

Children's Complex Healthcare Needs Assessment

(1) Male, aged 15

What do you enjoy about home / school / leisure time?

Home / leisure time –

- Playing video games
- Hanging out in the garden, balls/bats/bowling with my brother and friends
- Cooking with my mum

School -

- Really like the clubs available especially the Boccia (new club) and 'social club' as it gives you a chance to try new things and to talk to your friends (a social thing), play board games, listen to music etc. The 'social club' is open not just to the whole of our school but to other young people from other schools as well so it gives me the chance to meet new people from outside of my school as well. The 'social club' is also now wheelchair friendly so that's great.

What things do you find difficult because of your health?

- Sometimes I am in pain and this makes it difficult to focus on my school work.
- I have problems with my sight and I have to wear an eye patch, it can get annoying when children and adults make comments and ask me why I am wearing it (even people like school staff that have known me for a long time, they still ask). I have been waiting 10 weeks for a new specially made contact lens, it was meant to be ready weeks ago but I am still waiting. I am use to wearing my eye patch but it does make things more difficult as I am only seeing out of one eye at the moment.
- School – can be difficult trying to catch up on work that you have missed because you are ill, you feel really under pressure from your teachers to try to catch up as soon as you can and because you have missed lessons that makes other lessons more difficult because you have missed related learning. The school does provide me with the chance to do catch up lessons during the school day but that means that I miss fun stuff like free time, break time, clubs etc.
- Sometimes because of the pain I get in my legs I sometimes use a wheelchair instead of walking, but when I do turn up in school in my wheelchair I get fed up with people asking me 'why are you in your wheelchair, you can walk!' I should not have to keep explaining myself to others.
- Using temporary ramps when in my wheelchair, the staff at school don't always want to put them out and they don't feel very safe so I need to rely on others pushing my wheelchair so I don't fall.

What is your experience (how did it make you feel, how were you treated) with health and social care settings?

- I am fed up with having to tell my story over and over again, if people (medical staff) bothered to read my notes they would not have to ask so many questions.

- I do feel that sometimes people don't always believe the pain I am in.
- I don't think the hospital and the school have very good communication, I think that the pressure is on my mum to let the school know what is happening all the time with my medical treatments and when I am off because I am ill.
- The hospital is sometimes late with my medication and also I am still waiting for my new contact lens and that is late, I don't like wearing my eye patch and I have had it for 10 weeks now.

What has helped / works well for you?

- The school does try to help me catch up on missed lessons with 'catch up' sessions.

What gets in the way or has been difficult?

- Appointments are very inflexible, you have to turn up on the day / time they say, and they (hospitals) will not change your appointment.
- Poor communication, sometimes an appointment is cancelled and they do not give you notice so you have already started travelling to the hospital or have already not gone into school so it's a waste of time.

What would help more or could be done differently?

- More flexibility with appointments (especially non urgent ones) so that school is not missed, why can't they have the appointments at the weekend or during school holidays?
- School being more tolerant, I am in the 'special resource' unit at my school and they know the medical conditions I have but they are always chasing up my mum for letters if I am ill to cover my absences, my mum really feels under pressure to let the school know what is happening all the time. I also don't have to go in and stay in hospital lots but I do have times when I am in too much pain or have to attend appointments so miss school and they are not always very understanding.

If you designed services what would they look like?

- Appointments that fit around you and your needs, why do I always have to travel to them?
- Hospitals / Doctors and schools working together to take pressure of parents.
- Schools supporting students more to catch up on lessons.

What do you enjoy about home / school / leisure time?

Home / leisure time –

- Playing X-Box
- Chilling with my friends both inside the house and out in local community (but only close to home)
- Hanging out in the garden, have an archery set, I enjoy playing that

School -

- Have left school now (I am free!) and I am glad I am going to college because hopefully it will give me a greater independence, I have chosen to do a foundation course in independent living because that is my aim to be able to live as independently as possible.

What things do you find difficult because of your health?

- Missing out on what friends are doing.
- Miss out on social opportunities, going out with friends.
- School – can be difficult especially in years 10 and 11 as there is so much work to catch up on, you feel really under pressure from your teachers to try to catch up but sometimes there is just too much and you miss things.
- Using temporary ramps when in my wheelchair, they don't feel very safe so I need to rely on others pushing my wheelchair so I don't fall. I had a really bad experience once and the ramp was not fitted properly so it tipped and I fell forward out of my chair, it was awful and embarrassing as I can't get myself up and others had to rescue me.

What is your experience (how did it make you feel, how were you treated) with health and social care settings?

- Because I am in hospital so regularly and for quite long periods of time when I am in ALL the hospital staff really know me well and know exactly how to treat me, they make my stay in hospital as good as possible, they are friendly and care well for me. They more or less make it feel like home to me. I also have made some really good friends with other patients. I am worried that I will soon be moving into adult services and they will not know me so I may not get the same care and treatment.

What has helped / works well for you?

- The fact that the hospital staff know me and my condition so well.

What gets in the way or has been difficult?

- Appointments are very inflexible, you have to turn up on the day / time they say, and they (hospitals) will not change your appointment. I had a consultation at Great Ormond Street and it clashed with one of my exams, we asked if the appointment could be changed but they said NO I had to attend and I missed the exam.

- Poor communication, sometimes an appointment is cancelled and they do not give you notice so you have already started travelling to the hospital or have already not gone into school so it's a waste of time.
- Missing out on education because you are too ill to do any work and I have had a couple of times when I have been ill for several weeks and there is just too much work to catch up on so you miss things.

What would help more or could be done differently?

- More flexibility with appointments (especially non urgent ones) so that school is not missed, why can't they have the appointments at the weekend or during school holidays?
- Better communication between the hospital and the school so that your parents are not under pressure to let the school know what is happening all the time.

If you designed services what would they look like?

- Appointments that fit around you and your needs, why do I always have to travel to them?
- More treatment available in local area – nurses to come out to me.
- Hospitals and schools working together to take pressure of parents.
- Schools supporting students more to catch up on lessons.

What do you enjoy about home / school / leisure time?

Home/leisure time – I play computer games, spending time with and doing things with my family, seeing my friends.

School – I like school and I'm doing really well with my education. I am in high groups for most things. We have also started working on transition which is good because I want to live independently, well as much as possible so it's good to start to understand what skills I need to enable me do this. I feel good about having a plan for my future.

What things do you find difficult because of your health?

- Accessing certain places such as the dentist, we were sent round the back to use the back entrance but even then there was a high step that I found difficult. So they made a temporary ramp with whatever they could find and this wasn't safe.
- Missing work at school and having to catch up. I recently spent 6 weeks in hospital and missed so much work. Being in high groups means that I have a lot of difficult work to catch up on and then I feel pressured to catch up with work alongside the other work that has been set daily. This leaves me with very little social time and feeling mentally and emotionally drained. Sometimes if I just had 20 mins for myself that would help.
- People not always understanding my disability and how it affects me personally
- High steps are a problem for me

What is your experience (how did it make you feel, how were you treated) with health and social care settings?

- Difficulty with accessing some places, mostly ok but there are still steps and stairs with no railings especially if I'm using my walking sticks.
- I feel mostly good when going to hospital appointments. There are good doctors and nurses and they know what they are doing. Now that I am older I am feeling more involved in decisions about my care and this gives me better confidence – after all I'm the one who knows about my body more than anyone.
- Upset that I waited so long for an operation. I couldn't get out and about and this meant I didn't socialise. I just sat around at home and I feel that it made me lazy. I felt very demotivated.
- Feeling good about planning for my future after school is finished
- When I was born my mum asked for a social worker to help her but she didn't get one. She has had to everything herself. Now that I am going to be going through transitions my mum has asked for a social worker again so that it can be assessed about how much support I may need to live independently because that is my ultimate aim.

What has helped / works well for you?

- Being seen by specialists who know exactly how I am affected by my condition and know exactly what to do about it.
- Being prepared for adulthood and having a care plan put in place to enable me to live an independent life.

What gets in the way or has been difficult?

Waiting for an appointment to be seen by a specialist can take a long time. I had problems with my knees and was in a lot of pain. I ended up waiting 8 months to be seen and it took 4 years to get the

surgery in needed. I had to take medication daily which had its side effects. Before that I was really well and you would not have known I had Cerebral Palsy as it didn't affect how I walked.

What would help more or could be done differently?

- No being under so much pressure to catch up on school work
- Not having appointments cancelled
- Shorter waiting lists for treatment

If you designed services what would they look like?

- More doctors
- Hospitals talking to schools about appointments and treatment
- Less issues around access to certain places
- Not having so much work to catch up on when school is missed
- When back at school more understanding after a period of being unwell, just because I'm back at school I may still not be feeling so good.

What do you enjoy about home / school / leisure time?

Home/leisure time – I have a room that is pretty well set up. I have a large t.v and I play computer games when I'm home. I can feel quite isolated at times.

School – School is good. I have a TA with me most of the time and she helps me throughout the day which is helpful

What things do you find difficult because of your health?

- Corridors can sometimes be hard to go down with my chair especially if there is not enough space to turn around. Temporary ramps make me very nervous because I can't stop myself from falling if my chair was to tip.
- I don't go out with friends; I mainly go out with my dad.
- When I go out there are sometimes doors that I can't get through and steps leading to doorways that are not suitable.
- Pressure from teachers to catch up on work, sometimes I can be unwell for months.

What is your experience (how did it make you feel, how were you treated) with health and social care settings?

- The hospital staff know me quite well, as I can sometimes spend a lot of time in hospital. They are always nice to me and friendly, but don't have time to sit and talk to me if I am on my own
- I am included in decisions about my care and treatment now that I am older, but I feel they listen to my dad more than they listen to me.
- Because I need round the clock care and I have to be turned at night I have to have a carer with me. When I have been in hospital I have sometimes been put on the baby ward because there are staff there to help me through the night. That was pretty annoying as babies cry and I wanted to be near people my own age.
- One of my carers who come in at night is partially deaf, this is difficult and frustrating as she doesn't always hear me at night and I worry because what if something bad happens. There is a real lack of communication

What has helped / works well for you?

- Being prepared for transitions after leaving school is good because we are planning for my future and that is something I think about a lot now that I am getting older.

What gets in the way or has been difficult?

- Hospital school does not always give me work that is relevant to what I am doing in my class.
- When I have been off school for some time, it is hard for me to catch up and this makes me feel a lot of pressure and can worry me a bit.
- There was one time that my dad was not well and had to go home from the hospital I was in. I didn't get fed and I felt they didn't care about me, this was pretty scary.
- Having to attend a hospital a long way from home

What would help more or could be done differently?

- It would be good if hospitals talked directly to schools, especially around appointments. The school could say when is not a good time because of exams, tests or important things going on at school and they could talk to my teachers about my health so they are more aware of what is going on and how this will impact on my school work.
- More staff in hospitals

- More one to one care to give my dad a break more.

If you designed services what would they look like?

- More doctors and beds in the local hospital so that I wouldn't have to go so far away.
- Hospitals talking to schools about appointments and treatment and recovery times
- Less issues around accessing to certain places.
- Less pressure from school during periods of being unwell.

What do you enjoy about home / school / leisure time?

Home/leisure time – I am happy at home. I have lots of things to do and of course my mum is there and she has the same condition as me so she understands everything.

School – School is good. I enjoy coming to school and I have lots of support from adults if I need it.

What things do you find difficult because of your health?

- I feel as though I have an invisible condition. To look at me you would think I was normal and didn't have any condition but I find things really difficult when I'm feeling unwell.
- If I'm out and use a lift for disabled people then people have said 'why are you using the lift it's for people with disability', I have to say I'm disabled, this upsets me because I shouldn't have to explain myself to people.
- Other young people at school sometimes say there is nothing wrong with me. They don't know what I am going through and it is frustrating.
- Stairs can be difficult to get up if there are not help rails.
- Pressure to complete work from school if I'm not well.

What is your experience (how did it make you feel, how were you treated) with health and social care settings?

- Ok, appointments can take a long time to wait for.
- I feel listened to when I go to appointments and the doctors always speak to me and my mum.

What has helped / works well for you?

- My mum having the same condition as she knows exactly how I feel and I'm able to talk to her

What gets in the way or has been difficult?

- Mainly people not understanding my condition. If others in my school had a better understanding of how my disability affects me, then I feel they wouldn't be so judgmental or say things that upset me.

What would help more or could be done differently?

Did not answer

If you designed services what would they look like?

Did not answer

What do you enjoy about home / school / leisure time?

Home - watching T.V, playing on my games, spending time with my family. I am pretty well set up at home as I have my bedroom downstairs with a wet room and our doors ways are bigger so my wheel chair easily get through them. We also have a ramp out into the garden so I can go out there when it's nice.

School – I like spending time with my friends and I enjoy most of my lessons. I have really good support from my TA and teachers

What things do you find difficult because of your health?

- Going out on trips or going into town can be difficult because there is always so much planning beforehand. We have to find out if there is wheel chair access or any other obstacle that will prevent me from doing what I want to do or going into somewhere.
- Because at times I don't use a wheelchair, people don't always see my disability and when I tic or my condition causes me to act a certain way, then people may stare at me. Some people will laugh or if I tell them about my condition then they will ask me why I don't shout out swear words. People have pre-conceived Ideas about my disability when they are a lot more complex. Sometimes people accuse me of putting it on, when I'm not, it's out of my control, and it's so frustrating and embarrassing. I wish people knew how they make me feel.
- I can feel very much under pressure at school with school work. If I have missed lessons because I have not been well then I have to catch up as well as doing the work I am set daily. I can sometimes miss out on break time because I'm doing a catch up session. Before I moved to this school I felt very isolated and the school I attended then were not very supportive of my condition, it was a though they didn't believe me. I was then moved to a special needs school. Whilst there I didn't really get taught the curriculum and fell behind in my learning I felt as though I was being left behind. But since moving to the school I am in now, I am taught what I should be and have caught up. A few of the ramps here, one especially is not very good and I don't feel safe using it. Because of my condition I am not always able to join in P.E and I can sometimes feel as though I've been put out the way until the lesson is over.

What is your experience (how did it make you feel, how were you treated) with health and social care settings?

- Sometimes I have to wait for such a long time for an appointment to come through, which is frustrating because I feel I don't always get the help when I need it.
- Appointments can be at different hospitals at times and I have to see different doctors than I normally do and they don't always know me very well.
- Now that I am getting older I find that doctors and other professionals are talking to me directly and I have more control over talking about my condition. When I was younger my mum did most of the talking for me.
- I have good experiences with doctors who I see often or understand my condition better as they are specialists in that area.

What has helped / works well for you?

- The support I get at school is good.

- Seeing the doctors I know is very positive

What gets in the way or has been difficult?

- Hospitals should speak to schools more, so they know when my appointments are or appointments could be arranged around important lessons or exams
- Long waiting lists for appointments
- Having to explain my condition and how it affects me, my symptoms change and this is not always understood.

What would help more or could be done differently?

- Flexibility with appointments so I don't miss out
- Temporary ramps to be made safer
- More time to catch up on missed work

If you designed services what would they look like?

- Not having to go to different hospital which can sometimes be a long distance away.
- More privacy when staying in hospital

This page is intentionally left blank