



PenCRU & Family Faculty

making childhood disability research
more relevant, useful and accessible

Family Faculty Meeting

14th July 2021 Zoom

Attendees: Bel, Annette, Chris, Alice, Ravi, Lizzy, Lynn, Fran, Annette, Lalitha, Kevin, Elise, Julia, Sam, Fleur

Current Projects:

Ravi Poorun: A new researcher with PenCRU investigating sleep in children with neurodisability.

- Poor sleep for children and carers in the FF is a common problem
- Access to Sleep Services is variable.
- Discussed research ideas including possibly a 'toolkit' of strategies to help.

Hospital Communications:

- The experience of disabled children in hospital was greatly affected by the quality of communication they had with the staff.
- Training package has been devised to be delivered in hospitals to staff.
- Implemented initially in Exeter and now more widely. [Read more...](#)

Parrot Study:

- Using prophylactic antibiotics to reduce emergency admissions for respiratory infections in children with neurodisability. [Read more...](#)
- FF members are involved. Contact us if you have relevant experience and want to join.

Healthy Parent Carer Study:

- Programme is being delivered by two charities: Contact and Council for Disabled Children
- Now adapted to online format using the help of Family Faculty members. "Thanks for organising such a great thing; it has been really helpful to me," said a course participant.
- Currently looking for more funding to continue the research. [Read more..](#)

Reset Study:

- Researching minimum level of services for disabled children during a national emergency.
- Talking to parent carers about their experiences of services during the pandemic. Family Faculty will be involved- we'll let you know how. [Read more..](#)