



Short Breaks Review Engagement Report Appendices

January 2018

Appendices

These appendices accompany the document “Short Breaks Review Engagement Report – January 2018”

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Appendix (i) Demographics of respondents

The demographics of the children of the respondents can be seen on [page 11](#) of the Short Breaks Review Engagement Report and roughly reflect the population SEND children in Hull. The information below shows the demographics of the respondents to the questionnaire. It is recommended that the Equality Impact assessment of the short breaks service is revisited in light of this information.

Distribution of respondent characteristics

Chart 16

Which of the following best describes you (the person completing this questionnaire)? (n=259)

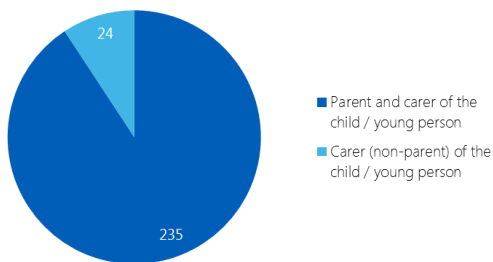


Chart 18

Ethnicity (n=141)

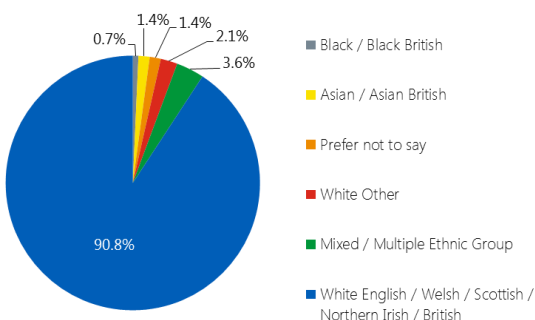
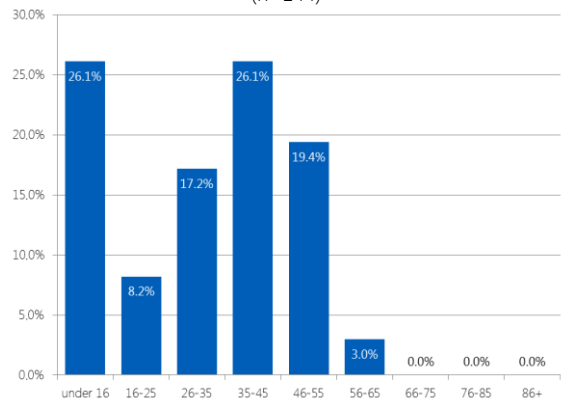


Chart 17

Age of Respondents (n=144)



NB. The survey was sent to parents and carers, it is unlikely that anyone under 16 completed the survey

Chart 19

Gender of Respondents (n=141)

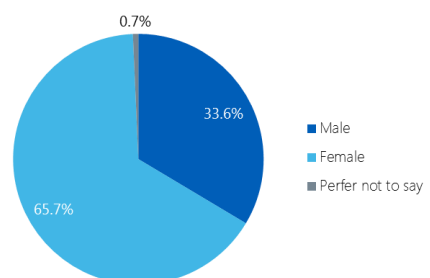


Chart 20

Religion or Beliefs of Respondents
(n=131)

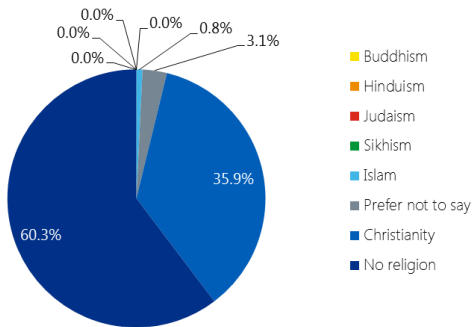


Chart 21

Sexuality
(n=134)

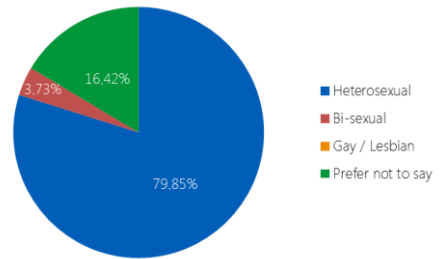
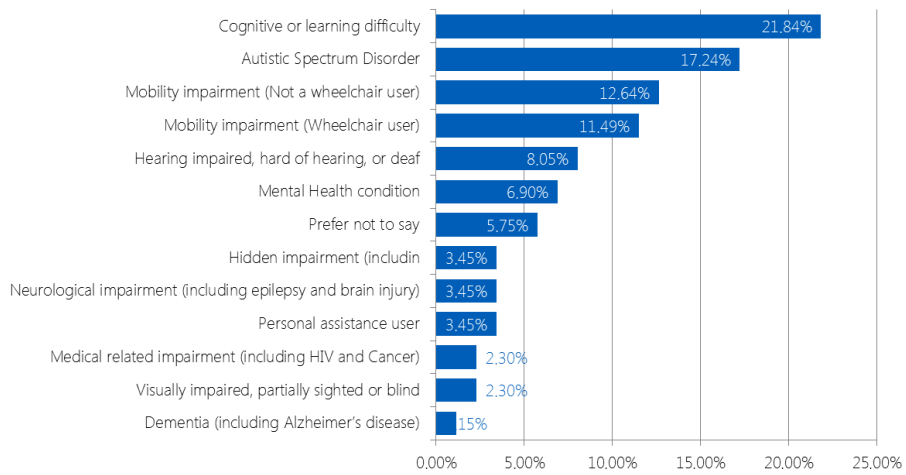


Chart 22

Do you identify with any of the following impairment groups
(n=87)



Appendix (ii)

Questionnaire



Short Breaks engagement for parents and carers of children and young people with disabilities in Hull (Age 0-25)

Dear Parent/Carer

Hull City Council (HCC) has a statutory duty to make a range of short break services available to meet the needs of disabled children and young people to enable their parents and carers to receive a break from caring.

NHS Hull Clinical Commissioning Group (CCG) supports HCC in commissioning these services.

Short Breaks for children and young people with special educational needs and/or disabilities come in many different forms and can:

- Provide opportunities for these children/young people to fulfil their potential through safe
- enjoyable experiences with or without their parent/carer
- Give parents/carers a break for caring, allowing them time to do day-to-day tasks, spend time with other family members, leisure activities or engage in education/training opportunities.
- Enhance the abilities of parents/carers to care more efficiently

Short Breaks can range from a few hours, an evening, overnight, weekend stays or longer. They can occur during the day, the evening, weekends and school holidays and can take place in or out of the home environment, in the community or in a residential setting.

We are working with Hull Parent Forum to understand what activities children and young people can access to give them and their families a Short Break. We want to understand what barriers there might be preventing access to these activities and how we can improve these services across the city.

This survey is anonymous and your response is important to us in shaping future services.

There will be opportunities for further consultation going forward.

Thank You

Jon Plant
City Childrens Safeguarding Manager
Hull City Council

A handwritten signature in black ink, appearing to read "Jon Plant".

Erica Daley
Director of Integrated Commissioning
NHS Hull CCG

A handwritten signature in black ink, appearing to read "Erica Daley".

Short Breaks engagement for parents and carers of children and young people with disabilities in Hull (Age 0-25)

This survey is also available on line at the following address:
www.surveymonkey.co.uk/r/HullShortBreaks2017

Please complete this survey about your child/young person with disabilities (If you have more than one child/young person with a disability please complete 1 per child).

Please tell us about your child / young person

Q1: How old is your child / young person?

Q2: Is your child / young person: Male Female

Q3: What school does your child / young person attend?

Nursery	<input type="checkbox"/>	Primary	<input type="checkbox"/>
Secondary	<input type="checkbox"/>	Special	<input type="checkbox"/>
College	<input type="checkbox"/>	Home educated	<input type="checkbox"/>
Other	<input type="checkbox"/>		

Please state the name of the school

Q4: What is the first part of your child / young person's home postcode?

Q5: We want to understand the level of need of your child / young person. Please tell us if they are in receipt of any of the following:

(Please tick all that apply)

	DLA Care Component	DLA Mobility Component
Low Rate	<input type="checkbox"/>	<input type="checkbox"/>
Medium Rate	<input type="checkbox"/>	<input type="checkbox"/>
High Rate	<input type="checkbox"/>	<input type="checkbox"/>

Personal Independence Payments (PIP)

Standard	<input type="checkbox"/>
Enhanced	<input type="checkbox"/>

Q6: What type of Short Break activities does your child/young person already access? (Tick all that apply)

- Sporting and leisure activities (e.g. football, swimming, dance class).....
- Social activities with other young people/friends (e.g. movie night, bowling).....
- Social activities with individual support outside the home (e.g. requiring a personal assistant).....
- Independence development activities (e.g. managing money, travel).....
- Educational activities (e.g. training courses, music lessons).....
- After school/youth clubs.....
- Creative activities and hobbies (e.g. painting, drawing, arts and crafts).....
- Caring in the home (e.g. providing personal care).....
- Supporting the child in the home (e.g. providing respite for carer).....
- Overnight break.....
- They do not access short breaks.....
- Activities in the school holidays
- Other – please specify

Q6a: Where does this short break take place?

Q6b: Does this meet your child / young person’s need for a short break?

Yes No

Q6c: Does this meet your need for a short break?

Yes No

If NO, please tell us why:

Q7: Please tell us what type of Short Break your child/young person needs but does not currently access?

Q7a: What is preventing your child/young person from accessing this activity?

- | | | | |
|--|--------------------------|--------------------------|--------------------------|
| Cost or availability of transport | <input type="checkbox"/> | Access to buildings | <input type="checkbox"/> |
| Do not know what services are available | <input type="checkbox"/> | Nothing in my local area | <input type="checkbox"/> |
| Time of day / week are not convenient | <input type="checkbox"/> | Language / Communication | <input type="checkbox"/> |
| Problems with environment e.g. too noisy | <input type="checkbox"/> | Attitude of others | <input type="checkbox"/> |
| Do not know how to access activities | <input type="checkbox"/> | | |
| Lack of staff expertise, knowledge or confidence | <input type="checkbox"/> | | |
| Lack of appropriate individual supervision/support | <input type="checkbox"/> | | |

Other (please state)

Q7b: When would this Short Break activity be most useful?

- During the week, during the day.....
- During the week, during the evening
- During the weekend
- During school holidays
- Overnight
- Anytime.....

Other (please state)

Q8 Would you be willing to contribute to the cost of a short break?
(This will be explored further with parents / carers before any proposals
are made) Please tick one.

Yes No Maybe

Q9: Please tell us anything else you wish us to know about Short Break
activities:

Q10: Which of the following best describes you (the person completing
this questionnaire)?

Parent and carer of the child / young person

Carer (non-parent) of the child / young person

Other (please state)

Please return this questionnaire in return envelope provided by Monday
21st August

If you want to have your details forwarded to a focus group or if you
need any help with this questionnaire please email;
hullparentsforum@hotmail.com or telephone 01482 467540

The information in this form is anonymous however if you would like to
contribute further please can you give us your name, email and mobile
number and we will let you know how you can be involved.

This information will be kept separate from your responses.

Name:

Email:

Mobile Tel:

Further information will be available on the Hull Local Offer website:
hull.mylocaloffer.org

About You

We know that people from different age groups, ethnic groups, religions, and sexualities access healthcare in different ways, they have different health needs and sometimes have differing experiences of care.

By telling us a little about you, we can make sure that everyone has the opportunity to receive care in a way that is most appropriate to them.

If you don't want to answer any of the questions please select "Prefer not to say". Your responses to this section will be completely anonymous.

Q01 What is your postcode?

Q02 Which GP Practice are you registered with?

Q03 What is your year of birth?

Prefer not to say

Q04 Which of the following best describes your ethnic background?

- White
English / Welsh / Scottish / Northern Irish / British
- White other (Please specify in the space below)
- Asian / Asian British
- Black / Black British
- Mixed / Multiple Ethnic group
- Prefer not to say
- Other

Q05 What is your religion, belief or faith?

- No religion
- Buddhism
- Christianity
- Hinduism
- Islam
- Judaism
- Sikhism
- Prefer not to say
- Other

Q06 What is your gender?

- Male
- Female
- Prefer not to say

Is there anything else about your gender you would like to tell us?

Q07 What is your sexual orientation?

- Heterosexual (Straight)
- Bi-sexual
- Gay / Lesbian
- Prefer not to say
- Other

Q08 Are your day to day activities limited because of a health problem or impairment which has lasted, or is expected to last at least 12 months

- Yes, limited a little
- Yes, limited a lot
- No
- Prefer not to say

Q09 Do you identify with any of the following impairment groups?

- Mobility impairment (Wheelchair user)
- Mobility impairment (Not a wheelchair user)
- Personal assistance user
- Cognitive or learning difficulty
- Visually impaired, partially sighted or blind
- Hearing impaired, hard of hearing, or deaf
- Mental Health condition
- Medical related impairment
(including HIV and Cancer)
- Neurological impairment
(including epilepsy and brain injury)
- Autistic Spectrum Disorder
- Dementia (including Alzheimer's disease)
- Hidden impairment
(including diabetes)
- Prefer not to say
- Other

Q10 Is there anything else about yourself that you think may have an impact on your healthcare needs?

Appendix (iii)

Questionnaire Free Text Responses

Q6c Does this meet your need for a short break? If no, please tell us why

- [Anon]'s mum has recently passed away, i could use more support for her such as short breaks activities as she is very active
- I don't get enough hours
- I don't get enough hours.
- Whilst this provides some time for me to carry out daily chores/activities that I'm unable to do whilst with my son it does not allow time for the rest of the family as my husband works and my eldest son is at school. The daytime respite provided does not support the needs of other family members.
- [Anon]'s mum has recently passed away (17.6.17). I could use more support for [anon] such as short breaks activities as she is very active
- It would benefit us more as a family if there were more leisure/after school activities available and accessible to and more during the school holidays
- The Saturday every fortnight takes less then four hours because we have to drop off [Anon] and his carer to and from Haltemprice due to the fact that the PA does not drive.
- As getting older feel overnight more needed
- Because I like to look after him myself he's my son and I need to have save on to take my children holiday thank you
- Not enough hours only six hours week
- Don't access any short breaks could sure do with one with two. It's on the add spectrum life is very hard.
- never been offered short or long breaks yet.
- Nothing ever offered
- Does not currently receive this
- He will benefit from attending after school activities/club.
- N/A
- I don't have transport which makes it very difficult for me to get my children to and from any activities. Transport was previously provided.
- My child has no access to short break unless with KIDS
- It does as gives my child the opportunity for a short break which makes me happy, but having another child with SEN it doesn't give us a break, just makes it a bit easier only having to manage with 1 child rather than 2.
- I have 2 SEN children. So whilst one may be accessing a short break I will have the other at home. I'm happy for my children to access a short break so long as their happy + enjoying themselves.
- he will benefit from attending after school activities/club
- Still having to take him to the activity and activity is very short (only 3 hours)
- he does not access any short break services
- have 2 younger children - needs time to do other things - no one will have the child because to difficult
- its been difficult to get him out of the house, has trust problems with anyone other mum or his grandma

- closing team down
- after school activities, music club
- not aware of service
- social worker said cant provide a care package and closed his case
- things arn't advertised very well, we was not aware
- the school holidays are to long for special needs children in summer it would be nice to ba able to have access to more than one week if possible. wee dont get any help at all even with a social worker
- [Anon] has only an home life he does not got to any club at school or out of school he has only 1 week at the (kids club) in school holidays, which he loves, but we haven't been told about any other clubs
- I was surprise to find out short breaks where clubs. To me this is not a short break for me because many of my daughter clubs are in East Hull and we live in West. One of her club starts at 6pm. Trying to get across the city in tea-time traffic is quite stressful. I have to drop her off and get home. Return for her within 2 hours. this can make me tired. I do it because my daughter gets alot of enjoyment out of her club. My daughter also does media club and dance class. It wouldnt let me tick more than 1.
- Just recently diagnosed with fibromyalgia and only just gone into adult services from Saturday no help from anywhere
- No break
- Mum poorly has a lot of problems, so Dad has to step in has his carer, Dad has been diagnosed with cancer and hospital are looking for a 2nd cancer. Just waiting for results to come in from biopsy and mum is finding things very hard to get some help as nothing, has ever been put in place if I am poorly with several problem and Dad goes through treatment we could do with some support for our son due to him been one to one at AM times and his needs around his disabilities. No one has ever put nothing in place for him to support us at this difficult time. He just goes some to karate to let of needs.
- [Anon] was in respite care but as left it was good she is 15 19 and don't want a older carer now has to do
- He do lots of activities at home and he doesn't need more I think.
- My daughter doesn't get a break and with her having 2 younger brothers she can feel a bit left out sometimes its hard for me to split myself between them she can become aggressive
- Would prefer a professional to give short break as, it really does not give foster carer a break. As always on call. This child does not access anything outside of carers family.
- Sometimes my son will not go with the PA. But he enjoys going to the youth group, when its available through KIDS.
- We did not know we were entitled to support. We have never accessed any support. I've rang for an assessment.
- does not any breaks or respite
- Mum sits in café and waits
- We do need more support but unfortunately the centre's keep getting closed, and the council/government don't realise how important this is to parents/carers of kids with additional needs, it's ridiculous.
- He doesn't access anything
- Never had anything like this before questions hard to understand.
- We have not been told about this until receiving this letter.

- We only get 1 session of LAFFS a month for [Anon], refused disability social worker refused direct payments we get nothing but 1 session month no respite for us & I have lots health needs now so could do with more
- n/a
- Wasn't aware of short breaks for help
- no P/A Don't know services
- short break is only 5 hours per month still relies on other to take her out or she can not go out on her own she struggles to entertain herself in the house
- like to be around friends with the same hobbies and likes
- not aware of services available
- always indoors or constantly watched as over friendly no sense of danger or stranger awareness
- I don't think that 5 days a year is enough.
- As my child is getting older he is requiring more mental stimulation due to his as pergers. He enjoys LAFFS but it only every 2 weeks and term time.
- never heard of them
- My son only goes out with us as a family he goes to Rugby and football and we also go on day trips. Holiday once a year. We pay for all this
- my son does none of the above
- Myself I do not have the money to take a break the only time I did was when kids gave us a short break payment. Stopped because daughters 20 years. [Anon] dosent have money left to be able to pay someone to take her on a short break.
- We receive one Saturday a month but by the time we've dropped off and picked up doesn't give much time for an activity with the other children.
- When [Anon] was younger, he received the higher rate, I then stopped claiming. I don't claim anything me and my partner both work full time I haven't been offered any of these or I wasn't aware of any.
- I would appreciate some time to unwind alone in my home as [Anon] is very demanding all the time and when she is at school I have to go out to work, also being able to spend quality time with my other kids.
- Not meeting needs at all.
- we have no help at all!
- as my son is now 14 i think it would be better for him socially to attend more social activities with other children of a similar age, he would prefer to stay at home but with the right encouragement he may come out of his self, this would help him with his independence.
- Not accessing - not aware off services
- Not been told about
- My daughter won't have a break because she wont leave me
- I feel that he should be able to get more respite, or activities he can do.
- N/A
- n/a
- IAFFP once a month 4 hours Kinloss once a month Sat afternoon till Sunday 1pm
- We need a short break from each other
- Because I have to be there together with my son. It means I have no break
- Gives me time to catch up with family and friends and rest from constant anxiety of when he goes out with friends, I have to use GPs on his Iphone to know were he is and, he has to regularly ring me to check in.

- We would like to be able to go away for a weeks holiday a year without caring
- YES and NO ticked both as although the activity and time is enjoyed she would love to do more without her parents we find all we do is catch up on jobs so don't feel like we have had a break!
- not enough suitable for his age in the school holidays. Needs to attend with a parent / carer sp preventing him socialising, improving confidence and being independent
- not long enough and in the holidays she could do with more
- we have never together as a family been offered or even knew about this service!
- Haven't ever had a short break as found it impossible to get one due to lack of facilities/support available
- None available
- Swimming every other Saturday does not meet the need of my son's short break because we (his parents) have to drive him and his PA to Haltemprise from East Hull and pick him up which takes off about 2 hours from the four hours he is scheduled to have.
- Would like to spend some quality time with my husband.
- But I wish it would be more.
- Don't have any short break activities apart from visits to local parks
- He does not use short breaks
- Our child doesn't get any support, apart from TA's at school and a bus pass.
- Only once per year - 2 nights not flexible
- Direct Payments £20 HRS a month. 3 extra each week when holidays
- No has we can't get him anywhere as we have younger siblings 2 and younger! And with him been 17 and several learning disabilities who needs one to one. It's hard to get him places that meet his needs. I asked for a social worker, to try and meet his needs and was told we can manage!!! Disgusting by lad has to miss out out if my sister can't get time off work! As I work too after school! It's a joke! As the things he can do my younger children can't!! It's so unfair
- N a
- Na
- 10 hours a month on no sleep plus working full time and having a severe physical and learning disability child is not enough
- We don't get enough hrs so rely on my mum who is 65 to do some of the respite for free
- Only once per year - 2 nights not flexible
- No enough hours lads is once a month
- We do not receive it
- Never been offered any breaks.
- We are funded for 20 hrs per week but only receive 3 hours per week. This is through continuing care and not Hull CC. That 3hrs is not decided by us and the day changes weekly, decided by the care company. It's not fit for purpose and certainly not family or child friendly. It suits the needs of the care company only, not ours.
- We would like/benefit from more than 1 in 4 weekends.
- I find it difficult to get my son to take part in activities they meet his needs
- Does not have access
- Single mum with two send children one wakes early one goes sleep late. I get no short break support never been offered it

- Our short breaks are always as a family and sometimes are just a ride out to bowling or for dinner or little things it would be nice to have a proper break away somewhere away from day to day life
- She has never been on a respite before.
- My daughter attends a daytime activity and movie/disco nights 2 nights a week. My son 12 also attends laffs one day a week in the holidays. We would love a break respite for an overnight to have a break away from them both at the same time as we don't have any other options available to us.
- I'm unsure on the above the question, we used to have direct payments but our old social worker stopped them. I've tried again and been turned down. We can't even get a disability (worker social). I feel that there's not anything for children. I'm ill myself and want help but you don't get anywhere.
- The service currently after school is for 2 hours and doubles in the holidays to 4 hours per week. However, L.A.F.S.S are to commence in the future to take over from the DSI Service/ Although this help is appreciated, I feel I would like an odd overnight break as [Anon] is quite disruptive early morning and late evening and impacts on siblings.
- It's the only group i know of for my son who attend term time once a week. Although the class is brilliant its not a break for either me my partner or my son!!! Nothing is advertised for children with special needs. It's disgusting that the council stop funding for groups that help sen children and their parents.
- Weve never been able to access this service
- Is still hard work because I'm with him and he's very challenging
- This is no where near enough for my child or me. Its actually useless as each month she becomes anxious as she forgets who the staff are so I often have To go settle her which gives me no time with my other child
- There either too young Thier too isnt a dsw to do a direct payment for him Not enough funds
- My eldest child has Autism. We have never been made aware of any short break provisions for him despite being referred for a DSW through school when it became obvious he was really struggling with general anxiety in the school enviroment, leading to demand avoidance and emotional meltdowns. We as a family haven't been offered ANY support what so ever to meet my child's needs nor have we been asked if we require any further support. Dealing with our child's disability means it is difficult to access family activities as a whole family and I feel like much of our attention is taken up by meeting our eldest needs rather than distrusted equally between the 3 children.
- My son is autistic and he is a runner. I have been waiting to get direct payment for a year. I got told he was to young for them when he was 4 but I have now been waiting for assessment for over 8 months now.
- More services need to be made more well known. My son was diagnosed with autism in January. Only to be left and nothing had been offered to us and when we try to follow up with our school special needs coordinator she has no idea about groups of other autism parents or to socialise with other autistic children
- We've never been offered any help of support since diagnosis. We just struggle on and have done for 4/5 years. When we completed an after school club form my daughter was given I was told she actually couldn't take part back there was no funding for the support she would need. This was heartbreaking as all her friends were telling her about these amazing things

and how she should join them and there we are having to explain she can't through no fault of her own.

- The times are a bit awkward and we don't have anyone for night time
- We haven't been offered anything. We get very little help
- I have 2 autistic children and don't receive any help with short breaks, it's hard to know where to look.

Q7 Please tell us what type of Short Break your child/young person needs but does not currently access?

- KIDS play scheme (Summer)
- KIDS play scheme
- Never been offered any.
- KIDS
- 1 week with KIDS (5 days)
- They do not access short breaks going swimming with mum and grandma
- been playing 2 years
- They do not access short breaks Sporting and leisure activities (e.g. football, swimming, dance class) Social activities with other young people/friends (e.g. movie night, bowling)
- Jack has no activities at all
- LAFSS once a month (4 hours), twice a week in school holidays and limetree 8 hrs
- LAFFS days out
- LAFFS + Direct payments.
- Drama class
- overnight break in Sunshine House
- KIDS only if he goes.
- overnight break
- 12 hrs per month for a P.A
- Attends active day care Mon and Friday/care on Wed.
- NONE
- KIDS
- LAFFS - Bellfield centre
- only 5 days at kids club
- Never knew about them
- LAFFS once a month
- grandparents look after my son at home
- *Dance class - mum used to stay but have been told parents can't stay.
- Overnight break
- LAFFS
- Overnight break
- Overnight break
- over night break
- overnight break
- School outward bounds
- We have never been offered any activities
- dont get any help
- only spending time with parents.
- Duke of Edingburgh (Silver)

- Overnight respite
- Nothing at the minute as we can't take him
- Never heard of any
- Direct Payments allowing us respite and the ability to work instead of claim benefits
- Duke of Edingburgh (Silver)
- overnight break
- Overnight breaks
- Overnight breaks
- Overnight breaks
- activities with his family
- laffs
- ive never been informed about short breaks
- could only tick one box
- Kids sensory group
- 1 overnight per month
- Can't tick all that apply as this question is a single choice option.
- Over night respite with activities
- Direct Payments, Sunshine House

Q7a what is preventing your child/young person from accessing this activity?

Other please state

- gets frustrated - left out
- See above
- and will let my children on away with out me and am not to show that like him to go away from use.
- We have no support which means limited access to things
- have been trying to access the running club but not getting any response
- not offered at school
- soft play - been cancelled had recent bereavement too find it difficult in noise
- Access to buildings due to my health and mobility conditions
- [Anon] has one to one at all times.
- Nothing has ever been offered for [Anon] need a lot of help and support in doing everyday tasks, very vulnerable at all times.
- Very active all the times. Just to let of some energy and to move him forward in life and everyday needs."
- Don't want one as been but left she like to so at with me to places at weekend
- Never been made aware of this service despite having previously asked social care for assistance.
- service no longer available
- There isn't much activities for disabled children to do during the school holiday's, as trying to do the normal things children would do like bowling, swimming, cinemas, are packed out and huge lines to wait in, that is a big problem.
- The PA's seem to make excuses up not to swim or forget there swimming kit.
- Other siblings so alternative divided
- Services are being cut all over due to funding and lack of unwilling to learn how many parents with special needs kids/teenagers and adults are in the council area, and

council/government are unwilling to support, leaving those who really want to help are left to struggle to support this network of carers

- Wont go anywhere without me (mum)
- Was turned down for direct payments we only wanted a few hours a week was told no as we apparently manage to well my mum can no longer help ads much due to own health & dads dementia
- "Single parent with 3 other children.
- 2 others also have speech + hearing difficulties and learning difficulties."
- [Anon] younger brother needs additional care and still uses a pram.
- [Anon] has trouble communicating with others so gets upset when people don't understand him.
- too young
- My son attends limetree court which is temporary until we find a member of staff for direct payments and has been such a nice experience the staff are lovely and what a difference I feel as a parent I have even got a job and feel part of society again
- not currently receiving anything
- "3 other children at home 2 of which are special school
- one parent family"
- "Social activities with other children overnight breaks.
- social outings with other children"
- I STARTED LOOKING FOR SOMETHING EARLIER THIS YEAR
- nothing in our area that caters for downs syndromes no clubs, no support for [Anon] needs!
- my son can have accident s and does find this embarrassing
- I would like my son to do dance street dance swimming exercising clubs
- my son is not very good in large groups and struggles to let you know what hes feeling and what hes ok with
- Any groups that [Anon] could attend would be great in college term or after he already goes to a club on Tues evenings which he loves any more or through day would be good.
- Disability play group was stopped due to funding
- doesn't like noisy hectic places limited on things to do due to ability and interests also not a lot in local area have to travel
- we have never been offered anything
- my son needs full 1 to 1 support for all his needs
- she wont leave me
- I had KIDS but had that taken off me and they give me info on bits, but not everything. I feel my son is getting held back as I don't know anything that I could do with my family.
- Currently not got access
- "full when apply.
- Say does not need the help awaiting further assessment"
- Lack of mnolers tomoling English from parents and lack of help for my son [Anon], lack of social of social worker
- I [Anon] has a school stamens band 4, on his recent assessment from the child psychologist his learning age 10 that of 8 to 9, also could be prone to be easily lead and vulnerable
- I'm told we can't access this
- i am always told she is too young - needs to e 8+
- we didnt know anything about this service and would like to find out more

- We only know of respite - which includes over night stays, this is an hours drive from us - and we don't want our child staying out - risk issues and vulnerability - not enough trust.
- Been trying to get extra help but been refused due to funding?
- As with Q7 +Q7a
- [Anon] does not have away disabilities
- We have never been offered anything like this but if available we would like to know.
- He needs 1 to 1 supervision at all times
- Lack of friends to join in activities with.
- Because I work and my parent is with the children. But because my lad is 17, and needs support in all areas it's hard for us to get him anywhere. And his siblings are so young they need to go to bed earlier.
- My daughter has seizures every night to know she has someone looking after her all the time
- Do not meet criteria allegedly
- Lack of funding from the council, we have asked twice for more hrs and we have been denied them
- Lack of friends to join activities with
- No funding
- I didn't know this was a statutory duty of the council! We've had one short break accessed through the young carers fund before our eldest children turned 18 but never accessed or heard of anything since that (4 yrs ago).
- I could tick all of the boxes above but the main one is knowing if anything available
- "Do not know how to access activities
- Nothing in my local area"
- Nothing in my local area
- Never been on one
- Never been offered overnight, and I am unsure how Sophie will react to it.
- Could only tick one box - there are a number of reasons
- Most of the above but it only let's you select one
- "I could tick a few of those boxes nowt in my area needs more support on one to one level has communication difficulties and is also hearing impaired"
- He needs encouragement to leave the home and do activities.

Q7b When would this Short Break activity be most useful?

- and after school
- to get him out of the home!
- Out of college time in college time. Even a weekend (Swimming)
- support at home
- During the week, during the day During the week, during the evening During the weekend
During school holidays Overnight Anytime
- During the weekend During school holidays
- not overnight
- no overnight.
- don't
- Whilst I am at college someone to be able to collect my son from school or wait for him at my house and wait/play/give some tuition until I return from college (1-2h) or work.
- to bond better as a family
- any week

- a mixture
- Evening, and school holidays
- Monday to Saturday I work shifts my husband works 7.30-4.30pm we also have to work Saturdays
- but in close to home
- during school holidays (A must)
- again only one box - there are a number of times it would be useful
- As I have stated during school holidays and school term

Q9 Please tell us anything else you wish us to know about Short Break activities

- i would like to know what is available
- if direct payment are cut i would be forced to give up work and claim carers allowance, im sure [Anon] would like those who can work to work!
- If direct payments are cut I would be forced to give up work and claim carers allowance, I'm sure [Anon] would like those who can work to work.
- I would like to know what is available.
- What suitable activities/short breaks are available to us in our local area.
- This should be provided for free by our local council. We already contribute when we pay our council taxes.
- think a booklet should be produced and given out to all special schools and disabled children or need of help
- any information would help as in East Hull there is no were i could leave Jack and let him stay safe
- I dont know much about Short Break activities. Its hard to find out information about Short Break Activities and what available.
- It would be nice to be able to find out what support is there, due to things getting worse with mum + Dad and help Jack to have an understanding in life, we feel more help could be put in place to help use have a break and move Jack to where he needs to be.
- The agency gets paid for me to have respite that I don't get they could pay.
- swimming activities more available, special stars play group - not age appropriate I pads used needs interaction
- I am a parent of a teenager of whom I'm filling this form out, I can honestly say I would not cope very well without the short break and respites support and I can also say this regarding other parents too.
- any info
- no - can't access
- My son does require adult supervision at all times due to his behaviour, he finds it difficult making friends.
- I have a 10 year old daughter some time for her and her brother to do together I don't mind helping towards cost
- [Anon] is 20 years old and loves going away or to Sheffield etc. Meadow Hall. But I don't have money to pay anyone to take her or pay for her a weekend away and she doesn't. There are no clubs or anything where she can go and fit in.
- Used to have respite on Friday - have 2 other children - don't get breaks with working and school runs.
- More information – sign posting from people had to find out from friends.

- I would like to know if there is any activities I could do as a family on a weekend, either on outdoors or sensory.
- Any information is much appreciate.
- if we could afford we would already be paying someone to support our child activities over and above the short break time already received sadly we cant!
- What is available/accessible? Who is entitled to the short breaks?
- Whilst these services would not make up for the complete lack of respite facilities it would offer both carers & young people constructive respite opportunities.
- I already pay for the entry to activities and fuel to get to each event but these are all special needs supported events.
- Do not cut funding for services to disabled children and their families it's already not enough.
- Whilst these services would not make up for the complete lack of respite facilities it would offer both carers & young people constructive respite opportunities.
- Not enough places to attend regularly
- Please tell me everything about short breaks as we literally know nothing! What is there for a 7yr old in Hull?
- Never ask before.
- What is available to us.
- I feel as though its only certain families that seem to get things. It should be available to all families.
- Any type of short break will be considered. I feel her behaviours are worsening, and would like Sophie to experience new things.
- They need to be advertised more. As a mum to a child with special needs I don't know anything about what is out there for my son. And the places I do know about are been cut because the council
- Should be more available our kids count as well and should not be overlooked because of a disability. As a parent I strive for my child to become a member of the community I want him to have self worth and feel a sense of belonging not have to contend with small minded people who think my child should not be allowed to join in because of his difficulties with the right support he can achieve he has lots to offer just not got enough opportunities to try things. Funding should not be cut for the vunreable it is appalling to even contemplate it These children should have all the same experiences and chances in life as their peers without a disability stripping funding even lower is disabling my child and others more than the disability they were born with.
- Not enough spaces at places like limetree! My daughter needs weekly respite in a familiar environment which can't happen once per month
- I'd love to know what's available and how to access it.

Appendix (iv)

Focus Group Feedback

Chart 23

Was the aim of this session clear?
(n=21)

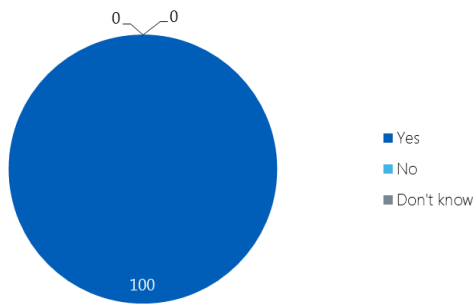


Chart 24

Was it clear how your views and experiences will be used?
(n=21)

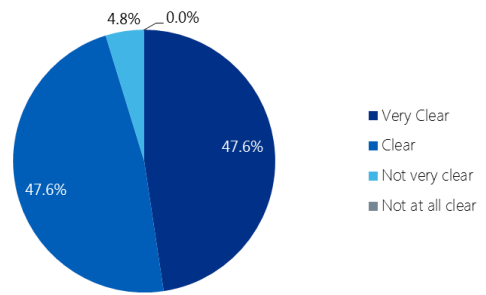


Chart 25

Were you able to give your views in a way that you felt comfortable
(n=21)

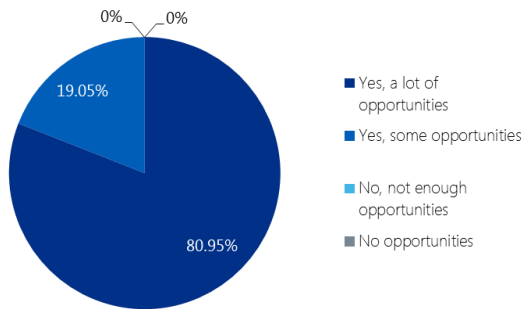


Chart 26

Were you able to give your views in a way that you felt comfortable
(n=21)

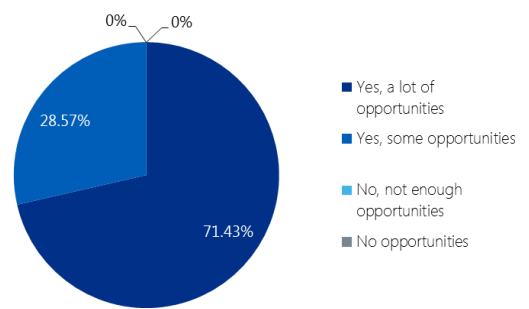
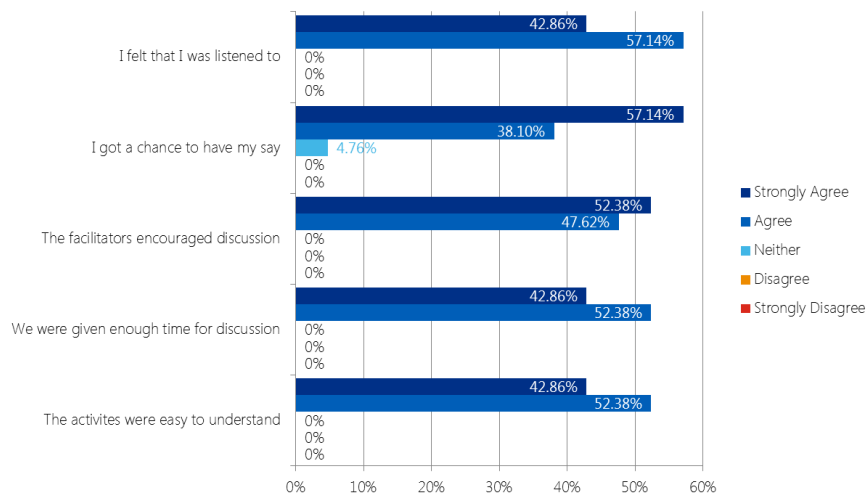



Chart 27

How much Participants agreed or disagreed with the statements about the session
(n=21)




Appendix (v)

Focus Group Activity 2



Hull
City Council



NHS
Hull
Clinical Commissioning Group

Short Breaks Focus Group

What do get you out of a short break?

What would you like to get out of a short break?

What does your child get out of a short break?

What would you like your child to get out of a short break?

What do you get from

- I get 2 hours a week at a time and on a day specified by the care provider, we are funded for 20 hours per week, we've had 5 carers in a year and no consistency, i get a short chance to Hoover the house or have a wee in peace but that's about it, i certainly dont get any downtime or chance to spend time with my other children
- I get 6 hours a week and have to use this time to do shopping and other bits
- A break to recharge mentally and physically
- Social emotional wellbeing

- Rest
- Knowledge my children are having fun and time away from me
- Physical break, maintain health enable sibling to attend his own activities
- Not accessing
- Don't currently access
- Not currently accessed
- Not currently accessing
- I don't get one
- Don't get one but would give me time to myself or time with siblings
- Never had access to short breaks (not allowed)
- I currently don't access short breaks
- Time for myself and others
- Head space
- Time for me to relax
- Time with other siblings
- Chance to do thing with sittings
- Time on our own
- Time to catch up with the housework
- Meeting other parents
- Some free time
- Ability to socially interact with peers
- Social inclusion
- Sleep like a normal person
- Knowing that my children are experiencing new activities
- Maintain critical wellbeing without this support i would be unable to continue to care for my child
- Even though my son has DLA and EHC plan
- Children - Lafss -every fourth week on Sunday
- Quality time with other kids
- Time with the wife
- Chance to have my quality time
- Been able to do things
- Time to catch up with friends
- Time with son on his own
- A break away from my child
- Quality time with partner and other family members
- Enables me to work and continue career maintain our standard of life as a family
- Recharge myself so i can look after my children
- Time with other 2 children
- Being able to shop without worrying
- Chance to do things which may be difficult with Hannah / Sam like shopping
- Time for me -getting a massage
- Some me time

What would you like to get from

- SLEEP!!!! and to have a break from going up and down in lifts or walking over drain covers
- I would like more hours to spend more time with my children

- To know i can relax whilst my child is being cared for in a safe environment
- Increase in hours 3/4 a week more to lessen the pressure on my mum who is 65
- For enough care to support all my children who are disabled not just one
- Time on my own especially holiday time
- Help in the home with nursing/ physical care e.g. mornings, bathing etc.!
- Feeling that the child could be socialising with his peer groups
- My time isn't that important but it would enable some planning for the future
- Time to do things on my own, with my other children
- School holiday 1 weekend time
- Rest to be able to carry on caring. to be able to work
- Better home environment
- Activities for my son to access like swimming, karate and active things
- I would like to get education, but i cant because there is not childcare appropriate for my son
- Full support for all 3 kids
- More time to my self
- More short breaks
- Time to go out on an evening
- Free time

What do your children get from

- an uninterested carer on minimum wage
- my child goes out on a 1 to 1 he goes where he like to go
- interaction with other
- social inclusion
- to be taken care of as he needs to be, extra therapies etc
- new experiences
- seeing peers would not otherwise be able to go to a sleepover
- he would create friends
- friendship, independence
- to be able to access activities with other children to build up his social awareness, independence without the need for his parents to always be with him
- if he got he could be able to access special group
- they would if got one mixing with others doing activities
- ability to cope better
- interaction with other children and different experiences
- his own space and time out
- time with friends
- time spent with friends
- can socialise with other people same age
- join in with other people
- fun, happy times
- socialise in safe environment
- fun
- new experiences
- new experiences
- access groups, socialise with peers
- time on his own in his own space

- activities she would not normally be able to do - summer camp
- he would have time away from home
- time to enjoy with other children
- learn new skills
- they enjoy would give them time out from us
- opportunities I can't give him
- sense of independence
- lots of support
- meeting with other children with the same behaviour issues and learning difficulties
- have fun
- time with friends
- make friends
- maintain living standards
- learning how to behave in his other situations apart from been at home (out in public)
- independence away from family we will not always be around
- he would benefit from extra social interaction
- spending time with others
- enjoy the activities
- interesting places to visit
- time away from me
- engage with people with same ability

What would you like your children to get from

- some time with someone who cares like we do
- to be able to go to mainstream groups
- to be happy safe and secure whilst away from home
- for the above to continue do not cut short breaks!!
- to be like a normal child
- fun and opportunities
- emotional support physical assistance
- some social interaction with his peer group
- if he could experience the above it would be very pleasurable for me
- space away from his brother who is also autistic, engagement and fun
- find some long lasting friendships
- he gets all his needs met
- longer break/more time away from parents
- groups needed for over 18's
- to enjoy it and be happy
- fun enjoyable activities
- time with friends

Appendix (vi)

Focus Group Transcripts

Friday 18th August 2017, 6:30pm – 8:30pm.
LAFSS, Belfield House, Middlesex Road, Hull HU8 0RB

8 Participants

3 Facilitators Colin Hurst, NHS Hull CCG
 Becky Colton, Hull City Council
 Natalie Jackson, Hull City Council

Activity 1 feedback

- S1** All right. Okay. So, time up. How did you do? Did you have more good than bads? About the same? About the same. Jolly good. Right. Okay, so, we're going to spend about 10 minutes combining them both. So what we're going to do is we're going to group together the good ones and the bad ones, because there will be similarities. Okay. And we're going to be anonymising as well. So, if you said, "Green Trees is fantastic and Ethel was brilliant," we'll take out Green Trees and we'll take out Ethel and then, we'll need to know what made it brilliant. Because what we're doing is we're getting what makes a short break good? What makes a short break, as it stands, bad? Okay. So, shall we start with the bad? And we'll start with you guys. We'll go one at a time. So, first bad one.
- S1** How is that a short break if they don't get a break? By the time we have to take them then, we have to pick them back up.
- S4** Okay. Right. I'm just going to write these rather than (Overlapping Conversation).
- S1** You need a piece of paper.
- S4** Yeah. (Overlapping Background Noise). (Overlapping Conversation). I mean, that's right. Well, we can make a note of it. Is that just one is it? All right that's fine. (Overlapping Conversation). No, we'll be all right. They're all on separate pads they'll be all right. Yeah, brilliant. Very good. So, traveling between things means you don't really get a break. Have you got a bad one? Similar or different?
- S5** Cost can be expensive.
- S4** Okay.
- S5** Like my daughter goes to special Olympics. She's in the nationals and the game last week that cost like £300 for her to enter. Then there's the kit, if I'd have paid full price for the kit then that would have been another £300. So, the cost can be quite expensive for some clubs. The actual cost for her to go and train every week isn't that bad. Don't think I'm complaining. But for her to go in the big competitions, it's very expensive. Like if there's a hotel fee, you've got to pay for that. If there's a travel for her to get there, you've got to pay for that. Bethany loves it, don't get me wrong. If you ask her, she's got some ribbons from last week. But the cost, it can be really bad. (Overlapping Conversation).
- S4** Cost.
- S5** Yeah.
- S4** So, you're saying that like some cost is inevitable but sometimes, it can get quite bad.

- S5 Like for her to train every week, it's only £3.00. So that's not too bad. But when it's the big competitions, it's ridiculous. There's the World Summer Games coming up. That's going to be close on to £2,000 for her to go...if she goes. If she gets chosen.
- S4 Yeah.
- S5 But it's in Abu Dhabi, so, you've got like flights. You've got hotels. You've got all that to pay for. The club itself picks up some other costs. But inevitably, the parents have to as well.
- S4 Yeah. Okay. The travel cost. Another bad one?
- S2 Lack of funding from services due to cutbacks, e.g. transport.
- S4 Okay. So, it's a bit of both. So, that's cost. So that's kind of linked to the cost of running it. Not necessarily the cost to you, necessarily, but then the transport's been cut. So, that kind of links together. Yeah. A bad one?
- S6 I've got the age restriction, it's upsetting us that it does (Overlapping Conversation), it does finish at usually 16 but obviously youth clubs finish at 18.
- S4 Okay. So it's that upper limit that's the problem.
- S6 Yes. And after 18, what comes then?
- S3 Between 19 and 25, there's like...there is things going for them, but there isn't a lot out there at the moment. So, it's a sort of standstill. Get all the help till they're 18, or you eventually find help for them when they're 18. But then, it just stops. And they've got nothing to (Overlapping Conversation). And that's when [inaudible 00:13:52] disco nights. It gives that little bit of an age range. But they stop at 21. So, when it gets to 21, it all stops for them here. And then, they've got nowhere else to go. Because obviously they can't go out to pubs and stuff. I think they need to be in the right environment for them.
- S4 Yeah. Okay. Very good. Another bad one?
- S5 Get a social worker. You either get one because you think the child really needs one. I mean, really, really needs one. Or if your child's [inaudible 00:14:26] don't need it or even they do, you can't say anything. Because they say that you don't need it. (Overlapping Conversation).
- S6 And they're saying that because your child isn't bad enough, you can't get a social worker. If you don't need a social worker, you can't get a break for anything.
- S2 Yeah, you need that to get your short breaks, don't you?
- S3 To everything.
- S6 I was going to say, my son he's got a social worker for three months and they're all part time as well. And when we need to get hold of the social worker, they're not there. And oh, yeah, we'll leave a message for anything else. But they don't get back to you whatsoever.
- S2 It's [inaudible 00:15:08] if you had a problem. Because that's where we found [inaudible 00:15:11] sometimes when you phone up the places, I've been told, "Oh, it sounds like your child he don't need the service." And it does, and you've got to fight people at the beginning to get [inaudible 00:15:22] services. (Overlapping Conversation).
- S2 It's like what you just said, it's like the environmental factors that stops them going to mainstream. It's the environment. Yeah.
- S4 Okay. Next bad one.
- S2 Not always located within your area.
- S4 Okay. So, it's kind of linked to the travel (Overlapping Conversation). We'll put travel.
- S2 There's loads of things we need still (Overlapping Conversation).
- S4 Okay. Brilliant. Okay. So, how many more bad ones have you got?
- S6 One, two...we've got (Overlapping Conversation).
- S5 It's hard to get a budget for a PA.

- S4 Okay. So, similar to funding.
- S3 So, it's weeks (Overlapping Conversation).
- S4 It's a bit like the getting a social worker. We'll put that there. Smashing.
- S2 The times can be difficult. By the time like you get home from work, school, college, et cetera, then, they close.
- S4 Okay. So that's similar to...well that's a bit like travel.
- S5 Put the transport one down. (Overlapping Conversation). (Laughter). The paperwork. The paperwork you have to fill out.
- S4 Okay. So, it's kind of accessing services. Yeah.
- S2 To try and get people to [inaudible 00:16:41] in.
- S4 Okay.
- S6 There's so much paperwork you have to fill out with all the clubs and stuff that we go to. I know it's necessary paperwork, but there's so much of it.
- S4 Okay. So, kind of do it a bit of it simpler. Have you got another bad one?
- S3 Not always there and (Overlapping Conversation).
- S4 There's not enough information. Very good. (Overlapping Conversation).
- S5 It usually [inaudible 00:17:15].
- S4 Have you got any more bad ones?
- S2 Yeah. Trying to get PA's for your child's needs.
- S1 Yeah. So, we've got PA's already.
- S2 And it's...some children come back from the groups hyperactive. So, when we have to calm (Overlapping Conversation).
- S4 Okay. (Laughter). A bit of a happy by product. (Laughter). Put that with the access. Okay. Have you got any more bad ones?
- S2 No.
- S4 No? Good. Well that wasn't so bad actually, I thought it would be worse. Jolly good. So, there's a couple of duplicates here. You all seem to agree that there weren't any that you were like 'oh I don't agree with that' you all kind of were in agreement with those. That's fair. Good. All right, good ones.
- S5 Parents get a break.
- S1 Parents get a break. Jolly good. Good one, from you guys?
- S2 Yes, just writing it down separately. (Overlapping Conversation).
- S4 Very good. Whilst you're doing that, I just want to tell you about free parking. We haven't got a huge amount of time. We don't encroach on your short break time. So, we're only going to cover very specific things. But if there is something that's particularly a burning issue, we don't cover it. It's completely free and open. So, you just put it on there. We'll take it away and find out the answer or try to support you. Okay. But we just park it there. So, otherwise, we end up talking about...We're not trying to solve everybody's problems. We're not going to be able to have time for that. So, I forgot to say about that earlier. So, good. Right. (Overlapping Conversation). Shall we go through some of your good ones? First (Overlapping Conversation).
- S2 (Overlapping Conversation) safe environment.
- S4 Safe environment. So, what do you mean by a safe environment?
- S2 That we know we can leave him and that they're safe and they're happy with the staff and that they're not going to rebel and escape. Yeah.
- S7 They're supervised.
- S4 So, they're kind of qualified to look after them. Yeah. (Pause) Smashing. Next one.

- S3 They enjoy themselves.
- S4 Yeah. Kind of flipside of that earlier, didn't we, when we...
- S3 The kids enjoy (Overlapping Conversation). (Laughter).
- S2 Able to socialise.
- S4 And a lot of the kids in the same situation?
- S3 Yeah. They're allowed to socialise with everybody else, don't they? With their abilities sort of thing.
- S4 How are we doing on the (Overlapping Conversation)? Are you all right? (Overlapping Conversation) very good.
- S5 Parents can give lots of information to others.
- S4 So it's a bit of a support network for you guys. Yeah.
- S3 Feedback. (Overlapping Conversation) (Laughter). That one.
- S4 That's great. I'll take that. (Overlapping Conversation). We'll get back to you again.
- S6 We've got parents can have a bit of support. Support each other.
- S4 That's similar. Yeah. We'll put that as similar. It's kind of that group there.
- S6 Is that it?
- S2 Yeah, that's it.
- S6 Right. Okay.
- S4 Any more?
- S2 That's it.
- S1 The children get a break away from the parents and carers.
- S4 Okay.
- S3 It gives them that, a bit of independence, doesn't it, away from home.
- S4 Smashing. Any more?
- S2 They have fun.
- S4 I think we've got fun. Yeah.
- S2 Enjoy themselves.
- S4 Enjoy themselves. Yeah. Any other benefits that you guys can think of? It doesn't matter if you can't. We've got time today.
- S3 Well, if they go on breaks, they get to see a lot of different places, don't they?
- S4 Yeah. So, experience things they wouldn't. Yeah.
- S3 And it's like [inaudible 00:21:40] days out. Yeah.
- S4 Smashing.
- S6 They can just be themselves can't they?
- S5 Learn new skills.
- S4 So is that the kids or is that you guys?
- S1 The children.
- S5 Well, I suppose we can (Overlapping Conversation) (Laughter).
- S3 As a PA, I can sort of like help. With like [Anon], I can help them be a bit more independent and pay for things and stuff like that she couldn't normally be able to do.
- S2 Being able to pay for things.
- S3 And you help her social skills as well.
- S5 They're more likely to learn from a non-parent as well.
- S3 Yeah, and she does from me. Before, she just used to walk into people. And I was like, "No, [Anon] you've got to let people pass." And now, she does that. She pulls herself to the side. So, she's getting that social. With a PA, they get that...
- S7 Life skills.

- S3 Yeah, the normality as well, being amongst people that you know.
- S4 Smashing.
- S3 Haven't got special needs. They can learn that way. Yeah.
- S2 Smashing. Okay. We're going to leave those...we're going to leave that for now. We may well come back to them in a bit. Something similar. So, the next thing that I would like you to do. So, this is something to do on your own. I've got some more sheets for you. If you want to pass those around. It's one each. So, people who didn't write earlier. You'll need a pen. There's an envelope there. So, what I want you to do is [inaudible 00:23:37] as well. So, on the...

Activity 3 feedback

- S4 Smashing. If you're done, I'll take it off you, if it's all right. (Pause) Yeah, [inaudible 00:28:28]. (Overlapping Conversation). (Laughter). Smashing. (Overlapping Conversation). Right, okay. While you guys are finishing off...the last workshop, what we're going to do is we are going to...and you've seen this before at the car wash places, you know, the hand car wash places. There's a big sign outside that basically says for a fiver we'll wash your car, for six quid, we'll wash it and polish it, silver grade we'll wash it and polish it, all that. So, you can see this all over the place now. So, this is a list of things that we're going to do. So, what we're going to do, first of all, is just write a list of things that a short break should be. Okay. So, a car wash, these things should happen. So, what things should happen with a short break? So, it's quite general. And what we're going to do is we're going to say...we're going to work out what a bronze, silver and gold is. So, what you must absolutely have in a short break, that's your bronze service. So, silver service bit extra, gold service bit extra. Okay. So, does anybody want a drink, nobody has to go to the loo or anything like that? Good. Okay. So that has been described for us. So, anybody. First thing, off the top of your head. It doesn't need to be complicated.
- S1 Staff should be trained.
- S4 Staff should be properly trained. So, staff should be properly trained. We can use some of your good and bad things as inspiration? Would that be helpful? Yeah. So...
- S1 DBS checked.
- S2 DBS checked. Okay. So, the bad things first. So, (Pause) one of the things you said was bad was the paperwork is hard to understand. Filling out forms. So, in an ideal world, how would it be better?
- S6 Use easy words to understand. [inaudible 00:31:11] on there, no technical language.
- S8 Forms come back to Hull City Council. Can't we just do one that covers them all?
- S4 That sounds like an eminently sensible idea to me. (Laughter).
- S8 Just one form [inaudible 00:31:27].
- S4 One central form. Yeah. (Overlapping Conversation).
- S2 And sharing of information.
- S1 Yeah. Groups talk to each other [inaudible 00:31:43] place to place to place. So why don't they just talk to each other?
- S2 So both paper and discussion.
- S4 So, you're saying that you do all the kind of running around.
- S6 If you're [inaudible 00:32:00] that place that you can get certain things, and then, you've got to be at a certain other place to see where it's heading basically. Or where is it? Where's the [inaudible 00:32:10].

- S4 It's a bit like you were saying with the transport. So, there will be things going on but then, there's no transport. So, you have to arrange for (Overlapping Conversation).
- S6 You have to arrange for transport. You have to arrange your stay. You have to arrange education see where it is and why it ain't got back to you and why the college...and college say 'oh it'll come back through them' the transport saying 'we'll sort it'. And it never happens to be honest.
- S4 So, plain English forms and more sharing information. Very good. So, what else should a short break be? Also think about the things that you wrote on your sheets and your envelope that you want to get out of it. How (Overlapping Conversation)?
- S6 It should be fun for the children and the staff should be really good, entertaining sort of staff, you know fun staff which makes...draws the children in to keep going.
- S3 If you have staff which are miserable, the kids aren't going to go. So, if you have good fun staff.
- S6 Yeah.
- S7 And they should be understanding of the kids' needs.
- S6 All abilities across the board. And every child is different, and they're not all the same.
- S4 But there will be similar traits and similar conditions and those kind of things.
- S6 But not all the staff understands most of the kids' needs, either.
- S4 So that kind of rapport or relationship with the kids.
- S6 Yeah, fun and friendly, sort of staff doesn't it?
- S5 If they have a meltdown, they'll be able to calm them down.
- S5 So, how would you...
- S6 Staff training.
- S4 Staff training. So, it's not about them seeing the same person regularly. It's more just about them being trained to be able to cope with the situation. Okay. Good. So, we've got quite a lot around staff. Needs to be fun for the children. So, what about you guys? So, from your point of view, what was...?
- S6 It gives us time spent with the other children, with the brothers and sisters.
- S5 And also, it would be nice to have things central rather than at one side of Hull [inaudible 00:34:14]. So, everybody can sort of access it easier. And if it's on a bus route it would be a lot better. Because things like last is we all have to have cars to get here. If I were to put him on a bus, it would take me an hour and a half from West Hull to get...and it would take me two buses. But if it was like on central and it was near a bus stop, then, the kids could get on one bus ride. In the summer time, they might be able to access them by themselves when they get trained up on the bus route, and that would give the parents a bit more a break because it affords them a bit more independence as well.
- S5 There used to be one, years ago, there used to be one that was Central Hull. It's not there anymore. It used to be called Active in Hull. That was Central Hull. That used to only be one bus route. Through government funding and everything. It's not there anymore. That was Central Hull.
- S4 Okay. So, where across the city are you guys from? Are you all from different parts of the city?
- S5 I think I'm the furthest one. I'm near KC Stadium.
- S4 KC Stadium area.
- S6 East Hull.
- S2 East Hull.
- S8 Here.

- S4 You're from here. Okay, good.
- S8 I'm on the road on [inaudible 00:35:26]. (Overlapping Conversation).
- S3 I'm East Hull.
- S4 So, it's mainly east because of where it is. It makes sense. Thank you. Okay. So, we've got well-trained staff. We've got fun for the children and we've got central. It gives you time with the other siblings. Is there anything else? Is it just time with the siblings or is it more time to do for you or...?
- S8 From my point of view, yeah. Hannah has a problem shopping. She doesn't like shopping. So, we use that opportunity...
- S7 Do things.
- S8 Shops you know.
- S4 Little shops.
- S8 Yeah. And it just makes a two hour a half hour shop. (Overlapping Conversation).
- S4 Okay. So, to kind of get on with other things.
- S5 Because I have two children with learning difficulties I'd like to spend time with my husband without actually having them winging at me. (Laughter).
- S2 And to get that extra time being with your partner or your husband. There isn't anything there. It's always the child or whatever or we're at clubs. It's always a discussion about them isn't it, than about anything else. (Overlapping Conversation).
- S8 Well it is, isn't it? That's what it is from morning to going to bed it's (Overlapping Conversation).
- S1 And you have a typical 18-year-old, they'll be out and about now. Because we haven't so we're with him all the time. We've got no escape from him. So, but they do come to these clubs, which is nice when they're like when you know, at home sort of thing and they've gone to the club it's nice you know.
- S3 [inaudible 00:36:57] city. There's no point of you going all the way home to come all the way back.
- S2 Yeah. That's where I stay now. But when I [inaudible 00:37:04] as kids, they had their mini bus. But just like the mini bus, that's stopped now. They're asking the parents to take them to Dorchester. And I do that on a Tuesday night for a music group. But by the time I get to Dorchester, I'm coming back home and then, I'm back again. (Overlapping Conversation).
- S4 So, thinking about what we're going to be doing in a minute. So, would gold service be having...I'm not talking about a limousine, but at least a mini bus, at least a mini bus.
- S2 It would be nice a mini bus, the child go on a transport thinking of the time. And it would be nice if it's local. (Laughter).
- S4 Well, that's fair enough. Okay. So, we've got well-trained staff for the children and the time for you guys, central bus routes. Are there any...what else did we say on...we've got safe environment. I've kind of already covered that. So, on the good things, you said that it was things that they wouldn't necessarily experience. Do you want to put that on there, like a bit of a description of the activity? Some of you said around particular PA it was useful because then, they could learn skills that would make them a bit more independent. Other people are saying that it's the kind of different experience, things they wouldn't normally do, opportunity for them to be themselves. So, those are some things. Do we want to put those things down or...?
- S8 Yeah. I mean, it's good for them to meet their peers in an environment without parents looking over their shoulders all the time. It gives them a sense of independence. I feel like [inaudible 00:38:47] teenager [inaudible 00:38:51] because obviously most of the children are

- too young to be out on their own. It's different. So, [inaudible 00:38:56] and the parents are outside (Overlapping Conversation).
- S7 [inaudible 00:38:59]. But she knows I'm (Overlapping Conversation). She's totally different but [inaudible 00:39:05]. (Overlapping Conversation).
- S2 [inaudible 00:39:09] disco night. We sat on another table and your daughter was over there (Overlapping Conversation). (Laughter).
- S7 But because I was there, she kept looking and (Overlapping Conversation).
- S8 [inaudible 00:39:24] in front of peers to do that, you know.
- S4 So, we're looking....we've said safe environment, independence. We kind of said that on there, didn't we? So...what do we think about things they wouldn't normally experience. Is that something that you want to put down? Would that be nice to have? It doesn't have to be essential. It can be whatever you like because we're going to grade them in a minute.
- S2 Accessing kind of [inaudible 00:39:58]. I mean, we could possibly push them around in wheelchairs or whatever out of these kind of places without the support being there.
- S4 Good, okay. I'm conscious of time. So, what we're going to do is we're going to go through these and decide whether they are bronze, silver or gold. So, staff properly trained, DBS checked. So, would we say that that is...
- S8 I would say gold. (Overlapping Conversation).
- S4 Just to be clear. So, the bronze is the absolute minimum. So, if I take my car to car wash, I'm going to pay as little as possible. So, regardless of whatever I decide to go with, I will always get the bronze package. So, the bronze packages will always be...there's no way...we can add...I don't know.
- S2 So, staff training would be bronze. (Overlapping Conversation). Has everybody got that?
- S4 We say that's bronze. That's bronze. Okay. So, plain English, sharing of information. This was around the forms and the way that you access services. Would you say that's essential? Bronze, silver, gold.
- S3 It's essential. Because we can't access the services if we don't understand them properly.
- S4 Yeah. (Pause). Okay. So, transport. To the session, wherever it might be. Do you think that's a bronze, silver or gold?
- S2 Silver.
- S3 It should be a bronze but it would be a gold once it was funding and everything. (Laughter).
- S4 Just so we're really clear. So, what will happen with this is I'm not going to go to the council and going to say, "Right. There's totally a cracking deal lads. All they want is this. And that's what (Laughter)." Because what this does is it puts the priorities in place for me. So, I can say, "These are high priority. These are nice to have. And these are..." Because the thing is...so, for example, with the transport. So, some patients are eligible. From an NHS point of view, they're eligible for patient transport. And the van goes from the hospital, out where they live, back again. They pick up the next person, they go back out. So, they could be going back and forth, back and forth, dropping the same person off, living three doors down from each other. Whereas if they just did one trip, dropped all those people off then and save themselves loads of money. So, if things like...so, although you might think that transport's a gold thing, they might say, "Oh, well actually, we've got a problem with community transport in this department. So, if we just put another five grand in, we're covering two places, rather than just one service." So, don't think what you're going to choose here is a done deal, because that's not how it (Laughter). That's not how it works, okay? So, transport.
- S5 I would say it's a silver.

- S4 Silver. So, we can make it...because one of your problems before was that you're traveling there, you're traveling back. So, some kind of deal would be good. And not everything on this has to be provided by council. It might be that there's charities or other voluntary groups or those kind of things. So, fun for the children. (Overlapping Conversation). It should be a basic.
- S3 Kids won't go if it's not (Overlapping Conversation). That's right.
- S4 So, staff are fun, friendly, understanding the children's needs. Is that the same as being trained properly? Or is that kind of like (Overlapping Conversation)?
- S3 Well it's their personalities isn't it? But it's with training as well isn't it? I suppose if we understand [inaudible 00:44:02], you can't make a serious person (Overlapping Background Noise). They shouldn't be in this job if that was the case.
- S4 Yeah.
- S2 Silver then.
- S4 We all agree on silver?
- S2 Yeah.
- S4 Okay. (Pause) Staff trained for situations. We've already kind of said staff training was bronze. So, siblings. Right. I think we should split these down. They might all be bronze, they might not be. Well, so, time with siblings, shopping. So, we said kind of jobs, other things. So, it's not kind of time spent with somebody. So, it's time spent doing something. And then, time for husband or wife or partner. So, what would do you reckon...if you had to put them in some kind of order, what would be your order? (Overlapping Conversation).
- S6 Bronze.
- S8 And it's sort of part of the idea, isn't it, to actually give people this respite. And enables us to spend...so, it is a bronze, because it happens, doesn't it? What do you think?
- S2 Well you're only asking for essentials, aren't you? But (Overlapping Conversation).
- S8 That's the idea really, isn't it, to give a couple of hours respite for each of the other siblings to enjoy.
- S2 It's supposed to work both ways, isn't it? They're supposed to get it and we're supposed to get it.
- S5 It depends on the amount of time, I suppose, doesn't it, how long you get.
- S4 Okay, right.
- S5 So maybe silver.
- S2 Okay. So, shall we say...we'll say that this is bronze because the time is the key? And also, there's a legal obligation to provide rest and caring. But the amount of time is what determines whether it's bronze, silver or gold. Yeah. So, the amount. I'll just put amount in three colours so I remember. Jolly good. So...
- S3 So, I suppose you could put then about the youth groups and the [inaudible 00:46:18] from the 18 and upwards in the gold. Because they're supposed to have it until the age of 22. But a lot of groups finish at 18 even at 16, you said. So, in a sense, we could separate like for the...bronze could be everybody gets a break, possibly a silver maybe a gold to get the adult range in of 19 to 25, or the 16 to 25.
- S4 Okay. So, the age range...so, a bronze service would be what? School age, is that what you're saying?
- S5 (Overlapping Conversation) school to 18.
- S2 Groups they finish at 18.
- S4 And then, silver would be...
- S5 Nineteen to 25.

- S4 Eighteen to 25. And the gold is what? Yeah. That's a good way of looking at it. So that's interesting. So, would you say...I'm not trying to put words in your mouth or anything, but is there a particular age group where you really need it?
- S5 Nineteen to 25. I think because a lot of our children are...mine is 19.
- S8 Mine is 17.
- S5 And they're all approaching. So, there's a lot approaching and I've been there with the 18. And seeing [inaudible 00:47:54] lose all her groups. And she didn't have any groups to start with, it took us ages to find them. And when we did find them, she's having a good time. And then it will like all stop.
- S7 It's made an impact, doesn't it?
- S5 And they're like 'what do we do?' Because they're going back to watching TVs and going back into the bedroom and being isolated again.
- S4 So, you'd say that that was quite a big gap, really, at the moment.
- S5 And I think it's important for the 19 to 25. Because some groups, if they are 19 to...plus adults, when they're mixing with 50-year-olds at 19, there's a bit of big gap. But the 19 to 25, it's just a nice little gap. So, they can just keep all together again.
- S4 Yes. Okay. Good. So, I'm very conscious of time. It's just gone...well it's five past eight. Is everybody happy with that? Yeah. Cool. Brilliant. We'll finish up the slides and then, we'll get out of your hair. So, questionnaire closes on the 21st of August. I've got some questionnaires here if people...If you could put the light on, that would be lovely. (Overlapping Conversation) than anything else. (Laughter). So, if you haven't filled out one of those, they are available online as well. So, you might have filled it out online. If you start it filling out, it sounds really familiar, stop. But if not, if you could fill them out, that would be great. If you could fill them out now and give them back to me, even better. If not, there's a free post envelope...

Thursday 7 September, 6:30pm – 8:30pm,
St Ninians Church, Chanterlands Avenue, Hull HU5 4DJ

10 Participants

2 Facilitators Becky Colton, Hull City Council
Natalie Jackson, Hull City Council

Activity 1 feedback

- S1 Right. So, I've just started recording then. So, we'll start the first activity. So, what we're going to do is we're going to do it in groups. So, we'll do it in groups of...let me [inaudible 00:00:17]. So, if we do it in groups of three, so, okay. So, if we have two and two and a three. Is that okay? Yeah. So, are you okay to swap places is that all right. Sure. Thank you. So, we're going to spend 10 minutes, 10 to seven, until 7:00. What we want you to do...you've got two post it notes, a pink and a blue. On the pink card, we want you to list all the good things about short breaks. If you do it on an individual one. So, if you said one was the carer, one was the activity, can you just make sure they're on separate ones, because we're going to be using them in a bit. On the blue ones, can you write down all the bad things about short breaks? So, pink one good. The blue one bad. And then, do it on individual ones. Does that make sense? Okay with everyone? Yeah.
- S2 In a case if you had two [inaudible 00:01:23] in one, to have something to write down.

- S1 Well, if you've not been on a short break.
- S2 Never.
- S3 We've never done (Overlapping Conversation).
- S2 Never (Overlapping Conversation) disabled, the only help we get is through [Anon].
- S1 Right. So, you're not currently...
- S2 We've had something through KIDS before. But that was from some part...that was in KIDS a few years back.
- S4 Has anybody accessed them?
- S1 Does anybody access them?
- S2 But we've never physically had any means of getting...of knowing how we get to them or anything. All we've known is [Anon] saying like at one point that we've got to pop there for, like a short break (Overlapping Conversation). I don't know where it was.
- S1 Would you write what the good things would be about having a short break if you've received one?
- S1 What you'd like and then, any concerns that you have as well. (Overlapping Conversation).
- S2 There won't be really any concerns. (Overlapping Conversation) you won't know until you've been on it.
- S1 So, at the moment then, if you want to write any good things, what you would get from a short break, is that okay?
- S2 Yeah.
- S1 So, if your child went on a short break, what would be good about it? What would be good for you? What do you need from it?
- S4 What do you need to give you a break from caring, from those carers [inaudible 00:02:35]? What would help you have a break?
- S1 Is that okay as well?
- S2 [inaudible 00:02:44]. Thank you.
- S3 Which one do we write?
- S2 That's close enough. I don't know if it's...
- S3 What do you mean by what would benefit you, if you went on short break? Well, I don't know. I've never been there before so.
- S2 When you do anything, it's always with the kids anyway.
- S6 So, if you had...so, at the minute, there's a variety of short breaks that are available. All different ones, you know, day times, different groups. So, what sort of thing would help you to have a break? So, would you like your child to access a specialist club? Or would you like them to access a mainstream club? Do you need someone to take the child out? Do you need them to have an overnight because you don't get any sleep? Do you need...do you see what I mean?
- S3 Yeah, I see what you mean now. Yeah.
- S6 What do you really need help with?
- S2 [inaudible 00:04:27] it's too complex.
- S3 So, I'm looking at it, it's all 24/7. You can't really pinpoint anything, to be honest.
- S2 It changes daily, you know.
- S6 It does. Yeah. In that case a short break for you would need to be flexible. (Overlapping Conversation). Not necessarily once a week on a Friday, but maybe on holidays or when you need it.
- S3 Right.

- S6 Say, perhaps somebody like a carer who comes and takes the child out for a couple of hours to give you a break. Will that sort of thing help?
- S3 Yeah, it would.
- S2 [inaudible 00:05:06] I want it [inaudible 00:05:09].
- S6 Have you got a social worker?
- S2 No. That's something [Anon] going to start fighting for. But it's only diagnosed at the minute with one on one which is not covered by social services he's currently going through SD testing now. So, till we get that, they won't touch him.
- S6 Well, you still need a break if you need a break. It won't actually change anything if he's got a diagnosis or not.
- S2 No, but social service don't seem to want to get involved. It seems like they don't want to touch us [inaudible 00:05:45]. That's a polite way of putting it. I could be a lot nastier. That's the only reason we got the kids was because we kind of threatened them a bit.
- S3 We went to the papers didn't we?
- S2 Yeah, we threatened them. And then, social worker came and all she did was point us to kids and disappear and we've never seen her again.
- S3 That's what I mean, we don't get anything. And we don't know what is available and what...
- S4 Very difficult when you don't know what's out there.
- S2 And nobody ever said how we had to find out. That's the one that you've normally got. So, we don't have nobody. (Overlapping Conversation). And I think it's wrong really.
- S6 So, would it be helpful if say, for example, somebody took them out or somebody came in to help you in the home?
- S3 It would be easy if someone took them out. Because it does affect the whole family. So that would be great I think.
- S1 So that they had a break as well. That's the whole point of the break.
- S2 He thrives on one to one attention. Because we've had people who come to the house, because the girls are around. They're wanting to know what he's doing and that sort of stuff. That kind of makes it worse for him. So, he doesn't get the one to one [inaudible 00:07:09] that he wants.
- S4 And it will be a bit intense [inaudible 00:07:15], isn't it. He's got (Overlapping Conversation) too much.
- S2 Yeah, he gets very angry, especially because it's his friend. That's the way he sees it. It's his friend not yours.
- S4 Okay. so, put that then. Whatever you think would help (Overlapping Background Noise). Because it's difficult, isn't it? it's difficult. That's the whole point. It's a legal responsibility. (Overlapping Conversation).
- S3 So, what we'll just put...write respite.
- S4 So, would you like him to do something?
- S2 Respite and one to one, I suppose.
- S3 One to one respite. (Overlapping Conversation).
- S2 Handwriting [inaudible 00:08:02] anyway. Mine's horrible. It's all right if...do you work...you'll work alongside [Anon] then won't you?
- S4 Yeah. I'm not employed by KIDS but I work there. (Overlapping Conversation).
- S2 She's got a lot of tribunal responsibilities.
- S3 What else is on offer?
- S4 Well, some people have direct payment so that's like somebody who takes the child out like he was saying as one to one. And might take him to a club or a group or the cinema or

some sort of park or something for a couple of hours. Some people get on overnight break. So, he might go to a residential overnight place. It depends on the needs of the child. Your social worker would have to assess it, do social care assessment. And they would say what you have been eligible for or something. But these specialist play groups, for example. So, they would go off to a specialist that's got other children with disabilities. So they're all together and they do various sort of you know, recreational stuff, cinema nights and stuff like that. There's stuff in the summer holidays. So, they have a [inaudible 00:09:27] children and do recreational stuff everyday. So, that gives you a break in the summer holidays

- S2 That's probably the worst time, isn't it? Cause he's around the girls.
- S3 Yeah. I don't go nowhere [inaudible 00:09:38]. It just causes a lot of (Overlapping Conversation).
- S2 (Overlapping Conversation) changes frequently.
- S4 Summer holidays parents tell us all the time it's very difficult.
- S2 It's not too bad, which one...they're constantly around. You can't separate them.
- S3 Yeah. (Overlapping Conversation). But we're trying to get the best routine.
- S4 So, the bad thing then, is that you don't know anything about it is that what you're saying? (Overlapping Conversation). (Overlapping Background Noise).
- S3 I'll [inaudible 00:10:25] services, taking her GSE. [inaudible 00:10:37].
- S2 V-I-C-E-S.
- S1 Okay, so these (Overlapping Background Noise) it is things like what you're saying, like communication. If it is things like communication it's still things we need to know about it's still [inaudible 00:10:59] understand. (Overlapping Conversation).
- S2 Social worker, that's what he needs. That's what I thought, too. (Overlapping Conversation)
- S3 We can't do [inaudible 00:11:07], can we?
- S7 (Overlapping Conversation). And then, we didn't have the services in East Reading. So, we moved to Hull because we were in a position to do so. (Overlapping Conversation).
- S3 [inaudible 00:11:37] with our like autistic child with ADHD.
- S2 We don't know till he's done it that's the problem. Till he does it, we don't know.
- S7 We won't get [inaudible 00:11:44], because [inaudible 00:11:46] stopped in December, because all of the (Overlapping Conversation).
- S3 We're not going to get [inaudible 00:11:52] if we don't say nothing. I don't know. (Overlapping Conversation). Till he does, we don't know. What would you want that's what we need to think? (Overlapping Conversation). Well, I know, but let's put...If we don't ask, we don't get.
- S2 What are you trying to ask for?
- S3 I don't know.
- S2 Well, there you are, don't ask me then. (Overlapping Conversation).
- S3 Full time care [inaudible 00:12:16].
- S2 That would be nice.
- S6 Right. This is what we think you can help me with. Yeah.
- S3 Do I call [inaudible 00:12:44] and ask them what's the [inaudible 00:12:46]? (Overlapping Conversation).
- S7 (Overlapping Background Noise) assessment [inaudible 00:12:47] which is great but it's (Overlapping Conversation) for adults. So, if those parents without (Overlapping Conversation) always different. As soon [inaudible 00:12:57] dependence (Overlapping Conversation). (Overlapping Background Noise) top of the shelf, right. So, if they've never

been to [inaudible 00:14:09] or anything like that. (Overlapping Background Noise) on the weekend.

- S3 Put one to one. (Overlapping Background Noise).
- S4 So that short break was provided by the school. (Overlapping Background Noise). (Overlapping Conversation).
- S7 I was in the East Riding when he first started going to St Anne's. (Overlapping Conversation). I literally fought to get him in there.
- S1 One more minute, and then, we'll have a look at what you've got. Yeah, siblings, you see. That's an interesting point. (Overlapping Conversation)
- S3 I thought this meeting was actually (Overlapping Conversation) to explain what was available.
- S2 But she was saying [inaudible 00:16:10] which we're never going to get. It's pretty pointless which is slightly annoying. (Overlapping Conversation) he's at that age now where it's pointless...he's in year 10 so...even trying [inaudible 00:16:26] get through all that.
- S4 You're not necessarily eligible for that.
- S2 Exactly.
- S1 Are you all okay with that activity? [inaudible 00:16:33] because you weren't yet getting them. But still there's answers where you're saying [inaudible 00:16:39] communication [inaudible 00:16:43]. They're all still valuable stuff we want to hear from you. Right. So, we'll take a couple of [inaudible 00:16:49] here. There's still some good ones there. So, I'll take a good one from yourself. Thank you.
- S2 [inaudible 00:16:55].
- S1 All right. So, overnight stays and one to ones. So, that's a good one, a short break. So a good one for yourself. Yeah. So, [inaudible 00:17:12] to do extra therapy. What's that I'm sorry? [inaudible 00:17:18]. Thank you. So, learn new skills and activities. Definitely.
- S5 So, we've got one to one respite.
- S1 A good one from this side? So, allowing non-disabled child quality time with the parents, which is what we're saying about the siblings, wasn't it? Yeah.
- S7 More quality time I think. (Overlapping Conversation).
- S1 The child gets new experiences. So, like you learn skills and activities to get your new experience as well. Anymore good ones?
- S5 One more. (Overlapping Conversation). We'll stick it out (Overlapping Conversation).
- S1 Yeah. (Overlapping Conversation). No problem. So, to be able to access activities like peers. There we go.
- S2 [inaudible 00:18:31].
- S1 So, rest for the career. So, you may be able to sleep.
- S5 To allow you to keep your children with you.
- S8 I meant by that like if somebody did give me a short break I [inaudible 00:18:49] somebody else would have to look after them. Yeah.
- S5 Thank you. Teach independency skills to the child. Allowed to sleep like a normal person.
- S1 So, gives child a social life.
- S5 Could ease child's anxiety.
- S1 Reduce stress and anxiety.
- S5 Interact with new children. And to give siblings time apart. Change the child for the better through learning...through new people. (Laughter). (Overlapping Conversation). Allow more family time.
- S6 We've kind of got that already. But we just want to get it in twice.
- S1 Well, that's what it is about.

- S5 A rest to allow you to cope. Well, that's important even if some of them seem to have an overlap we want to record each one that goes up there. So, if there's a common theme coming out more strongly, we can make sure that that's put in.
- S1 That's definitely what we will do when we're looking at [inaudible 00:20:40]. It is what you say, it's about getting yourself that rest. It's about the child getting that new experience, the skills as well. The ability to access activities like the peer...with the peers, the siblings. So, you want that time as well to spend it if you've got other children as well.
- S8 I didn't always mean with their peers you know, [inaudible 00:21:03] so my children...
- S1 Oh, like the peers. So, not necessarily with peers but doing activities similar to the peers. That's what you meant. Okay.
- S7 As well even just doing something they like to do which they just want to do with you all the time, to just give you a break from that. So they can go off and still do it because that's what makes them happy. But you don't have to do it that day.
- S1 Yeah. So, you still get your break and they'll still enjoy it. So, you're both getting something. Yeah. Let's have a look at some of the bad things about short breaks. Did you get one over here? Yeah? So, don't know anything about these services. It's a good one, because that's what we want to know, we want to know that you don't know anything about these services. So, it's a really good one. Thank you. Yeah.
- S5 Unable to access your break.
- S4 Is there a reason?
- S9 For that one for me. That was one of mine receives short breaks and one of mine doesn't. And I was told that he was actually at the time, which [inaudible 00:22:10] that he was too young for a short break.
- S1 So that was primarily because of age then.
- S9 That's what I got to know. I got told he wasn't eligible to be assessed.
- S1 Yeah. We'll pop that on there if that's okay. Just (Overlapping Conversation). A short break should be anywhere up to 25. (Overlapping Conversation) 0 to 25. So, means tested. Do you mean for like eligibility like the credibility going there.
- S7 Because we found....because we're not eligible for the majority of things. A lot of the stuff then you say to people, when you go for an appointment, they say "do you work? And you say "yeah" and you get a "hmm". And that's all you get. They don't even bother asking.
- S1 So, it feels like you were working, that is not [inaudible 00:23:12]. (Overlapping Conversation). Yeah, it should...it's not (Overlapping Conversation).
- S8 That it be made clear.
- S1 But if you're just being made to feel like (Overlapping Conversation). So, social worker, lack of information and knowledge. Is that your social worker lacks information or lack of information you've received from the social worker?
- S10 I put that because like I got told there was an age criteria which actually I found out that there wasn't.
- S1 Right. So, the information you've received. (Overlapping Conversation). Oh, have you come for short breaks? All right. Come on in.
- S11 Thank you. (Overlapping Conversation).
- S1 All right. Welcome to our focus group. We have been going for a bit...so covered quite a bit about what short breaks are. What we're currently doing at the minute is just doing activity where we're just trying to find out like the good things about short breaks and the bad things about short breaks. Does your child currently access short breaks?
- S11 Yes, summer scheme and (Overlapping Conversation).

- S1 Yes, so there's current access. Yeah. The kind of things we'll be [inaudible 00:24:46] at the moment for group was just around that to get overnight stays, to get the...the carer gets to rest. The siblings...you get time with the siblings, that your child gets to learn new skills, activities, knowledge, that they get to...you get more family time, parents can get the break, interact with other children.
- S5 Learning new skills as well.
- S1 So, they're kind of good things. You've got any other ones you want to add to that? Or just kind of throwing you in there.
- S4 What do you get out of having a short break? What does your child get out of having a short break? What is good about it?
- S11 The same when you break for us and for siblings and also, you know, interaction with other children in the group, within the group. Some more experience really for my son. Yeah. (Overlapping Conversation).
- S10 A new experience.
- S9 Or a different experience.
- S11 A different. Yeah.
- S1 So, I was going to introduce. I'm Becky. I'm from Hull city council. I work on the project team regarding the short breaks review. We're independent. So, we've come in to gather your thoughts, your ideas for us, for your opinions, thing on short breaks. My colleague [inaudible 00:26:22] is from the same team as myself. So, we're supporting each other. And then, Laura is from Hull Parents Forum. So, we've kind of covered the good parts. We're just going through the bad. We'll continue collecting them. Then, we'll see if there's anyone who missed what. You may want to add to it. Is that okay? So, communication is really poor. So, is that communication from health workers? Communication about short breaks itself?
- S9 Short breaks.
- S1 About short breaks itself, about the activities.
- S9 Yeah. I found that the routine of the social worker and they said they could go away and find out, someone is going to contact me regarding short breaks and payments [inaudible 00:27:07]. (Overlapping Conversation). And nobody got back to me. I chased it, nobody got back to me again. And (Overlapping Conversation) for about three years. It's just something that I just haven't gotten round to getting done again.
- S1 That's when you need it, isn't it? It's absolutely what you need.
- S5 So, the child will get separation anxiety if given overnight care
- S1 So, was that from on the [inaudible 00:27:41] from social worker. Okay. So, told not to have more children if you can't cope with what you have...[inaudible 00:27:50] that one.
- S10 Social worker.
- S1 Social worker again.
- S5 We've got another one. We didn't know about short breaks. Again, extremely important there.
- S1 (Overlapping Conversation) I didn't understand what short break my child could access. So, similar to the one you've just said. Yeah. That's kind of our finding at the moment.
- S10 Or what you're entitled to or like what hours [inaudible 00:28:26] respite or you just get told that, "Oh, you seem to be managing all right." Do you know what I mean? You don't need it. That's what you're told.
- S5 We've got extra work for the parent calming their child down. After the break.
- S3 Yeah, that one down there. We get told we don't need it.
- S1 So, it could increase the child's anxiety if there's no consistent care or place to go.

- S3 We get told we don't need it. What did you say? [inaudible 00:29:07].
- S10 I was also told that we don't provide baby sitting and I've been told that (Overlapping Background Noise) it was last year. Oh, yeah. Parents of typical children somehow cope so we can to.
- S5 Another (Overlapping Background Noise) criteria up here as well.
- S2 Would you happen to know why we got a letter, when the questionnaires were sent out, given the fact we've never had a social worker and he's unlikely to get one.
- S1 Did it get personally to you?
- S2 To our house.
- S1 To your house.
- S2 I mean, everybody here has got social workers.
- S1 Yeah. It went out (Overlapping Conversation) it went out to everybody who's special education needs.
- S7 So that it goes through...it could have been done through the school.
- S8 Yeah.
- S3 It was special schools or...
- S2 No, he's not at a special school. It's...
- S1 Has he got any HTP?
- S2 Yeah, he's got a care plan. Yeah.
- S1 That's why.
- S9 Same as us we don't have social care.
- S2 (Overlapping Conversation). It's a bit silly because he's not going to get one now because he's at that age now, to do the full process. (Overlapping Conversation).
- S1 But you're entitled to a social care assessment.
- S2 It's a long process, isn't it?
- S1 There is a guidance of how long it should take.
- S2 Well, they said it will take quite a while. This [inaudible 00:30:38] team has got to do an assessment or something.
- S4 [inaudible 00:30:40] how many ring in and asking for an assessment.
- S1 I mean, if you want to leave your details, we can always see if we can get somebody to contact you to talk about it with you, at the end or while doing this. [inaudible 00:30:53] we'll get somebody to contact you who can talk it through with you. So, we haven't got the experience of (Overlapping Conversation).
- S2 No, exactly. We was under the impression that it was being done in the sense of you don't know how to get it, you can. But there was no explanation of there's nobody there who specialise in it or anything like that, of coming here.
- S1 All right. No. This is all to do about information gathering [inaudible 00:31:12].
- S2 They never said on the phone, you see, when they rang in.
- S4 I can talk to you after that. I can talk to you quite (Overlapping Conversation).
- S2 (Overlapping Conversation) the way it had been given to us as if we've got access to these sort of services and we don't.
- S1 Right. Okay.
- S4 But it's people like you we need to hear from. Because if you don't get things that you really need, that's the information that they need. Because if people aren't getting what they absolutely and vitally need and it's you know...

- S2 That's what's frustrating. You know, a lot of these people obviously have had various things in whatever ways that have helped children. But it's highly unlikely we're ever going to get access to that. So it's kind of annoying listening to it.
- S4 I know, I can totally feel you.
- S2 No disrespect to anybody. I mean, it's not your fault.
- S4 I can see where you're coming from completely. But what I would say is request a social care assessment, because you're entitled to an assessment and you don't know what will come out of that until you ask for it.
- S2 Well, I've had to get in touch with some nurse team. Is it [inaudible 00:32:09]? Yeah, I've got to get in touch with them and they've got to do some assessment or something.
- S4 Right. Contact (Overlapping Conversation).
- S2 I don't know if they're related to (Overlapping Conversation).
- S4 I'll speak to you at the end and put you in touch with the local offer and they can...have you been on the local offer that's on the website?
- S2 I don't think Rosemary's ever put us through to anything like that. No.
- S4 It's a website. I'll tell you all about it at the end.
- S3 Okay.
- S4 All right. I'll catch you at the end.
- S3 All right. Thank you.
- S5 Just got another one on [inaudible 00:32:31] criteria again. So, you're given short breaks.
- S1 We've got another one about access, so, not being able to access the services. And will my child's care needs be met? So, while they're at the...while you're having your short break, is that period [inaudible 00:32:48] will my child's care needs were met.
- S9 Oh, that was us?
- S1 So, could you explain that a bit more?
- S9 Because we've never had it I wouldn't know what was available. And I worry that you know, he's under continuing care at the moment, and I think is there someone there that can do the medical stuff? Is there someone there who can deal with him if he is in complete meltdown? (Overlapping Conversation).
- S1 Oh, right. Yeah, of course. Yeah.
- S9 Someone to mother him in effect, not just the carer.
- S5 So, we've got activities are not in the right time frame for carer. And no respite from mainstream schools.
- S1 So, medical and care needs are available. So, again, is that while the break as well yeah? And being offered 20 hours respite per week are only given to...at the carer's given discretion and not any use to the parents. So, we're saying that this short break is not actually meeting the need of the parents?
- S9 [inaudible 00:33:48] anybody.
- S5 We've got another one. Being told my child isn't disabled enough to access services. And told other parents cope helping a disabled child, why couldn't I?
- S1 No guideline as to who is eligible. So, you're not sure who can get them. Short break is not long enough if there's travel involved. So, that means if you've got to go to short break, you've got to drop your child off and then...
- S9 Picking him up.
- S10 You pick him up, it's like an hour. And then you was travelling half an hour there and half an hour back.
- S1 It's not really short break anymore. (Overlapping Conversation).

- S9 If you're too tired to drive as well, well it's dangerous (Overlapping Conversation).
- S7 [inaudible 00:34:37] football training (Overlapping Conversation). You drive all the way there to sit for half an hour and [inaudible 00:34:42] all the way back. If you eat your tea in the car at least you're getting a break, but you don't (Overlapping Conversation).
- S1 When you call and they ask what you would rather them telling you what they offer. Saying what you need rather than telling you what they offer. So, when they ring, they're not saying, "This is what we have available."
- S7 Yes. So, when you ring them, and somebody's asked...said to you, "Why don't you give them a call?" So, you give somebody a call and they say, "Oh, what you ringing for?" and you say "oh I don't know."
- S3 You don't know unless you're in the know.
- S7 And they just seem to assume that everybody knows what you mean.
- S1 Okay. You've got anymore to add to that one? Okay. Thank you for that activity.

Activity 3 Feedback

- S1 Just put in the envelope (Overlapping Background Noise). Thank you. Great, thank you. Right. So, we're on the last activity now. So this one, we want to design a short break. Okay. Again, if you're child has not had a short break, what would a good short break be for you and your child, if you had one, if you don't have access to it? Okay. How we're going to do this is a bit like the car wash scheme. So, say you went to a car wash and you said, "I just want my car to have a quick wash and I want to go. That's all." But then, if you said, "Actually I want my car to have a wash. I want the wheels to be done and I want a hoover." Then, that might be silver. But then, if you said, "Actually, I want all of that in bronze. I want all of that in silver. Plus I want you to wipe all my door frames down, I want you to give it a good polish. I want you to give it a wax. I want a free air freshener. I want it steamed cleaned. I want the works. Then, that's gold. Does that make sense? So, what we're trying to do is design a short break. What short break to you would be in your gold package? What short break would be in a silver? What short break would be in the bronze? So, your bronze might be, for example, I want knowledgeable trained staff. Good communication. Do you know that might be silver? Sorry, bronze. Your silver might be I want good, trained skilled staff and I also want transport to my place where the child is going to for an activity. Your gold one might be I want all of that. Plus I want some holiday overnight stay. Do you know, we're kind of building up what would be a bronze short break for your child, or a silver, what would be your gold? We're trying to make a picture of a short break? Does that make sense?
- S7 Do you know what I find really frustrating? Really, really frustrating? Cause obviously, fostering my nephew for nearly 18 months, he's nearly 16. As a looked after child they get short breaks and they go on residential trips. It's all free. It's all paid for. Somebody comes and picks him up, takes him away for three or four days, brings him back. If that's Children and Care Council, somebody comes and picks him up, takes him out for a couple of hours and brings him back. Somebody comes, takes him out for lunch. And yet, you have a child with disabilities. [inaudible 00:48:54] no fault on their own and they get absolutely nothing in comparison to looked after children. And yet, they're probably more in need than what the looked after children are as a comparison. Sorry, just (Overlapping Conversation). You know, they're both in need, both are children in need. All children with disabilities and stuff are children in need. So, why are they not entitled to the same?

- S1 (Overlapping Conversation) we'll put it on the...you want to write on that blue one. Do you know [inaudible 00:49:28]? (Overlapping Background Noise). Your suggestions today are [inaudible 00:49:40] it's not saying that is what's happening. It's not saying what you put in gold means it's really good it's going to lose that service. It isn't about that. What we're trying to find out is what's the essential stuff in that bronze? What would you think is silver? What would be a gold package? It might be that your gold package is something that we is...it might be an activity where you think that would be a gold activity. Whereas there might be some mainstream place out there that might be able to deliver this gold activity for you. Or it might be transport in your gold one, like transport to the venue. Or they might be a bus that could be put on that could take everybody to all these venues to get there. So, gold isn't necessarily saying "it isn't going to happen 'cause it' going in gold". Gold might be "they think that's a gold service. How can we review and meet that?" [inaudible 00:50:40] nothing tonight is what is set in stone to say that is what's happening. We're going to lose it 'cause they think it's gold, it's not. To think that it's [inaudible 00:50:46] to think it's gold, it's not. To think that it's [inaudible 00:50:48]. It's not about that. What we're trying to find out is what is your package.
- S4 So, it's just what would basically...what are the essentials of having a short. So, (Overlapping Conversation) over that. (Overlapping Conversation). You would put [inaudible 00:51:08] your overnight. You would put your transport on that bronze and you wouldn't put that in gold because that's the thing that you need to survive.
- S1 So, what would be (Overlapping Conversation)?
- S2 [inaudible 00:51:18] that one day. We're sat round here because actually, we need it. It's not that we want it.
- S5 If it's [inaudible 00:51:23] to be the bronze category. (Overlapping Conversation).
- S6 Gold could be something like [inaudible 00:51:37], you know, oh if the children could go away for two weeks in the summer. So to me, that's quite something (Overlapping Conversation). (Laughter). That's amazing.
- S1 If that's what's your gold, put it. (Overlapping Conversation).
- S8 Everyone is going to have a different feeling of what they need out of a short break aren't they? (Overlapping Conversation).
- S11 (Overlapping Conversation) to be something we can choose in between. Because at the minute, [inaudible 00:52:03] we have no choice. There's only either direct payments or what else? (Overlapping Conversation). That's it. And there is no other choice. Like my son would be happy to attend [inaudible 00:52:14] after school club. Child minders as we discussed, after school clubs. And we can't because nobody's able to pick him up from [inaudible 00:52:22] because [inaudible 00:52:23] school is kind of like out of the system. Because we have transport, because we have charities, beautiful charities. What else do we need? Yes, we do need a choice. We do need choice. Like direct payments. Okay, if I get four hours of payment, I have to employ someone. I don't need that paper work because I'll be busy. Why can't I use that money for something I like, like swimming? And then, at the end of a financial year, I can prove that I actually I spent that money on my son rather than (Overlapping Conversation).
- S4 Personal budget.
- S11 I know that some [inaudible 00:52:57] do that. (Overlapping Conversation) don't.
- S4 It's like your personal budget.
- S11 And I can keep the receipts all year round. And then, I can...because (Overlapping Conversation).

- S9 I said to Sean like, it would be really nice to take my kids out but then employ a cleaner so when I came back the house was tidy and I didn't have all that to do as well.
- S4 It's different ways of using. It's the same package on the same budget, the sort of notion of budget if you like, that you would have anyway. It's looking outside the box.
- S11 They don't to help you to find someone. You don't have to struggle with the paperwork. You've got a lump sum in your account, then you use it for whatever you want. You can even find a child minder, even your friends can look after...well, obviously no if she's [inaudible 00:53:41]. There are so many services. You can use that money for special language therapy. So, I can't see why not.
- S4 You can request one if you've got an AHCP.
- S11 Can I?
- S1 Yeah. (Laughter). Right. So, let's look at bronze then. Let's look at bronze then. So say bronze then. If you think that is (Overlapping Background Noise). Bronze. This is what you think should be bronze, silver and gold. This is you. So, there's the short break. This is not us telling you, this is you telling...If you think everything needs to go in bronze, bronze and you think silver. Well, the only thing that you think would be gold would be a holiday that's fine. What I'll do is write some on post it notes. So, has anybody got one that think is bronze. But what you would expect from a short break as a bronze package? Rest, yeah. So, rest then. Yeah. I can write them if you like [inaudible 00:54:43]. (Overlapping Conversation) (Laughter). So, enough rest then. Yeah. Any more?
- S4 You want a normal life, don't you?
- S1 A short break. What service [inaudible 00:55:17] a short break. What would you like for you and your child? So, it's ready for a child (Overlapping Background Noise).
- S9 [inaudible 00:55:30] care.
- S1 Excellent. (Overlapping Conversation).
- S7 Trustworthy staff.
- S1 Trustworthy staff. Yeah. (Pause).
- S10 Overnight care whether that be in the home or somewhere else. (Overlapping Conversation). Which means you get a good night's sleep, that's the thing. (Overlapping Conversation).
- S7 If you had them in your house, you would have to get [inaudible 00:56:13] book a hotel room to go stay overnight somewhere wouldn't you. Because if there's something to facilitate that. Do you know? If you've got a lot of medical equipment say at home...
- S1 So, do you mean for yourself to go and stay at a hotel? So, if we say stay at a hotel then, do you think that would go more that way or bronze?
- S8 Bronze.
- S1 Bronze. [inaudible 00:56:35].
- S2 Depends on the child. You can't just bracket everything into categories, because they're all different. So, they all need different things. And it's impossible to bracket.
- S1 (Overlapping Conversation). So, hotel accommodation.
- S8 Something like [inaudible 00:56:55] all night on and off.
- S7 [inaudible 00:57:02] anybody else.
- S1 Any other ones?
- S8 I mean, like transport if it's a long way away. I mean like having to put all 4 kids in a car and then having to travel and I might [inaudible 00:57:19] to drop him off somewhere.
- S1 Is it bronze?
- S8 Yeah. But I won't be able to do it otherwise. It's not...
- S7 [inaudible 00:57:30] offering to look after children [inaudible 00:57:32].

- S1 How about the child?
- S8 One to one support and sometimes two to one as well, depending on the [inaudible 00:57:43]. Tailored care really (Overlapping Conversation).
- S9 Good assessment in the beginning.
- S7 Yeah, definitely.
- S1 What other types of activities. (Overlapping Conversation).
- S7 What suits the person that comes or...you know what they think it should be. Because some children don't want to be in a big group with other children. Some children like it just on their own.
- S2 Would it not be to just give the option to the child? So, if there was a set budget, a set amount, that it was ours to spend because they've not pick what they did as an example. (Overlapping Conversation). Because I know my lad, for example, if he had the offer of going somewhere, he'd want to go. I don't know, Laser Quest or paint ball or something silly like that. That's what he'd want to do. Not just oh, well, they're taking you to go do this, you know, make do with it sort of thing.
- S11 [inaudible 00:58:46] ask the children, group of children what they want to do. Because my son's really quiet and shy. He still didn't tell them what he wants to do. Anyway, he was happy. (Laughter). He was happy still.
- S1 Any other ones? No.
- S7 What about the other siblings? You know, get opportunities for the other siblings to do things as well.
- S1 So, activities (Overlapping Conversation). [inaudible 00:59:15] or activities like [inaudible 00:59:18].
- S8 The young carer's thing it's only on for about 8 weeks or something isn't it? And then that's it. It finishes. (Overlapping Conversation).
- S4 And then, when they get to a certain age... (Overlapping Conversation).
- S9 They're too old for that. They've got to go to a youth club. They don't want to go to a youth club even though it's for young carers. (Overlapping Conversation).
- S10 Do they still do the young carers fund thing through [inaudible 00:59:39].
- S2 Anyway that's what Rosemary got his access to. That was the one I couldn't remember what it was.
- S4 Is it for...his brother or sister?
- S2 For the eldest girl. Yeah.
- S4 That will be it then. Yeah.
- S2 We never heard of it. (Overlapping Conversation). She said she wasn't sure if it had come back. It's just a one off, she said. We don't know...every year, we're getting it back each year.
- S4 Yeah, they do that. Once it's (Overlapping Conversation).
- S2 That was a couple of years ago, I think, that was.
- S4 Well, I don't think we've heard yet. I'm not sure. I'll have to have a look for you. About next year.
- S3 (Overlapping Conversation) three years ago when we got that.
- S2 We say it's a few years ago, because we went to that thing over Christmas didn't we? Took them to Skegness for Christmas.
- S3 It's worth ringing every year.
- S2 Well, we just waiting for Rosemary to say she's... to let us know (Overlapping Conversation).
- S3 We're not the type to ask for something.
- S2 What about like the time of day for the activities like (Overlapping Conversation).

- S8 I think weekends are more better because, with my lad he's home at like 4 o'clock and sometimes he's too tired and doesn't want to go out, do you know what I mean? And he just wants to stay at home so the weekends and like holidays. We'll be like (Overlapping Conversation). That's the hardest, I think, school holidays. (Overlapping Conversation).
- S9 I struggle with before and after school, I really struggle with it as well. And also because I've got my two [inaudible 01:01:01] really struggle with. (Overlapping Conversation).
- S9 So, it depends on the child, doesn't it?
- S7 Because we wouldn't want to work a weekend because we work all week [inaudible 01:01:10] colleagues [inaudible 01:01:13] on the weekend so nights are better for us or school holidays.
- S11 And Daniel is tired after school. But I still like to keep him busy. Otherwise he'll just bash all the toys in his room so I like to give him that push.
- S1 So, it depends on the child, doesn't it?
- S10 And I think that comes out of it's always been mentioned a good assessment in the beginning and obviously if you get a good assessment. (Pause)
- S1 Social worker that will listen.
- S7 One that fits with you as well. So that if you don't get on with one because you can't get on with everybody. So, you can change if need be.
- S10 But they have some level of understanding of disability as well maybe.
- S6 Or they read about you before they come.
- S3 So what's actually wrong?
- S8 Or they all say, "What do you want?" Well, we don't know what we want because obviously [inaudible 01:02:05] disabled. So, do you know what I mean? We don't know what you offer and stuff like that. And if we don't know, then, they're going to go, "Well, this is what we offer. We can offer this, this and this." Do you know what I mean?
- S10 I think as well, not to be made to feel guilty. So then, you felt let's stop trying to fight it because you think that you're a bad parent because you actually need help.
- S4 I'm wondering if there's anything on here that would tally with anything we've said. There's a couple of parents who couldn't come. And they've messaged me to say, "Can you say...can you give my views?" So, I've just copied and pasted it from their messages. And whether it will fit with any of these, you can pick out whatever and you can have it. So, somebody said, "They seriously need to rescuttle all plans of decreasing budgets. Kids in families need more support, not less. Had I known about these focus groups sooner, I would have been able to attend one. The situation is out of control. The council have already gutted last budget. Any further reduction means the service in essence won't be there, and that's the only means my son has for days out to new places. Direct payments and other forms of respite shouldn't be withheld from families. These could be used to help parents to work outside the home. Respite and assistance is necessary for our sanity. Parents driven around the bend are not healthy. They can't contribute to society and actually drain the resources the council says it's desperate to protect to a much higher degree than parents of children who receive appropriate support. If the council better managed the resources, the manpower it has, budgets may be increased in most areas. It is time for them to stop digging their heels in refusing to listen. Please read my post out at one of the forums. They need to know what we know and we are sick of how ridiculous they are being with SCN funding short breaks, EHCP's personal budget is transport, sensory therapy activities ad infinitum. I have taken out the swear words. (Laughter). There's another one. Similar to you really, that they didn't know about it. "I just want you to say I never actually knew about short breaks due to lack of knowing where to seek and look for help. I'm a mother of seven children and two that have

been diagnosed with autism. My five-year-old has really bad sensory issues and we cannot go out as a family unit now. My other children miss out on days out as the two AST boys cannot cope and it's such a shame my normal functioning children cannot have a day out due to the difficulties. And me and my partner are having relationship issues due to not being able to function as a family would. It's sad that there isn't much help after diagnosis. It really does affect every day living. I'm currently on anxiety medication due to stress with life." So, maybe I don't know, if you put on...

- S1 I've been writing some stuff on here as well.
- S8 [inaudible 01:05:12] on that don't you? People who've got children with special needs have obviously [inaudible 01:05:16] they end up going on medication or having therapy for themselves. Because it just gets too much for them. And they need the help, do you know what I mean?
- S4 And if that helps.
- S8 [inaudible 01:05:29].
- S4 Inappropriately, perhaps they wouldn't get to that point.
- S8 [inaudible 01:05:33] (Overlapping Conversation). But like if you were helped in the first place you wouldn't have to have all this therapy paid for and medication and stuff so.
- S4 That's why it's good that you've all come to say what you need, what's good, what's bad. Because they need to know. That's the whole point of why they're doing it.
- S2 It's how much they take heed of it, the big bosses. How worried are they about the jingle in the pocket.
- S11 I always say (Overlapping Conversation) now, who will benefit in the future? Because obviously they will be working for [inaudible 01:06:19] but for us one day. And if we don't give them support now, they won't be able to live independently. And there's more and more (Overlapping Background Noise) with special needs. And I just wonder how it's going to be, what's happened with my son, how it's going to be. Will he ever be able to work? Will he be able to find a job? How is he going to find rent? He has no (Overlapping Background Noise). Where will he live? It's just he's the only one and there's no speech and language therapy, there's no occupational therapy. And he's delayed in so many things. There are so many gaps. And he's 11 already. They just need to hurry up. (Laughter).
- S4 It's a big worry, isn't it?
- S5 So, if I just stick on there as well, sort of continuity I suppose which we're picking up soon whatever is going to be delivered as a short break needs to be robust in terms of delivering what is on offer and improving on where it can. And actually having some sort of continuity so it's not a case of chop and change as they go through, which is totally reliant on budget, especially looking at the service in itself. Does that basically encompass what was said? (Overlapping Conversation)
- S4 Yeah, what the child needs. What's your need as opposed to this is what we've got. So, this is what you can have or you can't have...that's what you're saying.
- S8 You should be able to...like if you've got a child with [inaudible 01:08:01] and they should be able...the government or whoever, city council should be able to email and say, this is what's on offer, you know. This is what you're entitled to. So, parents know what they can have. They might not need a lot of it, but some of it might be more beneficial to people, you know what I mean? If you're informed, then you know (Overlapping Conversation).
- S6 So more like communication on actually what is available for your child. Not for every child but for your child. (Overlapping Conversation).

- S7 Especially if you've filled out a DLA form. You put all your specific information on that DLA form and you've followed it up with consultants and everything else. So, why can't they tailor make something from there to send to you? Or point you in the direction of cerebral palsy or epilepsy society or something like that. So, you've got somewhere you can go to. Because that is the most lonely place. When you get that diagnosis, then, you just go "oh".
- S8 And you've got to try and find the support yourself like my little boy's autistic and epilepsy. I didn't know anybody who had a child with epilepsy. And I felt like I was alone. I had a break down, a massive breakdown, do you know what I mean? And it was really hard. And I just thought to myself...I just felt if there was someone out there who could've supported me, maybe I wouldn't have got so bad.
- S10 [inaudible 01:09:13] maybe be aware of other groups or (Overlapping Conversation) Hull Parents Forum, like that as well.
- S8 Like him having a chromosome disorder I didn't know anybody. It's really rare, and it's hard you know. And I've opened a Facebook page to support other parents, because there's nothing, do you know what I mean?
- S10 And sometimes, their parents (Overlapping Conversation).
- S8 But they're asking me and I'm like "I don't really know". So, we're just trying to make (Overlapping Conversation).
- S4 Do you all know about the local offer? No. Okay. Well, the local offer is something that each local authority has to put out in terms of what they provide for children with SCM disabilities in the city, so, in Hull. So our local offer, mostly they're on websites. But you can get printed information as well. So, it's a website. If you type in local offer Hull, it will come up. You can type in whatever you need. So, basically, anything that is out there for disabled children in Hull should be on that website. However, it's only been going for not very long. So, obviously she is adding to it as she knows about things. So, obviously the lady, Vicky, who's the Local Offer officer is really lovely. And if you know of any groups that, you know, charity stuff and stuff like that, she will add it on for you. But also all the statutory stuff is all there. And there's links to the short break statement which the council have to provide. So that will show you what exactly is on offer so you could just click on the button and it will all come up and say what they you know. But there's other stuff as well. So, it's definitely worth remembering Local Offer.
- S6 Is that one which one is that one? Is it that one over there? Just to say like if your child receives the right support in the beginning, he might not need as much support as an adult.
- S4 Yeah. I think what came out of this...these comments was that the support and the short break for the parent...obviously the child would have a short break as well. For the parent is to enable them to maintain their mental health and wellbeing. And that's what I would pick up from that. If somebody has a breakdown and a crisis, who's going to look after that child? (Overlapping Conversation).
- S1 So, are we all happy about what's on this bronze one over here? So we've said about the staff, competent staff. So, rest, stop feeling guilty, transport, hotel accommodation, lump payments, overnight care, activities with siblings, child should be able to pick their own activities, trustworthy staff.
- S8 Sorry. Knowing when the criteria [inaudible 01:12:14] being entitled to like an overnight trip do you know what I mean? So, just going "no you can't have it." "or I'll have a word with the managers." And the management going "oh no you can't have it." (Overlapping Conversation).

- S11 When somebody would contact me with regards to referrals, [inaudible 01:12:32] oh we don't know. You should know, within two weeks, within six months, whatever. But I need to know.
- S4 Yeah, fair enough.
- S6 Was it on there like enough support? I know it says rest. But if somebody was to give me half an hour you know I wouldn't class that as a rest. (Overlapping Conversation). (Whispers)
- S1 If you need to go, yeah. That's fine. Yeah. Does anybody want to add to that one?
- S6 If we think of anything else can we email?
- S1 Yeah, email us. I'll give my email address. Do you want to write it?
- S4 Do you want to write it down [inaudible 01:13:36]?

Saturday 9 September, 11:00am – 12:30pm,
Ings Library, Savoy Road, Hull HU8 0TY

4 Participants

2 Facilitators Becky Colton, Hull City Council
 Natalie Jackson, Hull City Council

Activity 1 Feedback

- S1 Are we all labelled out? On the walls, we've got there a good list and a bad list. It's not like Santa's so don't worry, you don't get presents. And what we're going to do is we're going to try and group them all together. So, does anybody want to read them out to us?
- S4 Yeah. I can do.
- S1 Mike. Okay. Give us a positive and a negative from each side then, I suppose.
- S4 Am I going first? (Laughter). I think one of the big positives that it'll opens up different new interests not only for the child but probably for the parent as well. The bad thing at the moment is that for us there's a lack of knowledge of what services and facilities are out there. so that's probably the larger element of the negativity. We'll offset these because we haven't got as many. I think what it does though for the child, it increases their ability to make more friends whilst also additionally, it creates additional time for siblings. But we also felt that if you wanted to do it together, to build family awareness, it also builds bonds and adds or develops those bonds that siblings already have. Sadly, though there's limited awareness of what goes on. What it can do, we think, is it will build personal independence. It will assist their freedom of understanding things. It also establishes the support network for them. And potentially, it could decrease obsessive behaviour, i.e. focusing on individual topics, subjects, something that they obviously dwell on too much, you know, in our case Sponge Bob Square Pants, is what I would suggest in our house. And what it does is...we'll end on a good one. Sometimes there's none or limited access, but actually what it can do for both parties, it could increase their personal responsibilities and time and just make them probably a little bit more relaxed and in control.
- S2 Very good.
- S1 Right then ladies, you're up next.
- S5 Ours is more or less the same. (Laughter). We put obviously on the positive, it's social interaction for the child. It's also social interaction for the adult as well. Yeah, obviously time with the siblings and help in holidays. That's a big one for me.
- S6 But then, also lack of (Overlapping Conversation).

- S1 Yeah.
- S6 Lack of information.
- S5 Do you all know other people with children who have got disabilities.
- S7 We don't. But I only know you because your child went to the same school as Emily many moons ago. But we don't...It just seems like you're just left to get on with it. Joseph's not a very social person and doesn't like going out. And it's a struggle to get him anywhere. But once he's there, he does, in his own way enjoys it. But he just doesn't do social right now. He just can't cope with...
- S3 He would need a lot of support to access that.
- S4 So, we're similar. In many respects. There's probably been a little bit...I won't call it apathy, but there's probably been some we're going to cope, we're going to do it on our own. And that's a lot easier obviously when the child's younger and smaller. But also then you realise that you know you're getting a little bit older. Work's quite demanding. So, you have to open your eyes basically and say, "Right, what's out there? What can we best maximise it?" And equally, as well I think the things where we see Ryan really benefit is on the school trips that he goes on. Say, for example, in this coming term, which they did last autumn term as well, they go to a forest school once a week. And he really enjoys the outdoor side of things. And he loves the outward bounding that they do. But that's because I suppose he's in that bond with people. So, we've seen that. I think it's opened our eyes in relation that we need to wake up, understand what's out there and start the ball rolling nice and early. So that you know, when he does leave school, hopefully we're still going to be working. So, therefore, we need to be looking at what are his options, where can he go? You know, his situation is he's never going to work. He's never going to live independently. So, it's about how do we best make his time quality time? But also that we can still underneath that, you know support both emotionally and financially in all aspects, really. Yeah. But I think the thing is you balance it. Oh, yeah. Sometimes the balance goes one way that you're not...it tips you over. But equally as well as I say, I think you just need to take your head out of the sand sometimes. And going back to your original question, yeah, we do know a few people. But that's only through personal friendships already. It's not as if we've gone out there and sought that through a network type of scenario. And I have to say, they're all pretty much the same. They're all pretty much the same as us, in the respect of this, crack on in their own little way. And I suppose you've just got to wake up sometimes and think where he's 13, time's rolling on. I can remember when the eldest lad was only three, and he's 24 now. So, you know that time moves on. So, have to jump on the waggon quicker rather...sooner rather than later in that respect.
- S3 A lot of parents say that the best information they get is from each other, other parents.
- S1 We notice that when the kids that come to the movie night, that the parents [inaudible 00:35:54] because we sort of encourage...we did a focus group on their coffee sessions and they all have really good relationships with each other. They made friends that somebody brought a cake in for somebody else. And they'd only met through that service. I think it's like you said, it's networking for your child as well as for you as parents and carers.
- S3 It's a common bond, isn't it? You're all in the same boat, it might be a different type of boat but it's a boat.
- S7 I find that things like that are always like during the day and you're at work, and you just can't access them. So, I could only come here today because it's Saturday. So, all the groups that kids do and things on Facebook and stuff like that, they're all like 10:00 a.m. meetings. (Overlapping Conversation).

- S3 (Overlapping Conversation) early evenings or weekends.
- S7 And the support group that we got in touch with CAMS because of Joseph's anxieties and anger issues. And they said, "Oh, we can do one with us." But that's in West Hull. (Overlapping Conversation). Especially when you're just getting home from work, and then, it's at...they did nothing for us CAMS... at 6:00. And like you finish work at 5:00.
- S4 Trailing across towns really easy isn't it? (Overlapping Conversation).
- S7 No, not at all, it's just a nightmare.
- S4 Yeah, you're more stressed getting there, aren't you?
- S7 And he's stressed out and your daughter's stressed out. And then, you're like...you haven't even had tea yet. It's just too much like hard work.
- S1 Are we all alright with all of those. We can see that we've got some similarities we grouped them. And what we do is we group what we think is similar answers and then, we get the gentleman from the CCG doing all the analysis for us. So, we keep them, and then, he will put that all together, like common themes. And feedback on that one right then. So, we haven't finished yet. We've got...can you see that up there? Workshop two. So, what we've got is we've got my glamorous assistant.
- S2 So, we've got forms which we need you to fill out. It's got a few questions. The first question is what do you get out of your short break? So, we know you're not accessing Short Breaks. So, in there just put, we're not currently...just put that you're not currently accessing it. What would you like to get out of a Short Breaks? So, what would you like to get it out of it? What does your child get out of a Short Break? Just change that. What if your child got one, what would you like your child to get out of it? And then, what does your child get out of Short Breaks? What would you like your child to get out of Short Breaks? They're kind of going to be the same question. So, just answer the second one to the bottom if that's okay.
- S1 They all come with an envelope so that you could put whatever you want on there. Pop it in the envelope and seal it so it's anonymous (Overlapping Conversation).
- S2 You don't need to put your names on it.
- S1 And what we'll do is we'll take them away and we'll look at the separately. (Pause) Oh, there we go. That's better. (Overlapping Conversation). (Pause) (Overlapping Conversation). It's basically every local authority. Legally, has to publish all information about what is offered in the area for children and young people with [inaudible 00:41:30] disabilities. So, Hull's... It's called Hull's Local Offer and the statutory stuff is all about the Short Breaks. It'll click on, send you a link to the Short Break statement which is everything that we do offer. That will tell you exactly what's available, how to access it, how to access the social care assessment, which you can have if you've got a child with a disabled child with special needs. (Overlapping Conversation). But it says it all on there. It says all other activities that are available. So, all the charity stuff, all the really good voluntary sector stuff that's out there that you might be able to access, information about schools. It should have everything. It is a work in progress though. So, she's putting stuff in all the time. So, she always wants people and providers to say when things change. If we need to know how to access, I don't know, the pads, wheelchairs, Short Breaks, how to get on the EHCP...all the information's there. So, it's definitely worth a look.
- S3 We found a lot of people don't know about it (Overlapping Conversation).
- S2 Last year...was it last year?
- S3 No, it was this year.
- S2 This year, weren't it, it is building up.

- S4 I mean, don't get me wrong. I know that obviously you should self-serve as well in respect of trying to find out more information.
- S1 You don't know what you don't know.
- S2 Yeah. But that's easier said than done in many respects. I think the thing that's probably confused me more than anything, this is probably in the real early days when Ryan was going through his diagnosis and those types of things. You know you have that competing sort of status I think, between the different departments, not so much the local authority, I'd have to say. Because obviously a lot of that contact was with the NHS. But it's like with speech, it's with this, it's with the other. And there's no real conjoined thinking. And there's no real sort of let's have...almost let's use it as a case study, and then bring the relevant agencies in. And that only really seems to happen once they actually want to make the diagnosis in the panel for autism, I'm talking specifically, because that's all I really know about. And that, I think once then that happens, then they leave you alone. And I think that seems to be something, if you like, the major thing. Because it's like when you were mentioning earlier, right at the beginning of the session. I mean, Ryan accesses a psychiatrist through CAMS but that's because he has ADHD, and that was through that diagnosis and medication for that. But his actual autism diagnosis happens...diagnosis happens, that's it. And so, it's very difficult, I think sometimes, especially when you're dealing with government agencies. Department for Work and Pensions seems to [inaudible00:44:33] in relation to trying to channel the understanding with organisations like that. You don't need to access NHS medical care. Because it's progressive, obviously, and a condition that can't be improved in that respect. So, you do feel as though there's a lack of communication that comes across.
- S1 Lack of support.
- S4 Yeah. Support, communication. And I think a general sort of like really lack of understanding as well by outside bodies.
- S1 Put that on orange.
- S4 I will do.
- S1 And I'm going to pop it in that. (Overlapping Conversation)
- S6 No. I'll just write in that (Overlapping Conversation).
- S3 I work in a local pharmacy and I see quite a lot of families who come in with early diagnosis for their children. And obviously I can relate and I can talk to them about my experiences. But a lot of the community, they don't know. So, there's a lot of families who I deal with on a day-to-day basis, and they know nothing as well. So, it's (Overlapping Conversation).
- S4 Yeah. I agree. And I think it polarises you a little bit as well doesn't it. We were talking about it, weren't we, where we were saying, you develop an inner and an outer steel towards other people in many respects. Because you're a little bit, I suppose, reticent about thinking well, "Does that person really figure it out?" And generally, I'd have to say it don't. I mean the reason why I mention DWP specifically; well I work for DWP. And so, I've worked there for 30 years. And working from the inside and understanding from the outside, you know that that organisation just in simple terms, don't get it. Ain't got a clue. They ain't got a clue with the people with the people who come through the door, they haven't got a clue with the people who they actually deal with. They ain't got a clue with people actually who they employ who fall into those brackets as well. So, you look at that from the perspective of this is supposedly an organisation that's out there and campaigning and championing. They're just not. and again, I think that then puts you internally with barriers. But as I mentioned, to yourself. Ryan's situation actually, he probably might be an awful lot better person than I am. I recognise people when I see them in the street or I think I understand certain scenarios. And

I try and be as helpful as I possibly can. Whereas maybe 10 years ago, I ain't saying I would have been totally rude, because I wouldn't be. But I just walked on by and I wouldn't have paid any attention. Whereas actually, it's honed me more as a person, and I think that is one of the huge benefits. But it does sort of highlight...you see lots of other people and you see lots of other people going through similar, because everybody's is different init. But then, you also see lots of other people who you just think, you just don't get it. You just don't get it. And the bit that amazes me is...and I'm going back to the psychiatrist at CAMS. He's lovely the new one that we've got, I think three, four years maybe. But even he still sort of like starts his conversations with Ryan the same way. Ryan's non-verbal. He's not going to come back to him and tell him how I'm feeling. But we always have the same, how are we feeling? How is it going? And you feel as though...

- S1 So, lack of understanding from the professional.
- S4 Exactly. And you think...you sometimes feel you want to stand up. You want to say to him, "Come on. You know he don't understand comprehensive conversation. You know he can't have a conversation with you. He don't understand his feelings unless they're in the rawest way.
- S1 Put that down for me. On Orange as well with regards to lack of understanding from the professionals.
- S4 And I just think it's...
- S3 It's the same when you go to your GPs though.
- S4 They're even worse.
- S3 We have the [inaudible 00:48:23]. (Overlapping Conversation) no understanding at all.
- S7 We had this problem but a little bit differently, because Joseph does talk and he does appear to understand. But 90% of the time he has no idea what you're talking about. And he'll just say yeah. We had an assessment recently [inaudible 00:48:40], and the woman was asking him all these questions and he just goes, yeah. Do you go out with your friends? Yeah. He doesn't go out with anybody. Yeah. And you're like (Overlapping Conversation)
- S6 That's why I didn't bother because I knew that he would never be able to do an assessment. I just thought yeah.
- S7 Oh, I did it and he got it. And you know he carried on getting what he gets now. Because if we didn't get the support, you'd just fall over, wouldn't you? We just couldn't do it. We couldn't go anywhere without the car. But you tend to have to fight and fight for every single (Overlapping Conversation). And that's so wrong.
- S4 I think it's the [inaudible 00:49:14], isn't it? That's all I've (Overlapping Conversation).

Activity 3 feedback

- S1 Speaking of cars, we have got another workshop to do. And (Overlapping Conversation) it's a car wash scenario. So, talking about Short Breaks, discussing obviously...unfortunately you've never had the opportunity to access them. But we're looking at it as if we were to build a Short Break. So, when you go to the car wash, you pull up in your car and you look on the front and you think right. What (Overlapping Background Noise)? Polishing, do I want it Valeted, usually at a car wash I don't know if you can that properly, there are different levels of service. You have your bronze which is probably a hand wash and they do your doors and they would clean your wheels. And then, they'll have silver which will be all things which are in the bronze but a little bit extra. So, you'll get your windows inside and out done. And then, you'll have the gold, which is all of the bronze, all of the silver and then a little bit

added onto the extra on top of that. So, what we need to do is we need to look at building a Short Break. So, we need to look and see what you believe is...Bronze would be your essential. So, this is your essential thing. This is what you would expect...so, an understanding of the situation that you think that's essential. Then, you would expect that whoever's looking after your child or dealing with that situation will have an understanding. So that's essential. And then, you'd look at right, what would I like on top of that? So, then, you would look at what would I like on top of that? So, that's what we're going to do. We're going to write it down on post its what we believe would be your essential level. Then, we'll look at your silver, then, we'll look at your gold. Just to let you know that this is just to get an indication of what your views are. It's not going to be taken away to the local authority CCG. Say like nobody's mentioned transport as an essential, so that's it. They're not getting it. It's just to get a view. That's why we're doing a different way of...lots of focus groups to get different opinions from people. So, right. A bronze one. If you were having a Short Break, bearing in mind we've discussed the different types of Short Breaks. It's not just an overnight stay. It could be a Short Break in the home. It could be help in the holidays. It could be something like that. So, your child is attending something and you needed a bit of respite for it, which is a short break, what would your essential criteria be? What would you need from that?

S7 You need to get them to where they need to go.

S1 So, it would be transport. What else?

S7 Trust. Trust for who's with your child.

S1 So, trust for the people that are looking after your child.

S7 It's huge yeah.

S5 Who is going to be the person so lots of parents who may get a Short Break then struggle to find the right person to help.

S1 Can you think of anything else that absolutely would be your base line, would be what you would expect as the first level.

S6 Trained staff.

S1 Trained staff. Yeah. So, that's somebody that's aware of your child's situation and is equipped to be able to deal with their predicament.

S3 They would have the awareness then.

S1 And what about for you as parents and carers? Looking at the child's needs, which is great, because that's what it's about. But about you as a parent and carer? What would your essential level be? Like the gentleman who needed the time to do his shopping, that sort of thing. How would you utilise your Short Break? What would the base level for you? It's hard to think about (Overlapping Conversation).

S4 It is really.

S2 Remember when we said about [inaudible 00:52:56] evening. [inaudible 00:52:59] evenings.

S1 So, would it be like having multiple (Overlapping Conversation)?

S6 Suitable times.

S4 Yeah, timing is everything.

S6 Everybody's different.

S4 Yeah, absolutely.

S5 Meeting individual needs.

S7 What is the right time for me might not be for my husband because he's the carer and I work.

- S1 Short Breaks can be used for husband and wife, mum and dad to spend some time together. A lot of people ships that pass in the night. Don't get to no time with each other. So, that would be if you were having a Short Break, your child was attending an activity, you're at work and your husband's off, and you're wanting the Short Break for you, too, it's not (Overlapping Conversation).
- S7 It's not benefiting us.
- S1 So, timing is crucial.
- S4 I'm just going to jump back a little bit to the child though. But a bit variety as well, of the activity.
- S2 Variety of activities. Yeah.
- S1 Yeah, that's great. So, this is like your base line, what you would expect. Your access to Short Break, you're given a Short Break, this is what you would expect to get. If you wanted something a little extra, what would you like on top of that? So, it's meeting everything at this point. It's meeting your bronze, but you want the silver level. So what extras would you maybe want on top of that?
- S4 I think, shall we say the cream on it, would be like frequency, you know. So, say if we're saying the base line is maybe once a week, one hour a week or something like that, then, I'd like to see that frequency a little bit more during the week. So, there's (Overlapping Conversation). Yeah, and some consistency, continuity in relation to...
- S1 You would hope that would be on your bronze...
- S4 You would, wouldn't you I suppose.
- S5 That would depend on the individual's request for a Short Breaks. If someone's only wanting it for a few hours, one afternoon or for a weekend or an overnight stay, your continuity would obviously, like you said, be on the next layer on the cake, wouldn't it?
- S6 I put consistency on that.
- S1 Bear in mind everything that's on the bronze, you're already getting. So, the silver is extra on top of that as well.
- S7 I've written down, in my case, the sibling to be involved as well. Because they tend to get left out.
- S1 Is that for bronze, silver.
- S7 Bronze...No, silver. Sorry. Because the support is for him but she would like to be involved.
- S1 Support is for everybody though really. That's what it is for.
- S7 Because she tends to get...
- S1 Because then in that element like we were saying looking at it from your point of view, parents as well. It's like you know son's getting what he needs, daughter getting involved, you two are getting some time together. So that would meet all of that. Any more examples [inaudible 00:55:57]? Should we jump to gold? So if there was something that you could have that would be absolutely the cherry on the cake, that would be ultimate perfection in your idea of a Short Break?
- S7 We'd all go together.
- S5 Yeah.
- S1 That would be nice.
- S3 The time they go together, family break.
- S7 It's not a break but it's somewhere different so we can all do (Overlapping Conversation).
- S3 (Overlapping Conversation) previously with, do you know when it was aiming high? Do you remember the government initiative called aiming high and the city council had a certain budget for Short Breaks? And we did a lot of consultation around Short Breaks and what

parents wanted. And because there was the money to spend in those days, so, parents said, actually it would depend. We want to do sort of different things. And what they said was it would be really nice to go somewhere together. Actually, that's a break away from hospital appointments, away from the stresses of home.

- S7 Because there are places that you can go together that are autistic focused. And their siblings can get involved. But the parents don't have to be with them. They could be in another complex. But they go off and do with trained support and stuff like that. And then, the parents can go...
- S2 So, you're together.
- S7 You're together. You don't have that separation issue. They can do what they want to do during the day. You can go off and then, come back together at night.
- S3 [inaudible 00:57:27] have you heard of that? That's like an outward bound.
- S7 There have been websites, there's quite a few that would help. They're really expensive.
- S3 But you would all go together, then, the child (Overlapping Conversation).
- S1 Would that be...silver, gold, maybe? Gold. To help to fund [inaudible 00:57:45].
- S4 I think the gold for me is probably unachievable, and that would be sustainability of it.
- S1 Yeah, we'll put that on.
- S4 Yeah, but it's an ever changing landscape, isn't it?
- S1 It is. Is that gold then?
- S4 It would be for me. Because then, obviously I'm thinking from Ryan's perspective. He likes routine. He likes things obviously that he knows he can rely on. So, therefore, if he knew he was going to something once, twice, whatever, times a week, for however many weeks, you can build that in and you can have that conversation. even though I say he's non-verbal, he does understand. So, actually that sustained approach, it would be the goal. But resourcing and funding, obviously, dictates what can and cannot be achieved. So that really would be the...it wouldn't be the cherry. It would be all the cherry bowl I think. (Overlapping Conversation). It would be the cake shop, yeah. It would be the full cake shop.
- S7 Some things they only last like the course is for 10 weeks or the course is for 8 weeks and then, that's it. So, it's done after that.
- S4 I mean, the one I think of is Ryan's accessed some gymnastics once and he really, really enjoyed it. Don't get me wrong. I know that it was only put on by British Gymnastics or whatever the organisation was called. And it was really good. And it happened and he really enjoyed it. But then it stops. And you know, it was then going to come back and it never did. And so, you know, again, it's just that sustainability element. And that is really difficult to achieve in today's landscape really.
- S3 Look on the local offer because (Overlapping Conversation).
- S4 Yeah. Well, I've never heard of that. I'll definitely be googling that this afternoon. Yeah.
- S3 I'm sure there is a special gymnastics.
- S2 Is it Sutton gymnastics, Sutton village gym do a special gymnastics session. And I rang them about it because we were going to do an event (Overlapping Background Noise). But I think it only runs through the 6 weeks' holidays.
- S4 Yeah. But it's just getting to understand what's out there and (Overlapping Conversation). Don't get me wrong. When I say gymnastics, I mean, running around doing trampolining. I don't actually mean gymnastics. (Overlapping Conversation). Yeah, they have the gravity one. Because I remember my son... He's told us about that and he's going to take him isn't he so.

- S5 I think ones during the week during the day. But the other one is on a teatime on a Thursday (Overlapping Conversation).
- S4 Yeah. That was the one he was talking about (Overlapping Conversation). I read about the cinema things. Yeah. They rotate them around the region don't they?
- S5 He went to the Sponge Bob one, didn't he, at the...
- S4 The Odeon. There's a lot of them in [inaudible 01:00:27]. (Overlapping Conversation). (Laughter). But in fairness, not as much. As I need to know.
- S7 But the timings on Sundays isn't the best (Overlapping Conversation).
- S6 (Overlapping Conversation) everyone it's like it's got to be relatable...age relatable because a lot of things that...
- S1 That would be like...do you think that would be a bronze level though? You wouldn't want your child of one age going to something that's age inappropriate.
- S6 Yeah.
- S1 Age appropriate.
- S3 Age as in chronological age or (Overlapping Conversation).
- S7 And he might not want to do something...
- S2 So, it's kind of meet all the age brackets for Short Breaks (Overlapping Conversation).
- S3 Age appropriate to their disability.
- S6 Even though he's 16, he's not a typical 16-year-old. But he doesn't want to do things that like a seven-year-old would like to do or a normal 16-year-old would want to do. It is difficult.
- S7 It's like Joseph's 16 but he's got the social understanding of a six-year-old.
- S5 And that's like Ryan, isn't it?
- S7 But he doesn't want to do the six-year-old stuff.
- S4 No. That's the problem.
- S7 That's what he understands.
- S4 It's developing the balance of it. It's really difficult, I know what you mean?
- S3 So, would you...say there was a group for...
- S6 You'd have to find a happy medium wouldn't you, you'd have to think. Because sometimes (Overlapping Conversation) he'll get teased because he's still obsessed with Harry Potter or still obsessed (Overlapping Conversation). And he'll try and be more grown up about it. But he just can't. He just can't grasp it. And it's really hard to explain.
- S4 I know exactly what you mean. [Anon] 13 and he's a big 13, tall. And he loves Sponge Bob but he also loves Dora and Diego. And Dora and Diego probably the ones that you hear more when you're out. You get those looks of people...he looks like he's 13, 14, 15, yet he's listening to a programme that's for a three, four, five-year-old. But that's just what he likes, you know. And that's the problem. Because then on another occasion, he will act like a 13-year-old. And so, you're perpetually trying to gauge, aren't you, which way are we going today? Are we going to be that child today? Or are we going to be that child today? You never know.
- S7 Yeah, because [Anon] still watches Peppa Pig. (Overlapping Conversation) watch it, if you don't think...he would watch it. He'll just come down the stairs...
- S1 It's like the flexibility might (Overlapping Conversation).
- S7 Is he going to be 16 today or is he going to be six or is he going to be 12?
- S1 You want him to be with his peers.
- S5 Yeah, that's the thing for me, he's with his age group.

- S6 Because I think if they mix more with their age group, then, they tend (Overlapping Background Noise)
- S5 I think he'll always go back to that.
- S4 Absolutely, actually I've just had a thought whilst we were... On the...I don't know if I'd be the silver...silver probably would be... Just based on that conversation there. Ryan goes to Tweendykes School, which obviously is connected to Winifred Holtby. And they do a lot of volunteering in the school. And I think a lot of the children with special educational needs really benefit from the other children.
- S2 So that mixing.
- S4 Yeah. Say, like within these activities...and again it's a balance init. But if you could get children with an appreciation, which might come from other siblings in that respect (Overlapping Conversation). But also, you know say like...I don't know. Say, it's pre coursework for somebody who's going to be looking at vocational learning and they're wanting to move into the care sector or something along those lines, maybe bringing those people in in relation to giving them experience but also creating that bond as well and understanding.
- S1 Engaging youngsters or...
- S4 Engaging youngsters who have an interest and who have an understanding and a benefit. And I think from that vocational perspective, if they're doing whatever qualifications are these days, it's been a long time, you know they're working towards that, that can then have a feed off and a trade-off. And it might be that additional funding can come from you know, things like you know, work placements and funding agencies and so on and so forth.
- S2 Which may go back to earlier on when we were saying about bringing barriers down where you don't feel like people...
- S4 Yeah, equally as well with that.
- S2 Maybe that can change all that to society really can't it. If you just getting in their young with them in school, that they're growing up as well.
- S1 Are we all done with that, do you think? The ones that are silver and gold.
- S4 That might be a good thought for the day. That's it.
- S1 I mean, it is difficult because you're obviously not accessing the services at the minute. But I think you've done a pretty good job of giving us that perspective of people that are accessing the service. So, what we'll do again is we'll take these away and Colin will analyse the information we've got there, based on the recordings and stuff like that as well. That will be that bit. So, the things gone off. We can't see it anyway. Right. So, the next step...just to let you know what the next steps are. The questionnaire that you all completed, that's now closed. And the website that it was linked to was all closed. So, all that information is now being collated. Our focus groups, we've had...we had one a week from Friday, we had last Thursday, we've got today. We've got another one on Monday. So, we've got four focus groups that's happened. Once all focus groups are done, all the feedback from the events, all the information from the questionnaire, all the findings that go to cabinet in December to do an informed discussion. So, depending on what they say and service development, there might be an opportunity to be involved again. But we have got your contact details. And your contribution today has been fantastic. So, we really appreciate that you've come and spent the time with us. If the service does change, there will be further engagement or consultation. And again, more opportunity to be involved at that point. As it stands at the minute, we are just fact finding. It's just information, gathering opinions and finding out where to go from there. So, the information we've gathered from the focus groups gets

added to the questionnaires. And it will be used to identify the future and shape the provision (Overlapping Background Noise) of Short Break services. So, before any changes, there'll be co-production sessions. So that's with all the different partners that are involved. And there will be a formal consultation that will happen. But that's not what's happening in December. That's an informed discussion. And then, further down the line, will be formal consultation about the services and stuff. So, what I'm going to ask you to do...is I won't keep you any longer...if you can just quickly fill the feedback form in for us. Just to say how you felt the session went, what information you've gathered from it, you know. If you (Overlapping Background Noise). Don't worry. (Overlapping Conversation)

Monday 11th September, 1:00pm – 2:30pm,
The Octagon Walker Street, Hull HU3 2RA

4 Participants

3 Facilitators Colin Hurst, NHS Hull CCG
Becky Colton, Hull City Council
Natalie Jackson, Hull City Council

Activity 1 feedback

- S2 Right. Okay (pause) We've actually finished the one year on. We can always add to it as we go. (Overlapping Conversation). Right. Shall we start with the... we'll start with the bad things first so we can end with some good news. So, have you got a bad thing? So, what's this one? So, hard to access services for my youngest-... So, how do you mean, hard to access services?
- S4 I get help with two of the others, but whenever I try and get help for the third, I get cut down a lot.
- S2 Do you get given a reason why?
- S4 Not really. No.
- S2 Is it a different person that you go to, or a different team? No?
- S3 So, it's from-... so, you've got a social worker for the first two?
- S4 She's all three.
- S2 Right. The same social (Overlapping Conversation).
- S3 Right. But the first two get short breaks and the other one...
- S4 Nothing.
- S3 ...Because they've been assessed as needing nothing, then?
- S4 No, he needs a lot.
- S3 So, has he been assessed?
- S4 He's physically the worst. Yeah, he's got diagnosis. We keep asking her and she just, "we'll do it," and never do.
- S3 So, you've asked for a social care assessment and never had one?
- S4 Yeah.
- S2 Okay. (Overlapping Conversation). There's been a change from a-...
- S1 It means that one, because my son accesses (Overlapping Conversation). If there's an emergency come in, you get the phone call to say, "Sorry, we can't have him in that night because there's not enough rooms." Yeah.
- S2 Ah, right. Okay.

- S1 They're normally really good, like I said it's (Overlapping Conversation).
- S4 (Overlapping Conversation) So they have other children that go there?
- S1 If there's an emergency, "Oh, they have to move in to the building." Then they have to ring up and readjust all the timings (Overlapping Conversation).
- S2 So, it's cancelled at short notice?
- S1 Yeah.
- S2 Yeah? Next one?
- S5 I feel like my life's dictated to by the panel. Because my direct payments are done through my social worker. And even when nothing's changed, it has to keep going back through the panel to be approved for me to have my hours. (Overlapping Conversation) Whereas if nothing's changed, why can't it stay the same?
- S2 Okay. So, you're just kind of continuously going back to the panel, telling them the same thing, is that what you're saying?
- S5 Yeah. Or my social worker does.
- S2 Okay.
- S6 Mine sort of backs up [Anon] really, what she's just said.
- S2 Yeah. So, hours applying for [inaudible 00:04:15] as good as a social worker involved. So, yeah, so they're kind of linked, aren't they? In fact, they're kind of...
- S6 [inaudible 00:04:23] in the panel (Overlapping Background Noise) job.
- S2 So, if you've got a good social worker, you get loads, and if you haven't, you get... (overlapping conversation)
- S6 Yeah. (Overlapping Conversation).
- S2 ...which kind of links to what you were saying before, doesn't it?
- S1 Mine's been off ill for eight weeks.
- S6 I think a lot of it depends on the pressure that they're being put under as well.
- S1 They are, because they've only got (Overlapping Conversation) part-time.
- S5 I mean, she comes regularly. And she's nice enough. But it just seems like everything's hard work.
- S1 It is.
- S2 Okay.
- S1 A fight for everything, really. You have to fight for everything.
- S6 That sounds [inaudible 00:04:55].
- S5 Yeah. I mean, apparently, I was only given direct payments anyway, because I was working at the time. And [Anon] was under 16 and stuff like that. But then, he had a few mental health problems. My mum's gone in a home. So, I've lost my child care. And so, everything's actually worse, and I need more hours and not less. And she's itching to get rid of them.
- S1 Well, mine got cut because he had a kick-off and they had to evacuate the building. Because... and I understand why, don't get me wrong. But that was because of his recent mark on his brain. And then, we got cut four days a month instead of... we shouldn't have lost it ever.
- S4 Because his needs are more.
- S1 Yeah. (Laughter). We've had a hard six months. But they've got there now. He's back on plan how he should be, but it's took us all this time to get it put back.
- S2 So, it took six months to get you back on track.
- S1 (Overlapping conversation) yeah.
- S6 So, really, you're only going to get as good as what your social care assessment is. So, if you get a poor social care assessment, for example, that assesses you as not actually needing what you need...

- S1 Oh, I needed it. They knew I needed it.
- S6 Then, you're not going to get-...
- S5 And I think it also impacts on how (overlapping conversation) proactive you are as a parent. If you're somebody that isn't confident in approaching people (Overlapping Conversation).
- S1 Yeah, if you haven't got a gob on you, it's really (overlapping conversation)
- S5 No. You have to fight and you have to shout.
- S1 (Overlapping conversation) isn't it? I'm sorry, but it's true, isn't it? You've got to have a gob on you. And I find that... because they say to me, "You should ring me when you're struggling." But you see, that's (Overlapping Conversation).
- S5 (Overlapping Conversation) you get the answerphone, or they're going to ring you back (Overlapping Conversation).
- S1 Christmas, I rang up because I really didn't know what to do with my son. And the answer was, "Ring the police." He's non-verbal, he's severe autistic, what are the police going to do? Do you know-...
- S3 And that was from your disability social worker?
- S1 That was... the one who was on call. Yeah. I got an apology. I got an apology for it, but that didn't help at that time. And when you're vulnerable, it's hard to ask for help as it is (Overlapping Conversation).
- S5 I was talking to somebody the other day whose son was threatening to commit suicide at 14. And she rang CAMHS and they said, "There's nobody here until after the weekend. But we'll try and get back to you within 24 hours after Monday." This was on the Friday night.
- S2 Did they not give you the single point of access number? No?
- S5 No. She had nothing.
- S1 I mean, that isn't unusual. You do hear it a lot, it's not unusual.
- S5 That's not unusual.
- S6 I would say, and people, parents tell us this a lot. You don't feel... a lot of people don't feel comfortable asking. (Overlapping Conversation).
- S5 (Overlapping Conversation) You don't feel listened to, you don't feel respected.
- S6 I don't want my child to go to respite, you know. (Overlapping Conversation). I don't want her to be away from me. I want to do things as a family...
- S1 I struggle (Overlapping Conversation).
- S6 ...Like everybody else does, go to BigFun with all four of them, do whatever. I don't want her to be, have to go with somebody else. But the fact is to have a normal life, that's what you have to do. But sometimes people are made to feel like, well, you're asking a bit too much here. You should really... you know, you've got stuff. Don't ask for anymore. Because you know, there's nothing there to-...there's no leeway. You won't get any extra. So, you know.
- S1 There isn't enough funding, there isn't enough rooms, there isn't enough-... And I mean, I'm really fortunate, I am. Because at least one of mine gets something, do you know? But the other two are autistic-... Asperger's. But for them, because they didn't have the social worker, even though we had for [Anon], they've missed out on so much. But again, it's like you said, you can, if you ask for stuff, you can feel like you're doing something wrong. You're in the wrong.
- S2 Okay. So, we've had one from everybody, so we'll start back at this end. So, bad things still? So, what've we got? So, not enough consideration given to working families. How do you mean?

- S6 Well, I work... me and my husband both work full time. And I've always felt that if I ask for any more hours, well, it's been told to me anyway, that I should either use my DLA or I should rely on family.
- S5 Which is what I was told the other week when I said I wanted to start looking for a job because I don't want to be on (Overlapping Conversation) benefits. And I was told to save my overnights, which is the only social break I get. (Overlapping Conversation) save that up and use that to pay carers for [inaudible 00:09:29].
- S6 And it's not just that, but you haven't got the choice, have you? If you could use regular childcare-...
- S5 (Overlapping conversation) And I'm going to be working around school hours, I mean, during school holidays, I'm going to need the extra help for child care.
- S6 At the end of the day, you can't use regular child care for our children because you know, they're not regular children, let's be honest.
- S4 There isn't any, is there?
- S5 There isn't any. And if I'm working minimum wage and I'm paying somebody minimum wage, I'm working for nothing.
- S1 Yeah. You're cornered, you're cornered.
- S6 I mean, my son, if he was non-disabled, he would be walking to school and getting himself his breakfast and getting dressed and he'd be walking to school.
- S1 That's exactly the same for my teenagers at the moment. You can't-... all three of them, you can't just... I should be able to lie in bed once my husband has gone to work and then, get myself sorted. They're 18, 16, 14. Do you know...? But you don't-...
- S6 But I don't think DLA should be used as a reason for us not to request more hours, if DLA was to be used for child care, then direct payments for child care wouldn't exist. It's like a cross (Overlapping Conversation).
- S1 Well, Shaun, he's two on one at all times.
- S4 Well, they should... they do say that you can't... am I right in this? You can't use your short breaks as a child care. However, that's because the council should be providing suitable child care. But people are telling me they can't access suitable child care for their child because they're older (Overlapping Conversation) So, no suitable child care is an issue.
- S5 I mean, out-of-school close off at the age of 12. My daughter's 12 now. And transport only goes home to school, school to home. So even if she went to a child minder, the transport couldn't take her to that child minder, if I worked out-of-school hours (Overlapping Conversation).
- S1 (Overlapping conversation) college, about six years ago, I wanted to go to college. And a mainstream nursery said they would take Shaun on. That was before all the kicking off and stuff. And they said they would take him on, and it was at Parkstone school. When I took him, after all the assessments he was [inaudible 00:11:29] in and everything else, when I took him for that first day, the lady who was going to look after [Anon] cried and said, "I don't think I'm going to cope with him." (Overlapping Conversation). So, that stopped there. And whether I'd applied for college (Overlapping Conversation).
- S2 So, that's kind of properly trained staff, really.
- S1 Well, it puts parents' lives on hold. I know you love your kids and you're supposed to look after your kids and all that. But you're being told you should go out and work and do something. But I can't-... how can I do this when my kids are like this?
- S5 And we're not being supported in being able to facilitate going out to work and...? (Overlapping Conversation)

- S6 I'm sure that people would rather we were working than claiming benefits.
- S5 I mean, surely they'd like a tax payer paying back into the pot rather than just taking out of it. (Overlapping Conversation).
- S1 [Anon] is two on one at all times across the board, his risk assessments, the lot.
- S4 Did he used to go to counselling?
- S1 Yes.
- S4 Has it got [Anon] as his carer?
- S1 No, no. But he's a bit [inaudible 00:12:25]. Your face is familiar, so I've probably seen you somewhere along the way (Laughter). (Overlapping conversation)
- S2 Has anybody else got qualified staff in their-...? Because you were saying about the staff when you went to the school, didn't have... Has anybody else got qualified staff?
- S1 It was the-...
- S4 If they're not qualified you mean?
- S5 With all due respect, unless you've got a disabled child, you can't understand our point of view. Because you expect when your child gets to a certain age, they can dress themselves, they can toilet themselves. They're sleeping through the night. We don't get that.
- S1 Like I said, [Anon] goes to work. (Overlapping Conversation) And although he's two at all times, it's only me looking after all three of them. And it's like... and I've got quite a few ailments myself. But it's like, oh, you're alright. And it is like (Overlapping conversation)
- S2 You'll get by, yeah.
- S4 You feel like you should have to cope, so.
- S2 So, we've got hard to access some services due to funding and staffing...
- S6 Oh, let's go to some good, because I'm getting depressed. (Overlapping Conversation).
- S5 We all try to stay real positive, don't we? (Overlapping conversation) We are fun people, honestly.
- S2 Parents should be allowed to attend panel reviews. So that's...
- S6 I don't know what other people's thoughts are on that, but-...
- S1 No, I think it's a really good one.
- S6 (Overlapping conversation) I don't know if it would be a good thing or a bad thing really. But for me it'd be good, (Overlapping Conversation) personally I'd like to go. (Overlapping Conversation).
- S5 Well at least then we'd be able to argue our case (Overlapping Conversation) point of view.
- S6 Or at least have the minutes, have the minutes, because they're discussing our families.
- S2 Hmm. That's interesting. Because from a health service point of view, you get access to records. So, theoretic-... I'm not saying that that's how it should be, but that's how you do for-... but you do for [inaudible 00:14:02]. (Overlapping Conversation). (Laughter). You should get a letter from a consultation (Overlapping conversation)
- S5 You do... you see your assessment paperwork, though, don't you? You just don't see them in (Overlapping Conversation).
- S6 Yeah, you see what the social worker fills it on your behalf. But you don't actually know what's said (Overlapping Conversation).
- S1 Unless all your files get lost. I've had that.
- S5 I can't say I've (Overlapping Conversation).
- S2 So, any more bad... have you got any more bad-...?
- S5 I was told that if I get direct payments, I can't access other services such as [inaudible 00:14:30].
- S2 So, we've kind of got that as well.

- S4 So, you can only have this...
- S5 Or that. You can't have both.
- S4 Right. So, it's not as flexible as you would like it to be.
- S2 So, this or that, which doesn't make a great deal of sense.
- S6 I don't know how applicable that is. But it's just something I've encountered.
- S2 (Overlapping Conversation) some care providers allowed to charge double the amount an hour given. How do you mean, sorry?
- S6 So, like I won't name names, but certain care providers will charge like £14 an hour and we're actually given a certain amount of money. (Overlapping Conversation). I mean, we pay 7.50 an hour but obviously you get a little bit more, don't you, for tax and national insurance...
- S5 If they go through an agency...
- S6 If you go through an agency, and I don't think they should be allowed to do it. I think they're making money off the back of families with disabled children. (Overlapping Conversation).
- S2 So, the amount that you get is... so, you get 7.50 an hour.
- S6 To pay the carers. But obviously you've got your NI and tax on top of that and a little bit for holidays and (Overlapping Conversation) stuff. But then...
- S2 So, that's over. That should be over. But then, you get charged 14.
- S6 Yeah, by certain organisations.
- S4 So, therefore you're using up more hours.
- S5 It's double, isn't it? Yeah.
- S2 (Overlapping conversation) You're halving the amount of hours that you can have, yeah. So, anymore bad ones? Have you guys got any more bad ones? Yeah. So, it doesn't give me time for myself. So, (Overlapping Conversation).
- S5 I always have to take my children with me. (Overlapping Conversation).
- S2 So, it doesn't-... so you don't get a short break even when they (Overlapping Conversation).
- S4 Yes, I see what you mean.
- S5 If they all went on together...
- S2 They all need to go at the same time, really. (Overlapping conversation)
- S4 So really, they should... yeah, like you say...
- S6 People-... they need to be considerate of the families with more than one disabled child.
- S2 Sixty percent who aren't, it's not meeting their needs because the kids are having a great time, but you're not getting a break at all, which is the whole point of it. Have you guys got-... has anybody else on this side got any more bad ones?
- S5 No.
- S2 No, right. We'll (Overlapping Conversation).
- S3 So, you could put about people, therefore, who've got more than one-... children with a disability. (Overlapping Conversation). There's quite a lot (Overlapping Conversation).
- S2 Oh, yeah. We picked that from the surveys as well.
- S4 There is quite a lot. Yeah.
- S2 So, shall we go through the rest of your bads?
- S5 Yeah. I often feel that it's more about budget rather than my child.
- S2 So, it's more about budget than child. Yeah.
- S5 (Overlapping Conversation) rather than basing it on the individual needs of the family, it's, well, you know we are [inaudible 00:16:47].
- S3 And so, it's provision-based rather than assessment of your need. Right. Because that's kind of like the opposite of how it should be.

- S5 Because one tying in with that one, I've also put always feels that we're under scrutiny to how we use it, as opposed-...
- S2 Yeah, which is similar to this kind of panel thing. So...
- S1 [inaudible 00:17:11] because it's twisted. (Laughter). (Overlapping Conversation).
- S2 So, limited availability.
- S5 Like the kids play scheme. I've been told I need to apply now for next summer holidays. And I always end up leaving it too late. Yeah, because they're oversubscribed. There just isn't the availabilities and things.
- S2 So, that's kind of linked to those two.
- S4 How is that funded?
- S3 Some's local authority, and it's topped up with... yeah. So, all the activities that they do, horse-riding and stuff like that, that's all fundraised. (Overlapping conversation) Yeah, fantastic.
- S2 So, you have to give lots of notice.
- S6 There's two there, but I don't really know (Overlapping Conversation).
- S2 But that's not reciprocated when they need to change it, they just tell you at short notice. Yeah.
- S6 That's just [inaudible 00:17:58] different councils having different rules. We wanted in to East Yorkshire, but we didn't because of the way that they...
- S1 They said there isn't as much if you move in-... yeah, we had that. If you move in to East Yorkshire, (Overlapping Conversation).
- S6 They said that we would have got like three, four hours a week, which there's no way I could have continued working. But I don't... see, this is just about Hull City Council, isn't it (Overlapping conversation)
- S2 Well, no, that's fine. Because what will happen is that they'll look to other councils to see (Overlapping Conversation) for solutions. So that's kind of separate to (Overlapping Conversation).
- S1 And (Overlapping Conversation) East Yorkshire, one of my friends, she really struggled.
- S2 No that's fine. We can keep that in because it's different.
- S6 And that's just for all of us, I think really. We just have to fight tooth and nail for hours
- S2 That's kind of linked to those (Overlapping Conversation).
- S1 (Overlapping Conversation) anything.
- S4 It's quite draining, isn't it?
- S1 Even down to wheelchairs. (Overlapping Background Noise).
- S5 I know this is not like, children. But my mum's in a nursing home. She doesn't weight bear or transfer or anything now. And we asked for a wheelchair assessment. We couldn't go to the appointment with her, so, her carer took her, which we had to pay for the carer to do it out of her hours. And then, because she could sit up in an easy chair, she wasn't allowed a wheelchair and we was like, well how the bloody hell is she meant to get into it in the first place? (laughter) Social care across the board is horrendous.
- S6 Wheelchair assessments is a totally different ball game, isn't it?
- S2 So, if... wheelchair services we can (Overlapping Background Noise) [inaudible 00:19:28] health. So, there's a card on the table over there. So, if you take that, we can sort that out for you. Okay. So, once we've done-... so, we've done all that. So, the good things, we'll go through good things. Good. So, we'll go (Overlapping Conversation).
- S1 (Overlapping Conversation) we've tried to be more positive than negative. Yeah.
- S6 I couldn't be without my direct payments.

- S2 So, first, your best one.
- S6 My best one, that one.
- S2 So, direct payments allow me to continue your career. (Overlapping Conversation). Your best one?
- S5 Helps to alleviate her separation anxieties (Overlapping Conversation) because she gets into a routine of going to someone else, rather than me.
- S2 Right. Okay. So, I'll put that-... so, (Overlapping Conversation). So, this is around the same service or person.
- S5 I mean, even if I go in the kitchen, she's up my backside. (Overlapping conversation)
- S1 (Overlapping conversation) (Laughter)
- S2 So that's really... we'll come onto that in the next bit (Overlapping Conversation). So, same person or service.
- S6 (Overlapping Conversation) they're less dependent on you, you know what I mean?
- S5 I mean, she's really socially interactive with other people as long as I'm in eyesight. But that's what you need to work on, isn't it (Overlapping Conversation).
- S1 My daughter's like that, but as soon as you're out of it, her security blanket's gone.
- S5 And this is the other reason why she goes to my sister's because it's a family member who she trusts and she'll go there and let me have a break.
- S1 I don't have that, you see. (Overlapping Conversation).
- S2 So, that's really important that [inaudible 00:21:09] because otherwise, it's just not going to work. Yeah, okay. Yeah, have you got any good ones?
- S6 Peace of mind when in a nursing setting. So, if they're-... so, my child gets continuing care. She goes to Sunshine House. That is in a nursing setting where I know there's qualified nurses. If anything happens, they're on the ball. They ring me up. If she's ill... I mean, if she's got a temperature or something like that, then, obviously I have to cancel it and I can't send her because there's other children that are vulnerable. But if she's screaming, for example, which she does quite often, they are able to deal with her, and they know what to do and they don't panic. And they would alert me to stuff that I wouldn't necessarily notice. Like they said to me, "Oh, she's doing so and so. Maybe you ought to speak to your neurologist because it could be like a seizure." I was like, "Alright. I didn't know anything about that." They absolutely know. So, when she's there, I actually can sleep, because... I do still worry about her, obviously. But you can switch off to some extent. (Overlapping Conversation).
- S4 All night? (Overlapping conversation)
- S6 Yeah, pick her up in the morning.
- S4 So, that's nice for Stan as well, for him to have time with you and dad.
- S6 That's the thing. Yeah. (Overlapping Conversation).
- S5 Well, that's what I've put on here-... (overlapping conversation)
- S2 So, you've got siblings, quality time? Everybody's got that? Okay. Yeah. So, if I take those off everybody.
- S6 And not just quality time, but allowing them to do stuff that they otherwise wouldn't be able to do.
- S1 ...They can't do. There's so much mine can't do without (Overlapping Conversation).
- S6 Well, I've put give siblings a break.
- S2 So, that's kind of related, so enables siblings (Overlapping Conversation) kind of linked...
- S6 To have their own friends, for example.
- S4 So, it's not just about the disabled child.

- S2 Have you got that as well, have you? It gives my sons a chance to interact with other children.
- S1 For that one, I did (Overlapping Conversation).
- S2 What's that one? Gives me (Overlapping Conversation). Yeah. So, these are all kind of related. Smashing, yeah. So, we've got, it helps psychological and emotional wellbeing of parent and child, so it helps the bond between you both and keeps you both sane.
- S6 Not necessarily the bond. I think just everything about health and wellbeing really, emotional, psychological, you know, I think everybody... whether the child's got special needs or not, needs some time out. Obviously, I think it's a bit more important when you have got a disabled child. Because they're obviously a lot more (Overlapping Conversation).
- S5 When you're not so mentally exhausted as well, I think it makes you a better parent (Overlapping Conversation).
- S1 Yeah but, I think as well, like you...
- S5 Just getting a full night's sleep (Overlapping Conversation).
- S1 Well, that doesn't happen in my house. You're the same, because we've got three of them with obviously different needs. But because they've still got their special needs, when that one goes away, you're still not getting your sleep. You're still coping, you're still (Overlapping Conversation). It doesn't work. It just doesn't work. Mine didn't get diagnosed till... [Anon] was nearly leaving school after fighting all them years. And [Anon] was just going into senior. So, you've got all of that as well, haven't you? The diagnosis and stuff, so.
- S2 So, has anybody else got ones related to that?
- S5 Well, these two are pretty similar.
- S1 What's the related one?
- S5 Encourages social reaction-... encourages social interaction with others, and improves their social skills. (Overlapping Conversation).
- S2 So, I'm going to put those-... I'm going to put that in the middle there because that's similar. Pop that one-... Social skills. I'm going to pop that there because that's similar, so, I'm going to-...
- S4 Social activity of the child. That's what you want to put.
- S5 I mean, children learn through play, don't they? They learn the boundaries and how to socially interact (Overlapping Conversation).
- S2 Is that your one? So, social activity. So, is that, for you... so that's for the child, their social activity?
- S6 Their social aspect, yes. So, being with their peers who are at the same level. And doing appropriate activities. (Overlapping Conversation) For example, the stuff that she did on the play scheme, there's absolutely no way she could go to a regular group, you know, like every other kid, if you wanted to, could go to... you know. (Overlapping conversation) Whatever.
- S5 I mean, she started off with Deaf Society, going to swimming lessons, but they only did like, one lot of sessions.
- S2 Can you just... give me two minutes.
- S5 So, now when she goes to swimming (Overlapping Conversation).
- S1 We've given him information overload, aren't we? (Overlapping Conversation). We've give him information overload. (Laughter)
- S5 Because, like the ones that came with the Deaf Society (Overlapping Conversation) when she's got her ear plugs in... (Overlapping Conversation).
- S6 (Overlapping Conversation) it was vibrating, it's his phone was ringing... (Overlapping conversation)

- S5 ...And they're telling them to jump in to the pool, when she's in the ordinary group, she can't hear or whatever what they're doing.
- S4 So, you need that, yeah, special class.
- S5 Yeah. But they only did the one session, didn't they, at Haltemprice.
- S4 Oh, what a shame.
- S5 Yeah. And then they sort of left it to the others. But you see, [inaudible 00:26:44] kind of her own worst enemy, because she is quite social with people, and because she's willing just to get in and do stuff as well, they forget she's got extra needs. Yeah.
- S6 I think it's really important that parents, husbands and wives, or wives and wives, and husbands and husbands have quality time together.
- S2 Yeah. So, we've kind of got that with... this is kind of related to this. This is spending time with kids, spending time with partner, using the time in a particular way.
- S4 I think it's, yeah, basically it's just keeping your mental health, because, you know...
- S2 Yeah. (Overlapping conversation)
- S6 ...The last thing you want is relationship breakdown, parental breakdown. You have a, you know... (Overlapping Conversation) actually, it's really common.
- S5 (Overlapping Conversation) and then he ended up self-harming. That was just because we couldn't get the support that we needed.
- S1 I suffer with depression and anxiety. And I've got other ailments and everything else. Well, in fact, I'm on 32 tablets a day to keep me going. But still, you still have to carry on. You haven't got an option, because who else is going to be there? And that's it, we was on about what you just said, spending time with partners. [inaudible 00:28:08]. I can't remember the last time me and [Anon] just spent a night together, or... and you yourself with your partner. It just doesn't seem to exist. I don't even know why we're together half the time, I'll be honest. I can honestly say I love my husband (Overlapping Conversation). He's absolutely brilliant. But a couple of years ago, we had time out with each other. I don't think we've got anything in common anymore, do you know? I think it's just become a habit. And just become that... He goes to work, he comes home, I've done the tea. The kids, we'll sort them, do you know? And I think it just becomes that madness of just (Overlapping Conversation). Yeah. Normality, isn't it, really? But I've still got loads of good stuff. (Laughter). We are comical in our house, by the way.
- S2 What other good things have you got?
- S1 Well, I've got... he used to go [inaudible 00:29:00] and he loved them days out, because they do, they did a lot of them.
- S2 So, it's enjoyable for them?
- S1 Yeah. And again, it kind of contradicts itself with Lime Tree, this one.
- S2 It fits them ones, yeah.
- S1 Because even if it's an emergency, we'll get the phone call to say he can't come in. But vice versa, if there were an emergency as for our pipes froze-...
- S2 If you were in an emergency.
- S1 No, no, I was in an emergency. My pipes froze at Christmas time. So, I rang up and asked if there was (Overlapping Background Noise). And they said yeah, so, I got him in. They got him in. And there was-... and I did get it sorted. And they said, "Look, we've managed to get the staff in for overnight. We've sorted the kids out. He might as well stay in overnight." So, like I say, it kind of works both ways, that. Kids. Absolutely.
- S2 Have we got-...? So...
- S6 New experiences, just like what [Anon] was saying, really.

- S2 Yeah. So, similar...
- S1 You couldn't access that, they can.
- S2 So, it's similar to that (Overlapping Conversation).
- S5 Like Laura said, knowing that she's in safe hands when I'm not there to care for her.
- S2 Properly qualified people. Yeah.
- S1 No, I pick my son up now. (Laughs)
- S2 People who know what they're doing as well. So, they don't necessarily have to be a nurse or a doctor or anything like that. Have you got-... have you got your last one? Yeah? So, being able to do activities we wouldn't necessarily be able to do as a family (Overlapping Conversation).
- S4 Is that because they're-...
- S6 That's because we need three adults, one per child, because they're all ADHD so, they're all at different directions.
- S4 So that enables you to do something everybody else (Overlapping background noise)
- S6 (Overlapping Background Noise) horse riding, which I've never tried with (Overlapping Conversation).
- S1 She wouldn't dare, would she? (Laughs)
- S6 I wouldn't, [inaudible 00:30:36] wouldn't know what's hit them.
- S5 Them two are very similar. (Overlapping Conversation) gives me a break. It gives me the opportunity to socially interact with my peers. Otherwise, your life just revolves around that child and nothing else. And then, you end up losing friends. And then, you lose your support network.
- S1 Your family drift away as well, because they don't know how to help you. And if you're normally the strongest one in the family and you can't deal with it, they don't know how to deal with it.
- S6 Yeah. It's... I've got emotional break and a physical break. Because it's tough in both ways. It's tough... you know, physically, you need that break, because if my back goes (Overlapping Conversation).
- Sx (Overlapping conversation)
- S5 (Overlapping conversation) When I had to lift her into a car seat (Overlapping Conversation).
- S2 So, that's kind of enjoying (Overlapping Conversation) so that's enjoying particular things.
- S6 Exactly. So, it's very physically demanding. And then, you know, you have to keep yourself well otherwise you can't carry on (Overlapping Conversation).
- S2 So, that's similar to the familiarity (Overlapping Conversation) able to talk to staff.
- S6 Then, where would you go? Emergency care. And that would cost a fortune, wouldn't it?
- S2 So, your last one was being able to talk to staff openly. So, it's not just important that your children have are familiar with the services (Overlapping Conversation) It's important from your point of view (Overlapping Conversation).
- S1 I think it's-... Yeah. Where we access is like KIDS, when the staff come and pick him up, you can ask them anything. You just be open and honest and [inaudible 00:32:12] the same to you. And at Lime Tree, they're very open and honest with you. I'd rather ring Lime Tree than ring the social worker, because I'm not likely to (Overlapping Conversation).
- S6 But is Lime Tree good, though?
- S1 Lime Tree's amazing.
- S6 They've threatened to take [Anon] down on a couple of occasions on a night when [inaudible 00:32:22] has been stuck in traffic.
- S1 I'll tell you something, it's been amazing-... it's amazing.

- S6 And I just-... I've started saying, "right, well take him, then." (Laughs)
- S4 To be fair, I have had to pick her up from there once when I missed the bus. (Laughs)
- S6 [inaudible 00:32:35] Road to Hessle. And Lime Tree is back at (Overlapping Conversation).
- S5 So, if you accidentally get stuck (Overlapping Conversation).
- S1 It's his second family, though. I feel so, like, once he's there-...
- S4 So is he happy there?
- S1 He's amaze-... he kicks me out the door. If I drop him off he goes like (Laughter). Well, he doesn't, he can't talk, but you know what he's saying. (Laughs)
- S4 So, he knows where he's going?
- S1 He's very confident. He knows it's his time out. Because it's not just ours, it's his as well, away from the family, so.
- S4 But the thing is, as much as you need a break, you wouldn't want them to feel like, and I don't ever want to feel like (overlapping conversation) she's got to go somewhere.
- S1 Yeah. Because I felt that way when he first used to go. (Laughter). (Overlapping Conversation).
- S5 (Overlapping conversation) is, oh, so you'll just get fed up of me, then, and then you can divorce me. And I'm like (Overlapping Conversation).
- S1 [Anon] says (Overlapping Conversation) he said the only reason you don't sell me is because it's too much paperwork (Overlapping Conversation). (Laughs)
- S5 (Overlapping Conversation) I says to her, I'll always love you, I don't always have to like you, but I do love you. (Laughter).
- S2 Have you got... is that your last one?
- S6 So, sleep. Sleep. Your own mental health. Very important.
- S5 I think what needs to be looked at across the board is this kind of speculate to accumulate. If they put the money in and give us support now, it's not going to impact on the health service and mental health (Overlapping Conversation).
- S1 (Overlapping Conversation) You're going to end up, I'll tell you something, yeah, if it carries on, you're going to end up with a lot of kids in care, because they're closing every-... wherever they can cut, they are.
- S4 But that would cost and all, wouldn't it? (Overlapping Conversation) in the long run.
- S1 I mean, if it weren't for the Lime Tree, I can honestly say I'd have had a proper breakdown by now.
- S4 (Overlapping Conversation) To build the foundations (Overlapping Conversation).
- S1 He would be in permanent care, yeah. [inaudible 00:34:12] because I pulled this all together, but it's realistically...
- S2 Right. Okay. So, we're going to come back to those in a minute. So, what we would normally do now is we'd go through and cross out all of the names. So, like Lime Tree or [inaudible 00:34:27]. Most of what you've said is fairly generic.
- S1 Yeah, yeah. It's just the one he accesses so it's easy.
- S2 So, the ones that they access is around enjoyment, and it's around familiarity and those kinds of things. So, we can do that. So, what we're going to do now is individually, and I'll tell you why it's individually in just a minute. So, take one of those each. One there for you. So, what I want you to do, we'll take (Overlapping Background Noise) we'll take about five or ten minutes, yeah, five minutes individually. (Overlapping Conversation) Yeah, so what I'd like you to do is write down... so, you've got space for three things. You don't have to write three things. What you-... what do you get out of a short break? So, what do you currently get out

of it? So, if you experience short breaks, what do you get out of it? You don't have to write three, but if you have three, that'd be great. And then, what would you like...

S5 Do you want us to put what sort of short breaks we access?

S2 No. No. And then, what you would like to get out of it. So, what you would like to get out of it, you might already get out of it. So that's totally fine. If you don't, that's totally fine. And then, the same thing for your kids as well. And the reason why we do this like this is that not everyone's always comfortable in saying honestly what they would want to get out of it, because they're worried that people might judge them. So, yes, so nobody's going to see these...

Activity 3 feedback

S2 You never know. Some people can be... Some people don't always think they can say what they think all the time. So yeah, so they'll go in the envelopes, and then, so they won't be attributed to you. There's no way we're going to know who's written what. Yeah. So, just take five minutes for that. (Long Pause). That's smashing, thank you very much. So, we've got... alright. Right. Okay, so, the next thing is what we're going to do is design a short break. So, we're going to write down all the things that a short break should be. So, obviously it's general short break, not a specific one. So, how do we know it's a short break, type thing. So, we're going to do is a big list of all the things that should be included in a short break. And then, we're going to through and decide-... you know when you get your car washed, or it's in the big hand car wash things. Bronze package, they'll basically just wet your car. Gold package, they might rub it, and then... (laughter) do you know what I mean? So, it builds up. So, whatever you get in the bronze, you get in the silver. Whatever you get in the silver, you get in the gold. So, what we're going to do is do a list of things that a short break should be and then, decide whether they would be in the bronze, the silver or the gold package. Yeah? Now, just so you know, when we've done this before, people were a bit cagey at the beginning about saying what they thought should be in and shouldn't be in. We're not going to take this list to the council and say, "A-ha, we've tricked them. This is the absolute minimum that they will let you get away with." That's not how this works. So, we're looking at what's essential and what would be good to have, nice to have, is what happens when we feed that back, so, one example is transport. We talked a lot about transport in one of the focus groups. And they said, "Well, they're never going to pay for a taxi to go and pick them all up." And I said, "the council and the health service are working a lot closer now. So, we're both commissioning services, we're both working together on this. And we have a patient transport service. So, for the sake of 50 quid a week, we could expand that service potentially, if there was a need for it." So, it's one of the ways of highlighting what's essential, what would be great. And just because you've said it's part of the gold service doesn't necessarily mean that that that would immediately dismiss it. Because if we can make a quick win, if we can give you a couple of things off the gold by making savings across different agencies, then we'll do that. So, we'll use these as some inspiration, the good and the bad. So, obviously we want to stop the bad things happening and keep the good things going. So, what... just kind of shout out what needs to be...

S5 Safe environment, not only the place like Sunshine House or Lime Tree, but also like (Overlapping Conversation) if they're on play schemes and things, having people...

S6 Safeguarding [inaudible 00:41:57] minimum.

S2 So, not just like the physical, but training.

- S5 Yeah. Making sure there's trained staff on hand to deal with if they fall off a horse or whatever.
- S2 Yeah. Okay. So, safe environment. Yep. Anything else?
- S1 Enjoyment.
- S2 For who?
- S5 Yeah, it's got to be fun.
- S1 For the kids.
- S2 Smashing. What else? (Pause) (Laughter). You can have whatever you want on this list.
- S6 (Overlapping Conversation) Extra money for transport costs. So, if the carer wants to take them out for the day out on the bus...
- S2 So, is that not included in the...?
- S6 No.
- S1 Direct payments, you mean. (Overlapping Conversation).
- S5 Well then, they tell you to go to the library and wait six weeks to get a bus pass.
- S1 Yeah, I'm just going through that now, yeah.
- S2 Okay, I'll put transport in, just because transport costs is a bit...
- S6 Because like, my mum is one of my direct payment carers for my little boy. But she can't...
- S5 Take him out and afford to take him...
- S6 She can't use his car, because she lives in Lincolnshire. There's a... for the insurance with motability, there's...
- S5 There's a five-mile radius around (Overlapping Conversation).
- S1 Oh, is there really? I never knew that. Wow.
- S6 Yeah. So, she has to use her own car. She's 65 and on a pension, obviously. You know, this direct payment money's a little extra for her. But she has to... Well, I usually (Overlapping Conversation) just give her 20 quid.
- S2 So, that's limited insurance.
- S5 But obviously, it would be better with his chair and everything to go in your car and you use hers, wouldn't it? (Overlapping Conversation).
- S6 Because it's a bigger car, yeah.
- S1 Absolutely. Yeah.
- S6 Just as an example.
- S1 No, it's a good one.
- S2 No, that's a good example. Because it's not (Overlapping Background Noise) cost of transport. That's the intricacies of why it can't be done. Because if we went to council and said, "Oh, the cost of transport," they'll just sort of laugh and say, "Well, we can't afford transport either." But if it's around limited insurance, there are solutions to those kind of problems that come (Overlapping Conversation).
- S6 The solution would be [inaudible 00:44:18] change to their guidelines really. Because it only came in in the last four years, about four years ago they brought that in, yeah, that rule in.
- S1 I didn't even know that existed, I'll be honest.
- S4 Because you can change it so that anybody's on your insurance, can't you?
- S5 As long as... yeah, yeah. You can only have two named drivers as well on your motability insurance, can't you?
- S4 You can't, you have it open access, so anybody you (Overlapping Conversation).
- S1 Yeah, I was told two people.
- S5 I was always told it was only two.

- S4 You don't have to name them. If you've got different carers, your social worker can send a letter and they just put you on open access policy. That's what I've got.
- S1 That's good to know.
- S6 So that, you can maybe rub that off (Overlapping Conversation).
- S4 I haven't named anybody on mine.
- S2 No, no. We'll leave it on, because it's important.
- S6 And me and [Anon] are obviously named drivers, but my mum, I was told my mum couldn't be insured for it because she lived more than five mile or whatever it is.
- S4 No. Speak to your social worker. That's what I did. (Overlapping conversation)
- S2 So, do we want to equal...? There's this kind of, you're being told one thing, you're being told something else. So, equal information.
- (Overlapping conversation)
- S6 You don't know what you don't know, and you don't know to ask a certain question.
- S1 Information is not given freely, is it?
- S5 Not always the person that you ask knows the answer. So, it depends who you ask to who knows what information.
- S1 Because when you do sometimes... I mean, when the kids were younger, not so much now. But when the kids were younger and you'd say-... and they say, "Well, what is it you need from us?" And you're sat there and you're going, "I don't know what's there to know what to ask for. What can I ask for if I don't know what's there?" Yeah, it's... you know.
- S4 I think to be able to be [inaudible 00:46:03] to attend I think, as well ideally. But that again is for...
- S2 So, the panel meetings. Is that where they decide...
- S4 How many hours you can have.
- S1 What you get and why you get them are they entitled to it. (Overlapping Conversation). This is all based on what your social worker tells them.
- S5 Yeah. Or your casefile (Overlapping Conversation).
- S6 Or what has come out of your assessment.
- S1 I think this is important as well, what you're doing right now I think. Like if there were open opportunities to have meetings every now and again for parents to go to a council.
- S4 That's what KID's for, isn't it?
- SX I'm going to recruit you shortly. (Overlapping Conversation).
- S2 So, if we can just kind of look into the assessment thing a bit more. So, is that because you're worried that they're not fighting your corner enough?
- S1 Yeah.
- S2 Or is that...
- S6 My social worker, she's lovely. But she's not very proactive. She's not...
- S1 I just feel their hands are tied as well, I really do. I mean, nobody's ever said that to me, but you get that feeling that (Overlapping Conversation).
- S5 (Overlapping Conversation) They're under pressure to keep to budget. And this is don't ask, we don't get.
- S1 Yeah, we've only got this and this is what you can, yeah.
- S2 So, you kind of want assurance that they're actually looking at what the needs...your needs are rather than (Overlapping Conversation).
- S5 They've got to be as proactive as we are.

- S6 They've got to ask the question, why aren't parents allowed to go to the pole meetings? I mean, if it's obviously just a blanket decision, it might be a little bit difficult. Because some parents, it might not be appropriate for them to go, for whatever reason...it is a difficult one.
- S2 Because of safeguarding (Overlapping Conversation). Yeah, okay.
- S1 And you don't want to end up in full on arguments because I suppose if it's about your child, it is personal. Whereas their (Overlapping Conversation) isn't it. Absolutely. Yeah.
- S2 So, what was that? Sorry. You can go to...
- S6 Well I would just say, for an example, if you go to a tribunal that they're discussing you aren't they because it's to do with living allowance.
- S5 Yeah. If you're with DLA, you can appeal, but people don't tell you you can first ask for an independent review before you to go to appeal. Because once you appeal, then, you lose your right to appeal for six months. (Overlapping Conversation).
- S2 So, is there no (Overlapping Conversation) appeal?
- S1 In this last six months, we lost our car. We lost our disability and everything, because of our social worker was filling forms in, but she fell ill. And it never got in in time. So, we lost everything. And we had to try and fight for all that again and whys and what's and... so like I said it's been a horrific six months.
- S2 So, the best (Overlapping Conversation). So, are we saying that the best...so, in an ideal world, you wouldn't have one person...you wouldn't be reliant on one person to sort it all out?
- S1 Yeah, it would be ideal that. Because the person who's picked my files up has kindly...
- S4 Starting from scratch.
- S1 (Overlapping Conversation) that was coming into KIDS for some funding for her to go on holiday, it's the first time we've heard about it.
- S4 The young carers grant.
- S1 And that was stuck in file since January. And I rang them up and they said they hadn't received the files. So, the girl who picked the files up sent me the form that was unfilled and then, went on holiday. She's on holiday for two weeks now.
- S4 So, the disability team needs to be fully staffed or (Overlapping Conversation) staff.
- S2 So, cross cover.
- S1 I do ring the head of the pod which obviously, she's overloaded as well. So, unless you scream at her...
- S6 I can't get a hold of my social worker very often. (Overlapping Conversation) that are also supporting disabled children as well, because they're actually taking pressure off the council. But it should come from central government, not necessarily the individual council.
- S2 Right. Because we're probably not going to be able to change that. I mean, I can...
- S6 The councillors can though.
- S2 Well, (Overlapping Conversation). I'll make a note of it that there should be more central funding.
- S6 It should be mentioned. But I think...
- S4 They do rely on voluntary sector staff a lot.
- S6 They do. I think that needs to be acknowledged by the council, actually.
- S2 Okay. I'll make...
- S1 There's a lot of volunteers. (Pause)
- S1 Right. Okay. So, back to the ideal short breaks. It needs to be a safe environment. It has to be enjoyable for the kids. Transport will be good. Equal information freely given so everybody knows everything. You can attend an assessment or at least have an appeal.

There's more involvement, and you will be assured that people are working for you. You're involved in the planning of services. So, things like this. You're not reliant on one person to access. Because if they're off sick...

- S4 Yeah. I think the capacity of the disability team... that's what you're saying, isn't it? You can't get a hold of your social worker if you need to you know...
- S1 And you used to have link worker didn't you? If that person [inaudible 00:51:28] you could get a hold of, and then the link worker would do something but... I haven't had a link worker for years. So, I don't know if they even exist anymore.
- S4 They do have assistants, social care. (Overlapping Conversation) activities as well that are a variety factors (Overlapping Conversation) that are appropriate to...
- S5 Age and stage.
- S4 Yeah, age and stage.
- S5 Age appropriate.
- S6 Our children don't...I mean, apart from (Overlapping Conversation).
- S5 (Overlapping Conversation) a three-year-old is no good giving them 12-year-old activities.
- S4 Yeah, age appropriate, learning appropriate, learning ability.
- S5 And if you have more than one child with special needs for them to be able to access a play scheme or whatever...
- S1 They should be able to do a family unit. Yeah.
- S5 Just to give the parents a proper break. (Overlapping Conversation).
- S2 It's almost like a family ticket type.
- S5 Do you get a short break?
- S1 You see it doesn't matter for me now, because are mine teenagers. But for you, you're still going through this...and it's still difficult to (Overlapping Conversation). That's exactly it. People say how do you come? It's my normality. That's the answer I give them. I don't know any different.
- S5 Well, that's what I always say. So, what's abnormal becomes normal because that's the (Overlapping Conversation).
- S1 (Overlapping Conversation) where is the guideline of what would be, you know. Giving parents guidelines.
- S6 And working to be seen as a form of respite as well needs to be acknowledged.
- S2 It's been...sorry.
- S6 The families that want to work that choose to work, it needs to be acknowledged that that's their respite. (Overlapping Conversation). That is what they choose to do with their hours.
- S1 My husband says...
- S6 That's my respite.
- S1 When he goes to work he's getting a break. That's what he actually says. (Overlapping Conversation).
- S2 So, it needs to actually be a break.
- S5 (Overlapping Conversation) actually to communicate with your peer group. It's just for going out and seeing daylight some days.
- S1 My husband, has sat down to me and said...before he said 'I don't know how you haven't had a breakdown yet.' I said, "Because you keep leaving me to go to work, so I'm alright." (Laughter). [inaudible 00:53:48]. Because on top of all of that, not just looking after your kids. You've still got the everyday life of cleaning, cooking, sorting out. So, it's not just (Overlapping Conversation).
- S4 So, would that be something that would help you?

- S1 Definitely. I had to call someone in coming in to help me clean up because I [inaudible 00:54:06] making cups of tea and stuff. But I think it's important for some families (Overlapping Conversation).
- S4 That might be a break to some people.
- S1 Yeah. That's what I'm saying. To some families, being a break from...
- S4 Like domestic.
- S1 That's the word. Because there isn't anything like that. Somebody said something about home help. And I said, "I don't know anybody who'd come in and help me." I'd feel uncomfortable. But there is some people who would benefit from that, instead of having to do the washing and the ironing, that could spend time on the kids or whatever. Because...
- S5 Even just going and soaking in a bath. While somebody did the ironing or something (Overlapping Conversation).
- S6 I get in the bath for about at least an hour and a half (Overlapping Conversation) if I'm watching (Overlapping Conversation).
- S1 I'm going home to six baskets of ironing after (Overlapping Conversation).
- S5 (Overlapping Conversation) every time I get in the bath, somebody wants the bathroom and needs to ask me a question.
- S2 Are we talking about the amount of time?
- S1 Okay. Yeah. I think it's...
- S6 It's going to be different for everybody, isn't it?
- S1 Everybody. Because again, everybody's so individual in their lives in how they run it.
- S6 And also, it fluctuates throughout your life and to your disabled child. So, sometimes...
- S5 Some needs are more (Overlapping Conversation).
- S6 Yeah, absolutely. They might have been ill. They might be experiencing some crisis or trauma. And things fluctuate and change, and you need help at different times of your life.
- S2 So, it needs to be flexible.
- S1 And I think that (Overlapping Conversation).
- S5 It also needs to be flexible around like school holidays and things, Yeah theres like the kids play scheme. And you might get your direct payments week to week, but (Overlapping Conversation). That's only the 6 week holidays. During the half term holidays, there's nothing.
- S6 Yes, there's nowhere else for them to do it.
- S1 Lime Tree do...sorry, Laughs they do days, don't they? If you can get in because the waiting list's that long. But there's only KIDS that I know that will take them for a full week. And that's in the whole of Hull. And even their [inaudible 00:56:10] haven't got their kids [inaudible 00:56:11]. (Overlapping Conversation).
- S4 Because the holidays are really difficult for people.
- S2 So, it needs to have enough room...
- S1 And the services really.
- S6 The kids are out of routine for a start, so that brings its own issues. They're not at school, so, there's extra time at home to have to carry all the rest of it. And it's a really mega stressful time.
- S1 Holidays are terrible, aren't they?
- S5 Extra provision for holidays when the kids are off [inaudible 00:56:43] and they haven't got the routines.
- S4 A lot of parents tell us they really struggle.

- S5 It's that about kids often go into meltdown don't they. Either they go into meltdown once they go back to school or they go into meltdown because of loss of routine (Overlapping Conversation).
- S4 Yeah, because that adult provisions so it'll be all the time, I would expect.
- S1 And I think in emergencies, they need somebody to be able to contact and get a reasonable...Like I said, if you're even in a place what I got was unbelievable. So, you need somebody who actually knows about special needs kids when you're ringing them up. I don't know. Like I say, if your kids are in there, go to somewhere like this, and then, there's a crisis, that child might not be able to just go on at that time if somebody's ended up in hospital. Do you know what I mean? There needs to be like emergency services. I don't mean the ambulance service and all that. Yes, the need to be back up plans for kids that are on...not everybody else's statement. Not all the kids have a statement. But if there is a member of the family that has to go in...
- S5 But I often put it off because of having somebody to take care of [inaudible 00:57:54] while I was gone. I couldn't rely on (Overlapping Conversation).
- S4 So, like a special circumstance (Overlapping Conversation).
- S6 (Overlapping Conversation) That goes in with your flexible doesn't it a bit.
- S1 Last Tuesday, I had an operation on my throat. And they said, "You need to chill out for 72 hours and let everybody else run around you." I'm thinking (Overlapping Conversation). I ended up in hospital with my son on the night time, and stayed in hospital with him for a full week. So, then sorting my other two kids out, because [Anon] needs two on one. So, my husband had to stay over as well as me.
- S4 So, it's when you're in a crisis.
- S1 That there's somebody there to support.
- S4 Is there a network when you're in a crisis? Never mind preventing the crisis to start with.
- S1 There isn't.
- S6 If we get a phone call from school, either me or my husband has to go and get him and that's it. (Overlapping Conversation)
- S1 It's very difficult as well.
- S2 So, in an ideal world, what else should a short break be?
- S2 A party. (Laughter).
- S6 It would be nice to go together, wouldn't it?
- S4 Yeah, if you've got more than one.
- S1 As a family, yeah.
- S2 For the family ticket idea. So, people actually get a break.
- S6 But your break, instead of being split up as a family where the disabled child goes to (Overlapping Conversation), you're actually doing activity as a family like every other family can do. But potentially, somebody came with you to support you, to help you. Or you were able to go to a place that could accommodate that.
- S2 So, how would that be a break?
- S6 Well, you've got someone to support you to do what you're doing.
- S1 Yeah. You've got a carer to support you to back up.
- S5 You know how when you go to Butlin's or whatever and they have the baby sitting service. We can't access any of that because they aren't trained to...
- S4 So, to take a carer with you.
- S5 You would have to take a carer with you.
- S2 So, to support (Overlapping Conversation).

- S6 I would've loved to have took a carer with me to Spain for a fortnight.
- S1 I paid my mum when we got married took her with us to America.
- S6 (Overlapping Conversation) same time it wasn't a holiday. That's the thing. I was just beside myself.
- S4 But do you want to have them to go somewhere and you go off on a holiday without them?
- S6 No. I would have wanted to take a carer with me. That would've been perfect.
- S1 It would be nice if you had one night during your week's holiday, where you and your husband could go off to a meal rather...than you knew there was some child care there that would support [inaudible 01:00:24].
- S4 When the kids club on holiday when they would do some kind of... So that you're not a million miles away if they do need you.
- S1 Yeah. Or maybe just... I know this sounds daft and I know that's about the kids. But maybe a respite for parents just to go to... (Overlapping Conversation). It sounds really daft but maybe just like a couple of caravans on the site where the parents could go and have a genuine break, away from the (Overlapping Conversation).
- S4 If you have a carer in your home to help you with stuff, that's lovely and that would help in a certain way. But you potentially, can't really relax because you've got somebody in your home.
- S5 But then if like with direct payments it was allowed to be a relative or someone your auntie or (Overlapping Conversation). Yeah, if they could come and stay at your house while you got a short break.
- S1 You see I could let my mum (Overlapping Background Noise), but she couldn't stay on her own to look after them all. She'd have to have somebody with her, do you know?
- S6 (Overlapping Conversation) direct payments to pay for a carer to come on holiday with you. But you've got to save your hours up. And when you don't get enough in the first place, it's hard.
- S4 But that's where the flexibility will come in. Because that really should be written into your assessment.
- S2 So, would you (Overlapping Conversation).
- S6 It's a gold standard, I think, to be able to take a carer on holiday with you. I would put that.
- S2 Shall we start going through these? (Overlapping Conversation).
- S5 Is there any like overnight place type things? You know like kids doing the week's scheme. You know, like in America, all the kids go off to the camp for a week, don't they? And they stay in like dorms and things. Why couldn't they do some sort of like summer camp for special needs kids?
- S4 Overnight respite summer camp.
- S5 Where they maybe go for like four days, three nights.
- S2 So, just kind of getting my head around this. So, let's say as it stands you get two hours a week. Would a summer camp week be more valuable than those two hours a week?
- S5 I think if it was one where they did overnight as well, like I say, like four days, three nights. Then, the family is getting a complete break. And it affects all mental health (Overlapping Conversation).
- S1 It wouldn't be any good for me because I need the weekly (Overlapping Conversation).
- S2 So, what I'm trying to get to the bottom of is it better to have lots of little couple of hours here and there or is it better to have once a week big chunk (Overlapping Conversation).
- S6 I think that would be a gold standard as well. It should be on this.
- S1 It's holidays.

- S5 You still have your few hours a week, but then have the option of a summer's holiday (Overlapping Conversation).
- S4 You're saying, you can either have that or that.
- S6 I wouldn't have the summer camp.
- S2 No. I'm trying to get to...like because obviously...
- S4 It's in addition, isn't it?
- S2 Yeah, it's an addition. So, that's gold. Right. Okay, that's fine. So, should we go through these and kind of label on...I think that's bronze. So, safe environment. I think that's probably in your bronze package. (Overlapping Conversation). Yeah, okay. (Overlapping Conversation).
- S4 Over the weekend.
- S5 Not everybody (Overlapping Conversation) like yourself (Overlapping Conversation).
- S2 Sorry. Have you got something else to add to the list?
- S1 We've just been saying that it's hard to go shopping. Just somebody to come in the house and have all three of the kids or whatever.
- S4 So, that you can go shopping.
- S1 So, she could just go have a bit of a shop.
- S6 I've got my husband. So, he stays.
- S1 But then don't you want support? That's what I'm saying.
- S6 I'll do it on my own because I don't drive, he drives. So, I'll get in the cab (Overlapping Conversation) on holidays. Yeah.
- S1 That's what we're saying. (Overlapping Conversation). So if he could drive you it would be easier.
- S2 So, just on what you're saying with a break...
- S5 (Overlapping Conversation) on day-to-day basis. You can't jump on a number 1 and go into town or owt.
- S2 So, with the actual break, would you say that those kind of household living kind of activities is bronze.
- S1 Yeah. Shopping, I'll tell you something, shopping is so massive, it really is.
- S4 Domestic help, isn't it?
- S1 Yeah. So, if you...
- S5 If I could go shopping and get it back at home and packed away, in half an hour. But if she's with me, it takes me about three (Overlapping Conversation).
- S6 The eldest kicks off and breaks things, I don't even bother.
- S4 So, you need somebody to just look after her while you could go shopping, to enable you to get your (Overlapping Conversation).
- S1 It's massive. (Overlapping Conversation).
- S2 It's short household cover (Overlapping Conversation). So, we're saying that's kind of bronze.
- S5 Yeah. During the week, it's...
- S6 So, that's the basic thing that people need to function. (Overlapping Conversation).
- S2 And the kind of holidays it's kind of gold. Then, in the middle, you've got your silver.
- S1 They're like essentials, aren't they?
- S2 So what would be covered in that bronze?
- S6 Oh, that one [inaudible 01:05:50] then.
- S2 So, here you were saying around time with your partner, time with your kids, time to get things done. Is there any variety in there or is that the absolute basic?

- S1 That's the basic. Yeah. And it also depends on how your kids are that day or how you're feeling and (Overlapping Conversation).
- S5 How many kids there are and what ages they are and what their needs are individually.
- S6 Just to get this to enable us to carry on doing our caring role. This is not because we want (Overlapping Conversation).
- S1 It's just very difficult just to do everyday tasks is very difficult. You put the washer on. You've got one kid kicking off because it's too noisy. So, you have to wait till that one's in bed who don't go to bed till 11:00 on a night because you can't send a 17-year-old to bed. Do you know? Its half 8, come on love. You can't do it. So, you've got to be...you're doing washing overnight, and then, you know...
- S5 I mean, I'm forever getting in trouble where my friends are like, for God's sake, go to bed. It's 3:00 in the morning, why are you still on Facebook? Because I'm like, I know I'm going to be up in half an hour anyway.
- S1 And then, you get, "Why can't you come out with us?"
- S4 It really helps you to maintain your normal life, a healthy balance, that everybody else can achieve.
- S1 It would be nice to have (Overlapping Conversation) the family. (Laughter).
- S5 We do a 12-hour shift, we go to our job, and we come home and we'd rest and we'd eat and we'd sleep and interact and everything else. But as full time carers, you never get that break, it's 24/7.
- S1 You've also got...
- S4 The emotional.
- S1 Yeah, but it's also as well, which some people say, "Well, you're the parent, anyway." So, why do you get carers when you're the mum and dad? I'll tell you what? I'll move in yours, you come in mine for a week and tell me then. My friend did it once. She came and lived with me for a week, one of my best friends. And her words was, don't ever fucking ask me to come and stay with you again. That was her words to me. She said, "That was one of my hardest weeks I've had to do." She was French (Overlapping Conversation). I don't know. It might go further because [inaudible 01:08:13] to look at the swear word than the rest.
- S2 Okay, so going through the rest...I'm really conscious of time because we're way over the hour. So, transport. Where do you think that's...? Bronze, silver, gold?
- S5 I would say bronze because not everybody has transport.
- S1 And it's hard for me to use some transport as well.
- S6 Transport is quite a broad spectrum.
- S4 The thing is if you haven't got the transport to get them to their break, how do they have their break?
- S6 Well, the KIDS put transport on and that's essential.
- S2 It's considered as bronze. And then, provided is silver. I mean considered (Overlapping Conversation) there's no point...
- S5 I mean you could put it like as a bronze standard.
- S4 Depending on their individual circumstances.
- S6 It depends on the issue. (Overlapping Conversation) for example, I could, potentially take them to that play scheme. They're there all day, I would pick her up. That's okay. I could manage that. Somebody else might live somewhere different and not be able to do it. However, if it was for an hour's session or half an hour session, then that is not a break for me. Because once I've got the wheelchair in the van, it takes me however long to tie her up,

- to ratchet her in. Then, she's crying in the back (Overlapping Conversation). (Laughter).
Then, she's crying and I'm looking in the mirror and (Overlapping Conversation).
- S1 It's not worth it. No. I've turned things down where it's been for like two hours because it's not worth all the hassle.
- S5 By the time you get there, you get (Overlapping Conversation). Then, you've got to go back again.
- S6 And we physically can't take them because we're at work. So...
- S2 So, this needs to be properly considered.
- S4 So, depending on the person.
- S5 Depends on when, where (Overlapping Conversation).
- S6 So, tailored around the family.
- S2 So, I'll put that here and tailor to the needs because obviously tailored. That needs to be tailored. (Overlapping Conversation).
- S1 Tailor the needs and then (Overlapping Conversation). (Laughter)
- S2 Okay. So, equal information freely given. Is that bronze, silver or gold?
- S6 I think it's just basic standard.
- S4 But you won't be able to access it if you don't know.
- S2 So, attending the assessment or being assured that they're working for you.
- S6 I think at a minimum get the minutes of the meeting. I don't know really. Does that like fit in with all that.
- S2 Do you need to be in the room do you think?
- S1 Not necessarily all the time. Because it's having the time to get there as well.
- S5 You don't have to be in there but optional.
- S4 But this is only really to do a panel. I mean, I don't really know how it fits in with the short break. (Overlapping Conversation).
- S4 I'm assuming whatever type of short break you have, there will some sort of selection process.
- S2 So, okay. So, let's change it then so the assessment process...
- S4 Fits in with that. I think it's a bit...
- S2 So, is the assessment practice needs to be transparent, is that what you're saying? So, you need to know that...it needs to be obvious.
- S6 But it needs to be transparent. I think if it is a panel assessment [inaudible 01:12:10] assessed like that, But I think parents definitely should be given the opportunity to attend various because at the end of the day (Overlapping Conversation).
- S5 We should know what criteria is required as well for them to attend various...
- S1 You're aware that a lot don't you, that don't fit the criteria. (Overlapping Conversation).
- S5 How do we know what we can and can't apply for?
- S6 I'm not going to let the council [inaudible 01:12:32] options. (Laughter).
- S1 You don't ask, you don't get.
- S6 Well, they didn't mention but...
- S2 So, as a parallel example for the health service, we don't...we don't provide everything through the health service. So, if you want to go away and be a page 3 model, you need to get your tits done, we won't pay for them. However, if you have a medical condition, if there is medical need, then, we would do it. But (Overlapping Conversation). (Laughter) medical need, then, it's considered. It's considered at a panel. But the whole process...
- S5 You'd have to be assessed first.

- S2 Yeah. So, a clinician has to assess you. You're part of the assessment (Overlapping Conversation). But the decision is behind closed doors, but it's very...so, our policy is really clear. So, you need to meet these criteria to qualify for it on the health service. If you don't meet this criteria, then, your clinician can make a case for you to be considered.
- S4 Yeah. So, you want clear criteria then.
- S2 So, I'm just saying that that's an example.
- S4 It's a good example actually (Overlapping Conversation).
- S6 (Overlapping Conversation) get them to do it anyway.
- S2 Well no because they won't get paid any more. That's about how it works. (Overlapping Conversation). (Laughter).
- S1 It's what keeps me sane I tell you. (Laughter).
- S2 Okay. So, involved in the planning service. I'm just really conscious of time. So, involved in planning services. (Overlapping Conversation).
- S6 Social care package, you're involved in that issue of care assessment.
- S4 Yeah, it's in the code of practice.
- S6 Yeah. So, that's very basic.
- S1 And can I say put in layman's terms as well. Because there's a lot of stuff that I don't understand they write down.
- S4 If it's jargon.
- S1 Yeah, there's a lot of that. And I really am a bit dumb with stuff like that.
- S4 And you don't necessarily know unless you [inaudible 01:14:44] or see it all the time. (Overlapping Conversation) clear.
- S2 So, I've got...put that in the information in layman's terms. It needs to be clear, the criteria. The assessment is transparent. So, not relying on one person to access. So, this is all about the access of services, isn't it?
- S4 So, not everything has to go through a social worker. You can self-refer as well.
- S1 That will be good.
- S5 Not everybody has a social worker. Because the only reason they (Overlapping Conversation).
- S2 So, you only get a social worker if you're on direct payments. What if you're not on direct payments, you (Overlapping Conversation).
- S6 You're not automatically entitled to one.
- S4 You're entitled to an assessment.
- S5 But a lot of people don't have a disability social worker. So, therefore, it's you've got to be able to self-refer (Overlapping Conversation).
- S6 (Overlapping Conversation) you're assigned to a team. I don't know about an assessment but I know if you can get direct payments, for my son I have a social worker. Because it has to be referred. (Overlapping Conversation) how it works. (Overlapping Conversation).
- S1 And I've got one for [Anon] but not for [Anon] and [Anon] even though they're on the same (Overlapping Conversation).
- S4 So have they been assessed as not needing anything?
- S1 [Anon] has been assessed as needing, but her age she is, she's not going to get [inaudible 01:16:06]. She's not going to get anything that she needs because she's 14 now. So, by the time she's waited on the waiting list she'll be past the old, yeah. (Overlapping Conversation)
- S2 Short break is run (Overlapping Conversation).
- S1 She's 14. She goes on the waiting list for [inaudible 01:16:20]. (Overlapping Conversation).
- S2 The short break service needs to...and this is in the requirements from birth to 25.

- S1 That'll be a good one because I tell you (Overlapping Conversation). It is.
- S4 If she's assessed to need (Overlapping Conversation) meet that need in whatever way. If that's you know (Overlapping Conversation).
- S2 So what would be a better way of doing this? Is it self-referral or (Overlapping Conversation)?
- S6 There needs to be an option for families that (Overlapping Conversation).
- S1 It's only fair on the social worker (Overlapping Conversation).
- S2 Okay. So, we're looking at how to get over this social worker being off sick type of thing. So, we've got self-referral through the school, through your GP. Is there any...?
- S4 But you're still going to need an assessment, aren't you? (Overlapping Conversation) to assess what you need.
- S6 The social worker assistant potentially could do that.
- S2 Why does the social worker have to do the assessment?
- S5 Who or what is the panel made up of? Is it other social workers or is it people from the council that are allowing you the money for the (Overlapping Conversation)? Actually, who does the panel (Overlapping Conversation)? Because we don't actually know who this panel is.
- S1 It's one of them black balls that they rub and say no.
- S5 Maybe that assessment information (Overlapping Conversation) a separate entity to the social services side of it.
- S1 Independent.
- S5 Yeah. An independent assessment. That's what I mean.
- S4 Well it's still got to be a social care assessment, but what (Overlapping Conversation).
- S5 Obviously, they've been trained within health and social (Overlapping Conversation). But nobody knows who this actual panel consists of. Is it people appointed by the council? Is it people appointed by social services? Is it people appointed by the health service?
- S6 That's an idea. Why can't we have an advocate for parents on these panel meetings?
- S1 That's what I said (Overlapping Conversation).
- S2 Would an advocate be bronze, silver or gold?
- S5 I would say bronze. Yeah. Just a basic standard that there's somebody there that (Overlapping Conversation).
- S6 They could tender that out, that service out. The council could tender that out as a service to KIDS or to another organisation in the (Overlapping Conversation) for a partner to provide an advocate at the panel review meeting.
- S2 I've got a couple of leaflets around health and social care (Overlapping Conversation).
- S4 Have you two heard of the local offer?
- S6 I just think that would be a good idea to do that... provide that. (Overlapping Conversation)
- S2 So, the rest of this is we've kind of said is bronze, cross cover, link worker. Okay. So, variety of activities. So, when you say variety of activities, what do you mean by a variety of activities?
- S5 Swimming, Horse-Riding, cinema, theatre...
- S6 Bowling.
- S5 Beach trips, bowling.
- S1 Yeah, because if you're working (Overlapping Conversation). If you're on a certain amount of money, it's very hard to access funding to do things as well. Like you look to your needs. That's exactly how it works for everybody I suppose. As you're listing your means, there's not that much spare to go and do like you just said, do other things as a family. If you're on

benefits you can get funding. And you're more likely (Overlapping Conversation) to get accepted for funding than you are (Overlapping Conversation). That should be equal opportunities that, I think.

- S4 But that's something over and above your short breaks, isn't it? Short breaks aren't being tested. Anybody's entitled to them (Overlapping Conversation).
- S2 So, these things that the...would not normally have the opportunity to do. Or are they...
- S6 I think that's basic. It's basic. Like KIDS scheme they do lots of different things on lots of different days. And that is like a basic thing for kids to provide that but you come up with that haven't you yourself, as a priority. For that service that you're delivering.
- S4 But they do something different every day. So, that they can have variation. So, they can access something they would not normally be able to do because they wouldn't have the support of a professional.
- S1 That's what I'm saying the funding. If you did want your child to go horse riding, you couldn't afford it. If you are on benefits, you can get funding towards it if you're working and means [inaudible 01:21:40].
- S5 But also with these placements, a variety of activities also acts like a taster session to see what does work and what your child enjoys. You know, they might go into volleyball and go I hated it. I daren't pick the ball up, I daren't do this. But then, they might go horse riding and really benefit from that. So, it acts like a taster session as well as (Overlapping Conversation).
- S6 And if they're really enjoy it (Overlapping Conversation) for half an hour to go to horse riding (Overlapping Conversation).
- S5 But then, you can look at applying for funding.
- S1 But you can't if you're working (Overlapping Conversation).
- S2 So, this (Overlapping Conversation) I suppose this is one of those that we're looking at is rather than you paying £15 an hour and you paying £15 an hour and you paying £15 an hour, before you paid 30 quid an hour to hire an instructor, then, we don't have to give you 15, and you 15 and you 15, because we're saving money by providing it. (Overlapping Conversation) the council. (Overlapping Conversation). Well, I don't know. This is what I'm trying to get to the bottom of. It seems silly that you're all paying individually because that's just a massive industry.
- S6 But then that's not a short break, is it? Because I'd take my (Overlapping Conversation) are disabled and that's fine (Overlapping Conversation). And I'm happy to pay for it for her to do that. But that's not a short break because I'm taking her and I'm sitting and waiting. And I'm physically lifting her onto the horse and I'm watching the two ladies battle with (Overlapping Conversation) pulls their hair and spits on them. And then, I take her home. So that's not my short break.
- S1 But if it was somebody...if the carer (Overlapping Conversation).
- S6 If somebody picked her up and dropped her off and took her horse riding and then, brought her back home, that's a break.
- S1 That's what we're all about. So that could kind of meet your needs but they're still getting something they're interested in as a child. They want to do that, but if you're not able to do that, you can't. And that's what we're saying where funding comes in. If you're working, you can't access that funding. (Overlapping Conversation).
- S6 (Overlapping Conversation) is separate. It's like for example the kids play scheme they do something different every day. And I think that that should be (Overlapping Conversation).
- S1 If it works for them, yeah, the kids.
- S6 Because that is just a basic thing (Overlapping Conversation).

- S5 I mean if they do things in the play scheme that they enjoy, then, that's maybe something that we could do with (Overlapping Conversation).
- S2 So, you think that would be enjoyable for kids.
- S6 What would make that thing accessible? The reason they could do it at that time is because they've been taken (Overlapping Conversation).
- S4 And because they have the support of people to do it. It's not like our children could just go swimming or just go to a big farm or go to the beach of their own accord.
- S1 You can't even get them on the beach. Because they're in the wheelchair (Overlapping Conversation).
- S4 (Overlapping Conversation) go swimming, otherwise it's too cold, there's no changing stuff. They need support to do it because they need lifting and carrying. They need (Overlapping Conversation).
- S1 That's another thing (Overlapping Conversation). When you go to some of the [inaudible 01:24:43] you can't because there's no way to change your kid (Overlapping Conversation). I can't do anything. I have to change them in the First Aid. And then, I have to get a member of staff to walk him through the men's while I walk through the women's. Meet him at another side and I have to change him in a first Aid room.
- S2 So, support mainstream access. So, the minimum is council [inaudible 01:25:04]. (Overlapping Conversation)
- S5 (Overlapping Conversation) changing spaces.
- S1 That's huge, that one.
- S5 Even for older children. There's no good putting a bench on with the changing mat on because they're (Overlapping Conversation).
- S1 And my lads arse ain't small anymore. (Laughter).
- S5 You're trying to change them in the boot of a car.
- S1 That's what I've just said. My lads (Overlapping Conversation).
- S4 You can go to the Guild Hall, there's a changing place there, did you know that? Go to the Guild Hall and ask for...you know the side bit (Overlapping Conversation) changing place. Up, down, hoist, everything.
- S2 This is set for (Overlapping Conversation).
- S7 It's not in the Guild Hall. It's the Wilson Centre.
- S4 No, it's in the Guild Hall.
- S7 Have they? The Wilson Centre did have one. (Overlapping Conversation)
- S4 Has it? No, Guild Hall (Overlapping Conversation).
- S2 Well, wherever really. (Overlapping Conversation).
- S4 Yeah, a proper bed. Loads of room. Fantastic.
- S2 So, with the mainstream access, the council (Overlapping Conversation). Would you say that [inaudible 01:26:17] is silver or gold?
- S1 I think it's really important, that one.
- S5 What?
- S1 The changing, when you're out and about in the council facilities (Overlapping Background Noise). (Overlapping Conversation).
- S5 We said that was a basic need. Everybody has a right to go to the toilet (Overlapping Conversation). I mean in hospital, you have curtains around because everybody has the right to their dignity and privacy. So, why shouldn't a disabled child?
- S1 Or a disabled adult. That rights possible for them all really.

- S2 So, we don't have time. So, flexibility. So, we did say about the urgent support being part of the flexibility. So, urgent support I'm assuming you're putting as bronze. And then, so, we also said around flexible on the review. So, how often it's reviewed, would that depend on...?
- S4 As and when required, I mean, rather than it being led by the parent.
- S1 I see my social worker...she has to be (Overlapping Conversation).
- S2 Being realistic. I'm not going to assess you every week. It cost too much.
- S1 Review every year.
- S2 So, would a year...?
- S6 I think it's six months at the minute.
- S5 She comes to see me every three months. (Overlapping Conversation) she said she needs to go to the panel.
- S2 So, you think a review every six months would be basic? And anything above that would be bronze or gold. Yeah.
- S6 Well, it should be reviewed when required. We should be able to ring and say, "Look, my circumstances are changed. I'm absolutely struggling."
- S1 And you shouldn't have to feel you have to get to breaking point before...because that's exactly how it is. You have to get to breaking point, and then, there's still not all the support there for you either.
- S2 [inaudible 01:28:15] holidays, long lists. That's a capacity [inaudible 01:28:22]. It's hard to grade that capacity. So we won't grade that bit.
- S4 But we do kind of need that as a basic, because if you can't get hold of your social worker and you have got an emergency crisis situation, that your (Overlapping Conversation).
- S2 Yeah. We've got through the emergency support.
- S4 If the disability team doesn't have capacity to deal with your call...
- S2 Well, there needs to be provision is what we're saying.
- S1 They put you on the on call social worker. But they've not got the information of the job (Overlapping Conversation). It didn't even go to the records. They didn't even access the records before we even gave any information...you know what I mean? [inaudible 01:29:00]. We've got no staff so we can't do anything about it.
- S4 So, the on call person needs to be able to do more.
- S1 To be able to signpost properly. And be able to access the kids' files.
- S6 [inaudible 01:29:11] safeguarding, data protection and all that. (Overlapping Conversation).
- S1 (Overlapping Conversation) this one. And they're now just like I did. I'm using mine for instance because I knew that as a fact and they're saying ring the police. If he knew the facts...give me a couple of minutes. I'll just read these notes and I'll get back to you. He was never have given that information. Like I said, I did get an apology for it. But that's how it should have been done.
- S2 Right. I'm going to draw a line under that just because we're way out of time. So, that's it. Thank you ever so much for coming. If you could (Overlapping Conversation). If you wouldn't mind filling out one of these forms just to say how things went for you. That would be lovely. Just so you know what happens next. So, all of this will get written up. If everyone's happy, we'll send you out that report. You don't have to read it if you don't want to, just to show you what we're up to (Overlapping Conversation) council. And then...because what we can do is keep you notified on what the decision from the council was. And then, if you want to be involved in the future, we'll tell you about that as well.

