Peninsula Cerebra Research Unit

PenCRU
Childhood Disability Research

Learning to spin plates at the annual Family Fun Day

University of Exeter Medical School

Annual Report 2012

Contents Page

Cerebra Chair’s reflections on progress in 2012

Welcome to the PenCRU 2012 Annual Report; this has been another very successful year for the unit. This year’s report is structured around three main sections, Involving Families, PenCRU Programme of Research, and Communicating about Research. You can also find out about us, some of the key people we collaborate with, and see details of our newer research grants, publications, presentations and other academic activities.

PenCRU has continued to develop a national and international reputation for our ability to involve families of disabled children in research. Families’ involvement really does drive almost everything we do. We continue to be impressed that members of our Family Faculty take time out their busy lives to carry out all sorts of roles with us. We strive to carry out the research studies that families think are important. To do this, we need to find ways to engage families in identifying and prioritising what are the most important research questions. Then we need families to be involved in designing our research so that potential participants want to take part and stay in the project until the end and that we answer the questions that really matter to them. Finally we need families to help us tell people what our research has found out, so that the findings are used to inform decisions about health care. The section on Family Involvement in this report describes the ways in which we have achieved these goals.

As well as our initiatives locally, it is exciting to see Chris Morris and PenCRU taking a leading role in the James Lind Alliance (JLA) Childhood Disability Research Priority Setting Partnership. This national project engages families and clinicians to identify and prioritise treatment uncertainties for improving the health and wellbeing of disabled children, and enables families to really influence the research agenda. The British Academy of Childhood Disability Strategic Research Group manages the Priority Setting Partnership in collaboration with representatives from the James Lind Alliance, National Network for Parent Carer Forums, and Council for Disabled Children.

The section of this report describing PenCRU’s programme of research shows how the range of topics addressed in our research is growing, with further success in securing funding from the National Institute for Health Research this year. All of the projects are progressing well, which is testament to the hard work of the PenCRU team and input from members of the Family Faculty. An emerging research theme is promoting the health and wellbeing of parents of disabled children, building on our research on peer support. This topic was strongly endorsed by the eight parents at our PenCRU Advisory Group in December and will be a focus of our activities in the coming year.

Communicating about research is also fundamental to PenCRU, including raising awareness of what research is, and relaying what we can deduce from research that has been carried out. Our *What’s the Evidence?* summaries exemplify this theme of our activities. These are summaries of what is known from research evidence that try to answer questions that families have asked us. Another product this year is a template for plain language summaries of our own research findings designed in collaboration with parents. These summaries will be written with input from parents and will be published at the same time as our academic publications. 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 educational 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 childhood 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. The charity also maintains their own in-house research and provides direct grants and advice to parents, carers and professionals.

The relationship between Cerebra and the University of Exeter Medical School (formerly Peninsula Medical school) 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 12 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.

Camilla McHugh BA
Family Involvement Coordinator

Camilla has experience of working closely with children and their parents in a variety of settings; she has worked in a research setting for the past five years. She is the primary contact who liaises with our Family Faculty to provide information and support for families working with the unit, and ensure 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 works 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.

Members of the team at the annual Family Fun Day

Family involvement

The ethos of the unit remains to involve families in all aspects of our research and related activities. Last year we set in place a recruitment and retention strategy to inform more families about us and our work. This time last year we had 158 members of the Family Faculty; we now have 253 contacts.

We understand the amount of time that families have varies so we are conscious of being flexible and adaptable to accommodate this. The table below lists what some parents have experienced by getting involved with us....

Parents told us about their experiences of working with us:

- *A sense of autonomy; A space for reflection; Confidence; Lunch; A break from banging my head against the brick wall of 'services'; Lunch; Social enrichment!!!; Inclusion; Money; Lunch.. . .*
- *At the first meeting I realised that everyone was dressed 'all proper like' and I realised my very comfy, falling to pieces jumper was covered in the 'marks' of caring [mainly felt-tip pen]; yet my experience was of acceptance and equality. I experienced being appreciated and being listened to, which was quite a buzz.*
- *I continue to be struck by the deeply un-controlling manner by which sessions are organised and facilitated at PENCRU; I would encourage other's groups to get proficient in such skills; to appreciate the freedom it affords; and to actively oppose practices that rely on imposing 'on to' those they are involved with for their results.*
- *I have enjoyed looking at online information; I have helped to read through materials to see if they make sense to a parent/carer. Not only do I feel I'm being of some use to others in my situation, but I also get useful up to date information as well. I feel like the insight I have is of some use to somebody and if I can help anyone by my experiences I am very glad to.*
- *I have been involved with PenCRU for a few months on a variety of projects and have thoroughly enjoyed my experience on each visit.... I feel as if I have made new friends and I am, in some small way, helping to contribute to assisting families with disabled children now and in the future.*
- *It was good to be sat around a table with parents of special needs children and to be able to share experiences with them..... The fact that PenCRU covered expenses and lunch was excellent. Doing this is likely to encourage people to participate.*
- *Feeling that others have had similar struggles and we're all in this together even if I haven't met these parents who've shared the same difficulties we've faced. In other words, our struggles are part of a wider picture and we're not isolated or failing.*

Our unit meetings

Families have been actively attending meetings here at the unit more than ever this year. The table below shows the numbers of parents who came to meeting for each project:

Project	Number of parents involved
Peer Support	11
CHUMS	4
Social Inclusion	12
MeASURe ASD Review	11
ADHD School Interventions	2
Gastrostomy and tube feeding	2
Hospital Communication	4
Sleep Positioning *	0
Computer Games working group	3
Children and Young Peoples Involvement working group	6

* In 2012 we have conducted searches and started to bring together the results. No parents expressed an interest in being involved with this stage.

Our Advisory Group has a strong influence on our programme of work and other activities; we hold meetings twice a year. They are well attended; four parents participated in June, and eight came in December. We are conscious that we are in a big county and it is not always easy for families to travel to our meetings due to time. This is particularly the case for families in North Devon who have expressed an interest in our work. We therefore set up the 'PenCRU travelling working group' and hosted a day in Barnstaple to discuss topics on our programme of work. The day was a great success and we hope to return in the near future.

An Advisory Group meeting

Presenting our activities and programme of research in the community

An extremely important part of our family involvement is engaging and circulating in the community. This helps us understand the 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. This face to face contact helps encourage and support families to come and get involved in research. It has been another very busy year; the Family Involvement Coordinator attended support groups, parent forums and various Local Authority events.

We have built up very strong relations with many of these groups and we are regularly invited to have stands at the events they put on for families in the community. Listed below are a few we have attended.

- Parent Carers Voice Parent Information Day – at this event we chaired a workshop on 'finding reliable information on the internet'
- Parent Carers Voice Annual Conference
- Torbay Parent Participation Forum 'meet the parents day'
- Devon County Council Conversation Events
- Aiming High Consultation Days
- Mayfield Special School Garden Party
- Torbay Council Disability Awareness Day.

The Family Involvement Coordinator was also invited, and became part of, the 'Support to Parents and Young People Design Group' for the Devon County Council Special Educational Needs and Disability (SEND) Pathfinder.

Public and Patient Involvement (PPI) community

PPI is an emerging area for research and the Family Involvement Coordinator has built up relations with colleagues in our own institution, but also within the community by being a member of the South West PPI forum and attending events such as the PPI market place.

This year was also very exciting as it was the INVOLVE biannual conference in Nottingham. We applied and were successful to present on how we involve families in PenCRU. Two members of the Family Faculty co-presented with us and our presentation was well received, and two other parents also came to the conference. This was also a great opportunity to meet colleagues and other groups who are working in this area. We all worked hard, but also had great fun!

On our way to the INVOLVE conference

Building a Partnership

We have established a shared learning programme called 'Building a Partnership'. We encourage families to identify research related topics they would like to learn more about and coordinate with families and colleagues to devise and set up the resulting workshop. These workshops are designed to support parents to be partners in the research and are held once or twice a year. This year the chosen topic was 'Introduction to Research', delivered by Andy Gibson and Kate Boddy, our colleagues in PenCLAHRC. It was well attended by parents; see below some of the feedback.

- *It was so good...very interesting, informative and fun!*
- *Presenters were a good team, knowledgeable, open, entertaining, funny and informative. A first class presentation.*
- *Very informative and friendly.*

Annual Family Fun Day


Vinny sharing his talents

This was our third annual Family Fun Day, something we as a unit really look forward to. This year the families voted to go to Dartmoor Zoo and 120 people attended. We had a fantastic day and were very lucky to get possibly the only sunny day of the summer. At popular request, Vinny the mime artist was there again to entertain us with his usual talent, flare and gentleness. This event is an opportunity for us to thank the families who have got involved with us over the year and to get to know each other in a less formal setting.

We had an amazing day and we sent home some very tired children. We are looking forward to seeing where we go in 2013...

Children and Young People's involvement

This year saw the launch of our Children and Young People's (C&YP's) involvement. We hosted a working group in April which was attended by 14 people made up of parents, siblings and children and young people with disabilities. We discussed and explored the way we can positively involve C&YP in the work we do. We all worked really hard in the meeting and the C&YP designed some fantastic leaflets, see picture. These designs were pulled together to create a leaflet which we are using to actively recruit new members to the Children and Young people's Faculty. This is ongoing.

We are building relations with local and national groups who have experience of doing similar work; we want to learn from them to ensure this work is a positive experience for C&YP. Here are some of the comments and suggestions from the group.

- *Worthwhile and useful.*
- *More arty things. Well done.*
- *Perhaps some games or we could go for a walk and talk about what we do. Very good.*
- *The presentation was great and clear to understand.*

There are a wide variety of ways that families can get involved in the work of the unit and we are always trying to find new ways to encourage and support families to get involved. Some of the ways that families have got involved this year are:

- being members of the Family Faculty
- being kept informed of our work
- submitting ideas for research
- being part of the PenCRU Advisory Group
- being part of specific project advisory groups
- helping us design new studies by joining working groups
- feeding back via email
- help design posters of our projects and involvement activities
- reviewing information leaflets for individual studies
- helping us write plain language summaries
- contributing in writing their experiences to add to publications
- reviewing PenCRU publicity documents
- assisting with the dissemination of results of studies
- attending conferences and co-presenting
- assisting us in the collaboration of work with outside institutions

Plans for 2013

In 2013 we plan to continue to recruit, encourage and support families to get involved in research. We are going to be particularly focused on the Children and Young People's involvement. We hope to set up an active C&YP group who will meet several times in the second half of the year. It is vital that this group have a voice in the work we carry out and bring their own interests to the research we carry out.

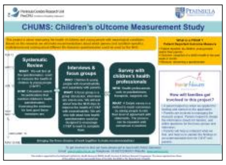
We have several events in the diary within the community and look forward to meeting new parents as well as re-connecting with families we already know.

We have planned and look forward to the Building a Partnership workshop we are hosting in February which came from a parent request at the Advisory Group. The workshop will focus on the social, medical and other theoretical models of disability in a research context, which we hope families will also be able to use and apply in their day to day lives.

Programme of research

The following pages describe our programme of research, and the progress we made in 2012. If you are reading the electronic version of the report, you can click on the posters to read how members of our Family Faculty are involved in these projects.

__CH__ildren’s o__U__tcome __M__easurement __S__tudy (CHUMS): Informing the NHS outcomes framework: what outcomes of NHS care should be measured for children with neurodisability?



Click to open this poster

A. Janssens, C. Morris, A. Allard, B. Beresford, J. Williams, R. Tomlinson, S. Logan, A. Tennant, C. Jenkinson, J. Thompson Coon, V. Shilling, C. Green, K. Antonio

The **CH**ildren’s o**U**tcome **M**easurement **S**tudy (CHUMS) is a collaborative project, involving researchers from the Council for Disabled Children and Universities of York, Leeds and Oxford, NHS paediatricians, and parents of disabled children. The aim is to identify what the NHS is trying to do for disabled children, and whether those outcomes can be measured. There are three streams of research:

1. A systematic review of literature: We identified 51 candidate patient reported outcome measures (PROMs): 37 generic, 8 chronic generic and 6 health utility instruments. Taking into account the different age-specific versions and parent or proxy and self-reported versions results in a total number of 123 different versions. We are continuing to extract and tabulate evidence about the psychometric properties of these PROMs, and map the constructs measured to the International Classification of Functioning, Disability and Health (ICF). We have also identified 408 papers where these measures have been used in neurodisability studies and are scoping which PROMs are used for which conditions.

2. A qualitative study of children and parents : We have completed 6 focus groups with parents and 8 with young people and 6 interviews with parents and 4 interviews with children or young people. The team for the qualitative study are all familiar with the data and further analysis is underway. A coding framework for the analysis was constructed and all data have been coded; 25% of these data were coded by a second member of the team as a quality assurance indicator: reliability between them was excellent.

3. An online Delphi survey with clinicians: We have a group of 309 health care professionals from a broad range of professions signed up for the survey. Three rounds of the survey have been completed with responses of Round 1: 245, Round 2: 242, Round 3: 221. One or two more rounds will take place early this year. The 'aspects of health' clinicians told us they target for children with neurodisability have been mapped to the ICF to compare with what our candidate PROMs measure. The survey has also unexpectedly resulted in the development and refining of a definition of neurodisability.

Non-pharmacological interventions for Attention-Deficit/Hyperactivity Disorder (ADHD) delivered in school settings; a systematic review of quantitative and qualitative research

Click to open this poster

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

This project is a systematic review of ways of supporting children with ADHD that do not involve drug treatment and that can be provided in school settings, such as classroom management programmes or psychological therapies. A systematic review means that we will carefully search all the available literature, and put the findings of many studies together, to try and find out which ways of supporting children work better at reducing symptoms of ADHD and other related problems, and which provide the best value for money. We will also look at factors that may help or hinder the successful delivery of these interventions and how the interventions impact on parents, carers and teachers. During 2012 around 25,000 articles were screened, before arriving at over 100 relevant studies that are currently being analysed in order to find out:

1. How effective school-based non-drug support programmes are for children with ADHD (e.g., in improving ADHD symptoms and achievement)

2. How the support programmes are experienced by children with ADHD and all those involved (e.g., parents, teachers and peers)

3. What children, parents and teachers' experiences of ADHD at school tell us about the support children with ADHD need.

Promoting positive attitudes towards disability

Click to open this poster

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

This PhD project is at the half-way stage; two parts of the research are nearly completed, with an aim of submitting for publication in the next few months.

The first part is the systematic review, which brings together previous research that has measured the association between children's attitudes towards disability and the amount of naturally occurring contact (non-intervention contact) they have with disability. A final set of 35 articles were located and the majority provided evidence that naturally occurring contact successfully improved children's attitudes towards disability.

The second part of this research is a survey, which was administered in 20 schools across Devon, and included a total of 1578 non-disabled children. The results show the children who had more contact with disability had higher levels of empathy and lower levels of anxiety towards disabled people, leading to better attitudes.

The final part of this project will involve using the information found from the review and survey to design an intervention to improve children's attitudes to disability. The results from this work will help inform the contents of future school-based interventions.

What are the benefits and costs of providing peer support to parents of disabled children?

V. Shilling, C. Morris, A. Hawton, J. Thompson Coon, S. Logan.


PARENT-TO-PARENT SUPPORT FOR FAMILIES OF DISABLED CHILDREN

Click to open this poster

This project, funded by PenCLAHRC, is a pilot evaluation of the peer support service offered by Face2Face (F2F) in Devon and Cornwall. It will explore the benefits and costs of offering peer support to parents of disabled children. There are three streams of research:
1. A systematic review of the existing literature on peer support for parents: In 2012 we completed the systematic review which will be published in Developmental Medicine and Child Neurology. With the help of parents from the project stakeholder group and the Family Faculty, we have written a plain language summary of the review, which has been published alongside the journal article and on our website.

2. Costing study: In 2012 we completed data collection for the costing study; 29 befrienders across Devon and Cornwall recorded the time they spent on different aspects of their volunteering for Face2Face over a period of three months. This information, along with annual expenditures and number of families entering and leaving the service in a 12 month period (complete cases) will enable us to present a much clearer picture of the costs of providing the service in terms of time, resources and money.

3. Qualitative research comprising interviews with parents who have given or received support through Face2Face and relevant health and social care professionals: In 2012 we completed data collection for the qualitative research. We interviewed 12 parents who had received befriending through Face2Face, 22 befrienders and 10 health and social care professionals from a range of services. Comparing and contrasting the perspectives of parents, befrienders and professionals will enable us to identify similarities and differences which will enable providers to reflect on the service in line with parents' experiences.

Information gathered from this study will help us to understand more about the benefits and costs of this particular service and will also help us to design a larger more definitive evaluation of the effectiveness and cost effectiveness of providing peer support to parents of disabled children. The findings from this study will be disseminated in the autumn of 2013 via academic publications and more broadly through websites such as the Mentoring and Befriending Foundation and Cerebra.

MeASURe: Measurement in autism spectrum disorder under review

H. McConachie, C Morris (and many others)

Children with autistic spectrum disorder (ASD) are diagnosed from about 2 years old and there is evidence that some early life interventions are effective at helping children with ASD to develop and progress, and have improved quality of life. A problem faced by researchers and NHS staff is that there are many different measurement tools that can be used to evaluate children's ASD characteristic behaviours. It is not known whether these tools measure things that are important to the children and their families, or whether healthcare staff and teachers find them useful.

PenCRU are part of a large team of researchers around the UK, led by Professor Helen MacConachie at the University of Newcastle. This is a systematic review that aims to answer the research question, "what is the validity of tools and outcome measures used in measuring and monitoring autism spectrum disorder (ASD); and how well do these reflect and measure issues of importance for patients and carers?"

One of PenCRU's key roles in the project has been to involve families by running one of three Parent Advisory Groups; the others are in London and Newcastle. The Exeter parent’s group met for the first time in July, and again in November. The parents have helped to identify and then prioritise the types of outcomes that could be measured. The group will meet again towards the end of the study to help interpret the findings of this research.

ASD Advisory Group meeting

Improving communication with disabled children when they have to spend time in hospital

Click to open this poster

C. Lloyd, S. Sharkey, C. Morris, V. Edwards, A. Martin, R. Tomlinson, J. Choules, B. Hart, S. Logan

This study, funded by PenCLAHRC, assesses whether a parent-delivered programme of training for paediatric ward staff improves the effectiveness of communication with disabled children and their parents in hospitals. There are three stages:

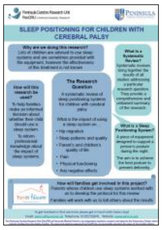
1. A structured review and synthesis of qualitative studies reporting children’s, parents’ and professional views of disabled children’s experience as inpatients. The systematic review was completed and published during 2012.

2. Qualitative research with parents of children with communication difficulties and ward staff to understand their experiences of communication. Interviews with parents and a range of professional ward staff were carried out. We tried several strategies to recruit children and young people with communication impairments. We had previously struggled to recruit this group but following some changes to the recruitment process we successfully completed five interviews. The analysis is in its final stages of completion.

3. Developing and evaluating a training package for staff to enhance communication with disabled children when they have to stay in hospitals. We are currently exploring sources of funding to enable us to develop, pilot and evaluate a parent-delivered training package which will be informed by work from the previous two stages.

Sleep Positioning for children with cerebral palsy: Cochrane review

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



Click to open this poster

This is a systematic review to determine whether commercially available night-time postural management systems, compared with usual care, reduce hip migration in children with cerebral palsy. The evidence appears inconclusive as to whether the provision of night-time postural management helps to prevent hip deformity. Although there is a biomechanical basis for such intervention, the equipment can create problems for the child and family. The protocol is here http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD009257/full.

In 2012 we screened 1207 articles before arriving at 17 potentially relevant articles which were analysed in order to find out whether they met the inclusion criteria for the review. None of the 17 articles met the criteria, based on study design (not Randomised Controlled Trials), outcome measures, article type or ineligible intervention (not looking at sleep systems alone). To allow us to capture relevant, high quality research that did not have an RCT design and was therefore not eligible for inclusion in the Cochrane review, we are preparing a second systematic review that is not registered with Cochrane. Two articles have been included in this review. The results of the two reviews are being written up and will be submitted for publication by the spring.

The effects of night positioning on sleep, postural deformity and pain in children and young people with cerebral palsy - an exploratory study

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

The aim of this programme of research is to find out if using commercially available night-time postural management systems makes children more comfortable in bed, reduces pain, improves sleep, prevents deformity and avoids the need for surgery. This is an exploratory 'pilot' study to help in the development of a protocol for a larger clinical trial. The trial is funded by the NIHR *Research for Patient Benefit* programme and led by Dr Terry Pountney at Chailey Heritage Clinical Services in Sussex.

The trial has been approved by the ethics committee and launched formally; several recruiting sites around England are now up and running. More details are available here www.sussexcommunity.nhs.uk/get-involved/studies_chailey_heritage.htm

***S**upporting **T**eachers **A**nd child**R**en in **S**chools (STARS): a cluster randomised controlled trial with parallel economic and process evaluations.*

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

The Supporting Teachers And childRen in Schools (STARS) study is funded by the NIHR *Public Health Research* programme. The STARS study will examine whether the Incredible Years Teacher Classroom Management (TCM) course may enhance teachers' skills in promoting socio-emotional well-being among their pupils. If effective, TCM could transform the classroom from an environment where many children currently struggle to cope, particularly boys from low socio-economic backgrounds, into one where many more children can thrive. Enhancing teachers' skills potentially benefits all children that come into contact with that teacher over subsequent years, so TCM may be a particularly cost-effective way to assist the most vulnerable children in our society.

In 2012, we completed a second feasibility study, which involved 20 teachers attending the teacher classroom management course in order to test our data collection procedures and to provide experience to our group leaders. We obtained funding for the pilot and main trial and have successfully recruited our first cohort of schools (15) from Torbay and Devon, with very high completion rates of baseline data (teachers on themselves, n=15, teachers on children n=388, children n= 387, parents n=271). The teachers in the intervention arm have completed half of the course and we are now actively recruiting schools for our second cohort, while conducting literacy and numeracy testing with a sub-sample of 70 children.

More details are available here: http://clahrc-peninsula.nihr.ac.uk/project/9-supporting-teachers-and-children-in-schools.php

Development of a functional classification system of eating and drinking for children and young people with cerebral palsy

D. Sellers, T. Pountney, L. Pennington, A. Mandy, M. Hankins, C. Morris

This research is developing and testing a classification system to describe the eating and drinking ability of children with cerebral palsy (EDACS). Similar systems for classifying movement and manual ability have been widely adopted, and improve communication between clinicians and families, between clinicians, and between researchers and others. The project is funded by the NIHR *Research for Patient Benefit* programme and led by Diane Sellers, a Speech and Language Therapist at Chailey Heritage Clinical Services in Sussex.

A descriptive classification system has been produced with input from an international group of researchers, clinicians, parents and people with cerebral palsy. The next stage of this research is testing the reliability of the classification system; this work is in progress.

More details are available here:
www.sussexcommunity.nhs.uk/get-involved/eating_drinking_classification.htm

JLA Childhood Disability Research Priority Setting Partnership

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

The James Lind Alliance (JLA) Childhood Disability Research Priority Setting Partnership is a UK-wide initiative that will identify the important questions which remain unanswered about the effectiveness of treatments. It will take into account the views of disabled young people, their families and the clinicians who care for them. It will then prioritise the unanswered questions into a 'Top 10' list of topics for research. Similar exercises conducted with the JLA in other health areas have given patients a real influence over what research is funded.

The British Academy of Childhood Disability Strategic Research Group initiated and manages the James Lind Alliance (JLA) Childhood Disability Research Priority Setting Partnership in collaboration with representatives from the James Lind Alliance, National Network for Parent Carer Forums, and Council for Disabled Children. Chris Morris secured funding for the project from the Paul Polani Fund, Royal College of Paediatrics and Child Health; the Steering Group is chaired by Katherine Cowan from the James Lind Alliance.

The Steering Group was established, and invitations for family support organisations and professional societies to join the partnership were sent at the end of 2012.

Further details of the project are available http://bacdis.org.uk/research/psp.htm

Projects in development

Potential therapeutic benefits of 'active' home video games

We began to explore the possibility of a project to look at the positive impacts that playing active home video games, such as the Nintendo Wii, might have in children with disabilities.

In 2012 we wrote a *What's the Evidence?* article following our searches for existing literature. We continued to work with parents to refine ideas for this project and have asked all members of our Family Faculty to take part in an online survey to inform our thinking. There are separate surveys for children and parents, broadly asking:

1. What consoles and games are used?
2. What games are played, which are preferred and why?
3. Whether any health benefits have been noticed as a result of playing these games?
4. Demographic information about ages, conditions and specific difficulties

We are beginning to build up national contacts through the British Academy of Childhood Disability (BACD) network with professionals interested in this area of research and there are preliminary plans for holding an open one-day event in 2013, and to form an interest group so that all interested parties can regularly come together to discuss ideas and potential collaboration.

Safety and efficacy of complementary and alternative therapies for children diagnosed with Attention Deficit Disorder with Hyperactivity (ADHD)

A scoping review was carried out to ascertain the evidence base for the use of complementary therapies for the treatment of children diagnosed with ADHD. After short listing those for which there was evidence available, the views of the Family Faculty were sought. Families were most interested in changes in diet, and after another round of consultation in 2012 the top three treatments the families were interested in were eliminating artificial additives, eliminating aspartame, and omega 3 supplements.

As the review needed to focus on one therapy only, short summaries of evidence were produced for each of these treatment options to enable families to make an informed decision about which treatment option should be taken forward into the full review. The omega 3 supplements were the most popular choice.

The protocol for the systematic review was completed in 2012, and PenCRU are now awaiting the results of a more recent systematic review on complementary therapies for ADHD before commencing the full systematic review.

Healthy parents

Many parents of disabled children are at risk of chronic physical and psychological health problems, and which appear to be pervasive and likely to worsen over time. This theme will build on our research study evaluating the costs and benefits of peer support for parents of disabled children. The findings of our systematic review of qualitative studies were consistent with the growing awareness of the positive and 'protective' psychological and physical health effects of sharing a social identity with others. Hence who delivers a complex health or social intervention, and whether they are perceived as sharing an identity and experience, may be influential on the effectiveness of that intervention.

There is considerable further scope for research to review evidence of factors affecting the health and wellbeing of parents of disabled children. There is much to learn from various interventions developed or under development aiming to improve parents' health, and also to critically appraise the outcome measures that are used to evaluate the effectiveness of such interventions.

Our exploratory work on this theme was and will be heavily informed by working in partnership with parents in our Family Faculty. A focus on promoting parents' health wellbeing was very strongly endorsed by parents in the PenCRU Advisory Group.

Communicating about research

Telling people about research results in way that makes them easily understandable and useful is a challenge. Parents and disabled young people have helped to produce many of our reports and documents to ensure they are accessible. PenCRU is part of an international network of childhood disability researchers collaborating with the *CanChild* Centre for Childhood Disability Research, McMaster University, Canada, collectively aiming to develop and enhance the dissemination of childhood disability research findings.

What's the Evidence?

PenCRU responds to questions from families and professionals about therapies and health services for children and young people affected by disability or who have special or additional health needs. What's the Evidence? reports are written in response to these questions. These reports summarise the evidence for different services and treatments to help families make decisions about care for their child.

In 2012, eight new What's the Evidence? summaries were produced. These included:

- Is Applied Behaviour Analysis (ABA) an effective therapy for Autistic Spectrum Disorder?
- Do active computer games have therapeutic and/or social benefits for children with motor impairments?
- Is there any evidence that Constraint Induced Movement Therapy (CIMT) is effective at improving manual ability in children with hemiplegia?
- Is there any evidence that eliminating aspartame from diets can improve children's ADHD symptoms?
- Is there any evidence that eliminating artificial additives and food colours from diets can improve children's ADHD symptoms?
- What is Locked In Syndrome, what methods of rehab are available, and what chances are there for recovery?
- Are Lycra orthoses or suits effective for children with hemiplegia? Could they cause any muscle weakness, and are there any long terms benefits?
- Do omega 3 supplements reduce symptoms in children with ADHD?

Plain language summaries and videos

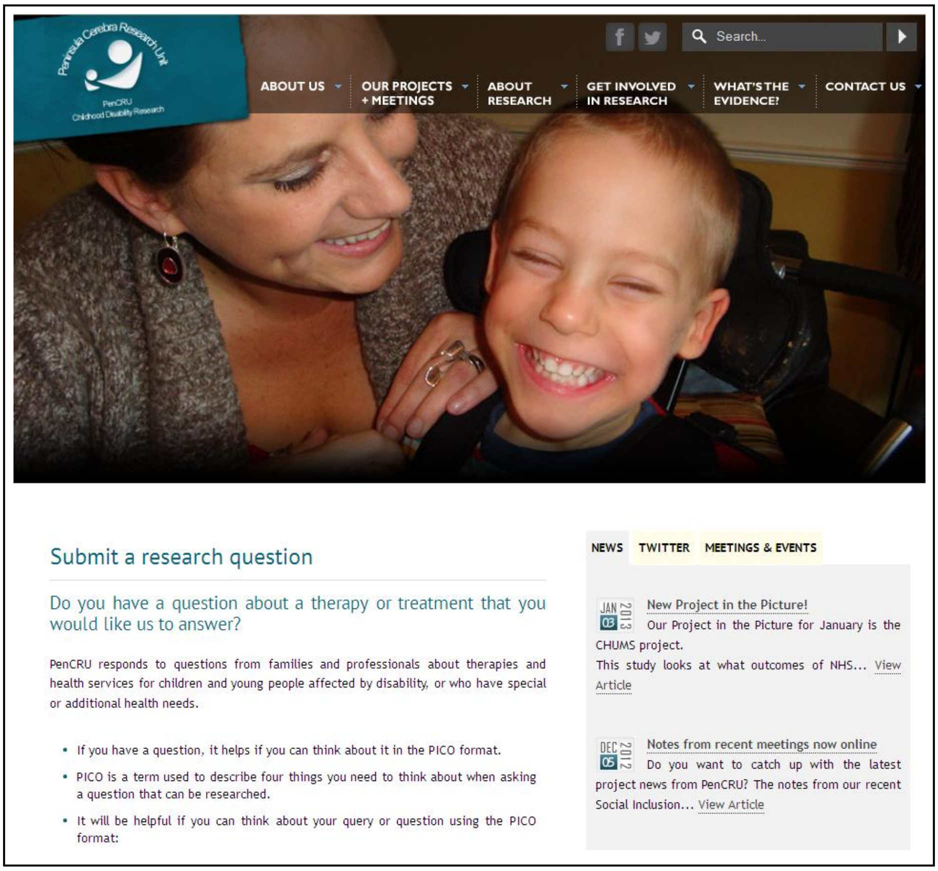
Consistent with our objective of providing information to families, we have developed, with parents, templates for appropriate content and design of plain language summaries of our research findings both in terms of content and presentation. We are exploring novel 'storytelling' methods such as online videos where a parent or young person interviews a researcher about what they did in their research and what the findings might mean for disabled children and their families.

Website

The PenCRU website makes a lot of information available to families and professionals about research, our programme of work at the unit, and how they can get involved. It lists upcoming meetings at the unit, and is used to publish notes from previous meetings, our quarterly newsletters, and our What's the Evidence? summaries. The website is also used to make research study documents available to participants.

This year, the website has been updated to include a page explaining each of the research projects we are leading on or a partner in. We have also expanded the 'get involved in research' section of the website, which outlines the different ways families can get involved in the unit and what families can expect when they get involved in different types of research project. An online form added to the website this year enables families and professionals to submit queries and research questions to us, and we have added a page with a flow diagram to explain how we respond to these queries.

PenCRU uses Google Analytics to keep track of the number of visitors to the website. In 2012 there were 3,158 unique visitors to the PenCRU website. Our What's the Evidence? homepage, CHUMS project page, and the 'projects we are working on' page were the most commonly viewed pages. Most visits were from the UK (75%), but the site also had visits from the US, Canada, Germany, Belgium, India and Australia.



Submit a research question

Do you have a question about a therapy or treatment that you would like us to answer?

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

- If you have a question, it helps if you can think about it in the PICO format.
- PICO is a term used to describe four things you need to think about when asking a question that can be researched.
- It will be helpful if you can think about your query or question using the PICO format:

New Project in the Picture!
Our Project in the Picture for January is the CHUMS project.
This study looks at what outcomes of NHS... View Article

Notes from recent meetings now online
Do you want to catch up with the latest project news from PenCRU? The notes from our recent Social Inclusion... View Article

Social Media

In June 2012 PenCRU set up social media profiles on Facebook and Twitter. The aim was to use social media to make our research available to more families and health professionals and reach more researchers. It is also possible to use Twitter to connect with other organisations such as Cerebra. The unit tweets news and updates about our work, research, events, and conferences. Our followers on Twitter include individual parents, researchers and professionals, charities, research groups, and local and national government organisations. The PenCRU Facebook account also informs our followers with news and updates from the unit.

By December 2012 the unit had 53 followers on Twitter and 37 likes on Facebook. Several PenCRU tweets have been re-tweeted by Cerebra, reaching an audience of over 2000.

'I have always wanted to see proper research-based methodology applied to the issues faced by real people, and the questions you are exploring are of huge importance to our family. It's so hard for non-specialists to access this sort of research and you have done an excellent job of presenting these results clearly and in language ordinary people can understand.' - a comment submitted to the PenCRU website

Newsletter

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

Children playing together at the annual Family Fun Day

Collaboration with Cerebra

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

Cerebra Annual Conference

Cerebra's Annual Conference in 2012 pursued a theme of promoting 'wellbeing' for children, parents and carers. Chris Morris presented about ways in which health and wellbeing are measured, and outlined the objectives of the CHUMS project. Our colleague Siobhan Sharkey presented on the qualitative research she has been carrying out about improving communication with disabled children when they have to spend time in hospital. The event was extremely well attended, but if you missed it then all the presentations are available on the Cerebra website: www.cerebra.org.uk/english/whatson/annualconference/conference2012/Pages/AnnualConference2012.aspx

Overview

- Concepts of health & wellbeing.
- Measuring outcomes from the patients perspective.
- The feasibility of do[illegible]ith children.
- Why patient-reported outcomes are important.
- Some relevant research we are carrying out.

Click to view video

Communication with children and young people as Inpatients

PenCru Research Team

Dr Siobhan Shark
Ms Claire Ll
Dr Chris Morr
Ms Camilla McHugh, Family Involvement Coordinator

ors
PenCRU Family Faculty and Paediatric Health Care Professionals

Click to view video

Annual visit by Cerebra

We really enjoyed hosting Cerebra's annual visit to PenCRU this year. Chris Jones (Chief Executive), Tracy Elliot (Head of Research), Kelly Gadd (Head of Parent Support) and Michael Imperato (Trustee) all came along to find out more about what we do.

Cerebra annual visit

We prepared 12 posters about the work we do and how we involve families in each of our research projects and general activities. We would like to thank two of our parents, Julia and Kirsty, for their help reviewing and editing the posters so they were clear. It was a great day and the families who came along enjoyed the opportunity to meet and talk to some of the Cerebra team.

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 the people we were fortunate to have worked with this year, and who have contributed to the success of PenCRU in 2013.

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.

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.

Sarah Dean PhD CPsychol MCSP MSc Grad Dip Phys BSc (Jt Hons)
Senior Lecturer in Health Services Research
Dr Dean has expertise in qualitative research and developing outcome measures, and has been involved in our work developing ways to measure children's inclusion/participation.

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.

Hannah Parsons BSc (Hons)
Web Developer
Hannah is part of the website and database team. She designed and maintains our 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.

Ginny Humphreys Grad Dip Phys MSc DPT
Head of Therapy at Vranch House School and NHS Centre
Ginny is a member of our Advisory Group and collaborates on research about postural management and evaluating the use of sleep systems.

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.

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.

Terry Pountney MA MSCP
Head of Research, Chailey Heritage Clinical Services
Terry is a research physiotherapist well known for her work related to postural management systems. She collaborates with PenCRU on two studies relating to cerebral palsy.

Diane Sellers BA MA 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, and a PhD student at the University of Sussex. She is leading the development of the eating and drinking classification system for children with cerebral palsy.

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. She leads the 'MeASURe' project we are involved in about appropriate outcomes for young children affected by autism.

Zara Todd BA (Hons) MA
Participation Research Project Worker, *Alliance for Inclusive Education (ALLFIE)*

Zara is supporting a group of young disabled people recruited as young researchers. She advises PenCRU on issues surrounding the creation of a Children and Young People's Faculty.

Academic publications

Shilling V, Morris C, Thompson-Coon J, Ukoumunne O, Rogers M, Logan S. Peer support for parents of children with chronic disabling conditions: a systematic review of quantitative and qualitative studies. Developmental Medicine and Child Neurology. In Press.

Morris C, Shilling V. What is the role of parent and community organizations in child health promotion? In Ronen G & Rosenbaum P (Eds) Health, Participation and Quality of Life in Young People with Neurodevelopmental Conditions: Theory, concepts, evidence and practice. (In press)

Gilbert R, Woodman J, Logan S. (2012) Developing services for a public health approach to child maltreatment. The International Journal of Children's Rights, 20(3): 323-342

Ford T, Edwards E, Sharkey S, Okoumunne O, Byford S, Norwich B & Logan S. (2012). Supporting Teachers And childRen in Schools: The effectiveness and cost-effectiveness of the Incredible Years Teacher Classroom Management programme in primary school children: a cluster randomised controlled trial, with parallel economic and process evaluations. BMC Public Health 12:719.

Shilling V, Edwards V, Rogers M, Morris C. (2012) The experience of disabled children as inpatients: a structured review and synthesis of qualitative studies reporting the views of children, parents and professionals. Child: Care, Health and Development 38(6):778-88.

Morris, C. (2012) Orthotic management of neurodisability. In Gada S (Ed) Community Paediatrics (Oxford Specialist Handbooks in Paediatrics). Oxford University Press

Mann J, Henley W, O'Mahen H, Ford T. (2012) The reliability and validity of the Everyday Feelings Questionnaire in a clinical population. Journal of Affective Disorders. [Epub ahead of print]

Whear R, Thompson-Coon J, Boddy K, Ford T, Racey D & Stein K (2012) The effect of teacher-led interventions on social and emotional behaviour in primary school children: a systematic review (Teacher training potential to improve social and emotional behaviour in children. British Journal of Educational Research.

Telford C, Green C, Logan S, Langley K, Thapar, A, Ford T. (2012) Estimating the costs of ongoing care for adolescents with Attention-deficit Hyperactivity Disorder. Social Psychiatry and Psychiatric Epidemiology. [Epub ahead of print]

Morris, C. Majnemer, A. (2012) Activity and participation: An overview of generic measures. In: Majnemer, A. (Ed) Measures for children with developmental disabilities: an ICF-CY approach. Clinics in Developmental Medicine No 194/195. Mac Keith Press: London.

Moran P, Kelesidi K, Guglani S, Davidson S & Ford T. (2012) What do parents and carers think about routine outcome measures and their use: a focus group study of CAMHS attenders. Clinical Child Psychology and Psychiatry 17, 65-79.

Grants awarded

Morris C, on behalf of BACD Strategic Research Group. (2012-2014) Setting priorities for childhood disability research: a JLA Priority Setting Partnership. Paul Polani Fund, RCPCH / BACD. £20,000.

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. (2012-13) MeASURe: Measurement in autism spectrum disorder under review. NIHR Health Technology Assessment Programme, £263,910.

Ford T, Edwards V, Sharkey S, Ukoumunne OC, Byford S, Shotton C, Norwich B, Logan S. Supporting Teachers and Children in Schools (STARS). (2012-17) NIHR Public Health Research Programme £1.7 million.

Ford T, Stein K, Thompson Coon J, Norwich B, Taylor E, Shotton C, Morris C, Pritchard W, Garside R, Logan S. (2012-13) Non-pharmacological interventions for Attention-Deficit/Hyperactivity Disorder (ADHD) delivered in school settings; a systematic review of quantitative and qualitative research. NIHR Health Technology Assessment Programme, £308,000.

Morris C, Shilling V, Allard A, Thompson Coon J, Green C, Williams J, Tomlinson R, Beresford B, Jenkinson C, Tennant A, Logan S. (2012-2013) Informing the NHS Outcomes Framework: what outcomes of NHS care should be measured for children with neurodisability? NIHR Health Services and Delivery Programme, £247,419.

Russell G, with Collishaw S, Kelly S, Ukoumunne O, Golding J. (2012-13) Increased diagnosis of developmental disorders: are there really more children with autism, dyslexia and ADHD? Economic and Social Research Council, £154,254.

Members of the Family Faculty

Major presentations

Morris, C. 'Health and wellbeing outcomes'. Cerebra Annual Conference.

Morris C. 'Patient reported outcome measures (PROMs) for children and young people'. Institute of Child Health, University College London.

McHugh C, East A, Hunt J, Morris C. 'The involvement of families in childhood disability research' NIHR Involve Conference

Morris C. 'Partnerships between families, clinicians & researchers to identify research questions'. International Cerebral Palsy Conference.

Morris C. 'The role of parent and community organizations in child health promotion'. American Academy for Cerebral Palsy and Developmental Medicine

Janssens, A. 'Cross-boundary working between child welfare and child and adolescent psychiatry: Collaborative Practices in Flanders'. The International Association for Child and Adolescent Psychiatry and Allied Professions (IACAPAP), Paris (23/07/2012)

Janssens, A. 'The use of Routine Outcome Measures in Child and Adolescent Psychiatry'. St-Jozef Child and Adolescent Psychiatric care Jubilee Conference

Meetings attended

Prof Stuart Logan attended:

International Society for Social Pediatrics and Child Health, ISSOP

Dr Chris Morris attended:

- British Academy of Childhood Disability (BACD) Annual Meeting.
- European Academy of Childhood Disability (EACD) Annual Meeting.
- American Academy for Cerebral Palsy and Developmental Medicine
- International Cerebral Palsy Conference
- NIHR INVOLVE Conference

Dr Astrid Janssens

- Cerebra Annual Conference, London (2/10/2012): "Promoting the well-being of children with complex needs"
- IACAPAP Annual conference, Paris (July 21st to 25th 2012): "Brain, Mind and Development"
- St Jozef Child and Adolescent Psychiatric care Jubilee Conference, Hasselt (Belgium, 7/12/2012):"Maatschappelijk verantwoorde zorg in kinder- en jeugdpsychiatrie. Hoe doe je dat?" (Public acceptable child and adolescent psychiatric care: How do you do that?)

Teaching and supervision

Prof Stuart Logan

PhD students:

- Rachel Besser (awarded 2012)
- Shelley Brown (awarded 2012)
- Andrew Williams, in progress
- Sarah Walker on hold (maternity leave)

Also Academic Supervisor for Sarah Tickner (SpR in Public Health)

Supervisor for Alice Martin (Academic Clinical Fellow in Child Health)

Dr Chris Morris

PhD Student:

- Megan MacMillan, in progress

External Examiner

Prof Stuart Logan

Louise Hartley, PhD Thesis, Birmingham, 2012

Dr Chris Morris

Karen McConnell, PhD Thesis, Queens University Belfast, 2012

Parents catching up at the annual Family Fun Day

Advisory Committees and Steering Groups

Prof Stuart Logan

Prof Logan is currently

- Member of South West Peninsula Academic Health Science Network Steering Group
- Member of Children's Policy Research Unit Advisory Board
- Member of CREEP Advisory Group (Engagement in Research: Does it improve performance at a clinician, team, service and organisational level in healthcare organisations?)
- Member of Healthcare Quality Improvement Partnership (HQIP) Advisory Group
- Member of NIHR HTA Rapid Trials Board

Prof Logan has been a member of the NHS Evidence Advisory Committee (NICE) and Chair of the NIHR Research for Patient Benefit Programme South West Regional Funding Committee. He was also: Chair of MENDS Trial Steering Committee (HTA funded trial), Member of the NIHR Carbon Guidelines Committee, Member of the NPEU (National Perinatal Epidemiology Unit) Advisory Committee, Chair of the SMILE External Advisory Group (SMILE is a feasibility trial investigating the Lightning treatment for CFS/ME), Member of 'Why don't children take their medicine' initiative (MCRN), Chair of the University of Exeter Science Strategy for Translational Medicine, Personalised Healthcare And Public Health Committee, Chair of NIHR HTA Newborn Screening Programme Participant in COMET (Core Outcome Measures in Effectiveness Trials), Participant in NIHR HS&DR Programme seminar to identify the broad themes which will go to form the agenda for our future programme of research focused on quality, access and delivery of health services and Member of the Neighbourhood Health Watch Steering Group (partnership with Devon Partnership NHS Trust, Devon & Cornwall Police and Health Innovation & Education Cluster).

Dr Chris Morris

Dr Morris is currently

- Member of the British Academy of Childhood Disability Strategic Research Group
- Trustee/Director Mac Keith Press
- Trustee for the Orthotic Education & Training Trust

Dr Morris was an external advisor for the NICE Guidance CG145: Spasticity in children and young people with non-progressive brain disorders: management of spasticity and co-existing motor disorders and their early musculoskeletal complications. He was part of an External Advisory Group for the Study of Participation of Children with cerebral palsy Living in Europe (SPARCLE 2). He was also part of an Expert Advisory Group for the report for the Office of the Children's Commissioner: 'Nobody made the connection: The prevalence of neurodisability in young people who offend'.

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Peninsula Cerebra Research Unit
PenCRU Childhood Disability Research

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