

This purpose of this report is to bring together responses from public consultation to inform the decision making process in relation to the 0-25 short breaks element of the IIS business case

Aiming High Short Breaks Public Consultation Report

IIS 0-25 Business Case

Cath Millington. November 17th 2014

Final Consultation Report

0-25 IIS Proposal

Short Breaks Element

Executive Summary

This report brings together the responses to the public consultation in relation to the aiming high short breaks 0-25 IIS business case. The consultation commenced on the 8th September 2014 and closed on the 15th November 2014. There has been a large response to the consultation from parents, carers, providers and professionals, totalling 317. This is 65.9% of the 481 families and providers contacted, although other respondents could have completed the questionnaire online. A number of views were expressed by direct email or letter; these have also been included within the report. The full collated reports of all responses from parents, carers and providers are available on request.

There is a predominantly strong disagreement to the proposals with 253 (85.19%) either strongly disagreeing or disagreeing with the proposal. Only 23 (7.74%) of respondents either agreed or strongly agreed with the proposal. 297 (93.6%) answered this question.

There has been a large amount of free text submitted around the potential impacts of the proposals, which have been grouped into:

- *Reduction in supporting families to stay together.* Families and providers report that this would have potentially devastating impact on some families as they would not be able to cope without these breaks. Parent/carers also use the respite time to spend time with siblings. By accessing the short breaks, families report they are able to 'recharge' their batteries and it enables them to continue to care for their children.
- *Impact on the child to develop to their full potential and on their well-being.* It is reported that short breaks enable children, who are usually isolated within their own homes, to meet together and form valuable friendships whilst learning social and independence skills.
- *Lack of access to other provision.* Families and providers report that there are no other activities that many of the children and young people who access this service can engage in due to levels of need and disabilities.
- *Potential impact on social care.* Many respondents felt that this proposal would have a substantial impact on social care, with families reporting they would need a social worker if they could not access aiming high. This could also lead to more costly respite provision in the long run.
- *Reduction in preventative services.* It was felt that this proposal was going against the council's priority for investing in preventative services, and families will end up in crisis.
- *Potential impact on the voluntary and community sector.* Providers felt that alternative funding streams were no longer available, as these routes had been saturated and parents would not be able to afford the provision either through personal budgets or without the subsidy provided through aiming high.

- *Legalities.* Many families have raised questions in relation to the legalities of this proposal relating to the Breaks for Carers of Disabled Children Regulations 2011 and other current legislation
- *Stockport's Current Model.* Providers felt that Stockport's current short breaks model was an exemplar project across Greater Manchester and that it kept families together and prevented the need for more costly health and/or social care interventions.
- *Alternative solutions.* Two respondents did talk about alternative solutions which included the use of personal budgets and there could be a potential to use more volunteers and set up co-operatives in local communities.

Background

The purpose of this report is to bring together the consultation findings of the short breaks aiming high element of the 0-25 IIS proposal. The aim of this element of the proposal is to reconfigure short breaks and respite provision for children and young people with special educational needs and disabilities who are not eligible for social care intervention and respite. The service currently provides short breaks for families and children including one to one support, commissioned group based breaks and individual direct payments.

The proposal is to reduce the current budget from £400,000 to £100,000 over the next two financial years.

Methodology

The consultation commenced on the 8th September 2014. 468 questionnaires were posted out to families who have used the short breaks service over the past 12 months and questionnaires were also emailed to those families we had email addresses for, as duplicates to the postal questionnaires. A separate questionnaire was developed and given to providers of the short breaks commissioned (13 providers) and available for other relevant professionals to complete. Accompanying the questionnaire was a summary of the proposal and a frequently asked questions information sheet in order to explain the proposal in more detail so that people could make an informed response.

Three focus groups for parents and carers (20 attendees) have been facilitated by independent consultants Mustard; and one for children and young people (3 attendees) who have used the service, this adopted story telling techniques. One focus group has been held for providers of short break services, (8 organisations) again facilitated by Mustard. Where providers could not attend, an in-depth telephone interview was undertaken the feedback from these focus groups is incorporated into the thematic headings below.

- **Return Rates**

There have been 317 responses to the consultation in total, which is 65.9% of the questionnaires sent out (although other people could have responded via the online link). These are broken down into:

- 149 (47%) respondents to the online questionnaire for parents and carers

- 118 (37.22%) respondents to the paper questionnaire for parents and carers
- 50 (15.77%) respondents to the online questionnaire for providers and other staff

In total:

- 248 (78.23%) were parent/carers of children with a disability
- 1 (0.32%) was a parent/carer of a non disabled child
- 1 (0.32%) was a sibling of a disabled child
- 19 (5.99%) were short break providers
- 27 (8.52%) were other professionals working with children and young people with a disability
- 16 (5.05%) respondents stated themselves as 'other'
- 199 (62.78%) respondents were parents and carers whose children accessed a short break from the service.

Summary of Respondents Data

Gender	Male 34 (12.5%)	Female 229 (84.19%)	Not Answered 9 (3.31%)
Disability or limiting long term illness	Yes 49 (18%)	No 208 (76.47%)	Not Answered 15 (5.53%)
Ethnic Group	White 240 (88.56%)	Mixed 5 (1.85%)	Asian/Asian British 6 (2.21%)
	Black/Black British 6 (2.21%)	Other 3 (1.11%)	Not Answered 11 (4.06%)
Religion or Belief	No religion 60 (19.93%)	Christian 97 (32.24%)	Muslim 3 (0.99%)
	Hindu 2 (0.66%)	Buddhist 0	Jewish 0
	Sikh 0	Other 5 (1.66%)	Not Answered/Asked 134 (44.53%)
Age	Not Answered 120 (38.09%)	10-15 2 (0.63%)	16-25 4 (1.27%)
	26-35 34 (10.79%)	36-45 74 (23.49%)	46-55 76 (24.13%)
	56-65 5 (1.59%)	66-75 0	75+ 0

Results

We asked respondents to let us know to what extent they agreed/disagreed with the proposals. Of the 297 respondents that answered this question:

- 211 (71.04%) of those strongly disagreed with the proposal (177 parents and carers, 34 providers and professionals)
- 42 (14.14%) disagreed with the proposal (33 parents and carers, 9 providers and professionals)
- 11 (3.70%) neither agreed or disagreed with the proposal (11 parents and carers, 0 providers and professionals)
- 12 (4.04%) agreed with the proposal (10 parents and carers, 2 providers and professionals)

- 11 (3.7%) strongly agreed with the proposal (10 parents and carers, 1 provider and professional)

We asked respondents to let us know what the potential impacts of the proposal could be. There is a large amount of open text submitted within the questionnaires and an attempt has been made to group this into themes. The below also incorporates the feedback from the focus groups held.

- **Supporting families to stay together**

Many respondents highlighted the short breaks provision helped families to “recharge their batteries”, “continue to care” and “spend time with other siblings in the family”. Families and providers state that “families rely on this service to keep them going and that it would be devastating for families if this service no longer existed and would lead to family breakdown”. “We would have no help in the summer holidays and I would become a prisoner in my own home”.

“Some families will regularly have no sleep and are dealing with complex and challenging behaviours - they are desperate for a break. We are not talking about children who just need a boost to their social skills”. Many parents and carers talked about their own mental health and how this proposal would have a negative impact on their mental health if they could not access breaks for their children. Many families also reported being isolated with no family support network around them. “I am a working single parent and direct payments give me the only respite I get. The quality of family is already pretty; low, but without respite it would be non-existent.”

- **Impact on the child to develop to their full potential and on their well-being**

Here families talked a lot about the value of group activities through aiming high, where they have helped them to “make friends with like-minded children” and children have reported “it is the first time they have found a friend”. “The breaks have enabled children to build confidence and social skills”. Parent/carers reported that the short breaks were the only “safe environment where they felt confident in leaving their child”. Families reported that the breaks help them to understand acceptable and unacceptable behaviour and providing a shared experience in a more mainstream setting. Many families reported there would be nothing else for their children to engage in if the short breaks were not available. “My son would be permanently house bound other than school hours.....Aiming high helps him to socialise which is a valuable lesson in life and if taken away would cause childhood depression”. “It would be devastating for my child, he cannot lead a ‘normal’ life and it would have a huge negative impact on him rendering him a recluse”.

“ADAPT is the panel who take newly diagnosed children from CAMHS and plan their care. 90% of these children are referred to the ASD partnership and aiming high... This proposal will impact on our discharges and omit a vital step in their care plan”.

- **No access to other provision**

21 (9.38%) families reported there were other short breaks their child could access that are not provided by the aiming high short breaks service. When these were listed, some of them are funded by the aiming high service and others would need to be privately paid for, which many stated they could not afford. 90 (40.18%) felt there were no other short breaks for their children due to their needs. 113 (50.45%) did not know if there were other services they could potentially access for a short break.

It is reported that “a lot of the children that access these breaks cannot access mainstream provision and if the proposal goes through there will be nothing for them. This will lead to further isolation and mental health problems”.

Many of the children that access this provision “need one to one support also funded through aiming high which would make it impossible to access any other provision”. Many parent/carers reported that due to their low incomes, they would not be able to afford any other provision and this would

leave them isolated. *"I would have to give up work as I cannot access any other childcare and have no family around to support me"*.

- **Impact on social care**

A lot of the respondents said they would want a social worker if they could not access aiming high to ensure they could get some respite, *"otherwise families would begin to fall apart as they could no longer care"*. *"The impact on social care could potentially be huge as families want a social worker just to get some respite"*.

Many providers felt that *"many families of children with disabilities access support via aiming high and this in turn means that they do not require a social worker to be allocated to them, thus leaving social workers available to be involved with families who are at either level 3 or level 4. The implications of this on social workers overall caseloads and ability to effectively offer support/services to those families will be compromised"*.

"It is not like bin collection, if you collect your rubbish once every two weeks, you have got a choice to take your rubbish to the tip. It's not like that with a child. There is no other choice"

- **Preventative Services**

Respondents felt that the proposal *"Seems to contradict the Councils aim to protect preventative services"*. *"This service is a preventative service and therefore should be a priority to fund as it will lead to crisis intervention in the long run and more costly services"*. *"The Aiming High Short breaks team keeps these families balanced, by supporting them, signposting them, being at the end of the phone - in short preventing these families from needing the intervention from an already over stretched social care team."* *"How can the council propose to bolster preventative services when they are proposing to cut a preventative service for the most vulnerable?"*

- **More costly in the long run**

One respondent summed up many responses by saying *"We are all aware that these are difficult times and cuts are needed, however targeting this group makes no sense. The money saved from cutting this service will result in more costly intervention from social care - ultimately leading to social care overspending"*. *"Aiming high is a preventative service - why is a more cost effective preventative service being cut? Especially given the Local Authorities brief of investing in preventative services"*. *"It appears to save money in some areas, but the impact of this could be significantly greater in financial terms, on crisis responsive services. There is plenty of evidence that preventative and stabilisation services impact positively on high cost services. Removal of funding in this area is a false economy"*. *"We would be devastated if our sons respite was taken away. We would probably end up in crisis and need a social worker and probably costing you more"*.

- **Impact on the Voluntary and Community Sector**

30 (68.2%) of providers did not feel there were opportunities to continue to deliver short breaks without the aiming high funding, whilst 2 (4.5%) did. People felt there would be *"a huge impact on our voluntary and community sector, this will be devastating"*. A number of local providers will find it *"impossible to continue"*. *"There is an assumption that voluntary & community sector will be able to fill the gaps left by the reduction in services, whilst they are already having a reduction in the grants that they receive"*.

"Eventually these services will be saturated. There is scope for a more personalised approach to these services, and these may actually provide examples of more suitable solutions (in individual cases), but, short breaks are, by their very nature, supposed to give some respite to families".

"There's been an awful lot of speculation, conjecture and guesswork regarding the 'bubbling up' of new voluntary and community sector providers. The evidence of these new providers actually materialising is absolutely non-existence. The personalisation of services for children and young people with disabilities and additional needs has been under way for 2 years – in this time I've not

seen one single new provider who will deliver a more person centred service at a lower cost. In short, existing providers will fold and there's no new providers filling the space. So if a parent has a personal budget - how are they going to purchase support if there are no providers they can purchase support from? Voluntary and community services will fold".

"Activities are subsidised by Aiming high at present, if this goes families will be charged the full cost rising from £15 to £70 per day".

- **Legalities**

Some parents and carers questioned the legal status of this proposal in relation to the Breaks for Carers of Disabled Children Regulations 2011 (3B) *"where a local authority must have regard to the needs of those carers who would be able to provide care for their disabled child more effectively if breaks from caring were given to them"* and 4(1) stating *"a local authority must provide so far as is reasonably practicable, a range of services which is sufficient to assist carer's to continue to provide care or to do so more effectively"*

Families have asked *"How Stockport MBC propose to meet the needs of carer's and their obligations under the legislation"*

A group of parents in the focus group stated *"They should expect legal challenge if they take this away. We've started conversations and we are happy to do it. Our children need an advocate".*
"There are bits of the legislation they don't seem to be paying attention to..."

- **Stockport's Current Model**

Many providers and families felt that Stockport has an excellent model of short breaks, one provider summed up responses by saying *"In Stockport we have a good model and a good record of inclusion.... Should be held up as a beacon not getting rid of..."* Providers felt that the services keep families together, develops young people to their fullest potential and acts to prevent the need for more costly health and/or social care interventions. That the service should be celebrated for its impact and value for money in short, medium and long term preventative interventions.

- **Alternative provision/Solutions**

30 (68.2%) of providers did not feel there were opportunities to continue to deliver short breaks without the aiming high funding, whilst 2 (4.5%) did. *"There is an assumption that voluntary & community sector will be able to fill the gaps left by the reduction in services, whilst they are already having a reduction in the grants that they receive"*. One parent stated *"It is taking a layer off people who don't really have anything else"*.

"Eventually these services will be saturated. There is scope for a more personalised approach to these services, and these may actually provide examples of more suitable solutions (in individual cases), but, short breaks are, by their very nature, supposed to give some respite to families".

Suggestions of alternative ways forward if the proposal was agreed included by 2 parent/carers *"Private providers could offer services to families with a budget, this could be a long term project that is put to tender over the next few years"*. *"Families could also set up area co-operatives and lead their own respite sessions within their communities and be supported by community leaders/church or schools in the local areas"*.

Mitigation

Based on the feedback received from the results of the consultation exercise, included here are details of how the issues would be mitigated against if it were to be implemented. Issues are also extracted from the issue log within the business case.

Issue	Source	Mitigating Action
Reputational risk	Risk Log	Wide consultation
Understanding the impact of changes on service users	Risk Log	Consultation with service users and families. On-going monitoring of impact through case load management in social care
Development of new models	Risk log/consultation	Support the VCS to access differing funding streams and set up to deliver with personal budgets
Reduction in support for families, and opportunities for friendships and to reduce isolation for CYP	Consultation	The local offer will provide a wide range of information for families. Where families require social care intervention, respite support will be available. Strengthen links with the supporting families' pathway and wider integrated children's service.
Lack of access to other provision	Consultation	The newly established local offer will provide a wide variety of information for families on what is available. Workforce training and support to other sectors to ensure inclusivity
Potential impact on social care	Risk log/consultation	Local offer to provide information to enable families to avoid crisis situations. Monitoring of caseloads and expenditure within social care. Introduction of personal budgets for eligible families. Further integrate pathways with the integrated children's service
Impact on the voluntary and community sector	Consultation	Support to the sector provided to access alternative funding streams, preventative commissioning strategy to better align funding from SMBC. Support to sector to be fit for purpose and market ready to deliver in line with personalisation agenda. Support within local communities to establish co-operatives and volunteer bureaus.
Legal Challenge	Consultation	Ensure proposals are in line with legislation. Engage legal expertise in implementing decisions made.