

Chapter 25

Challenges and Opportunities

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25.1 Global Perspective

A landmark convention by the United Nations (UN) that is likely to have the most impact on persons with disability in recent history is the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) [1]. The UN adopted the UNCRPD in 2006 with the intent to change the attitudes and approaches to persons with disability, including children. The convention is premised on providing the foundation of human rights for all persons with disability regardless of their disability; it puts persons with disability in equal position to those persons without disability in terms of their rights of access to services and opportunities. This is a critical piece to current efforts by the community advocating for persons with disability whether in the realm of vocational rehabilitation or return-to-work and

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social security and disability evaluation. The guiding principles of the UNCRPD emphasize the rights of persons with disability with regard to nondiscrimination, full and effective participation and inclusion in society, acceptance of persons with disability as part of humanity, and having equal opportunity, and accessibility [1]. These are essential principles when assessing persons with disability and will need to be integrated in health and health-related policy by the government and organizations that provide services and care for persons with disability so as to optimize their functioning and mitigate their disability. As a major life area of participation for most individuals, work is an integral part of life and everyday living and can seriously be impacted with the presence of a health condition. Hence, our ability to capture disability and work disability in particular is critical.

Published in 2011, the World Report on Disability's [2] definition of "disability" is mainly predicated on the World Health Organization's International Classification of Functioning, Disability and Health (ICF) [3] where disability is defined as an umbrella term for impairment of bodily structures and bodily functions, activity limitations, and participation restrictions. Furthermore, disability occurs when there is negative interaction between the health condition and contextual factors such as environmental factors and personal factors that may impact the body and the societal role of a person [3]. The adoption of this broad definition of disability is the first step towards a common understanding of disability and coordinating efforts so as to mitigate disability at the level of the individual while also taking into account the public health perspective.

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) emphasizes the rights of persons with disability with regard to nondiscrimination, full and effective participation and inclusion in society, acceptance of persons with disability as part of humanity, and having equal opportunity, and accessibility. The International Classification of Functioning, Disability and Health (ICF) is a framework by the World Health Organization (WHO) to understand disability based on impairment of bodily structures and bodily functions, activity limitations, and participation restrictions of a person.

25.2 Vocational Rehabilitation and Disability Evaluation

The ICF provides a comprehensive framework, a consistent classification, and relevant ICF Core Sets for disability evaluation and vocational rehabilitation. The relational concepts of illness and functioning and the emphasis on personal and environmental factors are in concordance with recent advances in social security. An integrative biopsychosocial model is increasingly being considered and used in social security institutions in many countries in the world. The ICF also provides an

understanding of the multifocal aspects of functioning that could be used easily in vocational rehabilitation settings and social security systems.

Helping individuals find jobs that are aligned with their interests and abilities is a key task of job development, and vocational assessment should help individuals select suitable occupational goals and services needed to promote their success. Thus, vocational rehabilitation professionals need to assess the correspondence or “fit” between the individual’s interests and abilities and the needs and requirements of the individual’s current or prospective work environment. Where the “fit” is less than optimal, they may determine how to improve it through various types of interventions, such as job accommodations, skills training, and counseling. The ICF framework is ideally suited in providing a holistic approach to vocational rehabilitation that is sufficiently comprehensive for purposes of vocational rehabilitation planning and service provision. Ultimate employment success often depends on the result of variables interacting at both micro (individual) and macro (societal) levels; the ICF can help vocational rehabilitation professionals identify the multiple factors at these levels that have an impact on employment. Identification of these factors can then provide the basis of vocational rehabilitation strategies that are more precisely calibrated to address problems and improve the likelihood of success. A particularly important advantage of the ICF framework is that it helps vocational rehabilitation professionals be more aware of the environmental factors that have an impact on individuals’ ability to perform successfully at school and/or work, as research suggests that environmental variables are likely to be overlooked, while personal characteristics are given more attention.

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25.3 Challenges

The full integration of the ICF in social security will take some time. While the framework and to some extent the classification have been adopted in many social security organizations to support and clarify the assessment of the individual’s functional ability and disability, the classification is not widely used. The uptake and progress in implementation might be slow, since social security organizations by tradition act slowly. Changes in policy and working methods have to be channeled through political procedures and could take a long time to prepare, discuss, and decide. An overall general challenge is to make this process as quick and efficient as possible.

Social security organizations need to change their approach to disability evaluation. Many have retained a disease-oriented approach, and there is a need to change to a strong focus on functioning. This indeed requires a paradigm shift and progressive approach in social security. Many countries have started this process. There is a need for functioning assessment and evaluation of work ability in two settings that can be seen in a continuum. One setting is vocational rehabilitation where we need assessments to guide the return-to-work processes; another is the need for assessments to determine the right to benefits. We need to develop ICF-based instruments for these two settings.

It is also a challenge to clarify, define, and describe the link between functioning (as represented by ICF) and disease (as represented by International Classification of Diseases [4]) in the evaluation of rights to disability benefits. One way to address this challenge is by using disease-specific ICF Core Sets. That, however, would add another layer of complexity given the frequent comorbidities that we see in disability evaluations. With the upcoming 11th revision of the ICD, we will see a more integrated biomedical and biopsychosocial approach [5].

The ICF framework is well suited for describing and assessing the individual's functional capacity and has gained increasing acceptance. However, disability evaluations in social security have to take into consideration several more elements than functional ability, e.g., sociomedical history, prognosis, and causal links. A single classification cannot capture all of these, and the ICF cannot provide a framework for all the questions that need an answer, nor was it ever intended to be a one-size-fit all approach. Rather, the strength of the ICF lies in its inherent role in lending an integrative approach to understanding and measuring functioning and disability alongside other health-related approaches and models.

It could be said that a classification of functioning also should be able to describe changes in functioning given the proper measurement. Change in functioning is an essential part of disability evaluation in social security. This book pointed out that one way to meet this challenge is to do consecutive measurements and assessments on the individual; an approach that is standardized, robust, and reliable. This would then give an assessor a series of snapshots to estimate as accurately as possible the changes in a person's functioning.

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The vocabulary and definitions of terms provided by the ICF have been assimilated into social security organizations in Europe to some extent. The classification is also receiving more acceptance as a language independent of professions. From the view of social security, there remain challenges related to environmental and personal factors. The environmental factors are at the moment not precise enough

for use in social security and would need further development and “granularization” so those factors can be operationalized in a sensible and practical manner. The evaluation of work ability usually requires a more precise description of work demands, work situations, and work environment than the ICF can currently provide. There is a strong need to expand the ICF classification in this dimension in the coming years. Anner et al. [6] have also suggested further development of the environmental factors in order for us to better capture disability and identify the environmental influencers [6]. In the ICF, there is no obvious place to classify vocational rehabilitation interventions of various types. One way of doing this could be to classify them as environmental factors. That would, however, require that a new type of qualifier – interventions – be introduced into the classification, with the possibility to qualify both for positive and negative effects.

The lack of classification of personal factors is one limitation in using the ICF. Other inventories or instruments are necessary if one wants to describe personal factors, like motivation or sense of coherence, in a standardized way in disability evaluations in social security. At present, this standardization is carried out depending on the country, setting, or national policy.

Nevertheless, by taking into account factors of the individual and the environment, the ICF even in its current form brings about a comprehensive overview of the different factors that may impact disability. Without these contextual factors such as social support and type of health services or peer support and access for work productivity, it will be quite difficult to put disability into context as some of those factors can minimize, strengthen, or neutralize the effects of rehabilitative intervention [7, 8]. There are instances when personal factors such as age together with the mental health status may be significantly associated, and which may in turn affect the level of disability at work [9].

The complexity and length of the ICF has hindered its acceptance in some vocational rehabilitation settings. The ICF Core Set for Vocational Rehabilitation [10] should help expedite its use in clinical settings. However, the ICF Core Set for vocational rehabilitation needs further research to assess its further validity and utility in real-life settings. This research could also help identify the areas that are not yet specifically coded in the ICF, particularly for relevant and work-specific environmental factors and categories of activities/participation. Currently, the ICF does include codes for many variables that are known to have an impact on employment outcomes, such as various forms of social support and assistive technology. However, there appears to be a need for additional categories that identify items of importance during the vocational rehabilitation process, including specific items relevant to the job placement process, such as job-seeking skills training, on-the-job support, and job coaching. More precise codes and definitions are also needed in the area of work and employment (Activities and Participation) which can be potentially be mapped to existing job classification systems like the International Standard Classification of Occupations by the International Labour Organization (<http://www.ilo.org/public/english/bureau/stat/isco/>), or O*NET (<http://www.onetonline.org>). In addition, there is a need for more clear-cut strategies for identifying vocational rehabilitation interventions when using the ICF. A

current problem in job placement research is the lack of consistency in research methodology. The ICF has the potential to address this problem, but without sufficient and precise inclusion of vocational rehabilitation interventions, its potential may be reduced.

Within the ICF, the contextual factors, namely, environmental factors and personal factors would need to be further developed in terms of conceptualization and classification. The more precise clarification of these factors will enhance our understanding of interventions targeted towards disability.

Several authors have pointed out that the ICF is too comprehensive to be used in toto. The use of short list – ICF Core Sets – is one way to develop the use of the ICF further. ICF Core Sets for specific diseases were the first to be created according to a defined methodology, and they have been followed by Core Sets for specific settings. The EUMASS Core Set for disability assessment in social security is one example [11], and the development of the ICF Core Set for vocational rehabilitation is another [10]. In social security, the use of disease-specific or setting specific- Core Sets should be discussed and tested. Some European countries have a strong medical influence on the decision process in social security, with a corresponding emphasis on diagnosis. In these countries, modified disease-specific ICF Core Sets might be useful. There are shortcomings with disease-specific ICF Core Sets, and perhaps the most important in social security is the high prevalence of comorbidity in benefit claimants. In many cases there is a combination of somatic and mental conditions that together could limit activity. In such cases, there would be a need for several ICF Core Sets, and that is undoubtedly a complex and cumbersome task to do. Hence, using setting-specific Core Sets would be more cost-effective when several comorbidities exist.

Whatever type of ICF Core Sets are used in social security, it should be remembered that instruments and protocols based on ICF Core Sets have a dual purpose. Guiding the individual back to work is the primary objective and, if that is not successful, to evaluate the need for financial support. The instruments will be different in scope, scaling, and content depending on the situation.

The ICF needs a robust and feasible operationalization to be “useable” in practice. The ICF Core Sets are merely the framework and classification for the gathering of information on clients. There is a need for concrete tools, instruments, or questionnaires that can be used in clinical practice and in research.

In this book, we have given several examples of the development of ICF-based tools and questionnaires. Other chapters have also shown how the ICF can be linked to already existing clinical instruments. There is a need for further development and continuous improvement of tools and questionnaires in clinical vocational

rehabilitation in line with these examples. In social security, this development process has just begun and work has started to link the ICF to existing and newly developed instruments in disability evaluation.

An interesting challenge is how to select the proper tools and ICF Core Sets for clinical work and work in social security evaluation.

An ICF-based system in vocational rehabilitation and disability evaluation can refer to the use of ICF Core Sets and ICF-based or ICF-compatible tools. With this approach, however, the purpose of the evaluation needs to be carefully focused to the needs of the client and the assessor and must be specific to the context, health condition, or setting.

In order for us to be able to capture and measure disability, it is imperative that we define disability and its different components. At a glance, disability as a terminology can be simple and straightforward, but more often than not, defining disability can be a daunting and complex task depending on which stakeholder is being asked. For a patient, disability depends on the chronicity and severity of the health condition and how it impacts their activities of daily living, for example, walking, recreation, and self-care such as putting on socks and shoes [12]. For a payor, defining disability depends on the value of a particular intervention that can be determined by the relationship (ratio) between positive outcomes over cost. For a healthcare provider, it might depend mainly on clinical outcomes with limited input from the patient. Furthermore, the understanding and knowledge of disability can have regional differences and scope likely due to legislation differences among countries [13].

As an integrative biopsychosocial model, the ICF [3] sheds light into the multidimensionality and nonlinearity of disability in a structured way that shows different aspects of functioning such as those related to body functions, body structures, and activities and participation of an individual that define disability, for example, the ability to make a distinction between mental and physical forms of disability to inform intervention [14].

One benefit to using the ICF is that the model promotes seeing disability through a multidisciplinary lens, hence breaking down silos between health professions. Multidisciplinary care is becoming more and more important as to how persons with disability are being assessed and treated and provides the benefit of multiple perspectives on the disability, especially with regard to setting of also diverse rehabilitation goals for patients [15]. However, the notion of multidisciplinary care has been challenged and found to be non-evident in terms of its effectiveness [16]. One major caveat to this matter though is the specificity of the population and

health condition. However, the patient population in disability evaluation and vocational rehabilitation settings are diverse and hence, would benefit from multidisciplinary care.

Disability can also be seen from an economic perspective highlighting the role of cost associated with the health condition. This cost can be direct costs or indirect costs, both of which burden the individual, their families and caregivers, and the society in general. There is a lack of a standard health metric that can be applied in strategic decision-making concerning disability and burden of disease [17], and this lack of metric contributes further to our challenge in examining the economics of disability or work disability using a common standard.

For us to be able to measure whether or not we are mitigating the effects of disability and addressing its adverse effects, we ought to know what we are measuring and to have the necessary and appropriate disability tools or measures. Many sophisticated methods of capturing or measuring disability have been presented in the literature such as Rasch analysis for reducing a list of items into an essential list of domains, for example, efficiently and precisely quantifying disability for low back pain patients [18] or employing computer adaptive testing in the clinic. However, the question is which method works and for what purpose?

Different stakeholders see disability differently. This diversity in the perception of disability challenges people involved in disability research and practice to measure disability taking into account the population where the measurement is taking place, the frequency of measurement, and the impact of knowing the outcomes.

25.4 Opportunities

The critical importance of vocational rehabilitation has been gaining ground in health conditions never thought of before like cancer [19] and in developing sophisticated ways of delivering a consumer-centered telemedicine [20].

We need to review what we know about commonly administered functional capacity evaluation measures as to whether or not they provide us with comprehensive biopsychosocial aspects rather than the physical aspects alone [21]. We also need to do a better job with patients who have mental health conditions like depression and whose disability would not be readily apparent compared to a physical form of disability [22]. We need to be able to look at applications relating to the cross-cultural applicability of the ICF, for example, in indigenous people with their unique experiences [23].

In clinical work, tools developed from the ICF have been used to follow the rehabilitation process in vocational rehabilitation. Similar tools can be developed in

social security, where they can provide us with the necessary, structured, and transparent information for multi-professional evaluation of disability.

This book demonstrates how ICF Core Sets can be linked to existing patient-reported outcomes by providing principles on how to choose, implement, and operationalize the ICF Core Set for vocational rehabilitation. Also in social security, client-reported outcomes are used. By linking these to the ICF, they can be matched to outcomes reported by the assessor.

Clinician-reported outcomes on functioning have always been a key step to disability evaluation in social security. There is a need to further develop this area and to assure the reliability and validity of these measures across different health conditions and healthcare settings.

In social security, there is a challenge to find a balance between the concern for an individual's uniqueness and the need for general policy on disability. The adoption of ICF-based instruments would make it easier to standardize tools, questionnaires, and protocols. In such a situation it might be tempting, and natural, to overlook the unique experience of the individual hence, prudence is advised.

Health and disability are always evolving in terms of how they are conceptualized and measured. Upward trends in chronic diseases and telemedicine are gaining emergence in clinical practice and research that can impact how vocational rehabilitation and disability evaluation are performed and delivered. With the advancement in modern outcomes measurement, our ability to capture functioning and disability has vastly improved compared to decades ago.

The ICF is a standardized framework and classification for studies on individuals' functioning and the relation between functioning and the environment. It may be possible to match individual functioning with demands at the work place and this should be one focus of national and international studies.

The component of personal factors in the ICF needs to be developed. In social security, some of these factors have more importance than others, and in particular motivation for return to work has been claimed as essential both to describe, to assess, and, if possible, to influence the course of the return-to-work process. There must be an effort towards the testing of scales and questionnaires. There is also a need to follow how individual clinical cases in vocational rehabilitation develop over time and with the use of ICF-based tools this is possible. There is also a need for further research on ICF-based tools and instruments with the aim of having optimal clinical utility and feasibility of these instruments and tools.

In social security, the ICF can support efforts to reach greater transparency and fairness of decisions. The framework and classification, as well as recent developments in Core Sets, have been taken into use in social security institutions. The ICF meets the need for a stronger emphasis on return-to-work processes and on the individual's functioning and work ability in disability claims.

The ICF is necessary to measure functional capacity of the claimant in social security, but it should be emphasized that the functioning assessment only constitutes a part of the whole disability evaluation process.

For social security, there is a strong need to develop the environmental factors of the ICF and start working on further developing the personal factors.

For both vocational assessment and job placement, applying the ICF model can alert practitioners to those areas where clients need to improve or develop a skill in or where environmental supports and modifications are needed. Often the types of interventions that are needed fall into two main categories: those directed to changing the individual through some type of remediation, such as establishing or improving a skill (e.g., skills training, job-seeking skills training, etc.) or those targeted to changing the environment, often in the form of support (e.g., providing job coaching, assistive technology). In the vocational rehabilitation setting, when an individual's potential skill level is low, this often means the person needs more support in the environment. For individuals with severe disabilities, a combination of skill development and environmental supports and/or modifications is often needed.

Tools based on the ICF would be useful for gathering client information in vocational assessment and job placement. Vocational assessment should be holistic and take into account all aspects that are relevant to the person's work functioning, including personal, social, cultural, medical, and psychological factors [24]. The ICF provides a comprehensive framework that can help organize, integrate, and interpret a vast amount of information from multiple sources, including interview data, medical reports, and test results. It should be possible to link many existing assessment instruments to the coding structure of the ICF [25]. The ICF framework can also help vocational assessment professionals develop individualized recommendations for services that help eliminate or minimize barriers to employment.

The comprehensive classification of the ICF provides a foundation for vocational rehabilitation planning, both in vocational assessment and job placement. It can help prevent vocational rehabilitation professionals from overlooking important areas of functioning and opportunities for interventions by ensuring consideration of multiple factors that are important for success, such as social aspects of the workplace and the impact of stigma.

During job placement, the ICF framework could also help organize information in a way that helps expedite planning and problem-solving. The ICF highlights the role of functioning, rather than diagnosis or disability type, which is what is needed for determining appropriate job accommodations and other interventions at the job site that will promote a successful outcome.

A number of studies have tried to identify variables associated with successful vocational rehabilitation outcomes, both in terms of client characteristics and service variables. There is a need to link services to outcomes and to find out what works, what is most effective, and for whom. Much of the research in job placement is hampered by a lack of consistency in methodologies that allow cross-comparisons among studies. In addition, multiple variables are not consistently

defined. The ICF conceptual framework could address this inconsistency, which is needed for evidence-based practice.

Job placement research also suggests that approaches that are tailored to meet the needs of individuals with specific types of disabilities are more effective than a one-size-fits-all approach. The Individual Placement and Support model [26] is an example of an evidence-based approach that is individualized to meet client needs within the actual work setting to reduce the impact of vocational barriers and functional limitations. Research examining the ICF framework in relation to employment outcomes has thus far been limited to a handful of studies. The few studies that have been published suggest that the ICF has potential as a useful tool in identifying factors that are related to work participation. However, more research in this area is needed.

The ICF provides a foundation for vocational rehabilitation planning, both in vocational assessment and job placement. It can help prevent vocational rehabilitation professionals from overlooking important areas of functioning and opportunities for interventions by ensuring consideration of multiple factors that are important for a successful program.

Evidence-based practice in job placement should include examination of environmental factors that can act as barriers or facilitators. Research indicates that successful placement outcomes in vocational rehabilitation are associated with multiple interventions that go beyond the focus on the workplace and include those that can enhance independent functioning more broadly, such as agency collaboration, an effective working alliance between the client and rehabilitation counselor, and services to families [27]. ICF-based tools can provide vocational rehabilitation professionals with precisely defined functional strengths and limitations; ideally, this information could be linked to occupational information databases.

More research is needed to match existing instruments with the appropriate ICF categories. New instruments could also be developed, based on the Core Set for Vocational Rehabilitation. Questions have also been raised about the validity of the ICF qualifiers [28] and how to apply the ICF codes and qualifiers in a consistent manner [29]. There is a need for developing methods to make use of the ICF coding in a more streamlined and less time-consuming manner for vocational rehabilitation professionals, such as through computerized adaptive testing or related tools. With broader acceptance of the ICF, especially by public vocational rehabilitation programs, it should ultimately be possible to track individuals' progress and outcomes to determine what works, what is effective, and with which individuals, given their unique combination of strengths, barriers, and environmental contexts.

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