

Definition, data collection, disability and human rights – challenge and response

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The disability rights movement has an uneasy relationship with attempts to define disability, and with disability-related statistics. Persons with disability may experience the objectification and subjectification that is associated with some research of this kind as an abuse of their human rights. This tension was evident in the development of the ICF, and it remains the source of an ongoing struggle at the many interfaces between social and scientific research and disability rights. Although it could not be said that this issue has been resolved in the ultimate formulation of the ICF, it would be fair to say that the ICF, at the time, represented very substantial progress towards accommodating many of the concerns of the disability rights movement. However, the debate has been reignited in the formulation of a United Nations convention on disability and human rights where there are calls for the incorporation into international law of a new definition of disability based exclusively in the social model. This paper will explore the contours of this debate. It will be argued that whatever may be the tensions associated with defining disability, and with disability-related data collection, both are essential to the realisation of the human rights of persons with disability. The utility of the ICF, compared with proposals for a new definition of disability being promoted in the development of the convention, will be explored in light of this.