

## Our day at the zoo!



On a beautiful sunny Saturday in September, Cerebra South West and the Cerebra Research Unit co-hosted our first Family Fun Day at Paignton Zoo. It was a fantastic opportunity for the families and Cerebra members to get together and enjoy a family day out. The zoo was chosen by two of our parents as a suitable, accessible venue. We started the day with introductions and the chance to meet each other over tea/coffee/juice and biscuits; then the families enjoyed time wandering around the zoo before we reconvened for our own private 'Feathered Feats Bird Show'; again requested by parents, which was a huge success and enjoyed by all!

Thank you to all the families who came and enjoyed the day with us and to the volunteers who came along to help push wheelchairs up the hill. It was a thoroughly fun day for all!

Here are some lovely pictures that David and Sophie did of the day.



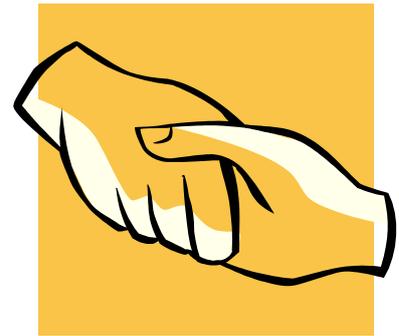
# Building a Partnership Event - 5th October

## By Amy Francis (parent)

I recently attended the "Building a Partnership" event organised by the Cerebra Research team. We were small in number, with only 10 or so parent/carers represented, but as usual we were opinionated, passionate and vocal!!! The event was to help us understand where we could fit into the actual setting up and running of any future Cerebra research, as lay people.

We had presentations from several different research based groups, the first being "Folk.us". Some of you may remember them as they helped Cerebra to set up the first question finding meetings. The second presentation was from Jennifer Newman from Medicines for Children Research Network, [www.mcrn.org.uk](http://www.mcrn.org.uk). The third and final presentation was from Kate Martin, from the Council for Disabled Children, [www.edcm.org.uk](http://www.edcm.org.uk). Kate is from the people who put together the "Every Disabled Child Matters" piece of work.

One of the concerns raised by the parents/carers is that there are certain times when, for whatever reason, our children take priority over every aspect of life and several of us raised the issue of having to take a back seat in the research process at these times. The Cerebra team reassured us that this would not be a problem and they appreciate any input they can gain from us. Another issue was that our children have many different levels of communication and compliance but we hoped that our children would still have involvement in the research process. The Cerebra team will be getting advice from both Kate and Jennifer to ensure that as many families who wish to be involved are!!!



The meeting helped me to see that Cerebra are looking for our, and our children's input, into all aspects of the research that they undertake - from not only asking the questions but to looking at the research that is already out there right through to answering questionnaires to assisting with the final writing of the conclusion papers!

Cerebra Research are hoping that as many of us as possible are able to join and help them in some way. They also realise, refreshingly, that with our children we may not be able to commit all the time and that they may have to look at alternative methods to enable ALL our children to take a part in the research process.

Hopefully there are even more families out there that would like some part in helping the Cerebra Research team and that you can be reassured that you are not going to be signing yourself or your child up for life! As always after much discussion and a delicious lunch we all came to the conclusion that we would like some part in the research of the future and let it begin!!!

## Social Inclusion

We know that social inclusion is an important topic for families so it was no surprise that our meeting in September was well attended (7 parents) and very productive. Parents shared their experience, good and not so good, around inclusion and we have identified some key topics that we need to consider when developing our research programme to promote the social inclusion of disabled children. Some ideas we discussed for the research programme included:

Mapping the social networks of disabled children

Measuring social inclusion using questionnaires

Measuring people's attitudes towards disabled children and people

Measuring families' experiences of attitudes towards them and their children

You can read about these ideas in more detail at <http://tiny.cc/xv6i2>

As part of the social inclusion programme we hope to work with inclusion teams across Devon, Plymouth and Torbay councils. We plan to organise a meeting between these teams early in December to share ideas and experiences of what works and what the challenges are.

We were also lucky enough to have Jess Oliver, a Psychology student from Oxford University, join us for 2 weeks work experience over the summer. Jess worked on the social inclusion project, finding out about what research has been done about attitudes towards disabled people. She has written about her time with us on page 6.

If you would like to be involved in helping to develop this programme of research, please get in touch. You can read the notes from the last meeting at <http://tiny.cc/xv6i2>

## Cerebra South West

Hi, my name is Helen and I am the Regional Officer for Cerebra in the South West. I have been with the charity about 9 months now based in Plymouth and I cover the Devon and Cornwall area bringing the services that Cerebra parent support can offer to families across this area. Cerebra has lots of practical services to offer from grants to help with equipment to vouchers for wills and trusts. I also am on hand to help with DLA forms, connecting services and also advocacy in all sorts of meetings. If you feel that I could help you with one of these services or you would just like someone to have a chat with then please get in touch. If I can't help you I will almost certainly know someone who can. My telephone number is 07827 848610 or my email is [HelenB@cerebra.org.uk](mailto:HelenB@cerebra.org.uk) I look forward to hearing from you and perhaps meeting you in the future.

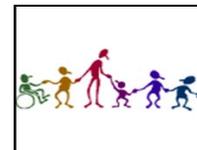


## Join our Family Faculty!

We are always keen to hear from parents and carers who would like to be part of our Family Faculty.

Membership of the Family Faculty does not commit you to anything, but will mean that you are kept informed about the work that we are doing and will be offered the opportunity to get involved.

In the future, we would also like to involve children in the work of the Cerebra Research Unit. This will help us understand what things they think are important. Currently, around 96 families are members of the family faculty but we would like the group to grow even bigger—the more people that are involved the better! If you would like to join, please get in touch. Email [cerebraresearchunit@pms.ac.uk](mailto:cerebraresearchunit@pms.ac.uk) or telephone 01392 72 2901/2968



## Improving communication with children with disabilities on the ward study



We are continuing with our study to develop a training package for health professionals to help improve communication with children in hospital. We have now completed the interviews with families whose children had recently been on children's wards in either Exeter or Barnstaple hospitals. We asked families about the things that were good, not so good and any suggestions they could make to improve their time in hospital. We are extremely grateful to the fifteen families who took part in the interviews as their first hand experiences have given us vital information to aid the design of the training package.

The families discussed their times in hospital as either inpatients or day-patients, and they were generally very positive about their stays. However, some families had less positive experiences and were keen to suggest ways in which their time in hospital could be improved. Many common themes about their hospital experience have emerged, and parents and the children have made some great suggestions about how communication between health professionals and other families like theirs can be improved.

The next stage is to interview health professionals from Exeter and Barnstaple to gather their views and suggestions on how to improve communication with children with communication difficulties. We aim that these interviews will be completed early in the New Year.

If you would like any more information about the project, please contact Vanessa Edwards on 01392 722978 or [Vanessa.edwards@pms.ac.uk](mailto:Vanessa.edwards@pms.ac.uk)

## Where we've been lately and where we are going soon

We have been to the zoo again! This time it was London Zoo for the Cerebra Annual Conference in October. Professor Stuart Logan gave a talk about the work going on here at the Cerebra Research Unit and about all the different meetings and groups that the Family Faculty have been involved in.

We will be going to another conference in November held by the INVOLVE organisation. INVOLVE is a national advisory group which supports greater public involvement in NHS, public health and social care research. Two parents from the Family Faculty will be coming to Nottingham with us to give a talk about how we work together to do research. The title of the talk is: The Cerebra Research Unit: a partnership in childhood disability research.

Val has been out and about visiting schools including Woodlands, Oaklands Park and Dame Hannah's and we hope to continue to develop our friendships with the schools we know well, and hopefully some new ones!

We have continued to build relations with the different teams at the councils. This will help us to understand how the different services work and fit together. This month, Val was at the Children's Integrated Disability Service in Plymouth.

On November 23rd Val will be at the Plymouth Parent and Family Forum—do come and say hello!

## Continence services

In September we hosted a second meeting to discuss continence services for disabled children. This meeting was attended by 4 health care professionals and 7 parents. We made good progress thinking about how to develop this topic into a research questions however the group felt that it was difficult to take the matter forward without more involvement from the service commissioners and the teams working within the service to make sure that we have a balanced view when developing the research.

Since the meeting in September, Chris and Val have met again with some members of the continence service in Devon. We are organising another meeting early in the New Year where we can bring together members of the continence teams for Devon, Plymouth and Torbay with families and commissioners. The working title for our research which we will take forward to our next meeting is "what constitutes an adequate continence service; what could a good service look like?"

The notes from the meeting in September are available at <http://tiny.cc.5crpk>

## Navigators

Parents often tell us that it is difficult to find their way around the different services or to know who to contact. A number of parents expressed an interest in being involved in the Navigators group to think about how to map how the services for children with disabilities and additional needs are organised across Devon, Torbay and Plymouth and to help us to identify what services families want, the services that disabled children use, and any places that disabled children and families value and should know about. We are not the only people that think this is important—in the recent Department of Health report Achieving equity and excellence for children they recognise that families need "support to navigate the system" particularly families of children with multiple needs.

We had a meeting on 16th September with two parents but we are unsure how to take this forward as a piece of research. If you have any ideas or top tips on how you get around services we would love to hear from you! You can read the Department of Health Report at [http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/@ps/documents/digitalasset/dh\\_119490.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_119490.pdf)

## Have your say about the website!

We would like to talk to families about what you think of our website. Do you find it helpful? Is it easy to use? Is it time for a new look? We would welcome any comments that you have about the website and forum. We are also very interested to hear what your children think of the young persons section of the website. If you have any comments please let us know by email or telephone.



We would like to start a group to review the design and content of the website and the forum to attract more families and make it more interesting and usable for families. If you or your children would like to be part of this group please get in touch, we hope to have the first meeting at the beginning of 2011.

**NO TECHNICAL EXPERIENCE REQUIRED!**

**Jess Oliver** is a psychology student studying at Oxford who came and did work experience with us over the summer. Here is what she said about her time here:

Over the summer I spent 2 weeks working with the Cerebra research unit on their social inclusion project, specifically investigating attitudes towards those with disabilities. Here's a summary of some of the research I looked into:

The main technique used to investigate attitudes involves questionnaires and surveys, in which an individual is presented with a series of statements, such as "disabled people are friendly", and must indicate the degree to which they agree or disagree. This type of research has been used with the general public, as well as with professionals such as health staff and teachers. While it is possible that people may not always be entirely honest about the attitudes they hold, research has demonstrated that the more knowledge and experience people have had with those with disabilities, the more positive their attitudes tend to be. Importantly, attitudes are learned dispositions, which, through contact and education, it may be possible to change.

Research with young children in preschools has used a technique called "playmate preferences" to investigate children's attitudes toward their disabled peers. Children are asked who they would rather play with and given different choices from their classmates, either able-bodied or with special needs. One study found that children with special needs received very few positive preferences and concluded that it is important to begin to integrate knowledge of disabilities into education so that positive attitudes and relationships can arise. A very recent pilot study, published in October of this year, involved the participation of 9 to 11 year olds in two 90 minute sessions promoting disability awareness in school. This promising study found that the brief programme greatly increased attitudes, knowledge and acceptance of people with disabilities.

All in all it was a great experience, and I hope the Cerebra Research Unit carry on their good work.

Two of the articles that Jess mentions are:

Nabors et al. (1997). Playmate preferences of children who are typically developing for their classmates with special needs. *Ment Retard.*, 35(2), 107-13.

Ison, N., et al (2010). "Just like you": a disability awareness programme for children that enhanced knowledge, attitudes and acceptance: pilot study findings. *Dev Neurorehabil.*, 13(5), 360-8.

## Wheelchair services

A parent raised wheelchair services, particularly those to special schools, as an issue. We organised a meeting in September to bring together parents and health professionals to gather information and views on the current service. The meeting was attended by 4 health care professionals and 6 parents. We learnt that there is currently a national and local review of wheelchair services going on, although it is not known whether parents are being involved in this review process. Helen, from Exeter Mobility Centre, told us about their wheelchair involvement group, run by the users themselves. This group is mostly attended by adult users but it would be possible to set up a separate user group for young people and their carers organised by parents and carers. At the moment there are no plans to develop this topic into a research project. The notes from this meeting are available at <http://tiny.cc/iel0s>

## Advisory Group

We have an advisory group that meets every few months. The advisory group provides suggestions and guidance to the team about various activities that we are involved in and is crucial to the success of our work.

Three parents came to our meeting in September. The minutes of this meeting can be found on our website <http://tinyurl.com/3x28nvm>

We realise that some families are unable to attend meetings during office hours so we thought of holding our next meeting either on a Saturday morning or early one evening to give more families the opportunity to be involved. However when we looked at your responses on the family details questionnaire it seemed that the majority of people were happy with a weekday during school hours. We are always happy to consider this option again in the future if parents ask us to.

We are very keen to encourage more parents and carers to join us. If you would like more information about what would be involved then please get in touch. Our next meeting is on Thursday, February 3rd 2011.



## Here is what Julia said about attending her 1st meeting:

"If you are a parent thinking about attending for the first time, it is a little daunting, but take that step if you can. I received a warm welcome from a friendly group of people and quickly realised it was an opportunity to get involved to a greater or lesser degree, as suited your personal circumstances, which was reassuring - there were no great expectations that would be difficult to fulfil. It was an opportunity to make a bit of a difference, no matter what your background was. All are very welcome. Go on, why not give it a try...."

## Friendly Reminder

You may remember that we sent you a family details questionnaire earlier this year. These are really helping us to form a picture of the diversity of our family faculty. We hope you don't mind, but if we haven't received your completed questionnaire, or if you have joined our family faculty since the summer, we have popped a details questionnaire in with your newsletter. As always, we realise that you are very busy and that Christmas is fast approaching, but we would be very grateful if you could find a few minutes to complete the form and return it to us in the envelope provided. Thank you in advance!



## Upcoming meetings

Advisory Group: February 3rd 2011 10:00

**We are in the process of organising dates for many of our future meetings. If you have told us that you are interested in a particular meeting, such as Social Inclusion or Continence Services, we will email you when we have fixed a date. You can also check our website for dates or give us a call.**



We are able to meet the cost of child care to enable parents to attend meetings as long as a receipt is provided.

The service provides one point of contact for children and families to get the information they need, whether it is about education, health or social care. They produce a newsletter which is sent out three times a year in February, June and October. It contains information about the Integrated Children's Services, news about new services, other agencies and groups, as well as forthcoming events.

The local information co-ordinators will help you get information about the services and support available to you in looking after your child. You can get in touch with them to ask any questions by phone or email.

Eastern Devon

Sue Phillips

01392 385932

sue.a.phillips@devon.gov.uk

Southern Devon

Cathy Hill

01392 386066

cathy.hill@devon.gov.uk

Northern Devon

0800 056 36 66

## Folk.us Training Events 2010/2011

Folk.us works to support and help develop service user, patient and carer involvement in research. One of the ways they achieve this is by developing and delivering training courses. Folk.us research methods training is designed for service users, carers and patients. We also welcome researchers who are working with service users in research. Folk.us involvement training is for both researchers and service users, patients and carers. All workshops are free. Do let us know if you would like any specific training events, want to help lead a training session or want to explore training in different locations across the region.

- |   |                                |          |               |
|---|--------------------------------|----------|---------------|
| • Qualitative Research Analysis                                   | 25 <sup>th</sup> November 2010 | Exeter   | 11.00 – 14.00 |
| • Taking the 'but' out of service user involvement in research    | 6 <sup>th</sup> December 2010  | Exeter   | 11.00 – 14.00 |
| • Taking the 'but' out of service user involvement in research    | 27 <sup>th</sup> January 2011  | Plymouth | 11.00 – 14.00 |
| • Running a Focus Group   | 17 <sup>th</sup> February 2011 | Exeter   | 11.00 – 14.00 |
| • Doing Interviews II : Reviewing and developing pilot interviews | 17 <sup>th</sup> March 2011    | Exeter   | 11.00 – 14.00 |
| • Developing Questionnaires                                       | 12 <sup>th</sup> May 2011      | Exeter   | 11.00 – 14.00 |

For more details and to book a place, see [www.folkus.org.uk](http://www.folkus.org.uk)

## Contact the Team

**Website:** [www.pcmd.ac.uk/cerebra](http://www.pcmd.ac.uk/cerebra) **Email:** [cerebrereserchunit@pms.ac.uk](mailto:cerebrereserchunit@pms.ac.uk) **Phone:** 01392 722968/2901

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