

PaCC Position Statement: Brighton and Hove City Council's proposed budget 2018/19

Date: 30.1.18

This is the response of the Parent Carers Council (PaCC) to the Brighton and Hove City Council's proposed budget 2018/19

PaCC recognises the difficulties BHCC face when making decisions to set the budget for 2018/19. We welcome Officer's and Councillor's commitment to listening to the voice of parent carers in the city.

Families, Childrens and Learning Directorate Proposals Proposed saving of £150,000 from...

PaCC request that the short breaks budget is protected at current levels. PaCC consider that the proposed savings targets related to short breaks and social care (total £150,000 p.159) are unachievable; due to there being significant unmet needs in the city.

We outline our reasons below:

Families are at breaking point PaCC members report that too many families in the city are at crisis point. Significant difficulties are faced by families

- There are about **3,400 children** with significant special educational needs or disabilities in Brighton and Hove
- **Money worries:** 55% live in or on the margins of poverty. 36% say their caring role means they can't work and 32% have had to take less senior roles or reduce work hours. 17% of parent carers reported skipping meals as there wasn't enough money to feed the whole family
- **Health issues:** 70% have experienced physical or mental ill-health as a result of their caring role
- **Relationship breakdown:** - 36% are single-parent families.
- **Feel isolated:** 46% report that they don't have enough social contact and a further 19% report that they have little or no social contact and feel isolated
- **Exhaustion:** 43% haven't had a break from their caring role in the past year and 32% said that they have never had a break. Only 37% say they get a good night's sleep

(Data from :Amaze parent carer questionnaire 2017)

Long waiting times PaCC members report that capacity within the children's disability team is already low and waiting times for assessment are long. A significant number of parent carers report that they are told by the children's disability team, that an assessment will not take place unless there is a family emergency. Families are being pushed to the brink of crises, so we are very concerned reducing the team's capacity further will be detrimental to the essential front line provision of short breaks.

Insufficient overnight respite PaCC members report that families' need for residential overnights is high. Historically, budgets at Drove Rd and Tudor House are overspent and provision limited.

Lack of personal assistants PaCC members report huge challenges to recruit personal assistants (PAs) who are experienced and trained appropriately. Families report that PAs are unwilling to work for the small number of hours that form many respite packages. Retention of PAs for families with CYP with challenging behavior in particular is very poor. PAs leave quite quickly as the demands of looking after the CYP are too great. The parent/carer community also reports that the role of parent carer as an employer is incredibly onerous, and some parent carers cannot manage this added responsibility.

New hubs and respite provision The budget papers report that they are hoping to extend and vary the short breaks offer by asking the new Heads of the 'hubs' (being set up in the East and West of the city) to provide 'extended day' care/activities. The community of parent carers is waiting to hear who will be able to access these and what they will look like and we very much want to be involved in their co-production. The PaCC community is clear there will be an ongoing need for residential overnight short breaks for those families who need a longer break (due to their CYP significant additional needs, including very challenging behavior and or 24/7 medical needs) and we would like a commitment that these remain an essential part of the short breaks offer.

PaCC Recommendations:

PaCC welcomed Regan Delf's commitment to protect the number of short break residential overnights in the previous year's budget. PaCC seeks reassurance that this commitment will be maintained.

PaCC welcome Brighton and Hove's continued commitment to reduce agency placements, PaCC fully supports CYP being kept in the city, close to their families.

Recommendations:

- PaCC Reps must be part of the co-design/co-production of the council's review of the way respite and short breaks are delivered. We would like to see a project timetable for this work and project plan. The short breaks review must look at all options, including the use of capital funding to build a new, fit for purpose, residential short breaks and social care building in the city.
- The current costs per overnight short break are excessive and we believe can and should be lowered to allow the budget to benefit more families.
- The project should also include a commission to improve PA recruitment, training and retention, in the city.

Our final recommendations to inform you further

Watch the powerful Amaze film. <https://youtu.be/HFfRI8d9u90>

We urge you to talk to your colleagues in the council who have recently visited the residential short breaks respite homes in the city, Drove Rd and Tudor House. Councillor Andrew Wealls, Cllr Dan Chapman, Cllr Caroline Penn witnessed first-hand the two excellent residential provisions in the city, and reported how informative these visits were; a sobering experience in understanding the impact of caring for a CYP with challenging behavior and/or 24/7 medical needs.

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PaCC feel that it is important to offer to facilitate a focus group with a small group of councilors and parent carers, so that councillors can fully understand the issues for families around respite provision prior to finalising the budget.

We thank you again for taking the time to read our position statement and looking at the supporting documentation. Case studies and quotes from parent carers can also be emailed as supporting evidence.

Please do get back to PaCC with any questions and do let us know if you would like to attend the social care focus group with parent carers.

PaCC have welcomed the opportunity to join the Project Groups in co-designing more detailed proposals. We support their inclusivity and aspiration for co-production with all stakeholders. The PaCC representatives have talked widely with other parent carers to harness a wide range of views. Our position statement is a summary of these views, and will be used to inform our contribution to the Project Groups.

PaCC welcome any communication on any of the issues contained in this document. You can contact us by emailing Fiona England

*PaCC Chair fiona@paccbrighton.org.uk or calling **01273 234862***

*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, 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 about **350 signed up members**. This position statement was developed through discussions with our Steering Group members and our nine partner groups: Barnado's Link Plus, Brighton Pebbles, Extratime, Autism Support and Awareness Promotion (ASAP), mASCot, T21, Sweet Peas, Amaze Face 2 Face and Children's Hearing Services Working Group (CHSWG).*