

Research Request – Impact of funding on self-reported functional capacity and perceived difficulty Vs actual functional performance

- Brief**
1. Search for evidence that self-reporting of functional capacity is influenced when funding for supports is involved i.e. that self-reporting of capacity may be an unreliable way to assess function when money for supports is dependent on the person's responses.
 2. Search for evidence that perceived difficulty does not equate to actual functional performance. We need some evidence that supports that a person could have severe difficulty doing something but still be able to do it independently – this is about the legal test for Access to the NDIS under s24.1(c)

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Please note:

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Delegates have access to a wide variety of comprehensive guidance material. If Delegates require further information on access or planning matters they are to call the TAPS line for advice.

The Research Team are unable to ensure that the information listed below provides an accurate & up-to-date snapshot of these matters

Question 1

Search for evidence that self-reporting of functional capacity is influenced when funding for supports is involved i.e. that self-reporting of capacity may be an unreliable way to assess function when money for supports is dependent on the person's responses.

Literature investigating whether self-reported functional capacity is impacted by the possibility for compensation/financial gain has primarily focused on claimants of injury compensation. Controversy has often surrounded injury compensation in relation to the motivations and personal characteristics of claimants [1]. These criticisms include suggestions that claimants were “sick” prior to the event, that claimants are malingering or exaggerating symptoms for financial or other secondary gain and that the system encourages people to “stay sick”[1]. Various meta-analyses and prospective observational studies have identified that participants who are receiving compensation routinely self-report greater pain and disability [2-5]. A meta-analysis of the association between compensation status and the experience and treatment of chronic pain found that patients who received compensation self-reported a greater experience of pain (Effect size = 0.60, $p < .0002$) and reduced treatment efficacy [2]. Similarly, Binder et al [4] performed a meta-analysis to evaluate the impact of financial incentives on disability, symptoms and objective findings after closed head injury. The authors found greater abnormality and disability in patients with financial incentives despite less severe injuries (ES = 0.47, $p < 0.001$). Both studies concluded that financial incentives have a powerful effect on perceived level of disability, however, they note that other factors need to be taken into consideration such as psychiatric history, evidence of malingering or health status.

Similar to Binder et al [4], a prospective observational study comparing long-term disability and health related quality of life outcomes of patients with lumbar disc herniation found that moderate or severe physical examination findings were less common in patients receiving workers' compensation (62% vs. 82%, $P 0.003$) [3]. Interestingly, those on workers compensation (less severe injury) were less likely to report improvements in either back or leg pain compared to those not receiving workers' compensation (53.7% vs. 72.2%, respectively, $P 0.001$) and that workers' compensation is associated with an increased likelihood of long-term disability (adjusted OR of 2.55, 95% CI 1.01_7.11). The authors conclude that because diagnosis critically depends on the symptoms reported by patients, the disability compensation process can skew pain perceptions and their functional impact.

An investigation into whether symptom exaggeration is a factor in complaints of cognitive dysfunction in patients with fibromyalgia (FM) who are claiming disability payments compared to those who aren't was performed by Gervais et al [5]. Results showed that a significant proportion of

the patients in the FM Disability group (at least 35%) demonstrated incomplete effort, a behaviour associated with over reporting and exaggeration of cognitive difficulties, at the time of assessment and would probably produce invalid results on ability tests. It should be noted no differences between demographic characteristics of both groups were reported. A pattern of higher symptom reporting consistently observed in the FM Disability group, which obtained significantly higher scores than the FM No Disability group on all SCL-90-R (self-report symptom checklist) scales. These results clearly indicate that tests of effort designed to detect incomplete effort and potential exaggeration of cognitive deficits have a role to play in the assessment of patients with FM, particularly where eligibility for medical disability benefits owing to claimed cognitive impairment is an issue.

This is a very complicated area in which it is hard to find definitive answers. The compensation process takes place in complex contexts that are different for each claimant, a variety of motivations and influences impact in different ways on each person. However, various studies have identified that the possibility for financial compensation can impact symptoms, subjective level of disability and possibly end up rewarding disability.

Table 1 below provides an overview of included studies.

Table 1

Title	Study design/question	Results	Conclusion
Rohling et al. (1995)	<p><u>Meta-analysis</u> of the association between compensation status and the experience and treatment of chronic pain</p> <p>Focus on workers compensation, Veterans Affairs, civil suit settlements and social security disability insurance</p>	<p>32 included studies, 3,802 pain patients and 3,849 controls (non-compensated)</p> <p>- Patients who received compensation self-reported a greater experience of pain (ES = 0.60, p <.0002)</p>	<p>Clear that receiving financial compensation is associated with a greater experience of pain and reduced treatment efficacy.</p> <p>The authors suggest that it is possible that patients that seek compensation have a more difficult time managing pain, however, included studies lacked characteristics on psychiatric history, evidence of malingering or health status.</p>
Atlas et al. (2006)	<p>Prospective, observational study.</p> <p>To compare long-term disability and health related quality of life outcomes of individuals receiving</p>	<p>172 receiving and 222 not receiving workers compensation</p> <p>-Groups had similar physical examination findings, but among patients with advanced imaging studies available for review, <u>moderate or severe findings were less common in</u></p>	<p>Measured differences in clinical characteristics, baseline features, or initial treatment received could not explain differences found.</p> <p>For patients with back pain, those who enter the workers' compensation system face an</p>

	<p>or not receiving workers' compensation at baseline evaluation</p> <p><u>Lumbar Disc Herniation</u></p>	<p><u>patients receiving workers' compensation</u> (62% vs. 82%, P 0.003).</p> <p>-Patients initially receiving workers' compensation were less likely to report that their predominant pain symptom, either back or leg pain, was improved compared to those not receiving workers' compensation at baseline (53.7% vs. 72.2%, respectively, P 0.001)</p> <p>-Workers' compensation claim is associated with an increased likelihood of long-term disability (adjusted OR of 2.55, 95% CI 1.01_ 7.11).</p>	<p>adversarial process that can end up rewarding disability.</p> <p>Because the diagnosis critically depends on the symptoms reported by patients, the disability compensation process can skew pain perceptions and their functional impact.</p>
Binder et al. (1996)	<p>Meta-analysis</p> <p>To evaluate the impact of financial incentives on disability, symptoms and objective findings after closed head injury</p>	<p>18 included studies, 2,353 participants</p> <p>The data showed more abnormality and disability in patients with financial incentives despite less severe injuries (ES = 0.47, p <0.001).</p>	<p>The effect of monetary incentives is more powerful for patients with mild head injury than those with moderate to severe injury.</p> <p>Authors suggest that the effect of financial incentives on symptoms and objective cognitive abnormalities be considered. A formal measure of motivation and effort should be conducted because the absence of these measures means clinicians are oblivious to malingering.</p>
Gervais et al. (2001).	<p>To examine whether symptom exaggeration is a factor in complaints of cognitive dysfunction using 2 new validated instruments in patients with fibromyalgia (FM).</p>	<p>A significant proportion of the patients in the FM Disability group (at least 35%) demonstrated incomplete effort, a behaviour associated with over reporting and exaggeration of cognitive difficulties, at the time of assessment and would probably produce invalid results on ability tests.</p> <p>No difference in demographic characteristics between groups (age, education, pain duration,</p>	<p>Our results clearly indicate that tests of effort designed to detect incomplete effort and potential exaggeration of cognitive deficits have a role to play in the assessment of patients with FM, particularly where eligibility for medical disability benefits owing to claimed cognitive impairment is an issue</p> <p>Any disability related assessment or other</p>

		<p>memory problem, how much pain, verbal scores)</p> <p>Only 2 patients with FM who were working and/or not claiming disability benefits scored below the cut-offs for exaggeration of memory difficulties</p> <p>Pattern of higher symptom reporting consistently observed in the FM Disability group, which obtained significantly higher scores than the FM No Disability and RA groups on all SCL-90-R (self-report symptom checklist) scales</p>	<p>investigation of the neuropsychological status of patients with FM that does not employ formal effort testing procedures to screen for exaggeration of memory or other cognitive problems runs the risk of drawing conclusions based on invalid test data or questionable self-reported symptoms and limitations.</p>
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Question 2

Search for evidence that perceived difficulty does not equate to actual functional performance. We need some evidence that supports that a person could have severe difficulty doing something but still be able to do it independently – this is about the legal test for Access to the NDIS under s24.1(c)

Literature in this area is scant, with most studies investigating the correlation between subjective questionnaires compared to objective measures of functional capacity rather than an individual's level of capacity to perform a task independently. A prospective cohort study [6] of participants with non-specific low back pain compared self-report measures (Roland Disability Questionnaire, Oswestry Disability Questionnaire, Quebec Back Pain Disability Questionnaire) to the Isernhagen Work Systems Functional Capacity Evaluation (FCE). The self-reported measures were consistent with moderate to severe disability. In contrast the results from the performance-based measures suggested that the participants should be able to work at a physical intensity level of moderate to heavy. This led to little to moderate observed correlation between the self-report and performance-based measures (Spearman rank correlations: Roland-FCE (-0.20), $p > 0.05$; Oswestry-FCE (-0.52), $p < 0.01$; Quebec-FCE (-0.50), $p < 0.01$). The authors concluded that self-report of ability to perform certain activities cannot be interchanged with the actual ability to perform that same activity, and that both performance-based and self-report measures of disability should be used in order to obtain a comprehensive picture of the disability. Similarly, Gross et al [7] and Goverover [8] found a moderate and non-significant correlation between subjective and objective functional measures respectively. Both studies investigated different populations (multiple sclerosis and low back injuries) and used different performance measures. However, both concluded that performance can be impacted by many factors and that reliance solely on self-report assessments of everyday activities may provide information that may not reflect actual performance in everyday life.

In the realm of mental health, Bowie et al [11] examined the convergence of schizophrenia patients' reports of their everyday functional status (using a self-report of real-world functional outcomes) and found that 24 (36%) of the patients were accurate estimators, 27 (40%) were over-estimators, and 16 (24%) were under-estimators. Patients who underestimated their functional skills had the highest level of cognitive ability, but also the highest level of self-rated depression. This study provided evidence that patients with Schizophrenia give internally consistent self-reports across different domains, but that self-reports were not associated with objective indices of functioning.

Self-efficacy has been investigated as a potential factor which influences the relationship between self-reported functional capacity and disability [9]. The Prosthesis Evaluation Questionnaire –

Mobility Scale (PEQ-MS), World Health Organization Disability Assessment Schedule 2.0 (WHODAS 2.0) and Self-Efficacy of Managing Chronic Disease (SEMCD) scale were delivered to patients with dysvascular transtibial amputation and found that the relationship between perceived functional capacity and self-reported disability is partially mediated by self-efficacy. This means that lower self-efficacy can impact on a person's perceived functional capacity.

The relationship between perceived and objective cognitive functioning in a large sample of MS patients has been investigated by Middleton et al [10]. Results showed that perceptions of global cognitive functioning during the course of their daily lives were unrelated ($r = -.11$) to objective performance, indicating that MS patients' metacognitive skills are well preserved. These results have important implications for clinical practice. A patient's complaints of cognitive difficulty are often the primary criterion upon which referral for neuropsychological assessment is based. Therefore, basing cognitive impact solely on subjective symptoms is not advisable and complaints of cognitive difficulty should be corroborated by reports of caregivers and by brief screening measures.

Self-report instruments may provide useful information about the client's view and perspective, such as issues related to cultural background, motivation, perceptions, and life choices. However, subjective measures do not always correlate with a patient's actual real-world functional capacity.

Table 2 below provides an overview of included studies.

Table 2

Title	Study design/question	Results	Conclusion
Reneman et al. (2002)	<p>Prospective cohort study</p> <p>To investigate the concurrent validity of two approaches to disability measurement in patients with chronic nonspecific low back pain (CLBP).</p> <p>self-report measures used were: the Roland Disability Questionnaire (Roland); the Oswestry Disability Questionnaire</p>	<p>Study compared the results of self-reported and performance-based measures of disability in 64 <u>consecutive patients</u> with CLBP.</p> <p>The mean scores from the self-report measure are as follows: Roland 13.5 (scale 0–24), Oswestry 28.2 (scale 0–100), and Quebec 37.8 (scale 0–100) consistent with moderate to severe disability. In contrast the results from the performance-based measures suggested that the subjects should be able to work at a physical</p>	<p>Self-report of ability to perform certain activities cannot be interchanged with the actual ability to perform that same activity.</p> <p>A performance measure should be used to measure "a person's ability to perform an activity," whereas a questionnaire should be used to measure "a person's self-reported</p>

	(Oswestry); and the Quebec Back Pain Disability Questionnaire (Quebec). Performance was measured using the Isernhagen Work Systems Functional Capacity Evaluation (FCE).	intensity level of moderate to heavy. Little to moderate correlation was observed between the self-report and performance-based measures (Spearman rank correlations: Roland-FCE (-0.20), $p > 0:05$; Oswestry-FCE (-0.52), $p < 0:01$; Quebec-FCE (-0.50), $p < 0:01$).	ability to perform an activity.” Results are interpreted to suggest that both performance-based and self-report measures of disability should be used in order to obtain a comprehensive picture of the disability in patients with CLBP.
Gross et al. (2005)	To evaluate the association between performance on the Isernhagen Work System Functional Capacity Evaluation (IWS-FCE) and various clinical and psychosocial factors Cross-sectional study Pain Disability Index Pain Visual Analog Scale Isernhagen Work System Functional Capacity Evaluation Floor to Waist Lift	170 workers compensation claimants undergoing functional capacity evaluations for low back injuries. Self-reported ratings of perceived disability on the PDI and pain intensity using a VAS were moderately associated with both performance-based functional indicators, weight lifted on the floor-to-waist lift tasks and the number of failed FCE tasks.	Performance on the FCE appears to be influenced by both physical factors and self-perceptions of disability and pain. Functional capacity evaluations should be considered behavioural tests influenced by multiple factors, including physical ability, beliefs, and perceptions.
Goverover et al. (2005)	To investigate the relation between subjective and objective performance-based measures of functional status in persons with multiple sclerosis (MS), and to compare their performance with healthy controls -The Executive Function Performance Test (EFPT) -Functional Assessment of Multiple Sclerosis (FAMS)	All correlations between subjective and objective functional measures were non-significant Scores on the FBP (but not the FAMS) were significantly associated with EFPT performance. Thus, the current results support and extend previous findings that depressive symptomatology may distort patients' perception of their instrumental ADLs and Quality of Life	Reliance solely on self-report assessments of everyday activities may provide information that may not reflect actual performance in everyday life

	-Functional Behaviour Profile (FBP).		
Miller et al. (2018)	<p>Describe the relationships between perceived functional capacity, self-efficacy, and disability and 2) identify if self-efficacy mediates the relationship between self-reported functional capacity and disability after dysvascular transtibial amputation.</p> <p>Data taken from a baseline RCT</p> <p>-Prosthesis Evaluation Questionnaire – Mobility Scale (PEQ-MS). -World Health Organization Disability Assessment Schedule 2.0 (WHODAS 2.0) -Self-Efficacy of Managing Chronic Disease (SEMCD) scale</p>	<p>38 men with dysvascular transtibial amputation.</p> <p>The relationship between self-reported functional capacity and disability is partially mediated by self-efficacy. Relationships between WHODAS 2.0 and PEQ-MS ($r = -0.61$), WHODAS 2.0 and SEMCD ($r = -0.51$), and PEQ-MS and SEMCD ($r = 0.44$) were significant ($P < .01$). Controlling for SEMCD ($P = .04$), the relationship between PEQ-MS and WHODAS 2.0 remained significant ($P < .01$).</p>	Evidence that the relationship between perceived functional capacity and self-reported disability is partially mediated by self-efficacy
Middleton et al. (2006)	<p>(a) examining the relationship between perceived and objective cognitive functioning in a large sample of MS patients; (b) expand the construct of perceived cognitive functioning to include both perceptions of <i>global cognitive functioning</i> and perceptions of <i>performance on specific cognitive tasks</i>; (c) identifying variables that contribute to the discrepancy between perceived and objective cognitive functioning in MS patients.</p>	<p>221 patients with MS and 31 controls</p> <p>perceptions of global cognitive functioning during the course of their daily lives were unrelated ($r = -.11$) to objective performance on the array of tasks composing the cognitive battery results of the present study indicate that MS patients' metacognitive skills are well preserved</p>	These results add to the understanding of patients' expressed concerns regarding their cognitive functioning in the wake of multiple sclerosis, suggesting that such concerns should be interpreted with caution by clinicians.

	<p>-Cognitive Battery of tests</p> <p>-Perceived Cognitive Functioning</p> <p>-Depression, Anxiety, Fatigue</p>		
Bowie et al. (2007)	<p>To examine the convergence of schizophrenia patients' reports of their everyday functional status (using a self-report of real-world functional outcomes) with the reports of their case managers and to identify the correlates of the level of accuracy of these reports.</p> <p>Specific Levels of Functioning (SLOF)</p> <p>Functional capacity assessments</p> <p>Performance-based skills assessment</p> <p>Social Skills Performance Assessment (SSPA)</p> <p>Beck depression inventory</p> <p>Self-rated Quality of Life Scale</p>	<p>24 (36%) of the patients were accurate estimators, 27 (40%) were over-estimators, and 16 (24%) were under-estimators.</p> <p>The correlations of patients' self-reported Work skills with depression were greater in magnitude than case manager ratings.</p> <p>Patients who underestimated their functional skills had the highest level of cognitive ability, but also the highest level of self-rated depression.</p> <p>Across the functional skill domains, case manager ratings were more highly correlated with objective measures such as cognitive performance, UPSA performance, and SSPA performance than were self-appraisals. Patients' self-ratings tended to be correlated with measures of subjective outcomes, such as depression and quality of life, but less so with the objective measures of functional skills and cognition.</p>	<p>Schizophrenia patients give internally consistent self-reports across different domains, but that these self-reports were not associated with objective indices of functioning</p>

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