

Rehabilitation Research Review

Making Education Easy

Issue 9 - 2009

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Welcome to the ninth issue of Rehabilitation Research Review.

The first paper that I have highlighted for this issue provides us with evidence indicating that an individualised stroke self-management intervention can lead to a change in self-efficacy in individuals following a first-time stroke. Such findings are very encouraging for clinicians and patients alike.

The shortcomings of the New Zealand Disability Strategy and the implementation of Objective 11 are discussed in another paper, which nevertheless maintains that New Zealand's experience provides cautionary lessons that Indigenous peoples and governments in other countries can use in the development of culturally comprehensive disability policy.

I hope the issue is of interest and I welcome your comments and feedback.

Kind regards,

Kath McPherson

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Changing self-efficacy in individuals following a first time stroke: preliminary study of a novel self-management intervention

Authors: Jones F et al

Summary: These researchers developed an individually targeted intervention (stroke workbook) based on self-efficacy principles, incorporating sections to increase mastery, vicarious experience and feedback, designed for use with individuals disabled after first time stroke. The study recruited 10 stroke survivors who had a wide range of functional impairments, including mild language difficulties. There were 7 men and 3 women, with a mean age of 61.5 years. Length of time post-stroke was an average of 24.2 weeks following first stroke. Measures of self-efficacy included the Stroke Self-Efficacy Questionnaire, General Self-Efficacy Scale, Recovery Locus of Control Scale, Rivermead Mobility Index, Rivermead Activities of Daily Living Scale, Subjective Index of Physical and Social Outcome and the Hospital Anxiety and Depression Scale. During the 14-week study period, visual inspection of the data showed steady improvement for each participant on the majority of variables. A randomisation test indicated a statistically significant change in Stroke Self-Efficacy Questionnaire scores and Recovery Locus of Control Scale scores, following introduction of the intervention. Other target variables measuring functional activity, participation and mood showed mixed results that were not statistically significant.

Comment: It's a small study with a small population but... what is great about this paper is that it describes movement beyond yet another study detailing an important link between these characteristics to one that attempts to make a difference. There is more to be done of course, but it's good to see practical steps emerging from the long observed relationship between self-efficacy and other positive health outcomes.

Reference: *Clin Rehabil.* 2009;23(6):522-33.

<http://cre.sagepub.com/cgi/content/abstract/23/6/522>

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The ICF-CY and Goal Attainment Scaling: Benefits of their combined use for pediatric practice

Authors: McDougall J and Wright V

Summary: These researchers describe the International Classification of Functioning, Disability and Health-Child and Youth (ICF-CY) and Goal Attainment Scaling (GAS) as they pertain to paediatric rehabilitation. They explain how these tools can be used together to provide consistent clinical care that is family-centred, collaborative, well directed and accountable. Specifically, the ICF-CY offers a framework through which clients, families and service providers can together identify the areas of clients' needs. The use of GAS facilitates translation of clients' identified needs into distinct, measurable goals set collaboratively by clients, their families and service providers. The paper provides examples of integrated GAS goals set for the various components of the ICF-CY. It also discusses the utility of GAS as a measure of clinical outcomes for individual clients.

Comment: This paper looks at the two 'holy grails' at the moment – ICF and GAS. I've heard a number of service providers concerned about the comparative lack of research in the field so if you work with children – this is one to read.

Reference: *Disabil Rehabil.* 2009;31(16):1362-72.

<http://tinyurl.com/nju3fv>

***Disclaimer:** This publication is not intended as a replacement for regular medical education but to assist in the process. The reviews are a summarised interpretation of the published study and reflect the opinion of the writer rather than those of the research group or scientific journal. It is suggested readers review the full trial data before forming a final conclusion on its merits.*

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At a cultural crossroads: Lessons on culture and policy from the New Zealand DISABILITY STRATEGY

Authors: Wiley A

Summary: This study evaluated the implementation of Objective 11 of the New Zealand Disability Strategy: promote the participation of disabled Māori. A year-long qualitative outcome evaluation was conducted using semi-structured interviews with ministry officials, service provider organisations, Māori consumers with disabilities and caregivers to Māori consumers to answer two primary questions: (1) Does the NZDS provide a framework for effective, culturally appropriate policy for support services for Indigenous peoples with disabilities and (2) what lessons can be learned for future attempts to implement similar frameworks in other countries? Common themes included issues surrounding the effectiveness of the NZDS and the conflict between Indigenous worldviews framed within a mainstream service paradigm. Themes unique to specific interview groups covered areas such as accountability structure design, perceived levels of cultural competency, collaboration across sectors and information exchange.

Comment: Every now and again I think that the Disability Strategy is a useful reference point, but I'm somewhat surprised that the mismatch between what the strategy aims for and what it achieves does not cause more frequent and more noisy outrage. That said, this paper does suggest that some key targets have been addressed regarding culturally appropriate rehabilitation. There is further to go, however, if we are to address the persistent, and indeed in some cases expanding disparity in access to services / outcomes for Māori.

Reference: *Disabil Rehabil.* 2009;31(14):1205-14.

<http://www.informaworld.com/smp/content~content=a912819053~db=all~jumtype=rss>

Tales of the unexpected? Hidden resilience in poor households in Britain

Authors: Canvin K et al

Summary: This study examined what could be learned, from a health inequalities policy perspective, about resilience in low-income households if: the voices of people experiencing hardship were heard; resilience was conceptualised as a process, rather than as an individual trait; and the social context and conditions that helped or hindered that process of resilience were identified. Participants recounted how they coped with very difficult situations, their achievements in these circumstances, the transitions they had made in their lives and what had helped them. Transitions had been influenced by the presence of family and community support, respectful attitudes and behaviour of service providers, and the chances offered to them to engage in activities that bolstered self-esteem.

Comment: This is not actually a paper about rehabilitation but its relevance is in highlighting a move towards positive approaches identifying and building on peoples' resilience and strengths. It is no coincidence that 'family and community support, respectful attitudes and behaviour of service providers, and the chances to engage in activities that bolster self-esteem' are felt to be key to helping manage transitions. Poverty and disability are common partners and these suggestions seem to me a good starting point for supporting people using our services.

Reference: *Soc Sci Med.* 2009;69(2):238-45.

<http://tinyurl.com/l7nlqn>

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PREVENTION. CARE. RECOVERY.

Te Kaporeihana Āwhina Hunga Whara

Rehabilitation focused on returning to productive life

Assessing pain in children with intellectual difficulties

Authors: Breau LM and Burkitt C

Summary: These researchers discuss current methods available for assessing pain in children with intellectual and developmental disabilities. Self-report is one route for a small number of higher-functioning children, although observational measures have the most consistent evidence to support their use. The Noncommunicating Children's Pain Checklist--Postoperative Version is recommended for children and youth ≤ 18 years of age. It is recommended that other measures are consulted for specific applications. Changes in function and maladaptive behaviour should also be considered as possible reflections of pain. The article also recommends improving children's coping skills, as these may reduce the negative impact of pain.

Comment: Accessing the views of those who have difficulty expressing them is by definition, difficult but – clearly important. There are an increasing number of assessment schedules and measures around for doing this, including a pain measure for adults after stroke with communication difficulties (Jackson et al. Clin Med. 2006 Nov-Dec;6(6):580-5) and it's good to see this option for children.

Reference: *Pain Res Manag.* 2009;14(2):116-20.

<http://tinyurl.com/n7jh5z>

Comorbid chronic pain and depression: Who is at risk?

Authors: Miller LR and Cano A

Summary: Wayne State University researchers studied a representative community sample of 1,179 Michigan residents and found that the prevalence of chronic pain, defined as pain persisting for 6 months, was 21.9% percent. Approximately 35% of those with chronic pain also had depression, but depression was not associated with pain types or sites. In an analysis of several demographic factors, participants with chronic pain or comorbid pain and depression were more likely to be older, women, employed less than full-time, and have less education than persons without either condition. Depression tended to decrease with age while pain tended to increase. The study also showed that African Americans were more likely to have chronic pain with depression than Caucasians. Further analysis showed that racial differences were not attributable to possible socioeconomic factors but might be associated with differences in the use of pain coping strategies. Though income was not a significant risk factor for the study, the researchers indicated that occupational factors, such as physically demanding work and poor or no health insurance coverage, may account for the link between lower socioeconomic status and pain, and that financial strain and stress are closely linked with depression.

Comment: The inter-relationship between pain and depression is a complex one. It certainly seems unlikely that a simple causal relationship (i.e. that pain leads to depression) will explain matters. But given that a) such a high proportion of people with pain are likely to be depressed (35% in this study) and b) the presence of depression is likely to make it even more difficult for people to manage their pain – its presence should definitely be considered.

Reference: *J Pain.* 2009;10(6):619-27.

[http://www.jpain.org/article/S1526-5900\(09\)00008-X/abstract](http://www.jpain.org/article/S1526-5900(09)00008-X/abstract)



Independent commentary by Professor Kath McPherson, Professor of Rehabilitation (Laura Fergusson Chair) at the Health and Rehabilitation Research Centre, AUT University in Auckland.

Kath has been at AUT since 2004 and has been building a research, teaching and consultancy programme focused on improving interventions and outcomes for people experiencing disability.

Disability, capability, and special education: towards a capability-based theory

Authors: Reindal SM

Summary: This article addresses the critique and the rationale for advancing the capability approach as a viable, innovative alternative to existing perspectives in special education. The author notes that the capability approach is claimed to be more closely aligned with the understanding of disability as presented by the World Health Organisation's International Classification of Functioning, Disability and Health (ICF) than the social model, which has been promoted within disability studies. The article analyses the claims behind both approaches and proposes a refined version of the social model, the social-relational model, as a better framework for an understanding of special education and disability. The author argues that this understanding is more in line with the insights and contributions of the capability approach; the social-relational approach can incorporate both additionality for the individual child (the individualist approach to disability) and inclusivity of the system (a social approach to disability and inclusivity). The author concludes by suggesting that further investigations are needed in order to explore those capabilities that require strengthening in order to prevent disability understood as capability-poverty, both within school settings and society generally.

Comment: In the last issue of RRR, I mentioned capability theory as a potentially interesting approach to considering rehabilitation. Well, clearly I'm not the only person interested in exploring the approach – I have come across a number of other discussions around it, having had my interest piqued. This is an interesting paper exploring both the social model of disability and capability theory in relation to the ICF. I think we will hear more on these issues as people (including disabled people) identify and confront the limits to the social model.

Reference: *Eur J Spec Needs Educ.* 2009;24(2):155-68.

<http://tinyurl.com/I97ehI>

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PREVENTION. CARE. RECOVERY.

Te Kaporeihana Āwhina Hunga Whara

Committed to improving sustainable rehabilitation outcomes for all clients

An equality of condition framework for user involvement in mental health policy and planning: evidence from participatory action research

Authors: McDaid S

Summary: Discussions about user involvement in the mental health services throw up four major areas of concern: the capacity of service users to participate, their lack of participation skills, the need for a positive organisational culture and the need for arenas of participation. This article discusses the findings from a case study conducted amongst a small group of Irish mental health service users, to explore how they could more equally participate in advisory committees. The issues raised by participants demonstrated that barriers to equal participation in decision-making can arise from unequal cultural, physical, mental and economic resources, time, power, 'stigma' (prejudice) and lack of respect for their experiential knowledge and emotional expression. The article states that if inequalities are not addressed as part of the process, involvement itself can perpetuate injustice, reinforcing lack of respect, lack of power and lack of resources. It can also isolate service users, instead of providing opportunities for their mutual support and empowerment. According to this article, the evidence demonstrates the need for more broad-based research into the democratic disadvantage faced by people with a diagnosis of mental illness. It proposes that enabling equal user involvement in strategic decision-making requires going beyond creating arenas of participation, to ensuring that service users' structural disadvantages are addressed in order to enable their equal participation in the decisions that affect their lives.

Comment: Engaging 'service users' in 'service design' is getting more profile – and I think quite rightly. If we are wanting to map *what we do to what people need*, it seems a pretty fundamental foundation that has often been missing. Whilst this paper is targeted particularly towards mental health policy, I found the clear specification of power and resource differential between service users and delivery agents useful to consider. If we are to work in true partnership, co-opting one disabled person onto a working party or advisory group is clearly insufficient. Some real challenges exist and indeed, service users' ideas on how to address those challenges is undoubtedly part of the solution.

Reference: *Disabil Soc.* 2009; 24(4):461-74.

<http://tinyurl.com/npma27>

VINTAGE PAPER

Reflections on Dobermanns, poodles, and social rehabilitation for difficult-to-serve individuals with traumatic brain injury

Authors: Ylvisaker M and Feeney T

Summary: These researchers describe contributors to social and behavioural outcome of adolescents and young adults with chronic integration problems after traumatic brain injury (TBI). The article outlines and illustrates a contextualised, everyday routine-based approach to intervention, highlights the procedures that are critical to the success of this approach and illustrates the approach with case material. These researchers argue that adolescents and young adults with significant social reintegration problems after TBI deserve special attention because of their resistance to traditional rehabilitation efforts and because of the extraordinary social and economic costs associated with failure to help them achieve satisfying lives outside restrictive medical, rehabilitation, or penal settings. They consider that their approach to intervention and support applies to many members of other disability groups as well, as it has as its core the concept of positive, supported, everyday routines of action and interaction. It uses applied behavioural and counselling strategies intended to help individuals fashion a self-concept that is emotionally satisfying, offers intrinsic motivation, and is adequately consistent with both their pre-injury understanding of self and the new constraints and possibilities of post-injury life.

Comment: Mark Ylvisaker died on 24th May 2009.

This is the first paper I ever read by Mark (and Tim). Of course the title is itself clever and lures you in, but the actual paper not only lures you in, it keeps you coming back for more – well it has kept me coming back for years. I read the paper not long after finishing my PhD exploring the transition from hospital to home for people with significant brain injury (both traumatic and non-traumatic). From that study (and from an increasing number of other studies) it was apparent that many people found it very hard to live a life post injury that 'fitted' with their pre-injury idea of themselves. Mark and Tim eloquently describe a process of what they call 'binkification' as potentially contributing to that experience. OK - 'binkification' is a made-up term (a fabulous thing to do in an academic paper) but it makes sense when you read the paper I promise. One of the challenges to rehabilitation in this and many other Ylvisaker et al. papers, is that as professionals, we may create some of the difficulties people experience when we try to 'make people fit our rehabilitation processes' rather than 'making rehabilitation processes that fit the people we serve'. Mark's argument that one's sense of self plays an integral part in regaining a life after injury or illness is persuasive. His argument that working with someone in their rehabilitation means really working with 'them', not simply delivering a service or 'package' of care, is a challenge we could all do with every now and again I suspect, despite our protestations that of course – this is what we always do.

Mark Ylvisaker will be greatly missed – a fuller obituary is to be found at the NZRA website <http://www.rehabilitation.org.nz/content/column/obituary-mark-ylvisaker>

Reference: *Aphasiology.* 2000;14(4):407-31.

<http://tinyurl.com/lcrtam>



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