

## Recent publications

PenCRU was invited to write a paper for the journal Paediatrics and Child Health on **resources for parents raising a disabled child in the UK** that has recently been [published online](#).

The paper aims to inform UK paediatricians and child health care specialists about resources that can help to support and empower parent carers of disabled children so they can signpost families to them.

If you would like us to send you a copy, please contact the team.

## Facebook



Can you help us develop our Facebook page? Our Facebook page is a great way to comment on what we are doing and share information you think would be useful for other families, and we want to make ours even better!

Do you or your child have experience of creating a Facebook 'fan-page'? If so we would love your help in developing our PenCRU Facebook page!

We would like to know how to best engage with other groups and pages and if you have any ideas about how to design the page. Please do contact us if you're interested in helping with this.

### Contact the team

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

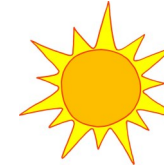
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## Autism: Parent Experiences of Dentistry (APEX-D) inclusion criteria widened!

The aim of this current project is to identify key strategies to improve access to general dental care for children with autistic spectrum disorders in the prevention of dental caries (tooth decay).

We are now in the process of interviewing parents about their experiences of taking their child(ren) with autism to high street dentists. To widen participation, parents of children with an official **or** a working diagnosis of autism are invited to share their experiences.

We have also increased the age-range of the child to include parents of 4–13 year olds. So, if you, or anyone you know, would like to share your dental experiences and you live in Devon or Somerset and have visited a high street dentist in the last two years, please get in touch.

## Staff news

Our team has grown again! Hannah Morris joined us in May as a researcher 3 days/week.



Hannah has a background in public health. Prior to working for PenCRU, Hannah worked as a researcher at a national alcohol harm awareness charity and in health service delivery research.

Hannah is currently working on updating the What's the Evidence? Summary: 'Is Selective Dorsal Rhizotomy an effective procedure for children with Cerebral Palsy?' Look out for this coming soon!

Katharine Fitzpatrick, our Family Involvement Coordinator, returned from maternity leave in July and she will also be working 3 days/week. A big thank you to Kath Maguire who has supported PenCRU in Katharine's absence.

## CATCh-uS Update

Interviews for the study are now well under way. Helen and Anna are really pleased to have completed interviews with 7 young people and 9 parents/carers, with several more booked in. This has included travelling around Devon and to London, Newbury, Coventry and Nottingham.

The interviews, which aim to find out about young people's experiences of ADHD services (especially transitioning from child to adult services) have taken place using a variety of methods and places including face-to-face at home or in clinic and remotely using Skype.

The team has interviewed 21 paediatricians and child psychiatrists from various regions. Interviews with clinicians from adult services working with young adults with ADHD are planned for the autumn.

We have also launched an online survey for service users, which has been developed in collaboration with parents from the Family Faculty. It takes less than 5 minutes, so please complete [this survey](#) if you can, Thank you!

## Research Priority Setting—Scoliosis

As mentioned in our last newsletter, the Scoliosis Partnership is working with the James Lind Alliance to provide a clear direction for future scoliosis research so that funding can be targeted to the issues that people with scoliosis, their family, friends and health professionals have identified as priorities - and so that people with the condition will benefit.

- Are you affected by scoliosis?
- Do you have a friend / family member with scoliosis?
- Are you a health or social care professional supporting patients with scoliosis, their families, friends or carers?

If you can answer 'yes' to any of the above questions, the Scoliosis Partnership are interested in your questions about diagnosis (including screening & risk of progression) and management (including treatment, care & psychological effects) of scoliosis. A link to the survey to gather your questions can be found [here](#).

To find out more about Scoliosis Research Priority Setting Partnership please click on the links below.

[Web](#)

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We would like to thank everyone who has been involved with PenCRU's activities over the last academic year by attending meetings, conferences and events; reviewing summaries and sharing your experiences with each other and our researchers. We hope you have a happy

