Peninsula Cerebra Research Unit

PenCRU
Childhood Disability Research


Children enjoying the annual Family Fun Day

University of Exeter Medical School

Annual Report 2013

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Cerebra Chair's reflections on progress in 2013

Welcome to the 2013 Annual Report; this has been hugely successful year for PenCRU. The biggest news was that the charity Cerebra has awarded a new grant to support the work of the unit for six further years until 2019. The extension of our funding allows us to consolidate on the ground work achieved until this year, building relations with families and Cerebra, and opens up opportunities as we move forward with our programme of research.

We were particularly pleased with the media's response to the renewal of our award from Cerebra, which led to interviews with parents who have worked with us on BBC Radio and TV, other local radio stations and the ITV West Country News; we were also featured on the BBC website!

Families' involvement really does drive almost everything we do, and we have developed a national and international reputation for our ethos, approach and methods. During 2013 parents in our Family Faculty have been involved in a range of activities; these include developing their own ideas for research topics, helping PenCRU carry out research in progress, and helping to tell people about the research we do through plain language summaries and presenting with us at conferences. Learning from our close working with parents, PenCRU is also developing research theme focusing on ways to support and promote the health and wellbeing of Parent Carers.

Significant progress has been made in all our specific research projects, and several have reached completion. It was once believed that the final step was producing the academic paper and getting that published; however we now realise that there is another stage in terms of getting the research to influence and change practices and policies. Part of that process is getting the research to people making the decisions about treatments, therapies and services in their day to day lives, including families, clinicians and health service managers, in an accessible format.

The National Institute for Health Research (NIHR) will issue a themed call for research about children and young people with long-term conditions in 2014; this follows the recent report by the Chief Medical Officer, Dame Sally Davis, titled 'Our Children Deserve Better'. The report featured several contributions by PenCRU staff, including findings emerging from the CHUMS study about measuring outcomes for children with neurodisability and our work to capture the views of children and young people. This call by NIHR is a great opportunity for child disability research.

The James Lind Alliance (JLA) Childhood Disability Research Priority Setting Partnership is making great progress; Chris Morris and a Steering Group that comprises parents, a young person with a neurodisability, charity representatives and clinicians lead the project. The work is identifying and prioritising treatments and therapies that we (as a community) are uncertain whether they improve the health of children and young people with neurodisability; it will report a Top 10 priority topics for research in the summer. The findings could not be more timely, being published as we expect during the year of NIHR is focused on funding research about children with long-term conditions.

I hope you enjoy reading this report and look forward to further close collaboration with families and Cerebra over the coming years.

Professor Stuart Logan
Cerebra Chair in Paediatric Epidemiology

Mission statement

PenCRU carries out a broad programme of applied research that aims to improve the health and wellbeing of disabled children and their families.

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’. You can read more about how families are involved in our work in this report.

In addition we work in partnership with agencies providing health, social and education services for children across Devon, Plymouth and Torbay. We believe that the partnership between families, service providers and researchers is vital to improving the lives of people affected by disability.

We also pursue research with colleagues engaged in childhood disability research across the UK and worldwide.

How we are funded

Cerebra is a UK charity that aims to improve the lives of children and young people with brain-related and other neurological conditions. PenCRU is one of several academic centres to receive funding from the Cerebra charity. A new award was granted for the period 2014-2019. Cerebra also maintain their own in-house research staff and provide direct grants and advice to parents, carers and professionals.

The relationship between Cerebra and the University of Exeter Medical School (formerly Peninsula College of Medicine and Dentistry) evolved from the conception, design and completion of a randomised controlled trial evaluating the effectiveness of osteopathy for children with cerebral palsy. Professor Stuart Logan was subsequently awarded the title of Cerebra Chair in Paediatric Epidemiology and the charity provided funding to establish the research unit.

The charitable funding from Cerebra supports the core activities of the research unit, principally building partnerships with local families and service providers, identifying issues and research questions and reviewing the evidence, and then designing research studies to address these questions. PenCRU also receives support from the National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care for the South West (PenCLAHRC). For major research projects we require substantive additional funding for which we apply to schemes operated by the National Institute for Health Research, Medical Research Council and charitable agencies that fund research.

PenCRU is an independent academic research unit at the University of Exeter Medical School. The views and opinions expressed by PenCRU do not necessarily represent the views of the Cerebra charity.

PenCRU team

Stuart Logan MB ChB MSc (Epidemiology) MSc (Politics) MRCP FRCPCH Cerebra Professor of Paediatric Epidemiology

Stuart Logan is the Director of the Institute of Health Service Research at the University of Exeter Medical School and Honorary Consultant in Paediatrics in the Royal Devon and Exeter Hospital. His particular interest is the generation of research of direct relevance to policy and practice and useful to practitioners and to families. His major areas of research are the evaluation of complex interventions, and on the effects of social inequalities on child health.

Chris Morris MSc DPhil
Senior Research Fellow in Child Health

Chris has 20 years clinical experience as an orthotist and 14 years experience in childhood disability research. He has been awarded Masters and Doctoral degrees by the University of Oxford for research about children with cerebral palsy. His main research interests include epidemiology, qualitative research with children, and the appraisal and use of patient-reported outcome measures.

Meghan McCrory BSc (Hons) MSc PGCE
Family Involvement Coordinator (began post July 2013)

Meghan McCrory has a varied background in working with children with disabilities and their families. She is a qualified Primary School Teacher, has a Masters in Psychological Research Methods, and a degree in Psychology. She is the primary contact who liaises with our Family Faculty to provide information and support for families working with the unit, and ensures families have a role and say in all aspects of PenCRU activities.

Claire Lloyd BSc (Hons) MSc
Associate Research Fellow in Child Health

Claire is an Associate Research Fellow in Child Health. She has experience in research with children with disabilities and their families. Claire has worked closely with families developing and carrying out several projects.

Val Shilling BA (Hons) PhD CPsychol
Research Fellow in Child Health

Val has a background in psychology and a Bachelors degree and Doctorate from the University of Manchester and is a Chartered Psychologist. Her research interests include patient and particularly parent experiences and communication in healthcare. She is currently working on a pilot evaluation of the peer support service offered by Face2Face (F2F) in Devon and Cornwall to explore the benefits and costs of offering peer support to parents of disabled children.

Astrid Janssens BSc (Hons) MSc PhD
Research Fellow in Child Health
Astrid has a Masters degree in Experimental Psychology and Anthropology, and a Doctorate in Medical Sciences. Astrid's research background is in children and adolescents' mental health and the organisation of services taking care of them. Her main area of work is the CHUMS project.

Sarah Bailey BSc (Hons) MPH
Associate Research Fellow in Child Health
Sarah completed her Masters degree in Public Health at Cardiff University in 2010, and prior to that studied Biomedical Science. She has experience of working with young people with additional needs.

Megan MacMillan BSc (Hons) MSc
PhD Student, Institute of Health Service Research, University of Exeter
Megan is a psychology graduate studying for a PhD, supervised by Mark Tarrant, Chris Morris and Professor Charles Abraham. Her PhD is titled 'Understanding children's attitudes towards disability and promoting positive attitudes'. This PhD project aims to discover what factors are associated with attitudes to disability and to use these factors to modify children's attitudes.

Anna Stimson BA (Hons)
Research Administrator
Anna joined PenCRU in November 2012 to provide part-time administrative support to the unit. As a mother to three young children, and a school governor, she has an active interest in the work that we do.

Camilla McHugh BA
Family Involvement Coordinator (left post June 2013)
Camilla helped to establish the Family Faculty since the beginning of PenCRU, and has now moved to work on another research project in the Child Health Group.

Team news update

During 2013, Camilla McHugh, Sarah Bailey and Claire Lloyd left PenCRU to pursue other activities. We are hugely grateful for all their hard work and contributions to making the unit a success, and wish them all the best for the future.

Family involvement

The ethos of the unit is to involve families in all aspects of our research and related activities.

We understand the amount of time that families have varies, so we are conscious of being flexible and adaptable to accommodate this.

Family Faculty

designed by Matt aged 14

This includes looking into ways to increase involvement opportunities for those parents who have been working with us for some time, and are interested in getting involved at a deeper level.

We regularly request feedback from parents who work with us. Here are some of the things parents have told us this year:

‘It’s great to see other families in the same situation as we are and to see how they deal with day to day dramas. It is an excellent organisation.’

‘Thank you for the amazing outings, they’re really fun and thanks for your research.’

‘I really like being able to be involved in the bits that interest me. I love the fact I can dip in and dip out depending on how my life is at a particular time!’

‘I enjoy the training & seminars & learning & new things & opinions which are listened to.’

Families relaxing at the annual Family Fun Day

Our unit meetings

Each project holds a number of meetings throughout the year, and families play an important role in these meetings. The table below shows the numbers of parents who attended meetings for each project during 2013.

Project	Number of parents involved
Peer Support	5
CHUMS	4
Attitudes to Disability	5
MeASURe ASD Review	5
ADHD School Interventions	1
Hospital Communication	9
CP Wheelchair seating	3
Children and Young Peoples Involvement	2
Other	7

Note: We are also keen to engage with other interested members of the public, and in addition to the parents shown above; current and retired professionals working in relevant fields have also attended meetings for several projects.

Advisory Group

Our Advisory Group has a strong influence on our programme of work and other activities. The Advisory Group meets twice each year. They are usually well attended; 3 parents participated in June, and 10 came in December (the lure of the mince pies, perhaps).

We use our Advisory Group meetings to consult the Family Faculty on the way that PenCRU runs, and the various operational challenges that arise.

Advisory Group meeting

Our most recent Advisory Group was a chance for us to review the information that we send out to advertise the unit to families. We will be using the information we collected to create new leaflets in 2014. We also discussed new research opportunities regarding education and dentistry.

Presenting our activities in the community

Maintaining a presence in the community helps us to understand issues that families are faced with in their day to day lives, and also gives us the opportunity to tell them about PenCRU and what we do. As such, face to face contact helps encourage and support families to come and get involved in research, and is an extremely important part of our family involvement.

This year has been very busy. Families are experiencing many changes in the services that are provided for their children, and there has been much to learn!

We have built up very strong relations with many groups and we are regularly invited to have stands at the events that are put on for families in the community. The Family Involvement Coordinator has attended support groups, parent forums and a number of Local Authority events throughout the year.

Listed below are a few of the events that we have attended.

- Devon Parent Carers Voice events across the county
- North Devon Face2Face launch
- Face2Face Exeter
- Engaged Futures
- North Devon Forum for Autism parent support group
- South West PPI Forum
- A number of visits to SEN Schools

Family Involvement Coordinator out in the community with the PenCRU display board!

Building a Partnership

We have continued to run our shared learning programme called ‘Building a Partnership’. We encourage families to identify research related topics they would like to learn about, and then coordinate with families and colleagues to devise and set up a workshop event. These workshops are designed to support parents to be partners in the research and are held once or twice a year. This year the topic chosen by parents was ‘models and theories of disability’. The agenda covered the social model of disability, and the World Health Organisation’s models of health and disability.

Eleven parents took part in the workshop and provided feedback on whether the event was useful, understandable, interactive, the appropriate length and if they were able to actively take part. The feedback was positive with some great suggestions for how to improve the session. The general consensus was that they would like to learn more about the social model of disability and how it can be used in their day-to-day lives. Some of the group felt that the World Health Organisation models were less accessible and needed to be put into context with everyday examples and stories.

Annual Family Fun Day

The Annual Fun Day is 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. As a unit we really look forward to our annual Family Fun Day event.

2013 saw our fourth Family Fun Day. After consultation with parents, Bicton Park was selected as the venue of choice; it was a sunny and fine day (despite the rainy weather the week before).

Vinny the mime artist was there to entertain us, much to everyone's delight! Following a suggestion from the Family Faculty, we brought along our display board for the first time to enable us to include elements of PenCRU's research in the day.

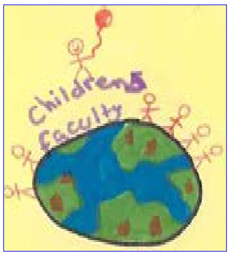
We filled our display board with questions to prompt feedback on the work of PenCRU, and to find out how we could encourage more people to become involved. We also had members of the PenCRU team on hand by the board throughout the day so that families could ask us questions. This worked well – and we look forward to another similar event next year!

Some comments from the children that attended:

'It was a great day. I would love to come here again.'

'I really liked the train and I saw lots of interesting things.'

Children and Young People's involvement



This year saw the consultation phase of our Children and Young People's (C&YP's) involvement.

From this consultation phase we learnt that while it seems a natural step in the PPI development of PenCRU to involve C&YP, the mechanism to achieve this is somewhat more complex and challenging than involving parents. We have carried out and submitted to a journal a systematic review of published research in which disabled children and young people were described as being involved.

The next step for PenCRU is to pilot some engagement with a small number of schools, which will be completed in the first half of 2014. We will use the learning outcomes to apply to our long term goal of developing a C&YP Faculty. The aim of which will be to embed C&YP involvement within all PenCRU activities. We have received a small amount of funding for this work.

Conferences

This year we attended the The 25th European Academy of Childhood Disability conference at The Sage in Newcastle-Gateshead. The conference was a great opportunity to share the research that PenCRU does with the wider academic community. Members of the team presented their work in a mix of poster and verbal presentations. Two parent members of our Family Faculty came along and a great time was had by all!

Members of PenCRU and the Family Faculty at the EACD meeting

Conference poster presentation

We were also very excited as the PenCLAHRC Patient and Public Involvement Team held their first conference in Exeter. The conference was a great success and focused on the latest developments in patient and public involvement in health services research. Again, this was a brilliant opportunity for PenCRU to showcase a range of our research projects, but also our involvement strategy. Members of our Family Faculty co-presented on a number of presentations which were received with great interest by the other delegates.

Finally, this year we were pleased to host the joint British Academy of Childhood Disability and British Association for Community Child Heath South West Meeting. It was a good day filled with fascinating talks. Two parents from the Family Faculty co-presented about their experiences of being involved in the Peer Support project. The presentation followed an unconventional, yet informative, format centred on a comical play.

The play highlighted attitudes that researchers can have towards the input of parents in research.

PenCRU in the media

We have received increased media coverage this year, in part due to the renewal of our core funding. This has been positive for publicity of the unit however it has also highlighted the challenge that we have as a unit of communicating effectively what we do. For example, initially when the BBC created visual images to accompany our report they used images of dry ice and lab based research. This is an ongoing area that we will be considering in the upcoming year.

2 October 2013 Last updated at 06:13

Childhood disability research funded for six more years

Devon researchers specialising in childhood disability have secured funding for their work until 2019.

The Peninsula Cerebra Research Unit (PenCRU), based at the University of Exeter Medical School, will get nearly £800,000 from national charity Cerebra.

Their work includes evaluating peer support for parents of disabled children.

It also reviews complementary therapies and promoting positive attitudes towards disability in schools.

PenCRU works with families across the county, encouraging them to become involved through a Family Faculty group.

PenCRU said the money will be used to continue to build the partnership they have developed with families

Related Stories

Guide rebuts special needs myths

'Empower myself'

Julia Melluish, from Paignton, is the mother of six-year-old Harrison, who has cerebral palsy, is registered blind and has severe developmental delay - a type of learning disorder.

She said: "When you become a parent to a severely disabled child, you lose yourself. You find yourself suddenly immersed in a world you know nothing about.

"When I found out about PenCRU, I had just reached a point where I had stopped feeling so desperate.

PenCRU staff talking to families

Programme of research

The following pages describe our programme of research, and the progress we made in 2013.

James Lind Alliance (JLA) Childhood Disability Research Priority Setting Partnership

C. Morris, K. Cowan, M Busk, A Walker, A Allard, M Fenton, K Robison, D Simkiss.

The aim of the Childhood Disability Research Priority Setting Partnership (PSP) is to identify prioritise the most important research questions in neurodisability to families and clinicians. The survey to identify topics was open for six months in 2013 and identified over 800 suggestions from around 400 parents and clinicians. The Steering Group has reviewed these and once duplicated issues and out of scope submissions are accounted for there are around 60 research questions going forward to prioritisation.

The CHUMS study

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.

This study funded by the NIHR examined what outcomes of NHS care should be measured for children with neurodisability using questionnaires completed by children and/or parents. The research is now completed and the report being prepared for publication in the NIHR Library. We are also disseminating the findings through academic journal articles and conference presentations; the first paper describing our work to seek consensus on a definition of 'neurodisability' was published in 2013.

The EDACS study

D Sellers, L Pennington, A Mandy, M Hankins, C Morris

The EDACS study, led by Diane Sellers at Chailey, involved developing a valid and reliable eating and drinking ability classification system for children with cerebral palsy. The project is completed and two papers have been published; the first was a systematic review of existing ways to classify eating and drinking that identified the need for a new method, and the second paper describes the development and preliminary testing of the reliability of therapists and parents using the EDACS.

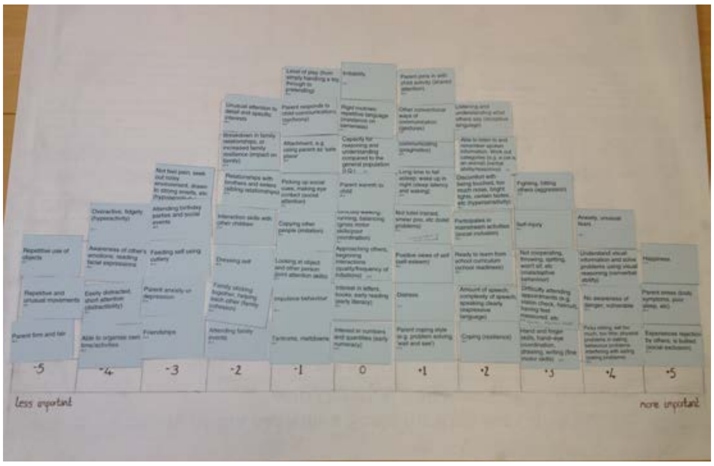
Hospital communications

C Lloyd, S Sharkey, C Morris, E Thomas, R Tomlinson, R Gumm, S Logan.

This study aims to improve communication between paediatric ward staff and disabled children when they have to spend time in hospital. The systematic review from phase one has been published, analysis of the interviews with families and professionals in the second phase was completed in 2013 and a paper is submitted for publication. The next stage involves piloting training based on what we learned from the earlier work and guided by parents is in progress; the first training session took place in 2013.

The MeASURe study

McConachie H, LeCouteur A, Parr J, McColl E, Law J, Rodgers J, Jones G, Gringras P, Charman T, Simonoff E, Green J, Garland D, Morris C, Macdonald G, Livingstone N, Beresford B, Pickles A, Baird G, Terwee C.



MeASURe is reviewing tools used to measure aspects of Autistic Spectrum Disorder in young children, and how well these reflect issues of importance for patients and carers. The review is at an advanced stage. Parents in Exeter have met three times to identify and prioritise issues, and to prepare for the analysis and interpretation of the findings. One parent from our Family Faculty will represent the group at a discussion meeting with clinicians and young people in London to consider the findings.

Sleep positioning in cerebral palsy: Cochrane review

Lloyd C, Logan S, McHugh C, Humphreys G, Parker S, Beswick D, Beswick M, Morris C, Wyatt K.

This systematic review is appraising evidence of whether commercially available night-time postural management systems reduce hip deformity in children with cerebral palsy. The review did not identify any high quality evidence regarding the effectiveness of sleep systems. A second wave of searching will be undertaken to update the review in 2014.

Sleep systems for children with cerebral palsy: a pilot randomised controlled trial

D Cowan, T Pountney, D Porter, J Underhill, G Humphreys, C Morris.

This pilot randomised controlled trial, led by colleagues at Chailey, tests a research design for assessing how night-time postural management equipment affects sleep, comfort, pain and deformity in children with cerebral palsy. The pilot study has faced several challenges and struggled to recruit sites; there has been considerable learning about barriers to running trials of postural management equipment and across paediatric therapy services. The pilot trial will complete and the learning shared widely.

Benefits and costs of peer support for parents of disabled children

Shilling V, Morris C, A Hawton, Thompson-Coon J, Rogers M, Ukoumunne O, Logan S.

This project is evaluating the benefits and costs of providing one-to-one peer support to parents of children with disabilities. The project is largely completed. The systematic review was published; the qualitative and costing studies are analysed and papers are being written for publication in academic journals. A full report of the evaluation will be made available on the PenCLAHRC website.

Promoting children's positive attitudes towards disability

M. MacMillan, M.Tarrant, C. Abraham, C Morris

This study, led by PhD student Megan MacMillan, involved a systematic review and a school-based survey with children to understand factors affecting children's attitudes towards disability. The review is completed and has been published, and the survey is completed and analysed and is being written up for publication. The next stage involves examining relevant educational materials designed for children in mainstream schools. Megan plans to complete her PhD in the summer 2014.

School based interventions for ADHD

D Moore, J. Thompson Coon, B. Norwich, E. Taylor, C. Shotton, C. Morris, W. Pritchard, R. Garside, S. Logan, K. Stein T. Ford.

This systematic review examined non-drug interventions for children with ADHD delivered in schools. The review is completed and a report submitted to the NIHR HTA Programme. Cerebra convened a 'sell out' event in Bristol that involved stakeholder consultation regarding the findings. One parent from our Family Faculty was involved from the application for funding through to the production of the report.

Supporting Teachers And childRen in Schools (STARS): a cluster randomised controlled trial

T. Ford, V Edwards, C. Shotton, B. Norwich, S. Logan, O. Okoumunne, S. Byford, W. Pritchard, P. Jones.

The STARS study is funded by the NIHR Public Health Research programme, and is examining whether the Incredible Years Teacher Classroom Management (TCM) course can enhance teachers' skills in promoting socio-emotional well-being among their pupils, improve academic attainment and child enjoyment of school. STARS has successfully recruited 45 primary schools and 1167 families across Devon to participate in the study and will recruit the final 35 schools to start the study in September 2014.The TCM course has been successfully delivered to 10 teachers so far with another 20 teachers currently attending the course, with an additional 50 teachers attending TCM over the next two years. The study will be completed by June 2017.

Systematic review: involving disabled children and young people as partners in research

S Bailey, K Boddy, S Briscoe, C Morris.

This systematic review examined what is currently known about involving children and young people as partners in research. The review is completed and a paper has been submitted to an academic journal. The findings are extremely useful to inform the involvement of children and young people with PenCRU.

Children and Young People project

M McCrory, S Blake, V Shilling, S Logan, C Morris.

This ongoing work, supported by the Catalyst public engagement programme at Exeter, is working to involve disabled children and young people in research and PenCRU activities. Contacts have been made with several local schools. We will engage with disabled children and young people early in 2014.

Active Console Games

W Farr, I Male, S Bailey, D Green, C Morris.

The impact of active console games on children and young people with motor impairments. Several parents and professionals have discussed this idea. We are collaborating of a funding bid with colleagues in Oxford and Sussex for a study to evaluate Wii games in children with CP (decision pending).

PenCRU holding a parent meeting

Communicating about research

PenCRU aims to provide better, accessible information to all families and people with brain injury and neurological disorders. We want to help families obtain the best current evidence to help them in making decisions. We want to involve families in setting the research agenda and enable active engagement of parents and children in all aspects of the research process.

What's the Evidence?

PenCRU responds to questions received directly from families and professionals about interventions and health services. To ensure that research evidence is available to families and practitioners in a form that is comprehensible and accessible, and any implications for policy and practice are highlighted, we have developed a system of appraising and summarising the current research available on a chosen topic in our What's the Evidence? summaries. We produce reports about both NHS and complementary or alternative treatments. These summaries are published electronically on our website and are widely accessed. They aim to help families make informed decisions about care for their child.

During 2013 we produced new What's the Evidence? summaries:

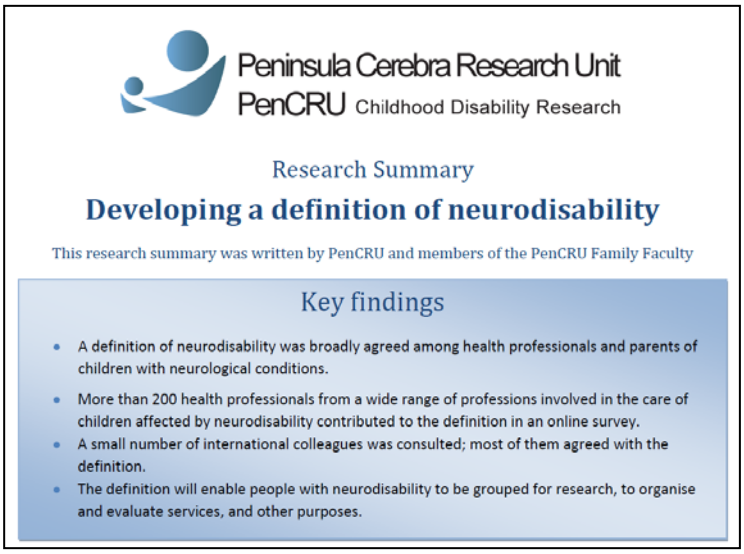
- Are Feldenkrais Method or Anat Baniel Method effective therapies for children with cerebral palsy?
- Dentistry for children and young people with learning disabilities and challenging behaviour.
- Is there any evidence which shows at what point (i.e.. 5, 10, 30 minutes after seizure onset) it is best to use emergency medication when treating a child who is likely to/known to suffer cycles of prolonged or repeated seizures or status epilepticus?
- How effective is speech therapy for verbal dyspraxia in children with a learning disability?

We also checked and updated existing What's the Evidence? summaries to see if there was any new information available:

- Is Applied Behaviour Analysis (ABA) for children with Autistic Spectrum Disorders (ASD) effective?
- Is constraint induced movement therapy (CIMT) effective at improving manual ability in children with hemiplegia?
- Does eliminating artificial food colourings and additives from a child's diet affect symptoms of ADHD?
- Is there any research evidence about the effectiveness of the Scotson Technique?
- What are the effects of massage therapy for children with Cerebral Palsy?
- Does eliminating aspartame, an artificial sweetener used in some foods and drinks, from children's' diets affect symptoms of ADHD?
- Do omega 3 fatty acid supplements reduce symptoms in children and young people with ADHD?
- What is selective dorsal rhizotomy and is it an effective therapy for children with cerebral palsy?
- Do Lycra orthoses (splints) improve function and movement ability in children with hemiplegia, or other types of cerebral palsy?

Plain language summaries

To make some of our more involved research work readily assessable to non-academics, we have worked with members of our Family Faculty to develop templates which allow us to produce plain language summaries of our research findings. These are kept to a manageable length for parents with limited time and highlight key points both in terms of content and presentation. They include explanations for any technical terms that are used, and provide details of how to obtain further information if required. They are all available on our website and in paper form.



Peninsula Cerebra Research Unit
PenCRU Childhood Disability Research

Research Summary

Developing a definition of neurodisability

This research summary was written by PenCRU and members of the PenCRU Family Faculty

Key findings

- A definition of neurodisability was broadly agreed among health professionals and parents of children with neurological conditions.
- More than 200 health professionals from a wide range of professions involved in the care of children affected by neurodisability contributed to the definition in an online survey.
- A small number of international colleagues was consulted; most of them agreed with the definition.
- The definition will enable people with neurodisability to be grouped for research, to organise and evaluate services, and other purposes.

- Hospital communication study plain English summary PDF 417KB
- Benefits and costs of peer support plain English summary PDF 501KB
- Positive attitudes towards disability plain language summary PDF 732 KB
- Developing a definition of neurodisability PDF 394 KB

Social Media

PenCRU developed social media profiles on Facebook and Twitter in mid-2012, and has continued to use these channels to try and engage with more families and health professionals and other researchers throughout 2013.

PenCRU
@Pen_CRU
PenCRU carries out a broad programme of applied health services research that aims to improve the health and wellbeing of disabled children and their families.
Exeter, Devon · pencru.org

242 TWEETS	113 FOLLOWING	106 FOLLOWERS

We tweet news and updates about our work, research, events, and conferences, and re-tweet information from other sources that we believe is relevant and of interest to the families of disabled children. The PenCRU Facebook page also informs our followers with news and updates from the unit, including details of meetings and publications.

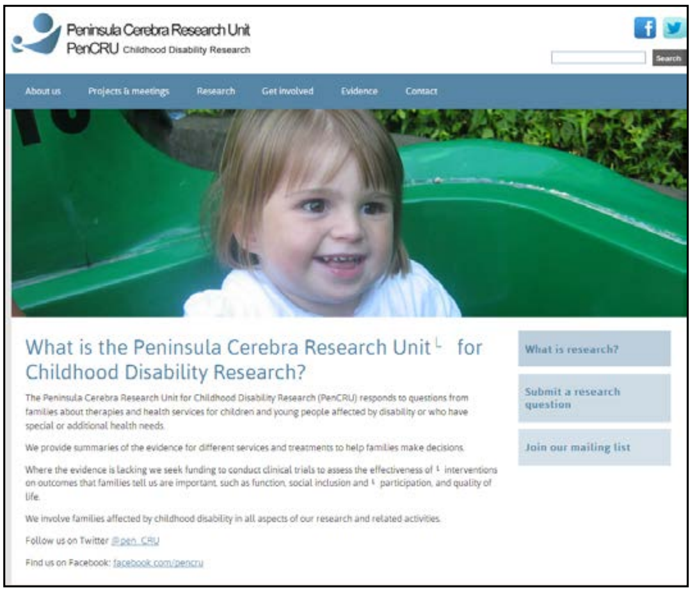
During 2013 the unit doubled its number of followers on Twitter from 53 as of December 2012, to 106 as of January 2014. Our closed Facebook page had 53 'likes' at the same date.

We are keen to explore new and innovative ways of communicating information about PenCRU and our research. For example, using YouTube videos and other formats.

PenCRU
is on Facebook.
To connect with PenCRU, sign up for Facebook today.

PenCRU responds to questions from families about therapies and health services for children and young people affected by disability or who have special or additional health needs.

Website


Peninsula Cerebra Research Unit
PenCRU Childhood Disability Research

What is the Peninsula Cerebra Research Unit └ for Childhood Disability Research?

The Peninsula Cerebra Research Unit for Childhood Disability Research (PenCRU) responds to questions from families about therapies and health services for children and young people affected by disability or who have special or additional health needs.

We provide summaries of the evidence for different services and treatments to help families make decisions.

Where the evidence is lacking we seek funding to conduct clinical trials to assess the effectiveness of └ interventions on outcomes that families tell us are important, such as function, social inclusion and └ participation, and quality of life.

We involve families affected by childhood disability in all aspects of our research and related activities.

Follow us on Twitter @pen_CRU

Find us on Facebook: facebook.com/pencru

The PenCRU website is often families and professionals' first point of contact with the unit. It provides information about research and our programme of work at the unit. All of the upcoming meetings at the unit are advertised here, and it is used to publish notes from previous meetings, our quarterly newsletters, annual reports, etc. and to make research study documents available to participants.

We have a designated area which explains in detail the different ways that parents and professionals can get involved in the work of the unit, and how they will be supported in doing so. We have recently added a new section of testimonials from members of the family faculty who told us about their experiences of working with PenCRU.

Each of the projects PenCRU is involved in has its own page providing topic specific information and there are also pages listing all the What's the Evidence? and Plain Language Summaries we have produced to date.

An online form enables families and professionals to submit queries and research questions to us, and we also provide clear details of how the unit can be contacted by a wide range of different methods.


Peninsula Cerebra Research Unit
PenCRU Childhood Disability Research

2013 QUARTERLY NEWSLETTER Issue 14

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!

www.pencru.org

Newsletter

PenCRU produce a quarterly newsletter with up to date information about our programme of work, activities, upcoming meetings and items of interest.

The newsletter is circulated to families and professionals who have expressed an interest. Under advice from the Family Faculty we continue to produce a hardcopy which we send to families. We also publish all editions of the newsletter on our website.

Collaboration with Cerebra

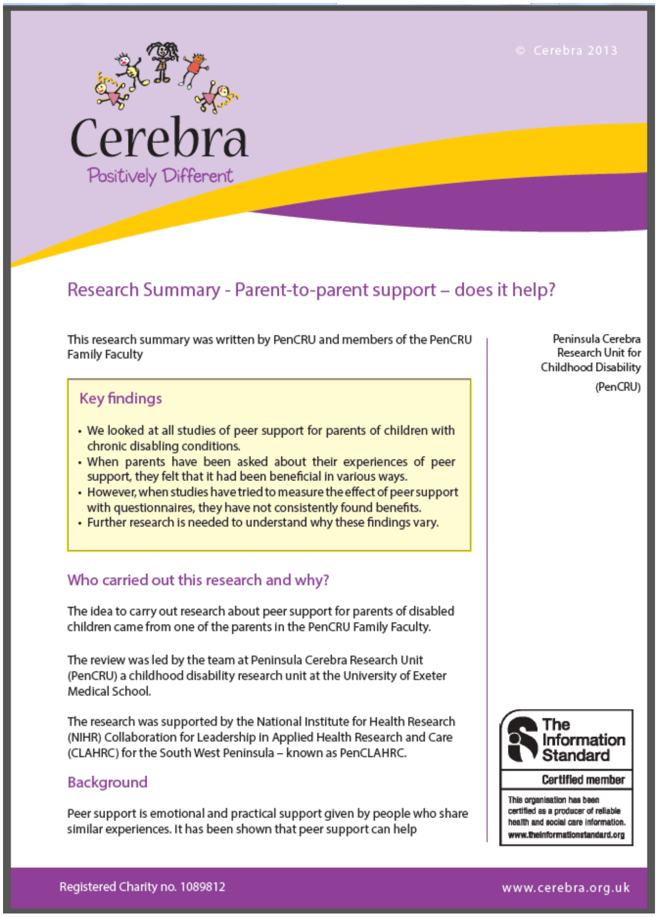
We continue to liaise closely with the team at Cerebra, sharing details of queries raised by families and using this information to steer our activities.

Annual visit by Cerebra

We enjoyed hosting our annual visit from Cerebra. Tracy Elliot, head of Research at Cerebra; Liz Fleming, a trustee and Jane Margetson, Lead Research and Education Officer came to hear presentations from the team about the work we have been doing this year. Several members of our Family Faculty also came along to tell Cerebra about our work.

Local Cerebra Events

This year we have also enjoyed participating in Cerebra events.



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Cerebra
Positively Different

Research Summary - Parent-to-parent support – does it help?

This research summary was written by PenCRU and members of the PenCRU Family Faculty

Peninsula Cerebra
Research Unit for
Childhood Disability
(PenCRU)

Key findings

- We looked at all studies of peer support for parents of children with chronic disabling conditions.
- When parents have been asked about their experiences of peer support, they felt that it had been beneficial in various ways.
- However, when studies have tried to measure the effect of peer support with questionnaires, they have not consistently found benefits.
- Further research is needed to understand why these findings vary.

Who carried out this research and why?

The idea to carry out research about peer support for parents of disabled children came from one of the parents in the PenCRU Family Faculty.

The review was led by the team at Peninsula Cerebra Research Unit (PenCRU) a childhood disability research unit at the University of Exeter Medical School.

The research was supported by the National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care (CLAHRC) for the South West Peninsula – known as PenCLAHRC.

Background

Peer support is emotional and practical support given by people who share similar experiences. It has been shown that peer support can help

The Information Standard
Certified member
This organisation has been certified as a producer of reliable health and social care information.
www.theinformationstandard.org

Registered Charity no. 1089812

www.cerebra.org.uk

PenCRU Plain Language Summary published by Cerebra

We presented at the Devon & Cornwall Parent Carer Forum, an event for parents to find out about the research that Cerebra funds. PenCRU delivered two presentations; one by the Family Involvement Coordinator about what PenCRU does and how parents can be involved, and one from a PenCRU Researcher about 'What's the Evidences'.

We also attended an internal Cerebra Academic Chair meeting, where we delivered workshops for Cerebra staff on finding information and promoting positive attitudes to disability.

Cerebra convened an event in Bristol that enabled stakeholder consultation regarding the emerging findings of our research about school-based interventions for ADHD.

These meetings were a brilliant opportunity to showcase the work that PenCRU does and to find out about other research activities within Cerebra. We look forward to similar events in 2014!

Who we work with

We collaborate with a large number of colleagues at the University of Exeter Medical School and the University of Exeter; also NHS clinicians and people in other universities and organisations. The list below recognises some of the people we were fortunate to have worked with this year, and who have contributed to the success of PenCRU in 2013.

Professor Katrina Wyatt BSc (Hons) PhD
Senior Lecturer in Health Services Research
Dr Wyatt advises the unit on methods for involving children, families and members of the public in research; and also research methods for promoting health.

Professor Tamsin Ford MRCPsych PhD
Clinical Senior Lecturer in Child and Adolescent Psychiatry
Dr Ford is a child psychiatrist and collaborates closely with the unit for studies relating to child mental health topics, specifically Autistic Spectrum Disorders and ADHD.

Mark Tarrant BA (Hons) PhD
Senior Lecturer in Human Sciences
Dr Tarrant is a social psychologist and works with us on the programme of work about social inclusion, specifically promoting positive attitudes towards childhood disability.

Andy Gibson BA (Hons) MA PhD
PenCLAHRC Research Fellow for Patient and Public Involvement
Dr Gibson manages the involvement of patients and members of the public in research conducted by PenCLAHRC. He has worked closely with the unit on several projects.

Kate Boddy BA MA MSc
PenCLAHRC Associate Research Fellow for Patient and Public Involvement
Kate has expertise in systematic reviews and involving patients and members of the public in research. Kate led the ‘shared learning’ workshops to help parents find information.

Jo Thompson Coon BSc PhD
PenCLAHRC Senior Research Fellow (PenTAG)
Dr Thompson Coon has expertise in evidence synthesis and has been working with us on several systematic review projects.

Morwenna Rogers MSc BSc
PenCLAHRC Information Specialist
Morwenna has been involved in several systematic reviews by helping us design and manage comprehensive searches of academic databases.

Siobhan Sharkey BA (Hons) PhD
PenCLAHRC Research Fellow in Qualitative Methods
Dr Sharkey is a qualitative health researcher with a background in anthropology. She leads on the analysis of the transcripts for the ‘Communication in Hospital’ study.

Colin Green MSc PhD
Associate Professor in Health Economics, Head of Health Economics Group
Professor Green has collaborated with us to provide specialist input regarding economic evaluations, and also in the CHUMS project.

Annie Hawton BSc MSc
Research Fellow in Health Economics
Annie's interests span both psychology and health economics approaches. Annie is working with PenCRU on the costing component of the peer support evaluation study.

Vanessa Edwards RGN BA (Hons) MPH
PenCLAHRC Research Fellow in Child Health
Vanessa worked on the systematic review and conducted interviews for the 'Communication in Hospital' study. She is now leading on the STARS project with Dr Ford.

Brahm Norwich MA MSc PhD
Professor of Educational Psychology and Special Educational Needs
Professor Norwich's broad area of interest is special needs and inclusive education. He is part of the team for the systematic review of school-based interventions for ADHD.

Helen Evans and Jenny Brent
Web Marketing Officers
Hannah and Jenny have advised on the development and evolvement of the PenCRU website.

Local Authority and NHS staff

Dr Richard Tomlinson B Med Sci MB BS MSc MRCPCH
Consultant Paediatrician
Dr Tomlinson is an integral member of our advisory group and has been involved in several previous and current projects including the CHUMS project.

Dr Eleanor Thomas BSc (Hons) MRCPCH
Consultant Paediatrician
Dr Thomas specialises in community child health and has been involved in the Steering Group for the 'Communication in Hospital' study.

Dr Rebecca Gumm BMBS MRCPCH
Paediatric Clinical Trials Research Fellow
Dr Gumm has been leading the training for hospital staff, designed with parents' input, to improve communication with disabled children when they have to spend time on the ward.

Dr Alice Martin BMBS MRCPCH BMedSci
Paediatric Registrar & Academic Clinical Fellow
Dr Martin is a specialist trainee in paediatrics and has been involved in the study about communication when disabled children are inpatients.

Diane Sellers BA MA PhD MRCSLT
Research Fellow & Speech and Language Therapist, Chailey Heritage Clinical Services
Diane is a Speech and Language Therapist at Chailey Heritage Clinical Services in Sussex. Diane leads the development of the eating and drinking classification system for children with cerebral palsy.

Dr Jane Williams MB BS Dip Child Health FRCPH
Consultant Paediatrician, Nottingham University Hospitals NHS Trust
Dr Williams has expertise in childhood neurodisability and is a former Chair of the British Academy of Childhood Disability. She is collaborating with PenCRU on the CHUMS project.

John Shaw
Programme Lead, Devon Special Educational Needs and Disability (SEND) Pathfinder
John has been involved in providing services for disabled children and their carers for many years; he is leading major initiatives to improve integration of services.

Jo Siney
Children's Integrated Disability Service Manager, Plymouth City Council
Jo manages the services for disabled children and their parents/carers in Plymouth; she has been supportive of several of our projects.

Other universities and organisations

Crispin Jenkinson BA MSc DPhil
Professor of Health Service Research, University of Oxford
Professor Jenkinson's interests include quality of life and health status measurement. He is collaborating with PenCRU on the CHUMS project.

Alan Tennant BA PhD
Professor of Rehabilitation Studies, University of Leeds
Professor Tennant has extensive expertise in developing outcome measures, and is one of the leading exponents of Rasch measurement methods. He is collaborating with PenCRU on the CHUMS project, and involved in discussions about measuring inclusion/participation.

Amanda Allard BA BSc MSc
Principal Research Officer, Council for Disabled Children
Amanda has worked in children's policy both as a researcher and campaigner; her work at CDC is developing the health and participation services. Amanda is a key collaborator in the CHUMS project appraising NHS outcomes for disabled children.

Professor Bryony Beresford BSc (Hons) PhD
Director, Children and Families Team, Social Policy Research Unit, University of York
Professor Beresford has a strong track record in applied childhood disability research. Many of her projects have used qualitative research methods and she has been at the forefront of developing methods/supporting the inclusion of disabled children directly in research.

Helen McConachie MA MPhil PhD
Professor of Child Clinical Psychology, University of Newcastle
Professor McConachie's research focuses broadly on the health and wellbeing of children affected by disability and their families. Helen leads the MeASURe project about appropriate outcomes for young children affected by autism.

Tim Adlam BEng (hons) MSc PhD CEng MIMechE CSci MIPEM
Head of Mechanical Engineering, Designability & Visiting Research Fellow, University of Bath
Tim approached us to help with his research to develop appropriate seating systems for children with whole body extensor spasticity, particularly because of our ability to engage families.

Grants awarded in 2013

McHugh C, Morris C. (2013-14) Engaging disabled children and young people in research, and supporting them appropriately to be involved. Catalyst: Public Engagement Seed Fund, University of Exeter. £4350

Morris C, Shilling V, Janssens A, Lloyd C, Bailey S, McHugh C, Logan S. (2014-19) Involving families in developing ideas for research, designing collaborative studies, seeking research grants and producing outputs directly useful to families. Cerebra. £796,303

Logan S, et al (2014-2018) PenCLAHRC. The NIHR Collaboration for leadership in Applied Health Research and Care for the Southwest. £10,000,000

Academic publications in 2013

Cowan, D., Smith, M., Gardiner, V., Horwood, P., Morris, C., Holsgrove, T., Mayhew, T., Long, D., Hillman, M. (2013). Mechanical and electromechanical devices in Taktak A,Ganney P,Hegarty F,Long D,White P (eds.) Clinical Engineering, Academic Press.

Janssens A, Hayen S, Walraven V, Leys M, Deboutte D. (2013). Emergency psychiatric care for children and adolescents: a literature review. Pediatric Emergency Care, 29(9) 1041-1050 1010.1097/PEC.1040b1013e3182a1393e1047.

Koc Erdon S, Janssens A, Deboutte D. (2013). Psychisch functioneren van Turkse kinderen vergeleken met hun Vlaamse schoolgenoten [The emotional wellbeing of Turkish children compared to their Flemish peers]. Tijdschrift voor orthopedagogiek, kinderpsychiatrie en klinische kinderpsychologie (TOKK), 38(1), 15-31.

Lin N, Logan S, Henley W. Bias and sensitivity analysis when estimating treatment effects from the Cox model with omitted covariates. Biometrics doi: 10.1111/biom.12096

MacMillan, M., Tarrant, M., Abraham, C., Morris, C. (2013). The association between children's contact with people with disabilities and their attitudes towards disability: a systematic review. Developmental Medicine and Child Neurology doi: 10.1111/dmcn.12326. [Epub ahead of print]

Martin A, Ford T, Goodman R, Meltzer H, Logan S. (2013) Physical illness in looked-after children: a cross-sectional study. Archives of Disease in Childhood, doi: 10.1136/archdischild-2013-303993. [Epub ahead of print].

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. Author URL

Morris, C., Shilling, V. (2013). The role of parent and community organizations in child health promotion. In Ronen G & Rosenbaum P (eds.) Life Quality Outcomes in Children and Young People with Neurological and Developmental Conditions: Concepts, Evidence and Practice, London: Mac Keith Press.

Morris, C., Janssens, A., Tomlinson, R., Williams, J., Logan, S. (2013). Towards a definition of neurodisability: a Delphi survey. Developmental Medicine and Child Neurology, 55(12), 1103-1108.

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? NIHR Health Services and Delivery Research (In press).

Sellers, D., Mandy, A., Pennington, L., Hankins, M., Morris, C. (2013). Development and reliability of a system to classify the eating and drinking ability of people with cerebral palsy. Developmental Medicine and Child Neurology doi: 10.1111/dmcn.12352. [Epub ahead of print]

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 doi: 10.1111/dmcn.12313. [Epub ahead of print]

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. Dev Med Child Neurol, 55(7), 602-609.

Vanhooren F, Simons A, Janssens A, Glazemakers I, Deboutte D. (2013) Multi Familie Dagbehandeling (MFD) bij kinderen en jongeren met anorexia nervosa : een pilootstudie [Multi-Family Treatment for children and young people with anorexia nervosa: a pilot study]. Tijdschrift voor orthopedagogiek, kinderpsychiatrie en klinische kinderpsychologie, 38(1), 2-14.

Williams AJ, Henley WE, Williams CA, Hurst AJ, Logan S, Wyatt KM. (2013) Systematic review and meta-analysis of the association between childhood overweight and obesity and primary school diet and physical activity policies. International Journal of Behavioral Nutrition and Physical Activity, 10(1):101.

Woolfall K, Shilling V, Hickey H, Smyth RL, Sowden E, et al. (2013) Parents’ agendas in paediatric clinical trial recruitment are different from researchers’ and often remain unvoiced: a qualitative study. PLOS ONE 8(7): e67352. Doi:10.1371/jpurnal.pone.0067352

Wyatt KM, Lloyd JJ, Abraham C, Creanor S, Dean S, Densham E, Daurge W, Green C, Hillsdon M, Pearson V, Taylor RS, Tomlinson R, Logan S. (2013) The Healthy Lifestyles Programme (HeLP), a novel school-based intervention to prevent obesity in school children: study protocol for a randomised controlled trial. Trials, 14:95. doi: 10.1186/1745-6215-14-95.

Major presentations

Bailey S, Franklin A, Dovey-Pearce G, Morris C. Involving young people in health services research: sharing evidence, ideas and experience and identifying opportunities for the future
New Developments in Public Involvement Research.

Bailey S, Boddy K, Briscoe S, McHugh C, Stone T, East A, Morris C (2013) Involving disabled children and young people as partners in research: a systematic review. [poster] European Academy of Childhood Disability.

Fredlund M, McDonald B, Shilling V. Evaluation of one-to-one peer support for parents of disabled children: a collaborative research project with Face2Face. BACD/BACCH SW.

Fredlund M, McDonald B, Shilling V. Evaluation of one-to-one peer support for parents of disabled children: a collaborative research project with Face2Face. New Developments in Public Involvement Research.

Janssens A. Health outcomes for children with neurodisability: which outcomes are important, and can they be measured using Patient Reported Outcome Measures. BACD/BACCH SW.

Ketelaar M, Morris C, Kolehmainen N, Busk M, Rijpstra L. Partnerships between families, service providers and researchers: why and how? [Instructional Course] European Academy of Childhood Disability.

Lacey S, Stone T, Morris C. Involving Families in Childhood Disability Research: Building a Partnership. New Developments in Public Involvement Research.

Logan S. Melbourne – Complex interventions. Children’s Trials Day: From Inspiration to Action, Murdoch Childrens Research Institute, Australia.

MacMillan M. Children’s attitudes to disability: a cross-sectional survey with schools in the South West of England. BACD/BACCH SW.

MacMillan M. Determinants of children's attitudes towards disabled people. British Psychological Society Social Psychology Section Annual Conference.

MacMillan M. Children’s contact with disabled people and their attitudes towards disability: a cross-sectional survey. European Academy of Childhood Disability.

Morris C, Janssens A, Tomlinson R, Williams J, Logan S. Towards a definition of neurodisability: a Delphi survey. [poster] European Academy of Childhood Disability.

Sellers D, Pountney T, Pennington L, Morris C, Mandy A, Hankins M. (2012) Development of a functional classification system of eating and drinking ability for individuals with cerebral palsy. [poster] European Academy of Childhood Disability.

Shilling V, McDonald B, Fredlund M, Petherham S, Morris C, on behalf of the Peer Support Study Stakeholder Group. Evaluating formalised peer support for parents of disabled children: qualitative findings from a programme evaluation. [poster] European Academy of Childhood Disability.

Shilling V, Hawton A, Bailey S, McDonald B, Fredlund M, Petherham S, Morris C, on behalf of the Peer Support Study Stakeholder Group. Evaluating formalised peer support for parents of disabled children: experiences of involving parents in carrying out a programme evaluation. [poster] European Academy of Childhood Disability.

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Peninsula Cerebra Research Unit
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Family Faculty
designed by Matt aged 14