Cerebra Research Unit

Peninsula Medical School

Childhood disability research based in Devon

Annual Report 2010

Contents Page

Reflections on progress in 2010

The Cerebra Research Unit at Peninsula Medical School continues to evolve. As can be seen from this report for 2010, considerable progress has been made in developing partnerships with local families with disabled children and service providers.

Before reflecting on the year I want to reflect briefly how the relationship between the charity Cerebra and Peninsula Medical School came about. Cerebra's helpline was receiving a large number of queries from families about whether osteopathy was a helpful treatment for children with cerebral palsy. So, at Cerebra's request, we designed a clinical trial with meaningful involvement from families to address the question. The study exceeded the recruitment target, with over 150 children taking part, and all but a handful of children stayed in the study until the end. We attribute this success to the importance of the topic to families, and by involving families in designing the trial the procedures were highly acceptable. The results are soon to be published. However, one key reason for involving families is that the results are then useful to them when making decisions about whether to use such treatments.

The ethos of involving patients and members of the public in research also underpins our *PenCLAHRC* research programme, funded by the National Institute of Health Research. The Cerebra Research Unit at Peninsula Medical School benefits greatly from being under the umbrella of *PenCLAHRC* in terms of academic support and sharing of resources. It is commendable that we have recruited over 100 parents to join our Family Faculty. Many of these parents have played an active role in shaping the partnership strategically and by being involved in various projects. As we build the partnership with families I am extremely heartened when told how much families enjoy, and feel supported, when working with us. I commend and thank our staff for making families feel so welcome, as their involvement is vital to what we are trying to achieve. Amongst our challenges for the future is involving more children in our research. The Family Fun Day at Paignton Zoo was a fabulous occasion and helped to foster trust and friendships consolidating partnership and new links. You will see some of the lovely photos from the day illustrating this report.

Reflecting on the staff, whilst Chris completed his first full year leading the unit, there have been some changes in 2010. We wished Claire well as she took maternity leave last March and were then pleased to meet her son, Alfie. We welcomed Val when she arrived in June and have benefited greatly from her experience and motivation. As we expect Claire to return part-time in 2011, further changes are planned. Camilla will be taking on more responsibility to use her natural flair in working with families as the Family Involvement Coordinator; we hope Val will take responsibility for a specific project.

On the back of the progress made this past year, I believe we can be very optimistic about achieving our targets in 2011 and beyond.

Professor Stuart Logan
Cerebra Chair in Paediatric Epidemiology

Our Mission

The Cerebra Research Unit at Peninsula Medical School 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.

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. The Cerebra Research Unit at Peninsula Medical School is one of five 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 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. For major research projects we require additional funding for which we apply to schemes operated by the National Institute for Health Research and other public and charitable agencies that fund research.

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

Who We Are

Unit staff

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

Cerebra Professor of Paediatric Epidemiology

Stuart Logan is the Director of Health Service Research at the Peninsula 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. He is also involved in the teaching of evidence-based practice to medical students and clinicians working in child health.

Chris Morris MSc DPhil

Senior Research Fellow in Child Health

Chris Morris has 20 years clinical experience as an orthotist, and 10 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. Chris came to Exeter in September 2009 to lead the Cerebra Research Unit. His research interests include measuring outcomes in childhood disability, qualitative research with children, and the appraisal and use of patient-reported outcome measures.

Val Shilling BA (Hons), PhD, CPsychol

Research Fellow in Child Health

Val Shilling has a background in psychology and has worked in research for over 10 years. She has a Bachelors degree and Doctorate from the University of Manchester and is a Chartered Psychologist. Val came to Exeter in June 2010 from Liverpool University where she managed an NIHR HTA study of recruitment to randomised controlled trials of medicines for children. Her research interests include patient and particularly parent experiences and communication in healthcare.

Claire Lloyd BSc (Hons) MSc

Associate Research Fellow in Child Health

Claire has a Bachelors degree in Psychology and a Masters degree in Health Psychology. Claire was instrumental in the early work to establish the family faculty and in making links with local family support groups. She has experience in research with children, and has worked closely with young people and their parents in a variety of settings. Claire has been on maternity leave for the latter half of the year and we look forward to her return in 2011.

Camilla McHugh BA

Research Support / Family Involvement Co-ordinator

Camilla provides essential research and administrative support to the unit. In the last year she has also taken on the role of liaising with our family faculty to provide information and support for families working with the unit. As of January 2011, she is moving into the role of Family Involvement Coordinator.

Research Associates

Katrina Wyatt BSc (Hons) PhD
Senior Lecturer in Health Services Research
Dr Wyatt was involved in managing the osteopathy trial and continues to provide advice to the unit on involving children, families and members of the public in research.

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

Vanessa Edwards BA (Hons) MPH
PenCLAHRC Research Fellow in Child Health
Vanessa was the trial manager for the osteopathy trial. Currently she is the lead researcher for the Communication in Hospital study.

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. She has been involved in our work relating to measuring inclusion/participation.

Mark Tarrant BA (Hons) PhD
Senior Lecturer in Human Science
Dr Tarrant is a social psychologist and has been working with us on the programme of work about social inclusion, specifically social identity and public attitudes to towards 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.

Jo Thompson Coon BSc PhD
PenCLAHRC Research Fellow (PenTAG)
Dr Thompson Coon has expertise in evidence synthesis and has been working with us on the scoping review of complementary & alternative therapies for children with ADHD.

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.

Rod Taylor BSc (Hons) MSc PhD*Professor of Health Service Research*
Professor Taylor has worked with us to develop the protocol for a clinical trial of Lycra-based orthoses. His Clinical Trials Unit (PenCTU) also provides database support.

Richard Tomlinson MSc, MRCPCH
Consultant Paediatrician
Dr Tomlinson is an integral member of our advisory group and has been involved in the development of several projects including the Lycra trial and CAMs for ADHD.

Ginny Humphreys Grad Dip Phys, MSc, DPT
Head of Therapy at Vranch House School and NHS Centre, Exeter, NHS Devon, Head of Profession for Paediatric Physiotherapy
Ginny is an integral member of our advisory group and has been involved in the development of the Lycra trial and research about postural management and sleep.

Alice Martin MRCPCH BMBS 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.

Hannah Parsons BSc (Hons)
Web and Managed Learning Environment Officer
Hannah is part of the website and database team at Peninsula College of Medicine and Dentistry. She designs and maintains our website.

Visiting Students

Stuart Read
Stuart was a visiting student in 2009/10 whilst studying for BSc in Psychology at the University of Exeter. He was supervised by Tamsin Ford and Claire Lloyd while completing a thesis that involved a qualitative study of the views of parents of children with cerebral palsy about their experience of children's services. Stuart obtained a first grade classification and the study is being written up for publication. Currently Stuart is studying for a Masters degree for which his thesis project is being supervised by Chris Morris.

Jessica Oliver
Jess was a visiting student during the summer 2010 between terms studying for a BSc in Psychology at the University of Oxford. Jess spent two weeks with us gaining research work experience. She spent the time very helpfully reviewing and summarising the literature on measurement of perceived stigma, and attitudes towards disabled children.

About our Family Faculty

We have built up a faculty of 103 families from around Devon and the UK who are interested in our work. Our members are mainly parents of children with disabilities in Devon, with a few from farther afield. We have recruited our members by various different means; by attending different local parent support meetings such as, Parent Carer Voice, Plymouth Parent partnership, Face2Face and by placing articles in the different parent newsletters such as Primary Times, DISCplus, Torbay Parent partnership and local special needs schools.

Membership of the Family Faculty does not commit members above being informed about the work that we are doing and to get involved at a level that's suits them. Examples of family involvement are: taking part in the Advisory Group or committees for specific studies, working with us to design studies, reviewing information leaflets about specific studies or Cerebra Research Unit publicity documents, assisting with disseminating the results of studies, or any other aspect of the work that we are doing in which individual members have an interest. We appreciate that the amount of time that families have varies so we understand when our families dip in and out of being involved.

We have gathered more detailed information about 50 of our families who told us more about their 54 children.

- 75% of the children are boys and the median age is 8 years (ranging from 2 – 18).
- Nearly 40% of the children have a diagnosis of Cerebral Palsy, around 25% have a diagnosis of ASD, ADHD or both and around 10% have Down's Syndrome.
- Around half of the children are attending special school, around a third attend mainstream school and the remainder attend both except two children who are not attending school.
- 10 are only children, median number of siblings 1 (range 0-4)

Annual Event: In September Cerebra South West and the Cerebra Research Unit co-hosted our first Family Fun Day at Paignton Zoo. This event was organised with the input of parents to thank the families who have been involved with us and it was a fantastic opportunity for the families and Cerebra members to get together and enjoy a family day out.

INVOLVE conference: In November two parents and members of the research team gave a presentation at the INVOLVE Conference in Nottingham explaining how local families and the Cerebra Research Unit are working together. INVOLVE is a national organisation promoting public involvement in NHS, public health and social care research.

Here are some of the comments made by parents who have been involved with Cerebra Research Unit activities throughout the year:

"I must say what a pleasure it was to be at the advisory group meeting today, I really was made to feel welcome and enjoyed taking part, I shall look forward to getting to know everyone better and becoming more involved in the work…"

Kim, Advisory Group meeting, March 2010

"My husband and myself would very much like to thank everyone at Cerebra Research Unit for such a fab day at the zoo. Both my children went along with their daddy and grandma. Jacob and Lexie had the most wonderful day and didn't leave until 7pm!!!!! We really appreciate the effort that must have gone in to fund raising for this and the organising of it too".

Wendy, Annual Event at Paigton Zoo, Sept 2010

"Just to say that Mark, Luca, Lydia and neice Leah would like to say thank you for a lovely day out at the zoo. I wish I could have been there! The children seemed to really enjoy it and were full of conversation about it when they got back."

Dee, Annual Event at Paigton Zoo, Sept 2010

"We had a lovely day at the zoo on Saturday! Thank you so much for organising the event - - it was great to meet you all face to face at last!"

Julia, Annual Event at Paigton Zoo, Sept 2010

"*Cerebra Research Unit are hoping that as many of us as possible are able to join and help them in some way. They also realise, refreshingly, that with our children we may not be able to commit all the time, and that they may have to look at alternative methods to enable ALL our children to take a part in the research process*."

Amy, Building a Partnership event, Oct 2010

"If you are a parent thinking about attending for the first time, it is a little daunting, but take that step if you can. I received a warm welcome from a friendly group of people and quickly realised it was an opportunity to get involved to a greater or lesser degree, as suited your personal circumstances, which was reassuring - there were no great expectations that would be difficult to fulfil. It was an opportunity to make a bit of a difference, no matter what your background was. All are very welcome. Go on, why not give it a try...."

Julia, Building a Partnership event, Oct 2010

"Last November I attended the Involve Conference, with the team from Cerebra Research Unit, I was able to help with the presentation, that they gave on the work that they do, and share some of my experience with a small group of people involved with research , I was able to attend other talks and learn more about research.
The whole experience was a positive one , it was nice to be able to contribute and have a say about a subject that is so close to my heart, to feel a part of something that in the long run, will hopefully make a difference too others, as more research is done. The team put me very much at ease I felt valued and listened too, and we became closer as a group, which will help us, as we all work together over the coming weeks/months, putting together questions for research."

Kim, INVOLVE conference, Nov 2010

Our Approach

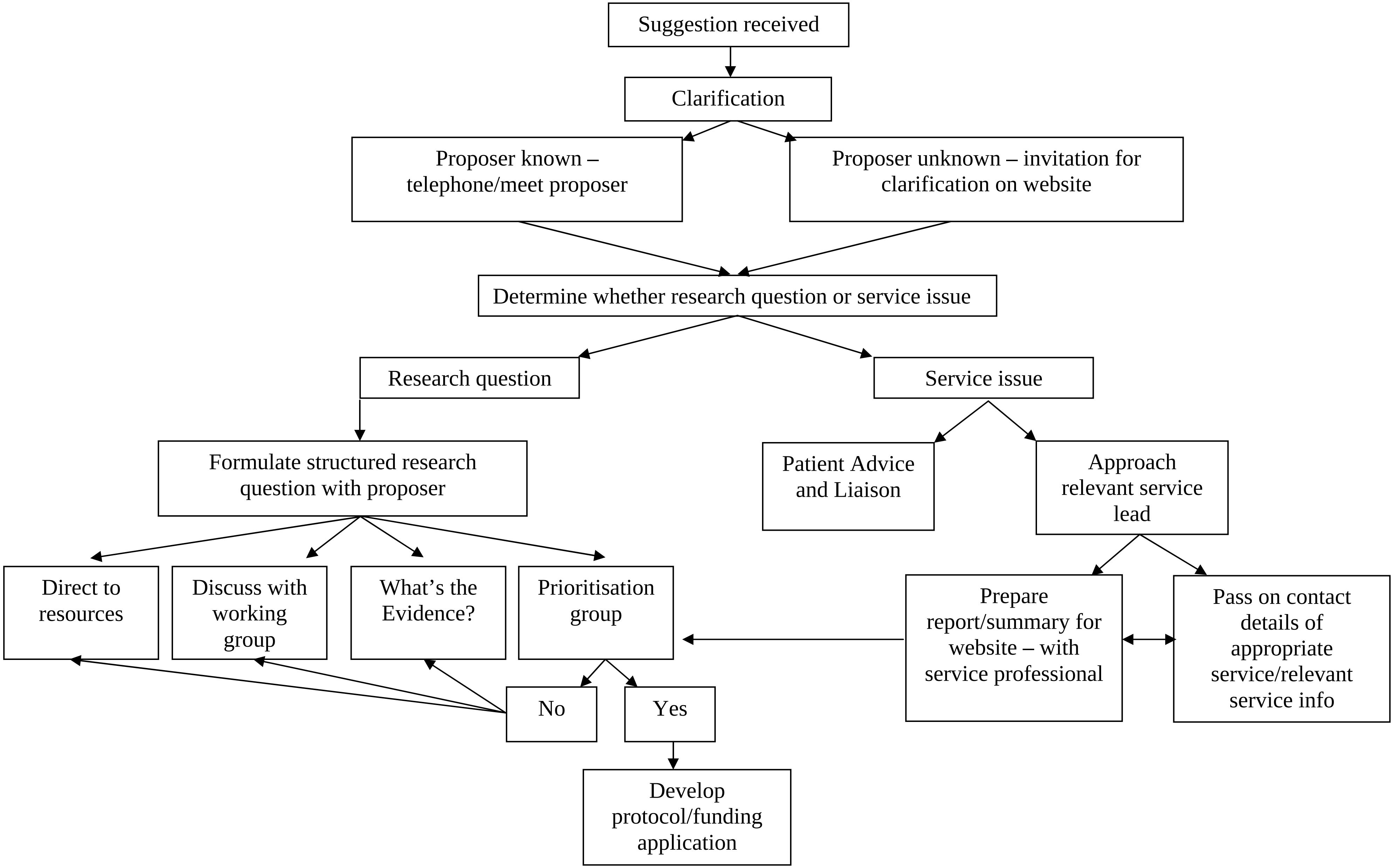
Developing research

The Cerebra Research Unit is part of the Peninsula Collaboration for Leadership in Applied Health Research and Care (PenCLAHRC). PenCLAHRC is a collaboration of Universities and NHS organisations in the South West of England which aims to deliver high-quality health research that influences medical practice, ensuring that research addresses issues that are relevant to patients and carers and results in beneficial new treatments and services.

The unit 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 regarding specific treatments to help families make informed decisions. Where the evidence is lacking we seek funding to conduct clinical trials to assess the effectiveness of interventions. Our focus is on outcomes that families tell us are important, such as function, social inclusion and participation, and quality of life.

Questions received from families or health professionals enter a process of prioritisation as detailed in the flowchart on the following page. The first step is to clarify the question before determining whether it is a potential research question or a service issue. Research questions are then divided into those topics that have been researched elsewhere (in which case the proposer is directed to the appropriate resources or we will produce a 'What's the Evidence?' summary) or are identified as potential projects that are carried forward to a relevant working group or discussed at a prioritisation meeting. Projects that are prioritised are developed into protocols to seek funding. Parents are involved in the prioritisation process from the outset and only questions felt to be important to members of our family faculty are carried forward to the next stage.

Question Prioritisation



Advisory group

The management of the research unit is overseen by an advisory group made up of the research team, parents, health professionals and the Cerebra South West regional officer.

The advisory group meets four times a year to discuss the general running of the Research Unit and to plan future work and events.

We have a Devon focus, including Plymouth and Torbay, although we also collaborate with colleagues engaged in childhood disability research across the UK. We seek to develop future collaboration with colleagues across the UK and worldwide.

Building partnerships

Central to our ethos is to work in partnership with families and the agencies they interact with for health, social and educational services. By bringing these groups together to help develop research projects we also hope to facilitate emerging partnerships between families and the service providers.

During 2010 we have developed a network of contacts throughout Devon, Plymouth and Torbay working in the councils, NHS and schools. Plymouth and Torbay are unitary authorities with different systems and procedures in each and both different to Devon. This diversity provides us with considerable challenges in familiarising ourselves with how the services in each region are structured but also provides us with a unique opportunity to consider the variation between regions in our research.

In the coming year we hope to expand this network further and would also seek to bring together professionals from different regions. In December we organised a meeting between members of the Inclusion Services teams from the three regions. With parents they were able to discuss different aspects of their practice and will work with us to develop a research programme around social inclusion.

Communication

Our website was developed with the help of a group of parents in 2009. We use the website to provide information on current projects and upcoming meetings but also to provide research summaries in our ‘What’s the Evidence’ series. In this series we produce brief, readable summaries of the published evidence on topics or treatments that have been suggested by parents.

The website also provides a platform for our forum, where parents and young people can discuss topics of interest and importance to them.

In 2011 we will redesign the website with input from our advisory group and family faculty.

We produce a quarterly newsletter which is sent to all families registered on our family faculty, all professional s that we have made contact with and all special schools in the region.

Our Programme of Work

Social inclusion

This group has met several times over the year to develop a research programme to promote the social inclusion of children with additional health needs. We are looking at ways of defining and measuring inclusion using the principles of equality of opportunity and freedom to choose to be involved. We also want to develop ways to measure the attitudes of people towards disabled children and their families; that is amongst the general public, other children, and professionals such as teachers and health staff. We want to investigate ways to define and measure any perceived stigma experienced by parents, carers, children with additional health needs and their siblings. The aim is to seek ways in which attitudes can be modified to reduce stigma and promote social inclusion and wellbeing.

Continence services

Accessing and receiving appropriate continence services causes huge frustration for many families of incontinent disabled children. Our continence group has met twice over the year. We have brought together parents, service commissioners and the teams working within the service to make sure that we have a balanced view when developing the research. The working title for our research is “what constitutes an adequate continence service; what could a good service look like?” The topic has also had a national profile following lobbying by *Mumsnet* and the campaigning organisation Every Disabled Child Matters.

Navigators

This group met in September. Parents often tell us that it is difficult to find their way around the different services or to know who to contact. A number of parents are interested in working with us to think about how to map how the services for children with disabilities and additional needs are organised across Devon, Torbay and Plymouth and to help us to identify what services families want, the services that disabled children use, and any places that disabled children and families value and should know about. We are working with parents to decide how to take this forward as a piece of research.

Building a Partnership

This group first meet at an event hosted in October 2010. We are working with families across Devon to develop ideas for research projects about things that are important to them. We held the event to consider how families can and want to be involved in our research. There were presentations from representatives from the Medicines for Children Research Network, the Council for Disabled Children and "Folk.us" and productive discussions about how we can work together in Devon.

In the future this group will help us to support parents and children to be partners in our research, looking at ways of making involvement easier and more attractive particularly to families who might not have prior knowledge or experience of research. We are also keen to develop ways to measure and evaluate the impact of families’ involvement in research.

Lycra

Parents who contacted us following an advert through the charity HemiHelp and others from our Family Faculty were heavily involved in developing a protocol to evaluate Lycra-based orthoses (splints). The group also involved a paediatrician and physiotherapist, as well as people with expertise in clinical trials. Together we came up with a design for a clinical trial to explore the effectiveness of Lycra-based sleeve/glove orthoses to improve handling ability of children with spastic hemiplegia. The proposal was submitted to a major funding organisation with one of the parents is a co-applicant.

Projects in Progress

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

V. Edwards, A. Martin, C. Lloyd, R. Tomlinson, V. Shilling, J. Choules, B. Hart, C. Morris

This study will develop a training package for health professionals to help improve communication with children in hospital. We have completed a review of the literature, and interviews with families and health professionals to gather their views and suggestions on how to improve communication with children with communication difficulties. These interviews are now being analysed and the results will be used to help us design the training package. Parents will be involved in designing and delivering the package to professionals.

Funded by PenCLAHRC

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

Academic lead: C. Morris

The project will conduct a systematic review of the existing literature on providing peer support to parents of children with a disability and carers in a broader context. The second phase of the project will conduct a pilot evaluation of the Devon division of a national peer support group for parents of children with disability to assess how peer support works and its impact in terms of outcomes, through qualitative research. Information gained from the pilot evaluation will be used to develop a protocol for a larger scale more definitive evaluation of the effectiveness and cost-effectiveness of providing peer support.

Funded by PenCLAHRC

Development of a Functional Classification System of Eating and Drinking for Children and Young People with Cerebral Palsy

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

This research will produce a classification system to describe the eating & drinking ability of children with cerebral palsy. Similar systems used to classify movement and manual ability have been shown to improve communication between clinicians, and between clinicians and families; it will also be useful for researchers. The project is led by Diane Sellars, a Speech and Language Therapist at Chailey Heritage Clinical Services in Sussex.

Funded by the NIHR, Research for Patient Benefit 2009-13.

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 a 'sleep system' to control posture helps children with cerebral palsy by allowing them to be more comfortable in bed, reduce pain, improve sleep, prevent deformity and avoid the need for surgery. This is an exploratory pilot study to help in the development of a protocol for a larger clinical trial.

Funded by the NIHR, Research for Patient Benefit 2010-3.

Safety and efficacy of complimentary therapies for children diagnosed with Attention Deficit Disorder with hyperactivity: A scoping review of the literature

C. Morris, J. Thompson-Coon, C. Shotton, J. Margetson, R. Tomlinson, T. Ford, R. Marlow, A. Richards, E. Ernst

The purpose of scoping the literature is to ascertain whether there is any potential evidence base (clinical studies or trials) for the use of various complementary therapies for the treatment of children diagnosed with attention deficit disorder with hyperactivity. No critical appraisal of any studies will be undertaken at this stage. If any potential evidence base is found to exist this might, at a later stage, form the basis of a systematic review of the literature to better inform parents and carers about therapy options.

Funded by Cerebra

Cochrane Review – Sleep Positioning for Children with Cerebral Palsy

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

The aim of this systematic review is 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 other problems for the child and family.

Projects Seeking Funding

Informing the NHS Outcomes Framework: what outcomes of NHS care should be measured for children with neurodisability?

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 NHS Outcomes Framework will include patient-reported outcome measures (PROMs) as one way of assessing whether the NHS is working effectively and efficiently for patients. This research will identify which PROMs would be the most appropriate to assess the effectiveness of NHS care for children with neurodisability.

Status: submitted to NIHR Health Services Research Programme

Evaluating a Lycra-based sleeve/glove orthosis to improve the bimanual ability of children with spastic hemiplegia: an exploratory randomised controlled trial

C. Morris, R. Taylor, R. Tomlinson, R. Buckingham, G. Humphreys, L. Jones, C. Green

This research programme aims to find out whether Lycra-based orthoses are effective in improving the ability of children with hemiplegia to manipulate objects with both hands. Lycra-based splints are popular with some therapists and families but not available widely as we do not know whether they are an effective treatment. The first stage is an exploratory (pilot) study to develop an acceptable clinical trial that provides a 'fair test' of whether Lycra-based splints help children with hemiplegia to use both hands together.

Status: pending decision on funding

Improving the Transparency and Completeness of Reporting Public Involvement in Health Research: Guideline Development

C. Morris, K. Wyatt, B. Hanley, K. Staley, R. Humphreys, D. Altman, I. Simera, A. Hirst

The aim of this project is to improve how public and patient involvement in research is described and reported in written documents. This will be achieved by the production and dissemination of explicit guidance detailing what information should be included in a complete and transparent report.

Status: Funding was sought but not awarded, no further work on this project is planned.

Who we Talked to in 2010

Local Authority Organisations

- Devon County Council
- Plymouth City Council
- Children's Integrated Disability Services (ChIDS), Plymouth
- DISCPlus (Devon's family information service for children with additional needs)
- Inclusion Services Devon and Out of School Inclusion Devon
- Inclusion Works, Plymouth
- Torbay Inclusion Project

NHS

- Chailey Heritage Clinical Services, East Sussex
- Children's Wards at Royal Devon and Exeter, and North Devon and District, Hospitals
- Continence Services Devon, Plymouth and Torbay
- Nuffield Orthopaedic Centre NHS Trust, Oxford
- Exeter Mobility Service
- South West Orthotics Group

Parent support and consultation groups

- Parent Carer's Voice in Exeter, North Devon, South Devon
- Plymouth Parent Partnership
- Torbay Parent Partnership
- Face2Face (nationwide peer support network)

Devon Special Schools

- Dame Hannah Rogers
- Ellen Tinkham
- Oaklands Park
- Vranch House

Patient and Public Involvement

- Folk.us (Folk.us works to support and help develop service user, patient and carer involvement in research)
- TwoCan Associates (TwoCan help voluntary and statutory organisations to involve service users, patients, carers and the public in their work)

Academic Groups and Charities

- Children and Families Team, Social Policy Research Unit, University of York
- Council for Disabled Children, National Children's Bureau
- HemiHelp
- Triangle
- Medicines for Children Research Network

- Development and Disability Research Group, University of Newcastle
- Academic Department of Rehabilitation Medicine, University of Leeds
- National Perinatal Epidemiology Unit, University of Oxford
- Health Service Research Unit, University of Oxford
- Department of Education, Roehampton University, London
- Complementary Medicine, Peninsula Medical School

Publicity

The work of the Cerebra Research Unit at Peninsula Medical School has been featured on local radio stations and in local newspapers. Extracts of these are available on our website www.pcmd.ac.uk/cerebra

- BBC Radio Devon
- Heart FM
- Exeter Express & Echo

Academic Publications

Wyatt K, Edwards V, Franck L, Britten N, Creanor S, Maddick A, Logan S. Cranial osteopathy for children with cerebral palsy: a randomised controlled trial Archives of Disease in Childhood. In press.

Edwards V, **Wyatt K**, Logan S, Britten N, Consulting parents about the design of a randomised controlled trial of osteopathy for children with cerebral palsy, Health Expectations. In press.

Morris, C, Bowers, R, Ross, K, Stevens, P, Phillips, D. Orthotic management of cerebral palsy: recommendations from a consensus conference. NeuroRehabilitation. In press.

Morris, C, Doll, H, Davies, N, Wainwright, A, Theologis, T, Fitzpatrick, R. (2010) The Oxford ankle foot questionnaire for children: review of development & potential applications. Prosthetics and Orthotics International 34(3):238-244.

Morris, C. Majnemer, A. Activity and participation: An overview of generic measures. In: Majnemer, A. (Ed) Measures of outcomes for children and youth with developmental disabilities. Clinics in Developmental Medicine No. Mac Keith Press: London. In press

Rosenbaum, P, Gorter, JW, Palisano, R, **Morris, C**. (2010) The relationship of cerebral palsy subtype and functional motor impairment: a population-based study. Developmental Medicine and Child Neurology 52(7): 682–683.

Jenkinson C, Dawson J, **Morris C**. Aspects of methodology. In Jenkinson C, Peters M, Bromberg M. (Eds) Quality of Life Measurement in Neurodegenerative and Related Conditions. Cambridge: Cambridge University. In Press

Langley K, Fowler T, **Ford T**, Thapar A, van De Bree M, Harold G, Owen MJ, O'Donovan MC & Thapar A. (2010.) Adolescent clinical outcomes for young people with attention deficit hyperactivity disorder. British Journal of Psychiatry 196, 235-240.

Russell G, **Ford TJ**, Steer C & Golding J. (2010). Identification of children with children with the same level of impairment as children on the autistic spectrum and analysis of their service use. Journal of Child Psychology and Psychiatry, 51, 643-651.

Sayal K, **Ford T** & Goodman R. (2010). Trends in recognition and service use for Attention Deficit / Hyperactivity Disorder in Britain. Psychiatric Services 61, 803-811.

Shilling, V. Wiliamson P.R. Hickey, H. Sowden, E. Beresford, M.W. Smyth, R.L. Young, B. Communication about children's clinical trials as observed and experienced: qualitative study of parents and practitioners. PLoS ONE (accepted)

Shilling, V. Wiliamson P.R. Hickey, H. Sowden, E. Smyth, R.L. Young, B. Processes in recruitment to randomised controlled trials (RCTs) of medicines for children (RECRUIT): a qualitative study. Health Technol Assess (in press)

Major Presentations

Logan, S. (2010) Getting EBM teaching and learning into the system. PGIMER: How to Teach Evidence Based Medicine Course. Nov. 2010 Chandigarh, India.

Logan, S. (2010) Childhood disability research in Devon and the UK (update October 2010). Cerebra Annual Research Conference, October 2010, London.

Logan, S. (2010) Evidence-based screening during the first five years of life. European Society for Social Pediatrics & Child Health. Turkey.

Logan, S. [Chair] (2010) Why Don't Children Take their Medicines? NIHR Medicines for Children Research Network (MCRN). May 2010, London.

Morris, C. Shilling, V. Antonio, K. Hart, B. (2010) The Cerebra Research Unit; A partnership in childhood disability research. INVOLVE Conference 2010 Public involvement in research: innovation and impact.

Morris, C. (2010) A year in the life of a new childhood disability research unit: building a partnership with families and service providers. Royal Children's Hospital, Melbourne, Australia.

Morris C, Edwards V. (2010) What's it like being in hospital? A synthesis of qualitative studies about disabled children's experience as in-patients. Developmental Medicine and Child Neurology 52 S4:67

Morris, C. (2010) Recent developments in healthcare for persons with cerebral palsy: ISPO 2009 Consensus Conference. Australian National Member Society of the International Society for Prosthetics and Orthotics: Advanced Instructional Course on Management of Cerebral Palsy. Melbourne, Australia.

Morris, C. (2010) Orthotic management of cerebral palsy: understanding the effect of orthotic intervention. Australian National Member Society of the International Society for Prosthetics and Orthotics: Advanced Instructional Course on Management of Cerebral Palsy. Melbourne, Australia.

Morris C, Doll H, Theologis T, Wainwright A, Davis N, Churchman D, Willet K, Fitzpatrick R (2010) Overview of the development phases of the oxford ankle foot questionnaire for children. Value Health 13(3):A184-A184

Davies N, Morris C, Wainwright A, Liabo K, Wright P, Fitzpatrick R, Doll H, Willett K, Theologis T. (2010) Evaluating health services for foot and ankle problems in children: development of the Oxford ankle foot questionnaire for children. Journal of Children's Orthopaedics 4(S1):39.

Shilling, V. Hickey, H. Smyth, R. Sowden, E. Williamson, P. Young, B. (2010) Communication about clinical trials as observed and experienced: the views of parents and practitioners. Royal College of Paediatrics and Child Health Annual Meeting, Warwick University, UK

Editorial, Peer Reviews and Committee Work

Editorial work in 2010

Stuart Logan is the Editor in Chief for *Child: Care, Health and Development*.

Chris Morris is an Associate Editor and Editorial Board Member for *Developmental Medicine and Child Neurology*, and a Trustee of *Mac Keith Press*. Chris is also on the Editorial Board for *Physical & Occupational Therapy in Pediatrics*.

Peer reviews for other academic journals in 2010

- Prosthetics & Orthotics International (CM)
- Child: Care Health & Development (CM) (VS)
- PLoS ONE (VS)
- Pediatrics (VS)
- Trials (VS)
- Gait and Posture (CM)
- Clinical Rehabilitation (CM)
- Archives of Disease in Childhood (CM)

Specialist Committees

Stuart Logan is 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 is 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 UoE Science Strategy Translational medicine, personalised healthcare and public health committee

Chris Morris serves on a number of committees

- Member of the Strategic Research Group, British Academy of Childhood Disability
- External expert advisor to the NICE Clinical Guideline Development Group for 'Spasticity in children and young people: the management of children and young people with a non-progressive brain injury.'
- Trustee for the Orthotic Education and Training Trust.
- Advisory Group for *4Child* Four Counties Database of Cerebral Palsy Hearing Loss and Vision Loss (*4Child* ceased in October 2010)

Drawings by David & Sophie, sent to us following the Family Fun Day at Paignton Zoo

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