

Aiming High Consultation Events

Independent Report

**Prepared for: Staffordshire
Children's Trust**

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1.0 Introduction

This report summarises the feedback from people who attended four public consultation events held in Staffordshire regarding the Aiming High proposals, particularly relating to Short Term Break Services. Parents attendance figures and the dates of the events are shown below:

Britannia Stadium	24	19 January
Tillington Hall, Stafford	31	21 January
Chase Park, Cannock	19	28 January
Uttoxeter Racecourse	8	4 February

Each event followed a similar format:

- 20 minutes presentation by County Council regarding Aiming High outline proposals
- 2 x 1 hour 'focus groups' with attendees
- 10 minutes presentation by Charlotte Bailey, the Parents Commissioner

Each 'focus group' consisted of 4-7 parents/carers and was facilitated by a professional from the County Council, Primary Care Trust or their partner agencies. They followed a loosely structured discussion guide and each group was digitally recorded with participants' permission. Anonymous verbatim quotes from these recordings have been used to illustrate this report.

Attendees were also asked to complete a very short questionnaire, focusing primarily on their preferences for future short term breaks. The responses to this questionnaire are contained within this report. Different options for short term breaks were presented to participants in the form of 'playing cards' – each card representing activities/care to a nominal value of £300. People were asked to choose four cards to a combined value of £1200 – having the option of choosing 4 of one card, 4 different cards or somewhere in between.

It should be noted that whilst this report refers to 'parents' throughout, this should be read as including carers, foster parents, grandparents and other relatives – all of whom attended the consultation meetings and all of whom have similar feelings, needs and concerns. Likewise the term 'disabled children' is wide reaching and in this instance includes any child with any kind of disability or special needs.

Finally, it should also be noted that we can only report upon the views expressed by those people who attended the meetings – they may be different to those who did not attend.

Demographic Details of Workshop Attendees

Parent or Carer?	%	Gender	%
Parent	86	Male	15
Carer	10	Female	80
Age	%	Number of children in household	%
Under 25 years	1	1	32
25-34 years	11	2	42
35-44 years	45	3	13
45-54 years	25	4+	6
55+	13		
Marital status	%	Disabled Child's gender	%
Married/living with partner	74	Male	71
Separated/divorced/widowed	21	Female	23
Disabled child's age	%	Extent of their disability	%
Under 5	11	Mild	4
5-11 years	40	Moderate	32
12-16 years	32	Severe	52
Over 16 years	12	Profound	8
Nature of their disability	%		
Learning disabilities	68	Speech & language difficulties	50
Physical disabilities	39	ADHD	13
Sensory disabilities	31	Behavioural & emotional needs	40
Complex Health Needs	14	Other	13
On the Autism Spectrum	51		

NB: figures don't add to 100 as 2 respondents did not complete the whole questionnaire

2.0 Current Issues

2.1 Information

Throughout the meetings there was a widespread, indeed universal, feeling that parents are not told about the different support services that are available to them. This lack of information starts from the moment of birth or diagnosis of a problem – parents often reported feeling ‘abandoned’ from the very start.

When your child is identified with a disability, no matter what disability, why can't a pack be given to the parents? A list of organisations that are out there that can help with services...

There were also many complaints that health visitors and social workers are not aware of the support services, facilities and grants that are available to parents of disabled children. Social workers were also felt not to be proactive in making suggestions and giving advice. This could of course be because they are not aware of the options, in which case there is an obvious need for training/education in this area – or, at the very least, to provide social workers with information that they can refer to.

The situation does not seem to get any better as the child reaches school age. This is particularly the case if they go to a mainstream school, because then parents don't get access to the information that comes through the special schools network. The children often aren't able to tell their parents about events they've been told about, or they forget to tell them, or forget to give them the note; as a result information really does not seem to be filtering through.

2.2 Assessment

2.2.1 Social Workers

Many parents were reluctant to ask for a social worker because of negative connotations and fears around them...

- People will think I'm a bad parent
- Social services will think I can't cope
- Social services might take my child into care

Others admitted to initially being in almost a state of denial about the fact they have a child with disabilities, which prevented them from seeking help and support...

...I remember the first day I took my kid to special school, I sat in the car with a tear in my eye, nobody wants to be a member of that club really do they...I think it's how involved with them you become...we've had wonderful staff and teaching assistants...we had a social worker and he was useless, he was exactly what I would expect a social worker to be, he was a bit doughy and a bit vague and stuff but he turned out and this guy was fantastic and when we couldn't get transport from respite to school for ...he went and took him himself in his own car...

Others who do want and need a social worker said they'd had to fight tooth and nail to get one – and the wait could be for years.

Well I fought for four and a half years to get a social worker. My son was under the CDC clinic and it was (name of social worker) and she retired when he was four. I fought and fought for another social worker because she was looking after both our children, and I kept phoning up and saying, "Can I have a social worker?" and they said "Well you're on the waiting list," and after about three years I'd had enough. I said, "Well where the hell am I on the waiting list then?" It wasn't until my daughter was re-diagnosed that I contacted the society for ... children and they've got a family worker, and she actually wrote to my MP and social services and said, "It's disgusting," and that was when I got a social worker, well two came along at once. I said this is ridiculous, I only need one social worker, I only want to explain myself once.

We've had a social worker for (child) who was fantastic, however, I've been told now if I want a social worker for (2nd child) I've got to go through the whole process again, and I can't face picking the phone up and ringing First Response because I've got to go through the whole process all over again.

The whole process was a nightmare, they never phoned me back, they never did this and that, every time I was disappearing into a black hole, it took me about 4 months to get through to somebody...

There were also complaints of many changes in social worker when people do eventually get one, which results in a lack of continuity of care and understanding of both the child and the problems faced by the family.

A couple of people felt the role of social workers has changed over the years as the Council has contracted out more services – they felt this made the support services more remote...

Social workers' roles have changed over the years haven't they and they are now more about buying services in rather than providing direct support to the families ...so that's what's missing the kind of practical day to day help.

If you split something into client and contractor, it all becomes more formal and you do lose the hands on involvement of the people in the middle...it's all quite impersonal really and that's what happens when you contract services out.

In contrast, people generally seemed quite happy with the service provided by family support workers, although there were some complaints about their visits being too infrequent.

2.2.2 The Assessment Procedure

The assessment procedure emerged as one of the principal bones of contention among parents – it was considered to be convoluted, inflexible and often unfair. There was a strong feeling among some that the Assessment of Needs Matrix is biased towards physical and visible disabilities and is not fair to those with mental problems such as autistic spectrum disorders. Others felt they have to exaggerate their child's disability to get the support they need.

We're lucky, because my daughter is in a wheelchair we are under the disability team which means that we've got a social worker, an OT, and they're all under one umbrella but my son is outside that, he doesn't meet their criteria.

We went to Panel 12 months ago and we still haven't received any paperwork back and I've got two children both with exactly the same diagnosis. The social worker came out and went through the matrix of needs and they both got exactly the same levels on the matrix of need and one got five and a half hours with a worker, and one got kicked out of the Panel and told we've got nothing. But they've both got exactly the same diagnosis!

One of the main issues was felt to be that assessments are made by a central panel – comprised of people who are far removed from the case and don't fully understand the child's specific disabilities and hence the problems the parents are facing. The closed system doesn't help this perception; the decisions are felt to be secretive and parents feel powerless over a decision that is crucial to their lives.

They do have a silly system whereby before this assessment we filled in a diary of what we actually do but that's not representative of what really happens because, it's 'put (child) to bed' for instance, that doesn't tell you the difficulties that we actually encounter, how much is involved.

When we went through it the form was all lost in translation and the person who came to fill in the form openly admitted that she knew nothing about autism. So actually somebody has come to assess the child, who doesn't know anything about the condition of the child and I don't think that's right at all.

...it always seems like you see these people looking at you, and they're thinking, how much is that going to cost me? How is that going to affect what I do? They're not thinking about our child, they are thinking about the impact that child is going to have on them, and that's where they take their baseline from and decide what they can do for our child. They can't afford to provide what it says on the statement of special educational needs.

Other parents of severely disabled children feel the emphasis is all on moderate disabilities; they feel even teachers at special schools can't cope with the extent of their child's disability. Parents of deaf children also feel they are neglected and not understood; for example they complained that there is no support for them to learn sign language. Parents of Downs Syndrome children feel all the focus is on autism, whilst those with autistic children feel their problems are really not understood. Basically, it all reflects a strong feeling among the majority of parents that many people within the authorities don't understand, and don't care about, the problems they and their child are facing – whatever their disability.

Sometimes, however, social care services and assessment do work – and can make a huge difference to the child and the family...

I've had quite a good experience really, I've got a daughter who is 22 now and she moved into Adult Services and everything from everywhere seemed to come together and she got all the help she needed. "I said why isn't this available for children?" Because for the children it just seemed to fall apart. Recently we've got a social worker and things seem to be coming together ...

The social worker that has been appointed to (younger child) has done a very full and detailed report on (child) and on our family, on our situation and she's written it all down to go to panel to see about direct payments and the help that we can tap into. She's sent me a copy of this report and if I meet any other professionals or anybody else, in any capacity, I can say, "Here you are this is (child) and this is our family, this is the stress we are under and this is what's going on at the moment," and you can add to it or whatever. It's fantastic and it's a brilliant report.

What is sad is that, eventually, when we've done our fighting and battles and things are in place, it's very good. If we can get people who understand and we're persistent and polite, then when it's in place and you get your kids being cared for, with an education, in health and social care, who understand and listen to us, it works and our children can flourish.

Overall I can't fault the care that (child) has had, as I said we are proactive and we have a really good relationship with all the professionals who see (child), they take us seriously, they aren't patronising. Maybe it's the type of person you are as well and how you come across. They'll give me their mobile or e-mail so we can liaise without having to call the health centre and leave messages. So gladly we have been lucky and I'm really pleased, particularly with the people that see (child) regularly like his physio...

2.2.3 Statements of Educational Needs

The statementing process was felt to be very difficult to understand for parents. Requests were made for the process and its importance to be clearly explained at the outset, and then made easy to access and understand, with parents being able to review the document annually to check its ongoing relevance and accuracy.

Professionally we get a lot of parents phoning us up all the time saying what can we do about this, this and this and they wave the statement at you of the child's needs and it's got absolutely nothing on it and nobody has explained it to them. Nobody explains to parents how important that document is at the start and it's not made easy to access either.

So what was on his statement from how many years ago you may as well rip it up and put it in the bin because he's a different child now...

Statements were also sometimes felt to be increasingly hard and/or time-consuming to get.

...the school applied in October for a statement for this child to give him more support and that statement has not yet gone in and that is what annoys me immensely, it is too slow...

2.2.4 Children in Mainstream Schools

Those parents with children in mainstream schools often complained of staff not understanding, or not seeming to want to understand, their child's condition – being said to have the attitude of 'well they'll just have to fit in with all the other children'. This not only impacted upon the child's education, but also on their ability to participate in extra-curricular activities such as school trips, sports and after school clubs. Whilst this criticism was levelled primarily at mainstream schools, there were also some instances of special schools not always fully understanding children's difficulties.

You know at the further education college, the teachers are not told what each child's disability is, they don't know how to serve that child best because they don't know what is wrong with them...

I feel very strongly that in this area we need a specialist, somebody to go out to our schools with this information that's coming out now, this research that they've had for the last twenty years, it's amazing information that's not getting into Staffordshire. It's in other counties, and they advised us that we need possibly about two people for the county to actually go into the schools and pass on this information... My daughter is at special school and I don't feel even they know what is up to date, the right techniques to teach children. (Downs Syndrome)

He gets two hours a day, one to one funding but the visual impairment service would go in and say (child) needs to do this, this and this with him but they wouldn't sit with the nursery staff and show them, this is how you can do these activities, they just say how come you're not meeting his needs so the nursery got quite frustrated by that because they are more than willing to do the one to one but nobody is necessarily showing them.

These criticisms seemed to be particularly made by parents of children on the autistic spectrum. Their comments typically related to challenging behaviour and subsequent exclusions, and is certainly an area where they would like to see significant improvement. Some felt that the issue is with the schools not wanting to learn about disabilities...

I went to a Jigsaw meeting last week and they were saying they are going to put people into schools, to train them. One particular school, in Stone, two members of staff came, a teaching assistant and the special needs co-ordinator and they work with children as a group, they went back to the school and said this training is available for all teachers to come in and learn about autism and how to deal with it, this is what you need in place for Downs Syndrome and she was told by all the members of staff, all the teachers, it's nothing to do with us, we're not bothered, they didn't want to know. The training is there to go into school and it's all paid for, they don't have to fund anything and they didn't want to know. It caused ructions, and you think what's going on if you're getting that in schools. The Head Teacher should be saying, we'll attend regardless, this is important.

This is a real area for improvement given that autistic children generally don't have learning difficulties and need to go to mainstream schools...

My eldest had a hellish time in mainstream primary school, he really did, he had no friends, he was constantly being wound up and goaded and then lashing out and then excluded, when it came to high school it was all agreed that they didn't think he would cope in mainstream high school, so we looked around the special schools and he wouldn't fit there either with an IQ of 144, and his words were they're going to stick me in a class full of Harry's (Downs Syndrome sibling) and I'm going to go nuts, which is not fair, there was no place for him.

We then discovered, quite by accident, about Netherstow Family Autistic Unit run by Autism Outreach and I fought tooth and nail to get him in there but I did have to fight really hard. They told me there were no places...it went through and eventually I won and I got him in there and he is fantastic and you need these units in every single high school.

It's the attitude at his new school, it's so different. You get over one attitude, oh no we can't do that, he's got to fit in with us and this next school is yes we can do this...it makes a world of difference.

2.3 Emotional Support and Advice

2.3.1 Isolation Among Parents

This was a fundamental finding from the consultation, as many parents reported acute feelings of isolation and a complete lack of emotional support – they felt that no-one is ‘there for them’ and that no-one understands or cares about the problems they face on a daily and ongoing basis. It is important to recognise that these feelings were widespread among those who attended the workshops – they may be even more so among those who could not attend, or who could not pluck up the courage to, and those who were unaware of the workshops. Some people at the workshops knew of others who literally never leave their home...

...they’ve done two (social groups) at Marshlands...some of the parents hadn’t been out for seven years...

I’ve got to say I’ve never felt so lonely in my whole life.

Most people with disabled children are really isolated, most of your really good friends are in the same boat as you are, and we are the only ones that you can talk to.

These meetings highlight what a parents’ plight is because on a day to day basis you just get on with it.

These feelings of isolation seem to stem from various factors:

- Geographical isolation (especially in Moorlands?) and transport difficulties – journeys can be very difficult (or even impossible) with some children either in a car or on a bus. Those who don’t have a car said they felt completely stranded.
- Some feel alone and embarrassed when out with their child among parents with able-bodied children – they feel others don’t understand their child’s problems and disapprove of their behaviour. This is especially true of children on the Autistic Spectrum, because they don’t have any physical disabilities that are immediately noticeable. Their parents fear they just look like naughty children and that they appear to be failing to control their behaviour...

The difficulties with (child) is when we go anywhere, like the swimming baths, it's society in general isn't it, they point and stare and make comments and I think you get this really hard skin, just the thought of going out in public sometimes...

They just think with autism "oh you're naughty, give him a smack."

My child is very active, she likes to climb and that kind of thing...you don't want other mothers staring at you if your child doesn't do what it should...

- Parents can even feel lonely among friends who don't have a disabled child – they find it difficult to be honest about their problems, as they suspect they may be testing the extent of their friend's sympathy or be perceived as always miserable or complaining.

For some these feelings of isolation are addressed if their child goes to a special school, as they then get the chance to meet other parents – often becoming involved in parent groups and forming deep and long lasting bonds. But if the child is taken to school by taxi this can actually worsen the situation as they never get to meet other parents and communications with the school can break down – notes get lost etc.

Perhaps there's a poster up in school but that's no good to parents because they don't go into schools.

Part of the problem is because they are picked up and taken home from school you don't actually speak to other parents and stuff. You don't have physical contact unless it's at parents evening.

The need for emotional support seems to be strongest in the early years – to come to terms with and understand what's happened, its implications, what life will be like, to cope with problems as they arise etc. Whilst other parents can provide a 'shoulder to cry on' and share their own experiences, there is a real need for the authorities to recognise that they have a vital role to play as well.

...if somebody had sat down and said these are the issues that people in this situation face the penny might have dropped a bit quicker and I wouldn't have gone through all the pain of trying to get him to go to nursery school when he was four, it was a disaster...I'd got nobody to say "look this is what is happening and what shall I expect," I felt just kind of left.

Others who had been forced to give up employment after the birth or diagnosis of their child often suffered from a loss of personal identity. Combined with strains upon relationships, this seemed to often

result in depression – in some cases very acute depression. This was not only true of mothers, some fathers also reported suffering immense (and ongoing) emotional trauma. These feelings were compounded even further when the other parent was also disabled, as was the case for several people who attended the workshops.

...you just don't get a life really do you that's not involving sorting out the children, and battling and fighting for everything the children deserve...it's really hard to hang onto who you are as a person yourself and it impacts on our ability to earn a living, I've given up my career...we give up our pension rights...we just become ... and ...s mum.

2.3.2 Isolation Among Children

In addition, the children themselves are often reported to be isolated as a result of difficulties in communication and interaction with their peers, and typically few of their peers having similar disabilities. But parents feel their children do need that social stimulation – even if they can't get directly involved in activities or social interaction.

...she finds it difficult to understand what other kids are doing...she's got no-one that she can associate with that is her own age...

This was compounded by practical issues such as difficulties in transporting children to social events, living a long distance from their school and social events often being held too late in the day.

This isolation was often felt to increase as the child gets older, which is extremely difficult as this is when able-bodied children would be developing closer links with their friends and becoming less dependent on parents. Teenagers' parents said they really need support from peers and others – to understand what's happening to their bodies, to mix with the opposite gender etc. However, parents find it very difficult to take them out, often due purely to their physical size. This was seen as a really undesirable situation and one that parents would definitely like more support to overcome.

Families have said to us that as the children get older they tend to go out less and less, the kids are bigger, they are harder to handle, they are heavier to manipulate, they are more obvious if they throw a tantrum, whereas if there is a group of you it's better than if you are stuck on your own in a situation where they do that. It's quite daunting.

2.3.3 Parent Support Groups

Some parents at the workshops attend (or actually organise) parent support groups that offer a wide range of activities and excursions and seem to really add value to their, and their children's, lives.

We (support group) do trips or activities during most holidays...and we go bowling once a month on a Monday evening and that has worked very well and brought on a lot of the children socially, parents go with the children and then we do various activities. Last year we went to Drayton Manor, ...North Staffs Adventure Playground and the Monkey Forest, Severn Valley and we went on a canal boat and we go fishing two or three times a year at Albrighton Moat Project which is very good, and Bantock Park.

Who funds that?

Well last year we had local network fund and we also had some money from ... (Children's Disability Services). It was a one off payment and our youngsters are getting older, so some of our group now are getting towards adulthood, so how long we can access funds from children's services we don't know, so we're not sure what's going to happen at that point. It's quite good because it involves dads as well, and other siblings. I think we took about 40 to Severn Valley and to Drayton Manor, we went to the pantomime and that was very successful it worked very well.

That said, there were several reports of social groups that had been set up but were poorly attended, with just a few parents turning up. This was attributed to difficulties in transport, working parents and other commitments, but communications and hence awareness of the group may also be an issue. It should also be noticed that the parents requesting social groups were those who had made the effort or been able to attend the workshop – they may well not be representative of the wider Staffordshire population of parents of disabled children in this respect.

At Greenhall we had a coffee morning and it was the same four mums every time... the same four to five out of seventy parents...we sent it (leaflet) out with the kids every night), kept pushing it out...we had people coming to do speaking and it was the same four, sometimes six, every time and the same at the disco...that's happened every time I've been on one. Some people don't want to talk about their problems, some of them work or have siblings at home...there are various reasons why people don't go...some just don't want to just come and talk...

2.4 Accessing Public Services

2.4.1 A Constant Battle

There was a very widespread (indeed almost universal) feeling that it's a constant battle to get help from the authorities and access services for disabled children. Many said it takes prolonged determination and even aggression, and is really the last thing they need – the rest of their life is enough of a struggle.

Basically you fight for everything to secure it for our children, it's not handed to you...

You have times where you just can't fight any more.

When we ask for things it's not for things we want, it's not a Christmas wish list, it's what we need.

I asked three years ago about the toileting of my daughter and the time that went by, being referred to one person and then another and then a health visitor comes round and anything coming out of that was literally months. It was literally three years from me asking for help and something happening. You are constantly phoning.

You don't know what you are missing or what you have missed in terms of health or information or just a network. You don't know unless you accidentally hit on it or somebody says, "Have you tried this?" "Did you know this?" There's enough stress anyway coping from day to day without having to run around trying to find all the things that might be on offer that you don't know about.

You ring the council and they talk to you like you are something off their shoe, they're not interested...

I've got full care of (child) who is nine, he is severely autistic, behavioural problems coming out the roof, we've just gone through a terrible phase of self harm...totally out of control, now he's passed that phase and we're going into a grab and smash now, anything he sees he picks it up and will trash. He has no speech, he's ten in July and I just think it's fight, fight, fight, that's all we seem to be doing, running yourself ragged and getting nowhere.

My youngest boy started having violent outbursts and stuff and he got really out of control and was attacking me with knives and I had black eyes and stuff, and I just got to the stage where it was too much and I couldn't cope and I had to get some help in then. Hormonal, teenage boy and I felt a bit out of my depth...

A few people did however say that things had improved over the last couple of years, and others with experience of other counties felt that Staffordshire is actually one of the better ones. The challenge is to continue these improvements so that no-one has to fight for anything!

2.4.2 A Lack of Joined Up Services

Parents frequently complained that the partner organisations don't share information with each other – hence parents have to repeat all the problems they and their child face time and time again. This is really very depressing for them because when listed the child typically has many problems that they are then reminded about, but conversely no-one ever asks for the child's positives or about the progress they might have made over the last year etc.

I think the only thing I find unhelpful is that nobody talks to you, you've got the NHS here and social services here and the council here and you're having to explain yourself ten times over. And then if a new doctor comes in you are having to explain, if you have to go to another service you have to explain it all over again and sometimes you can't remember what you've said a previous time. It's important you don't forget especially with hospitals because we deal with four hospitals.

That's all the bad stuff but actually living with ... is an absolute joy... There is no nastiness or agenda or politics with these kids, they are just honest and full of joy and show it when they feel it. When he sees you he waves his arms with sheer joy...

This lack of communication was also felt to be fundamentally inefficient in terms of use of public sector resources. There were, however, several examples of a professional finally taking the initiative and sorting things out – which shows it can be done...

I had to fight for three years to get a 'Children with Disabilities' assessment done. They kept on sending me a social worker from Codsall because that's where our social work office was, a woman came out from child protection and she said, "I don't know why they've sent me here, I don't know about autism." I had to keep going through the system and eventually the chap I've got now is absolutely fantastic and I can't fault him ... he's seen (child) at his worst and the problems I face day to day. Nobody was talking to each other regarding (child) and on top of everything else I was having to chase this person and that person and in the end he said lets get a meeting and we thrashed it out around the table, and at the end of it I felt a weight had been lifted because everybody was talking to everybody. For months I'd been chasing people, everybody was saying it was somebody else's job and it was all sorted in a twenty minute meeting.

I banged my head up the wall with my health visitor for three years saying this child is not normal, I was told I was a neurotic parent with her first child, and to get him in a playgroup, he needed to socialise...we got him into playgroup and within two weeks we had the SENCO lady ... and she was just like a fairy godmother, she got him into the child development centre, an assessment...

This lack of communication between the authorities was often felt to be particularly apparent during the two main transitional stages – which represent huge hurdles for both parents and children to overcome. That said though, Connexions was often praised for organising and helping parents and child through the transition to adult services.

There should be more links between child services and adult services because they are two totally separate things and neither of them seem to communicate or understand so you've got to go from one to the other, there's no continuity.

2.5 Short Term Break Services

2.5.1 The Need for Flexibility

The first thing to say here is that no single service, or even a multiple combination of services, will meet the needs of all parents, all children, all siblings, all the time. Every child is different, every family situation is different and every year is different, and so the extended short term break services will have to be completely flexible to take all this into account.

A lot of these things need to be a lot more flexible, the children that are disabled are all different, even with autism there are so many different levels and the same with parents, some of us have gone through marriage breakdowns and disabled children. All circumstances are entirely different. Everything needs to be flexible to take all these different needs into consideration.

We tend to lump children with special needs all in one and it's such a vast spectrum...their needs are so different...it's no point going well, 'Here's a gymnastics club for children with special needs', they all have such different abilities and unless you are absolutely spot on with each child they are not going to get anything out of it. Something like an after school club or an evening club where the facilities work specifically geared to children with special needs, not a snooker table where they can't pick it up, something where they might like to watch Postman Pat or sit and have a story read.

2.5.2 Overnight Stays

It was evident from the workshops that some parents really don't want their child to spend any nights away from them – it can be more stressful than their usual routine at home. They were very concerned about how their child would react to a stay in an unfamiliar environment and whether the standard/type of care would be what they are used to and need. This seems to be particularly the case when the child is younger.

Other parents however really welcome the chance to recharge their batteries. Sleep deprivation was a real issue among parents of children with sleep problems – which in turn seemed to be very common. A good night's sleep was all the parent(s) wanted and really did need it to be able to carry on coping.

In addition, many had to follow very set routines day in and day out. Respite care gave them back their freedom, if only for a short time, and the chance to spend time with their partner, go shopping, go for a meal, for a walk etc. 'you are a slave to their routine'. This lack of freedom and sheer exhaustion was felt to negatively impact on their relationships with their spouse – divorce rates among carers were reported to be very high – and so the opportunity to put something back into their relationship was felt to be hugely beneficial for both them and the child. In these instances even a baby sitter for just a couple of hours so they could go out for a meal would be really welcomed.

It is challenging but you also want that support around you don't you. We feel they are able to give (child) opportunities, and we enjoy him being part of our family life because of the level of support that we get from Staffordshire even though we've had to fight for it. We really value what we get and the fact that we are able to do so much stuff with him and he's able to experience so many things because we get those breaks. We do get the opportunity to do things without ... which means that when he's at home we can concentrate on him and making sure that he goes swimming or his trains and all the things that he enjoys doing, because we are not ground down by the experience.

In addition, depression and anxiety seemed reasonably common, with several people saying that respite care and support was quite literally essential for their sanity and emotional stability.

Our lives are very difficult and stressful, I've been on the edge of a nervous breakdown a few years ago but I've got a good GP who pulled me through.

...we've had 2 or 3 nights (respite care) and when we've got there I've cried because it's being able to completely switch off and I'm not used to switching off, I'm always on the go and always on edge.

As the child gets older parents often felt that overnight stays are beneficial to the child themselves, to help prepare them for the outside world through creating change and introducing new carers.

I think it would do (child) as much good as it does us. He is getting to the stage where he is getting hard work, he's still in nappies. If we don't dress him he doesn't get dressed and if we don't feed him he doesn't get fed...

It's got to come eventually because you've got to cut the apron ties, they've got to live in the real world, we're not getting any younger and what's going to happen to them if they don't socialise.

2.5.3 Shorter Breaks

Within the 'playing cards' exercise, those people who chose shorter breaks (rather than or as well as overnight stays) almost always selected activities based purely on their child's preferences and abilities – something they would enjoy.

I've put horse-riding and sporting activities because that's what he wants to do. He loves his sports but there isn't so much of it around with the support.

I've put day trips down, for the future, trusting somebody else with him really. Sporting activities because he quite likes tenpin bowling and he loves soft play.

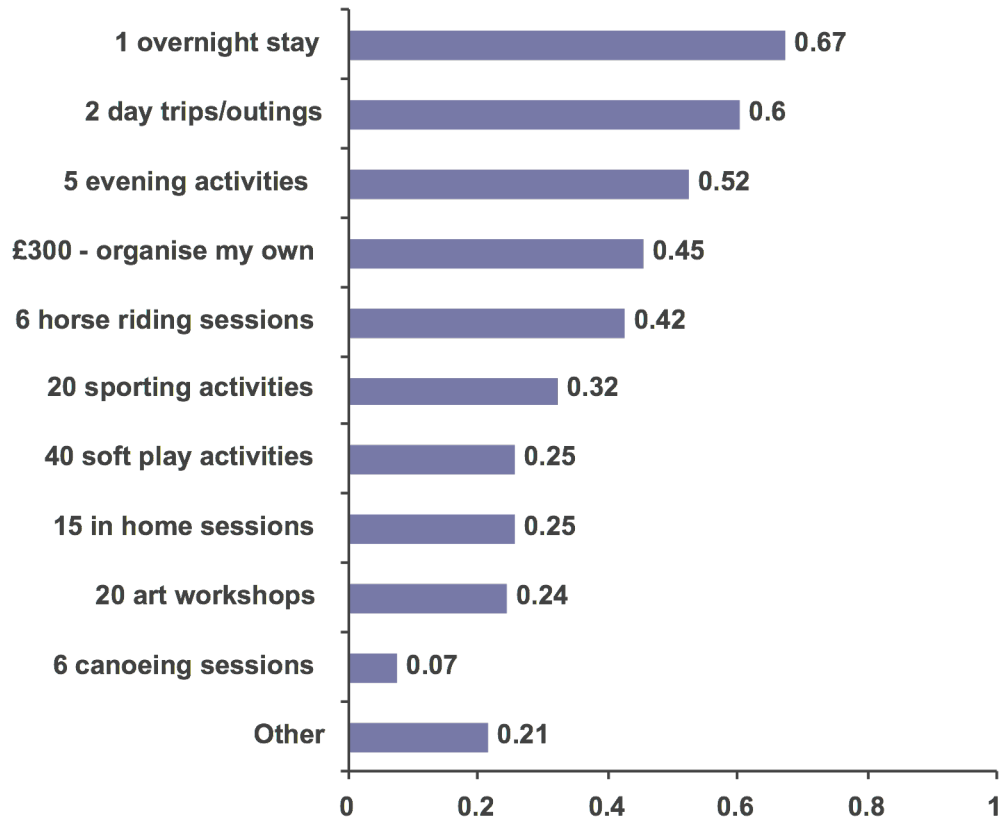
Mine is quite similar as well, the soft play, he's really into all that now. I think in the future maybe something like horse riding, the art workshops and again the money to organise something.

At the moment I'd be thinking more of short spates of time that he would go to do something rather than anything that would be overnight or all day. I don't feel like I need the respite, maybe down the line I might so it would be more for him to get involved in doing some activities really.

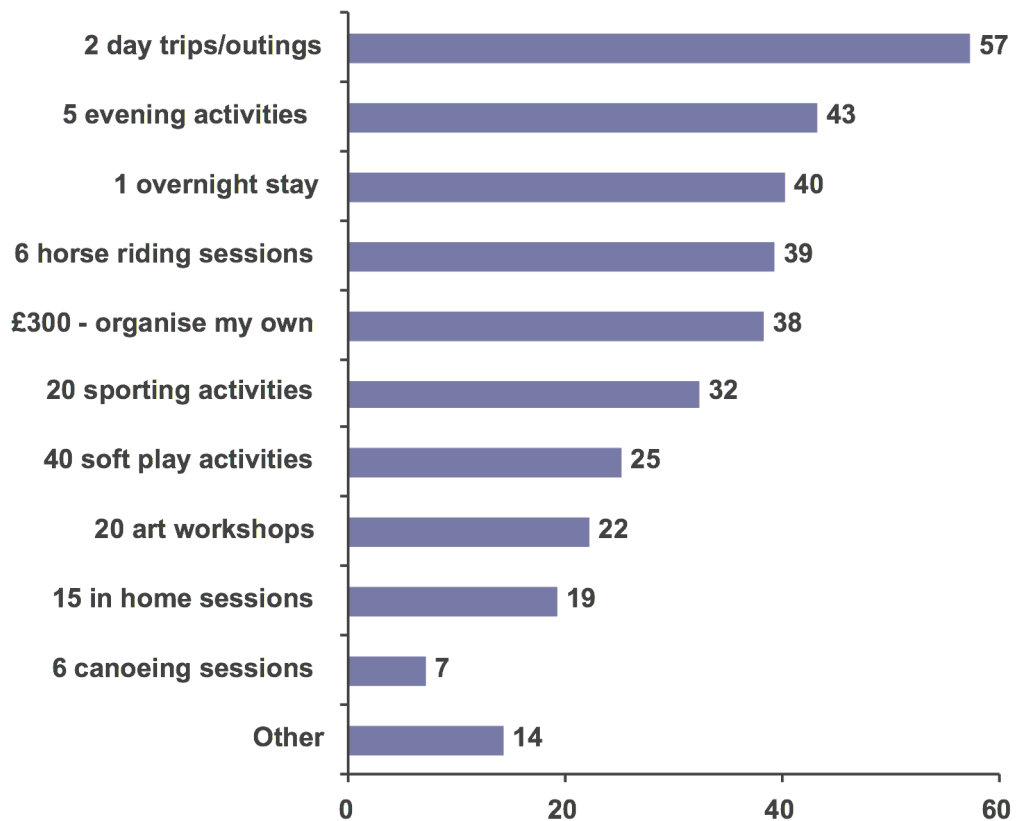
When we look at people's selections from the 'playing cards', the most popular options in terms of mean scores were overnight stays, day trips and evening activities, followed by money to organise their own care/activities and then horse-riding sessions. The order changes though when we look at the percentage that chose each option at least once: day trips become the most popular, followed by evening activities and then overnight stays. The reason for this is that as previously stated, 60% of attendees didn't want any overnight stays – but those who did often said they needed at least two, which increases the mean score. These responses are shown overleaf.

Even within the relatively small sample size of 84, there were some significant differences in preferences between sub-groups. For example soft play sessions were very popular among parents of children aged under 5; horse riding sessions and art workshops were much more popular for girls than boys, whereas the reverse was true for sporting activities. Canoeing sessions were often chosen by the few parents whose children have only mild disabilities, but were rarely chosen by anyone else. The need for overnight stays increased along with the extent of the child's disability.

Short Term Break Options: Mean Scores



% who chose each option at least once



2.5.4 Other ideas

Parents' ideas for other short breaks and activities included...

- Theatre and performing arts groups
- Trampolining sessions
- Three wheeled trikes sessions
- Babysitters for the evening
- General outdoor activities

2.5.5 Direct Payments

Several people said they had been allocated Direct Payments but complained about how difficult they are to access; they said they'd had to jump through hoops to get them, with far too much paperwork and bureaucracy (almost too much to make them worthwhile).

It's taken a lot of work and a lot of PA's and interviews and advertising and all these people traipsing through your home, my tolerance levels have just been exhausted with it but basically I just asked anybody and everybody I knew who I thought would be interested in (child) and able to have (child) preferably with a bit of training. I didn't realise there was so much paperwork involved and every month weighing up the receipts, the expenditure and having to prove it, it's an absolute nightmare because how can you do that...

However, once they have been allocated, Direct Payments often seem to work well as long as parents are happy to do the paperwork and with the agency and staff in question.

In the best instances parents say the payments give them direct control over their support and the flexibility they want - especially if they can contact the carer personally rather than go through the agency every time they want to arrange or change care times.

We've gone to an agency and we have a lady called ... who is an absolute angel. I don't even go through the agency now, I text ... and she'll drop anything to come for...

But, initially some worry about 'who they will get' and don't actually want that level of control and responsibility – nor the paperwork.

You see with direct payments you are given this sum of money but the actual practicalities of getting somebody to come and take your child out and induct them into how your child is. You've got to be confident that they are doing that, it's such a lot of energy and time and then if they decide they don't want to do it in six weeks time you've got to start right back at the beginning. So although I've got this sum of money I could quite easily give up and say take it back.

The principal problem with Direct Payments seems to lie in a general shortage of suitable carers in the county resulting in parents struggling to find someone who will, or can, care for their child. Even when they have done so they can then face further problems due to staff turnover; a carer leaving results in real disruption for them – not only in finding a replacement but then rebuilding a relationship with the child.

I also access direct payments. I get 14 hours a week but you cannot get PA's for love nor money. I handed back something in the region of 300 hours last year because I couldn't get any PA's. I think everybody is struggling but particularly those with severe complex needs because the rates for disability are the same regardless of whether it's moderate learning difficulty or complex needs, it's all personal care.

So if you are going to choose a job the majority of people will choose the easier option where they've just go to do some level or supervision

Whilst the County Council does provide a list of childminders, those on it were not felt to be interested in, or trained for, care of children with special needs. *'It's a complete and utter waste of time'*

2.6 Valued Organisations

Throughout the consultation a number of organisations were cited as providing facilities and support that is highly valuable to both parents and children, and makes a real difference to their lives. These were located throughout and around Staffordshire and included:

- Parent Partnership Service (for their relative independence and advice)
- Special schools

With your special schools you've got your school nurses there ..., three days a week, you can ring her and she will ring you... I can pick the phone up now and get hold of ... and if she's not at (special school) they will give you the phone number to get her at (other special school), she's constantly there for you. You can always access the services through the school, they will back you up for everything...

- Voluntary social get togethers
- Independent play schemes e.g. Bips & Lips in Biddulph (now folded due to loss of funding?)
- Play areas e.g. Adventure Playground in Newcastle, JJs in Macclesfield, Funsters, Snoozlem

The Newcastle one is fantastic, the door has to be push button to get in or out and they won't let the kids out until the adult is with them. They have additional staff on a Saturday afternoon so if I need an extra pair of hands I just have to ask. I get to meet other parents, I get to sit and relax knowing that my children are in the complex somewhere and that they are happy, and I know they can't escape.

- Sporting activities e.g. Riding for the Disabled (but reported to be long waiting lists), Special Olympics
- Special needs nurseries e.g. Peter Pan
- Respite care e.g. Horton Lodge, Wolstanton, Tri-Alpha, Cannock Resource Centre, Kipling Residential

It (Cannock Resource Centre) is fantastic and the staff now are exactly what we need and are able to deal with him, they know which groups to put him in, because at first it was two staff to just him, he couldn't go out in a group...They take him on holiday, they take them to farms and Cannock Chase, swimming. Sometimes they'll just use the centre because they've got an outdoor play bit and it's like a house. They're going to have him on a Monday night and start cooking his tea...start doing life skills with him...they've obviously got their hands tied as to how many kids they can have and they can't supply the hours...

- Family Link – reported to be a fantastic service although can be difficult to access for those children with complex or challenging needs and/or older children.

I have family link for (child) and (child). They both work absolutely brilliantly. I get direct payments for all three children and I get direct payments with overnight for (child). The problems I've had is fighting to get it, that has been the main problem, actually accessing the service but once I got it it's been fine. (child) had difficulty getting the service ... with her being a very violent and active child with challenging needs... We were turned down by one family who she started to go with because they said that she needed two adults to one child, which makes me feel even worse because although I'm married, my husband has also got special needs so I'm like basically the one parent over the three special needs and it's like they can't cope with just (child) on her own when it's just her and it just felt like a slap in the face really.

(Family Link Carer) I think one thing that could have helped us with the Family Link, that would have made a big difference, she's eleven now and she's been coming for about 8 years and initially it was possible to lift her up and move her around and now it's not. We would have liked to have had an adaptation downstairs in the toilet area that we've got which would be perfectly big enough to get a wheel in shower and because of how the system is there wasn't the finances available either from the disability team or the family placement, it's not classed as equipment so we carried on having her without the facilities to actually look after her in an ideal world, but balance that against what she gains from coming then it wasn't essential but that could have put a lot of family link carers off because they didn't have the facilities there to continue a link which from what I understand that can happen, the children can go in and they are young and very easy to manage and take out and about but then as they get older then they perhaps have to go into a residential short term break which the families might not want if you've established that link already.

- Autistic youth club – but only once a month (would like to be more frequent)

- Charities and voluntary groups e.g. Jigsaw. There were varied reports on Mencap, some finding their support really valuable, but others a waste of time.

There are however, two core issues relating to these valued services:

- Many parents are simply unaware of their existence. Simply attending the consultation workshops proved to be a valuable exercise as parents swapped experiences and information with others.
- For some the distance they have to travel is simply not possible; even those with a car can find the journey time outside their child's 'tolerance zone'.

2.7 Specific Requests/Problems

Within the workshops, several criticisms were made about Staffordshire public services, where gaps in provision are having a significant negative impact upon families' lives. The main ones were as follows:

- Lack of speech and language therapy and physiotherapy, hydrotherapy and occupational services in Staffordshire. Long waiting times and poor service were consistent complaints and the situation was believed to be getting worse. In the main these concerns were expressed by parents with children in mainstream schools – they felt quite 'abandoned' in this respect and found accessing these services extremely difficult.
- Allocations of adult nappies – the average was reported to be three, but after great struggles could sometimes be increased to four or five. This was felt to be totally inadequate: '*how many times do you go to the toilet in 24 hours?*'
- Lack of full time residential care for 18+ in Staffordshire and poor communication about the options that are available.

...he can stay in foster care until he is 18 and then he goes into Adult Services...we were suddenly told that it is our responsibility to find out where he can go and what's going to happen to him after, we didn't realise this until we went to the last review and found out that there isn't anywhere in Staffordshire he could go because none of the colleges are 52 week residential colleges and there aren't any in Staffordshire and they would be unable to cope because he has no speech...he's got severe learning disabilities and he can't read or write...he has no understanding of what letters are, he's got no money sense or no sense of danger so he needs somewhere that he's going to be secure as well...

- Public swimming pools being too cold.

3.0 Conclusions: What Do Parents Want?

3.1 Information

One single, comprehensive source of information for all the services that are available, that can be tailored to specific cases.

Well that's why I'm here because there are loads of things for (child) to do but I don't know about them, how can I take him to things I don't know about? If somebody said to me yes there's a youth club where he can go to. My car is adapted for a wheelchair and I'll take him anywhere he wants to go...he wants to go independently...he wants to go out...I don't know anywhere, I don't know where the scouts are...

The obvious solution to this seems to extend and improve the Staffordshire Children's Trust or County Council's website, or introduce a new one that is specifically for parents of disabled children (with an easily remembered domain name). Either option should have 'search' option: search by age of child, area and nature/extent of disability to provide personalised links. The site should provide 'everything the parent needs to know'; either on the website itself or through links to other sites (or preferably a combination). This would include...

- Medical information relating to the child's condition
- Advice on support and grants that are available, and how to access them
- Activities for disabled children
- Parents groups
- Equipment suppliers
- Specialist clothing
- Nappy suppliers
- Support groups & charities
- A database of approved carers for disabled children
- Education courses for parents
- Online advice on how to deal with sleep problems, challenging behaviour etc
- Holiday companies for families with disabled children etc.
- Information on hospitals, doctors surgeries etc

The website could offer parents the option of 'membership', whereby they only have to input relevant information about the child once and then log in on further visits, which would then direct them to relevant sections of the website.

We would strongly recommend that the website includes the option for parents to join a parents' forum or chat room whereby they can contact other parents for emotional support and advice. This chat room should be 'open all hours'; thereby reflecting the fact that many carers have little sleep.

There could also be the option for a section of the website specifically for the children; offering a variety of games and information that is accessible/relevant to different disabilities.

The website needs to be easy to navigate and tailor-made to its market; containing appealing visuals and clearly laid out. It also needs to be frequently updated.

The majority of people do have internet access at home now and the website could also be publicised and made available through public libraries. There will still, however, be a minority of parents who cannot (or do not want to) access the website and so we'd suggest that for these people key information from the site should be contained in a printed 'Parents' Pack' that should be promoted and made readily available.

Attendees at the workshops also suggested there should be an equivalent website or network for the healthcare professionals too, as well as some means of contacting a relevant professional who could help them.

A network for all the professionals, that we as mothers and carers could have access to...you can't remember all the small things and then you think oh my god I should have told her that...something like she spoke a whole sentence...

There is no-one to go to that can say this is the range of services we have, lets talk about your child and your child will benefit from this and this or we can offer you this. You go to whoever you hear from, it's hearsay, it's bits and pieces and no-one seems to co-ordinate with one another and I think that's where it would be lovely to have somebody that you could ring up and explain the situation and have them say this could be appropriate for you, I'll put you in touch with these people. Again they've got to know about your child haven't they? Everybody here will have their own individual problems with their child, they're not going to be the same.

3.2 Education

The area of education falls into two areas: education for parents and education for children.

Taking the latter first, parents' requests generally focused upon a real desire for **more training and support for staff in mainstream (and also some specialist) schools** so they can understand a child's disability and thereby deal with it.

the CLDN has been really helpful because we had an issue at (special school) about the way that some of ... behaviour was being interpreted, quite wrongly because people were approaching managing him in the wrong way completely so what the CLDN did was set up a multi-agency meeting and everybody who is involved in the care of ..., so us, the school, the social worker, everybody comes together and we have an agreed way of managing certain behaviours so that ... doesn't get labelled as having challenging behaviour. Because ... behaviour isn't challenging, it's the failure to respond to things that he does that might lead to that. ... has a communication passport that goes with him everywhere he goes and that is all about ... because he can't speak and it's just a reminder to people who have never worked with ... or might not have read it for a while and it just says I may do this, you can help me by reacting in this way. That's been really good and the fact that that's been driven by the PCT through the CLDN has been really helpful.

There were also frequent requests for greatly **improved education for parents** of disabled children. This could take the form of college courses, talks at support groups or one-to-one advice. Subjects requested included learning how to lift, handle and communicate with their child, first aid, how to toilet train older children, dealing with and managing challenging behaviour and obsessions, dealing with sleep problems, plus relevant sign language courses.

I was funded by social services but to go to college (sign language) and the first thing you learn is 'I live...' well that's no good... you want to say here is some beans on toast or your drink is there.

...somebody to come in and give you practical advice. I want someone to come in and give me a programme, 'Do this, step one.' There must be somebody out there that is an expert on challenging behaviour...

3.3 Emotional Support and Advice

Those people who attended the workshops consistently requested ‘somewhere to go’ – literally so they could get out of the house and mix with others. This stemmed from various needs...

Somewhere to go for themselves just for a coffee and a chat

Somewhere to go for their child – they worry about their child being isolated and not stimulated – don’t want them sitting alone in front of TV for days on end.

Somewhere to go as a holiday – outdoor education centres that include provisions for disabilities would be ideal. Many would like to go with the child as well; a family holiday.

Somewhere to go where disabled and able-bodied children can mix – especially siblings.

Her sister has tried to go with her as well, and friends but they felt very alienated because they are the only ones there without special needs and it is very difficult for a 14-15 year old to go into that environment. You know people coming up to them very close and people with Downs Syndrome can be very affectionate, and at 14 they don’t want any touching do they. But they found it difficult so they stopped going.

This wasn’t the case for all parents however; some preferred their child not to be put into a situation with able-bodied children, as they were concerned about bullying and the child being either made fun of or ignored. Others felt that their child (typically those with ADHD) would not be able to cope with such a situation and hence there would be a real risk of violent and disruptive outbursts.

We did try him with after school activities but we just got asked politely to not come again because he can’t cope with the unstructuredness of it. At Disability Sports they are trained and are able to manage and they are quite strict which he needs, he needs boundaries. We are thinking about riding for him but again with Riders for the Disabled because they are more equipped to cope with his outbursts and things like that. He goes swimming and his teacher has taken a year to get to know him and realise that he shouldn’t be around the other kids when they are all swimming together.

Somewhere to go as their child gets older – as the child’s behaviour/disabilities become more difficult to deal with physically, combined with the parent getting older and less able to deal with the

problems themselves, parents often said that being with others was increasingly important for both them and their child.

It's so easy when they are small and you can cope, they are your children and you have this sense of coping with it and it's not until they do become 6ft teenagers and their behaviour is worse that you suddenly think wow - and you're getting older as well. The whole caring thing really does change

It should be noted though that this desire for social interaction might not be as widespread among the total population of Staffordshire carers; those who attended the workshops often had children with severe or chronic disabilities and were sufficiently confident and able to attend the workshop. Those who did not may not be able, or even want to go somewhere to mix socially. There was some feeling even among those who attended the workshops that current facilities/support groups are orientated towards severe disabilities and that it's hard to find ones where there's a mix. Others said that social groups they'd been to were too 'poor me' and they'd left feeling depressed rather than uplifted; a delicate balance needs to be found!

You need something but we felt more that we wanted to have discussions with other parents about the reality of what it's like.

And about solutions, not problems, not isn't it terrible being us...

I think more informal sessions so you can actually get to know the parents and find out what has worked for them...

3.4 Access to Services

Parents want professionals and other people working in the partner agencies to listen to them, respect them and recognise that they each have individual needs. They also want them to return their calls and get back to them when they've promised to do so.

Some professionals are more willing than others to learn for themselves and that makes a big difference, the attitude of the professionals and willingness to learn more and listen and to accept that they don't know everything.

You know more about your child than they do...

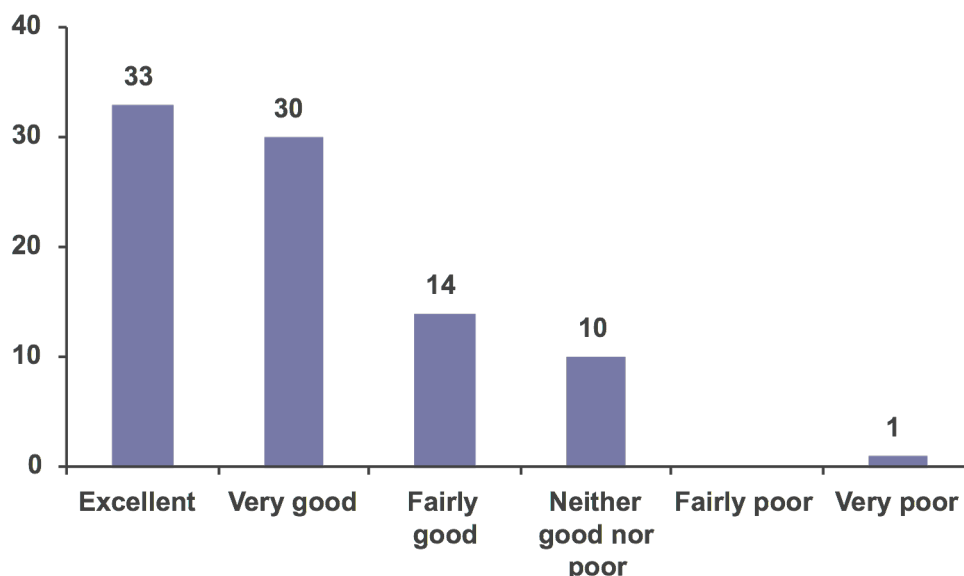
It's not just listening to the parents either, it's listening to each other and sharing information...not acting on what others have told them...

...obviously we're very reliant on the social workers involved as well and I'm very fortunate in that the ones that are involved with me are very helpful and they do get back to me if I ring and that's really important...as parents you can be feeling very vulnerable if you've got a child with disabilities as well...you don't always get the answers you want but you get reasons for it and what you can do about it.

3.5 Short Term Breaks

Firstly, the proposals to broaden short term breaks away from purely overnight stays must be viewed as excellent; this is exactly what parents need, as reflected in their questionnaire responses. Comments made at the meetings indicate that the minority who rated the proposals as only 'fairly good' or 'neither good nor poor' did so because they were sceptical as to whether they will ever come to fruition. They were also questioning about what would happen after the two year period; will it all fall by the wayside?

Overall, how do you feel about the proposals?



As seen earlier in this report, the most popular options overall were day trips, overnight stays and evening activities. It is clearly apparent though that a range of options will need to be provided for parents to select from, to meet their and their child's particular circumstances.

Parents often made requests regarding the practicalities of support and services provided; not only relating to Short Term Break services but also relating to services they could access on a day-to-day basis with their child.

These are detailed below:

- **Local** services and centres...

We discussed this about five years ago and because of how diverse Staffordshire is, children from the south of the county are having to travel to Cannock to get respite, whereas it would have been nice to have a small centre for the children in their areas...I've been to the Cannock Resource Centre and I think it's really lovely but I don't think it's being used to its full potential.

(child)...s respite is at Wolstanton and it is a long way to travel but they have bent over backwards...he has his four nights in there and the girls are absolutely brilliant...they've got a ball pit and a sensory room, for the older kids there are chalets, all individual with TV's, computers, trampoline, and it's brilliant.

Well why can't we have that in Stafford, why have our kids got to travel every time?

There seems to have been so much money poured into the young services, like Surestart teams and it's massive and then they hit five and they go to school...but it gets worse as they get older...it gets more demanding, it would be so nice if we could have something like a nurture ground, more locally based community accessible units where we can meet socially and have our own parent forums...

In cases where local services are simply not possible, it would be greatly beneficial to some parents if **transport** could be organised to enable them and/or their child to participate.

- Evening activities that are at a **convenient time**: 5pm or 6pm was mentioned. This gives the children time to get home from school (which is often some distance away), have something to eat and then get out again; 7pm onwards is too late as the children often have a very strict and early bedtime routine. Others wanted activities to be straight after school, but only if transport to the session and preferably home could be organised.
- **Cheap or free activities**: families are often on a fixed (and low) income and struggling to make ends meet. This is said to be even more so for single parent families.

- **School holidays** were almost always reported to be a very difficult time, with a change in routine often affecting the child's behaviour and very little to keep them, and their siblings, entertained. Requests were made for days or sessions of mixed activities which didn't give the children time to get bored as they could flit from one activity to another in a safe environment.
- **The ability to choose to 'stay or go'**. Depending on the extent and nature of the disability, some parents were happy to leave their child and welcomed the break – others would not be comfortable doing so and wanted to stay – even if just to watch from a distance, or to be called upon if needed. These sessions were requested for all ages; not just up to 13 as was reported to be currently the case.

That's the thing all activities tend to stop when they are 13. Because although they are physically mature they are not mentally mature. Some of them still are 8 years in their head even though they've got teenage hormones. They still enjoy the activities that are put on for 8 year olds.

North Staffs Adventure Playground is better for the older ones but sheer distance, they haven't widened it to Cannock which is a shame because I think they could without a huge amount of work

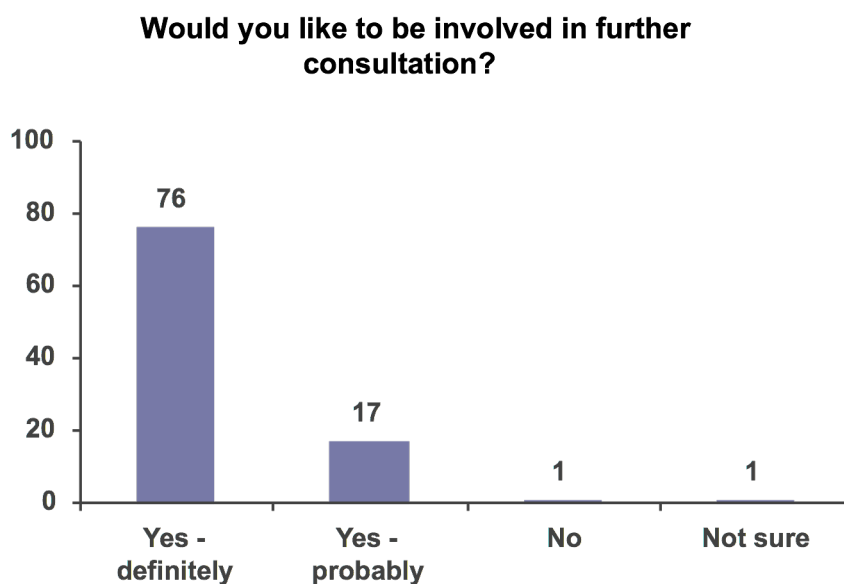
- **Suitably qualified, trained and briefed people** to run the courses and provide the short term break care.

...we just need some time where he is with other people who are motivated to have a good time with him and understand his needs...

One idea that emerged in a couple of the workshop sessions was for special schools to also offer their facilities and activity/play sessions to disabled children in mainstream and other special schools, especially during weekends and in school holidays. If this were possible, it would seem an excellent means of meeting many of the needs outlined above.

4.0 Future Participation and Involvement

There was a strong desire among those who attended the events to be involved in future consultation and developing the Aiming High proposals. They really enjoyed the event and the chance to put forward their views, and were keen to see the proposals come to fruition. In essence they wanted to be kept ‘in the loop’. This is reflected in the graph below which is derived from the self-completion questionnaire.



People were keen to be involved in ongoing communications and dialogue. They suggested that printed newsletters could be mailed out to inform people of upcoming events and developments – similar to the ‘Parent in the Know’ newsletter. Others felt that an emailed version would be just as good. It should be noted that they generally assumed that their details must be on various databases and so it would be easy for the authorities to do this; they did not anticipate that data protection would be an issue. One way of getting round this would be to ask parents to ‘sign up’ to receive future communications.

The extent to which participants enjoyed the Aiming High events was evident in their responses in the self-completion questionnaire relating to forms of ongoing consultation. Almost all wanted further similar events and the vast majority wanted to participate in future focus groups.

I think at least an annual meeting...we do find it useful to talk to you guys and people like ourselves...perhaps you could have a once a year forum, where in the morning it's a session where there are speakers to talk about sleep etc. and in the afternoon get us to fill some stuff out, like a seminar...

...I think as long as it doesn't become a moaning shop.

It's about making sure people are accountable and about reporting back to us about they've done because very often you do get a bit of consultation fatigue because you are asked what do you want us to do, how can we improve things and then three months later, how could we improve things.

Telephone surveys were not popular. Indeed any form of quantitative research would need to be carefully thought through due to the difficulties parents of disabled children face in 'putting themselves in a box'; questionnaires would need to be based upon initial qualitative feedback and incorporate great flexibility to cover individual circumstances.

Again though it must be remembered that these are the preferences of those who attended the workshops: those who didn't are likely to have very different preferences.

Ways in which we could involve people in our decisions	
	%
Large events like today's	91
Focus groups with other parents/carers	85
Face to face meetings with Council staff and other parents/carers	73
Surveys sent to you by email	53
Online forums	49
Individual meetings with Council staff	37
Telephone surveys	14

On average, parents who attended the workshops said they were willing to travel up to 30 minutes to attend future consultation sessions and around one in four for up to 45 minutes. Again though this is unlikely to be the case for those who did not attend due to transport difficulties.

