



PenCRU Annual Family Fun Day Bicton Park

We had a brilliant day on Saturday 14th September at Bicton Park. The Annual Fun Day was to say thank you to members of the Family Faculty who have been involved in our work and research activities, and to get to know each other better. Vinny the mime artist was there to entertain us, much to everyone's delight, and a great day was had by all. We look forward to another similar event next year!



What do you think?

For the first time this year we brought our display board along to the Family Fun Day to ask for feedback. We were very grateful for everyone's comments on the day. If you have any comments about the work that we do, or ideas for future research please get in touch. We would be particularly interested to hear your thoughts about what we can do to help you to become more involved with projects at PenCRU and your ideas for how we can involve disabled children and young people.

Where we've been

We were pleased to host the joint British Academy of Childhood Disability and British Association for Community Child Health South West Meeting here in Exeter. It was a great day, packed with interesting talks. Two parents from the Family Faculty co-presented a fabulous presentation about their experiences of being involved in the Peer Support project. Details about this project on our website. The presentation followed an unconventional, yet informative, format centred around a comical play. The play highlighted attitudes that researchers can have towards the input of parents. We look forward to many more collaborative presentations with members of our Family Faculty in the future—look out for opportunities to get involved!

How do we respond to questions from parents?

We receive lots of questions from parents and professionals about treatment options for disabled children and young people. How we respond varies; the question may already have been answered elsewhere, we may write a 'What's the Evidence' summary about it, or we may decide to pursue it as a research study. A recent example...

- A parent asked us about dental imaging techniques for children and young people with learning disabilities and challenging behaviour, who are unable to cooperate when at the dentist.
- We carried out a brief search for information online but didn't find a clear answer to the question.
- We emailed all the parents in our Family Faculty to ask them about their experiences with their child at the dentist.
- A range of positive and negative experiences were reported, and several parents had the same challenges as the parent who asked the initial question.
- Next, we carried out a search of relevant websites and academic databases to answer the question with a 'What's the Evidence' summary.
- The 'What's the Evidence' summary was sent back to the parent to see if it answered their question, and we also sent it to a dental professional to make sure it was accurate.
- The summary is now available on our website and is being used by the parent who asked the question.

Recent 'What's the Evidence?' publications

Is there any evidence that Feldenkrais and the Anat Baniel Method are effective therapies for children with cerebral palsy? www.pencru.org/evidence/anatbanielandfeldenkrais/

Dental imaging for children and young people with learning disabilities and challenging behaviour. www.pencru.org/evidence/dentistry/

Emergency medication and outcomes for seizures in Sturge-Weber Syndrome. www.pencru.org/evidence/emergencymedicationforprolongedseizures/

Do you have a question about a treatment or therapy that you would like us to answer? Get in touch! pencru@exeter.ac.uk

You can see some examples of questions we have been asked and the outcomes of these questions on our website, alongside all our previous 'What's the Evidence?' summaries at www.pencru.org/evidence/

Building a Partnership - we need your ideas!

We are collecting ideas about what you would like the next 'Building a Partnership' event to be. This is an opportunity for you to get some hands on experience and learn about research, and also for us to learn from families.

So far we have hosted sessions on:

- Constructing research questions
- Searching the internet for reliable information
- Introduction to research
- Models of disability

These sessions were designed by families and delivered by researchers. If you have something that you would like to know about research processes, methods or a related topic then please let us know.



We have updated our website

Our website has undergone a few changes—take a look! We would love to know what you think. www.pencru.org



Find us on Facebook
facebook.com/pencru



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

Recent Publications

If you would like to receive copies of any of these and are unable to find them online then please contact us. Plain English versions of some of these can be found on our website.

McHugh C, Bailey S, Shilling V, Morris C. (2013) Meeting the Information Needs of Families of Children with Chronic Health Conditions. *Phys Occup Ther Pediatr.* 33(3):265-270 <http://informahealthcare.com/doi/full/10.3109/01942638.2013.799628>

Morris C, Janssens A, Tomlinson R, Williams J, Logan S. (2013) Towards a definition of neurodisability: a Delphi survey. *Developmental Medicine and Child Neurology.* doi: 10.1111/dmcn.12218. [Epub ahead of print] <http://onlinelibrary.wiley.com/doi/10.1111/dmcn.12218/abstract>

Shilling V, Morris C, Thompson-Coon J, Ukoumunne O, Rogers M, Logan S. (2013), Peer support for parents of children with chronic disabling conditions: a systematic review of quantitative and qualitative studies. *Developmental Medicine & Child Neurology,* 55: 602–609. <http://onlinelibrary.wiley.com/doi/10.1111/dmcn.12091/abstract>

Upcoming Publications

MacMillan M, Tarrant M, Abraham C, Morris C. (2013) The association between children's contact with disabled people and their attitudes towards disability: a systematic review. *Developmental Medicine and Child Neurology.* (In Press)

Morris C, Janssens A, Allard A, Thompson Coon J, Shilling V, Tomlinson R, Williams J, Fellowes A, Rogers M, Allen K, Beresford B, Green C, Jenkinson C, Tennant A, Logan S. Informing the NHS Outcomes Framework: what outcomes of NHS care should be measured for children with neurodisability? *Health Services and Delivery Research* (In press)

Sellers D, Pennington L, Mandy A, Morris C. (2013) A systematic review of ordinal scales used to classify the eating and drinking abilities of individuals with cerebral palsy. *Developmental Medicine and Child Neurology.* (In Press)

Staff news: We have a new Family Involvement Coordinator!

Hello, I'm Meghan! I have recently joined the PenCRU team to replace Camilla as the Family Involvement Coordinator. I come to this role from a varied background of working with children and their families. I am a qualified Primary School Teacher, have a Masters in Psychological Research Methods, and a degree in Psychology. I am really pleased to be working in a place where the input of families is central. If you have any questions or would like to meet me to discuss how I can best support you in my new role don't hesitate to contact me.

Email: m.mccrory@exeter.ac.uk **Tel:** 01392 722968



New Cerebra Pro Bono Programme

The *Cerebra Pro Bono Programme* has been newly established at Cardiff Law School. The Programme will provide free legal support for disabled children and their families. For more information please contact the Cerebra helpline on 0800 32 81 159 or email info@Cerebra.org.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. We also welcome attendance via facetime!

Meeting	Date	Time	Location
Peer Support Project Stakeholder Meeting	Thursday 7 th November	10.00-13.00, includes lunch	Veysey, 006
Promoting children's positive attitudes towards disability	Tuesday 19 th November	10.00-12.00, followed by lunch	Veysey, 006
ASD MeASURE study	Thursday 21 st November	10.00-12.00, followed by lunch	St Luke's Campus, room WKN
PenCRU Advisory Group	Thursday 5 th December	10.00-12.00, followed by lunch	Veysey, 006

Contact the team:

Email: pencru@exeter.ac.uk

Phone: 01392 722968

Website: www.pencru.org

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



Stuart



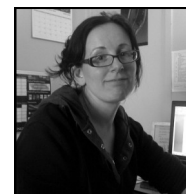
Chris



Meghan



Claire



Val



Astrid



Sarah



Megan



Anna

