



Peninsula Cerebra Research Unit
PenCRU Childhood Disability Research



PenCRU and Family Faculty Handbook

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Welcome to PenCRU!

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The PenCRU team and some members of the Family Faculty

Hello and welcome to the PenCRU and Family Faculty handbook! We want this handbook to be a clear statement about how PenCRU and the Family Faculty work together.

This handbook was co-produced with members of our Family Faculty.

Here are some things parent carers in the Family Faculty told us:

“To be able to come and make use of my intellect saves my sanity... people forget we had responsible jobs before we became carers”

“It’s as much about what I can learn from other members as what I can offer”

“An opportunity to meet other parents, who have now become my friends”

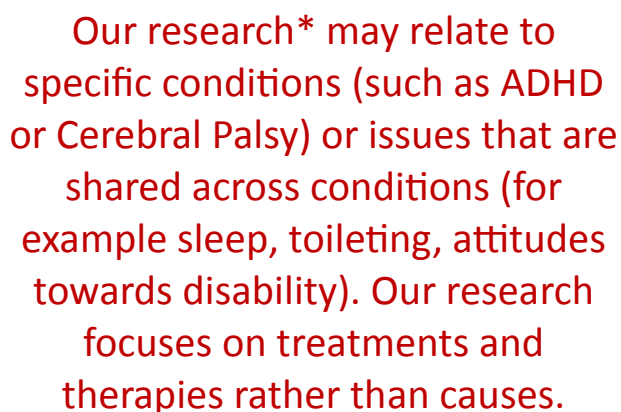
“I feel valued equally without having to make the same level of commitment”

What is PenCRU?

PenCRU is a childhood disability research unit based at the University of Exeter Medical School. The driving force behind PenCRU is our Family Faculty. With the Family Faculty, we seek to carry out research that aims to improve the health and wellbeing of disabled children and their families and that is useful and relevant to their lives.

Who else do we work with?

We work in partnership with professionals from agencies providing health, social care and educational services for children across Devon. We also pursue research with colleagues engaged in childhood disability research across the UK and worldwide.



Our research* may relate to specific conditions (such as ADHD or Cerebral Palsy) or issues that are shared across conditions (for example sleep, toileting, attitudes towards disability). Our research focuses on treatments and therapies rather than causes.

We believe that a partnership between families, service providers and researchers is vital to improving the lives of disabled children and their families.

How are we funded?

Most of our funding comes from the charity Cerebra* which enables us to have a core team of people to carry out activities to:

- build partnerships with local families and service providers,
- identify issues and research questions and review the evidence of treatments and therapies, and then
- design research studies to address these questions.

For major research projects we need to apply for additional funding, for example to the National Institute of Health Research (NIHR)* which is the government organisation that funds health related research in the UK. We also welcome other sources of funding. If a project is funded, our team numbers can increase for the duration of the funding.

What does PenCRU do?

PenCRU carries out a broad programme of applied research that aims to improve the health and wellbeing of children with neurodisability* and their families by utilising perspectives of families, researchers and professionals. Examples of conditions that neurodisability* includes (but are not limited to) are Autistic Spectrum Disorder, Cerebral Palsy, Down's Syndrome, Attention Deficit Hyperactivity Disorder, Global Developmental Delay and Angelman Syndrome.

Fundamental to the ethos of the unit is the meaningful involvement of families affected by childhood disability in all aspects of our research and related activities. This includes setting our research agenda and deciding how to carry out specific research projects. We achieve this involvement through our Family Faculty.

Definition of neurodisability

Neurodisability describes the group of congenital or acquired long-term conditions that are attributed to impairment of the brain and/or neuromuscular system and create functional limitations. A specific diagnosis may not be identified. Conditions may vary over time, occur alone or in combination, and include a broad range of severity and complexity. The impact may include difficulties with movement, cognition, hearing and vision, communication, emotion and behaviour.

- Morris C, Janssens A, Tomlinson R, Williams J, Logan S. Towards a definition of neurodisability: a Delphi survey. Dev Med Child Neurol. 2013



Membership of the Family Faculty



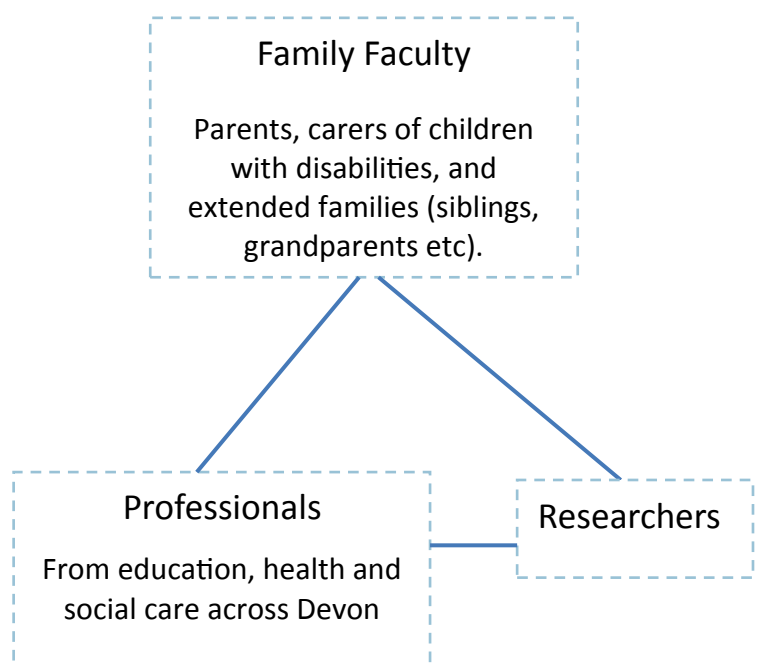
What is the Family Faculty?

Our Family Faculty is made up of families and carers of children with neurodisability*.

We take a 'life course approach' with Family Faculty members—although our research focuses on children and young people up to 25yrs old, you can still join if your children are now adults!

Our ethos is to involve the Family Faculty in all aspects of our research and related activities. This includes setting our research agenda and deciding how to carry out specific research projects.

We would like families to work with us as part of the team; there is no need to have any experience of research. Getting involved with our programme of work is different to being a participant or a subject in research.



What work do we do?

Respond to questions from Family Faculty members

We produce brief, easily readable summaries of the published evidence on topics or treatments that have been suggested by parents and carers. These are called 'What's the Evidence?'

Develop and undertake research

We develop research questions that have been suggested to PenCRU by families or professionals. We also collaborate with other researchers on their ideas. Sometimes NIHR commission research on topics important to the NHS. Usually we need to apply for funding and if successful we carry out the research.



PenCRU and the Family Faculty

Communicate research

We raise awareness of what research is and produce 'plain language summaries' of research findings. We also communicate research through our website, social media and newsletters.

Build partnerships

We build partnerships between families, researchers and health professionals. We have a learning programme called 'Building a Partnership' to support Family Faculty members to be partners in research. Family Faculty members identify research related topics they would like to know more about and as a team we set up a workshop to investigate the subject together.

Family Involvement in childhood disability research

What is involvement?

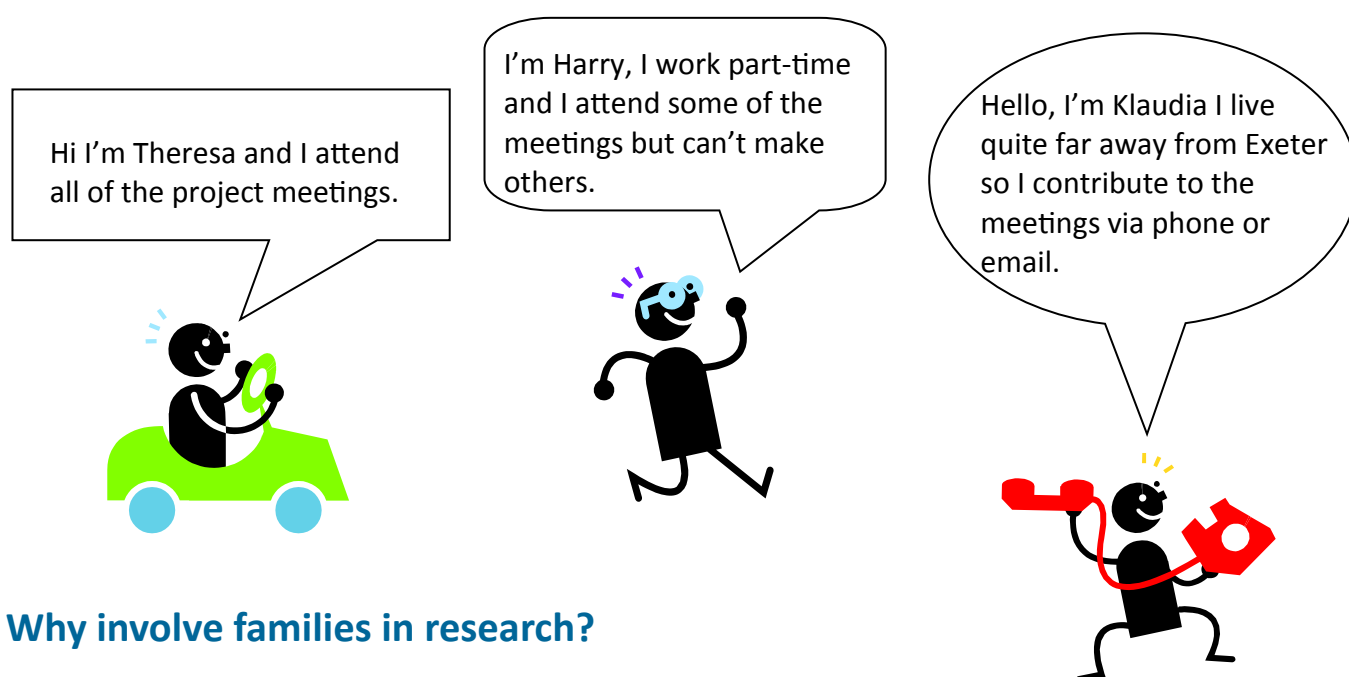
Involvement is giving families of disabled children a say in shaping our research programme. We support families to be part of the research team and be involved in many aspects of the research from what research we do, and how we design studies, to telling others about the results. Members of the Family Faculty can choose which activities to get involved with, and step in and out as it suits them depending on their circumstances at the time.

We do research 'with' people, not just 'on', or 'to' or 'for them'.

- PenCRU ethos

PenCRU have a mailing list for members of the Family Faculty. Through this, we keep everyone aware of involvement opportunities. We hold 3-5 meetings termly to discuss research projects. Families do not need to have any experience of research to attend these meetings! The expertise they bring is experience of being part of the family of a child with disability. Involvement in the project meetings can also be via phone or email.

All members of our Family Faculty are valued.



Why involve families in research?

To ensure that the research PenCRU carries out addresses families and children's needs. We believe that by involving families we increase the effectiveness of research evidence in practice. Ultimately we hope our research will improve the health and wellbeing of disabled children and their families.

How does PenCRU involve families in research?

Members of our Family Faculty are kept informed of different ways in which they can get involved. Examples include: suggesting research questions, being part of working groups, being co-applicants on funding applications and co-investigators on funded projects, being co-presenters at conferences and telling people about PenCRU and the results of PenCRU projects.

Our Family Faculty have opportunities to get involved in various activities!



Welcoming New Members

People interested in becoming a member of the Family Faculty can join in the following ways:

1. Enter contact information online on the PenCRU website.
2. Chat to a member of our team at an event/conference.
3. Contact PenCRU directly via email/phone.
4. Contact PenCRU via social media on our Facebook or Twitter account.

Once you have given us your contact details and a few optional details about your family, we will send you a welcome email or letter with the link to this handbook online.

If a member of the Family Faculty is interested in participating in a project group, they can do so by either attending the project group meeting (usually held in the PenCRU offices, Exeter) or by contributing remotely. Please see 'Engaging Remote Members' section below for more details.

What you can expect from attending a meeting

Our PenCRU and Family Faculty meetings are friendly and informal. You will be treated as an equal and an expert. You can claim back reasonable travel and childcare costs to attend a meeting and you will receive a financial acknowledgement for your time. We also include a lovely lunch in the meeting too!

Please find details of our expenses and acknowledgement policies and forms in the 'About Us' area on the PenCRU website.

If you would like to talk to a Family Faculty member who has been involved in a meeting please do contact us and we will put you in touch!

Engaging remote members

We understand that some people can't attend meetings due to work or distance; or prefer not to attend in person. If a person is unable to attend a meeting but would still like to contribute, we ask them to please let us know and we can arrange the best way for them to do that. Many of our Family Faculty members make valuable contributions in this way before and after meetings.

Working Together

PenCRU and Family Faculty 'Mutual agreement about working together'

It is important in all the workings of PenCRU and the Family Faculty that mutual respect and trust exists. To this end, all PenCRU staff and Family Faculty members are asked to read through and take account of the following list when working with PenCRU and other Family Faculty members.

We agree to:

- * Treat other Family Faculty members and PenCRU staff with respect and courtesy.
- * Respect the confidentiality of information shared by individuals.
- * Respect confidentiality concerning projects discussed. Please see the confidentiality policy for more information.
- * Try and stay on topic during meetings.
- * Allow each other to speak in turn.



Other things to remember!

- * Nobody is 'just' anything, so no one is allowed to say 'I know I'm just a parent...'. Everyone's opinion is valued equally.
- * There is no such thing as a silly question or comment about a project topic.
- * Please let PenCRU know if you can attend meetings, and also if circumstances change and you are no longer able to attend, so we can plan numbers for lunches and for parking permits.
- * If there is any dispute with another Family Faculty member, or PenCRU member of staff, we ask people to please let us know. There is a formal procedure that can also be used if required. (Please see the complaints procedure policy online for more information).

Key dates and achievements

2002

Stuart Logan leads clinical trial of nutritional supplements for Down's Syndrome.



2006

Cerebra* fund Stuart Logan to lead clinical trial of osteopathy for Cerebral Palsy.

2009

Funding from Cerebra research programme for 5 years.

2008

Cerebra fund Stuart Logan as Cerebra Professor of Paediatric Epidemiology.



2009

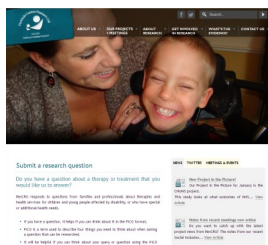
Launch events in Plymouth and Exeter. PenCRU is named to avoid confusion between the research unit and the charity.

2009

Project to improve communication with disabled children in hospital

2010

Family Faculty established and growing number of parents get more involved.



2010

PenCRU website is re-designed with parents.

www.pencru.org



2010

First 'What's the Evidence?*' summaries written in response to parents' questions.

2010

First 'PenCRU Family Fun Day*' held to thank families for their involvement with the unit.



2010

Shared learning event with parents to identify research questions and search for evidence.



2011

PenCRU are funded by NIHR* for a major study evaluating PROMs

2012

First Plain Language Summary written with Family Faculty about peer support for parents.



2012

PenCRU funded as co-investigator on two NIHR* funded studies on autism and ADHD.

2012

PenCRU leads a research priority setting partnership on behalf of the British Academy of Childhood Disability.



2012

PenCRU leads a workshop on involving families as partners in research in America.



2013

A definition of neurodisability* is developed by PenCRU, Family Faculty and 200 clinicians.

2014

Cerebra extends core funding support for PenCRU until 2019.



2013

PenCRU joins Twitter and Facebook to reach more people.

2014

PenCRU reports on core outcomes for neurodisability*.

2014

PenCRU Plain Language Summaries* featured in NIHR* Make it Clear campaign.

2016

A Family Faculty member attends a 'train the trainer' course and successfully delivers a Building a Partnership workshop to other FF members.

2015

PenCRU launches Healthy Parent Carers project and successfully runs the first programme.

make it clear

Acronyms and phrases explained

Advisory Group— The Advisory Group usually meets twice a year to oversee the management of our unit; we discuss ideas and plans for our programme of work.

Cerebra—Cerebra is a unique charity set up to help improve the lives of children with brain related conditions through research, education and directly supporting the children and their carers.

Family Fun Day—PenCRU's Family Fun Day is held each year to say 'Thank You' to members of the Family Faculty who have been involved in our work and research activities, and as a chance to get to know each other better! It's a free day out for families and takes place in a different location in Devon each year just after the Summer holidays.

Information Leaflet— Information leaflets are written to provide participants in a research study clear information about the study so they can make an informed decision about being involved. Our Family Faculty members can contribute to the writing and/or reviewing of participant information leaflets and help us think about how to inform participants about a study.

NIHR—National Institute for Health Research. The government funded research 'arm' of the NHS.

Plain Language Summaries—A plain language summary is a brief version of an academic paper or other document, that has been written to be accessible to everyone. It is written clearly, and includes explanations for any technical terms that are used. Our Plain Language summaries have been written by members of our Family Faculty and members of our research team together.

Research— We carry out research to find out more about a certain issue. This can involve discovering new information, adding to information that already exists, or questioning what is generally believed about something.

Neurodisability— Neurodisability describes the group of congenital or acquired long-term conditions that are attributed to impairment of the brain and/or neuromuscular system and create functional limitations. A specific diagnosis may not be identified. Conditions may vary over time, occur alone or in combination, and include a broad range of severity and complexity. The impact may include difficulties with movement, cognition, hearing and vision, communication, emotion and behaviour.

'What's the Evidence?' summaries— Our 'What's the Evidence?' reports are an ongoing series of reports designed to summarise what is known about the effectiveness of a particular treatment or therapy. These reports are a synthesis of existing research and are not new studies that we have carried out. The reports are written in response to queries from families about the research that exists surrounding specific therapies and treatments. We produce reports about both NHS and complementary or alternative treatments.

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