health and other SEND** needs, cite the need for early help, buddying and mentoring opportunities, alongside whole family support within the social prescribing model.

**Recruitment of staff issues across all care services are of high concern, this includes recruitment for Personal Assistants (PAs)** this continues to compromise access to provision specified in social care plans. A staff recruitment strategy is needed including staff retention planning, and families ask that all social care staff are trained, have access to supervision and support networks.

**Direct Payment Admin processes**, families feedback that these remain a huge administrative burden and ask that these processes are reviewed to reduce stress and increase the time for parent carers to manage the immense difficulties of day-to-day life.

**The Short breaks and activities offer for 16–25-year-olds must be developed**, as opportunities for this age group are insufficient, impacting transition to adulthood outcomes. Families ask that preparing for adulthood processes improve and start earlier, this includes social care working in partnership with housing planning. This needs to be prioritised in the transition strategy being developed by BHCC Health and Adult Social Care (H&ASC).

**Young people with SEND would like access to holidays** without their parents but with the correct support. Young people recognise the difference between what is available for non-disabled young people, and this increases isolation and mental health issues.

**Community provision needs to be more inclusive.** Families want to feel welcomed and confident that staff have been trained to understand the support needs of families with SEND. Wheelchair access remains a barrier to access services and families report a lack of adapted facilities for CYP with physical disability needs.

**More communication for families.** Parent carers ask for regular updates from BHCC regarding social care, and also information re the timeline of actions from the SEND Strategy and the Adult LD Strategy. Families also feedback that replies to emails and requests for assessments are not always replied to in good time.

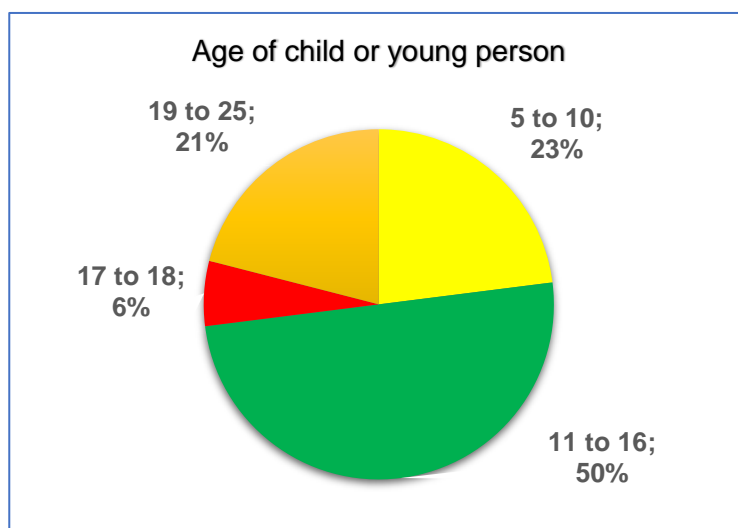
**Families acknowledge that good support and communication from Social Care staff** working across all teams makes an enormous difference to improved day to day life and CYPs outcomes.

## Report:

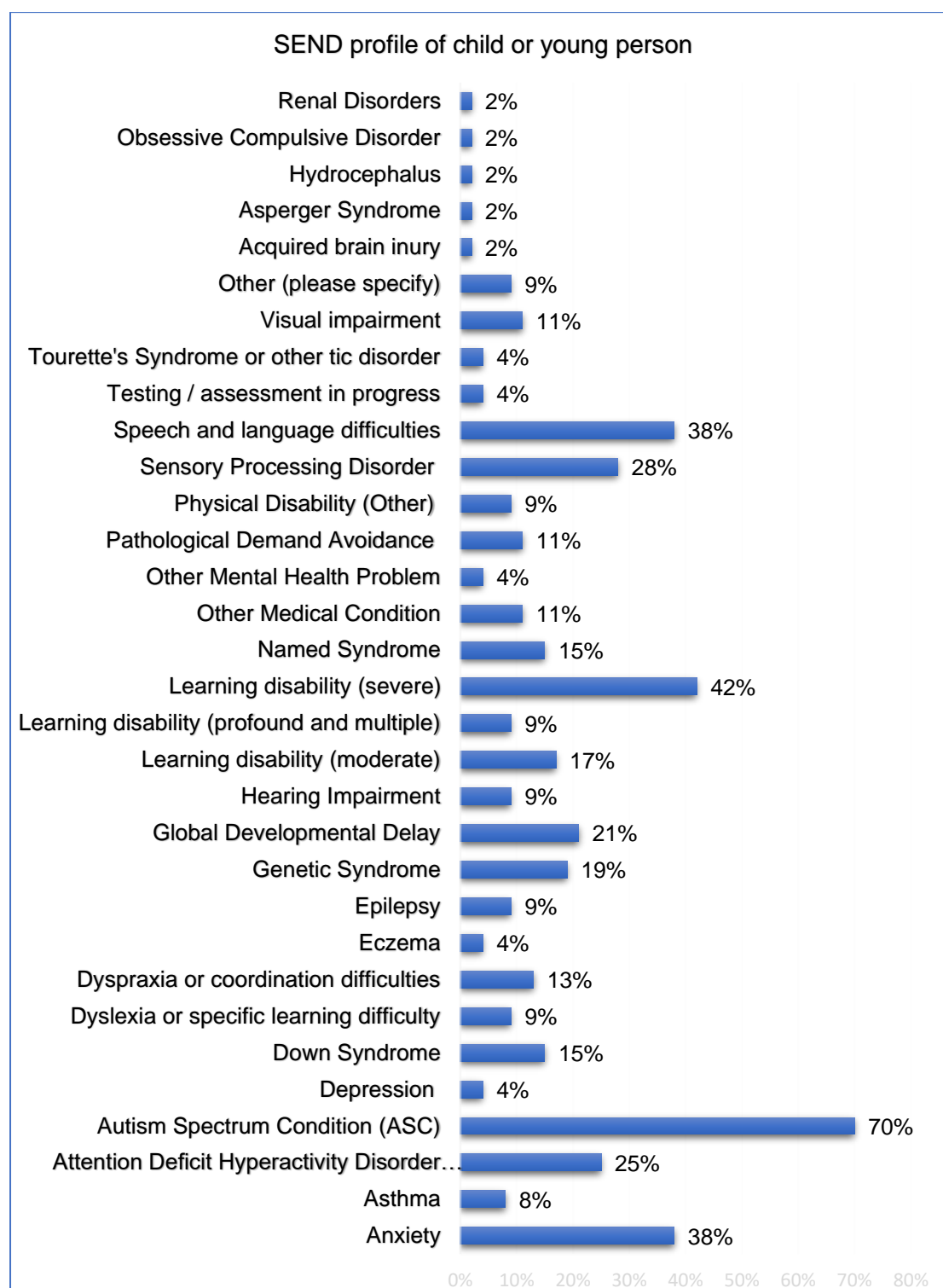
The online survey was launched in the Autumn Term 2023; we received 55 completed questionnaires. Additional feedback was collected at PaCC coffee mornings, PaCC focus groups and one to one conversation between PaCC Reps and parent carers from their communities.

Below here are data and feedback from our parent carers. For a copy of the full report please email [admin@paccbrighton.org.uk](mailto:admin@paccbrighton.org.uk)

### 1) Age of child



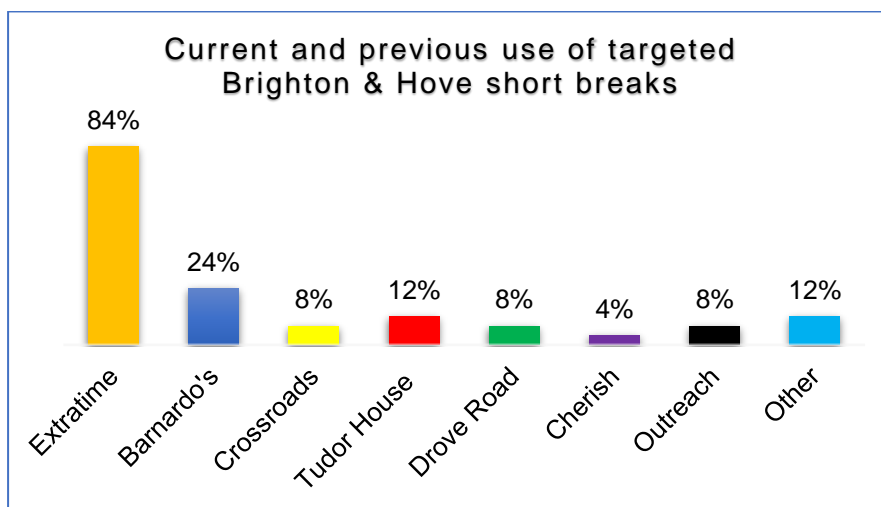
## 2) SEND profile of child or young person



Named Syndrome: 4q deletion syndrome, Angelman's, D I George, KCNH1 Disorder, Pitt Hopkins Syndrome, Tetrasomy 18p, Williams.

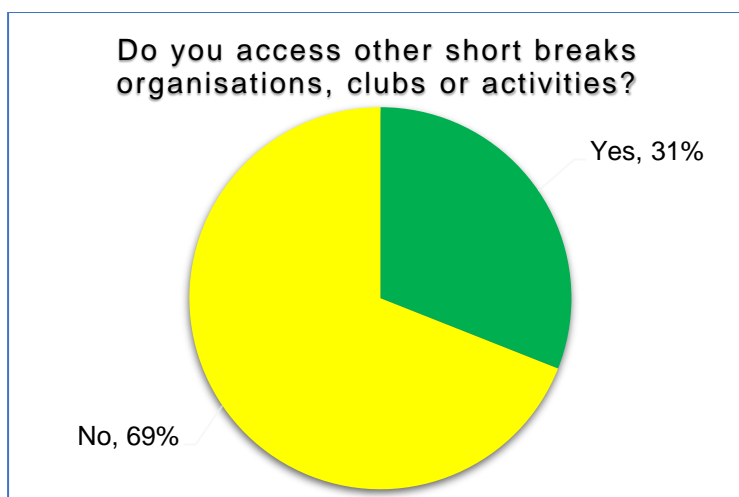
Other: CRMO, Chromosome 18p short arm deletion and cerebral dysfunction and chromosome 4 duplication and heart condition, DDX3X, FASD, Selective Mutism

### 3) Current and previous use of Brighton & Hove Short Breaks



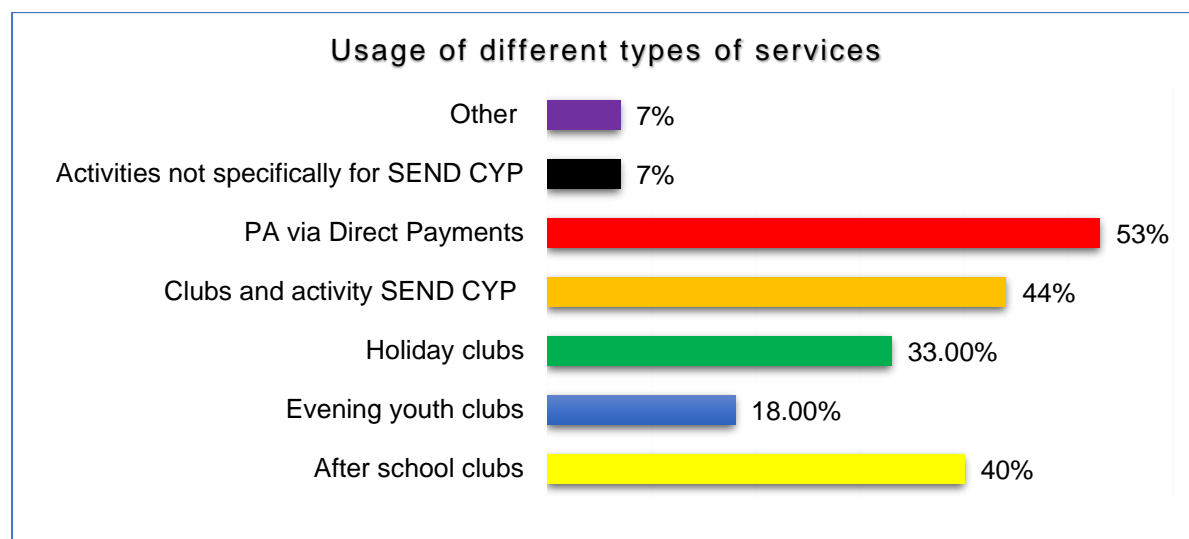
Other: Direct payments day and overnight care, direct payments and employ Pas, shared lives

### 4) Access to other short breaks organisations, clubs, or activities



Yes: DSDT, Brighton Pebbles, Amazing Futures, DSDT, Carousel, gig buddies, mascot café, Different Planet Arts, Ferring, Albion & Parable, Spiral, Kangaroos, Pebbles Brighton, Othello.

## 5) Usage of different types of services



## 6) Are you happy with the services offered?

- **Organisations/ services with positive feedback** - Extratime, Barnardos, Brighton Pebbles, Parable Dance, Albion in the Community, Amazing Futures, Amazeballs, Little Lambs, mASCot café, Down Syndrome Development Trust (DSDT), Grace Eyre Purple Playhouse, Blue Camel Club, Heartventure Cherish, Outreach and Crossroads.
- Positive feedback was received also about Kangaroos, Ferring Country Centre, Aiming High Worthing but families said out of area organisations are too difficult to get to and not accessible by public transport.
- **Families report there is insufficient availability of short breaks and activities** for CYP with SEND, and there is a high level of concern of what will happen now Extratime has closed and Barnardos is closing.
- Recruitment and retainment across all care services is impacting families, a long-term recruitment strategy and investment needed.
- **Wrap around care - pre/post college needs to be offered to allow parents to work** and our CYP to have the same opportunities as neurotypical children.

### Barriers to access short breaks and activities include:

- Families report issues around the Specialist Children's Disability team not recognising non-Learning Disability profiles, and some medical areas of need. The eligibility criteria and processes are unclear, and families want services to talk to each other and be more joined up.
- There are concerns that short term contracts with providers do not give the support needed for the growth and development of overnight short breaks.
- Waiting lists or families told services are full and no waiting list to join.
- Staffing issues cause last minute cancellations.
- Poor accessibility for wheelchair users
- Medical training is needed for staff across all organisations and for PAs, information about how this happens is not clear.
- Organisations/services do not meet the needs of CYP with specific SEND needs.
- Significant gaps in provision for 16+
- Lack of information on the Local Offer- families need accurate information, all held in one place.

- Safeguarding concerns if an organisation offers provision but needs are not being met.

#### Residential Short Breaks Drove Rd and Tudor House received positive feedback:

- Families report these residential services are their only reliable source of a break.
- Families raise concerns that without an increase in residential overnights capacity more families will be forced to take the only remaining option of their CYP going into full time care.

#### After School/College Clubs – Mainstream:

- Positive feedback in primary schools including good feedback on inclusion funding to support children needing 1.1 support.
- High levels of concern re lack of after school clubs and activities that CYP with SEND can access at secondary school and college.

#### After School/College Clubs – Specialist settings:

- Currently an offer in the West Hub but not at the East Hub.
- SEMH offer needs to be developed.
- 16 + offer appears non-existent and needs to be developed.

#### Personal Assistants (PAs) employed via Direct Payments:

- A few families report that this method of support can work well, whilst a high number of families have lost faith in the PA/Direct payment model as it has not worked for them for a lengthy period of time.
- Those issues include:
  - a significant level of concern re lack of PAs, including those with specialist experience.
  - PA pay is too low including the overnight rate, making it hard to retain and employ staff. Potential PAs enquiring about jobs with families say they can earn a much better hourly rate working in supermarkets, cleaning etc,
  - The council must recognise that for many families, PAs need a high level of expertise, and this is not reflected in the pay rate. A basic and higher rate of pay to reflect the complexity of the CYPs need is needed.
  - Families need trust and greater flexibility to use their DPs as laid out in the national DP guidance, including saving their DPS to enable longer breaks e.g.: after surgery, family crisis, to take a proper break etc.
  - BHCC have been promising to introduce personal budgets, this needs to progress.
  - Processes for families are too onerous on top of the caring role i.e.: advertising, interviewing, extremely high regular admin/paperwork tasks, families ask for an increase in clear support for this from both Possability People and People Plus.
  - Training- PAs need medical training where applicable, ditto personal care training.
  - More information is needed to support employing PAs e.g. being unreliable or untrustworthy there are no procedures or any support on how families can deal with these issues.
  - Implement a light touch assessment process for families that are coping but need some access to services and who do not need or want social care assessments as the gateway to services. This will free social workers up to support families most in need.
  - The Disclosure and Barring Service (DBS) process does not work efficiently, families lose PAs in the lengthy timescale/months. Families ask why BHCC do not

recognise existing DBS especially when the person works within BHCC. Families say other organisations use a portable DBS electronic process that is quicker.

- PAs need more support and a place where they can meet and talk with other PAs
- Less people are driving meaning many PAs cannot take CYP out.

#### Concerns around language/terminology for Short Breaks and activities:

- Families request that BHCC ensure that there is a clear definition of what constitutes a short break as per the legal framework, and that short breaks offer meaningful and sufficient lengths of time for parent carers to have the respite time that they need and to be able to work e.g.: a night out without CYP is a break, a self-care day is a break, weekend respite is a break. The required number of hours to fit in work hours.
- Community based activities are essential for CYPs wellbeing and development, but these are not breaks; they involve dropping off, hanging around until pick up, supporting CYP at the activity etc.

#### **7) Do you currently access short breaks with Continuing Health Care (CHC) Funding?**

- Most respondents said they are not accessing the CHC funding whilst others are unaware of this funding and would like more information about Continuing Health Care
- Some of the family's feedback that their CYP have complex health needs.

#### **8) Barriers to accessing Brighton and Hove Short Breaks**



I have been told my child/young person is not eligible: child-staff ratio not sufficient; CYP not independent enough to access the service; CYP without a diagnosis of LD; services do not think the family is in crisis



My CYP is on a waiting list for: Extratime Youth Club; Extratime; Kangaroos; Tutor House

The short breaks available do not meet my CYP's needs: CYP cannot cope with busy environment; Covid had a massive impact on accessing short breaks 1:1 not available; no overnight respite suitable.

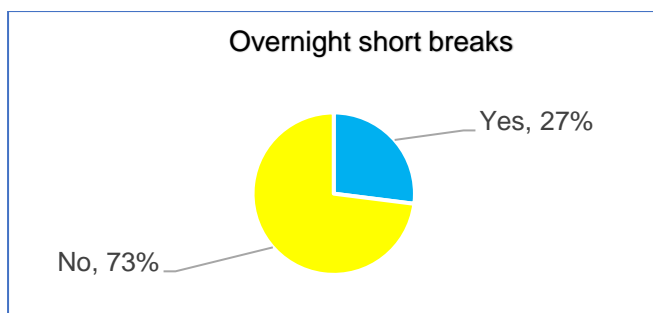
**9) When do parent carers need a short break? Ranked in order of importance:**

1	Holiday schemes
2	After school clubs
3	Direct payments with a PA
4	Evening care
5	Family based overnight care
6	Domiciliary care (sitting) in child's own home and community
7	Outreach
8	Other

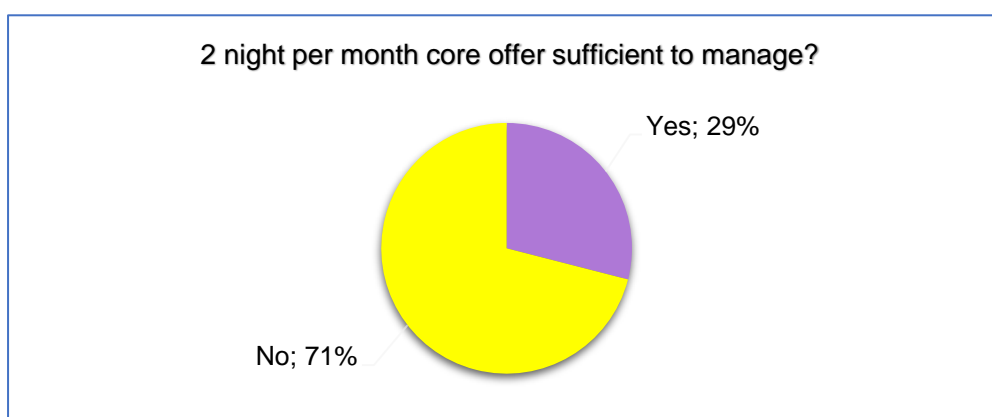
**10) Which of these short breaks are most important in the future? Ranked in order of importance:**

1	Holiday schemes
3	Direct payments with a PA
2	After school clubs
4	Evening care
5	Family based overnight care
6	Domiciliary care (sitting) in child's own home and community
7	Outreach
8	Other

**11) Have you been offered overnight short breaks?**



## 12) Is the 2 nights per month core offer sufficient for your family?



## 13) If 'No' to Q12, what do you need?

### Processes and eligibility

- Clearer information on all social care processes, assessments, and eligibility criteria.
- A sufficient pool of available PAs who are sufficiently skilled across all areas of complex needs and health needs.

### Residential overnights

- More overnights per month at Drove Road and Tudor House or elsewhere
- Greater flexibility around when the overnight is and more weekend nights.
- Siblings benefit from residential overnights as it means as a family, we can do more with them, the core offer limits this too much for our other children to access the wider community.
- Beech House is not suitable for some YP over 18. There does not seem to be any alternatives.
- Families are told Beech House is full, and families report bed blocking as planning for moving into housing accommodation is delayed and housing options are limited.

### Support For Parent Carers

- Parent carers want more Mental Health support for themselves throughout crisis situations.

### Community and organisation support

- Outreach to be accessible so CYP can access the community without parental support.
- Support for CYP who are out of school so parent carers can work.
- Meaningful support for Emotionally Based School Avoidance (ESBA) CYP
- CYP who present as being anti-social need more to do in the city, not all CYP like groups.
- Holiday clubs for CYP with SEND across all areas of need.
- Holiday clubs for over 16s to 25 years old
- Access to more inclusive affordable activities as a family, as well as access to relaxed events, e.g. swimming pool/soft play/ other events locally (SEND sessions in public services are often scheduled at difficult times e.g.: early morning or evening) and public sessions are too busy and noisy for CYP with SEND.
- More support for siblings is needed, their lives are very compromised.
- More performance, music, art activities that involve theatrical based organisations like Same Sky and Different Planet Arts. These organisations 'get' our children, and ensure they make the most out of life and can encourage them to try new things.

#### Transitions and preparing for adulthood.

- Families want better pathways and more timely transitions to adult services and increased Post 16- 25 Short Breaks.
- Families want better housing planning for the future.

#### Families raised issues and concerns around the core offer.

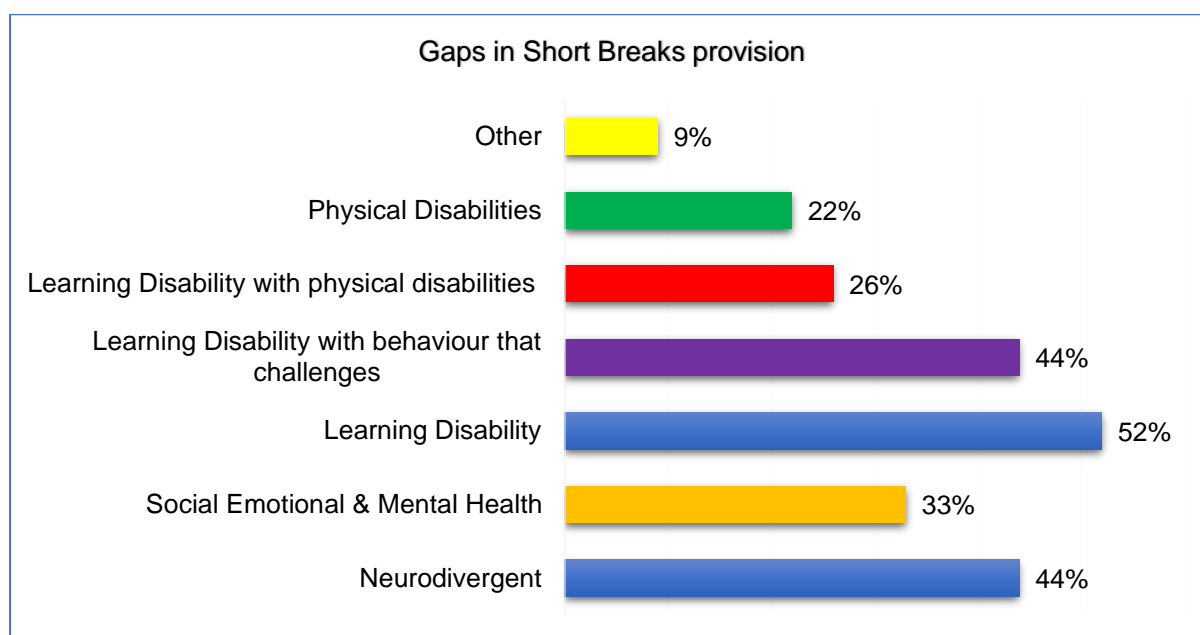
- Different families have very different needs, a blanket core offer is unlawful.
- The council's policy of reducing respite to a core offer means CYP and staff do not have the time to develop meaningful relationships. For CYP with complex needs, anxiety, and specific medical needs this is concerning and unworkable.
- The narrative of a core offer is unhelpful, families being told they are being supported when the reality does not reflect this. Families do not want the relationship with decision makers to feel like gaslighting.
- A reduction in residential overnights can remove the Looked After Child (LAC) status for certain CYP which increases the workload for other frontline services.
- Some CYPs needs are so high and two nights per month is not a sufficient break to cope and recharge for the rest of the month.

### **14) What other types of support would help your family cope better?**

- More overnight respite services
- More inclusive, affordable, accessible, and local family activities at reasonable times of the day, during school holidays and at weekends
- More daytime care for children who are not in school due to EBSA, to enable parents to work.
- Holiday clubs in the school holidays and after school clubs that are suitable for CYP's needs to enable parents to work.
- More information on activities suitable for children, teenagers, and young adults with SEND
- Help with the task of organising activities for the young person.
- More activities young people can access without a parent needing to be present.
- Holiday schemes suitable for wheelchair users
- Someone to take the young person out for the day to activities.
- Transport to take the young person to activities.

- More involvement with organisations that understand the needs of the young person and can offer a variety of experiences and activities, giving our young people the opportunity to try new things.
- Greater flexibility and trust in parent carers to use Direct Payments package as a personal budget, enabling parent carers to choose how best to meet their young person's needs.
- An easier assessment process to enable parent carers to access services more easily for their young person, rather than lengthy social care assessments.
- Someone to talk to in crisis situations.
- Transitional supported accommodation to prepare YP for full-time supported living in the future.
- Overnight respite to be on weekend nights rather than weekdays, giving a block of time to enable them to go away.
- PA overnight respite in the home, to reduce disruption for their young person, with the parent carer then given the opportunity to have an overnight funded stay elsewhere.

### 15) What are the gaps in Short Breaks provision and what would you like to be developed?



#### Neurodivergent

Attention span makes it difficult to access many mainstream games activities etc; buddy schemes for high functioning YP who perhaps need a lighter touch support; lack of understanding of the complexity of ND needs; PA support, mentoring; possibility of overnight respite; same as for LD; very tricky to get this right for a 'group' of children 1:1 is much better; leaders trained in PDA

#### Social Emotional and Mental Health

Parent carers ask for Early intervention and family support within a social prescribing model; 1:1 support; key worker mentoring; PA support; short breaks with staff with specific SEMH experience. A greater focus on the needs of CYP adopted from care, better provision for

CYP living in kinship arrangements. Improved joined up working across education, health, and social care, including voluntary sector.

#### Learning Disability

Sufficient services so that parent carers do not have to give up work; services to consider the groupings of CYP attending a service; more contract care placements; focus on specialist staff recruitment and staff retention; mainstream activities to be more inclusive for CYP with LD

#### Learning Disability with behaviour that challenges

Too many organisations do not offer personal care which excludes CYP; an increase in trained staff in this area; more support for families who need to recruit PAs on a 2-1 ratio; Families report they struggle to get heard. Families report concerns that issues around challenging behaviour are sometimes wrongly identified; parent carers report the root cause of behaviour is distress, due to SEND needs not being met. For some families, parenting courses mean time is lost and crises accelerate, the focus needs to be addressing and meeting SEND needs.

#### Learning Disability with Physical Disabilities

Families report feeling isolated as the citywide offer is so inequitable for CYP with SEND compared to neurotypical CYP; Parent carers want BHCC to forecast needs going forward so that services are there when they need them; Staff must be inclusive to enable CYP with physical disabilities and motor skills deficits to join in

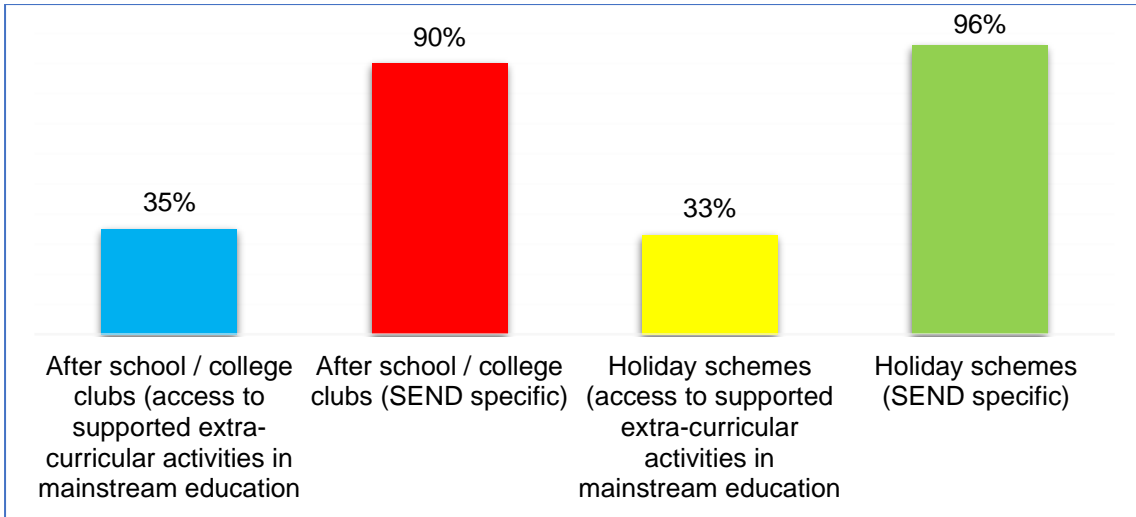
#### Physical Disabilities

Families feel forgotten, everything is focused on able bodied CYP; medical training for staff is a barrier to accessing services; organisations and groups are not inclusive; BHCC free up or create housing stock and recruit paid live-in carers to provide family-based care this would be more cost effective than crisis agency placements.

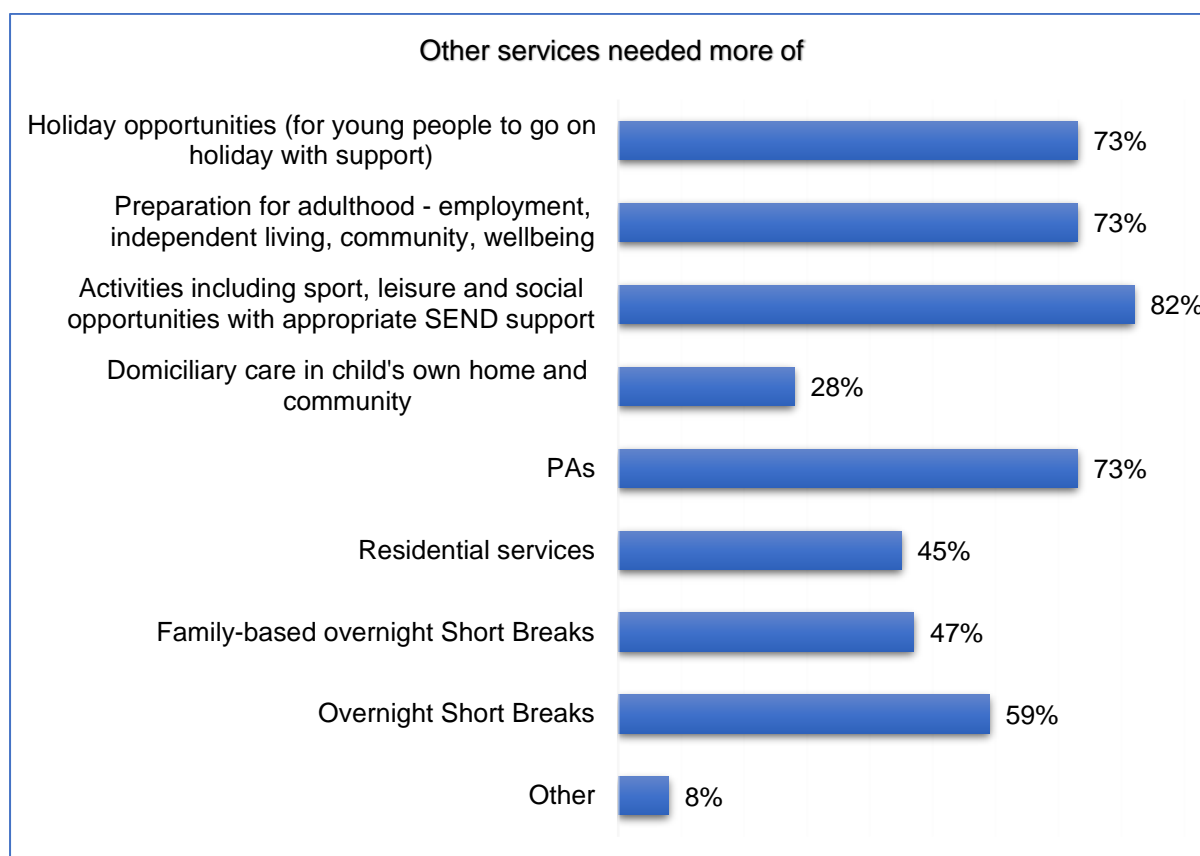
#### Other

Activities that bring the whole family together; more activities for CYP with PMLD; more sensory sessions; staff trained on Makaton; a service level agreement about health care training to all care settings; a recommendation to look at the Wakefield Mockingbird care support model [Mockingbird - Care4us](#)

### **16) What after school / college clubs / holiday schemes services do we need more of in the city?**

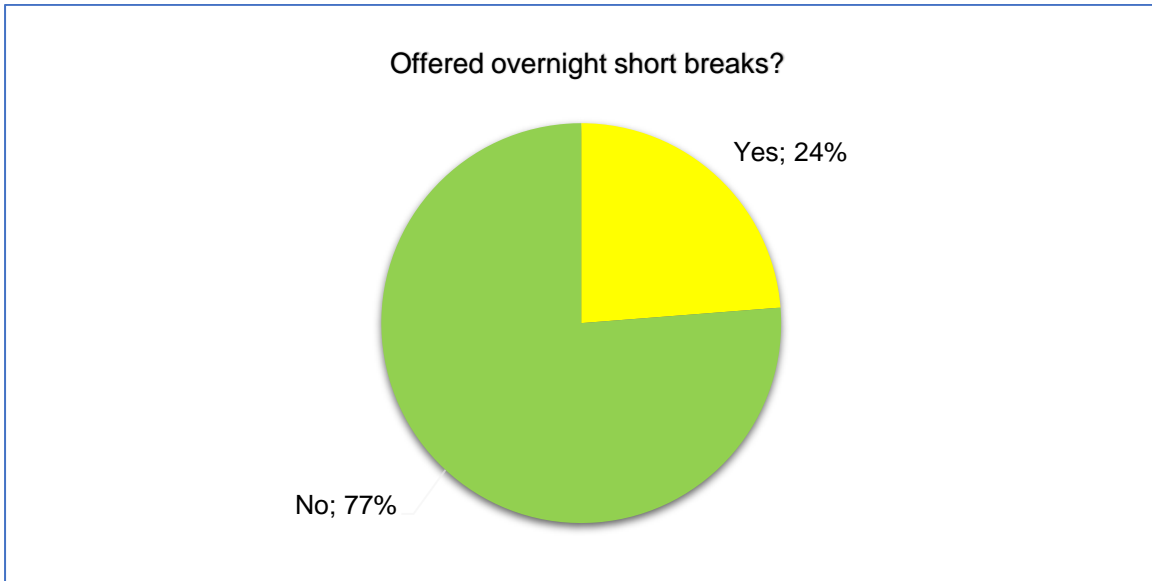


## 17) What other services do we need more of in the city?

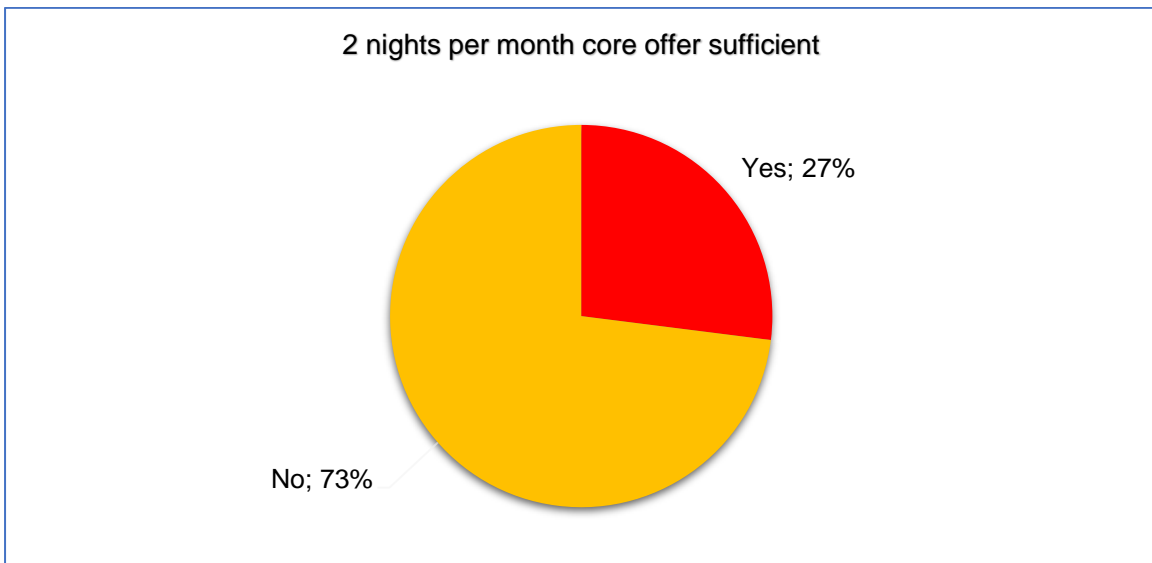


- BHCC could employ more staff that can work across care services, including PAs.
- BHCC should consider freeing up a LA flat where parents can stay when overnight care is in place in the family home.
- Domiciliary care in CYPs own home alongside community domestic services e.g.: a laundry service employing SEND young people.
- It would be good to see more Special Olympics in Brighton and Hove.
- Holiday opportunities (for young people to go on holiday with support) e.g. Lodge Hill in WSCC has holiday accommodation that could be rented by groups of friends supported by PAs. Families say YP do not want to go on holiday with them, they want independence with the correct support.
- Day trips for families with CYP with SEND and or PAs.
- Day trips for YP with SEND with PAs
- Longer term contracts needed to support growth and development of overnight short break placements and investment needed in family based short breaks.
- A little bit of overnight care investment started at a young
- Family based care is well supported and there is longevity of placements compared to sticking plaster approach of DP's. Carers need to be valued and recognised for the unseen "soft" support they provide to families- emotional support to parents; health coordination; benefit application; housing support etc.
- More family-based support and activities as per Brighton Pebbles.

**18) Have you been offered overnight short breaks?**

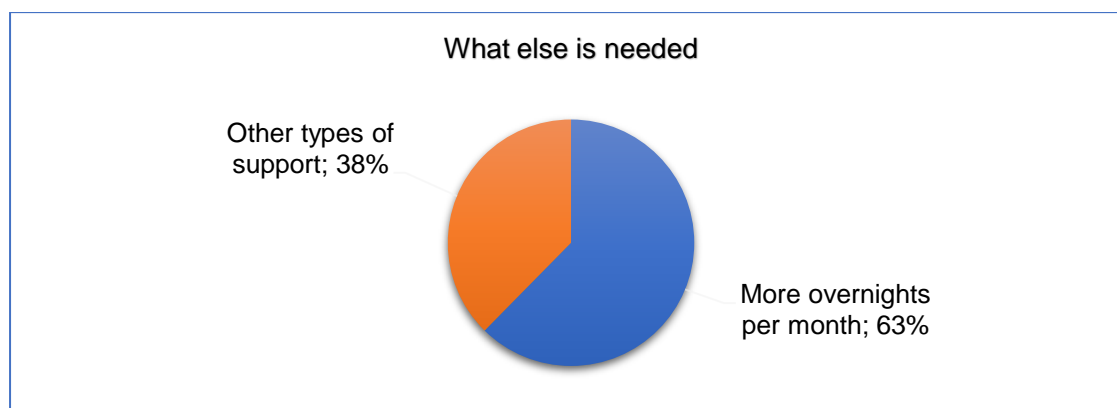


**19) Is the 2 nights per month core offer sufficient for you to manage as a family?**



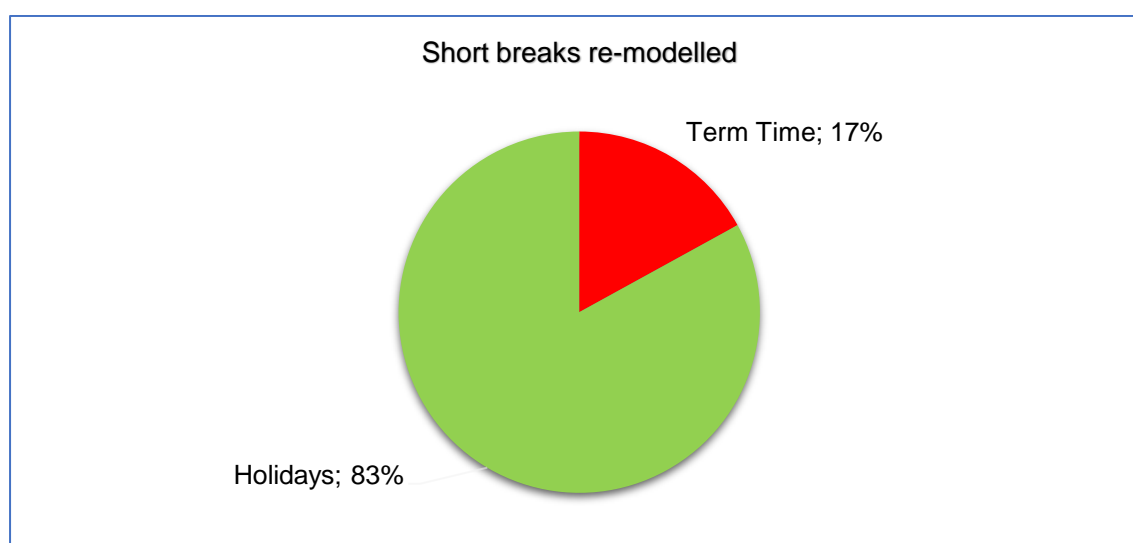


## 20) If replied 'No' to Q19, what do you need?



Overnights: some parent carers ask for between 2 and 3 more overnights per month, whilst some others ask for between 7 to 10 overnights per month.

## 21) How would you like to see Short Breaks remodelled to enable parents, children, and young people to achieve more ordinary lives?



Term Time: after school provision 5 days a week; evening breaks; help so that we can go to work.

Holidays: enable families to have a short holiday without the SEND child; holiday clubs attended by SEND CYP and neurotypical; group holidays for YP with carers to broaden their experiences, greater flexibility of offer; mainstream providers to be trained on how to communicate with SEND families; a centre where parents can drop their CYP and not worry about; youth clubs where CYP can meet and socialise day and evening during college holidays; routine throughout the year; SEND CYP specialist clubs for working parents; more DP funding

## 22) How can after school and holiday clubs be strengthened using inclusion funding?

- All clubs to have an Inclusion Policy and a clear booking procedure so to be able to assess children's needs.
- Increase discount for SEND children at existing clubs.
- More premises to be allocated and secured.
- Trained staff who are well rewarded for their hard work.
- Staff to be trained in tube feeding.
- A PA-funded worker who meet children at school/college gate in small groups.
- Travel should be provided by school/college or alternative minibus arrangements available when a child access holiday provision outside Brighton & Hove, i.e. East or West Sussex
- Smaller groups
- Mixture of activities; some to be available on a regular basis so children become familiar with routine and peers.
- Specific holiday clubs for LD/LD autism and challenging behaviour
- Same provision as in mainstream
- More provision in secondary schools

### **23) What is important to your young person when thinking about transition planning and post-18 short breaks?**

- Transition planning to happen on time, not after a young person reaches 18.
- Information on what's available /clearer pathway.
- Pathways to independent living and support for all cohorts. We need so much more by way of work experience and apprenticeships, and supported/independent living choices for young adults, these should be built into social care planning.
- Planning - having something in the diary weekly so children can look forward to it and relax at home the rest of the time.
- Finding what the children want to do.
- Easier process; panel to be more transparent; what is the process and criteria.
- Less outsourcing to profit making private companies.
- Parents to be involved in commissioning of supported accommodation.
- More respite homes which should reflect the children's aspirations, e.g. have some flats where children can sleep over, learn domestics and other skills.
- Promote independence.
- Friendships outside the family
- Same level of short breaks should roll over and, if needed, to be increased
- Specific holiday resorts, like Centre Parks (so families do not feel different all the time) or a holiday home that families can book.

### **24) What is working well with existing Short Breaks providers and activities your child attends?**

- PA makes an enormous difference.
- Land to build housing for YP - evidence business plans from other Counties.
- Inclusive, aspirational, well organised, and staffed providers
- Properly funded; reliable
- Providers who collect children from school.
- Dance and drama; would like to do basketball but she needs 1:1
- Hertfordshire; lots of groups; housing bought specifically for YP with funded carers.
- Extratime
- The Simon Trust

- Tutor House (but not long enough – not proper mini break)
- Beach House
- Drove Road
- Brighton Pebbles
- Amazing Futures
- Ambito Day Centre
- Calvert Trust
- Different Planet Arts
- Oily Cart AMICI
- Parable Dance
- Ferring Outdoor Centre
- Sailability
- Othello (they offer 1:1)
- Down Syndrome Development Trust (they collect children in their minibus)
- Barnardos Support Worker (they base children's respite from the children home)
- The Newman Holiday Trust changes lives  
<https://www.newmantrust.org/holidays/holiday/south-holiday>
- Freedom Leisure (SEND only session/small group)
- Mockingbird - Trainee Contract Carers buddied with experienced Contract Carers In the U.S.A there is an established University Halls of residence model which acts a springboard to supported accommodation.
- Spiral Holidays
- Outreach (good but understaffed)
- Little Lambs kindergarten
- Oreland (for children with Williams syndrome)
- Camp America model