

Appendix

All Age Disability: short breaks and respite engagement

Responses received to open comments questions (anonymised)

Responses to open comments questions 18-20 are listed first.

Are there...

Q18

...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 responses:

"Holiday child care and wrap around school care as is available for ALL mainstream children not a few hours here and there at a time and date given to you which may or may not fit. Essentially one parent is unable to work full time or during school holiday due to lack of suitable provision and this HAS TO BE WRONG AND DISCRIMINATORY...."

"I will require better 18-25 year services for PMLD within the next few years. I believe this is very poor at the moment."

"Carers Trust"

"Homestart is a fantastic service for families with under 5's. This can be a very challenging time when you spend lots of time in hospital corridors waiting for appointments so it is great to have an extra pair of hands for other siblings. Parents need a single point of contact within the Council to find out what is available preferably a person to talk to at least on the phone (the Local Offer just doesn't deliver in this regard and lots of people don't have access to internet). Can't find out much about short break activities on there where you don't need an assessment. Information about assessment uses too much jargon and not user friendly enough. All services need to be more clued up about additional needs, eg. Health visitors, school nurses who should be identifying that there is a problem or a support need and then know where to go to get information for the family or help them get it. There needs to be development of meaningful and structured activities/services for young people with very complex needs once they reach 18 with a planned transition into them - many of them are in education till age 19-21 and parents still need breaks from caring and young people need ""out of education"" activities. There isn't much out there that isn't for older people, or people with a generic learning disability (who are often quite able). Not somewhere where they go just to mill around (or be pushed around in a wheelchair) all day to give carers a break, but something with skilled one to one support and a planned, individual daily itinerary. Lots of challenging behaviour comes about because people are unable to communicate with support staff and vice versa, they are bored and just don't want to be there. Big gap in service here in Kirklees. There needs to be a move away from the tick box gardening, animal care, catering/cookery approach. Not everyone wants or is able to participate in this. I feel very disheartened when I see people treated in this way - they certainly don't have any choice. We can't bear the thought that that's what's out there for our son."

"Easier access to local authority services such as sports centres and play gyms. They are completely un-autism friendly"

"Given budget cuts, think that DP should be more flexible in buying the services that are available already or a minimum charge should be applied as compulsory for weekend day activities which are on offer. eg. YPAT playscheme now do some charges. Given the hourly cost to use DP in the home, it is more use to pay for the services put together from what Kirklees has on offer"

"Local youth group or weekend activity group offering support which my son could attend now that he is a teenager."

"After school clubs... Why cant schools stay open through the week and on a weekend? This allows parents to meet and support each other, the facilities are all there and the children are familiar with the buildings so stress and anxiety is minimized. As a working parent it is very difficult to get together especially when your child is transported to and from school."

"Day care at Highfields is a important part of [service user]'s life. She gets to be with her friends and we can get things and attend appointments while she is there."

"Help and advice on who to turn to, should not have to fight for everything.my fight fie respite took in total 2 and a half years"

"We need in Kirklees some places for example like zone but it should be only for special needs & their families. With card it show the people attending is their the special needs family. On my self my child love to go zone but the people attending there they not welcoming my child because the kids go there all they don't have any disability. He's different from their children & they looked at my child different way ."

"Assistance to help young adults to find ways of mixing with others in a safe environment - most find this very difficult"

"Tell people what they can apply for"

"A weekly Saturday over 16 club."

"dont know"

"Poor quality of care and facilities in local care homes makes short breaks more difficult than it should be. Although the allocation of money from the council is adequate , its difficult to spend it as we would like as I can't find a care home where my partner would be safe"

"As a lone carer (well into her 70s) with no other family to support me I have found it difficult to plan for the future of my daughter when I am no longer able to care for her at home. Social workers have informed me that I can not make plans where she will go until the time arises only then can thing be put into place. I would like some support system for people like myself who worry now (If something happens to me tomorrow) what will happen to my daughter? I have been to support groups of other carers but they all seem to have other family who could take over that responsibility"

"Since we don't qualify for short breaks/respite the services we use are generally mainstream or those provided through support groups. Support groups are very important as they provide information and often organise activities that they know will be valued by the young people and their families and suitable for them."

"Sometimes practical help at home is needed if there is no other family support available"

"Services need to broadly available and if foe eg parent is unwell, or requires more assistance then we should be able to get professional care and help for those extra interim period"

"None"

"information about places that offer disability provision for respite breaks, follow up help for carer and cared for."

"Information needs to be in place sooner for a child transitioning into adulthood about respite services to allow a smoother transition especially if the child has autism which affects their ability to manage change. This seems to be missing I only found out by chance about adult services because a family member works in the local authority. I have spoken to other carers who literally know nothing about theses services as a potential option. We shouldn't have to hit crisis before support is given we need things in place to prevent us going into crisis and then costing service more money."

"short notice in home respite"

"short breaks, respite together for couples , couples don't always want to be seperated it can make them more worried especially when they always spend time together"

"help to run a direct payment, help to understand a direct payment, help to be a good employer, help to learn the laws of being an employer, help to recruit staff, help to retain staff"

"Help to run a direct payment, help to understand direct payments, help to be a good employer, help to learn employment law, help to recruited and retain staff."

"The timing of social service reviews is very hit and miss. These should be on a defined time basis, eg every year, and not let drift so the frequency is less frequent than the recommended. Reviews take too long to be finalised and for the paper work to come through once the visit has been made by the social worker. Not seeing the same social worker is a big irritation and indicates a lack of continuity. I appreciate that there is staff turnover in any organisation but the current system does not lead to a feeling of ongoing support."

"Support for the carer in ongoing assessment for the cared for"

"Have asked for but been declined weekend overnight respite care"

"More support with finding care providers when using direct payments."

"I am also disabled and managing things like direct payments has been quite stressful in as much as we have to find the services we want to access or the p.a. in our case. Help and guidance to ease our dependents into living away from home. More opportunities for them to mix with their peers. My daughter does not attend waves or any similar scheme because she does not want to. But she does enjoy Saturday club."

"Never knew about direct payments, still not sure what they are, it was mentioned by Mencap after I independently looked for activities for my daughter who is 29yrs old. Someone came to help me fill in an assessment to apply for some sort of funding, it was confusing, lots of paperwork, told was in system, but received nothing. Sometimes I may need treatment myself, then I cannot take my daughter anywhere and then I desperately need accessible and flexible transport for her."

"We use Direct payments and Ypat. Direct Payments is used for morning care for my son and Ypat is for after school 2 nights a week and on a Saturday. We use this time to spend with our 8 year old, who is very much pushed to the side and neglected because of all the attention my child with special needs gets. The care that is provided by Ypat is outstanding. They interact with children and care for them as if they were there own. I have been to over night repiste centres where I have seen with my own eyes, members of staff not interacting with the children and looking more like a prison rather than a home for home experience. YPAT is a life line to us where they provide social skills with other children. I feel our family would fall apart without this service. They have everything all under one roof which direct payments doesn't provide."

"care during school holidays"

"it has been a pity that the independent living team was disbanded. [Staff member] was brilliant, and is sorely missed"

"I have a back problem. As I get older my daughters gets bigger and would need more support at home and out and about."

"No allocated social worker. you lose all support during transition into adulthood"

"Activities in the School holidays like WACKY which are really popular with disabled people."

"More respite breaks for over 18s as services are extremely limited."

"dedicated team member to ring up when issues occur"

"More short breaks and holiday activities and more varied"

"I cannot get out to any regular activity due to my not being able to drive and my wife is not available to drive me on a regular basis."

"Needed help before it was put in place; took me (parent) getting a critical illness and having a nervous breakdown before anything was provided."

"Carers trust is the short break service we use"

"Support groups for parents/children both before and after diagnosis."

"Very hard to find any care care for my 11 year old who is in high school. I work so cannot be there for him but services are very hard to access and you have to fight to get support for your child to have age appropriate care. He need support at home as he has homework which need to be carried out and this cannot be completed in an out of school club environment."

"The playscheme my son attends is on a Saturday and for school holidays, when my husband left they quickly allowed [service user] to step up from half day on Saturday to full day. This has been soooo helpful as in allowing me to spend time with [service user]'s siblings. I pay a voluntary contribution and would

have quite happily paid much more for using this scheme. I have been told I will not be able to have direct payments so should this scheme close (YPAT) as shall surely struggle."

"A designated key worker who can help to bring all the services together and can give support and advise about accessing services."

"Enrichment sessions at Hollybank Trust"

"Huddersfield Support Group for Autism have recently relaunched. They provide a summer playscheme for 1 week over the holidays. They have excellent knowledge of autism and seem to retain the same staff from one year to the next which helps with continuity. They also run family days out to the zoo 3 times a year. They need more helping hands on these trips out as I struggled with my son and daughter and was surprised to find little help. The committee who run the support group are passionate about helping families with autism which is a great relief for families who often feel judged about their child's behaviour."

"Don't understand direct payments any more"

"Social care with only a few carers"

"Swimming"

"Future planning for elderly carers"

"More respite for children in Kirklees & stop blaming budget cuts!"

"provision of respite care through the local authority"

"LIKES SWIMMING"

"WHOLE FAMILY ACTIVITIES ACCESS"

"Sport activities Madressas"

"Parents support each other without the help of the Council"

"Allocated care worker, someone who is a personal contact, yearly assessments for change in care need"

"as a parent of a child with additional needs (diagnosed 4 years ago) I feel that there is very limited information to services such as PCAN, short breaks and respite, direct payments etc.. I have briefly heard about these services but would not know where to start when looking for information or a person to talk to regarding options and criteria."

"i would like support or policy on how to deal with neighbours which complain about a disabled child playing in their own garden. complaints such as not able to leave windows open when the child is playing because they do not like the sounds the child makes. Letters put through the letter box."

"Services need to be in small number groups as well as small age groups. The idea that 18 year olds and people in their 60s or 70s can have their needs met together in one group is absolute nonsense."

"I have never been offered any help or any of the services at the services"

"Activities during the weekends"

"Before school club"

"YPAT is very valuable to us as it provides important activities for my child when there is nothing else in the holidays"

"No recognition of the invaluable contribution made by family members, friends and neighbours on an informal and occasional basis. That contribution can only be given recognition through small gifts etc paid for from the direct payments funding. Why not small cash sums too, given that bank statements are reviewed on a regular basis? See also National Audit Unit paper on 'onerous' accounting requirements imposed by some local authorities. Also, does the Kirklees Direct Payments Policy Document referred to in the DP contract actually exist?"

"more support with direct payments like a help line"

"Not enough services for full time care for autism"

"swimming"

"We have no support at all, we find out things from other people we meet or members of our family who stumble upon things"

"More summer holiday activities in the local community"

"Over the years we have noticed that Dewsbury has always lost out to Huddersfield and more and more centres/services are based in Huddersfield. Tax payers' money from Dewsbury/Batley/Heckmondwike/Mirfield/Gomersal/Birstall all have been diverted to Huddersfield or

Halifax Dewsbury has the highest number of disabled and Genetic disorder Children/Adolescent ideally center should be located in Dewsbury area."

"Very few clubs activities available to suit young adults"

"More support needed"

"my husband will not visit anywhere without me"

"Central Stars youth club"

"There are not enough venues for young adults to go to. There seems to be better provision for those under 18."

"YPAT is very important to us along with Orchard View"

"Don't know"

"specialist schools to provide more support during school holiday terms to allow the child to develop more within the learning spectrum"

"YPAT holiday scheme gave me time to spend with my other child and for a short time put her needs first. My daughter would have missed many opportunities if not for this service"

"Life long skills/teaching how to catch bus or weekend clubs to teach how to be independent. Sport activities for kids and clubs or youth hubs or clubs for 7 year olds and over with learning difficulty. See below for forums and support training and access ideas I have put forward. Support groups in community to bring communities together and support families and understand or accept their disabilities."

"more important to ensure that current support services are properly funded and administered - there is a huge variation in the quality of outcomes"

"Compass Bridge at Elland is a wonderful place for the children to go. It is one of the few places where my son can go and I don't have to stay with him, but I know he's safe. It runs during school holidays with a wide range of activities. Also Shabang is a fabulous place for families to meet."

"YPAT at weekends and its holiday club are vital as we struggle to find good quality supervised activities for our PMLD son. As a working mum it's very difficult to get all the time off in school holidays and my son really enjoys it there"

"Acknowledgement of the needs of carers for high functioning family members living alone or with partners, some outside the local authority. Adequate training and support for social workers to train and gain experience of work with people with high functioning autism; also resources to enable them to listen to and acknowledge the needs of family members providing such support."

"Specialist childcare for parents with health conditions"

"Better 6th form provision in Kirklees. It's currently very poor!"

...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 responses:

"age appropriate activities for teenagers with learning disability"

"Wrap around care at all special school and holiday club provision as is afforded to children in mainstream, not expecting this to be free by the way but just available would be a good start."

"Support and services for 18-25 year age group"

"It would be good to have a South Kirklees version of a YPAT type venue for children with very complex needs who need to have skilled support to access lots of activities. This could also be used by service users with their Direct Payment PA's. When my son was little we liked the idea of shared lives and were allocated a family, our son had several visits to get him used to it then they were taken off us literally at the last minute because another family were deemed ""more important"" - this was because the shared lives family had adaptations and which my son didn't need but other child did. Hopeless. Badly managed and massively damaging to us at a very hard time in our lives. Shared Lives is a great idea but need more ""foster"" families with specialist skills and adaptations (not a cheap fix). As our son got older, he got bored in a home type setting and preferred to go to a location where there lots of different activities on site and needed to be supported by skilled worker with alternative communication skills and experience (like YPAT).

The staff initially lacked alternative communication skills. More emphasis needs to be put on alternative communication as lots of children have difficulties with oral communication. This needs training and upskilling of staff wherever they are based. Communication is a fundamental human right and people can't make choices without it. These skills can reduce challenging behaviour. Think about the ages of the children and the type of service/activities they might want to access at different ages."

"Playscheme provision every weekend and all through school holidays"

"Use of locations which are not so Dewsbury based as it is long distance to many South Kirklees users. Also, many activities for children who understand how to take part in normal day to day life activities, however not many other services for those that cannot."

"It would be nice to have visits from yoga instructors, massage therapists, football/sports coaches...they come to us rather than having to take our children to places that are inaccessible and ill equipped.....again, why can't this take place in our local special schools?"

"Would welcome support in identifying careers who can come into our home and look after our son"

"More help and advice"

"Help to volunteer and work after 18 - what happens when young people are over 25? their needs and disabilities don't disappear!"

"So many parents they prefer staying at home. Because we don't have special place for our special needs."

"More parent forums"

"The work by YPAT has enabled my child to achieve things I didn't know was possible. It is invaluable and I would like to see them continue their key working and contact they maintain with me as a parent. They could do a in person meeting with me or home visit as I'd prefer this to telephone calls when discussing my child's developments only because I feel that this support boosts my wellbeing as a carer."

"more support to prevent us getting into crisis"

"For SEN children in mainstream school with support (either with or without EHC), their ability to access out of school clubs/activities depends very much on level of support offered by school. If no support is available that child cannot attend those clubs/activities. The support given is for school hours only and only extends beyond that if e.g. the TA running the club is happy to have that child in it. Mainstream activities are similar - very dependent on whether the provider feels they can cope with your child. Especially difficult if your child has complex medical needs (can they cope with epileptic fits, a child with a feeding tube?) and also behavioural - autistic kids can be hard to handle without knowledge of the best approaches. Many mainstream providers will only take your child if you agree to be there too. That is not really the point, the child/young person isn't developing outside the family unit and if you have to be there with your child this might be impossible if you have other children and other family commitments. Part of the problem for those on the autistic spectrum is that the child/young person does not want to leave the house - they need to but don't want to. What services will help to make them more independent?"

"A service that could provide at a few hours notice some help with a problem"

"experience and professional staff required to cater for the needs of our children developing on existing and new skills to help develop our children's needs. The time allocated for support is never enough especially if support is required to have a day outing. Traveling takes up care time and doesn't give you flexibility for care which means you still lose out"

"More provision for under 8s"

"Happy with present services"

"Care for the middle aged. Only choice is old people's facilities/homes which is depressing for younger clients."

"but better provision of nursing respite would help a lot of people"

"Yes. More respite beds in homes who know how to care for people with dementia"

"Specialised services to meet the needs of people with autism. Not challenging behaviour units as not everyone with autism is aggressive."

"social workers to provide information about respite and applications to benefits"

"respite , short breaks, for couples together"

"get rid care navigation and train up social workers so they can do more than just the assessment. this would save the council money. help find to find two carers per disabled individual so you do not have to be on a care companies rota."

"Replace care navigation with social workers who are trained to do more than just fill in the assessment, help to find 2 carers per disabled individual so that you do not need to be on a care companies rota."

"Mental health support for cared fo and carer"

"Possibly weekend activities for older people with profound and multiple learning disabilities."

"overnight respite for all who request it"

"Support for those of us with physical disabilities needing care aged in the 'middle years' (30 - 50) - most community groups are either for young people or elderly or people with learning disabilities."

"My daughter attends Saturday club in Dewsbury but it only goes up tp 25 yrs, she is 24. I have found this club invaluable for her mixing with her peers building her confidence and independence. I would very much like her to continue with a similar scheme in the future"

"My daughter is severely visually impaired and has learning difficulties aged 29 yrs, seems lots of services for children up to 18-25yrs and elderly 50 to 80yrs but very little that I am aware of in between. Mencap does help her with some of her needs, but not her visual impairment, but they do understand her additional problems. Is there anything for my daughter with severe visual impairment for her age 29yrs in Kirklees?"

"I think more money should be invested to a service that is needed by the children and parents. I feel by taking this away can lead to further problems for the families ain need and for the children themselves."

"evening and weekend activities which are locally based are great"

"There is a distinct lack of before and after school care for my 13 year old boy who has Asperger's and Dyspraxia. This prevents me form getting suitable employment that does not involve leaving him alone at home for too long. maybe a list of people eg: students who would be available to sit with an older child at home and assist in them becoming independant. Activity sessions to help a child, who avoids sport as much as possible, to become more active."

"Services to help young people become more independent like making tea, personal hygiene -limited at school due to class sizes. more classes for children and their carers on PECS and Makaton to help children communicate better with parents/siblings at home/school."

"Needs of care do not improve, yet services are removed and you are left to struggle"

"day time activities during school holidays"

"Holiday placements although we pay for private adult daycare using direct payments plus parental top up, would like to see more local provision"

"Short breaks we access at present only run to age 19. We would like additional support after age19"

"Respite should be more age aware i.e. 18 to 30 rather than the present system of anybody over 18 which can go up 70+ etc. this is because activities vary with different age groups."

"better carer support especially if carer is also diagnose with serious health issues"

"More frequent weekend activities"

"Don't know what you are looking for in an answer.q"

"Support for my son to become independant; ie travel training"

"Kias is an excellent resource but needs more support"

"Young People's Activity Team for children with severe disabilities should always be available to run for parents who find this respite service a 'life line'. Equally the children, my son included, benefit immensely from this service, they love spending time with their friends and enjoy time doing activities with the staff and having days out. I feel this service is so worthwhile for our families."

"PCAN have been a good source of info and i enjoyed their carers day. We need more support like this during the day to help those who often don't see other parents (single parents). Other parents seem to understand more than the professionals."

"Yes I would like some respite where I can take my carer e.g an holiday"

"Kirklees providing social care"

"Places for disabled (learning difficulties) to be able to stay long term with support and caring staff."

"More understanding of mental health issues that come along with learning disabilities ie autism, aspergers"

"More funding into Services for Disabled children"

"Overnight stay rest bite care for younger people and not just Care Homes"

"Help for eye tests as traditional opticians have turned out ti be unsuitable and doctor unwilling to refer for specialist eye test."

"Tea time care at respite without night stay"

"Organised Holidays for those with special needs"

"More choice of council run or approved day care centres"

"ACCESS TO FLEXIBLE SPPORT IN THE HOME WHEN NEEDED. ACCESS COURSES EG. FAMILY CARE/SUPPORT ESP NEW PARENTS ADVICE"

"Your services should be maintained as they are now. ."

"When 2 weeks respite is agreed there is no further contact to ask if these needs are enough and if not what else can be offered."

"i would like more visit from carers who come to the home and play with the disabled child within the home and garden."

"Never been offered any help or any summation about the services"

"Help for families that have children with dyspraxia and not just severe disabilities"

"Before and after school care so I may work"

"I personally would benefit from some kind of centre like the Zone that's adapted for children with disabilities and special needs soft play/ sensory and staff who are qualified in this area as I find It difficult for my child to fit in with the ones available he gets overwhelmed and the noise can be a problem also as he doesn't understand he's different and parents of able bodied children can be negative towards him and other children when we have been to these places ie: such as birthday parties ,treats etc which can be upsetting"

"Response times of subsidiary services (eg. Carers' Trust, and incontinence service) are far too long. I would suggest a response time within two weeks and an implementation time within two further weeks should be the standard. If this cannot be achieved the fundamental principle of the Care Act is lost and there is little point in offering these services at all."

"a service to help us get the support we need. like somewhere we could contact to get advice on what is out there for us without feeling like we are being a nuicance"

"Sitting service and or a befriending service"

"Smaller units to provide respite for older people with physical disabilities who find it hard to adapt to the larger units and need more one to one"

"I would like to see MENCAP in Kirklees offer more short term Respite"

"Cost saving can be met by providing services only during weekends (6hrs saturday and 6 hrs sunday) During school holiday at least 4 times per week maximum 6hours/day Should abolish evenings and nights service(as most of the children comes from school /or academy are tired and i cant see any benefits of providing services in the evening or at nights . As a parents we are happy to provide extra cost from their funding so it helps council to run this services. possibly by job sharing and reducing hours of staff can help in meeting cost target."

"Gradual introduction to support living built up over a period of time"

"For the people who care for the families in their own home"

"More trips"

"Short breaks in supported living for young adults to prepare them for independent living in the future."

"Don't know"

"Breakfast clubs for children with educational need as this does not happen may also help reduce transport cost as parents may like to take the child before work"

"Transition to adult services for teenagers is particularly poor little information. One event at the Stadium is not great if you have a hospital visit that day. As hospitals become specialists in certain fields families have to travel to get appropriate care."

"Life long learning skills on weekends or evenings , Sports and activities, volunteering or work experience/jobs/ trips day outs"

"more important to ensure that current support services are properly funded and administered - there is a huge variation in the quality of outcomes"

"Somewhere like Compass Bridge , only more local !"

"As we're not looking for anything else at this time, other than what we currently receive, I'm not aware what exists & what doesn't. Until the time arises I can't really comment."

"More like YPAT, on Sundays and more days during school holidays. There are very few things that PMLD children can attend where they are well looked after and people understand there needs. I'm surprised that the council does coordinate more with the special schools (Castle Hill etc) to run more holiday things / out of school things as the facilities are there, just need to staff."

"Support for people to be accredited as experts by experience, to provided care and support for high functioning people on the AS spectrum. Support from agencies like Specialist Autism Services who withdrew from Kirklees because of Kirklees refusal to fund such services. However, this would have to preceded by adequate resources for assessment and diagnosis. Because of the lack of staff competent to support and refer for diagnosis - and adequate resources for diagnosis - people are simply not diagnosed. So no-one believes that the need is there....."

"School holiday care"

"More social interaction Develop social skills"

...other support the council could provide to help parents come together and support each other?

Please provide any information or ideas you have that might help us:

62 responses:

"more clarity over information and what is available- I have had to ask other parents to find out about summer play schemes for children with autism. Greater sharing of information via special schools as well"

"Facebook page (if there is one I am unaware of it) An email mailing list with regular updates Get together sessions"

"More information needs to be shared about support groups like PCAN, Down's Syndrome and Friends etc. However, not everyone wants to go to a support group; they might want to access social media closed groups specific to their child's disabilities. So more information out there about these - and not just web based. Professionals involved, whoever they may be, need to make it their business to point families in the direction of relevant information, not just say have a look on the Local Offer (cop out)."

"Provide school transport to both mine and his mother's address, many families these days don't consist of two parents and their 2.4 children!"

"As mentioned above with regards financing, think the council should think a bit outside the box on how DP could work"

"See above"

"[Service user] takes up all our time now looking after her. We have not got the time or energy to meet other parents"

"More information for new parents."

"Work questionnaire sent to be sent to over 18's"

"Go to zone look around then make for our special needs something similar but in safe way ."

"More locations for activities"

"A parent group?"

"more understanding of the nature of disability"

"Use the local offer to show what support groups are available - encourage support groups to include themselves on it. Carry on supporting financially those groups that you currently do - the spend is worth it. Listen to support groups if they identify a need or lack in an area especially if they have an idea for filling that need but may need a bit of resource (often only temporary) or source of help/advice to put that idea into action. Encourage them to identify this need with you so you can help. They may have ideas for fundraising too to achieve this aim."

"A lot of work is still required to reach out to our south Asian communities. PCAN does well with coffee mornings but more funding needs to be in place for open fun days to raise awareness and bring families together for support. Language barriers means that many of our families within the Asian communities do not get the necessary provision that they need for care and services for support or not known about and voices are not heard. Provisions are also taken away without informing us"

"Quarterly meetings"

"more information sent out to carers regarding available services/events"

"As above. better communication about what happens when transitioning into adult service , what are the options/ differences. Carers/ parents rights around power of attorney."

"having sessions on everyday of the week so parents who actually work for a living can attend, not just people who stay at home"

"NOT just parents but also husbands, wives, siblings and friends and family. Some carers also work full-time so providing carers support groups on a weekend/evening and not just during the day would be very helpful."

"I know of no such scheme in Kirklees."

"It is presumed that parents are parents of younger children, I am sure there are plenty of parents of disabled adult children out there. As soon as I say I am a parent of a disabled daughter, it is assumed she is of school age."

"I feel we will not be able to live as a family if we lose our support system which is YPAT"

"Support groups"

"maybe a drop in session where people can call in for a chat and advice in their time of need? signposting to specific support IE: tutors for extra support with school work.."

"Groups like PCAN social so they can chat to each other, sharing problems and learning about things to help. Also, PCAN have interpreters which is better as a language barrier"

"We need more professional care and reliable services which is consistent"

"As above"

"Regular meetings with other parents/carers in similar situations would benefit some"

"Social gatherings where cares etc. can discuss problems and possibly forums where ideas and problems can be shared."

"provide support for organising parents groups and mentoring schemes"

"PCAN has been totally invaluable. Before this it was impossible to connect with other parents in a similar situation and i felt constantly isolated and depressed, as a single parent with no family in the area."

"Local meeting groups, easy to access information, easier access to education department"

"Continue to run the respite services, play schemes and after school clubs."

"Not applicable"

"N/A"

"Care swaps"

"FAMILY EVENTS/ACTIVITIES TO GET PEOPLE TOGETHER WHO MIGHT OTHERWISE BE ISOLATED"

"GROUP SUPPORT"

"yes that would be good"

"Family forum"

"You should take responsibility and not reduce services by helping parents to come together to support each other"

"Take into account the carer's needs this is very important."

"many single parents with children with additional needs feel isolated and struggle to find the time to socialise as a family. would it be possible to promote somewhere that families with additional needs can enjoy activities together and let off steam? there are possibly some places that do this, but again maybe some promotion for the whereabouts and help with travel?"

"Support groups"

"Parent groups"

"More groups for parents to attend with or without children"

"an evening social gathering or group for families who work fulltime while being carers in the evening"

"That's too much to deal with"

"get parents involved in activities with the kids"

"Parents with young children will lose out if Children's centres close. What will the Council put in there place"

"council should encourage direct payment to the appropriate agencies by parents and should provide the list of all agencies and individual qualified persons so parents have got flexibility to arrange services directly from them."

"Don't know"

"better communication lines across all departments to allow all departments to give information and feed back to parents as some people don't know what to do or what's out there"

"Most are led by volunteers more funding for those that try to path find for other families"

"Online or community help support groups or sessions. Training courses how to deal with kids with disability, care, talk therapy for kids with emotional issues including water/aqua therapy at local sports centres,"

"Home safety grants to benefit disabled child"

"plenty of specific local support groups operating - need an overarching ""Forum for Equality & Diversity"" or ""Access & Inclusion Network"" which brings together all these groups to enable effective consultation and communication with the council"

"Please see my comments above"

"Not until Social Services acknowledges the need without prolonged work on the part of carers to bring high functioning people on the AS Spectrum into the support system. In particular, the council could acknowledge carers - and the people they care for - as experts by experience without the need for diagnosis, which is increasingly becoming a barrier to support for people on the AS Spectrum and their carers who are not taken seriously, some being labelled ""over-protective"" and ""obstructive""."

"Emotionally young but physically older can't access age appropriate activities"

"Parents meetings"

...other support the council could provide to local communities to help them come together and develop support needed within local communities?

Please provide any information or ideas you have that might help us:

53 responses:

"I'm really not sure what is meant by this question? I need support from specialist services with trained staff, We are already involved in great local communities that are specialised - the school, and the services my daughter attends. (Respite, after school clubs and holiday clubs)."

"There needs to be a higher profile about disability in local communities - a big PR exercise might help with this so that local people or organisations might come forward with ideas, projects or with any luck some money. It must be remembered that children with very complex needs require VERY SPECIALIST support and this does not grow on trees and it is expensive. Funding would have to be available through Community Partnerships so spending money is required to develop these locally. Perhaps start with groups who are already out there to determine if they would want to expand their activities. Voluntary organisations do not last forever without much funding as people move on or get burnt out. So sustainability is an issue here."

"Make venues autism friendly!"

"Work with more local charities and playgroups to provide schemes/locations to use which are more suited to the needs of the child"

"Local Community Centres could be useful for service users to attend after they had spent their day in Adult Day Services. Children have Breakfast and After School Clubs but adults do not have this. In my case, somewhere for the service user to go until I returned from work would be useful even if it were just a place for them to listen to music and buy a coffee etc."

"Use of local special school during holidays for playscheme."

"See above"

"Local groups for people with disabilities"

"Bring back child development unit back to huddersfield"

"I have been trying to set up a work situation for our young adults but too much red tape and not enough Kirklees staff to support us meant a year on nothing happened - momentum lost so given up trying"

"i have no more idea"

"Drop ins"

"better facilities"

"If someone qualifies for respite/short breaks then that child has high needs and often complex medical needs too. Your average church hall might accommodate a wheelchair and have a disabled loo but won't have a changing table for disabled kids/adults. It might also be unsuitable for other reasons e.g. too easy to ""escape"" from, and other health and safety issues that are not a problem for most but would be for high needs people. It may not be possible or cheap to adapt such venues. There is also the need to have people qualified to help. Can your average well meaning local group deal with tracheostomy issues, multi-sensory impairments? I agree that much can be done to integrate more disabled children and adults into the community but there will always be some with very complex needs who would need a purpose built building/room and qualified staff. It is also often the case that although community activities are open to all the family - which is often a nice thing to have all the family together - sometimes there is a need for the disabled person to do something on their own and independently and to have time apart from the family. This benefits the disabled person as they do something on their own and also the family as there is time to do activities with the siblings that are impossible to do when the disabled person is there."

"A book of Resources available should be created informing parents about what services are available. Local offer on the computer doesn't work for all as not everyone is computer confident. This should be made available in different languages. Social workers need to be given an active role to help promote information for services available and be the voice for parents where a need is required and not identified"

"Quarterly meetings"

"probably, dealing with the council is always difficult, they do not know their own processes or services, and do not give you the information you need, everything is a secret."

"this is not a good idea"

"Again, people with physical disabilities in the age range 30-50 seem to be missed out completely in terms of community groups and support in the local community."

"Work schemes for the more able. Independent living skills. More opportunities to mix with their peers"

"I do not know of any parents in my situation , a carer for an adult child, I don't know where to look, apart from the internet, it seemed if there was a group either it was too far away, or it wasn't an appropriate age group (for my daughter) or not quite for her disabilities."

"We need to plan charity events and get sponsors to help us keep these services going. It would be devastating if this amazing service (YPAT) was to be withdrawn from our lives."

"Communities could do day trips together. Women only community group (Thornhill Lees) do day trips for whole families so they can enjoy together. Need support group for siblings to understand more about disability and conditions to support each other."

"As above"

"As above"

"As above"

"There is very limited services available to young disabled children within Kirklees. The very few provision that exist is hard to access at times and it is not publicised enough for people to know what is available"

"better provision in parks, Kirklees Active Leisure etc."

"Meeting rooms, advertising"

"Not applicable"

"Carer's count are very useful. Perhaps extend their activities."

"More groups coordinated by local authorities"

"MAKING PLACES ALREADY THERE INCLUSIVE TO PEOPLE WITH SPECIAL NEEDS"

"Ensuring more public places are accessible"

"It seems very difficult to: (A) find out what is available (B) access what is available"

"Maintain current services"

"More facilities not closing existing ones"

"No everyone's needs are different due to culture, religion etc"

"support groups for siblings"

"yes, if feel there is need for support in the local community"

"How do parents find out who offers Short term Respite for Adults in the communities Does the Council have a booklet, not everyone has internet"

"in all this cost cutting, we are forgetting that most of the children are coming from poor background, Asian communities (Genetic disorder/consanguineous marriage) and in my observation it is usually a mother who is the sole carer or supporter of the disabled child, as father is working full time to meet ends together due to low socio-economic status/deprived area, We need to support them mentally /psychologically by providing service near to their places."

"Local hubs to access support activities etc"

"Local hubs providing care and support for young people and their families."

"Don't know"

"More communication eg news letter or flyers of what is available to people to help or assist them and make the process more simple instead of complex and red tape"

"Work with other religious sect in communities to use and work, train or support families. (Mosques & churches or community halls) more awareness and acceptance of autistic children and adults and educate the communities and recognise that there are hidden disabilities, disabled get bullied ALOT whilst playing outside and often forced to coop away inside and we need support in communities as well as schools for this to make children aware of hidden disabilities and autism and accepting or helping them /befriending. evening activities and volunteering opportunities to build confidence and work skills for 16+ disabled children. New modern college for disabled in Dewsbury with sensory garden and animal care, sports and art. Dewsbury college is deprived whilst Huddersfield has stolen all budget and revamped their town. there are no job opportunities in Dewsbury for special needs who are able to work but can't due to lack of jobs or opportunities and end up needing to travel far to Huddersfield/Leeds but no support to get there and they struggle or unsafe. Kids activity clubs in Batley all diminishing but are vital and needed and no funding given council need to recognise this is very much needed and kids cooping away at home are becoming obese as no sports in community. Sport centres are expensive for some and we can use community halls or mosque rooms/grounds to use for sports where families can pay a small charge (£1) to come and do activities on weekends. There are so many venues available and I think it's time you liaise with mosque and use their venues and bring everyone together as that's what they are there for-the community. Simply just using a room but no religious talk to be used so other non religious families can join and feel welcomed without having to worry about it being a religious event. Free Courses on first aid for disabled families and disabled children or 16+. Involvement from mosques and communities to raise awareness and acceptance for autistic children and other disabilities. Basketball, football, swimming and cricket or other activities for disabled children. We are lucky to have football, rugby and cricket grounds in Batley where we can use them to encourage sports and job opportunities or activities for special needs. Use sport centres for volunteering or job opportunities for special needs or autistic children 16+ . Training courses for 16+ on independent living and work travelling etc . Support for isolated families and access to support from councils . Create a forum or support group online where families can forward ideas or ask for help and even a voting system for ideas that are put forwards this way we can liaise with councils to help our children and council to support us and understand needs"

""Community Disability Champions"" - volunteer activists whose mission is to "".... listen, and relay key messages from the disabled community to Policy Makers and Implementers"

"Not many clubs in Holmfirth area ,"

"Please see my comments above"

"More use of the special schools resources (hydrotherapy / rebound / sensory room etc, just need to pay / get staff to run it. Some other local authorities pay for schools to do this and it works very well as pupils are already in a safe environment."

"Difficult to say when it's becoming increasingly obvious that resources are getting tighter and that the will to meet such needs is diminishing. And what resources are being targetted at the needs of minorities with AS spectrum conditions?"

"Not sure what this refers to, so cannot answer"

Of the support currently available...

Q19 ...what works well for you and your family? Why?

190 responses:

"Respite works well so I get time with my partner"

"we have 6 hours of YPAT every other Saturday"

"Self managing child care needs as there does not seem to be any other way"

"After school club YPAT. 3 days per week means I can continue to work to support us and my daughter socialises and interacts with peers from other special schools in the area. She has access to equipment that I cannot provide at home like ball pool, sensory room and specialise equipment. I have peace of mind that she is supported by trained staff who can deal with her gastrostomy needs as well as her care needs.

Orchard view - gives my daughter time away from home and helps build relationships with other children and adults as well as her own personal identity. It gives her opportunity to partake in different activities. Giving me a break and a 'sleep in'. Holiday clubs - socialising with others, appropriate activities, new experiences, personal identity, a break for me."

"The weekend respite is ideal for me and my sister as it gives us both a break from each other, her a chance to meet new people and me to have a bit of me time as she can't walk very far, appreciate the help but one weekend a month would be a big help"

"The weekend and holiday support"

"Holidays with Waves Day Centre because our son is with familiar adults & members. There is no settling in period for him. We are happy because we know the staff & trust them to provide a safe, exciting holidays in settings that are new to him."

"YPAT is great - our son loves going there, the support has become very specialist over the years including staff using alternative communication (picture symbols, some signing) and making appropriate communication resources for the setting to make it work. It is the only service that he can attend away from the home as none of the generic short breaks are accessible to him as a deafblind person. It gives us a proper break and time to do things in our home as well as time to do things with our other son.

Incredibly valuable service to us, not sure we would have survived without it over the years caring for a person who need 24/7 care and supervision. Carers Trust (formerly Crossroads is great). The staff are well matched to your needs, they are very highly trained, the support is consistent and it has let us get a social life back. We didn't realise till our social worker asked us that we hadn't been out for years...and years... This and YPAT have been proper breaks for us as carers and we don't feel guilty about sending our son somewhere he doesn't want to go or leave him with people who are not appropriately skilled/trained. Direct Payments is a mixed bag - some really good, like being able to choose a worker (albeit from a very small pool), having some control about the hours worked (limited if you don't have many hours a week) and it's been good to have care in the home when our son has been unwell so wouldn't have been able to go anywhere and therefore just missed out. Our son also stays overnight at his school 2 nights a week now as after 17 years we simply can't handle the totally disruptive nights any more or survive on 4-5 hours sleep. We can go to bed early and know we don't have to get up - we are exhausted a lot of the time and can't do our paid jobs properly with no or very broken sleep."

"Respite - either overnight or during the day during school holidays"

"My son loves YPAT after school clubs and holiday playschemes."

"Single parent therefore the respite nights work extremely well as well as weekend day clubs"

"The 56 respite nights I receive are sufficient for me to appreciate a break from my caring role. The 5 days per week Day Service is good for the service user in providing a wide range of activities and social

wellbeing for them, as well as being good for me in allowing me, as the carer, to live my own life and work full time."

"Direct payments. Flexible as PA is local so if there are any changes in my son's health we can contact her and change arrangements at short notice. They offer a personalised 1:1 service and have a good relationship with all the family. YPAT. Offers activities during school holidays which gives our son the opportunity to mix with his peers, try various activities with the support of an enthusiastic, caring team who are capable of meeting all his needs which makes us feel confident that he is safe while in their care."

"YPAT- it allows me the time/opportunity to spend time with my other daughter and family. It breaks up the weekend...looking after my daughter is exhausting and the respite gives me head space and time to relax."

"Respite at cherry trees works fairly well because they can cope with periods of a week or so at a time, though the majority of our use is for weekend stays. Direct payments works well because it provides flexibility to employ different people to care for our son"

"It has taken 7/8 yrs to get [service user] to except going to shady trees to give us a break. The staff there take great care of [service user] so we can relax and rest while she is away."

"Social worker communication and school communication."

"I like going to respite for breaks away. I like it when they take me out to different places."

"School help, transport from school to respite is good"

"Direct payments to enable choice of day centre and respite care - this enables me to work and my daughter to be independent"

"at the moment the support available is not bad. It's ok with me & my family"

"Saturday Club is excellent - helps to learn about friendships and meeting to interesting things (away from the supervision of mum and dad)"

"Respite in terms of summer holidays"

"SPROUT, PCAN"

"Wpat loves mixing with others can be quite a loner direct payment with a one to one to build confidence respite one night so we get a brake from routine n the child to be more independent with our there parents"

"I love the respite breaks and aft such clubs this gives me time to do shopping and visit family and friends, it also lets my child have days/ nights to see his friends and be surrounded by other like children which my child loves"

"Saturday club in Ravensthorpe for young people."

"YPAT & ORCHARD VIEW"

"weekend activities- breaks up what would otherwise be a long weekend"

"Holiday club"

"A carer visiting the home for several hours allows company for my partner and a break for me. Facilities in our adapted home and the standard of care provided are good or better"

"Domiciliary home care, Day Centre with transport within 4 miles of home, Respite"

"As said above we don't qualify for support although do use support group (PCAN). Disabled young person accesses a youth club (but I help at it) and did access Guides in the past. Support groups are very valuable for many reasons, support from other parents, good information and sometimes activities organised for either the parents or by the parents for the children."

"Nothing"

"The day care provides the chance for both the care and cared for to socialise with other people, which would not happen otherwise"

"I am able to go out once a week knowing my husband has someone with him. I have help 2 times a day with washing and dressing."

"Being able to employ someone you know and trust for care"

"Direct payments because I can employ someone my son knows and trusts"

"Respite breaks and weekend activities such as YPAT on a Saturday"

"Home support, carers visiting 4 x per day. Now need 2 people to mobilise even with necessary equipment."

"Direct payments mean carer and cared for can have proper time together, not simply being in the same room but carer constantly having to do the caring jobs, organise appointments etc"

"the availability at Cherry Trees to provide the respite needs required and the helpful approach by the staff"

"Short breaks help and having a PA support helps my daughter to have some activity personal to her outside of the family unit."

"Services provided by making spaces, a contractor t the council"

"short breaks together as this helps both people to get rest and relax as someone else is doing the work, eg meals, cleaning, making the beds so that precious time can be spent together. If seperated each person gets very upset in many cases when they are used to spending time together also this causes too much stress and upset. If one partner refuses to be on their own neither partner get a break to benefit health"

"receiving a direct payment, having a pre payment card"

"Receiving a direct payment, having a prepayment card."

"direct payments/respite payments. Because we can decide when we use the money., who we employ and what standards we expect for our daughter."

"As a carer time to recuperate"

"Day Care in the Special Care Day Centre. Our daughter is provided with a safe, secure and stimulating environment. Respite Provision is also good."

"after school clubs. My son has got used to going and now asks to go. He looks forward to it"

"Home support is vital for me to enable my husband (who also has mental health issues) to be able to work. I am able to access hospital appointments and medical needs more easily because of my support package and also achieve some level of independence with household tasks and social activities. Respite care has been invaluable for both me (the disabled person) and my husband and son (my carers)."

"We employ a carer which works well, and use respite to give us all a break"

"I am not sure that anything works well. Saturday club maybe."

"Once you find a group/organisation that my daughter can go to is great."

"YPAT- The staff are amazing. They provide excellent care. They are able to do fun activities with [service user] that I cant do. They are excellent at protecting our children and are aware of safe gaurding when it comes to the children. They have a relaxed based of multi sesory rooms etc to cater for all the children of all different needs. 'Activities' its in their title and that is exactly what they do, the way they look after our children is at the highest level possible and I wouldnt trust my child with anyone unless they could offer a level of care that I can."

"Overnight respite After school club"

"I use a mixture of day care , PA support and respite services. Birch Tree is wonderful, as is Calvert Trust Kielder, so I am using some locally based services and a respite service which is a true holiday too"

"I can make sure I have the caters I get along with and trust"

"PCAN Kirklees... excellent friendly support from fantastic people who help guide you through the minefield of SEN. Compass Bridge at Elland.. allows my son to be sociable and interact with other children like him and not feel pressured into conforming. He is allowed to be himself. Growing works ... same reasons as above. everyone is equal and allowed to be themselves and take part in activities in a safe environment"

"Direct payments which we use to send out son to Active Social Care on Saturdays, they cater for his individual needs & Orchatd View because they provide over night respite in a safe adapted building."

"I have no complaints it work's for me"

"Respite works really well and short holiday breaks"

"YPAT Local , daughter likes it there. I have quality family time with other children when daughter is there her needs take over. I can go shopping much quicker"

"After a long and stressful unnecessary battle, we are finally finding that direct payments is meeting our needs"

"Overnight stay"

"Support at home, weekend and holiday clubs. Have peace of mind that person is being looked after."

"Overnight respite - gives others in the family quality time together without worry"

"Booking short breaks over three months in advance works really well."

"Short breaks during college holidays. Provides social outlets and helps develop confidence and independence"

"Shared lives respite"

"YPat Saturday club works well and allows for family activities to be done while young person is at club."

"We are told how much we have but it is difficult to know what this actually buys. When some ones needs change (AS IS THE CASE WITH elderly PEOPLE WITH DEMENTIA knowing your needs is difficult) flexible care is therefore necessary. Privatisation results in too many groups who cannot provide the backup and cover needed when problems arise suddenly. The young people doing the front line job are very good but under paid and stressed therefore they break under the pressure leaving the people being cared for at a loss. As a person progresses into dementia they find the smallest of change TRAUMATIC therefore it goes without saying they need continuity of carers and respite . I am on to my Third group of carers this year and to my second respite location."

"DP scheme works well for us as we can tailor it to our needs more directly"

"Weekend activites to spend time with other child"

"The short breaks over the school holidays. They provide an opportunity for my child to be involved in activities in his home area that are fun but also with people like him"

"My wife goes and stays away several times a year on business. She also goes and spends time with friends. The money allows me to have care at home whilst she is away. These work trips also give my wife a welcome break from looking after me."

"Respite hours at home from Carers Trust. works brilliantly and allows me to actually leave the house without worrying."

"That I get a short break once a fortnight where I can do things with my other child"

"Compass bridge, easy to access pick relevant parts"

"The activities at compass bridge really work for us in in the school holidays as there there are a wide variety you can pick the activities which work best for your child and they offer transport from at a local pickup point,"

"We attend two inclusive club where the whole family can attend. I am a single mum of two boys and doing activities together is very important. We would not have managed the last couple of years with out the network of people areound these clubs - Shabang and Sprout"

"The two nights per month I receive currently for my son are an immense help to our family. I am not of particularly good health and have no social worker due to all [service user]'s care being in place. My son attends respite as mentioned and a playscheme every Saturday along with holiday play schemes this gives me valuable time with my sons sibilings, doing things we ordinarily cannot do when [service user] is with us, also [service user] gets to spend quality time with trained staff and loves spending time with his friends who are of a similar ability."

"The support is not only tailored to my son needs but that of my and family as well. I am extremely happy with the services he receives, it has enabled me to continue with my caring role as well has working and spending quality time with my partner. It also allows my son the opportunity to socialise with his peers and develop independent living skills, along with his overall development."

"Able to attend day centre works well"

"visist from a carer - helps my wife get out when I am at work - otherwsie she is nearly housebound at these times. Also th elocal MS/Neuro group provides a social envinment where my wifes condition is understood and accepted - it ofen isnt in other more regular social situations - this also allows her to recover adn re-develope social skills and socail awareness.."

"I have the freedom to chose my own respite using direct payments"

"Day Care & Respite but also working with physio & OT for my needs."

"Short break respite is vital for the wellbeing of the whole family."

"Direct payment and respite"

"The respite provided for my son by YPAT and orchard view and hsga really help me to have quality time with my daughter. If my son were at home he tends to resort to standing in the shower for hours or sat wrapped in a duvet. He gets socialization and interaction at his respite. The transport provided to get him

to the groups also helps immensely as I am a single parent with 2 children. I find it very difficult to take both children out by myself. All of these groups that my son attends provide structure to his day which he benefits from and which shows in his behaviour."

"Direct payments works well"

"Carers trust"

"My daughter having respite once a week allowing me to work and also have a little time for myself"

"Respite gives us a chance to do what we like to do"

"[Service user] is happy going to Mill Dale"

"Shared lives but not enough available. Day centres for learning new past times and hobbies"

"Respite is stimulating for my son, he makes new friends. The day trips are fantastic even getting to the top of Snowdon in a wheelchair! He always goes to re-vitalise in Southport."

"It gives parents a rest or a chance to go out together."

"As elderly parents now we do appreciate the rest respite gives us"

"The 40 nights allows us to take a holiday and also allows [service user] to rely on others"

"The Sunday respite gives us time with our 2 older children and allows our 2 younger (disabled children) to go and have fun"

"Short term breaks Carers Trust etc"

"Have no support."

"Orchard View and YPAT are both lifelines for our family with the much valued and appreciated service they provide."

"18 - 25 Saturday clubs as weekends are difficult and long without day care. Will be hard when he grows to 25."

"Day care"

"direct payments==because it gives flexibility"

"LIKE TO GO TO MILL DALE 2 NIGHT PER MONTH"

"PROVIDES FREE TIME FOR THE CARER ON A REGULAR BASIS"

"2 DAYS PER WEEK DAY TIME CARE"

"LOVES GOING TO YPAT. IT IS A SAFE COMFORTING ENVIRONMENT AND GIVES ME PEACE OF MIND TO HAVE A BREAK"

"AFTER SCHOOL CLUB ENABLES ME TO BE ABLE TO WORK AND EARN AN INCOME"

"YPAT WORKS, IT ALLOWS FOR A YOUNG PERSON TO BE WITH OTHERS WITH HIS NEEDS. IT ALSO SUPPORTS OUR FAMILY TO WORK"

"RESPITE"

"AFTER SCHOOL CLUB"

"After school clubs, so I am able to work full time"

"the timing of activities, transport is the main issue"

"Regular breaks"

"Both myself and the person I care for (my wife) were initially reluctant to accept respite care - I saw it almost as a failure on my part. Now we have used it for a couple of years it is a very important feature allowing me to have a short time to recharge, rest and catch up with things that being a carer are usually not possible. She has MS, is unable to stand, has very restricted movement and has to be hoisted from a downstairs hospital bed into a chair where she spends her days. A carer attends twice daily to help put her to bed and get her up in the morning. I act as the other carer (two are needed) - having been trained by the agency involved."

"The right staff to care for my son"

"overnight respite as it lets us recharge our battery and we know she enjoys being there. she likes going to playscheme and helps us too"

"Respite within a family setting"

"Day care services and shared lives respite"

"Flexibility of service in case of emergency"

"Central Stars Youth Club, excellent respite for the users and rest of the family"

"Central Stars Youth Club"

"I currently receive 2 weeks respite this worked ok until my condition has deteriorated."

"Respite overnight care at Orchard View and YPAT evening play scheme sessions are a real lifeline for our family"

"Evening youth club and Saturday club as they are in small age and number groups so there is plenty of support if any of the young people get overwhelmed."

"Short breaks twice a month offers carer a rest from the full time caring role"

"I have had no support over them from the school my child attends"

"Day services and respite help us to keep the Shared Lives placements running successfully"

"Care taken of our daughter is excellent when at Cherry Trees"

"Respite is helpful to enable carer to relax"

"I currently have 3 nights respite care a month, 7 hours Carers trust a month, 10 hours direct payments a week this works for me as I am able to have time with family in Bridlington and friends in Barnsley."

"Ypat as it's familiar"

"Orchard veiw /wpat / direct payment"

"YPAT always good drying holidays when there os nothing else to do Orchard View excellent care"

"Respite works for me as a single parent as it can be quite draining and stressful having to cope alone and we both need a break at times"

"Arrangements which we source and organise for ourselves."

"Choice by using direct payments"

"the support we use was all set up a while ago, newsletters would be usefull to let us know whats new"

"Day centre and respite because it gives a break"

"Babysitting. As allows time together as a couple. After school club, as have no option for childcare"

"Evening and weekends activities. It gets he out and to socialise"

"Respite, so we can catch up on sleep"

"Respite"

"respite"

"Central Start and WACKY have been a massive help for my son to socialise with his peers and helped him gain confidence and become more independent"

"flexibility of direct payments enables respite to be taken when required"

"Having provisions that my daughter can access in the weekdays, holiday clubs afterschool clubs"

"Respite for [service user] Saturday club activities"

"The support we get from Shared Lives is excellent and works well for us at the moment"

"YPAT my child enjoys this service. it is an excellent service with caring staff. Orchard View we couldn't cope without this service"

"Like a short holiday for me. Respite Away for my husband to have a rest too"

"MENCAP IN Kirklees day services"

"helpful staff at Respite centre alternative dates offered if first choice not available transport provided to pick up/drop off at day centre"

"Respite Care it helps your child to boost their confidence away from home"

"it is local and avoid family travels for hours ts available on weekend so gives time to my wife for her self, short breaks help her psychologically and physically."

"Using direct payments for holidays with private day centres. Company of others and carers. Family able to totally relax"

"Direct payments, Respite Care and play schemes all worked for me"

"Orchard View. Excellent service and care. All valuable services. YPAT , Active needed for our child"

"Short breaks are very important"

"Currently Respite and Weekend clubs that my child attends give the rest of the family time together and for him to do things that he enjoys"

"Central Stars is fantastic to give our foster child a social life"

"Having a nice break just doing our own thing"

"Overnight stays as it allows us an extended period of time off-duty to do things that our son would not enjoy."

"home care which is done in house at convenient times"

"Carer's Trust, enables us to stay connected as a couple and also discuss any problems we may be having with our child."

"Use of play scheme during school holidays allows us as parents to spend time with our other child and do activities which may be difficult to access if our disabled child were with us. Direct payments enables us to arrange flexible care"

"It means I can go places with my mum and dad which ordinarily I couldn't go to because the play scheme looks after my brother in the holidays. without it we would be stuck at home a lot and I wouldn't be able to spend time with them doing fun things that disabled people cannot do.it is extremely important to me."

"We haven't found/or been offered anything."

"My child spends time with his peers not at home with mum isolated !!!"

"YPAT"

"the ypat club has given my child social skills and allowed to mix with different aged peers to progress with better social ud play understanding and play therapy"

"YPAT is a wonderful support during the holidays"

"Knowing that when my child is at YPAT he is safe, secure and staff will be able to meet his needs. To be honest the only time I could relax was that 1 day during the holidays that he went to YPAT."

"Nothing as everything is in editing list. Respite helps but it's limited and so long to kick in and set . Caters trust have let us down and not supportive with lack of respite care assistants"

"It gives us a rest from full time care of our teenage autistic son. Who has difficulties sleeping on a night."

"The holiday playscheme is a massive help as it gives my child a holiday club and allows me to have son time with other child to do normal activities. I don't know how I would manage school holidays without this."

"Motability Scheme / Social Workers / Direct Payments / CHC team / SEN team / District Nurses / local Doctors and Hospitals (especially local A&E dept) / Housing Benefit / Discretionary Housing Payments"

"Compass Bridge gives my son a chance to get away from us for a day ! After school clubs are good ."

"It all works well. It enables us to work outside school hours & have some quality time together as a couple or with friends. It is benefits our daughter as she is socialising with other children & doing activities which she probably wouldn't do without the support"

"Hollybank respite - they have nurses that can deal with all sons medical issues, and have amazing facilities and staff. There's always lots to do. YPAT - again an excellent team of staff although the building is in need of update the staff and the activities which they do with the children more than make up for it."

"We use the same company to provide respite when we go on holiday. The company arranges for the same member of staff."

"There isn't any carer support for us. So we do and fund it ourselves. A life of our own would be nice."

"Compass Bridge works well as the activities can be tailored for your child. YPAT is great as it gives parents a break"

"short breaks or overnight stays because gives us personal time and to spend time with other family members"

"Respite is very good, allows us to holiday on our own and other free time"

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

126 responses:

"lack of flexibility in how we can access YPAT"

"Lack of suitable provision"

"Everything we access is great. A good routine is in place."

"It's fixed times..would prefer more flexibility"

"Our son enjoys 1 evening per month with Carers Trust when he goes to swimming sessions. We find that we sometimes don't feel like going out in the evening so the break ends up being more for our son's benefit."

"Overnight care in the home. Can still hear all the disruption and are still awake all the time. Plus our son knows we are there and will seek us out. Care in the home when our son was little because we couldn't distance ourselves sufficiently in the same house and he wanted us. It was hard to switch off being able to hear everything. When he had very high health needs as a toddler/younger child, we weren't comfortable going out in case of emergencies, which were frequent at that time. Care in the home is OK now he's older but still no escape for us unless we go out. Why should we have to go out of our own home? Also we can't really afford it as less money coming since our son was born. Direct payments is as bad as it is good. First of all had to agree assessed hours, open a new bank account, register with HMRC, choose a payroll provider from a list, do risk assessment (hadn't got a clue at the beginning and no guidance given), identify skills required and recruit. Very difficult to find suitable people and nowhere to go to find appropriate staff. Very hard to get someone to come and work for 3-4 hours per week or an hour per day - not worth their while. Oh and got a contract from Kirklees which was gobbledegook as far as we were concerned - all legal jargon. We are responsible for monitoring money in and out and sending stuff off for audit. Only provided with manual monitoring forms so made own electronic ones to make life easier. DP office keeps moving so don't know where they are or how to contact them. Never hear from them unless they are after your monitoring (all about money, not about service). Responsible for getting payroll information to provider on time and then paying staff. Staff management, supervision, hiring, firing - no training or guidance provided, just left to get on with it until Fish Insurance stated to provide enhance insurance a few years back which includes HR advice line and a ""how to"" risk assessment leaflet (been asking Kirklees for help on this for 5 + years - no response). No help with training - complete avoidance by Kirklees in my experience. Been asking for behaviour management for myself and care workers for over 5 years. Have to organise staff hours every week/month and work around their holidays/sickness etc. No alternative care cover if son's PA is off sick or on holiday. Big responsibility all the time and starts all over again when people leave. Big responsibility all the time and can be very stressful. I find I do most of the admin after midnight as have no other time to do it and I make mistakes when I am tired. An electronic timesheet would be massively helpful - been asking for one of those for years as well. No faith in DP service - they lost my paperwork twice (I have to keep records for HMRC), sent me someone else's monitoring and bank statements back once and when I rang to advise them they expected me to send a big heavy envelope back at my own expense!! Don't know if DBS checks are covered by Kirklees any more. Got a letter off them recently for monitoring - no phone number except council switchboard. No named person. If I rang the switchboard, wouldn't know who/what to ask for. Last time I tried to ring via Switchboard, went through a number of people to get to right place. I only stick with DP because there is nothing else outside of YPAT."

"Playschemes need to cover all of the school holidays not just one day or one week."

"Drop off and pickup times does not allow much can do from 3.30 and up to 12 the next day during weekend and holiday periods, therefore have to use two nights"

"My package works well."

"Its taken me a very long time to get Direct Payments despite many referrals.....i would really like to see this process simplified"

"The lack of flexibility at cherry trees - bookings have to be made months in advance. We also find that the support plan for looking after our son doesn't get transmitted consistently to staff at cherry trees"

"Changing where [service user] gets respite . It takes years for her to settle so we can have a weeken / Monday - Friday stay. If [service user] has to place she has respite she can stop eating / drinking"

"Cuts in social care e.g socail worker"

"Amount of help for siblings"

"If evening and weekend services were cut - young adults would be stuck with their parents/carer's and lose their independence."

"Not finding place to spend together with my special need one with siblings"

"Long distances in the evenings and late nights when there is college in the mornings"

"Location of ravensthorpe not the easiest to get to due to location"

"iYSS - can't access without support, can't work out how to get support"

"Lack of regular activities young people with autism can access that are supported."

"Direct payments and having to manage my own staff. It's difficult and not as supportive ... I like the parental support work Ypat has begun, it means I do not feel alone"

"officious individuals who don't understand our needs"

"Care homes don't work. Facilities are basic and staff lack training / experience and knowledge Care navigation team and Client Financial affairs weren't helpful or efficient in organising direct payments"

"The removal of disability learning team (physiotherapist etc from day centres) Care workers are now expected to do the exercises and support that qualified physios did"

"Some services such as Compass Bridge and the Duke of Edinburgh in Mirfield offer holiday schemes to a wider group than just those entitled to respite/short breaks but not aware for a long time that these were available to people like my daughter. Now she's older she has her own views on what she'd like to do but these activities might have been something she could have done if I'd known."

"Transport has always been a problem because of erratic timekeeping or instant route changes, and no information given when this happens."

"Continuity of care. Change in staff means they don't necessarily know much about your child, the trust and relationship requires time. Our children also find change very difficult and when services are taken away it has a knock on effect on behaviour and confidence and their condition which only leads to us asking for more help. And then this creates more stress for parents and children to battle to get what they then need. It is also important that places for care are suitable for physical needs with accommodating facilities of care eg changing places. Age restriction should be avoided especially when the child may be older but have learning difficulties. And it should be open to the whole family"

"Lack of provision for my 5 year old"

"Present support is adequate"

"x"

"Everything is either hard to find, hard to get to and if these can be achieved, expensive to pay for. Different people give different and sometimes diametrically opposed answers to questions, social workers rarely know what to do and give incorrect responses. Cared for person rarely fits into the box that they have been put in."

"As above"

"Any application for benefits. paperwork is very poorly written and lacks the information required so multiple applications are required before success."

"separation"

"Care Companies - too restrictive - you are rushed, no continuity in staff - money making organisations, care navigation- time is limited with the worker, gateway to care - merely pass you through to someone else and CQC medication policy - you cannot be given any medication or lotion that has not been prescribed by a doctor."

"Care navigation - limited time with the worker, gateway to care - just pass you through to someone else, care companies - too restrictive, CQC medications policies - can't have any non prescription medications,"

"Not enough respite beds available"

"No spur of the moment activities/holidays."

"No over night weekend respite offered"

"Initially I found it difficult to find a reliable care agency - more support from the council would have been helpful here."

"The battle for funding and direct payments. The lack of freely offered information - everything must be asked for, and you have to know about it to be able to ask"

"Direct payments for a P.A. P.As are very difficult to find, cannot always do the hours that are needed so we end up with a compromise rather than what we need."

"My daughter was out of the 'system' as soon as she finished her education, after that nothing. No advice, no support on what to do next. I have just 'got through' these last few years without help. It is only because the internet has now become more accessible, that I could find information before that it was virtually impossible. Apart from telephoning people perhaps, but who would I ring?"

"Over night respite hasnt worked for us yet as I havent found anywhere where I have seen suitable for my son and where I have found the staff are at the same standards as YPAT. I have always said that if YPAT did sleep overs, then they would be amazing"

"Not enough care during school holidays"

"Quite hard to fit working hours into day care provision. Also difficult to find reliable PAs . I am very lucky to have a PA who has been providing my daughter with support for many years. Continuity is important"

"Having new staff or different staff to my usual staff without being informed or asked"

"not a lot of things for both of my children to do together due to age difference and often individual activities that they do want to do are timed at the same time so impossible to get to both on public transport"

"Ypat after school club because they don't cater for a child's individual needs. Crossroads same reason."

"Nothing"

"A central person,(e.g. social worker) required to assist and open up the doors of support and need.. Our child required a wet room but we had to battle a lengthy process to get this need in place which a social worker could have completed. This would have saved time energy and stress and would of have been accommodated quicker. The length of time has created more hazard for our child and us"

"Not able to access as no diagnosis"

"Lack of information"

"During holidays, restricted to just two days with some services and not able to choose which days for person to go on for holiday club. Need more choice in holiday clubs."

"The short breaks are limited and we would like more opportunity to buy into additional breaks"

"Lack of respite budgetfor one of my family relying on goodwill of my family to give me a break"

"Not enough respite places available and as previously mentioned age difference too large with people from 18 to 70+"

"The stress of acquiring the care Mam needs with the stability she needs and we can cope with in our home."

"i think sometimes the finance part is more important than the actual help you get and really it should concentrate on the help"

"There are not enough activity days and they tend to be limited in activities that they offer."

"YPAT - hours were not long enough. I am a worki g single parent, YPAT hours ,eant I had to take A/L anyway whilst my son was on playscheme - in which case i preferred he was with me !"

"7 hours a month of short rt break services isn't a great deal when I have 2 children with disabilities"

"Places which are too far away and don't offer transport. Also some places do not offer enough support."

"as I work anything during the week that I am not able to get my child to after school. but If I had direct payments the PA may be able to access some of these"

"The worry of play schemes/ respite centres closing is a constant worry when that's of funding being removed are mentioned. The thought , I imagine, for a lot of parents of not having this help in place is a constant worry. Will this impact on parents mental health."

"I now have to pay for the afterschool club which was an assessed and highlighted need within my son's child in need plan."

"Nil"

"Home Care- [service user] doesn't lake strangers helping her, needs people she knows"

"Constant fighting with services to obtain even the minimum amount of support. I would like to be able to spend my time being a Mum rather than a warrior and an advocate."

"I find the travelling to mirfield difficult. The hours for 1 night at orchard view are short which means i can't really plan to go too far away unless i use up a lot of our allocated hours.(eg my family in harrogate)"

"Respite because my condition can't deal with the heat in nursing homes"

"Meets care"

"ST works well for us"

"Slow communications of staff and social workers"

"Respite works well for us"

"All the paperwork involved with direct Payments"

"Lack of choice of Home care providers- stuck with the only provide who is prepared to cover a rural area"

"IF HE COULD COME FOR LONGER OR MORE OFTEN"

"THE COUNCIL THAKING THESE SERVICES AWAY FROM ME!"

"CLOSING YPAT"

"TAKING YPAT AWAY, BECAUSE WITHOUT IT I WOULD FIND DIFFICULTY WORKING"

"Not being able to access holiday clubs and weekend clubs"

"transport issues,"

"family members cannot be together - that creates more stress"

"My wife's respite is at a nursing home outside Kirklees. When it became clear that respite care was needed we looked at local care/nursing homes within the area and our feelings ranged from some being inappropriate for my wife's condition to absolute horror at what we found.A list had been provided by out social worker. My wife does not have dementia and needed to be with clear- minded people.The one providing respite is the only one we visited where I can feel confident in the care she receives and know she is happy there."

"Better explanation of direct payments and support"

"Nothing"

"No Central Stars"

"At present I need more respite in order to fulfil my needs"

"travelling far on my own with all children. support workers limited to time and policies"

"overnight respite which frightens me a little as i have never left my daughter in another establishment overnight."

"Respite in homes and any large groups with wide age ranges."

"Mill dale are accommodating to our needs, no complaints"

"We struggle on our own because we've never been offered any support"

"My child needs constant supervision and prompting so s unable to do things independently, this means she is always with a member of the family when doing social activities."

"placements working fine"

"The fact that clients cannot arrive until after 3.30 pm and have to leave by 11.00 am. This means 5 days away (4 nights for us) involves 6 nights for our daughter. More flexibility is needed. (Cherry Trees have been helpful in this regard once or twice)."

"Closing Ypat meaning my.son will need to travel for 30 minutes to new facility"

"N/a"

"Inflexible LA provision and 'imaginary' accounting processes."

"The cost of overnight respite especially when a one to one is involved"

"the lack of information"

"When services are far away or keep closing down"

"restriction on shared lives policy to not provide respite in own home"

"The time scales allocated hubs"

"Respite they put up so many barriers, my son doesn't behave and makes life difficult so they cant cope and don't have time for him"

"I have no support no social worker"

"When you try to get hold of someone and nobody is there"

"refusal of day centre bus to take and return suitcases to day centre/home"

"We would prefer Respite to begin around 12pm on the first day instead of 3pm"

"No benefit for us to have services in the evening and at nights and if we have to travel for hours to drop them and to pick them up"

"Some evening activities finish too late. Also tired after day college"

"Quite happy at the moment"

"Lack of flexibility and lack of choice."

"respite not enough time available"

"More Respite needs one more demanding and her age is adding to this wanting more independence"

"No issues"

"N\A"

"Opportunities to attend day time activities and a wider variety of activities. We had a 'buddy' via Mencap for a short time but she moved out of the area and has never been replaced!"

"Restbit"

"not given any respite or break to allow to recharge our batteries"

"It would be very helpful to be able to use YPAT more"

"Caters trust don't have enough trained staff for families and we were in a waiting list for too long missing out on support."

"Social Housing (there is no pre-adapted stock) / Home Adaptations / Special Equipment provision (both home and education) / access to Physiotherapy & Hydrotherapy / Occupational Therapy / Wheelchair service"

"Transport - YPAT holiday club can transport son, but not on a weekend, so we only go once every 4 weeks to the Saturday club, its an hours round trip, and costs over £30 in a taxi)"

"Care inside the home, because my child likes to get out and about"

...what should be changed? Why?

111 responses:

"I would prefer some flexibility in the use of YPAT in that we could swap the odd saturday and maybe use that day allowance in the school holidays instead. It seems very rigid"

"Childcare options for working parents who are unfortunate enough to have a child with additional needs which precludes them from mainstream placements and who don't have extended family or friendship networks who step in to help-frustrating and isolating"

"Try to be more flexible in days and times that support is offered"

"There is no flexibility, things have to be booked in advance. If we want to make a last minute arrangement we use Waves Cottage in Slaithwaite for an overnight stay, which is expensive. Our flexible arrangement with Shared Lives has yet to be tried out."

"That the Council should stop seeing Direct Payments as a cheaper alternative to specialist provision and understand what it is like to be on the receiving end. All staff who are involved or who offer direct payments to people should have to attend a workshop designed and run by service users on using Direct Payments so they can put themselves in other people's shoes and have some understanding of what support there needs to be for people to use them effectively and well. There should be a viable Direct Payments Support Service so people understand what they are getting into and doing. This includes but is not exclusive to: a database of direct payments PA's out there (JMA payroll do this currently for their clients but it is limited) to make recruitment easier (not an agency who will charge people), advisers who can explain the whole process properly and all that it entails and provide users with resources to help them. Creation of helpful resources on using DP - a kind of ""What direct payments are and how to use them"" to include hints and tips on recruitment and management, what to do when things go wrong, managing money (advisers have said to me in the past ""Oh you don't need to know how to budget"" - but you do as often extra holiday care money etc is paid in one lump at the beginning of the year for the whole year), monitoring information, how to register with HMRC etc etc. Run some workshops that people can attend so they feel more confident about it - delivered by experienced DP users. How to do a risk assessment. How to access training. Make sure that training is available for carers and for DP staff - there are a lot of common denominator topics. Fish Insurance run free workshops on HR stuff which are really great and aimed at the DP users - get them in. SCOPE was commissioned to deliver the original DP Support Service in Kirklees and it was excellent. Since it came ""in house"" it has declined dramatically. Resource needs to be identified to enable service users and carers to use DP to meet their identified outcomes - it is not just a Cheap Fix. Work needs to be done with care agencies in Kirklees. Not many provide care for people under 18. Some of those that do are not registered with CQC or other bodies. They need to understand that working with children and young people is not just about doing personal cares/feeding but about enabling them to experience the world around them - very different approach. Agency staff and DP PA's need somewhere to go with children/young people with very complex needs as

they can't always access parks, sports centres, soft play etc. There needs to be provision for young people with complex additional needs once they hit 18 years old. Currently there is nothing for the very complex end. Places are either aimed at older people (not an appropriate peer group and different needs), people with Autism or those with generic learning disabilities who are often very able in comparison. These complex young people need to be able to go somewhere where they will have an individually structured day of activities and relaxation which are meaningful to them. Not just sent somewhere to mill around aimlessly or be pushed around in wheelchairs, not giving them any choice or purpose, to give their carers a break. I see people in this situation and it is heart-breaking. It fills us with dread that this is a possible future for our son in Kirklees. There needs to be a gradual transition from one type of support to another."

"As above."

"Think more flexibility and departments working together more. DP should be able to be used to buy services from Kirklees or reduce DP to families and make more services available, charges for weekend activities"

"Happy as it stands."

"Awareness!! nobody tells you there's help available it's wrong that you only find out through talking to a parent or by complete chance"

"More respite provision. Greater flexibility in booking system."

"Nothing I want [service user] to stay at shady trees."

"More money to families with disabled children. More after school facilities for children with additional needs so parents could return to work."

"Also offer of direct payments I kept getting shot down when I would ask about it. I would like a few hours a month to get someone to help bath and sort child out"

"Ask most parents we all have the same feeling"

"Continue to provide the support and availability of Saturday club and other similar opportunities"

"More locations"

"More support for parents"

"empathy would be god!"

"Care homes should charge more money for the service to allow them to upgrade facilities, retain staff and offer better nutrition"

"Better information on availability of schemes to wider group (see above). Clearer information on who qualifies for short breaks/respite. There are many parents who struggle with no support at all as they don't qualify but mainstream offers do not suit their children for many reasons (location, suitability of building, people who run it couldn't manage that disability etc) An example might be there is a disabled swimming club in Kirklees which is serious lessons and training but no disabled ""fun"" session where you don't have to be there with your child or so parents have said. (There might be but no-one can find any details!)"

"Keep the services and improve them and help to maintain a good relationship with staff so that they stay"

"More provision for younger children so they have the same access to activities and social situations as everyone else"

"Nothing should be changed"

"x"

"Limits on what is excluded from direct payments eg food with accommodation. It is essential to eat when in respite and if using a respite type fully catered situation, costs more than eating at home. Help to negotiate the system, better and more accurate information on changes and correct paperwork supplied to all parties. Copies of agreements in writing for reference. Ongoing follow up - a few weeks of Care Navigation is rarely enough and more complex cases have more complex issues to sort out and organise. Proper assistance for as long as it takes to get a suitable package in place and then regular follow-ups by the same worker. Direct contact provided for when named person is not at work - most social workers seem to work a 3 or 4 day week, have young children and take long holidays. One person who gets to know the situation and can continue to advise without closing the case every few weeks."

"Restrictions on what a DP should and shouldn't be used for it becomes very confusing leading to the money not being used for fear of being accused of misappropriation of funds (to scary). As long as this is not abused and benefit the child/ young adult as well as meeting family needs."

"Clear information. Social services should provide the direct access to benefits and respite services rather than a general point in the rough direction."

"take into account to help couples stay together"

"Care Companies should be closed down. all disabled people should receive help to employ their own staff. social services should be closed down and the money given to the NHS so they can give people the proper care and support they need according to their medical condition."

"Care companies should be shut down in favour of direct payments with help being provided for disabled people to have PAs."

"offer all families overnight weekend respite despite family situation"

"More support in finding support workers when in receipt of direct payments."

"Information on all available services should be freely given. It should be much easier to access direct payments, not told - 'we don't do that'."

"Help to find suitable systems to facilitate our dependents lives. Such as finding a P.A. or maybe a bank of PAs whereby you could use those that your relative has built a rapport with, for the hours and help that you need."

"I would have appreciated someone to be able to discuss options after she had finished her education. Not just what she could do during the day, but also what would be available to her socially, my daughter got to the point where she had no friends and was becoming reclusive. It was bearable for her when I could take her out and about, but as my health started to fail, we did not do anything or go anywhere, until I searched for help for her."

"More training should be done and staff selected to understand that they need to care for the children and not be able to sit on their back sides doing nothing and watching television. When children are left in their chairs and neglected then I am not willing to send my child to a respite place like that. You only have to VISIT these places to witness this. By far, YPAT is the best place that offers us help as a family"

"Happy with the service"

"waiting lists for CAMHS pathway for autism are far too long and need to be addressed as a matter of urgency"

"There should be more choices of care."

"nothing."

"see question 18."

"Network channels for professional help needs to be improved. Services of help are initially there but then lost in transition to adulthood."

"Flexibility"

"Better explained objectives"

"Services should be open all week. Gives more flexibility."

"age limit should be increased up to 25"

"There is no parity in the amount of respite given."

"As above"

"We need to wake up and take back control of our social services and NHS. Privatisation is not working."

"Easier information reading material and support through any process you may have to go through to get the right help"

"More activities and more varied. Because as a working parent is really hard to find things to do with a disabled child during holidays that all the family can join in"

"should be easier to access the info/get provision. First 9 yrs of my sons life I got no help, despite him being disabled enough to get DLA, having a full statement etc. I became ill because of the incredible stress I was under, with no help/access to support."

"Easier access to services tailored to meet all Childrens needs"

"Help parents work and support their children, make access to direct payments less of a fight"

"Stop centres such as YPAT, respite centres and help in the home having funding cut. Surely children with severe disabilities are or should be a top priority. Governments and councils cannot just brush them aside as I feel families will suffer and the cost long term on the health services and mental health charities will be immense and costly,"

"Parents should not have to fund support services which the council have deemed our children require to and these services should be funded using the council budgets. Also, considering the nature of these services and how imperative they are for both our children and families the funding should not cut as it has in previous years as this affects all who access the services and how they are run."

"Nil"

"Home Care- regular person"

"ACTIVE need to have an open day so families get more of a insight into what happens there. ACTIVE needs to be more personalised"

"More choice like an holiday like normal people do"

"No agencies just Kirklees providing care services directly"

"More respite"

"Everythings ok for us"

"1 member of staff, 1 job. Things get lost in non communications."

"More respite services available in the Mirfield / Dewsbury area"

"Make available some overnight rest bite care for the younger persons and not just care homes"

"More than 28 days respite a year provided. It can be a 24 hour, 7 day a week job!"

"more funding so as to encourage providers to make services more widely avaiable"

"MORE SUPPORT AVAILABLE IN SIX WEEKS HOLIDAYS. MORE FLEXABILITY IN TIMES AND HOURS"

"NOT YPAT!"

"PEOPLE SHOULD RECOGNISE THAT SUPPORT SUCH AS YPAT IS VITAL FOR CHILDREN AND FAMILIES TO STAY TOGETHER AND MAINTAIN A HAPPY HOME"

"NOTHING"

"Any child with special needs should be able to access same provision"

"families should be able to decide what respite/break would best help them cope"

"See above!! More playschemes for young adults who are in full time education, especially in the six weeks holidays"

"Nothing"

"Maintain provision"

"It would be better if direct payments had their on Assessors to come out and look at the change in needs. When I rang to ask for this I was told you have to contact Social Services for a re-Assessment first."

"More activities should be provided for the 18-30 age group."

"Not sure"

"We do not yet access services for social activities - maybe when we look further into it direct payments may address the then needs so I am not able to answer this question fully."

"Nothing"

"Easier booking system."

"More staff so we wait less time"

"The fundamental disincentive to make some provision for oneself, especially in later life, and the grossly unfair treatment of those who have."

"?"

"as above"

"more info. available for parents of which is on offer"

"to have more things available during evening and weekends for my son to socialise.ie. sports/dance and drama groups"

"the policy should revert back to previously when carer could support in own home because of physical disabilities which have required adaptations to own home"

"More staff smaller units"

"I needs to be more straight forward not as a complicated as it is now"

"Its not just the Council it happens in other places Someone in person at the end of the phone"

"willing ness to help accommodate suitcase on bus"

"Evening and nights facilities should be abolished Weekend hours should be reduced to 5-6 hrs /day Staff should reduce their work hours or job sharing. Parents should be happy to contribute little extra from their funding."

"We should get PA free!!!"

"Cant think of anything"

"There seems to be a shortage of provision and opportunities to access short variable breaks and prepare over a long period for independent living."

"as the needs increase so should the care package when needed most"

"N/A"

"N\A"

"Nothing"

"More resources"

"more help and better respite for the people and more out of hours school clubs and week end clubs"

"If the hours could be increased that would be great! School holidays can get a tedious for any child but a non-verbal child with hyperactivity can find them quite upsetting without regular entertainment."

"A similar setting but for young adults/older teenagers"

"Because it's letting families down and families breaking up or being isolated and breaking down. Camhs need improving as the waiting list is also effecting support at home, school and out and about for families who are struggling to cope without a diagnosis at the right time if need."

"In general, what works best is when we have control of the budget and service providers have to compete for it - exemplar is the Motability scheme, and also Direct Payments which we would rate as

""outstanding"". Opposite extreme is when we have to compete with other service users for scarce resources - eg Home Adaptations / Home equipment / Wheelchair Service which we would rate variously as ""poor"" to ""not fit for purpose"""

"Transport for Saturday / Sunday clubs would be great More days available during school holidays would also be good"

"There should be funding available for those who are caring for the disabled people as it is expensive going on holidays in order to get respite."

"I am happier now with Respite and day care than every before"

...is it important to you and your family when we provide support? Why?

162 responses:

"yes as we have varying needs and it would be good to have flexibility (within reason) to access respite at different times of the week"

"So both parents can work and maintain a decent standard of living for our family as well as career aspirations, having a child with additional needs should not mean one parent has their career options distorted which can in turn impact on psychological wellbeing."

"Yes, as above. Being able to work and provide for us is very important to me. Having an after school club until 6pm Supports this."

"It's invaluable because we are able to enjoy those activities/ events which otherwise we are unable to without the support there for my daughter"

"The evening activities are for our son's benefit really. There is not much time left when dropping him off & being back to collect him is taken into account"

"We need support in school holidays and weekends. Our son requires 24/7 care and supervision and it is exhausting. We need to get a break from caring, recharge our batteries and do something different and spend some time away from him. He also needs a break from us and do something different, experience different places. Our other son is always at the back of the queue and we need to be able to give him attention and spend time with him. We feel very tired and under pressure most of the time and there is always something to do: forms to fill in, EHC plans, school reviews, social work reviews, making alternative

communication resources, sourcing specialist equipment, sorting out DP as well as all the ""hands on"" stuff and I wouldn't like to think what would have happened to us without any support, but I don't think we would have managed. We have no local extended family for support and we are both also caring for parents in their 80's. We would probably both have had to give up work, lost our home and be relying on the benefits system, assuming our relationship survived. So the support is vital to us for our own wellbeing and sustainability as carers as well as giving our son chance to have new and different experiences."

"Very. Families with a child with a disability struggle to function and getting a break enables us to keep going. It's tough enough so please don't take any of our services away"

"It gives my son the chance to socialise with peers and gives me a rest."

"Every family and child is different and needs of the child change as they grow, so this is difficult to answer. Current services work well enough for us however can see where improvements can be made as mentioned already"

"Support is important to me as I am a single carer. The respite allows me to take a break from caring and the daily support allows me to go a job and earn a living. This helps me look after my own wellbeing and balance my own life as well as care for my family member."

"Yes. We need support during school holidays as this gives us time to spend with our daughter which benefits the whole family. Support on a weekend is vital too so that we can have a break from the role of carers."

"YES. Its absolutely essential. Unless you've looked after a child with multiple disabilities you will never understand how exhausting it is both physically and mentally. We need these breaks and we are truly grateful when we get them."

"Currently our priority for respite is at weekends but it's also needed during the week sometimes."

"Yes immensely. Without support I wouldn't be able to care for my child and would have prob had a breakdown."

"Because it is lonely having a child with disability and no help"

"To enable my daughter to spend time away from parent/carer - have a better life situation It enables me to work and have quality of life, not to be a carer"

"Yes. It is it's not easy living with special needs. The people looking from outside they think it's easy the truth is not. Small things make bigg different for us"

"Develops the skills, interests and relationships for the individual. He really looks forward to this. Also gives a break to other family members to do other things"

"Yes so the service can be more diverse"

"Alternative is a break down in family"

"Yes it gives us abit of resbite to do normal every day things which we carnt do when the children are about"

"Because I can see more of my family whom live in Bridlington and friends in Barnsley"

"Yes definitely I can't do this alone"

"because often behaviours have us clashing and we cannot cope"

"Respite is extremely important for people like myself who have a demanding care role that (without respite) would wear them down. Short breaks can allow me to provide better care and have some time off"

"Yes. As a loan carer with no other family to support us, finding independent support would certainly add to the anxieties of being a carer. My daughter would probably have to go into a carehome."

"Since we don't get support, I can't really answer this but I would say that it is important that siblings are not forgotten. If there is no support on a weekend for example it might mean that the sibling can never join football or drama because the parents cannot look after the disabled child and take the sibling somewhere else. On a more mundane level siblings can have some one to one time with parents if the disabled child is elsewhere even if that's just to get a bit of help with homework. This means taking the disabled child out of the house and finding something or somewhere to go- depending on the complexity of need this isn't always an easy task."

"Without the support we would not be able to carry on living at home together, could not manage as we have no family support"

"Without this support I would be tied to the house and unable to live a life myself. Also my health had begun to suffer before the support was in place."

"Yes. A family is made up not just the child in need but siblings to and it is important that we get the flexibility to work around them to keep things running smoothly."

"Vital as I have coped as long as humanly possible with minimal support previously. It took an emergency situation to make me realise I needed more help."

"Yes. Full time carers need a break from 24/7 needs and this is the only way to get it."

"We would not be willing to have relative living with us without the support"

"as long as this is offered to reduce / prevent crisis from happening. need to be proactive support not reactive."

"Yes. it needs to be on time and in the right place. Havnt got the time or energy to chase fools."

"very as unless you have the finances to pay full private help there is desperation no where to turn too"

"Yes we are all individuals and should have a choice when we do what we choose to do in order to live our lives. ie get up at 6am if we choose to."

"Yes. We are all individuals and should have a choice about how we live our lives as well as what we do and when."

"Yes to provide information, support and to relieve the feeling of serving a life sentence"

"We could not manage without the Day and Respite provision. It is vital for our family that it continues at the same level."

"I am a single parent who's ex husband will only stick to the court order and refuses to help further"

"With direct payments I can be flexible as to support at home and respite care, this is very important to me as some weeks I may need more support than others. Being able to contact someone within the council directly would also be beneficial - having a named worker and a direct phone number to them."

"It is essential to allow me to work, which is why we had to employ our own carer"

"If we didn't have any support we could not keep our relative living with us due to my health and the limitations that puts on us."

"When life changes in key stages throughout life there should be guidance. There is help from birth to starting school, there was some help during education (even then it wasn't easy I had to fight for the slightest thing) then when a disabled child leaves education, I found there was nothing, no-one to ask or advise me. I know I am not going to be around for ever, so another stage should be what happens when they are left alone, if there is no-one to care for them. and finally when a disabled person reaches pension age."

"I feel that the help mwe receive from YPAT at the moment and Direct Payments helps us at the times and days that they are provided. If we lose YPAT, we will have nothing and I will literally have a nervous breakdown and my 8 year old younger son will do without as al the care and attention is put on to my older child with severe special needs"

"Very difficult to find other areas of support for children with these needs"

"Yes so my mum can have a break"

"yes.. He is well supported in school for his academical needs but his social needs are more apparent at weekends and in holidays."

"Yes, all of the family need a break."

"Yes I wouldn't be able to function, I wouldn't be able to have a life and niether would my wife."

"Want to continue with YPAT as it give us a break any my daughter really enjoys going there and is happy when she comes home and we are happy because she's happy and also get the chance for us to do our own thing for a while"

"It opens up more choices for the family to plan other activities. Child/adult in need gets independence, socialisation and gives more structure to family life."

"Yes, as it has to work for everyone"

"Receiving some stress free time"

"Yes."

"To be able to spend one to one time with other members of the family"

"Yes as we need a break and rely of respite care for this."

"yes. it provides a break and he gains so much from it"

"Very important, if no support available there would be no break for both young person and other family members."

"My Mum has lived with me and my husband for 16years. In the last few years we have needed support. First in the form of respite and then with carers to help get her up and then put her to bed. At the moment my Mam needs watching 24 /7 and it goes without saying that my husband and I need respite in order to continue to keep her at home. She is in the last stages of her life (been in hospital % times this year and we were told they did not expect her to pull through but she has however we have been referred to palliative care and hopefully will be seen at home not hospital from now on providing adequate care can be accessed for Mam in form of carers visits and us in form of respite at Castle Grange . Forgot to mention she goes to Day centre once a week which gives me 6 hours (much needed break)."

"To make the caring role easier on those whom have to care while still going through their own bad health issues"

"To able to spend time with our youngest"

"yes it is, without the support my son will not be able to have the fulfilled life he has"

"Yes, because without the respite assistance it would be very difficult for my wife to have any breaks from delivering care to me."

"flexible is crucial, allows for real life ! At an earlier age - took till my son was 9 and i was on brink of collapse !"

"Yes, sometimes everything is overwhelming and just need a break"

"Every parent and siblings needs a 'time out' or somewhere there disabled child can attend and feel secure in the knowledge that their child is cared for in a safe and friendly environment. School holidays, especially the six weeks hols can be a very trying and tiring time with no care services in place."

"I feel that I have the right support at the right time at the moment."

"Yes so don't feel alone"

"It Allows me to spend time at work knowing my partner is safe and receives help whilst I am there."

"because it means my parents get the break they need and i get to be a little bit more independent without relying on my parents."

"life quality would be very poor for all concerned & very difficult"

"It helps enormously..... it gives us as carers a life"

"I cannot take my son to see my parents or we cannot take him on a plane abroad or to far away as i would not cope. So respite is important so that i can see my family or go on holiday with my daughter safe in the knowledge that my son is happy in respite care. Having a son with autism has and will impact on all of my family so we will always need support."

"Yes it is because I'm disabled and I need the help"

"Good personal care"

"Every little helps us"

"Yes it's a break for [service user] and parents"

"Of course, we sometimes need breaks and certain times to arrange holidays etc."

"I am 77 years old and looking after a son with MS. He lives alone and the support provided has been essential."

"Any help is gratefully received"

"Its good to get out on our own for a change"

"Essential!! My son has various mental issues and without a break would be very difficult to take care of him."

"It allows us to refresh and and get ready for the week, its also allows us valuable family time with our older children"

"Very important as we are mostly at the end of our tether with our caring role"

"It is very important as it allows a routine and for attending appointments, spending time with other child and getting a full nights sleep."

"yes -it would be impossible to continue to live at home without a wide range of support throughout the day. also to be able to have respite when required"

"YES, ITS A BREAK FOR THE PARENTS"

"YES GIVE A LITTLE ""SELF "" TIME"

"YES, BECAUSE WITHOUT IT I WOULD NOT BE ABLE TO WORK AND WOULD THEREFORE HAVE TO RELY ON THE GOVERNMENT FOR INCOME SUPPORT"

"YES, WITHOUT IT MY PARTNER OR I WOULD HAVE TO GIVE UP WORK!"

"YES A BREAK WHEN MY CHILD IS CARE FOR EXCELLENTLY"

"YES, AS I NEED TO WORK, I DO NOT HAVE ANY OTHER SUPPORT"

"yes, this encourages and rich and fulfilling social life for those with the least opportunities."

"Not really, its just good to know that there IS support"

"Please see earlier"

"So I can gave a break and my son can be cared for in his own home"

"as above - we are better equipped to look after her after knowing we have respite. it is good for us and our daughter"

"Any support is always welcome, Respite in any form is vital for parents and carers"

"To allow carer to continue to work and allow carer some free time to have a break"

"Yes, without recent support placement would have broken down"

"Absolutely"

"extremely important"

"Yes, conditions of disability in certain cases change over time and these needs have to be addressed quickly."

"do not have support of extended family so Orchard View and YPAT provide that much needed short break service"

"weekends and holidays periods"

"It is important for our daughter to access social activities without us to build her confidence and independence."

"Mill dale offers our daughter a good service and allows carer rest"

"Yes. We are currently managing as a family but can see that things will soon need to change in order to meet our child's changing needs. Support should be available when sought"

"Very important to keep the placements going"

"My wife and I need time together and our daughter needs time without us."

"Very important as every bit of help counts"

"If I don't get the support I wouldn't be able to go see my family in Bridlington they can't get to see me, same with visiting friends"

"Yes"

"Yes to give respite n my child to meet other children to mix with others"

"We could not possibly manage without the council providing this support - respite and short breaks. Many more children would end up in full time care if families could not manage"

"Yes it is important that we have support for us to be able to make life a little bit easier for us and anyone else in the family or who we come in to contact with ..for advice and answers to things we might not be sure of and encourage development and maybe independence"

"we as a family manage our sons day to day needs, but occasionally need assistance"

"I the only family support we get is when our autistic daughter goes in for respite"

"Extremely. Allows you to feel normal"

"so he can socialise and get to know people with similar disabilities"

"to take the pressure off the rest of the family"

"Because it give the parents and siblings time to other things. help takes the responsibility and restraints of a disabled child"

"yes for gaining social interaction extra to school"

"not really"

"Because other siblings are not left out"

"As a family these service help us for a break and doing family things"

"It is very important for us all caring is a 24/7 hard life. We all need a break. Services allow this without them families breakdown"

"We have to support at present apart from family we don't have help apart from direct payments, which is great but I feel guilty putting everything on family"

"Yes"

"Not recorded messages Yes, we have support but it seems to be when we are in crisis"

"Yes. provides Respite to carer to help continue Care for the look after person"

"Yes, because at some later date your child will have to leave the family home and this is the first step"

"yes ,It should meet family s requirements ,ideally weekends and school holidays possibly 2-3 days during weekdays"

"Yes. Parents are on duty as long as son is at home. There is no ""off button"" and parents are not getting any younger"

"Yes, couldn't cope at all if we didn't have short breaks"

"Yes, Extremely important as without the support currently available to us we would not be able to cope with day to day basic tasks"

"Lots of information for the events"

"We're fine, if we need it we will ask"

"Of course it is important for all the reasons outlined above. Parents are on duty 24/7 and take on the major burden of care for a disabled child/adult. The responsibility does not stop when the child gets to 18 however old the parents are. Ageing parents have to continue this care which includes getting up early to ensure the child/adult is ready for college/daycare and need to be there to pick up the child/adult at the end of the day. Ageing parents also can't rely on support from their own grandparents as they might have done when the child was younger as they are now too old to help."

"yes always"

"We struggle during the main school holidays ie Christmas and summer. These are the times we really need help."

"Orchard View, YPAT and Direct Payments All the services to enable a young person to have time out and we can have time with the younger children"

"Yes, for the reasons given"

"it is extremely important to us and we couldn't do many things without it"

"To develop social activities with different people, both able & disabled and a wider age group."

"It gives my child time with his peers and to have time away from each other"

"Yes it gives us a break"

"yes for support and the development of the children and allowing breaks for the parents to focus on themselves once in a while"

"Very important. I'd struggle with my sanity during the school holidays if we didn't have access to YPat!!"

"Yes its important to us. Any family can go though a difficult patch and accidents and illness can occur in anyone's life. These young people are not the same and extended family if available are unable to meet the need. These young people need to know that somewhere safe and familiar can be available"

"We cannot cope on our own and need this support to manage and keep a happy healthy family. We are not robots and we do get tired and need a break. We cannot travel abroad due to disability and taking mess or equipment or afford to and respite is all we have for a short few hours break. It's so needed and appreciated."

"My son can have random violent outbursts with little or no warning."

"Yes, it is hard for people to understand how hard it is with a disabled child and any respite is appreciated and necessary to have the energy to keep going."

"It is fundamental to the health, well-being, inclusion and happiness of both the cared for person, and their family"

"Yes , or people can easily feel isolated."

"It is, because if she was a normal 14 year old child she would be socialising with friends & taking part in activities without being supervised constantly. Due to her disability this doesn't happen. If we didn't have

support I wouldn't be able to do my job nor would we have a social life & quality of life..the same goes for my daughter."

"Weekends, School holidays, so I can work, or do other things I find much more difficult with son there. He also gets fed up with not being able to go out etc / doesn't have access to friends etc so YPAT is a lifeline."

"It is essential. Caring for two disabled adults means that me and family need respite in order to recharge ourselves."

"Yes, because we et our won time and to spend time with other children"

"Of course how else can carers have some life of their own and till keep adult children at home"

Q20 **Do you have any further comments?**

120 responses:

"I just wanted to say that at no point were we given any choice - the panel chose YPAT on our behalf, and that was our only option. Whilst overall i have been very impressed with YPAT, it is clearly over subscribed and therefore not able to offer any flexibility. We also had to wait a while after funding to get actually involved. I have been made to feel that I should be grateful that I can access YPAT for my son and when I have asked for some flexibility in attendance, it has been refused. I would love to see something for 11+ children that is more age appropriate and focuses on inclusion in ""normal activities"" perhaps alongside normally developing peers- perhaps evening as well as weekends"

"PLEASE get your acts together and start to provide flexible affordable local suitable childcare options for children in Kirklees with additional needs or put money into mainstream priovisons so that they can start to offer support. Disabled children should in this day and age not be treated differently to their mainstream siblings an peers."

"As previously mentioned there is no opportunity for spontaneity & this is what we miss. Because of this we use our direct payments with our son's independent day care provider. This is expensive & I realise that this would not be an option for some people. When he was younger he accessed respite within a residential setting. Whilst he was not unhappy there he never really wanted to go & spent a lot of time in his room. I feel that such a setting is not right for him. Because our son has not been educated locally he has few contacts where we live. His social life revolves around the day care provider"

"Don't cut support like short breaks - don't just push people onto direct payments and put stressed people under even more pressure (especially as the DP house is not in order); do some investigation into how much it would cost you to manage families in crisis or take children into care - these services are part of a prevention agenda and it would be short-sighted to remove them."

"YPAT do an amazing job. Thank you"

"No."

"We are extremely grateful for the support we receive as it makes a great deal of difference to all the family. It offers our son the opportunity to have time away from us and allows us to do things which we may not be able to do due to his disabilities and health needs."

"My husband and I completely understand that budgets are tight, and are appreciative of the respite our son gets. However there is no doubt that our lives are very constrained due to our son's disabilities and we find this frustrating. There may be potential in identifying carers within the local community, who are trustworthy and capable of looking after individuals with special needs."

"We have health problems ourselves now after yrs of caring for [service user] and are xx and xx yrs old now. We need regular respite to help us continue to look after [service user]. If you change where [service user] goes to respite / or the amount of respite she gets now, I'm not sure how much longer we would be able to keep [service user] at home and we would have to look again at a residential place for [service user] as we are struggling with the respite / da care provision we get now. We could not cope with less respite or a change to where [service user] gets respite."

"They have said I can't use my direct payment money for my respite. I think you should be able to use the direct payment money for respite."

"Stop making everything into a fight for any type of help, social workers need to be sympathetic and help."

"I think support is very different for every family. Some seem to get a lot of support and others not enough, when the young person has the same disability. When Post 16 support ends what happens then, young people have aspirations to work and do what their siblings/friends do but all the hard work from staff and services just ends! Joining services up should help but should have been done sooner."

"Thank you for giving me the chance to say what I want . Please take it seriously. We need some safe place we can spend with our special needs & their siblings together .wit out any one blamed to another when people have the same problems they understand each other and support each other. We can't feet with people who don't have same life we have . Thank you again."

"Very valuable service"

"People do not know where to go for help"

"The help I get from the disability team is a god send please don't cut this children will suffer"

"The survey is a bit confusing because it isn't that clear who it is aimed at. Clearly those who qualify for respite/short breaks but some of the questions are much wider which is why I did complete it. It is important to understand the nature of the disability too as there could be some very specific needs which have very specific requirements, it could be that some people can access a wider range of activities but others may need something very specific to them."

"I often feel I dont get any support and are left to make decisions for my hubby that I cant make without feeling very guilty or selfish,"

"As social care and services are at a premium these days I think that although things could always be better compared to other areas we are not doing to bad."

"Please keep present clubs and respite care as it is at present."

"Major problem with the punctuality of invoicing by Kirklees. Despite many efforts to get this issue sorted we still have to wait long periods before receiving an invoice which includes 3 and 4 stays in respite"

"I appreciate cuts need to be made but consideration needs to be given to the impact of having nothing for both the person/ parents"

"We are parents/stepparents of a growing extended family ranging from 5 months - 68 years, none of whom live with us. None of the adults register on Social Services radar, so they have little support apart from us. We are on call 24/7/12 but because Social Services have no interest in them, we have no opportunity for respite. This questionnaire is therefore irrelevant to our needs."

"No mention of alzheimers or dementia on your list of disabilities. very dissapointing. By all means contact me to explain your thinking [phone number] [respondent]"

"please look at each situation and take into account couples together needs especially where long term illness is concerned and dementia as this is not going to get better for the person with dementia or the parnter but short breaks are so vital to cope daily it is the 24hours of living with someone with this type of issue that is very wearing."

"Assumption are unhelpful. Carers can have there own disabilities. Husbands and wives do like to do respite activities together."

"Husbands and wives like to do respite activities together, carers can have their own disabilities and or health conditions,"

"High quality centres catering for short term residential stays are virtually non existant in this area."

"This survey isn't really aimed at elderly carers caring for the elderly"

"As far as we are aware our daughter receives funding completely from the NHS and Social Services do not have any input into her provision so we are not sure that this survey applies to her."

"I have been offered Orchard View in the past then was refused when i asked for it"

"The service for care and respite is a vital lifeline for many of us living with chronic illness and disabilities every day. It is very important that this service is provided and continues in an efficient way."

"Yes. I strongly believe that if our dependents were to remain is school for longer they would build up their skill set and that would save a lot of resources down the line in that they could do more for themselves. It is proved that children/ adults with a learning disability carry on learning in a school situation better than the alternatives that are on offer. and they need repetition and continuity to be able to do this. Only full time education can give the continuity and repetition required."

"I had a birth plan, and plan for my education, there seemed to be a plan that guided me through life, even an end of life plan. I know sometimes it doesn't always go to plan but it was a guide. It would be helpful to have a life plan for someone who is disabled, with some of the 'what ifhappens' built in, it could also address what both the disabled person and their carers would want to happen in the future. Then information could be given to them that was relevant for them, instead of an armful of leaflets and booklets, that is overwhelming and mostly not appropriate for the disabled person or carer. And not having to 'google' to maybe we may by chance find the info that is out there."

"Please look at all the care providers carefully and don't take these services away from us. They are our life lines. By taking YPAT away, will mean more problems for families. This service means the world to us. I feel anxiety now at the thought of it leaving and feel we will fall apart as a family if we lose it because we will not receive the quality time as a family that we need"

"Difficult to manage in emergencies. I have relied heavily on my other children when there have been family bereavements or my own ill health"

"The services provided are a much needed lifeline to parents & carers and without them or if they were cut there would be a lot more children in care which in the long run would cost the council a lot more money in the long run. Also the respite/services helps to keep families together."

"This service is the main stay of my existence, before this I just existed, now I live to the best of my abilities and it's all down to the help I get. A BIG THANK YOU>"

"Holiday schemes at YPAT very important because we need to do things with other children as well. Need to have time for that and my daughter gets very bored at home during the school holidays. and it's difficult to manage without the summer full week break."

"The child/adult in need should be the centre of importance. These services of respite care, professional care is very important and create more problems when services are lost and has major negative impact on the rest of the family."

"When children are finishing young children services, adult services should be better explained what is available"

"Some families get a lot of respite, others get next to nothing. There doesn't appear to be any logic behind it other than the one who shouts loudest and causes the biggest fuss (even threatening to sue the council) get everything and gentle unassuming folk who are already exhausted and don't have the energy to fight anymore, get nothing. It also depends on which social worker you get."

"Up until the age of 18 more respite places and support were available but as soon as the young person reached 18 everything was cut back to bare minimum and most things suddenly stopped but the young person still had the same or even greater needs. This all happened virtually over night."

"There has been a very poor provision in Kirklees for after school/summer activities for disabled young teens"

"My husband is better supported in a well known environment i.e. at home. so I put in care for him when I have breaks"

"Respite has allowed me to cope with very difficult circumstances with no other family support. I see parents all the time who are literally drowning under the pressure of having a child with disabilities. My son's father and I split up due to increased pressure/stress, and I think if there had been more support available in the early days this would have helped. I also think it's crucial for my son to be able to develop independence skills - without respite he would become an adult who still needs his mum at bedtime. At the moment I think he will manage independent/supported living."

"It is very important for me as a parent to get a break, a chance to do something for myself whilst knowing my child is being looked after"

"Surely it is the local council, councillors, government and parents of disabled children who have a Duty of Care and it does not lie solely with the parents and families. Funding should not just be cut and the needs of our wonderful children just swept aside as if it is of no future consequence. The long term effects would be catastrophic. My family and my children are eternally grateful to the respite and care my son has received."

"I have been made aware that this survey will determine the future of the support services with the council provide, yet the invitation to complete the survey did not express how important it was to complete and

therefore feel that this was done intentionally. As a person with a disabled son, who receives such support services, we NEED these services and the thought of losing them would severely impact on my entire family and is unbearable to think about."

"No"

"From my own experience with looking after [service user], help is needed very much when life changes happen and Day Care and respite are very important services you provide"

"The courses run by the surestart centres have been useful (eg family links) but still need to be tailored towards sen esp. Autism."

"The care element of my direct payments, PA's and care company work perfectly with good management, the situation where respite is seen to be I need to go to a respite centre needs to be looked at. As I am 41 outgoing and do not need to sit in a nursing home for 7 days and get ill, I need support to get away and enjoy myself you must understand that respite must be flexible and if I'm with my care company my PA's get a break and if I'm with my PA's my care company get a break i should be able to decide how I use my respite as a break feel free to contact me on [phone number]"

"My husband needs good quality care facilities better than Years Care which is very patchy. He needs two quality care workers not just one to cover for holidays."

"My name is [respondent]. I have filled in this form as my mentally handicapped daughter cannot read or write. [Service user] is xx years old."

"Fed up with filling in forms, just get on with the jobs on the ground. Less paperwork more practical work needs to be done"

"Form filling for finances could be shared between various dept. It does become a chore to be frequently asked to provide information about benefits etc and proof of power of attorney."

"[Service user] stays at Cherry Trees and perhaps a good idea for more activities going on there for young adults staying here."

"Please stop blaming budget cuts and stop trying to cut services. We believe any cuts need to be made at Director Level and more investment needs to be made further down the chain. now is not the time to be making cuts to much needs Disabled services"

"Orchard View and Ypat are brilliant services which parents rely on, particularly in our family situation where relatives will not provide any support whatsoever."

"Would like to be able to buy extra nights certain times when allocation runs out. If nights are available after booking completed. If want to go to meet family in Manchester and stay over night we have to set off early next day to get back for 11am. Would like to be able to pay extra for a later stay."

"CARES FOR A SUFFERS WITH OSTEROPOROSIS, RA, OA, COPD, ASTHMA,SOB, REPIACOMENT-JOINTS DO NOT FULLY UNDERSTAND WHAT ""DIRECT PAYMENTS"" COVER THE QUESTIONNAIRE SEEMS A LITTLE AMBIGUOUS IN PARTS AND IS CONFUSING TO DETERMINE REFERENCES TO ""CARER"" OR ""CARED FOR"""

"PLEASE DONT CLOSE YPAT. IT IS A LIFELINE FOR MANY PARENTS WHO NEED SOME SUPPORT IN LOOKING AFTER THEIR CHILDREN AND PROVIDES A POSITIVE ENVIRONMENT FOR THEM TO HAVE SOCIAL INTERACTION"

"IT HAS TAKEN A WHILE TO BE GIVEN ACCESS TO ANY SUPPORT FOR MY SON. WE HAVE FINALLY GOT IT AND WE ARE HAPPY WITH THE SERVICE. MY SON HAS DEVELOP[ED IN LEAPS AND BOUNDS SINCE STARTING YPAT. WITHOUT IT I HAVE NO ACCESS TO ANY CHILDCARE AND I AM WORRIED THAT HE MAY REGRESS"

"THIS SERVICE HAS ALLOWED MY CHILD TO BE PART OF SOMETHING FOR TH FIRST TIME. AFTER YEARS OF SEGREGATION AND ISOLATION HE IS FINALLY PART OF A SUPPORTIVE SCHEME THAT HAS ALLOW HIM TO GROW!"

"THE BUILDING YPAT RAVENSTHORPE NEEDS TO REMAIN OPEN AS IT IS FIT FOR PURPOSE"

"NEED YPAT, AS I NEED AFTER SCHOOL CARE SO I CAN CARRY ON WORKING"

"Not having the after school club would mean my child would lose out on developing her social skills and independent skills. It would be hard for her to settle into a new routine and take time for her to get used to different adults which in turn might lead to a negative change in her behaviour. If she was to travel to a different location, this would also create problems, not being able to spend quality evening time with her

family. Not having peace of mind that my child was not in a safe, friendly and stimulating environment would have a huge impact on day to day family life."

"YPAT is a excellent service"

"Life would be a lot more difficult and stressful without respite, not just for us but for her as well. She loves being at home but she also loves being at Orchard View. This is obvious when we pick her up, she's happy to come home but also happy to be there with her friends and also her own company."

"We have used Orchard View and YPAT for many years with our eldest foster young person, but find now she is xx years old there isn't much support. We also have a foster child and he is too young to access many of the services out there. I think a review of services for all ages would be extremely helpful"

"I would like for my son to have the opportunity to access the short breaks/respite when needed in a couple of years time. Further cuts in funding for such important opportunities cannot be cut further"

"Keep all youth services and disability groups going and bring in more services for them"

"Central Stars is an excellent respite provision. Our users enjoys the weekly experience in a safe and nurturing environment. The rest of the family enjoy the absence of the user for 2-3 hours. A week to relax and recharge without the continued demands of the users. This break allows the whole family to be stronger together"

"Central Stars is the only youth club for children and young people in Huddersfield who have a disabilities. Due to government cuts all facilities for disabled young people have suffered. Young people need to socialise and have a feeling of belonging. To develop in their social skills and to grow in self esteem and have a feeling of self worth. This helps the young people with disabilities to grow into young people who are accepted by the community. Central Stars helps to achieve this. It gives them and their families respite care. For a few hours a week it gives both the young person and their family time. The young person time to have an enjoyable worthwhile experience. It gives parents/carers time to spend with their own children which at times is not always practical Central Stars is RESPITE CARE for all children and young people with Disabilities!"

"Because Direct Payments cannot re-assess their clients we have to go through Social Services for Re-Assessment. Have you tried this!!!!. I asked them to come out on the 6th July and they finally turned up on the 20th September."

"Orchard View and YPAT are vital services which need to continue. Without these services, our family would not be able to visit certain elderly relatives, go to vital appointments and spend more focused quality time with our elder child. Orchard View ensures that on respite visits the rest of our family can have a full nights sleep A brilliant service, much needed by families"

"As an parent, dignity and respect are important to me and the thing that concerns me the most is the fact my daughter would not be aware of undressing in front of a boy, closing the toilet door, therefore not allowing others in. I am just a bit anxious about leaving her overnight and therefore would like more reassurance about safety etc."

"No"

"This is the first time I've heard of anything like this in the first email I have ever received to do with my child and her. Special-needs"

"Without the support from day services and respite these placements would fail"

"I'd like more support to know what my daughter is able to receive help with"

"Keep YPAT and Orchard View as they are. They are vital services"

"Without being able to have access to some of the facilities provided it would make coping with daily tasks more challenging without being able to give to the body and mind a complete rest at times so mentally and physically we are fit to provide the daily care needed for our children"

"Give everyone an equal share of the funding for which we qualify and leave us to make our own arrangements, but with a safety net for those unable to do so."

"Not enough easily available info. of what there is and places adults with a disability can attend. Lots of the services closing down but no suggestions of how these young adults can now get together and enjoy activities and other peoples company to encourage them how to socialise and be accepted in the community"

"none"

"Thank you for all the staff support , my daughter enjoys Orchard View, as a mum I am grateful. Thanks Zoe for the services you provide"

"I realised everything comes down to money but there isn't enough help availability and we need to feel happy and safe that our children and being looked after well when in Respite"

"The support we have had from the Council services at the moment is good(only in crisis)"

"No Staff at Cherry Trees are always very helpful"

"in my view most of the time public consultations are like tic box exercise ,most of the decision have already been taken ,well in advance by the councillors"

"There is need for young people to mix with others to improve social skills.. Using direct payment for PA means young person is with that single carer Where does a PA go with a young person? Everything is costly and there are few activities for young people"

"I have worked for Shared Lives until I was finished in April 2016. The people had kept in touch with me Always enjoyed my Short break visits and also Respite Care when needed"

"These services are very important to our family and are needed for us to carry on looking after our disabled child. The care he needs is 24/7 and we all need time to recover and have a break from each other"

"My husband will not mix with others but me so its stressful. Looking forward to Short breaks makes us happy. meeting up with people and interacting"

"Support from Short break Respite, after school clubs, holiday play schemes and direct payments allows us to do normal daily activities that some people take for granted. e.g. Dropping my other kids to school, taking them out or event having their friends over. For us as parents to get a break, also for my child that uses these services to access activities that we cannot carry out or provide at home. For him to spend time with his friends and stay over at the Respite centre and to have staff that trained to deal with him and support us when we need it"

"We are so grateful for all the work Central Stars put in to running the youth club. It has been vital for our foster child. We were near a placement breakdown before she started going there!!"

"As has been said earlier, a parent's care is 24/7. Help in the provision of respite and breaks makes a huge difference to the quality of life of both the child/adult and to the whole family. It is not a nice-to-have, it's necessary for physical and mental well being. By looking after our own young people we save the council a fortune in what would otherwise be 24/7 care fees. I think this is often overlooked and should be properly recognized. Supporting families with children and adults with disabilities is a cheap way of solving what would otherwise be an expensive social problem."

"na"

"All the services need to remain for families like us. It would be good for more Respite homes to be built and that would enable more hours per child/young adult when the young adult turns 19 year old. They should be grouped by age in services and not put with older people with disabilities"

"Just to ensure the play scheme service is still available during school holidays."

"my brother loves the play scheme and so do we thank you"

"Disgusting that they are trying to reduce funding for children and parents who need support. People who make these decisions don't know what it's like to live with a child with additional needs. How much respite service is valuable on both child and parent side"

"yes the council needs to be putting in more help for the children and parents to develop and meet all aspects of the daily lives through out the life span of the education needs and development work skills for life and employment and trying to allow these children to grow up to lead a normal life and full filling as they can to support themselves along the journey"

"Thank you for providing YPAT, it really is a godsend. More of it would be appreciated :-)"

"Myself and family have for 16 years been let down by [staff member], who I will never forgive for failing to help us , psychologists, senco teachers, heads, gps doctors and council. Became depressed this year and isolated for too long from community as children in streets including adults failed to understand or recognise what autism was (a hidden disability) need to make them aware and accept so we can have a decent life and get on. There is so much Kirklees space and land in Kirklees we need a disability centre where we can go and learn or train and set up support and it's specially made for special needs and

disabilities. Close some old building down and create 1 big huge hub or centre for special needs/disability children and adults post 16+ to get jobs and learn or work and be independent when they are able to. Support employers to employ disabled people and widen the support or opportunities by allowing them to work in all factors such as schools, companies big or small including in the council. I don't often see disabled people or 16+ disabled employed by council. Why? Obesity in special needs has to be looked at. Lack of services and support are half creating these health issues."

"My son really looks forward to these days of respite, and we, his family enjoy a break from constantly following him around on eggshells and tenterhooks awaiting the next outburst."

"The holiday playscheme needs to remain in place. Children without disabilities have access to holiday clubs therefore you cannot discriminate against disabled by removing these facilities."

"I would like to see the survey results and if possible help further"

"I contacted various places after being given a leaflet with information about summer holiday activities , never receiving any correspondence from them !"

"I realise there has to be cutbacks but where care & support for disabled young people is concerned, it would have a massive impact on the health & wealth of families if this was taken away, resulting in people claiming benefits due to lack of income & could easily effect families Mental Health. So whilst savings are made in one area costs would rise in others."

"I only hope you keep all the current services for PMLD children, any additions would be very grateful for. It really is difficult to put into words just how much a difference these services make. It allows us to function more as a family along with our other children."

"We really appreciate having respite nights."

"When carers Count started, we tried to talk to them about our family and their and our needs. It was quite obvious that they didn't understand; it's also obvious that they have opted to go on and meet more obvious and easily met needs. The only Kirklees groups pushing for children's support needs in this area are PCAN and Whole Autism Family Group. Both are small, entirely white, and hugely overworked. WAFG tries to deliver support and secured funding this summer for activities, which were somewhat circumscribed by members family needs. It is obvious that they are struggling with the paperwork from funders who need evidence of activities, that needs were addressed, of continuing need, and of progress to self-sufficiency. While the will to develop is evident, the understanding of what is needed and the internal resources to develop and implement growth plans is not evident. Further, the understanding that people living with AS Spectrum conditions do not necessarily adapt well to change and growth is equally lacking on the part of Kirklees."

"There are not enough services available"

"I would like some where I can stay with my daughter"

"Out of all the services the council provides my child enjoys YPAT the most, there should be more local services available like YPAT"

"I appreciate that Kirklees have to save money, but please not at the expenses of families who have to plan and adjust their lives around caring for a very long time"

"1. Im sure there's lots out there by way of support but its not joined up and therefore extremely difficult

Q6 **Are you completing this survey as a...? (other)**

to navigate way through 2. Failing to add a quality 6th form provision to the New Southgate school is a massive opportunity lost and exposed KMC's lack of commitment to provide good post 16 provision 3. The ""system"" adds high levels of unnecessary stress on young people with disabilities and their parents/carers. Everything takes forever to sort and nobody puts the young person at the centre of the system"

service provider

No one in my house use respite

Parent carer of a child who does not qualify for short breaks/respite, PCAN trustee carer

Carer of an Adult who uses short breaks

Interested party
 Parent/professional
 carer Of an xx year old lady
 i am full time carer for my husband who has mixed dementia. I take respite breaks
 I use the money so that my wife can have respite from caring for me.
 parent of under 18 does not use respite or short breaks.never knew about this service.
 Husband
 Parents of someone under 17 years old who do not yet use short breaks/respice
 parent/carers who has never used short breaks/respice
 Parent of a child with a disability who is never heard Of short breaks / respice
 Parent of a child who does not yet use respite services but will soon benefit from this sevice
 we have never used this service
 Parent/carers of child under 17 who doesn't use short breaks/respice
 Parent who has a child who does not use respite
 Family member
 Hav'nt used this service before.
 I am just in the process of filling in athe carers assessment form. Its not an easy form to fill in
 KIRKLEES SHARED LIVES
 Carer - big extended family ages 6 mth - 68 all on autistic spectrum
 No Respite

Q11 If you / family member do receive short breaks / respice services, do you know how many hours that you are allocated each month?

97 (54%) Yes - please tell us how many hours each month:

98 responses:

"16"	"56 annual"	"6"	"52 hr"	"5 nights"
"14 nights"	"56 nights"	"12 hours"	"48"	"dont use"
"6 nights/m"	"1.6 d/ mon"	"7"	"24 per mth"	"56Night py"
"5 pcm"	"28 days"	"24 hours"	"168 pweek"	"6hrs/week"
"1dy/sch ho"	"10"	"16"	"4nights pm"	"12Night py"
"Unsure."	"N/A"	"38 Nights"	"4 nights m"	"5night pm"
"3/wk D/pym"	"48"	"3 Nights"	"76 days"	"4wks py"
"12"	"43.3333"	"1 week"	"48"	"24/48 PMTH"
"72"	"10"	"3 WEEKS"	"3 nights"	"35 hours"
"6 n/p/m"	"2 nights"	"4NIGHTS/MO"	"28 hours"	"13"
"1 night"	"4.5days"	"28"	"2 nights a"	"3NIGH PMth"
"Holidays"	"4 weeks a"	"49 A YEAR"	"6 nights"	"Aprox 6 ."
"2 nights"	"I get cash"	"4 nights"	"2nights"	"12"
"3 nights"	"Fortnightl"	"18"	"2.3 nights"	"12"
"46"	"60 HRS"	"12 HRS"	"Once a wee"	"12hr/month"
"28d. a Yr"	"11.5hr/pwk"	"48 HRS"	"7"	"2 x 24 hrs"
"16"	"2nights"	"5HRS"	"2Nights pm"	"approx 80"
"14 hrs"	"56 nights"	"48 HRS"	"3night pmt"	"0"
"Not sure"	"22"	"10 to 15"	"3weeks"	"48days py"
	"4"	"56 nights"	"4nights pm"	

Q12 How willing are you / the person to travel to get the right service you need?

Please use the box below for any additional comments you have:

82 responses:

"currently i travel 20 mins from Huddersfield to YPAT I would rather not have to travel further than that"
 "Within reason bearing in mind we have other children and we work"
 "unable to answer this question as we provide the service"
 "Within reasonable distance I.e. Within Kirklees"

"However, this is not always possible, for example holiday clubs at YPAT. YPAT is a long way from my home and travelling there and back takes up a large chunk of the break offered plus I have commitments with other family members and work. So during holidays we take up the offer of transport or it would be very difficult for our son to attend which he loves doing."

"I am unable to because of work commitments"

"This would depend on the venue as I, the carer, work full time and need to get to my place of work."

"Within reason. Have often wondered why out of school clubs/respite don't use existing special schools eg. Castle Hill to run their services from?? surely this is more cost effective and nearer to service users?"

"[Service user] can't sit up for long without her leg going purple and swelling up so she is restricted with traveling time"

"I am willing if u have to but with another child and two step children it's not possible"

"Within reason, for example travelling 30 miles for respite 6pm to 8pm wouldn't be worth it"

"Would have to be bus don't drive could take some time to get there"

"Too difficult with 2 disabled children"

"The person I am caring for can only travel on a stretcher"

"Depends on access to suitable transport, distance and time taken for journey"

"To travel outside the local area"

"We are willing to travel (30mins) providing that the journey doesn't become so long that it becomes more tiring for our child and makes him loose interest"

"Needs suitable nursing care so go where this is available"

"Impossible to travel"

"within huddersfield area"

"travel within reason distance"

"We traveled to Norfolk for our main respite this year - Nancy Oldfield Trust"

"N/A"

"my child can be a danger when traveling with one adult only"

"As my conditions are quite rare, I am willing to travel to respite places that can provide the best care for me."

"I can take her locally, but not any distance due to my own health issues."

"I am willing to travel to ypat because they provide an excellent level of care to my child"

"Calvert Trust Kielder"

"I use public transport so this has to be factored into travel times/distances/cost etc for the support needed"

"I get direct payments and deal with all my needs for respite, this means I get between 3/4 weekends away a year."

"but don't drive. I have 2 other children, no family in the area. my husband works shifts and uses the car for work. my daughter cant tolerate noise, coughing, sneezing and starts screaming so using public transport is very difficult."

"Could do with assessing for more help with respite care. Assessment team let us down and did not follow through with the need of our child and family"

"Not allocated hours , but gets 2 nights per month"

"For the right service maximum traveling time should be no more than one hour. The service providers should ideally pick up and drop off where possible so that family can have peace of mind."

"As long as the transport is wheelchair friendly"

"I would travel wherever to get the right services"

"I am limited to the distance i can travel as I also have a Medical problem which stops me from driving."

"However as a single parent with 3 children and who is in the process of obtaining a larger vehicle fuel costs would increase, the respite we receive a moment is very local."

"Travel is diifcult - the repite care allows me to go to work and the person requiring the support can not always drive - depending on her condition at the time"

"I feel more important to keep services local where possible but if it means travelling I would consider this"

"Cannot travel without support"

"Both YPAT and Orchard view are in north kirklees which involves quite a lot of travelling for all the family."

"We have no transport and have to use taxis"

"Not able to travel on hid own, unfamiliar places and understanding, time."

"My son in law drives the car for me to take my son for respite care in Southport"

"We currently travel 2 miles, this is far enough"

"Unable to travel far.due to lack of transport. My daughter dislikes long journeys."

"Not any further than the 30 minutes already travelled to respite and Saturday club"

"DUE TO WORK COMMITTMENTS I NEED A LOCAL SERVICE"

"WORK COMMITMENTS"

"PREFER TO STAY WHERE IT IS AS EASY TO ACCESS"

"if we can but both the disable child and his mother cannot travel"

"if the service is in another town, it would be difficult for travelling and fitting around the other children."

"We are willing to travel short distances"

"Within reason"

"But am surfing from severe pain down one leg which is stopping me from walking even short distances at the moment"

"Unsure what is envisaged as ""travel"" but I would be willing to take my child a reasonable distance within south Kiklees"

"as a single mum of 2 kids, one who is disabled. it would be to much hard work having to travel with them, plus having to attend hospital appointments not everyone has the time or money to be traveling about."

"10miles"

"This is in the form of babysitting, however also stems playscheme"

"But the service needs to be local within my area I live"

"depends on transport"

"Travelling is hard it takes two adults to transport to and from any service"

"am willing to a degree, 15-20 minutes drive otherwise it becomes stressful"

"Motorised wheelchair"

"It just depends by how far, taking in travel to get there. It depends by how far taking in travel to get there"

"It should not be more then 10 minutes drive/we also needs to consider time for picking them up form the center as well"

"This would rely on parents to take young person to and from activities"

"my child cannot travel without 2 adults to support long distance"

"The person needing respite needs to be transported to the location. He is unable to be left with unattended transport provision."

"Mum and Dad takes me"

"We travel now"

"we use ypat on 2 weekends per month at ravensthorpe for grandson to learn to mix with diffrent peer groups and socialising skills"

"Travelling is an issue for sin due to sensory issues and anxiety"

"Obviously distance permitting"

"does not travel well; needs special equipment to accompany; does not adapt well to changes in routine, carers or environment - respite has to be conducted in the home"

"Within a reasonable & practical distance"

"However I do not drive due to medical condition, so need transport for my disabled son"

"Depends on how appropriate the service would be and how far. Also whether any appropriate stand-in support could be made available. Difficult when dealing with high function autism,"

"Unable as cannot drive due to medical condition which prevent myself form driving"

"~At the moment we travel 9 miles , that's fine"

Q13

How do you / the person normally get out and about? (please select all that apply)

12 (5%) Other (please specify)

32 responses:

"School provide transport"
"Motability car"
"Wheelchair"
"Rely on parents for transport. Cannot travel independently"
"Patient transport service for travel to hospital"
"See note above re transport"
"Wheelchair accessible transport"
"Transport provided to college, otherwise in family car with family. Can walk alone locally on well"
"Though at the moment not really possible as condition has worsened considerably, equipment not ready"
"Motability vehicle essential for wheelchair"
"Bed bound. Cannot get out"
"wheelchair or walking frame"
"motorbility vehicle WAV which we, her parents, drive"
"I drive my disabled daughter locally, but any distance for holidays, she travels by mencent minibus"
"Adapted vehicle for wheelchair use"
"mobility scooter"
"we use special mobilehome vehicle that carries all of the equipment and medication when we travel"
"When I am not at work I drive, otherwise the person requiring care has limited options"
"with support"
"Carers"
"Motability car usually driven by my mother"
"school transport"
"Wheelchair accessible vehicle - motobility)"
"My child can not leave the house alone"
"mobility scooter"
"Adapted van"
"If its in Dewsbury then we use our own car but if huddersfield/or halifax then needs transport"
"Not an independent traveller"
"mobility car only(he's driven)"
"needs transport from home to school and around with escort due to his complex needs"
"wheelchair adapted vehicle and accompanying carer support"
"arranged transport to day care and sometimes respite"

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)**

32 (16%) Other (please specify)

60 responses:

"lack of flexibility on attendance which over summer has meant my son hasn't been able to access the service for over 6 weeks (it was closed on one of his allocated Saturdays)"
"The issue is for us is with holiday child care which is basically unavailable therefore restricting my ability to work and bring a decent income into the family"
"unable to answer"
"Recently got a match from Shared Lives but this has taken about 3yrs & only came about by the manager of Waves being a Shared Lives Carer. She offered to take on the role for us. Waves Day Care in Slaithwaite arrange holidays for their members so our son accesses this. The family contributes towards this"
"I have included restrictions on other family members attending, but this only applied when other son was a little boy and wanted to attend. As he got older, he was not longer interested and his own friendship

group and activities. Direct payments has been an up and down struggle, it working well now, but if anyone leaves, back to square 1."

"Drop off and pick up times restricted given other activities can do with other family members, would be helpful to use Direct Payments to buy more hours at respite/short breaks"

"YPAT is an invaluable service however its an hour round trip. Only just been awarded 3 hours Direct Pymnts a week and this has been great but would like more hours."

"It has taken years to get [service user] to except going for 3/4 night stays. So wouldn't want her present respite provision to change"

"We don't use respite"

"Not really used as yet but could be very valuable in future"

"Never been told about it !!"

"Only really works in our own home"

"Didn't qualify. Some local activities not geared up for SEN"

"Hubby has ended up in hospital from respite twice, I am quickly loose faith in the care homes ability to look after him"

"It is quite a distance from home"

"Most activities happen in Huddersfield rather than our locality"

"Homes not able to give specific care needed. Has come home early."

"appropriate care ie nursing not available, direct payments only option that works"

"Neglected in respite care home so now respite is at home"

"Insufient support and evidience of good support given by the team leading up to a whilst my child hit crisis which lead to a distrust in the capabilities of the team and of the service"

"not enough finance allowed and not enough days allowed"

"no information provided by social worker we had to use google."

"No information provided by social worker we had to use Google"

"we are happy with the place we use for our daughter but good places are limited"

"I do not not know what we would do without YPAT, On seeing other services that provide respite, no one compares to the standards of care that YPAT provide"

"I arrange this with direct payments"

"Plan very far ahead.3 mths in advance which is incovenient as circumstances change. Unit next to Milldale Ln has been shut which has had a major impact on the amounts of care, level of care & services,loss of 8beds,staff changes impacts on the confidence and trust on us as a whole family"

"I use the carers allowance to have my breaks. It is too disruptive for my husband to go into respite care. day care by himself is not helpful due to anxiety"

"Services are often set up for children who are physically disabled and have a learning disability. My child always seems to not be able to access services as she only has a physical disability"

"The local authority run respite was not suitable. I had to fight to secure a place at a suitable provision. Not enough providers available."

"have respite with my pa's"

"YPAT and Orchard View have been wonderful. I just wish they could be more like these services in the Colne Valley area. ACTIVE are good but do not give as much feedback to parents about the child. ACTIVE although closer to where we live feels like a business and is less personalised. ACTIVE needs to have an open day for families to see what happens there."

"Conditions within the respite centres too warm can't cope with heat which results in me been ill at the end of it"

"I would like to get more hours, I only get 28 hours"

"My daughter loves it"

"n/a"

"WOULD LIKE MORE PLACES WHERE SIBLINGS COULD BE INVOLVED IN THE ACTIVITIES"

"FANTASTIC! ALLOWS BOTH MYSELF AND PARTNER TO WORK AS SCHOOL TEACHERS"

"Driven by carer/s"

"How do you get to know what you can access?"

"A fear of leaving a young girl in a area with grown up boys as my daughter has no awareness of personal care and whats appropriate."

"We have direct payments so arrange our own respite."

"Never heard of it"

"not had one"

"Not received any assistance"

"Having 5 days away involves 7 nights of respite - why?"

"na"

"33% difference between LA rate and market rate; not all homes advertising respite care have dedicated respite beds"

"There are too many reasons put in place for us not to go. i.e. he has to be able to come home if he asks"

"At the moment we do not have Respite Care. We had it once/twice when younger"

"Transport for the day care refused to take suitcases for us. Causing us to make 4 extra journeys to deliver and collect suitcases from Respite centre. allegedly no room on bus for cases full bus every day"

"When we received care at Orchard View it was monthly opportunity for parent to have regular break. In adulthood this drops off and we went without for a long time. Fulltime caring is exhausting, there is no spontaneity or opportunity to change the relentless routine of care. Parents need a regular break to keep sane"

"Active is a valued service, my child enjoys"

"Used play scheme during school holiday periods."

"not been given apart from once all parties agreed should have break but could not find the right people for the child"

"We missed out years of support and respite as we never knew about it. We now very ill and mentally broken after coping in our own for years and no awareness of this support"

"never been able to use commercial short-breaks / respite / activities - in general not suitable to our circumstances / very expensive / poor value for money"

"Our situation has been ignored despite two carers assessments - they were not even acknowledged, so we work outside the council system"

"Compass Bridge & YPAT works well. There are others which I would like to use but cannot due to location"

"Have little knowledge of them"

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?

If you do not wish to take up the offer of a direct payment, please use the box below to explain why:

26 responses:

"Too complicated for what we need"

"I do not want to become the employer and have the uncertainty of getting staff. I also prefer my daughter to socialise in different settings rather than being isolated in our home."

"I want to spend my time looking after [service user]. Not being a employer with all the problems that involved."

"We have used it in the past. This was cancelled when we got NHS funding which is fine hassle free and suits us"

"I am not aware that we qualify for one."

"I'm happy with things as they are"

"I prefer for the council to make the arrangement"

"The care package in place is the best available provision for our daughter."

"too complicated and confusing"

"Got refused"

"we have used this in the past, there was a huge amount of paperwork and organisation that t along with employi g someone, and I found the whole thing very confusing. I also found it very difficult to recruit. We now use Active which is much better/less stress for me."

"We fund ourselves from our savings and disability money"

"By paying direct debit she has to pay when she's not there"

"Enough to sort out"

"We didn't know direct payment could be used for respite and short breaks. I have been paying the bills.

Yours, [respondent]."

"if NOT IN CENTRE AND OFF SICK, WE STILL HAVE TO PAY BY DIRECT DEBIT"

"PRESENT ARRANGEMENT SATISFACTORY"

"I DO NOT WANT DIRECT PAYMENT!"

"NO, I DO NOT REQUIRE DIRECT PAYMENT. HAPPY WITH YPAT"

"The current system works very well"

"Personal choice"

"Doesn't suit our lifestyle"

"We applied 3 years ago and heard nothing . The system we have works well for our situation"

"I want my child around his peers not one to one with an adult"

"I used a direct payment for 1 year but it was working out to be very expensive (hourly rate covered but we still had to pay petrol money, entertainment and food costs) and it was very hard to find a suitable trusted carer. I therefore cancelled our direct payments."

"Very happy with Respite at Cherry Tree as is my daughter"