

**Keywords: ICF, Core sets, Occupational Therapy**

**Published reference:**

McIntyre A, Tempest S (2007) Disease specific core sets of the International Classification of Functioning, Disability and Health (ICF): two steps forward and one step back? *Disability and Rehabilitation* 29:18 pp 1475-1479

## **Abstract**

The International Classification of Functioning, Disability and Health (ICF) is advocated as a biopsychosocial framework and classification and has been received favourably by occupational therapists, disability rights organisations and proponents of the social model of disability. The success of the ICF largely depends on its uptake in practice and it is considered unwieldy in its full format. Therefore, to make the ICF user friendly, the World Health Organisation (WHO) have condensed the original format and developed core sets, some of which are disease specific. The authors use the ICF Core Set for stroke as an example to debate if by reverting to classification according to disease, the ICF is at risk of taking two steps forward, one step back in its holistic portrayal of health.

## **Introduction**

The International classification of Functioning, Disability and Health (ICF) (WHO 2001) has global acceptance as a model of health and functioning by many agencies, professions and more importantly by people with disability. The occupational therapy profession has embraced the ICF as a means to consider the interplay between an individual, their environment and their occupation and also to communicate this beyond the profession. The interactive nature of the ICF framework allows the complexities and dynamics of participation opportunities and restrictions for an individual to be communicated (McLaughlan Gray 2001). This consideration of the “lived experience” of an individual within their own context complements the concepts of client centered practice and occupational performance and is therefore compatible with occupational therapy philosophy and beliefs (Brintnell 2002, College of Occupational Therapists 2002, Law and Baum 2001 p 9-10). Occupational therapists are increasingly working in interagency and interdisciplinary teams within community health and social care settings. They therefore need models and frameworks that reflect and complement such practice, whilst being compatible with occupational therapy models (Baum 2002, College of Occupational Therapists 2004).

Classification of disability started in the 1960's as an attempt to ensure better understanding of the outcomes of disease and provide services for people with disability. Early models of disability such as the Nagi model (Nagi 1976) and the International classification of Impairments, Disabilities and Handicaps (ICIDH) (WHO

1980) did not involve people with disabilities in their development. The ICDH (WHO 1980) for example, was strongly criticised by the International Disability Rights Movement for its strong medical focus, concentrating on the consequences of diseases in a hierarchical way (Hurst 2000, 2003). However it must be appreciated that development of classifications beyond diagnosis were a well meaning attempt to make sense and increase awareness of the consequences of disease upon individuals. As the ICDH was published at the same time as the International Disability Rights Movement began, it could be said that this classification was superseded by a global shift in attitude to disability before it had even gained momentum.

The ICF as the successor to the ICDH has been considered more acceptable to the International Disability Rights Movement due to the interactive and dynamic framework of the ICF, along with the introduction of contextual factors. The contextual factors and the stronger consideration of participation issues within the ICF meant that the emphasis has changed from a purely medical to a bio-psycho-social focus where the need for social change to solve disablement could be easily communicated (Hurst 2003, Schneidert et al 2003). However the ICF is still criticised today for the desire to classify individuals according to disability (Barile 2001, Pfeiffer 2000, Whalley Hammell 2004).

## **The Debate**

### **Development of the ICF Core sets**

A major rationale for the ICF was to act as an international standard to measure the outcomes of health related states (WHO 2001), however Stucki et al (2002a) identified

that the ICF in its original form (with more than 1400 categories) was too lengthy and impractical for everyday usage. Therefore it was advocated that short lists (or core sets) of relevant concepts should be drawn up for specific health conditions and health care situations to encourage the use of relevant outcome measures and interventions. Brief and comprehensive core sets were devised for each of 12 chosen diseases. The brief core set consists of a minimum number of concepts and is recommended for research purposes with the comprehensive core set being advocated for clinical practice (Stucki & Grimby 2004). Once the pilot studies are completed it will be of interest to see if these two versions are used as recommended by the developers.

It is argued that it is helpful to develop specific core sets as this approach is congruent with existing condition and site specific outcome measures (Grill et al 2005, Stucki et al 2002b). However it could be considered that core sets that are classified according to specific diseases (for example stroke), are entrenched within a medical model once again. It was determined that core sets should be devised for medical management of specific diseases as many physicians still see disability as the consequence of a disease process or health condition (Stucki et al 2002b). However, it was the fact that the ICF has shifted away from this medically biased view, that has made it more attractive and help it to gain additional and international support (Hurst 2000).

### **Development of core set for stroke**

In the initial development, it was felt that the disease specific core sets would tend to focus on domains within body functions and activity and participation (Stucki et al 2000b). In reality, when the ICF disease specific core sets were published, consensus

agreement had identified that approximately 20% of core set content are environmental factors (Weigl et al 2004). For example, 25% of concepts listed in the core set for Stroke are environmental factors (Geyh et al 2004). This suggests a strategic change that as holistic occupational therapists, we must welcome and support.

There are other reasons to support the development of disease specific core sets. Whilst functioning and health may not be solely the consequence of a stroke, for example, there is a clear association that may justify a condition specific core set. Bury (2000) warns us not to move too far away from acknowledging that impairments as a result of a specific health condition such as stroke, do impede functioning.

The development of the core sets for stroke was partly in response to disease specific clinical guidelines e.g. the Intercollegiate Stroke Working Party guidelines (Geyh et al 2004). Thirty-nine experts from twelve different countries were involved in the consensus conference to develop these core sets. However, there were no representatives from occupational therapists, service users, carers, or the Disability Rights Movement and out of the thirty-nine experts, twenty-five were doctors, 7 were physiotherapists, 2 psychologists, 1 social worker and 1 sociologist (Geyh et al 2004). Worryingly, evidence from site specific core set development also identifies that the membership of the consensus process strongly determine the content of core sets, as in one instance some concepts relevant to practice were only identified by therapists and not by other members of the consensus group (Grill et al 2005).

Nonetheless, the development of the ICF itself has involved people from a variety of backgrounds and is based on consensus and discussion. Disability movements, health workers, social care workers and service users have all been part of the developments at varied levels (Haglund and Henriksson 2005). Therefore, there is further work required with the core set development and piloting to mirror the same amount of collaboration in the original development of the main ICF framework and classification.

### **Use of core sets in practice**

Use of the ICF within the multidisciplinary team has already been documented as being beneficial to clarify team roles and facilitate clinical reasoning (Tempest and McIntyre 2006). Therefore the introduction of the ICF core sets can further guide multidisciplinary teams and individual practitioners in service delivery. The disease specific core sets also allow for quick description of how a client with a specific health condition presents, as they have been developed using empirical studies linking diagnosis and aetiology with specific areas of functional difficulty (Ustün et al 2003). This implies the disease specific core sets are necessary to facilitate the use of the theoretical biopsychosocial framework and classification in practice. However, if as occupational therapists, we are working with people with co-morbid conditions and multiple pathologies, we would need to use more than one disease specific core set to ensure we had considered all the possible factors impacting on occupational performance. This seems unwieldy and it is difficult to see how this could be user friendly or client centred in practice. It also undermines the original rationale for the development of core sets.

Another function of the core sets is to facilitate the mapping of existing outcome measures to the components of the ICF. This has proved a difficult challenge to date, as many of the stroke specific outcome measures cut across a variety of domains (Salter et al 2005). In addition some tools measure different factors. For example, the Functional Independence Measure (FIM) measures assistance required, whereas the ICF considers individual's capacity and performance (Stucki et al 2002a). In order to enhance the uptake of the ICF in practice, further research needs to be carried out to map its component parts to existing measures, whilst not losing the holistic nature of the ICF (Perenboom and Chorus 2003).

Any framework and classification is only as good as it is used within practice. Hurst (2000) believes there is a risk that medical professions will only use the components that they are comfortable with i.e. health condition and body functions and structures. Therefore, core sets that focus specifically on the disease within the title may be reducing a person to their disease label and the concerns from Hurst may be valid. Conversely, inclusion of environmental factors within the core set may encourage consideration of these concepts by professions and agencies that traditionally would not do so.

The ICF is still under development and requires careful and balanced scrutiny to avoid it being sidelined or misinterpreted by individual groups. There is also a risk that practitioners may interpret the ICF in different ways as domains of the core concepts and principles require further development and definition (Imrie 2004).

## **The ICF core sets and occupational therapy**

The main challenge for occupational therapists using the ICF and the core sets is the lack of recognition of the personal factors and subjective dimension to health and disablement (Ueda and Okaqa 2003). However within the core set for stroke there is a section for user reported issues across the domains (Stucki and Grimby 2004), therefore allowing the demonstration of personal factors of the individual to some degree, and increase the client-centeredness of the classification.

A subjective dimension has been suggested to encapsulate factors including satisfaction, values and attitudes to life (Ueda and Okaqa 2003). Occupational therapy models and subsequent assessment tools (e.g. the Canadian model of Occupational Performance and Canadian Occupational Performance Measure) acknowledge the importance of satisfaction. This is not a unique idea within health and social care. Therefore, the ICF and any subsequent developments including the core sets are at risk of missing the opportunity of truly reflecting the holistic nature of health and disability.

Nonetheless, the ICF resonates with essential occupational therapy and occupational science principles (McLaughlin Gray 2001) as emphasis is placed on activity and participation and their significance in the maintenance of health. Therefore, even in the disease specific core set versions, occupational therapists are still able to demonstrate the complex nature of disability; i.e. that it is more than the remediation of impairments.

## **Conclusion**

### **Two steps forward?**

For the first time, there is an internationally recognised and inter-professional framework that allows us to demonstrate that disability is a result of the interaction between the environment, the individual and their health state. The disease specific core sets still allow us to document this holistic and complex interplay. The ICF core sets for Stroke provides an example of this as it contains a large number of environmental factors which demonstrates the importance of the surroundings and life situations on health and rehabilitation programmes (Geyh et al 2004).

Disease specific core sets can facilitate clinical reasoning and appropriate choice of outcome measures, therefore enhancing the use of evidence based practice in occupational therapy. By being more “user-friendly” the disease specific core sets could help raise the profile and impact of specific diseases on occupational performance for a particular client group to a larger audience.

### **One Step back?**

By reverting to disease and site specific core sets the ICF is in danger of reverting to a medical model of disability, with disability being seen as the consequence of disease, rather than being a means of conveying social disablement for both groups and individuals alike. Because of this it may lose its support by the International Disability Rights Movement. The core set development has been influenced by the skill mix and

experiences of consensus groups, therefore minimal therapy involvement and no user involvement in disease core set development is a missed opportunity.

Rather than encouraging clinical reasoning and client centred practice the use of the core sets (especially inappropriate use of the brief core sets) could stifle reasoning and encourage prescriptive practice. Currently the core sets are all health care based, whereas occupational therapists are increasingly working outside of the health care system, and are encouraged to use the ICF because of it's relevance to interagency working. The World Health Organisation prides itself on developing a global classification and framework; however how relevant will core sets be in developing countries where there is no luxury of disease specific services?

### **The next steps?**

It may be too early to conclude that the introduction of the disease specific core sets are two steps forward or one step back, given that these are still in the pilot stage of development. There is further work to do to enable the ICF to truly reflect the multifactorial nature of disability. Further adaptation to classify personal factors is essential to acknowledge the importance of the individual's perspective (Wade 2003). Therefore, at present some commentators have stated that the ICF should be used as an adjunct to occupational therapy terminology as it is currently insufficient as our professional language (Haglund and Henriksson 2005). The ICF could be an opportunity for occupational therapists to use the global language to describe our own area of expertise to a larger community (McLaughlin Gray 2001). The core sets could be the practical application to allow us to achieve this goal, with occupational therapists also

using the common language of the ICF to raise awareness of the holistic nature of disablement in relation to specific diseases.

Therefore, when exploring the relationship between the ICF and occupational therapy, maybe our greatest role is to contribute to the critical analysis and further developments of the framework, classification and core sets (Hemmingsson and Jonsson 2005). Rather than allowing the development of the core sets to be backward step, occupational therapists can seize this opportunity to influence the direction of the next steps in ICF development.

## **Acknowledgements**

The authors would like to thank the members of the Post-Graduate Seminar Group, School of Health Sciences and Social Care, Brunel University for their comments and feedback.

## References

Barile, M. (2001). Globalisation and ICF eugenics: Historical coincidence or connection? The more things change the more they stay the same. *Disability Studies Quarterly*, 23(2), 208-223.

Baum, C.M. (2002). Creating partnerships: Constructing our future. *Australian Journal of Occupational Therapy*, 49(2), 58-62

Brintnell, S. (2002). WHO – International Classification of Functioning, Disability and Health – development and Canadian content. *WFOT Bulletin*, 45(5), 33-37.

Bury, M. (2000). A comment on the ICIDH2. *Disability & Society*, 15(7), 1073-1077.

College of Occupational Therapists, (2002). *From Interface to Integration: A strategy for modernising Occupational Therapy services in local health and social care communities*. London, College of Occupational Therapists: Author

College of Occupational Therapists, (2004). *Guidance on the use of the International Classification of Functioning, Disability and Health (ICF) and the Ottawa Charter for Health Promotion in Occupational Therapy services*. London, College of Occupational Therapists: Author

Geyh S, Cieza A, Schouten J, Dickson H, Dommelt P, Omar Z, Kostanjsek N, Ring H, Stucki G, (2004). *ICF Core Sets for Stroke*. *Journal of Rehabilitation Medicine – Supplement*, (44) 135-141.

Grill E, Ewert T, Chatterji S, Kostanjsek N, Stucki G, (2005). ICF Core Sets development for the acute hospital and early post-acute rehabilitation facilities. *Disability and Rehabilitation* 27 (7/8) 361-366.

Haglund, L., & Henriksson, C. (2003). Concepts in occupational therapy in relation to the ICF. *Occupational Therapy International*, 10(4), 253-268.

Hemmingsson, H., & Jonsson, H. (2005). An Occupational Perspective on the Concept of Participation in the International Classification of Functioning, Disability and Health- Some Critical Remarks. *American Journal of Occupational Therapy*, 59( 5), 569-576.

Hurst, R. (2000). To Revise or Not to Revise? *Disability & Society*, 15(7), 1083-1087.

Hurst, R. (2003). The International Disability Rights Movement and the ICF. *Disability & Rehabilitation*, 25(11/12), 572.

Imrie, R. (2004). Demystifying disability: a review of the International Classification of Functioning, Disability and Health. *Sociology of Health and Illness*, 26(3), 287-305.

Law, M., & Baum, C.M. (2001) Measurement in occupational therapy. In Law, M., Baum, C.M., Dunn, W., (Eds) Measuring occupational performance: Supporting best practice in occupational therapy. Thorofare, NJ. Slack Inc.

McLaughlin Gray, J. (2001). Discussion of the ICIDH-2 in Relation to Occupational Therapy and Occupational Science. *Scandinavian Journal of Occupational Therapy*, 8(1), 19-30.

Nagi, S.Z. (1976). An epidemiology of disability in the United States. *Milbank Memorial Fund Quarterly Health and Society*. 54(4) 439-467

Perenboom, R.J.M., & Chorus, A.M.J. (2003). Measuring participation according to the International Classification of Functioning, Disability and Health (ICF). *Disability and Rehabilitation* 25 (11/12) 577-587.

Pfeiffer, D., (2000). The Devils are in the Details: the ICIDH2 and the disability movement. *Disability & Society*, 15(7), 1079-1082.

Salter, K., Jutai, J.W., Teasell, R., Foley, N.C., Bitensky, J., Bayley, M., (2005). Issues for selection of outcome measures in stroke rehabilitation: ICF activity. *Disability and Rehabilitation*, 27(6), 315-340.

Schneidert, M., Hurst, R., Miller, J., Ustün, B. (2003). The role of environment in the International Classification of Functioning, Disability and Health (ICF). *Disability and Rehabilitation* 25 (11/12), 588-595.

Stucki, G., Ewert, T., Cieza, A. (2002a). Value and application of the ICF in rehabilitation medicine. *Disability and Rehabilitation*, 24(17), 932-938.

Stucki, G., Cieza, A., Ewert, T., Kostanjsek, N., Chatterji, S., Ustün, B., (2002b). Application of the International Classification of Functioning, Disability and Health (ICF) in clinical practice. *Disability and Rehabilitation* 24 (5), 281-282.

Stucki, G., & Grimby, G. (2004). Applying the ICF in medicine. *Journal of Rehabilitation Medicine (Supplement 44)* 5-6.

Tempest, S., & McIntyre, A., (2006). Using the ICF to clarify team roles and demonstrate clinical reasoning in stroke rehabilitation. *Disability and Rehabilitation* PrEview article, 1-5 DOI: 10.1080/09638280500276992

Ueda, S., & Okaqa, Y., (2003). The subjective dimension of functioning and disability: what is it and what is it for? *Disability and Rehabilitation* 25 (11/12) 596-601.

Ustün, T.B., Chatterji, S., Bickenbach, J., Kostanjsek, N., Schneider, M. (2003). The International Classification of Functioning, Disability and Health: a new tool for understanding disability and health. *Disability and Rehabilitation*, 25 (11/12), 565-571.

Wade, D. (2003). Editorial: New wine in old bottles: the WHO ICF as an explanatory model of human behaviour. *Clinical Rehabilitation* 17, 349-354.

Weigl, M., Cieza, A., Andersen, C., Kollerits, B., Amann, E., Stucki, G. (2004). Identification of relevant ICF categories in patients with chronic health conditions: A delphi exercise. *Journal of Rehabilitation Medicine (Supp 44)*, 12-21.

Whalley Hammell, K. (2004). Deviating from the norm: a skeptical interrogation of the classificatory practices of the ICF. *British Journal of Occupational Therapy* 67 (9), 408-411.

World Health Organisation (1980). International classification of impairments, disabilities and handicaps: a manual of classification relating to the consequences of disease. Geneva, WHO.

World Health Organisation (2001). International classification of functioning, disability and health. Geneva, WHO.