



### Cerebra Visit 2014

It was a pleasure to welcome Liz Fleming (Cerebra Trustee), Tracy Elliot (Head of Research) and Jane Margetson (Lead Researcher), from Cerebra for their annual visit in March.



The PenCRU team, and 6 parents from the Family Faculty, provided our visitors with updates on the work that PenCRU has been doing. This included research project presentations, the work on involving C&YP, how we have involved parents, and details of events we have attended in the community.



Our new Associate Research fellow Sharon (see later in the Newsletter!) ran an activity to demonstrate how our parent meetings run, which was fun for everyone. Members of the Family Faculty provided moving and insightful presentations around their experiences of working with us and what activities have stood out to them over the past year.

**We received this feedback from Liz Fleming:**

*'It has been so interesting today to hear first hand about some of the research that is taking place at PenCRU. The fact that the research is closely linked to the Family Faculty is very encouraging as this fits so well with the aims of Cerebra...*

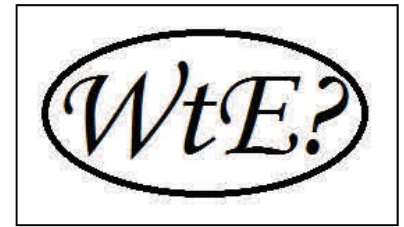
*I was most impressed with the inspiring stories that some of the parents told today. Parents have given time to the Family Faculty despite busy lives. This involvement has allowed them to use expertise and skills gained elsewhere and they feel they provide an important contribution which has been valued thus giving them confidence and a sense of empowerment which had been sadly lacking due to their family problems/commitments. What a difference this has made to their lives!'*



## Recent 'What's the Evidence?' publications

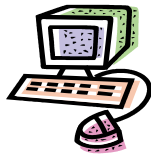
Three new summaries of evidence have been produced since the last newsletter:

- How effective is speech therapy for verbal dyspraxia in children with a learning disability? <http://ow.ly/wx59z>
- Children with additional needs and a parent/carer in the military <http://ow.ly/wx5iz>
- What are the outcomes of using yoked prism lenses for children with neurodisabilities such as cerebral palsy and autism? <http://ow.ly/wzbx0>



If you have a question about a treatment or therapy that you would like us to answer, please contact Sharon [S.F.Blake@exeter.ac.uk](mailto:S.F.Blake@exeter.ac.uk) or complete the online form <http://ow.ly/wzb95>

## Online Communications



Since January, we have been reviewing how we communicate online using our website, Twitter feed and Facebook pages. We will discuss our strategy in the next Advisory Group meeting (July 17th) but would appreciate any feedback before then. What do you think of our website? Do you visit our Facebook page or follow our Twitter feed? Is our information news relevant and interesting, clear and easy to find?

If you have any comments or views you would like to share please email Sharon ([S.F.Blake@exeter.ac.uk](mailto:S.F.Blake@exeter.ac.uk))

[www.pencru.org](http://www.pencru.org)

Find us on Facebook  
[facebook.com/pencru](https://www.facebook.com/pencru)

Join us on Twitter  
[@pen\\_cru](https://twitter.com/pen_cru)

## New projects in development for PenCRU

It is an exciting time for PenCRU and a time of change. Many of the projects we have been working on are coming to end, and we are in the process of developing a number of new projects.



As always, families have been key in developing these ideas with us.

We are currently developing projects around themes such as:

- Parent Carer Health and Wellbeing
- Patient Reported Outcome Measures
- Young people with ADHD transitioning to adult services
- Disabled children at school
- Oral health and dentistry
- Active Computer Games

If you would like to find out about how to be involved in any of these projects please get in touch: [pencru@exeter.ac.uk](mailto:pencru@exeter.ac.uk)

We are also looking at ways for including children and young people further in our unit, and considering new ways to involve parents.

If you have any suggestions or ideas let us know!

## You may be interested to know...

Cerebra have created information guides for parents and professionals interested in managing disabled children's transition into adulthood.

You can read them here: <http://ow.ly/wx5C2>

## Recent Publications

If you would like to receive copies of any of these and are unable to find them online, please contact us.

Allard A, Fellowes A, Shilling V, Janssens A, Beresford B, Morris C. (2014). Key health outcomes for children and young people with neurodisability: qualitative research with young people and parents. *BMJ Open* 2014;4:e004611 <http://ow.ly/wx5Jr>

MacMillan, M., Tarrant, M., Abraham, C. and Morris, C. (2013), The association between children's contact with people with disabilities and their attitudes towards disability: a systematic review. *Developmental Medicine & Child Neurology*. <http://ow.ly/wNmQo>

Sellers D, Mandy A, Pennington L, Hankins M, Morris C. Development and reliability of a system to classify eating and drinking ability of people with cerebral palsy. *Developmental Medicine and Child Neurology* 56: 245–251. <http://ow.ly/wx5Tt>

Sellers D, Pennington L, Mandy A, Morris C. A systematic review of ordinal scales used to classify the eating and drinking abilities of individuals with cerebral palsy. *Developmental Medicine and Child Neurology* 56: 313–322. <http://ow.ly/wx60s>

Janssens A, Williams J, Tomlinson R, Logan S, Morris C. Health outcomes for children with neurodisability: what do professionals regard as primary targets? Accepted for publication in *Archives of Diseases in Childhood*. (Coming soon)

## PenCRU Family Fun Day 2014

It's time for us to start thinking about the annual PenCRU Family Fun Day— a free day out for families to say thank you for being members of our Family Faculty. Recently we have had brilliant days at Paignton Zoo, World of Country Life, Dartmoor Zoo, and Bicton Park Botanical Gardens. Where next...? Please email and let us know which were your favourites or any other suggestions for venues to: [pencru@exeter.ac.uk](mailto:pencru@exeter.ac.uk)



**Cerebra Annual Conference**  
**'Problem solving':**  
**accessing decent services**  
**and support for children**  
**with complex needs and**  
**their families**

**Cerebra**  
Positively Different

Tuesday 7 October 2014, 09.30-16.00  
Royal Society of Medicine, 1 Wimpole Street,  
London, W1G 0AE. <http://ow.ly/wNOKc>

A one day conference providing academics, practitioners, educators and carers with up to date, evidence-based information on the commonly encountered barriers experienced by disabled children and their families in accessing their legal rights and practical approaches to breaking these barriers down.

To book or for more information contact Rachel Shailer at:

[rachels@cerebra.org.uk](mailto:rachels@cerebra.org.uk) or call 01267 244225.

## Plain English Summaries

A plain English summary is a brief version of an academic paper or other document, that has been written to be more widely accessible to everyone. Information is displayed clearly, and explanations are included for any technical terms that are used. We have produced plain English summaries of a number of our publications. These have been written with members of our Family Faculty.

### Hospital communication study

<http://ow.ly/wx6aE>

### Benefits and costs of peer support

<http://ow.ly/wx6oU>

### Positive attitudes towards disability

<http://ow.ly/wx6wH>

### Developing a definition of neurodisability

<http://ow.ly/wx6ST>

### Families views on most important outcomes for children and young people with neurodisability

<http://ow.ly/wPlyG>



### Staff news: We have a new Associate Research Fellow

Hi, I'm Sharon and joined PenCRU in January.

I worked in children's services for ten years before coming into research and I am passionate about the difference research can make for services for children and their families, particularly when the research includes and indeed comes from the voice of the child/carer.

One of my roles is to respond to any queries you may have about the evidence base for treatments/therapies or issues relating to childhood disability. Don't hesitate to get in touch if you'd like to know 'What's the Evidence?' ([S.F.Blake@exeter.ac.uk](mailto:S.F.Blake@exeter.ac.uk))

### Upcoming PenCRU meetings:

Listed below are the upcoming meetings, please see our website for up-to-date information. If you would like to come along to any of these then please get in touch to find out more.

We also welcome involvement via email/facetime/teleconference.

Meeting	Date	Time	Location
Healthy Parent Carers	Wednesday 18th June	10.00-13.00, including lunch	Veysey, room 005
Hospital Communications	Friday 4th July	10.00-13.00, including lunch	Veysey, room 006
Sleep systems for children with cerebral palsy	Tuesday 8th July	10-.00-13.00, including lunch	Veysey, room 006
PenCRU Advisory Group	Thursday 17th July	10.00-13.00, including lunch	Veysey, room 005

### Contact the team:

**Email:** [pencru@exeter.ac.uk](mailto:pencru@exeter.ac.uk)

**Phone:** 01392 722968

**Website:** [www.pencru.org](http://www.pencru.org)

**Address:** PenCRU, University of Exeter Medical School, Veysey Building, Salmon Pool Lane, Exeter, EX2 4SG

