



SNAP PARENT CARER FORUM
CENTRAL BEDFORDSHIRE

Short Breaks Survey Results

March 2017

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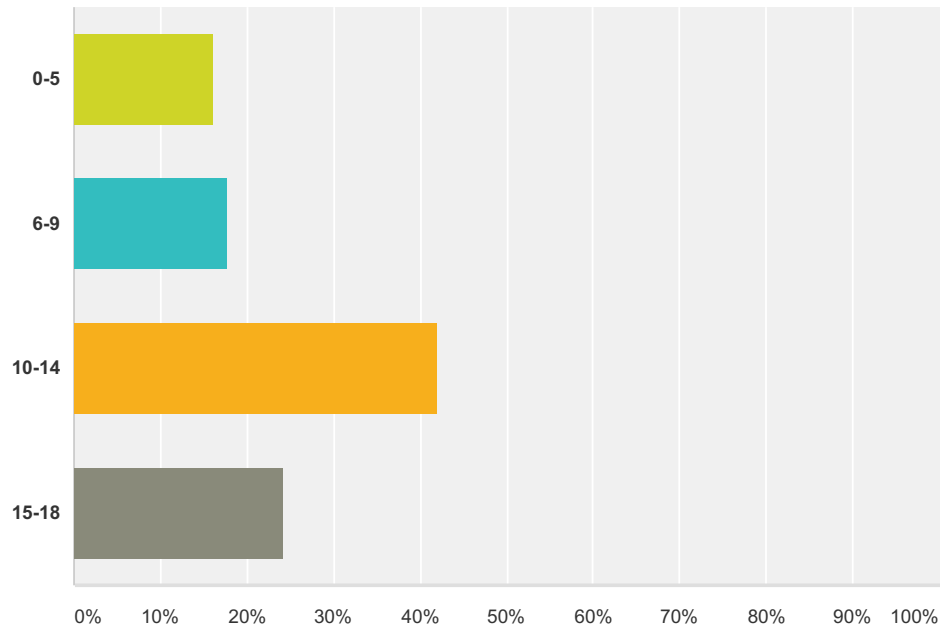
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Short Breaks Survey

Q1 How old is your child?

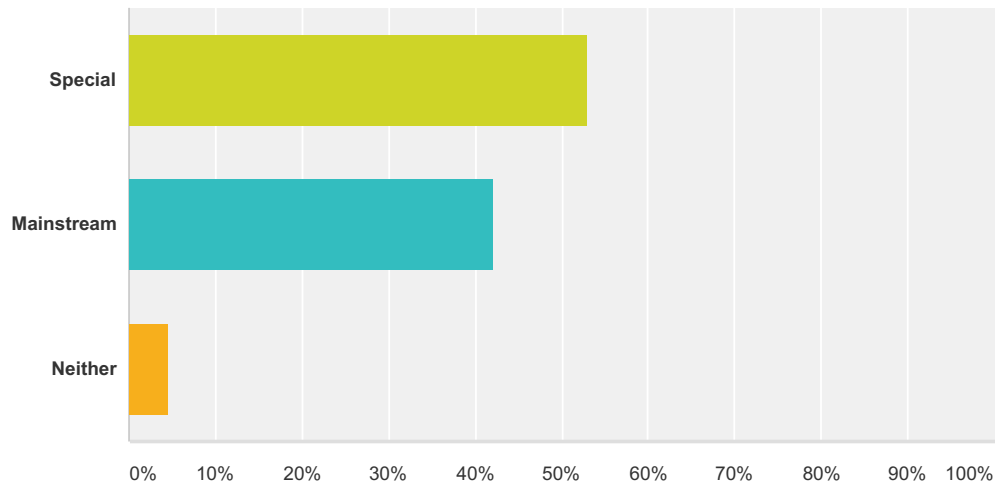
Answered: 62 Skipped: 2



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?

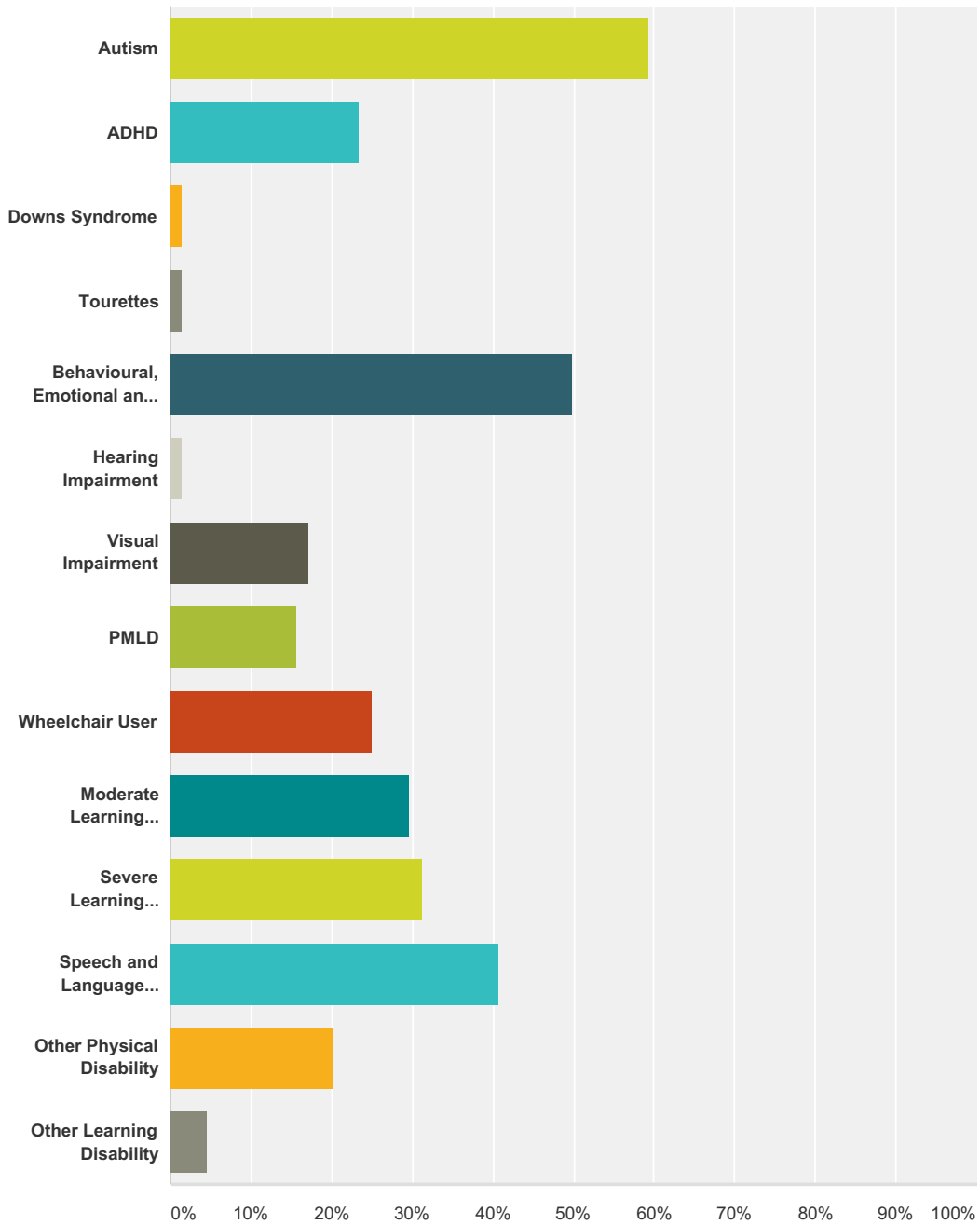
Answered: 64 Skipped: 0



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

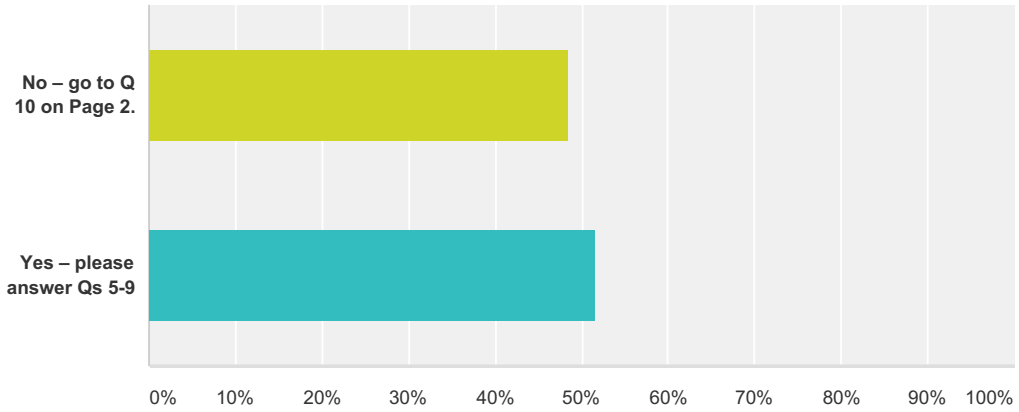
Short Breaks Survey

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		

#	Other (please specify)	Date
1	cerebral palsy	3/13/2017 6:44 PM
2	Severe sleep disorder OCD severe anxiety	3/2/2017 4:43 PM
3	Sensory processing disorder, joint hypermobility syndrome	2/28/2017 3:08 PM
4	Dyspraxia	2/23/2017 7:09 PM
5	Health needs	2/22/2017 10:28 AM
6	Pelizaeus-Merzbacher Disease	2/22/2017 9:57 AM
7	Cerebral palsy	2/21/2017 3:08 PM
8	Lacks confidence/self esteem	2/21/2017 2:50 PM
9	Sensory Processing Difficulties	2/21/2017 1:14 PM
10	epilepsy	2/20/2017 6:47 PM
11	Epilepsy and Dyspraxia	2/20/2017 5:34 PM
12	Cerebral Palsy	2/17/2017 9:48 PM
13	Epilepsy, genetic condition COL4A1, tube fed, ent problems	2/17/2017 8:49 PM

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. ?

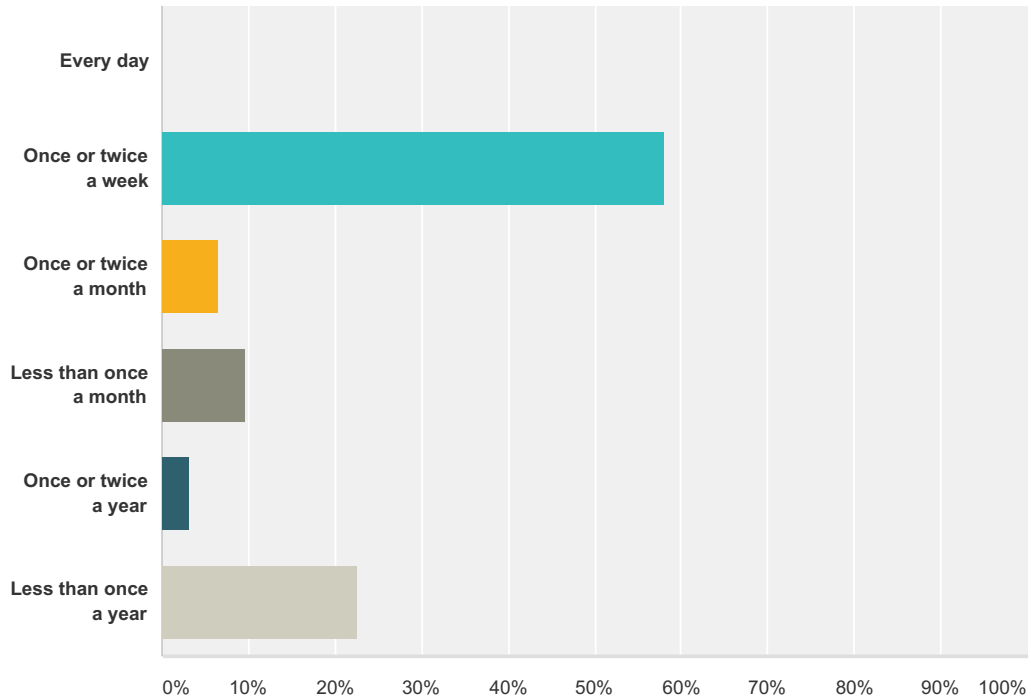
Answered: 64 Skipped: 0



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

#	Comment:	Date
1	Attended beavers when younger for a short period but found it very hard to cope.	3/13/2017 6:44 PM
2	Actually he never attends them. We have tried taking my son to all sorts of mainstream clubs and activities but he has been asked to leave all of them. The only such things he attends are the Wanted Fun and Summer Schemes run by Autism Beds and No Limitz	3/12/2017 9:40 PM
3	He has tried to attend in the past but has been unsuccessful. So much so that we have been asked to leave a number of clubs/lessons.	3/12/2017 5:41 PM
4	They quickly decide not to go as feeling different and treated differently	3/10/2017 1:34 PM
5	gymnastics, swimming occasionally, lesser degree of success	3/6/2017 12:57 PM
6	We have tried mainstream clubs but none have been successful	3/2/2017 4:43 PM
7	Cubs Swimming lessons Lunchtime clubs at school	2/23/2017 1:28 PM
8	He used to when very little but now not suitable. Swimming pool too cold, activities on offer not suitable even with parents	2/22/2017 9:57 AM

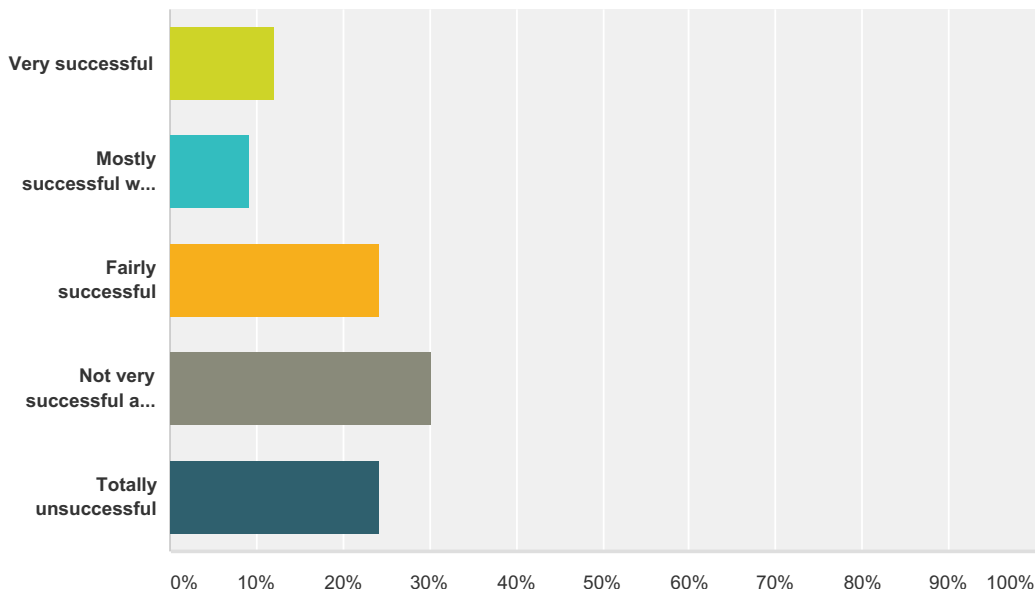
Short Breaks Survey

9	She did attend swimming but has now stoped The teacher was good with her but she didn't interact with any of the mainstream children	2/21/2017 3:23 PM
10	no longer goes as could not cater for her.	2/21/2017 2:50 PM

Short Breaks Survey

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

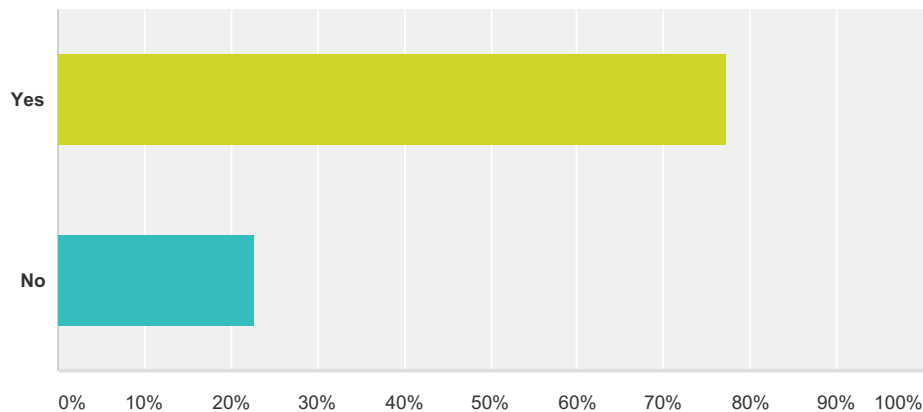
#	Comments:	Date
1	The leaders did try, but it was just not a suitable environment for him.	3/13/2017 6:44 PM
2	We have tried taking my son to all sorts of mainstream clubs and activities but he has been asked to leave all of them. Essentially the environment proved so stressful for him that his anxiety led to problems. The only such things he attends are the Wanted Fun and Summer Schemes run by Autism Beds and No Limits	3/12/2017 9:40 PM
3	They did not understand him or his needs. They could not give him the specialist attention he needed and meet the needs of the rest of the group with the staffing levels they had. He has 1:1 support in school and without this level of support could not access the services.	3/12/2017 5:41 PM
4	Being treated as odd not finding it easy to interact with others and ending up isolated	3/10/2017 1:34 PM
5	Could not understand my child's sensory issues with regard to the echo in the swimming pool and hearing the instructor. They thought he was not listening	3/8/2017 4:02 PM
6	Mixed, gymnastics much better	3/6/2017 12:57 PM
7	bullying, attitudes of adults and poor acceptance and understanding of different children or their needs. Children with autism don't cope well in bright, busy and noisy environments.	3/2/2017 4:43 PM
8	The only successful one was an after school club at Kempston outdoor centre, where the school staff provided a lot of extra support, advice, knowledge and practical help. There have been no appropriate after school clubs for years.	2/28/2017 3:08 PM
9	Quite fearful of him and unsure as to how to talk to him or try to integrate him.	2/22/2017 9:57 AM

Short Breaks Survey

10	Have answered this in lady question	2/21/2017 3:23 PM
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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

#	Please give details	Date
1	He could not cope with the environment, other child and families found his behaviour difficult and as a result we were asked to withdraw him and not attend in the future.	3/12/2017 9:40 PM
2	Wrong staffing ratios in group settings. So not enough staff to give the extra support needed. A lack of awareness of his needs so people unable to support him. Other parents complaining about his behaviour. Him being disruptive and spoiling things for other children. We have been asked not to attend again because he was not getting anything from the session and therefore we were wasting our money. We have been told he couldn't attend again due to his behaviour. We have tried: gym club at school, multi sports, piano lessons, violin group, Maths academy, swimming lessons and been turned away or given up at all of them. We have been humiliated, ostracised and felt unwelcome in many places.	3/12/2017 5:41 PM
3	They just refuse to go	3/10/2017 1:34 PM
4	Too many people to one instructor? Limited ability and lack of understanding to join sports activities	3/8/2017 4:02 PM
5	Joins clubs. Then he finds he does not fit in and leaves no longer trying.	3/7/2017 5:22 PM
6	Lack of understanding of autism. Not being informed of swimming teacher's absence, therefore a very distressed child who won't go to swimming lessons anymore.	3/6/2017 12:57 PM
7	Some don't want you, others treat you like you are invisible. Mostly the environment isn't typically for kids with sensory difficulties which causes emotional and behavioural problems	3/2/2017 4:43 PM
8	Staff not understanding they need carers, Staff not understanding physical needs. Not being able to provide suitable trained trampoline instructor, climbing instructor(they do exist elsewhere). Not providing bins for continence products in disabled changing rooms. Cold pools and cold changing rooms	2/28/2017 3:08 PM
9	Having an understanding of the difficulties of the child	2/23/2017 7:09 PM
10	My child's emotional difficulties, which has meant that my husband or I have attended to support him	2/23/2017 1:28 PM
11	No knowledge or understanding of autism/severe learning disability	2/22/2017 10:31 AM
12	Lifts not working, untrained staff, unsuitable for wheelchair users.	2/22/2017 9:57 AM
13	Lack of support meaning they are never able to stay in these activities for long periods	2/21/2017 11:04 PM
14	my child didn't know how to interact with the others and them with her	2/21/2017 3:23 PM

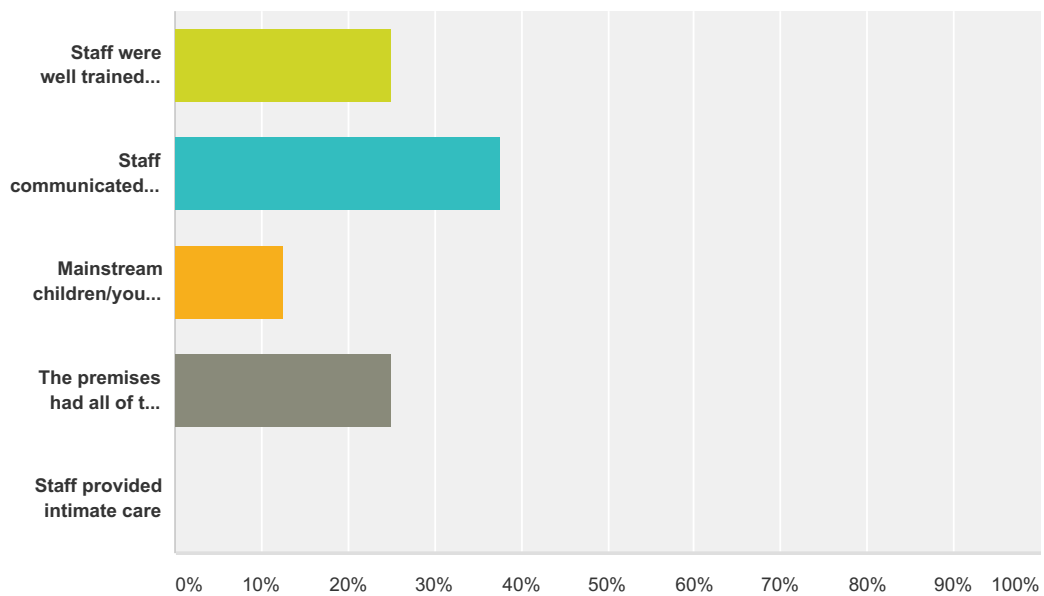
Short Breaks Survey

15	No suitable access to swimming pool	2/21/2017 3:08 PM
16	not been able to get one to one support	2/21/2017 2:50 PM
17	Swimming - over crowded classes makes it hard for my son. School football - my son gets frustrated very easily so I have to stay with him and encourage him	2/21/2017 1:14 PM
18	Not on the same mental level as other children that would be attending the club	2/21/2017 11:41 AM
19	Not understanding ASD and quirks asking you to stay to help	2/20/2017 10:41 PM
20	My daughter needs 1-1 care by somebody trained so no mainstream clubs could meet her needs	2/20/2017 7:24 PM
21	Communication. Not understanding games and activities so left the club	2/20/2017 6:21 PM
22	Lack of training for staff. Adverse reactions from the parents of the other children (the children themselves were fine).	2/20/2017 5:42 PM
23	He needs 1:1 support to access clubs especially scouts.	2/20/2017 5:34 PM
24	Sensory overload, not enough staff to give him the focus he needs to understand what is required from him. Other children pick on him and this leads to him feeling depressed.	2/20/2017 5:31 PM
25	Swimming. Had to have private lessons as he would have been at the level of a pre-schooler, aged 8. Stopped when progress stalled completely and he was no longer able to change in the ladies changing room with me.	2/20/2017 5:28 PM
26	Lack of understanding of their condition, lack if integration in to the group as a whole	2/19/2017 3:33 PM
27	Judged and not feeling welcome by other mums and feeling sorry for me.	2/17/2017 8:49 PM
28	Mainstream activity leaders are not aware of the restrictions and behaviour associated with my son's disability. His dad had to join for him to be able to attend.	2/13/2017 3:07 PM

Short Breaks Survey

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

#	Other (please specify)	Date
1	None of the above. The reverse in fact !	3/12/2017 1:40 PM
2	Non of the above. See answers to question 7. The only successful clubs/groups services accessed have been run by Autism Bedfordshire.	3/12/2017 9:41 AM
3	Nothing was good.Not suitable.	3/7/2017 9:22 AM
4	Also find mainstream parents both understanding and supportive.	3/6/2017 4:57 AM
5	Great changing facilities at Flitwick Leisure Centre but room often cold and main pool too cold. Finally getting better attitude to 2 carers accompanying my son.	2/28/2017 7:08 AM
6	I need to tick more than one of these..... Staff communicated well with us as parents and we worked in partnership Mainstream children/young people and their parents were patient and understanding about my child's needs	2/23/2017 5:28 AM
7	Cannot agree with any of the above.	2/22/2017 1:57 AM
8	also - Mainstream children/young people and their parents were patient and understanding about my child's needs	2/21/2017 7:12 AM
9	also want to pick - Mainstream children/young people and their parents were patient and understanding about my child's needs	2/21/2017 6:50 AM
10	The only good thing is he can access a club	2/20/2017 2:41 PM
11	Nothing	2/20/2017 10:21 AM
12	NA	2/20/2017 9:34 AM
13	Swimming instructor was helpful but unable to get him past a 5m swim on his front after 2 years of private lessons weekly.	2/20/2017 9:28 AM

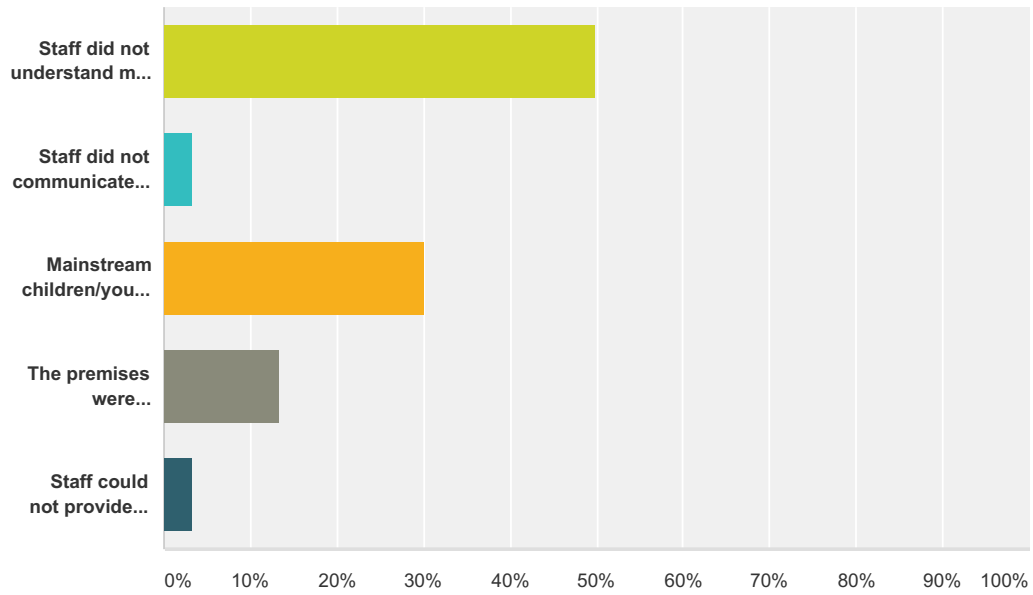
Short Breaks Survey

14	Staff very friendly and welcoming. Mum's not so much.	2/17/2017 12:49 PM
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Short Breaks Survey

Q9 What was not good about the service?

Answered: 30 Skipped: 34

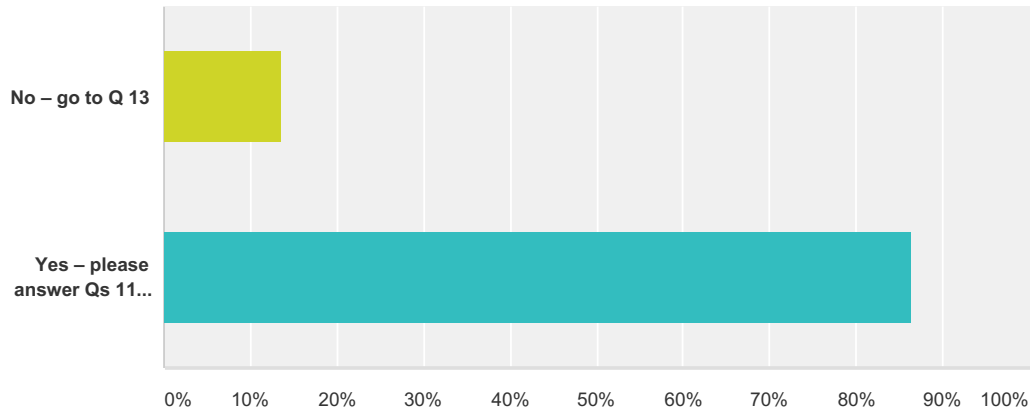


Answer Choices	Responses
Staff did not understand my child/young person's needs or know how to support them	50.00% 15
Staff did not communicate well with us as parents and generally did not ask for our views	3.33% 1
Mainstream children/young people and their parents did not understand my child and were 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

#	Comments:	Date
1	The first 4 answers all apply.	3/12/2017 9:40 PM
2	Staff ratios inappropriate. Other parents intolerant.	3/12/2017 5:41 PM
3	Other children bullied her which is an indication parents have not offered education to the children	3/10/2017 1:34 PM
4	Most of the above	3/2/2017 4:43 PM
5	also Staff did not communicate well with us as parents and generally did not ask for our views, The premises were inappropriate for my child's needs and did not provide the right environment/facilities and Staff could not provide intimate care	2/28/2017 3:08 PM
6	However, staff have been willing to learn how to help our child, and have made efforts to be inclusive and encourage his independence	2/23/2017 1:28 PM
7	Also want to pick - Staff did not communicate well with us as parents and generally did not ask for our views Mainstream children/young people and their parents did not understand my child and were not tolerant of their needs Staff could not provide intimate care	2/22/2017 10:31 AM
8	All of the above	2/22/2017 9:57 AM

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

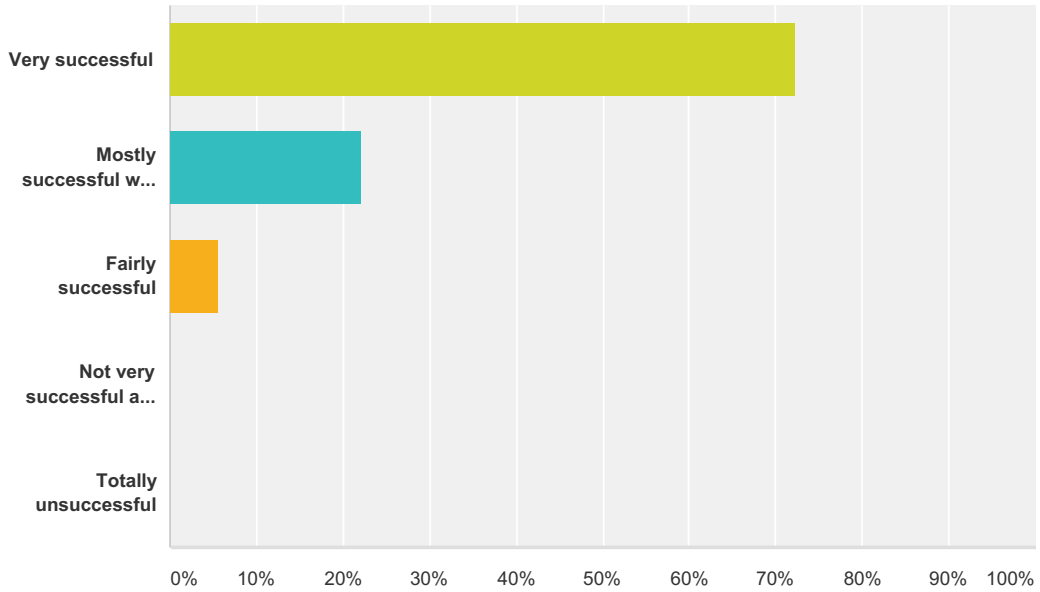
Answered: 59 Skipped: 5



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?

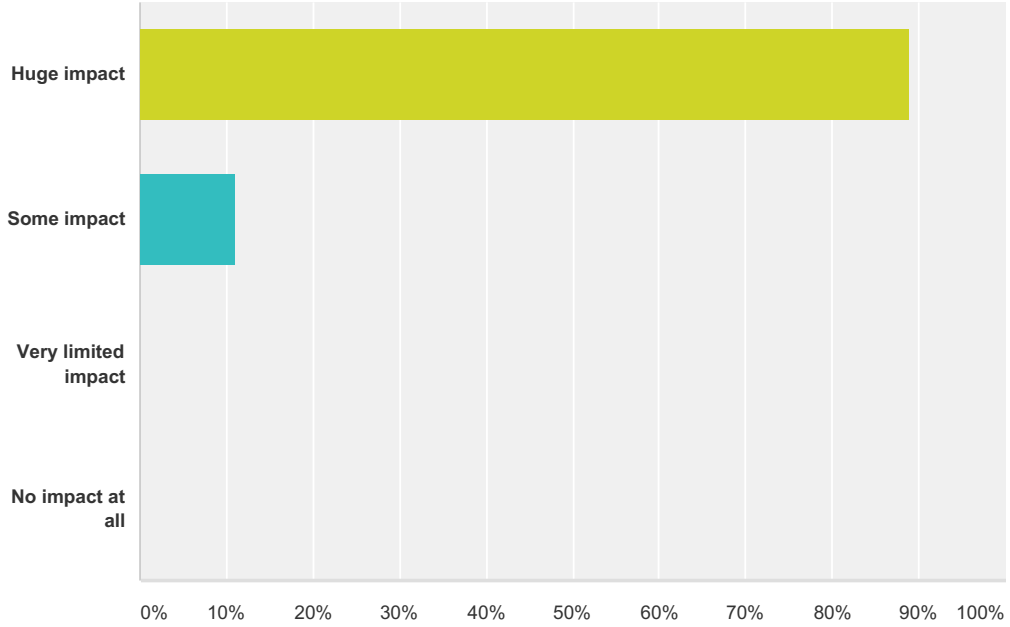
Answered: 54 Skipped: 10



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?

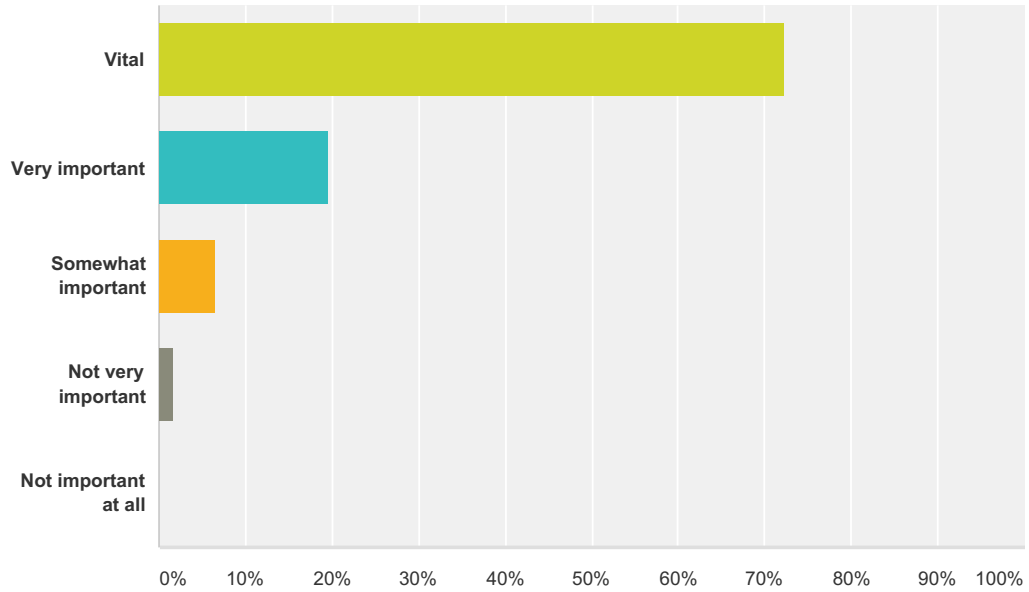
Answered: 54 Skipped: 10



Answer Choices	Responses	Count
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?

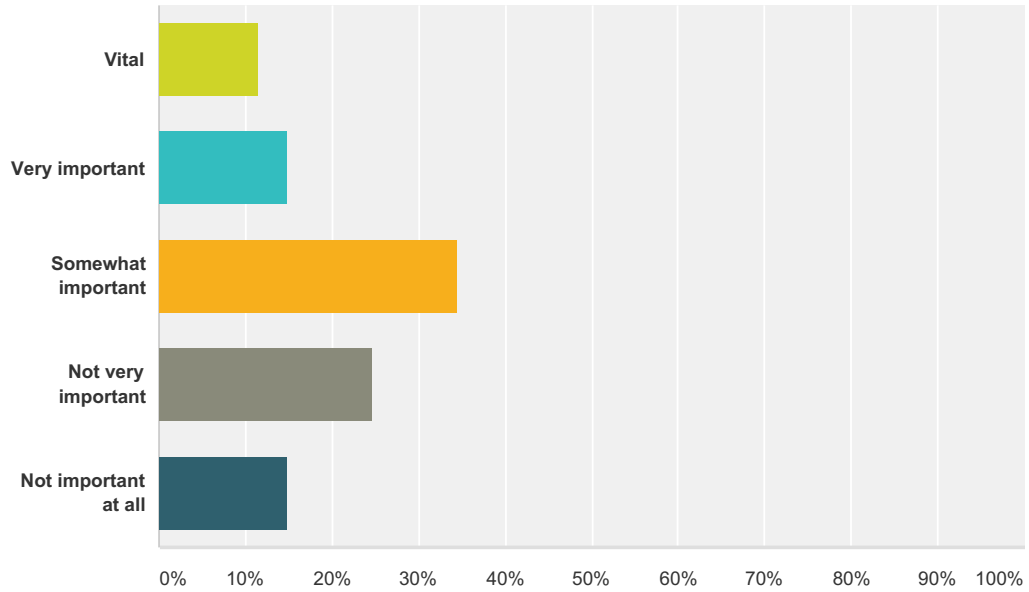
Answered: 61 Skipped: 3



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?

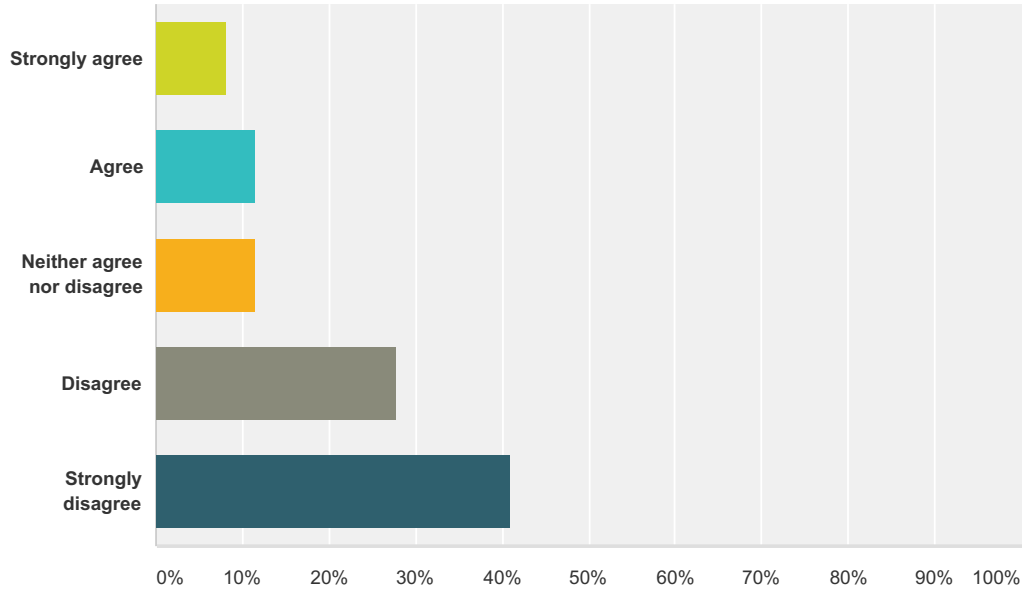
Answered: 61 Skipped: 3



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?

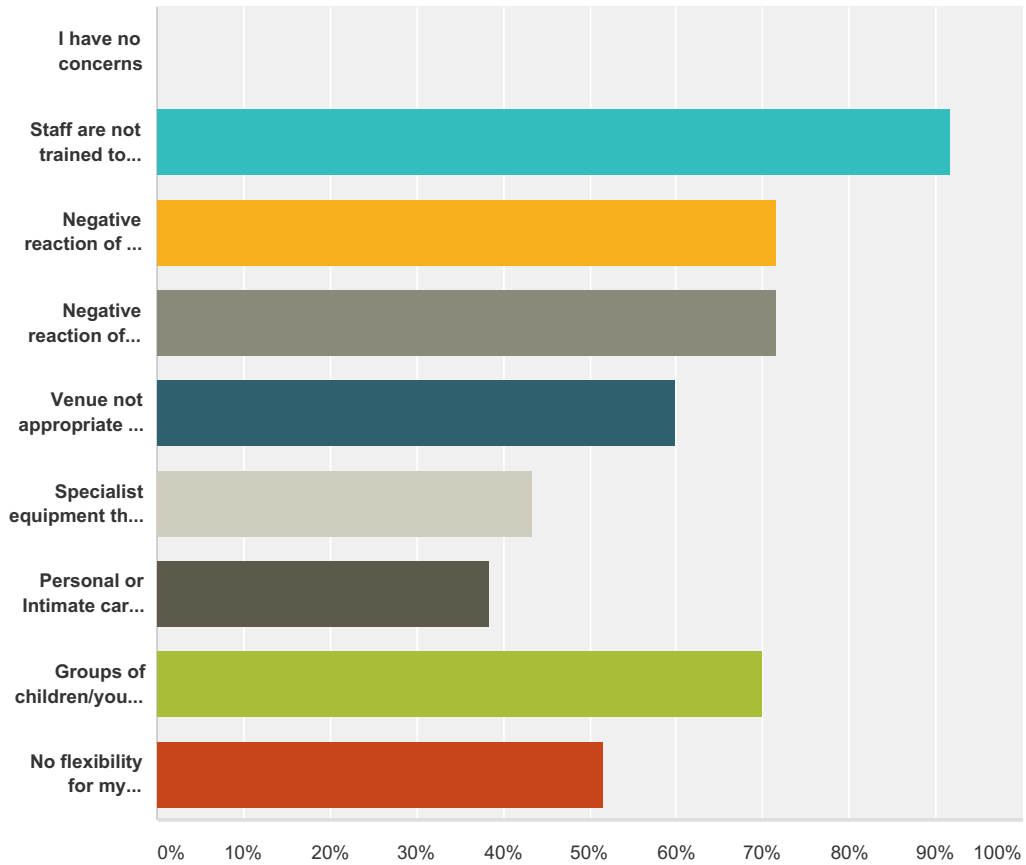
Answered: 61 Skipped: 3



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?

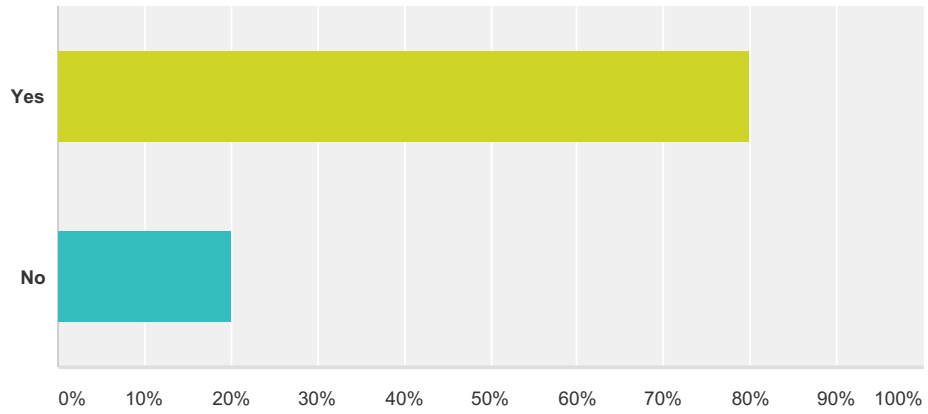
Answered: 60 Skipped: 4



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

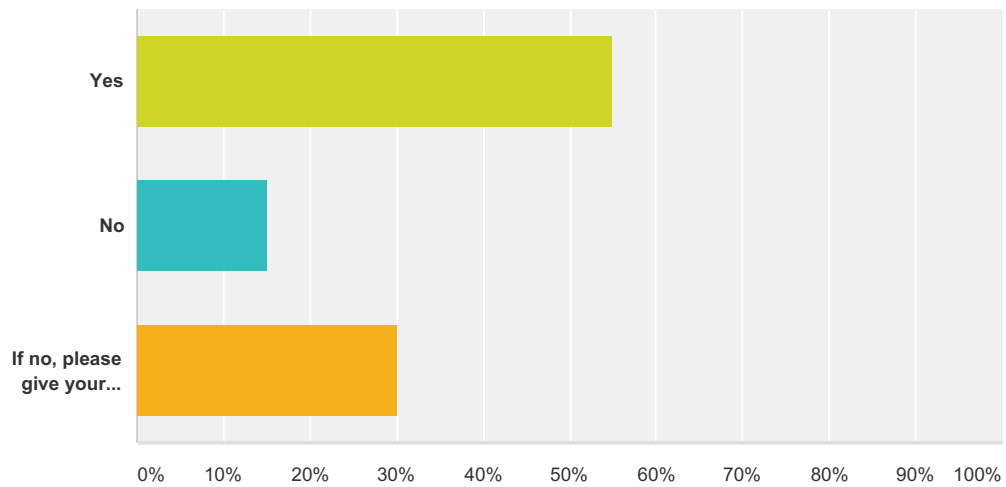


Answer Choices	Responses	
Yes	80.00%	48
No	20.00%	12
Total		60

Short Breaks Survey

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

#	If no, please give your reasons	Date
1	It was too hard to understand!	3/10/2017 6:48 AM
2	I was not aware of it. I will look for and complete now I know there is one	3/10/2017 5:37 AM
3	Despite being a qualified teacher, I found it impossible to understand. It is a misleading document. I could not make your help course, but have had a few pointers from Emma Reed at Autism Beds and will fill out before 15th. This survey makes it much clearer to understand and thanks for doing it. I can see what the other survey is getting at now...	3/6/2017 5:00 AM
4	I feel the questions are difficult to understand and misleading. I feel the questions have been worded to trap us into losing essential services that we desperately need and will isolate our vulnerable children. If we lose our lifeline our lives will be substantially changed because we cannot access the venues the council are offering and this shows how little they understand the difficulties we face on a daily basis.	3/2/2017 8:51 AM
5	Not yet	2/28/2017 7:01 AM
6	I didn't understand how to fill in, as was very confusing. This survey was easier to fill in, Thank you.	2/28/2017 6:10 AM
7	Not yet anyway..... It's very lengthy; and at the moment my family doesn't access these services so I'm not sure if it effects me.	2/23/2017 5:30 AM
8	Social working coming around this week to discuss short breaks review	2/22/2017 2:00 AM
9	Unaware	2/21/2017 2:13 PM
10	It was bias and the questionnaire are led questions with not enough info to complete properly	2/21/2017 6:57 AM
11	Will do	2/20/2017 10:23 AM
12	I have not seen a copy of it.	2/20/2017 9:36 AM
13	Too difficult to even understand what was being asked!!	2/20/2017 9:32 AM
14	I don't use short breaks provision, even though my son may qualify for it.	2/20/2017 9:30 AM
15	Have not got round to it yet	2/17/2017 12:37 PM
16	i will complete it next!	2/11/2017 1:04 PM

Short Breaks Survey

17	I wasn't aware this was going on.	2/9/2017 2:26 AM
18	Haven't had the time to go through all the info yet	2/8/2017 8:45 AM



SNAP PARENT CARER FORUM

CENTRAL BEDFORDSHIRE

Conclusions from our Short Breaks Survey.

The purpose of this survey was for the forum to gain the views of parent carers who would be affected by the potential cuts to the short breaks services. Some parents and voluntary sectors reported that the CBC survey was too long and complicated for them to complete, we therefore wanted to give parent carers another option to help support the process.

SNAP has worked with the Head of Service for Children with Disabilities & Children's Health regarding the review of Short Breaks provision in Central Bedfordshire. Parent carers have informed SNAP of the impact of a proposed reduction in spending on voluntary agencies that are providing specialist social opportunities and how that would affect their families.

The SNAP survey received 64 responses from parent carers who have children with special needs and disabilities ranging from 0-18. The aim of this survey was to gather information about the challenges and successes of integrating their children into the universal and specialist services on offer for young people with Special Education Needs and Disabilities (SEND).

From the results of our survey we found the following information:

53% of the children and young people attend a special school and 42% attend mainstream schools.

58% visited mainstream/universal clubs once or twice a week, 77% of families reported encountering difficulties trying to access these clubs or activities. The consistent theme of the reasons is that the staff were not qualified to understand the child's needs; other parents made the families feel unwelcome and sensory overloads of children due to the environment. It is worth noting that our survey recorded 0% of mainstream services being able to offer intimate care. There are many barriers for families to access universal services and they should have a choice in the provision needed to support their children.

86% of families who responded to our survey access specialist clubs and activities. 72%

families reported that these clubs were very successful in supporting their child or young person's needs, 0% reported they were unsuccessful in this. Furthermore 88% reported the loss of the specialist services would have a huge impact on their families, with 72% stating the importance of their child accessing a specialist provision. In conclusion, the voluntary agencies in Central Bedfordshire are well established and their services valued and well used by families.

We asked if children and young people with less complex needs should access mainstream instead of specialist services, 40% strongly disagreed and 27% disagreed with this.

Question 16, asks specifically what the concerns are with using mainstream/universal services, 0% reported they have no concerns. There is a real mix of concerns, the main one, 91%, is the appropriateness of staff training followed, at 71% by other parents and children's negative reactions towards them as a parent or towards their child in a mainstream/universal setting.

80% of parent carers reported they were aware of the CBC Short Breaks survey with only 55% reporting they completed it.

Short breaks are vital for parent carers, they enable families to function, for parents to work and rely less on benefits, social workers and GP's, and develop their own self-worth and autonomy. They literally keep families together and functioning as a unit which reduces the burden on the local authority, when families can no longer cope. Our survey demonstrates that universal services need significant investment in training and development of their staff. Furthermore, how will you influence the mainstream parents and their children to *include and not exclude* families who have disabilities? Many disabilities are hidden and are displayed in behavior such as Autism, ADHD and behavior, social and emotional difficulties. A huge investment is needed to change and challenge the general public's perceptions and responses towards our children, young people and their families. This is one of the reasons that 86% of families who completed our survey rely so heavily on specialist provision.

SNAP PCF would ask you to read the survey responses along with the comments parents have made as they highlights the many issues families come across when accessing universal provision, and that for over 50% of families, universal provision has been unable to cater adequately for their needs. Specialist provision offers families support, a break from caring and a safe space for their child's leisure time. Children with disabilities are complicated and their needs can be specific and expensive. Voluntary agencies are already offering inclusive provision to meet those needs.