



SPECIAL NEEDS ACTION PANEL
CENTRAL BEDFORDSHIRE

A review of Short Breaks within Children's Services

Short breaks is a term used to describe a group of services that includes overnight and daytime respite, approved carers and specialist after school clubs, holiday clubs and play schemes.

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Introduction

SNAP - The Special Needs Action Panel – your local parent carer forum, is an independent group of parent carers whose role is to ensure the voice of families of children and young people with Special Educational Needs and Disabilities 0 to 25 years is heard. We work with health, education, social care and other agencies to promote effective two way communication and partnership and co-produce services. SNAP brings a valuable independent perspective and constructive challenge to the future planning of services.

Co-production

Co-production happens when service providers and service users recognise the benefits of working in true partnership with each other. This process is adopted ‘from the start’, when planning, developing, implementing or reviewing a service. It means that all the right people are around the table right from the beginning of an idea, and that they are involved equally to:

- Shape, design, develop, implement, and review services.
- Make recommendations, plans, actions, and develop materials.
- Work together right from the start of the process, through to the end.

Consultation is not the same as co-production. A stage of consultation can be part of an overall co-production process. It usually occurs after the early stages of co-production have been completed.

The purpose of the Focus Groups

SNAP facilitated the Focus Groups for parent carers in order for them to talk directly with Mr Ken Harvey, Head of Service, Children with Disabilities and Children’s Health about the proposed cuts in short breaks funding. This was a unique opportunity as short breaks service providers were still working towards facilitating their own individual meetings with the Local Authority.

The aim of the Focus Groups was to give families the opportunity to have a say in designing future services that support them. ‘Give me the information to create a model of what you need’ K Harvey.

Legislation

Part 3 of the 1989 Act sets out local authorities' powers and duties to provide support services for children in need and their families. The definition of children in need includes children who are disabled within the meaning of the 1989 Act 7. Short breaks can be provided by local authorities through the use of their powers under:

- section 17(6) of the 1989 Act, which grants local authorities a power to provide accommodation as part of a range of services in order to discharge their general duty to safeguard and promote the welfare of children in need; and
- section 20(4) of the 1989 Act, which grants local authorities a power to provide accommodation 'for any child within their area (even though a person who has parental responsibility for him is able to provide him with accommodation) if they consider that to do so would safeguard or promote the child's welfare'.

6.5. Local authorities should always be clear about the legal basis on which services are provided. Their decision to provide a short break under section 17(6) or under section 20(4) should be informed by their assessment of the child's needs and should take account of parenting capacity and wider family and environmental 7 Section 17(11) states: '... a child is disabled if he is blind, deaf or dumb or suffers from mental disorder of any kind or is substantially and permanently handicapped by illness, injury or congenital deformity...' 134 factors, the wishes and feelings of the child and his/her parents and the nature of the service to be provided.

6.6. This guidance amends Local Authority Circular (2003) 13: Guidance on accommodating children in need and their families, by clarifying the decision making process for local authorities in respect of providing short breaks accommodation to children. This guidance does not amend the Circular for other purposes.

http://www.centralbedfordshire.gov.uk/Images/Short_Breaks_Statement13_tcm3-12934.pdf

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/245580/Short_Breaks_for_Carers_of_Disabled_Children.pdf

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Process

SNAP held two Focus Groups. Details of the Focus Groups and an invitation to contribute were sent to the schools and groups below and they were asked to distribute to families of children and young people with SEND.

Special Schools

- Ivel Valley School
- The Chiltern School
- Weatherfield Academy
- Oak Bank School
- St Johns School
- Grange School
- Ridgeway School

Specialist provision in a mainstream school

- Ramsey Manor Lower School
- St Swithuns Lower School
- Biggleswade Academy
- Arnold Academy
- Streetfield Middle School
- Manshead School
- Samuel Whitbread Academy
- Lancot School
- Silsoe Lower School
- Harlington Upper School
- St Georges Lower School
- Parkfield Middle School
- Heathwood Lower School

Colleges

- Bedford College
- Central Bedfordshire College

Voluntary Sector

- Autism Bedfordshire
- Families United Network – FUN
- Bedford & District Cerebral Palsy Society – BDCPS
- Carers in Beds
- Outside – In
- SNAP

The invitation to attend the Focus Meetings was sent to the above on Friday 25th May 2016. The invitation also gave parent carers the opportunity to submit a question which would be read out, should they be unable to attend or want to remain anonymous.

The Focus Groups were held at different times of the day and at different locations to try and reach the widest cohort.

At the meetings Mr Ken Harvey explained the necessity for efficiencies and the remodelling of local services following reductions in funding made by Central Government in the Autumn Statement 2015. He asked for evidence of:

“Which services help families the most and why?”

This was split into 3 categories – Services for Children
Services for Young People
Services for Families

and

“How could services be delivered in a different way to improve outcomes”

Again split into 3 categories - Services that could be delivered differently
What outcomes would it improve?
What is important to get right?

One Focus Meeting addressed the questions asked by Mr Harvey; however the other Focus Meeting was a parent-led question and answer session.

Findings

Which Services help families most and why?	
Services for Children	Why?
<ul style="list-style-type: none"> • Families United Network (FUN) – Saturday Club <ul style="list-style-type: none"> ▪ Holiday Club • Autism Bedfordshire (AB) – Summer Clubs <ul style="list-style-type: none"> ○ Loads of Autistic Fun(LOAF) • Opportunity Playgroup • Kingfisher • Core Assets Respite Services • CHUMS • Bedford and District Cerebral Palsy Society (BDCPS) • Special Needs Out Of School Club (SNOOSC) 	<p>Independence Confidence Reduced Anxiety Life skills New opportunities Peer relationships Break from parents No bullying Fun</p> <p>“it is the only place my mainstream child can go and have the opportunity to play and interact with other children who suffer from the same issues as he does” Parent</p>
Services for Young People	Why?
<ul style="list-style-type: none"> • FUN – Saturday Club • Youth Club • Kids in Action • Otters Swimming Club • BDCPS – JJ’s <ul style="list-style-type: none"> ○ Holiday Club • Mencap – Youth Club <ul style="list-style-type: none"> ○ Holiday Club • Hi 5’s • Boost Sports Club • Kingfisher • Community Support Team • Special Needs Out Of School Club (SNOOSC) 	<p>Self Confidence Self Esteem Social Skills Independence Social Interaction Family Participation 1-1 carers of peer age Activities at an appropriate age/ability level Families starting to Let Go</p> <p>“Continuity is so important for our children and changes without a long timescale don’t give the young person time to adjust” Parent</p>

Services for Families	Why?
<ul style="list-style-type: none"> • FUN – Saturday Club • Carers in Beds • Otters Swimming Club • Outside In • The Avenue • Mencap Holiday Scheme • LOAF • BDCPS – Carers Breakfast • Special Needs Out Of School Club (SNOOSC) 	<p>Respite for Siblings and Parents Support Training Family Social Time Sharing Experiences Learning from Others Sense of Community Relieve Stress over 6 week Summer Holiday</p> <p>“We don’t go to groups for a rest, none of us chose this” Parent</p> <p>“Continual support and guidance cannot be measured” Parent</p>

SNAP has collated parents’ views from the discussions into the following themes:

- Impact on Family Life
- Early Interventions
- Universal Services
- Parent Carer concerns regarding Local Authority Practice

Impact on family life

Quotes from Parents:

“If it weren’t for these services my children would be Looked After”

“My family has been heavily supported by the local authority in the past and we are forever thankful. However, if there are not services for families to access then the local authority are likely to see an increase in families reaching crisis. Ensuring that groups etc are sustainable for families to access must be cheaper and safer than families reaching breaking point”

“My child is up all night; the only time I get to sleep is during the day when he is at school. Once every three weeks I use LOAF, it is not just what my son gets out of it, it is the only time I get to feel normal”

“I only received help when I had a breakdown at work”

“Without services like LOAF, these vulnerable children won’t be able to grow and gain the social skills they so desperately need in life. By not cutting these services now they will save on all sorts of services in the future, whether it be mental health, supervised housing, counselling or respite care.”

“I have never seen him interact with other children as well as he does there. In fact he has already made friends with two boys of similar age who live locally”

“I can’t even go to Ashridge with my children without support – my youngest runs toward the car park whilst my other child rolls in dog poo, which one am I supposed to run to first?”

“How long is too long to wait for help.”

Early intervention

- Do we currently have enough short break provision? “No” K Harvey

From SEN questionnaire 2014 gathering parent carer views, when asked “How satisfied or dissatisfied are you with the social care support and services provided by CBC if you currently use them for your child/young person with special educational needs” from 131 responses there was a net satisfaction rate of 17.86% in regard to respite and short breaks.

Local Authority cuts to funding for voluntary services will disadvantage them as this will lead to them losing funding from other sources. If charities or services fold they can take years to re-establish with children and young people missing out on their expertise. This has already been acutely felt by parent carers in the east of the county as LOAF in Biggleswade has been closed.

Families going into crisis will cost more. Early intervention and the respite this provides for families under pressure can help prevent escalation requiring multiagency intervention. SNAP's understanding is that if a need has been assessed then the Local Authority has a duty of care to meet the assessed need.

Prisons are full of people with SEND and the suicide rate is high, "if early intervention goes you will get a generation that will cause problems and may be a burden in years to come." Parent.

Often the first point of contact is the GP. They are of limited help and the voluntary services guide parents through the system.

Short breaks enable parents to work and become less dependent on benefits.

Universal services

By universal services we mean mainstream services that are available to everyone, for example leisure centres, libraries and swimming pools.

Children with complex needs are unable to be accommodated successfully without extensive and expensive staff training.

Parents will need to know:

- What training has been completed and to what level?
- How many staff have been trained, are they the right staff with the right attitude?
- Who will fund this training?

Training needs to be continuous and updated with succession planning. It is vital for children, young people and families to build up trust and relationships with staff.

You cannot influence the attitude of parents of mainstream children and young people who may see the children with additional needs as taking up more resources. "A parent was accessing universal services with their child who has Downs Syndrome. The child took longer to get on and off the equipment. The other parents were tutting and complaining that their children were compromised as they therefore got fewer turns in a session. The parent of the little girl had to sit and endure." Parent

Swimming pools – disabled changing facilities may be more readily available but they don't account for vulnerable young people who can, because of their age, no longer change with their opposite sex parent. "Inclusion goes beyond changing facilities." Parent

Children with additional needs do not fall into the age bands of universal services. Age is not commensurate with ability.

“Specialist provision gives me confidence as a mum that the needs of the my children will be met, that the staff will have specialist knowledge, skills and experience enabling them to support and care for my children with dignity, compassion and enthusiasm. For my children it means that they have an amazingly good time unhindered by staff that do not understand them or are unable to communicate with them. In contrast universal services do not have the knowledge, skills and experience to support my children, this means I needs to invest time ensuring these qualities are brought up to an acceptable standard. In addition, I worry when the children are at these provisions that they are not being supported adequately, the children may react adversely to inexperienced staff making it a negative experience for all involved.” Parent

Could the voluntary services offer training to staff or hire out their own staff to assist?

Could staff from universal services visit short break providers to learn from their good practice?

Parent carers concerns regarding Local Authority Practice

1. How far ahead is the Local Authority looking? Parents want to know is it a two to three years or ten year vision?
“Planning for the next financial year will begin this September, the model will be clearer at this point” K Harvey
2. “£30,000.00 is wasted annually on ‘No Shows’.” K Harvey
 - Could the Local Authority make a member of staff responsible for offering the vacant place at short notice thereby not wasting a resource and also reducing the waiting list? Although it may be difficult to find the right mix of children it is not impossible.
 - Could the Local Authority write into the Service Level Agreement with the voluntary services that they will have waiting lists and ensure all places are filled?
 - Some parents felt that there should be a charge to the families who do not attend, having booked.
 - Could money be saved within the Children with Disabilities team, for example on agency workers and reviewing decision making Panels?
3. Criteria – Parents often don’t know or understand the criteria that their children must meet in order to be entitled to access services. The criteria are not listed on the Local Offer and there is no clear pathway to access Children with Disabilities or Short Breaks. This causes immense anxiety. Some issues do not feature on the criteria i.e. emotional state and sensory issues.

“In communications with our family in 2015 the Local Authority acknowledges that there was an existing gap in service from children who do not meet the Children with Disabilities threshold. What is being done to close that gap and how will you stop that gap from widening when you are removing the funding from an experienced and dedicated service provider” Parent

4. Historically voluntary services have not discriminated between children and young people from neighbouring authorities. When the proposed cuts go ahead Central Bedfordshire families will be hugely disadvantaged.

5. Joint Commissioning/Person Budgets/Direct Payments

- How does Continuing Health Care criteria dovetail with Children with Disabilities Criteria regarding short breaks funding? Could they work more cohesively to joint fund some short breaks when there is a primary health need?
- If parents use direct payments they would be more aware of costs and maybe less likely to “no show” not turn up having paid. They can pick and choose services and employ their own carer.
- However, having a direct payment remains the parents’ choice. Not all parents have the time or capacity to manage the work involved. Families need services to exist in order to access them. There is no directory of carers.
- “There is no point in having a personal budget and nothing to spend it on.” Parent

6. “The Local Authority needs to encourage schools to provide clubs after school etc. Could there be an incentive for schools to do this?” Parent

7. Could the Local Authority look at good practice in other Local Authorities?

8. Adult Social Care provide personal budgets to pay for short breaks run by voluntary services at their subsidised rate. How does Adult Social Care contribute to the grant?

Conclusions

It is clear from the Focus Groups that the proposed cuts will hugely affect the children, young people and families that currently access short breaks.

Reducing the available overnight respite beds would affect fewer families but these are families that need the most support. Cutting clubs will affect more families who may have less complex needs. Some of these families may be able to access universal services however as stated in our findings families fear the readiness of these services, the training of the staff and the attitude of mainstream parents.

A long term strategic plan with service providers must closely reflect and match current and future need. It is imperative that the Local Authority make long term plans and are aware of children and young people that may access the services in the future. It must be a dynamic service.

Services need to be good value for money and it is essential that the Local Authority meets with and works with service providers to reduce wastage and minimise the effects of the cuts.

The Local Authority also needs to look at its working practice to ensure that it too is working as efficiently as possible to reduce wastage and minimise the effects of the cuts.

There must be clear information for parents about criteria, access to support and appropriately trained carers. Pathways must be defined and easy to navigate.

It is important that co-production continues in order to accurately represent the view of parent carers. SNAP welcome the views of parent carers via your_say@snapcentralbeds.org

It is important to remember

Short break provision holds families under pressure, together. They provide dignity, self-esteem and support in addition to respite. They are **more** than clubs. They are essential to the well-being of our families the cuts will be keenly felt.

“As families we did not choose this.” Parent

Addendum

The Focus Meetings, upon which this report was based, took place in June 2016. The evidence collected is anonymous and anecdotal and based on the questions, comments and letters of those who took part. The report, therefore, represents a small sample of those who will be affected by the proposed cuts to Short Breaks and cannot be used to represent everybody affected.

Since we initially circulated the report, we have had contact from Service Providers and families who are concerned that the existing gap in services for children who do not meet the Children with Disabilities threshold will widen. Questions remain as to how the Local Authority will work to bridge that gap and work to stop the gulf widening further. Some of those present were concerned that their comments were not recorded exactly as they wished.

SNAP parent representatives wrote this report in good faith, having taken extensive notes from both meetings. We recorded as accurately as we were able and assembled a document which draws on the experiences of parent carers, quoting directly from those who participated. We stand by our findings. We do not have permission to share the emails and letters we received from parent carers directly with the Local Authority. However, SNAP encourages those who wish to contact the Local Authority directly, to do so. SNAP concurs that it is vital that all parent carers have a voice, regardless of their child's ability or whether they meet the Children with Disability Team criteria. SNAP has been assured that all comments will be read, although the Head of Children with Disabilities will not respond to individual comments outside of completing the Members report. The email address is Ken.Harvey@centralbedfordshire.gov.uk.

SNAP works hard to ensure that the views of fellow parent carers are represented to the Local Authority. A parent carer survey will be sent out by the Local Authority in October 2016 and SNAP has ensured that all parent carers will have a voice in this. SNAP continues to report trends and provide constructive challenge on behalf of our members. We encourage all parent carers to email SNAP with details of their experiences via our *Listen Ear* campaign, yoursay@snapcentralbeds.co.uk.