

## **Consultation on the design of Short Break Services for Children and Teenagers with disabilities**

### **1. What are Short Break Services?**

Short breaks are opportunities for children and young people with disabilities to spend time away from their primary carers, and provide opportunities for their parents and carers to have a break from caring responsibilities. In Central Bedfordshire, Short Breaks can include day, evening, overnight, weekend or holiday activities that take place within the home of the child or young person, in the home of an approved carer, a residential or a community setting. Short breaks come in many different forms and can be anything from a couple of hours to days – the length and type of break will depend on the needs of the child and their family.

### **2. Purpose of Consultation on the design of Short Break Services**

Local authorities across the country are looking to find ways to save money. This is essential because the amount of money provided to local Councils from Central Government has greatly reduced over recent years and in future the (£10.5m) grant funding that the Council currently receives each year will disappear altogether by 2019/20. So, the Council needs to find new ways of working to make sure services to the most vulnerable are protected.

#### **The way short break services operate now**

The Council currently supports young people with disabilities (between the ages of eight and eighteen) and their families with short break services. These are provided in partnership with a range of voluntary organisations, including:

- Autism Bedfordshire
- Bedford and District Cerebral Palsy Society
- Families United Network
- Special Needs Out of School Club

#### **The proposals for change**

The Council's annual budget for services for children with disabilities is £4m and it is proposing to make savings to this budget of £158k each year. £68k of these savings would be made by reducing the amount of funding it provides to voluntary organisations and to work with them, parents and carers, to find new and more cost effective ways of supporting children and young people with disabilities and their families.

The Council also proposes to reduce funding (of £90k each year) for Occupational Therapy Services and Disabled Facilities Grant.

The proposed changes would see a new approach to assessing who would be eligible to receive specialist support, so that services for children and families in greatest need would be protected.

For those children and families who may have lower levels of need, the Council proposes to redesign services in partnership with parents, service users and other organisations.

The sort of services that could be redesigned would include short breaks being developed at Universal Services such as the Council's Libraries, Leisure Centres and Swimming Pools as well as other services accessible to the public. As part of these proposals parents could be asked to contribute to the costs of these services.

### **3. The Consultation Process**

The Special Needs Action Panel (SNAP) 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 0-25 years is heard. SNAP has been working with Central Bedfordshire Council in preparing for this consultation.

Focus Groups with parent carers were held in June 2016 resulted in a feedback report entitled "A Review of Short Breaks within Children's Services" and this has been used as the basis for the consultation and key questions about how changes might be introduced. This included:

- Opinions on proposed increase in cost effectiveness
- Opinions on proposed protection of services for those in greatest need
- Opinions on proposed development of new service models for those with lower levels of need
- Opinions on proposed application of new eligibility criteria
- Opinions on changes to the funding model – reducing grant funding to voluntary organisations

The consultation document was made available both as an online survey and a paper questionnaire.

The consultation was launched on 9<sup>th</sup> December 2016 and concluded on 15<sup>th</sup> March 2017 in order to maximise the opportunity for the public to respond.

The consultation was supported by a comprehensive communications campaign which directly targeted current and future service users and alerted the public to the opportunity to express their views through various promotional activities.

Activities included:

- A news release was issued to all local newspaper groups at the start of the consultation in December. It also featured on prominent online news sites such as Houghton Regis News Desk, Dunstable News Desk
- Notifications were posted on the voluntary organisations' Facebook pages to encourage them to promote the consultation
- Regular updates were posted on CBC social media channels (Facebook and Twitter) to encourage people to take part in the consultation with individual Facebook posts reaching up to 1,900 people
- Email bulletins were issued encouraging people signed up to various topics (latest news, fostering, schools etc.) to take part in the consultation
- Updates were published in various council newsletters (Staff Central, Members' Information Bulletin, Connect, fostering newsletter, Central Essentials etc.) to promote the consultation and get staff engaged in it, and to encourage those in a position of influence such as councillors to promote it further
- Schools were contacted directly by email to highlight the consultation
- The consultation was promoted directly to families of children with disabilities through February half term holiday clubs.
- A direct email to parents and carers of children and teenagers with disabilities
- A direct postal mailout to 650 parents and carers of children and teenagers with disabilities.
- Promotion through SNAP
- Promotion through special schools and mainstream schools

Promotional posters and paper copies of the questionnaires were distributed to our Customer Service centres and Libraries.

In addition to inviting feedback via the survey the Equality Forum were provided with a briefing of the proposals on 16 June 2016.

A sustained online campaign was also managed with promotion via social media, email bulletins and the website.

The short breaks consultation website had 1613 visits in between December 2016 and March 2017, demonstrating the level of interest and reach of the campaign. The top methods used to find information included 563 hits from direct email links, 377 from Google searches, 276 from Facebook, 219 from Gov Delivery bulletins and 39 from Bing searches.

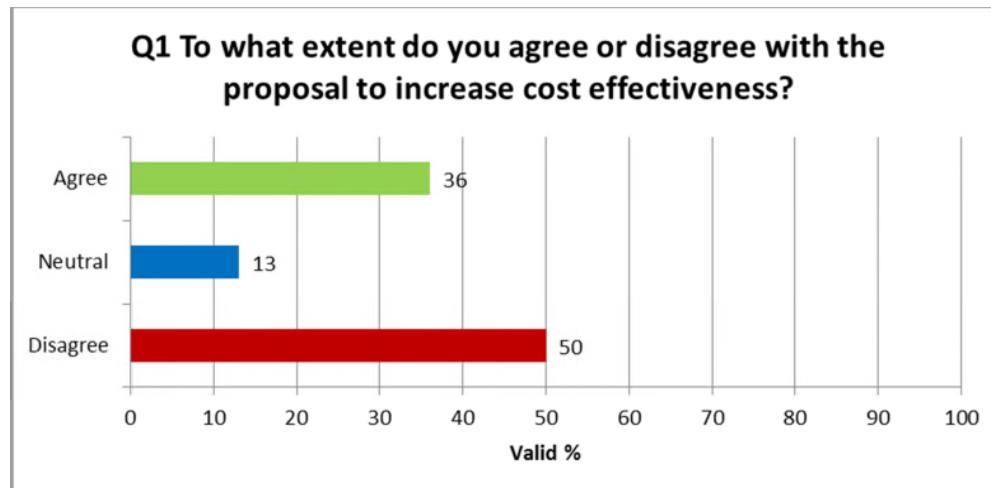
#### **4. Feedback on the proposals**

In total 118 Central Bedfordshire residents participated in the consultation by completing the survey.

## a. Cost effectiveness

### Q1. To what extent do you agree or disagree with the proposal to increase cost effectiveness? (Please tick one)

113 people responded to this question.



Half of respondents (50%) indicated that they disagreed with the proposal to increase cost effectiveness. However over a third of respondents (36%) agreed with the proposal and 13% remained neutral.

### Comments on the proposal:

46 respondents provided additional comments. An analysis of the comments indicated the value that parents of children and teenagers with disabilities place in the current services; repeat themes included:

- All children should access the service (11 respondents)
- Services should be maintained (9 respondents)
- Families rely on the service (8 respondents)
- Wrong service to cut (7 respondents)

*'I believe cost effectiveness is essential in all services but not if it is interpreted as a reason to cut services which give young people the necessary support'*

*'By cutting funding to services and charity groups children and young people will not be able to access social activities/groups outside of school. They will become isolated.'*

### Variations by respondent type

The majority of respondents who are currently using or anticipate that they would be eligible to use the short break provision were opposed to the proposal to increase cost effectiveness. Opinions of respondents who were not service users were more balanced.

If respondents had 1 child or teenager with a disability there were more likely to object to the proposal for increasing cost effectiveness. Respondents with 2 or more children were more likely to support the proposal to increase cost effectiveness.

Respondents with children or teenagers with long standing illness or health condition were more likely to disagree with the proposal to increase cost effectiveness. Views of respondents with children or teenagers with physical, learning or sensory difficulties were more evenly spread.

Respondents who considered that they had a disability were more likely to have a spread of opinion on the proposal. Respondents who did not have a disability were more likely to object to the proposals.

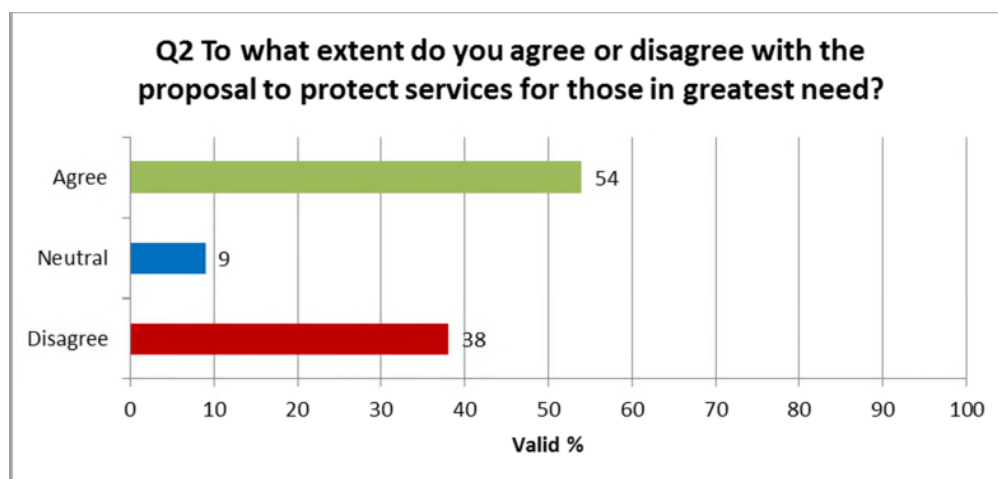
### **Summary**

There are mixed views about the degree to which the focus on cost effectiveness should be increased with some respondents highlighting the need to maintain services for all vulnerable groups of children and young people.

#### **b. Protecting services for those in the greatest need**

##### **Q2. To what extent do you agree or disagree with the proposal to protect services for those in greatest need? (Please tick one)**

112 people responded to this question.



Whilst the majority of respondents (54%) indicated that they agreed with the proposal to protect services for those in greatest need, a significant minority (38%) indicated that they disagreed and 9% remained neutral.

*(Numbers may not add up due to rounding)*

## **Comments on the proposal:**

50 respondents provided additional comments. An analysis of the comments indicated a widely held opinion that all vulnerable children should be able to access services, repeat themes included:

- All vulnerable children should be able to access services (24 respondents).
- Concerns that the threshold criteria was unclear

*'Every child matters. I cannot agree to some vulnerable children being at a substantial disadvantage in order for other vulnerable children deemed worthy of support to keep theirs. Taking away specific support and understanding of essential services will leave vulnerable children & families even more isolated than they already are.'*

## **Variations by respondent type**

Respondents with 1 child or teenager with disabilities was more likely to agree with the proposal to protect services for those in greatest need. Views of respondents with 2 or more children with disabilities were more likely to have a balance of views.

Respondents with children or teenagers with long standing illness or health condition were more likely to agree with the proposal protect services for those in greatest need. Views of respondents with children or teenagers with physical, learning or sensory difficulties were more evenly spread.

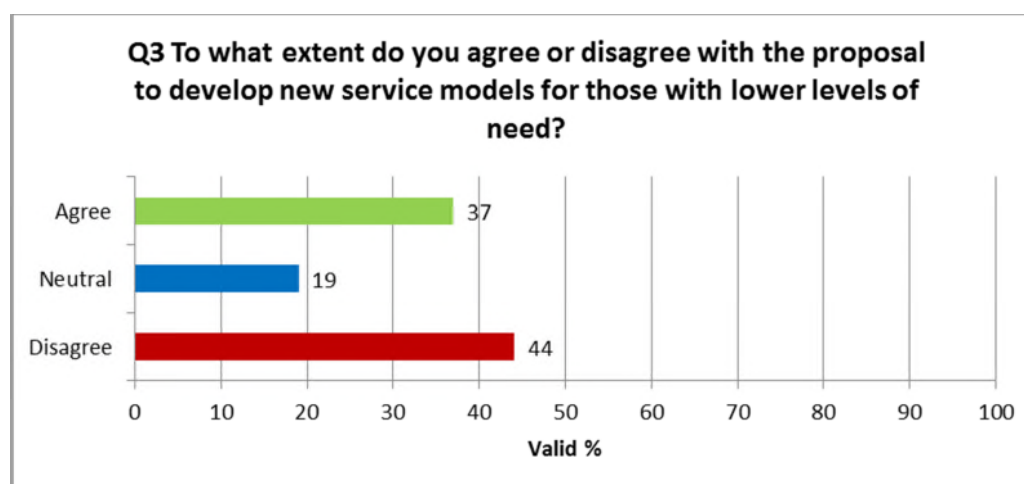
## **Summary**

There are mixed views about the degree to which services should be protected for those in greatest need with some respondents highlighting the need to continue to provide support for lower levels of disability.

**c. New service models for those with lower level needs**

**Q3. To what extent do you agree or disagree with the proposal to develop new service models for those with lower levels of need? (Please tick one)**

113 people responded to this question.



Opinion towards the proposal to develop new service models for those with lower levels of need was more balanced with 44% of respondents indicated that they disagreed and 37% agreeing with 19% remained neutral.

**Comments on the proposal:**

48 respondents provided additional comments. An analysis of the comments indicated repeat views that all vulnerable children should be able to access services (14 respondents) and that current services should be maintained (9 respondents). Repeat themes included:

- All vulnerable children should be able to access services (14 respondents)
- Concerns expressed about using universal services (10 respondents)
- Current services should be maintained (9 respondents)
- Concerns about faith in Council to provide a new service model

*'We really value the work and expertise of the voluntary organisations. They could + should be involved in developing services and training up staff in areas of 'lower levels of need' They should receive more funding in order to support "universal services".'*

*'By 'new service models' I assume you mean universal services?? I am not convinced that staff working in universal services have the skills, attitudes or outlook needed to do all that would be required to*

*successfully include disabled young people in their settings. Sadly, it can often be the case that parents are left to battle for change with a mainstream provider, which is stressful and disheartening for them. What help will be available for families if they feel that the universal service that their child is accessing is not willing or able to make the necessary changes or adjustments to include their child?’*

### **Variations by respondent type**

Respondents with 1 child or teenager with a disability are more likely to disagree with the proposal to develop new service models for those with lower levels of need. Respondents who have 2 children or teenagers with disabilities are more likely to agree with the proposal. Respondents who have 3 children or teenagers with disabilities are more likely to have a balance of views.

Respondents with children who have physical disabilities were more likely to agree with the proposal to develop new service models. Respondents with children who have sensory impairment were more likely to disagree with the proposal. Respondents with children who have a learning disability or long standing illness had a balance of views.

Respondents who did not have a disability were more likely to disagree with the proposal to develop a new service model. Respondents who had a disability had a balance of views.

### **Summary**

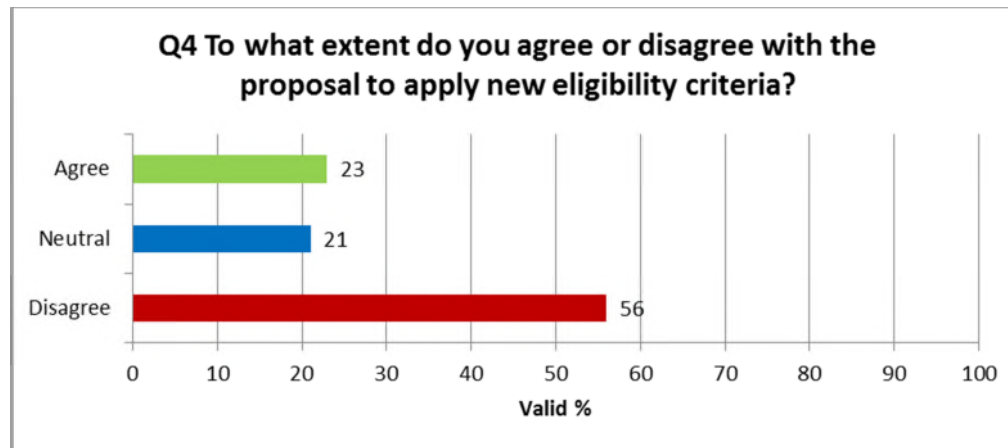
Views were more evenly split about the degree to which new services models should be developed for those with lower level needs. Some respondents indicated that it might be possible, with voluntary sector support and appropriate training within universal services to develop new service models. However; other respondents expressed concerns about the appetite for change and levels of staff competency within universal services.



#### d. New eligibility criteria

##### Q4 To what extent do you agree or disagree with the proposal to apply new eligibility criteria? (Please tick one)

115 people responded to this question.



The majority of respondents 56% of respondents indicated that they disagreed with the proposal to introduce a new eligibility criteria, with 23% agreeing and 21% remained neutral.

*(Numbers may not add up due to rounding)*

#### Comments on the proposal:

42 respondents provided additional comments. An analysis of the comments indicated repeat views that all vulnerable children should be able to access services. Repeat themes included:

- All vulnerable children should be able to access services (15 respondents)
- Concerns that the criteria might be too restrictive (9 respondents)
- Concerns that there was a lack of information regarding the new criteria (8 respondents)
- Concerns that Autism was not adequately accounted for in the new criteria (6 respondents).

*'I cannot agree without information about what the criteria will look like. I can see your tables on what title you give each layer of need, but nothing about where that places a family on the 'need scale'. The care that a SEN child needs does not necessarily correspond with the stress it puts on a family. A much wider investigation is necessary for each case.'*

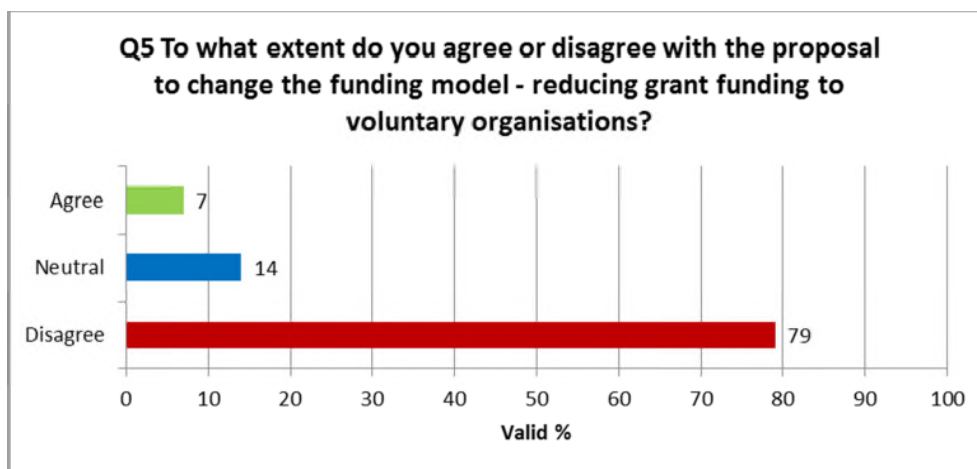
## Variations by respondent type

Respondents who do not current use or anticipate using short break services were more likely to have a balance of views on the proposal to apply a new eligibility criteria.

### e. Funding model

**Q5 To what extent do you agree or disagree with the proposal to change the funding model - reducing grant funding to voluntary organisations? (Please tick one)**

114 people responded to this question.



A significant majority (79%) of respondents indicated that they disagreed with the proposal to change the funding model.

### Comments on the proposal:

57 respondents provided additional comments. An analysis of the comments indicated repeat views that voluntary organisation services are too crucial to cut. Repeat themes included:

- Voluntary organisation services are too crucial to cut (15 respondents)
- The resulting impact may be that families and children may become isolated as a result (12 respondents)
- This may cause voluntary organisations to cut services (11 respondents).

*'The voluntary organisations are the experts. The ones that I have had dealings with work with both children, young people and parents. They provide much needed services that are tailored to what their users want and need. They totally understand the needs of their users and are highly trained. To reduce their funding would be misguided. It is short sighted...'*

## f. Short break services

### Q6 What do children, teenagers and families value most in good short break services? (Tick top 5 most important)

110 people responded to the question. The results indicate that children, teenagers and families have different views on the value in the service provided. Based on the top responses the key areas of value are:

- **Children:** Having fun (56%), developing friendships (55%), social skills (53%) and building self confidence (44%).
- **Teenagers:** Building self confidence (62%), independence (56%), social skills (54%), self esteem (51%), developing friendships (49%) and gaining practical life skills (46%).
- **Families:** Rest (65%), family participation (46%), friendships (44%) and continuity (41%)

#### Other options:

17 respondents provided suggestions for additional options. Repeat themes included:

- Tailored surroundings that match the needs of the child (8 respondents)
- Understanding and expertise (6 respondents).

*'All of the above are important but what isn't here is safety, deep understanding & expertise that gives you the complete relaxation of knowing for the only time your child/young teen is away from you that they are safe, completely supported, understood & happy. That is what a short break means to us. We cannot get that at school or anywhere other than the voluntary organisations. Can you replicate that?...'*

### Q7 How do you currently find out about the short break local offer? (Tick all that apply)

118 people responded to the question. The main sources of information currently used are:

- Voluntary Organisations (51%)
- Council website (22%)
- Children's Centres (8%)
- GP/Doctor (6%)
- Council Customer Services (3%)

40 people provided suggestions for other sources of information about the short break offer, repeat themes included:

- Social workers (10 respondents)
- Schools (8 respondents).

### **Q8 How could we improve access to information about the short break local offer in future?**

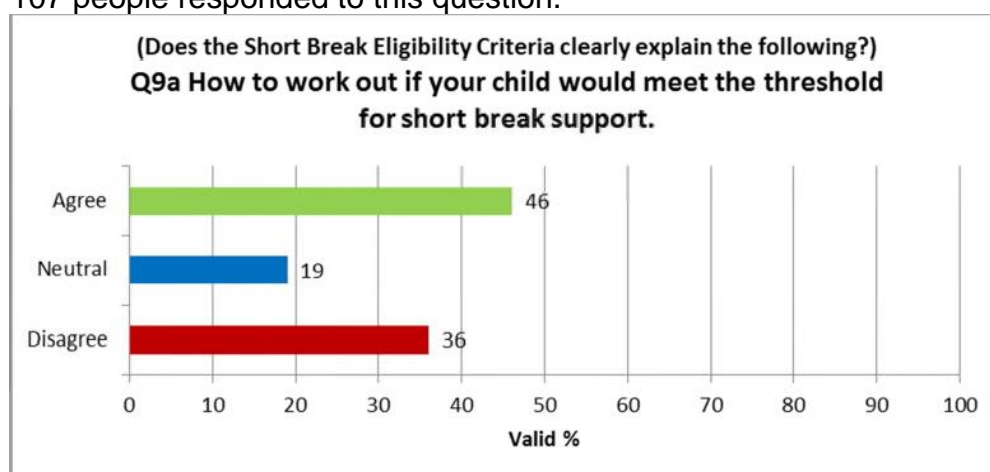
50 people responded to this question. The most frequent suggestions put forward included:

- Via schools (15 respondents)
- Better information on where to look (10 respondents)
- Email mailing system (7 respondents)
- Use databases to help identify people to keep up to date (6 respondents)

Others highlighted a perception that there was a lack of information about the short break local offer (6 respondents)

### **Q9a Does the Short Break Eligibility Criteria clearly explain the following: How to work out if your child would meet the threshold for short break support? (Please tick one)**

107 people responded to this question.

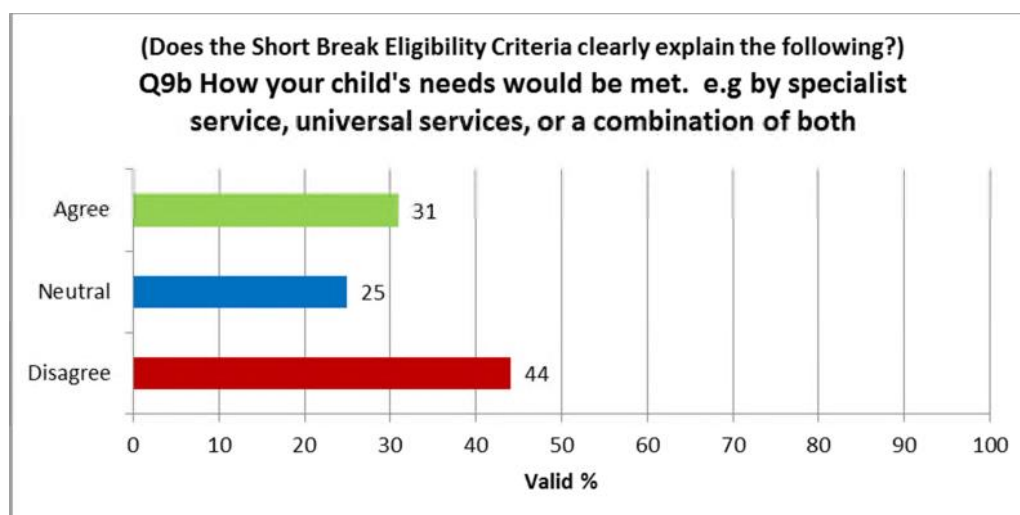


A majority of respondents (46%) indicated that the criteria clearly explained how to work out if their child would meet the threshold for support, with 36% disagreeing and 19% remained neutral.

*(Numbers may not add up due to rounding)*

**Q9b Does the Short Break Eligibility Criteria clearly explain the following: How your child's needs would be met. E.g. by specialist service, universal services, or a combination of both? (Please tick one)**

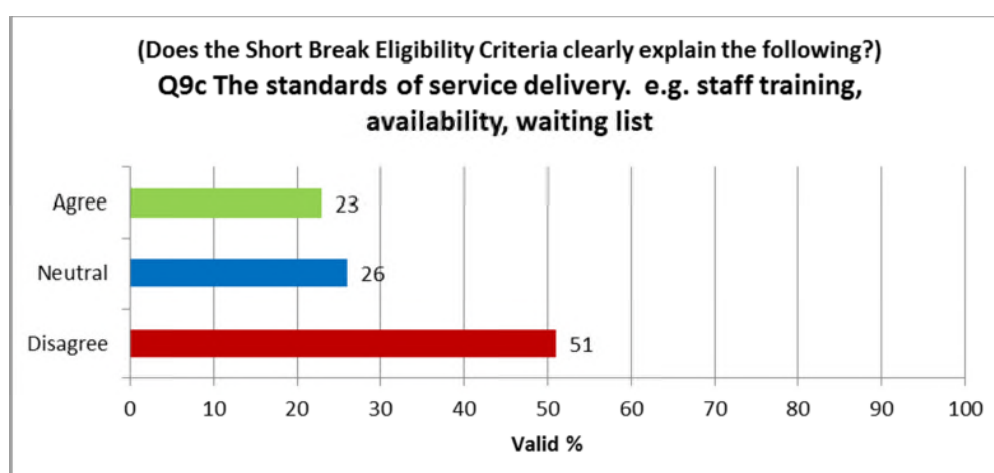
105 people responded to this question.



A majority of respondents (44%) indicated that the criteria did not clearly explain how their child's needs would be met. 31% agreed the criteria was clear and 25% remained neutral.

**Q9c Does the Short Break Eligibility Criteria clearly explain the following: The standards of service delivery. E.g. staff training, availability, waiting list? (Please tick one)**

105 people responded to this question.



The majority of respondents 51% indicated that criteria did not clearly explain the standards of service delivery. 26% agreed that the criteria was clear and 26% remained neutral.

**Q9d If you have answered disagree or 'strongly disagree', please explain what would have helped you to understand the Short Break Eligibility Criteria? (Please tick one)**

47 people provided additional comments. The most frequent comments were:

- Criteria is not fully understood (12 respondents)
- Clear instructions on how to interpret the criteria is needed (10 respondents)
- Service standards not fully explained (8 respondents)
- More detail is needed (7 respondents)
- Autism is not fairly reflected (6 respondents)
- Simplify the wording (6 respondents)
- Explanation needed for those with multiple disabilities (4 respondents)

**Summary**

Responses indicated a mixed level of understanding of the eligibility criteria, how it would be applied and what support would be provided as a result. Some respondents also expressed concern that certain types of disability were not reflected in the criteria.

**g. Service redesign/universal services**

**Q10 From the list below please tick the options that you feel are important for the Council to consider when developing this type of provision? (Tick all that apply)**

114 people responded to this question. The options in order of importance to respondents are:

- 63% of respondents felt it was important to use **specially trained staff from voluntary organisations** to visit the library, leisure centre, swimming pool to run sessions for children and teenagers with disabilities.
- 57% of respondents felt it was important to **use specially trained Council staff** who are permanently based at the library, leisure centre, swimming pool to run sessions for children and teenagers with disabilities

- 56% of respondents felt it was important to use **multi-purpose rooms** and facilities at universal services to run sessions for children and teenagers that are **dedicated to their needs**. (i.e. not open to the general public).
- 40% of respondents felt it was important to provide opportunities to integrate children and teenagers into universal services. (i.e. shared access with the general public).

26 respondents provided other suggestions in support of retaining the status quo. Repeat themes included:

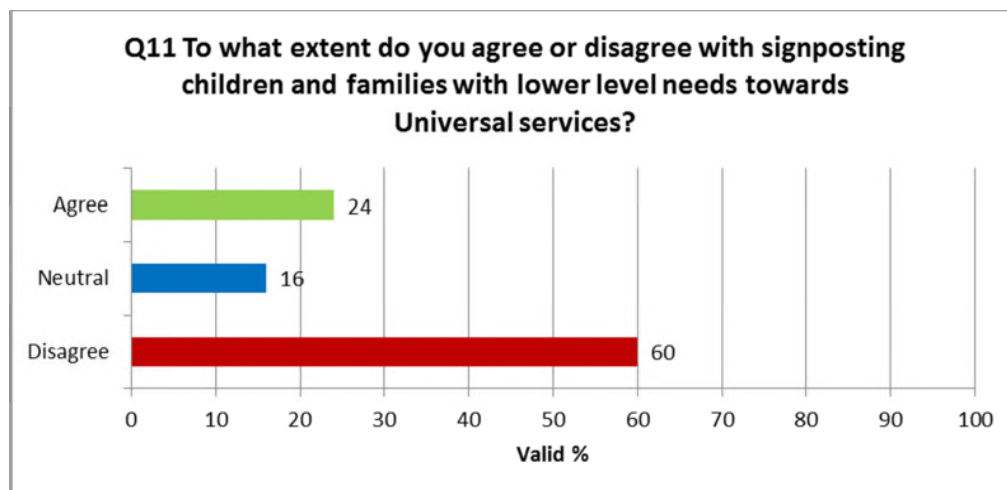
- Voluntary organisations already provide this provision (9 respondents)
- Protect grant funding to voluntary organisations (6 respondents)
- Universal services are unsuitable (6 respondents).

### **Summary**

Responses indicated that priorities focused on the importance of using specially trained staff and providing dedicated sessions in multi-purpose rooms. Far less priority was placed on the need to integrate children and teenagers into shared access with the general public. This suggests that families place greater importance on the provision of specialist support above the objective of achieving further integration.

### **Q11 To what extent do you agree or disagree with signposting children and families with lower level needs towards Universal services? (Please tick one)**

112 people responded to this question.



The majority of respondents (60%) indicated that they disagreed with signposting children and families with lower level need towards Universal services. 24% agreed and 16% remained neutral.

55 people provided additional comments. Repeat themes included:

- Universal services are unsuitable (11 respondents)
- Concerns about children becoming isolated (7 respondents)
- The needs of children with disability are all different ( 7 respondents)
- The family needs support too (7 respondents).

*'We have tried integrating my teenager into universal services since he was born and this has been unsuccessful, he has been asked to leave every since [sic] universal group he has attended at one time or another. He has no friends, no social life, no independence despite turning 16 next month. The only groups he can access are those run by Autism Beds and No Limitz. You cannot cut funding to these sorts of groups. You have no idea of what is like for the children you refuse to support in trying to access universal services.'*

*'All needs are important and changing into universal services so quickly without enough trained staff and understanding could make a manageable problem or behaviour for a disabled person a bigger problem and harder to deal with. Snowball affect'*

### **Summary**

The majority of respondents disagreed with signposting children and families with lower level needs to universal services, with existing service users expressing concerns based on personal experiences regarding a lack of support and resulting negative impacts.



**Q12 Do you have any concerns about the idea of integrating children and teenagers with lower needs into universal service provision? (Tick all that apply)**

114 people responded to this question. The options in order of importance to respondents are:

- Access to well trained and knowledgeable staff (74%)
- Attitudes of mainstream children and teenagers (72%)
- Attitudes of parents of mainstream children and teenagers (68%)
- Ensuring that the premises is developed with children and teenagers with disabilities in mind i.e. separate changing facilities, specialist equipment, safe access, parking etc. (66%)
- Mixing children and teenagers of the same age but with different ability levels (54%)
- Intimate care (47%)

20 people provided additional comments. Repeat themes included:

- Staff support (6 respondents)
- Environment/safety (6 respondents)
- How universal services will be adapted for children with disabilities (4 respondents).

*'I am concerned about the ratio of support, the environment, how concerned staff will be to ensure they don't stand out. How tailored will it be to the child/young person. How will you provide a calm noise free environment?'*

*'The level of understanding and tolerance of other service users. How will the young people accessing the services feel to be the only 'different' person in a group. There will not be the level of acceptance and understanding from their peers as there are in specialist settings. Many young people with Autism will not even contemplate going to any universal service. I know that from lots of experiences and on the occasions when we tried to access universal services when are son was a lot younger it always ended in disaster or we were asked to leave. Would you like a full list of the universal services we have tried to unsuccessful access in the past?'*

**Summary**

In addition to a requirement for knowledgeable and well trained staff, respondents expressed significant concern about the attitudes and behaviours of mainstream parents, children and teenagers. Further thought would also need to be given to the provision of specialist equipment and facilities.

**Q13 How else can the Council ensure that services are sustainable?  
(Tick all that apply)**

115 people responded to this question. The options in order of importance to respondents are:

- Ensure that we are putting the needs of children and teenagers at the heart of service provision by working with voluntary organisations to ensure there is no overlap or duplication of services (67%)
- Help voluntary organisations to work together to share expertise and knowledge (59%)
- Develop standards with partners including voluntary organisations to ensure that outcomes for children and teenagers are being achieved (56%)
- Help families to attend short break sessions by ensuring there is adequate provision in their local area to reduce travelling time (55%)
- Look at ways of managing vacant short break places to ensure that all opportunities have been taken up (53%)
- Provide advice and support to enable teenagers over the age of 16 and their parents to access direct payments (43%)

22 people provided additional comments. Repeat themes included:

- Maintain services without additional cost (7 respondents)
- Provide more support to parents (6 respondents)
- Cut staff salaries (4 respondents)
- Cut less important services (3 respondents).

*‘Ensuring that all social workers and school staff are fully aware of what current short break opportunities are available in the county and are communicating these clearly and regularly to all those families that can benefit. Find a way to acquire and collate all of the data from schools on their pupils with disabilities so that there is a clear picture of the overall need that exists in the county, and update this regularly. Gather data from all of the EHCPs (Education Health & Care Plan) to understand what services are needed in the county and where, in order to meet many outcomes that will be common among many children and young people.’*

**Summary**

Respondents indicated clear support for more integrated working between voluntary organisations, a focus on locally based services and a need to put children and teenagers the centre of service provision with clearly agreed standards and outcomes.

## **h. Open Field Commentary**

### **Q14 Do you have any other comments on the future design of short break services?**

In response to the invitation to make a further comment about the proposals, some 52 respondents chose to do so. Repeat themes included:

- Families depend on services provided by voluntary organisations (13 respondents)
- Do not cut funding to voluntary organisations (11 respondents)
- All vulnerable children should access services (9 respondents)

*"I am very worried about the impact that taking voluntary services away from disabled children & young people children will have. how can you replace what will be lost? Will we be left with no quality of life? Autism Bedfordshire have been invaluable to helping learn about a condition, shoulder to cry on, help with forms that need filling, provision of support for child in caring environment and advice on behavioural issues. They are a 'whole' service. How will you provide the same thing?" My son went to a farm with them, held a lamb, fed+ held chicks, fed lambs, went on a tractor. The lamb fell asleep on his lap & my son was peacefully happy. He said 'I have never felt so happy!' How will you replace that!*

*"My life is spent solely caring for my son, I have no family within 100 miles. Disability doesn't help you keep friends it distances you, especially when the gap between your child and theirs widens. When you have no sleep, no breaks and no life to freely call your own it can be deeply lonely. Autism Bedfordshire have picked me up when no one else would so many times and without their support, expertise, and understanding, my life would have been in crisis. How as a council can you replace this? Vulnerable families will be severely affected by taking the funding from our lifeline voluntary organisations. If we could access the universal services, we would be using them. Take away our lifeline and we will have nowhere to turn. PLEASE DON'T DO THIS TO US."*

*"Short break services should be designed for those with special needs at every level, not just the most severe. Children with special needs are a target for bullying by typical children and even by some adults. It is vital that their confidence, self esteem, and independence skills are built up during childhood up to age 18 to give them the resilience they will need to survive with a measure of independence in adult life. If children with mild and moderate needs are not properly catered for now, they are at higher than average risk of developing mental health difficulties. This means they will need more support in adult life than they would have done if their needs had been properly catered for in childhood..."*

*"I have seen a number of attempts to run specialist services through universal services and it often fails for many reasons. It must be more cost effective in*

*the long run to work with voluntary agencies to ensure that children with moderate and high level of needs are given the correct services reducing safeguarding and family breakdowns. From experience, it's a no brainer."*

*"... There is no way that universal services will be suitable for many families with Autism but what you are proposing for Autism Bedfordshire is going to lead to a cut in their existing services. For many young people with Autism the services provided by Autism Bedfordshire are the only things they access and now we risk losing them. Autism is a lifelong, developmental disability that affects how a person communicates with and relates to other people. You will note that the definition never mentions having a learning disability you can be affected by your Autism just as much even if you do not have an associated learning disability. You will not be able to just walk into universal services just because you have a high cognitive ability if you have Autism. It affects many people in the community across all walks of life and if anything needs more not less funding."*

## **i. Profile of respondents**

The data collected indicates that ....

75% of respondents indicated that they were either current service users or anticipated using short break services for children or teenagers with disabilities. 25% of respondents were not service users. This is a good indication that the consultation reached key stakeholder groups.

87% of respondents were looking after 1 child or teenager with a disability. 10% looked after 2 children or teenagers with a disability and 4% looked after 3 children or teenagers with a disability.

Of those who had a child or teenager with a disability 77% felt that they met the threshold for access to specialist short break services.

The most prevalent disability or condition of the children and teenagers was learning disabilities (71%), then sensory impairment (46%), long standing illness or health condition (42%) and physical impairment (33%).

Other conditions included autism spectrum disorder (23 respondents), ADHD (24%) and Asperger's (14%).

77% of respondents were female and 23% male.

The majority of respondents (46%) were aged between 45-59 years and 30-44 years (38%). In smaller numbers, view of the following age groups were also represented in the consultation - under 16, 20-29, 60-64 and 65-74.

Although the majority of respondents (88%) did not have a disability, 12% of respondents considered themselves to be disabled.

The respondent profile was similar to the average for Central Bedfordshire as a whole, with 91% of respondents identifying as White British, 1% Asian/Asian British, 2% Mixed and 2% Chinese.

## **j. Other Feedback**

### **Equality Forum Consultation Feedback**

The Panel received a report starting with the premise that Council resources must be targeted to areas of greatest need and that all services must deliver value for money.

Comments were made, including:

- The focus should be on the children with the highest needs
- SNAP represented a very helpful group of parents with a constructive approach
- Respite for families with disabled children was vital and procedures were in place to identify families at risk who needed respite most acutely.

Panel members were encouraged to send in any further comments on the consultation.

## **k. Conclusion**

The findings of this consultation have emphasised the value that current service users place upon the voluntary organisations associated with the Children with Disabilities Service. There is a clear desire to see voluntary organisations remain involved with the service and to be an integral partner in any future service redesigns. Respondents also supported the facilitation of greater integrated working between the voluntary organisations.

The proposal regarding cost-effectiveness provided a varied level of support, with suggestions that it should not be the overwhelming driver for change. Concerns were expressed around prioritising support exclusively for those with higher level needs. The role of early intervention with lower level needs was highlighted by a number of respondents as being important in a preventative role, helping to ensure that children and young people do not require higher levels of support later on in life.

The findings indicated that creating new service models for those with lower levels of need might be possible, and that the support of the voluntary sector would be crucial in developing new approaches. Respondents highlighted the expertise of these organisations and recommended that any future training for universal services staff should be carried out with their involvement. However

it must also be noted that many respondents expressed a clear preference for retaining specialist support in the first instance.

Further concerns regarding the potential use of universal services highlighted that careful thought should be given to the environment of these locales and how specialist equipment and the safety of the children would be properly factored into discussions. In addition to this, there were concerns about the attitudes and behaviours of the general public towards disabled children and their families and how this created a significant barrier to integration. The prospect of having services provided in a greater variety of locations in Central Bedfordshire proved a favourable one.

Results also highlighted a lack of understanding of the proposed eligibility criteria which would be used to determine levels of need. Responses indicated that there was some confusion about how it would be applied and that there was a lack of understanding about what support would be provided as a result. This would suggest further consideration would need to be given to clarifying the eligibility criteria before implementation, along with additional promotional activities to help clarify to parents the range of service provision on offer.