ISSUE 2

PERSON CENTRED REHABILITATION TEAM

Health & Rehabilitation Research Centre, Division of Rehabilitation and Occupation Studies, AUT

AUGUST 2007

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1. UPDATE

Welcome to the 2nd edition of the PCR Team Newsletter providing an update on activities since May. Please contact us if you would like further information, or wish to give feedback. We intend to circulate these updates quarterly, so please let us know if there is anyone else you think may like to hear from us, or if you would rather be removed from the list. In the three months since our last news letter, key features include:

- ***Outputs***: In addition to papers listed overleaf, findings from the New Zealand WHOQoL focus groups were presented to the international team developing the new questionnaires in Tromso, Norway in June.
- ***Grants:*** We have been awarded $687,000 from the Health Research Council (HRC) for a study titled "*Improving health interventions and support for mothers experiencing disability".* This new project is due to start in October this year, and we would be very pleased to hear from anyone who would be interested in either taking part or hearing more about the planned project. The collaborative project team includes researchers at *AUT* (Kath McPherson, Debbie Payne, Ruth DeSousza & Lynne Giddings) with researchers from *UNITEC* (Dianne Roy), *University of Auckland* (Cynthia Farquhar) and the *Medical Research Institute for New Zealand* (Matire Harwood). Contact Kath McPherson for more information: Kathryn.Mcpherson@aut.ac.nz
- ***To watch out for:*** With our partners in the National Institute of Rehabilitation Research, we have set up a PhD scholarship fund. More news about how to contribute to and apply for this fund will be announced in a future newsletter.

2. FOCUS .....

In each update, we are planning to focus in a bit more depth on a particular project or researcher. This month we describe a project being run by Margaret Jones, an Occupational Therapist working with children who have had a traumatic brain injury. Margaret won funding for this project through the Health Research Council as part of a Disability Research Placement Programme Scholarship (2007-2009).

Community Participation for New Zealand Children who have had a Traumatic Brain Injury - Part I

Researcher: Margaret Jones (NZROT)
Supervisors: Professor Kathryn McPherson and Dr Clare Hocking

This study is the first part of a 3 part PhD study.

Traumatic brain injury (TBI) poses a significant social and emotional cost to New Zealand children and their families, as well as to the wider community in meeting children's rehabilitation needs as they move through childhood and adulthood (ACC, 2007). Studies overseas have shown that this type of injury has a marked impact on young children's' ongoing development, and results in families experiencing ongoing feelings of stress and burden (Ylvisaker et al., 2005).

The aim of the study is to describe the aspects of community participation that are important for NZ children with TBI, both in general, and as perceived by children, their parents/whanau, & teachers. The study also aims to describe the facilitators and barriers to successful participation.

This first phase employs Case Study Methodology to explore the perceptions of children and other key stakeholders, including parents and teachers. Data will be gathered at home and at school, and will include demographic details, semi-structured interviews, participant observations, photographs of objects significant to children's participation, and document review.

Recruitment of participants has begun through the Child Rehabilitation Service, Wilson Centre, Waitemata District Health Board.

The second phase of the project will explore suitable measures of participation for the group using criteria derived from Phase 1, and Phase 3 will use the measure to describe the children's participation.

Contact: Margaret Jones, **margjone@aut.ac.nz**

References:

Accident Compensation Corporation (2006). ACC injury statistics 2006 (1st ed.). Retrieved July 19, 2007, from http://www.acc.co.nz/about-acc/acc-injury-statistics-2006

Ylvisaker, M., Adelson, P. D., Braga, L. W., et al. (2005). Rehabilitation and ongoing support after pediatric TBI: Twenty years of progress. Journal of Head Trauma Rehabilitation, 20(1), 95-109.

3. QUIZ RESULTS

The Health & Rehabilitation Research Centre (HRRC) recently held an open day for staff at AUT where each group was able to demonstrate some of their research activities.

As part of the display put on by the PCR Team, we invited staff to complete a quiz telling us what they thought were the main issues for people with disabilities in relation to quality of life (*from the WHOQol study), and physical exercise ($^+$from the study investigating barriers to physical activity for people with stroke).

The results of the quiz are shown opposite, together with the answers which came out of the study focus groups. Similar perhaps, but definitely different.

	Staff assumptions	**What people with disabilities/chronic illness said**
What are the things that matter most to people with disabilities in terms of their **quality of life**? *	● Work/occupation ● Relationships ● Functional independence ● Community participation ● Transport/getting around ● Respect ● Effective support ● Quality accommodation ● Freedom ● Financial security	● Being able to communicate ● Being seen as a person and treated as individual ● Human connection – physical and emotional ● Getting around, access to things ● Sense of achievement ● Being able to do the things that really matter ● Being able to think ● The importance of having choice ● Dignity
What are **the top barriers** to physical activity for people with chronic illness? $^+$	●Support from others ●Transport/access ●Cost ●Lack of time ●Motivation ●Depression ●Poor self-efficacy ●Other people's attitudes ●Fatigue/Physical limitations ●Lack of information	●Family influence (restriction due to fear of injury etc) ●Fear of falling and lack of control ●Feelings of embarrassment ●Depression ●Lack of visible improvement with physical activity ●Confusion over information ●Told not to 'over do it', but no clarity over how much exercise this meant ●Role of activity in preventing deterioration was poorly understood ●Mental fatigue and exhaustion
What are **the top facilitators** to physical activity for people with chronic illness?$^+$	● Motivation and having purpose ● Success of recovery ● Positive feedback about exercise ● Support (Social support, encouraging environments, group facilities) ● Planning ● Previous fitness level and abilities	●Family influence (transportation, motivation, support) ●Feeling a sense of burden or reliance on others – motivated people to be active and independent ●Positive feelings from exercise ●Determination, attitude, positive outlook ●Motivation ●Self perception

4. 2007 SELECTED RESEARCH PUBLICATIONS

(FULL LIST PUBLISHED JULY & DECEMBER)

Kayes N, McPherson KM, Taylor D, Schluter PJ, Kolt *G. The Physical Activity and Disability Survey (PADS): reliability, validity and acceptability in people with multiple sclerosis. Clinical Rehabilitation 2007; In press.*

Kersten P, McPherson KM, Lattimer VA, George S, Breton A, and Ellis B. *Physiotherapy extended scope of practice - who is doing what and why?* Physiotherapy 2007; In press.

Lewis JS, Kersten P, McCabe C, McPherson KM, and Blake DR. *Body perception disturbance: A contribution to pain in Complex Regional Pain Syndrome.* Pain 2007; 1872-6623 (Electronic)

McPherson KM and Reid DA. *New roles in health care: what are the key questions?* Med J Aust 2007; 186(12): p. 614-5.

McPherson KM, Kersten P, McNaughton H, & Turner-Stokes L, *Background to neurorehabilitation.,* in Management of Neurological Disorders: an evidence-based approach. Candelise L, Editor. 2007, Blackwell Publishing: Edinburgh, UK.

McPherson KM and McLeod R, *Survivor perspectives on quality of care,* in A handbook of cancer survivorship, F. M., Editor. 2007, Springer: New York.

Moloczij, N., McPherson, K., Smith, J. & Kayes, N. *Help seeking at the time of stroke: Patients perspectives on their decisions. Health and Social Care in the Community* 2007 ; in press.

Taylor WJ and McPherson KM. *Using Rasch analysis to compare the psychometric properties of the Short Form 36 Physical Function score and the Health Assessment Questionnaire Disability Index in people with psoriatic arthritis and rheumatoid arthritis.* Arthritis Care & Research 2007; 7(5): p. 723-729.

Williams V, Bruton A, Ellis-Hill C, and McPherson K. *What really matters to patients living with chronic obstructive pulmonary disease?* An exploratory study. Chron Respir Dis 2007; 4(2): p. 77-85.

5. CONTACTS

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MEMBERS OF THE TEAM

From top left: Christine Cummins; Marta Lee; Greta Riley; Nicola Kayes; Debbie Payne; Margaret Jones; Natasha Moloczij; Joanna Fadyl; Kath McPherson

6. STAFF NEWS

Joanna Fadyl ***(front, 2nd from left)***

Jo joined the team in October 2006, working on a project evaluating two new interventions focused on goal setting in brain injury. She has also been involved in the WHOQol focus group study. Jo has a BSc in Psychology, and is studying for her Masters in Health Science at AUT.

The News: Jo has been awarded her first research grant from AUT to conduct a pilot project exploring factors influencing decision making about seeking paid employment amongst people recovering from spinal injury.