

What do you think about short breaks and respite services for disabled children, young people and adults in Kirklees?

Findings from public engagement with service users, families, carers and residents in Kirklees during September and October 2016.

Introduction

Kirklees Council is changing; our vision is to work with partners and communities to support people and families to plan ahead, stay well and get support when they need it.

Disabled children, young people and adults, and their parents and carers have told us that joined up services across all ages would help improve support to disabled people living in Kirklees. We've started work to develop an All Age Disability Service.

We, together with commissioners of health services, are looking at how we can help families to come together to support each other, and enable local communities to develop local support services.

Health and Social Care organisations are experiencing increasing demand for care and support services, whilst having significantly less funding available. We need to make sure the money we do have is spent on the right services to meet individual and families' needs.

To help inform decisions on these changes, public engagement took place over six weeks from 7th September to 21st October 2016.

Method

People could take part by completing an online survey, by using a paper survey, or by attending a face to face engagement session. Anonymised feedback notes from these sessions are provided as an appendix to this report.

We received a total of **224 survey responses**. The survey asked a series of closed questions and gave opportunities for open comments on various aspects of short breaks and respite. A full list of anonymised open comments received is available as an appendix.

Summary of results

A summary of results for key questions is detailed below. Findings are reported in the order of closed (quantitative) questions to provide an overview, followed by open (qualitative comments) questions, and then demographic information at the end.

Where useful, options have been reordered to reflect their ranking within the results. Please note percentages may not always total 100%, due to rounding.

8 out of 10 respondents stated they are current users of short breaks / respite. 15% have never accessed the service, while a handful of responses received were from previous users:

Q10	Please choose the statement below that best describes your family's situation:		
	180 (82%)	We currently receive short breaks / respite	} 85% of responses received from families that use short breaks / respite or have in the past
	7 (3%)	We used to receive short breaks / respite but no longer do	
	27 (12%)	We have never received short breaks / respite but would like to have done	
	6 (3%)	We have never received short breaks / respite but have not wanted them	

41% of respondents stated they care for someone 17 and under who uses short breaks / respite, while 36% stated they care for an adult respite user. 14% stated they are short breaks / respite users themselves (3% of these being 17 and under). The quality of comments received to open questions later in the survey indicates that the majority of responses were received from those that care for children and young adults.

Just over half of respondents that use the service were able to provide how many hours their family receives, with comments showing a great variation in the amount of support people are making use of.

Q12	How willing are you / the person to travel to get the right service you need?	
	163 (79%)	I am willing
	44 (21%)	I am not willing

While most respondents stated they are willing to travel, comments focused on associated problems. Respondents highlighted that the journey to and from respite can take up a large chunk of the break, so if the journey is too time consuming it ceases to be worth the effort. Many service users need the support of one or two adults to travel, adapted vehicles etc and any change to the existing travel routine could cause further anxiety and issues. Many carers also pointed out their own competing responsibilities and commitments such as getting to work, transporting other family members, and their own support needs.

Q13	How do you / the person normally get out and about? (please select all that apply)	
	49 (22%)	Walk
	49 (22%)	Public transport
	187 (85%)	Car
	50 (23%)	Taxi
	82 (37%)	Transport arranged
	12 (5%)	Other (please specify)

Car use to access short breaks and respite was by far the most popular response, with pre-arranged transport also popular. Fewer respondents stated they make use of public transport or walk to the services they access. 'Other' comments included school-provided transport; specially adapted vehicles; wheelchair use in general; and that some service users don't get out and about as they are unable to leave the home.

Q14 **It is our future intention to work closely with local communities to develop more inclusive services. What has been your experience of short breaks / respite? (please select all that apply)**

138 (68%)	It has worked well
50 (25%)	I would like more choice
47 (23%)	It wasn't always available when I wanted it
22 (11%)	The location hasn't been convenient
20 (10%)	Transport issues
17 (8%)	Waiting lists
15 (7%)	Restrictions on other family members attending
10 (5%)	Age group restrictions have been a problem
32 (16%)	Other (please specify)

Results indicate that while there is much positivity around short breaks and respite currently working well for families, there are many challenges around choice and availability. Many of the 'other' comments provided elaborated on the above themes, though some also mentioned different experiences such as concerns over safety and quality of care; having to plan months ahead creating a lack of flexibility or spontaneity; the appropriate specialist care being unavailable; and a lack of knowledge of the service.

Many people find that a direct payment offers more flexibility. A direct payment is a sum of money given to a person for them to buy the goods or services such as short breaks and respite.

Q15 **Please can you tell us more about your use of direct payments?**

110 (53%)	I use a direct payment
60 (29%)	I do not use a direct payment but would consider doing so in future
39 (19%)	I do not use a direct payment and do not wish to take up the offer of a direct payment

Just over half stated they make use of direct payments. Of those not currently using direct payments, there is some appetite to do so in future. Comments from those that felt they wouldn't wish to take them up include being satisfied with their current arrangements; feeling that direct payments are a more complicated system to be involved with; not wanting to take on employer/employee relationship; and a view that direct payments are a more costly approach (with some basing this on previous experience).

Q8 **Do you / the person attend (please select all that apply)**

93 (43%)	School
84 (39%)	Overnight stays within a respite home
77 (36%)	Weekday activities during the day and / or evening (including playschemes)
58 (27%)	Care and support in your own home (day and / or night)
48 (22%)	Weekend activities
30 (14%)	Evening activities
24 (11%)	Further education (6th form or college)
22 (10%)	After school clubs
21 (10%)	Overnight stays within a family based services (foster / shared lives carer)
11 (5%)	None
2 (1%)	Preschool or nursery
1 (0%)	Breakfast clubs

Q16

From the services you use, please select the three services which are most important to you and your family:	
105 (51%)	Weekday activities during the day and / or evening (including playschemes)
103 (50%)	Overnight stays within a respite home
82 (40%)	Weekend activities
77 (37%)	Care and support in your own home (day and / or night)
43 (21%)	Evening activities
42 (20%)	After school clubs
25 (12%)	Overnight stays within a family based services (foster / shared lives carer)
5 (2%)	Breakfast clubs

Results here show a clear strength of importance placed on both weekday and weekend activities, and overnight stays. Breakfast clubs and overnight stays within a family based service received fewer responses here, though this is likely due to these services being used less frequently or by fewer respondents.

Considered alongside comments received to later questions, it is possible that those services showing as most important are also those which provide a greater break for carers, as well as being most valuable to service users.

Q17

To what extent do you agree with the following statements?					
	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
There is just about the right amount of short breaks / respite services to help and support you in the parent / carer role	31 (15%)	49 (24%)	33 (16%)	51 (25%)	41 (20%)
	39% agreement				
Support should be more flexible to enable siblings to attend activities together	37 (21%)	40 (22%)	89 (50%)	10 (6%)	3 (2%)
	43% agreement				
More short breaks / respite services should be provided within local areas	97 (49%)	60 (30%)	37 (19%)	3 (2%)	2 (1%)
	79% agreement				
There is just about the right amount of support and advice with setting up and managing a direct payment	12 (6%)	43 (23%)	63 (34%)	37 (20%)	33 (18%)
	29% agreement				

The clearest response here was around the location of services; with 8 out of 10 respondents agreeing that more short breaks and respite should be provided locally, and just 3% disagreeing.

Views on the amount of support available were very mixed, while the majority agreed with flexible services enabling siblings to do activities together.

Results indicate that more support is needed with setting up and managing Direct Payments, with this being echoed by some in later comments.

The next set of questions (Q18-Q20) provided respondents with opportunities to put forward their ideas on various aspects of a future short breaks and respite service.

Many detailed, thoughtful and emotive comments were received, short summaries of which are given below. These summaries can only give a flavour of respondents' views. It is highly recommended that the full set of comments are read in order to understand the depth of feeling and variation in views and circumstances of the families involved.

Q18a	Are there...	
	Yes	No
	87 (48%)	93 (52%)
	...other support services you feel we have missed which are important to you?	
	Please provide any information or ideas you have that might help us:	
	(92 comments received)	

Many comments received here mentioned the need for better information about what's available. There was a sense that some families had missed out as they struggled to find out what they may be entitled to. Several respondents felt that having a single point of contact would be beneficial – someone they could talk to, both to signpost them to what may be available and also to support them through the Direct Payments process.

Some respondents would like to see more personalised, structured care rather than generic group activities, while others felt that it would be useful to have more opportunities for disabled young people to mix with their peers.

Easier access to take part in specific activities including swimming and sports centres were mentioned by some. Better provision in school holidays and at weekends also came up.

There were several comments demonstrating respondents felt services for young adults were lacking, with some voicing a need for support in helping their dependents to live away from home, and to learn life-long skills (e.g. catching a bus) and independence.

Q18b	Are there...	
	Yes	No
	91 (56%)	72 (44%)
	...new types of care and support services you would like to see developed?	
	Please provide any information or ideas you have that might help us:	
	(88 comments received)	

Many of the comments received were reflecting on existing services and improvements that could be made to them, mainly around increasing the amount of support available. Respondents felt more support in accessing services and finding out what their options are would be helpful. Ideally short breaks and

respite would be available closer to home, and with greater options for when this is used e.g. evenings, weekends, wrapping around school hours. A few comments mentioned how useful short notice support would be, to help with unplanned issues.

As with the previous question, some respondents would like to see development around life skills (cooking, personal hygiene), potentially leading to an introduction to supported living. These comments linked with others around the need for better provision for young adults 18+ and 25+, as some felt that support dropped off at these stages or that it was unhelpful and unrealistic to group under service users under 30 in with middle aged and older service users.

There were some interesting comments on the potential to develop a befriending type service, for example students who may be able to spend time in the young person's home and share life skills. One respondent emphasised the potential benefits of a 'shared lives' approach though felt this needed to be very carefully managed.

Q18c	Are there...		
		Yes	No
...other support the council could provide to help parents come together and support each other?		69 (46%)	82 (54%)
Please provide any information or ideas you have that might help us: (62 comments received)			

Various comments were received showing an interest in bringing parents together informally for information sharing, support and social get together. Some felt it would be useful for the council to run drop in sessions, where busy parents could call in for advice and a quick chat, to help reduce isolation. Again, a general improvement in access to information was mentioned. Other respondents felt they did not have the time or energy to support other parents on top of their existing commitments.

Some felt that the council should support the wider family, for example by recognising that parents may not live together, and providing transport more flexibly. Also that those carers who work full time require support at different times.

Quality existing support from PCAN was mentioned frequently, with continued financial support to existing parent groups and the potential for training courses for parents, all provided as ways the council could help parents.

Q18d	Are there...		
		Yes	No
...other support the council could provide to local communities to help them come together and develop support needed within local communities?		64 (45%)	78 (55%)
Please provide any information or ideas you have that might help us: (53 comments received)			

As mentioned previously, it was felt by many that the council should provide information in various formats (offline as well as online) to enable carers to access the right support for their families. Some felt

that the council's role should be in reducing red tape, enabling access to funding for community groups and ongoing support to help maintain the momentum of volunteer activities.

There were comments about the council enabling communities to use the specialist provision available in special schools outside of school hours, and to open up mainstream activities and venues to disabled people, including making them friendly to invisible disabilities.

The varied and often complex medical and social needs of service users, and the limitations these can place on the type of support required, was cited as an obstacle in developing community-led support. Cultural differences were cited both in terms of a possible hindrance to community support (i.e. one size doesn't fit all) though some ideas for bringing different communities together were also mentioned, e.g. using religious buildings for inclusive meetings, focusing on secular activities.

Of the support currently available...

Q19a **...what works well for you and your family? Why?**

(190 comments received)

A large number of responses spoke highly of the Young Persons Activity Team (YPAT). People believed that the facilities offered were extremely valuable, allowing children to socialise, gain access to specialist equipment and be supported by well-trained staff that are experienced in delivering care needs. Several benefits for carers were also emphasised, including the creation of time to work, relax or spend time with other family members.

Several respondents also highlighted the benefits of respite facilities that offer overnight and weekend services. This included the ability to catch-up on sleep, perform activities that the dependent would not necessarily enjoy and have a decent period of time without worrying about the wellbeing of an individual.

The flexibility of direct payments was often cited as a major benefit of the service. Carers enjoy the fact that they can choose who to employ and when to receive support. Other advantages of the service included the ability to change arrangements at last minute, personalised 1-to-1 sessions and the availability of home-care.

Of the support currently available...

Q19b **...what doesn't work for you and your family? Why?**

(126 comments received)

A large number of respondents expressed concern at the complexity when registering for care. Direct payments were the most concise example of this, with people being overloaded with instructions and paperwork abundant with legal terminology. This, combined with the overall lack of explanations meant that some respondents had to submit multiple applications or simply could not figure out how to obtain support.

Respondents were also concerned with cuts and the future of short break and respite services. Parents were apprehensive that the removal of facilities would impact on wellbeing of both themselves and their children. There was a general consensus that the removal of care staff could break down relationships and create an unstable environment that dependents could struggle with.

Comments were also made regarding transport and access of the short breaks and respite facilities. Some respondents stated that the services were not worthwhile, simply as they would have to travel for hours and not receive a satisfactory break. The lack of flexibility and weekend transport from YPAT was also an issue, with one respondent having to pay over £30 for a taxi every 4 weeks.

Another issue highlighted by respondents was the timing of the services. People often felt that the fixed times offered by the facilities were problematic and that there was an overall lack of flexibility. With regards to YPAT, many respondents believed that there should be more opportunities to use the service, including overnight and during school holidays.

Of the support currently available...

Q19c **...what should be changed? Why?**
(111 comments received)

Responses to this question were generally similar to those asked in the previous question. Several respondents again emphasised the general administration issues present when registering for respite services. The general consensus was that accessing care is not straight forward, largely due to a lack of awareness and unclear support information.

Numerous individuals also expressed a demand for a greater level of support and respite provision. In a similar manner to the previous question, people most commonly stated that there should be a greater provision available during nights, weekends and school holidays. There was also a belief that more services should be available for young adults that continue to need help during the transition to adulthood.

A number of respondents also gave remarks that were somewhat political. Most common statements of this nature included the removal of agencies and care companies whilst increasing funding to public sector authorities such as local councils and the NHS. Some were also keen to reverse funding cuts and focus instead on upgrading facilities.

Of the support currently available...

Q19d **...is it important to you and your family when we provide support? Why?**
(162 comments received)

The overwhelming majority of people firmly believe that short break and respite support is essential to their wellbeing. Although a couple of respondents stated that the support was not important, they did not provide reasoning on why they felt this way.

There was a strong belief amongst carers and parents that support allows them and their dependents to lead a life that is as close to normal as possible. Respite provision allows carers the opportunity to re-charge, maintain their employment status, preserve their psychological wellbeing and spend time with other members of the family. Similarly, dependents also receive a stable environment, an opportunity to socialise and the development of their skills, interests and relationships.

Respondents were also strongly believed there would be a severe decrease in quality of life if this support were to disappear. A number of people believed that they would suffer health impacts and be physically unable to cope. Comments were also made regarding the potential break down of families, largely due to people being tied down and the overwhelming feeling of entrapment.

Q20 Do you have any further comments?

(120 comments received)

The majority of further comments mirrored or expanded upon themes that arose throughout the survey in particular in question 19. A large majority of the comments focused on how short breaks and respite are invaluable for the service user, the carers and the family as a whole. Many respondents used very emotive terms to describe the services such as 'a godsend', 'a lifeline' or referring to the service as the 'main stay of my existence.'

Respondents reiterated that closing these services would have far reaching detrimental impacts for the carer's mental wellbeing and ability to care effectively as well as to the service user's progression and quality of life. There were also a number of comments that suggested any cuts to these services would cost the council more money in the long run, for example through the need for full time residential care because carers would no longer be able to cope.

Some respondents made comments about improvements to the current services such as advocating for more support with navigating the service and in particular the transition from children's care to adult services, along with several comments about the need for increased flexibility.

There was also a handful of comments that highlighted the benefits of the social interaction service users receive through these services, often citing that the environment and the activities are something carers cannot replicate for them at home.

Who took part?

- 72% of survey respondents were female, 27% male, 1% preferred not to say.
- 82% stated they are White, 14% said they were from a Black and Minority Ethnic (BME) background, 3% preferred not to say.
- Some respondents provided a postcode, with relatively equal coverage across North and South Kirklees, and a handful of postcodes from the surrounding area. While this indicates a good spread of responses from across the local area, due to the self-selecting nature of the engagement survey it cannot be assumed that results are representative of the Kirklees population.

Counting all adults and children how many people live in your household?

	0	1	2	3	4+
Adults 18 and over	1 (0%)	29 (13%)	100 (47%)	52 (24%)	33 (15%)
Children 17 and under	18 (14%)	38 (30%)	47 (37%)	14 (11%)	11 (9%)

How many people in your household use short breaks / respite?

	0	1	2	3	4+
Adults 18 and over	45 (29%)	92 (59%)	14 (9%)	2 (1%)	2 (1%)
Children 17 and under	29 (25%)	79 (69%)	6 (5%)	0 (0%)	0 (0%)

Do you or the person(s) accessing short breaks / respite services have any medical conditions (diagnosed by a doctor or other Health Care professional)? Please select the conditions which represents the disabilities of all people in your household. (please select all that apply)

	Person 1	Person 2	Person 3	Person 4	Person 5
ADHD/ADD	9	1	2	-	-
Asperger syndrome or high functioning autism	8	1	1	-	-
Autism	53	5	5	2	-
Autistic spectrum disorder (ASD) - Other	36	2	1	-	-
Cerebral palsy	27	1	1	-	-
Chronic illness	10	5	2	-	-
Cystic fibrosis	-	-	-	-	-
Diabetes	9	5	1	-	-
Down's syndrome	23	-	2	-	-
Dyslexia	9	3	-	-	-
Dyspraxia	12	2	1	1	1
Epilepsy	37	1	1	1	-
Global developmental delay	30	1	1	-	-
Head injury	6	-	-	-	-
Hydrocephalus	4	-	-	-	-
Learning difficulty or disability	104	9	4	3	-
Mental illness	17	5	1	1	-
Multi-sensory impairment	19	2	2	1	-
Muscular dystrophy	4	-	-	-	-
Other diagnosis	41	12	-	-	-
Other physical injury / impairment	17	7	-	-	-
Pervasive development disorder	1	-	-	-	-
Profound and multiple learning disabilities	25	2	1	-	-
Profoundly deaf	9	1	-	-	-
Spina bifida	-	-	-	-	-
Spinal injury or problem	6	4	-	-	-
The disorder has no name	5	-	-	-	-
Visual impairment or registered blind	24	1	-	-	-
Prefer not to answer	5	2	1	2	2

All local authorities must maintain a list of disabled children and young people, aged 0-25, in its area so that services can meet their needs. In Kirklees this list is called the 'Children and young people with additional needs register'.

Have you heard of the register?

39 (19%)	Yes, and I have registered
18 (9%)	Yes, but I haven't registered
148 (72%)	No (these respondents were signposted to information on the register)

What next?

Findings and comments received through this public engagement will be considered alongside other data by Kirklees Council's All Age Disability board in November 2016.

This will help Senior Managers, together with commissioners of health services, to draft proposals for the future of short breaks and respite, and consider how we can best help families and communities to develop local support services.