

## **Short Breaks for Disabled Children Paper consultations July 2013**



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### **1. Introduction**

This report will concentrate mainly on the needs analysis carried out for the purposes of re-commissioning short breaks for disabled children services in 2014. Views have been sought from parent/carers of disabled children, disabled young people and professionals working in the field of disability. Other recent consultations have been used to support the needs analysis and include the youth parliaments that took place in June 2013. Due to few returns from children with complex needs and life limiting children, this report uses a national consultation named 'square tables' which took place in Spring 2011 and focuses on palliative care children and young people. The report also uses Wiltshire's Primary Care Report "Feedback on Children's Hospices" written in January 2013. The conclusions to this report will also act as recommendations to the short breaks commission of 2014.

### **2. Method**

The needs assessment was carried out during July 2013 by Briony Waite, Dee Chaddha and Kay Sibley. The information that was gathered consisted of quantitative information which was collected through the use of a questionnaire, and qualitative information which was gathered through focus groups.

Questions in the parent carer questionnaire covered the range of short breaks currently available and whether parent/carers were satisfied with the range as well as asking questions about what the best environment is for a short break to take place and transport.

The young people's questionnaire focussed on what sorts of activities they would like to participate in their spare time as well as how do they find out about short breaks and transport..

#### **2.1 Questionnaires**

The questionnaire was agreed with stakeholders including parents/carers. The Family Information Service administered questionnaires to all schools in BANES that catered for statemented children. Staff also dropped off printed questionnaires in bulk to schools with high numbers of SEN children. The Council consulted with the two special schools: Threeways and Fosseway School using separate questionnaires for children and young people and parents/carers to complete. It was widely distributed to include Children Centre's, Disabled Children Strategy Group (DCSG), Transitions Board and specialist groups such as Bath and North East Somerset Inclusive Sports and Physical Activity Association (BISPAA), Wheels4all and commissioned short break services who were asked to promote with service users.

Providers were also given a questionnaire to complete and covered the areas of what worked well when delivering a short break, what are the gaps in service and whether they feel there is a good spread of short breaks in the area.

## **2.2 Focus groups**

A number of focus groups were scheduled and facilitated. There were two focus groups held at the special schools and two other sessions set aside for consultation with parent/carers of children attending mainstream schools at the Radstock Carers' Centre and Parkside Children's Centre. Six parents attended the Fosseyway focus group, five parents attended Threeways School and no parents attended Radstock or Parkside Centre consultations. A range of questions covered the parents/carers knowledge of short breaks and their feelings about what worked well and why, what didn't work well and why, problems with access and what more activities parents would like to see be available.

A focus group also took place at Time2Share and involved six young people. The range of questions covered were about the range of short break opportunities available, the types of provision they knew of whether they liked them or what they would like to change about them as well as other activities they would like to see take place.

## **2.3 Further Consultation**

### **2.3.1 Primary and Youth Parliament**

Both Primary and Youth Parliaments took place in June 2013. Both Parliaments were completed in one day. Over 30 schools participated in the Primary Parliament and the themes included safe play and how to stay physical and emotionally well. Ten schools participated in the Youth Parliament and themes included safe places to hang out, staying emotionally and physically well, preparation for training and work and transport in B&NES

### **2.3.2 National 'Square Tables' Events**

In Spring 2011, a national consultation was carried out by the Children Hospice UK and Association for Children's Palliative Care (ACT) who hosted "Square Tables" events. Thirty seven unique events took place across England designed to deepen the level of shared understanding of children's palliative care. Each event brought together life-limited and life-threatened young people and their families, a range of health, education and social care professionals and providers as well as countless other representatives from across the community including faith and business leaders.

This report also draws on findings found in Wiltshire Primary Care report "feedback on children's hospice services" written in January 2013

## **3. Summary of Key Findings**

### **3.1 Parent Carers Consultation**

There were 107 responses from parent carers.

- 38% (41) were from parents with children aged 5-9,
- 25% (27) from 10-14 years,
- 23% (25) from 15-19 years and
- 15% (16) from 0-4 years.

72% (77) of these children were male. Children and young people with ASD constituted the single largest group (37%) in the sample mainly due to the majority of responses coming from families of children attending Fosseyway School. 12% parent/carers listed communication/

speech and language as the primary impairment whereas 3% listed complex disability. There were few responses received from families of children with high end health care needs.

Parental confidence in provision is paramount for parent/carers to encourage their children to attend provision. Confidence and trust came from knowing the organisation and the staff who work at the settings. Parent/carers valued the fact that there was one to one support from a caring practitioner who knew their child's individual needs. Parents/carers also rated the staff known to their child/ren, quality of staff able to build positive relationships with their children in a safe environment as a high priority. Over half (53%) of respondents said they preferred an environment with mixed disabled and non-disabled children.

63% of replies stated that their family does access short break opportunities. Feedback confirms that Parents/Carers in Special Schools are much more likely to know what short breaks are, what types of provision this encompasses, how to get information about activities and to use them on a regular basis. Parent/carers from outside specialist settings report that there should be more information about short breaks and the range of activities on offer (details of activity). This is especially important for disabled children accessing mainstream settings.

Overall parent/carers reported satisfaction with current levels of provision. Some settings did report a waiting list for access to activities. There were a few parents/carers awaiting confirmation of places on play schemes at the time of the consultation but overall there were 2.8% (3) of parent/carers who stated they were on a waiting list.

The barriers in accessing transport are more hidden and include young people not being able to use the bus when dark as it is more difficult to locate bus stops due to impairments, cost of transport to provision. 47% (51) said they were willing to contribute to transport costs

### **3.2 Children with complex needs and life limited disabilities**

Through the 37 National 'Square Tables' events parents found the current assessment system requires them to repeat information about their child's and family circumstances on multiple occasions to health, education and social care. Several square tables discussed the viability of some kind of "health passport" which could travel with the child at all times. This also applied to families entitled to access hospice services. Timely information and support for families of life limiting children is needed with clear explanation of the role of children's hospice with clear referral criteria and routes to hospice provision. Parent carers also called for more flexible responsive services inside and outside the home.

The use of direct payments and personalised budgets were seen in a positive light to parent/carers of children with palliative care needs. It was noted that in some areas while direct payments were already in place there were no provider agencies available to purchase social care services. This has been echoed by the Disabled Children's Team (DCT) suggesting the broader range of services to be in personal care, medical procedures, overnight care in family home, as well as accompanying and supporting parent to get child to medical appointments

In regards to hospice stays some families experienced additional days on top of their allocation which could be booked in if their child was recuperating after a hospital stay. Some families commented on how valuable this 'stepped discharge' was to them.

Some hospices ran weekly groups, clubs or one off special events for hospice users or siblings outside normal stays. Several parent/ carers who were interviewed benefited from those groups, although some said they could not participate as they did not live nearby.

Several parents said that trips to cinema, shopping or bowling was an important part of the hospice experience both for the sick child and their siblings as this was difficult to arrange at home.

Many parents were facing their child's transition from children's services to adult services with great anxiety. There is limited support for parent/carers and are dissatisfied with the range of opportunities available to them. Families that care for a child with delayed cognitive development felt that the themes of transition was not appropriate for their child which concentrated on independent living, further education and finding work.

### **3.3 Children and Young people's consultation**

The majority of responses for this questionnaire were from children and young people who attend Fosseyway School. There were 134 responses to the questionnaire with

- 71% (96) from students from Fosseyway School,
- 16% (21) from 13 different mainstream settings and
- 10% (13) from Threeways School.
- 69% (92) were male.
- 45 % ( 56) of the questionnaires were answered by 10-14 years,
- 33% (41) by 15-19 years and 21% (27) by 5-9 years.

There were no responses from the 0-5 age group. There are few responses received from families of children with complex needs or high end health care needs.

67% (89) of respondents already attend activities in their free time and engage in a range of activities and experiences. They have aspirations to try out many more. There are a vast range of activities that young people would like to access similar to their non-disabled counterparts and include swimming, playing on computer, cycling/BMX/Mountain, Football, Cinema, Bowling/ day trips, Socialising with others. As a result young people can see that their social lives have improved, they are able to build confidence which helps them build friendships outside school. Results of the Youth Parliament show that young people value the youth provision that existed and specifically mentioned the SOFA project. They particularly valued groups that were low cost and provided food as part of what they do.

Children and young people like staff who are known to them, understand what their individual needs are and who are kind and supportive. 65% of respondents said adult support is rated the highest as what is needed to carry out activities followed by money at 61% with transport being mentioned four times in the additional comments.

There is a reliance on parent/carers giving lifts to provision which becomes more difficult if there are other siblings wanting to do different things. Staff members sometimes pick up and drop young people off to provision to enable them to attend. 71% (71) of young people report they mostly get transported to clubs by their parent/carers 33% (43) said they did not attend any activity in their free time. Through Youth Parliaments young people suggested that public transport for under 18's should be free or if this could not happen then a youth bus pass that could be purchased at reduced cost would encourage young people to use buses more often. Young people also suggested having a scheme similar to dial a ride that operates later in the evening and at weekends.

Young people generally hear about activities either through their parent/carers or at school. Young people feel there is a need for better information about what is available e.g. a readily available map of what is where with links to Facebook.

Older children and young people identify that there is an anxiety about what happens to services once young people turn 18 years old. There is a perception that there is nothing for young adults locally and little to no support to carry out activities dwindled. All young adults who attended Square Table events were dissatisfied with the range of opportunities available in regards to support offered when transitioning from child to adult services.

At the Youth Parliament a group which comprised mostly of the young people with disabilities put on a role play that poignantly demonstrated the levels of discrimination encountered by disabled young people when applying for jobs. This included - travel using public transport for wheel chair users, communication issues for BSL sign users and having difficulties with hearing. This highlighted a need for schools and colleges to help prepare disabled young people for potential obstacles to work and how to overcome them and to training organisations and potential employers to provide for the needs of disabled people.

### **3.4 Provider Consultation**

Providers supplied the consultation with comprehensive answers to all the questions the Council asked which has resulted in some valuable feedback about short breaks. Generally providers have a good rapport with BANES when delivering short breaks and the majority 64% believe there is a good spread of short breaks across the area. There were 11 responses from providers of short breaks with over a third (5) from providers who specialise in supporting children with multiply complex needs 18% (2) of which support life threatening children.

Seven of the eleven providers charge for their sessions. Other costs were incurred by participants but this was more optional such as paying for food while at the session or paying for additional mileage to go out on trips. Sessions cost in the range of £1 - £7 per session with one service offering an overnight stay for £83.49. Families have reported to providers that short breaks are vital for the carer to have a break and like the regularity of sessions. Delivering short breaks which include the whole family have been received positively.

64% see play as a central feature when delivering provision showing creativity to their approach and flexible methods of working so that the young people can take ownership of an activity that is taking place. Where children with complex needs/ life threatening conditions are concerned a more family centred approach to activity is adhered to. Access to a regular venue and recruiting staff from a list is proved to work well when delivering short breaks.

Providers suggest that there should be more provision offered to families in the school holidays, half terms and Christmas. This could be in the form of a club but also one to one support so that young people can engage in leisure or social activities of their choice. Also there little provision for under 5's. Two providers identified that there was a lack of provision for 18 – 25 year olds to move onto, to maintain existing friendship groups and level of social independence which creates less space for younger members to join the club. There is also a lack of provision which supports the development of independent skills such as daily personal living and budgeting skills. The voluntary sector has addressed this issue and one provision currently runs a life skills project on a weekly basis.

DCT highlight the need for behavioural support with parent/carers in the family home to safely manage their children with disabilities such as ASD and challenging behaviour. BSL/ Makaton training would better support deaf children and children with complex needs in short break activities.

45% of providers report that they know children who cannot access their service. Reasons include not being able to provide transport, sessions not long enough, activities not adapted for children with complex needs. Transport to group venues is also seen as a barrier.

In regards to capital expenditure and short breaks providers some suggestions include a text messaging service (could only offer then the actual phones and computer equipment/ programme needed for operation – no running costs) off road wheelchairs, more resource sharing/ libraries for sensory equipment outdoor play equipment and storage.

### **3.5 Children with complex needs and life limited disabilities**

More specialised services suggest that families would like more services delivered in the home in particular during school holidays. One provider reports that there has been a lack of provision where the child can access an occasional overnight break. Other overnight short break provision that needs development is for those children with complex, physical and learning disability and medical needs.

Issues identified for this group of children by providers included recruitment of suitable staff, high costs associated with ratios of staff needed, providing activities for more complex children, and difficulty in raising awareness of clubs. There have also been issues around suitability of venues and considerations needed when allocating spaces to children and what type of dynamic this will make.

## **4. Conclusion**

There are more disabled children and young people accessing short break opportunities than in previous years. Parent/ carer main criteria when accessing short breaks is that they have confidence in the staff members to meet the individual needs of their child. Young people like staff who are known to them when accessing a short break and who are supportive and kind. Youth provision that exists in the area is valued by young people especially those that were low cost and provided food as part of what they do.

There is a general perception that there is a good spread of short break services in the area. Providers report there is a lack of provision for 0-5's and 18-25's. There is also a lack of occasional overnight provision and for those children who have complex, physical and medical needs. Transport has been identified as a barrier to accessing short breaks provision by all three groups.

Report written by Kay Sibley,  
Project officer Short Breaks for Disabled Children,  
August 2013.

Appendix

People that were consulted:

Children Centre's  
SENCO's - Mainstream schools  
Parent Carer Aiming High Carer's Centre Database  
Transitions Board  
BISSPA  
Wheels4 all  
DCSG

Specialist providers

BAPP holiday provision at the hut	KIDS Life Skills
BAPP Holiday provision at Threeways	KIDS Saturday Club
BAPP Life Skills project	Multi Sports and swimming After School Clubs
BAPP Summer of fun activities (SOFA) Holiday provision	National Autistic Society (NAS) after School club
BAPP Teenage Rampage	SWALLOWS Base House
Beaumonts	Threeways After School Club
Crossroads	Time2Share Befriending
Direct Payments	Time2Share Cinema Group
Family Link	Time2Share dinner group
Fosseway After School Clubs	Time2Share skittles
Fosseway Holiday Provision	Time2Share Wireworld
Gateway Youth Clubs	Waynsdyke Play Association Saturday Club
Gateway Saturday club	Youth Action to Gain Access (YAGA)
KIDS Holiday provision	

## **Short Breaks for Disabled Children for Parent/ Carers**

This questionnaire is for parents/carers of disabled children and young people. The purpose of this questionnaire is to seek your views on short break services in Bath and North East Somerset and identify how these services can be improved.

This information will be used to shape Bath and North East Somerset's commissioning intentions for 2014 onwards

Please could you return your completed questionnaire by **19<sup>th</sup> July 2013**

### **About your family**

Please could you provide some basic information about your child

### **Where do you live?**

**Please state the first part of your postcode**

### **How old is your child?**

- 0-5 years
- 6-10 years
- 11-15 years
- 16-20 years

### **What gender is your child?**

- Male
- Female

**The Disability Discrimination Act 1995 defines disability as: 'A physical or mental impairment which has a substantial and long term adverse effect on the ability to carry out normal day to day activities'**

### **Do you consider your child to be:**

- Disabled
- Non disabled
- Statemented

Not Statemented

**Please briefly describe your child's needs (e.g. communication, mobility, continence)**

**If a professional has given you a diagnosis of your child's condition, please state the condition**

### **About short breaks**

#### **A short break....**

- Allows disabled children and young people to experience new relationships, environments and positive activities
- Provides a necessary and valuable opportunity for primary carers (usually but not always, mum or dad) to have a break from their caring responsibilities, and to recharge their batteries
- May include day, evening, overnight or weekend activities and could take place at home, at an approved carer's home or in a community or residential setting
- May mean taking part in an activity with other disabled young people or being supported to take part in local activities open to everyone
- Can also mean supporting parents in their caring role so that the whole family can enjoy activities together

**1. How much do you think opportunities to play and to be in a playful environment (e.g. staff, activities that are distinctly different from school) is an important part of your child's short break?**

- Essential to a good quality short break
- Good but not essential
- Indifferent as long as they are safe

**Please comment on response..../ add any additional comment**

**2. Here is a list of short breaks provision; does your family access any of these services?**

Please select

- Yes
- No

BAPP holiday provision at the hut	KIDS Life Skills
BAPP Holiday provision at Threeways	KIDS Saturday Club
BAPP Life Skills project	Multi Sports and swimming After School Clubs
BAPP Summer of fun activities (SOFA) Holiday provision	National Autistic Society (NAS) after School club
BAPP Teenage Rampage	SWALLOWS Base House
Beaumonts	Threeways After School Club
Crossroads	Time2Share Befriending
Direct Payments	Time2Share Cinema Group
Family Link	Time2Share dinner group
Fosseway After School Clubs	Time2Share skittles
Fosseway Holiday Provision	Time2Share Wireworld
Gateway Youth Clubs	Waynsdyke Play Association Saturday Club
Gateway Saturday club	Youth Action to Gain Access (YAGA)
KIDS Holiday provision	

**Other Please specify**

If you require further information about the services listed above please contact the Family Information Team (FIS) on 08000731214, Text: 07980998906 or email [fis@bathnes.gov.uk](mailto:fis@bathnes.gov.uk) or access the Rainbow resource on <http://www.rainbowresource.org.uk>

**3. Are you on a waiting list waiting for a short break / activity for child to participate in or not been offered the dates you have requested for a short break/ activity for child to participate in?**

If so please name the provision here

**4. What would be required to best meet the needs of your child to fully access the provision Please tick**

**Environment**

- Fully accessible Venue
- Venue with specialist equipment i.e. hoists
- Regular activity to be based in one venue
- A secure/ enclosed environment i.e. rooms which can only be unlocked by Phob key
- Being with other disabled children only
- Being with disabled and non-disabled children as well
- Important for siblings to take part in activity
- A non-school venue

Other (Please state)

**Staff Skills**

- Ability to respond to individual needs of child
- Being able to respond to certain behaviours i.e. challenging behaviours
- Staff trained to provide personal care i.e. toileting
- Be qualified to administer medication (more complex healthcare)

- Staff can engage with and build trusting relationships with child
- Staff are known to parent/carers

Other (Please state)

**Range of Activities**

- That are age appropriate
- Outdoor
- Indoor
- 1:1 support
- Opportunity to be in a group
- Opportunity to take a short break on their own with support
- Offsite (day trip/ activity)
- Residential (camping/ group activity away for weekend)

Other (Please state)

**5. What would improve the short break services available to you and your family?**

**6. What sorts / types of provision/ activities would you like to see for 0-5 years children with disabilities?**

**7. What sorts / types of provision/ activities would you like to see for 6-10 years children with disabilities?**

**8. What sorts / types of provision/activities would you like to see for 11-15 years children/ young people with disabilities?**

**9. What sorts / types of provision/activities would you like to see for 16-20 years children/ young people with disabilities?**

**10. Transport has been identified as a barrier to accessing short breaks. Would you be able to travel to short breaks provision using your own transport?**

Please select

- Yes
- No

**If no, would you be willing to make a contribution towards transport costs to enable your child to access short breaks?**

Please select

- Yes
- No

**11. Is there anything else you would like to say about short breaks?**

If you want to find out more about short breaks please follow the following link or contact the Family Information team (FIS) on 08000731214, Text: 07980998906 or email [fis@bathnes.gov.uk](mailto:fis@bathnes.gov.uk)

<http://www.bathnes.gov.uk/services/children-young-people-and-families/families-disabled-children/short-breaks-disabled-children>

Bath and North East Somerset council is interested in hearing your views. We work in partnership with Parent Carer Aiming High Group (PCAH) who represents all parent/carers in the Bath and North East Somerset area. To find out more about PCAH, please follow this link [www.pcah.org.uk](http://www.pcah.org.uk) or contact Lorraine Frapwell at: The Care Network, 1 Riverside Cottages,

Radstock, Bath BA3 3PS. Tel: 01761 431388 Email:  
[Lorraine.Frapwell@banescarerscentre.org.uk](mailto:Lorraine.Frapwell@banescarerscentre.org.uk)

**Thank you for taking part in this questionnaire.**

Please return questionnaires to:

Admin  
Freepost 748  
Bath  
BA1 5TZ  
Kay Sibley  
Children's Service  
Bath & North East Somerset Council

Email: [Kay\\_sibley@bathnes.gov.uk](mailto:Kay_sibley@bathnes.gov.uk)

Tel: 01225 395437

## **Short Breaks for Disabled Children Questionnaire for Providers**

This questionnaire is for providers who deliver short break services for disabled children. The purpose of this questionnaire is to seek your views on short break services in Bath and North East Somerset and how these can be improved.

This information will be used to shape Bath and North East Somerset's commissioning intentions for 2014 onwards

Please could you return your completed questionnaire by **19<sup>th</sup> July 2013**

### **1 Name of provider**

### **2 What short breaks services do you provide?**

Please list

### **3 How much are play values incorporated into your short breaks provision (e.g. play activities, environments and staff)?**

- Play is central to provision with playworkers
- Where possible play is incorporated
- Not essential as long as children are safe

**Please comment on your response.....**

### **4 How would you enable children and young people to carry out activities / tasks that they ask to do?**

**5 Do you have a waiting list of families wanting to access the short break service provided or have been unable to offer dates that families have requested for a short break?**

- Yes
- No

**If yes please state the service and the number of people on the waiting list or number of people you have not been able to offer a service to at the time families requested the short break and when this was.**

**6 Do you charge for any of the services stated above?**

- Yes
- No

**If yes what do you charge for each service you provide?**

**7 What disabled groups of children access your service? i.e. autistic children**

**8 Do you know of any children who are unable to access your service?**

- Yes
- No

**If yes, what is the unmet need?**

**9 (a) What has worked well when delivering short breaks for you (the provider)**

**9 (b) What hasn't worked as well when delivering short breaks for you (the provider)**

**10 (a) What has worked well when delivering short breaks for families (the service user)**

**10 (b) What hasn't worked as well when delivering short breaks for families (the service user)**

**11 Have there been any issues (useful and/or challenging) in finding the right venue from which to offer your short breaks provision?**

**Please comment on your response and where possible offer solutions/ideas for future development.**

**12 What improvements can be made to create better access/ experience for families to your provision?**

**13 Do you think there is a good spread of short breaks in the area?**

- Yes
- No

**If No please identify any unmet needs**

**14 The Council are currently deciding how they will commission capital money allocated to short breaks. Are there any capital purchases i.e. specialist equipment which would enhance the provision you and/or create better access to your provision?**

**15 Is there anything else you would like to say about short breaks?**

**Thank you for participating in the questionnaire**

**Please return questionnaire to**

Admin  
BA748  
Bath  
BA1 5TZ  
Kay Sibley  
Children's Service  
Bath & North East Somerset Council

Email: [Kay\\_sibley@bathnes.gov.uk](mailto:Kay_sibley@bathnes.gov.uk)

Tel: 01225 395437