

## We are going to the zoo— do you want to come too?

Cerebra South West Region and the Cerebra Research Unit at the Peninsula Medical School are holding a joint Family Fun day at Paignton Zoo on Saturday September 18th. We would love you to join us, please get in touch if you would like to come as places are limited.



## Nappy Services

We held the first meeting to discuss nappy services on June 10th. Three parents and one health care professional attended this meeting, which was a fascinating insight into the many difficulties families face accessing and using services for incontinent disabled children.



Notes of the meeting can be found on our website

<http://tinyurl.com/34hnyqz> . We are planning to convene a meeting in the autumn to raise the issue with service commissioners & NHS providers, and perhaps local politicians. We have also raised the issue with the appropriate research funding agency, the NIHR Service Delivery & Organisation programme [www.sdo.nihr.ac.uk](http://www.sdo.nihr.ac.uk) who consider commissioning research in response to suggestions. Please get in touch if you would like to join the group.

## 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 80 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.

We are also updating the details that we hold about families, helping us to direct correspondence to the appropriate people when working on topics relevant to particular conditions.

## Have you heard.....

The Dame Hannah Rogers Trust has opened Hannahs at Seale Hayne. As well as services specifically for children and adults with disabilities the centre has a shop, cafe, gallery and much, much more. Adult users are a key part of the team running the centre. Chris and Val will be visiting the new facilities this month—we'll tell you all about it in the next newsletter. In the meantime, find out more at [www.hannahssealehayne.com](http://www.hannahssealehayne.com) or why not visit? Entry is free, Saturday—Thursday 10am—5pm.



# Development of a Functional Classification System of Eating and Drinking for Children and Young People with Cerebral Palsy

Chris Morris is a member of the team developing this classification system. The project is led by Diane Sellars, a Speech and Language Therapist at Chailey Heritage Clinical Services in Sussex, and funded by the Research for Patient Benefit programme of the National Institute for Health Research.

Cerebral palsy affects a person's control of movement. Biting, chewing and swallowing movements are often affected. Children with cerebral palsy who cannot move their mouth muscles to eat and drink efficiently are likely to have problems eating enough food to grow and to stay healthy. Some children have problems with chest infections because particles of food or drink enter their lungs when they swallow. These difficulties continue throughout their lives.

Classification systems have been developed to describe, in one of five levels, a child's ability to sit, stand & walk (Gross Motor Function Classification System), and to handle everyday objects (Manual Ability Classification System). These classification systems enable people to communicate with each other more clearly about a child's level of function. Parents have found these 'levels' of function both acceptable and useful, and are able to classify their own child's function as they know the child best.

This research will produce a classification system for eating & drinking ability. We need families to be involved in designing the system so that we ensure the system is meaningful to children and parents. Please contact us if you would like to be part of this project. You can read more here: <http://tinyurl.com/33rpjrs>

## 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.

Two parents came to our meeting in June who helped us develop the family details questionnaire and plan the annual event. The minutes of this meeting can be found on our website: <http://tinyurl.com/39gbdhn>

We realise that some families are unable to attend meetings during office hours so we thought of holding our autumn meeting either on a Saturday morning or early one evening to give more families the opportunity to be involved. When we put this to the group, the majority preferred a weekday morning. However, we will 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.



## Programme of research to promote social inclusion

Preparations are continuing to develop a research programme to promote social inclusion of children with additional needs. One of the main barriers to inclusion appears to be the attitudes of people that families encounter, and stigma that some families experience. We believe that both of these are things that can be changed, and that doing so will improve the inclusion, health and wellbeing of disabled children and their families.

The project has several parts that link together. We will look at ways of defining and measuring inclusion. We also want to develop ways to measure the attitudes of people towards disabled children and their families, amongst the general public, other children, and professionals such as teachers and health staff. We will also investigate ways to define and measure perceived stigma experienced by parents, children with additional needs and their siblings. The aim is to seek ways in which attitudes can be modified to reduce stigma and promote inclusion. The measurement is done using questionnaires. We know that this can sometimes be a bit tedious, so we need families to help us design them to be as appropriate as possible, and to think how to gather the information.

We have discussed the project with several parents who have helped to shape the way we think about this research. Chris has also discussed the project with the Director and staff at the Council for Disabled Children



([www.ncb.org.uk/cdc](http://www.ncb.org.uk/cdc)) who are keen to be involved. Locally, Chris and Val have been meeting inclusion co-ordinators in Devon and Torbay and will be visiting the Plymouth service in August. We have also discussed the ideas with the Commissioning Lead and those responsible for delivering for services in Devon. We are keen that families are active partners in designing the research. In October we will be submitting an 'outline' application for funding. If the project gets through the first phase successfully then there is a second deadline in March next year. We are holding a meeting with families in September and further meeting will be convened as the project progresses. Do get in contact if you interested in being part of this project.

## Helen Bear—Cerebra Regional Officer

Hello I'm Helen and I am the new Regional Officer for Cerebra in the South West. Not only am I new to Cerebra I am also new to the Devon and Cornwall area, this means as well as getting to support families in a valuable and practical way I will also get to find my way around this beautiful part of the country. I am married to a serving soldier and have an 18 year old son and a small dog called Jess. We arrived back in the UK in January and I am very excited to be working with Cerebra and I cannot wait to get out and begin supporting families.



## 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. To help us do this, we are interviewing children with disabilities and their parents/carers about a recent stay on children's wards in either Exeter or Barnstaple. We are asking about the things that were good, not so good and any suggestions they could make to improve their time in hospital.



We have now interviewed several families and they have told us some very interesting things about their time in hospital. Already, some common themes about their hospital experience are emerging from talking to the different families. Parents and the children are making some great suggestions about how communication between health professionals and other families like theirs can be improved.

We aim to interview up to 20 children and their parents/carers soon after they have been discharged. So far, we have talked to 6 families who have recently been in Bramble Ward, Royal Devon & Exeter Hospital and 2 families who have been in Caroline Thorpe Ward, North Devon District Hospital in Barnstaple. Ideally, we would like to complete all the interviews by the end of this summer. When the family interviews are completed, we will also talk with health professionals to gather their views too. Once all the interviews are completed, we will use them to help us design the training package for health professionals.

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

Did you hear Chris and Kim, one of the parents from our family faculty, who were interviewed on Radio Devon in June? If you missed it, you can find a link to the interview on our website: <http://tinyurl.com/2vmjbsb>

Chris was also interviewed for Heart Radio in North Devon about the study to improve communication: <http://tinyurl.com/3yp8eoh>



Chris presented a poster about our review of what is known about disabled children's experiences as inpatients at the European Academy of Childhood Disability in Brussels.

Val has been to some Parent Carer Voice and Face2Face meetings to chat with families and find out what topics families think are important topics for research. If you have any suggestions for other groups that we might visit, or topics for research, please get in touch.

## What are we working on at the moment?

We seek to involve families of disabled children as partners in all our activities. As well as the **advisory group** and the **nappy services group** we are developing lots of exciting projects at the moment and we hope to involve as many families as possible. We know families of disabled children have busy lives and we realise how difficult it can be to commit to attending meetings. However, if any of the groups below are of interest to you, please get in touch, you can be involved as much or as little as you choose - even if you only have time to put your thoughts in an email we would like to hear them.

### Website group

This is a new group that will review and consider the design and content of the website and the forum to attract more families and make it more interesting and usable for families. The group will help us to decide how the website should look then Hannah does the technical stuff!

### Mapping services for disabled children in Devon

We are hoping to map how the services for children with disabilities and additional needs are organised across Devon, Torbay and Plymouth. This group will 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. The aim is to produce a map!

### Social inclusion

This group is developing research to promote social inclusion of disabled children by examining attitudes to childhood disability and stigma experienced by families, and how these can be changed to improve the health and wellbeing of children and families.

### Building a partnership

This is a group to help us to support parents and children to be partners in our research, and to evaluate the impact of families' involvement.

Our first goal is to organise an event in the autumn with some guest speakers including the Council for Disabled Children and Folk.us. The event will consider ways in which families can be involved in the generation of research ideas and the design of projects, making involvement easier and more attractive particularly to families who might not have experience of research before. We will also have at least one talk about how we can involve the young people themselves in this process.

### Lycra

The lycra study will explore the effectiveness of lycra sleeve/glove orthoses to improve handling ability of children with hemiplegia. We have submitted the study protocol and we are waiting to find out in the autumn if it will be funded. One of the parents from the family faculty is a co applicant on the grant.

## Friendly Reminder

You may remember that we sent you a family details questionnaire in June. These are really helping us to form a picture of the diversity of our family faculty. We realise that this is a very busy time of year for families but we would be very grateful if you could find a few minutes to complete the form and return to us, if you need a new one, just let us know.



## FINDING RELIABLE INFORMATION ON THE INTERNET

The Internet is now the primary source of information for many people; however finding reliable sources can be tricky. Dr Matthew Ellis, a Consultant Paediatrician in Bristol, wrote an academic article about looking for information. He has very kindly summarised the paper below.

### Key points

Begin your internet search about a specific condition with Contact a Family at [www.cafamily.org.uk](http://www.cafamily.org.uk)

Include the search term 'EVIDENCE' when researching specific interventions or treatments/therapies

Include the search term 'GUIDELINE' when researching specific conditions

Parents and carers need information when a child is diagnosed with a disabling health condition. Around 70% of British parents use the internet to access health information, typically after a recent consultation. Most families will use their preferred search engine to identify relevant sources of further advice. Unfortunately the information available at this stressful time of maximum vulnerability is of variable quality.

In preparation for a recent seminar reviewing evidence based therapy for children with neurodisability I looked at the information available on the net for parents seeking help for an autistic child with a sleeping problem. The results were mixed.

Using the search terms SLEEP DISORDER and AUTISM on Google UK the first hit takes one to the National Autistic Society's website entry entitled 'Sleep and autism: helping your child' (1). After a very helpful and balanced introduction and discussion of the various factors affecting sleep the reader is introduced to a range of approaches under the heading 'What can we do?' First up are.... '**Natural remedies**'..... 'Many of the natural remedies available from health food stores are supposed to treat insomnia and other sleep disorders. These may have similar effects to conventional medicines but carry less risk of side-effects than conventional sedatives. You could also try contacting a homoeopath.' The entry goes on to provide the contact details for the Society of Homoeopaths. The implied equivalence of effectiveness of 'natural' and 'homeopathic' remedies with 'conventional sedatives' is misleading.

For **Melatonin** the equivalent entry reads 'Melatonin supplements must be prescribed in the UK. For further information you should consult with your GP. Some foods are rich in melatonin such as oats, rice, sweet corn, tomatoes, plums, bananas and brazil nuts but current research is not clear whether a melatonin-rich diet could be effective in helping children to sleep'. The levels of melatonin in food are low and to provide dosage equivalent to a pharmaceutical preparation would require extraordinary consumption eg 20 bowls of oats contain an equivalent dose to a 2mg pill.

Simply adding in the search term EVIDENCE substitutes as first hit the NHS Evidence Note 14 (2) a readable four page summary of the current evidence relating to the use of melatonin in children with neurodevelopmental impairment.

Alternatively adding in the search term GUIDELINE substitutes as first hit (3) a very helpful parents guide published in association with the SIGN (Scottish Intercollegiate Guidelines Network) guideline on autism spectrum disorders, an authoritative and evidence based approach to all aspects of this disorder.

*Article continues on next page*

Most patients and carers will find their way to a voluntary sector self help group site. Indeed the highly successful collaboration between the Royal College of Paediatrics and Child Health (RCPCH) and Contact a Family (CaF) <http://www.cafamily.org.uk/> explicitly encourages paediatricians to point families in this direction. CaF provide a useful leaflet detailing how to find medical information on the internet(4).

Going via Contact a Family to voluntary sector condition specific sites remains probably the best first step to suggest to families. Adding the search term GUIDELINE when researching a specific condition is likely to focus the search further on authoritative evidence based material. If carers are looking at a particular intervention adding the search term EVIDENCE will enable them to critically evaluate their results.

#### References

<http://www.nas.org.uk/nas/jsp/polopoly.jsp?a=3376&d=1071> (accessed May 19 2009)

[http://www.nhshealthquality.org/nhsqis/files/EN14\\_Melatonin\\_Final.pdf](http://www.nhshealthquality.org/nhsqis/files/EN14_Melatonin_Final.pdf) (accessed May 19 2009)

<http://www.sign.ac.uk/pdf/pat98young.pdf> (accessed may 19 2009)

<http://www.cafamily.org.uk/pdfs/paptInternetLeaflet.pdf> (accessed May 19 2009)

Dr Matthew Ellis PhD FRCPH is a Consultant Paediatrician with an interest in Neurodisability, Community Child Health Partnership, Bristol.

## Get Chatting on the Forum!

The forum is a great place to talk to other families about issues that are important to you. It is very easy to join although we do have to ask you to register for security reasons.

We have noticed that while lots of people read the posts on the parent forum not many people add comments. There has also been very little activity in the young people's forum.

Please do let us know if we can make the forum more appealing to you and your child.

## Upcoming meetings

Most of our groups are on hold for the summer holidays. We will be in touch in the new term.

Building a Partnership: July 21st 11:00

Advisory Group: September 23rd 10:00

Nappy services: September—date t.b.a.

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

## Staff News

Val joined the unit on the first of June from Liverpool University. She has a background in psychology and most recently has been working with parents, young people and practitioners looking at how best to talk to families about clinical trials of medicines for children. She also likes sailing!



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.

On the DISCplus website there is a directory of services for children with additional needs and their parents and carers. It has information about services provided by:

Devon County Council and the Health Service

voluntary sector organisations and charities

private organisations.

For example, if you are looking for a support group for your child's specific condition, this would be the place to look. [www.devon.gov.uk/discplus](http://www.devon.gov.uk/discplus)

The information is supplied through a website so that it can be kept up to date easily. However not everybody has access to the internet so you can call your local information co-ordinator who can pass the information to you over the phone or print out the relevant pages and post them to you.

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.

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