

APEX—Autism Dentistry project update

This research aims to identify key strategies to improve access to general dental care for children with autism spectrum disorders in the prevention of dental caries (tooth decay). The research involved interviewing parents of primary school aged children about their experiences of taking their child with autism for a dental examination. Interviews have now finished—thank you to those of you who participated! Nicole and Sharon are now working on analysing all the information they received.

Recent Publications

Megan has published the last 2 papers from her PhD on children's attitudes to disability. One explored school based interventions to promote positive attitudes towards disability, and the other analysed a questionnaire which measures children's attitudes towards disability. To read a summary of Megan's work and see all four publications see <https://goo.gl/hEJKaw>

Please contact us if you would like us to email you a PDF or to post a paper copy of any of our publications <https://goo.gl/GhPi9g>

PenCRU meetings

Details of our Family Faculty and working group meetings will be posted on our website: www.pencru.org/projectsmeetings/upcomingmeetings/

Please check in the new year for details of those scheduled for next term.

If you are interested in coming along to any meetings then please get in touch. If you cannot attend a meeting but would still like to contribute, please do let us know. There's lots of other ways to get involved.

Contact the team

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PenCRU Newsletter December 2016 Issue 23

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Healthy Parent Carers project update

The Family Faculty working group met in November to interpret findings of the pilot programme using CLANGERS that ran earlier this year. The report is being drafted and we will be exploring ways to take this forward next year.

New project focusing on parent carer health & wellbeing

Are parent carers in the UK at risk of poorer health and well being compared to other parents? The Clinical Practice Research Datalink is an anonymised database of NHS primary health care records. Sarah, formerly a researcher with PenCRU, has gained experience of using this database in her PhD.

In a new project led by Sarah we will use the database to compare the health of mothers of disabled children with mothers of non-disabled children. If we find a difference between the two, we can use this as evidence to justify more resources for parent carer health. The project is being made possible from support from NIHR Collaboration for Leadership in Applied Health Research and Care South West Peninsula (PenCLAHRC)

Thank you to everyone who has been involved in these projects so far!



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Staff Updates



Sharon Blake left her post as a PenCRU researcher in September to pursue new opportunities with the Law Department of the university. We are very grateful for all her contributions to the unit over the past couple of years. However, Sharon will continue to be a research associate with the unit and is supporting Nicole with her work on our APEx-D Autism Dentistry project. Hannah, our other PenCRU researcher, began her maternity leave at the end of November and we wish her well of course as we await her news! We interviewed for new researchers at the beginning of December and look forward to Gretchen and Helen joining us in the New Year.

Parent Carer Handbook Project

Mac Keith Press publishes the leading childhood disability research journal and a series of text books. At the end of November a group of Family Faculty parents participated in a meeting with Mac Keith Press staff to discuss whether a handbook for parent carers of disabled children would be useful. The Mac Keith people were very impressed with the knowledge and advice the Family Faculty members were able to share with them.

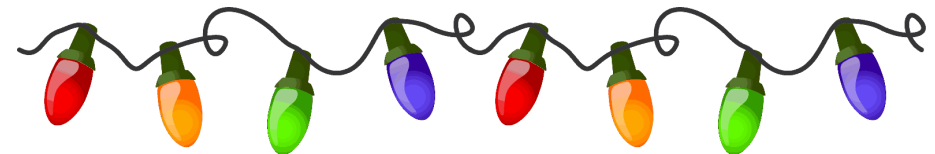
We are currently collating all the feedback we received about the ideas for topics for the book and the style and format of the book and will be letting you know in the New Year what the next steps for the project will be.

What's The Evidence?

We have published three new evidence summaries. These examined: [Brain surgery for epilepsy in Sturge-Weber syndrome](#); [Selective Dorsal Rhizotomy](#) for children with cerebral palsy; and the [Frankish model of psychotherapy for people with learning disability](#). A big thanks to all our Family Faculty members who helped to review these summaries! Our What's The Evidence? webpages have also undergone a revamp following feedback from our Family Faculty. Take a look at our new pages! <https://goo.gl/cq3s3b>

Family Fun Day 2016!

We had a brilliant day out in September at Paignton Zoo. The Annual Family Fun Day was to say thank you to members of the Family Faculty who have been involved in our work and to keep in touch with some members who we haven't seen for a while. As usual the amazing Vinny was there to entertain us and get us juggling and spinning plates, much to everyone's delight, and a great day was had by all.



Welcome to our new Family Faculty members

Our Family Involvement Coordinator Katharine recently attended a Devon Parent Carer Voice network day at Buckfast Abbey and a sleep event in Exeter organised by Cerebra. It was great to catch up with existing members at these events and a special welcome to the new parents who signed up. We're looking forward to getting to know you—please do not hesitate to contact us if you'd like any further information about PenCRU and the Family Faculty!