Systematic literature review on ICF from 2001 to 2009: its use, implementation and operationalisation

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Abstract

Purpose. To present a systematic literature review on the state of the art of the utilisation of the International Classification of Functioning, Disability and Health (ICF) since its release in 2001.

Method. The search was conducted through EMBASE, MEDLINE and PsychInfo covering the period between 2001 and December 2009. Papers were included if ICF was mentioned in title or abstract. Papers focusing on the ICF-CY and clinical research on children and youth only were excluded. Papers were assigned to six different groups covering the wide scenario of ICF application.

Results. A total of 672 papers, coming from 34 countries and 211 different journals, were included in the analysis. The majority of publications (30.8%) were conceptual papers or papers reporting clinical and rehabilitation studies (25.9%). One-third of the papers were published in 2008 and 2009.

Conclusions. The ICF contributed to the development of research on functioning and on disability in clinical, rehabilitation as well as in several other contexts, such as disability eligibility and employment. Diffusion of ICF research and use in a great variety of fields and scientific journals is a proof that a cultural change and a new conceptualisation of functioning and disability is happening.

Keywords: ICF, disability, functioning, health

Introduction

The International Classification of Functioning, Disability and Health (ICF) was formally endorsed by the World Health Organization in 2001 [1]. With this classification, the WHO intended to complement purely health condition-related information, provided by the International Classification of Diseases, 10th revision (ICD-10) [2], that is used to report mortality and morbidity data, with information on health and health-related outcomes in terms of functioning. Together, information on diagnosis plus information on functioning provides a broader picture of the health of individuals and populations. In fact, morbidity and mortality data, although useful for calculating life expectancy, are not sufficient to capture the overall health status of populations, since information about non-fatal health outcomes is becoming more and more relevant because of the so-called epidemiological transition – the shift from infectious diseases to increased prevalence of chronic non-communicable diseases. Since the early 1990s, WHO has also been involved in the Global Burden of Disease (GBD) study which, in its last update [3], reported the growing burden of non-communicable diseases, which now account for nearly half of the total GBD. In fact, almost 45% of the adult disease burden in low- and middle-income countries is now attributable to non-communicable diseases, and population ageing and changes in the distribution of risk factors have accelerated the non-communicable disease share of total disease burden in many developing countries. Therefore, collecting information on health state and...
health outcomes is of primary interest for all countries.

Unfortunately, data are not consistently gathered worldwide, and the same is true across Europe. As a report from Brunel University showed some years ago, there is no common measurement and definitions of disability across EU countries [4]. Different definitions of disability are relevant to different policies and the necessity of using a plurality of definitions to ensure relevance raises a problem of coherence in disability policy: people may be designated as disabled for one policy and not for another, and sometimes they encounter gaps in provision as a result.

If, on one side it is acceptable for policies to use different definitions of disability, the same is not acceptable for generating prevalence information: what is needed is a common framework for defining and describing disability and health. From the public health perspective, the usefulness of ICF goes beyond that of measuring population health: with ICF it is possible to identify those environmental factors that, having an impact on areas of participation such as education, transportation, or housing, may be determinants of health [5]. The ICF can plausibly claim to be a universal tool for classifying states of functioning since its underlying model reflects our best understanding of the complex phenomena of functioning and of disability, which is herein intended as a decrement of functioning of a person with a health condition in a hindering environment. Heretofore, disability has been construed as an all or nothing phenomenon: a distinct category to which an individual either belongs or not. The ICF presents functioning as a continuum, relevant to the lives of all people to different degrees and at different times in their lives: therefore, disability is not a category that applies only to a minority of people. Decrements in functioning may be the result of decrements in intrinsic capacity or problems with body functions or structures; or they can result from features of the person’s physical, human-built or social environment that lead to problems in performance over and above decrements in capacity. Very likely, decrements in functioning are the result of both processes, and viewing disability as an interaction between health condition and environmental factors is the key to how disability can be measured, and how interventions to reduce it can be evaluated.

To this point in time, considerable research has focussed on the implementation and utilisation of the ICF in several contexts: clinical, education, statistics, policy development and policy support. However, we lack precise information about the impact the ICF has had on research. In 2009, Jennifer Jelsma produced a literature survey on the utilisation of the ICF [6]. She concluded that the ICF has already made a major impact on the way in which data concerning disability are conceptualised, collected and processed. She stressed that the classification is being used across disciplines, health conditions, sectors and settings, and that utilisation in developing countries must be encouraged. Her paper, however, had major shortcomings as the papers she analysed represented a convenience sample and not all papers published up to and during the period between ICF’s release and the publication of the literature survey were included; therefore, the results of the paper should be carefully interpreted.

The aim of this article is to present an updated systematic literature review on the state of the art on the utilisation, operationalisation and interpretation of the ICF in a variety of settings since its release in 2001–2009. Specifically, we aim to evaluate the extent of implementation in different countries, in different years, and the extent to which, and the manner in which the ICF has been used in different settings and research fields.

Methods

The search was conducted using three electronic databases: EMBASE, MEDLINE and PsychInfo, covering the period between ICF release in 2001 and December 2009. The search strategies were developed for all the databases with slight differences between them due to the particularities of each database. In all the cases advanced search methods were used with different combinations of the following keywords: ‘ICF’, ‘international classification functioning disability health’, ‘classification functioning’, ‘classification disability’, ‘classification handicap’ and ‘classification health’.

In the selection process, papers were included if they met the following inclusion criteria: date of publication from 2001 till December 2009; ICF or International Classification of Functioning, Disability and Health mentioned in the title or abstract; the language of the abstract was English. Book chapters were excluded. Papers were excluded if they mentioned ICIDH or ICIDH-2 only, if they were on ICF-CY only or if they were on persons aged <18 years only. The rationale for these exclusions is that studies connected to the description of functioning and disability in children and youth with the ICF suffered from the lack of specific categories able to capture the specificity of the development in children and youth. In fact, limitations that in an adult can be seen as a problem, in children could be due to an incomplete stage of development, both for physiologic and pathologic reasons. The increase in children and youth competence, participation and independence should be measured with the ICF-CY, which contains several age-specific categories. Furthermore,
due to its recent publication (2007), we preferred to limit our selection to the adult population measured with ICF when considering papers reporting on clinical issues.

After the selection, all the abstracts were read independently by two researchers (MC, RQ) and assigned to one of the six categories, which were created and defined consulting the literature and using the expertise in the field of ICF.

The Conceptual papers category contains articles that discuss the concepts included and used in the ICF and that describe the biopsychosocial model of functioning and disability. Also in this group are articles that compare ICF with other classifications and the biopsychosocial model with other health and disability models, as well as comments and editorials relevant to the concepts of the ICF. The Development of ICF and of ICF related instruments category contains articles on the development of the ICF and ICF-related instruments and is divided into subcategories: ICF core sets, ICF-based instruments, ICF checklist, development of the personal factors classification for ICF, comments and editorials on the development of ICF. The third category Clinical contexts includes theoretical and practical discussions about ICF implementation or operationalisation in clinical sector, including rehabilitation, in specific health conditions or groups of health conditions. The category Non-clinical contexts includes articles about the ICF in areas other than clinical, such as education, labour, legislation, support to technology development and support to policy. It is divided in theoretical discussion on possible applications of the ICF in non-clinical contexts, and in practical applications of ICF as well as commentaries and editorials. This group was left quite broad because the choice of search databases kept the researchers aware of possible trends of findings. The fifth category is Linking papers which includes work of linking instruments to ICF categories. The sixth category of the systematic review includes articles in which the ICF is only mentioned.

When the information in an abstract was not sufficient in order to categorise the paper, then the full text of the papers was read. In case of disagreement between the two researchers (MC, RQ) the third researcher (AR) who was blind to the decisions of the first two, read and categorised. In case of further disagreement the final agreement was found through discussion among three researchers.

Results

The searches yielded 5086 citations and 670 were eligible in the analysis (Figure 1). They came from 34 countries and 211 different journals. Four authors appeared at least ten times as first authors: A. Cieza (15), G. Stucki (14), E. Grill (12) and M. Leonardi (11). Information on frequencies of publication year and prevalence of the categories is reported in Table I. The majority of publications were categorised as conceptual papers (30.8%) or papers reporting experiences from clinical contexts (25.9%). A decrease in publication rate was observed in 2008, accompanied by a growth in 2009, which was the year with the largest number of published papers.

Figure 2a reports the distribution of papers divided by country of origin, limiting the inclusion at the threshold of 10 papers; Figure 2b reports the distribution of papers divided by journal, limiting the inclusion at the threshold of 10 papers. The majority of selected publications are from the US (21.9%), Germany (14.7%) and The Netherlands (10%). Those publications included in Figure 2a constitute 91.4% of total publications. Disability and Rehabilitation and the Journal of Rehabilitation Medicine are the two journals in which the majority of papers were published (18.3% and 8.3%, respectively) and journals with at least 10 publications (Figure 2b) constitute 42.4% of total publications.

Considering the region of origin of papers according to WHO’s regional division of the world (Figure 3), it is evident that the majority of published research is from American and European countries.

Conceptual papers

A total of 206 papers were included in this category. The majority of these papers were published in
Disability and Rehabilitation (39 papers), Aphasiology (10 papers) and the International Journal of Speech Language Pathology (9 papers), but the vast majority of papers included in this category (126 out of 207) were from journals that had less than 10 papers included in this systematic review. Articles in this category group were mostly North-American (60 from the US and 26 from Canada, corresponding to 41.6% of the total) or European (75 from different EU countries, corresponding to 40.5% of the total). Descriptive statistics for subcategories are reported in Table II. Most of the papers have been published in 2005 and 2006.

The majority of papers from this group (171 out of 206) describe the concepts underlying the ICF classification [5,7–176]. Included here were articles that explained the biopsychosocial model of disability and functioning provided by the ICF, its components – body functions, body structures, activity and participation, environmental factors, barriers, facilitators, capacity, performance and qualifiers in general – but without the practical application or theoretical description of possible application or operationalisation.

A few papers [177–182] were theoretical papers focusing on the comparison between the ICF and other classifications or between the biopsychosocial...
and other health and disability models. Among these models were a nursing diagnosis classification, assistive technology models, the Disability Creation Process model and capability-based theory.

Some papers [183–209] were theoretical papers, included in supplement or special issues of different journals, reporting comments or editorial notes on the utilisation or implementation of the ICF.

Finally, two papers were included in the category ‘other’: Jelsma’s literature review [6] and a paper by Schuntermann on the experience with ICF in Germany [210].

**Development of ICF and of ICF related instruments**

A total of 103 papers were included in this category. The majority of these papers have been published in *Disability and Rehabilitation* (23 papers) and in the *Journal of Rehabilitation Medicine* (19 papers), and were mostly from Germany (41 papers). In general, European countries produced 76.7% and North America 15.5% of all the literature in this field. Descriptive statistics for subcategories are reported in Table III. Most of the papers were published in 2005 and 2009.

This category contains articles on the development of the ICF and ICF-related instruments and is divided into subcategories: ICF core sets, ICF-based instruments, ICF checklist, development of the personal factors classification for ICF, comments and editorials on the development of ICF.

A total of 54 papers [211–264] described the development and validation of disease-specific ICF core sets. Only some studies refer to a theoretical application of core sets in clinical contexts and were included in this category due to their relevance as operationalisation of these ICF-derived instruments. Some of the articles on core sets’ development for specific diseases or health conditions report list of ICF categories relevant for patients in specific settings, such as acute or post-acute settings. The majority of these papers were published between 2004 and 2005 and the number of them has decreased in the last years.

A total of 45 papers [265–308] were on the development of other ICF-based tools or on the validation of existing ICF-based tools, such as the WHO-DAS II. The majority of tools are for neurological and musculoskeletal diseases. The development of these tools is a new development that has received researchers’ attention principally from 2007 onwards. The measures developed or validated using the ICF classification covered areas for evaluation in the field of rehabilitation and clinical settings: functioning in general and physical functioning in specific as well as self-care and domestic life; distress; activities and participation with different health conditions; home and community participation; community reintegration; wheelchair outcomes; impact of disease; perception of disability; perceived impact of problem. Articles in which ICF was used for developing data collection protocols were also included in this category.

Four papers [309–312] were included in the category ‘other’. They focused on the codification of rehabilitation discharge information, data sets on spinal cord injury, a screening tool for risk factors in

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leprosy and a paper describing the utilisation of natural language processing for automated functional status information coding.

No papers were found to be included into the subcategories created to describe the development of the ICF checklist, the development of the ICF personal factors classification and comments or editorials.

Clinical contexts

A total of 173 papers were assigned to the category describing studies focussing on the description of disability of patients in clinical contexts. Disability and Rehabilitation contributed to this category with 27, the Journal of Rehabilitation Medicine with 13 and the Seminars in Speech and Language with 10 papers. The vast majority of clinical papers included in this category (101 out of 176), were found in journals that had less than 10 papers included in this systematic review. Most of papers were from the US and from the Netherlands (37 and 22, respectively). European countries produced 56.3% and North America 28.7% of all the literature in this field. Descriptive statistics for subcategories are reported in Table IV. Most of the papers were published in 2007 and 2009.

A total of 91 papers [313–404] focused on theoretical descriptions of how the ICF could be applied in clinical contexts.

A total of 32 papers [405–436] described practical applications of the ICF in clinical contexts but not in specific health conditions. They include the development of methodologies and application of tools for health professionals [409,413,425,428,434], and the description of disability of diverse groups of patients from different clinical settings [338,405,419, 423,427–431], and the identification of relevant categories of ICF [407,410,411,414,417,418,420, 422,424].

A total of 47 papers [437–483] described the use of ICF in the contexts of a specific health condition, the most frequent being stroke [439,469,470,472,473], multiple sclerosis [444,464,465,467,477], rheumatoid arthritis [440,443,449,454,474], traumatic brain injury [455,457,459] and HIV/AIDS [441,446,447].

Two papers [484,485] were comments on the spread of core sets and use of ICF framework for interpreting hand function outcomes. One paper [486] was included in the category ‘other’ reporting the validity and reliability of a questionnaire for the assessment of symptoms and functional limitations in low back pain.

Non-clinical contexts

A total of 62 papers dealt with theoretical descriptions or practical applications of the ICF in contexts other than health were included here. They are mostly concerned issues of disability eligibility, employment, education, ICF training. Disability and Rehabilitation contributed to this category with 16, the Journal of Rehabilitation Medicine with 5 and the International Journal of Rehabilitation Research with 4 papers. Approximately half of the papers included in this category (34 out of 62) were from those journals that had less than 10 publications included in this systematic review. The majority of papers were from the US and Italy (22 and 7, respectively). European countries produced 48.3% and American countries 40.3% of all the literature in this field. Descriptive statistics for subcategories are reported in Table V. Most of the papers were published between 2007 and 2009.

A total of 36 papers [487–522] reported theoretical descriptions of how the ICF could be applied in

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contexts different from health, such as disability eligibility, education, employment or statistics. Themes covered the theoretical reasoning on how ICF could be implemented in the national legal systems, issues on national data collection using the ICF, teaching of ICF in different disciplines and fields, ICF and services for people with disabilities and theoretical description focussing on the provision of assistive technologies in sectors like education and employment.

A total of 25 papers [523–547] described practical applications of the ICF in contexts such as disability eligibility, education, employment or statistics. There is a big diversity of themes and areas of ICF applications in this subcategory: education, legal issues, employment, data collection, participation in community life, urban planning and assistive technologies.

One paper [548] was included in the category ‘other’ and it explained the development of a medical English-Swedish dictionary.

No publications were found to be included in the categories referred to comments or editorials on the use of ICF in contexts such as disability eligibility, education, employment or statistics.

**Linking papers**

A total of 73 papers [549–621] were included in the category dedicated to papers describing the content of established assessment tools or research protocols by means of a linking exercise to ICF categories. The majority of these papers have been published in 2006–2007 (15 out of 73 each year) and in 2009 (18 out of 73). Disability and Rehabilitation contributed to this category with 11 and the Journal of Rehabilitation Medicine with 10 papers. The vast majority of papers included in this category (44 out of 73) were from those journals that had less than 10 papers included in this systematic review. Most of the papers were from Germany and Canada (24 and 10, respectively). In general, European countries produced 65.7% and American countries 24.6% of all the literature in this field.

Most of linking papers followed the structured process based on the ICF linking rules developed by Cieza et al. [598] and updated in 2005 [582]. The linking exercise was primarily used for content comparison and analysis of different measures, most often health-related quality of life measures for different health conditions, disease-specific instruments measuring physical functional abilities and functional outcome measures.

**ICF only mentioned**

A total of 53 papers [622–674] were included in the category of papers in which the ICF was mentioned in the background or in the discussion, but no operationalisation of its concepts was carried out in research methods, and therefore findings of papers were not based on the ICF. The majority of these papers were published in 2009 (11 out of 53) and 2007 (9 out of 53). The vast majority of papers included in this category (36 out of 53) were from those journals which had less than 10 papers included in this systematic review. Most of papers were from the US and from Germany (12 and 6, respectively). European countries produced 66.2% and American countries 28.4% of all the literature included in this category. The majority of them were from the field of rehabilitation.

**Discussion**

Our aim was to report the most accurate and up-to-date review of the state of the art of ICF in scientific literature in the last nine years. We found that the majority of published research on the ICF use, operationalisation and implementation is from North America and European countries. The US produced the highest number of publications but more than half of papers are from European countries. While North America produced a great number of theoretical articles, European researchers have been working more extensively on practical applications of the ICF, both in clinical and in other contexts. This may
be the result of common initiatives undertaken by European governments, as well as research centres and, most importantly, by research supported by the European Commission. In fact a classification like the ICF, and particularly its innovative approach to functioning, health and disability, is not only expected to be implemented in health and other sectors, such as education or employment, but it is also expected to influence policy-making and culture more generally.

Clinical applications of the ICF are, in a sense, the widest context in which literature has been produced. In this broad category, we include both direct applications of the ICF aimed at describing functioning and disability in selected groups of patients, as well as the development of ICF-based tools and papers linking of assessment tools to the ICF. Taken together, they constitute 52% of all the publications included in this literature review. What is interesting to note is that there is a trend towards the development of ICF-based assessment tools. This is the result of some years of ICF application aimed at describing disability in selected diseases, through the identification of relevant categories and the development of disease-specific ICF core-sets. However, in the last 2 years this research field seems to be less relevant, but we believe that this was the base of knowledge that was needed to launch the development of ICF-based assessment tools.

Similar considerations are applicable to the implementation of ICF-based protocols and application experience outside the clinical context. In fact, we observed a growing number of papers related to non-clinical issues, in particular in disability eligibility criteria, as well as education, legal issues, employment, data collection, participation in community life, urban planning, and provision of assistive technologies. We reported that 62 papers, representing approximately 9% of all publications, focused on a practical application or theoretical description of ICF use in such fields, and most of them were published after 2007. This means that the ICF is starting to be implemented outside clinical settings. We also have to acknowledge that the results of this systematic research are mainly coming from medical and psychological databases, so the use of other data sources might yield to even larger variety of applications and different trends on the use of ICF in different contexts. However, what is clear is that these recent developments on the use of ICF are the result of years of scientific work, in which the ICF model has been presented in a variety of contexts and different ways for its use, operationalisation and implementation have been proposed. In conclusion, this kind of implementation in clinical settings, research, surveillance and reporting of the ICF was both aimed for and expected by the WHO when ICF was released.

We found that approximately one-third of selected papers were on the description of ICF basic principles, and were equally distributed during the period 2001–2009. Approximately, 60% of them were not published in the most common journals. Our opinion is that the ICF is reaching the interest of a large number of disciplines, and is not specific to the field of rehabilitation, or to those interested in disability. In a sense, a cultural change is happening: disability associated with chronic condition is the outcome of improved healthcare and population ageing, and therefore researchers, clinicians, social workers, policy makers and administrators need a framework to improve their understanding of this phenomenon. The fact that ICF is nowadays diffused in so many scientific journals, even if in many cases it is only mentioned in the background, is evidence of the cultural change that is happening.

On the basis of these considerations, we believe that the data from this literature review are the most important evidence that can be brought to bear on the theoretical and practical advantage of using the ICF. Disability can be measured using a variety of assessment tools that are generally specific to a disease, or for a restricted number of functions or activities. Yet, when decision makers need to allocate funds, plan social services and pathways for their implementation, they need to rely on a most comprehensive description of disability and to have a broader definition than just a body function, a body structure or some activity problem. ICF, in our opinion, represents the most comprehensive classification system, since it makes it possible to describe disability at the level of the body, in terms of impairments, at the level of the person, in terms of activity limitation and at the societal level, in terms of participation restrictions. Moreover, it makes it possible to report on the presence and effectiveness of environmental factors. The ICF’s biopsychosocial model of disability thus provides the common language needed for evidence-based policy development.

Future research should also consider how low and medium-resource countries might be supported in the development of research or implementation programmes that include an ICF-based data collection. The rationale for this is that WHO’s GBD data [3] clearly shows that prevalence of non-communicable diseases is rising more quickly in these countries. Therefore, it is likely that in few years these countries will have to face the same situation as European and North America, in which increased life expectancy, matched with increased prevalence of chronic diseases, make it difficult to manage health and social systems. In addition, researchers should continue to plan ICF-based research through the development of ICF-based assessment tools.
This will make it possible to produce international reports on the health state of populations based on more than merely mortality rates. Given the trend towards longer lives and presence of chronic and disabling health conditions, this approach is preferable.

We decided to exclude papers focusing on use of ICF in children and youth only (aged less than 18), since the ICF is lacking some age-specific categories that are able to describe issue specific of children and youth’s development. WHO requested to an international ICF-CY working group to update ICF so as to capture children and youth’s functioning better. A 5 years work of amending ICF with international field trials resulted in the modification of existing ICF categories, in the attribution of new contents to unused ICF categories, in the modification of inclusion and exclusion criteria and, finally, in the expansion of qualifiers. However, few years have passed since ICF-CY’s release: information on its operationalisation deserves a separate literature review.

Future research should also consider the need to develop and implement a classification of personal factors. The need for a classification of personal factors has been recognised by several authors and lists of personal factors have been proposed in the ICF core sets. Personal factors are features of the individual that are not part of a health condition or health state, or otherwise classified in the ICF – including for example gender, race, age, lifestyle, social background, education and occupation. Though there is no personal factor classification in the ICF they are included in the conceptual model. There is a need to define the notion of personal factors and to develop a list of these factors, which might be considered risk factors for the development of a disease, or factors that can either improve or worsen an individual’s functioning status.

We have to acknowledge some limitations in the approach we have taken that might be improved in future research. The defined categories sometimes overlapped and since the methodology required us to assign articles to only one category some of the categorisation decisions may be debatable. Moreover, our categories were created on the basis of the main trends of ICF use according to the literature and the research experience in the use of ICF: therefore, some categories could be added in future research or divided in sub-categories for providing more detailed information. Particularly, if the trends that we observed can be confirmed, the fourth category ‘ICF in other contexts’, might be split into more categories, to better describe applications in the field of disability eligibility as well as employment of persons with disability.

As was mentioned before, the choice of databases was prevalently health and medical and it would be important to include more data from other fields, such as social and economic policy, law, health systems research, public administration, geography, architecture, urban planning, employment, transportation, communication, education and other areas, where the ICF is finding its place. This study gives an overview that is not a complete or includes all ICF publication, but it can serve as the basis for further work and a starting point to look at, not only what is done in future research, but also how it should be done.

Conclusions

Most of the papers included in the systematic literature review came from European and North American contexts and mostly from clinical and rehabilitation. There is a constant scientific activity in the diffusion of ICF by means of theoretical papers, which are published in a wide variety of journals from a wide variety of disciplines. The ICF is now being applied outside the health sectors, such as in education, disability eligibility and labour sectors. On the basis of the identified research trends, it is likely that these relatively new areas will continue to expand. When more ICF-based assessment tools will be available, a more accurate reporting on the health state of population will be possible.

An ICF application that will become very important is the ICF use for the monitoring of UN Convention on the Rights of Persons with Disability [675,676] where ICF should be seen in the wider context of description and measurement that is ultimately demanded by policy-makers who are called up to address social inequalities and inequities experienced by more fragile and sometimes marginalised members of society.

The application of United Nation’s Convention on the Rights of Persons with Disabilities [675], which enumerates rights in terms of fundamental areas ranging from family life, legal capacity and education, to political participation, employment and access to fundamental services, such as health and rehabilitation, will need a common metrix and a common monitor instrument. Persons with disabilities require, as the UN Convention clearly acknowledges, not merely declarations of human rights, but evidence-based monitoring mechanisms for the implementation of policy changes that address the violations of rights and other inequities.

For the UN Convention to move beyond political rhetoric into concrete action, in short, it too requires the preliminary steps of describing the disability experience in a manner that can assist policy-makers in fulfilling the obligations under the Convention and
ICF, with its bio-psychosocial model, and can be the instrument for this [677].

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