

a bit good but a bit not good too

Children and young people's views about Specialist Health Services

Consultation undertaken as part of The Care Quality Commission Review of Support for Families with Disabled Children

Triangle
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- Jose King for attending the All Join in Group to help the children understand what the consultation was all about, and to consult directly with some of the children.
- Those who facilitated the groups and individual visits for Triangle.
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- The young people for the artwork and Rosie Holman-Nicholas for the design.

Introduction and Background

The Care Quality Commission (CQC) is undertaking a national review of the support given to families with disabled children. The aim of the review is to promote improvement in the delivery and commissioning of health support for families with disabled children. It will do this by assessing the quality of the local health support provided to families in each local area of England. Although this review is principally focusing on support for families, and therefore primarily consulting with parents and carers, CQC also wished to gather the views of disabled children and young people.

Triangle's Involvement

Triangle is an independent organisation, based in Sussex but working across the UK. We have extensive experience of participation work with children and young people, especially disabled young people, and have previously consulted around experience of different services including health care.

Triangle was commissioned to gather the views of disabled children and young people.

Triangle was commissioned to run two separate workshops targeting different age groups. We also undertook some individual visits to ensure that we engaged with the widest range of children.

We consulted with our own consultative groups from Triangle and with other children and young people in person, by phone and by email.

Who took part

We consulted with 22 children and young people aged between 7 and 27. This sample comprised of 11 girls and 11 boys. The ethnicity of the majority of participants (n = 19) is White British. 3 children and young people described their ethnicity as Asian. Children participated in this consultation in a number of ways, 14 were consulted within two of Triangle's consultative groups, All Join In (n = 9) and the Senior Consultative Group (n = 5), four were visited at home on a one to one basis, and four took part via email.

The Care Quality Commission defined the following categories as target groups:

1. Children with experience of specialist health services
2. Children with long term complex health care needs
3. Children with long term physical and learning disabilities

17 of the 22 children and young people who took part fall into all three of these groups. Three of the children fall into categories 1 and 3, i.e. they have long term disability and use specialist health services, but do not have current long term complex health needs. Two of those who took part fall into categories 1 and 2, i.e. they have long term complex health needs but not a long term disability.

To summarise this another way, all 22 children and young people in this sample have experience of specialist health services, most (17) have long term physical disabilities and or learning disabilities and most (19) have long term complex health care needs.

A wide range of long term physical and learning disabilities and long term complex health care needs were represented in the group. These include physical disabilities, such as cerebral palsy, acquired brain injury, hemiplegia, dyspraxia, cleft palate, arthrogyposis, and complex health care needs including cystic fibrosis, Behcet's disease, diabetes, anaphylaxis, and hydrocephalus. The sample included five Deaf young people. Some children and young people have learning disabilities ranging from moderate to severe and some have autism.

For the purpose of clarity, the responses of the children and young people have not been broken down in to these categories for the following reasons:

- The majority of the children in the sample fit the criteria for more than one category
- The findings indicate that what children and young people have to say does not differ according to their impairment or condition
- Experiences of specific impairments and health conditions will be different for each individual.

The consultation

We were given a list of questions from Jose King looking at 3 main areas: experiences, involvement and improvement. We broke the questions down into easier language; we asked the buddies from All Join In – an inclusive group of children aged 9 to 14 to help us.

The three main focus areas were:

Children and young people's experiences – What type of support have you had? Has it met your needs? What is it like to receive support? What is good and bad about your experiences? What would better support look like for you?

Involvement of children and their families – How can CQC know that families are well enough involved in the care planning for their children/young people and in making services better? What can we look out for to make sure families are involved?

Improvement – How will CQC know that poor services are getting better? What should we be looking for?

How we worked

We consulted with two of our existing consultative groups:

All Join In which is an inclusive group of young children, aged 3 to 14 years old, that meets monthly to provide consultation and advice to Triangle and through Triangle to other organisations. The group works in a range of ways, including through art, sign, music and play.

The group were sent a letter (see Appendix A); we produced focused communication and consultation resources including photo sets, symbol sets and objects of reference, medical dressing up outfits and equipment and medical equipment. The All Join In group always has three different areas in the room; the art area, thinking area and doing area. For this consultation we used these areas as follows:

In the art area, we made cut out people and thought about the medical people that help the children, we thought about words for people that help children stay well and children designed their best or ideal doctor or nurse.

In the doing area, we used dressing up clothes and medical equipment to think about good and bad experiences, we asked the children to show us and tell us and asked the following questions, 'What's good / bad about them?', 'What's the perfect doctor?' and 'If you were in charge, what would you do?'

In the thinking area we worked with post-its, discussion and also a simple questionnaire, (see Appendix B) asking who helps you and your family, what they do and don't do, and what 's good and bad about them.

Triangle's **Senior Consultative Group** is an inclusive group of young people aged 16 and over who are deaf or disabled. The group uses speech and British Sign Language and other communication methods. We looked at the questions and spent time as a group and with the young people individually answering them. We did this as we felt some of the health needs of the young people were quite private.

We made **individual visits** to some children and young people at home whose needs restricted them from attending our groups and one young person chose to answer via email rather than an individual visit as they were very busy with various appointments. These children and young people were also sent a letter, see Appendix C. We made one individual visit to a young person at a local residential unit. We also emailed the questions to some children and young people who lived a distance away or who found group work difficult.

All the young people consulted with were either paid or given a voucher. We told all the children and young people about confidentiality; that know one will know who said what unless we were worried about their safety, then we would think about who to tell and that we wouldn't use their names in this report.

Findings

The main findings are addressed to the children and young people who took part, as the ideas belong to them. This is also Triangle's routine way of working as it enables us to check immediately with children whether we have properly understood.



(Artwork from the All Join In Group)

Summary of findings

Experience of health services

The children and young people who took part in this consultation all have experience of specialist health services, some have long term complex health care needs, and some additionally have long term physical, learning and sensory disabilities. Multiple appointments with a range of health professionals are a common experience and part of their everyday lives. This part of the consultation explores children's experiences of getting specialist health support, specifically to determine if this support is available when needed, and if it is provided by people with the right skills and training. The majority of children reported that they and their families do get support with their health care needs, but the level of support does not match their support needs. The majority of children and young people felt that the health professionals they encounter do have the right skills and training to help them, although they had some ideas for improvements. Children talked about the good and bad experiences they have had. In recounting good experiences, children notably talked about particular nurses or doctors and games designed to make a procedure easier for children. Bad experiences included poor communication experiences and lots of waiting.

Involvement in health services

This part of the consultation explored children and young people's experiences of being involved in planning their care and helping to make services better. The majority of children and young people reported that they were not involved in planning their care. Moreover the information gathered suggests that this group of children are not consulted about what they think about the people that provide this care, or able to choose who provides this care. It was clear that children were not familiar with the concept of complaining. During discussion children suggested that relevant accessible information about complaining and how to complain would be useful. Similarly it is evident that there is a lack of accessible information aimed at children and young people explaining different services or procedures. The majority of children were not invited to meetings.

Making health services better

This part of the consultation explored the improvement of specialist health services and how this improvement is perceived by children and young people. Children identified several things that would improve their direct health care experience. These included a more homely environment, continuity of care, privacy, being listened to and being at the centre of communication. Children were asked if they were an inspector working for the Care Quality Commission what would they be looking for. Interestingly, children and young people suggested that as an inspector you would not only be looking for happy patients and positive service feedback, but at practical issues around communicating with children and being careful whilst taking blood. In order to ensure that children and families are actively involved in making health services better, children have suggested that the information in this consultation is used, and furthermore that the Care Quality Commission keeps asking what would make a difference.

What is this report about

The Care Quality Commission wanted to find out what you think about the health services you use. Their job is to make sure that we all get the best from the medical and health people that help us, like doctors, hospitals and ambulances. We wanted to know all about the health people who support you and your families, what's good and bad about your experiences, about choices you have, if you can complain and what would make the health services better.

What happened and what you told us



Some of you came to groups at Triangle, at All Join In. Some of you met Jose King who works for Care Quality Commission. We visited some of you at home or school. Some of you took part by email or phone.

You showed us what you thought and felt in lots of different ways; talking, making faces, signing, using photos, pictures, symbols, drawing, pointing, smiling and laughing. We did artwork and used happy and sad faces so that you could show us what you meant. Some of your artwork is in this report. When you didn't want to tell us, you shrugged your shoulders, looked and walked away. We have put your words in **bold** so that they stand out because that is the most important thing about this report; letting everyone know what you think.

Your experience of health services: Workshop at All Join In

We asked you questions and played to find out which health services you used, who you saw, who helped your families, if the health services worked together, how they were with you, what was good? What was bad?

These are the questions we asked you: 'Do you have help to eat, drink, stay well, get about and do things?', 'Who helps you?', 'What do you think about the help you get?', 'Do any of these people help you?' We showed you a list of 13 people that might help you with your health needs. You ticked between 8 and 11 of these people. This is what you told us about your experiences of health support.

You told us a lot about difficulties communicating with the people that help you with your health, because they do not use British Sign Language. **I just sit back and watch mum talk to the doctor, sometimes I'm not allowed to say anything, sometimes I just go out the room and play. I don't talk to the dentist, it hurts I don't like it too much. The doctor at school was the best, he was very kind when I was hurt, I could tell him. He didn't sign but he did pointing.**



We asked you 'Can you tell us about nurses?' **The nurse at school is a lady, one left and we just got a new one. I had my thumb seen to by the nurse at school.** We asked you 'Do the nurses sign?' **No they talk and I don't understand them. I have never met a nurse who can sign. I have never met a doctor that can sign. There are no doctors that sign.**

Someone else told us **I met a doctor that signed, in hospital. Well he signed a little bit. 'Have you ever met a bad nurse?' there was a bad nurse who crashed her car outside school. I get a lot of health things at school, which is a bit good but a bit not good too. Mum is best at helping.** 'What makes a good doctor?' **How they talk to me – using sign language and talking to me right.** 'Do you go to clinics or meetings about you?' **Yes, lots. To the 'dw clinic' (we didn't understand this). I felt sad, and my mum felt sad. The doctor went and my teacher and the cw (?csw): it was about if I'm doing well, if I'm doing good.**



Someone else told us **I went to the hospital to see an audiologist, they were cross because they said I didn't come for my appointments but they didn't write to me so I didn't know I was meant to come because I didn't get a letter.** About meetings: **I not sure if I should be involved. Would be better to make sure an interpreter is there and things discussed remain private.**

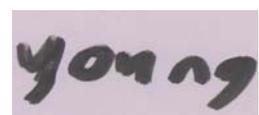
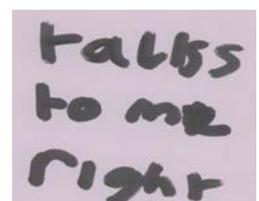
Jose asked about hospital, 'What would you give them a gold star for?' **Lines, bloods – doing it right. Doing it slow.** Jose asked 'Do people ask you what you think in hospital?' **no ... well, its something to do with packed lunches;** on questioning this meant the menu form you fill in as an inpatient.

We asked you questions and played to find out about good things that had happened to you from your health services, what a good health service is, how they can show you that they are making them better.

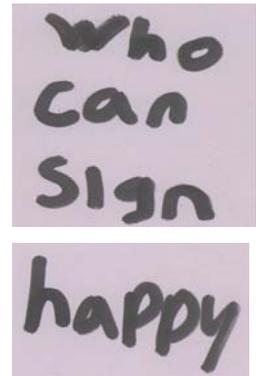
You drew around each other and us, we all wrote on the cut out nurse and dentist; some children and grown ups wrote on post-its and stuck them on.

This is what the post-its said:

- **A hospital should be good, clean, not messy, lots to play with.**
- **Need to get balance between helping people (children) and not frightening them**
- **Good health people tell you what is going to happen so you are not nervous**
- **Good health people don't try to feel for you, because they don't know what it is like to be you**
- **Autistic children at my school should not be made to feel different and they should be able to choose their helper**
- **About doctors: should be kind, young (25) talks to me right**



- Doctor, someone who is strict and tells you what to do. They need to be really clear and need to know what things to check. Needs to have a shave and make sure he looks clean
- A doctor, someone who's good at listening. Makes a good check that everything is alright
- Having things like interpreters if the doctors don't sign
- About dentists: hate fillings, not at all go to dentist, man dentist, and lady there too, gave me sticker and toothpaste
- About optician: put glasses on me, good they man? Want lady one



Your experiences of health services: Individual Consultations

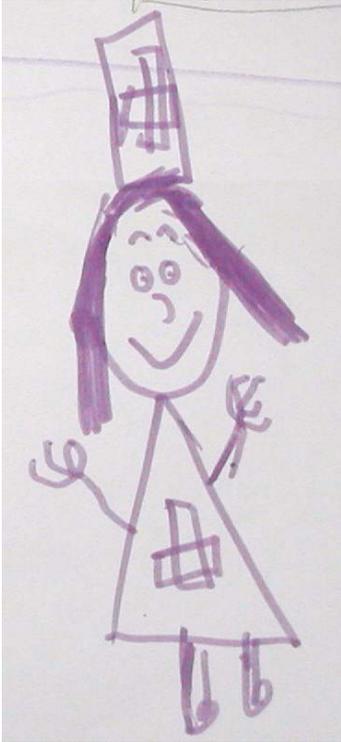
We asked you what health needs you have. You all told us different things. Some of you had several health needs. One of you said **asthma, eczema, urticaria, back operation for scoliosis, feet and calves-tightening of tendons**. Others told us that **I have operations on my hands and arms to straighten them ... I have hydrocephalus and right sided hemiplegia ... I was born with a cleft lip and palate**. Other health needs you told us about were **Behcet's Disease; Down's Syndrome; Cystic fibrosis, I need help keeping my lungs clear; Cerebral palsy**. Someone told us **can't walk**.



We asked you 'Who helps you with your health needs?'. Some of you told us that lots of people in different places help you with your health. **I see doctors and nurses at Hassocks-local Drs, in London at Great Ormond Street and in Brighton at The Alex. I know quite a few of them. I see the dentist who helps look after my teeth. I saw paramedics who helped me when I was tiny and I see surgeons. I go to The Alex not just for check ups, had quite a lot of operations and sometimes they help my chest and ears. Another young person told us I am cared for by a specialist cleft team based at Guys Hospital so all my support has been in one place.**

You told us about different therapists that help you with different health needs, **I had a SALT (speech and language therapist) at Guys to help me with my feeding ... I receive regular physiotherapy and I have orthotic equipment to aid my walking in the form of a splint and inserts in my shoes ... physio- different ones they get me active to keep my lungs clear ... OT (occupational therapist).**

Other people you told us about were **Consultant paediatrician ... respite care, ophthalmologist, I am seeing the eye person tomorrow as I need glasses audiologist, orthotics ... helps with my wheelchair I went to see him today. Dentists, doctor in village, doctors in Brighton at Alex, Doctors from London come and see me at Brighton, , nurse who takes my line out, he helps my lungs function, I see other nurses when I stay at the hospital, sometimes I see a psychotherapist she helps children understand things. And the dietician who helps me with what I eat. Some of you also told us about other people who help you with your health **social worker carers at home.****



We asked you 'Does anyone help your family with your health care?'. Most of you told us that someone does help your family with your health care, but not all the time. One young person told us **Yeah a bit/sometimes. Physiotherapist helps me not to get anxious (I can smell fear). Others not so good.**

Someone of you gave examples **yes, the SALT told mum what foods to give me and what to do if I said no to them ... putting my socks on and doing my shoe laces up ... Yes all my family- they are getting help to put my stairlift and shower in at home ... Regular hospital appointments ... Getting on/off my pony . Cutting up food etc** Some of you told us that your family did not get any or enough support to help with your health needs **I don't get any support , my mum helps with a few things when I need her to ... The doctors help mummy and daddy not my brother.** One of you told us a bit more about the support you and your family need **My Mum sleeps with me 5 nights a week and has help for the other 2. She also has 6hrs help on a Sunday. My Mum said it's not enough though and she needs more support.**

We asked you 'What's good about the help you get?'. Some of you told us about particular people. **When having my back operation the good support came from a specialist – K*, he was cute ... A good experience I have had of getting support, was when I was having problems with my shunt. The surgeon dealt with the situation very quickly, and extensively ... the nurse let me on the computer when I was sleeping at the hospital, I was there quite a long time ... the team who support me have been involved with my car since I was born so I haven't had to change to lots of different doctors.**

Some of you told us about bits of equipment you liked **I like the blowing machine which sees how hard you can blow, it has games on it ... the OT gave me a blue strap for my arm so now I can put my make up on but I haven't got to walk yet.**



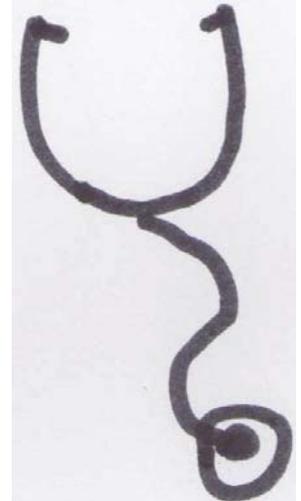
Other good things you told us about the help you get are **All of the people are good and usually the medicines work, that's good ... I like my carers who look after me at night and have fun days out on Sundays.**

We asked you 'What's bad about the help you get?'. One young person told us that not everyone knew what they needed to know about you to make you feel safe or OK. **Others needed to be told- don't ever put me on my stomach because I can't breathe and I panic and lash out. Also don't keep me away from the door; I don't like the sensation of being stuck.**

You also told us that people at the hospital had not told you what was going to happen and when it was going to happen. **They also forgot to tell me about the MRI scan and expected me to just do it....I did try but couldn't as I'm claustrophobic. So again the surgeon said 'just do it before we operate'. It would help if they spoke to me and mum beforehand not want till I get in hospital.**

You told us that it was not OK to say something was going to be alright when it wasn't **when they needed to take my blood I hate it and I want to tell them to F-off. It's no good telling me it's alright cos it isn't.**

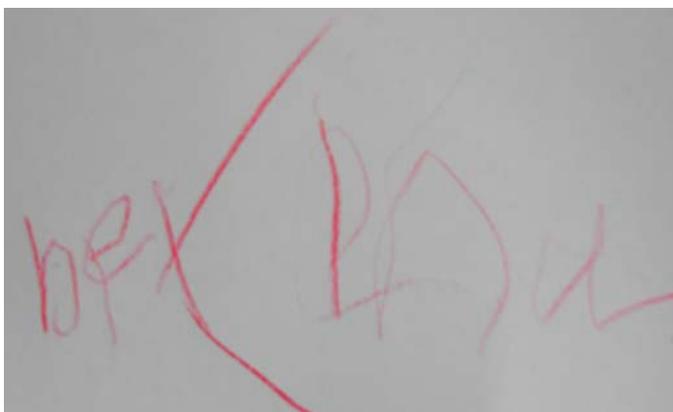
One of you told us Other bad things you told us about the help you get are ... **not having enough skilled carers to ask ... Nothing ...I don't like some staff ... for people to turn up on time lots of waiting in hospital.** For one of you a bad thing was not waiting in hospital, but waiting for a long time afterwards **a bad experience I have encountered is having to wait over a year to get a piece of equipment to help my arm and hand work more effectively.**



We asked you 'Do you and your families get support when you need it?'. Most of you told us that you and your family have to wait to get support when you need it. **We have to wait. Once I was crying to death as something was wrong on my chest, the DR said the skin was running but I had to wait 3 hours. We just went to the hospital and they saw us ... Yes, Sometimes we have to wait but usually we see them on the same day. We have to wait when we get there.**

Some of you told us that you do not get support when you need it and some one else said you do not get enough support. **No support is currently offered normally our first port of call is our G.P. or our private physiotherapist ... Not enough.** One of you told us you and your family gets support when you need it **yes straight away- I am a spoilt girl- you laughed.**

We asked you 'Do the people that help you respect your cultural or religious beliefs?'. Some of you said **yes**. Most of you didn't know **you shrugged**, we asked you 'Do you have any beliefs?' you **shook your head no** some one else told us **I don't have any**. We described different foods you might need; you said you **didn't need any**.



We asked you 'Do the different services you use work together to provide support. Most of you thought that services did work together?' **yes, all the people work together ... mostly ... yep altogether.** However, this was not the case for all of you **London hospitals don't know Brighton hospital people, they are as far from each other. Maybe they speak on the computer or phone, but they do ask mummy the same questions.**

We asked you 'What it was like when you moved from child to adult services and what helped make this a good experience?'. Someone told us **what helped make the transition from child to adult services easier was that I already knew the staff in adult services and the location was the same so the transition was fairly easy. Although I was not offered as many appointments as I had in Child Services.**



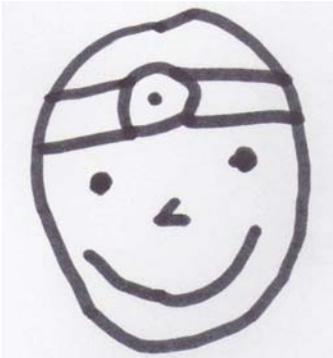
We asked you 'Do you think that the people that support you have the right skills and training?'. Most of you told us that they did **they have helpers that know about mouth and hands and things so yes ...All the people that have input to my care do have all the skills and training to provide me with the support that I need ...Yes, they are really good ...Yes they all have the right training.** Someone else told us that at school people had the right skills and training, but when you need support at home **my Mum trains them at home.** Some of you told us that not everyone has the right skills and training, **my doctors got enough and all the others yes. Sometimes the physios haven't - you laughed ... Not always. If they don't know about autism why have they got he bloody job!**

Your involvement in health services

We asked you about your experiences of being involved in planning your care and helping to make services better. Most of you told us that you were not involved in planning your care. One young person told us **I don't have any involvement with my care as yet perhaps when the machine to aid me with my arm is available I will have more input.** We asked you 'What would make you feel empowered?'. We thought about what empowered means, to be confident to be assertive, to be able to show what you think and feel about services. This is what you told us **there is nothing about being in hospital that makes you feel empowered. You're just being poked and prodded all the time ... Being informed of my condition and all the options available to me ... to be asked what help I need ... Talking about things, being confident- I am already ... Being given all the information and being able to ask questions. Visiting wards and hospitals before operations.** Someone else told us **I have felt assertive at times to be able to ask for services that would assist me, but as always within the public sector things do have a tendency to take some time.** For some of you empowered means **lots of communication and sympathy ... lots of different activities.**



We asked you to tell us what you think and how you feel about the different people you see. One of you described all the people that help you that you see in different places **Brighton Alex doctors is the best because I have been there more times the nurses are very nice. London doctors, I don't know them that well but they are quite nice, nurses are the same. Hassocks doctors I know some of them, quite nice, the nurses are good. Dentist, quite nice, I like it when she puts the metal thing in my mouth- you smiled. The SALT very good to me always smiled and said hello.** One of you told us that the people that help you don't ask you how you feel about them **no they don't ask,** some one else said **I tell them.** One of you had an idea about what to do if you had difficult feelings about the people that help you with your health, **if they had a thing after the surgery and you were really annoyed with them- if they had a punching bag with their face on it.**



We asked you 'Have you been asked to choose what help you get?', 'Are you involved and can you influence your support?'. Most of you told us **no ...not often ... The only involvement I have in my support is to consistently phone and request information, not a lot is forthcoming ... No am just told who to see , they tell me what help I need.** Someone else told us that you were involved and you could choose what help you get **yes at home my Mum and me interview new workers and I see if I like them.**

We asked you if you have been asked how you feel about the help you get. Some of you told us that you haven't been asked but your Mum has, **not really- mum said she was asked 5 years ago, but not me ... My mum has.** You also told us that it is your parents who ask you about how you feel about the help you get, **only by my mum. I think they are crappy. If they don't know about autism and aspergers how are they gonna help the people who are scared and anxious ... At home again – my Mum asks if I like the new carer.** One of you told us that some people who help you ask you how you feel, and others don't **the dentist asks and I tell him, the others don't ask.** Someone else told us **to the best of my knowledge I do not recollect any time when I have been asked for any kind of feedback.**

We asked if you have seen changes since you told people how you feel. Some of you told us you hadn't **No. I told them the doors were a horrible colour. It makes it look unfriendly. They should make it look like home, they didn't listen. I also told them about being on my tummy and how it must make others feel bad as well-if you have had a back operation and people are behind you.** One of you had seen changes that made a difference **yes my hours for respite were increased from 4 to 6 hrs per month.** Some one else told us **I was happy anyway with dentist.**



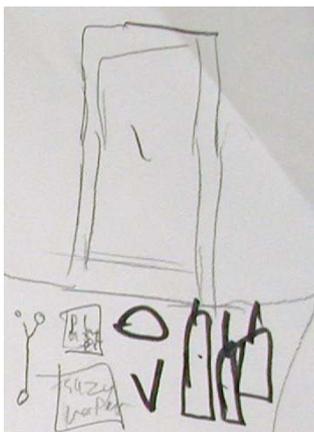
We asked you 'Can you complain about the people who help you?'. One of you said **yes,** most of you didn't know about complaining or how to complain about the people that help you. This is what you told us **No one said ... Not used to complaining, but I do tell the doctor or dentist ouch! I said to mummy and the doctor what I didn't like but only to people I didn't know ... I have to confess that I have not complained about the**

support services. One of you told us you couldn't complain because **I can't write.** Another young person told us **complaints have been dealt with quickly.**

We asked you if you have been told about how you can complain about the people that help you. Some one told us that they haven't had any information about complaining **No, I asked if there were any leaflets. I have looked at all the leaflets when the doctor talks to mum and dad and there aren't any about complaining.** Some of you didn't know and some of you couldn't remember **Can't remember.** Mum said - **for adults there are obvious procedures but not the kids.** Some of you thought that the information would be available if you needed it **I am sure there are procedures and information about how to complain but I have not made use of them ... Yes but I haven't needed them.** One of you said **No but I could tell them.**



We asked you 'Do the people that help you tell you about what kind of help you need?'. Some of you told us **yes when I met them they told me.** Some of you weren't sure, **mainly, but I have done a lot of research myself ... sort of, sometimes they explain to my mum and dad and mum and dad then explain to me.** We asked if you could choose who explained to you, you told us **I wanted mum and dad to explain to me.** We asked you 'Are you given the right information about available support?', one of you told us **in my opinion I have not been given any more information about available support.** Some of you told us more about the people that help you **the dentist told me first, the doctors just say I'm going to touch your arm or something ... we went to see a specialist nurse who was supposed to be for children with 'special needs'. I thought she was listening but when we arrived (for surgery) nothing was in place which was really stressful.**



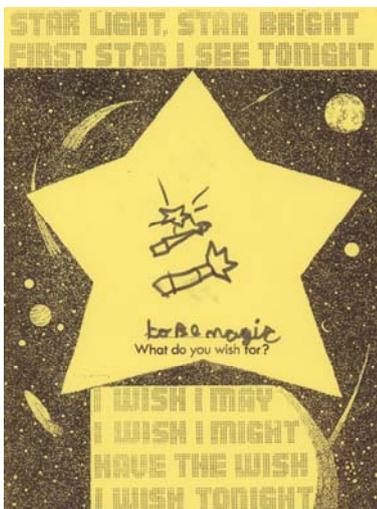
We asked you do you go to meetings where you can say what you think about the help you get. Most of you told us **no ... no, I don't really have choices. I don't go to meetings ... I'm too young.** Some one told us **no, sometimes the other doctors are there which is like a meeting, there are training doctors too.** Your Mum said that there is an annual review that you go to **you nodded.**

Making health services better

We asked you 'What makes a good experience?'. This is what you told us **Home. If it was more like home it would be way better but it's not and if smelt like home it would have been better but it doesn't ... Having the same people, playing on the computer ... That when I do my breathing huffs into the machine there are games and funny pictures like popping balloons and zapping aliens, you have to huff hard to do that. ... They should close the door when they are doing something private to you. When**

you are relaxing in your room they should leave you so it's peaceful and quiet. You have to ask for things but they do listen when you ask. Getting prizes for being brave, doing nice things to me, talking to both me and Mummy. Listening ... Making friends on the ward and activities organised by play therapist. Someone told us that what makes a good experience is how they are with me, that they make me happy.

We asked you 'If you were an inspector working for the Care Quality Commission, what should you be looking for?' and 'What signs would tell you that things are going well?' Some of you told us what a good service should be doing **happy and contented patients, with good feedback about the care, continuity and regularity of appointments ... Happy clients and positive feedback ... A really good service would be constantly striving for the best for their clients on an individual tailor made basis. Good records on the individual and feedback from the client and/or parents ... Children that are happy and active (as far as possible) and their time occupied (not left to get bored).** Some of you had some ideas about what services should be doing **make sure the person looking after children meets the kids before they go in. Make sure a plan is put in place that we agree and it actually happens.** One of you told us that in a good service you wanted people who help you to **be kind** (see adjacent image) and that **if a child wasn't doing their huffs properly that he said that's not good enough or strong enough that wouldn't be right if he helped and said try harder that would be kind. I would look for them to be kind not cruel.** Someone else thought that a good service should be checking that people are doing their jobs properly **making sure that they take bloods, and temperature correctly as sometimes it hurts.** You told us **be nice to children.**



The Care Quality Commission are going to make sure that poor services make plans to get better. We asked you how we could know that you and your family have been involved in these plans. This is what you told us **after you've been into hospital they should send you a form to fill in, in private ...By using the information in this questionnaire ... We could fill in a form explaining our needs and wishes.** Someone else told us **good records on the individual and feedback from the client and/or parents.** One of you suggested **ask families like you are doing here – ask what would help and what would make the difference.**

We asked you 'Would you want to know what we have found out about your local services for example by leaflets, website, posters, or local radio?'. The two most popular ways you wanted to receive this information was by websites and leaflets; **leaflets, so I know what's happening ... Leaflets are good because they have writing and a picture so you can see what they are talking about ... leaflets to read together and go back over.** We asked you 'Would you or your families use this information?', some of you said **yes ... probably.** Some of you didn't know **don't know ... you shrugged.**

Thank you for telling us what you think about so many things. We hope you like the way we have put your ideas together, and we hope you will get lots of chances to say what you think about things in the future.

Appendix A

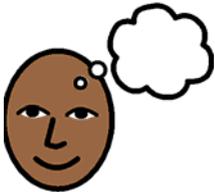
Dear Child's name ★

We are looking forward to seeing you all again on Saturday 12th June from 2pm to 4pm at Triangle.

Jose King from London will be coming to the group. Her job is to make sure that we all get the best from the medical people that help us, like Dr's, hospitals and ambulances.



In the art area, we will be making cut out people and thinking about the medical people that help you.



In the thinking area we will be thinking about who helps you and your family, what they do and don't do, and what's good and bad about them.



In the doing area, we want you to show us what would make the perfect medical people. You can dress up and show us!

Please bring something for show and tell if you want to.
Buddies: Please come at 1.30 to help set up. Thanks.

See you all on Saturday! ★

From Maxime



Appendix B

Thinking about help to stay well

project CQC specialist health support

group All join in

Date: 12th June 2010

Do you have help to eat, drink, stay well, get about, do things?

What do you think about needing help?



Who helps you?

Who is the best at helping you?

Who is the worst?



What do you think about the help you get?



Do any of these people help you?



TA/INA
Doctor (which kind)
Nurse (which kind)
Physiotherapist
Occupational therapist
Speech therapist
Interpreter
Audiologist
Dietician
Phlebotomist
Radiographer
HCA
Nursery nurse
Dentist
Others?

**Do you go to any clinics or meetings?
Tell us about them?**



Who decides what you need to stay well?
Does anyone ask what you think?
Can you complain if you aren't happy?

What could be better?

Thank you for your help

★
Dear Name ★

Jose King from the CQC has asked to find out what young people think about what medical care they get.

Her job is to make sure that we all get the best from the medical people that help us, like Dr's, hospitals and ambulances.



Do you get help from people like physiotherapists, speech and language therapists, and others who may give you medicine or help you with your diet or moving around?

We want to know if you have ever got help from any of these people and what it was like?

What was good? What was bad? What helped?

We also want to know if you have ever been asked to help these services get better at what they do?

If you would like to take part Maxime will come to visit you to find out what you think.

You will also get a £10 voucher for taking part.

Please can you let us know by Friday 18th June.

Looking forward to hearing form you,



Ainslie