

Aiming High 2021 Consultation Report

Overview

The Aiming High consultation ran from Tuesday 13 April to Tuesday 11 May 2021 (4 weeks) and aimed to obtain wide engagement from both existing and potential service users, as well as a range of other stakeholders.

People were able to respond via an online survey, a consultation response form or by attending a virtual consultation session. Due to covid-19, consultation sessions were held virtually and information sent electronically wherever possible.

- Information was emailed directly to all families who currently receive a service from Aiming High, those on the waiting list and families who have registered to receive information from Aiming High (approx. 800 in total). Hard copies were posted to families without email access if they were a current service user or on the waiting list.
- The consultation was promoted by Swindon SEND Families Voice, the local parent and carer forum, recognised by the Department for Education and National Network of Parent Carer Forums.
- Information was circulated electronically to a wide range of local services, groups and organisations. This included social care and health services, schools, local short break providers and other local community groups (approx. 240 contacts in total).
- Two virtual consultation sessions were held (daytime and evening), which were advertised and open to all.
- STEP (Swindon) also facilitated a consultation session with young people with disabilities who attend their Thought Tank participation and Saturday Groups.

To view the original consultation documents go to: <https://localoffer.swindon.gov.uk/shortbreaks>

Percentages in this report have been rounded to the nearest whole number.

Respondents

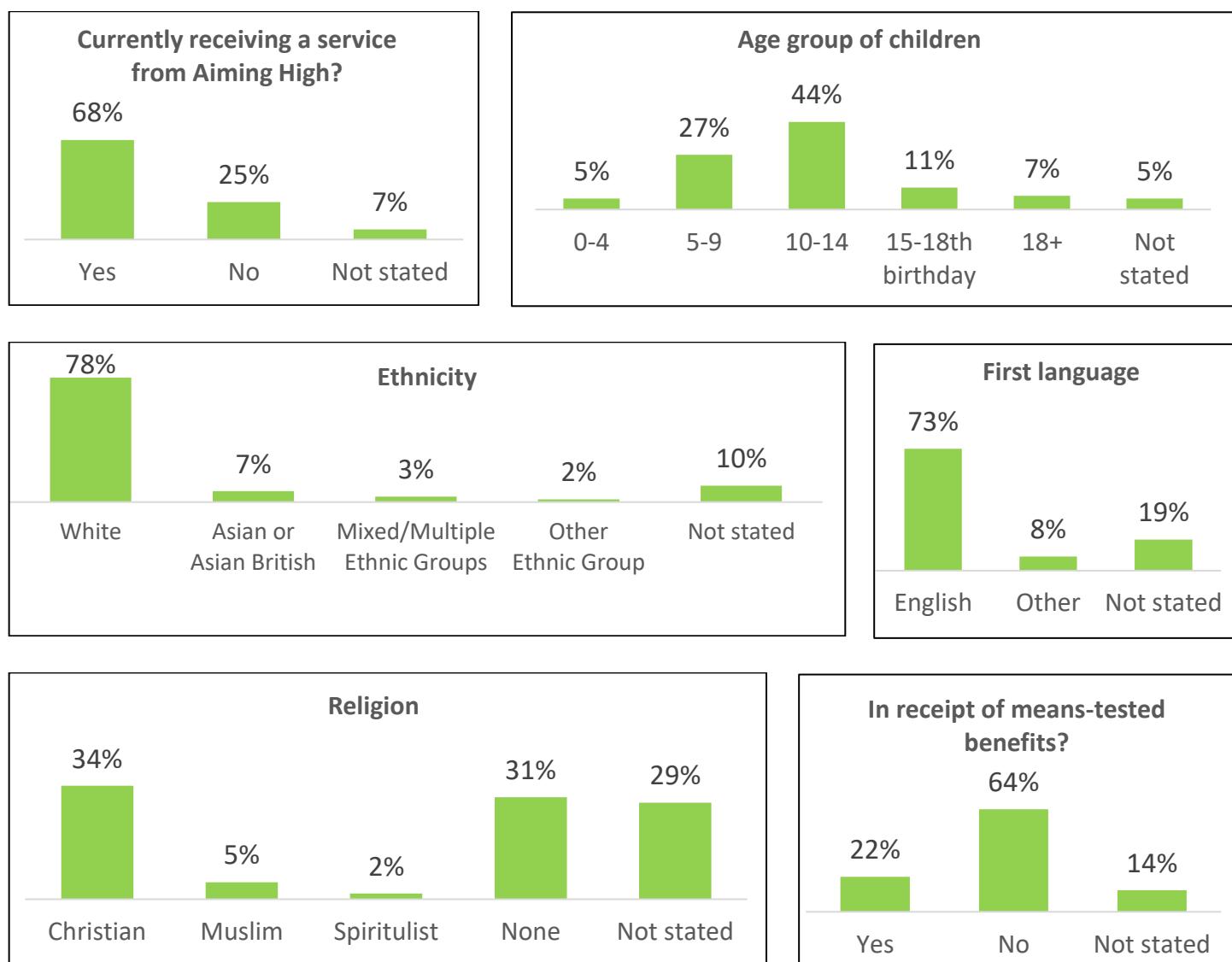
Total responses received:

Response type	Parents / carers	Professional / service provider / representing a group	Young people	Total
Written response	59	24	0	83
Consultation session	7	*	18	25
Total	66	24	18	108

*5 of the 7 parents / carers attending a consultation session had dual roles, also representing a group or acting in a related professional capacity.

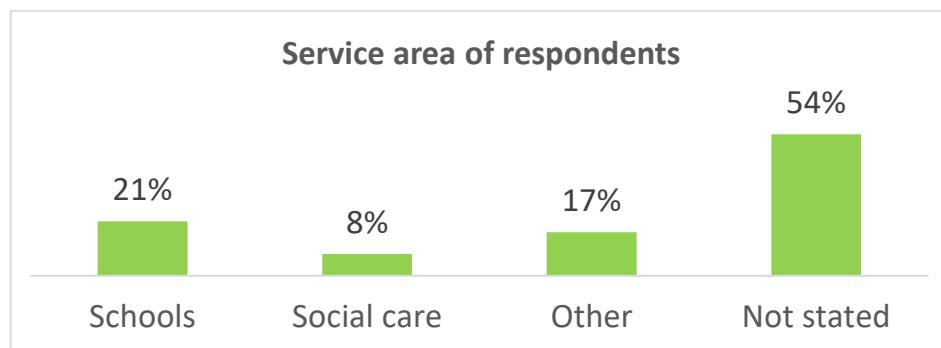
Parents / Carers:

Parents and carers returning a written response form were asked a number of voluntary monitoring questions. This information was not collected at the consultation sessions.



Service providers / professionals / representing a group:

The 24 professionals / service providers who responded came from the following service areas:



Young people:

18 young people with disabilities (aged 11-19 years) took part in the consultation process, facilitated by STEP (Swindon). The group represented a range of disabilities, geographic areas of Swindon and school settings.

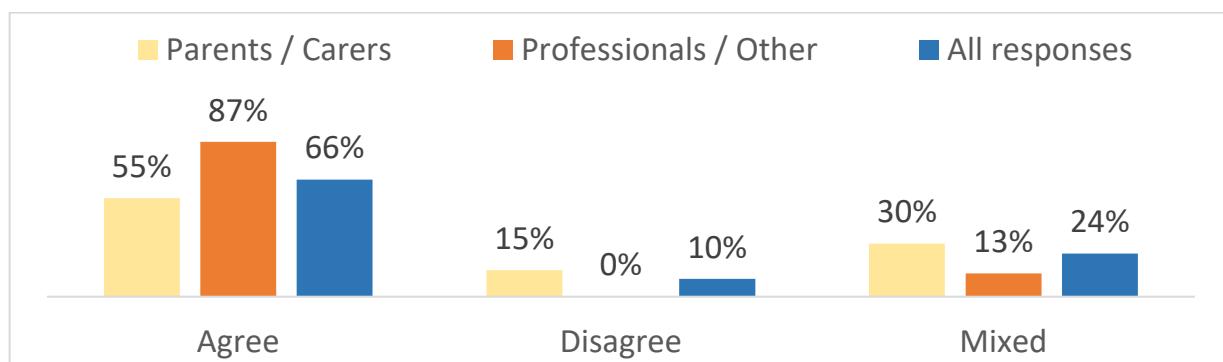
Responses

Questions were open ended (rather than multiple choice), allowing for more detailed comments. Not every respondent answered every question. The information below represents the total responses received for each question. Please note that some comments overlap into multiple themes.

PROPOSAL 1: Changes to the Aiming High criteria and a yearly service update for all children

13 respondents skipped this question. Of the written responses received:

	Parents / carers	Professionals / other	All
Agree	55%	87%	66%
Disagree	15%	0%	10%
Mixed comments	30%	13%	24%
Total responses (100%)	47	23	70



Main themes:

Overall, almost two-thirds of the written responses were broadly in agreement with the proposed criteria changes. This was lower amongst just parent/carers, although still more than half (55%). 10% of all responses disagreed and approx. one-quarter of responses were mixed, with comments for and against the changes.

- Of the 46 responses in agreement with the proposed changes:
 - Many commented that the changes seemed reasonable / fairer / would help ensure resources are focused on those most in need (30)
 - Several noted the annual service update as a good thing, because needs can and do change (8)
 - The need for good communication was raised, to ensure families are given plenty of notice and support with the changes. The timeframe/support needed could vary, not one size fits all (5)
- 17 responses were mixed with comments for and against. 7 responses did not agree with the proposed changes, stating that it set the criteria too high and was too rigid. Themes included:
 - Instead of changing the criteria, more resources need to be put into Aiming High (6)

- Concern that the new criteria would mean some children and families will fall through the gaps (4)
- The annual update would be a cause of stress, worrying each time if services will be taken away (2)
- The consultation sessions (and 2 written responses) picked up on the specific needs of children with disabilities such as autistic spectrum conditions, and felt that the proposed criteria did not take their needs into account. These children may attend another activity and get by, but often mask behaviours and may not get any social benefit. The Aiming High clubs offer a valuable peer group and socialisation, which they do not gain elsewhere. There was discussion about the need to offer support and alternative services for those who would no longer meet the Aiming High criteria if it changed. It was suggested that there could be 'step down' clubs with lower staffing levels, to make this more affordable.
- The consultation sessions also raised the need for better inclusion and training amongst community groups and activities, and how Aiming High could support this. One written response also noted this.
- Other individual comments:
 - The proposal creates more barriers for children with disabilities; would discriminate against children on the cusp of needing support / need to take into account the impact of Covid-19
 - Need to ensure there is consultation with other parent groups to ensure all views are represented
 - Rather than waiting lists, allow more eligible children to register and then have a flexible booking system for groups, so families book ad-hoc as needed / available
 - The new criteria makes sense for groups but not direct payments
 - Provide cash payments for those who are not eligible / do not meet the criteria
- Specific issues about the wording of the proposed new criteria:
 - Some clarifying questions about the criteria – need to make it clear what would happen if a child needs more support; who would determine whether the child is able to access another activity; also need an appeals process.
 - Need to explain why the parent / carer's need for a break has been removed from the criteria.
 - Proposed wording 'we may need to contact other professionals' – parents may see this as a barrier. For example, a child with ASC may mask their behaviour at school, so a school professional may not see the behaviour.
 - 'Not open to the disabled children team' – this is confusing and sounds negative. Need to rephrase this to explain how it works.

Young people's view:

83% (15/18) agreed with the proposed changes

Young people's comments in favour of the proposals:

- Think it is good that they will be checking every year to see if the service is still needed and is the correct service for the child.
- This may give more disabled children a chance to get support.
- Good that the children that really need the support get the help they need.
- I understand that some young people with disabilities have more needs than others and those that need the most support should be able to get it.
- It's better because more young people may be able to get the support they need (if young people maybe only get to go to one club). It's not fair if someone gets to go the Aiming High and STEP groups, they are getting double groups and some children don't have any, they should have to choose, then more children will get a group to go to.
- I think it's fair that we only get to go to one group.
- It's better if more young people get the help if these changes are made.

Young people's comments not supporting the proposals:

- I go to both STEP and Aiming High groups and I do not want to have to choose, it is not fair on me to have something that I enjoy taken away from me, I would miss all of my friends that I have been with in these groups.
- I go to two groups; I do not want to give that up, I think it's fair but how would I choose what group to give up, it would be upsetting for me.
- Unfair that they cannot attend Aiming High if attend another club, is not encouraging young people to socialise.

General observations and questions from the young people:

- If you are told your circumstances have changed and you are no longer able to go to Aiming High services you should be supported by Aiming High to find other options and services.
- Why is the service only available to children aged up to 18 years old, should be open to older young people up to 25 years. What's available social groups wise for young people/young adults aged 19-25 years? This age group has the need for places to go and socialise (with others of the same age as them not adults who are much older) that are safe and supportive.

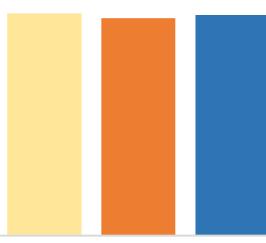
PROPOSAL 2: Price increase

12 respondents skipped this question. Of the written responses received:

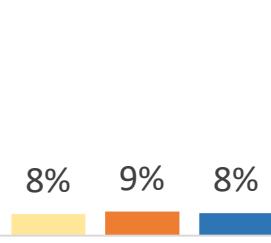
	Parents / carers	Professionals / other	All
Agree	84%	82%	83%
Disagree	8%	9%	8%
Mixed comments	8%	9%	8%
Total responses (100%)	49	22	71

■ Parents / Carers ■ Professionals / Other ■ All responses

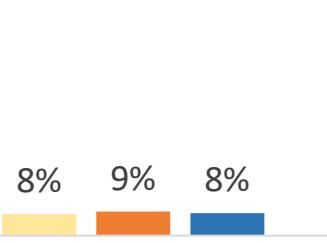
84% 82% 83%



8% 9% 8%



8% 9% 8%



Agree

Disagree

Mixed

Main themes:

Overall, the majority of responses were in agreement with the proposed price increase. 8% of all responses disagreed and 8% were mixed, with comments for and against the increase.

- Of the 59 responses in support of the price increase, many commented that it seemed reasonable and a fair increase. Other themes:
 - Agree with / understand the reasons for the increase, but some families will be genuinely unable to afford this (7). This was also raised during the consultation sessions. Families of children with disabilities may be more likely to have a lower household income and it is important that no child is excluded because their parents cannot afford to pay. It needs to be clear that, where cost is a barrier, families can get in touch to discuss. It was noted that this may not always be based on receipt of benefits and there needs to be a transparent policy.
 - DLA could/should be used to help with this cost (4)
 - Noted that it has been a long time since the last increase in 2016 (4)
- 6 responses were mixed and 6 responses felt that the increase was too much. Individual comments included:
 - The increase would make the groups more expensive than mainstream equivalents
 - Would make the service unusable, create a bigger divide and exclude the most vulnerable
 - Unaffordable for some. Concern that families may lose out; need to be aware of the income levels of families using the service and the impact of Covid-19.
 - Impact on families with multiple children and/or single parents
 - Need to ensure the service supports the silent majority, not just the vocal minority
 - Agree with the increase but feel their particular service is not worth the extra cost
 - Suggested a smaller increase
 - Need to be transparent about where the money goes. Could it be used to help increase the groups?

Young people's view:

67% (12/18) agreed with this proposal.

Young people's comments in favour of the price increase:

- Yes, think that's fair.
- If it's a club you really want to go to then you will pay the extra money.
- Yes, as will raise more funds to make the service better.
- Yes, £3 per hour is reasonable.

Young people's comments against the price increase:

- No, because it costs more to do the same thing.
- No, because parents would then have less money to spend on other things for the rest of their family.
- Not good for poorer families with children that need extra help, not sure it's fair BUT do understand that kids with disabilities may cost a bit more to support.

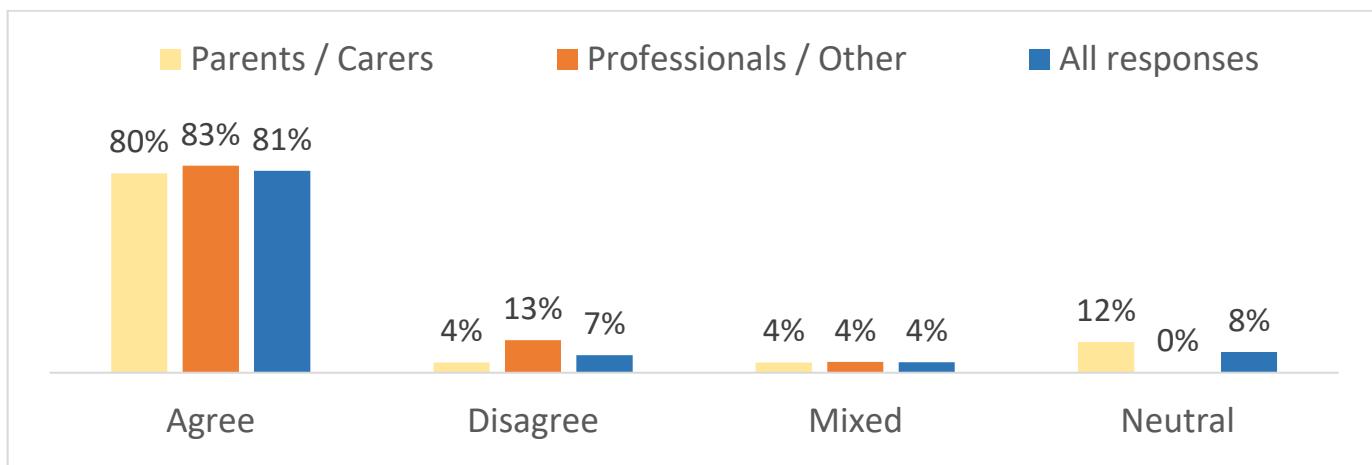
General observations and questions from the young people:

- Would it be free or at a lower price to families on benefits or who really do not have the money to pay for the sessions? Families should not be excluded because they can't afford to pay, they could be the most in need.

PROPOSAL 3: Transport charge

11 respondents skipped this question. Of the written responses received:

	Parents / carers	Professionals / other	All
Agree	80%	83%	81%
Disagree	4%	13%	7%
Mixed comments	4%	4%	4%
Neutral	12%	0%	8%
Total responses (100%)	49	23	72



Main themes:

The majority of responses were in agreement with this proposal.

- Of the 58 responses in support of the charge, many commented that it seemed reasonable and fair. Other themes included:
 - Need to take into account that some families will be unable to afford the increase – cost should not be a barrier (5). This was also raised during the consultation sessions. As with proposal 2, it was felt that a clear policy for concessions would be needed.
 - DLA could/should be used to help with this cost (5)
 - Other parents transport their children to groups and pay for petrol / wear and tear, and it takes up their time (3)
 - Need to clarify what the 'exceptional circumstances' are in order to qualify for transport (2)
- Of the 5 responses not in agreement, themes included:
 - Concern that the charge could impact on those most in need / exclude the most vulnerable. If a family already meet the exceptional circumstances for providing transport, this cost may make the service inaccessible for them (8)
 - Not enough of a saving to make it worthwhile (2)
 - To go from free to £3 is quite a jump (1)
- 3 respondents said that transport should be available to all, at higher / cost price.

Young people's view:

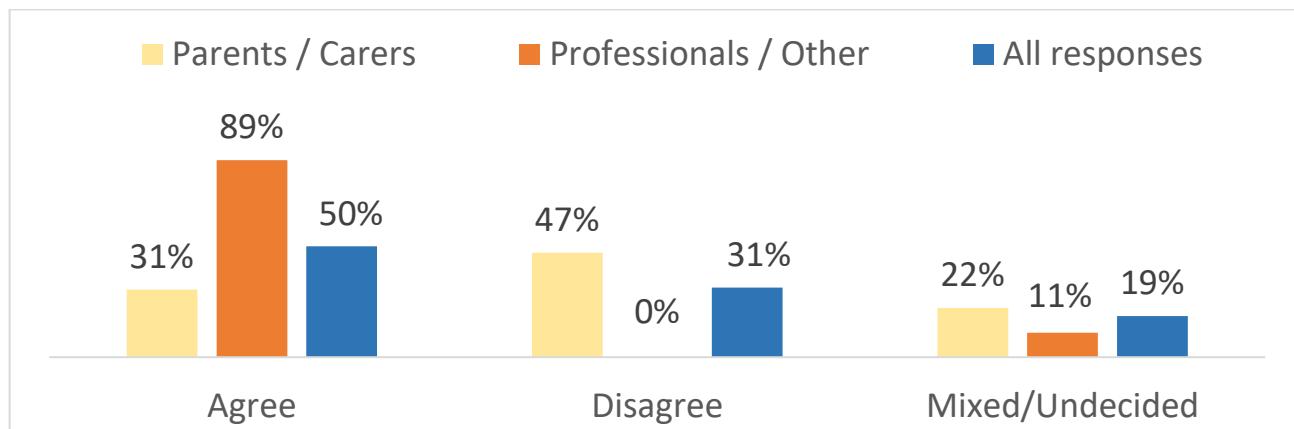
The majority of young people were **not in favour** of this additional charge (80%):

- Bit too much, as well as the price increase being asked per hour to attend the sessions, should be one increase or the other.
- Not fair if families are poor, it could mean they can't come to the group because they can't afford to pay for the transport.
- All these increases in cost may force people who need the support to leave.
- Could exclude families who don't have enough money.
- The 20% that supported this increase said that it is a good way of getting additional money in to make the Aiming High service better.

PROPOSAL 4: Charge for direct payments

29 respondents skipped this question. Of the written responses received:

	Parents / carers	Professionals / other	All
Agree	31%	89%	50%
Disagree	47%	0%	31%
Mixed comments	22%	11%	19%
Total responses (100%)	36	18	54



Main themes:

The response to this proposal was very mixed. This was also reflected in the consultation sessions, with views put forward for both sides. Some responses felt strongly that there should be a charge and others felt very strongly that this would be unfair. The response varied across different types of respondents; most professionals supported the proposal, whilst more parents and carers disagreed.

Some people found this proposal confusing and felt they could not comment. The proposed 'charge' would be deducted from the child's direct payment funding upfront, with a reduced amount being paid to families. The family would then need to top this up as their charge (or just have less hours of support).

- Of the 27 responses that were in support of this proposal, the main reasons stated were consistency and fairness across all services. Other comments:
 - Any charge should be applied to **all** direct payment users, not just new direct payments set up after the consultation. This feedback came from a combination of those who supported the proposal, disagreed with it and those who were undecided. (12)
 - Would need to be gradual and well explained / need to flag up very far in advance. Perhaps phase in for existing users, giving them plenty of notice to prepare for the charge (4)
 - The estimate £5k saving would allow more families to have a service (1)
- 10 respondents were undecided or had mixed views on this proposal.
- Of the 17 who disagreed, many felt very strongly about this proposal.
 - Direct payment users already have to pay for activities and this would be an unfair extra charge (9)
 - There is a difference between the service types – children attending groups access a building, staff, set activities and a planned session. Families receiving direct payments don't have access to this, and also have to do a lot more work themselves – paperwork, employment etc. (5) One response raised that the administration/staff costs of direct payments is negligible compared to running the Aiming High groups, and this should be taken into account.
 - Families may just choose to have less hours rather than pay a charge (4) – some saw this as a positive choice whilst others said this would be a negative.
 - For some families direct payments may be their only option, so it is not fair to charge them when they have no choice (2)
 - Direct payments only cover pay of £10 per hour for workers, which is not a lot. Some families top this up out of their own money. The additional charge would mean even less of a service (2)
 - Would cause additional complications with the payroll process (1)
 - May push people towards other services (e.g. groups) and add to already long waiting lists (1)
 - May push people towards requesting a social care assessment (1)
 - Need to review all aspects of direct payments (1)
 - The consultation sessions raised the question of whether families should be offered a cash grant instead of direct payments. However this would mean families would not be able to employ a worker, as there are additional factors such as insurance, payroll, training etc that need to be covered.

Young people's view:

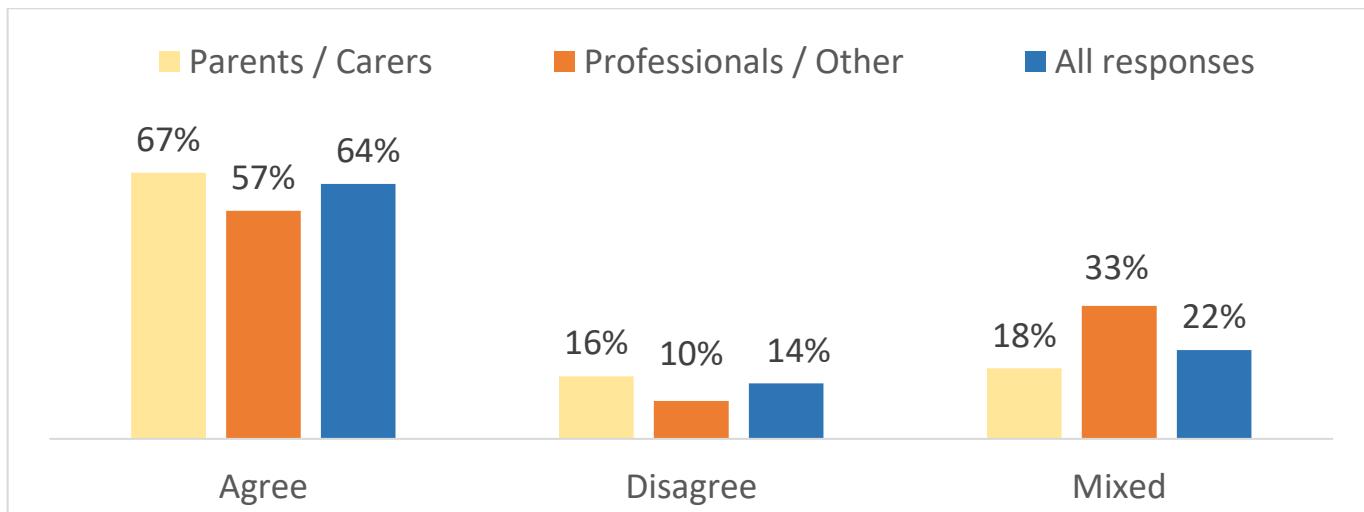
The young people found this question difficult to understand (30%). However, the following comments were made:

- Don't think it's fair if only new families had to make the payment. If they are going to make the change it should be for everyone, new and old. That's the only fair way to do it.
- Think it's good that any savings made will go back into helping more disabled children and making the service better.

PROPOSAL 5: Small grants for children on long waiting lists

11 respondents skipped this question. Of the written responses received:

	Parents / carers	Professionals / other	All
Agree	67%	57%	64%
Disagree	16%	10%	14%
Mixed comments	18%	33%	22%
Total responses (100%)	51	21	72



Main themes:

- Overall, almost two-thirds of responses were broadly in agreement with this proposal. Of the 46 responses supporting grants, many commented that this was a good way to offer some form of support to those waiting for a service, and enable parents to buy some useful resources to support their child. However two main areas of concerns were raised, and this came from a mixture of those who agreed with the grants, disagreed and had mixed views:
 - The money would be better spent on increasing the number of groups, or offering it to other providers to run groups. Need to stick to Aiming High's core aim, which is inclusion. Giving out grants does not address the core issue. (14)
 - How would this be monitored to ensure it is spent appropriately? Who would decide what purchases would be appropriate. Some felt that previous grants during covid-19 had not always been spent appropriately. (13)
- Other comments raised:
 - Suggestions of more controlled ways to offer resources e.g. vouchers or an in-house toys/ tech/ equipment library (5)
 - Use the funding to run stay and play sessions instead, or to enable access to other SEN friendly sessions run by other providers (4 and also raised during consultation sessions)
 - Wait to see the impact of the other proposals first – particularly proposal 1 (criteria), before making a decision on grants (2)

- If grants go ahead they should be means tested (2)
- Could Aiming High provide training courses/support for staff from other service providers so that those providers build confidence to support disabled children, building inclusion in the wider community? (1)
- There are other places families can apply to receive grants (1)
- Have a rota to share out the available spaces instead (1)
- Could be less than £150 (1)
- Should allow children to receive another service whilst on the waiting list (1) (*This is already possible; the grants would be for children where there is no other suitable service in the interim*)

Young people's view:

100% of young people agreed with this proposal:

- Yes, think this is a good idea.
- It's fair that families that are waiting should get something, it's not their fault they are having to wait for a long time.
- Yes, it's a good idea as long as families getting the money spend it on their children / supporting them.
- It's not fair that they have to wait so it's fair they get some money to spend on their child.
- It would give indirect help, which is good.

PROPOSAL 6: Updated Short Breaks Statement

17 respondents left comments about the Short Breaks Statement. The young people made no comments on this question.

Main themes:

- Keep the Statement current and concise, make sure it is clear and easy to understand
- Consider an easy read summary / video
- Good to have the information all in one place
- Update the definitions especially regarding disability
- Update the local needs assessment
- Clarify / update the section on Early Help Plans / assessments, and how EHCPs fit into this
- The outcome quotes are useful and help people relate

Other comments

37 respondents left other comments. The young people made no further comments.

Main themes:

- Many comments were about the importance of Aiming High and preventative short breaks (23). Themes included: How much Aiming High has helped families; the quality of the staff and level of knowledge and training; the importance of short breaks to prevent needs escalating:
 - *This service is an essential lifeline to many children and their families.*
 - *Aiming High is the only support my child will access due to her anxiety. The staff have always supported her and encouraged her to do activities.*
 - *Aiming High is a godsend for my eldest son, who loves this group.*
 - *This is great service and the help it's given to my daughter is amazing*
 - *My son attends the monkeys group once a month. It is the only place he looks forward to as there are no other places we can take him.*
 - *My son used aiming high for 13 years and has just left the service as he's 18. It is a wonderful service and the volunteers are amazing.*
 - *Aiming High has been a life saver for our family! Even 4 hours a month makes so much difference for my son. He is so happy to go there! The staffs are friendly and very nice too. I wished they provided longer other kinds of sessions/ respite too.*
 - *Aiming high is an absolute life saver of a service , my kids love going to group especially in holidays they have made new friends . So thank you so much for all the support you have given us*
 - *my son greatly values and enjoys the group he attends, it is a chance for him to be away from us, independently. (as well as being a child with additional needs he is also a young carer too.)*
 - *I value his access to groups highly and he loves going (which is unbelievably nice to be able to say as he struggles so much with so many things).*
 - *I've always found the short breaks team fantastic and also the services provided are brilliant.*
 - *Aiming High helps to prevent and delay children entering into statutory social care services, perhaps this data could be used as evidence.*
 - *If early intervention isn't happening then a knock on affect later down the line will Cause many families looking at foster care and or even residential schools placing many outside of the Local Borough.*
- Gaps in short break services / need for other options (9):
 - Need for overnight short breaks (3)
 - Need for grants (2)
 - Building independence in the community (2) (consider refreshing the group structure)
 - Gap for children with autistic spectrum conditions and ADHD (1)
 - Autistic spectrum condition are over-represented; other needs such as ADHD are not as well catered for (1)
 - Hard to find direct payment workers (1)
 - More resource needed for Direct Payment Support Advisor (1)
 - Lack of options for those under 6 (1)
- Need better awareness about Aiming High (6):
 - What efforts are being made to ensure all relevant families know about Aiming High?

- Families who need Aiming High support should be referred, not told to ring a number
- How do struggling families find out about Aiming High?
- Need greater visibility in the SEN community
- Send information to all schools, have information sessions at different times, topic based meetings for parents and carers, have training available and parent support groups that can meet up.

- Need to increase the service (4):
 - Child loves coming to groups, wish they could have more / wish more children could get a space (2)
 - Consider increasing the capacity of the after school, Saturday and school holiday groups. This may mean more money needs to be spent on Aiming High. Important to respond to the children on the waiting list as they are indicative of the current unmet need across Swindon. (1)
 - Look for grants / lottery funding / sponsorship; think outside the box (1)

- Other comments raised:
 - Don't just rely on one parent group; work with other groups such Swindon Carers Centre and Swindon Advocacy Movement to gain wider views (2)
 - Miss the wider family support offered by the old Hop Skip & Jump (2)
 - Ensure no family suffers as a result of these changes (1)
 - Try and address the root causes and not the symptoms otherwise the problem will persist in future (1)
 - Offer of support with arts based activities from local cultural organisation (1)
 - The work associated with direct payments can feel overwhelming for families (1)
 - More support / structure for parents in managing their hours would be helpful (1)

Next steps

The findings from the consultation will now be taken back for review, to help inform the final decisions about changes to the service. We will keep you updated on the next steps through our Aiming High contact lists, the short breaks webpage (<https://localoffer.swindon.gov.uk/shortbreaks>) and through Swindon SEND Families Voice.

If you have any questions about this consultation please contact Aiming High on 01793 464080 or aiminghigh@swindon.gov.uk .