“How does Cerebral Palsy affect children and their families?”
By R Bisson aged 16 2013

Introduction

a- Research Aims
I researched how children with Cerebral Palsy are affected in their daily life, and also how the families of such children are affected. I wanted to research this as I was surprised by how little people really know about Cerebral Palsy, and I wanted to learn more about the condition myself as a member of my family is affected by it. I also aimed to enlighten others so as to build a society that better understands disabilities like Cerebral Palsy. The purpose of the research was to provide a snapshot of the experiences and perceptions of a child with Cerebral Palsy as well as those of the families of affected children. This snapshot could be used to draw conclusions and would allow me to achieve my aims.

b- Cerebral Palsy
Cerebral Palsy is a condition which results in abnormal brain development. This can result in many difficulties, most commonly affecting movement and control of movement. Other effects may become apparent, such as in learning, speaking, hearing, or difficulties with personal care and perception of their environment.

One in 400 children in the UK has Cerebral Palsy, and it affects people of all backgrounds. The most likely cause of Cerebral Palsy is a difficult or premature birth. As there is no prenatal test for Cerebral Palsy, it can only be diagnosed from around the age of two, which is when most children have developed full gross motor function (crawling to walking). It is seen as a possible condition in children who have not reached the normal developmental milestones by the age of two.

No two children with Cerebral Palsy are affected in exactly the same way, so each child requires a different hospital care programme, in which they will see all the specialists that are relevant to them at regular intervals so that they can receive all the help they need. There is no cure for Cerebral Palsy, but measures can be taken to make the lives of affected people easier, which is the purpose of their hospital care programme.

There are three main forms: spastic, dyskinetic, and ataxic. Spastic is the most common form, but all three cause problems with moving and controlling movement.

c- Research Training
During September 2012, I received research training which taught me how to conduct research that was ethical, sceptical, and systematic. These were the main principles of good and valid research. Other important principles are impartiality, accuracy, and practicality. I decided on my research topic and method in October 2012.
Methodology

a- My research method
I used a method called Systematic Participant Observation, which involved observing a child affected by Cerebral Palsy and seeing the world from their perspective, recording what I observed in a diary. I chose this method as it allowed me to gain real insight into how Cerebral Palsy can affect children and how their view of the world differs from that of children who are not affected by it. Revealing the experiences of this child will allow me to make the general public more aware of Cerebral Palsy.

b- The setting and time period
The setting for the observation was at the child’s home in East Anglia, and the time frame was the period 22nd October to 24th December 2012. I decided to use the child’s home as the setting as this is the environment in which the child would feel most comfortable. This allows me to observe their natural reactions and behaviour. Using a different setting would affect the observation in that the child may not feel comfortable and as such would be less willing to show their true perspective of the world around them. Therefore, it is essential that the child is observed in their natural home environment.

The time period was chosen as it is not too close to the start of a new school year, and it contains many times that the child may find exciting (birthdays, Christmas, Halloween), which allows me to observe how the child changes in the lead up to exciting times as well as how they react and behave in everyday life. As I aimed to see how the child reacts in stable, everyday situations as well as how they respond to change, this time frame was perfect. A two month period also allows me a sufficient amount of time to collect qualitative data and identify trends, which is important if the conclusions I am to draw are to be valid.

c- Was it good research?
Good research is:

- Ethical- I informed the child and their mother of the research and gained consent from the mother before proceeding. I changed the names of the subjects in the report, to ensure anonymity.
- Sceptical- I avoided ‘cherry-picking’ data and entered the research project with an open mind and no real prediction. When recording my observations, I abridged the observation data for Standard English sentence structure as well as chronology, but included the quotes of the child where possible.
- Systematic- I did my observation in a similar way each day, and at a similar time each day.
- Impartial- It is important to note that I am actually related to the child in question. I am aware that this meant I had to adapt my approach to the research study to ensure that my data and conclusions would still be valid.
- Accurate- My relationship to the child I observed means that I was able to interpret his views and to interpret and abridge his speech appropriately. It also means that the child feels comfortable around me. Furthermore I could draw on my experience as a relative whilst also remaining impartial and sceptical.
Practical- Being a relative also means that accessing the child was less of a problem and that the child’s mother trusts that my research will be conducted properly, as detailed above. I have remained impartial despite this so that my observations are valid.

d- My actual process
My actual process was:

- During term time- I had a 10 to 20 minute talk with the child, in which I asked them about their day at school. I noted their response down, abridging for chronology and sentence structure but staying true to their actual comments. This part allowed me to see their perspective on the world as well as how well they communicate. The rest of the evening was a first-hand observation of the child in their home environment. This part was more detailed and allowed me to observe their reactions and behaviour.
- Outside of term time- All my data was from a first-hand observation spanning the entire day.

e- Limitations
The limitations of this method include:

- I am only observing one child with the condition.
- Not all of my data is primary and I have no way of ensuring that it is accurate or representative of the child.
- There is opportunity for bias in that the child is a relative.
- The child seems less involved due to me having to abridge his comments.
- I will become better at observing and recording data over time, so my observations in December may be better and more accurate than those in October.
- There is considerable potential for human error in this method.

The report

Part 1- The child

a- An introduction to the child observed
The child who was observed for this research is a six year old boy who I have named child C. He lives in a house in East Anglia with his mother and sister. His father lives elsewhere in East Anglia, and his contact with child C and his sister is fairly regular (fortnightly), them having moved away from him not long before child C’s first birthday.

Child C was diagnosed with mild Diplegic Hypertonic Spastic Cerebral Palsy (meaning stiffness in the legs) and developmental delay at around the age of two, and has received help from a number of medical professionals since then. These include:

- Speech therapist (but discharged halfway through the study, in November)
- Physiotherapist
- Two Paediatricians
He attends a mainstream school in East Anglia, and receives ‘medical hours’ (support) in school for some of his needs. He may be requiring a statement in the future, which will allow more of his needs to be catered for. Child C’s frequent hospital appointments mean that his attendance is not as good as it could be, but despite this he generally seems to be a keen and able learner when given the right help.

**b- How Cerebral Palsy has affected the child**

Child C has a marked developmental delay, as well as his stiff legs and small size, and the combination of these factors means that he:

- Is not always aware of what is correct behaviour.
- Expresses emotion in a simple and primitive manner, often shown as extreme anger or tearfulness.
- Is dependent upon his mother and sister for most of his care.
- Uses a pushchair on longer journeys.
- Wears a nappy at night.
- May have learning difficulties which become more apparent in the future.
- Has to do physiotherapy exercises on his legs to reduce their stiffness.
- Has Botox injections in his legs to reduce their stiffness.
- Sometimes has communication difficulties, but these have not featured here due to me abridging his speech.
- Hates loud noises.
- Often reacts strongly to new events or changes.
- Relies on a regular schedule which he checks many times.
- Has help with feeding, washing, and dressing.
- Bases his behaviour and vocabulary on that shown by people around him.
- Fixates on small details and has the mind of a younger child.
- Craves attention and hates being left alone for any time.
- Is not always aware of danger, so requires supervision.

Some of these effects have featured in the observation, so I have explored them further in the analysis.

**Part 2- The analysis**

**a- Analytical Method**

I typed up the observation notes onto the computer so that I could store them more securely. I soon realised that I had a lot of data, and that to effectively analyse it I would need to code the data and split it into 3 main themes. These were:
• Child C’s behaviour and the events of the day.
• Child C’s reactions and perception of the world.
• The reactions of others to child C.

I feel that these three themes will allow me to explore what he does in the day, what he experiences, how his disability limits him, how he perceives and reacts in his environment, and the people around him.

b- What trends did I find within each theme?

Child C’s behaviour and the events of the day

His behaviour is that of a much younger child, “After dinner I weed on the floor upstairs again and did another poo.” (1st November) and this also illustrates that child C is not always aware of what is correct behaviour.

The stability of child C is questionable in that he will change from a happy boy who is hugging his sister into a violent and angry one who destroys people’s possessions and lashes out. This kind of behaviour is consistent with tantrums, also a feature of the behaviour of much younger children.

He appears to have a fairly regular routine during a week, with ‘school day’, ‘town day’, ‘staying day’, ‘seeing daddy day’, or ‘holiday’ being used to inform child C of what is going to happen during a given week. This routine is often disturbed in the lead up to special days, and child C often gets confused if a day is both a school day and his birthday, or both a staying day and Christmas day.

Child C’s reactions and perception of the world

Child C tends to describe his day in a simple way, generally only giving one detail per sentence. “My barn was red. It was big.” (24th October).

Child C often feels more comfortable talking to people who he knows, given that he uses a lot of idiolect, such as saying “2” for level 2 books, and “Heritage” for a custard cream biscuit. He becomes angry and frustrated if he is not understood, and will usually coerce others into helping him in strange situations or when he is ignored or not understood.

His descriptions of each day (‘school day’, ‘town day’, ‘staying day’, ‘seeing daddy day’, or ‘holiday’) are also idiolect, and were formed by child C himself to allow him to understand the main point of each day. Although this schedule relaxes child C, he checks many times to make sure his schedule has not changed. “I asked sister if it was school day. She said yes.” (21st November).

Expressing emotion appears to be something that child C finds difficult, often expressing anger by hitting people or throwing things at them. He laughs when very happy and will often hug the source of his joy, whether this is a toy or a person. Therefore, child C’s emotional stability is questionable in that the wrong word (usually the word ‘no’) can make him change from a happy boy who is hugging his sister into a violent and angry one who destroys people’s possessions and lashes out. Discipline is sometimes ineffective in these cases, and he appears to learn little from discipline.
Child C also seems to struggle when he has to tell people how he feels, using simple descriptions such as "I like it" "I didn’t like it" "sad" "good" "OK" "hurt". He has little empathy, and rarely understands why his sister and mother get cross with him, although he usually picks up that they are cross. He will carry on with what he was doing, or will laugh provocatively.

He can get confused if he feels more than one emotion, “I liked that but I didn’t actually......it was too loud” (26th October). This affects his range of emotions in that he often feels both anger and sadness but cannot separate the two, so he will often be crying and shouting at the same time. He is very methodical in that he will deal with one emotion at a time, but this often means that child C takes longer to calm down than most children.

Child C responds well when people are nice to him and do what he has asked them to do, but this is not always possible. As child C craves attention and is very impatient, he gets angry when his requests are delayed.

He also responds in a positive way when he is given the opportunity to be independent, such as when “I handed in my homework in the blue folder. I felt very grown up.” (15th November). He responds very well when getting praise for effort “My teacher said well done.......I was very happy.” (15th November) and for achievement “My teacher said she would put me on to level 3 books. I was on level 2 books.............I told Mummy and sister...very happy with me” (10th December). This shows that child C is reliant on others for recognition and emotional stability. If he does not get this recognition, he will become angry and will lose motivation. The praise is not just required for big achievements, but also for small ones. This is consistent with his behaviour and responses resembling that of a child younger than six.

As child C relies on his sister and mother for so much, he will often believe what they say without questioning it, unless they are saying 'no' to him. An example of this is, “I wanted to see Santa but sister said he wouldn’t come if we were awake. I went to sleep and so did sister” (24th December) which shows that child C believes strongly in things.

The reactions of others to child C.

Child C’s sister and mother often bear the brunt of his outbursts, and attempt to restrain and calm him. His mother has commented that this makes her unsure of whether child C knows that he is being annoying, and that it makes her even more cross with him.

His family are not allowed to be hypocritical (the sister went to sleep too on Christmas Eve). They also have to be good role models for child C, given that he bases his vocabulary and behaviour on that which his family shows. They must also praise him for any efforts to ensure that he remains motivated.

His sister and mother do a lot for him and presently cope with the challenges he presents, but he is still disciplined for bad behaviour. Although there are reasons for this behaviour, his family still feel that child C needs to improve his behaviour and not act like a toddler. His behaviour is treated in a similar way to that of any other six year old, but it is understood that some of his behaviour may be down to his
condition so they try not to be too harsh on him. His mother says that looking after child C is stressful, but she would not change him. This shows that there are strong bonds within the family, possibly strengthened by child C’s condition.

Child C’s need for attention means it is very difficult for child C’s mother to look after both children, and his sister is often the second priority. As she is older, she is more independent but still needs her mother for some things, so this is difficult for her.

c- What was surprising?
I found it surprising that child C used complex language when describing his day at school, like “reading comprehension” (22\textsuperscript{nd} October). However, this may be because this phrase is often used at school and is an example of child C basing his vocabulary on that which he hears often. The drawback of this is that there is the potential for child C to learn rude and offensive language while out in town or if he overhears arguments. He won’t understand that these words are wrong but will have to be punished for using them.

Another surprising thing was that child C experienced bullying at school, but this was not a trend as it only featured in the first week of the study. Child C reacted to this by telling “them to stop but they did not stop” (24\textsuperscript{th} October). He tells teachers and his family about the bullying, so it is good that he has learnt that telling people about the bullying does work.

Child C also sees ordinary things as really special. This may be to do with his active imagination, or his tendency to fixate on details, or the fact that he may be proud of this thing, such as in the case of the plant he grew “I think my plant is really special” (25\textsuperscript{th} October). This really opened my mind to how child C experiences the world in a different way, and sees relatively ordinary things as interesting and special.

Normally, child C’s visits to see his father go well, but when the structure of these days changes, (e.g. the zombie incident at the bus station around Halloween, and when his aunt was also there) child C becomes nervous. This affects him in the long term, in that he is unable to forget such events and will check frequently that they will not occur again. Changes to his everyday schedule elicit a similar response. If the changes are perceived by him as good, he becomes excited. If they are perceived as bad, he becomes nervous and angry.

It also surprised me how much child C’s sister and mother do for him and the amount of time this takes up. Child C’s poor treatment of them “After dinner I went upstairs and weed over my sister and the floor” (3\textsuperscript{rd} November) suggests that he is not appreciative of this help or does not understand why he needs it, or why his poor treatment of his family provokes a reaction “I didn’t understand why she was cross with me” (1\textsuperscript{st} November), but he would be likely to struggle to cope without the help of his sister and mother.

d- What support is in place?
As well as his primary support network of sister and mother, child C receives help from a number of medical professionals. His outlook is good because of this, and had he not received this help early, his condition may presently be much worse.
As well as appointments with medical professionals, child C receives help at school in the form of medical hours. This allows the school to help him in lessons and with feeding at lunchtime. His leg exercises, and some adapted PE lessons, are also included in the medical hours. Child C may require a statement in future to ensure that his needs continue to be met.

School is very important for children in that it helps them to achieve their full potential. Child C has this potential, which is why he attends a mainstream school. In order for him to realise his potential, he needs to attend school. His many hospital appointments have an impact on his attendance, but he also tends to see school as a negative part of his life due to preferring the security of being at home with mother and so would prefer not to go. In the future child C’s mother hopes that he will begin to enjoy school so he can learn and achieve.

Child C may need help coping with change in the future. Many disabled children and adults require a structure in their lives, and if this is disrupted they can find it difficult to cope. Currently, child C likes it if he is informed of change in advance, and will check many times to ensure that his schedule is not disrupted. During Christmas, Halloween and his birthday, his schedule will undoubtedly change. He enjoys these times of year, but the change makes him excitable, difficult to control, and constantly worried about whether certain events will still happen. This is why he checks his schedule more during these times. This shows that his schedule is very important to him, and is a form of support that both he and his family will use to ensure that everyone is clear about what will happen during the week. Coping with change is clearly difficult for him, and he may need help with this in the future, particularly when making decisions.

There are also specific measures in place to support the rest of the family. His mother gets support from the family worker and school groups as well as advice from the medical professionals who see child C. His sister attends young carers groups, which she finds helpful and fun. She wishes, however, that more measures were in place to support families living with disability, particularly to support the siblings of a disabled child.

- Are the themes caused by child C, or his condition?

Cerebral Palsy often causes developmental delay, and those affected need help with many aspects of everyday life. This, and child C’s small size and leg problems, is because of his form of Cerebral Palsy.

Although it can be partly attributed to his condition, child C’s behaviour and treatment of others is mostly down to child C himself. This means that not all children with Cerebral Palsy will behave in this way, but it adds an extra strain on his family. The elements of his behaviour that may be down to his condition are:

- how he reacts to things
- how he expresses himself
- his developmental delay means that he does not always know what correct behaviour is

Child C’s perception of his environment and how he copes with change reflect a combination of child C’s personality and his condition.
It is quite difficult to verify whether the perceptions of affected children are altered from those of children of a similar age who do not have Cerebral Palsy, as so much of the condition shapes the child’s personality as they grow up. Therefore, not all children may be affected in the same way.

**Conclusion**

In conclusion, child C’s behaviour is erratic: he can’t always recognise when his behaviour is inappropriate and only recognises appropriate behaviour through getting praise from others. The structure of child C’s week is clearly defined and regular, which helps him to be aware of future events. Any changes to this structure will unsettle child C, and this happens regardless of whether the change is perceived by him as small or big. Child C relies on his sister and mother to cater for his needs.

Child C has a marked developmental delay, meaning he finds it hard to express himself and will behave differently to what is expected of a six year old, and also requires medical help to allow him to move effectively. He has a simplistic perception of his routines (school day, seeing daddy day etc.) and emotional states (expressing himself as happy, sad, or angry at any given point in the day). The help that he receives appears to be sufficient for now, but he could require more help in the future, particularly to help him cope with change and manage his emotions in a more positive way.

Child C’s family are supportive, and usually react to him in a positive way, however sometimes they have to react more negatively to inappropriate behaviours, but still need to be mindful of his capacity for understanding. As in many situations, general members of the public find it difficult to know how to react to child C, so sometimes react in a way that makes child C sad. Crucially, child C’s limitations due to Cerebral Palsy are managed by his family in a way that lets him lead a life similar to that of other six year olds and so his differences are not necessarily a barrier to his future development.

**Evaluation**

* a - *My research method*

The validity of the research could be affected by the fact that only one child was observed. Cerebral Palsy affects all people differently so the child who I observed will not be representative of all children affected. I also only observed this child for a two month period. Whilst it cannot be assured that these two months are representative of this child, it provides a snapshot of the experiences of families living with Cerebral Palsy.

I tried to see the situations in my observation from the child’s perspective rather than my own so that my data was valid. Most of my report is based on primary qualitative data, but using secondary data in the form of talking to the child allowed me to see his perspective on the world in more detail. Therefore, my method allowed me to explore all aspects of the child and so it was effective.

My observations became more detailed as time progressed, meaning that the ones made in December may be more accurate than those made in October. The potential for human error in this research method was considerable, and there is still opportunity for bias in that the observed child was a relative. However, I tried to remain impartial and sceptical, and was also systematic in my observations.
Consequently, my research method was good and ensured that my observations and conclusions were valid.

The research was also ethical in that no full real names were included and I had informed consent from the child’s mother and other participants.

If I were to conduct this research again, I may observe more than one child and try to do my observation over a longer period. I could extend the research by observing the same child at the ages of eleven and sixteen to show how children with Cerebral Palsy progress and develop over time.

b- How could the research be used?
The research could be used to make medical professionals more aware and help them improve their services relating to Cerebral Palsy and the support for families of those affected. It could be used to make people more aware of the effect on whole family units and in particular to provide more services to help the siblings of disabled children. It could also be used to support families of children recently diagnosed with Cerebral Palsy, as this can be a stressful and uncertain time. This research could also be used to better inform the general public. It could also improve the support provided by mainstream schools so that children with Cerebral Palsy are given the same learning opportunities as all other children.

c- Did I achieve what I wanted to achieve?
I myself learnt more about the life of the child I observed and about their perception of the world. This made me more acutely aware of what the child and their family cope with every day and opened my eyes to the reality of living with disability and how it can affect the entire family unit.

My aim was to conduct research that provided a snapshot of the experiences and perceptions of a child with Cerebral Palsy as well as those of the families of such children. I feel that my research method, and the conclusions that I was able to draw using it, allowed me to achieve this aim.

This research into Cerebral Palsy and its effect on children and their families is by R Bisson, aged 16.