

## **Consultation on an offer for children with disabilities or additional needs – Consultation feedback**

### **Introduction**

1. Southampton City Council undertook public consultation for 12 weeks between 21 November 2017 and 12 February 2018 regarding proposed changes to the short break service offer for children with disabilities or additional needs and proposed changes to the eligibility criteria which allows access to these services.
2. The proposals were discussed at Cabinet on 14 November 2017 and the Cabinet agreed that the proposed changes should be consulted with key stakeholders and the public before final decisions are taken.

### **Aims**

3. The aim of this consultation was to:
  - Ensure the public and key stakeholders understood the proposed changes.
  - Ensure any resident, business or stakeholder who wished to comment on the proposals had the opportunity to do so, enabling them to raise any impacts that the proposals may have
  - Provide feedback on the results of the consultation to elected Members and key officers to enable them to make informed decisions
  - Ensure that results are analysed in a meaningful, timely fashion, so that feedback is taken into account when final decisions are made.
4. This report summarises the principles and processes of the public consultation. It also provides a summary of the consultation respondents both for the consideration of decision makers and any interested individuals.

### **Consultation principles**

5. The council takes its duty to consult with residents and stakeholders on changes to services very seriously. The council's consultation principles ensure all consultation is:
  - Inclusive: so that everyone in the city has the opportunity to express their views.
  - Informative: so that people have adequate information about the proposals, what different options mean, and a balanced and fair explanation of the potential impact, particularly the equality and safety impact.
  - Understandable: by ensuring that the language used to communicate is simple and clear and that efforts are made to reach all stakeholders, for example people who are non-English speakers or disabled people.
  - Appropriate: by targeting people who are more likely to be affected and using a more tailored approach to get their feedback, complemented by a general approach to all residents, staff, businesses and partners.
  - Meaningful: by ensuring decision makers have the full consultation feedback information so that they can make informed decisions.
  - Reported: by letting consultees know what was done with their feedback.

6. Southampton City Council is committed to consultations of the highest standard, which are meaningful and comply with the following legal standards:
  - Consultation must take place when the proposal is still at a formative stage
  - Sufficient reasons must be put forward for the proposal to allow for intelligent consideration and response
  - Adequate time must be given for consideration and response
  - The product of consultation must be carefully taken into account.
7. Public sector organisations in Southampton also have a compact (or agreement) with the voluntary sector in which there is a commitment to undertake public consultations for a minimum of 12 weeks wherever possible. This aims to ensure that there is enough time for individuals and voluntary organisations to hear about, consider and respond to consultations. This consultation was for a total of 12 weeks.

### **Approach and methodology**

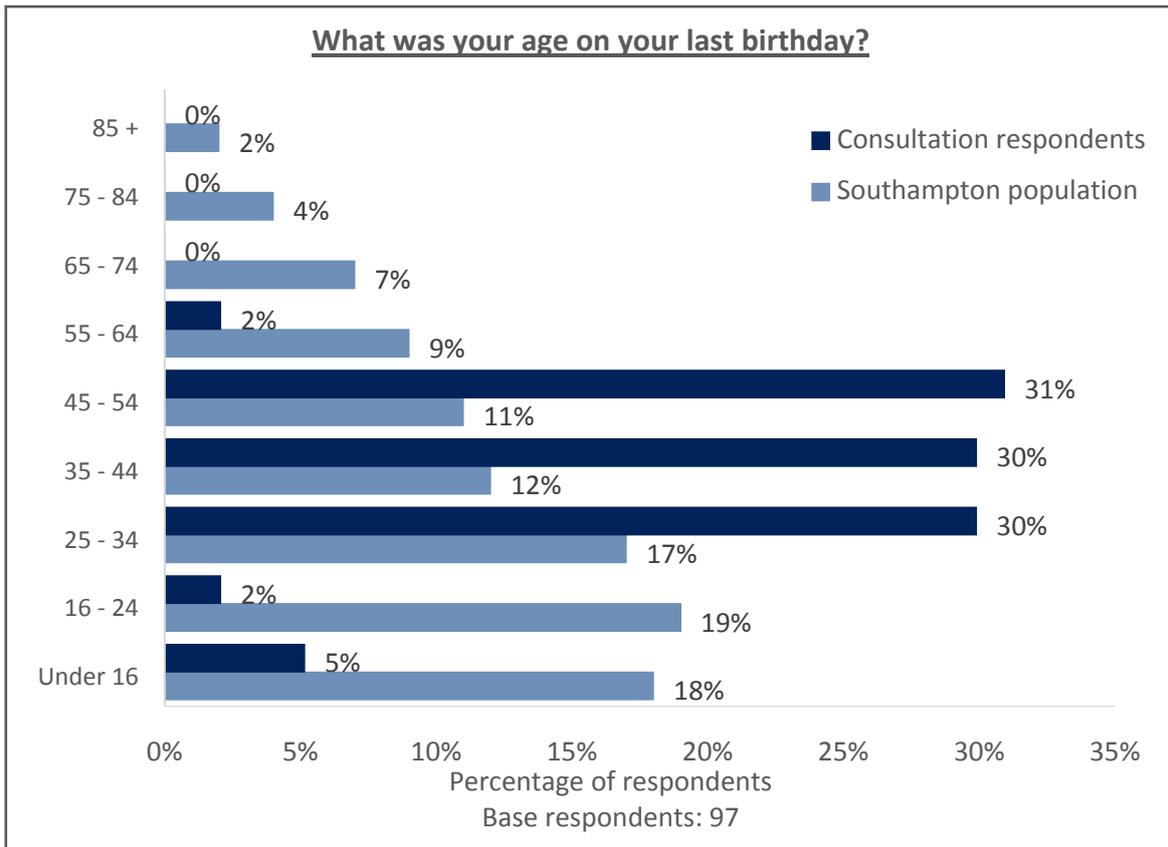
8. The consultation on an offer for children with disabilities or additional needs sought views from relevant individuals and stakeholders. The formal written consultation ran from 21 November 2017 to 12 February 2018.
9. Deciding on the best process for gathering feedback from stakeholders when conducting a consultation requires an understanding of the audience and the users of the service. It is also important to have more than one way for stakeholders to feedback on the consultation, to enable engagement with the widest range of the population.
10. The agreed approach for this consultation was to use a combination of online and paper questionnaires. This approach enables an appropriate amount of explanatory and supporting information to be included in a structured questionnaire, helping to ensure that the public are aware of the background and context to each of the proposals. It is therefore the most suitable methodology for consulting on a complex issue.
11. In addition, a total of eight consultation sessions were held, seven for parent/carers and one for short break providers. They were held on different days of the week and times of the day at five venues across the city.
12. The sessions consisted of a presentation giving the background, information about the engagement work with the Parent/Carer Forum and details of the proposals. Case studies were provided to help attendees understand more clearly what the potential impact of the proposals might be on different families. The sessions were then opened up for comments and questions from attendees. A list of Frequently Asked Questions was also made available. Feedback from these sessions was captured and included in the analysis of consultation results.

### **Promotion and communication**

13. Throughout the consultation, every effort was made to ensure that as many people as possible were aware of the proposals and had the opportunity to have their say. Particular effort was made to communicate with existing service users, parents and carers as they are the most likely to be directly impacted by the proposals should they be implemented.
14. The consultation was promoted in the following ways:
  - a. The Southampton City Council website
  - b. Emails and post to Buzz Network members
  - c. Buzz network newsletter
  - d. Short break providers sharing details with the families they support
  - e. Southampton Parent/Carer Forum:
    - i. Social Media (Facebook & Twitter)
    - ii. Forum meetings
    - iii. Outreach to wider parent/carer support groups
  - f. Leaflets
  - g. Information about the consultation was sent to all Special Educational Needs Coordinating Officers
  - h. Information was sent to all 75 schools in Southampton
  - i. Information was sent to the third sector through local SEND charities
  - j. Facebook Live with the Parent/Carer Forum coordinator and SEND service manager

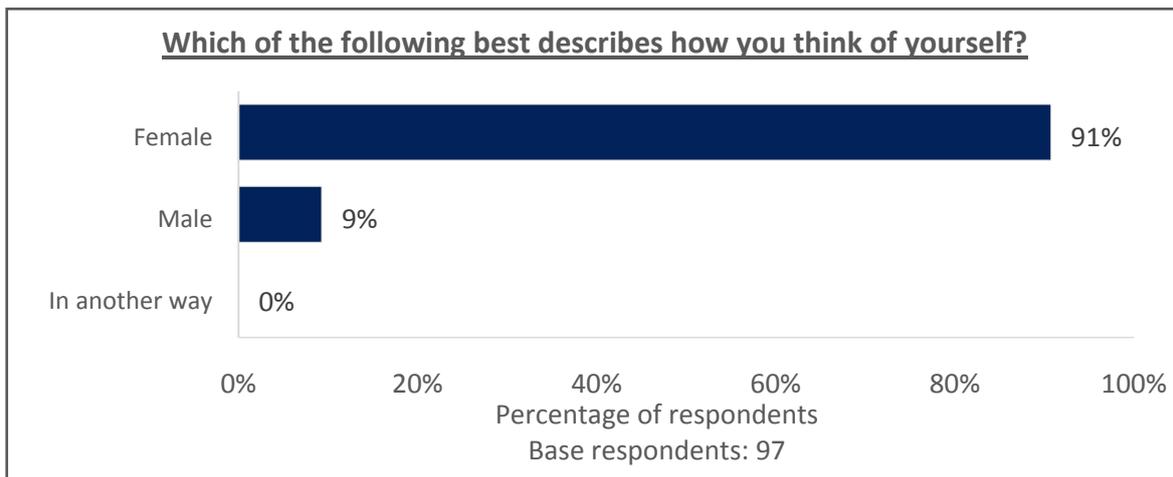
### **Consultation questionnaire respondents**

15. In total, 99 people responded to the consultation either through the paper or online questionnaire. All the questionnaires that had at least one question completed were included in the analysis to ensure every bit of feedback was considered.
16. Figure 1 shows the age breakdown of consultation respondents compared to the mid-2016 population estimate for Southampton. The age groups between 25 and 54 were over represented in the consultation when compared with the Southampton population and the age groups under the age of 25 and over the age of 54 were underrepresented.



*Figure 1*

17. The gender breakdown of respondents was 91% female and 9% male (Figure 2). Females were significantly overrepresented when compared to the Southampton population as the mid-2016 population estimate for Southampton reports 49% female and 51% male.



*Figure 2*

18. Figure 3 shows the ethnicity breakdown of respondents to the consultation. The proportion of people that describe themselves as White is overrepresented as 85% of the population described themselves as White in the 2011 census. All other ethnic groups are underestimated in the consultation when compared to the 2011 census. 8% of the Southampton population in the 2011 census described themselves as Asian or Asian

British, 2% mixed or multiple ethnic groups, 2% Black, African, Caribbean, Black British and 1% any other ethnic group.

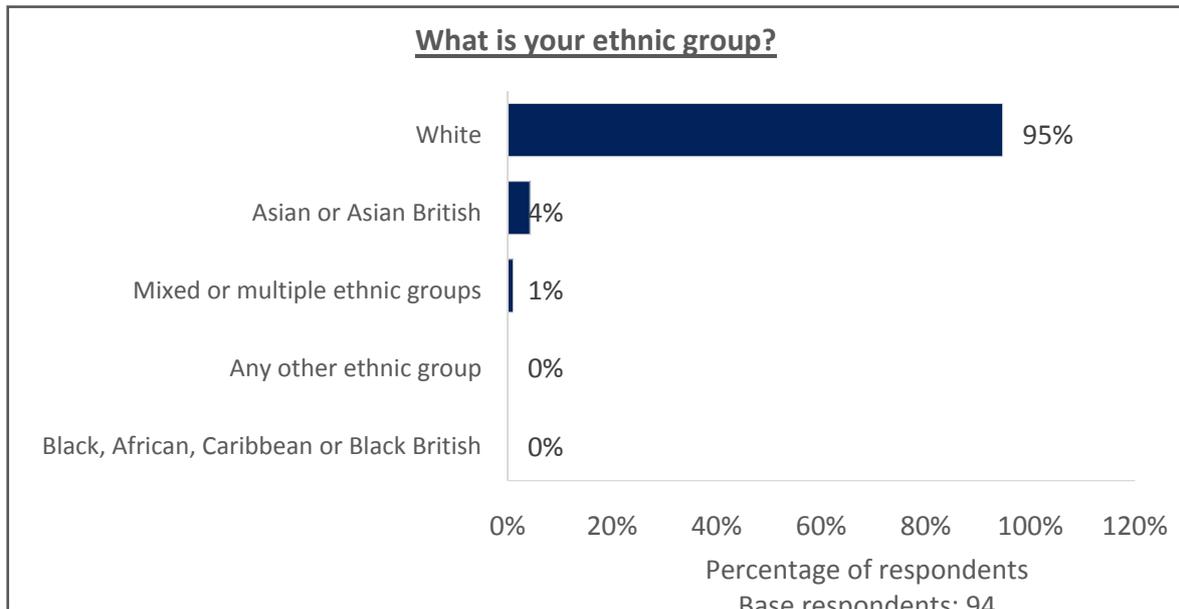


Figure 3

19. Figure 4 highlights the interest of the respondents to the consultation. The largest proportion of respondents to the consultation were parents and carers of children that currently access services. A further 10% of respondents described themselves as professional and 9% were parents and carers of children who do not currently access the services.

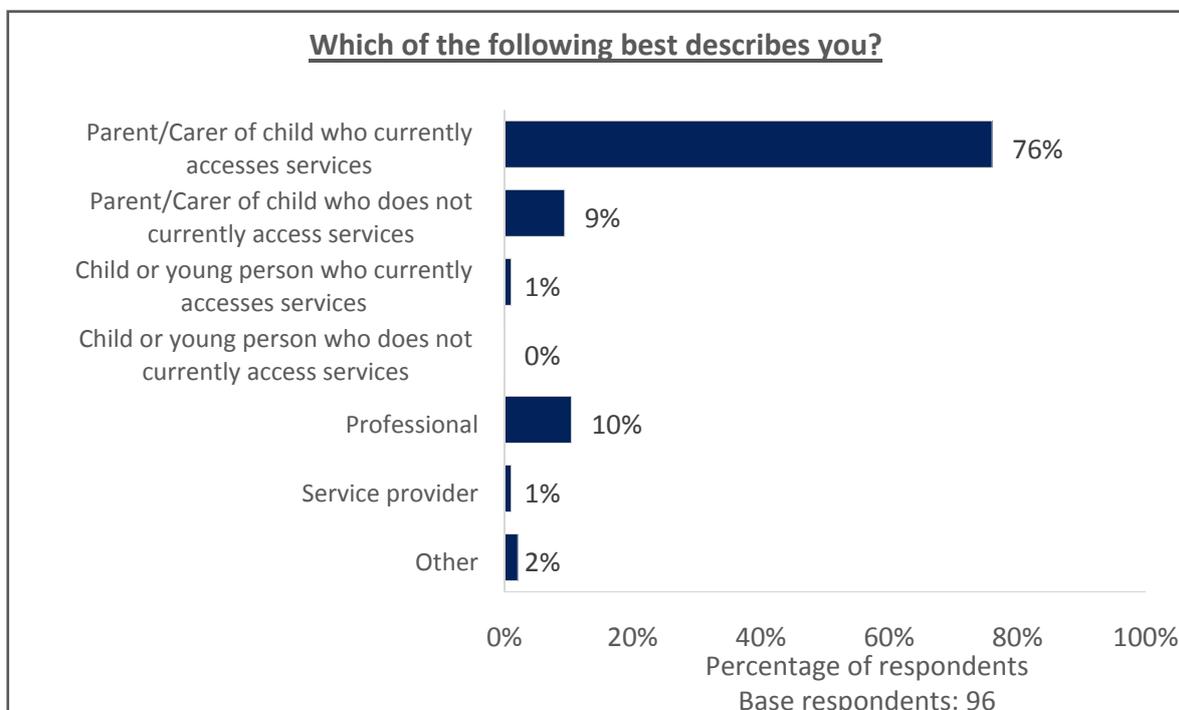
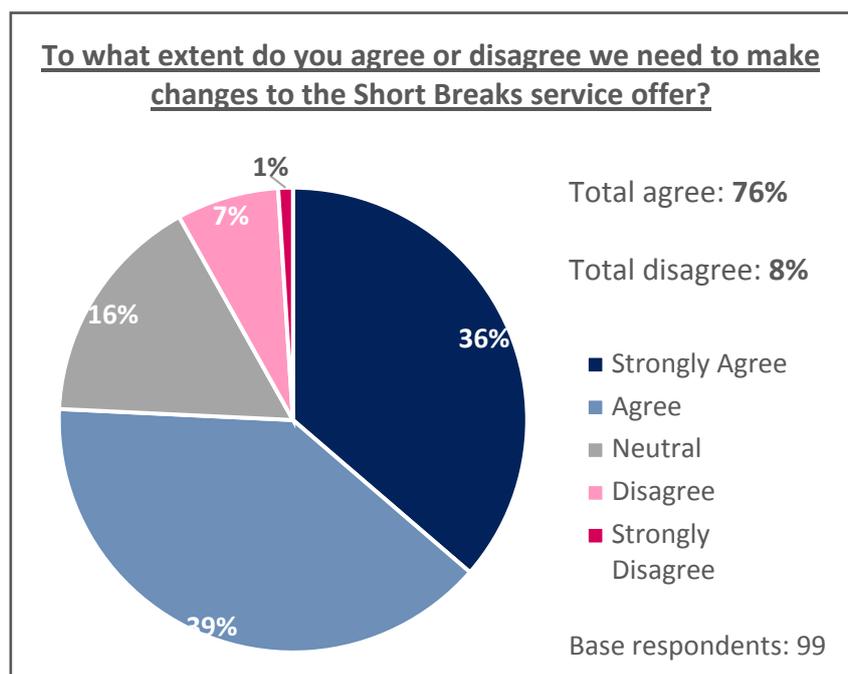


Figure 4

### Questionnaire feedback

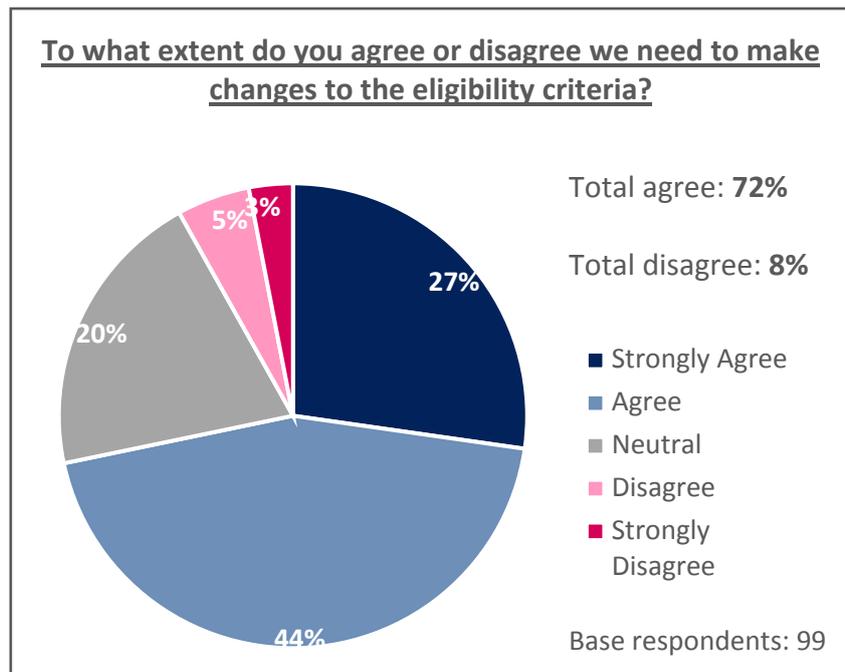
20. In total, 99 people answered the consultation questionnaire either through the online or paper version.

21. The first question asked respondents to what extent they either agreed or disagreed that changes needed to be made to the Short Breaks service offer (Figure 5). All 99 respondents answered this question and overall 36% strongly agreed with changes to the service and 39% agreed. In total 76% agreed to some extent that the changes needed to be made to the service. In total 8% disagreed with making changes to the service. Of this, 7% disagreed and 1% strongly disagreed.



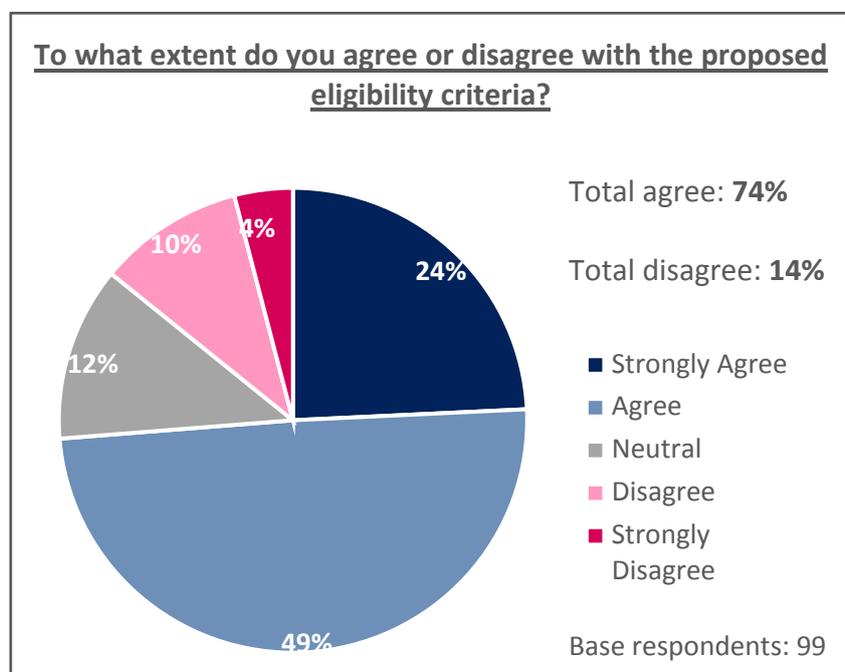
*Figure 5*

22. The second question asked respondents to what extent they agreed or disagreed that changes needed to be made to the eligibility criteria for the short breaks service (Figure 6). In total, 27% strongly agreed and 44% agreed that changes should be made to the eligibility criteria and 5% disagreed and 3% strongly disagreed.



*Figure 6*

23. Respondents were informed about the proposed eligibility criteria and were then asked to what extent they agreed or disagreed with the proposal (Figure 7). Overall, 24% of respondents strongly agreed with the proposed criteria and 49% agreed. This totalled 74% that expressed agreement generally with the proposal. In total 14% expressed disagreement with the proposed eligibility criteria, of which 4% strongly disagreed and 10% disagreed.



*Figure 7*

24. Respondents were then asked to write down any comments they had on the proposed eligibility criteria. When analysing the free text comments from the questionnaire, all

comments from all questions were analysed and categorised together. For example, if a respondent commented on the eligibility criteria in a different free text question that comment will have been regrouped with all other comments on the eligibility criteria to ensure that an accurate picture of opinions can be calculated across the entire consultation. In total, 62 respondents provided a comment to at least one question in the questionnaire.

25. Figure 8 shows the themes of comments surrounding the proposed eligibility criteria and the number of people that mentioned this somewhere within the questionnaire.

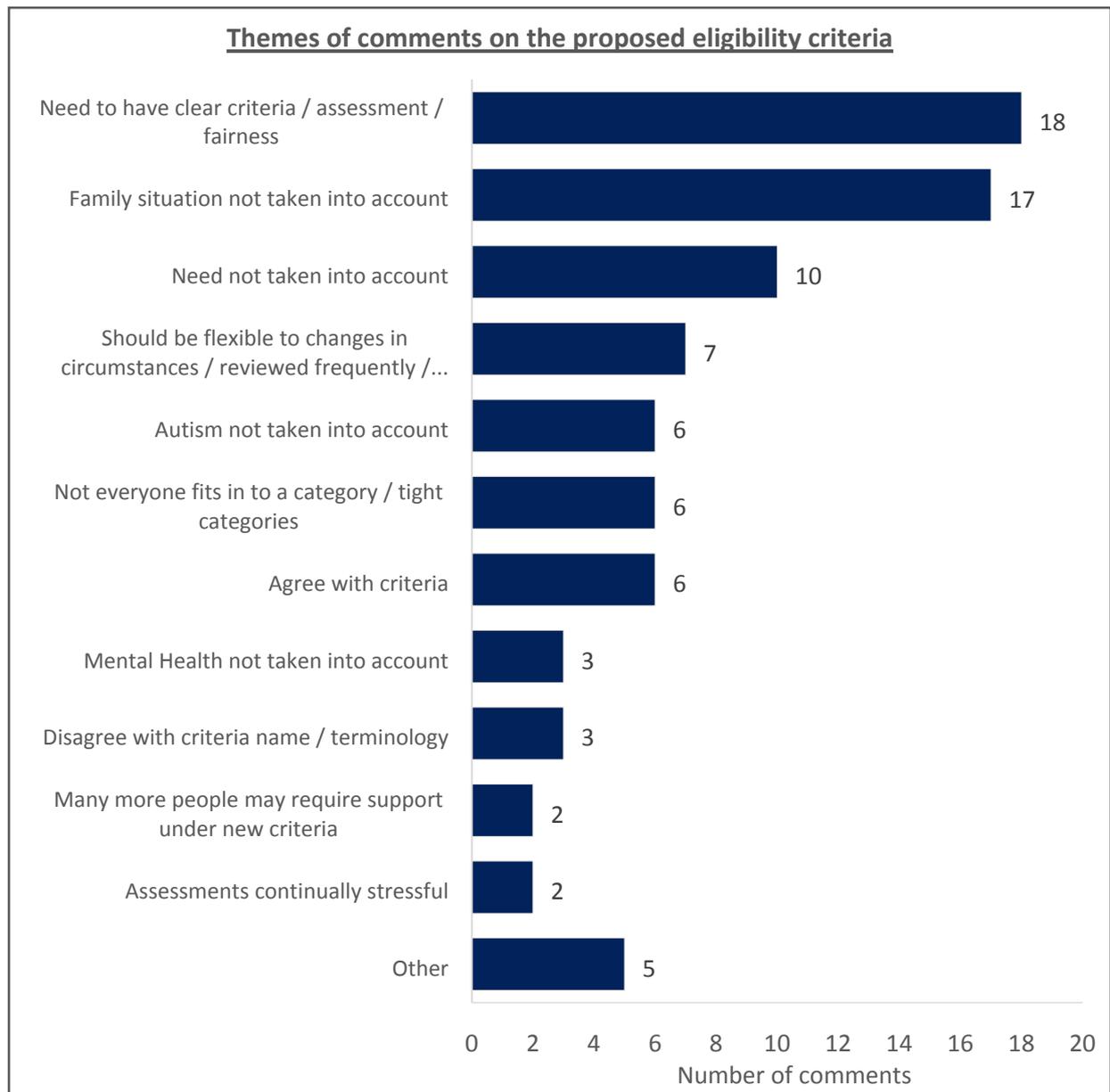


Figure 8

26. In total 18 respondents to the survey wrote a comment about the need to have clear criteria and assessment. Examples of quotes that encompass the sentiment of these comments include:

*“assessment frameworks should be clear and concise”*

*“This would depend on the people who evaluate the the families and whether they start from scratch with every family, it’s hard to judge a case on one visit or one day. So although there is a criteria there it is not exactly plain and simple”*

*“The criteria for intervention should also be clearer.”*

*“the eligibility definitions are not very clear and some will be difficult to assess/measure. For instance, at the low level, you state that the children will have low level additional needs? These will have to be qualified. What is low level? Who decides what is low level? ...The proposal is silent on the assessment referral. Will high (substantial/critical) needs still require referral by a professional OR will their be possibility for self-referral?”*

*“There is not enough information given on what criteria will be used to assess disabled people, how this will be done, or how the appeal process will work where disable people dispute their level of disability.”*

27. The second most mentioned theme of comment regarding the proposed eligibility criteria surrounded the request for the family situation to be taken into account during assessment. In total 17 respondents wrote about this and examples of comments include:

*“I think the situation of the family should be considered as well at each level, as single parents obviously have more pressure and less assistance, and some families are very supportive and helpful whilst others are not therefore providing some families with more breaks than others and more time to spend with siblings”*

*“It is the only time I have a full night sleep! Being only carer I have to keep going on zero sleep, working on zero sleep, caring on zero sleep”*

*“having extended family and a network of friends is no guarantee that they will be able and/or willing to assist with caring for a child with special needs... Due consideration should be given to families who have several children with disabilities who may end up being assessed under different criteria, yet, the overall impact on the family/parents is profound. For instance, disproportionate or disjointed provision of respite leaving one sibling always in the care of the parents means the parents never get their respite”*

*“Nobody but the parents know the impact a particular disability has, and some parents will find a disability more disruptive of their daily lives than other.”*

*“I do believe vulnerable families will loose out”*

28. The third most reported comment was that respondents felt that needs of the individual were not being taken into account. In total 10 people commented on this. Examples include:

*“You can't put moderate learning disabilities and profound disabilities in the same category! Their needs are completely different! If anything profoundly disabled children like my son require substantially more health and social care.”*

*“How will you assess the level of the child's needs - I assume there will be a criteria for this also, and a request for additional information?”*

*"I am concerned that the access to substantial and critical levels will be too tight and may be budget driven rather than needs driven."*

*"My concern is to get the dla isn't possible for all children that have additional needs"*

*"I think families with children on the autistic spectrum that have invisible needs in a lot of cases will lose their personal budget and I do not believe this is fair. These families are the families that are most in need as are not recognised as needing support or do not easily qualify for other types of support."*

29. The fourth most frequently recorded theme of comment surrounding the proposed eligibility criteria highlighted that circumstances can change and eligibility should be flexible to this and reviewed frequently. For example, comments that reflect this include:

*"This seems faire as long as it is understood that children and circumstances change through no fault of their own and if necessary their band may change and they may then need more support."*

*"People personal situation change all the time and rely on the support that has been always there"*

*"I am only concerned when we joined the buzz network on this new criteria when we joined would be low. Things for our child has progressed quickly since we joined. We would now be in the medium. Will you be sending out anything so we can be reassessed."*

30. Six respondents felt that individuals with autism had not been taken into account within the proposed criteria. Some of the comments that highlighted this include:

*"I think the autism families will loose out"*

*"You still use the criteria as learning disability but not include autism. There are children and young people in Southampton with autism that need support at the substantial and critical level and you are still failing them."*

*"Although a parent of a child with a disability, I also work with children with additional needs, and have at times been shocked to be told that children with very severe autism, LD and associated behaviour difficulties were told they did not qualify for Jigsaw, when they most clearly should have-"*

31. Six respondents expressed a concern that not everyone would fit in to a proposed category. Comments that encompassed the sentiment of this opinions include:

*"Big jump between med and sub"*

*"The potential problem with this eligibility criteria is that everyone has to agree for each individual child. Eg: the parents may feel the need is critical but social services may say substantial. So how would that issue be resolved fairly if the situation arose?"*

*"Again it seems fairer but sometimes families and children do not fill neatly into these categories and so you may find some families slipping through the net."*

32. There were six respondents that wrote a comment in support of their agreement with the criteria. For example:

*“It immediately seems fairer, and the words used to describe the differing levels reflect why the amount of support needs to be differentiated.”*

*“I think it's a good proposed criteria and is inclusive to all disabilities as some are at lower levels whilst others obviously are more severe and will be a good system to identify an individual's level of need and signpost to the relevant services more appropriately as clearly the current system is failing families and young people in Southampton.”*

*“I think it is a good way to assess the needs of service users and provide the relevant help.”*

33. Three respondents commented on how they felt that mental health had not been taken in to account in the proposed eligibility criteria. Examples of these comments include:

*“Children/young people with mental health difficulties will not meet your criteria which means that they will not receive any support at all.”*

*“I do agree with the criteria that are there but am disappointed to see no acknowledgement of mental health issues which can and seriously impact a child's ability to access education, health and social opportunities.”*

34. Three respondents expressed a disagreement with the naming of the criteria or the terminology used. Comments that encompassed this disagreement include:

*“I don't believe that in the 'substantial' level the word disability should be used in regard to learning i.e i feel it should read; have significant difficulties”*

*“Secondly, their names need to be clearly related. When you talk of low and medium, it is natural to expect a high level. However, you jump to substantial and critical. I suggest, low, medium and high....Others might disagree, but please consider using the phrase 'children and young people with disabilities' rather than 'disabled children and young people”*

*“I think that, for clarity, the 'critical' criteria should read 'and/or' not just 'or' as many will have both learning disabilities and physical disabilities. Will the 'substantial' criteria also allow supported access to enhanced/adapted mainstream provision? This feels important for a number of reasons, inclusion and visibility being one but also the fact that much mainstream provision would be available if there were some minor adaptations and a staff member one to one with the service user. Not sure if it is clear from this description?”*

35. Two respondents felt that under the proposed eligibility criteria there would be many new individuals that would be eligible for support. The comments included:

*“You say that there is no cut to funding but if there are more families using the same amount of funding then this is a cut! You should be making more money available equal to the increase in numbers of families needing support.”*

*“I think the proposal is positive on the whole. I am concerned however that Jigsaw will become inundated with an increased need due to those at substantial & critical level. Jigsaw already struggles.”*

36. Two respondents emphasised how stressful assessments can be and highlighted the following issues:

*"I think we should learn lessons from the Work Capability Assessment disaster also- vast amounts of money have been spent assessing and regularly reassessing vulnerable people- this has been widely reported to adversely affect these people's mental health and ability to cope. Undergoing reassessment has been very stressful for me and my family and has adversely affected us, I hope we won't have to go through this again for a long time, as you need stability as a foundation to cope, and if respite entitlement that you desperately need to keep going is regularly under threat, this is bound to have a negative impact. Also, the assessment process is going to cost a fortune as we now have lots of social workers doing it- if frequently reassessed it will waste money that would be better used to help the children and families."*

*"Lots of money will be wasted making assessments, which will be instructive, and an invasion of privacy to what is already a stressful life with a child with a disability"*

37. There were a further five respondents with comments surrounding the proposed eligibility criteria. These included:

*"The DLA assessed the child at a medium care rate when so clearly he should have been awarded high rate, so this is one problem with being overly reliant on DLA awards as sometimes it seems they will underaward to see if they can get away with it, and if the parent does not feel up to challenging the decision their child may be doubly let down by the system."*

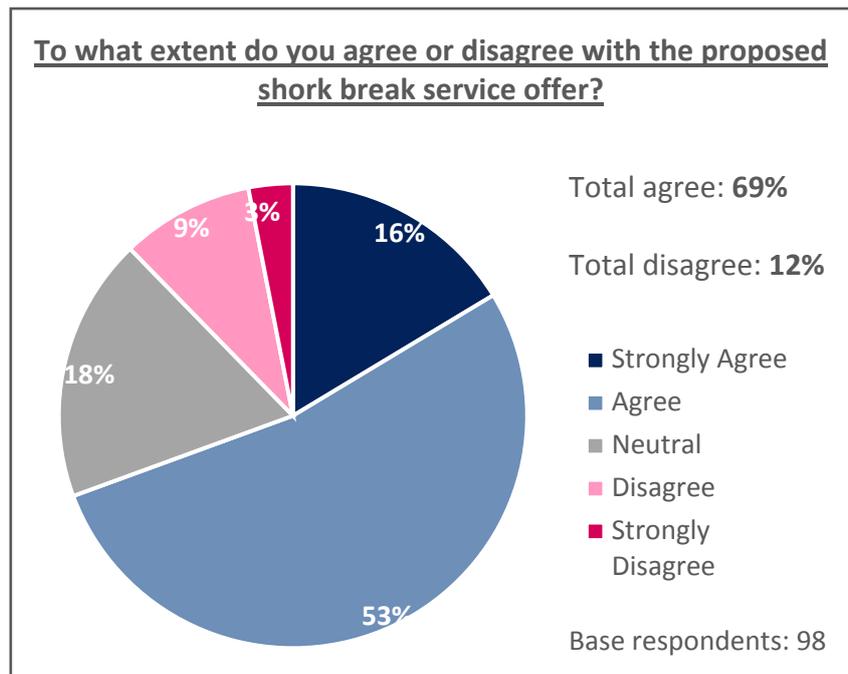
*"Re visit your eligibility criteria"*

*"I think 4 criteria are one too many and will confuse parents. 3 should suffice."*

*"The potential problem with this eligibility criteria is that everyone has to agree for each individual child. Eg: the parents may feel the need is critical but social services may say substantial. So how would that issue be resolved fairly if the situation arose?"*

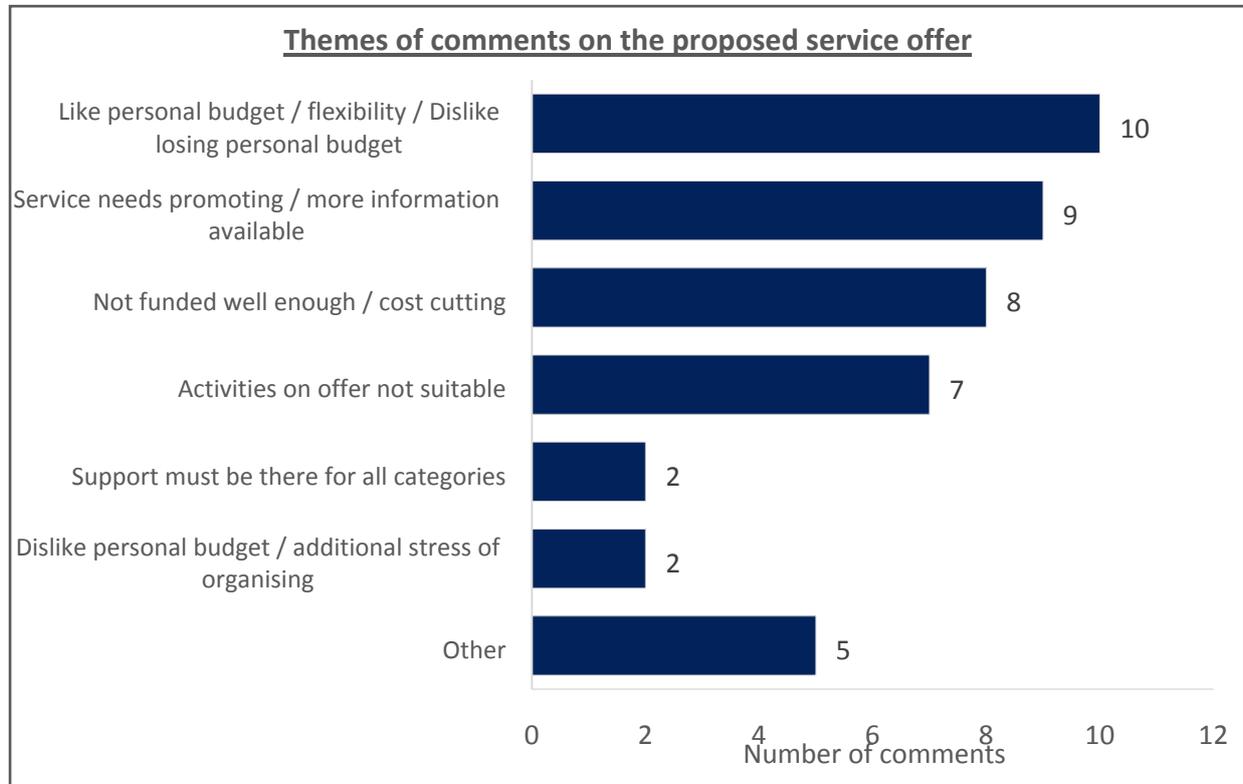
*"My concern is to get the dla isn't possible for all children that have additional needs"*

38. After a description of the proposed short break service offer in the questionnaire, respondents were then asked to what extent they agreed or disagreed with the proposed service offer. Figure 9 shows the results of this. Overall, 16% strongly agreed with the proposed service offer and 53% agreed which totalled 69% that expressed overall agreement with the proposal. Overall, 12% of respondents disagreed with the proposed short break service offer. Of this 3% strongly disagreed and 9% disagreed.



*Figure 9*

39. Respondents were then asked to provide any comments they had on the proposed short break service offer. Figure 10 shows the themes of comments surrounding the proposed service offer and the number of people that mentioned this in a question within the questionnaire.



*Figure 10*

40. The most mentioned theme of comment regarding the proposed service offer by 10 people was that they like their personal budget and the flexibility it has to offer and dislike the idea of losing it. Comments that encompass the sentiment of this include:

*“for a lot of families accessing this gives them freedom of choice to suit their own individual families needs.”*

*“One of the benefits of the personal budget was not having to worry too much about logistics; the proposed changes restrict us a lot more.”*

*“Personal budgets for all will ensure the money is only being spent on care provided.”*

*“I think it is unfair to take the personal budget away from medium level families, the budget is sometimes used for rest bite that the family would otherwise not receive!”*

*“I believe that a lot of families and children will be affected with changes to the personal budget, as for some families the personal budget works better, and allows for the child to do activities & fun things. For example, my child struggles with new people & busy places, and crowds more than just a handful of people. The personal budget allows for me to take him to places he likes & is able to cope with, and do things that he enjoys & is able to do as and when it best suits his needs.”*

41. The second most mentioned theme surrounding the proposed service offer was that the service required better promotion and more information available. In total nine respondents mentioned this. For example, respondents said:

*“So much is learnt from other parents or carers and that isn’t fair to people who are isolated or don’t have the ability themselves to find out.”*

*“the reason the personal budget take up has increased so much for Buzz families is that SCC were not transparent in advertising this as an option. It was parents who made this available to other parents through word of mouth and support groups.”*

*“Unless someone whispered the service Jigsaw to you, you wouldn't really know about them. It is like a secretive department within the SCC.”*

*“Not all families have an allocated social worker and this makes it more difficult to obtain help and support...Also they are less likely to even know that these services exist because they have no one who can direct them to these services”*

42. Eight respondents felt that the proposed service offer is not funded well enough and that there are cuts to the service. For example:

*“Where I do think we’ve gone terribly wrong with the bus network is that not enough money has been set aside for those children who aren’t able to access the wide range of pleasure breaks for one reason or another but usually because of severe and prepare and disability and family situation”*

*“You say that there is no cut to funding but if there are more families using the same amount of funding then this is a cut! You should be making more money available equal to the increase in numbers of families needing support.”*

*“While we are being told there is no cut to funds (though they aren’t increasing with inflation) and this is just about redistribution, over the years Jigsaw services have already been substantially cut, and many beneficial services stripped down, so it seems to me if people risk losing the support they have and need to share the funds more widely, that the ‘cake’ we are sharing from is not big enough. I agree that it is ridiculous that someone who is on a minimal level of support on the SEN register could have a personal budget, but I very much doubt much of the money is being spent this way, which is why I agree in essence with reallocating funds but it is much more complex than just a statistical tick box analysis needed”*

43. Seven respondents felt that the activities on offer were not suitable to the individual. Comments that encompass the sentiment of these feelings include:

*“Again especially families with a child with autism who find group situations and clubs extremely challenging if not impossible.”*

*“And seeing as the only help I currently receive from short breaks or jigsaw is £200 every 6 months for a child with a substantial lifetime condition with significant needs/ learning disability to pay for access to disabled activities/ play schemes which he needs as he certainly cannot cope with mainstream ones then I certainly don't feel it's ok to accept less help from the proposals”*

*“Children with Autism that are assessed as being Medium, may have a limited choice of short breaks that they would actually want to use. My son does not like cinemas, leisure centres, theme parks, museums or soft play centres.”*

44. Two respondents stressed the importance of support being in place. For example:

*“It is vital that carers and their children have access to adequate provision. This service is a lifeline to a lot of families and helps families feel valued in the role they do on a day to day basis.”*

*“What I would not like to see is a decrease in support. Nobody asks to have a child with additional needs nobody wants to ask for help but when someone does that support should be on hand and available.”*

45. Two respondents wrote about their dislike of a personal budget and how it adds additional stress and organising. Comments included:

*“Whilst I appreciate that it may be easier for the local authority and cheaper to operate personal budgets for service users. They are not value for money for families as directly purchasing Services for families that are over wrought and so busy caring for their child trying to work trying to manage family situations put even more stress and strain on them. With the best will in the world I just do not have the time to manage direct payments which is why I have never access them for our family it would be impossible to purchase the level of care which has been assessed on their need that we have now.”*

*“Firstly, it looks as if personal budgets are being foisted on us whichever way you read these proposals. As a single parent carer I do not have the time or the energy to become an employer/ do additional accounts etc, the last thing I need is additional responsibilities in the interests of self preservation and my ability to carry on caring.”*

46. There were a further number of comments around the proposed service offer including:

*“There are still issues with the 'substantial' category and receiving a timely offer of support.”*

*“it depends on what providers offer and how it is managed, surely if they are providing a service for people they have to be controlled and it has to be maintained?”*

*“Allowing personal budgets to be sent spent on things like cinema trips by families who could well afford this is really quite worrying. As I said I’ve seen parents asking for ideas on social media of what to spend their personal budget on many wanting to spend it on frivolous things and not in conjunction with their young person. I warned about this several years ago and it has not been managed well.”*

*“I like the idea of the short breaks card.”*

*“I am not convinced that the discount card would be used by families with similar children.”*

47. The next section of the questionnaire asked respondents about the naming of both the Jigsaw and Buzz Network service. Respondents were asked whether or not they felt the name should be changed. For the Jigsaw service, 65% of respondents felt there should be no change to the name of the service compared to 35% that felt the name should change. For the Buzz Network service, 68% of respondents felt there should be no change to the name compared to 32% that felt the name should be changed. Figure 11 below shows these results.

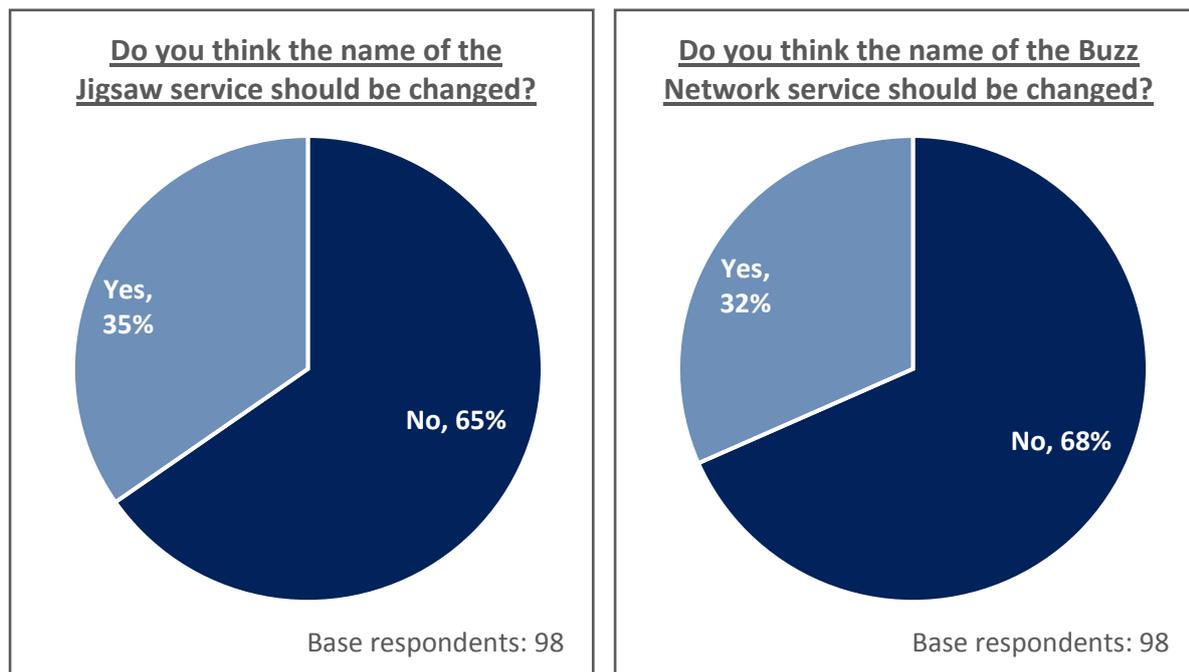


Figure 11

48. Respondents were then given the opportunity to suggest any new names for the services if they felt they should be changed. The following suggestions for names for the services were recommended.

**Jigsaw name suggestions:**

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*Buzz Network Plus*

*Children with Additional Needs Service (CANS)*

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*Children's support services team*

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*Gateway*

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*Something along the lines of children services*

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*Southampton Childrens Social Services*

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*step-up*

**Buzz network name suggestions:**

*Child support voucher scheme*

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*Children and Family Short Break Service*

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*Gateway*

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*Inclusivity network*

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*We need something nationally recognised like the Hampshire Gateway*

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*Connections*

49. In addition there were comments that did not specifically provide a name suggestion, but made a suggestion on how names for the services should be devised. The following suggestions were made.

**Jigsaw service name comments:**

*Because what does 'Jigsaw' really mean? Can be misleading or misinterpreted by families.*

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*I think jigsaw is quite fitting because it is like fitting a puzzle together, however to reevent a service in my opinion you need to demonstrate change and wha better way than the name. But I also think there should be some sort of pack or letter than explains the service, what's available and the aims.*

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*It should say what it does jigsaw doesn't really explain anything. The criteria for intervention should also be clearer.*

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*Just call it what it is or does.*

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*No but this name is not touchable*

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*Something that has what it is in the title.*

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*Something that reflects the service. I haven't got a name in mind.*

**Buzz Network name comments:**

*Again, call it what it does.*

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*Buzz doesn't mean anything to me to be honest, and like I said with jigsaw to reevent a service and show change the best way to start is to change the name in my opinion.*

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*A title that fits with the service and young people's needs makes its more transparent and easier to understand Jigsaw and buzz network have no relation really to the service offer and is confusing to parents and probably the young people.*

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*As I was involved directly in choosing the original name I think it should be changed as this service no longer reflects the values and that it was set up for. I realise that there is less money available because of government cuts but removing a high level of support to some*

*families will literally be a disaster for them. As bus network was named when we had true funding and government ring fenced backing it would be tainted to carry on using it in the current climate. The management of the personal budgets under the bus network has frankly been appalling I have seen parents constantly asking on Facebook what to spend their budget on and these budgets have just been handed out willy-nilly without much*

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*Something that reflects what it is, most people don't know.*

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*The name Buzz Network doesn't mean anything other than now being familiar. It was linked with the old parent forum now which has now been disbanded so a fresh name that says what it does on the tin is needed.*

50. The next part of the questionnaire asked respondents whether there were any alternatives that the council should consider. In total, 22% of respondents felt that there were alternatives that the council should consider. 78% of respondents felt there were no alternatives to the current proposal that should be considered.

51. Respondents were invited to share any alternatives or suggestions that they felt the council should consider. Figure 12 shows the themes of comments surrounding suggestions and alternatives and the number of respondents that mentioned these in a question within the consultation.

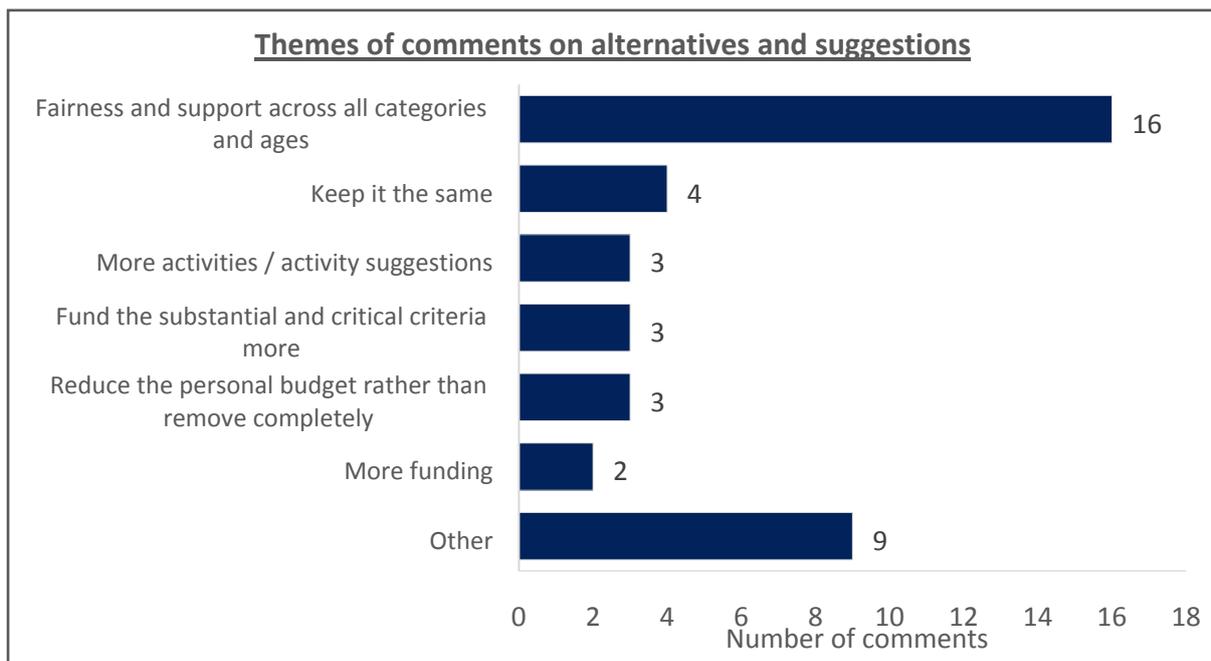


Figure 12

52. The most frequently reported suggestion or alternative to the current proposals was to be fair and provide support across all categories and age groups. In total 16 people raised this suggestion and the following comments provide examples of these:

*“It needs to be fair across all disabilities and learning and care needs”*

*“It seems like we would be penalised for not being so needy when we are a family that would actually benefit from more help and support.”*

*“Unfair to lose personal budget for families with low or medium disabilities, maybe a lower budget for them would work better.”*

*“What is out there for profoundly disabled children to access the community, there are lots of services for those with moderate learning disabilities.”*

*“I am quite astounded that you seem to be sending the message that only children with critical needs require integrated support from health and social care working closely together.”*

53. There were four respondents to the consultation that wrote that they would like the service to remain as it is currently. Comments included:

*“Why are you changing something that works for most families.”*

*“I feel the way it is run at the moment is the best solution for all. By doing it the new way you're actually putting children in two categories which could be unfair on each child”*

*“Option to keep a personal budget at the medium Level”*

54. Three respondents suggested that there should be more activities available or suggested activities themselves. For example:

*“There needs to be some analysis of what young disabled teens who are cognitively able would like as a service. One of my service user recently asked me to help him get 'out and about”*

*“I hope there is activities for the early years group too. At the moment all the short break activities are for over 5yrs!”*

*“I think it is important that play schemes for complex children are still very important. I fell these should be accessible from the same age as they go to school. Offer for things that families can do together or just child + siblings.”*

*“Whilst I agree Southampton does have a good Sure Start offer (0-5), the younger children who access the Short Breaks service (and those who will continue to access it) should still have access to applicable and age appropriate activities.”*

55. Three respondents felt that the substantial and critical criteria should be funded more. For example:

*“Funding should only be given to families/children who meet the Substantial and Critical eligibility criteria”*

*“Perhaps remove the personal budget for those who have minor needs on the SEN register, limit funds to those with a Statement/EHCP or significant need , otherwise keep the old systems in place.”*

56. Two respondents felt that the service should be better funded. Comments included:

*“Adding funding to services that are a lifeline to families rather than cutting budgets.”*

*“More money available, SCC should be proactive as other local authorities are in topping up the shortfall in social care funding from other sources, not sitting waiting for more money to come to them.”*

57. In total, three people felt that perhaps rather than losing their personal budget completely it would be better to still receive a smaller amount. Comments included:

*“Do more direct payments with smaller amounts rather than not being open about this option and people feeling that have to spent almost double the amount on picked services”*

*“I agree that the amount of the personal budget may be too high at the current yearly amount awarded but feel that a personal budget at a lower amount is still very much needed.”*

*“Unfair to lose personal budget for families with low or medium disabilities, maybe a lower budget for them would work better.”*

58. There were a further 9 suggestions and alternatives supplied by respondents to the questionnaire. These included:

*“The age of the carers should be considered, young people may not want to be seen with older carers. Also issues of diversity of carers should be considered regarding cultural needs.”*

*“I think there should be some sort of pack to welcome people to the service as a whole. Explain the difference between the services and what is available to them.”*

*“A photo ID card for the service user which goes with the child so any carer can take it and it can't be misused”*

*“I also now believe because of the punitive cuts that councils are having to enforce because of government cuts, that families Who have higher incomes and could actually do without a personal budget and provide or pay for what their child needs to access could be a way to move forward and provide for those families who are on much lower incomes or in work poverty or on state benefits. It is ridiculous at the moment that families who may have an income of £50,000 for example can still access personal budgets because they couldn't quite afford to provide and access what their child needs by paying for the services of which there are plenty if you have money.”*

*“Will there be a transition period, especially for families who will find themselves receiving less financial help under the new 'system'?”*

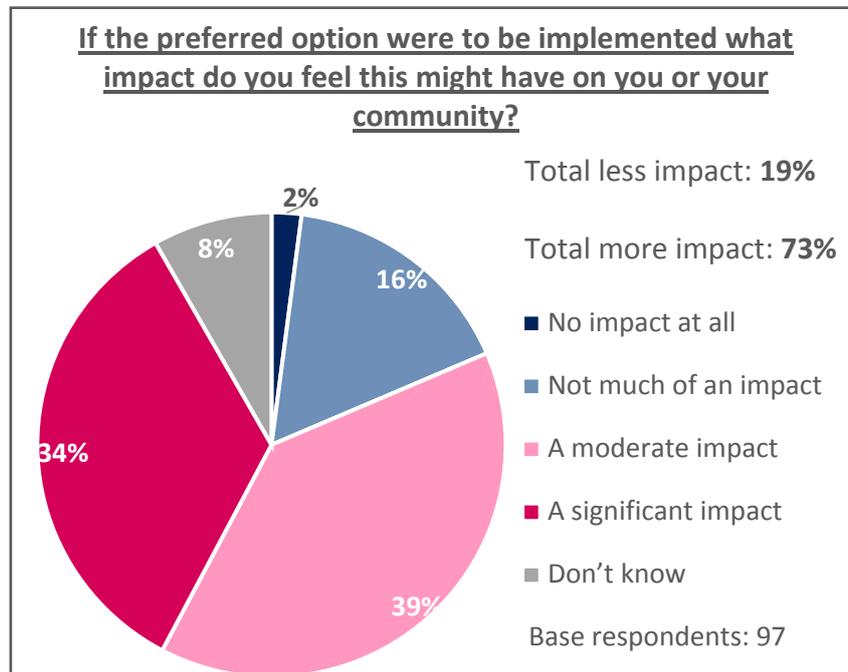
*“I also find it amazing that the resources offered by Jigsaw are not available online! At the very least, within budget constraints, Jigsaw needs a dedicated website or a page or two about who they are, what they do and resources (or links to these) that parents/carers can read and hopefully download. For instance, the tips on good sleeping habits. Why wouldn't that be made available online? The tips about direct payment, why isn't that online? Toilet training, etc. I could go on and on.”*

*“Stop paying the very expensive care agencies to provide the short breaks. Our experience has been that they will claim their fee, however not provide a service. Our son did not get support for nearly one year without support.”*

*“Should be able to be done online as I know there is not much staff to cover everyone”*

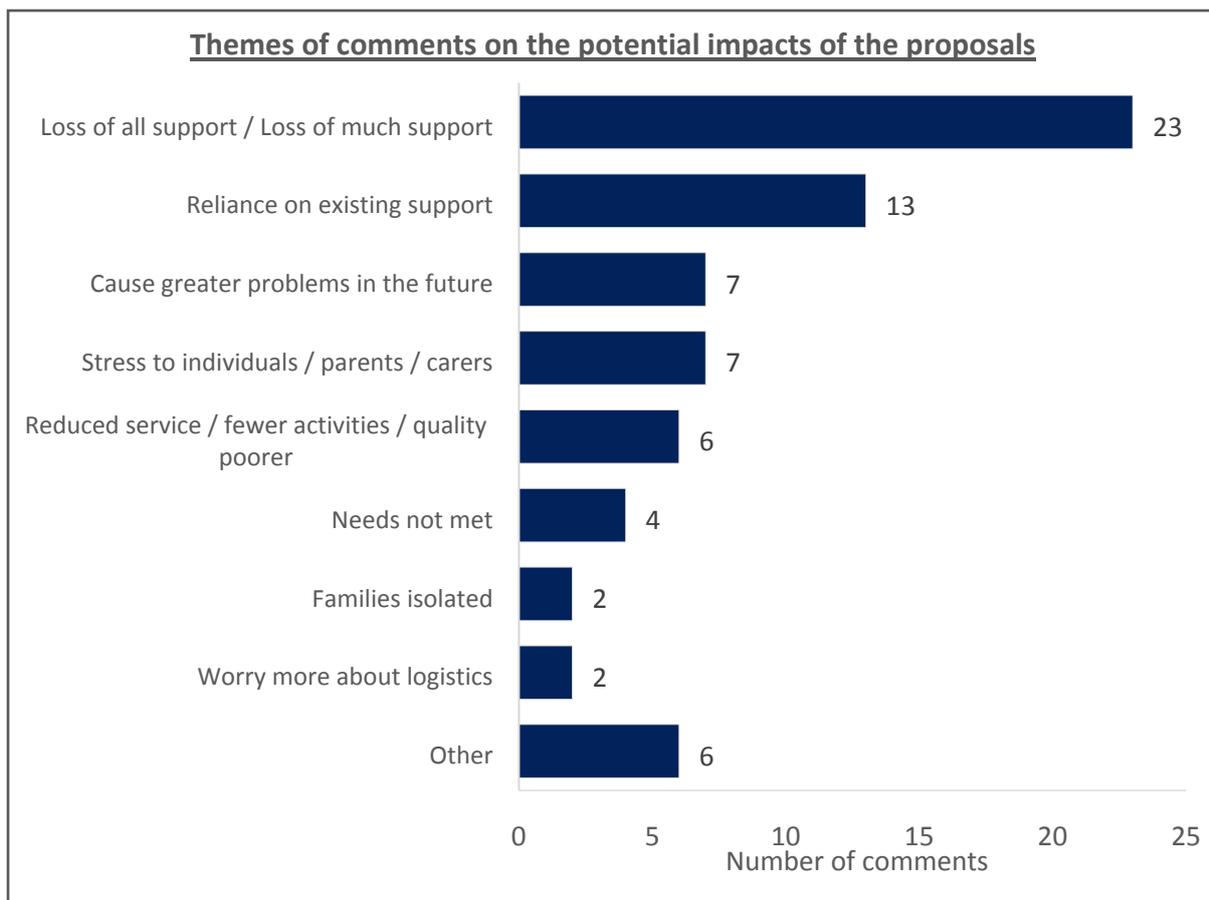
59. The next question within the questionnaire asked respondents what impact the proposals would have on them or their community if they were to be implemented (See figure 13). Overall, 2% of respondents felt there would be no impact at all and 16% felt there would not be much of an impact which suggested around 19% of respondents felt there would

be little impact. In comparison 73% of respondent felt the proposals would have a moderate or significant impact on themselves or their community. Of this, 39% felt there would be a moderate impact and 34% a significant impact.



*Figure 13*

60. Respondents were then asked to outline any personal impacts or equality issues that may have been overlooked in the formation of the proposals. Figure 14 shows the themes of comments provided and the number of people that provided a response on this within the questionnaire.



*Figure 14*

61. The most frequently written concern and impact of the proposals was the loss of all or much of the support that the individual currently receives. A total of 23 respondents mentioned this within a comment on the questionnaire. The following examples encompass the sentiment of these comments:

*“Lots of disabled people would fall between the cracks and not get any choice in what they are offered, (or get no help at all), if they are not classed as the most severely disabled.”*

*“Reading the criteria it is likely my son will meet the Medium level and therefore lose the personal budget we have used to enable him to enjoy 1:1 support. This allows him to feel independent and allow for us to undertake activities with our other child that is too difficult for our son.”*

*“My son accesses Mencap and for him this is a life line I honestly don’t know how he or we would manage if he wasn’t able to attend, he won’t care about changed or availability.”*

*“Please, please don't affect my son's respite and his short breaks residential respite. Without this he couldn't function and I couldn't function!”*

*“I know there’s a need to reach families that need help but just worry for some that are already receiving help that then may be taken away.”*

62. In total, 13 people wrote about their reliance on the service currently and how this would be impacted by the proposed changes. The following comments are examples:

*"You must understand that for families like mine who have completely relied on the support and overnight breaks that we get from Jigsaw to change at this juncture in time to something different before going into adult services is completely unreasonable unfeasible and I would not hesitate to take action about it"*

*"The only reason I can work is through the support I get through DLA Buzz direct payments and having a carer who I top up her hours so I can work full time."*

*"This service is a lifeline to a lot of families and helps families feel valued in the role they do on a day to day basis."*

*"everyday people that rely on the services that will be affected a by a great deal."*

63. Seven people expressed concern over a reduction in support leading to greater problems in the future. Examples include:

*"we will end up with more families in crisis which will lead to more of these children/ young people in boarding schools or care."*

*"This will have negative impact upon the community, as they live in the community and will be a burden rather than a useful asset if they do not receive the help they need."*

*"Families have to get to crisis point before they get additional appropriate support from social services."*

*"To get a respite would help so much to recharge and continue what we do rather than becoming ill or any injuries would mean someone would have to come in and take over."*

64. Seven people wrote about the stress that the proposed changes would cause the individuals, parents and carers. Comments included:

*"Lots of money will be wasted making assessments, which will be instructive, and an invasion of privacy to what is already a stressful life with a child with a disability."*

*"I'm actually lying awake at night worrying about this ! I had one breakdown before we got our respite package I do not intend having another by having it taken away from us."*

*"He would not feel comfortable accessing groups due to the noise and his difficulties engaging with others due to his autism."*

65. Six people spoke about the impact of proposals resulting in a reduced service, with fewer activities and poorer quality. Examples of quotes encompassing this theme include:

*"I worry about whether there will be enough subsidised activities for my children's ages and needs, and where they will take place."*

*"it is a pity that SCC is downgrading the service they offer to MOST disabled young people."*

*"The money has helped us do so many fun things a lot of memories just worry without the budget if we could still make these memories"*

66. Four people felt that the needs of the individual would not be met if the proposed changes were to be implemented. Quotes include:

*“Funding across the city has been cut and support is being cut so to do this is another step in the direction of not looking after the most vulnerable people are disabled children and young people”*

*“It is only through a personal budget that many disabled people can have their needs meet, and the taking away of this choice is to put most disabled people in Southampton at a disadvantage”*

67. There were two comments relating to families potentially becoming isolated as a result of the proposals. For example:

*“They didn’t provide any dates over Christmas and Christmas was a nightmare because of it, we were unable to go out of the flat for one day...therefore we spent more than a week without getting any fresh air as I have very limited family support and my son won’t even walk to the corner shop”*

68. Two respondents expressed concern over managing the logistics themselves as a result of the proposal. For example:

*“One of the benefits of the personal budget was not having to worry too much about logistics; the proposed changes restrict us a lot more.”*

69. There were a number of further impacts that respondents raised in relation to the impact of the proposals. These included the following comments:

*“Please remember that a large proportion of children with special needs can not manage change, and if you take away services that they currently access or allow them to access through buzz, jigsaw or the payments then this could put a huge pressure on the child and their families”*

*“You will need to carefully consider the impact on the children themselves. For some, it has taken years to build trusting relationships, e.g. with care workers and to have that suddenly taken away can lead to some serious repercussions.”*

*“some families who currently receive the buzz fund may not be able to afford doing things without this help. For example i pay for my son's swimming lessons with his and if i didn't receive the buzz budget i wouldn't be able to afford to take him. And on other days out so it really helps us.”*

70. The final question relating the proposed short break service offer asked for any further comments that the respondent may have. When analysing the free text comments from the questionnaire, all comments from all questions were analysed and categorised together. For example, if a respondent commented on the eligibility criteria in this free text question that comment will have been regrouped with all other comments on the eligibility criteria to ensure that an accurate picture of opinions can be calculated across the entire consultation. A lot of the comments submitted within this question related to a specific part of the consultation and have therefore been included and counted in the themes of comments reported on the proposed criteria, service offer, alternatives and suggestions and impacts.

71. Themes of comments for the question “any further comments” included:

- a. There were 13 people that commented positively on the proposals generally.

- b. There were 7 people that commented on the consultation process. These comments will be discussed later.

72. The positive comments generally on the proposals included:

*"I appreciate all the hard work the SEND team and the parent carer forum have put in to this proposal. There certainly is more of a parent and young person's voice in Southampton over the last year or so."*

*"I can see clearly it needs to change. I fully understand that."*

*"I am very excited by the proposal. As a social worker in young people's palliative care I am frustrated by the length of time for assessment and the lack of opportunities for many young people who are life limited."*

*"I think it's amazing that the SPCF has worked so hard to include every family no matter how little or how much affected. It is definitely time that Southampton families in need of help, support & respite breaks get what they do desperately need. The Southampton parent carer forum is incredible & long may it continue."*

*"From what I have observed myself the system definitely needs redefining as some families in Southampton do have access to loads of help whilst everyone else struggle alone."*

#### **Public sessions feedback**

73. A total of 52 parents/carers attended the sessions as well as 10 representatives from short break providers or schools. A Facebook Live session was held on 8<sup>th</sup> February and has been viewed 677 times. Full details of all session dates, venues and attendance is provided below.

<b>Date &amp; Time</b>	<b>Venue</b>	<b>Number of attendees</b>
22/11/17, 10am-1pm	Rose Road Association	8
28/11/17, 11am-1pm	Civic Centre (Providers only)	7
11/12/17, 10am-12	Springwell School	2
10/01/18, 10am-12	Great Oaks School	3
15/01/18, 6-8pm	Southampton Mencap	3
24/01/18, 5-7pm	Civic Centre	6
29/01/17, 1pm-3pm	Rose Road Association	10
07/02/18, 10am-12	Rose Road Association	20
08/02/18	Facebook Live	677 views

74. The main areas of feedback from the sessions was:

- Negative views on the use of the term 'critical' within the 4 eligibility levels. 'Complex' was suggested as an alternative
- Suggestions of closer working with other local authorities to have the same/similar short break offer
- Concerns about the personal budget no longer being available at the medium eligibility level and the impact this would have on families

- Questions around how the proposals (if agreed) would be implemented and whether new assessments or re-assessments would be required
- Suggestion that schools could be used to provide more short breaks at the weekend and during school holidays
- Lack of short break provision for children aged under 5 years
- Concerns about whether mainstream community activities would be sufficiently skilled to support children with disabilities or additional needs, particularly those with autism.

75. Questions around how the quality of community activities will be monitored.

### **Other feedback**

76. Three written responses were received separately from the online survey or consultation sessions. Two were from short break providers - Royal National Institute of Blind People (RNIB) & Southampton Mencap - and one was a transcript of a Facebook conversation and poll of families on the proposals.

### **RNIB**

77. The response from RNIB focussed on the proposed eligibility criteria. They expressed strong disagreement with the proposal and were concerned that the eligibility banding (low, medium, substantial & critical) would introduce unfair barriers to accessing short breaks and make a decision about the person before an assessment is put in place. RNIB did not comment on the proposed service offer or whether the service names should be changed.

### **Southampton Mencap**

78. The response from Southampton Mencap was broadly supportive of the proposals. However, they expressed concerns about some aspects of the new eligibility and service offer, in particular:

- The effect on families of the removal of personal budget option for those at the medium level
- The significant work involved in implementing the proposals
- The challenges of supporting mainstream activities to apply for funding and to adapt their services
- The importance of specialist playschemes continuing to be available

### **Facebook Poll and Feedback**

79. A poll was set up on Facebook during the consultation by a parent interested in finding out people's views on the Buzz personal budget and One2One service. 136 people took part in the poll with the following results:

- The Buzz Budget of £200 really helps our SEN child and we want to keep this in the future – 103 votes
- The budget helps us taking our son on trips and fun activities that really help his condition – 20 votes
- The respite 1:1 service really helps our SEN child and we want to keep this in the future – 10 votes

- I currently receive the personal budget but would choose the 1:1 service if the waiting list was shorter – 3 votes
- I don't need the personal budget or 1:1 service and would not miss it if it was scrapped – 0 votes

80. The main areas of feedback were:

- Concerns about the long waiting list for 1:1 support through Buzz
- Concerns that removal of the personal budget option would reduce the choice available for families

81. Positive feedback about the 1:1 service

### **Feedback on the consultation process and approach**

82. The council is committed to make the whole consultation process as transparent as possible. As a part of this, any feedback on the consultation process itself received during the course of the consultation is summarised in this section.

83. Overall, out of the 99 people who answered the consultation questionnaire, a total of 7 people commented on the consultation process itself.

84. The comments made regarding the consultation process are shown below:

*Without full disclosure of the preferred option and what it entails this consultancy is flawed and is open to challenge due to not being sufficiently informed of the impacts of the choices offered.*

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*Alternative what?*

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*I can't really comment until I know what the levels correspond to in terms of the support offered.*

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*I hope the local authority does its utmost to get this consultation out there so that it can gather as many opinions and ideas as possible. I have only become aware of it via the parent carer forum - nothing at all from the Council or from Buzz network.*

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*I'm extremely concerned that all families are not being written to directly as well and you are solely relying on social media and web based media to spread this message. That is not full and proper consultation and could in fact land you in very hot water. I say this as a very long-term user of social media and electronic communication, however I know that family is on very low incomes are relying on pay-as-you-go phones to access any sort of social media and often cannot access web based content unless they either borrow or access computer facilities through libraries or through family and friends. Unless you make family is directly away through the post as well but particularly those who are in these positions then you are not consulting fully. The rationale for these changes has not been explained fully and frankly it should be in plain English and with more frank explanation of why you need to change these things. I am under no illusion whatsoever that whatever Parent feedback you get on this you will take absolutely no notice whatsoever. As I discovered the trouble is that parent forums become another home of the council and are not a fully Acting as a critical friend they are just an extension of bringing in change by the council but they have already been convinced to do it rather than acting as a critical friend. I'm exhausted by everything that's going on punishing families of disabled children and young people and I will be watching this very*

*closely and challenging any legality Around changes but also assessment. You assert that you are not meeting legal requirements at the moment but you don't "the appropriate parts of the Act around changes but also assessment. You assert that you are not meeting legal requirements at the moment but you don't "the appropriate parts of the Act, nor do you explain where you think that you are not acting legally. I am very cynical about this whole exercise and it's also not been publicised outside of social media and web based media which is extremely disappointing given all the feedback that has gone on in the past. The communication from Jigsaw sensually about changes of manager about changes in staff have been abysmal and communication from the bus network has all but stopped for many people with databases not been kept up-to-date and people slipping off the radar.*

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*The impact scales did not allow people to identify if positive or negative impact. Also I felt I had to respond 'neutral' in places as it was not a simple yes or no answer, more of a yes AND no answer.*

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*There needs to be more clarity on the short breaks proposals as to what they would actually mean to current members as I don't know whether I would come into the category of less/ more help than currently provided*

## **Conclusion**

85. The consultation sought views on proposed changes to the short break service offer for children with disabilities or additional needs and proposed changes to the eligibility criteria which allows access to these services.
86. In total, 99 respondents completed the questionnaire which ran for 12 weeks from 21 November 2017 to 12 February 2018. In addition, 52 parents / carers attended sessions on the consultation as well as 10 representatives from short break providers or schools.
87. The demographic breakdown of respondents to the consultation questionnaire showed that whilst certain groups were less represented than others, there was still engagement across a broad ranges of groups.
88. Overall there was a higher level of agreement (74%) than disagreement (14%) for the proposed eligibility criteria and also a higher level of agreement (69%) than disagreement (12%) for the proposed service offer.
89. The most frequently mentioned themes of comments in the questionnaire included: the need to have clear criteria and assessment; the need to take into account family situation during assessment, the wish for a fair level of support across all categories and the potential loss of support that individuals may face.
90. In conclusion, this consultation allows Cabinet to understand the views of residents and stakeholders on the proposals that have been consulted on. Therefore it provides a sound base on which to make a decision.