

# Short breaks provision in Camden: Parent Survey Results

February 2015



## Introduction

Healthwatch Camden heard from families of children with special educational needs that they were worried that the provision of short breaks may be affected by the budget cuts that Camden Council has to make from 2015.

Short Breaks (previously known as respite) are activities provided after school, at the weekend and during school holidays which allow children and young people the opportunity to do something independently from the parents who care for them. They also give parents and carers a break from their caring role. A requirement to offer short breaks is set out in regulations<sup>1</sup> (see footnote) and in national research carers have always strongly valued short breaks.

The impact of continuing cuts to core government funding, combined with unavoidable cost increases related to demographic and other pressures, means that the Council is facing a projected annual budget deficit of £70m by 2017/18. Decisions about how to save the first £30m of this budget gap were taken in September 2014. In December 2014, Camden Council set out proposals to make further savings over each of the next three years.

Camden Council says it has sought to minimise the impact on services for vulnerable children, including short breaks for children with disabilities. However, cuts in the region of £94,000 in 2015/16 and a further £190,000 by 2017/18 are being proposed. Statutory consultation is underway to review the short breaks local offer and update the Camden short breaks statement 2015-2016.

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<sup>1</sup> Breaks for Carers of Disabled Children Regulations 2011; these require local authorities in England to set out a range of services which will help parents of disabled children have time away from their caring responsibilities. Local authorities must have prepared a statement for carers which sets out the range of services above, eligibility criteria, and how these services are designed to meet the needs of carers in their area. Camden Council's statement can be found on the Local Offer web pages [here](#). Some short break schemes may be described as 'universal', which means they are available to all children and you don't need an assessment to access them.

For more information about short breaks law and research see the Every Disabled Child Matters website at [www.edcm.org.uk/campaigns-and-policy/shortbreaks](http://www.edcm.org.uk/campaigns-and-policy/shortbreaks)

Healthwatch Camden conducted a survey of parents who are currently benefitting from short breaks provision in Camden because we wanted to understand what contribution short breaks are making to the health and wellbeing of local families.

On the basis of the responses, Healthwatch Camden makes **three recommendations** to Camden Council's Children, Schools and Families Directorate.

The formal response to the recommendations from Camden Council is attached. (Appendix 1.)

We hope that this report of the survey results will help to give local parents and families a strong voice in the current decision making process around short breaks provision in Camden.

## Methods

Around 310 children are currently eligible for Camden's short break services.

This represents approximately one third of the total number of children with Special Educational Needs or Disabilities in Camden (900 - 1,000).

Camden's Short Breaks offer incorporates a range of different types of provision including places on specialist play schemes that have been contracted by Camden Council, support from an agency worker, access to a play provider and direct payments with which families can choose to purchase the short breaks support they chose. There are also short breaks opportunities available within mainstream provision through Camden's universal or mainstream services including the children's centres and the leisure centres or activities provided by the Integrated Youth Service or the Camden Sports Development Team with support from a carer.

As part of the short breaks offer there are five local organisations that currently have contracts with Camden Council to provide short breaks through specialist play schemes. These five organisations are: WAC; PACE; Action for Children; I Can Dance; Swiss Cottage School. A sixth organisation, KIDS, provides specialist play workers. Between them, these six organisations provide a service to approximately 140 families. The children of these 140 families represent a subset of the total 310 children eligible for some form of short breaks provision with the remainder accessing short breaks of different kinds such as home based short breaks, support from short breaks agencies and overnight provision or by allocation of a direct payment. It is important to note that some of these families have more than one

eligible child and that some eligible children access services from more than one provider organisation.

In designing our research, Healthwatch Camden wanted to work in partnership with the local organisations that have direct contact with the families that use the short breaks services.

We contacted all six of the organisations that currently provide specialist play scheme/play worker short breaks for Camden and asked them to conduct the questionnaire with their own service users on behalf of Healthwatch Camden. The questionnaires were not designed to elicit feedback on the service provided by the specific partner organisation but on the totality of the short breaks provision.

The survey included questions that used a multiple choice five point agreement scale as well as open response questions.

Completed surveys were returned to Healthwatch Camden and the results collated and analysed.

A copy of the questionnaire is attached as an appendix to this report (Appendix 2).

## Survey Response

Total completed surveys returned = 85

Total number of parents surveyed through six partner organisations = 140 (approximately)

Among those parents surveyed, we had a high response rate of approximately 57%

This means that the results of this survey are informed by feedback from the families of approximately 27% of all the children currently eligible for short breaks in Camden.

Respondents were asked to complete only one survey per family. Some parents have more than one child eligible for short breaks. Therefore a single completed questionnaire could represent more than one child in receipt of short breaks services.

Some families access short breaks from more than one provider. The possibility that some parents completed the survey more than once cannot be excluded. Duplication would affect the survey response rate (% total eligible). However, potential impact on the findings is judged small due to levels of consensus across responses.

The number of questionnaires returned by each partner organisation was as follows: Action for Children (6); PACE (18); Swiss Cottage School (8); I Can Dance (7); WAC (6); KIDS (40).

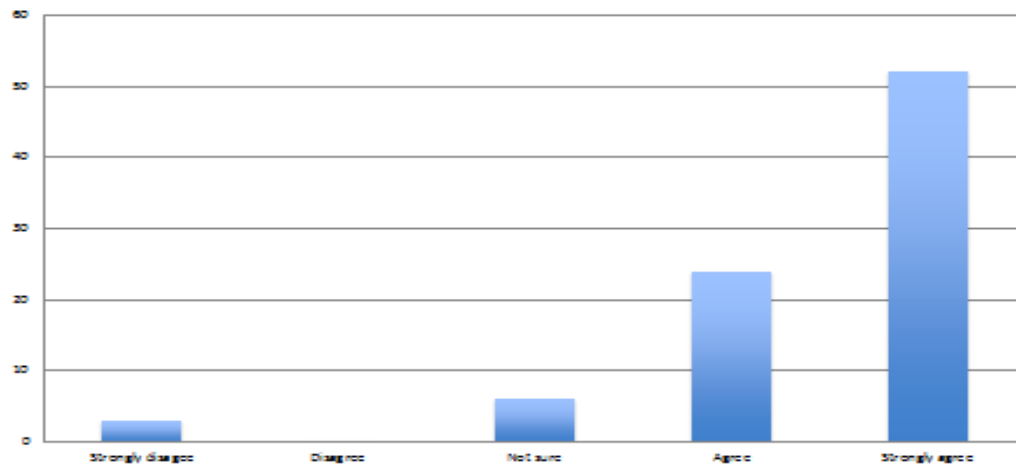
## Results

### Key Findings

- 93% of parents agreed or strongly agreed that the short breaks help them stay emotionally and mentally strong
- 89.4% agreed or strongly agreed that the short breaks help them stay healthy
- 96.5% agreed or strongly agreed that the short breaks help their child with special needs
- 95.8% (of those with other children) agreed or strongly agreed that the short breaks helped the other children in their family
- A reduction in the short breaks provision would contribute to increased stress and family pressure
- Anxiety levels at the prospect of a reduction in short breaks provision are already very high
- Families fear growing mental health problems may be a consequence of reductions in short breaks provision
- A reduction in short breaks provision would lead to a reduction in the capacity of families to cope with their caring responsibilities.

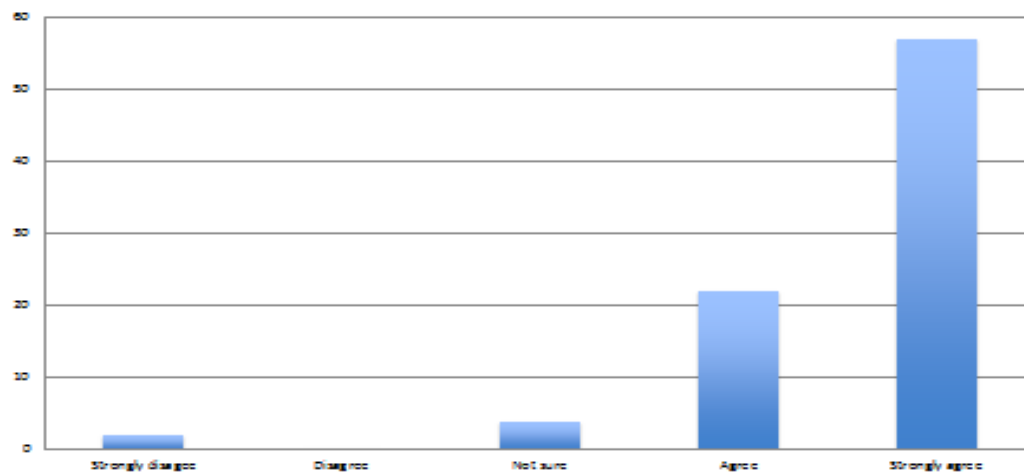
## Data analysis

### The short breaks help me stay healthy



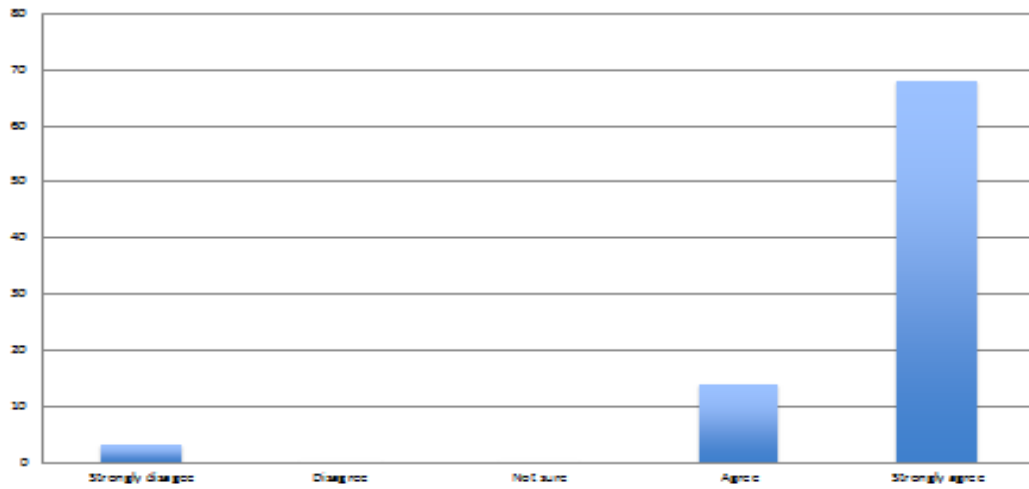
89.4% agreed or strongly agreed that the short breaks help them stay healthy

### The short breaks help me stay emotionally and mentally strong



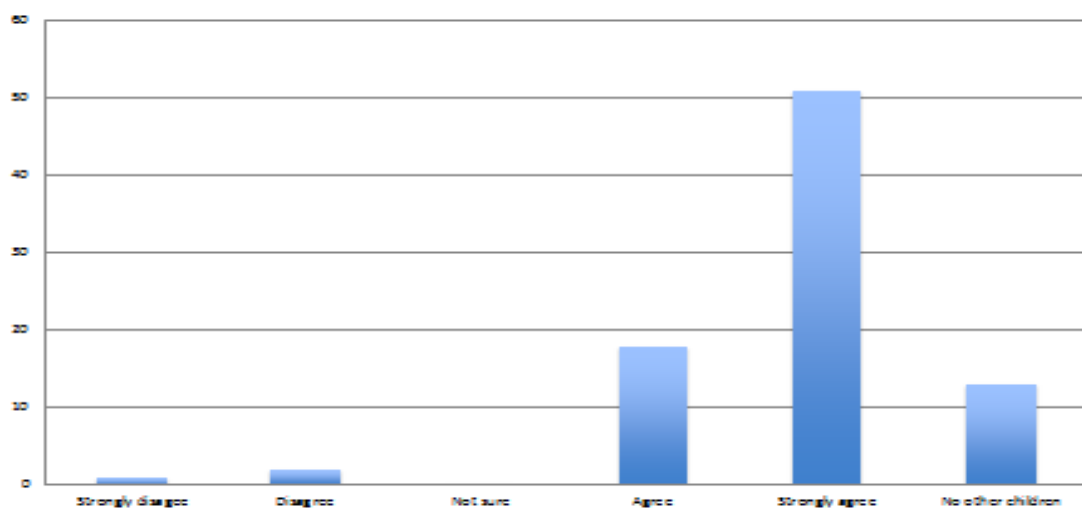
93% of parents agreed or strongly agreed that the short breaks help them stay emotionally and mentally strong

## The short breaks help my child who has special needs



96.5% agreed or strongly agreed that the short breaks help their child with special needs

## The short breaks help other children in our family



95.8% (of those with other children) agreed or strongly agreed that the short breaks helped the other children in their family

## What families told us:

Parents told us that they place very high value on the short breaks that are currently offered by Camden. They explained that the short breaks have a range of different benefits for the child and for the parents and for other children in the family.

The short breaks make an important contribution to reducing stress and anxiety and the exhaustion that is the result of constant caring. They help maintain parents' general health and play a particularly important role in maintaining mental health. The breaks are a necessary support to other children in the family whose lives are often profoundly affected by the special needs of their sibling. Finally, the breaks are a very valuable part of the support that is provided for the children themselves.

A strong message was that a reduction in short breaks provision would lead directly to a reduction in the capacity of families to cope with their caring responsibilities. This could, in turn, increase the demand for more care that is provided outside the family.

We also heard that families have already become very anxious at the prospect of cuts to their short breaks provision, despite the fact that consultation is still ongoing and final decisions about the budget allocations have not yet been made.

### Stress and pressure and anxiety

Parents said that the support offered by the short breaks services has helped decrease family stress and, in some cases, prevent family breakdown. They said that the chance for a break makes a significant difference to their wellbeing. The short breaks help families to remain resilient so that they can continue to care for their children.

*"I can get highly stressed and depressed if I don't have a break from caring."*

*"The short breaks are essential for the health and wellbeing of my child and the family as a whole."*

*"We have no family support so short breaks give us a chance to recharge."*

*"We are exhausted. We need some time when life resembles normality."*

*"Without the short breaks, I would feel very stressed and I am already really run down all the time and get a lot of colds etc. I probably would*

*have to leave my job which at the minute gives me some 'me' time. My job keeps me sane."*

*"The breaks help me stay employed although I have had to cut my hours down."*

*"Without the breaks my back would go and I wouldn't be able to provide care for my disabled child or the rest of my family."*

*"Ultimately if this service was reduced I would have to consider putting my child in residential care."*

*"We really need short breaks for our physical and mental wellbeing. It is extremely challenging living with a child with severe special needs and we would be devastated if short breaks were reduced."*

## **Deteriorating mental health**

Many parents referred to the important role played by the short breaks in maintaining mental health.

*"I would go crazy without the short breaks because my daughter needs my help all the time."*

*"I'd have a nervous breakdown without the short breaks."*

*"My mental health would suffer without the short break."*

*"I'd go mad without the short breaks. It has happened before – it was very bad for my son and a disaster for me."*

*"My depression would come back. My other children would be affected in a negative way and I'd have to give up caring completely, ultimately."*

*"I would be scared. I think I'd have a breakdown."*

*"It would give me a breakdown. I look forward and rely on short breaks."*

## Taking care of my own health needs

A commonly recurring theme was that caring for a child with special educational needs or disabilities can have a negative impact on the health of the carer and that short breaks help parents to stay healthy. Parents told us about some of the health implications of providing care with no respite.

*“I need a physical break from 24hr care for medical reasons.”*

*“My back could go. My physical and mental health could deteriorate.”*

*“I can see my GP [during the short break] as I don't get a chance to do these things when he is with me.”*

*“Sleep deprivation and depression.”*

*“Weight gain, obesity, high cholesterol & diabetes (I have lost 3 stone since I started getting time and rest).”*

## Time to myself

Parent put very high value on having a little time to themselves and a chance to re-charge.

*“When he goes with his [short break] carer I get to have a rest and do all the jobs I can't do when he's around. I can do things like helping his brothers and sister with homework or take them out.”*

*“Gives mum a chance to shop or cook in peace, or rest and I also need time for myself.”*

*“It gives us much needed respite, so we get a break and are able to re-charge our batteries.”*

*“It gives me time to rest and do things which I can't usually do when my child is around e.g. attend appointments.”*

*“The short break is great for me to know that I do have a break every Thursday – to give me time to do something for myself like a swim, a de-stressing thing for me to do.”*

## Impact on siblings

Many children with special educational needs and disabilities have siblings who do not have special needs. Parents told us that the short breaks are very important for the wellbeing of other children in the family.

*“I need to spend time with my other son.”*

*“A chance for his sisters and brother to have time without him taking over the house.”*

*“We can focus on our other children as well as their issues (including other health concerns). We have an opportunity to do something we cannot usually do in the presence of our Autistic child.”*

*“It’s good for her brothers to get some time with me without her needs impacting on them.”*

*“My other children already get upset at the amount of attention I have to give their brother. When they were young we could all do the same things together but I can’t do this anymore because their interests are very different from my son who has a disability. With less short breaks I would feel even more guilty about the lack of time I have for my children.”*

## Benefits to my child

Parent felt strongly that the short breaks bring significant benefits to the child.

*“The short break is great for my son. It has helped him to socialize away from school and become independent.”*

*“It helps my child to mix with other children in a safe environment.”*

*“It gives my son a routine/ familiar setting. He is safe and happy and I don’t worry.”*

*“Short breaks give our special children a social life & the chance to interact with outsiders so they are forced to communicate. It is a good change of scene and gives them a break from parents.”*

*“With no access for social life within community my disabled child would have no friends and not be included by local community.”*

# Recommendations

## Overview

The Healthwatch Camden survey revealed that parents in Camden place very high value on the current short breaks provision. Short breaks help many families live a more 'ordinary' life. They allow parents or carers some time to rest or spend with their other children, whilst their child with special educational needs or disabilities takes part in enjoyable activities. Parents told us that the support offered by the short breaks service has helped decrease family stress and improve and maintain the health and the mental health of parents. Many parents said that the breaks have enabled them to become stronger and better able to manage.

The survey responses indicated that there is a significant risk that a reduction in short breaks may reduce the resilience of families to the extent that they can no longer cope with caring for their own children.

The implications of reductions in parents' capacity to provide care could include: the provision of residential care inside or outside the borough; increased mental health service provision; increased demand for healthcare; additional support services for siblings.

In such cases, cost savings in the short breaks offer may be offset by significantly higher future additional costs incurred through the provision of other services.

## Recommendation 1

Camden should conduct and publish a thorough cost benefit analysis to assess the value of potential savings from cuts to current short breaks provision against the potential associated future costs of:

- a) increased residential care provision
- b) increased mental health needs among family carers
- c) Increased physical health needs among family carers
- d) negative impacts on siblings

*Evidence:* short breaks are of very high value to parents. Parents anticipate significant increases in stress and warn of declines in mental health and wellbeing and a decrease in capacity to care for their children with SEND and other siblings. Cuts to the short breaks programme are likely to be associated with increased expenditure in other areas of service provision.

## Recommendation 2

Camden should make full use of the potential of personal budgets to allow families to choose short breaks provision as a priority need should they wish to do so. Those conducting assessments should be aware of the options on personal budgets and should support families to get the benefits of them.

*Evidence:* Parents value short breaks very highly and should retain the choice to prioritise short breaks provision should they wish to do so.

## Recommendation 3

Camden should improve its management of communication with service users about potential changes to service provision due to budget cuts.

*Evidence:* the prospect and rumoured expectation of unconfirmed cuts to the short breaks programme is already causing undue stress.

## About Healthwatch Camden

Healthwatch Camden is an independent organisation with a remit to make sure that the views of local service users in Camden are heard, responded to, taken seriously, and help to bring about service improvements.

Our duties (which are set out under the Health and Social Care Act 2012) are to support and promote people's involvement in the planning, running and monitoring of services; to gather views and experience and to make reports and recommendations for improvement based on those views; to offer information and advice on access to services and choices people can make in services; and to enable local people to monitor the quality of local services. Our remit extends across all publically funded health and social care in the borough.

**Thank you.**

## Appendix 1

Response from Camden Council (Children, schools and families directorate) to the three recommendations made by Healthwatch Camden.

### **Recommendation 1:**

Camden should conduct and publish a thorough cost benefit analysis to assess the value of potential savings from cuts to current short breaks provision against the potential associated future costs of:

- a) increased residential care provision
- b) increased mental health needs among family carers
- c) increased physical health needs among family carers
- d) negative impacts on siblings

### **Response:**

Camden has already carried out a significant level of detailed cost benefit analysis work over the past 5 years as part of developing and implementing our complex needs strategy. We have also taken into consideration wider research studies on the social and economic value of short breaks services as preventative services.

The Camden complex needs strategy was developed to improve community-based resources and to reduce the need for placements in the independent / non-maintained sector, including the development of an enhanced local offer through the coordination and allocation of support to universal settings to enable effective early intervention and prevention. Strategies have been developed and implemented over the past 5 years following early intervention and prevention principles that investment in preventative services reduces the need for higher tier, more costly interventions. Commissioning of services has included investment in preventative services to ensure a balance of provision across the tiers of need.

As stated in your report, we understand the benefits of short breaks to help many families live a more 'ordinary' life, decrease family stress, improve and maintain the health and the mental health of parents and enable family resilience. For these reasons, Camden continues to prioritise investment in the provision of short breaks for disabled children and to minimise savings targets. As part of our complex needs strategy and in consultation with parents, children and young people, Camden has invested substantially in a broad range of short break services. In 2014/15 Camden invested £2.8 million in the direct provision of short break services for disabled children.

We have a short breaks savings target of £94,000 in 2015/16, which we aim to achieve through reviewing and reconfiguring some internal services. We are working to ensure families eligible for short breaks who want to continue to access these services can still do so in a more cost effective way using direct payments or a personal budget. We have a further target of £190,000 by 2017/18, which we will consult about further. This will mean Camden continues to invest at least £2.5million per annum in short breaks services for disabled children and young people.

We plan to minimise the impact of any savings applied to short break budgets through developing fair and transparent systems to bring together health and local authority funding for children with complex health needs to help offset any savings, with a greater use of personal budgets where appropriate. We aim to work together with families to enable better use of our reduced resources to achieve the best possible outcomes for our disabled children and young people. Families will continue to be assessed individually with care plans put in place based on the level of needs of each child and their family.

At this point it is not felt that further cost benefit analysis work would be a good use of resources or reveal new information that we are not currently aware of.

**Recommendation 2:**

Camden should make full use of the potential of personal budgets to allow families to choose short breaks provision as a priority need should they wish to do so. Those conducting assessments should be aware of the options on personal budgets and should support families to get the benefits of them.

**Response:**

Our Personal Budget policy is available on the Local Offer website:

[www.localoffer.camden.gov.uk](http://www.localoffer.camden.gov.uk)

Camden is committed to making full use of the potential of personal budgets to allow families to have greater choice, control and flexibility to meet the needs of their child and family in an individual and personalised way. Direct payments are already widely in Camden as part of short breaks care packages, where the family is allocated a budget to use to enable their child to access activities in the community with the support of their own support worker. Those conducting short breaks assessments are aware of this.

Personalisation Support in Camden (a subsidiary of Age UK) is commissioned to support families in managing their personal budgets, which can include helping to recruit carers/ personal assistants, managing all aspects of their payment and tax implications.

Work is underway to include a wider range of services available as personal budgets in Camden 2015/16 and 2016/17. We aim to encourage a greater personalised approach to the assessment of need and the provision of support to improve outcomes for children with special educational needs and disabilities. Our aim is to pilot further work on the use of personal budgets in Camden to encourage more creativity in the services families choose to meet their child's needs.

We have delivered training to staff who are supporting families through the new Education, Health and Care (EHC) needs assessments as part of the implementation of the SEND reforms. We will be continuing to roll out further training to include the use of personal budgets as part of short break and EHC needs assessments to encourage greater awareness and take up of personal budgets where appropriate and to enable those conducting assessments to support families to benefit from them.

**Recommendation 3:**

Camden should improve its management of communication with service users about potential changes to service provision due to budget cuts.

**Response:**

Following the Healthwatch report in July 2014 on specialist children's services in Camden: experiences of local families, it has been helpful to have a Healthwatch representative attend our children with complex and additional needs children's trust commissioning group to work in partnership in response to your previous recommendations.

As you are aware, we are currently in the process of consulting with all families who are eligible for short break services as we review and revise our short breaks statement. This is an annual process, however we understand that there are inevitably additional concerns at this time given the national context of central government cuts to local authority funding.

As part of wider council engagement, in September 2014, Camden held our largest pre-budget engagement exercise ever and over 2,000 people gave their views.

With regard to short breaks, we are keen to avoid rumours of unconfirmed cuts and to ensure we are doing all we can to communicate with families to avoid undue stress. This is why we are working hard to communicate with all short breaks families through a range of communication approaches as part of our current short breaks consultation, which runs to 31 March 2015. The Healthwatch survey will contribute to this short break consultation.

We consulted with the Special Parents Forum and the Reactive Forum, Camden's disabled children and young people's forum to seek their input on the consultation questions and materials prior to publishing.

As part of the short breaks consultation process, we are making direct contact with all of the current 310 families currently eligible for short breaks services and wider stakeholders, such as short breaks providers. We have written to all 310 short breaks families and posted copies of our consultation document. We have an online survey, including a children and young people's version. Our Mosaic InTouch newsletter has been emailed to a wider distribution list of families and includes information about the short breaks consultation with details of dates and venues of all meetings and events.

During the consultation period we are running a series of engagement events where children, young people, parents and carers can ask questions, share their views and receive support to complete consultation materials. We have developed children and young people's versions of the paper and online versions of the surveys and have taken these to the Reactive Forum and a range of children and young people's groups as part of the half term short breaks activities. We are asking young people for their views separately as their views may differ from their parents and carers.

We have a highly engaged group of parents with disabled children in Camden, many of whom have been involved in preparing and revising our short breaks statement, service design and commissioning processes for many years. Through our current consultation, we intend to consult with all eligible children, young people, their families and wider stakeholders and to work actively together with them to co-design new

solutions which build on existing good practice.

As part of the consultation process, we are inviting parents, children and young people to be part of a working group to help co-design solutions to improve short breaks services in Camden.

Feedback from the consultation process will be collated and summarised as part of the revised short breaks statement and published in April 2015.

## Appendix 2



### Questionnaire

## Short breaks as respite for families of children with special educational needs or disabilities

#### Tell us what you think!

Healthwatch Camden recently conducted some research about the experiences of local families who use Camden's specialist children's services. As a follow up to that work, we would like to hear a bit more about the way in which the current provision for short breaks helps to support families of children with special educational needs and disabilities. We will use what you tell us to make recommendations to Camden Council as they consult residents about the different types of cost savings they need to make over the next four years.

#### The survey is confidential.

1. Do you currently receive any support that gives you the chance for a short break from caring for a child who has special needs?

(Please tick any that apply.)

- a. Direct payment for purchasing help at home.
- b. One to one support at home or in the community.
- c. Place on a specialist play scheme for my child during school holidays or weekends or after school.  
If so, which scheme? (Please circle any that apply.)

WAC  
Other

Action for Children

PACE

I CAN DANCE

2. The short breaks help me to stay healthy.

strongly disagree      disagree      not sure      agree      strongly agree

3. The short breaks help me to stay emotionally and mentally strong.

strongly disagree      disagree      not sure      agree      strongly agree

4. The short breaks help my child who has special needs.

strongly disagree      disagree      not sure      agree      strongly agree

5. The short breaks help other children in our family.

strongly disagree      disagree      not sure      agree      strongly agree

OR there are no other children in the family

6. We need the short break because: (please use the space below to tell us some of the reasons why you value the short break)

7. If your short breaks were to be reduced, what might be the consequences for your health and your mental wellbeing?

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Email:.....

Thank you!

