

Central
Bedfordshire
Council
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Monks Walk
Chicksands,
Shefford SG17 5TQ



**TO EACH MEMBER OF THE
CHILDREN'S SERVICES OVERVIEW & SCRUTINY COMMITTEE**

04 July 2017

Dear Councillor

**CHILDREN'S SERVICES OVERVIEW & SCRUTINY COMMITTEE - Tuesday 11 July
2017**

Further to the Agenda and papers for the above meeting, previously circulated, please find attached the following additional report:-

11. Children with Disabilities Short Breaks and Efficiencies

To review the impact of the proposed efficiencies including those proposed for short breaks.

Should you have any queries regarding the above please contact Scrutiny on Tel: 0300 300 4193

Yours sincerely

Rebecca Preen
Scrutiny Policy Adviser
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Central Bedfordshire Council

CHILDREN'S SERVICES OVERVIEW & SCRUTINY COMMITTEE

Tuesday 11th July

Report title Children with Disabilities Short Break and Efficiencies

Report of: Cllr. Carole Hegley, Executive Member for Social Care and Housing (carole.hegley@centralbedfordshire.gov.uk)

Responsible Director(s): Sue Harrison, Director for Children's Services (sue.harrison@centralbedfordshire.gov.uk)

Advising Officer: Ken Harvey, Head of Service, Children with Disabilities (ken.harvey@centralbedfordshire.gov.uk)

This report relates to a decision that is Key

Purpose of this report

1. To report following feedback from the Consultation of Short Break provision.
2. To report of the proposed threshold and redesign of the provision.

RECOMMENDATIONS

The Committee is asked to:

1. Consider the report attached as Appendix 1 and the recommendations set out within it.

Overview and Scrutiny Comments/Recommendations

3. Overview and Scrutiny are asked to support the recommendations for the proposed changes.

Options for consideration

4. The proposed threshold criteria and model for short breaks is set out in Appendix 1.

Reason/s for decision

5. The reason for this proposal are set out in Appendix 1

Council Priorities

6. The proposal set out in Appendix 1 supports all of the Council's Priorities

Corporate Implications

7. As set out in the Corporate Implications section of Appendix 1

Legal Implications

8. As set out in the Legal Implications section of Appendix 1

Financial and Risk Implications

9. As set out in the Financial section of Appendix 1

Equalities Implications

10. As set out in the Equalities section of Appendix 1 and Appendix C

Conclusion and next Steps

11. As set out in the Conclusion and Next Steps section of Appendix 1

Appendices

As set out in the appendices section of Appendix 1

Background Papers

None

Central Bedfordshire Council

EXECUTIVE

Tuesday, 11 July 2017

Children with Disabilities Short Breaks and Efficiencies

Report of: Cllr Carole Hegley, Executive Member for Social Care and Housing (carole.hegley@centralbedfordshire.gov.uk)

Responsible Director:: Sue Harrison, Director of Children's Services (sue.harrison@centralbedfordshire.gov.uk)

This report relates to a decision that is Key

Purpose of this report

1. Note the findings of the consultation
2. Approve the revised model of delivering short break services to disabled children, teenagers and their families

RECOMMENDATIONS

The Executive is asked to:

1. Agree the proposed model of delivery for short break provision, including the efficiencies of £158,000.
2. Agree the revised threshold criteria.
3. Agree the timescale for the delivery of the model

Overview and Scrutiny Comments/Recommendations

1. Note the findings of the consultation
2. Note the proposed model for delivery of short breaks within the CWD Service

Background

3. There are 535 children and young people with a statement or Education Health and Care Plan in Area Special Schools in Central Bedfordshire. There are an additional 35 children who attend out of area schools in neighbouring authorities. There are currently 217 of those children

accessing support from the Children with Disabilities team and accessing short breaks.

4. Central Bedfordshire Council is under a legal obligation to provide or commission short breaks for children with a disability; additionally it is required to, through the production of a Short Breaks Statement, set out the range of services provided, any eligibility criteria and how the range of services is designed to meet the needs of local carers. The statement must be published and kept under review and updated when either provision changes or eligibility criteria change.
5. There were efficiencies against the Children with Disabilities budget of £158,000 in 2016/17.
6. The proposed efficiencies have to date not been able to be implemented and mitigation has had to be found in other cost centres to offset the costs.
7. There are further proposed efficiencies of £82,000 in 2018/19 and £80,000 in 2019/20 which were set against the Children with Disabilities budget after the start of this consultation and therefore will need to also be consulted on.
8. The Council meets its statutory short break duty through a range of provision including targeted short breaks, community support, playschemes, family link scheme and overnight provision residential provision.
9. The Council is committed to ensuring that the needs of this vulnerable group of children and their parents and carers are met by good quality provision which is aspirational for children and young people, and supports parents to care for their children in their own home.
10. The Council's financial position has given the opportunity for the short break services to be reviewed through a culture of coproduction.
11. The Council proposed an approach to the consultation which was changed following the initial feedback from the parent forum (SNAP). There were focus groups held with parents to inform the consultation process. This has enabled families to be positively engaged in the discussions about thresholds to services and the most effective use of the allocated resources
12. The model seeks to create a more personalised approach to short breaks.
13. Personalisation means making sure individuals are fully involved in planning for their own future, ensuring they get the support that is right for them, and that they have choice and control over how they live their lives.
14. Personalisation is often thought about as simply to do with personal budgets that children, young people and families can use to buy services

that support to improve their outcomes. Personalisation is about much more than this: it's about a fundamental change in how we think about and organise services and support and particularly how we think about disabled children, young people and their families.

15. The proposed changes to the delivery of short breaks is an integral part of the Children's Services Transformation Programme and the Special Educational Needs and Disabilities (SEND) Vision to deliver services which support early identification and intervention; greater choice and control; collaboration between education health and care services and successful transitions to adulthood.
16. Families fed back that they wanted to have support which offered them the opportunity for much needed rest, friendships and continuity of support.
17. Children and young people want to access opportunities which enable them to build confidence, develop friendships, learn social and life skills and have fun.

Feedback from the consultation

18. The Council's consultation on the design of short break services resulted in 1613 visits to the website in between December 2016 and March 2017 demonstrating the level of interest and reach of the campaign. In total some 118 Central Bedfordshire residents participated in the consultation by completing the survey.
19. Key issues that were raised include:
 - a. it is harder for children and young people with disabilities and their families to experience and contribute to everyday life in ways that others take for granted
 - b. parents are unable to take ordinary breaks from caring that others families have
 - c. parents consider short break provision to be a life line for them and their families
 - d. there is still some confusion about who can access services which needs to be resolved.
 - e. a consistent view that universal services are unable to cater adequately for disabled children for a variety of reasons.
 - f. investment is needed to change and challenge the public's perception and behaviours toward disabled children and their families
 - g. services needed to be value for money and that a long term strategic plan with service providers must closely reflect and match current need
 - h. the need for access to support from appropriately trained carers.
 - i. respondents with children who have physical disabilities were more likely to agree with the proposal to develop new service models.

- j. respondents of children who have a learning disability and therefore may have some associated challenging behaviour had a balance of views.
 - k. parents of those children with long standing illness or health conditions were most likely to agree to the protection of services to those with the highest need which might be due to the complex issues and the short time that parents will spend with their children who have life limiting conditions
 - l. parents have confidence in the current Voluntary Organisation providers
20. The SNAP survey of March 2017 concluded that short break are vital for parent carers to enable them to function, for parents to work and rely less on benefits, social workers and GPs and develop their own self worth. The short break keeps families together and functioning as a unit which reduces the burden and cost for local authority when families breakdown.
21. There was feedback from 3 of the 4 organisations who are currently grant funded to provide short breaks to disabled children and their families.
22. The key issues they raised included the importance of the grant funding providing a platform from which they are able to access other monies to support Central Bedfordshire children and families.
23. There was concern about the proposal for some children to access universal services and how well they might be prepared for this to take place. The matter of staff competence was a concern if the Council are to ensure that children's needs are to be met and whether the environments are suitable for this happen.
24. The organisations are willing to work with the Council to plan the way forward and secure their future but advocate that this done in a planned way to reduce the impact on the small organisations and the children and families they serve.

Proposed Service Model

25. The proposed model will promote resilience in families who can, where possible access support with a minimum of intervention from professional services.
26. The proposed model will improve the well being of disabled children and young people through improving access to positive, and where possible inclusive activities.
27. The proposed model recognises the vast range on needs of disabled children living in Central Bedfordshire. It also recognises that disabled children have an important role in our communities.

28. The proposed model would be a 4 tiered approach which provides information and advice, universal, targeted/early help and specialist support.
29. Information and advice (Level 1) will be given to families to support them in navigating the complex pathway through the range of support and services available to them. The SEND Local Offer will be key in supporting this. This will be available to all families with a child with SEND.
30. The universal offer (Level 2) will be enhanced to be accessible by services such as leisure, libraries, countryside parks and activities. This would ensure that all disabled children have the opportunity to access positive local activities in a safe environment. This will be available to all young people but with a focus on supporting those in the area special schools and specialist units.
31. The targeted early help offer (Level 3) would ensure that disabled children and teenagers who are eligible for services from the Children with Disabilities Team but only require a lower level of support access targeted services. They may need to be supported by people with specialist knowledge but could also access universal provision with support where appropriate. They may do this with the support of a direct payment or personal budget. This could all be accessed via an Early Help Assessment within the children with Disabilities Services
32. The specialist offer (Level4) would be via a social work assessment, or joint assessment with health colleagues where required for those children presenting with the highest level of need. The social work service would seek to support families to care for this group of often very challenging children in their own homes with overnight or specialist short breaks where needed. This group of children and young people will currently be at the stage in their lives where access to level 2 and 3 would present a high level of risk to the child or others.
33. Level 4 will include specialist interventions for families who are experiencing high level of challenges from their children in their own home
34. It is envisaged that the majority of children with disabilities will access provision at level 2 and 3. This will reduce the bureaucracy currently experienced by families who will have less assessments, meetings and decision making processes in seeking support and give them further control of their situation.
35. The review and monitoring of assessments and allocated provision will be robust to ensure that children are being allocated services which meet their needs.
36. The model will be supported, where assessed as appropriate, by a personal budget or direct payment which will promote choice and control in accessing short break provision. It is recognised that this change may

impact on Voluntary Organisations who to date have relied on local authority grants to support bids for match funding.

37. The above proposal will provide the transparency and clarity that parents have said they require from the services. The vision will set out what the service will deliver and the each level (1 – 4) will have associated provision strengthened, where needed, by robust commissioning arrangements.
38. The proposed model will also enable the targeted use of the children with disabilities budget whilst improving access to information and advice and universal provision available to children and families whilst meeting the required efficiencies.

The Council will work with the Voluntary Sector to determine their role in this proposed model and offer families the choice and control required through a personalised approach.

Reason/s for decision

39. This model of short breaks will offer all children with disabilities and their parents the opportunities for choice and control, which is required in the Children and Families Act 2014.
 - 40 The model will support families to understand their situation and promote resilience through a range of improved options
40. The proposed new model has been well informed by parents and carers of disabled children gathered during the consultation process.
41. The development of the new service model will provide access to opportunities for fun and development for a range of disabled children within Central Bedfordshire giving them equal access to activities in their communities.
42. Better outcomes for children and their families will be achieved through well planned interventions at the appropriate level and the flexibility that this offers.

Council Priorities

43. By enhancing universal services we provide the opportunity to make provision accessible to disabled children and young people and for them to be more visible in our community
44. The proposed model supports the SEND vision in ensuring that children can be cared for and educated from a secure family base.

45. A wider range of vulnerable children will be able to access support at an appropriate level.
46. The proposed model has been shaped by residents through a thorough consultation process

Corporate Implications

It will be important that Members understand the proposals and are able to support the implemented changes.

Legal Implications

47. The proposed model for the Council provision of short break to children and teenagers with disabilities will comply with the statutory requirements.
48. Legal duties in relation to short breaks include both duties owed to individual children and families in relation to assessment and care planning and wider commissioning obligations on local authorities. The guide covers the key statutory duties found within the following legislation:
 - a. Children Act 1989 – all disabled children are defined as children in need; the provision of services to children and families
 - b. Breaks for Carers of Disabled Children Regulations 2011 – support for parents to carry out their day to day tasks; parents to be supported to access leisure and learning
 - c. Chronically Sick and Disabled Persons Act 1970 ('CSDPA 1970') – provision of welfare services
 - d. Children Act 2004 – Council must produce a short break statement setting out the provision available to support disabled children and their families; direct payments
 - e. Children and Families Act 2014 – The identification of special educational needs and disability; the meeting of their needs through Education Health and Care Plans; Duty to joint commission
 - f. Care Act 2014 transition to adult social care

Further detail is provided in the Equality Impact Assessment at Appendix C

Financial and Risk Implications

49. There are efficiencies of £98k in 2018/19 and £80k in 2019/20 which were added to the MTFP during the consultation. The efficiencies are set against service provision which supports disabled children, young people and their families.
50. There may be some further challenges from parents and the Voluntary Organisations to the proposed changes.

Equalities Implications

51. Central Bedfordshire Council has a statutory duty to promote equality of opportunity, eliminate unlawful discrimination, harassment and victimisation and foster good relations in respect of nine protected characteristics; age disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex and sexual orientation. Public authorities have duties not to discriminate against disabled people by treating them less favourably or failing to make reasonable adjustments. Public authorities also have a duty to have due regard to the need to promote disability equality.
52. Section 149 of the Equality Act 2010 explains that this includes taking steps to meet the needs of disabled people that are different from the needs of people who are not disabled. Complying with section 149 may involve treating some people more favourably than others, but that does not permit conduct which would otherwise be prohibited by the 2010 Act (section 149(6)).
53. An Equality Impact Assessment (EIA) has been completed as part of considering the proposal for delivering efficiencies to children with disabilities
54. In concluding it is advised that further consideration needs to be given as to the extent to which families receive services under the Children Act 1989, the Chronically Sick and Disabled Person Act (Sect 2) and the Break for Carers Regulations 2011.
55. There is a concern based on previous experience that universal services are currently not able to meet the needs of disabled children.
56. There is a desire that specialist services are protected and also for the Council to take into account the needs of children with lower level of needs in order to ensure that crisis is avoided and families are able to continue to care for their children at home.
57. Families have indicated that the Voluntary sector could have an important role in helping to ensure that if changes are made, that provision at universal locations is delivered in an appropriate way. The need to ensure sufficient time to plan and deliver such changes has also been highlighted.
58. As a suggestion for mitigation of adverse impact, the EIA proposes that consideration be given to whether the proposed changes could be implemented over a longer timescale with the ongoing involvement of the Voluntary organisation

Implications for Work Programming – next steps

59. The proposal is that the development of the service be planned to take place from 2017 – 2020

Conclusion and next Steps

- 60. The proposed changes should be delivered over a 3 year period ensuring a smooth transition for families, consolidation of the new commissioning framework and the universal services offer.
- 61. Ensure that the Local Offer is updated to reflect the information to provide greater transparency of support at all levels by December 2017
- 62. Task and finish group to be set up for the Autumn to begin the work of consolidating the Universal Offer by December 2017
- 63. All Children with Disabilities materials to be update to reflect the changes by December 2017
- 64. Staff briefings to take place to ensure that there is understanding of the levels and implications for practice by October 2017
- 65. Discussion to take place with procurement colleagues to determine timescale for a tendering process for the provision currently provided by the Voluntary Organisations by December 2017
- 66. All actions should be progressed through a coproduction agreement
- 67. Review the Council's approach to supporting children and young people with autism as this was a key issue for parents in the consultation process by April 2018.
- 68. The additional efficiencies for the period 2018 – 2020 to be consulted on and an Equality Impact Assessment completed.
- 69. Report progress to Overview and Scrutiny in May 2018.

Appendices

The following Appendices are attached:

- Appendix A:** Consultation document
- Appendix B:** Voluntary Sector Consultation Responses
- Appendix C:** Equality Impact Assessment
- Appendix D:** SNAP 2017 report
- Appendix E:** Proposed model and threshold

Background Papers

None

Report author:

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Appendix A

**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 9th December 2016 and concluded on 15th 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.

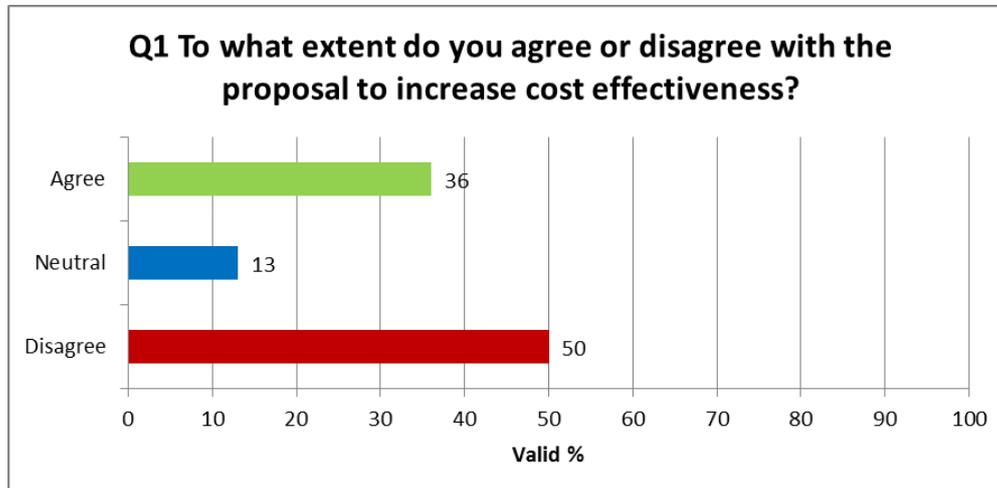
4. Feedback on the proposals

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.

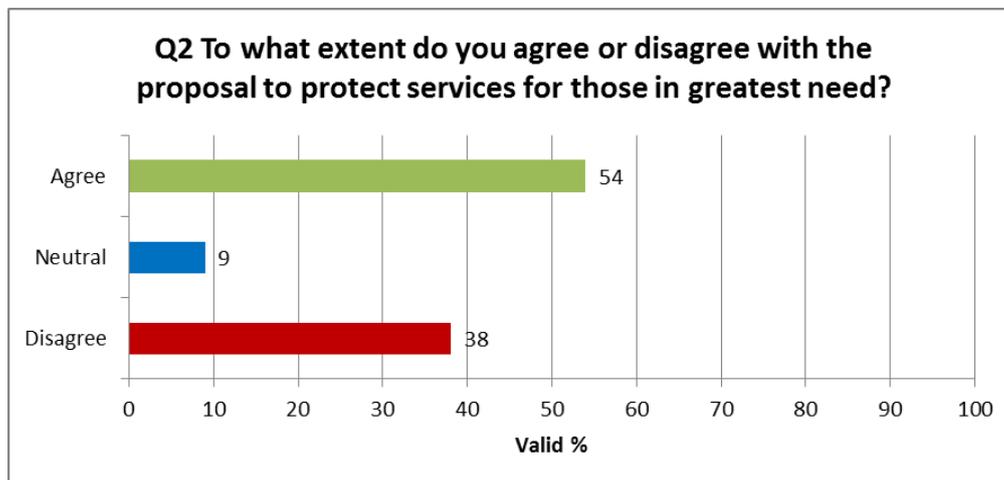
Summary

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.

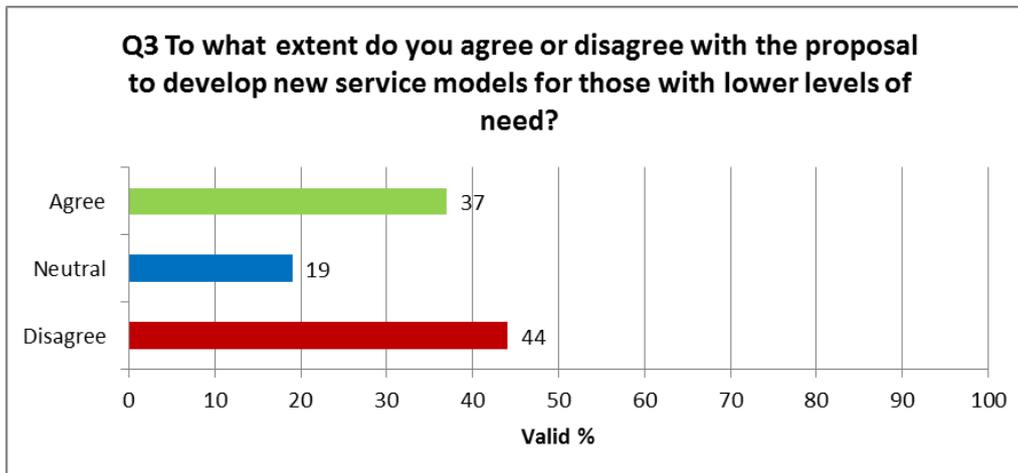
Summary

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.

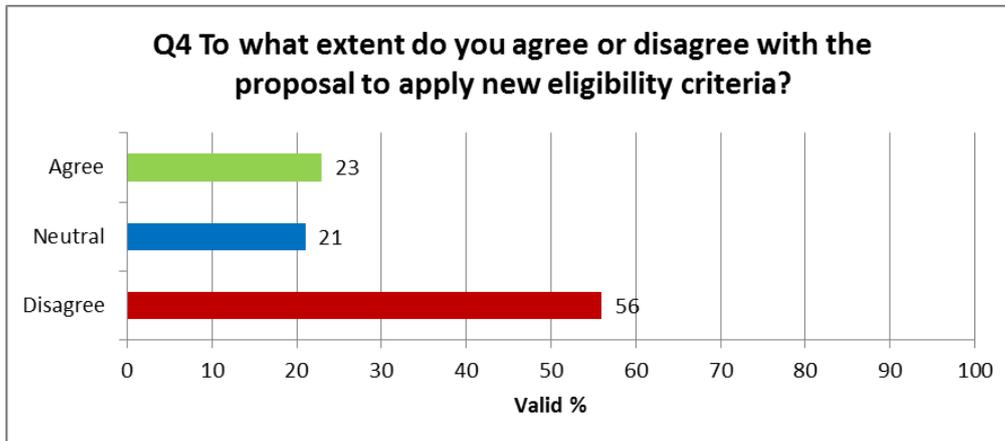
Summary

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.'

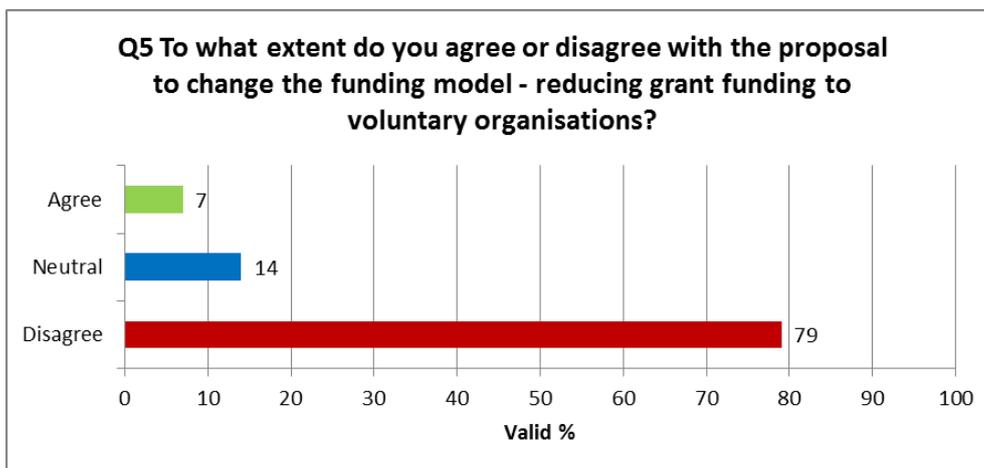
Variations by respondent type

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?

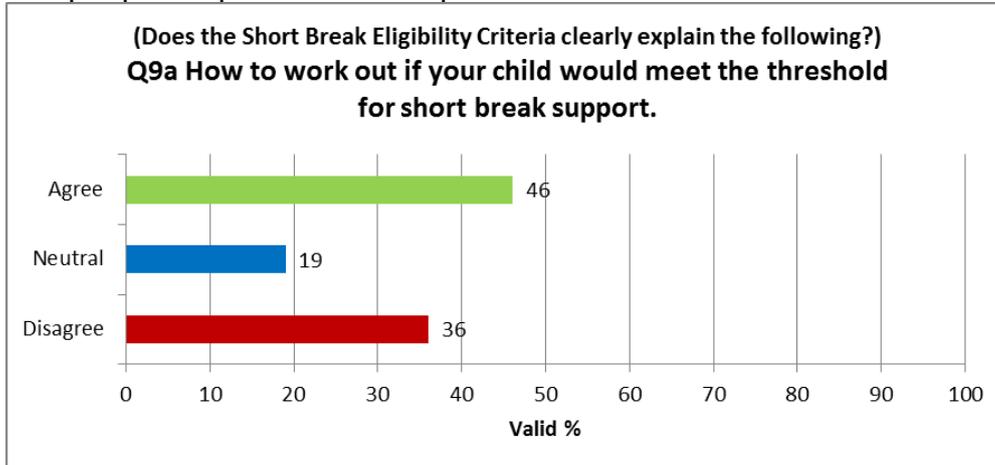
50 people responded to this question. The most frequent suggestions put forward included:

- 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.

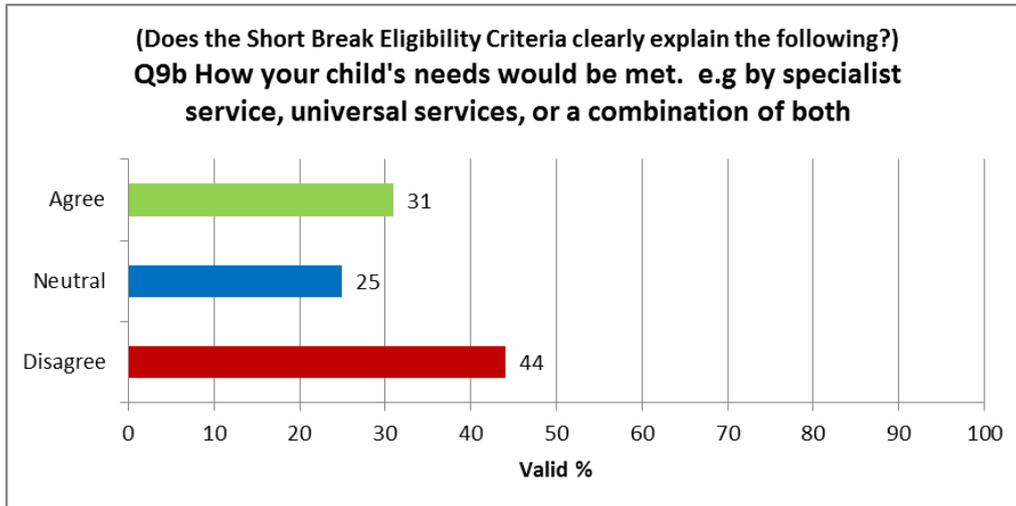


A majority of respondents (46%) indicated that the criteria clearly explained how to work out if their child would meet the threshold for support, with 36% disagreeing and 19% remained neutral.

(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)

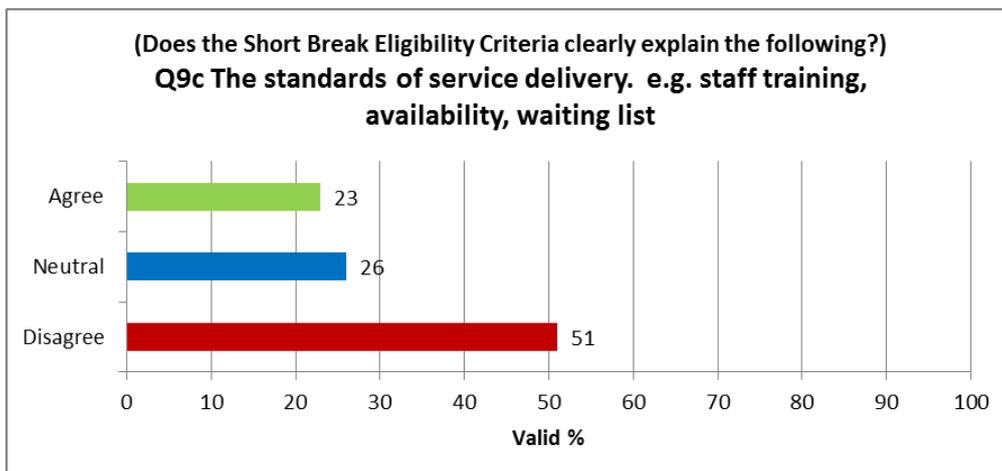
105 people responded to this question.



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 **specialty 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 specialty 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:

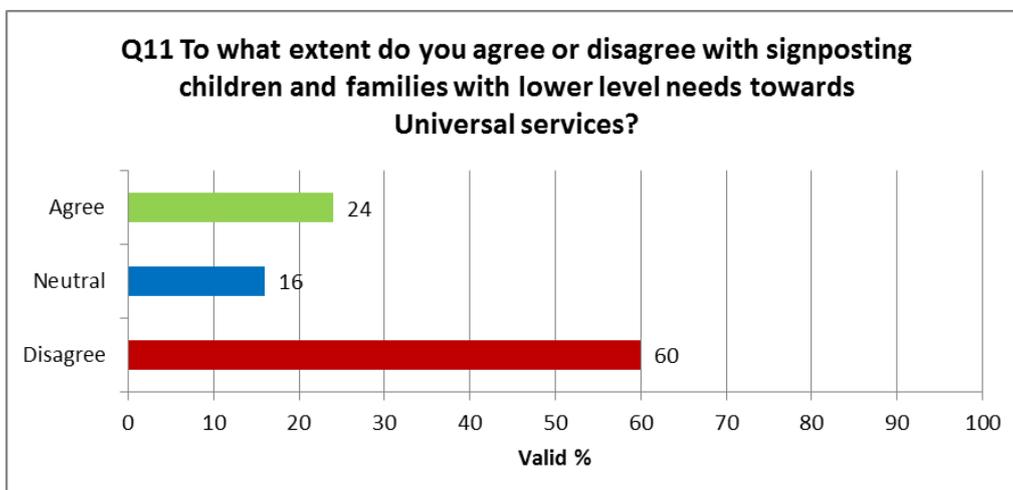
- Voluntary organisations already provide this provision (9 respondents)
- Protect grant funding to voluntary organisations (6 respondents)
- Universal services are unsuitable (6 respondents).

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 Limits. 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.

Voluntary Sector Consultation Responses

1) Autism Beds

Q1 Proposal to increase cost effectiveness

The proposal is brief and doesn't detail how the need will be assessed and met in other ways. We can only comment on the direct impact on our funding for life lines services: the proposed reduction of £68k in payments to voluntary organisations for short break provision. We strongly disagree that increasing cost effectiveness; by reducing payments to voluntary organisations for short break provision will be effective increase cost effectiveness.

We believe that the impact of Autism Bedfordshire being forced to reduce/remove services will inflate demand for costly social care support directly from the council. Currently, Central Bedfordshire receives £135k worth of services annually for an SLA that costs £35k. The SLA anchors our funding pot and attracts grants. Reducing/removing £35k risks the loss of services that cost £135k - this is not cost effective.

I would encourage full cost recovered in house services to be explored first; including £30k wasted annually on overnights that are not attended and the tens of thousands that families tell us that they have in their accounts to spend on direct payments, that go unregulated/reviewed and they cannot spend as they do not have suitable choices available to their needs.

Q2 Proposal to protect services for those in greatest need and

Q3 Proposal to develop new service models for those with lower levels of need

There is no definition that clearly defines; greatest need. Assuming that greatest level of need is the threshold criteria for CWD; All children with autism, including those who do not have intellectual impairment / Children receiving a service from social care / Children with special educational needs – all children with autism can fall into Meets Threshold for specialist services.

Autism (whether diagnosed as autism, classic autism, Kanners autism, autistic spectrum condition/disorder, Asperger Syndrome, High Functioning Autism) is a developmental, neurological disability; the impact of which can vary according to the level of anxiety/sensory processing of the individual. Some people with autism can also have a learning disability, but all people with autism will experience difficulty with weak central coherence and adaptive functioning – they would not receive a diagnosis if their difficulties were not impacting on their ability to function in a neurotypical society.

Like a learning disability, autism is life long – there is no cure. Autism is widely acknowledged to be an invisible disability but recent legislative changes protect the rights of those with autism (see the Autism Act 2009, Statutory Guidance 2010, Care Act 2014 and relevant guidance 2015) to the same levels of support as other disabled people without the need for a cognitive impairment (i.e. no IQ cut off).

A diagnosis of autism legally entitles children to the level of support described in the Central Bedfordshire Short Breaks Statement. With the Council proposing to target services on children with the 'highest/greatest' needs (this terminology without definition is extremely subjective) – those children being listed on the council's website as:

- Children receiving a service from social care
- Children with special educational needs

And proposing specialist Services would need to be withdrawn from:

- Siblings of children with disabilities

- Other children – i.e. children who do not meet the categories for the highest levels of need, but who may still meet a definition of disability under the terms of the Equality Act 2010 and the Children Act 1989.

The following two issues are extremely concerning and risky for 'other children':

They are a group of disabled children and their needs are not recognised/assessed. By limiting targeted services to those already in receipt of social care support, the council is effectively 'blocking up the door' to this group of disabled children, those in need go uncounted, registered and the council will be at risk legally of not understanding the level of need and therefore not fully understanding if they are providing adequate or sufficient short breaks/support.

For the council to understand and commission appropriately; a child's needs, needs to be properly assessed as, by trained professionals; the group that is titled 'other children', are at risk from having their needs neglected and the council is at risk from not complying with The Children's Act; in its duty to know the numbers of those with disabilities in order to understand the need within the area, to have an informed joint strategy and commission accordingly.

Q4 Proposal to apply new eligibility criteria

The new threshold criteria for CWD will only be an effective tool to measure and assess need if the social worker is trained, experienced and competent to understand some but not limited to the responses provided for questions 1-3.

Q5 Proposal to change funding model - reducing grant funding to voluntary organisations

As Q1 response

Q6 Opportunities universal services present to voluntary organisations as one way of meeting need for children and teenagers with lower level needs

They have facilities and staff. Over the last 25 years, we have attempted to work in partnership with these venues and over the last 7 years we have trained thousands of staff from Central Bedfordshire's leisure centres, libraries, swimming pools and play schemes. We have encouraged and supported members to integrate.

Parents, staff and Children told us in our January 2017 consultation that the barriers are being 'add on' group of people, that there is a lack of understanding, co-operation and empathy towards their needs and this dissuades members from continuing. Specialised services and support adequately meets the needs – other universal services are inadequate. The culture of acceptance and stigma still dominates; we are currently supporting the University of Bedfordshire and Autistic in conducting research and together working towards intervention programmes.

Q7 Issues the Council would need to consider

Staff induction, training, supervision and appraisal of working with/for children with disabilities would need expert care. Staff retention and turn over would need specialist training built into the common induction standards framework. The council would need to consider; that this may not work/breakdown, be underused; Strategic review points and appraisal of the effectiveness considered; how to monitor unmet need due to the inadequacies of the universal services and how to still meet the need.

Facilities redesign and staff training: e.g. facilities design may need to be adjusted to risk of sensory overload and the council's recognition that these steps are 'hassle' for mainstream providers. (The word hassle was used recently by one mainstream provider at Flitwick leisure centre – who repeatedly requested that we set up, run and organise the session at our own cost – audit trail kept).

Q8 Integrating children and teenagers with lower level needs into universal service provision

This would need to be workshopped, Staff induction, training, supervision and appraisal of working with/for children with disabilities would need expert care. Staff retention and turn over would need specialist training built into the common induction standards framework. The council would need to consider; that this may not work/breakdown, be underused; Strategic review points and appraisal of the effectiveness considered; how to monitor unmet need due to the inadequacies of the universal services and how to still meet the need.

Q9 Voluntary organisations working together to improve outcomes for disabled children, young people and their families

We do come together, we meet independently of central Bedfordshire with VOC – we do currently improve outcomes for disabled children, young people and their families. The proposed cuts put voluntary organisations under pressure to compete and prepare grant applications. There is a high risk that it will fragment the sector. There is limited overlap that would be appropriate and as opposed to a compliment and range of services that we can provide as part of the local offer – voluntary organisation will be under pressure to survive.

Q 10 Other ways the Council can ensure that services are sustainable

- Develop standards with partners including voluntary organisations to ensure that outcomes for children and teenagers are being achieved.
- Help voluntary organisations to work together to share expertise and knowledge.
- Provide advice and support to enable teenagers over the age of 16 and their parents to access direct payments

Q 11 Supporting the requirement for personalisation

Through our Community Support Services, effective in Bedford and Luton. Ensuring that we are putting the needs of children and teenagers needs at the heart of service and that every disabled child matters

Q12 Innovating to provide aspirational services for children, young people and families that are sustainable

Through funded and sustainable services – please see our previous proposals for more details.

Q13 Moving from a service level agreement and identifying alternative models that might enable effective partnership working with the Council

Which funding models are you considering? We are flexible and open to partnering with the council. We have standardised cost rates, however there was a lack of council framework around this – happy to explore together.

Q14 Ideas that would enable the Council to redesign services to ensure they are sustainable

Yes, provide adequate funding (see our proposal) to collaboratively have sustainable short break services, fund upwards of £35k and receive services that cost and are funded £135k, best quality and best price. Happy to workshop – you could recruit a facilitator from The Cranfield Trust?

In cases where a number of questions elicited a similar response, these responses have been edited with regard to repetition and an indication of this has been provided.

2) Bedford and District Cerebral Palsy Society

Q1 Proposal to increase cost effectiveness

BDCPS provide a good service which is very cost effective for the Council in terms of what is being delivered. The full cost of the support is greater. The Council need to see this as a life line which supports some very complex children to stay living at home. The funding to BDCPS is a small amount compared with one overnight in a residential service of having to go out of area.

Q2 Proposal to protect services for those in greatest need

This is important as the parents BDCPS are working with are under a lot of pressure in caring for their children and would not cope if the support were not available to them

Q3 Proposal to develop new service models for those with lower levels of need

It would be good to explore this but the children who BDCPS are working with have specialist needs which make it difficult to manage in some environments. It would take quite a bit of work for this to be effective.

Q4 Proposal to apply new eligibility criteria

The children that BDCPS support meet the criteria for the children with disabilities service so the organisation will not be significantly affected by the change

Q5 Proposal to change funding model - reduced grant funding to voluntary organisations

The funding from the Council provides a platform from which other grants can be applied for. BDCPS require this if they are to continue to provide the support

Q6 Opportunities universal services present to voluntary organisations as one way of meeting need for children and teenagers with lower level needs

Given the right support – equipment, staff, this could provide some good opportunities for disabled children to access local services. This will require quite a shift in thinking.

Q7 Issues the Council would need to consider

Premises, level of funding. What is that the Council is asking of the voluntary organisations. What is the best way of funding this, perhaps over a longer period of time.

Q8 How could children and teenagers with lower level needs be integrated into universal service provision?

They would have to build confidence with the parents by providing a safe place with well trained staff as the physical and learning needs of this group of children and young people make them vulnerable

Q9 Thinking more broadly, how could voluntary organisations work together to improve outcomes for disabled children, young people and their families?

BDCPS would be prepared to be involved in discussions about this. They are currently unique in the service they provide for children and young people living in Central Bedfordshire.

Q 10 Other ways the Council can ensure that services are sustainable

We would tick in order going down

- Ensure that we are putting the needs of children and teenagers needs at the heart of service provision by working with voluntary organisations to ensure there is no overlap or duplication of services
- Develop standards with partners including voluntary organisations to ensure that outcomes for children and teenagers are being achieved.
- Look at ways of managing vacant short break places to ensure that all opportunities have been taken up and
- Provide advice and support to enable teenagers over the age of 16 and their parents to access direct payments

Q 11 Supporting the requirement for personalisation

We would support the requirement through our Gateopener Service working with the CBC team to assist any families able and wanting to move to personalisation. We would disseminate information and encourage families to engage in exploration of personalisation as a means of meeting their needs if it is appropriate and supportive in their case. Try to ensure that it is a needs led option/service

Q12 Innovating to provide aspirational services for children, young people and families that are sustainable

We aim to provide services that are innovative in terms of meeting need and gaining best outcomes for young people and their families. Fully funded we could continue to develop appropriate and meaningful services with good outcomes. Less funding threatens our existence as we could not ethically take on complex young people without safe staffing levels. We would not be prepared to warehouse.

Q13 Moving from a service level agreement, and identifying alternative models that might enable you to work effective partnership working with the Council

We would struggle as a very small core team working across all roles to produce good tender proposals that would compete with nationals or other charities that have personnel with specific tender and funding roles. This puts us at risk of working hard to produce a tender proposal that is not likely to compete with the “experts” after some lovely feedback that we can use to improve for the next time we may not be around to bid/present.

We also find quantitative data does not help us as our numbers will never be large due to the complex needs of many of the young people using our services. See attached comparison from the start of being given an SLA by CBC . We would like to see a model that takes this kind of service cost and provision into account and appreciates the difficulty of producing effective and real data that demonstrates the outcomes. We would like to see more interaction in terms of observation of outcomes at service provision levels.

Q14 Ideas that would enable the Council to redesign services to ensure they are sustainable?

Provide adequate funding to support the voluntary sector to provide services that meet the needs of families and avoid costly long term need and family break down. Think long term benefit for the council as well as for the families. A residential place costs approx. 6 times a year more than the funding that each charity has been receiving on an SLA. For BDCPS that has meant CBC has paid approx. £7.48 per hour for care of a complex disabled person comparatively cheap to all other service provision with probably the same if not better in some cases outcomes.

Additional Submission from Bedford and District Cerebral Palsy Society

Comparison of the Changing Needs of Young People within Central Bedfordshire

Category of Need - No. of young people using BDCPS	2009	2017
1	12	19
2	3	9
3	19	16
4	3	17
5	0	6

An Analysis of the Category of Need Changes 2009-2017

The statistics show we have had a large increase in users over the 8 year period, the figures have almost doubled. This is primarily due to an increase in the service coverage we deliver and our support staff resulting in the capacity to deliver extended services.

In 2011 we lowered the age of our Stampede Saturday club to 5 years+ (from age 8 years +).

In 2012 we created ACE for 18-25 year old. Our previous age limit for services was 20 years.

In 2014 we created Little Sweet Peas delivering services to pre-schoolers 0-5 year olds. Our previous age range was 5years+. We also created Little Saplings which brought 5-8 year olds into our summer schemes with the previous age being 8years+.

There has also been a documented increase in the numbers of young people with disabilities and a recognition that these are becoming more complex.

“A report out today is the first analysis in 10 years of the numbers of children and young people with complex needs or life-limiting conditions and estimates that numbers have increased dramatically by over 50% since 2004, from 49,300 to 73,000 children and young people.”¹

As the only provider in Central Bedfordshire for complex needs operating in each of the school holidays, as well as weekends and evenings, this has led to an increase in demand for our services. We also do not require parent/carer support at our sessions making us a preferred option for short breaks.

The 8 year period shows that those in category 4 have increased 5-fold in numbers resulting in a need to have an increase in the trained workforce supporting this group with specialist skills. Category 5, our highest level of need of support was not something we were supporting in 2009 but has increased dramatically in the past 8 years. These young people often have palliative care status. Category 2 has also trebled and although the skills base for this category is lower, it is one which requires us to provide staff in greater numbers. All other categories have risen in line or greater than the increase in our numbers.

We currently train staff to meet the needs of young people for emergency rescue medication for epilepsy, oxygen, suctioning, gastro feeding, feeding difficulties, administration of regular medication, manual handling for care needs, first aid, safeguarding and communication difficulties. We are in the process of aiming to secure tracheostomy care training.

¹ Council for Disabled Children, Newsletter 27 Feb 2017

The level of complexity we support is also demonstrated by the number of children who have sadly passed away. We have 5 children from Central Bedfordshire who have bravely lost their battle with their condition. Of these 4 in category 4 and 1 in category 5.

We have had a consistent level of funding from Central Bedfordshire which initially offered some security but failure to review resulted in recent years in a loss of that certainty. It has also failed to keep track of the development of our services, the increase in users and in the complex care needs of those users. Our funding from another local authority for holiday childcare for the same period has increased in line with needs and demand for the service. In order to sustain our services to Central Bedfordshire we must have in an increase in the funding received.

DEFINITIONS

CATEGORY OF NEED

1	Has a mild to moderate disability, or is vulnerable due to age, that can be supported by an advanced beginner
2	Has a moderate disability that can be supported by an advanced beginner but needs 2 staff due to behavioural needs, of advanced beginner plus novice or above
3	Has health and care need and/or behavioural needs arising from their disability that requires a competent person who has had specific training to support their needs
4	Has complex health and care need and/or behavioural needs arising from their disability that requires a proficient person+ to support their needs with the support of another person competent or above to assist under direction of proficient person
5	Has complex health and care need and/or behavioural needs arising from their disability that requires a proficient person+ to support their needs with the support of another person advanced beginner or above to assist under direction of proficient person

CATEGORY OF STAFFING

Novice	An inexperienced member of staff who needs clear rules and instructions. They need complete supervision and support
Advanced beginner	A member of staff who is building their experience, has an awareness of policies and procedures but needs clear support and supervision
Competent	Has gained experience and has had training and has developed an understanding of ranging needs and can adapt to support these with some support
Proficient	Has a wide range of experience and training and responds flexible to needs with little direction with an understanding of policies and risk assessment. Is a mentor to other staff around needs.
Expert	Has a breadth of experience and training which they apply efficiently and effectively to any given needs without the need for direction, seeing the bigger picture with a true understanding of policies, procedures, risk assessments and responsibility. Is able to train and mentor others to meet the needs of those with disabilities

3) Family United Network

Q1 Proposal to increase cost effectiveness

Short break services provided by the voluntary sector already represent excellent cost effectiveness for the Council. By their nature, voluntary organisations work to secure funding from other sources in order to financially maintain their services for Central Bedfordshire families. By so doing, they enable the local authority to fulfil its short break obligations at a much reduced cost than would otherwise be the case. Voluntary organisations are built on a foundation of goodwill from people who are willing to give of their time for no payment or financial reward. This goodwill can be damaged and eroded if the Council continues to withdraw financial support from the services that Trustees and other volunteers work to provide within their communities.

Short breaks are well recognised to be a vital part of the support that helps keep families together - not just surviving, but being resilient and thriving.

We are aware of the legal duties on the local authority to provide short breaks for families with disabled children, under a number of different Acts and Regulations. We would like to have reassurance that all other avenues to avoid these cuts have been explored by the Council and that the Council can show that it is going to be able to provide a level of short break service which is sufficient to meet the needs of children and families in Central Bedfordshire after the funding cuts.

We are also anxious to ensure that the inevitable reductions to our services for Central Bedfordshire members will be replaced by the Council with alternative provision for those children and young people and families.

Questions

- 1) How much money does the Local Authority currently hold in its unrestricted reserves?
- 2) What if any consideration has been given by the Local Authority to using these reserves to avoid or reduce the need to cut spending on short breaks?
- 3) What if any consideration was given to increasing Council Tax as a way of avoiding or reducing the need to cut spending on short breaks?
- 4) Does the local authority know how many children with additional needs and disabilities there are in Central Bedfordshire?
- 5) How has the local authority determined what the likely need for short break services will be in Central Bedfordshire?
- 6) How has the local authority satisfied itself that the level of short break services after the cuts will be sufficient to meet this need?
- 7) How will the Local Authority meet its obligation to treat disabled children's best interests as a primary consideration in its decision-making process when deciding on whether the proposed cuts to the short breaks budget will go ahead?
- 8) How can the Local Authority show that, during its decision-making process, it has had due regard to the need to advance equality of opportunity for disabled children?
- 9) Can the local authority confirm that all children with additional needs and disabilities living in Central Bedfordshire will have access to a social work assessment, and that the eligibility criteria for accessing short breaks will be clear and accessible to all families?

10) Will the Council fulfil its duty to reassess all children against the new criteria before any services are withdrawn from them?

Q2 Proposal to protect services for those in greatest need

Only protecting services for those in greatest need can be short sighted and lead to increased costs down the line. Lack of appropriate and effective support for 'lower and moderate need' families can lead to these families becoming 'higher need' and then requiring much greater levels of support in the long run. Maintaining family well-being and resilience for those with 'moderate and mild' needs - through effective support - helps to ensure that these families are equipped to continue caring for their disabled child and do not hit a crisis point that then requires much costlier intervention by the Council

Q3 Proposal to develop new service models for those with lower levels of need

The proposal to develop short breaks services within existing universal provision for those children not meeting the 'blue' and 'red' threshold criteria, will mostly disadvantage the children with moderate needs and their families. The fact that their needs within an educational setting have been deemed significant enough to require an EHCP or Statement (and the additional funding that this brings) demonstrates that these children and young people have significant difficulties that inevitably will also be impacting on their family carers on a daily basis.

Only providing the option to access universal services removes choice from the family as they decide whether inclusion within a mainstream leisure activity is right for their child or not - depending on what is most appropriate for their child at any given stage in their social development. Accessing the less structured and socially fluid environment of a universal leisure activity is very different to accessing mainstream schooling. It cannot be assumed that if a child is able to manage within a mainstream school, then they are able to manage within a universal leisure activity.

Preparing universal services to successfully meet these children's needs, whilst also managing the expectations and lack of awareness of typical families using the service, is not impossible - but it will require significant initial and ongoing investment in staff training, and will need very effective communication between the provider and all users of the service and the wider community. Education and training for all staff involved in designing and delivering any universal leisure activity for disabled children will be vital. In particular, thorough training in: Autism, Aspergers, Epilepsy, Tourettes, ADHD and Downs Syndrome. Educating staff on how to communicate effectively with family carers will also be vital. In addition, training on the causes and effects of anxiety and other mental health issues will also be needed.

Q4 Proposal to apply new eligibility criteria

The eligibility criteria for short breaks services as they are written are based solely on the severity of the disabled child's impairments, and do not take into account the caring capacity of the child's family members or other family environmental factors. Looking at the child's disabilities in isolation of their family environment will not ensure that services are directed at those children and families that are in most need or in most danger of hitting a crisis situation. If one of the purposes of short breaks is to increase family well-being and resilience and prevent family breakdown, then the criteria for accessing services needs to be based on more than just the young person's impairments. The eligibility criteria, upon which a decision about access to services is based, needs to explicitly include assessment criteria for carer capacity and other family and environmental factors.

Q5 Changing the funding model - reducing grant funding to voluntary organisations

Changing the funding model from SLAs to personalised funding can be done, provided that there is plenty of notice for service providers and families to make the transition successfully; and that a

clear plan and timeline are formulated that addresses all of the administrative and financial challenges that such a transition will involve. Decisions about service plans and budgets for the next financial year are made in the January prior to the new financial year starting in April. Any proposed changes in funding need to be finalised before January to allow providers to plan their services in an effective and sustainable way. We need clarity and certainty about what funding will be available, how it will be available, and when.

Families will need a clearly explained pathway on how and when to request an assessment for short break services, and be given sufficient time to do this before any changes to their child's access to provision kicks in. Families should have at least six month's notice of any change so that they are able to request the necessary social care assessment in time to ensure that - where their child is found to be eligible - there is no break in the clubs and activities that they are attending.

The local authority will also need to ensure that there is sufficient capacity in their social care assessment process to accommodate many new families requesting assessments that have not needed to do so in the past.

Q8 Integrating children and teenagers with lower level needs into universal service provision

In order for universal services to successfully include SEND young people, the following would need to be considered:

- Universal services need to be able to offer flexibility in their approach to grouping children and young people e.g. allowing children with additional needs to access activities with younger typical children if this is deemed most appropriate and beneficial for them, in consultation with their family carers.
- Dealing with any resistance to this from other typical families and taking steps to educate all those accessing the service about the benefits of including young people with disabilities.
- Universal services need to be flexible enough to adapt their planned activities and clubs to accommodate the needs of children with additional needs; and that their registration or admission processes are set up in such a way that makes access to their services as easy and stress free for SEND children as for their typical peers.

For example:

- Making sure that family carers are fully consulted before the child attends
 - Allowing parents or a carer to attend with their child for a period of time if needed
 - Allowing free access, without long term commitment, for a couple of sessions to determine whether the service is right for the child.
 - Providing as standard a peer mentoring/friendship service to all first time users, from which SEND children can benefit without feeling that their additional needs are being highlighted.
 - Providing regular and unprompted honest feedback to family carers on the progress of their child, to reassure them, build trust and seek their advice.
- Staff running universal services must understand the need and benefit of communicating effectively with family carers; ensuring that the service itself is designed in such a way that, not only facilitates this, but embeds this practice within the service.
 - Universal services must send a clear message to the whole community (not just the parents of SEND children) that the club or activity is open to - and is ready for - children with additional needs. Universal services need to be committed to working proactively with other agencies and professionals.

- Providing someone that the child or their family can go to if the service is failing to meet the child's needs or where adjustments are needed to allow access for their child into the service.

Have any universal services within Central Bedfordshire been consulted about these proposed changes?

Have they been asked about their readiness and capacity to include children with disabilities within their services?

What specific support do they feel they will need in order to achieve this?

Q9 Voluntary organisations working together to improve outcomes for disabled children, young people and their families

Greater communication and regular contact between voluntary organisations, to ensure that everyone has a good working knowledge of the services that are being provided across the county. This means that children and families can be signposted easily from one organisation to another, and will help ensure that all available short break places are taken up. Sometimes, families who access one or two providers can still be unaware of services that are available to them at other providers

Better information and data sharing between all of the voluntary organisations about the capacity and take up of their services. Only by understanding the current capacity and uptake across all providers that are serving Central Bedfordshire families can we begin to make sure that we are providing the services that families want and need at the times and in the places that they need them.

More collaborative decision-making between organisations on the scheduling of our short breaks provision will help to either increase capacity where there is a demand or avoid over capacity. Understanding what resources, equipment or good practice all of the different short breaks providers have that can be shared.

Q 10 Other ways the Council can ensure that services are sustainable

Ensure that there is a clear and well-timed transition plan for any change in the way that funding of services is provided. Ensure that voluntary service providers have the time that they need to adjust their plans and working practices to successfully accommodate the changes that the Council requires. Ensure that families have the notice that they need of any changes that could affect them, to ensure that any change for their child is well-managed and stress free.

Q 11 Supporting the requirement for personalisation

FUN has always been willing to change the way it delivers and funds its services to accommodate personalisation. However, there needs to be a clear and concrete schedule and timetable for the transition from SLAs to personalisation, that spells out exactly how the funding arrangements will change over time, to ensure that services are sustained and not lost during the transition period through lack of funding. There also needs to be a clearly defined and practical model as to exactly how families will access services using a personal budget; how information sharing will work in order to ensure that services are offered and provided to those families that the Council deems to be most in need; and what the payment arrangements between the provider and the Council will be.

Q12 Innovating to provide aspirational services for children, young people and families that are sustainable

FUN is constantly listening to the families that use our services to determine what their current and future needs are. This informs what services we provide families and when. FUN will only

commit to running a service where we believe that families want it and it is financially sustainable for a significant period of time. We have no desire to raise family expectations that a service will continue to be accessible into the longer term if in fact it will not. This is why it is so vital to have a clear commitment from the Council as to what funding will or will not be available, and how funding arrangements will change over time. Without this information we are not able to ensure that our services remain sustainable into the future.

Q13 Moving from a service level agreement, and identifying alternative models that might enable you to work effective partnership working with the Council

We are willing to work together with the Council to implement any new funding model, provided that this is done in a timely and properly managed way; allowing us the time needed to adjust our service planning and budgets to ensure that services are not lost and families are not left without provision.

4) Special Needs Out of School Club

A response to the consultation was not submitted.

Appendix C The Public Sector Equality Duty

The Equality Duty requires public bodies to have **due regard** to the need to:

- Eliminate unlawful discrimination harassment and victimisation and other conduct prohibited by the Act.
- Advance equality of opportunity between people who share a protected characteristic and people who do not share it
- Foster good relations between people who share a protected characteristic and people who do not share it

Protected Characteristics:

- Age
- Disability
- Gender Reassignment
- Pregnancy and Maternity
- Marriage and Civil Partnership (elimination of discrimination only)
- Race
- Religion or Belief
- Sex
- Sexual Orientation

Due Regard means consciously thinking about the three aims of the Duty as part of the process of decision-making. For example:

- How they act as employers
- How they develop, evaluate and review policy
- How they design, deliver and evaluate services
- How they commission and procure from others

Advancing equality of opportunity involves considering the need to:

- Remove or minimise disadvantages suffered by people because of their protected characteristics
- Meet the needs of people with protected characteristics
- Encourage people with protected characteristics to participate in public life or in other activities where their participation is low

Fostering good relations involves tackling prejudice and promoting understanding between people who share a protected characteristic and others.

Complying with the Equality Duty may involve treating some people better than others, as far as this is allowed in discrimination law. This could mean making use of an exception or positive action provisions in order to provide a service in a way that is appropriate for people who share a protected characteristic.

Officers should:

Keep an adequate record showing that the equality duties and relevant questions have been actively considered.

Be rigorous in both inquiring and reporting to members the outcome of the assessment and the legal duties.

Final approval of a proposal, can only happen after the completion of an equality impact assessment. It is unlawful to adopt a proposal contingent on an equality impact assessment

Title of the Assessment:	Children with Disabilities – Payments to Voluntary Organisations & Other Provisions	Date of Assessment:	05/02/16 & ongoing
Responsible Officer	Name: Ken Harvey	Extension Number:	76599
	Title: Head of Children with Disabilities		
	Email: Ken.Harvey @centralbedfordshire.gov.uk		

Stage 1 - Setting out the nature of the proposal and potential outcomes.

Stage 1 – Aims and Objectives
<p>1.1 What are the objectives of the proposal under consideration?</p> <p>Budget Proposal Children With Disabilities (CWD) - £158,000</p> <p>The proposal can be broken down as follows;</p> <ul style="list-style-type: none"> • Removal of top up payment to Adult Social Care Occupational Therapy Services - £40k – this payment helps ensure that disabled children are assessed more quickly and essential equipment is provided • Removal of top up payment to Disabled Facilities Grant – £50k this payment helps to ensure that additional provision is provided to ensure that disabled children are safe in their own home • A reduction of £68,000 to Voluntary organisations which includes the following reductions to Service Level Agreements <ul style="list-style-type: none"> ○ Autism Beds – reduction from £35k to £17.5k ○ Bedford and District Cerebral Palsy – reduction from £35k to £17.5k ○ Family United Network – reduction from £30k to £15K ○ Special Needs Out of School Club – reduction from £30k to £15K <p>These organisations help support the provision of short break opportunities for children with disabilities.</p> <p>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.</p> <p>The Council's is proposing to target services on children with the highest needs:</p> <ul style="list-style-type: none"> • Children receiving a service from social care • Children with special educational needs <p>Specialist Services would need to be withdrawn from:</p> <ul style="list-style-type: none"> • Siblings of children with disabilities • Other children – i.e. children who do not meet the categories for the highest levels of need, but who may still meet a definition of disability under the terms of the Equality Act 2010 and

the Children Act 1989.

Families will be supported to consider accessing short break opportunities in different ways, for example via universal services such as leisure activities.

Following feedback from the voluntary organisations, it was agreed that the same level of funding would be made available for the period April – Sept 2016, in line with the period April – September 2015 and then it was proposed that 50% of 15/16 level of funding would be available from Sept 16 to end of March 17. In order to ensure that appropriate consultation takes place before a final decision is made in relation to future levels of funding, the voluntary organisations have recently been advised that funding will continue at 2015/16 levels for the remainder of the financial year 2016/17 and transitional funding will be provided at the beginning of 2016/17.

The review of all Children with Disabilities short break provision will take place from June 2016 – January 2017 reporting in March 2016. There will be full co-production with disabled children and their families on the review scope, review process and plans for future development and delivery of the services.

A transitional plan for the Voluntary Organisations will be in place to ensure stability for disabled children and their families and the organisations whilst the full review decisions are implemented.

The proposal only relates to the funding which comes to the above organisations from the Children with Disabilities Service and does not apply to any additional funding provided by other areas of the Council.

Voluntary organisations 1-4 above have been asked to come back with proposals for 2016/17 and an indication of the potential impact of the proposed reductions.

1.2 Why is this being done?

The Council is required to ensure that resources are targeted to areas of most need, and that all services deliver value for money. The drive for efficiencies and different ways of working is informed by national drivers that will see Councils' financial settlement reduce by approximately 15% over the next four years. There is a need to make efficiencies and identify areas where potential savings could be made. There is also a need to ensure that services are appropriate for the population of children living in Central Bedfordshire.

1.3 What will be the impact on staff or customers?

Current Access to Short Breaks:

For children to be eligible for a service from the specialist Children with Disabilities Team they must:

Be aged under 18 years old and live within Central Bedfordshire

Have a permanent and substantial diagnosed disability from one or more of the following categories:

- Severe or profound learning disabilities / autism
- Severe or profound physical disabilities
- Severe visual disability
- Severe or profound hearing loss
- Significant or profound sensory disabilities
- Multiple disabilities which together severely impact on quality of life

- Complex long term health needs
- Severe or profound social and communication difficulties related to disability

Children with the following disabilities would not be eligible for services from the Children with Disabilities Team unless they also have a diagnosed disability as outlined above:

- Emotional and behavioural disorders
- Mental Health Difficulties
- Medical conditions that are not permanent
- If the presenting problem is not related to the child with a disability (e.g. Another family member)

Families meeting Blue and Red Levels of the eligibility threshold will be eligible for the Local Offer

The children in Yellow and Green Levels can access main stream services through the Family and Youth Information Service.

Central Bedfordshire’s Local Offer indicates that there are currently two levels of support, depending on the needs of the child which meet the threshold for accessing services. This is a flexible system and families can move between levels as their needs change.

BLUE LEVEL These children with have a severe diagnosed disability in the categories outlined. Their disabilities are likely to have a moderate impact on family life and the children’s quality of life would be improved with access to universal services, signposting and up to 156 hours per annum of Short Breaks activities. These children will either have a severe diagnosed disability and be in special schools or have a severe diagnosed disability and be receiving a minimum of 20 hours per week 1:1 help in mainstream schools.

All eligible children and young people are offered flexible support so that they can take part in local activities. Children can access the Local Offer of **up to 156** hours of support which can include

- Up to 156 hours of direct payments – allocated cash, to a maximum of £1519.44, for the family to provide a personal assistant to support their child **or**
- Up to 156 hours of an alternative short break such as

* Youth groups	* Playscheme or holiday activities
* 1:1 support at home	* 1:1 community support

RED LEVEL Children in this category will have severe diagnosed disabilities in the categories detailed which are having a severe impact on family life and the children’s quality of life is severely affected. These children are unlikely to be able to access universal services and will need specialist provision in education, health and social care.

This level of support is available to fewer families facing extra challenges and includes:

- Families with a child with a life limiting condition;
- Families with a child with a disability whose severe behaviour difficulties challenge carers/siblings/other family members;
- Families with a child with complex health needs which require a carer with specialised training;
- Families with additional caring responsibilities.

Options can include:

Central Bedfordshire Council Equality Impact Assessment

- Overnight stays in a residential setting;
- A comprehensive package of direct payments or Short Breaks

	Meets Threshold for Services		Does Not Meet Threshold for Services	
Disability Category	Profound Impairment RED LEVEL	Severe Impairment BLUE LEVEL	Moderate Impairment GREEN LEVEL	Mild Impairment YELLOW LEVEL
Learning	Has a Statement of Educational Needs. Attends a Special School for children with severe learning difficulties	Has a Statement of Educational Needs. Attends a Special School for children with severe learning disabilities or has a severe learning disability and attends a mainstream school receiving a minimum of 20 hours 1:1 support a week	Has a Statement of Educational Needs Attends a mainstream school with limited support.	Does not have a Statement of Educational Needs
Mobility	Unable to walk. Totally dependent on others for mobility. Wheelchair user.	Unable to walk without aids or assistance. Able to manoeuvre self some of the time. May be able to stand or transfer with support.	Able to walk, but occasionally requires aids or assistance.	Able to walk/move independently, but with some limitation of function. May have poor co-ordination of movement.
Gross & Fine Motor Skills	Unable to use hands for any purposeful movement.	Mostly unable to use hands to complete tasks effectively. Able to use switch systems	Considerable difficulties with control of hands. Requires some assistance to complete tasks.	Some difficulties with control of hand movement for precise work.

Central Bedfordshire Council Equality Impact Assessment

Health	Unable to take part in normal social and educational activities.	Frequent or daily interruption of normal tasks. Significant interference with development and / or learning.	Intermittent but regular limitations on ability to perform everyday tasks. The child's development or learning may be affected.	Known health condition, which is under control and only occasionally interfering with everyday activities in a minor way.
Vision	Mobility restricted without special provision. Requires education by non-sighted method. Eligible for registration as blind.	Unable to read large print without assistance or aids. Severe visual field defect with impaired visual acuity. Eligible for registration as blind or partially sighted.	Able to read print with simple aids or assistance. Defect of at least half visual field. May be eligible for registration as partially sighted.	Severe or profound problem with one eye. Defect of less than half visual field. Able to function independently.
Hearing	Hearing loss over 95 dB.	Hearing loss between 71 - 95 dB.	Hearing loss between 41 - 79 dB	Severe or profound hearing loss in one ear. Hearing loss between 20 - 40 dB.

Central Bedfordshire Council Equality Impact Assessment

Communication	Unable to communicate needs by any method. Unable to use communication aids.	Limited or no verbal communication. Able to communicate basic needs without the use of language.	Delayed or disordered communication, including language disorders. Speech supplemented by another method of communication.	Mild delay of language development.
Personal Care	Total assistance required for bathing, dressing, toileting and eating.	Assistance required for bathing, dressing, toileting or eating.	Some supervision or assistance required for bathing, dressing, toileting or eating.	Occasional difficulties meeting own self-care needs.
Consciousness	Comatose. Intractable seizures, in frequent succession.	Regular seizures on a daily basis. Impacts on the child's learning or development.	Seizures day or night on a regular basis, usually once per week.	Occasional daytime seizure (up to one per month)
Behaviour & Social Integration	The challenging behaviours are impacting on all aspects of the child's functioning. The behaviours pose a significant risk to the safety of the child or others.	The challenging behaviours are impacting on some aspects of the child's functioning. Specialist provision is required for the child to function socially or within the family group.	The frequency or severity of the behaviours requires some specialist advice or provision.	Behaviours are occasionally difficult to manage. Special provision not required when managing the behaviour.
Safety and Supervision	Needs constant supervision both day and night. No ability to perceive danger to self or others.	Needs constant supervising during the day. Would place themselves or others at serious risk without supervision.	Requires supervision to perform daily tasks. Requires supervision significantly greater than that expected for children of the same age. Limited perception of danger to self or others.	On occasion, requires more supervision than other children of the same age.

It is more difficult to establish eligibility of under fives using the above classifications, The classification below is the eligibility criteria backbone for the under fives in Central Bedfordshire. The children receiving services from the Children with Disabilities Team in Central Bedfordshire would be expected to have a diagnosed disability.

	Meets Threshold for Services		Does Not Meet Threshold for Services	
Age	Profound Impairment RED LEVEL	Severe Impairment BLUE LEVEL	Moderate Impairment GREEN LEVEL	Mild Impairment YELLOW LEVEL
Under 5 years	Significant failure to meet developmental milestones.	Functioning moderately behind the level expected for age.	Functioning moderately behind the level expected for age.	Functioning slightly behind the level expected for age.
Over 5 years	Child is completely dependent on others to perform tasks.	Child is unable to perform tasks without aids or assistance most of the time.	Child requires some assistance to perform some tasks.	Some limitation evidenced, but able to function independently.

Information must demonstrate that the referred child needs more help or supervision than other children of the same age.

Proposed Future Access to Short Breaks:

In recent years it has been possible for the Council to apply the above thresholds more flexibly, so that some families in the green and yellow categories have also, on occasions, been able to access the more specialist services available under the Local Offer.

A revised Threshold Criteria is proposed as follows:

	Meets Threshold for Specialist Services		Need met through Universal Provision & Early Help	
Disability Category	Diagnosed Profound Impairment	Diagnosed Severe Impairment	Diagnosed Moderate Impairment	Diagnosed Mild Impairment
Learning	Has a Statement of Educational Needs. Attends a Special School for children with severe learning difficulties	Has a Statement of Educational Needs. Attends a Special School for children with severe learning disabilities or has a severe learning disability and attends a mainstream school receiving a minimum of 20 hours 1:1 support a week	Has a Statement of Educational Needs Attends a mainstream school with limited support.	Does not have a Statement of Educational Needs

Central Bedfordshire Council Equality Impact Assessment

Mobility	Unable to walk. Totally dependent on others for mobility. Wheelchair user.	Unable to walk without aids or assistance. Able to manoeuvre self some of the time. May be able to stand or transfer with support.	Able to walk, but occasionally requires aids or assistance.	Able to walk/move independently, but with some limitation of function. May have poor co-ordination of movement.
Gross & Fine Motor Skills	Unable to use hands for any purposeful movement.	Mostly unable to use hands to complete tasks effectively. Able to use switch systems	Considerable difficulties with control of hands. Requires some assistance to complete tasks.	Some difficulties with control of hand movement for precise work.
Health	Unable to take part in normal social and educational activities.	Frequent or daily interruption of normal tasks. Significant interference with development and / or learning.	Intermittent but regular limitations on ability to perform everyday tasks. The child's development or learning may be affected.	Known health condition, which is under control and only occasionally interfering with every day activities in a minor way.
Vision	Mobility restricted without special provision. Requires education by non-sighted method. Eligible for registration as blind.	Unable to read large print without assistance or aids. Severe visual field defect with impaired visual acuity. Eligible for registration as blind or partially sighted.	Able to read print with simple aids or assistance. Defect of at least half visual field. May be eligible for registration as partially sighted.	Severe or profound problem with one eye. Defect of less than half visual field. Able to function independently.
Hearing	Hearing loss over 95 dB.	Hearing loss between 71 - 95 dB.	Hearing loss between 41 - 79 dB	Severe or profound hearing loss in one ear. between 20 - 40 dB.
Communication	Unable to communicate needs by any method. Unable to use communication aids.	Limited or no verbal communication. Able to communicate basic needs without the use of language.	Delayed or disordered communication, including language disorders. Speech supplemented by another method of communication.	Mild delay of language development.
Personal Care	Total assistance required for bathing, dressing, toileting and eating.	Assistance required for bathing, dressing, toileting or eating.	Some supervision or assistance required for bathing, dressing, toileting or eating.	Occasional difficulties meeting own self-care needs.
Consciousness	Comatose. Intractable seizures, in frequent succession.	Regular seizures on a daily basis with significant impact on the child's	Seizures day or night on a regular basis, usually once per week.	Occasional daytime seizure (up to one per month)

	learning or development.			
Behaviour & Social Integration	The challenging behaviours are impacting on all aspects of the child's functioning. The behaviours pose a significant risk to the safety of the child or others.	The challenging behaviours are impacting on key aspects of the child's functioning. Specialist provision is required for the child to function socially or within the family group.	The frequency or severity of the behaviours requires some specialist advice or provision.	Behaviours are occasionally difficult to manage. Special provision not required when managing the behaviour.
Safety and Supervision	Needs constant supervision both day and night. No ability to perceive danger to self or others.	Needs constant supervising during the day. Would place themselves or others at serious risk without supervision.	Requires supervision to perform daily tasks. Requires supervision significantly greater than that expected for children of the same age. Limited perception of danger to self or others.	On occasion, requires more supervision than other children of the same age.

This revision to the criteria will result in children assessed as mild / moderate / no impairment being signposted towards universal services, possibly with the provision of specialist support.

The Council for Disabled Children, the Audit Commission and CSCI, have previously expressed concern about the complexity of eligibility criteria and the confusion this can sometimes cause. In 2009 the lawfulness of eligibility criteria was clarified by the Islington Judgement. Any changes to eligibility criteria therefore need to be considered in the light of this judgement.

Further detail relating to the Islington Judgement is set out in section 2.2.10 of the EIA.

1.4 How does this proposal contribute or relate to other Council initiatives?

Central Bedfordshire Five Year Plan 2015 - 2020

Priority - Protecting the Vulnerable; improving wellbeing

We will protect the vulnerable, be they children or adults, ensuring that they are not exploited, abused, or suffering as a result of neglect or lack of support. We will also work to improve the health and wellbeing of our residents.

Children's Services Transformation Programme:

The proposals included in this assessment support Children's Services Transformation Programme – to identify new ways of working with partners and children and families that will improve outcomes for the most vulnerable in Central Bedfordshire. This proposal will also contribute to the understanding of need in different localities which will support new delivery models in the future.

1.5 In which ways does the proposal support Central Bedfordshire’s legal duty to:

- Eliminate unlawful discrimination harassment and victimisation and other conduct prohibited by the Act
- Advance equality of opportunity between people who share a protected characteristic and people who do not share it
- Foster good relations between people who share a protected characteristic and people who do not share it

Disability is a protected characteristic under the Equality Act. Life chances for disabled children and young people are often disproportionately poor. The provision of quality Short Break opportunities can support families to live an ‘ordinary life’ whilst offering learning and leisure opportunities for disabled children and young people.

Under the requirements of equality legislation, all service providers must ensure that services are as accessible as possible for all sections of the community. The aim of the legislation is to help ensure that disabled people have equal access to services, with the intention that by increasing access to mainstream services, they are enabled to participate on more equal terms with wider society.

1.6 Is it possible that this proposal could damage relations amongst groups of people with different protected characteristics or contribute to inequality by treating some members of the community less favourably such as people of different ages, men or women, people from black and minority ethnic communities, disabled people, carers, people with different religions or beliefs, new and expectant mothers, lesbian, gay, bisexual and transgender communities?

Consideration will need to be given to the extent to which the proposal might have an adverse impact on disabled children and their families who do not meet the thresholds for diagnosed profound or severe impairment and who will be directed towards universal services.

Research indicates that disabled people can sometimes still experience barriers to accessing universal services. This can happen for example if staff members haven’t received appropriate disability awareness training and don’t provide a welcoming atmosphere that responds to differing needs and which challenges negative attitudes which can sometimes be displayed by members of the public.

Stage 2 - Consideration of national and local research, data and consultation findings in order to understand the potential impacts of the proposal.

Stage 2 - Consideration of Relevant Data and Consultation

In completing this section it will be helpful to consider:

- **Publicity** – Do people know that the service exists?
- **Access** – Who is using the service? / Who should be using the service? Why aren’t they?
- **Appropriateness** – Does the service meet people’s needs and improve outcomes?
- **Service support needs** – Is further training and development required for employees?
- **Partnership working** – Are partners aware of and implementing equality requirements?
- **Contracts & monitoring** – Is equality built into the contract and are outcomes monitored?

<p>2.1. Examples of relevant evidence sources are listed below. Please tick which evidence sources are being used in this assessment and provide a summary for each protected characteristic in sections 2.2 and 2.3.</p>		
<p>Internal desktop research</p>		
<input type="checkbox"/>	Place survey / Customer satisfaction data	<input checked="" type="checkbox"/> Demographic Profiles – Census & ONS
<input checked="" type="checkbox"/>	Local Needs Analysis	<input checked="" type="checkbox"/> Service Monitoring / Performance Information
<input checked="" type="checkbox"/>	Other local research	
<p>Third party guidance and examples</p>		
<input checked="" type="checkbox"/>	National / Regional Research	Analysis of service outcomes for different groups
<input type="checkbox"/>	Best Practice / Guidance	<input checked="" type="checkbox"/> Benchmarking with other organisations
<input type="checkbox"/>	Inspection Reports	
<p>Public consultation related activities</p>		
<input checked="" type="checkbox"/>	Consultation with Service Users	<input checked="" type="checkbox"/> Consultation with Community / Voluntary Sector
<input type="checkbox"/>	Consultation with Staff	Customer Feedback / Complaints
<p>Data about the physical environment e.g. housing market, employment, education and training provision, transport, spatial planning and public spaces</p>		
<p>Consulting Members, stakeholders and specialists</p>		
<input type="checkbox"/>	Elected Members	<input checked="" type="checkbox"/> Expert views of stakeholders representing diverse groups
<input checked="" type="checkbox"/>	Specialist staff / service expertise	
<p><i>Please bear in mind that whilst sections of the community will have common interests and concerns, views and issues vary within groups. E.g. women have differing needs and concerns depending on age, ethnic origin, disability etc</i></p>		
<p>Lack of local knowledge or data is not a justification for assuming there is not a negative impact on some groups of people. Further research may be required.</p>		
<p>2.2. Summary of Existing Data and Consultation Findings: - Service Delivery Considering the impact on Customers/Residents</p>		
<p>2.2.1- Age: e.g. Under 16 yrs / 16-19 yrs / 20-29 yrs / 30-44 yrs / 45-59 yrs / 60-64 yrs / 65-74 yrs / 75+</p>		
<p>2.2.2 - Disability: e.g. Physical impairment / Sensory impairment / Mental health condition / Learning disability or difficulty / Long-standing illness or health condition / Severe disfigurement</p>		
<p><u>2.2.2.1) Research:</u></p>		
<p>1.1) Still missing out? Ending poverty and social exclusion: messages to government from families with disabled children – Barnados 2002</p>		
<p>At present, a disproportionate number of families with disabled children are living in poverty, for the following reasons:</p>		
<ul style="list-style-type: none"> • Work – parents with disabled children are often unable to work because they cannot secure childcare suitable for their child’s needs. 		

- Extra costs – on average it costs three times as much to raise a child with severe impairment than a non-disabled child.
- Benefits – many parents are confused about entitlements and find procedures overly complicated. As a result, uptake is limited and the poorest families are not accessing the benefits they need.
- Lone parents – there is a higher rate of lone parents among families with a disabled child, which places greater pressure upon the caring parent.
- Minority ethnic families are more likely to have low incomes and unsuitable housing. In many cases they are less able to access services.

Families with disabled children also face many other difficulties.

- Unsuitable housing is a key issue for all the families interviewed. Some cannot use wheelchairs indoors because of narrow doorways; others have to carry their children upstairs. Families have to wait years for adaptations.
- Transport – many families have unmet needs, as most public transport is inaccessible and cabs are expensive.
- Access to services – families are uncertain about the services available, many of which can only be obtained following persistent pressure.
- Accessing community life – there are barriers preventing disabled children from accessing play schemes and other community facilities.

1.2) Improving the wellbeing of disabled children and young people through improving access to positive and inclusive activities - Social Policy Research Unit, University of York 2009

- Disabled children and young people appear to have very limited opportunities to access positive activities in their local areas.
- Disabled children, young people and their families want more and different things to do so that they can choose where and how they spend their free time.
- Participating in positive activities is associated with positive outcomes in terms of children's health, experiences of enjoyment and achievement and community participation.
- At the same time, disabled children and young people report that bullying or fear or bullying spoils their experiences of, or stops them accessing, inclusive activities or using local leisure and recreation facilities.
- Achieving inclusion for disabled children requires planning, resources and the active involvement of skilled staff.
- There is scope for children's centres, extended schools and youth services to become more inclusive. Examining service delivery alongside best practice examples would be of benefit.
- There is variability in how services have interpreted what inclusion means and this has led to different modes of service delivery, some of which are not genuinely inclusive.
- Disabled children and young people value provision which is designed to facilitate disabled children's participation in activities and interaction between disabled and non-disabled children. However, they also value provision for disabled children or young people only.
- Supporting the participation of disabled children and young people in positive activities requires much more than making a service inclusive.
- The provision of information about positive activities needs to be improved and some families will need active support to identify and join positive activities provided.

- Opportunities to access positive activities need to be provided in inclusive settings and in 'disability only' groups. The most appropriate setting will differ according to children and young people's own preferences, the nature of the child's impairment, and the type of activity.

1.3) The impact of the Aiming High for Disabled Children short breaks programme on the prevention of disabled children and young people entering the Looked After System - Together for Disabled Children 2011

It should be noted that the local authorities who took part did so voluntarily and that there was no randomisation of selection, therefore these findings may not be representative of the entire population of local authorities. Three strands were explored:

Strand 1 – Was there a reduction on numbers of children who entered the Looked After System?

Strand 2 – Was there a reduction in numbers of disabled children placed out of the area?

Strand 3 – Was there a reduction in the need for emergency, high cost placement?

Key Findings:

- Short break services appear to have prevented disabled children entering the Looked After System and thus potentially saved money for the LA.
- All participating local areas state that they are focussing on early identification and support as a means of preventing children and young people from requiring emergency and long term Looked After placements.
- All local areas have developed a wide range of holiday provision recognising it as the peak time for increased requests for children to be at risk of becoming 'Looked After' or for emergency placements.
- Short breaks have reduced the need for costly out of borough placements. In staying closer to home, children are potentially enabled to have improved engagement in their own communities and reduced transition issues.
- Targeted support via the Common Assessment Framework has had the added value of improving multi-disciplinary working relationships. Local authorities involved in this study see short breaks as part of their preventative strategy.

1.4) Contact A Family:

- 92% say that finding childcare for disabled children is more difficult compared to non-disabled children (Counting the Costs, 2014).
- 40% say they are unable to access the full free childcare offer of 15 hours per week (Levelling the Playing Field, 2015).
- The majority of disabled children participate in a limited number and range of leisure activities (Fair play for disabled children: Bevan foundation report, 2010).
- 99.1% of disabled children live at home and are supported by their families.
- 52% of families with a disabled child are at risk of experiencing poverty.
- The income of families with disabled children averages £15,270, 23.5% below the UK average income of £19,968, and 21.8% have incomes that are less than half the UK mean.
- Only 16% of mothers with disabled children work, compared to 61% of other mothers.
- It costs up to three times as much to raise a disabled child, as it does to raise a child without disabilities.
- 56% of parents with disabled children and children with special educational needs reported

there was a lack of sufficient childcare in their area.

- Only one in 13 disabled children receive a regular support service of any sort from their local authority.

1.5) Prevalence of childhood disability – Blackburn Spencer and Read 2010

7.3% (CI 6.9, 7.7) of UK children were reported by as disabled according to the DDA definition.

Patterns of disability differed between sexes with boys having a higher rate overall and more likely than girls to experience difficulties with physical coordination; memory, concentration and learning; communication.

Disabled children lived in different personal situations from their non-disabled counterparts, and were more likely to live with low-income, deprivation, debt and poor housing. This was particularly the case for disabled children from black/minority ethnic/mixed parentage groups and lone-parent households. Childhood disability was associated with lone parenthood and parental disability and these associations persisted when social disadvantage was controlled for. These analyses suggest that UK disabled children experience higher levels of poverty and personal and social disadvantage than other children.

1.6) Outcome following preterm birth AT Gibson 2007

Since the 1980s there have been changes in the population of disabled children. Increasing numbers of those with multiple and complex impairments are living longer and being cared for at home. This is due in part to improved survival rates for low birth weight and extremely premature babies.

1.7) Technology dependent children in the community – Glendinning, Kirk, Guiffrida and Lawton 2001

When children have higher support needs or complex impairments, some parents may have to take responsibility for administering medication, tube feeding, assisted ventilation, and resuscitation procedures as well as other treatments and interventions.

1.8) Palliative care statistics for children and young adults – Cochrane, Liyanage and Nantambi 2007

It is estimated that around 18,000 children and young people in England have multiple and complex impairments which result in their needing some form of palliative care.

1.9) Autism Levy Mandell and Schultz 2009 and Developing ADHD Taylor 2009

Recent years have seen a marked increase in numbers of children identified as having autistic spectrum disorders and attention deficit hyperactivity disorder.

1.10) Feeling down improving the mental health of people with learning disabilities Burke 2014

When disabled children have multiple impairments it is not uncommon for some of their needs and difficulties to go unrecognised because the diagnosis of one condition may over shadow another.

1.11) Exploring disability, family formation and break up Clarke and Mckay 2008

Research points to a clustering of childhood and adult disability within households.

1.12) Prevalence of childhood disability and the characteristics and circumstances of disabled children in the UK Blackburn Spencer and Read 2010

Almost half of disabled children (compared with a fifth of non disabled children) live with a parent who is also disabled. In addition a quarter of disabled children live with one or more siblings who are also disabled.

1.13) State of the Nation - SENDirect 2016**Why do families need Short Breaks?**

Short Breaks are a fantastic opportunity for parents to take a break from their caring duties, but they also help disabled children to become more independent and involved in their local community.

- 76% of parent carers said they have experienced stress or depression (*Short Breaks in 2015: An Uncertain Future, EDCM*).
- 66% of parent carers find accessing services and products that meet their child's needs stressful (*Baseline Survey, SENDirect, 2015*).
- Short Breaks have a direct positive impact on the lives of disabled children and young people who use them, making them more confident and independent (*EDCM, 2015*).

The Barriers Facing Families

- **It can be difficult for families to find out about their rights / entitlements:** Short Break statements are not always easily accessible to families. In some cases, the Short Breaks statement is incomplete, which means parent carers that live in these Local Authorities only have access to a limited amount of information about their eligibility and the application processes. We would suggest that best practice would be to include these in the local offer, as surprisingly only **91** Local Authorities have done so (*Emily Tyrell, 2015*).
- **It's time consuming and stressful to find out what's out there:** **66%** of respondents to the survey said it is stressful to find information on services and products that meet their child's needs (*SENDirect, 2015*). Contact a Family's research found that many parents were unaware of their Local Offer except those who are actively engaged in their local Parent Carer Forum (*EDCM, 2015*). Even if Local Authorities are not obliged to carry out formal assessments of needs to give access to a service, they must do so if they intend to refuse the children from the same service.
- **It can be difficult to negotiate the process of assessment:** **53%** of parent carers who responded to Contact a Family's research, and self-identify as having a disabled child, say that they have never accessed any form of Short Breaks service (*EDCM, 2015*). Not only does this suggest that a large number of eligible children are missing out, but also the lack of available information means that parent carers are missing out on the support that they need the most.

1.14) Understanding the needs of disabled children with complex needs or life-limiting conditions WHAT CAN WE LEARN FROM NATIONAL DATA? Council for Disabled Children and the True Colours Trust 2017

- There are **rising numbers of disabled children with complex needs and/or life-limiting conditions**, who, with their families, are likely to need support from health, education and social care continuously or at times throughout their life

- More than 10 years ago, the National Service Framework (Standard 8: Disabled Children and Young People and those with Complex Health Needs) noted In the past ten years, the prevalence of severe disability and complex needs has risen. This is due to a number of factors, including increased survival of preterm babies and increased survival of children after severe trauma or illness. There are up to 6,000 children living at home who are dependent on assistive technology. Children and young people with life-limiting conditions, such as cystic fibrosis, have better life expectancy.
- Three years later, Aiming High for Disabled Children: Better Support for Families (DfES, 2007) estimated that around 100,000 disabled children had complex care needs
- Better Care, Better Lives (DH, 2008), informed by the Independent Review of Children's Palliative Care Services, noted the challenge faced by service providers and commissioners due to: 'the change in the profile of children with life-limiting or life-threatening conditions over the last 20 years due to technological advances and increased survival rates of low-birthweight babies

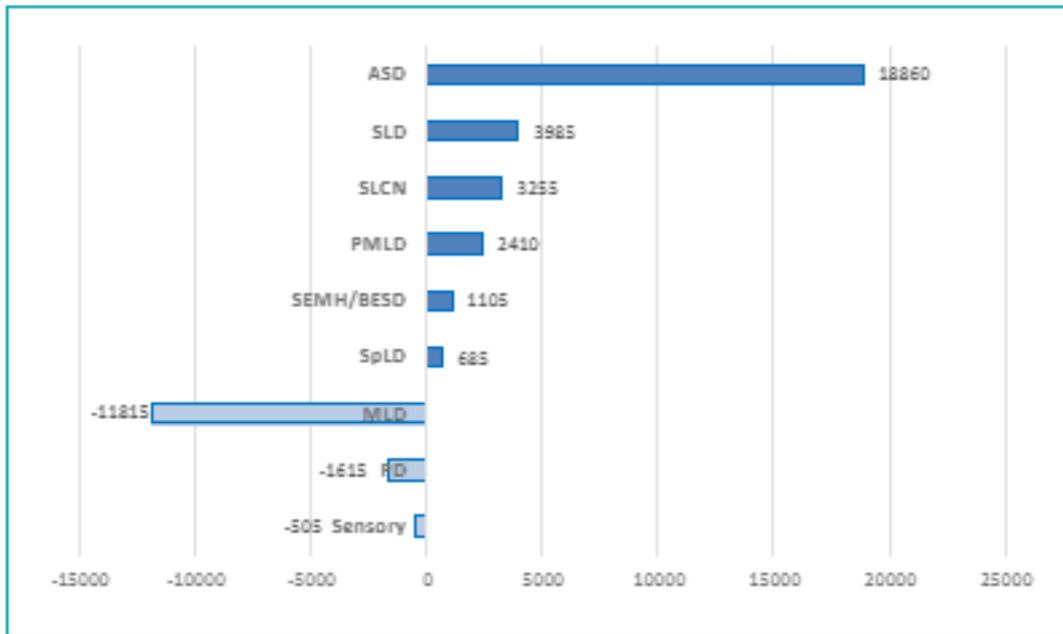
School Census data shine some light on these trends. The School Census collects detailed data on the great majority of school children in England

- a narrow estimate of the number of school children (broadly, aged 5-16 years) with complex needs is 73,000, made up of:
 - 10,900 children with profound and multiple learning difficulties
 - 32,300 children with severe learning difficulties
 - 27,500 children with autistic spectrum disorders in special schools
 - 2,300 children with multi-sensory impairments.
- The equivalent figure in 2004 was 49,300.
- This suggests that **the number of school children with complex needs in schools in England may have risen by nearly 50 per cent in just over a decade.**

The actual number is higher, as

- 13,500 children with statements/EHC plans placed in independent schools, which provide some of the most specialist placements
- 23,100 more young people aged 16-25 years with statements or EHC plans who are not included in School Census data, including over 1,000 aged 20-25 years.
- Nearly 118,000 children and young people with statements or EHC plans are placed in specialist schools and colleges. Special schools now cater for many more children with complex needs than in 2004 (Chart 1). The number of children with complex needs in mainstream schools has also risen over the same period.
- These **trends are not evident in the social care data**, partly because so **few disabled children are assessed as children in need** (0.4 per cent of all 0-17 year olds) or looked after under the Children Act 1989 (with only 2,250 children nationally whose main reason for being looked after is disability). It is clear from the data analysed **that thresholds for support from social services for disabled children and their families are high and vary widely from area to area.**

Chart 1: Change in the primary needs of children in special schools between 2004 and 2016 (increases on right, decreases on left)



‘SEN type’ – Codes and descriptions used in School Census reporting⁶⁵

SpLD	Specific learning difficulty (e.g. Dyslexia, dyspraxia)
MLD	Moderate learning difficulty
SLD	Severe learning difficulty
PMLD	Profound & multiple learning difficulty
SEMH	Social, emotional and mental health
SLCN	Speech, language and communication needs
HI	Hearing impairment
VI	Visual impairment
MSI	Multi-sensory impairment
PD	Physical disability
ASD	Autistic spectrum disorder (includes Aspergers syndrome).

Major efforts are being made to improve health data on children, with the introduction of a standard approach to recording childhood disabling conditions and the support needs of children, young people and families, as part of the mandated Children and Young People’s Health Services data set (CYPHS).

Two key trends were highlighted repeatedly, both contributing to rising numbers of disabled children with complex needs or life-limiting conditions:

- **improved survival rates** of preterm babies and babies with congenital conditions
- **increased life expectancy** for children with complex disabilities, including children with severe cerebral palsy, cystic fibrosis and Duchenne muscular dystrophy.

These perceptions are consistent with academic evidence, but hard to discern from national data. This contributes to a widespread lack of awareness and policy attention, locally and nationally, on the rising numbers of disabled children with complex needs and life-limiting conditions.

This matters, because **many local authorities and clinical commissioning groups (CCGs) have an incomplete and out-of-date picture of disabled children and young people in their area**, undermining the potential for forward planning and intelligent commissioning of specialist provision. Poor data has been highlighted as a challenge for local areas in inspection reports.

1.15) These are our children - A review by Dame Christine Lenehan Director, Council for Disabled Children Commissioned by the Department of Health 2017

An independent review which examined the care of disabled children and young people with challenging behaviour and complex needs which involve mental health problems and learning disabilities and/or autism. The review was commissioned by the Department of Health and carried out by the Director of the Council for Disabled Children. The review drew evidence from civil servants, clinicians, managers, parents and young people. The findings cover following areas: children's rights; articulating vision of care; what a good model of care should look like; the leadership and professional responsibility required to implement the model; supporting parents and families; developing coherent strategy within the system; commissioning; and the workforce. The review found that despite a number of Government initiatives, **there is not a clear vision for the treatment of children with complex needs involving challenging behaviour and a mix of mental health problems, learning disabilities and autism.**

Behaviour can be described as challenging when it is of such an intensity, frequency or duration as to threaten the quality of life and/or the physical safety of the individual or others and is likely to lead to responses that are restrictive, aversive or result in exclusion." *Challenging Behaviour: A Unified Approach, 2016*

The evidence shows us that our group of children tend to be in poorer families and live in challenging circumstances. Even for more affluent and settled families the cuts in local authority support services are biting hard. **The loss of local authority early intervention and short breaks services affects our group of children disproportionately.**

The continuing philosophical debates about causation and treatment of challenging behaviour is one of the main reasons that children fall between gaps and fail to get access to appropriate services. The system has a number of built-in barriers which restrict access to supportive interventions. Added to this, our children are complex in their needs and their presentation and they **do not always fit individual labels** of autism/ learning disability/ neuro developmental disability/challenging behaviour /mental health. It is more likely that they have a combination which does not fit neatly into any one team's existing definitions for service. Furthermore, mental health problems frequently don't manifest themselves until adolescence adding to the difficulties in getting clear diagnosis.

For example, in one local area even where they have a great positive behaviour support service for children:- *"The team did not have capacity to support those with less severe levels of challenging behaviour (no early intervention team) and there was nothing for young people with autism but no learning disability. One family of a 13 year old boy with autism were told by Social Services to call the police and although they were reluctant they had to call the police 47 times in 4 years. The GP prescribed liquid diazepam to the child and the family were told there was*

nothing more they could do and the family were told it was bad parenting. There was no family support, behaviour support, autism or CYPMH specialist support.”

In another area, “families explained that children where provision was good in schools were doing OK overall but these tended to be the children “in the middle” – those with more severe learning disabilities (and at risk of later ATU admission) were not able to access good support (except for those who happened to have a paediatrician who took it upon herself to be a key-worker above and beyond what she was required to do) and those with milder learning disabilities (and so at potential risk of encountering the criminal justice system later were similarly lacking support.”

NICE (The National Institute for Health and Care Excellence) has issued guidelines on *Autism Spectrum Disorder in under 19s: support and management*, *Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges*, and *Mental health problems in people with learning disabilities*. These **guidelines are all evidence based, all useful but can be a struggle to adapt for children whose needs spread across the boundaries of individual guidelines.**

2.2.2.2) Local Data:

2.1 Central Bedfordshire Joint Strategic Needs Assessment

Estimates for the number of disabled children and young people in Central Bedfordshire 2011/12

- Disability Living Allowance (DLA) Higher Care rate, Department for Works and Pensions (DWP), Feb 2011 (0.8%) – **607**
- Together for Disabled Children - Aiming High (1.2%) - **907**
- Disability Living Allowance - entitled cases DWP Feb 2011 (2.6%) - **1,970**
- Family Resource and General Household Survey, Office for National Statistics (ONS) & School Census - Spring 2011 (7.0%) - **5,292**
- Lancaster University (10.0%) - **7,560**
- Ages 0-24, 2010 mid year estimate ONS - June 2011 - **75,600**

It is estimated that only one in 13 disabled children receive a regular support service of any sort from their local authority. Only 8% of families get services from their local social services. (Contact a Family: Statistics)

The Central Bedfordshire Council Children with Disabilities Social Care Team work with up to 250 disabled children and their families at any one time.

The Children with Disabilities Register has 1100 children included on it.

Current data available to us indicates that Central Bedfordshire Children's Services are working to the Aiming High figure of 1.2%

Central Bedfordshire Council Equality Impact Assessment

School Census January 2011 – Primary Learning Difficulty/ Disability (LDD) Levels of need

	Nos. per category	Percentage per category	Nos. per 100,000 rounded up
Behaviour, Emotional and Social Difficulty (BESD)	699	25.5%	27960
Moderate Learning Difficulties (MLD)	428	15.6%	17120
Autistic Spectrum Disorder (ASD)	388	14.1%	15520
Speech, Language & Communication Needs (SLCN)	348	12.7%	13920
Specific Learning Difficulties (SPLD)	313	11.4%	12520
Severe Learning Difficulties (SLD)	189	6.9%	7560
Other (OTH) which may include children without a clear diagnosis	118	4.3%	4720
Physical Disability (PD)	113	4.1%	4520
Hearing Impairment (HI)	79	2.9%	3160
Visual Impairment (VI)	37	1.3%	1480
Profound and Multiple Learning Difficulty (PMLD)	26	0.9%	1040
Multi Sensory Impairment (MSI)	8	0.3%	320
Total	2,746	100.0%	109840
Total number of all children and young people on school census	39,214		

Source: Central Bedfordshire Council

Short break provision in Central Bedfordshire includes:

- Holiday activities.
- Out of school social activities during the week and at weekends.
- Sibling Group activities.
- Overnight Short Breaks.
- Support to access the community.
- Assisted leisure activities.
- Direct Payments.
- Day Care.
- Specialist Childminders (up to age 11).

2.2. Service Usage Second Quarter (July, August September) 2015

Autism Bedfordshire Summer Playscheme

Children 56	Hours total: 1210
CWD children – 22 39%	CWD Children 445 37%
SEND Children -12 21%	SEND Children 292 24%
Non CWD - 15 27%	Non CWD 308 25%
Unknown on mosaic – 7 13%	unknown 165 14%

LOAF

Children 50	Hours total: 477
CWD children – 5 10%	CWD Children : 60 hrs 13%
SEND Children - 11 22%	SEND Children : 105 hrs 22%
Non CWD - 15 (3 unknown) 30%	Non CWD : 126 hrs 26%
Sibs - 19 38%	Sibs: 186 hrs 39%

Autism Bedfordshire Wanted Fun

Children 38	Hours total: 343
CWD children – 4 11%	CWD Children : 39 hrs 11%
SEND Children - 13 34%	SEND Children : 131 hrs 38%
Non CWD - 21 (8 unknown) 55%	Non CWD : 173 hrs 50%

SNOOSC Summer Holiday Club 2015

Children : 22	CWD 15 68%	Hours Total 758	CWD 446 hrs 59%
Non CWD	2 9%		Non CWD 84 hrs 11%
18+	5 22%		18+ 228 hrs 30%

SNOOSC After School Club 3rd Q 2015

Children : 22	CWD 15 68%	Hours Total 344	CWD 188 hrs 54%
Non CWD	4 18%		Non CWD 96 hrs 28%
18+	3 2%		18+ 60 hrs 17%

SNOOSC Saturday Club 3rd Q 2015

Children : 15	CWD 10 66%	Hours Total 355	CWD 216 hrs 61%
Non CWD	2 13%		Non CWD 49 hrs 14%
18+	3 20%		18+ 90 hrs 25%

FUN Summer Holiday Club 2015

Children : 60	CWD 22 37%	Hours Total 995	CWD 446 hrs 45%
Non CWD	21 35%		Non CWD 84 hrs 8%
Sibs	15 25%		Sibs 240 hrs 24%
18+	2 3%		18+ 50 hrs 5%

Half Term Holiday Club: Children 31

CWD Children	11 35%	Hours Total	195
Non CWD children	11 35%	CWD hours	60 31%
Sibs	8 26%	Non CWD hours	90 46%
18+	1 3%	Sibs	45 23%

Special Events

Children	42	CWD hours	60 45%	over 18
18+	1 2%	non CWD hrs	40.5 30%	2hrs 1%
CWD	17 40%	Sib Hours	32 24%	
Sibs	12 29%	TOTAL 134.5		
non CWD	12 29%			

2.2.2.3 Local Consultation:**3.1 JSNA**

The 2011 consultation informed the authority that all partners including parents and children would like to see further improvements:

They wanted us to:

- Provide information from people who understand the issues for disabled children and their families.
- Increase the number of activities in Biggleswade and Leighton Buzzard.
- Increase activities and opportunities for teenagers which include those designed to develop life skills and independence.
- Increase support for the siblings of disabled children.
- Support families in managing children with challenging behaviour.
- Offer more flexibility in support services, especially at weekends and school holidays.
- Provide suitable transport arrangements for children to access short breaks.

3.2 SEND Parent/Carer Survey Feb - April 2014:

Central Bedfordshire Council's Support and Aspiration Board worked in partnership with SNAP (Central Bedfordshire's Parent/Carer Forum) to develop the survey. During its development it was agreed that 2 surveys should be circulated:

Survey 1- focussed on families with children with more complex special educational needs and disabilities (SEND)

78% of Parent/carers felt the support they are receiving meets their child's needs:
71% of parents/carers said it was difficult to find out about what was available to them.

The key elements of a successful service were identified as:

- Staff attitude
- Staff training/knowledge
- Close to home
- Information on how to access

The main changes listed as potentially making the biggest difference

- More local clubs and activities
- More information/awareness
- Flexibility

Suggestions for improvement included

- being sensitive to parents emotions and pressures
- More opportunities for children with profound and multiple learning disabilities/medical conditions
- Awareness of leisure facilities/youth centres/activities available and plugging of the gaps (weekends/evenings/school holidays)
- Support to access these, including trained staff
- Consideration of additional funding to local organisations to extend what they can offer, e.g BDCPS

Survey 2 - for families with children with SEND in mainstream schools, both with and without statements of SEN.

85% of parents/carers who responded were satisfied or quite satisfied with the support provided
 36% of parent/carers have children participating in after school activities

Suggestions for improvements included:

- Emotional support/social support for children
- Localised opportunities for families.

2.2.3 Carers: *A person of any age who provides unpaid support to family or friends who could not manage without this help due to illness, disability, mental ill-health or a substance misuse problem*

2.2.3.1) Research:

1.1) Contact A Family:

- One in five say that isolation has led to the break up of their family life (Forgotten Families, 2011).
- 72% of parents / carers experience mental ill health such as anxiety, depression or breakdown due to isolation (Forgotten Families, 2011).
- More than three quarters of families say that the opportunity to spend time with their spouse or partner away from the role of caring is poor or unsatisfactory (What Makes My Family Stronger, 2009).
- 53% of parents say that caring for a disabled child has caused major difficulties or the breakdown of their relationship (No Time for Us, 2003).

2.2.4 Gender Reassignment: *People who are proposing to undergo, are undergoing or have undergone a process (or part of a process) to reassign their sex by changing physiological or other attributes of sex*

2.2.5 Pregnancy and Maternity: *e.g. pregnant women / women who have given birth & women who are breastfeeding (26 week time limit then protected by sex discrimination provisions)*

2.2.6 Race: e.g. Asian or Asian British / Black or Black British / Chinese / Gypsies and Travellers / Mixed Heritage / White British / White Irish / White Other

2.2.6.1) Research:

- African Caribbean pupils and pupils from mixed white and Caribbean backgrounds are more likely to be identified as having special educational needs (SEN) and are over-represented among the behavioural, emotional and social difficulties categories.
- Pakistani and Bangladeshi pupils are under-represented in identification of Speech and Language difficulties
- Travellers of Irish heritage and Gypsy or Roma pupils are over-represented among many categories of SEN

2.2.7 Religion or Belief: e.g. Buddhist / Christian / Hindu / Jewish / Muslim / Sikh / No religion / Other

2.2.8 Sex: e.g. Women / Girls / Men / Boys

2.2.8.1) Research:

- Boys are more likely to be identified as having special educational needs: 70% identified SEN are boys.
- Boys are more likely than girls to attend special schools,
- Boys are nine times as likely as girls to be identified with autistic spectrum disorder;

2.2.9 Sexual Orientation: e.g. Lesbians / Gay men / Bisexuals / Heterosexuals

2.2.10 Other: e.g. Human Rights, Poverty / Social Class / Deprivation, Looked After Children, Offenders, Cohesion, Marriage and Civil Partnership

2.2.10.1) United Nations Convention on the Rights of the Child:

Article 3

- The child's best interests must be a top priority whenever anything is done that affects children.

Article 23

- Every disabled child has the right to a full life and to active participation in the community.

Article 31

- Every child has the right to rest, play and leisure.

2.2.10.2) UN Convention on the Rights of Persons with Disabilities:

Office for Disability Issue – HM Government UK Initial Report On the UN Convention on the Rights of Persons with Disabilities 2011

Disability legislation in the UK is characterised by an 'asymmetrical' approach introduced by the Disability Discrimination Act and carried forward into the Equality Act 2010. The asymmetrical approach to disability discrimination law in the UK is a fundamental acknowledgement that disabled people are a particularly vulnerable group in society and need additional support in the form of legislation to enable them to live and work on an equal basis as non-disabled people. It means that disabled people can be treated more favourably than non-disabled people, but one disabled person cannot be treated more favourably than another disabled person."

Paragraph 54 of [The First Report on the UN Convention \(link to Office for Disability Issues\)](#), November 2011.

Article 7 – Children with disabilities

The UK is continuing work to implement the UN Convention on the Rights of the Child (UNCRC) to make that Convention a reality. Through the HRA, the rights of all children to privacy, freedom of assembly, freedom of expression, freedom of thought, conscience and religion set out in the ECHR are incorporated in UK domestic law.

71. In the UK, a number of programmes are helping to deliver those rights. In England, following the publication of the 3rd and 4th Periodic reports to the UNCRC10, standards were included within the National Service Framework for children with specific needs – including disabled children. The Government provides grants to support low-income families with severely disabled children. It is providing £800 million to fund short breaks for parents with disabled children in the next four years.

Article 19 – Living independently and being included in the community

Article 23 – Respect for home and the family

Support for parents, families and carers of young disabled people

222. The UK recognises that the parents, families and carers of young disabled people can face challenging circumstances and may need co-ordinated and extra support to help ensure their well-being and that of the young person. This support is provided in a variety of ways.

223. Across the UK, the Government is providing £20 million for additional respite care for carers of severely disabled children. Up to £30 million funding has been made available in 2010/11 to support local projects developing children's palliative care services.

224. In England and Wales the 'Early Support' programme is designed to improve the quality and coordination of services for young disabled children and their families, whilst keeping parents at the centre of any decisions about their child. In England, the 'Recognised, valued and supported: Next steps for the carers strategy' launched in November 2010 sets out a framework for supporting the carers of both adults and ill and disabled children. £6 million of new funding has been made available to train GPs to identify and support carers. An additional £400 million will provide breaks for all carers, including the carers of ill and disabled children. Local authorities will also be provided with £800 million over the next four years to fund short breaks for families with disabled children.

In England, the '[Safeguarding Disabled Children – Practice Guidance](#)' explains how Local Safeguarding Children Boards, agencies and professionals at the local level are expected to draw up and agree detailed ways of working together to safeguard disabled children.

Article 28 – Adequate standard of living and social protection

The UK Government is committed to supporting disabled people, to improving the quality of life of

those facing disadvantage, and to tackling poverty by addressing its causes.

Disabled children

317. The Government is committed to tackling poverty and has enacted the Child Poverty Act 2010, which puts in legislation a commitment to eradicate child poverty by 2020. Children living in families with a disabled adult and children living in families with a disabled child are included among the groups disproportionately more likely to be in poverty and affected by socio-economic disadvantage

Article 30 – Participation in cultural life, recreation, leisure and sport

The latest data available shows that disabled people in the UK remain less likely to participate in cultural, leisure and sporting activities than non-disabled people.

2.2.10.3) Disability Discrimination Act / Equality Act

Definition of Disability:

A person has a disability if they have a physical or mental impairment, which has a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities. However, special rules apply to people with some conditions such as progressive conditions and some people are automatically deemed disabled for the purposes of the Act.

The definition covers physical or mental impairments. This includes sensory impairments, such as those affecting sight or hearing. The term 'mental impairment' is intended to cover a wide range of impairments relating to mental functioning, including what are often known as learning disabilities.

There is no need for a person to establish a medically diagnosed cause for their impairment. What it is important to consider is the effect of the impairment, not the cause.

A substantial adverse effect is something which is more than a minor or trivial effect. The requirement that an effect must be substantial reflects the general understanding of disability as a limitation going beyond the normal differences in ability which might exist among people.

Account should also be taken of where a person avoids doing things which, for example, cause pain, fatigue or substantial social embarrassment; or because of a loss of energy and motivation. An impairment may not directly prevent someone from carrying out one or more normal day-to-day activities, but it may still have a substantial adverse long-term effect on how he or she carries out those activities. For example, where an impairment causes pain or fatigue in performing normal day-to-day activities, the person may have the capacity to do something but suffer pain in doing so; or the impairment might make the activity more than usually fatiguing so that the person might not be able to repeat the task over a sustained period of time.

Day to day activities include - but are not limited to - activities such as walking, driving, using public transport, cooking, eating, lifting and carrying everyday objects, typing, writing (and taking exams), going to the toilet, talking, listening to conversations or music, reading, taking part in normal social interaction or forming social relationships, nourishing and caring for one's self.

Anyone who has HIV, cancer or multiple sclerosis is automatically treated as disabled under the Act. In some circumstances, people who have a sight impairment are automatically treated as disabled under Regulations made under the Act.

Progressive conditions are conditions which are likely to change and develop over time. Where a person has a progressive condition they will be covered by the Act from the moment the condition leads to an impairment which has some effect on ability to carry out normal day-to-day activities, even though not a substantial effect, if that impairment might well have a substantial adverse effect on such ability in the future. This applies provided that the effect meets the long-term requirement of the definition.

Public authorities have duties not to discriminate against disabled people by treating them less favourably or failing to make reasonable adjustments. Public authorities also have a duty to have due regard to the need to promote disability equality.

Section 149(3) explains what having due regard to need (b) entails. Section 149(4) explains further, by reference to section 149(3)(b), that taking steps to meet the needs of disabled people that are different from the needs of people who are not disabled includes, in particular, steps to take account of their disabilities. Section 149(5) explains further what need (c) entails. Complying with section 149 may involve treating some people more favourably than others, but that does not permit conduct which would otherwise be prohibited by the 2010 Act (section 149(6)).

The Council for Disabled Children advises that in practice this means that at the outset all children (disabled and non-disabled) should have access to universal services. Local areas should work towards eliminating discrimination and promoting equality of opportunity by building capacity in local services so that they are accessible by all children.

Where this may not be practical, for example for children on the autistic spectrum or children with multiple impairments who may require a high level of support and activities tailored to their needs, the Council for Disabled Children advises setting up specific services, such as youth activities or sports opportunities, for a specified group of children as a way of meeting the duties under the Equality Act. Given the need to ensure the most disabled children are not disadvantaged, a mixture of universal and specific services will be required in every area.

2.2.10.4) Children Act 1989

Disabled children can access services through Part III of the Children Act 1989 ('Local Authority Support for Children and Families'). All disabled children are children 'in need' for the purposes of section 17 of the Children Act 1989. The duty on local authorities under s17 of the 1989 Act is to provide a range and level of support services for children in need in their area, where possible to support them in the context of their families. Local authorities are required to assess and prioritise the way they meet the needs of children in their area.

Local authorities are permitted to use eligibility criteria and to take into account available resources when deciding whether to provide services following assessment. However, they should have due regard to their duties under the Equality Act in reaching this decision.

Where the local authority assess a child's needs they should do so in accordance with the statutory guidance, Framework for the Assessment of Children in Need and their Families

Services provided under Section 17 of the Children Act 1989 should safeguard and promote the welfare of children 'in need'. Services should be designed to:

- Minimise the effect on disabled children of their disabilities, and
- Give disabled children and their families the opportunity to lead lives which are as 'normal' as

possible.¹

Such services include services to a child at home, social or recreational activities, help with holidays and where necessary the provision of accommodation.

The Council for Disabled Children advises that:

- the definition of 'disabled' children in the Children Act 1989 is broad and that all 'disabled children' are children 'in need' and are entitled to an initial assessment.
- It is important that children are not seen as being in fixed bands. The banding of children undermines the principle of identifying and meeting individual assessed need.
- eligibility cannot just be based on the severity of the child's impairment but should take into account the other 2 sides of the assessment triangle (parenting capacity and family and environmental factors).
- The term 'disabled' child exists in law, but severe disability or complex needs does not. If you are targeting particular resources on children with severe disabilities, it is more helpful to state that 'this resource, such as one-to-one support will be provided to children whose needs cannot be met by mainstream or universal services.

2.2.10.5) The Chronically Sick and Disabled Persons Act 1970 (CSDPA)

The Council for Disabled Children advises that the interface between the CSDPA 1970 and the Children Act 1989 is not straightforward. CSDPA 1970 is one of the central pieces of legislation about the provision of social care services to disabled people. The Act covers both adults and children.

A High Court case (*R (JL) v Islington LBC*) re-stated that services under s2 of the CSDPA 1970 are available to disabled children.² Once an authority has assessed the needs of a disabled child and decided that the provision of services under CSDPA 1970 s2 is necessary in order to meet that child's needs, there is then a specific duty on that authority to provide those services; *R v Gloucestershire CC ex p Mahfood*.³

To make sense of the duty under section 2 CSDPA 1970, **local authorities need to have a process to decide which children will be eligible for CSDPA services**. This process needs to be fair and rational, and local authorities can take resource constraints into account when making this decision.

The CSDPA 1970 only becomes important if a local authority has assessed a child's needs under Section 17 of the 1989 Act and has identified needs, but is considering not providing services to meet those needs. If the needs can be met through the provision of one or more of the services listed in Section 2 of the CSDPA, then the local authority is under a duty to provide them. Local authorities must be careful that their eligibility criteria allow for consideration of the CSDPA 1970 before a final decision is made on whether to provide services.

Welfare Services which can be considered for Disabled Children under s.2 of the CSDPA

¹ The term 'normal' is found in Schedule 2 to the 1989 Act, but in keeping with Aiming High for Disabled Children this should be read as meaning a right to lead 'ordinary lives'.

² As specifically stated in CSPDA 1970 s28A

³ (1995) 1 CCLR 7

- the provision of practical assistance for a disabled child in his/her home (Homecare services); the provision for a disabled child of, or assistance to that disabled child in obtaining, wireless, television, library or similar recreational facilities;
- the provision for a disabled child of lectures, games, outings or other recreational facilities outside his/her home or assistance to that person in taking advantage of educational facilities available to him/her;
- the provision for a disabled child of facilities for, or assistance in, travelling to and from his/her home for the purpose of participating in any services provided by a local authority under Part III of the Children Act 1989 or services which are similar to those which could be provided by a local authority;
- facilitating the taking of holidays by a disabled child, whether at holiday homes or otherwise and whether provided under arrangements made by the authority or otherwise;
- the provision of meals for a disabled child whether in his/her home or elsewhere;
- the provision for a disabled child of, or assistance to the child in obtaining, a telephone and any special equipment necessary to enable him/her to use a telephone.
- the provision of assistance for a disabled child in arranging for the carrying out of any works of adaptation in his/her home or the provision of any additional facilities designed to secure his/her greater safety, comfort or convenience;

Disabled Children A Legal Handbook highlights that local authorities may encourage families to apply for disabled facilities grants to meet some or all of the costs of adaptations, however it is important to note that the fact that a grant may be available does not detract from the core duty under the CSDPA. This means that if the costs of the works that are required exceeds the current maximum mandatory grant, or the work is required to a second home (e.g. because the parents have separated) then the council will have to consider making the additional sums available to comply with the duty.

Works may include adaptations to minimise the risk of danger posed by a disabled child's behavioural problems.

Blatant failures to take action to ensure that a property is suitable for the needs of a disabled person may result in a violation of both the private and family life rights within the European Convention on Human Rights article 8 see 2.2.10.10.

The Council for Disabled Children advises that the **Islington Judgement** highlights the following issues in relation to eligibility criteria:

- Eligibility criteria must not be applied before there has been adequate assessment of the child and family's needs.
- Local authorities should ensure that they separate assessment of need from decisions on the provision of services; they must not allow their eligibility criteria to confuse or distort the assessment process.
- Eligibility criteria should never be applied mechanistically. Decisions should always take into account the particular circumstances and needs of the child and family.
- Local authorities should be aware of the specific legal powers and duties they are using when making decisions about services.
- Eligibility criteria must take full account of the statutory provision under which the local authority is acting.
- Eligibility criteria are appropriate in those situations where local authorities are using their discretionary powers to meet needs (for example, under section 17 or section 20(4) of the

Children Act 1989) but not in situations where they have established there is a *duty* to meet need (for example under section 20(1) of the 1989 Act and section 2 of the Chronically Sick and Disabled Person's Act 1970).

- Eligibility criteria should be informed by the local authority's duties under equality legislation which include duties to eliminate discrimination, to promote equality of opportunity and to encourage participation by disabled people in public life.

2.2.10.6) Carers legislation

Under carers legislation individuals providing substantial and regular care to a disabled person have a right to request an assessment. The Council for Disabled Children advises that while parents should be told that they have a right to an assessment, it is hoped that their needs as well as the needs of most children can be met without the need for such an assessment. (See section 4 Short Break Practice Guidance Draft)

2.2.10.7 Children Act 2004

The Children Act 2004 created important new duties on local authorities to safeguard and promote the welfare of all children in their area (section 11) and to co-operate with other agencies, including Primary Care Trusts, to achieve the 'Every Child Matters' outcomes (section 10). These duties must be considered whenever a local authority is carrying its functions towards children.

2.2.10.8) Childcare Act 2006

Section 12 of the Children Act 2006 requires local authorities to provide information about child care and other services which help to support parents with their children. There is a specific requirement to provide information which is helpful and accessible to disabled children, young people and their families. The Council for Disabled Children advises that local authorities need to be clear that all disabled children are entitled to universal services and information, advice and assistance and need to be aware of the reasonable adjustments being made to ensure that all children can access these services wherever possible.

2.2.10.9) Breaks for Carers of Disabled Children Regulations

The regulations took effect from April 2011, making it a legal duty for local authorities to provide a range of Short Breaks and a 'Short Breaks Services Statement'. Paragraph 6(1)(c) of Schedule 2 of the Children Act 1989 requires Local Authorities to provide services to assist carers of disabled children that will give them breaks from caring for a disabled child.

To meet the requirements of the Regulations Local Authorities must have regard to the needs of Carers in respect of their capacity to care for, or continue to care for their disabled child, and must provide a range of services designed to meet this need. [*'Carer' means a person who provides care for a disabled child and who is either the child's parent or a person who has parental responsibility for that child. 'Disabled' has the meaning given in section 17(11) of the 1989 Children Act (2)*]

Local Authorities were required by 1st October 2011 to publish a statement for carers about the Short Breaks available to disabled children and young people outlining:

- The range of services provided;

- Threshold to access Short Breaks services;
- How the range of services are designed to meet the needs of carers in Central Bedfordshire

A range of services must be provided which are sufficient to assist carers to continue to provide care or to do so more effectively: In particular local authorities must provide:

- Daytime care in the homes of disabled children or elsewhere;
- Overnight care in the homes of disabled children or elsewhere;
- Educational or leisure activities for disabled children outside of their homes;
- Services available to assist carers in the evenings, at weekends and during school holidays.

Local authorities must provide a service to carers of disabled children in order to :

- Allow them to care more effectively
- Allow carers to undertake education, training, regular leisure activities and/or day to day tasks.

The Statement is reviewed bi-annually by the Local Authority and disabled children and their parents and carers to ensure their needs are being met.

2.2.10.10) Human Rights Act

Article 8 – Right to Respect for Private and Family Life

- Everyone has the right to respect for their private and family life, home and correspondence.
- Right may be restricted, provided such interference has a proper legal basis, is necessary in a democratic society and pursues one of the following recognised legitimate aims:
 - national security
 - public safety
 - the economic wellbeing of the country
 - the prevention of disorder or crime
 - the protection of health or morals
 - the protection of the rights and freedoms of others.

Interference must be necessary (not just reasonable) and should not do more than is needed to achieve the aim desired.

Private life – The concept of ‘private life’ is broad. In general, it means that a person has the right to live their own life with such personal privacy as is reasonable, taking into account the rights and freedoms of others. The right is very wide-ranging, covering issues such as privacy, relationships with other people, life in the community, culture and language. Issues that may be particularly relevant include:

Participating in community life: private life may be involved if someone is unable to participate in the life of the community or access essential economic, social, cultural and recreational activities.

Family life – The right to respect for family life includes the right to have family relationships. It also includes the right for a family to live together and enjoy each other’s company.

Article 14 – Prohibition of Discrimination:

Article 14 of the European Convention on Human Rights gives people the right to protection from discrimination in relation to all the other rights guaranteed under the Convention. It means that everyone is entitled to equal access to those rights. People cannot be denied equal access to them on grounds of their personal 'status'.

How does Article 14 work?

Article 14 only works to protect people from different treatment in exercising their other Convention rights. It does not give people a general right to protection from different treatment in all areas of their life. The structure of Article 14 means that a person needs to be able to identify another Convention right in order to make use of the non-discrimination protection.

2.2.10.11 Section 3 of the Local Government Act 1999 ('the 1999 Act') and the statutory guidance issued under it

Authorities should be responsive to the benefits and needs of voluntary and community sector organisations of all sizes (honouring the commitments set out in Local Compacts) and small businesses.

Paragraph 7 says that 'Authorities should seek to avoid passing on disproportionate reductions – by not passing on larger reductions to the voluntary and community sector and small businesses as a whole than they take on'.

- An authority intending to reduce or end funding (where 'funding' means both grant funding and any fixed term contract) or other support to a voluntary and community organisation or small business should give at least three months' notice of the actual reduction⁵ to both the organisation involved and the public/service users.
- An authority should actively engage the organisation and service users as early as possible before making a decision on: the future of the service; any knock-on effect on assets used to provide this service; and the wider impact on the local community.
- Authorities should make provision for the organisation, service users, and wider community to put forward options on how to reshape the service or project. Local authorities should assist this by making available all appropriate information, in line with the government's transparency agenda.

2.2.10.12 Section 27(2) of the Children and Families Act 2014 ('the 2014 Act')

Section 27(1)(a) of the 2014 Act imposes a duty on a local authority to keep under review, among other things, its social care provision for children with disabilities. Section 27(2) requires it to **consider the extent to which that provision is sufficient** to meet the social care needs of the young people concerned. Section 27(3) of the 2014 Act imposes a duty on a local authority to consult with a wide range of local bodies when it exercises the functions imposed by section 27.

2.2.10.13 *DAT & Anor, R (on the application of) v West Berkshire Council [2016] EWHC 1876*

Mrs Justice Laing commented:

"I would accept Mr Broach's submission that there is an exceptional public interest in ensuring that when local authorities cut spending in a way which affects vulnerable children, they are seen to observe the relevant legal provisions, particularly where, as here, the amounts at stake are, in relation to the budget as whole, not large, and where there was flexibility in the money available to accommodate a smaller cut."

I am not satisfied by the terms of the new reports prepared for decision 2 that the Council was invited to consider the use of reserves, or, if it did, why it decided not to use them, since apart from the allusion to 'difficulty', the report does not explain whether or not it would be proper to draw on the reserves, and does not tell members what the 'difficulty' is; whether it is insuperable, or could be overcome.

**2.3. Summary of Existing Data and Consultation Findings – Employment
 Considering the impact on CBC Employees – Not Applicable**

- **Age:** e.g. 16-19 / 20-29 / 30-39 / 40-49 / 50-59 / 60+ **N/A**
- **Disability:** e.g. Physical impairment / Sensory impairment / Mental health condition / Learning disability or difficulty / Long-standing illness or health condition / Severe disfigurement **N/A**
- **Carers:** e.g. parent / guardian / foster carer / person caring for an adult who is a spouse, partner, civil partner, relative or person who lives at the same address **N/A**
- **Gender Reassignment:** People who are proposing to undergo, are undergoing or have undergone a process (or part of a process) to reassign their sex by changing physiological or other attributes of sex **N/A**
- **Pregnancy and Maternity:** e.g. Pregnancy / Compulsory maternity leave / Ordinary maternity leave / Additional maternity leave **N/A**
- **Race:** e.g. Asian or Asian British / Black or Black British / Chinese / Gypsies and Travellers / Mixed Heritage / White British / White Irish / White Other **N/A**
- **Religion or Belief:** e.g. Buddhist / Christian / Hindu / Jewish / Muslim / Sikh / No religion / Other **N/A**
- **Sex:** Women / Men **N/A**
- **Sexual Orientation:** e.g. Lesbians / Gay men / Bisexuals / Heterosexuals **N/A**
- **Other:** e.g. Human Rights, Poverty / Social Class / Deprivation, Looked After Children, Offenders, Cohesion, Marriage and Civil Partnership **N/A**

2.4. To what extent are vulnerable groups more affected by this proposal compared to the population or workforce as a whole?

The proposal focuses on services for children who have a disability and their families. They are, by definition, a vulnerable group and may experience challenging circumstances. The proposal may have the potential to impact adversely on children who meet the Equality and Children Act definitions of disability (and their families), but who do not meet the thresholds for diagnosed profound or severe impairment.

Analysis of existing service user data indicates that 157 children (47%) will continue to receive a specialist service and 179 (53%) will be signposted and supported to access mainstream services and opportunities.

Further consideration needs to be given as to the extent to which these families receive services on a:

- discretionary basis under section 17 or section 20(4) of the Children Act 1989) or
- statutory basis under section 20(1) of the 1989 Act and section 2 of the Chronically Sick and Disabled Person’s Act 1970 or the Breaks for Carers of Disabled Children Regulations)

A consultation with families and voluntary organisations will help to ascertain the likely impact of the proposals and the extent to which families feel that they are able to access mainstream

services and opportunities.

2.5. To what extent do current procedures and working practices address the above issues and help to promote equality of opportunity?

Recognising the important contributions made by Occupational Therapy Services and the Disabled Facilities Grant, £10k ongoing funding has been identified in order to retain an element of top up provision for these services in relation to disabled children.

Information to help children with additional needs:

Local parents have worked with the Council to produce a directory which contains detailed information about a range of services, equipment providers, benefits and support groups.

A Community Physical Activity Assistant has been appointed with a focus on increasing access to a range of leisure activities for disabled children.

Additional Opportunities in Disability Hubs. Consideration is being given to the ways in which activities can be provided in the Disability Hubs.

Facilitating culture change amongst professionals Support will need to be provided to encourage professionals to consider the varying options available in relation to universal services.

Consultation Process

- 1) The consultation process was developed and informed as a result of **focus groups** that were held with families in June 2016 which were facilitated by the **Special Needs Action Panel (SNAP)**. SNAP's purpose is to improve the services that are provided to children and young people with additional needs or disabilities, aged from birth to 25 years, who are living in Central Bedfordshire.
- 2) The Head of the Children with Disabilities Service attended the **Equality Forum** on 16 June to discuss the proposal. Further details can be found at section 5 of the EIA.
- 3) A **formal Central Bedfordshire Council consultation process** was launched in December 2016. This included parents / carers, disabled children, voluntary organisations and other stakeholders.
- 4) **SNAP Survey 2017** – The Special Needs Action Panel also launched an independent survey with parents

Overview of Findings

SNAP Focus Groups 2016 - Summary

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.

Which Services help families most and why?	
<p>Services for Children</p> <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 Artistic 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>Why?</p> <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>
<p>Services for Young People</p> <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>Why?</p> <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>
<p>Services for Families</p> <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>Why?</p> <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>

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

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

“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

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

Central Bedfordshire Council Consultation Process December 2016 – March 2017

Parents and Carers - Summary:

Overview proposals for change:

- The majority of respondents (50%) indicated that they disagreed with the proposal to increase cost effectiveness. A third of respondents (36%) agreed with the proposal and 13% remained neutral.
- The majority of respondents (54%) indicated that they agreed with the proposal to protect services for those in greatest need. A third (38%) indicated that they disagreed and 9% remained neutral
- Opinion towards the proposal for introducing 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
- 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
- A significant majority (79%) of respondents indicated that they disagreed with the proposal to change the funding model.
- the key areas of **value of short breaks** 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%)

Eligibility Criteria:

- The 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
- The 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
- 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

Service Development - Greater use of Universal Services

- 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).
- The majority of respondents (60%) did not agree with signposting children with lower level needs to universal services 24% agreed and 16% remained neutral.

Concerns included:

- Access to well trained and knowledgeable staff (74%)
- Attitudes of parents of mainstream children and teenagers (68%)
- Attitudes of mainstream children and teenagers (72%)
- Mixing children and teenagers of the same age but with different ability levels (54%)
- 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%)
- Intimate care (47%)

Service Sustainability

- 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%)
- Develop standards with partners including voluntary organisations to ensure that outcomes for children and teenagers are being achieved (56%)
- Help voluntary organisations to work together to share expertise and knowledge (59%)
- 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%)

Voluntary Organisations**Autism Beds - Summary**

- impact of being forced to reduce/remove services will **inflate demand for costly social care**

support directly from the council. Currently, Central Bedfordshire receives £135k worth of services annually for an SLA that costs £35k. The SLA **anchors our funding pot and attracts grants.**

- **£30k wasted annually on overnights not attended** and the tens of thousands that families tell us that they have in their accounts to spend on **direct payments, that go unspent due to lack of suitable choices**
- **diagnosis of autism legally entitles children to the level of support** described in the Central Bedfordshire Short Breaks Statement
- terminology without definition is extremely subjective
- proposing specialist Services would need to be withdrawn from:
 - Siblings of children with disabilities
 - Other children – i.e. children who do not meet the categories for the highest levels of need, but who may still meet a definition of disability under the terms of the Equality Act 2010 and the Children Act 1989
- By limiting targeted services to those already in receipt of social care support, the council is effectively **'blocking up the door'** to this group of disabled children
- council will be at risk legally of **not understanding the level of need** and therefore **not fully understanding if they are providing adequate or sufficient short breaks/support.**
- new threshold criteria for CWD will only be an effective tool to measure and assess need if the social worker is trained, experienced and competent
- over the last 7 years have trained thousands of staff from Central Bedfordshire's leisure centres, libraries, swimming pools and play schemes. Have encouraged and supported members to integrate. Parents, staff and Children say that **the barriers are being 'add on' group of people, that there is a lack of understanding, co-operation and empathy towards their needs and this dissuades members from continuing.**
- **Staff induction, training, supervision and appraisal** of working with/for children with disabilities would need expert care. Staff retention and turn over would need specialist training built into the common induction standards framework.
- this **may not work/breakdown, be underused;** how to monitor unmet need due to the inadequacies of the universal services and how to still meet the need.
- facilities design may need to be adjusted to risk of sensory overload and the council's recognition that these steps are seen as a **'hassle' for mainstream providers**

Families United Network - Summary

- Short break services **already represent excellent cost effectiveness** for the Council. Voluntary organisations secure funding from other sources in order to financially maintain their services for Central Bedfordshire families. This enables the local authority to fulfil its short break obligations at a much reduced cost.
- Goodwill of volunteers will be eroded
- Short breaks help keep families together, **not just surviving, being resilient and thriving**
- Legal duty to provide shortbreaks – what other options have been considered?
- Will there be sufficient services to meet need?
- Will CBC meet obligations to treat disabled children's best interests as primary consideration
- Will all children have social work assessment? Is there capacity for this?
- Lack of appropriate and effective support for 'lower and moderate need' families **can lead to these families becoming 'higher need'** and then requiring much greater levels of support
- **will mostly disadvantage the children with moderate needs and their families.** Their needs within an educational setting have been deemed significant enough to require an EHCP or Statement demonstrates that they have significant difficulties that inevitably will also be impacting on their family carers on a daily basis.
- cannot be assumed that if a child is able to manage within a mainstream school, then they are

able to manage within a universal leisure activity.

- **will require significant initial and ongoing investment** in staff training, and will need very effective communication between the provider, service users and the wider community
- **eligibility criteria do not take into account the caring capacity of the child's family members or other family environmental factors**
- **need plenty of notice** for service providers and families to make the transition successfully to personalised funding with a **clear plan and timeline**
- Families need a **clearly explained pathway on how and when to request an assessment** for short break services, and be given sufficient time to do this before any changes to their child's access to provision.
- Universal services need to be more flexible and able to deal with resistance from other families
- Who can families turn to if universal service doesn't meet their needs?
- Have universal services been consulted?
- Need better information sharing and collaborative decision making between organisations

Bedford and District Cerebral Palsy Society – Summary

- BDCPS provide a good service which is very cost effective for the Council in terms of what is being delivered. The full cost of the support is greater. The Council need to see this as a life line which supports some very complex children to stay living at home. The funding to BDCPS is a small amount compared with one overnight in a residential service of having to go out of area.
- the children who BDCPS are working with have specialist needs which make it difficult to manage in some environments
- The funding from the Council provides a platform from which other grants can be applied for. BDCPS require this if they are to continue to provide the support
- Given the right support in universal services– equipment, staff, this could provide some good opportunities for disabled children to access local services. This will require quite a shift in thinking
- They would have to build confidence with the parents by providing a safe place with well trained staff as the physical and learning needs of this group of children and young people make them vulnerable
- We would disseminate information and encourage families to engage in exploration of personalisation as a means of meeting their needs if it is appropriate and supportive in their case.
- Fully funded we could continue to develop appropriate and meaningful services with good outcomes. Less funding threatens our existence as we could not ethically take on complex young people without safe staffing levels
- We would struggle as a very small core team working across all roles to produce good tender proposals that would compete with nationals or other charities that have personnel with specific tender and funding roles.
- Provide adequate funding to support the voluntary sector to provide services that meet the needs of families and avoid costly long term need and family break down. Think long term benefit for the council as well as for the families. A residential place costs approx. 6 times a year more than the funding that each charity has been receiving on an SLA.

Additional Information

- large increase in users over the 8 year period, the figures have almost doubled, primarily due to an increase in the service coverage
- documented increase in the numbers of young people with disabilities and a recognition that

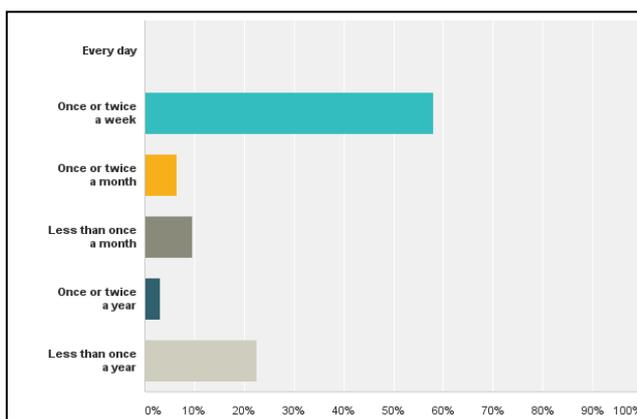
these are becoming more complex. Category 5, is highest level of need of support

Category of Need - No. of young people using BDCPS	2009	2017
1	12	19
2	3	9
3	19	16
4	3	17
5	0	6

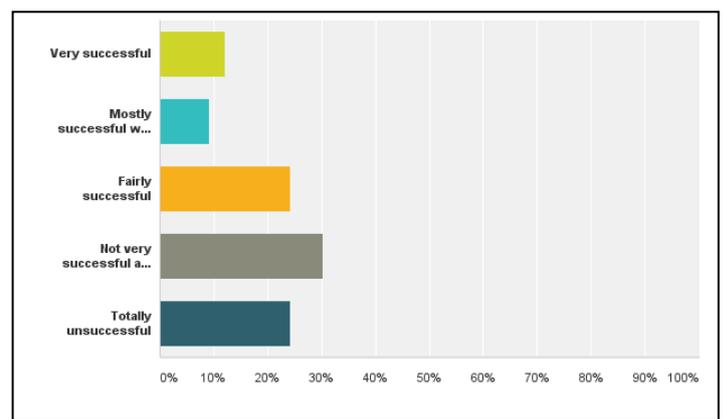
- currently train staff to meet the needs of young people for emergency rescue medication for epilepsy, oxygen, suctioning, gastro feeding, feeding difficulties, administration of regular medication, manual handling for care needs, first aid, safeguarding and communication difficulties. In the process of aiming to secure tracheostomy care training.
- CBC funding has failed to keep track of the development of services, the increase in users and in the complex care needs of those users. Funding from another local authority for holiday childcare for the same period has increased in line with needs and demand for the service
- Less funding threatens our existence as we could not ethically take on complex young people without safe staffing levels.
- Quantitative data does not help us as our numbers will never be large due to the complex needs of many of the young people using our services. Would like to see a model that takes this kind of service cost and provision into account and appreciates the difficulty of producing effective and real data that demonstrates the outcomes. Would like to see more interaction in terms of observation of outcomes at service provision levels.
- Provide adequate funding to support the voluntary sector to provide services that meet the needs of families and avoid costly long term need and family break down. A residential place costs approx. 6 times a year more than the funding that each charity has been receiving on an SLA, with probably the same if not better in some cases outcomes.

SNAP Survey 2017 Summary

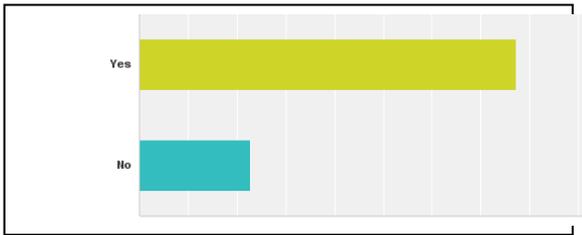
Attendance at mainstream activity?



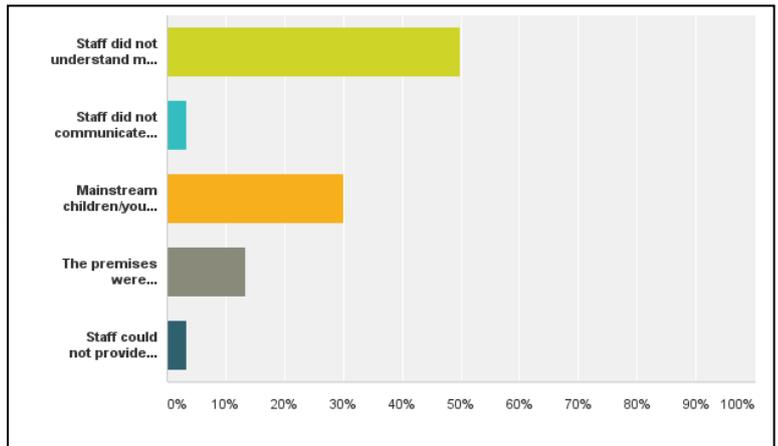
How successful were providers at supporting your child?



Difficulties

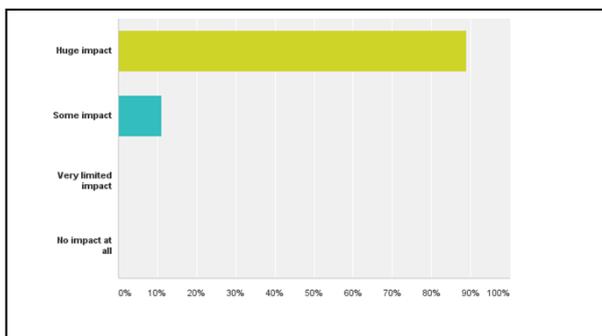


What was not good about service?

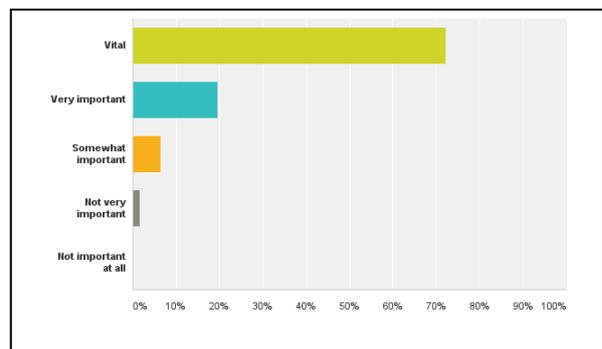


Answer Choices	Responses
Staff did not understand my child/young person's needs or know how to support them	50.00% 15
Staff did not communicate well with us as parents and generally did not ask for our views	3.33% 1
Mainstream children/young people and their parents did not understand my child and were not tolerant of their needs	30.00% 9
The premises were inappropriate for my child's needs and did not provide the right environment/facilities	13.33% 4
Staff could not provide intimate care	3.33% 1
Total	30

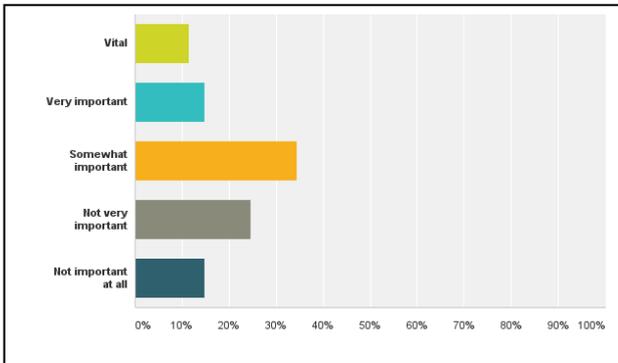
Impact if clubs not available?



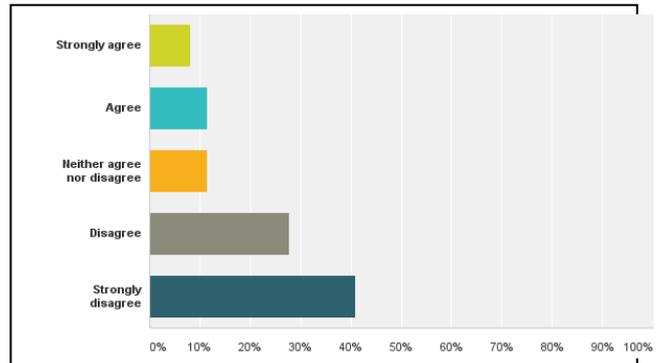
How important is it to access specialist clubs?



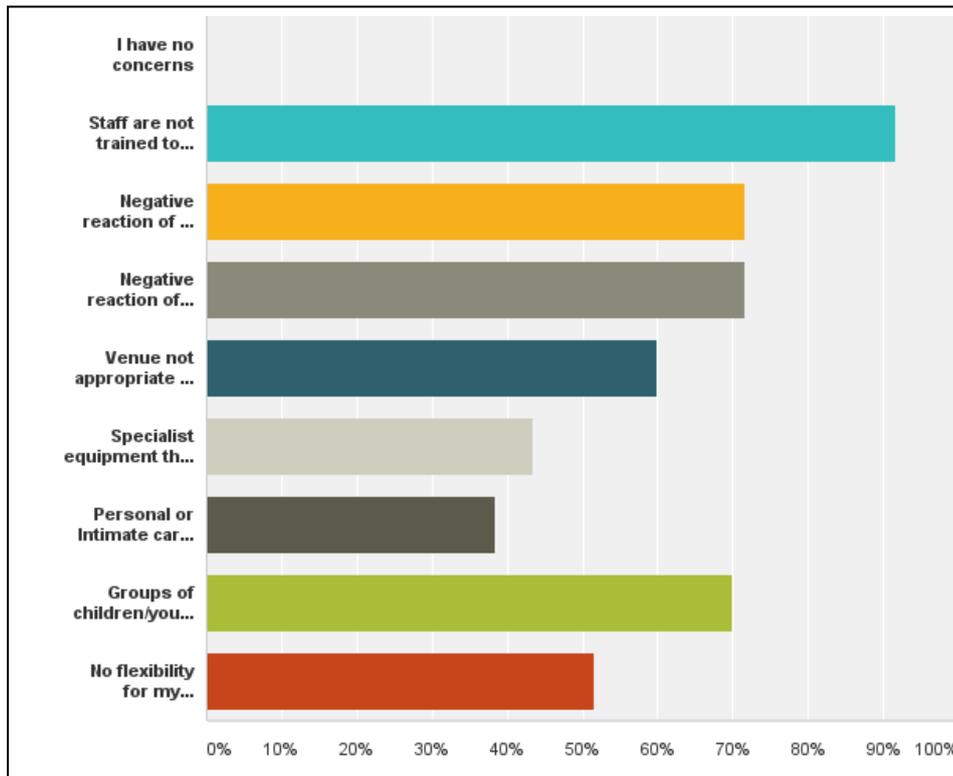
How important to access mainstream?



Signposting less complex needs to mainstream?



Concerns about accessing mainstream clubs



Answer Choices	Responses
I have no concerns	0.00% 0
Staff are not trained to support my child/young person appropriately	91.67% 55
Negative reaction of the other typical children/young people	71.67% 43
Negative reaction of parents of the typical children/young people	71.67% 43
Venue not appropriate to meet my child/young person's needs	60.00% 36
Specialist equipment that my child/young person needs is not available	43.33% 26
Personal or Intimate care is not provided	38.33% 23
Groups of children/young people are too large for my child/young person	70.00% 42
No flexibility for my child/young person to attend with children outside their own age group	51.67% 31
Total Respondents: 60	

<p>2.6. Are there any gaps in data or consultation findings? Non identified</p>
<p>2.7. What action will be taken to obtain this information? Not applicable</p>

Stage 3 - Providing an overview of impacts and potential discrimination.

Stage 3 – Assessing Positive & Negative Impacts					
Analysis of Impacts	Impact		Discrimination		Summary of impacts and reasons
	+ve	- ve	YES	NO	
3.1 Age	/	/	/	/	
3.2 Disability	√	√	?	?	<ul style="list-style-type: none"> • Eligibility criteria requires further clarification and details about how different needs will be met • Proposing specialist services would need to be withdrawn from children who do not meet the categories for the highest levels of need, but who may still meet a definition of disability under the terms of the Equality Act 2010 and the Children Act 1989 • Numbers of disabled children are increasing and becoming more complex • Short breaks help keep families together, not just surviving, being resilient and thriving • 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%). • ensure there is adequate provision in the local area to reduce travelling time • Lack of appropriate and effective support for 'lower and moderate need' families can lead to these families becoming 'higher need' and then requiring much greater levels of support • Voluntary Sector groups are highly valued for their expertise and support • The SLA anchors the funding pot for voluntary organisations and helps to attract grants. • Universal services need to be more flexible and able to deal with resistance from other families

					<ul style="list-style-type: none"> the barriers are being ‘add on’ group of people, that there is a lack of understanding, co-operation and empathy towards their needs and this dissuades members from continuing. Staff induction, training, supervision and appraisal of working with/for children with disabilities would need expert care. 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). will need very effective communication between the provider, service users and the wider community eligibility criteria do not take into account the caring capacity of the child’s family members or other family environmental factors need plenty of notice for service providers and families to make the transition successfully to personalised funding with a clear plan and timeline
3.3 Carers	√	√	/	/	<ul style="list-style-type: none"> 72% of parents / carers experience mental ill health such as anxiety, depression or breakdown due to isolation Value of short breaks: Rest (65%), family participation (46%), friendships (44%) and continuity (41%) Paragraph 6(1)(c) of Schedule 2 of the Children Act 1989 requires Local Authorities to provide services to assist carers of disabled children that will give them breaks from caring for a disabled child.
3.4 Gender Re - assignment	/	/	/	/	
3.5 Pregnancy & Maternity	/	/	/	/	
3.6 Race	/	/	/	/	
3.7 Religion / Belief	/	/	/	/	
3.8 Sex	/	/	/	/	
3.9 Sexual Orientation	/	/	/	/	
3.10 Other e.g. Human Rights, Poverty / Social Class /					<p>Article 3 The child’s best interests must be a top priority whenever anything is done that affects children.</p> <p>Article 23 Every disabled child has the right</p>

<p><i>Deprivation, Looked After Children, Offenders, Cohesion Marriage and Civil Partnership</i></p>					<p>to a full life and to active participation in the community. Article 31 Every child has the right to rest, play and leisure Disabled people are a particularly vulnerable group in society and need additional support. A disproportionate number of families with disabled children live in poverty</p>
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Stage 4 - Identifying mitigating actions that can be taken to address adverse impacts.

<p>Stage 4 – Conclusions, Recommendations and Action Planning</p>			
<p>4.1 What are the main conclusions and recommendations from the assessment? Consideration of research and consultation findings indicates that disabled children and their families are, by definition, a vulnerable group and can experience challenging circumstances. The proposal may have the potential to impact adversely on children who meet the Equality and Children Act definitions of disability (and their families), but who do not meet the thresholds for diagnosed profound or severe impairment. Further consideration needs to be given as to the extent to which these families receive services on a:</p> <ul style="list-style-type: none"> • discretionary basis under section 17 or section 20(4) of the Children Act 1989) or • statutory basis under section 20(1) of the 1989 Act and section 2 of the Chronically Sick and Disabled Person’s Act 1970 or the Breaks for Carers of Disabled Children Regulations) <p>The support and expertise provided by the voluntary sector is highly valued by families, providing opportunities for rest and family participation, whilst enabling children and young people to enjoy themselves and develop. Although there is a desire for services to be provided closer to home there is a concern, based on previous experiences, that Universal Services are not currently able to meet the needs of disabled children. There is a desire for specialist services to be protected and for the Council to also take account of the needs of children with lower levels of need in order to ensure that crisis is avoided and families are able to continue providing care at home. Many families have indicated that the voluntary sector could have an important role to play in helping to ensure that if changes are made that provision at universal service locations is delivered in an appropriate way. The need to ensure sufficient time to plan and deliver such changes has also been highlighted.</p>			
<p>4.2 What changes will be made to address or mitigate any adverse impacts that have been identified? Consideration will be given to whether the proposed changes could be implemented over a longer timescale with the ongoing involvement of the voluntary sector.</p>			
<p>4.3 Are there any budgetary implications? The proposed budget efficiencies may not be attainable in the current financial year.</p>			
<p>4.4 Actions to be taken to mitigate against any adverse impacts:</p>			
<p>Action</p>	<p>Lead Officer</p>	<p>Date</p>	<p>Priority</p>
<p>Develop service plan proposal including analysis of need and clear pathways to appropriate services</p>	<p>Ken Harvey</p>	<p>Ongoing</p>	<p>High</p>

Central Bedfordshire Council Equality Impact Assessment

Review timescales for completion	Ken Harvey	Ongoing	High
Review eligibility criteria with reference to consultation	Ken Harvey	Ongoing	High

Stage 5 - Checking that all the relevant issues and mitigating actions have been identified

Stage 5 – Quality Assurance & Scrutiny: Checking that all the relevant issues have been identified
5.1 What methods have been used to gain feedback on the main issues raised in the assessment?
Step 1:
Has the Corporate Policy Advisor (Equality & Diversity) reviewed this assessment and provided feedback? Yes
Summary of CPA’s comments:
The CPA (E&D) has been fully involved in the development of the EIA.
Step 2:
5.2 Feedback from Central Bedfordshire Equality Forum - 16 June 2016
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:
<ul style="list-style-type: none"> • 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.

Stage 6 - Ensuring that the actual impact of proposals are monitored over time.

Stage 6 – Monitoring Future Impact
6.1 How will implementation of the actions be monitored?
6.2 What sort of data will be collected and how often will it be analysed?
6.3 How often will the proposal be reviewed?
6.4 Who will be responsible for this?
6.5 How have the actions from this assessment been incorporated into the proposal?

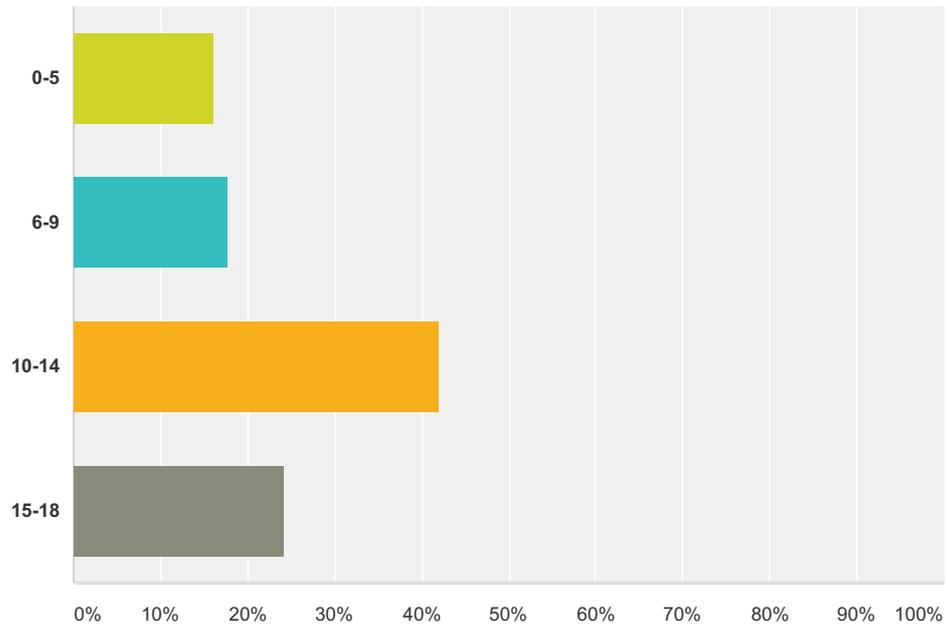
Stage 7 - Finalising the assessment.

Stage 7 – Accountability / Signing Off
7.1 Has the lead Assistant Director/Head of Service been notified of the outcome of the assessment
Name: _____ Date: _____
7.2 Has the Corporate Policy Adviser Equality & Diversity provided confirmation that the Assessment is complete?
Date: _____

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Q1 How old is your child?

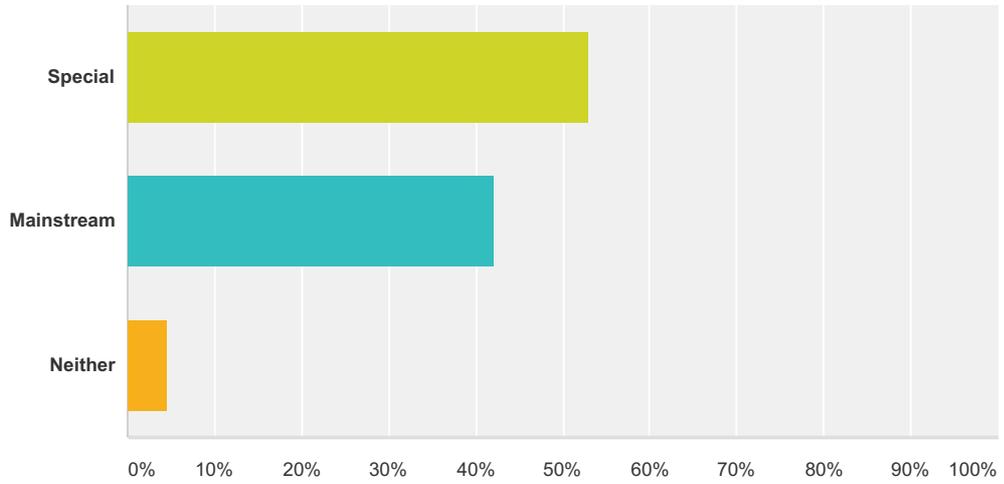
Answered: 62 Skipped: 2



Answer Choices	Responses
0-5	16.13% 10
6-9	17.74% 11
10-14	41.94% 26
15-18	24.19% 15
Total	62

Q2 Does your child attend a mainstream or a special school/college?

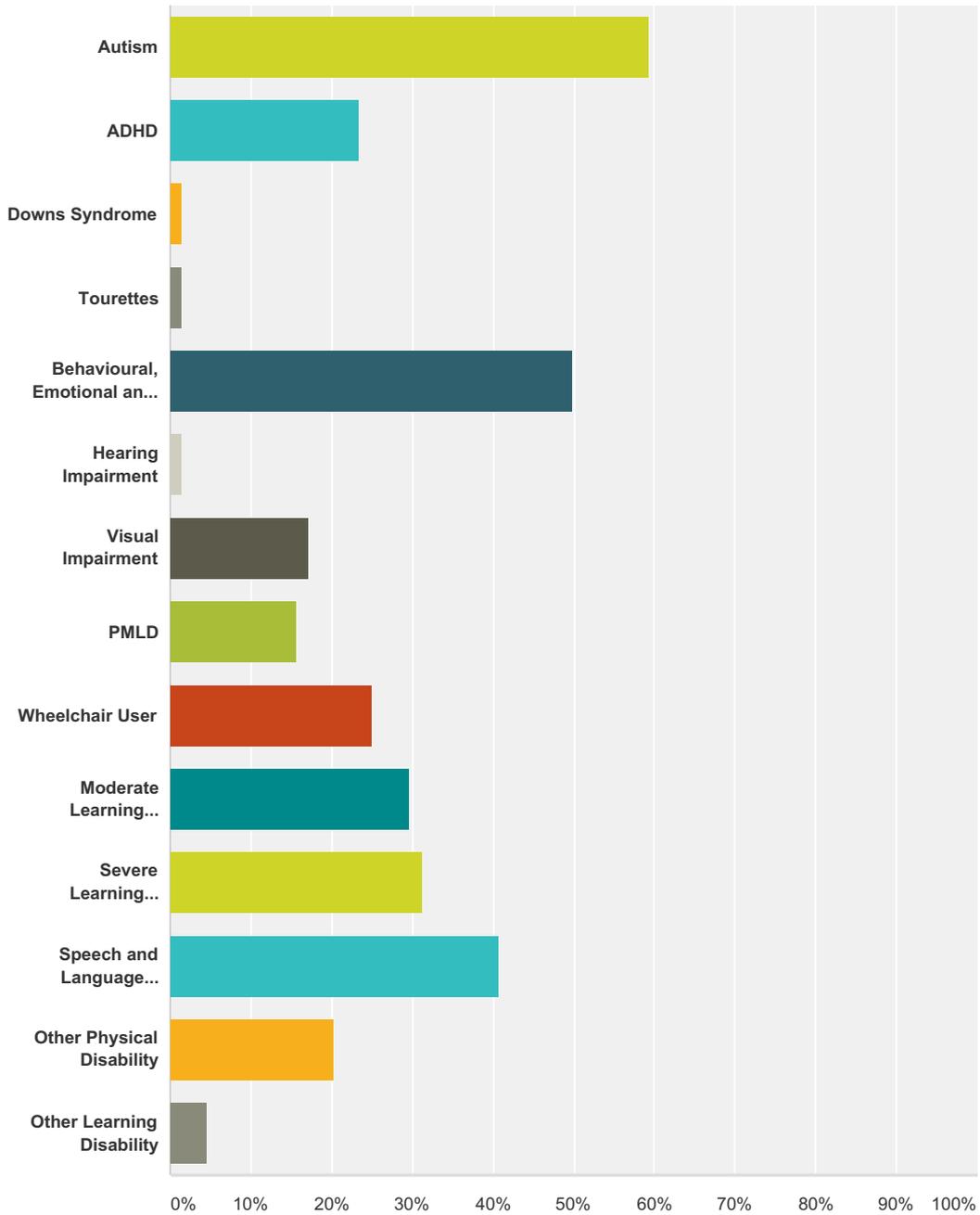
Answered: 64 Skipped: 0



Answer Choices	Responses
Special	53.13% 34
Mainstream	42.19% 27
Neither	4.69% 3
Total	64

Q3 What are your child/young person's primary additional needs or disabilities (please tick all that apply)?

Answered: 64 Skipped: 0

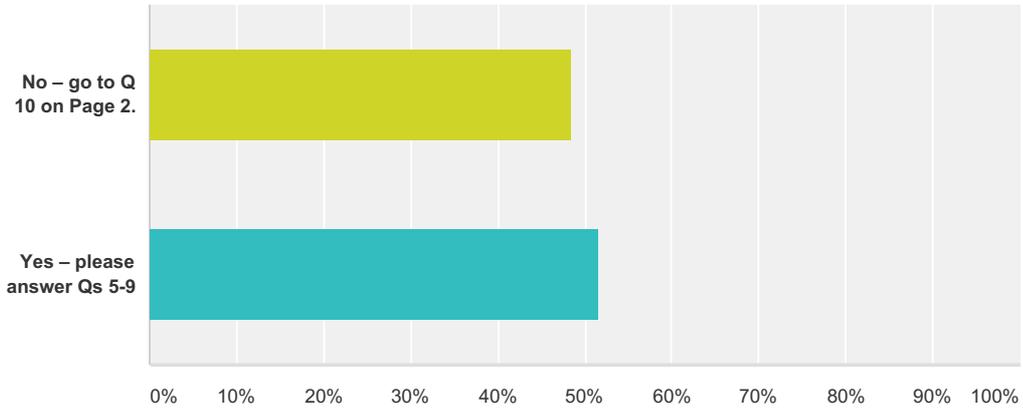


Answer Choices	Responses
Autism	59.38% 38
ADHD	23.44% 15
Downs Syndrome	1.56% 1
Tourettes	1.56% 1
Behavioural, Emotional and Social Difficulties	50.00% 32

Hearing Impairment	1.56%	1
Visual Impairment	17.19%	11
PMLD	15.63%	10
Wheelchair User	25.00%	16
Moderate Learning Difficulties	29.69%	19
Severe Learning Difficulties	31.25%	20
Speech and Language Delay/Difficulties	40.63%	26
Other Physical Disability	20.31%	13
Other Learning Disability	4.69%	3
Total Respondents: 64		

Q4 Has your child/young person ever attended any mainstream clubs or activities that are open to all children or young people, e.g. swimming clubs, scouts or guides, youth clubs, after school clubs, sports activities etc. ?

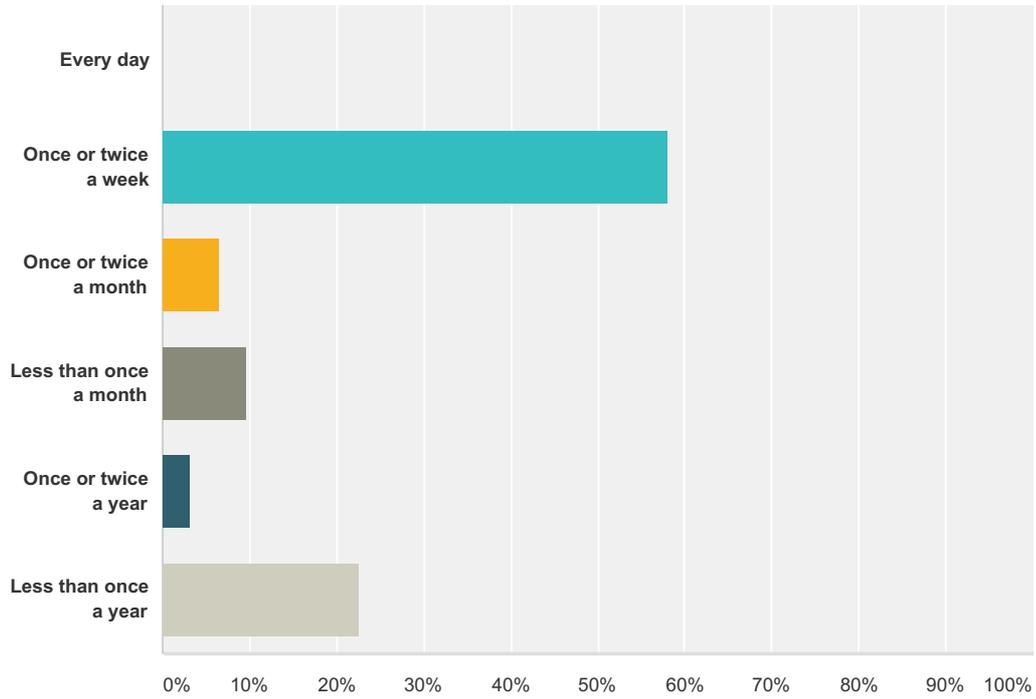
Answered: 64 Skipped: 0



Answer Choices	Responses	
No – go to Q 10 on Page 2.	48.44%	31
Yes – please answer Qs 5-9	51.56%	33
Total		64

Q5 How often does your child/young person attend a mainstream club or activity?

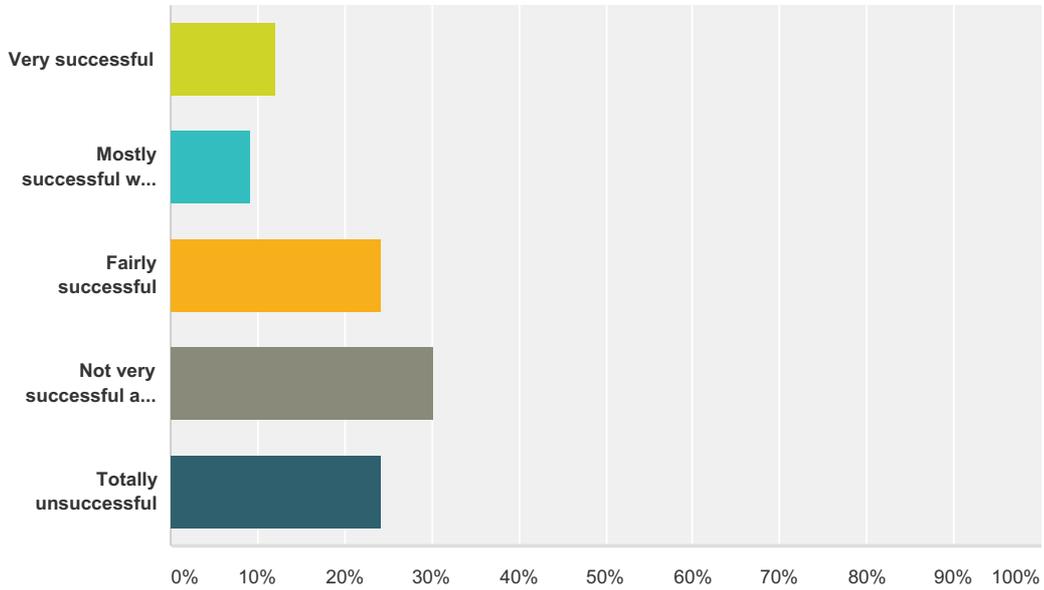
Answered: 31 Skipped: 33



Answer Choices	Responses	
Every day	0.00%	0
Once or twice a week	58.06%	18
Once or twice a month	6.45%	2
Less than once a month	9.68%	3
Once or twice a year	3.23%	1
Less than once a year	22.58%	7
Total		31

Q6 As a whole, how successful were the providers of these clubs and activities at supporting and integrating your child/young person into their service?

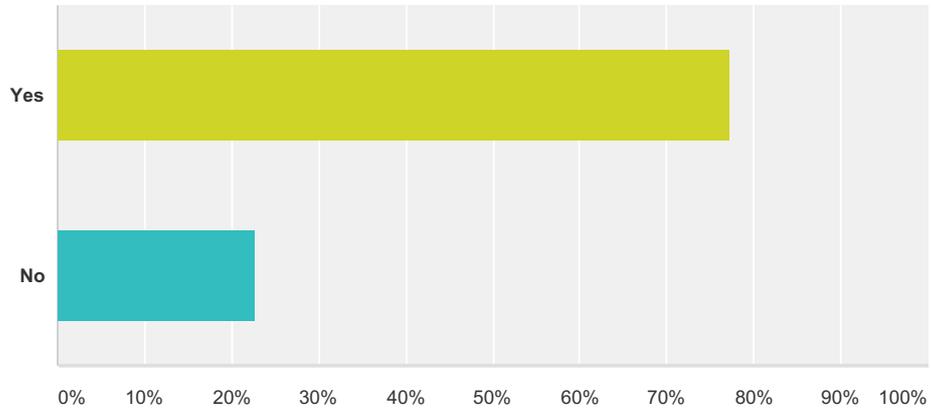
Answered: 33 Skipped: 31



Answer Choices	Responses
Very successful	12.12% 4
Mostly successful with a few minor exceptions	9.09% 3
Fairly successful	24.24% 8
Not very successful at all	30.30% 10
Totally unsuccessful	24.24% 8
Total	33

Q7 Have there been any difficulties that you or your child/young person have encountered when trying to access mainstream clubs or activities?

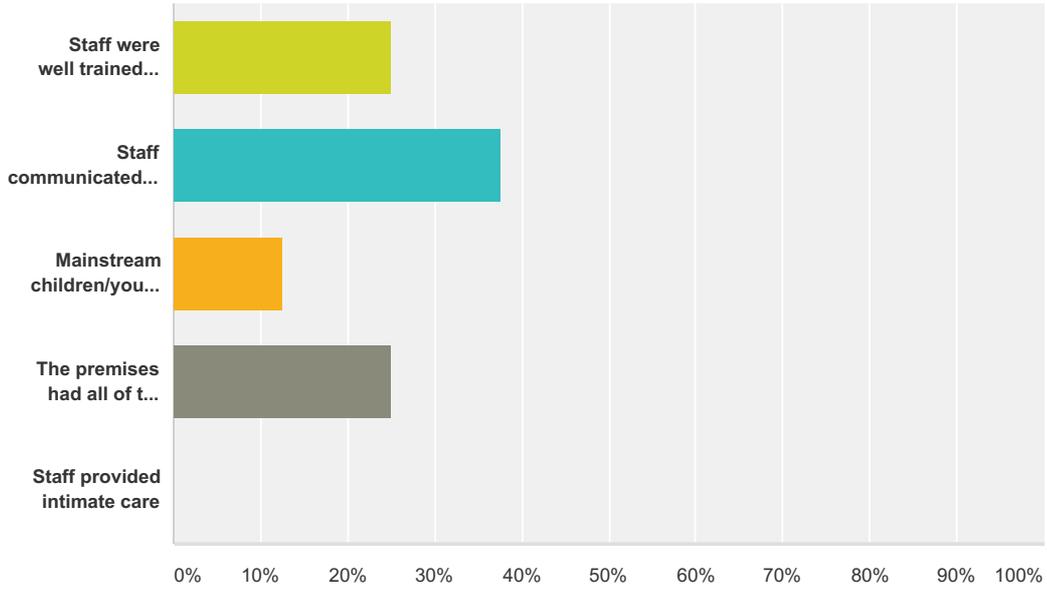
Answered: 35 Skipped: 29



Answer Choices	Responses
Yes	77.14% 27
No	22.86% 8
Total	35

Q8 What was good about the service?

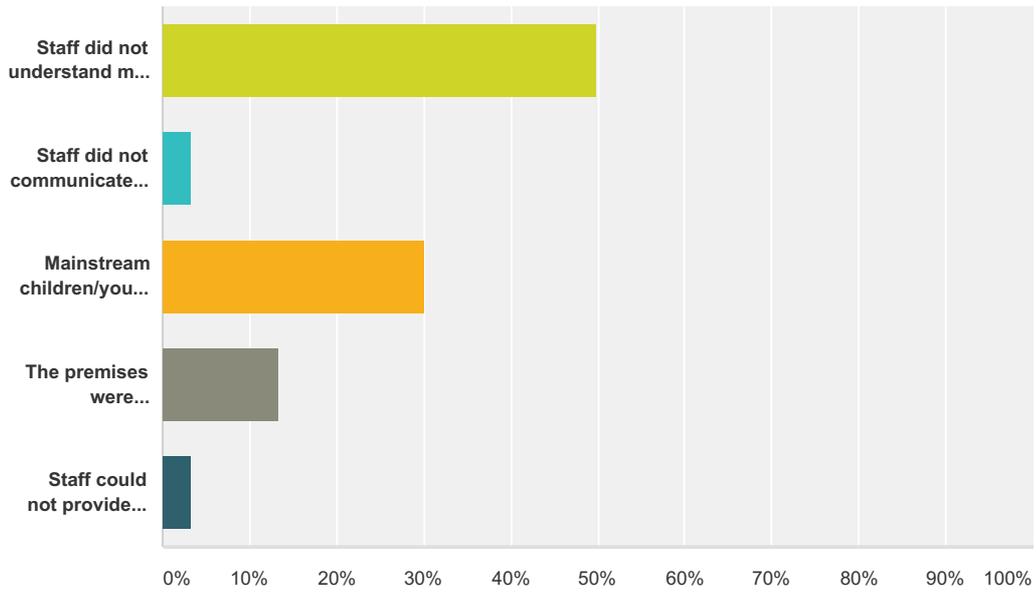
Answered: 16 Skipped: 48



Answer Choices	Responses
Staff were well trained and knowledgeable about my child/young person's needs and supported them well	25.00% 4
Staff communicated well with us as parents and we worked in partnership	37.50% 6
Mainstream children/young people and their parents were patient and understanding about my child's needs	12.50% 2
The premises had all of the features and resources it needed to meet my child's needs (e.g. security, changing facilities, parking etc.)	25.00% 4
Staff provided intimate care	0.00% 0
Total	16

Q9 What was not good about the service?

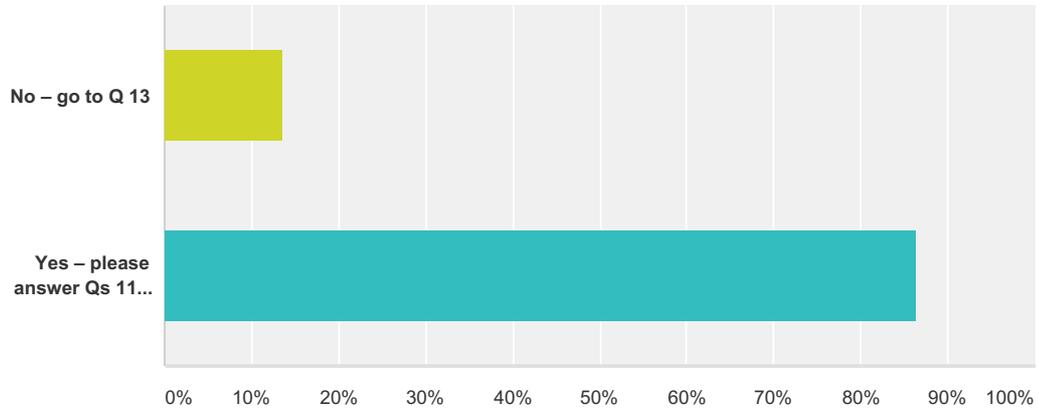
Answered: 30 Skipped: 34



Answer Choices	Responses
Staff did not understand my child/young person's needs or know how to support them	50.00% 15
Staff did not communicate well with us as parents and generally did not ask for our views	3.33% 1
Mainstream children/young people and their parents did not understand my child and were not tolerant of their needs	30.00% 9
The premises were inappropriate for my child's needs and did not provide the right environment/facilities	13.33% 4
Staff could not provide intimate care	3.33% 1
Total	30

Q10 Does your child access any specialist clubs or activities designed specifically for those with additional needs or disabilities?

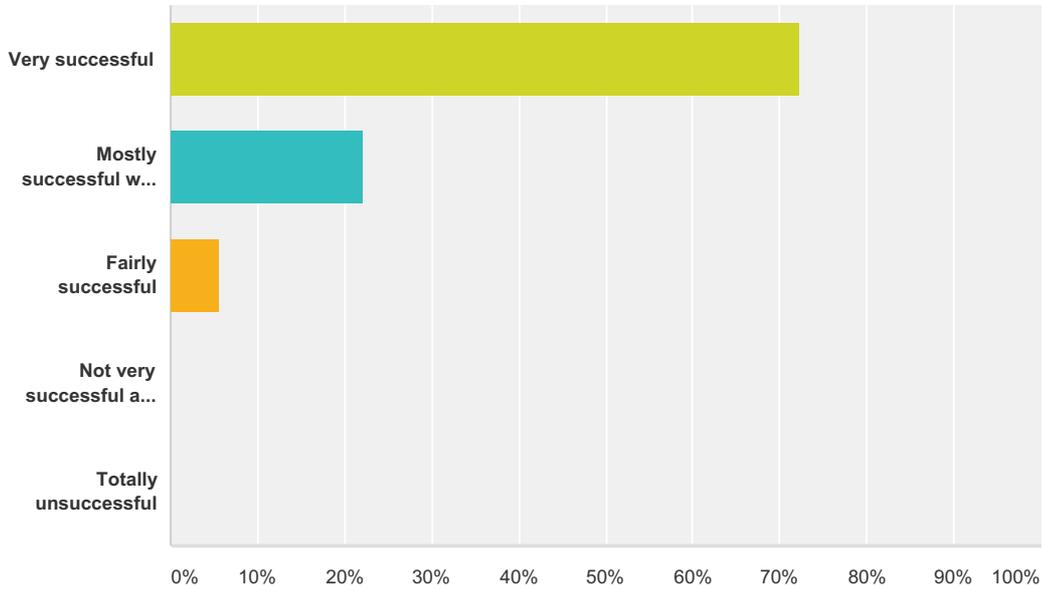
Answered: 59 Skipped: 5



Answer Choices	Responses	
No – go to Q 13	13.56%	8
Yes – please answer Qs 11 and 12	86.44%	51
Total		59

Q11 How successful were the providers of these specialist clubs and activities at supporting and meeting the needs of your child/young person?

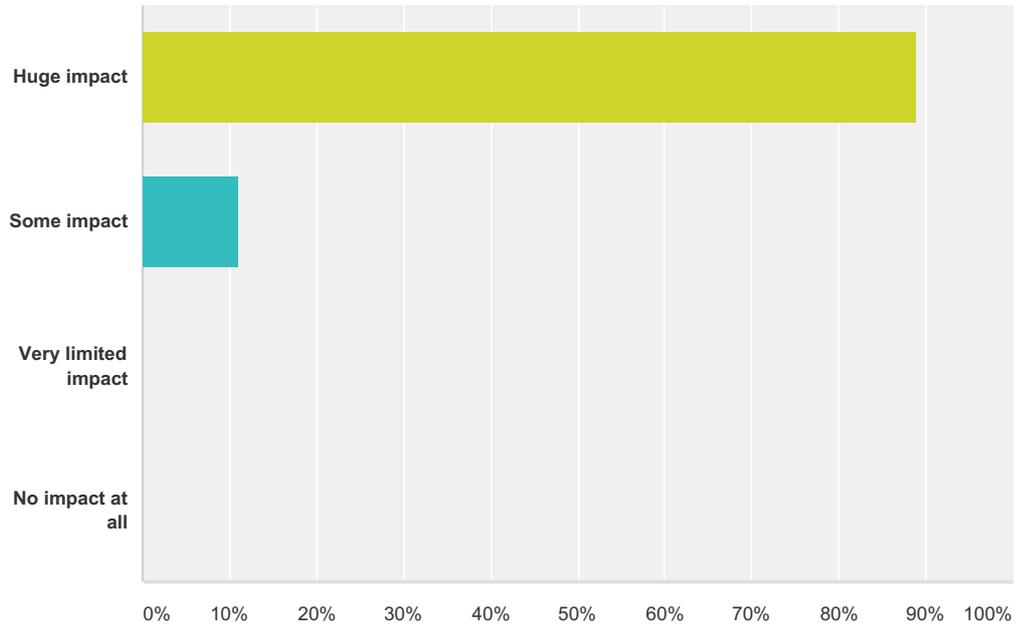
Answered: 54 Skipped: 10



Answer Choices	Responses
Very successful	72.22% 39
Mostly successful with a few minor exceptions	22.22% 12
Fairly successful	5.56% 3
Not very successful at all	0.00% 0
Totally unsuccessful	0.00% 0
Total	54

Q12 If these specialist clubs and activities were no longer available to your child/young person, what would the impact be on them and your family?

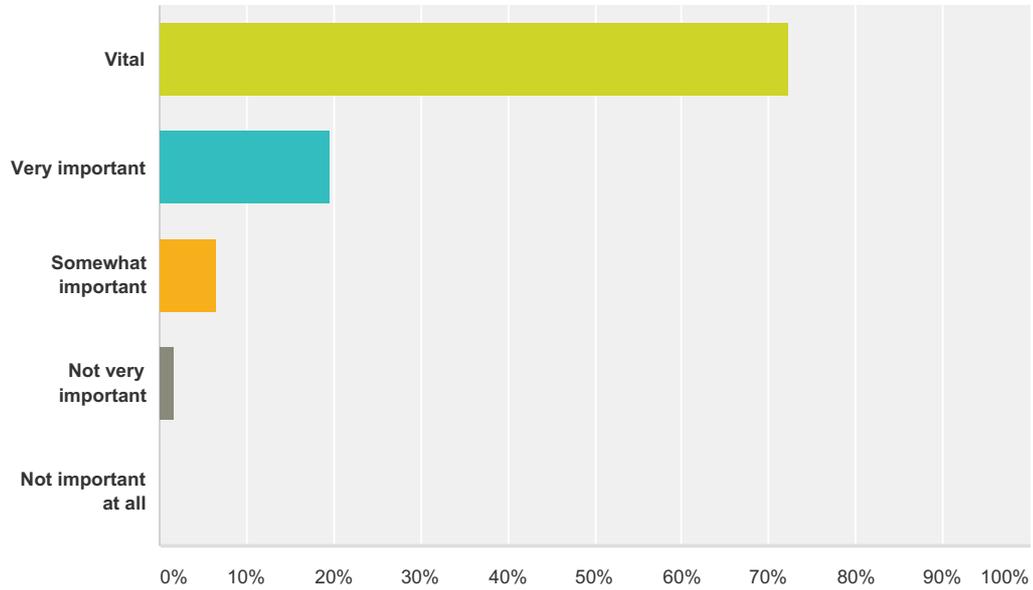
Answered: 54 Skipped: 10



Answer Choices	Responses
Huge impact	88.89% 48
Some impact	11.11% 6
Very limited impact	0.00% 0
No impact at all	0.00% 0
Total	54

Q13 How important is it to you that your child/young person is able to access clubs and activities that are specifically for those with additional needs or disabilities?

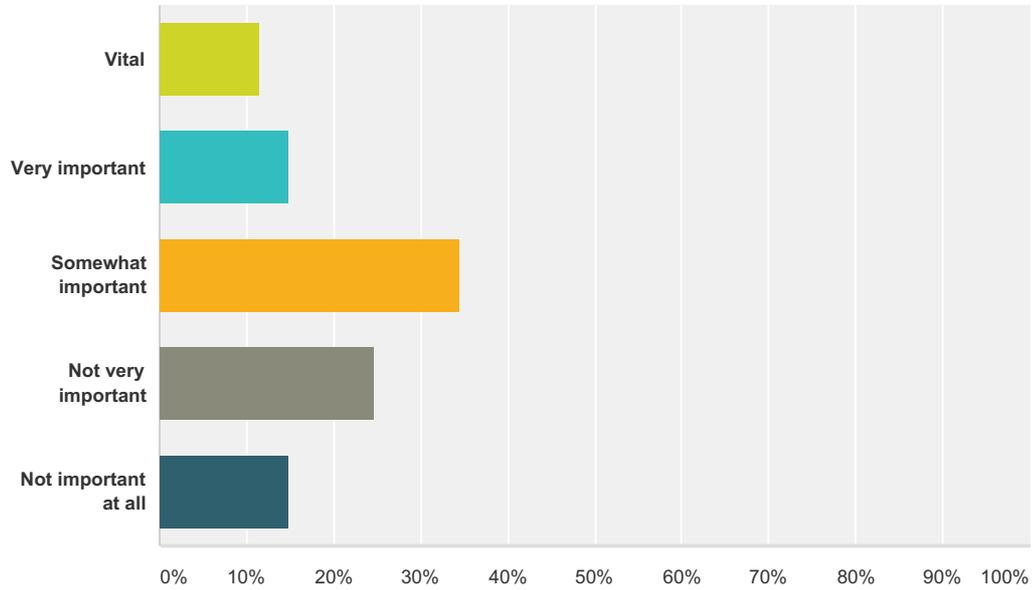
Answered: 61 Skipped: 3



Answer Choices	Responses
Vital	72.13% 44
Very important	19.67% 12
Somewhat important	6.56% 4
Not very important	1.64% 1
Not important at all	0.00% 0
Total	61

Q14 How important to you is it that your child/young person is able to be access mainstream clubs and activities alongside typical children/young people?

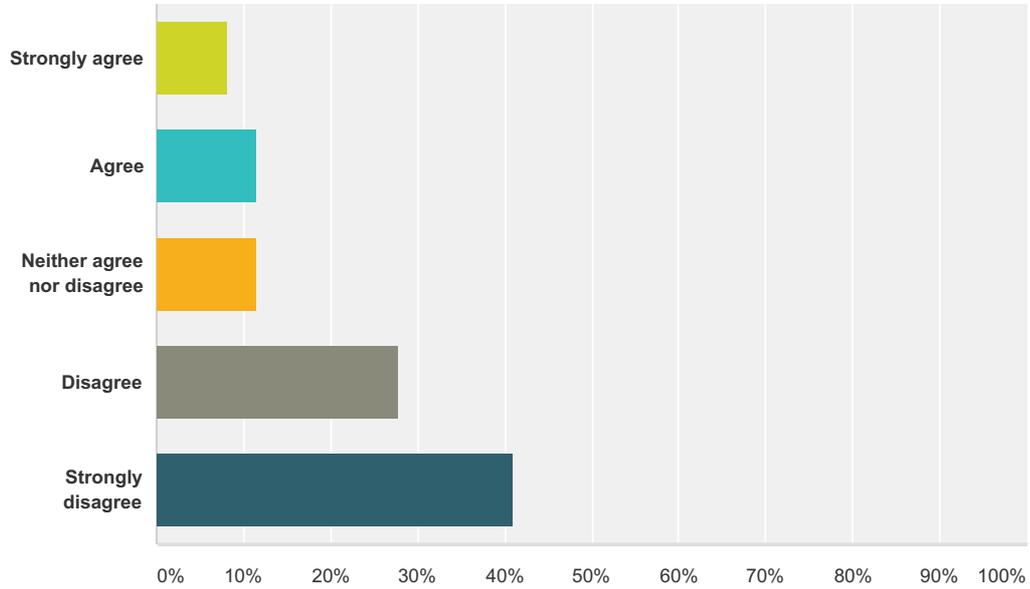
Answered: 61 Skipped: 3



Answer Choices	Responses
Vital	11.48% 7
Very important	14.75% 9
Somewhat important	34.43% 21
Not very important	24.59% 15
Not important at all	14.75% 9
Total	61

Q15 To what extent do you agree that children/young people with less complex additional needs or disabilities should be required to use mainstream clubs and activities, rather than specialist services?

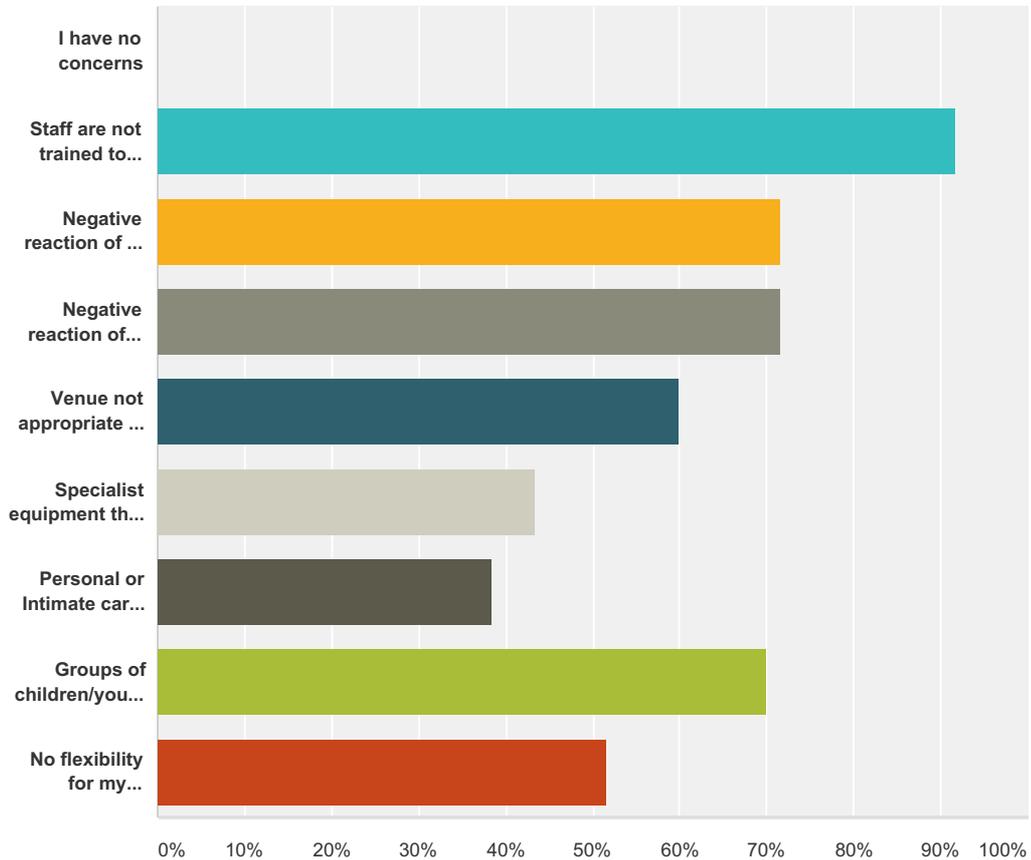
Answered: 61 Skipped: 3



Answer Choices	Responses
Strongly agree	8.20% 5
Agree	11.48% 7
Neither agree nor disagree	11.48% 7
Disagree	27.87% 17
Strongly disagree	40.98% 25
Total	61

Q16 What concerns, if any, do you have about children/young people with additional needs or disabilities being required to access mainstream clubs and activities alongside typical children/young people, instead of specialist services?

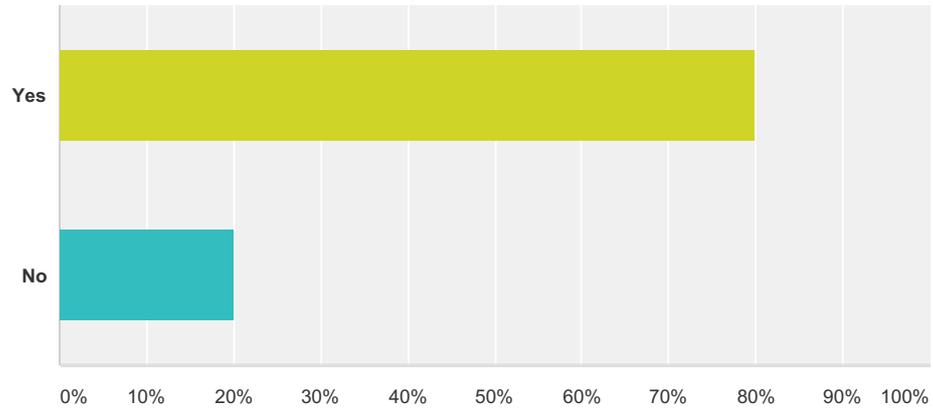
Answered: 60 Skipped: 4



Answer Choices	Responses
I have no concerns	0.00% 0
Staff are not trained to support my child/young person appropriately	91.67% 55
Negative reaction of the other typical children/young people	71.67% 43
Negative reaction of parents of the typical children/young people	71.67% 43
Venue not appropriate to meet my child/young person's needs	60.00% 36
Specialist equipment that my child/young person needs is not available	43.33% 26
Personal or Intimate care is not provided	38.33% 23
Groups of children/young people are too large for my child/young person	70.00% 42
No flexibility for my child/young person to attend with children outside their own age group	51.67% 31
Total Respondents: 60	

Q17 Are you aware of the Central Bedfordshire Council short breaks survey?

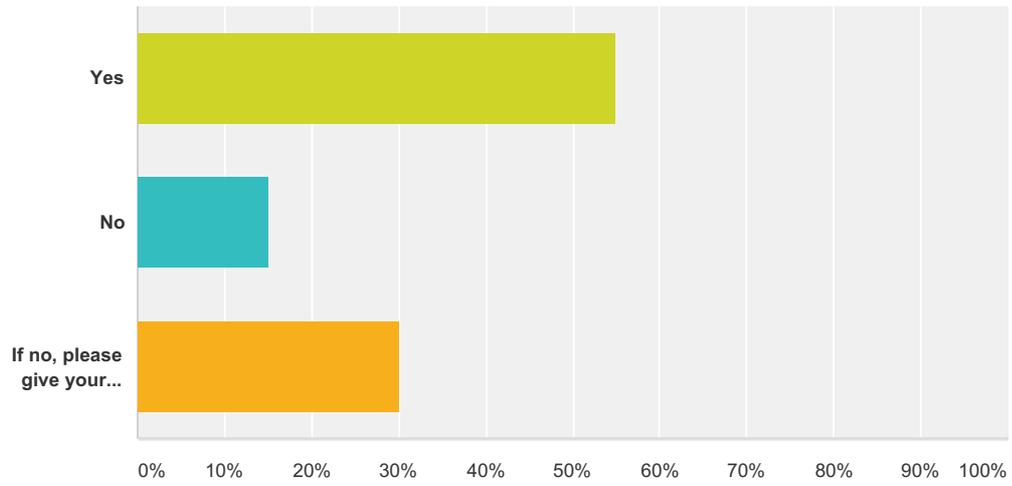
Answered: 60 Skipped: 4



Answer Choices	Responses	
Yes	80.00%	48
No	20.00%	12
Total		60

Q18 Did you complete it?

Answered: 60 Skipped: 4



Answer Choices	Responses	
Yes	55.00%	33
No	15.00%	9
If no, please give your reasons	30.00%	18
Total		60

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Threshold Criteria for CWD

	Meets Threshold for specialist Services		Need met through universal provision & Early Help	
Disability Category	Diagnosed Profound Impairment	Diagnosed Severe Impairment	Diagnosed Moderate Impairment	Diagnosed Mild Impairment
Learning	Has a Statement of Educational Needs. Attends a Special School for children with severe learning difficulties	Has a Statement of Educational Needs. Attends a Special School for children with severe learning disabilities or has a severe learning disability and attends a mainstream school receiving a minimum of 20 hours 1:1 support a week	Has a Statement of Educational Needs Attends a mainstream school with limited support.	Does not have a Statement of Educational Needs
Mobility	Unable to walk. Totally dependent on others for mobility. Wheelchair user.	Unable to walk without aids or assistance. Able to manoeuvre self some of the time. May be able to stand or transfer with support.	Able to walk, but occasionally requires aids or assistance.	Able to walk/move independently, but with some limitation of function. May have poor co-ordination of movement.
Gross & Fine Motor Skills	Unable to use hands for any purposeful movement.	Mostly unable to use hands to complete tasks effectively. Able to use switch systems	Considerable difficulties with control of hands. Requires some assistance to complete tasks.	Some difficulties with control of hand movement for precise work.
Health	Unable to take part in normal social and educational activities.	Frequent or daily interruption of normal tasks. Significant interference with development and / or learning.	Intermittent but regular limitations on ability to perform everyday tasks. The child's development or learning may be affected.	Known health condition, which is under control and only occasionally interfering with every day activities in a minor way.
Vision	Mobility restricted without special provision. Requires education by non-sighted method. Eligible for registration as blind.	Unable to read large print without assistance or aids. Severe visual field defect with impaired visual acuity. Eligible for registration as blind or partially sighted.	Able to read print with simple aids or assistance. Defect of at least half visual field. May be eligible for registration as partially sighted.	Severe or profound problem with one eye. Defect of less than half visual field. Able to function independently.
Hearing	Hearing loss over 95 dB.	Hearing loss between 71 - 95 dB.	Hearing loss between 41 - 79 dB	Severe or profound hearing loss in one ear. between 20 - 40 dB.

Threshold Criteria for CWD

INDICATORS	Meets Threshold for Specialist Services		Need met through Universal Provision & Early Help	
	Profound Impairment	Severe Impairment	Moderate Impairment	Mild Impairment
Communication	Unable to communicate needs by any method. Unable to use communication aids.	Limited or no verbal communication. Able to communicate basic needs without the use of language.	Delayed or disordered communication, including language disorders. Speech supplemented by another method of communication.	Mild delay of language development.
Personal Care	Total assistance required for bathing, dressing, toileting and eating.	Assistance required for bathing, dressing, toileting or eating.	Some supervision or assistance required for bathing, dressing, toileting or eating.	Occasional difficulties meeting own self-care needs.
Consciousness	Comatose. Intractable seizures, in frequent succession.	Regular seizures on a daily basis with significant impact on the child's learning or development.	Seizures day or night on a regular basis, usually once per week.	Occasional daytime seizure (up to one per month)
Behaviour & Social Integration	The challenging behaviours are impacting on all aspects of the child's functioning. The behaviours pose a significant risk to the safety of the child or others.	The challenging behaviours are impacting on key aspects of the child's functioning. Specialist provision is required for the child to function socially or within the family group.	The frequency or severity of the behaviours requires some specialist advice or provision.	Behaviours are occasionally difficult to manage. Special provision not required when managing the behaviour.
Safety and Supervision	Needs constant supervision both day and night. No ability to perceive danger to self or others.	Needs constant supervising during the day. Would place themselves or others at serious risk without supervision.	Requires supervision to perform daily tasks. Requires supervision significantly greater than that expected for children of the same age. Limited perception of danger to self or others.	On occasion, requires more supervision than other children of the same age.