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# Assessing Disability in Working Age Population

A Paradigm Shift: from Impairment and Functional Limitation to the Disability Approach

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## Acronyms and Abbreviations

ADL	Activity of Daily Living
AMA	American Medical Association
AT	Assistive Technology
CRPD	Convention on the Rights of Persons with Disabilities
CCT	Conditional Cash Transfer
DAS	Disability Assessment System
ECDA	Evaluation Center for Disability Assessment
FCE	Functional Capacity Evaluation
FIM	Functional Independence Measure
IADL	Instrumental Activity of Daily Living
ICD	International Classification of Diseases
ICF	International Classification of Functioning, Disability and Health
ICPS	International Classification for Patient Safety
PIP	Personal Independence Payments
SSDI	Social Security Disability Insurance
SSI	Social Security Insurance
WBG	World Bank Group
WHO	World Health Organization

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# Executive Summary

## Background

The objectives of this study are to present the basics of assessing working age population for disability benefits, to equip staffs at both the World Bank Group (WBG) and the World Health Organization (WHO) with a basic knowledge of the issues surrounding disability assessment, and to make a case for why adopting an approach to disability assessment based on the WHO International Classification of Functioning, Disability and Health (ICF)<sup>i</sup> is smart policy that corresponds well with the aims of modern disability policy and a recognition of the fundamental human rights of persons with disabilities, but also with the aims of other economic and social policies, such as labor market and fiscal policies. The report argues that, despite some limitations, there are good reasons for thinking that the ICF can serve as a design structure for reforming disability assessment, both in high income and low and medium income countries.

The study is a follow up work to the *World Report on Disability* that WHO and World Bank published jointly in June 2011.<sup>ii</sup> The *World Report* made it clear that the process of disability assessment is an important lever of disability policy in any country, yet little is known about how disability assessment is conducted. This study responds to that knowledge gap, but it also describes a paradigm shift in the assessment of disability, one that moves from prevailing Impairment and Functional Limitation approaches to a Disability-based approach. This paradigm shift, it is argued, makes sense given that labor market policy is currently shifting towards maximization of labor force participation of working age individuals experiencing poor health, and a fiscal policy increasing focused on affordability and sustainability of public spending on social benefits, including disability benefits.

## Context

Disability assessment is a gate through which anyone who claims publicly or privately provided disability related benefit, service or product has to pass. Every country has some form of disability assessment, some government authorized agency or agent charged with assessing whether a person is disabled or not, and to which degree. Most commonly and most visibly disability assessment is linked to social security benefits. But it also applies to eligibility for other social policy benefit: to access these benefits—from rehabilitation services, to care services, to assistive devices, to disability social pension, to social assistance in cash and in kind—people have to be officially declared to have a disability.

Disability assessment affects labor supply, government spending and individual welfare. Through the power vested in them, disability assessors make decisions that affect tens of millions of working age adults (on average 6 percent of working age population in OECD countries in the early 2000s) and influence the allocation of national resources that often surpass 1 percent of GDP in any given year (on average 1.8-1.9 percent of GDP in the

OECD countries). Yet, not much is known about how efficiently or effectively assessment processes are or the extent they meet basic credibility criteria such as validity, reliability and transparency. Thus far, despite their influence over significant human and financial resources, disability assessment systems and disability policies underlying them have largely escaped research attention and scrutiny. This study is an attempt to start responding to that situation.

## The Study

### *Disability assessment and determination*

**Disability assessment** is an authoritative determination about the kind and extent of disability a person has, as part of a larger administrative process usually called **disability evaluation** or **disability determination**. Disability assessment is part of a process that determines the eligibility of a claimant for some social benefit, service or protection that comprises a country's **disability policy**. These programs include social security and disability pensions; health and rehabilitation services; general social benefits such as income support; and employment-related benefits, such as unemployment benefits and workers' compensation. The **work capacity** or **work ability** assessment is the most prominent application of disability assessment, since being able to work is key to economic self-sufficiency and social standing.

Historically, disability assessment, and especially work capacity assessment, has also been closely linked to medicine, for the source of criteria of assessment, and the medical profession for assessors and adjudicators of eligibility. Medical criteria—it is commonly believed—are objective and clear and medical professionals are socially respectable and reliable. Taken together, this meant that the medical professional made a good 'gatekeeper' to public benefits. But essential to understanding the challenges of disability assessment is the controversy over the concept of 'disability' itself.

### *What is disability?*

Since roughly the 1970s on, it was common to speak about two 'models' of disability: the Medical Model of Disability and the Social Model of Disability. The **Medical Model of Disability** purportedly claimed that disability was essentially a medical problem located in an individual's body that required a medical or rehabilitative response. This was contrasted to the **Social Model of Disability** that denied that disability was fundamentally a matter of the condition of a person's body but was rather a social disadvantage experienced by an individual, a disadvantage created entirely by social, cultural and economic conditions and beliefs. In the last decade or so these debates have resolved in favor of the consensus view that disability is a complex phenomenon that involves both biomedical features of a person's body or mind and the impact of the overall, physical and social, environmental context in which the person carries out his or her life.

This **interactional view of disability** is the dominant one today and the most commonsensical: disability clearly is not solely about how a person's body functions, since

two people can have exactly the same impairment while one experiences a severe disability and the other little or no disability because they live in very different contexts that make very different demands on them. On the other hand, disability is not just about these environmentally or socially-created disadvantages, because the body and how it functions makes a difference as well. This interactional, or bio-psycho-social view of disability is at the heart of the WHO's ICF, formally endorsed by the World Health Assembly in 2001.

### *The credibility of disability assessment*

The credibility and perceived legitimacy of a country's disability assessment procedure depends on a few fundamental considerations. First, the assessments must be **valid** so there are no 'false positives' (people receiving benefits, but are not disabled) or 'false negatives' (people who should be receiving benefits, but do not). Second, they must be **reliable**, in the sense that two assessors following the same rules and criteria, should come to the same assessment of the same person (often called 'inter-rater reliability'). And third, the decisions must be **transparent** and **standardized**, so that the grounds for the decision-making are publically known and their application in particular cases independently evaluated. In short, the legitimacy of the disability assessment process depends on it being, and be seen to be, impartial, fair and based on objective evidence.

Nonetheless, depending on the social purposes and political objectives a policy or program is designed to serve, the criteria used for disability evaluation may extend beyond medical or even disability-relevant considerations to broader social considerations that may not be directly linked to the experience of disability. Historically, sharp policy has been the most volatile and reactive to historical events (such as a dramatic increase in the number of returning war veterans with injuries who demand returning to their old jobs), demographic, economic and social factors. These forces have often dramatically changed the objectives of the policy, but without altering the social importance of securing accuracy in the assessment of disability.

### *Models of disability assessment around the world*

Worldwide, strategies of disability assessment focus either on (i) health conditions and the impairments associated with them; (ii) functional limitations in basic or simple activities, understood independently of environmental or contextual differences; or (iii) disability fully understood as an outcome of interactions between features intrinsic to the person (health conditions, impairments and functional limitations) and the full range of environmental factors that, possibly uniquely, characterize the overall lived-context of the individual. Each approach has its strengths and weaknesses.

**Impairment approach:** Assessing work capacity on this approach is entirely a matter of measuring the severity of an underlying health condition and associated impairments. Although simple and straightforward, and by far the most common approach used worldwide, the Impairment approach has been strongly criticized both technically in terms of reliability and in terms of the underlying assumption that inferences from

severity of impairments can validly be made to levels of work capacity, without in any way taking into account the impact that features of the work place environment – how the job is structured, stress levels, the physical conditions, and the social and attitudinal conditions of employment. The interactional model, and evidence supporting it, strongly suggests that this approach is inadequate and distorts the assessment process.

**Functional Limitation approach:** This approach arose in the 1970s in response to criticism of the Impairment strategy from rehabilitation professionals who argued that physical examination and medical history-taking are an insufficient evidentiary basis for assessing work disability. They argued that a person’s work capacity depended on the extent to which the person could perform very basic actions such as lifting, standing, walking, sitting, carrying, pushing, pulling, climbing, balancing, stooping, kneeling, crouching, crawling, reaching, handling, fingering, talking, feeling, hearing, and seeing. These ‘functional capacities’ were thought to be essential predictors of work capacity. To assess these capacities a range of Functional Capacity Evaluation (FCE) tools, mostly health condition specific, were developed and recommended for disability assessment.

The Functional approach has been plagued with disappointing results in developing valid and reliable FCEs that have application, not only across health conditions, but internationally. There is also the concern that FCEs tend to focus on a person’s deficits—the capacities that the individual has lost—when it is commonly agreed a person’s physical and mental assets and strengths are equally important information for a work disability assessment. Finally, Functional approach suffers from the same problem as the Impairment approach: it only indirectly, by proxy, assesses work disability. Although both information about impairments and functional limitations in the performance of basic activities is essential for disability assessment, especially for work disability, equally important is information about the impact of the working environment on work disability.

**Disability approach:** The Disability approach attempts to *directly assess* disability rather than *indirectly infer* disability from a proxy impairment or functional capacity assessments. Direct assessment, in principle, gives equal consideration to all determinants of disability—medical, functional, environmental and personal. The disability approach, in its purest form, would be fully individualized and based on direct evidence. It would strive to provide valid assessment directly on evidence, on the assumption that the true object of assessment must be the person-environment, interactive outcome rather than any intrinsic feature of the person (impairment or functional capacity).

For many decades, although the Disability approach was acknowledged to be the theoretically optimal approach, it was argued that either the Impairment or the Functional Limitation approaches were preferable, because the very concept of ‘disability’ remained controversial and it was simply not practically feasible to collect and analyze information not only about the person (health condition, impairments, and functional limitations) but also about the person’s physical, human-built, attitudinal, social, political and cultural environment in order to produce a valid and complete

disability assessment. The second in particular is a substantial challenge to the Disability approach. And it is a challenge that the ICF, if it can successfully assist countries in transitioning to the Disability approach, must address.

### ***Introduction to ICF***

In May 2001, the *International Classification of Functioning, Disability and Health* (ICF) of the WHO was endorsed by the World Health Assembly. The ICF provides a comprehensive and standardized framework and language for the description of *Functioning and Disability*. The ICF model is the clearest expression of the interactive model of disability about which there is worldwide consensus and it is certainly the only model that has received unanimous international endorsement. As an international standard, the ICF provides separate classifications of the components of Functioning and Environmental Factors, each of which is composed of domains (chapters and blocks) and categories. Qualifiers are provided to describe the extent of the problems in Functioning, that is, the extent of Disability denoted by each domain and category variable.

‘Functioning’ in the ICF as an umbrella term including all aspects and dimensions of how humans function and act, from the concrete functions (and structures) of the human body and mind to the variety of simple and complex actions that a person engages in. These simple and complex actions are conceptualized from the perspective of the intrinsic capacities of the person to perform actions (the perspective of **Capacity**), and in terms of the actual performance of these actions in interaction with the complete context in which the person lives (the perspective of **Performance**).

Depending on the dimension of Functioning of interest, Disability is denoted as a matter of *Impairments* of Body Functions and Body Structures, *Limitations in Activities* and *Restrictions in Participation*. Functioning and Disability are thus overarching terms that identify these parallel dimensions. Although Functioning is conceptually linked to a health condition (a disease, disorder, injury or natural process such as aging), it is not a direct causal consequence but rather the overall experience of living with a health condition. The key issue is that Disability is created both by the underlying Health Condition and associated Impairments and by the lowered or raised levels of Capacity to perform Activities & Participation that result from Environmental Factors. **Health state and environmental factors are therefore both determinants of Disability.**

### ***Disability assessment and the application of ICF***

There is a growing recognition, certainly in the academic literature, that disability assessment should be based on the full, contextualised lived experience of health rather than merely on diagnosis, impairments or functional capacity evaluation. This is Disability approach, which not only directly assess disability status, rather than indirectly inferring disability from impairments or functional capacity, it also captures the person-environmental interactive model of disability, universally understood as the most defensible model of disability. Since the ICF is based on this model, it is reasonable to

turn to it as a feasible design framework for reforming disability assessment procedures for social, health, and employment policy.

First of all, the fact that ICF is the international standard classification of functioning and disabilities generates three sources of added value in the application of the ICF as a design framework for disability assessment:

**ICF is an optimal data reporting structure:** As ICF is a complete information collection structure, with an exhaustive and mutually exclusive list of domains, it offers the prospect of providing the full range and detail of information required for a complete disability assessment. Moreover, ICF not only helps coordinate existing data, it also identifies informational gaps, in particular information about the work environment that, as has been shown, greatly enhances the validity and reliability of work disability determination.

**ICF is the basis for process legitimacy:** Standardization of process, procedure and evidence is the administrative solution to challenges to legitimacy, and this is what the ICF can provide. Documentation of information in the language of ICF not only provides comparability, it also secures accountability. As the internationally accepted, scientific basis for describing the determinants and outcomes of functioning, disability and health, ICF is a solid basis for making the case for the legitimacy of a disability assessment procedure.

**ICF is an international platform for assessment and measurement:** Recent work on the development of ICF Core Sets and other breakthroughs in measurement strategies relying on ICF as an exhaustive, and consistent, classification of all domains of Functioning and Environmental Factors, have led to useable instrumentation with direct application to disability assessment.

### ***ICF and the paradigm shift in disability assessment***

Important as these general considerations are, realistically a country would need a strong argument for engaging in substantial reform of its disability assessment procedure. The basis for that argument is that the ICF captures the important paradigm shift in our understanding of disability. This worldwide recognized and adopted **interactional** conceptualization of disability calls for appropriate adjustments in disability policy, including disability assessment procedure. The arguments include:

First, ICF offers the prospect of feasibly constructing a complete functioning profile for the purposes of assessment, a profile based not merely on what a person cannot do, but also including the person's assets and strengths. ICF also offers the ability to systematically record the presence of environmental facilitators and barriers, and their impact on the person's performance in his or her actual context. These informational ingredients are fundamental to the Disability approach.

Secondly, ICF, for the first time, creates the conceptual and practical structure to predict disability trajectories over time in order to be able to flexibly respond to changing social

circumstances. Predicting how disability plays out in a person's life over time is not only beneficial for anticipating economic and social costs of disability, it also makes it possible to implement health and rehabilitation (including vocational) interventions that can, for example by building on a person's assets and strengths untouched by a chronic health condition, limit the overall impact of health problems. Essentially, it can help keep a person on the job, instead of leaving the labor market. With demographic ageing, it is becoming increasingly important to identify, and if possible, modify, ageing trajectories as individuals age into, or age with, chronic health conditions.

Thirdly, the fundamental ICF distinction between capacity and performance makes it possible to identify and target interventions that are key to programs such as return to work. An ICF-based disability assessment points us toward both sets of determinants of disability – intrinsic health conditions and impairments, on the one hand, and environmental factors on the other. Rehabilitation therapists have traditionally adopted this understanding of disability in their work, looking both at interventions that enhance a person's capacity, and at ways of improving performance by means of environmental facilitators, from assistive technology to workplace modifications.

Implicit in the ICF model is an important message related to the equalization of working environment to maximize performance irrespective of the functioning profile. Ensuring equality of capacity across the citizenry is beyond human knowledge and ingenuity – since people will always be intrinsically, and often irremediably, different in the health conditions they experience, their impairments and functional deficits and assets. People have different Functioning profiles and there is only so much humans can do medically and therapeutically to 'equalize' human capacity in general or work capacity in particular. Performance is a different matter. Although there are many practical reasons why achieving equalized work performance is also beyond our grasp, it is not an impossibility: the working environment, across the labor market, could in principle be made fully accessible to all workers, whatever their Functioning profile. If achieving this goal is unfeasible, striving for it is a plausible policy objective; indeed, according to the *Convention on the Rights of Persons with Disabilities*, it is a matter of basic human rights.

Despite these important assets, ICF also has limitations that need to be addressed. In particular, much of the explanatory power of ICF's interactive model depends on the crucial relationship between Environmental Factors and complex domains such as employment. Yet, critics have argued that the ICF may lack the theoretical capacity to live up to the demands that disability assessment procedures would require of it. Despite attempts to measure the impact of the built environment on performance, at this point there are no tested and usable tools for identifying the key environmental determinants of work performance, let alone measuring this impact. The Environmental Factors classification, moreover, is so lacking in detail as to be of little use in concrete applications, such as disability assessment. The application of the ICF component of Personal Factors, in part because of the vagueness of its definition, risks the unintended consequence of ascribing the inability of a person to perform successfully at work, not to the absence of

workplace accommodations or suitable assistive technology, but to personal motivational failure.

### **Challenges to the shift toward the Disability approach**

There are essentially two major challenges that need to be addressed: First, although all countries, regardless of their level of development, could benefit from shifting toward a more valid and equitable Disability approach to disability assessment, for many middle and in particular lower middle and low income countries, transitional processes need to be put into place to make it possible to move from an Impairment or Functional Limitation approach to a full Disability approach. Countries need to be assured that there are stable, transitional reforms that can be put into place in a sequence and at a pace that is practically feasible, given the country's resources, political system, and social and cultural context. The second challenge is addressing the potential burden of integrating information about environmental factors for disability assessment. This pertains both to technical concern for data comparability, for which ICF is of considerable assistance, but also to more practical problem of accessing this information by means of data collection and measurement tools, which at the moment do not exist.

### **Conclusion**

This study makes the general case for countries to make the shift in their disability assessment procedures toward what is called here the Disability approach, which directly assesses the phenomena of disability, both in terms of the health conditions and impairments of an individual, but also, and significantly for work capacity determinations, in terms of the features of the environment that shapes the disability experience. This study also makes the general case for using the resources of the ICF, its interactive model of disability and classifications, as a design framework for realizing the Disability approach to disability assessment. There is no simple, one-size-fits-all ICF template that can transform a country's disability assessment and evaluation procedures into those that implement the full Disability approach. And the ICF has limitations that need to be addressed with future research. Still, this study makes a plausible case for countries to build on the conceptual and practical resources the ICF offers to make the important paradigm shift in their disability assessment procedures, toward the more scientifically based and equitable Disability approach.



# Introduction

## Background

The objectives of this study are two-fold. First, it presents the basics of assessing working age population for disability benefits. Increasingly, the operational staffs of the World Bank (WBG) and the World Health Organization (WHO), as well as of other development organizations, are being requested by governmental policy agencies for technical advice and assistance on how to reform their disability assessment system. Often these inquiries seek advice on how to base disability assessment practices on a contemporary understanding of disability. This study therefore aims to equip staffs of both institutions with a basic understanding of the issues surrounding disability assessment and in particular to introduce them to the understanding of disability found in the WHO's International Classification of Functioning, Disability and Health (ICF).<sup>iii</sup> Secondly, while acknowledging limitations, both in conception and implementation, it makes a case for why adopting the ICF approach to disability assessment may be smart policy that corresponds well with the aims of modern disability policy that focuses on social and economic inclusion for individuals with disabilities, in the context of a recognition of their fundamental human rights. The adoption of ICF, for reasons given, may also assist countries, of all levels of income and capacity, of meeting their objectives in other important policy areas, such labor markets and fiscal policies.

This study is a follow-up to the World Report on Disability that WHO and WBG published jointly in June 2011.<sup>iv</sup> The World Report attracted enormous interest in and attention to disability, both as a human rights and development phenomenon. It remains the most authoritative report of its kind, extensively used by researchers, academics, policy makers and civil society organizations across the world. Originally written and published in English, it has been translated into a number of languages, including French, Spanish, Chinese, Portuguese, Japanese, Korean, German, Turkish, Arabic, and Romanian—amplifying its influence on policy makers and practitioners. The World Report uses WHO's ICF and its bio-psycho-social and person-environmental interactive approach to disability as a methodological framework. As will be described in more detail below in Chapter 3, the ICF approach understands disability as an outcome of an interaction between a person with a health condition and his or her physical, attitudinal and social environmental factors.

As a follow-up to the World Report, the World Bank and WHO agreed to jointly undertake two activities. The first activity was to develop and put into public use a comprehensive survey on Functioning and Disability (working title: Model Disability Survey) that will provide information on the lived experience of people with disabilities and can be used by countries to design and monitor the implementation of disability policies. After several years of development and testing, the survey is available for public use and is currently being implemented in several countries, including Sri Lanka, Oman and Nepal.<sup>v</sup> The survey

responds to a finding in the World Report (Chapter 2) that in 2010 the state of data about disability across the world was very poor and its recommendation to take steps to mend the situation.

The second joint activity, of which this study is the result, was to take a closer look at the processes of disability assessment—an important lever of disability policy in any country— and prepare a study on these processes. The preparation of the World Report revealed that, despite its significance, little is known about disability assessment or the variety of procedures used around the world, especially in low income settings. This study responds to that finding by beginning to fill in the knowledge gap about this important public institution, focusing on definitions, conceptual issues, approaches and methodologies, and the policy demands and expectations it is expected to meet. A crucial next stage would be an empirical study that reveal, and structurally classify, the plethora of disability assessment operational details that have developed, often without planning, at the country level.

While filling in the knowledge gap, the study goes a step further by making a case for a paradigm shift in the assessment of disability—one that moves away from one grounded in the prevailing Impairment and/ or Functional Limitation approaches to one that is informed by an ICF disability-based approach. The case is built on two sets of arguments. The first set is conceptual and normative. As the United Nations Convention on the Rights of Persons with Disabilities (CRPD)<sup>vi</sup> has been signed and ratified by the majority of the world's countries, the bio-psycho-social and person-environment interactive approach to disability, which is at the foundation of the CRPD, has become a guiding principle of their disability policies. However, the operationalization and practical application of the disability approach, including especially its application in disability assessment, is lagging in most countries. The reason is that the experience and knowledge from countries that have adopted the ICF into their disability assessment systems is not readily available. In many countries there is a wide discrepancy between a general macro level and up to date conceptual approach to disability, and an operational reality that still reflects old concepts and approaches. Moreover all countries, regardless of resource constraints can in principle benefit from this shift in paradigm, especially as the shift can be progressive with a gradual realization of benefits at each transitional step.

The second set of arguments contends that the paradigm shift is a smart move for countries because it responds directly to the demands of other important public policies. Two of these stand out: labor market policy whose orientation has shifted toward maximization of labor force participation of working age individuals experiencing ill health, and fiscal policy whose focus has shifted to concerns about the affordability and sustainability of public spending on social benefits, including disability benefits. Here the case for a paradigm shift in how countries assess disability is grounded in powerful, and very pragmatic, considerations that are found worldwide across all countries, irrespective of their income level.

## **Context**

Put simplistically, disability assessment is a gate through which anyone who claims any publicly or privately provided disability related benefit, service, or product has to pass. Every country has some form of disability assessment, however informal, and some government authorized agency or agent charged with assessing whether a person is disabled or not, and to which degree. Most commonly and most visibly disability assessment is linked to social security benefits. But it also applies to eligibility for a wide range of benefits—from rehabilitation services, to care services, to assistive devices, to disability social pension, to social assistance in cash and in kind.

Disability assessment affects labor supply, government spending and individual welfare. Through the power vested in them, disability assessors make decisions that affect tens of millions of working age adults and influence the allocation of national resources that often surpass 1 percent of GDP in any given year. Yet, not much is known about how efficiently or effectively assessment processes are or the extent they meet basic credibility criteria such as validity, reliability and transparency. Thus far, despite their influence over significant human and financial resources, disability assessment systems have largely escaped research attention and scrutiny.

Disability assessment has a significant impact over labor supply, in particular in the middle and higher income countries. As a consequence of disability determination, millions of working age adults leave the labor market every year and move onto some form of disability benefit. The OECD seminal report, published in 2010,<sup>vii</sup> estimated that in 2007, on average, about 6 percent of working age population in OECD was out of the labor market and on long term disability benefits (rising to 10-12 percent in some countries in the north and east of Europe). This rate was higher than the pre 2008-crisis unemployment rate. The situation reflects a growing trend in the numbers of working age adults leaving the labor market because of poor health and seeking disability pension. This is puzzling, because the health status of the population has steadily improved over the same period. The report concludes that “Working-age disability policy is one of the biggest social and labor market challenges for policy makers.”<sup>viii</sup>

Many countries spend significant public resources on disability benefits. The OECD average is about 1.8-1.9 percent of GDP, but in some of the OECD countries it is as high as 3-4 percent. Many new members of the European Union and European countries not in the EU, as well as countries in Central Asia, spend between 0.5 and 1.0 or more of GDP on disability pensions alone. With population ageing and a tightening fiscal situation, the sustainability of public spending on disability benefits has come under close scrutiny in many countries. Certain forms of disability benefits may not be sustainable and other policy tactics need to be developed.

Disability assessment does not exist in a policy and institutional vacuum. The decision taken by working age adults<sup>ix</sup> to knock on its doors is driven by many factors:

**First, it depends on the country's disability policy** and how it defines disability, what criteria and processes it specifies for deciding who is disabled and who is not, and the range of benefits available to people assessed as disabled. For example, in many countries, 20 years ago, mental health conditions, except in cases of severe mental disorders, would not be recognized by relevant regulation as a reason to be assessed as disabled. Similarly, musculoskeletal disorders, including lower back pain, were simply not considered disabilities but normal incidents of ageing. These days it is more commonly recognized that both mental health conditions<sup>x</sup> and musculoskeletal disorders are leading causes of working age disability; yet the social security law in many countries still limit the definition of disability to physical and sensory conditions.

Another feature of disability policy that strongly influences the rate by which working age adults leave the labor market are the basic parameters of social security benefits. In particular replacement rates for disability pension tend to be higher (often over 80 percent) and the vesting periods shorter than for old-age pensions. In many countries disability pensions automatically turn into old-age pensions once the disabled individual reaches mandatory retirement age, although the pension amount is unchanged. Furthermore, disability status is often linked to many other benefits, such as subsidized ("discounted" utility bills), transportation tickets, increased rates of other benefits, health insurance coverage and so on. In the United States, a person receiving a social security disability social insurance benefit qualifies for Medicare after 24 months. Although in low and middle income countries the range and level of benefits is very different, often the dynamics are similar, with similar consequences for the labor market.

Finally, the disability assessment system itself—its rules, the rigor and strictness with which they are applied, transparency, governance arrangements, and so on—plays a significant role as well. For instance, as argued below, an assessment approach based on impairments results in very different disability assessment outcomes than one that uses a full profile of functioning based on the ICF. Impairment-based approach tends to more quickly and automatically grants full, permanent disability, rather than, for example, coming to the assessment that a blind person can work, if provided with workplace accommodation. And in many low income countries, the informality of disability assessment, where it exists at all, means that very little is known about the basis of the determination.

**Second, the decision to seek disability benefits depends on the availability and generosity of many other public policies, notably old-age and early retirement pensions, unemployment insurance and health insurance.** Tightening early retirement provisions and increasing retirement age has in the last 20 years increased the numbers of people on disability rolls.<sup>xi</sup> In some countries, as high as 40 percent of the pre-retirement age cohort (60-64) are unemployed and on disability pension. Similarly, universal health insurance coverage can lessen the pressure on working age adults experiencing poor health to seek illness-related disability pensions, especially if they are unemployed. Paid sick-leave provisions that allow for absence from work because of acute episodes of ill-

health are important as well. They allow the return to work after an episode of sickness and for access to rehabilitative services during longer spells of poor health to increase the chances of returning to work.<sup>xii</sup> Finally, the availability and duration of unemployment insurance is crucial. The lack of, or overly restricted unemployment insurance provisions push workers in poor health, nearing retirement or with low education in low paid jobs to seek disability social insurance benefits.<sup>xiii</sup>

**Third, overall social and economic situation is an important determinant** of how many people seek disability benefits and require disability assessment. When the labor market is good and prospects for finding and staying in a well-paid job reasonable, many people with poor but manageable states of health, if provided with some reasonable adjustments in the work place, will stay on the job. But with high unemployment and no jobs, the demand for disability benefits will swell, and so will the numbers of beneficiaries. It has been empirically shown that the employment and disability rates move in the opposite direction, so that disability rates appear countercyclical to the levels of employment.<sup>xiv</sup>

Even when countries share similar basic features of disability policy, the fact of differences in design and implementation mean that countries at similar level of development and similar population health profiles may have very different rates of working age population on disability benefits.<sup>xv</sup> Yet whenever a significant fraction of the working age population is out of the labor force because of disability, policy makers have sought to reduce the fiscal burden by looking for ways for people in less than optimal health to stay in employment. Accordingly, “return to work” and “pathways to work” policies for people disability benefits have become more prominent, although the evidence in high income suggests that once adults are on disability benefits they rarely, if ever go back to work.<sup>xvi</sup> Working age adults tend to stay on disability benefits until they either reach old-age retirement or they die. With the improvements in the health status and better management of chronic health conditions, an increasing number of working age disability benefits recipients reaches the old age.

The failure of programs aimed at increasing the exit from disability benefits has shifted the focus of policy makers to efforts to decrease the inflow of working age adults into disability benefits. As the example of the Netherlands shows,<sup>xvii</sup> such a change requires changes in disability policy, often across the board. But it also requires that the disability assessment system make a paradigm shift in the way disability is conceptualized, operationalized and assessed: what needs to be assessed is what working age adults can do as well as what they cannot do and which services, accommodations and enhanced accessibility at home and at the workplace is required in order to return to work, instead of crossing the door into disability benefits.

It is, therefore, within this context—the need to maximize labor force participation of all workers—that this study has been developed.

## **The Study**

The study is presented in five chapters and five annexes. The first chapter, *Disability and Disability Assessment*, introduces disability assessment, explaining the contemporary understanding of disability, the credibility criteria of disability assessment, and the relationship between disability assessment and disability policy in general. Chapter Two, *Models of Disability Assessment around the World*, discusses the principles and strengths and weaknesses of three models or strategies of disability assessment: the Impairment, Functional Limitation, and Disability approach. Chapter Three, *Introduction to ICF* discusses the interactive ICF disability model, its understanding of human functioning and its two key aspects: Capacity and Performance. It also presents the structure and coding scheme of the ICF classification, ICF qualifiers and discusses the relationship between the ICF and the International Classification of Diseases (ICD). Chapter Four, *Application of ICF to Disability Assessment*, makes a case for a paradigm shift in disability assessment. Taking into account the benefits and limitations of using the ICF as a design framework for disability assessment, this Chapter argues that ICF is a) an internationally accepted data reporting structure; b) a good basis for process legitimacy; and c) on balance, a suitable platform for assessment and measurement with application both in high and middle and, through a gradual transition, in low income countries as well. The chapter concludes with a sketch of such a design framework for disability assessment grounded in the model and classifications of the ICF that offers a new orientation of disability policy, one that can maximize labor market participation for working age adults experiencing poor health. The final short chapter, *The Way Forward*, acknowledges some concerns about reliance on the ICF for disability assessment and suggests a research agenda that might meet these concerns.

The five annexes include Annex 1: ICF Minimum Generic Set and Disability Set; Annex 2: A Summary of Disability Assessment Systems in Eight Countries from around the World; Annex 3: A Practical Example of the ICF Implementation in Disability Assessment in Cyprus; Annex 4: A Note on Disability Benefits and Assessment in UK (a background paper for the study); and Annex 5: A Summary of the Background Paper on Disability Insurance.

# Chapter 1

## Disability and Disability Assessment

### Chapter 1: Summary

- *Disability assessment is an authoritative administrative process of determining the kind and extent of disability as part of a larger state administrative procedure called disability evaluation or determination.*
- *Disability assessment is extensively used throughout disability policy as an essential part of the determination of eligibility for services, products or protections authorised by a state official disability policy.*
- *Disability assessment for determination of employment benefits, or assessment of work capacity is the most common form of disability evaluation.*
- *Historically, disability assessment has been closely tied to medical sciences and medical professions, both for perceived legitimacy and certainty.*
- *The concept of disability has proven difficult to define, with two theoretical models predominating: the social and the medical models.*
- *These days, the consensus view (sometimes called the ‘interactive model’) is that disability is a multidimensional phenomenon with biological, individual and social features, that is an outcome of a complex interactions between intrinsic biological or health features of the individual’s body and mind, and the overall physical, attitudinal, interpersonal, and social and political context or environment in which the person lives, acts and experiences life.*
- *The WHO International Classification of Functioning, Disability and Health adopts this interactional model (the ‘bio-psycho-social model’).*
- *Disability assessment procedures can be judged in terms of validity, reliability, transparency and standardization; but they will also be judged as fit for the purposes of the policy for which eligibility is required.*
- *Disability assessment is significantly shaped by disability policy.*
- *Disability policy, like all forms of social policy, is determined by many factors and designed for many purposes and objectives.*

### What is disability assessment?

**Disability assessment** is the process of making an authoritative determination about the kind and extent of disability a person has, as part of a larger administrative process usually

called **disability evaluation** or **disability determination**.<sup>xviii</sup> This larger process typically involves officials other than disability assessors, such as case managers, vocational experts, social workers and administrative staff, and takes into account other features of the individual, such as age or financial situation, or general economic conditions such as the unemployment rate.<sup>xix</sup> Disability determination may be a complex, multi-layered process involving several steps and actors, as it is in most high income countries, or it may be a one-step, informal process conducted by a single individual as it is in low income countries.

Disability evaluation, which includes disability assessment as a component, determines the eligibility of an individual claimant for some social benefit, service or protection. The range of these benefits and services comprises a country's **disability policy**. The kinds of programs found in a national disability policy vary enormously, depending for the most part on the country's level of resources or development. In high resource countries, disability policy may comprise some or all of the following:

- Health and rehabilitation services, including access to assistive technology;
- Social security;
- Disability pensions (normally provided as part of social insurance/ social security);
- Health and social insurance benefits, including short and long term sick leaves;
- General social benefits such as income support and access to transportation; social pension for individuals with disability; housing or education services; social care service, both at home or in an institution; personal assistant services; subsidized utilities and tickets to cultural events, etc.
- Employment-related benefits; including unemployment benefits, workers' compensation, and access to vocational rehabilitation; and
- Protection against discrimination and human rights violations.<sup>xx</sup>

The disability policy of low and lower middle and middle income countries will not have this range of benefits, services, and protections, but nearly every country has some of them.<sup>xxi</sup> Moreover, since the adoption of the United Nations CRPD in 2006, many developing countries have been looking for ways to mainstream disability into regular social protection programs (as those programs may not adequately include disabled people), or to adjust the design of such programs to better serve the needs of disabled individuals and households (such as programs targeting poor households, conditional cash transfer programs, social pensions, child and family allowance, cash for work programs). For these programs to work, however, some way of determining eligibility by means of disability evaluation is still required. Disability evaluation is also used in the private sector to determine health and other insurance premiums and benefits.



In most high and many upper middle income countries, disability evaluation involves a series of steps, governed by law or regulations, which establish eligibility criteria for a benefit or service. One of these steps, and the most central, is disability assessment. Other eligibility requirements and related assessment steps may be added in order to make a decision on eligibility for a particular benefit: the claimant's age and gender, residency or citizenship qualification, the extent of his or her contribution to a contributory insurance scheme, the length of time the claimant was employed, how, or under which conditions an injury was sustained, the claimant's previous employment and future potential employment, whether rehabilitation or other health services are available to return the claimant to work, his or her current, or future potential income or access to other financial resources. The variety of these requirements is a reflection of the *ad hoc* and reactive nature with which disability evaluation has developed in most countries, with new requirements being added, or removed, in response to the perceived need to increase, or restrict, benefits.

Because of the diversity of information that may need to be assembled to make an overall disability evaluation, physicians and other health professionals who act as disability assessors will often be joined by social workers, employment counsels, and others. The process might involve assessment committees, tribunals, and other legal bodies as well as state officers/program administrators of various sorts to adjudicate appeals and finalize claims. As a consequence, the overall disability evaluation process can become extremely complex and take weeks or, if there are many steps involving appeals and reconsideration, even years to complete.<sup>xxii</sup> Although the process of disability evaluation varies enormously between countries, disability assessment of some variety always plays a central role. The fact that the process involves both financial and personnel resources—and can often be quite costly—is a factor in how a government will decide to structure its disability determination procedures.

Although assessing the extent of a person's disability is essential in order to determine whether he or she needs financial assistance, specialized health services, assistive technology, long term care or home support services, disability assessment for public benefits and services is most frequently understood as an assessment of **work capacity** (otherwise known as **work disability** or **work ability**).<sup>xxiii</sup> This makes sense since, both socially and from the individual's perspective, being able to work is key to economic self-sufficiency and social standing. Historically, almost all social welfare benefits in the Western world were initially linked to employment and the capacity to work. The very first recognizable form of disability evaluation was established in England's Poor Law of 1601 that distinguished between the true or 'worthy poor' who were legitimately disabled and so legally allowed to beg in the streets, and the 'unworthy poor' who were not disabled and could be imprisoned for begging or forced to work.<sup>xxiv</sup>

Historically, disability assessment, and especially work capacity assessment, has also been closely linked to medicine, for the source of criteria of assessment, and the medical profession for assessors and adjudicators of eligibility. Medical criteria, it is commonly believed, are objective and clear and medical professionals are socially respectable and

reliable. Taken together, this meant that the medical professional made a good 'gatekeeper' to public benefits.<sup>xxv</sup>

Around the world the number of successful applications for disability benefits, services and protections based on disability assessments varies enormously. This is not because of different levels of health in a population, or any other demographic difference; nor is it entirely a matter of differences in the wealth of countries,<sup>xxvi</sup> although natural disasters or conflict will obviously make a profound, short term difference. More typically, the different 'uptake' levels are the result of different eligibility criteria, different 'threshold' levels of severity of disability, and most importantly differences in how the term 'disability' is legally and administratively defined. Disability assessment process plays a very important role too. To understand the processes and challenges of disability assessment, in other words, we need first to understand what disability is and why there are so many, often extremely different, legal definitions of disability.

### What is disability?

The task of defining the concept of 'disability' has proven to be surprisingly difficult. For many years, since roughly the 1970s on, it was common to speak about 'models' of disability, and in particular to debate between two extreme alternatives: the Medical Model of Disability and the Social Model of Disability. The Medical Model of Disability purportedly claimed that disability was essentially a medical problem located in an individual's body that required a medical or rehabilitative response. This was contrasted to the Social Model of Disability that denied that disability was fundamentally a matter of the condition of a person's body but was rather a social disadvantage experienced by an individual, a disadvantage created entirely by social, cultural and economic conditions and beliefs. While the Medical Model relied on presumptions about biological 'normality' and medical problems or abnormalities that people suffer from, the Social Model insisted that although there are bodily 'differences' people experience, disability is created by the negative and discriminatory way society responds to these differences.<sup>xxvii</sup>

These debates about models have now more or less slipped into history, leaving behind the consensus view that disability is a complex phenomenon that involves both biomedical features of a person's body or mind and the impact of the overall, physical and social, environmental context in which the person carries out his or her life. Although it goes by various names, this view stresses that disability is the outcome of an interaction between intrinsic biological features of the person (that is, the person's state of health) and all aspects of his or her physical, human-built, interpersonal, social, cultural, and political world—the context in which he or she acts, works, and participates in all aspects of personal and social life.

This interactional view of disability is the dominant one today; it is also the most commonsensical. Surely, disability is not simply about how a person's body functions,

since two people can have exactly the same problem of bodily functioning—or impairment as it is typically termed—while one experiences a severe disability and the other little or no disability because they live in very different contexts that make very different demands on them: the fact that I have lost in an accident the first digit of my index finger on my left hand may mean that I cannot do my job—because I am a concert pianist—or it may not affect my employment at all. If my eyesight weakens as I age, I may have little problem reading or seeing my friends across the street because I have access to corrective glasses. But someone who has no access to glasses will be severely hampered in his or her day to day life, with the precisely same level of limited vision. Clearly, things in the world—the climate, products, buildings, and way cities are laid out, our attitudes and values, and the way the world is organized personally and socially all can make a difference in how we experience disability.

On the other hand, disability is not just about these environmentally or socially-created disadvantages, because the body and how it functions makes a difference as well. Indeed, some of the problems we have in our bodies make all the difference to our experience: If I have chronic pain, a missing limb, or severe depression; it does not really matter much how my community or society at large is organized since this will have little effect on my pain levels, the fact that I don't have a leg, or am depressed. Pain and depression medication will help, of course, but medication, though initially part of my 'environment' becomes part of me when I ingest it and—either temporarily or permanently—the way my body functions change. The body makes a difference in disability, and ignoring the body, or downplaying the importance of the body distorts the concept of disability.<sup>xxviii</sup>

As we will see in Chapter 3 below, the interactional conceptualization of disability is at the heart of the WHO's ICF,<sup>xxix</sup> formally endorsed by the World Health Assembly in 2001. The ICF formalizes and operationalizes disability as interactional (on the basis of what is called in the ICF the 'bio-psycho-social' model). The ICF arose from a consensus that formed in the late 1990s that an interactional approach was the most defensible way of moving beyond the unhelpful deadlock between Medical and Social models. As an international standard classification, the ICF also moved the debate from the theoretical and political to the scientific and practical levels, transforming the interactional model into a working framework for direct applications in epidemiology, clinical practice, research, and other domains.

Although the underlying intuition of the interactional model of disability is generally accepted, the old models, especially the Medical model, still has a powerful hold over how disability is assessed for policy purposes. This has led to the peculiar situation in which although no one would deny that disability depends both on the state of one's body and the state of one's environment, the way disability is assessed in countries around the world suggests that very different conceptions of disability are being presumed. In the next chapter these disability assessment strategies, and their strengths and weaknesses, will be categorized and described. For now, a general explanation for this state of affairs is offered; that is, despite appearances, disability evaluation is not a purely scientific or technical judgment but one that has been shaped by conflicting political, social, and

economic demands. The economic demands, for instance, include the need for higher labor force participation and constraints related to fiscal resources, but are also related to the levels of unemployment in a particular country.

#### Box 1.1: Key Terms

**Disability assessment:** A process of making a legally authoritative determination about the kind and extent of disability a policy or programme applicant (claimant) possesses as part of a larger administrative process to determine eligibility for specific benefits.

**Disability evaluation (determination):** The overall administrative procedure for determining the eligibility of an applicant (claimant) for a service, product, protection or programme on the basis of disability and other criteria.

**Disability policy:** All policies, services and programs provided by the state to individuals by virtue of disability, administered by the state or private agencies, and authorized by law or regulation, including services and programmes regarding health and rehabilitation, social security, pensions, health and social insurance benefits, income support, care services, access to subsidized utility services and transport, employment-related benefits, and protections against discrimination or to implement human rights.

**Work capacity:** the overall ability of an individual to perform the physical, mental and emotional tasks that are needed for the requirements of a particular job, or class of jobs.

**Models of disability:** Alternative conceptualizations—usually based on theoretical or political presuppositions—about what disability is, how it is experienced, how it arises, how it is socially received, and many other dimensions of the phenomena. Essentially, a model of disability is a theory of what disability is and entails at the bodily, personal, interpersonal and social levels.

### The credibility of disability assessment

The credibility and perceived legitimacy of a country's disability assessment procedure depends on a few fundamental considerations. First of all, the assessments must be **valid** to minimize 'false positives' (people receiving benefits, but are not disabled) or 'false negatives' (people who should be receiving benefits, but do not). Second, the procedure must be **reliable**, in the sense that two assessors following the same rules and criteria should be able to come to the same assessment of the same person (often called 'inter-rater reliability'). And lastly, the decisions must be transparent and standardized, so that the grounds for the decision-making are publically known and their application in particular cases independently evaluated.<sup>xxx</sup> In short, the legitimacy of the disability assessment process depends on it being, and be seen to be, impartial, fair and based on objective evidence.

Needless to say, disability is complex and difficult to measure and these credibility criteria are not easy to achieve in practice. Even in the most sophisticated and well-resourced countries time and other limitations mean that mistakes can be made (see Box 1.2 below). Assessors rely on the supporting evidence they are provided, which may contain errors, and there are invariably differences between assessors in how the evidence is evaluated

and weighed. Yet the overall accuracy of disability assessment is crucial for the political sustainability, and perceived fairness, of social security and other policies that rely on disability assessment. If expert disability assessors, following the rules they have been set down, regularly came to different judgments about the same applicant, then the process might be viewed as arbitrary and unjust. If assessors did not accurately match services or products to the people who actually need them, then the program would be criticized for being both wasteful and failing to meet legitimate needs. At the same time, however, some of this kind of mismatch is not caused by errors in assessment, but by how the program has been designed. For example, a health insurance scheme designed for persons with disabilities might be accurate in its assessment of eligibility; yet, the individual may not in the end receive the health care resources he or she requires because it is a managed care or capitation system that rations services to keep the scheme financially viable. In other cases, the determination of the benefit received depends on factors other than the extent of disability. Evaluators in workers' compensation programs, for example, once they determine the level and kind of disability from a work-related injury, will then base their determination of level compensation on the additional factor of the level of economic loss that this injury has caused.

#### **Box 1.2. Disability Assessment in the United States and United Kingdom**

David Autor and Mark Duggan (2006)<sup>xxx</sup> argue that the disability assessment system for Social Security Disability Insurance (SSDI) benefits is “effectively broken” (p. 20). Disability assessment in the United States is performed by the Disability Determination Services in about 1,400 branches across the country. Approximately 40 percent of applicants are awarded benefits at the first stage; in other words, the rejection rate is at about 60 percent. Over the years, the fraction of rejected claimants appealing the decision has been increasing steadily and currently most applicants challenge the initial decision. A majority of these request a hearing with an Administrative Law Judge. Eventually, about one half will end up being awarded the benefit through the appeal and adjudication process. As a consequence, in 1997, the Social Security Administration paid nearly half a billion dollars to claimants' attorneys: “Decisions about what constitutes a legitimate claim are gradually being taken from the Social Security Administration.... Accounting for all levels of appeal, more than 38 percent of awards to individuals who applied for Disability Insurance between 1997 and 2000 were made after an initial denial. ... The increase in the fraction of DI awards made on appeal raises the concerns that the Social Security Administration is gradually losing control of the decision making process on eligibility for disability benefits.” (pp. 22 - 23).

Based on the case study of the United Kingdom in Annex 4 below, a similar situation exists in the United Kingdom where the number of successful appeals against adverse decisions for Employment and Assistance Allowance and Work Capacity Assessment continues to rise. According to the Ministry of Justice, out of 327,961 appeals received for the period 2012-13, 225,236 were heard and about 43 percent were decided in favor of the claimant.

#### **Disability assessment and disability policy**

Disability assessment critically depends on disability policy, which changes over time and, like all social policy, answers to a range of demands and pressures, some of which are contingent on background social, economic, and even demographic trends.<sup>xxxii</sup> A recent

National Bureau of Economic Research study looking at the share of the population receiving disability benefits at older ages (60-64) in 12 high income countries found that the share varied by a factor of eight: from 17 percent in Belgium to 16 percent in the UK to 14 percent in the US to 6 percent in Italy and France to 2 percent in Japan.<sup>xxxiii</sup> Taking into account that the health status of the observed population cohort in the countries under study is similar, and that disability assessment processes are not dramatically different, although the strictness with which the criteria are applied may differ, these differences are largely ascribed to disability and other social policies, such as unemployment insurance, and old-age pension, specific to each country. Similarly, the increase in the share of working age population on disability benefits observed in many countries during the last decades, despite significant gains in the health status of the population, is explained by the change in disability policy.<sup>xxxiv</sup> Countries that have managed to reverse the trend, such as the Netherlands, have done so only by changing their disability policy, and in particular by decreasing the inflow into disability benefits.<sup>xxxv</sup>

In recent years across Europe, the decision to use disability pensions and other income maintenance policy as a final, social 'safety net' for people who are unemployed has come under intense scrutiny because these policies are economically unsustainable.<sup>xxxvi</sup> There has been a dramatic policy shift from providing short and long term sickness leaves, pensions and other forms of income support towards increasing the prospects of returning to work. These political decisions fundamentally alter the purposes for which disability policy serves, while leaving intact the disability assessment process and the need for accuracy.

Inasmuch as disability assessment is an important precondition for individuals with disability to access publicly financed disability benefits, the credibility of the process—its reliability, transparency and validity—are important. Credibility is crucial not only for the fairness, equity, and overall well-being of disabled people, but also for the fiscal sustainability of disability policy. However, there is one area of disability policy in which disability assessment plays almost no role; namely, disability anti-discrimination legislation. The purpose of these laws is to prohibit and compensate for unfair or unequal treatment to a person on the basis of disability, often in the employment sector. Anti-discrimination in particular, and human rights legislation in general, does not require in all cases that the aggrieved individual actually have a disability, as long as the party who discriminates treats the person unfairly, *believing, even mistakenly, that the individual has a disability*. Conversely, some national anti-discrimination legislation expressly prohibits people with certain health problems—alcohol and drug-addiction, pedophilia or kleptomania—from using the law to address discrimination against them even though these conditions as linked to disabilities.<sup>xxxvii</sup>

In summary, depending on the social purposes and political objectives a policy or program is designed to serve, the criteria used for disability evaluation will be shaped, not only by medical and disability-relevant considerations but also by non-medical social considerations that may not be directly linked to the experience of disability. Sometimes the purpose of the policy is viewed as being of such importance that it overrides reliance

on factual evidence. Laws to benefit people who are blind, for example, tend to ignore the factual issue of whether the person could, with suitable accommodations, perform a job that he or she has the educational background for, and so might not require the financial support in lieu of employment. Similarly, the social decision to allow people to retire with full pensions at age 65 is not based on any assessment of the actual work capacity of people of that age, a fact that is often cited in support of abandoning mandatory retirement age.

Social policy, in general, has been and will continue to be shaped by many factors and designed for many purposes and objectives. Historically, disability policy has been the most volatile and reactive to historical events (such as a dramatic increase in the number of returning war veterans with injuries who insisted on returning to their old jobs), demographic, economic and social factors. These forces have often dramatically changed the objectives of the policy, but without altering the social importance of securing accuracy in the assessment of disability.

## Chapter 2

### Models of Disability Assessment around the World

#### Chapter 2: Summary

- *The best way to categorize approaches to disability assessment is not in terms of how disability is defined or the objectives of the policy, but the assessment methodology or strategy.*
- *One suggested categorization is in terms of the extent of reliance on medical information and the extent of discretion granted the assessor. The more reliance on medical information, the more reliable and costly the procedure; the more reliance on discretion, the more flexible but less reliable procedure.*
- *For many countries, the process is so discretionary and so little regulated that it is best to call it informal or extra-legal.*
- *Although the medical/discretionary approach has its value, a more sensitive categorization distinguishes methodologies in terms of the varieties of human experience linked to disability – thus the Impairment, Functional Limitation, and Disability Approaches.*
- *There is also a different general approach that is used, one based on assessment of economic loss. Although common, this strategy is restricted to workers' compensation programs and presupposes a prior, if implicit disability assessment, standardly in terms of the Impairment approach.*
- **Impairment approach:** *inferring the existence and extent of disability from information about health conditions and/or impairments. This is the oldest and still most commonly used strategy, and is represented either by simple Baremas scales or complex tools such as the American Medical Association Guidelines.*
- **Functional Limitation approach:** *as a response to criticism of the Impairment approach, this approach added information about basic simple actions – lifting, standing, handling, hearing, seeing, and concentrating – to an assessment of work capacity. The application of this approach has led to development of Functional Capacity Evaluation (FCE) instruments.*
- **Disability approach:** *a full, direct and non-inferential description of all relevant dimensions of, for example, work capacity, including health condition, impairments, functional limitations and personal and environmental factors. This approach is based on the WHO ICF model of disability.*
- *Each approach has its strengths and weaknesses: although simple and feasible, the Impairment approach is strongly criticized as inadequate and logically flawed; while the Functional Limitation approach has improved disability assessment, the tools*



*used to measure capacities—the FCEs—has been unreliable and in some instances, invalid, and information about capacity to perform some basic actions does not predict work capacity; the Disability approach may not only have unintended consequences of limiting positive assessment, but in addition (because it attempts to provide a comprehensive environmental information, both proximate and distal), it may be difficult and costly to apply in practice.*

- *Despite practical limitations, a case can be made that the ICF is useful as a design framework for disability assessment as it provides the conceptual and practical basis for an operationalization of Disability approach to disability assessment.*

### **Disability assessment: classifying methodologies**

Given the variation in schemes of disability assessment around the world—designed for radically different policy objectives, in different socio-economic and political settings, and geographical areas—care must be taken when categorizing the basic approaches. It would not be possible or useful to categorize these approaches to mirror all of the many ways in which countries differ in resource levels and geographical and socio-political environments. It is far more useful to isolate basic characteristics of all disability assessment processes such as the following, which we can then look at one at a time:

- types of definitions or operationalization of the concept of ‘disability’;
- legally or customarily-defined criteria of assessment;
- objectives or aims of the policy for which assessment is required;
- assessment methodologies or strategies;
- assessment instruments used (if any);
- administrative arrangements in which assessment is conducted; and
- characteristics of disability assessors.

The definitions of ‘disability’ used for disability assessment are invariably legal definitions, which makes them very different from the kind of definition one might find in a dictionary. They are also different from conceptual or theory-based definitions since they do not depend on the actual meaning of the word ‘disability’ so much as the purposes the definition is designed to serve. A common sense definition of ‘work disability’, for example, might look like this:

*Work disability* is a condition that is experienced by a worker, because of an injury, disease or some other health problem that makes him or her unable to do the work required, to become employed or to return to work.

Compare this with the following two legal definitions currently in use in the United States:<sup>xxxviii</sup>

*“[Work disability is the] inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or which lasted or can be expected to last for a*

*continuous period of no less than 12 months”... “[a]n individual shall be determined to be under a disability only if his physical or mental impairment or impairments are of such severity that he is not only unable to do his previous work but cannot, considering his age, education, and work experience, engage in any other kind of substantial gainful work which exists in the national economy....”*

*“[A person’s work disability is] an incapacity that reduces his/her earning or working capacity by over 66 %, i.e., which makes him/her unable to earn a salary in any job of over one third of the wage that an individual would receive in the same area, in the same category of workers as (s)he belonged to before. The state of incapacity is determined, taking into account the working capacity, the general state of health, age, physical and mental faculties, and the aptness of the individual to follow a professional education.”*

What stands out is that these legal definitions do not define ‘work disability’ but instead present the criteria or considerations that a disability assessor is required to use -- namely severity, duration, and background considerations (“substantial gainful work which exists in the national economy” and “aptness of the individual to follow a professional education”). All of these reflect the objectives of the policy rather than what the word ‘disability’ actually means. The point is that legally-defined criteria for assessment can in principle include any requirement, restriction or constraint that policy-makers feel is relevant (or politically required) for the policy’s purpose and aims.

Since legal definitions and assessment criteria are in this way contextualized and dependent on national priorities and political requirements, legal characteristics are too various and unstable as way of categorizing basic approaches to disability assessment. Nor would it be useful to look at different policy objectives, since these too are highly contextualize to national situations and specific to the needs and requirements of the country. The only real option is to focus on the assessment methodologies or strategies since these will determine what assessment instruments are used, administrative arrangements are required as well as the qualifications of disability assessors. The challenge, then, is to classify assessment methodologies.

### **Medical information and discretion**

One approach to classifying disability assessment methodologies (borrowed from a 2002 Brunel University study)<sup>xxxix</sup> involves two dimensions of decision-making that can be used to distinguish the kind and quality of evidence and reasoning used to assess a person’s disability.

Methods of disability assessment can be more or less reliant on **medical information**—biological, physiological, pathological, psychopathological, symptomatic, or genetic data, and clinical information about health conditions and impairments. Assessment procedures rooted in medical information will tend to rely on medical experts, in particular physicians, as assessors, often directly employed by the administering agency. Indeed, physicians are relied on both as sources of medical information—from direct

medical examination, diagnosis, and treatment—and as expert judges or evaluators of the quality of the available medical information. Medically-oriented assessment processes incur high administrative costs because of the need for specialized medical personnel or scientific instrumentation. When an assessment procedure is less oriented to medical information, it will look to information about career plans, educational needs, social status, income levels, and the like, all of which are more readily available from self-report, and so cheaper to acquire.

Secondly, regimes for assessing disability vary considerably on the amount of **discretion** assessors are given to reach their judgments. Generally, the less assessment is structured by legislation or regulation, the more administratively informal it is and the more discretion the assessor is granted. When a relatively rigorous framework or instrument is used, such as a Baremas impairment guideline, then discretion is considerably restricted. Limited discretion tends to produce more consistency and so inter-rater reliability in assessment, but at the cost of ignoring individual differences or exceptional circumstances that might be relevant to the determination.

On the other hand, a greater reliance on assessor discretion sacrifices consistency and reliability for flexibility and more sensitivity to individual differences. Because they are perceived to be trustworthy, physicians are more readily granted discretion. But even with physicians as assessors, if short or medium-term outcomes of a particular assessment scheme do not serve the purposes of the policy or program, policymakers may choose to limit assessor discretion in order to more strictly control the assessment outcomes. (It would be naïve to think that any assessment regime involving human judgment could eliminate discretion entirely, or indeed that it would be beneficial to attempt to do so since that would eliminate human judgment.)

Combining these two dimensions, four possible general strategies of disability assessment can be identified: High reliance on medical information with high (or low) discretion and low reliance on medical information with low (or high) discretion. Although it is possible to find these combinations in practice, they are rarely found in pure form but tend to shift over time as policy-makers fine-tune procedures either to respond to changing circumstances or to shape outcome patterns. If it is perceived that too many people are successful in claiming disability benefits, then regulations may change and less discretion will be sanctioned, or more reliance on objective medical information or instrumentation will be demanded. All social policy can be adjusted to changing circumstances in this manner, without making fundamental administrative or institutional changes.

The matrix created by the interplay between a reliance on medical information and level of discretion, and the subtle shifts in procedure and outcome that these can create, help to explain the variation of disability assessment schemes around the globe. But there is one more important variation; that is, in many low income countries, disability assessment is carried out without any formal process or procedure at all, other than the judgment of a health professional or state official. Often these judgments are based on a paper record of medical diagnosis or an informal, face-to-face interview. This informal,

and to a considerable extent extra-legal approach is essentially pure discretion. Since in low income settings there are typically few available disability services and benefits to qualify for, this informality tends not to be perceived as a (particular) cause for concern. The major problem with such an 'approach', however, is that it is extremely difficult to get any reliable information about it and researchers have to rely on anecdotal evidence, or often mere speculation. Not being able to characterize how disability assessment is carried out for a substantial majority of the world's population is of great concern, and points to the need for wide-ranging research in this area.

Although there are many useful insights to be gained from categorizing disability assessment methodologies in terms of the health information/discretion matrix, at the end of the day it is a very general, anodyne picture of policy administration applicable across the social system and as such does not help us isolate what is fundamentally different about assessing disability. What is missing in the matrix is any linkage between the evidence and decision procedure used and the conception of disability implied or defined by legislation. A more useful approach, more sensitive to the nuances of disability policy, and certainly more valuable as a basis for policy recommendations, is one that highlights the varieties of human experience associated with disability. This experience is, so to speak, the center of gravity of disability assessment, and is what links together all other characteristics mentioned: legal definitions, criteria of assessment, methodologies of assessment, instrumentation, administrative arrangements, and characteristics of assessors.

### **Impairment, functional limitation and disability**

Surveys of approaches to disability assessment in use around the world, especially for the assessment of employment or work disability, reveals that there are basic approaches to assessment whose features and consequences are relatively stable.<sup>xi</sup> This makes it possible to map them onto different dimensions of the experience of disability, using the 'interactional' view of disability presented above.

Disability assessment may, therefore, have as its center of gravity either (i) health conditions and the impairments associated with them; (ii) functional limitations in basic or simple activities, understood independently of environmental or contextual differences; or (iii) disabilities fully understood as outcomes of interactions between features intrinsic to the person (health conditions, impairments, and functional limitations) and the full range of environmental factors that, possibly uniquely, characterize the overall lived-context of the individual. This three-part categorization of assessment strategies, or something very close to it, has been suggested before in the literature,<sup>xii</sup> but here for simplicity they can be labelled the **Impairment**, **Functional limitation**, and **Disability** approaches.

Some legal analysts argue that there is yet another and very different approach to the assessment of disability that falls completely outside of this three-part distinction. This is the so-called **Economic Loss approach** for calculating the decrease in earning capacity in

an individual who has suffered an injury. This strategy may arise in the determination of damages for an injury caused by another individual's negligence, or as in the case of workers' compensation programming, a determination of benefit from a work-related injury.<sup>xliii</sup> In either case, the two-step procedure first looks at medical evidence for a threshold verification of the existence of an injury or occupational disease and this is followed by a calculation—based on the claimant's previous income or an estimate of what the claimant could now earn based on wage trends—as to the income-earning capacity difference pre- and post- injury. This calculation is the basis for legal damages or the benefit the claimant will received for workers' compensation.

Although the economic loss approach is widely used, it is not in fact an assessment of disability at all but rather a method for quantifying the amount of benefits that presumes a prior determination of disability, often using an Impairment strategy. The link between the extent of work disability and amount of benefit is completely determined by economic decisions having to do with cost of living, wage trends, estimates of the costs of health and rehabilitation needs, and so on. One could argue that there is logical correlation between work disability and this calculation—since, for example, 0 percent work disability would correlate with 0 percent benefit; 10 percent work disability with 10 percent benefit, and so on—but the actual amount of the benefit is not itself a function of extent of work disability, nor is it strictly speaking an assessment of disability.

By the same token, although the purposes are very different, an estimate of the amount of care needs incurred from the onset of an injury or chronic health condition is often calculated without any explicit determination of the extent of a person's disability. These costs are highly dependent on a country's level of development, the availability of relevant resources and the market value (or other economic estimate) of the goods and services required for the needs assessments, presumed population norms concerning expected levels of employment, cost-of-living, poverty levels, and so on. The actual economic calculations are independent of, and typically rely on very different assessment methodologies, than disability assessment.

These tangential examples to one side, the three general strategies of disability assessment mentioned can be conveniently distinguished, first in terms of the operationalization of 'disability' each presupposes, and then, for concreteness, in terms of standardized instruments or guidelines characteristically relied on and the assessment criteria used to determine the presence and extent or severity of disability. For concreteness as well, the example of work capacity or work disability will continue to be the case-in-point to highlight these differences.

It is important to emphasize that as a general taxonomy, these are essentially ideal types rather than descriptions of existing national disability assessment regimes. In practice, the three strategies are not found in pure form but are merged, sometimes revealing inconsistencies in how the assessment procedures are applied for different policies at different times, different regions of the country or different sub-populations (for example, veterans are often assessed with different approaches than the general

population). Especially in high income countries with sophisticated, highly dynamic, complex and politically-contentious disability policy, even when a relatively pure form of an assessment strategy was originally put into place, over time political and economic pressures may produce hybrid *ad hoc* procedures that cannot easily be categorized.

### (a) Impairment approach

The Impairment approach understands the process of assessing a person's work capacity as one of assessing, or if possible measuring, the severity of an underlying health condition—acute or chronic disease, injury or psychological disorder, ageing—and in particular identifying, and if possible measuring, medically describable physical and mental impairments.

An impairment is understood as anatomical, physiological, or psychological abnormality or problem in functioning identified through self-report and verified by medically or bio-medically recognized clinical and laboratory diagnostic techniques and tests. Since body functioning is measurable on a continuum from (theoretically) perfect functioning to total lack or absence of functioning, in order to identify the range on that continuum that constitutes a 'problem' or 'abnormality'—and so an impairment—will depend on where a 'threshold' on the continuum is placed. That can be done bio-statistically in terms of population norms of normal levels of functioning or in some other manner.

Given the large number of biological functions (and bodily structures like bones and joints) at work in the human body, a determination of 'normal functioning' is not a trivial matter. Depending on the underlying health condition, determination of impairments can be made on the basis of diagnosis alone, especially when there is a straightforward and uncontroversial link between the disease or injury and the resulting impairments. In other cases, involving purely subjective symptoms such as pain or anxiety, self-report may be the only available source of information (especially if time is limited), although clinical collaboration is often sought. There are, of course, a vast array of clinical or self-report instruments in use for assessing physical and mental functioning, linked to specific diseases, or generic.<sup>xliii</sup>

As a strategy for disability assessment, the Impairment approach assumes that even for complex and environmentally-influenced phenomena such as the capacity to work, it is sufficient for assessment to verify the existence in the individual of an underlying health problem and the associated impairments and then to assess the severity of these impairments. The Impairment approach does not claim that disabilities are nothing more than impairments, or that disabilities are not complex products of intrinsic impairments and environmental conditions.<sup>xliiv</sup> The strategy merely insists that all that is required in order to validly and reliably assess disability is sufficiently robust information about health conditions and impairments. Disability assessment can be validly and reliably inferred from impairment assessment.

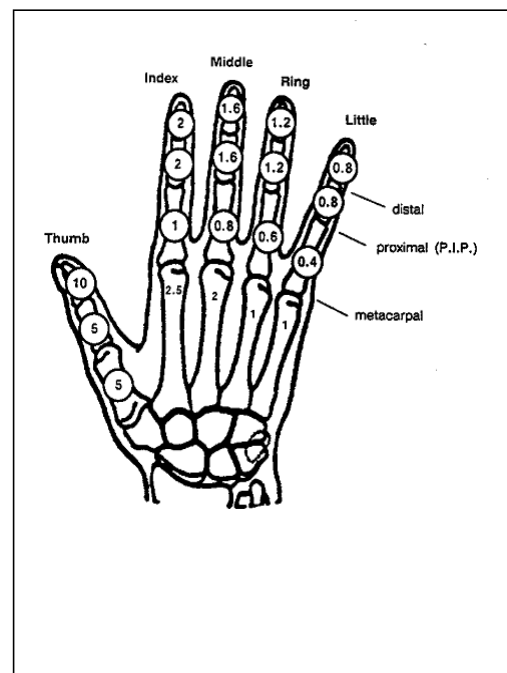
The Impairment approach is both the oldest, and the most commonly used strategy of disability assessment around the world. This remains true despite decades of unrelenting

criticism from many quarters that the impairment approach distorts disability assessment.<sup>xlv</sup>

The Impairment approach is closely linked to what is often called Baremas assessment, a term that comes from the 17th century French mathematician Francois Barrème who devised a table of ordered percentage values for different kinds and severities of bodily damage. Scales of compensation for war-related injuries date back much further: to mediaeval Europe (the so-called *Knochentaxe*, bone-rate or *Glidertax*, limb-rate). When Otto von Bismarck built up the German social insurance system, introducing for the first time benefits for children, workers' compensation, invalidity and old age retirement benefit, the Bareme approach was adopted. The approach then spread as the Bismarckian model for social insurance spread across Europe and the world.<sup>xlvi</sup>

**Figure 2.1: Bareme Table and Chart for the Hand**

Hand Amputation	Percentage
Thumb, including metacarpal	20.
Thumb, both phalanges	15.
Thumb, one phalanx	10.
Finger, index	5.
Finger, index at P.I.P.	4.
Finger, index at distal	2.
Finger, middle	4.
Finger, middle at P.I.P.	3.2
Finger, middle at distal	1.6
Finger, ring	3.
Finger, ring at P.I.P.	2.4
Finger, ring at distal	1.2
Finger, little	2.
Finger, little at P.I.P.	1.6
Finger, little at distal	.8



Technically, a Baremas method of assessment is any arbitrary ordinal scale that attaches percentage values to levels of disability based on impairment of some body part. Bareme scales are very commonly used around the world—primarily for workers' compensation assessment—and map particular impairments to 'whole body' disability percentages. Nearly every country of the world that has a formal procedure for disability assessment has at one time used, or continues to use, some form of the Baremas system. The example shown in Figure 2.1 is part of a Baremas chart and table in use in the Canadian province of Ontario to assess disability associated with specific impairments (amputation) of parts of the hand.

The most complex and sophisticated form of the Bareme system is the American Medical Association (AMA) *Guidelines to the Evaluation of Permanent Impairment* (more commonly called the *AMA Guidelines*), first published in 1958 and now in its 6<sup>th</sup> edition.<sup>xlvi</sup> The *AMA Guidelines* are used as the primary disability assessment instrument across the United States and in many English-speaking countries, and are informally relied on in many other countries. When the *AMA Guidelines* were first proposed in 1958, it was argued that the determination of impairments was a medical expertise, which led to the heavy reliance on physicians as disability assessors. Yet, the editors of the *AMA Guidelines* have always insisted that impairments are not the same as disabilities and impairment assessment is just the first step in a longer process of disability evaluation, whether for determination of workers' compensation or eligibility for social insurance or pension benefits: "Failure to recognize the differences between a medical construct, impairment, and a contextual construct, disability, results in significant confusion and controversy."<sup>xlvii</sup> The ratings in the *AMA Guidelines*, it is argued, do no more than provide a best medical guess, in terms of percentage ranges, of how much a person's life, and in particular his or her working life, would be affected by the impairments he or she has.

Given the practical difficulty of getting sufficiently detailed medical diagnostic information, the *AMA Guidelines* is viewed as the only solution for a workable national assessment procedure that is cost-effective. If one restricts one's focus to the costs and benefits directly linked to the assessment procedure itself, this is undoubtedly true. This is because a true disability assessment would have to take into account each individual's full environmental context, but doing so is expensive and time-consuming, and in some instances impractical. Although there is some debate on this point, the view is that the *AMA Guidelines* have a moderate degree of inter-rater reliability and construct validity.<sup>xlvi</sup> But be that as it may, from purely legal or administrative perspective, however, the *AMA Guidelines* are viewed with favor as an authoritative standard, and because of this will continue to be an attractive option.<sup>l</sup>

### **(b) Functional Limitation approach**

The Functional Limitation approach arose in the 1970's in response to criticism of the Impairment strategy, fueled by rehabilitation professionals who argued that physical examination and medical history-taking provided an insufficient evidentiary basis for assessing work disability.<sup>li</sup> This was especially true when assessors were asked to make a judgment about employability – the extent to which, with suitable rehabilitative services, residual functional ability could be augmented so that the person could return to work. It was argued that a person's work capacity depended on the extent to which he or she could perform very basic, and easily assessed, actions such as lifting, standing, walking, sitting, carrying, pushing, pulling, climbing, balancing, stooping, kneeling, crouching, crawling, reaching, handling, fingering, talking, feeling, hearing, and seeing. These 'functional capacities'—or 'basic activities' as they are often called—were thought to be essential predictors of work capacity. They were especially useful when more nuanced employment decisions needed to be made, such as whether the individual could find jobs that required the same skills as the old one, but did not make the same kinds of demands



on functional capacities that had been affected by the disease or injury. In the United States in particular, reliance on these indicators became a central feature of the work disability assessment for social security programing.<sup>lii</sup>

The attraction of the Functional Limitation approach was that impairment assessment alone, even in the sophisticated form of the *AMA Guidelines*, ignored the essential predictive features of work capacity, namely the ability to perform basic actions. To take a simple example, the *AMA Guidelines* assesses the disability associated with an impairment of the index finger as 20 percent. But this same impairment would make far more difference to the employability of a dentist than of a hotel manager as the two professions make very different demands on the basic action of fine hand movements. What is a trivial impairment for one job might be a serious employment impediment for another job. Functional information was required for practical work capacity assessment, and information about impairments was not sufficient.

In standard rehabilitation language, the Functional Limitation approach characterizes disability as an individual's capacity to perform a set of simple actions, and combinations of simple actions—the 'Activities of Daily Living' (ADLs)—as well as more complex actions, often requiring the use of simple tools—'Instrumental Activities of Daily Living' (IADLs). The focus on basic actions aligned well with the clinical life of the rehabilitation therapist in the assessment of patients for whom it is essential to know whether they have the capacities required for 'independent living' such as self-care, housework, taking care of children, shopping, managing medication, and so on. The clinical judgment that a patient could manage day to day life on his or her own was a clinical milestone of great importance. A wide range of clinical instruments were commonly used for just this purpose: the Functional Independence Measure (FIM) being the most popular.<sup>liiii</sup> Since it would not be clinically feasible to assess work capacity directly – given the wide range of different capacities required by different jobs and job expectations – at least a direct assessment of those basic activities (presumptively required for any job) would give a much more accurate picture of work capacity and employability. On the basis of functional capacity information, in short, the disability assessor would be on firmer ground when he or she inferred work capacity.

Responding to the need for instrument more focused on work capacity, a new range of Functional Capacity Evaluation (FCE) tools were developed and recommended for disability assessment. FCEs are standardized batteries of tests of basic capacities, designed for clinical use, that offer a summary evaluation of capacity to work. Worldwide there are many FCEs, some designed for generic application across health conditions (e.g. the Working Capacity Assessment used in the UK)<sup>liiv</sup> and a range of others linked directly to specific diseases or conditions (e.g. Disability of the Shoulder, Arm and Hand Questionnaire (DASH) and the Pain Disability Index), or more general, such as the Blankenship, Ergo Work Simulator and Ergo-Kit variation, the Isernhagen Work System, Hanoun Medical, Physical Work Performance Evaluation (Ergoscience), WEST-EPIC, and AssessAbility.<sup>liiv</sup>

Even in the context of disability assessment for social security and income replacement programs, where employability is not always the primary focus, the Functional Limitation approach offered the prospect of better disability assessments than resulted from Baremas tables that mapped disability-percentages onto impairments or disease symptoms. Moreover, the Functional Limitation approach could easily incorporate Baremas generalizations about the impact of impairments on work disability and, when available, augment or adjust these assessments accordingly by using a FCE instrument.

Since these instruments were introduced, most high resource countries have adopted a mixed assessment regime in which both impairment-based and functional capacity assessments are used in combination. Often the Impairment approach is used as a screening tool to distinguish between applicants with very severe impairments—blindness, deafness, tetraplegia, and severe intellectual impairment—who are assessed as immediately qualifying for benefits, leaving those with less severe or more complex impairment profiles to undergo a second more subtle assessment process using functional capacity assessment. This two-stage step has the additional advantage that, in light of general economic or demographic changes, the policymakers can adjust the rate of successful applications by manipulating the criteria at either stage.

### **(c) Disability approach**

The principle difference between the Disability approach and the previous two is that here work capacity is *directly* assessed rather than *indirectly inferred* from a proxy impairment or functional capacity assessment. Direct assessment, in principle, gives equal consideration to all determinants of disability—medical, functional, environmental and personal. The disability approach, in its purest form, would be fully individualized and based on direct evidence. It would strive to provide valid assessment directly on evidence, rather than an approximation by inference.

The Disability strategy assumes that the object of the assessment is a person-environment, interactive outcome rather than an intrinsic feature of the person (impairment or functional capacity). Disability assessments make the most sense when they are context-dependent rather than global; that is, an assessment of work disability or education disability rather than disability *sans phrase*. In this way, the environmental context is delimited by the focus of the life area, although with the recognition that with the relevant environmental determinants of work, disability may well extend far beyond the workplace itself to include, for example, features of public transportation and communication environmental factors. Finally, in principle, the Disability approach assembles information about the non-health aspects of the individual person: education level, skills, ambitions, temperament, life goals, and so on.

Recently, in high income countries such as the Netherlands, Germany, France, Sweden, Canada, and the United States, at some stage in the full disability evaluation process, steps are being taken to move beyond the Impairment and Functional Limitation approaches to the full Disability approach. This is also happening in less resource-rich

countries as well. Cyprus, for example, has fully applied the disability approach to its disability assessment. Argentina and Brazil have also introduced disability approach to a certain degree. The best evidence that a country's disability evaluation procedure is turning toward the Disability approach is when assessors are legally obliged or otherwise required to take into consideration the extent to which the claimant, if provided with rehabilitative or other services, could return to a previous job, or alternatively whether changes to the workplace could be effected to facilitate return to work. Conceptually, these issues can only be approached systematically if disability is understood as an outcome of an interaction between features of the individual (impairments, functional capacities) and the person's environmental context. Arguably, the notion of work disability, if taken seriously would force assessors in this direction since the determinants of successful employment are both personal (skills and capacities) and environmental (workplace and working conditions).

It should be noted, however, that despite the recognition that the Impairment and Functional Limitation approaches are inadequate for the kind of robust and information-rich disability assessment required for employment policy, these two approaches—singly or in combination—continue to be relied on. Part of the reason for this is entrenched traditions and the understandable tendency to avoid what might be perceived as a radical shift in policy and practice, especially since most disability policies are already highly contentious.

Another factor is that the interactional or disability approach challenges our common assumptions about the impact of even severe impairments on work disability. Although in most countries a person who is blind would be assessed at 100 percent disability, on the Disability approach that individual might not be assessed as having a work disability. This would be the appropriate assessment on condition that the person who is blind had full and adequate accommodation making it possible for him or her to work up the level of any non-blind peer. This shift in assessment outcome would involve a tremendous change in the perception of what disability is, and what people with disabilities are capable of—a shift that might simply be impossible for policy-makers to comprehend and accept.

Yet another contributing factor to the deeply rooted entrenchment of the Impairment and Functional Limitation approaches is that they have been the dominant strategies of disability assessment around the globe for quite some time and hence related instrumentation—such as the *AMA Guidelines* and *FCE*—are readily available. Furthermore, disability assessment professionals have been educated and trained to apply these approaches and related instrumentation. In contrast, it has only been in the last decade or so, with the development of ICF-based assessment instruments and other applications, that the full Disability approach to assessment has become more popular. However, while there is a long and scientifically respectable tradition of health and functioning assessment instrumentation in the rehabilitation professions, except in the special case of assistive technology, it is fair to say that the science of environmental assessment is still in its infancy<sup>lvi</sup>.

**Table 2.1. Impairment, Functional and Disability Approach to Disability Assessment: A Summary of Characteristics**

Approach	Conception of 'disability'	Standardize tool or guideline	Criteria
<b>IMPAIRMENT</b>	<b>Medical</b>  Health state (injury, disease or syndrome), Plus problems with body functions and structures	<b>Impairment guidelines:</b>  <i>AMA Guidelines for the Evaluation of Permanent Impairments</i> (6 <sup>th</sup> ed.)	<b>'Baremas' criteria:</b>  Presence of problem at the body level as indirect indicator of 'whole person' or disability rating
<b>FUNCTIONAL</b>	<b>Functional</b>  Problems or limitations in basic activities	<b>Functional Capacity Evaluations (FCE):</b>  <i>Functional Status Questionnaire</i> <i>Disability Assessment Structured Interview</i> <i>Work Ability Index, etc.</i>	<b>ADL/IADL criteria:</b>  Presence of a problem or limitation in basic activity as indirect indicator of disability rating
<b>DISABILITY</b>	<b>Disability</b>  Disability is the outcome of an interaction of health condition and environmental factors at the body, person and societal levels	<b>Disability Assessment:</b>  WHODAS2 <sup>vii</sup> ICF Checklist <sup>viii</sup> ICF Core Sets <sup>lix</sup>	<b>Bio-psycho-social criteria:</b>  Description of kind and severity of disability as an outcome of interaction between an individual's health and functional capacity and environmental factors
<b>INFORMAL</b>	Determined by assessor	Determined by assessor	Determined by assessor

### Strengths and weaknesses of the disability assessment approaches

Especially in middle and higher income countries, the evolution of disability evaluation for policy and insurance purposes since the late 19<sup>th</sup> century shows a gradual progression from simple Bareme or impairment-based approaches to complex and mixed medico-social evaluations involving multi-professional experts as assessors aiming at more direct, disability assessments. As these are neither purely clinical nor abstractly academic exercises—but rather official evaluations carried out in the context of an explicit legal, institutional and administrative framework—disability assessments must always seek a balance between considerations of quality (validity, reliability, transparency and standardization) and practical feasibility. It is against this complex background that the unique strengths and weaknesses of each of the disability assessment methodologies need to be evaluated.

### (a) Impairment approach: strengths and weaknesses

The Impairment approach to disability assessment, and especially the assessment of work capacity, has been and remains the most common approach used around the world, although increasingly in middle and high income countries the trend is to augment the Impairment approach with functional capacity information, and in some regimes, environmental information as well. Nonetheless, the Impairment approach is popular because it is intuitive and simple, relies on medical information perceived to be objective and reliable, and calls upon the expertise of medical professionals who are highly regarded as reliable and trustworthy. When some version of Baremas instrumentation is used—such as in the United States the *AMA Guidelines* or the *Social Security Impairment Listings*—the Impairment approach can claim a measure of both scientific legitimacy and administrative feasibility.

At the same time, it has been argued repeatedly that the Impairment approach is inadequate as a strategy for work disability assessment. Even on its own terms, a Baremas system that allocates percentage disability ratings on the basis of impairments confronts four technical problems:

- *Comparability*: how is it possible to quantitatively compare the rating for a fractured leg with that for schizophrenia in terms of disability?
- The *Paired Organs Problem*: why should losing one eye have a single disability rating when in some instances the lost eye was the person’s remaining eye?
- The *Whole Body Problem*: if a person has lost a finger (rated, say, as 10 percent disability), has back pain (20 percent) and depression (40 percent), does it make sense simply to add these ratings together for a whole person disability rating?
- The *Threshold Problem*: if a disability pension policy requires an 80 percent disability rating, is it conceivable that an assessor could distinguish between a person who rates 79 percent and one that rates 80 percent?<sup>lx</sup>

These and related puzzles are addressed in the *AMA Guidelines* (primarily by providing a discretionary range of percentage values rather than single values), but they are symptomatic of the larger problem of transforming a clinical judgment about an impairment into a precise percentage rating about whole person disability. Existing Baremas ratings show substantial variations between countries: an amputation below the knee is valued at 70 percent disability in Belgium, 50 percent in the UK, and 35 percent in Iceland.<sup>lxi</sup> Lack of comparability is compounded by the common sense observation that the same impairment may have very different impacts on different people depending on the other health conditions or impairments they have, not to mention the very different physical or mental demands that their jobs may require.

As already pointed out, the two most sophisticated Baremas schemes in the world—the *AMA Guidelines* and the *Impairment Listings* used by the US Social Security Administration for Social Security Insurance (SSI) and Social Security Disability Insurance (SSDI)—represent the state of the art of impairment tools for disability assessment. Yet even these

have been criticized on purely scientific grounds for inconsistency and ambiguity in disability rating, lack of consistency across organ systems, the failure of the ratings to reflect, functionally, what it means to live with an impairment, poor reliability and predictive capability arising from the absence of a sound medical evidence base and a total reliance on expert consensus.<sup>lxii</sup> They have also been criticised on grounds of fairness: there is a lack of parity in assessment between physical impairments and mental impairments;<sup>lxiii</sup> a tendency to rate impairments that affect only males as more serious than those that affect only females;<sup>lxiv</sup> and assumptions of 'normal' living conditions that are prejudicial between races and economic classes.<sup>lxv</sup>

In the face of these and many other criticisms, the defensive response has been three-fold: (i) there is no 'gold standard' for linking impairments to disabilities, so an expert-consensus methodology is the best there is; (ii) though impairments are very different from disabilities, still Baremas systems are useful guides for a first step in a more complex disability assessment; and (iii) whatever its faults, the Impairment approach is administratively feasible and sufficiently authoritative to satisfy the policy requirements of work disability assessment. On this last response, it is noteworthy that after a ten year, multi-million dollar effort to 'redesign' the disability evaluation process used by the US Social Security Administration, in order to more validly capture the contextual notion of work disability, the result was the decision to retain the Impairment approach:

"...disability is complex, and it has medical, functional, and vocational components. A complete and comprehensive assessment of all aspects of the definition would require a detailed clinical evaluation of the underlying medical cause(s) for the impairment; analysis of the expected duration of the impairment (prognosis); a comprehensive assessment of the work-related functional limitations attributable to the impairment as well as the individual's remaining functional capacity; a detailed vocational analysis of the individual's work history and acquired work skills, educational background, and age; and a thorough analysis of the individual's current vocational prospects. However, SSA does not have the resources to perform such an extensive assessment for every one of the 2.6 million disability applicants who will come through its doors in 2007."<sup>lxvi</sup>

#### **(b) Functional Limitation approach: strengths and weaknesses**

The Impairment approach is inconsistent with the clinical experience of medical and rehabilitation professionals for whom work capacity depends, not merely on the diseases, injuries and impairments a person has, but on the impact these medical problems have on basic and everyday actions that people need to perform. Sitting, standing, reaching, grasping, remembering, and concentrating do not, even in combination, fully capture what is required to perform all work requirements. But without these basic capacities, it would be extremely unlikely that a person would be able to perform most any job.

Over time, authors of both the *AMA Guidelines* and *SSA Impairment Listings* have transformed these tools to include some functional capacities. In the last, 6<sup>th</sup> edition of

the *Guidelines* a list of ‘adjustment factors’ have been added so assessors can use the claimant’s functional capacity status to modify the impact of an impairment on ‘normal activities’ such as walking and standing. In the *Listings*, since 2007, items such as ‘*Inability to ambulate effectively*’ and other versions of functional capacity have been included. These days, because of the strength of the argument in favor of the Functional Limitation approach, in high income countries it is rare to find an example of a purely Impairment based method of disability assessment.<sup>lxvii</sup>

Because of its origins in the rehabilitation literature, the Functional Limitation approach has been closely associated with rehabilitation questionnaires and other clinical instruments used for Functional Capacity Evaluation in work injury prevention and rehabilitation. These instruments are easily transferable to work capacity determination, especially for assessments of return-to-work potential. Although they differ in many respects, depending on their primary area of use, at the core of any FCE is a battery of clinical tests and self-report questions that identify the essential work-related functional capacities, with measurement algorithms to produce summary scores.

Despite concentrated clinical and research efforts to develop an international standard FCE for work capacity evaluation—one that has both scientific and clinical authority and is feasible to use—the results have been disappointing. Construct validity and inter-rater reliability are notoriously poor in all FCEs, and there has been much criticism of their failure to take into account either general mental capacities relevant for work, or more specific ones that are characteristics of specific kinds of employment.<sup>lxviii</sup> It also remains an open question whether the appropriate mode of assessment for FCEs is self-report, clinical performance testing or clinical observation, or some combination of these. In use, even the most popular FCEs tend to focus on a person’s deficits—the capacities that, because of injury or disease, the individual has lost. Yet, there is a consensus that a person’s physical and mental assets and strengths are extremely important information for a work disability assessment.

In the end, the fundamental weakness of FCE is that it is difficult to come up with the domains or areas of functional capacity that are highly and consistently correlated with a standardized ‘capacity to work’, given the enormous variety of work requirements and kinds of employment situations. As noted, the usual approach is to assume that certain ADL ‘basic activities’ are required for any job; yet even if we could agree on what these basic activities are, the list would never be complete enough to accommodate shifting patterns of work skills and requirements as the overall labor market alters to respond to economic or other national or global influences.<sup>lxix</sup> Traditional FCEs also ignore important individual differences in personality, motivation, and vocational interests.<sup>lxx</sup>

Most importantly, functional capacities in basic activities do not accurately predict employability since one’s capacity to work always depends on environmental or contextual factors. These factors include assistive devices that directly aid the individual at the work place, as well as facilitating environmental modifications and other accommodations that can positively restructure the workplace and the requirements of

the job. Together these factors can make it possible for a person with impairments to return to work, or to enter the workforce for the first time. Yet, these factors are ignored in functional capacity assessment.

In the end, the fundamental weakness of the Functional Limitation approach is essentially the same as the Impairment approach: it relies on a proxy assessment—and a weakly correlated proxy at that—of work disability. Medical evidence including information about impairments, although certainly important information for a determination of work disability, ignores the impact of functional limitations in the performance of basic activities. But when this additional information is considered—even assuming that unsolved issues mentioned above can be resolved—the results ignore the often determinative impact of the working environment on work disability.

### **(c) Disability approach: strengths and weaknesses**

The Disability approach to disability assessment addresses the weaknesses and limitations of both the Impairment and Functional Limitation approaches. First, it is a direct assessment rather than some indirect or proxy which, as in the case of the Impairment approach, is two steps removed from the reality under assessment. And second, at the core of this approach is a complete conceptualization of disability as an “interactional” phenomenon, providing a framework for its operationalization.

The critics of the Disability approach insist that it is not a viable option because the concept of disability is either too politically contentious for any direct standardized conceptualization or else, if some robust conception of disability is accepted, an assessment based on it is not feasible given the enormous amount of information about the person, the person’s work environment and all other contextual factors, that would need to be collected and analyzed.<sup>lxxi</sup> This very practical consideration can be easily transformed into a substantial theoretical obstacle given the realization that there may be no knowable ‘saturation’ point where we can be confident that we knew enough about the individual’s environmental context to make an evidence-based judgment about what in the person’s environment matters and what does not. Since in principle every feature of the physical, human-built, interpersonal, attitudinal, social, political, economic and cultural context is a potential determinant of the individual’s experience of disability, at what point could we be confident that we knew enough to sufficiently understand that experience for disability assessment?

The first of these assertions that the concept of disability is too contentious cannot be easily dismissed, even with the increased worldwide uptake of the ICF and the adoption by the United Nations of the CRPD that embodies an interactional conception of disability. Even if there are good reasons to be optimistic that the conceptual power of the interactional approach to disability is such that it will become the standard view, it remains to be seen whether the ICF provides countries with the knowledge resources and practical instruments needed for them to make the shift to the Disability Approach. This issue will be taken up in the next two chapters.



The more general concern about the feasibility of the Disability approach is another matter. It is true that in some countries, especially in Europe, the Disability approach has been consciously adopted, if only partially, as the basis for work disability assessment. The Netherlands is a notable example. Operationally, the Disability approach presumes that a substantial amount of information is in principle available: information about health conditions and impairments, about functional capacities related to the claimant's actual or potential employment options, and about features of the environment that define the workplace and the employee's position within it. Since health condition and impairment information tends to be more readily available, it is environmental or contextual information that counts as 'value added' of the Disability approach.

Given the sheer range and volume of environmental information, it is useful to distinguish between information that is proximate and directly descriptive of work disability and information that is more distal and indirect. The first set of data includes a description of work requirements or physical and mental demands (including the level of stress and other work pressures a worker will experience). It will also include broader descriptions of the work environment; including the physical environment—buildings, equipment, furniture, air, and sound quality; the interpersonal environment—co-workers and employers, customers and clients; and other work parameters—time and scheduling demands.

The second set of contextual data is about the more abstract and less well defined environmental factors that indirectly shape the work environment. Here we might include features of the labor market, in general or by sector, the overall level of political and economic development of the country, social attitudes towards the type of employment, relevant employment legislation, including health and safety requirements, anti-discrimination provisions, and so on.

All of these factors, proximate and distal, shape the work situation in ways that are relevant to a determination of an individual's claimant's work situation, and so to a claimant's level of work disability.<sup>lxxii</sup> What is most needed, however, is information both about, in the terminology of the ICF, environmental *facilitators* (e.g. the availability of work-related assistive technology, or work scheduling flexibility to accommodate health or impairment needs) and *barriers* (e.g. prejudicial or stigmatizing attitudes of co-workers, customers or employers, the absence of health insurance, or lack of availability of suitable employment in the labor market). Knowing both what helps and what hinders work performance allows the assessor to truly capture work disability.

Yet, in the face of this potentially enormous amount of relevant information about the work situation – even if we ignored the theoretical issue of defining the level of evidentiary 'saturation' – it is understandable why there is general skepticism about the Disability approach. It is the weakness of the approach. Although there is a substantial literature in vocational rehabilitation and related employment-related disciplines about the impact of work environmental factors on work disability—indeed no employment

counselor or therapists would ever doubt this—as yet there are no standardized instruments for assessing work environment for determination of work disability.

The challenge of the Disability approach, therefore, is to address this very practical issue of the feasibility of putting into effect an assessment process that is reasonably full and complete—one that does not rely on screening criteria or proxies for disability, but assesses, in a manner adequate to the purposes of the policy or program that requires assessment for eligibility, the phenomenon of disability itself. This is the challenge of the Disability approach. And this is the challenge that ICF needs to address as well. But to see this, we need to describe the ICF in some detail.

## Chapter 3

# Introduction to International Classification of Functioning, Disability and Health

### Chapter 3: Summary

- *The ICF provides a comprehensive and standardized framework and language for the description of functioning and disability.*
- *The ICF model is a clear expression of the interactive model of disability about which there is worldwide consensus.*
- *Simple and complex human actions are conceptualized in the ICF both in terms of the intrinsic capacities of the person to perform these actions (Capacity perspective) and in terms of the performance in the individual's actual environment (Performance perspective).*
- *All aspects of human Functioning are represented by the ICF component concepts of Body Functions, Body Structures, and Activities & Participation.*
- *ICF has a classification of Environmental Factors: the complete physical, human-built, interpersonal, and social universe in which people live and act.*
- *The ICF is only concerned with objective description, not the subjective assessment or evaluation of health-related states of Functioning.*
- *In the ICF, conceptually, both a person's health state and environmental factors are determinants of disability.*
- *The classification of the ICF is arranged hierarchically in a standard 'genus-species' or 'parent-child' arrangement.*
- *To be meaningful, an ICF code requires at least one qualifier. Qualifiers provide the full description of a person's level of Functioning or Disability.*
- *The distinction between the perspectives of Performance and Capacity is essential to the interactive model in the ICF.*
- *The ICF and the International Classification of Diseases (ICD) are best used together for most epidemiological, health systems, and health and disability policy purposes.*
- *The conceptual and practical linkages between these two international standards are in the process of being optimized with the development of the 11<sup>th</sup> Revision of ICD, due by 2017.*

In May 2001, the ICF of the WHO was unanimously endorsed by the World Health Assembly. The ICF provides a comprehensive and standardized framework and language for the description of *Functioning and Disability*.<sup>lxxiii</sup> To better understand the meaning of 'Functioning' as this term is used in the ICF, a multidimensional model is presented of the interaction between health features of the person and features of the person's complete physical, human-built, attitudinal, and socio-political environment. The ICF model is thus an expression of the interactive model of disability about which there is worldwide consensus. The ICF was explicitly developed to express the person-environment, interactive model. As an international standard, the ICF provides separate classifications of the components of Functioning and Environmental Factors, each of which is composed of domains (chapters and blocks) and categories. Qualifiers are provided to describe the extent of the individual's problems in Functioning; that is, the extent of Disability denoted by each domain and category variable. This chapter provides an introduction to the basic concepts of the ICF in order to set the stage for the next chapter in which both the added value, and the potential limitations, of the ICF as a design framework for disability assessment, within the context of disability evaluation procedures, will be discussed in detail.

### The interactive model of the ICF

'Functioning' is the technical term used in the ICF as an umbrella, or overarching, term to include all aspects and dimensions of how humans function, behave and act, from the essentially biological functions (and structures) of the human body and mind to the vast variety of simple and complex actions that a person engages in. These simple and complex actions are conceptualized from two perspectives: firstly in terms of the intrinsic capacities of the person to perform these actions, and secondly in terms of the actual performance of these actions, simple and complex, in interaction with the complete context in which the person lives (as characterized by environmental factors). The first perspective is called **Capacity** and the second **Performance**.

All aspects of human Functioning are represented by the ICF component concepts of Body Functions, Body Structures, and Activities & Participation. These concepts in turn are classified into mutually exclusive and jointly exhaustive sets of domains and categories (or classification variables) by the classifications of the same names. In addition, there is a classification of Environmental Factors that define the complete context in which human functioning takes place; that is, the complete physical, human-built, interpersonal, and social universe in which people live and act.

*(To avoid confusion, all ICF-specific terms will continue to be capitalized even though some of them—most notably 'disability'—are not technical terms but are commonly used to denote the phenomena that ICF is conceptualizing.)*

Functioning is the positive notion comprising of domains of human bodily functions and individual simple and complex actions, understood on a *continuum* from complete or optimal Functioning to no or total lack of Functioning. Disability is a derivative notion,

namely that range of the continuum of Functioning, for a specific domain, that we have reason to identify as being problematic. In the ICF, there is no suggestion, or any intention, to identify disabilities normatively as abnormalities or inferiorities; they are understood simply as levels of Functioning that, for various reasons, it is thought important to identify as sub-optimal or problematic for the individual. Disability, for a specific domain, thus presumes a given threshold or level of Functioning, below which is sub-optimal or problematic, for some reason. Significantly, *the ICF itself does not set or specify these thresholds or anchor points*. The ICF is an international classification, not a normative standard that set international thresholds for when, for a particular domain, a reported level of Functioning is sub-optimal or problematic – that is, a disability. Those thresholds will be set and justified by the user of the ICF, to serve the user’s specific needs.

While the ICF is a classification of dimensions of Functioning and Disability as experiences of the individual, it is not a description of the individual’s own perception, assessment, or evaluation of these experiences. The ICF provides the ‘vocabulary’ for an objective description of a state of affairs associated with an individual’s health state, and this is independent on the individual’s subjective judgment about this state of affairs. If, for example, an individual experiences a level of visual acuity that is below a threshold established in terms of population norms for this Body Function, the ICF can be used to describe this as an ‘impairment of visual acuity’. The individual him or herself may not care about this impairment, may assess it negatively or not, or may simply ignore it as irrelevant to his or her life. These reactions constitute an extremely significant, subjective perspective that is linked to quality of life or subjective well-being; but they have no effect on the objective fact of visual impairment. The ICF is only concerned with objective description, not subjective assessment of health-related states of Functioning.

Depending on the dimension of Functioning of interest, Disability is denoted as a matter of *Impairments* of Body Functions and Body Structures, *Limitations in Activities* and *Restrictions in Participation*. Functioning and Disability are thus overarching terms that identify these parallel dimensions (the dimensions and definitions of all these components are presented in Table 3.1).

**Table 3.1. Definitions of the Components of the Model of Functioning and Disability**

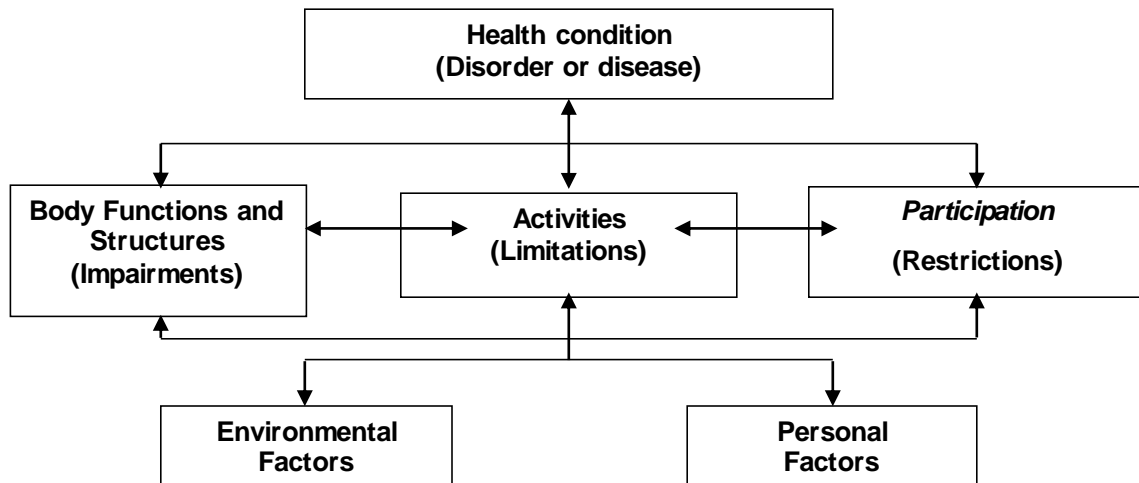
Positive	Negative
<b>Body Functions</b> are the physiological functions of body systems (including psychological functions)	<b>Impairments</b> are problems in body functions or structures such as significant deviation or loss
<b>Body Structures</b> are anatomical parts of the body such as organs, limbs and their components	
<b>Activity</b> is the execution of a task or action by an individual	<b>Activity limitations</b> are difficulties an individual may have in executing activities
<b>Participation</b> is involvement in a life situation	<b>Participation restrictions</b> are problems an individual may experience in involvement in life situations
<b>Facilitators</b>	<b>Barriers</b>
<b>Environmental Factors</b> make up the physical, social and attitudinal environment in which people live and conduct their lives and can act as facilitator or barrier	
<b>Personal Factors</b> are the particular background of an individual's life and living and comprises features of the individual that are not part of a health condition or health state.	

Although Functioning is conceptually linked to a health condition (a disease, disorder, injury or a natural process such as aging), it is not conceptualized as the direct causal consequence of a health condition but rather as the experience of living with a health condition. While it is often possible to accurately describe a level of Functioning independent of the environment, our actual experience of Functioning takes into account our world, so that our experiences are always the outcome of the interaction between health condition and Environmental Factors. The ICF also recognizes the possibility of interaction with non-health Personal Factors such as age, gender, educational and other life experience, coping style, and so on. This dimension has been left for future classification.<sup>lxxiv</sup> In principle, all domains of Functioning—Body Functions, Structures, and Activities & Participation—are therefore experienced as outcomes of interactions with environmental and personal Contextual Factors.

It is crucial for the application of ICF in the context of disability assessment to stress the fact that the dimensions of Health Conditions, Body Functions and Structures and as well Activities & Participation *viewed from the Capacity perspective* are all phenomena that are intrinsic to the human body and are, so to speak 'under the skin'. These intrinsic states can then be contrasted with the individual's lived experience of these states ('health states' for short) which is the Performance perspective on Activities & Participation. The Performance perspective captures what a person actually does in his or her world, and so is the outcome of the interaction between intrinsic health aspects of the person and Environmental Factors. This interaction is potentially very complicated, dynamic and multi-directional, since changes in any of the Functioning components may influence one or more of the other components, and in various complex ways people's actions and behaviours will have an impact on the environment as well. Given the complexity and dynamic nature of these interactions, any graphic representation is bound to oversimplify it. That said, the overall interactive model of the ICF is represented in

Figure 3.1 (and is labelled in the ICF, the ‘Bio-psycho-social Model of Functioning and Disability’).<sup>lxxv</sup>

**Figure 3.1: The Integrative Bio-Psycho-Social Model of Functioning, Disability and Health**



Contextual Factors, and especially Environmental Factors, on the ICF model as depicted in Figure 3.1 play an essential role in the underlying interactional conception of Functioning and Disability that is at the core of the ICF. As already mentioned, features of a person’s environment may act either as a *barrier* that increases the severity or extent of a Disability or as a *facilitator* that decreases the severity or extent of a Disability. When the environment is a barrier, the level of a person’s performance in Activities & Participation will be lower or more of a problem than it would otherwise be; when the environment is a facilitator, the performance level is better or less of a problem than it would otherwise be. Personal Factors operate in a similar fashion.

The key issue is that Disability is created both by the underlying Health Conditions and associated Impairments and by the lowered or raised levels of Capacity to perform Activities & Participation that result from Environmental Factors. **Health state and Environmental Factors are therefore both determinants of Disability.** As this is the essential feature of the interactive model of disability, ICF can be said to constitute the interactive approach to Functioning and Disability.

By operationalizing the interactive model, the ICF contributes to a better understanding of Functioning and Disability and so offers a more scientifically and conceptually justifiable approach to describe the lived experience of health. This model is also the basis for, and represented by the structure of the ICF classifications. Accordingly, all components of the model—except personal factors and health conditions—are classified in the ICF. Health conditions (diseases, disorders, injuries or traumas) are already completely classified by another of the WHO’s international health classifications, namely

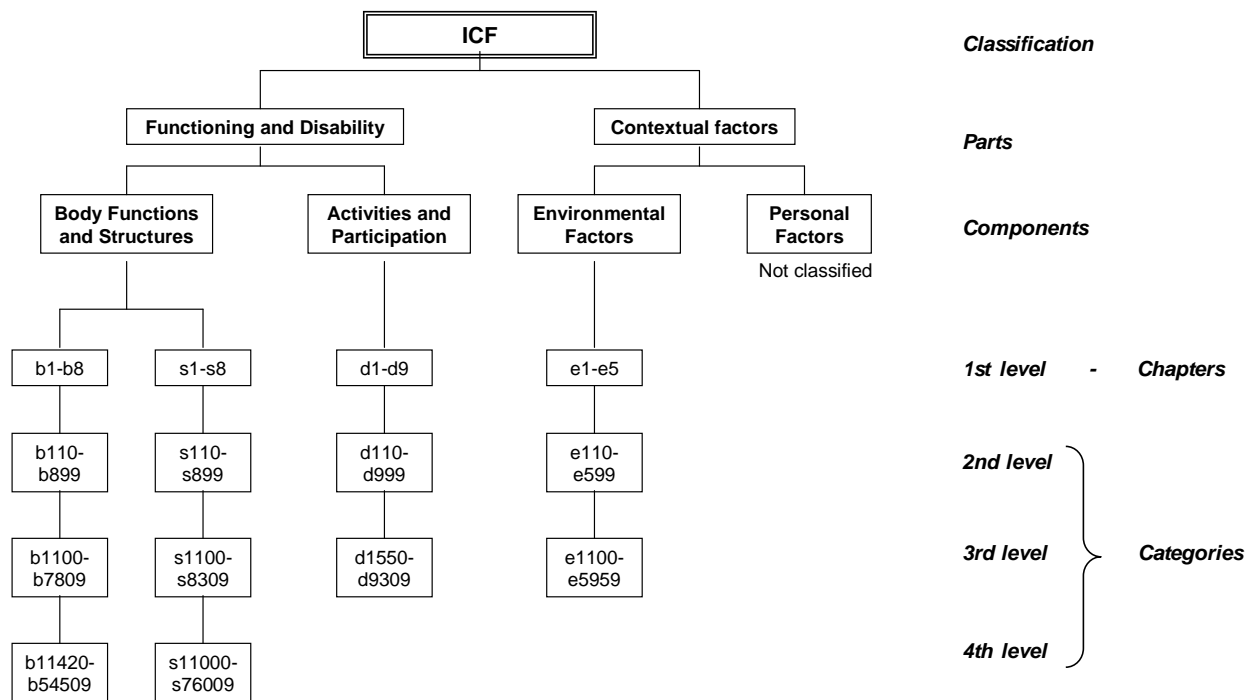
the International Classification of Diseases (ICD).<sup>lxxvi</sup> The ICD and the ICF are complementary classifications and users are encouraged to use them together.

### The structure and coding scheme of the ICF classification

The classification of the ICF is arranged hierarchically in a standard ‘genus-species’ or ‘parent-child’ arrangement. Overall, the classification consists of two *parts*: (1) ‘Functioning and Disability’ and (2) ‘Contextual factors’, each with two *components*: Part 1 consists of ‘Body Functions and Body Structures’ and ‘Activities & Participation’, and Part 2 consists of ‘Environmental Factors’ and ‘Personal Factors’. (As mentioned before, although Personal Factors are included in the model they are not classified in the ICF.)

In each of the four individual ICF classifications, *chapters* represent the first level of the classification. For coding purposes, each chapter is subdivided into the basic elements of the classification, called *categories*, which are organized in hierarchically arranged 2<sup>nd</sup>, 3<sup>rd</sup> and 4<sup>th</sup> levels. See Figure 3.2.

**Figure 3.2: The Hierarchical Structure of the ICF**



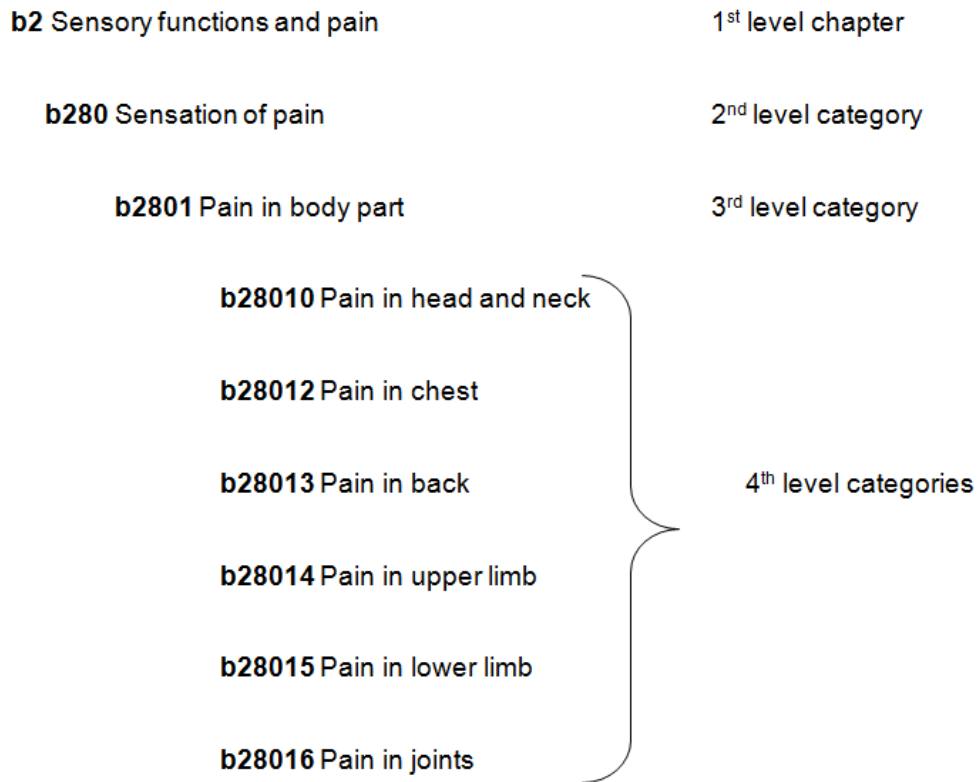
Source: WHO, 2001

The codes for each chapter and category constitute a standard classificatory language that can be applied unequivocally across countries, languages, cultures and professions for data collection and comparison. ICF codes are composed of a prefix (**b** for Body Functions, **s** for Body Structure, **d** for Activity & Participation, and **e** for Environmental



Factors) followed by a numeric code that consists of one digit for the first or chapter level, three digits for the second, four for the third, and five for the fourth level, as represented in Figure 3.3 below.

**Figure 3.3: ICF Hierarchical Structure – An Example**



The hierarchical organization of the ICF classifications allows users to choose either a broader description (by using a 1<sup>st</sup> level chapter or a 2<sup>nd</sup> level category) or a more detailed description (by using a 3<sup>rd</sup> or 4<sup>th</sup> level category) of an area of Functioning. The level of specificity increases with each lower level. The hierarchical organization allows users to choose the level of specificity required for their needs. In principle, to further increase granularity the category levels could be continued indefinitely by the user for more and more detailed sub-species. For consistency in data collection, the only requirement is that all lower levels can be ‘summed up’ to the next highest level so that all species and iteratively sub-species of a single genus can be denoted by the same genus category and corresponding code.

For all categories, except those in Body Structures, definitions and inclusions and exclusions are provided as shown in the following example:

## **d510. Washing Oneself**

Washing and drying one's whole body, or body parts, using water and appropriate cleaning and drying materials or methods, such as bathing, showering, washing hands and feet, face and hair, and drying with a towel.

*Inclusions: washing body parts, the whole body; and drying oneself*

*Exclusions: caring for body parts (d520); toileting (d530)*

These definitions and inclusions provide a detailed description of the meaning of the category and assist in the use of the ICF as a standard classification tool. Definitions and inclusions constitute the concrete operationalization of classification variables. Exclusions (where they exist) help to differentiate between related or easily confused ICF categories.

For convenience of use, chapters are often subdivided into blocks of categories. Blocks organize categories into common themes, as for example the block 'Muscle functions (b730-b749) comprising 'b730 Muscle power functions', 'b735 Muscle tone functions', 'b740 Muscle endurance functions, and 'b749 Muscle functions, other specified and unspecified'; or the block 'household tasks (d630-d649)' comprising 'd630 Preparing meals', 'd640 Doing housework' and 'd649 Household tasks, other specified and unspecified'. Technically, blocks are not part of the structure of the classification and usually are not used for coding purposes.

The categories of Functioning found in Body Functions and Body Structures, Activities & Participation are content categories or data points for collecting consistent and internationally comparable data. These constitute domains of the experience of Functioning and Disability—the experience of bodily functions, including mental functions, and the experience of performing simple and complex actions. All of these are experiences of Functioning—the experience of living with a health condition, or for short 'the lived experience of health'. The categories are not themselves categories of Disability or Non-disability, they are simply categories of Functioning.

To identify a point (or range) on the continuum of Functioning for a specific domain, it is necessary to use ICF qualifiers. By so doing, and in particular by identifying a level of Functioning for some domain that is below a specified threshold, the user identifies some dimension (and extent) of Disability. Once again, the ICF does not specify the thresholds, and so in a sense does not identify Disabilities as such. It was thought not to be the WHO's role as an international agency to dictate where on the continuum of, e.g. b515 Digestive Functions, an Impairment of Digestive Functions exists; that is a task for medical science and clinical practice. It is expected that scientific consensus has, or will, establish on the basis of good evidence where this cut-off should exist. It is even more obvious that it is not the WHO's role to specify where on the continuum of d850 Remunerative Employment a problematic level of remunerative employment exists; that is a matter for a designated authority to make a judgment on the basis of tradition, commonsense,

employment policy or political decision. Unlike Body Functions which are biological universal phenomena, it is more likely for complex Activities & Participation domains that thresholds will differ in different parts of the world, because of salient cultural, economic and political differences. Moreover, it is always the prerogative of users to set thresholds wherever they wish; it is also incumbent on the user to justify that important decision.

### ICF qualifiers

A ‘qualifier’ is a variable, attached to a domain in an ICF classification, that expresses a degree of severity (usually on a 5-point scale) or some qualitative dimension of that domain. For all of the components of Functioning (Body Functions, Body Structures, Activities & Participation), the first qualifier expresses the extent or severity of a problem in some domain of Functioning. Here a 5-point *generic* scale is expressed qualitatively as No (problem or difficulty), or Mild, Moderate, Severe and Complete (coded with the numbers 0 to 4). ‘No problem’ is understood to denote full or optimal Functioning, and ‘Complete problem’ the total absence of Functioning. In some situations, the description of Functioning or levels of Disability is not possible due to a lack of information or the inapplicability of an ICF category. In these situations, the codes .8 and .9 are used. (See Box 3.1). In the case of Body Structures, given the variety of dimensions in which structures can be problematic, a second qualifier presents a range of structural differences (such as total or partial absence, aberrant dimensions, discontinuity, and deviating position). (Given that the ICF does not established thresholds, it is not strictly speaking accurate to say that a ‘mild problem’ in Body Functions is an impairment, or that a ‘moderate problem’ in Activities & Participation’ a Activity Limitation or Participation Restriction: in each case a threshold value needs to be provided to make this determination.)

In the case of Environmental Factors, the first qualifier denotes the extent to which a feature of the environment, broadly construed, acts as a facilitator or as a barrier for a specific domain of Functioning. An environmental barrier is understood as a factor whose presence has a negative impact on the extent of Functioning (e.g. the impact of bad air quality on respiration) or whose absence has a negative impact (e.g. the impact of lack of support when performing housework). To denote this difference, a facilitator is marked with a plus sign instead of the dot (+X) and a barrier follows the dot (.X) – hence e310+2 means moderate facilitator ‘Immediate family’ and e310.2 means moderate barrier ‘Immediate family’.

To be meaningful, an ICF code requires at least one qualifier. Hence, an ICF code (composed of the letter and numeric code) is completed by at least the first qualifier placed after a dot following the numeric code, e.g. b28016.3. In case of an environmental facilitator, the dot alone denotes a barrier, and the plus (+) sign denotes a facilitator, e.g. e310+4.

**Box 3.1. ICF Qualifiers**

### Qualifiers for Body Functions, Body Structures and Activities & Participation

xxx.0 NO problem	(none, absent, negligible,...)	0-4%
xxx.1 MILD problem	(slight, low,...)	5-24%
xxx.2 MODERATE problem	(medium, fair,...)	25-49%
xxx.3 SEVERE problem	(high, extreme,...)	50-95%
xxx.4 COMPLETE problem	(total,...)	96-100%
xxx.8 not specified (used when there is insufficient information for the description of the extent of the problem)		
xxx.9 not applicable (used when the category is applicable, e.g. in 'b650 Menstruation functions' for men)		

### Qualifiers for Environmental Factors

xxx.0 NO barrier	xxx+0 NO facilitator
xxx.1 MILD barrier	xxx+1 MILD facilitator
xxx.2 MODERATE barrier	xxx+2 MODERATE facilitator
xxx.3 SEVERE barrier	xxx+3 SUBSTANTIAL facilitator
xxx.4 COMPLETE barrier	xxx+4 COMPLETE facilitator
xxx.8 barrier, not specified	xxx+8 facilitator, not specified
xxx.9 not applicable	xxx.9 not applicable

Qualifiers complete an ICF code and provide the full description of a person's level of Functioning or Disability. It is important to emphasize that the qualifier coding system is not intended to be, and certainly not to replace, standardized assessment and measurement instruments for domains of Functioning. The assumption is that ICF can, with this very simple qualitative scaling, be mapped onto clinical tools that are used in practice so that the tool's calibration and scaling is retained (since, typically, the tool has been validated for use). Most of these existing tools measure Body Functions and Structures, but there are also instruments in clinical for measuring Walking and other basic Activities & Participation. The qualifiers and classifications are the components of the ICF viewed as an international common language of Functioning. Although ICF is a standard for collating data collected from a wide variety of sources, ICF itself does not create, collect or analyse that data; that is for the ICF user to do.

### Performance and capacity

For Activities & Participation an important difference in perspective, already mentioned, is technically encoded by the two qualifiers, both of which denote the extent of difficulty or problem. The **Performance** perspective is represented by the first qualifier, and the **Capacity** perspective by the second qualifier. Because the distinction between Performance and Capacity is fundamental to the interactive model that ICF represents, and of special significance for the potential use of ICF as a design framework for disability

assessment, it is important to be clear about the difference between these perspectives on human Functioning.

**Performance** describes what an individual *actually does* in his or her current environment in light of all positive and negative impacts of Environmental Factors. Environmental Factors include all features of the physical environment, the built environment, products and technology, attitudes, and systems, services and policies across all aspects of the social, political and economic context—everything and anything that alter, worsen or improve, the experience of disability. Performance, in other words, is understood as the direct, non-inferential description of what the person actually does in his or her actual environment or context.

**Capacity**, by contrast, is a description of something that rarely can be directly observed but is usually inferred from evidence; namely, the individual's inherent or intrinsic ability to perform a task or an action, without the impact, positive or negative, of his or her environment. Since human beings are always in an environment of some sort, Capacity is an abstract notion, unlike Performance which is simply a description of actual states of affairs or events. As an abstraction, Capacity requires some form of operationalization for it to be accurately assessed or measured. In principle, an environmentally 'neutralized' setting—for example, a test setting—is the optimal environment for obtaining information about Capacity. Of course, no setting is completely environmentally neutral—gravity, air quality and pressure, light, and other environmental factors will always remain (although in the future, conceivably, we may find it useful to create standardized settings in space stations to neutralize the effects of gravity). But the notion of Capacity remains coherent despite this technical, measurement issue. A health problem, by definition, always creates some decrement in some set of Body Functions or Structures and this decrement will impact on a person's ability to perform actions: Capacity is the resulting, intrinsic state of health, measured along a continuum from optimal to 'less than optimal' or non-existent capacity to perform specific actions.

The distinction between Performance and Capacity, or something very much like it, is an essential conceptual aspect of the interactive model of disability. In the ICF, the interactive model presumes that it is possible, at least in theory, to distinguish between the impact of a health condition on a person's Performance and the impact of Environmental Factors and Personal Factors on that Performance. The difference between Performance and Capacity is implicitly, in other words, the description of the positive and negative impact of Environmental Factors and Personal Factors on Functioning.

The coding system for Activities & Participation using the two qualifiers captures this important difference, at least for Environmental Factors. For example, the ICF code d450.13 describes a person's Capacity to walk as severely limited (**3** = severe problem in Capacity) but the **1** (= mild problem with Performance) indicates that that limitation in Capacity is compensated for or positively impacted by some environmental factor, for example a walking assistive device. (More detailed information can be added with two

additional, optional qualifiers: a third qualifier to describe Capacity with assistance and a fourth for Performance without assistance.)

## ICF and ICD

The ICF is an international classification standard and scientific tool for the description of Functioning and Disability. The application of the ICF contributes to the standardization of health and health-related data and facilitates data collection and international comparison. From the outset, the WHO's aim in developing the ICF was to augment its institutional capacity to standardize health information by building on its existing classification of diseases and other health conditions; namely, *The International Classification of Diseases (ICD)*. ICD is the world's standard diagnostic tool for epidemiology, health management and clinical purposes. It is widely used for collecting mortality or 'cause of death' information, for monitoring the incidence and prevalence of diseases and other health problems and creating a picture of the general health situation of countries and populations. Although the ICF has many independent applications, as a member of the 'family of international classifications' the ICF completes the epidemiological picture by standardizing the collection of information about non-fatal health outcomes and associated experiences—the overall lived experience of health. Thus, ICD and ICF are best used together for most epidemiological, health systems, and health and disability policy purposes.

The conceptual and practical linkages between these two international standards are in the process of being optimized with the development of the 11<sup>th</sup> Revision of ICD, due by 2017. Unlike its predecessors, ICD 11 will be structured by a 'content model' that not only standardizes the representation of ICD entities for computerization, but presents information from 13 different dimensions of parameters or 'value sets', such as temporal properties, manifestation and causal properties. Significantly, one of these parameters is Functioning Properties that will provide information on how an individual with or experiencing the ICD entity may be limited in Functioning. The parameter of Functioning Properties is composed of (i) a selection of Activities & Participation domains (understanding, communication, mobility, self-care, interpersonal relations, life activities, and social participation); (ii) a linkage between ICD and ICF Contextual Factors; and (iii) a linkage between ICD signs and symptoms with ICF Body Functions.

With the publication of ICD 11, it will be possible to fully integrate ICF and ICD, in the sense that the application of an ICD term to identify a health condition experienced by an individual—say a claimant for disability benefits—will be automatically linked to a standardized set of Activities & Participation items found in the ICD item's Functioning Properties field. Since ICD is standardly used, worldwide, for a wide range of health and social policy purposes that include, and interact with the various components of disability policy, this linkage will greatly enhance the usability of ICF for disability assessment purposes.

# Chapter 4

## Application of ICF to Disability Assessment

### Chapter 4: Summary

- *Evidence from rehabilitation practice and research supports the view that the causes or etiology of an impairment should not be used to determine the impact on a person's life, and that in the case of work capacity, the work environment is as much a determinant as the underlying health problem.*
- *Ignoring the potential impact of a facilitating work environment distorts work capacity assessment.*
- *ICF is one of the best expressions of a fundamental shift in understanding of disability. It offers the possibility of creating complete functioning profiles, identifying both assets as well as deficiencies for disability assessment.*
- *Complete functioning profiles make it possible to longitudinally track disability trajectories of time, for more flexible and cost-effective disability programming.*
- *The ICF distinction between capacity and performance alters the disability assessment process by requiring information about the individual's environment—work environment in the case of work capacity—in order to properly assess disability, both at a point in time, and longitudinally.*
- *Despite its potential, there are limitations to the usefulness of the ICF, given the inherent problems of operationalizing, and measuring, the relationship between Environmental Factors and a person's Capacity to perform complex tasks such as those required for employment, coupled with the highly undeveloped character of the Environmental Factor classification and potential unintended consequences of using Personal Factors for disability evaluation.*
- *The ICF underwrites a normative standard for equitable disability assessment by showing that while striving to equalize work capacity is not humanly possible, it is both possible, and desirable, to strive to equalize work performance.*
- *A design framework for disability assessment grounded in the model and classifications of the ICF has the potential for realizing the Disability approach to disability assessment.*

### Disability assessment and the lived experience of health

The trend in middle and high income countries over the last two decades in disability assessment for social insurance, disability pensions and employment policy has been to

augment a purely impairment-based or Baremas scheme—based on medical diagnosis or a standardized list of impairments—with more individualized information about the claimant’s functional capacity, derived from self-report questionnaires, clinical interviews or performance tests. Yet, it is also commonly agreed that a more complete, valid and reliable disability assessment, especially for determining work capacity, requires, in addition, information about environmental barriers and facilitators, and in particular, features of the work environment that, if altered, could dramatically increase the likelihood that a person with impairments and functional limitations could go to, or return to the work that they are qualified to perform. The scientific and practical evidence supporting the perceived need for more environmental information comes from rehabilitation clinical practice and research.

Rehabilitation professionals have recognized that the manner in which a health problem or impairment plays out in a person’s life is far more relevant in the determination of the person’s capacity to work than the medical cause or etiology of the problem or impairment. This is a view called ‘etiological neutrality’.<sup>lxxvii</sup> A good example is chronic pain. Work capacity assessment protocols are regularly criticized for highlighting a distinction between pain that is directly linked to structural impairments—such as an intervertebral disc disorder or other injury—and pain that has no identifiable structural origins, usually called ‘somatoform pain’.<sup>lxxviii</sup> Because of a concern for malingering or faking pain, work capacity assessment protocols have put undue emphasis on the causes or etiology of pain. Yet, clinically, it is apparent that the impact of somatoform pain on a person’s capacity to work can be as severe as for any other kind of pain.<sup>lxxix</sup> From a rehabilitation perspective, in other words, the cause of pain is not particularly relevant; but the impact of pain is very important. This suggests that work capacity determinations should pain etiology as well (and deal with deception in a different way), since what is relevant to assessment is the lived experience of pain.

Because our understanding of mental disorders lags behind that of physical health problems, there is also a tendency in disability assessment to be sceptical about claims based on mental health diagnoses alone. Like pain-based disability claims, the traditional medicalization of assessment for mental health problems was in part a response to the perceived problem of malingering or fraud. But again, like chronic pain, the impact of mental health problems such as depression or anxiety on work capacity is both obvious and considerable. Indeed, both pain associated with musculoskeletal disorders and depression have been identified as among the top ten contributors to global disability, according to the Global Burden of Disease 2010 study.<sup>lxxx</sup>

Rehabilitation practice has also made it increasingly clear that the work environment—both the physical workplace and how a job is administratively structured—is as much a determinant of work capacity as the person’s health condition, impairments and functional limitations. Several studies of the determinants of successful return to work programs, for a wide range and severity of injuries and diseases, have shown that removing environmental barriers to work can be the most effective way of returning to work, and therefore of addressing work disability.<sup>lxxxi</sup>



Even when work capacity assessment is augmented with information about functional capacity, the significance of the work environment is not always taken into account. Most Functional Capacity Evaluations assess work capacity, not in light of the existing work environment, but in terms of some standardized clinical environment. The result is that assessments can be dramatically wrong: if because of a workplace injury a worker cannot stand or sit for long periods of time—as would be indicated by a FCE performance test—this does not mean the worker cannot return to his or her original job since a modest job alteration providing frequent rest breaks and periodic body position changes may make return to work a feasible option. Functional capacity assessment also merges the impact on work disability from health conditions with impact of the environment (family difficulties or co-worker attitudes) or even personal factors (lack of motivation).<sup>lxxxii</sup>

It is common ground among vocational rehabilitation experts that work disability is a function *both* of the individual's underlying health condition and impairments *and* features of the work environment. When no medical or rehabilitative health intervention can significantly alter the effects of a chronic health problem, which is true for many non-communicable diseases, age-related conditions, and serious injuries, then the only prospect for return to work will depend on changes that can be made to the work environment. Although there are no guarantees that making changes to the work environment will enhance work capacity in all cases, ignoring this possibility undermines the validity of work capacity assessment.

*There is, in short, a growing recognition that disability assessment should be based on the full, contextualised lived experience of health rather than merely on diagnosis, impairments or functional capacity evaluation. Given that the ICF incorporates, and operationalizes, a model of disability that is fully consistent with this evidence from rehabilitation practice, it is reasonable to be cautiously optimistic that the ICF might be good vehicle for reforming disability assessment practice.*

### **The general case for ICF as a design framework for disability assessment**

The fact that ICF is a globally accepted, international standard classification means that there are general considerations in favour of turning to the ICF as a design framework for disability assessment:

- ICF is an optimal data reporting structure;
- ICF is the basis for process legitimacy; and
- ICF is an international platform for assessment and measurement.

**ICF as optimal data reporting structure:** From the outset WHO's interest in developing and implementing the ICF was to create an information structure for collecting and analysing internationally comparable data about health and disability that would augment the standardization in causes of death traditionally provided by the ICD. In this sense, ICF completes the picture of health information by adding the essential domain of the lived experience of non-fatal health states and their health and contextual determinants.

The ICF was explicitly designed as a ‘Rosetta stone’ for functioning and disability information, making it possible to harmonize data collected from various tools and methodologies—from self-report functional questionnaires, FCEs, standardised rehabilitation assessment tools, administrative records and, at the population level, health and disability surveys. Connecting information in this manner improves accessibility to comparable data across data users and contexts, which has a positive impact on administrative processes such as disability assessment. As ICF is an information collection framework, with an exhaustive and mutually exclusive list of domains in the three component classifications, it offers the prospect of providing the full range and detail of information required for a complete disability assessment. Moreover, ICF not only helps coordinate existing data, it helps identify informational gaps, in particular information about the work environment that, as has been shown, greatly enhances the validity and reliability of work disability determination.<sup>lxxxiii</sup>

**ICF as the basis for process legitimacy:** Around the globe, disability assessment is the core component of an administrative process whose outcome is a determination of eligibility for a service, benefit or protection. The procedure for disability evaluation—whether formal or informal, simple or complex and involving one or multiple stages—remains essentially a creation of law and policy. As such, administratively and legally, it must be, and be seen to be impartial, fair and based on objective evidence. As we saw in Chapter 1, the level and extent of evidence required for a disability assessment depends in part on the aims of policy or program: a program providing assistive devices or vocational rehabilitation demands clinically-accurate descriptions of need, whereas a social assistance transfer may require merely a rough determination of ‘inability to work or take care of oneself’. But in each case, the determinations of eligibility must be perceived to be politically and legally legitimate.<sup>lxxxiv</sup>

Legal and administrative legitimacy is a matter of procedural fairness, commonly operationalized in terms of procedural transparency, impartiality and comparability (which together are often termed ‘procedural equity’). What research there is on disability determinations suggest that even the procedures used in high income countries of Europe and North America are open to charges of inconsistency (not treating similar cases in a similar way), bias (favouring or disfavouring claimants on irrelevant grounds), and unaccountability (not disclosing the procedures followed or the evidence used).<sup>lxxxv</sup> When disability determination lacks transparency or seems to be a procedural ‘black box’, it is impossible to know whether determinations are fair or arbitrary, based on information or the product of whim or prejudice. When evidence is not documented, or when it is not possible to compare the evidence used in one case with that used in another, then the process comes under disrepute and soon loses legitimacy.

Standardization of process, procedure and evidence is the administrative solution to challenges to legitimacy, and this is what the ICF can provide. Documentation of information in the language of ICF not only provides comparability, it also secures accountability. Transparent documentation of reasons for an assessment provides claimants with the grounds for objecting to eligibility decisions they deemed unjustified;

it also provides the common grounds for adjudicating such complaints. As the ICF constitutes the internationally accepted, scientific basis for describing the determinants and outcomes of functioning, disability and health, independently of how that information is used and by whom, its application to disability assessment can strengthen the legitimacy of a disability assessment procedure.

**ICF as a platform for assessment and measurement:** Because it is an international standard, the ICF is a solid basis for Functioning and Disability assessment instrumentation. However, although the exhaustiveness of its classifications argues in favour of the ICF as an international standard, it also makes it difficult to use in practice. Fortunately, we know statistically that 20 percent of the codes in the ICF will explain 80 percent of the variance observed in practice.<sup>lxxxvi</sup> And this has led to the development of the first generation of ICF-based tools – namely, the **ICF Core Sets**.<sup>lxxxvii</sup> Core sets are lists of ICF categories relevant to a specific health condition or health assessment setting or process that have been selected by a multi-method expert consensus strategy. **Comprehensive Core Sets** are designed to be sufficient to describe a meaningfully wide spectrum of typical problems a person with a particular health condition may experience, while **Brief Core Sets** are designed to capture the minimally sufficient number of categories to describe that experience.

To date, 34 ICF Core Sets have been developed using a standardized methodology, including a context-specific ICF Core Set for vocational rehabilitation.<sup>lxxxviii</sup> In addition, a Minimal Generic Set and a Disability Set have been psychometrically developed, in part based on these Core Sets (See Annex 1).<sup>lxxxix</sup> The Minimal Generic Set includes seven ICF categories relevant in both the clinical and general population, and is a subset of the Disability Set with 32 categories relevant solely for clinical populations. These core sets have been the basis for clinical documentation tools, and questionnaires specific to work rehabilitation.<sup>xc</sup> A parallel process is being used by WHO and World Bank in the development of their World Survey on Functioning and Disability (Model Disability Survey, intended as a basic tool for collecting comprehensive data on Functioning, Disability and Health across populations).<sup>xc</sup> Finally, the *European Union of Medicine in Assurance and Social Security* (EUMASS) developed a generic ICF-CS of 20 categories for social security evaluation developed from a formal voting procedure.<sup>xcii</sup> As a result, a number of OECD and European Union Countries; including Sweden, Denmark, France, Germany, the Netherlands, and others, have been moving towards adopting ICF into their disability assessment systems.

It is important to mention these developments since they address some of the perceived limitations of using ICF as a basic design structure for reforming disability assessment.

The experience of developed countries mentioned above shows that using the ICF is feasible in high income countries where, in some instances, substantial steps have already been made to include information about the environment for a more complete, Disability-style, assessment. But for many countries of the world the gap between this reform and current practice is simply too wide and it would be wholly unrealistic to expect the

country to take the risk of such a radical reform. What is needed to start the transition are simple tools that can be easily implemented, even in low resource settings such as Community Based Rehabilitation, for improved ICF-based disability assessment. This is the potential role for the Core Sets and especially the Minimal Generic and Disability Sets. These seven- and 32-item lists can be transformed into culturally and linguistically-appropriate questionnaires that provide an enhanced 'snap shot' for disability assessment. Their use can be combined and or compliment the assessment of the health status that is already in place for disability assessment. Although research has yet to be done to demonstrate the validity and feasibility of using these transitional tools to reform, what may well be highly unstructured and informal, disability assessment procedures in low income countries, their use signals the beginning of the paradigm shift, giving the opportunity to all parties concerned to see the value of the change and to get used to it. At the same time their use helps address important obstacles to the employment of ICF in disability assessment such as perceived complexity and intense human resources demands.

### ICF and the paradigm shift in disability assessment

The three general considerations just mentioned, important as they are for the legitimacy and credibility, are fundamentally procedural and merely restate the obvious that the ICF is an international standard produced by the United Nations specialty agency for health. It is unlikely that a country debating whether to take substantial steps to reform their disability assessment process would make the investment on these grounds alone. The stronger argument is that the ICF, despite its limitations, represents the best available expression of a shift in our understanding of disability that should be translated into disability assessment procedures. The added-value of this reform can be expressed in terms of the completeness of functioning profiling, the need for longitudinal profiling, and the importance of taking into account the environmental determinants of disability. Ultimately and in terms of work capacity assessment, it can be expressed as an effective tool to maximize labor force participation of persons experiencing ill health.

**Complete functioning profiling:** Because of the social and economic demands made on disability policy, disability assessment tends to be fundamentally negative: it is an attempt to identify what the claimant *cannot do*, the *problems in functioning* that he or she has, because of an underlying health condition. Similarly, work capacity determination has historically focused on the job requirements an individual *cannot* be expected to perform, because of an underlying health condition. Employment-relevant *inabilities* (as well as their severity and the prospects for improvement) constitute the policy basis for eligibility for benefits and services provided (in effect) as compensation for the unavailability of employment.

Yet it is clinically obvious that work capacity as a matter of fact depends as much on a person's capacities or functioning *assets* as it does on his or her *deficits*. A more relevant and valid assessment, and certainly one that has a wider range of policy applications,

would therefore be an assessment of both deficits and assets; that is, a complete functioning profile.

The ICF is a classification of domains of Functioning and only derivatively a description of problems of Functioning or Disabilities. Programmatically, in other words, ICF is a standardized tool for describing a complete functioning profile—assets as well as deficits. In the current state of the art, this potential has yet to be practically realized since the tools for ICF-profiling are still being developed and it will likely be many years before the rehabilitation professions will reach a consensus on which ICF-based tool is authoritative. Realistically, however, given the variation in disability evaluation regimes worldwide, it is unlikely that a single ICF-tool would be universally affirmed, or indeed would work satisfactorily for all regimes.

This being the case, the ICF is an international standard classification, which entails that it has a vital function as a *linking tool* that can harmonize data from different instruments and documentation protocols.<sup>xciii</sup> Disability assessment in the context of disability evaluation involves procedures shaped by a wide variety of cultural and social, economic and political forces that, although comparable across countries, need not be compatible between countries. Each country will need to craft its own instrumentation and documentation tools and procedures. The ICF offers conceptual guidance, and its classifications and coding structure make it possible to compare data across countries. As yet, however, there are no ICF-based profiling tools to which a country can use to produce more complete and appropriate functioning profiles.

**Longitudinal profiling:** Because of aging populations, unpredictable economic trends and the need for policy flexibility, on the one hand, and technological advances and planning strategies, such as universal design on the other, it is becoming clear that despite the increased direct administrative costs of periodic review and reassessment, it makes more sense to flexibly tailor pensions and income support mechanisms to changing circumstances.<sup>xciv</sup> Especially for return to work policies and programs designed to fund and provide vocational rehabilitation or related services, it makes more economic sense to predict *disability trajectories over time* in order to flexibly respond to changing social circumstances. There are two reasons why longitudinal profiling is advantageous:

- i) It is already commonplace in disability policy to distinguish between temporary and permanent health problems for benefit eligibility. Yet even with ‘permanent’ or chronic health conditions—high blood pressure, arthritis, asthma, and heart disease—it is now possible to track different life course trajectories that will affect the individual’s future health and disability status. Lifestyle changes—for good or ill—comorbidities, environmental changes, and other determinants may increase or decrease the slope of a chronic or progressively worsening health condition. Other chronic conditions may be episodic—as are some mental health problems—and it is important to be able to predict, and if possible prevent, these periods of worsening health. But, to have any prospect of **predicting the trajectory of a person’s health**, let alone changing the trajectory, it is essential to have a

complete description of the individual's Functioning status, and that means knowing both about a person's deficits and his or her assets. With demographic ageing, moreover, it is becoming increasingly important to identify, and if possible, modify, ageing trajectories as individuals age into, or age with, chronic health conditions.<sup>xcv</sup>

- ii) In middle and high income countries, employment policy relies on the provision of vocational rehabilitation interventions to improve work capacity for return to work to avoid moving the individual into permanent disability pensioner status. But rehabilitation is not merely 'fixing' functional deficits, it is building on and enhancing functional assets. The prospects of a person returning to work after a spinal cord injury, for example, are greatly improved if we know that the individual has upper arm strength and flexibility, since these assets can be enhanced for wheelchair use to counteract the immobility caused by lower body paralysis. This underscores the importance of collecting information about both deficits and assets, but it points to the value of periodic assessment to more flexibly predict the fit between individual and employment requirements.<sup>xcvi</sup>

**Role of environmental factors:** The fundamental ICF distinction between capacity and performance is helpful for conceptualizing the underlying difference between Impairment and Functional Limitation strategies, on the one hand, and the Disability strategy on the other. Essentially, Impairment and Functional Limitation approaches make the assumption that information about a person's capacity (for example, capacity to work) tells us enough to predict his or her actual and future level of work performance. Inferring work performance from work capacity is risky, since it assumes what is self-evidently not true, that all aspects of the person's workplace environment, or changes to that environment, have no impact on work performance.

In contrast, the ICF as the model for disability assessment not only lends itself to a complete functioning profile that takes both deficits and assets into account, but also an assessment of the positive and negative impact of environmental factors. To understand the impact of the environment on work performance presumes both baseline information—a current description of the workplace environment—and a description of the impact of workplace alternations (structural, attitudinal or organizational) to the workplace environment. This comparison is essentially an assessment of enhanced work capacity in light of environmental modification.

Although the science is still in its infancy, and there are no reliable or generally acceptable tools available, in principle environmental assessment is not a mysterious or impossible activity. In the employment area, it is indeed standard procedure for vocational rehabilitation therapists, assistive technologists, occupational therapists and vocational counsellors. Part of their job is to find ways to match the environment to the individual's current or projected work capacity so that, together, the outcome is work performance. Often this is a matter of finding and fitting assistive technology (AT)—either general AT such as wheelchairs, brail readers, TTD communications, or workplace specific AT, such

as flexible tables and desks or enhanced lighting. Often too it is a matter of workplace alterations, either physical or organizational.

### **How might the ICF affect the practice of disability assessment?**

If we bring together these three contributions of using ICF to design disability assessment—complete and longitudinal profiling and utilization of environmental information—how might this affect the practice of assessment? Here are two examples:

Example One: A person who is blind would on most existing Impairment and Functional Limitation assessment schemes be deemed 100-percent disabled, and in many regimes, fully work incapable as well, so as to qualify for the full sum of income maintenance and/or other benefits. Using the ICF approach, the outcome might be very different since the ICF requires, and makes feasible, a complete longitudinal profile, augmented with environmental assessment to take into account positive workplace assistive technology and environmental modification to enhance work performance. This might result, especially for a blind individual with a substantial marketable skill set, of an assessment of complete, or near-complete work capacity—one structured with an employment plan featuring the provision of appropriate AT or other environmental facilitators for support.

Arguably this result is not only more valid—since blindness, although a substantial deficit, can be offset by countervailing assets—but also more equitable; it is unfair to deny the blind individual the right to employment when with support employment is a genuine possibility. For severe impairments such as blindness, the Impairment and Functional Limitation strategies exaggerate the resulting work disability, denying society the valuable employment contribution the person could make, and denying the individual his or her human right to work.

This example should not be taken to imply that an ICF design will be more likely to or more readily deny eligibility for disability benefits. It is possible that the number of recipients might decrease, but only as a result of the creation of a broader range of innovative and more effective work-related AT and more creative and effective workplace environmental modifications, responding to the social need to develop a more productive workforce and shift social resources from disability pensions to workplace accommodations. These social shifts would naturally result when the disability assessment procedure validly profiled the individual's assets and functional decrements. The objective of the Disability approach is not to deny benefits but to rationally allocate them to those whose work disability cannot truly be enhanced through vocational rehabilitation or environmental modification.

Example two: As we age we accumulate impairments, which taken one by one may only be mild or moderate in severity: A person may need glasses to read, a hearing aid to follow conversations in a crowded room, some sort of mobility aid such as a cane or walker for developing arthritis (and medication for the joint pain) and he or she may be experiencing minor memory loss. None of these impairments might be severe enough on its own to substantially affect the outcome of a disability assessment. This would certainly be true

for a Baremas-like disability assessment system. To be sure, the experience of living with a collection of mild or moderate impairments might well be inconsistent with keeping a job. On the other hand, with adequate support, this set of health conditions may also be fully manageable and consistent with keeping a job or acquiring a new job. The ICF based disability assessment can capture the actual impact of the aggregate impairment severity, in light of the full environmental context.

Recent developments in the analysis of ICF-based health and Functioning data have in fact demonstrated the possibility of creating, statistically, metrics for functioning continua that would turn this insight into hard science. Eventually it might be possible to develop disability assessment tools that could aggregate impairment impacts on *capacity* in a scientifically rigorous manner.<sup>xcvii</sup> Using this approach, it would be feasible, by means of a complete Functioning profile, to accurately assess the impact of multiple, mild or moderate, impairments, so as to yield a composite score that—taking into account the current environment as well as what modifications or supports could be put into place—more validly, and therefore more equitable, assesses work disability. Given the enormous impact that aging demographics will have, especially in low income parts of the world, strategies for more successful accommodating mild or moderate impairments will become inevitable since the social cost of not doing so will be unimaginably high.

### **Current limitations in the usefulness of the ICF for reform**

It is important not to paint an overly optimistic picture of the added value of using ICF as a design structure for a reformed disability assessment – one that captures the Disability approach described in Chapter 2. It first must be acknowledged that there has been a fairly consistent opposition, especially among American researchers, to the ICF model, including especially the presumed distinction between Activities and Participation domains, the absence of a quality of life, and the undeveloped nature of the Contextual Factors component.<sup>xcviii</sup> Some of this criticism reflects a basic objection to the move away from the disability conceptualization, very influential in the United States, set out nearly fifty years ago by Saad Z. Nagi.<sup>xcix</sup> But other criticism has, quite correctly, been levelled at the crucial relationship between Environmental Factors and complex domains of Activity & Participation such as employment. Much of the power of the interactive model depends on this relationship, both its conceptual coherence and the ability to operationalize it for measurement purposes.

The ICF model depends on this linkage, but does not provide enough theoretical power to live up to the demands that, in use, a disability assessment procedure would require of it. It is clear that both the performance construct and the conceptualization of Environmental Factors are intrinsically difficult to measure.<sup>c</sup> Although some early attempts have been made to develop Environmental Factor instruments to measure the impact of the built environment on mobility,<sup>ci</sup> this work is very preliminary and at this point there are simply no tested and useable tools for identifying the key environmental determinants of work performance, let alone measuring this impact. The ICF itself may partly be responsible for this since the Environmental Factors classification is, by any



standard, a wholly inadequate classification. Its organization is unintuitive, its classification of the human built environment does not correlate with any classification scheme found in architecture or city planning, it characterizes the entire social, political and economic universe in terms of an unhelpful distinction between services, systems and policies, and it is so lacking in detail or granularity as to be of little use in concrete applications, such as disability assessment.

As for Personal Factors, the ICF is problematic for a very different reason. As noted there is no classification of Personal Factors in the ICF. One reason for this is that the ICF is vague about what these factors are. All that is said is that they are features of the person, other than health state, that include “gender, race, age, other health conditions, fitness, lifestyle, habits, upbringing, coping styles, social background, education, profession, past and current experience (past life events and concurrent events), overall behaviour pattern and character style, individual psychological assets and other characteristics.”<sup>cii</sup> This general collection of factors – some inherently social, like gender, others very close to Body Functions – makes the application of Personal Factors for assessment of disability dubious. More worrisome however, in part because of the vagueness of the notion, using Personal Factors opens the door to the possibility of ascribing problems in work performance, not to the lack of workplace accommodation or the need for environmental modification, but to a personal failure of one sort or another. It is conceivable—although certainly an unintended consequence of the application of the ICF to disability assessment—that important employment policies designed to get people back to work will be defeated on the moralistic ground that people lack the positive Personal Factors required to successfully work. As an example of what is sometimes called ‘blaming the victim’, this would be a very troubling and unintended result of relying on the ICF model.

All of these problems and limitations with the ICF are real enough, although at this relatively early point in ICF implementation, it is not clear how much these issues should offset the clear added-value of the ICF already described. Certainly, other than the ICF, there is currently no alternative approach that has both international recognition and widespread application, and combines the interactional model of disability with international standardized classifications. The ICF is the ‘only game in town’. The most reasonable option is undoubtedly to recognize both the strengths and weaknesses of the ICF and set out a clear research agenda to respond to its current limitations, while moving ahead with the implementation of the ICF aspects that are implementable and move disability assessment towards the full functioning profile. While environment as a facilitator and a barrier currently cannot be measured perfectly, it can be assessed accurately enough, as has been done in the area of rehabilitation. Therefore, before turning to this task in the next chapter, it is important to conclude with a final consideration that strengthens the case for using the ICF for disability assessment.

### **ICF disability assessment and human rights**

An ICF-based design framework for disability assessment is not only the best available tool a country can use in order to design a procedure capturing the Disability approach to

assessment the ICF framework also has social and ethical significance that reaches far beyond procedural and scientific adequacy.

The need for a complete—asset as well as deficit—profile and the requirement that information about the potential impact of environmental adjustment on improved performance be included in disability assessment, are considerations that are consistent with the expression of human rights found in the United Nations' CRPD.<sup>ciii</sup> The *Convention* describes the importance of environmental modification and adjustment in a variety of passages:

Article 2 specifies that states have general obligations,

*f. To undertake or promote research and development of universally designed goods, services, equipment and facilities... which should require the minimum possible adaptation and the least cost to meet the specific needs of a person with disabilities, to promote their availability and use, and to promote universal design in the development of standards and guidelines;*

*g. To undertake or promote research and development of, and to promote the availability and use of new technologies, including information and communications technologies, mobility aids, devices and assistive technologies, suitable for persons with disabilities, giving priority to technologies at an affordable cost;*

*h. To provide accessible information to persons with disabilities about mobility aids, devices and assistive technologies, including new technologies, as well as other forms of assistance, support services and facilities;*

*i. To promote the training of professionals and staff working with persons with disabilities in the rights recognized in this Convention so as to better provide the assistance and services guaranteed by those rights.*

Article 9 sets out the general state obligation of accessibility,

*1. To enable persons with disabilities to live independently and participate fully in all aspects of life, States Parties shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas. These measures, which shall include the identification and elimination of obstacles and barriers to accessibility, shall apply to, inter alia:*

*a. Buildings, roads, transportation and other indoor and outdoor facilities, including schools, housing, medical facilities and workplaces;*

- b. *Information, communications and other services, including electronic services and emergency services.*

And Article 27 on work and employment states that

1. *States Parties recognize the right of persons with disabilities to work, on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities. States Parties shall safeguard and promote the realization of the right to work, including for those who acquire a disability during the course of employment, by taking appropriate steps...*

These provisions underscore the importance that the international community has placed on workplace accessibility as a precondition for ensuring that people with disabilities enjoy the right to employment on an equal basis with others. The ICF model mirrors this human rights perspective on state responsibilities with respect to disability policy. The ICF in effect reinforces the message that a state's disability policy must not only make provision for the availability of health and social resources to improve capacity, it must also turn to the environment for supports and modifications for effective and equitable ways to improve performance.

The ICF reinforces another important normative message, namely that a fair and equitable disability assessment process would have as its outcome the equalization of performance, to the extent feasible for a country, given its economic, political and social context. Ensuring equality of capacity is not an option; that is, beyond human knowledge and ingenuity, people will always be intrinsically different in the health conditions they experience, their impairments and functional deficits and assets. People have different Functioning profiles, in short, and there is only so much we can do medically and therapeutically to 'equalize' human capacity in general or work capacity in particular.

Performance is a different matter. Although there are many practical reasons why achieving equalized work performance is also beyond our grasp even in high income countries, and can only be progressively realized in low income countries, nonetheless it is not impossible anywhere in the world. All countries, whatever the level of resources, can benefit from the removing of unnecessary obstacles to full participation by persons with impairments. All countries can benefit from measures to ensure accessibility and available of family and community life, health care, and education and employment. If these goals are out of reach, then human rights set out in the *Convention* are also out of reach. And that is not a conclusion that any country can be content with.

## **Conclusion**

A design framework for disability assessment grounded in the model and classifications of the ICF provides the basis for realizing the Disability approach to disability assessment. There are strong procedural, conceptual and normative arguments for moving toward the

Disability strategy. The question remains whether the ICF can assist countries in achieving this kind of policy reform. Does the ICF provide the conceptual and practical tools for implementing the Disability strategy? It is of course granted that there can be no simple, one-size-fits-all ICF template that a country could use 'off the shelf' to transform its disability assessment and evaluation procedures into those that achieved, or were transitional to the eventual achievement of the Disability approach. But there are good reasons for being optimistic that, with increased research and enhancement of the ICF, progress can indeed be made toward that end.

## Chapter 5

### The Way Forward

In Chapter 2, three model approaches to disability assessment were described— Impairment, Functional Limitation and Disability. There is a general consensus in the academic literature that the Disability approach is theoretically optimal: it seeks to directly assess disability status rather than indirectly inferring disability from proxy assessment of impairments or functional capacity; it is fully individualized and based on direct evidence both about the person and his or her environment; and it captures the best model of disability about which, again, there is universal consensus, in which disability is understood as a person-environment interactive outcome, rather than an intrinsic feature of the person. Because of the strength and validity of the Disability approach, several high income countries in North America and Europe have taken steps to transition their disability assessment procedures beyond the Impairment and Functional Limitation approaches towards the Disability approach. This is also happening in less resource-rich countries as well; such as in Cyprus, Argentina, and Brazil.

Despite the academic consensus, there is considerable country-level resistance to transitioning to the Disability approach. Some of this resistance is undoubtedly fuelled by vested interests of the central stakeholders in disability evaluation procedures, including very powerful and influential professional groups, such as physicians and other health professionals. Understandably as well, responsible bureaucrats are unwilling to suggest radical reforms in a process that often has a high political profile, especially when the advantages to the reform are not obvious and both the transitional costs, and the cost of running a new process, are either difficult to predict or are likely higher because of incremental investment cost than the status quo. However, in light of the economic and political drivers for change described in the Introduction to this study, the unsustainability of traditional disability programming and the need to maximize labor force participation in many countries around the world, creates an opportunity for countries to take political economy risks that reforming disability assessment processes may create.

As was discussed in Chapter 2, despite its substantial advantages, the Disability approach has an undeniable disadvantage, and one that in its ideal form might raise the specter of increased national costs of running the disability assessment regime. The Disability approach depends on access to a body of environmental information—in the standard example of work capacity assessment, this is primarily information about the workplace. In its ideal form, this is an enormous body of information, ranging from description of work requirements and physical and mental demands, to features of the physical environment—buildings, equipment, furniture, air and sound quality—to co-workers, employers and clients. Further afield, there is environmental information about general features of the labor market, the level of economic development of the country, social attitudes, and employment legislation and so on. Taken in its ideal form, the depth and breadth of this information poses a significant obstacle to the feasibility of the Disability approach. However, as the experience of rehabilitation medicine shows, while ideal quantity and quality of environmental information might be an ever expanding horizon, difficult to reach, there is a **reasonable** amount of information that is needed and can be collected to enable sufficiently accurate assessment of one's environment.

In Chapters 3 and 4, the case was made for using the World Health Organization's *International Classification of Functioning, Disability and Health* (ICF) as a guide for reforming disability assessment, and in particular a design structure for an assessment process implementing the Disability approach. The case for the added-value of using ICF in this fashion is complex and has been discussed and need not be rehearsed here. But as that discussion made clear, the ICF itself is not without its limitations, many of which bear directly on its usefulness for disability assessment.

There are essential two major challenges that need to be address. First, it has been argued that the advantages of the Disability approach are not restricted to middle and high income countries but are reforms that any country, whatever its level of development, can benefit from. If so, then certainly for low income countries, and possible for any country, transitional processes need to be put into place to make the shift from an Impairment or Functional Limitation approach to a full Disability approach. To borrow a notion from the human rights arena, in many settings, the reform of disability assessment is only plausible if it is *progressively realizable*. Countries need to be assured that there are stable, transitional reforms that can be put into place in a sequence and at a pace that is practically feasible, given the country's resources, political system, and social and cultural context.

The second challenge is, as mentioned, addressing the potential burden of integrating information about environmental factors for disability assessment. In the first instance, this is primarily a technical concern of data collection and analysis. On the ICF model, environmental information is relevant only with respect to the role of environmental factors as determinants of the kind and extent of disability. This presumes the availability of information collection instruments—survey, questionnaires, and clinical reports—that frame this data appropriately with respect to a factor role as facilitator or barrier. A companion concern is more theoretical, but nonetheless serious: at what point can an assessor be assured that environmental data has been assembled that fully accounts for the role of the environment as determinant of disability. Since there is, in theory, an infinite body of environmental information to draw on, when do we know we have, not only what is relevant, but what is sufficient for an informed judgment? This is the question of data 'saturation'.

Both challenges stand in the way of reforming existing disability assessment procedures towards the Disability approach. Although there are good reasons to turn to the ICF, both conceptually and practically, as the basis for designing this reform, the ICF does not address, let alone solve either challenge. This is not a criticism of the ICF—it was not designed, or intended, to address these issues. But the existing limitations of the ICF that were reviewed in the previous chapter further underscore the need for further substantial research to improve the applicability of the ICF to important policy domains, such as disability assessment.

This Report contributes to a broad research agenda on opportunities for reforming disability assessment, in the larger context of procedures of disability determination for social benefits, services or protections that comprise a country's disability policy. Specifically it set outs the general case, first for transitioning from Impairment and Functional Limitation approaches to assessment to the Disability approach and secondly for turning to the ICF as an overall design structure for this transition. In short, this Report presents the case for an important paradigm shift in how disability assessment should be performed. This shift reflects four fundamental ways of rethinking of the nature of disability and therefore how disability assessment should be accomplished:

**‘Etiological neutrality’** – this is a technical label for the fundamental difference between a standard medical; impairment or functional limitation approach to disability, in which specific diagnostic or etiological features of a health conditions are used to infer how that health state will be experienced in a person’s life; and the disability approach that focuses, not merely on what can be learned from etiology, but most importantly on how best to describe the experiment fully in light both the underlying health state and the impact of the person’s environment.

**Environmental determinants of disability** – the key to the interactive approach that ICF represents is that a full and accurate description of disability must take into account the environment determinants of disability, and how, in particular, these determinants effect the kind and severity of disability a person’s experiences.

**Disability as a continuous phenomenon** – the interactive model presents the phenomena of disability as continuous rather than dichotomous. This means that disability is also a matter of ‘more or less’, rather than ‘presence or absence’. The policy consequences of this logical feature of the ICF are twofold: disability needs to be determined, not a priori in terms of some fixed scale but in terms of the needs and objectives of a specific policy; secondly, disability is a dynamic situation that will change over time, both as the individual health state and level of impairments change, and as the person’s environment changes.

**The complete disability profile** – the most valid and intuitive profile of a person’s disability must take into account both decrements in functioning and functional assets. Both are required in order to determine the current disability state as well as its potential trajectory over time.

In light of these salient features of the Disability approach, and given the challenges to implementation just reviewed, it is clear that there is much left to be done in order to make the paradigm shift not only attractive to countries, but self-evidently feasible and cost-effective. We end this Report, therefore, with more specific research suggestions to address these challenges. This research agenda is the way forward.

### **Understanding the costs and benefits of disability assessment**

The most powerful argument for changing policy is that the costs of the current approach do not balance the benefits that are achieved. In the case of disability assessment there is an enormous gap in our understanding of the costs of using the Impairment or Functional Limitation approaches to determining eligibility for benefits, especially those benefits that are provided in lieu of employment or return to work. How much does it cost a country to provide a disability pension rather than invest in a person’s employability? What is the relationship between the costs of changing the workplace environment rather than sidelining the potential worker with a disability pension? What, in general, are personal and social costs of ignoring the potential of an individual to work, given suitable supports? These research questions are not only fundamental to a country’s decision to reform disability assessment, they are almost completely unexplored. More specifically:

- Research needs to develop a suitable metric for measuring the components of the disability experience—the underlying health condition, the level of functioning in various

domains, a summary or aggregate level of functioning across all domains, and the range of environmental determinants: physical, human-built, attitudinal, interpersonal, social, cultural, and economic.

- Research is needed to calculate the full costs of existing disability assessment, taking in account not merely the direct costs of administration, but the long term indirect costs of removing individuals from the labor force, rather than investing in ways to retain them, as well as the full, short- and long-term benefits of reframing disability assessment towards the Disability approach.
- We need a more accurate and sensitive model of the notion of ‘interaction’ so that better predictions can be made about the impact of environmental change—linked to the radically different kinds of environmental factors (assistive technology, buildings, attitudes, cultural views, policies and laws) that can impact, positively or negatively, on the lived experience of disability.
- Research on the concept of human productivity, and its determinants, could help to determine how, with targeted individual or social interventions – either in public health or some other impactful sector, such as transportation or communications – the most effective use of human resources can be achieved, in light of anticipated epidemiological and demographic trends.
- We need basic research to understand the ‘trajectories’ of different impairments across a lifespan and under different environmental conditions. This research would open the door to better preventative interventions both at the body level (pinpointing the best point in the development of a health condition or functional limitations at which interventions produce, over time, the best consequences in functioning) and environmentally (when should potential environmental barriers be addressed, across the employment sector, cost-effectively and with the best results in productivity).
- Given the long tradition in vocational rehabilitation and related fields of analyzing the impact of functional limitations on, for example, work capacity, it would be equally useful to understand, with similar levels of precision, the impact of functional assets, over time, on work capacity. Research also needs to be done to methodologically aggregate information both about functioning deficits and assets to yield an overall profile of an individual’s functioning trajectory over time. Further research might allow us to disclose clear patterns that are common across health conditions.

### **Environmental Information**

It is clear from the description of the Disability approach above that its feasibility depends on the availability of information that is not typically collected as an input to disability assessment, namely, information about the full environmental context in which the individual being assessed lives and acts. Although there is a well-developed science and practice of collecting health information—often about causes of death—only in recent years have the tools been developed to collect information about functioning and the lived experience of health. But the science and practice of collecting disability-relevant environmental information is not developed. The way forward, therefore, depends on research such as the following:



- Development of setting-specific classifications of environmental factors relevant to disability assessment.
- Development and validation of environmental assessment tools for workplace, home and community settings.
- Development and testing of ‘accessibility scales’ that can be used to rate workplace, home and communities environment with respect to representative disability classes, e.g. mobility, sensory, cognitive and mental health.
- Developing new methodologies for measuring the impact of specific environmental factors on work capacity.

### **Transition Framework**

The point has been made several times that the Disability approach is not, nor should be thought of, as a high income country luxury, a state of the art reform that are only achievable with very high levels of resource. In many respects, the opposite is true, since low and middle income countries may benefit more directly from the cost savings of avoiding high income country disability assessment regimes (based primarily on Impairment or Functional Limitation approaches) and moving directly from very informal assessment to some version of the Disability approach. Merely putting into place a questionnaire based on the Minimum Generic Set of ICF domains (see Annex 1) would be a relatively inexpensive way of moving beyond a purely medical determination of disability. This said, for the transition to be feasible, low and medium income countries need support to transition from the current disability assessment approach to one that takes into account the full range of relevant information. Toward this end, the following research will be important:

- Developing a complete comparative review of the legislative, administrative and procedural dimensions of disability assessment across the world and in particular low and middle income countries, including a review of country-level disability policies and programs that rely on disability determination, to supplement existing comparative analyses.
- Economic analysis of the costs of existing, informal disability assessment procedures—including assessor compensation, training, and documentation—from representative low and middle income countries.
- Case studies of successful reforms in disability assessment in low- and middle-income countries.
- Demonstration projects using questionnaires based on ICF minimal data sets—Core sets, Generic set, and Disability set—for information collection for disability assessment in low- and middle-income countries.

# **Annexes**

## Annex 1: ICF Minimum Generic Set and Disability Set

### Minimum Generic Set

<b>BODY FUNCTIONS</b> =Physiological functions of body systems (including psychological functions)	
<b>b130</b>	<b>Energy and drive functions</b>
	General mental functions of physiological and psychological mechanisms that cause the individual to move towards satisfying specific needs and general goals in a persistent manner. <i>Inclusions: functions of energy level, motivation, appetite, craving (including craving for substances that can be abused) and impulse control</i> <i>Exclusions: consciousness functions (b110); temperament and personality functions (b126); sleep functions (b134); psychomotor functions (b147); emotional functions (b152)</i>
<b>b152</b>	<b>Emotional functions</b>
	Specific mental functions related to the feeling and affective components of the processes of the mind. <i>Inclusions: functions of appropriateness of emotion, regulation and range of emotion; affect; sadness, happiness, love, fear, anger, hate, tension, anxiety, joy, sorrow; lability of emotion; flattening of affect</i> <i>Exclusions: temperament and personality functions (b126); energy and drive functions (b130)</i>
<b>b280</b>	<b>Sensation of pain</b>
	Sensation of unpleasant feeling indicating potential or actual damage to some body structure. <i>Inclusions: sensations of generalized or localized pain in one or more body part, pain in a dermatome, stabbing pain, burning pain, dull pain, aching pain; impairments such as myalgia, analgesia and hyperalgesia</i>

<b>ACTIVITIES AND PARTICIPATION</b> = execution of a task or action by an individual and involvement in a life situation	
<b>d230</b>	<b>Carrying out daily routine</b>
	Carrying out simple or complex and coordinated actions in order to plan, manage and complete the requirements of day-to-day procedures or duties, such as budgeting time and making plans for separate activities throughout the day. <i>Inclusions: managing and completing the daily routine; managing one's own activity level</i> <i>Exclusion: undertaking multiple tasks (d220)</i>
<b>d450</b>	<b>Walking</b>
	Moving along a surface on foot, step by step, so that one foot is always on the ground, such as when strolling, sauntering, walking forwards, backwards or sideways. <i>Inclusions: walking short or long distances; walking on different surfaces; walking around obstacles</i> <i>Exclusions: transferring oneself (d420); moving around (d455)</i>
<b>d455</b>	<b>Moving around</b>
	Moving the whole body from one place to another by means other than walking, such as climbing over a rock or running down a street, skipping, scampering, jumping, somersaulting or running around obstacles. <i>Inclusions: crawling, climbing, running, jogging, jumping and swimming</i> <i>Exclusions: transferring oneself (d420); walking (d450)</i>
<b>d850</b>	<b>Remunerative employment</b>
	Engaging in all aspects of work, as an occupation, trade, profession or other form of employment, for payment, as an employee, full or part time, or self-employed, such as seeking employment and getting a job, doing the required tasks of the job, attending work on time as required, supervising other workers or being supervised, and performing required tasks alone or in groups. <i>Inclusions: self-employment, part-time and full-time employment</i>

## Disability Set<sup>civ</sup>

<b>BODY FUNCTIONS</b> = physiological functions of body systems (including psychological functions)	
<b>b130 (G)</b>	<b>Energy and drive functions</b> General mental functions of physiological and psychological mechanisms that cause the individual to move towards satisfying specific needs and general goals in a persistent manner. <i>Inclusions: functions of energy level, motivation, appetite, craving (including craving for substances that can be abused) and impulse control</i> <i>Exclusions: consciousness functions (b110); temperament and personality functions (b126); sleep functions (b134); psychomotor functions (b147); emotional functions (b152)</i>
<b>b134</b>	<b>Sleep functions</b> General mental functions of periodic, reversible and selective physical and mental disengagement from one's immediate environment accompanied by characteristic physiological changes. <i>Inclusions: functions of amount of sleeping, and onset, maintenance and quality of sleep; functions involving the sleep cycle, such as in insomnia, hypersomnia and narcolepsy</i> <i>Exclusions: consciousness functions (b110); energy and drive functions (b130); attention functions (b140); psychomotor functions (b147)</i>
<b>b152 (G)</b>	<b>Emotional functions</b> Specific mental functions related to the feeling and affective components of the processes of the mind. <i>Inclusions: functions of appropriateness of emotion, regulation and range of emotion; affect; sadness, happiness, love, fear, anger, hate, tension, anxiety, joy, sorrow; lability of emotion; flattening of affect</i> <i>Exclusions: temperament and personality functions (b126); energy and drive functions (b130)</i>
<b>b280 (G)</b>	<b>Sensation of pain</b> Sensation of unpleasant feeling indicating potential or actual damage to some body structure. <i>Inclusions: sensations of generalized or localized pain in one or more body part, pain in a dermatome, stabbing pain, burning pain, dull pain, aching pain; impairments such as myalgia, analgesia and hyperalgesia</i>
<b>b455</b>	<b>Exercise tolerance functions</b> Functions related to respiratory and cardiovascular capacity as required for enduring physical exertion. <i>Inclusions: functions of physical endurance, aerobic capacity, stamina and fatigability</i> <i>Exclusions: functions of the cardiovascular system (b410-b429); haematological system functions (b430); respiration functions (b440); respiratory muscle functions (b445); additional respiratory functions (b450)</i>
<b>b620</b>	<b>Urination functions</b> Functions of discharge of urine from the urinary bladder. <i>Inclusions: functions of urination, frequency of urination, urinary continence; impairments such as in stress, urge, reflex, overflow, continuous incontinence, dribbling, automatic bladder, polyuria, urinary retention and urinary urgency</i> <i>Exclusions: urinary excretory functions (b610); sensations associated with urinary functions (b630)</i>
<b>b640</b>	<b>Sexual functions</b> Mental and physical functions related to the sexual act, including the arousal, preparatory, orgasmic and resolution stages. <i>Inclusions: functions of the sexual arousal, preparatory, orgasmic and resolution phase; functions related to sexual interest, performance, penile erection, clitoral erection, vaginal lubrication, ejaculation, orgasm; impairments such as in impotence, frigidity, vaginismus, premature ejaculation, priapism and delayed ejaculation</i> <i>Exclusions: procreation functions (b660); sensations associated with genital and reproductive functions (b670)</i>
<b>b710</b>	<b>Mobility of joint functions</b> Functions of the range and ease of movement of a joint. <i>Inclusions: functions of mobility of single or several joints, vertebral, shoulder, elbow, wrist, hip, knee, ankle, small joints of hands and feet; mobility of joints generalized; impairments such as in hypermobility of joints, frozen joints, frozen shoulder, arthritis</i> <i>Exclusions: stability of joint functions (b715); control of voluntary movement functions (b760)</i>
<b>b730</b>	<b>Muscle power functions</b> Functions related to the force generated by the contraction of a muscle or muscle groups. <i>Inclusions: functions associated with the power of specific muscles and muscle groups, muscles of one limb, one side of the body, the lower half of the body, all limbs, the trunk and the body as a whole; impairments such as weakness of small muscles in feet and hands, muscle paresis, muscle paralysis, monoplegia, hemiplegia, paraplegia, quadriplegia and akinetic mutism</i> <i>Exclusions: functions of structures adjoining the eye (b215); muscle tone functions (b735); muscle endurance functions (b740)</i>

<b>ACTIVITIES AND PARTICIPATION</b> = execution of a task or action by an individual and involvement in a life situation	
<b>d230 (G)</b>	<b>Carrying out daily routine</b> Carrying out simple or complex and coordinated actions in order to plan, manage and complete the requirements of day-to-day procedures or duties, such as budgeting time and making plans for separate activities throughout the day. <i>Inclusions: managing and completing the daily routine; managing one's own activity level</i> <i>Exclusion: undertaking multiple tasks (d220)</i>
<b>d240</b>	<b>Handling stress and other psychological demands</b> Carrying out simple or complex and coordinated actions to manage and control the psychological demands required to carry out tasks demanding significant responsibilities and involving stress, distraction, or crises, such as driving a vehicle during heavy traffic or taking care of many children. <i>Inclusions: handling responsibilities; handling stress and crisis</i>

<b>d410</b>	<b>Changing basic body position</b>
	Getting into and out of a body position and moving from one location to another, such as getting up out of a chair to lie down on a bed, and getting into and out of positions of kneeling or squatting. <i>Inclusions: changing body position from lying down, from squatting or kneeling, from sitting or standing, bending and shifting the body's centre of gravity</i> <i>Exclusion: transferring oneself (d420)</i>
<b>d415</b>	<b>Maintaining a body position</b>
	Staying in the same body position as required, such as remaining seated or remaining standing for work or school. <i>Inclusions: maintaining a lying, squatting, kneeling, sitting and standing position</i>
<b>d420</b>	<b>Transferring oneself</b>
	Moving from one surface to another, such as sliding along a bench or moving from a bed to a chair, without changing body position. <i>Inclusion: transferring oneself while sitting or lying</i> <i>Exclusion: changing basic body position (d410)</i>
<b>d450 (G)</b>	<b>Walking</b>
	Moving along a surface on foot, step by step, so that one foot is always on the ground, such as when strolling, sauntering, walking forwards, backwards or sideways. <i>Inclusions: walking short or long distances; walking on different surfaces; walking around obstacles</i> <i>Exclusions: transferring oneself (d420); moving around (d455)</i>
<b>d455 (G)</b>	<b>Moving around</b>
	Moving the whole body from one place to another by means other than walking, such as climbing over a rock or running down a street, skipping, scampering, jumping, somersaulting or running around obstacles. <i>Inclusions: crawling, climbing, running, jogging, jumping and swimming</i> <i>Exclusions: transferring oneself (d420); walking (d450)</i>
<b>d465</b>	<b>Moving around using equipment</b>
	Moving the whole body from place to place, on any surface or space, by using specific devices designed to facilitate moving or create other ways of moving around, such as with skates, skis, or scuba equipment, or moving down the street in a wheelchair or a walker. <i>Exclusions: transferring oneself (d420); walking (d450); moving around (d455); using transportation (d470); driving (d475)</i>
<b>d470</b>	<b>Using transportation</b>
	Using transportation to move around as a passenger, such as being driven in a car or on a bus, rickshaw, jitney, animal-powered vehicle, or private or public taxi, bus, train, tram, subway, boat or aircraft. <i>Inclusions: using human-powered transportation; using private motorized or public transportation</i> <i>Exclusions: moving around using equipment (d465); driving (d475)</i>
<b>d510</b>	<b>Washing oneself</b>
	Washing and drying one's whole body, or body parts, using water and appropriate cleaning and drying materials or methods, such as bathing, showering, washing hands and feet, face and hair, and drying with a towel. <i>Inclusions: washing body parts, the whole body; and drying oneself</i> <i>Exclusions: caring for body parts (d520); toileting (d530)</i>
<b>d520</b>	<b>Caring for body parts</b>
	Looking after those parts of the body, such as skin, face, teeth, scalp, nails and genitals, that requires more than washing and drying. <i>Inclusions: caring for skin, teeth, hair, finger and toe nails</i> <i>Exclusions: washing oneself (d510); toileting (d530)</i>
<b>d530</b>	<b>Toileting</b>
	Planning and carrying out the elimination of human waste (menstruation, urination and defecation), and cleaning oneself afterwards. <i>Inclusions: regulating urination, defecation and menstrual care</i> <i>Exclusions: washing oneself (d510); caring for body parts (d520)</i>
<b>d540</b>	<b>Dressing</b>
	Carrying out the coordinated actions and tasks of putting on and taking off clothes and footwear in sequence and in keeping with climatic and social conditions, such as by putting on, adjusting and removing shirts, skirts, blouses, pants, undergarments, saris, kimono, tights, hats, gloves, coats, shoes, boots, sandals and slippers. <i>Inclusions: putting on or taking off clothes and footwear and choosing appropriate clothing</i>
<b>d550</b>	<b>Eating</b>
	Carrying out the coordinated tasks and actions of eating food that has been served, bringing it to the mouth and consuming it in culturally acceptable ways, cutting or breaking food into pieces, opening bottles and cans, using eating implements, having meals, feasting or dining. <i>Exclusion: drinking (d560)</i>
<b>d570</b>	<b>Looking after one's health</b>
	Ensuring physical comfort, health and physical and mental well-being, such as by maintaining a balanced diet, and an appropriate level of physical activity, keeping warm or cool, avoiding harms to health, following safe sex practices, including using condoms, getting immunizations and regular physical examinations. <i>Inclusions: ensuring one's physical comfort; managing diet and fitness; maintaining one's health</i>
<b>d640</b>	<b>Doing housework</b>
	Managing a household by cleaning the house, washing clothes, using household appliances, storing food and disposing of garbage, such as by sweeping, mopping, washing counters, walls and other surfaces; collecting and disposing of household garbage; tidying rooms, closets and drawers; collecting, washing, drying, folding and ironing clothes; cleaning footwear; using brooms, brushes and vacuum cleaners; using washing machines, driers and irons. <i>Inclusions: washing and drying clothes and garments; cleaning cooking area and utensils; cleaning living area; using household appliances, storing daily necessities and disposing of garbage</i> <i>Exclusions: acquiring a place to live (d610); acquisition of goods and services (d620); preparing meals (d630); caring for household objects (d650); caring for others (d660)</i>

d660	<b>Assisting others</b> Assisting household members and others with their learning, communicating, self-care, movement, within the house or outside; being concerned about the well-being of household members and others. <i>Inclusions: assisting others with self-care, movement, communication, interpersonal relations, nutrition and health maintenance</i> <i>Exclusion: remunerative employment (d850)</i>
d710	<b>Basic interpersonal interactions</b> Interacting with people in a contextually and socially appropriate manner, such as by showing consideration and esteem when appropriate, or responding to the feelings of others. <i>Inclusions: showing respect, warmth, appreciation, and tolerance in relationships; responding to criticism and social cues in relationships; and using appropriate physical contact in relationships</i>
d770	<b>Intimate relationships</b> Creating and maintaining close or romantic relationships between individuals, such as husband and wife, lovers or sexual partners. <i>Inclusions: romantic, spousal and sexual relationships</i>
d850 (G)	<b>Remunerative employment</b> Engaging in all aspects of work, as an occupation, trade, profession or other form of employment, for payment, as an employee, full or part time, or self-employed, such as seeking employment and getting a job, doing the required tasks of the job, attending work on time as required, supervising other workers or being supervised, and performing required tasks alone or in groups. <i>Inclusions: self-employment, part-time and full-time employment</i>
d920	<b>Recreation and leisure</b> Engaging in any form of play, recreational or leisure activity, such as informal or organized play and sports, programmes of physical fitness, relaxation, amusement or diversion, going to art galleries, museums, cinemas or theatres; engaging in crafts or hobbies, reading for enjoyment, playing musical instruments; sightseeing, tourism and travelling for pleasure. <i>Inclusions: play, sports, arts and culture, crafts, hobbies and socializing</i> <i>Exclusions: riding animals for transportation (d480); remunerative and non-remunerative work (d850 and d855); religion and spirituality (d930); political life and citizenship (d950)</i>

## Annex 2: Examples of Disability Evaluation around the World

To get a sense of the variety of different approaches to disability assessment and, more widely, disability evaluation, we provide these summaries of processes from a representative sample of high, medium and low resource countries. (Since disability policy is highly dynamic, and disability assessment particularly so, what follows should not be viewed as an accurate representation of the current situation in the country represented.)

Country disability policy	Definition of disability	Disability assessment approach	Assessors
<b>USA</b> Social Security Disability Insurance (SSDI)	“Inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or which lasted or can be expected to last for a continuous period of no less than 12 months”  “Inability to engage in substantial gainful activity related to the inability of the person to engage in his/her own work activity or any other work activity which exists in the national economy and which the claimant is capable of performing by virtue of his/her work experience, age, education and the residual capacity (s)he retains to function physically and mentally”	Mixed: Impairment Functional Capacity Disability (partial)	SSA physicians and other health professionals
<b>Disability Evaluation Procedure</b> <ul style="list-style-type: none"> <li>• Evaluation of an applicant's substantial gainful activity.</li> <li>• Documentation of the severity and duration of the disability.</li> <li>• Evaluation of medical listings.</li> <li>• Determination of whether the applicant can perform past work, based on assessment of his or her residual functional capacity, which is the maximum work-related abilities the applicant retains in spite of their physical and mental problems.</li> <li>• Determination of whether the applicant can perform other work that is within his or her remaining physical and mental capacities.</li> <li>• Evaluation of an applicant's substantial gainful activity.</li> <li>• Has Medical Improvement occurred and is related to the ability to work.</li> <li>• Determination of exceptions that occurred that demonstrate the client should no longer be considered disabled or never should have been considered disabled.</li> <li>• Are the client’s impairment(s) severe? Does the applicant's disability cause work-related functional restrictions?</li> <li>• Determination of whether the applicant can perform past work, based on assessment of their residual functional capacity.</li> <li>• Determination of whether the applicant can perform other work that is within his or her remaining physical and mental health capacities.</li> </ul>			

Country Disability policy	Definition of disability	Disability assessment approach	Assessors
<p><b>INDIA</b> Disability Status Certification for all services and benefits</p> <p>Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Rules, 1996</p>	<p>"... 'person with disability' means a person suffering from not less than forty per cent of any disability as certified by a medical authority.</p>	<p>Pure Impairment (modified Baremas)</p>	<p>Medical authority (... any hospital or institution specified for the purposes certification by notification by the appropriate Government")</p>
<p><b>Disability Evaluation Procedure</b></p> <ul style="list-style-type: none"> <li>• The minimum degree of disability should be 40% in order to be eligible for any concessions/benefits.</li> <li>• ... Authorities to give disability Certificate will be a Medical Board duly constituted by the Central and the State Government. The State government may constitute a Medical Board consisting of at least three members out of which at least one shall be a specialist in the particular field for assessing loco-motor and visual including low vision/hearing and speech disability, mental retardation and leprosy cured, as the case may be.</li> <li>• Specified test as indicated in Annexure should be conducted by the medical board and recorded before a certificate is given.</li> <li>• The certificate would be valid for a period of five years for those whose disability is temporary. For those who acquire permanent disability, the validity can be shown as 'Permanent'.</li> <li>• The State Governments/UT Administrations may constitute the medical boards indicated in para 4 above immediately, if not done so far.</li> <li>• The Director General of Health Services Ministry of Health and Family Welfare will be the final authority, should there arise any controversy/doubt regarding the interpretation of the definitions/classifications/evaluations tests etc.</li> </ul> <p>Ministry of Social Justice and Empowerment Guidelines No. 16-18/97-NI ("Guidelines for evaluation of various disabilities and procedure for certification")</p>			



Country Disability policy	Definition of disability	Disability assessment approach	Assessors
<b>SWITZERLAND</b> Swiss Disability Insurance (IV)	<p>“Work inability refers to a total or partial inability to perform “appropriate” work in the former field of occupation due to an impairment of the physical, mental or psychological health. In case of long-term inability to work the appropriateness of employment in other fields of occupations is being taken into consideration as well.”</p> <p>”Reduced earning incapacity is required for disability [invalidity] and for being entitled to disability benefits and reflects the total or partial loss of the possibility of being gainfully employed in the labor market due to an impairment of the physical, mental or psychological health and after the completion of reasonable medical treatments and work reintegration measures. For the evaluation of earning incapacity only the influences of impairments [not of contextual factors] should be considered. In addition, earning incapacity should only be attested if it cannot be overcome from an objective point of view [i.e. treatment-resistance].”</p> <p>“Disability [invalidity] refers to the presumably permanent or long-lasting total or partial earning incapacity.”</p>	Biomedical, impairment-oriented approach	Physicians (including neuropsychologists)

**Disability Evaluation Procedure**

1. Claimant’s application for disability benefits at the Swiss Disability Insurance
2. Evaluation of the applicant’s medical history based on available medical records
3. Invitation of the applicant for the disability assessment performed by the (specialist) physician
4. Documentation of the applicant’s socio-medical history based on self-reported data, i.e. occupational background (e.g. previous jobs), educational background, biographical background, medical history (e.g. duration of disability [is it long-term disability?], past interventions [were they unsuccessful?], severity of complaints), and current functioning in activities of the daily life
5. Medical examination aiming at an objective assessment of the applicant’s physical or mental impairments, leading to the final medical diagnoses, and his or her functional capacity
6. Determination of potentially influencing contextual (i.e. environmental and personal) factors
7. Synthesis of socio-medical history and medical examination
8. Determination of work (in)capacity in the former job as well as in a hypothetical job on the labor market adapted to the applicant’s disability; based on the applicant’s diagnoses and functional capacity and without taking into account potentially influencing environmental and personal factors
9. Suggestion of a long-term prognosis with regard to the applicant’s disability and proposal of vocational and medical measures to improve the applicant’s work capacity
10. Decision on the applicant’s earning capacity by Swiss Disability Insurance, relying on the work capacity appraisal of the (specialist) physician
11. Determination of the final degree of disability based on the degree of the applicant’s earning capacity
12. Decision on type and amount of disability benefits based on the degree of the applicant’s disability and whether functional limitations are caused by the health condition or contextual factors.

Country Disability policy	Definition of disability	Disability assessment approach	Assessors
<b>KENYA</b>  Persons with Disabilities Act (2003, amended 2007)	"A physical, sensory, mental or other impairment, including any visual, hearing, learning or physical incapability, whether arising from natural or artificial causes, which is irreversible and long term and which impacts adversely on a person's capacity to participate in social, economic, cultural or political activities"	Informal with impairment basis	Medical assessors from government hospitals

**Disability Evaluation Procedure**

Based on questionnaire results:

1) What is the nature of the disability?

- Albino
- Physical
- Mental
- Visual
- Hearing
- Epilepsy
- Blind
- deaf/using sign language
- deaf/able to talk normally
- other (specify)

2) What is the major cause of the disability?

- By birth
- Accident
- Illness

3) At what age?

4) What is the severity of the disability?

- Severe
- Moderate

5) What is the individual's disability condition when not using any type of assistive device?

6) Which devices, if any, is the individual currently using?

Country Disability policy	Definition of disability	Disability assessment approach	Assessors
<p><b>AFGHANISTAN</b></p> <p>Comprehensive National Disability Policy (2003)</p> <p>Afghanistan National Disability Action Plan (2008)</p>	<p>No official definition</p> <p>“There is no standard terminology to describe different types of disabilities, levels of need and related terms in Afghanistan. Different names are being used for persons with disabilities that are sometimes discriminatory or demeaning.”</p> <p>Afghanistan National Disability Action Plan 2008-2011</p> <p>Adoption of ICF by Ministry of Labour, Social Affairs, Martyrs and Disabled -- MoLSAMD)</p>	<p>No explicit assessment method is used</p>	<p>Unidentified personnel at the MoLSAMD</p>
<p><b>Disability Evaluation Procedure</b></p> <ul style="list-style-type: none"> <li>• Persons with disabilities, registered with the MoLSAMD, receive welfare payments of 300-500 Afghanis per month (about 6-10 USD) based on the degree of disability. People registering for pensions are referred to the MoPH for an assessment of the degree of disability.</li> <li>• Persons with less than 60 percent disability receive 300 Afghanis per month.</li> <li>• No payment is made to people with less than 35 percent disability. It is acknowledged that the allowance is too low to provide a basic standard of living</li> </ul>			
Country Disability policy	Definition of disability	Disability assessment approach	Assessors
<p><b>SOUTH AFRICA</b></p> <p>Disability Grant (social assistance)</p> <p>Temporary incapacity and permanent (total and Partial) incapacity (compensation of occupational Injuries and diseases)</p>	<p>"...those who cannot support or maintain themselves financially or by some other means due to their daily functioning being severely compromised as the result of a health condition, causing limitations in their ability to provide for their daily needs."</p> <p>“A person is ... eligible for a disability grant, if he or she:</p> <p>(a) has attained the prescribed age; and</p> <p>(b) is, owing to a physical or mental disability, unfit to obtain by virtue of any service, employment or profession the means needed to enable him or her to provide for his or her maintenance.</p>	<p>Informal, no method described</p>	<p>Medical officer</p> <p>Social Assistance Act 13 of 2004</p>
<p><b>Disability Evaluation Procedure</b></p> <p>(a) he or she is a South African citizen, permanent resident or a refugee;</p> <p>(b) the disability is confirmed by an assessment which indicates whether the disability is -</p> <p>(i) permanent, in that the disability will continue for a period of more than 12 months; or</p> <p>(ii) temporary, in that the disability will continue for a continuous period of not less than 6 months or for a continuous period of not more than 12 months as the case may be:</p> <p>Provided that the assessment must, at the date of the application, not be older than three months;</p> <p>(c) he or she is unable to enter the open labor market or to support himself or herself in light of his or her skills and ability to work;</p> <p>(d) he or she does not unreasonably refuse to accept employment which is within his or her capabilities and from which he or she can generate income to provide fully or partially for his or her maintenance; and</p> <p>(e) he or she does not, without good reason, refuse to undergo the necessary medical or other treatment recommended by a medical officer.</p>			

Country Disability policy	Definition of disability	Disability assessment approach	Assessors
<p><b>NETHERLANDS</b> Disability Insurance Scheme (WIA) 2006</p>	<p>Vocationally handicapped (economic criteria)            “If an employee has lost at least 80% of his/her salary and there is scarcely if any chance of recovery, the employee is then considered fully and permanently occupationally incapacitated and will receive IVA benefits.”            “If an employee can earn more than 65% of his/her former salary with generally accepted work (this includes work duties other than his/her former work duties), he/she is then considered to be less than 35% occupationally incapacitated and is not entitled to receive WIA benefits”</p>	<p>Mixed: general medical condition, plus ‘residual functional capacities’            “Disability is assessed by comparing the wage the person earned before the onset of disability to the value of the labor he can still perform with his disability. This means that there is no direct link between the severity of disease or impairment and the level of disability. The disability assessment, therefore, is not a mere medical affair, but the result of a combined assessment by a medical doctor and a labor expert.”            Ad Bockting, Inclusion in working Life ISSA European meeting, Oslo</p>	<p>Specialised social insurance physicians and vocational experts employed by Social Insurance Institute</p>
<p><b>Disability Evaluation Procedure</b></p> <ul style="list-style-type: none"> <li>• Initial determination based on medical determination by Social Insurance Institute physicians.</li> <li>• Two year period begins, paid by employer who develops work reintegration plan.</li> <li>• If plan fails, social insurance doctor judges general medical condition; if medical status allows (the complainant is not bedridden or under treatment), an inventory of such capacities is made, to determine whether claimant has residual capacity to function in paid employment.</li> <li>• For those with residual capacities, the vocational expert uses an algorithm representing Dutch labor market (based on a catalogue of jobs and their physical and mental requirements) to determine if claimants residual functional capacities fits with a list of jobs that are commensurate with the claimant’s capacities, and their wage rates.</li> <li>• The vocational expert uses this list to assess one’s residual earning capacity. Whether there are any vacancies among those commensurate jobs is irrelevant.</li> </ul>			

<b>Country Disability policy</b>	<b>Definition of disability</b>	<b>Disability assessment approach</b>	<b>Assessors</b>
<p><b>CHINA</b> All policy under the Law of the People's Republic of China on the Protection of Persons with Disabilities (adopted 1990, revised in 2008)</p>	<p>"A restriction or lack, resulting from an impairment, of ability to perform an activity in the manner or within the range considered normal for a human being within his or her social context."</p> <p>"A physical, mental, or sensory impairment, whether permanent or temporary, that limits the capacity to perform one or more essential activities"</p> <p>A disabled person refers to a person who suffers from the loss or abnormality of a certain organ or function, psychologically, physiologically or in human structure, and has lost all or in part the ability to normally carry out certain activities. Disabled persons include persons with visual, aural, speech and physical disabilities, mental retardation, mental disorder, multiple disabilities, etc.</p>	<p>No specific approach or methodology officially described</p>	<p>Physicians and other experts appointed by State Council (China's cabinet of the central government)</p>
<p><b>Disability Evaluation Procedure</b> No explicit procedure officially described</p>			

## **Annex 3: Case Example: Applying the ICF to Disability Assessment: A Practical Case Study Based on the Experience of Greece and Cyprus**

Stathis Triantafillou, Psychologist

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ICF Hellenic Team: Venos Mavreas, Psychiatrist; Marianna Papadopoulou, Neurologist; Yannis Michopoulos, Psychiatrist; Kostas Francis, Child psychiatrist; Artemis Drosou, Physiotherapist; Andreas Karystinos, Psychologist; Sophia Koukouvinou, Psychologist; George Filippou, Occupational Therapist

In Collaboration with the Department for Social Inclusion of Persons with disabilities in Cyprus:  
Christina Flourentzou, Director and Maria Ioannou, Psychologist

***A note of caution: This is a practical example of the application of the ICF to disability assessment based on the experience of Cyprus. It is not meant as and it cannot be a blueprint, because the application has to be customized for each country.***

### **Introduction**

The International Classification of Functioning, Disability and Health (ICF) was approved unanimously by the WHO World Health Assembly in 2001. Since 2004, the Greek and Cypriot editions of the ICF have been developed, as well as a number of implementation tools to facilitate the adoption of the ICF into the design and implementation of disability policies in both Greece and Cyprus.

The ICF provides a consensus on the modern understanding of disability. It sees disability as interactional: the result of interaction between a person with a health condition and her or his environment. This is the definition embraced as well by the UN CRPD (2006). Operationalization of the ICF approach and its adoption as a guiding principle in the design and implementation of disability policies entails its application in the assessment and evaluation of disability.

This practical example of using the ICF in disability assessment is based on experience gathered in Cyprus. The experience teaches us that the reform of the disability assessment system (DAS) is: (i) institutional, because it reforms a public institution that performs an important public function; (ii) administrative, because it requires an appropriate administrative body with rules, roles and controls and human resources; (iii) technical, because it requires the development of technical criteria; and (v) political, because it involves diverse stakeholders, whose interests might not be in favor of reforming the existing system. This combination makes reform of disability assessment both complex and complicated, yet feasible, as the case of Cyprus shows.

Since 2004, the work of the Hellenic ICF team in Cyprus has involved the dissemination and implementation of ICF. One of the aims of the engagement has been to reform disability assessment system and to develop a mechanism for utilizing its results in order to assign state provisions. The initial situation regarding disability assessment in Cyprus was characterized by the

absence of clinical and functional assessment, absence of assessment protocols, a dominant “file assessment” based approach, short duration contact with the individuals to be assessed, quantitative results based on percentage system or based exclusively on medical criteria and assessment, absence of assessment tools and infrastructure and above all lack of objectivity and fraud. Furthermore, the implementation of the proposed ICF approach has encountered obstacles from state officials, health professionals and organizations of people with disabilities who have little information and understanding of the ICF. The team was confronted with many tasks in order to implement ICF and quite few times had to convince stakeholders of the value of the “wheel” or to propose “new wheels”.

The experiences from the countries reveal the great effort involved in disseminating and implementing ICF into the process of disability assessment. The ultimate goal of this effort was the establishment of a clinical and functional assessment for disability, an assessment based on ICF principles and tools and a continuous initiation of health professionals, state officials and disabled into the system.

***This document incorporates our experiences with the nuts and bolts of the reform of the DAS, and should be read keeping in mind that each country is different, with different institutional set ups and morbidity patterns and that, therefore, the nuts and bolts need to be customized. The basic ingredients are, however, the same: an administrative house that is well equipped and staffed, well-established clinical and functional assessment process, assessment protocols and tools, and transparent procedures, quality control and appropriate grievance redress mechanisms.***

### **The Case of Cyprus**

The project was planned in 2007 and launched in 2009 and its main target was the reformation of the disability assessment system that governs the distribution of state provisions. The project was financed by the European Social Fund and was managed by the Hellenic ICF Team under the umbrella of the Ministry of Labor, Welfare and Social Insurance.

The objective of the project was to identify and assess, based on a systematic and scientifically justified methodology, the disability of an individual and, optionally, his or her functioning. Also, it aimed to document suggestions for appropriate interventions that could support and enhance the person’s social inclusion. By applying the scientific basis of the WHO’s ICF, and by using specially designed assessment protocols, the certification of disability came to be based on a more scientific, reliable and objective basis, treating people with disabilities with respect and dignity, serving the public services with professionalism and upgrading the knowledge for all types of disability: motor, sensory, intellectual and mental.

According to Article 26 of the United Nations CRPD, programs and services for the integration and rehabilitation of persons with disabilities in all areas of life must be based on a multidisciplinary assessment.

The Disability Assessment Center is a new point of reference for disability in Cyprus. It provides the infrastructure where assessments take place and is located in the Department for Social Inclusion of Persons with Disabilities in Latsia, Nicosia. The Center’s operation began in December 2013 offering modern and accessible facilities and equipment, a reputable scientific background with the assessment protocols and the implementation guidebooks for the assessment

mechanism and with a network of medical doctors and rehabilitation professionals trained specifically on the use of the ICF as assessors and cooperating with the Department on a purchase of services basis. Persons with disabilities are referred to the Assessment Centre from different services of the Ministry of Labor, Welfare and Social Insurance, where they submit applications for social benefits and services.

These individuals have the opportunity to choose whether they wish to be assessed only on their disability or to be assessed in terms of their disability and functioning.

**Assessment of the health status and impairment (in local language “the assessment of disability”).** This is carried out by a team of two or three doctors with specialties directly related to the disability the person may be facing. Its aim is to identify, describe and certify the existence, type and degree of disability and to advise whether the person meets the criteria and conditions of the law and schemes for social benefits and services offered by the state, according to their disability status.

**Assessment of functioning.** If the person chooses to have functioning assessed as well, the second phase of assessment is carried out immediately after the disability assessment by a group of two or three rehabilitation professionals (physiotherapist, occupational therapist, speech therapist, psychologist), depending on the type of disability of the individual. The objective of the assessment of functioning is to identify, describe and certify the constraints the individuals may be facing in everyday life and the necessary interventions needed to reduce these constraints.

These interventions do not necessarily match the economic benefits, but involve the types of treatment or services needed by the individual or the need for specialized assistive devices such as wheelchairs or other aids. The interventions may also relate to education, training and employment, so that the individual can enjoy an increased quality of life and a more active participation in social inclusion.

**Complete assessment report of disability.** Individuals receive a Complete Assessment Report of Disability and a Disability Card after the assessment, which authorizes them to receive social benefits and services that they are entitled to as offered in the public sector.

***The following is an institutional description of some of the agencies, procedures and tools that were used to develop an ICF-based disability assessment system in Cyprus.***

## **The Evaluation Centre for Disability Assessment**

### **Required procedures and tools**

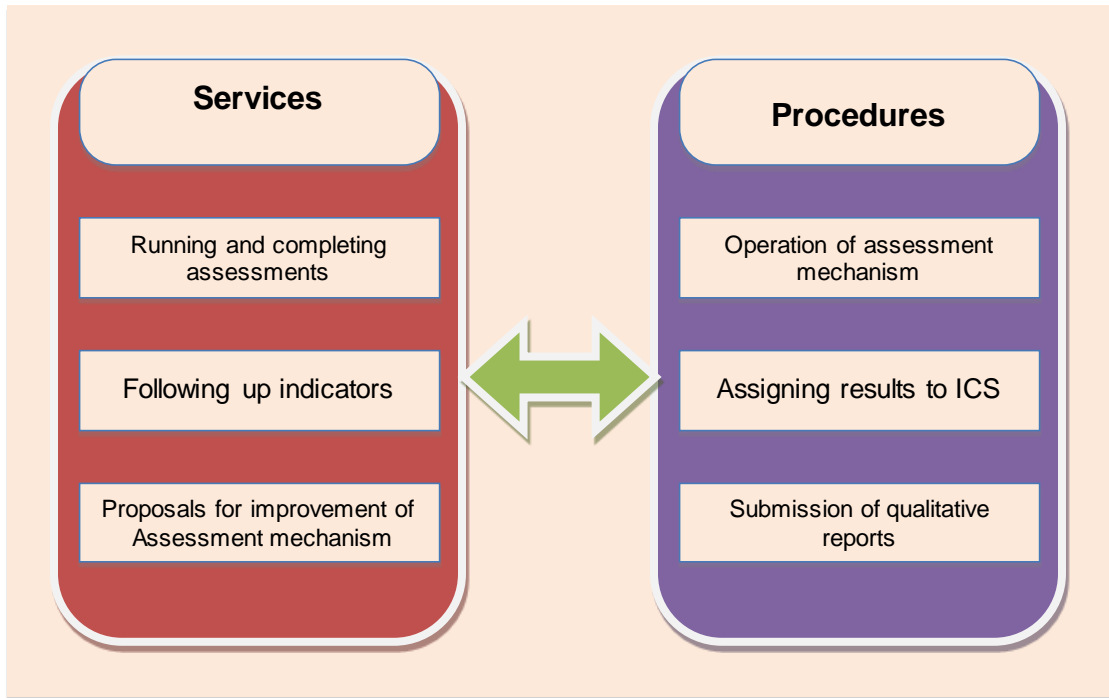
For the fulfillment of users' needs the Evaluation Center for Disability Assessment (ECDA) was created to develop procedures for

- conducting assessments;
- submitting qualitative reports for the support of the assessment procedures for information and dissemination to users; and
- transferring the assessment results, in the form of a holistic report to the Institutional coordinating Structure (ICS).



The ICS should undertake the management and retrieval of the results and the distribution of state's provisions. The ICS is the appropriate legal entity and can coordinate the operation of the numerous Evaluation centers.

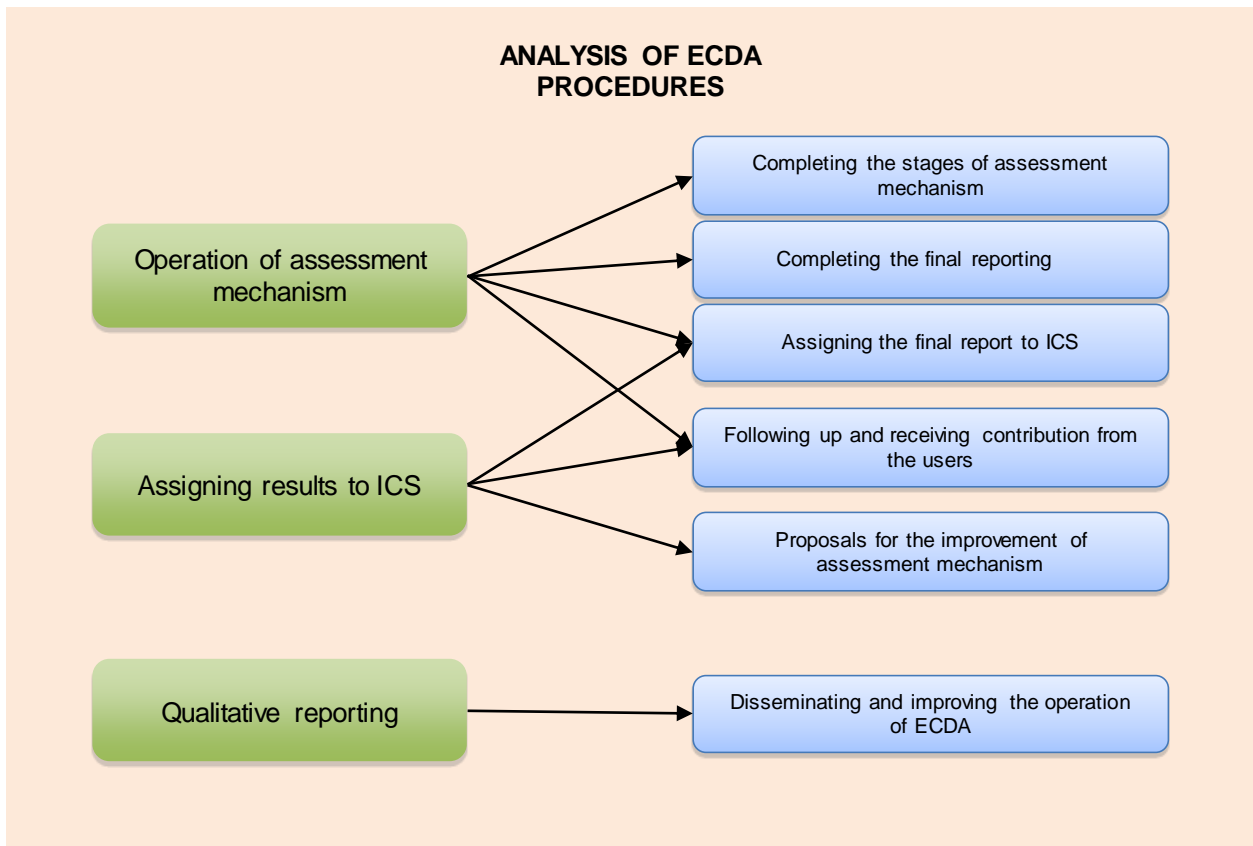
### Services and Procedures of ECDA



Analytically, for the execution of the above procedures, the following are required:

- completing the stages of holistic assessment;
- completing the final reporting;
- sending and assigning the final reporting to ICS;
- continuous application and study of the assessment mechanism in order to submit correctional interventions on its procedures;
- following up on the attitudes about and participation in the procedures;
- preparing a proposal for the improvement of assessment mechanism; and
- participating and supporting initiatives to secure benefits to the user.

## Analysis of ECDA Procedures



### Principles of the operational structure of the ECDA

The operational planning of the ECDA, which will be an integral structure of the ICS, should take into consideration the following:

- Facts and findings (reports and discussions) which emerge from the period of project's development and guide the operation of assessment centers and the implementation of assessment mechanism of ICF.
- Their role and obligations to ICS.
- Their everyday work with the vulnerable groups and their level of satisfaction to the new system.
- Restrictions which set objective parameters in the operation of the center.

Analytically, the most important milestones of the operational structure that should be accurately designed are the following:

- Basic group operations - activities
- Suggested operational structure
- Staffing
- Needs of Training
- Work flow and related documentation

- Description of work areas
- Areas of specification
- Description of work places
- Infrastructure and Equipment
- Conjunction mechanism with IT

Specifically, the involved staff should

- Be qualified in order to execute qualitatively the mission of ECDA, i.e. the application of harmonized assessment mechanism that addresses the stages of file preparation, actual assessment and completion of the file;
- Use the computer system in order to store data to be transferred to ICS.

The basic criteria used to design the ECDA operational structure are specific and general:

**The specific criteria include**

- Harmonization with the strategic goals of ICS
- Execution of the planned procedures
- Operation of assessment mechanism
- Flexibility and attainment of cost reduction

**The general criteria include**

- Minimum number of administrative levels
- Optimal control through immediate reporting
- Greater clarity on the roles and responsibilities
- Collaboration of staff (assessment's interdisciplinary team and administrative staff) in order to minimize delays in the execution of procedures
- Grouping of homogeneous activities
- Focusing on the level of satisfaction for staff and users

Additionally, the restrictions that should be taking into consideration include

- The number of the persons involved who are affected by the changes
- The minimum possible cost of the whole effort
- How to assess and mitigate the reactions to the coming changes

On the basis of the operational principle for staffing, there is a need to correlate the group operation with the required skills.

## Basic Group Operations

### Operational groups

Group	Basic Skills (Grade *)
Technical	Communication with users (2)
	Dealing with users (4)
	Disability policies (3)
	Knowledge of disability (4)
	Knowledge and use of IT (3)
	Languages (2)
	Overall behavior (4)
Administrative	Disability policies (4)
	Dealing with users (4)
	Knowledge and use of IT (4)
	Over all behavior (4)
Supportive	Disability policies (3)
Network of external evaluators	Knowledge of the new assessment (4)
	Disability policies (4)
	Knowledge and use of IT (3)
	Overall behavior (4)

### Suggested Operational Structure

The organization of the above-mentioned staff, on the basis of the operational principles for staffing, leads to the determination of the most suitable structure of the ECDA.

The ECDA centers are affiliated administratively to the responsible ICS. Each ECDA incorporates three organic units.

#### A) Technical

This unit consists of medical staff and rehabilitators and is responsible for:

- The assessment process
- Collaboration of the interdisciplinary team
- The final reporting
- The communication with the assessed
- The research and the needs of training
- The submission of proposals for improvement

#### B) Administrative

This unit is responsible for the administrative and the managerial operation of the center:

- The management
- The operation
- The follow up
- The communication

### C) Supportive

This unit is responsible to support further the operation of the center.

### D) Network of external evaluators

This Unit supports the technical staff of the center and is called upon request.

With the above described operational structure we believe that ICS will operate efficiently providing the necessary work and focusing on:

- The essential evaluation of disability
- The sufficient allocation of roles for the best results and direct decision making
- The clear differentiation of roles and responsibilities
- The best provision of services

The needs for technical, administrative and supportive staff are related to the support needed for every day operation. An analytic description is provided in order to record the real needs in relation to the nature of their work due to their

- Basic personal work
- Internal common work (interdisciplinary team)
- Supportive work outside of the center

### Staff requirements

ECDA STAFF		
	WORK PLACES	STAFF Number
<b>Technical</b>	Social Worker	1
	Medical Doctors	3
	Rehabilitators	3
<b>ADMINISTRATIVE</b>	Executive	1
	Secretary	1
<b>SUPPORTIVE</b>	Nurse	1
	Driver	1
	Janitor	1
	<b>Total</b>	<b>12</b>

### Assessment mechanisms

#### Stages of the assessment mechanism

Analytically, the work flow of the assessment mechanism is based on and executed in three stages, where professional staff and related documents are involved at each stage. These three stages are:

- Preparation of the Evaluation File
- The evaluation of Medical and Functional Assessment
- The completion of the evaluation procedure

#### **STAGE 1: Preparation of the Evaluation File**

- The process begins with the reception of the individual's application in the evaluation center where the file receives a unique number or a code from the National Registry Base and the file is referred to the director of the disability assessment center.
- The director of the evaluation center assigns the file to a specific social worker who acts as the case manager during the preparation and evaluation procedures.
- The assigned social worker is responsible for the flow of the file and the communication with the individual. The social worker contacts the individual and informs him or her that the social worker is responsible for the application and case in general. Furthermore the social worker informs the applicant that they should meet (at the center or at the applicant's home or by phone) to complete the general information questionnaire.
- The social worker informs the applicant by phone or letter that in order for the file to be complete for the evaluation, the applicant must submit to the center information and documentation of any past exams or evaluations from the applicant's physicians, therapists, or hospitals. Even though it is the applicant's responsibility to collect and provide all the evaluation and medical reports to the center, the social worker should assist the applicant during this process.
- The social worker checks the file for completeness writes the report and proposes to the director of the evaluation center an advocate physician and rehabilitation therapist.
- The director of the evaluation center assembles the files for evaluation based on the nature of the health condition, assigns an advocate physician and advocate rehabilitation therapist for every file and a meeting date is set to discuss each file and the assignment of the appropriate evaluating physician and rehabilitation therapist. During this task the weekly and monthly program of evaluations is set in order to have the most optimal management of time.
- The social worker informs the advocate physician and advocate therapist about the content of the file, asks for any further information or documentation if missing, composes the ICF vignette and chooses the appropriate protocol.
- The social worker reviews the completeness of the file and informs the applicant and the evaluators (physicians and therapists) of the date and time of the evaluation.

#### **STAGE 2: Medical and Functional Assessment**

- During this task and specifically at the evaluation date the social worker assigns the file to the advocate physician and the other two assigned physicians and they review the file, the ICF based vignette and the focused protocol (if needed they add any necessary codes in the protocol). The social worker welcomes the individual and informs him or her about the procedures and actions that will take place during the day and that the social worker will assist during the whole evaluation.
- The social worker escorts the individual into the physicians' evaluating room and the evaluation of disability begins. All three assigned physicians perform the appropriate clinical examination with the appropriate tools and methods. The advocate physician with

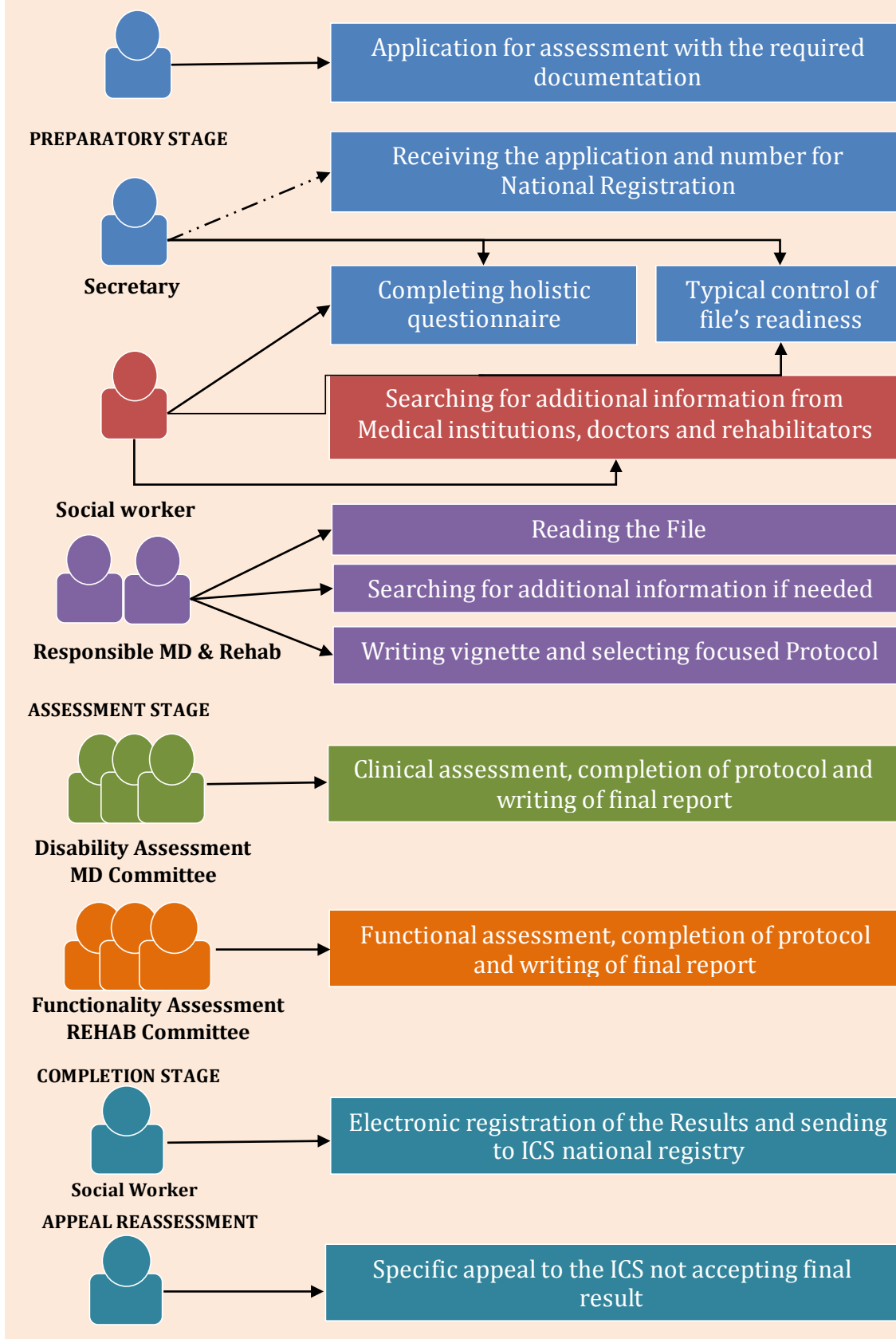
the consensus of the other two physicians fills out the protocol with the appropriate qualifiers and completes conclusive report results (the section that is predetermined for the physicians). Afterwards the social worker confirms that all actions and results of the evaluation are suitably and correctly filled.

- The social worker forwards the file to the rehabilitation evaluation room where the advocate therapist and the other therapists review the file, the ICF based vignette, the results of the physicians protocol and the rehabilitation focused protocol (if needed they add any necessary codes in the protocol).
- The social worker escorts the individual and the file to the rehabilitation evaluating room and the evaluation of functionality begins. The rehabilitation therapists perform the clinical examination with the appropriate tools and methods. During the evaluation the advocate therapist, with the consensus of the others, fills out the protocol with the appropriate qualifiers and the complete conclusive report results (the section that is predetermined for the therapists). Again, the social worker confirms that all actions and results of the evaluation are suitably and correctly filled.
- The social worker informs the individual that the evaluation process is complete. The copy of the complete conclusive evaluation report is given to the individual and is explained to the individual. If required, reevaluation dates are set and the individual is given the option to submit an objection within the period of 30 working days.

### **STAGE 3: Completion and Validation of the Evaluation**

- The completed file is forwarded to the director of the ICS (Institutional Coordinating Structure) by the social worker. There the relevant committee inspects the file, the process of the evaluation as well as the results, and assigns the degree of disability and determines the state provisions.
- The secretary of the ICS sends an electronic copy of the individual's results to the IT data base and a letter to the assessed person that provide him or her a sufficient time to appeal the outcome. In the case of no appeal the ICS itself or the relevant units then proceed to provide the determined benefits.

## ASSESSMENT MECHANISM





## **Work document and flow**

The staff requirements correspond to the basic structure of ECDA. The work to be done determines the quality and quantity of the provided services and the expertise of the administrative, scientific and supportive personal.

## **Methodology of the assessment mechanism of ECDA:**

The assessment mechanism determines the quality and quantity of the work to be done, specifically the tasks of the Assessment mechanism (Preparation stage, Organization of file, Assessment stage, Execution of assessment and Completion stage, Decision making).

The three stages determine with precision the work flow of every day and provide data for the duration of the administrative, scientific and supportive work as well as the amount and flow of the documentation required, as well as any other work that is needed.

## **Mechanism for correlating determination with degree of disability**

### ***Establishing a channel between ECDA and ICS***

The ICF assessment involves the clinical and functional assessments with the completion of protocols and leads to a holistic report that provides valuable and precise scores using the ICF **qualifiers**. The ICF protocol is divided into four sections: body structures, body functions, activity and participation, and environmental factors, and qualifiers are provided for each section. Every person assessed is scored for the extent of the difficulties on body functions and structures and restrictions in functioning in daily activities, school, and work and in life in general. In relation to his or her disability, assessors focus on components and codes of the protocol that are related to the health condition of the person.

After merging the qualifier scores for body structures and body functions, the assessors produce a Final Qualifier for the Medical condition. Similarly, after merging the scores for activity and participation and the environmental factors, the assessors produce a Final Qualifier for Functional work restriction.

A Final Qualifier is assigned for each part of the protocol and utilizes vignette knowledge and the actual assessment's scoring on codes relevant to the disability assessed.

The final qualifiers, one for the medical assessment (medical qualifier) the other the functional status (social restrictions) are the prerequisites for defining the **Dominant Qualifier** (DQ).

The **Dominant Qualifier** is the overall scoring of all the components of the protocol and so the final assessment of disability.

The decision regarding the dominant qualifier is made by the assessment committee within the Assessment Unit, since it requires complete knowledge of the assessed person and its decision is based on the clinical and functional profiles.

The dominant qualifier is transferred to the ICS which checks the assessment criteria in conjunction with the Dominant Qualifiers and Degrees to be assigned according to Final qualifiers provided for the Medical condition and Functional work restriction.

The Dominant Qualifier received by the ICS is correlated with the appropriate degree of disability. At present, most systems for disability assessment using a complete assessment of functioning based on the ICF use the following terminology for degree of **Disability** (appropriate to both adults and children):

- 1. Mild degree of disability** for cases where impairments are minimal and there is a slight limitation of activity that requires no special protection measures and social participation is reasonable.
- 2. Moderate degree of disability** for cases of reduced physical or low intellectual capacity leading to activity limitations, relative to age-appropriate expectations. These limitations result in a relatively significant restriction of social participation.
- 3. High degree of disability** for cases of the inability to function according to social roles appropriate to development and age, due to important functional limitations (motor, sensory, neuropsychiatric or metabolic), resulting from severe health conditions, in advanced stages with organ system complications. In this situation social participation is substantially restricted.
- 4. Severe degree of disability** for cases of those who, relative to age and stage of development, have no ability for self-care and a high degree of physical and psychological dependence. In this case the autonomy of the individual is very low due to severe limitation in activity, which leads to multiple restrictions in social participation. As a result, a person requires special care and constant supervision from another person.

On the other hand, many countries use three categories of work related disability based on the assessment of medical condition/ impairment:

- 1. Degree III:** characterized by loss of at least half working capacity and so being able to carry out a professional activity (corresponding to the capacity to work more than half of the regular work time).
- 2. Degree II:** characterized by total loss of working capacity, but presence of self-care capacity.
- 3. Degree I:** characterized by total loss of working capacity and self-care capacity.

It is possible to link these two groups of designations to the ICF scale used for the severity qualifiers for Body Functions and Structures and Activities and Participation:

ICF Medical Assessment

0 NO PROBLEM	(none , absent, not significant,...)	0-4%
1 MILD PROBLEM	(light,...)	5-24%
2 MODERATE PROBLEM	(medium, enough...)	25-49%
3 PRONOUNCED PROBLEM	(high, extreme,...)	50-95%
4 SEVERE PROBLEM	(total,...)	96-100%

ICF Functional Assessment

0 NO RESTRICTIONS	(none , absent, not significant,...)	0-4%
1 MILD RESTRICTIONS	(light,...)	5-24%
2 MODERATE RESTRICTIONS	(medium, enough...)	25-49%
3 PRONOUNCED RESTRICTION	(high, extreme,...)	50-95%
4 SEVERE RESTRICTIONS	(total,...)	96-100%

The role of the ICS, therefore, once it receives the **Dominant Qualifier** from the ECDA, is to inspect the status of the file and correlate the result with the relative degree. In case of the Medical Assessment the correlation of ICF and the two sectors are as follows:

ICF DQ	DISABILITY	INVALIDITY
<b>1</b>	MILD	
<b>2</b>	MODERATE	III
<b>3</b>	PRONOUNCED	II
<b>4</b>	SEVERE	I

### Tools of Implementation

The full implementation of ICF into Cyprus’ disability determination process required the development of a collection of tools: administrative, systems, and training. The administrative tool includes the medical documentation and system and scientific reports; the system’s tools are those based on the ICF classification; and the training tools include the training packages and guides. In detail:

<b>Administrative Documentation</b>
<ul style="list-style-type: none"> <li>Referral Application form for assessment</li> <li>General Information Questionnaire</li> <li>Social worker’s Report</li> <li>Report of Treating Physician</li> <li>Report of Rehabilitation Therapist</li> <li><u>Usual Documentation</u> <ul style="list-style-type: none"> <li>ID Certification</li> <li>Required recent medical examinations</li> <li>Notification Letter for the assessed</li> </ul> </li> </ul>
<b>System’s Tools</b>
<ul style="list-style-type: none"> <li>Vignette</li> <li>Focused protocols for disability in adults and children</li> <li>Social History-Vignette</li> <li>Open medical and functional protocol</li> <li>Medical and Functional reports</li> <li>Final (Holistic) Report</li> </ul>
<b>Training Tools</b>
<ul style="list-style-type: none"> <li>ICF Assessors Guide</li> <li>ICF Trainers Guide</li> <li>ICF Assessor’s Training Package</li> <li>ICF Training of Trainers Package</li> <li>Supplementary training Material</li> </ul>

**The Focused Protocol was the primary tool to integrate ICF** into the assessment system. The protocol was used to compile the individual’s complete functional profile. The term “focused protocols” was used to describe the set of codes relevant to certain type of disability. In the case

of a psychiatric health condition, for example, the corresponding protocol contains all the codes of Chapter 1 of body functions (B1. Mental functions), while the rest of the chapters were included only as headings. Obviously, a psychiatric patient may also have another health problem, diabetes mellitus for example. In that case, more codes that are not contained in the specific protocol are added as there is space provided for additional codes at the end of each protocol section.

The development of focused protocols was based on the type of disability and not on the type of disease in order to keep a safe distance from medical assessment. The rationale for definition of the type of disability was based on the usual groups of people with disability who claim social benefits and social care from the state following the assessment of their needs. So, five types of disability were used and corresponding protocols were developed: the **physical disability** protocol, the **psychiatric disability**, the **mental disability**, the **hearing disability**, the **visual disability** and the global protocol for cases that cannot be assigned to any of the previous categories. These five disability areas are the most common internationally.

In the case of medical assessment, twenty more focused protocols were structured for the work capacity assessment related to the following diseases: hearing problems, amputation, dementia, autism, spinal lesions (paraplegia, tetraplegia), cerebrum lesions (stroke, tumors, injury), epilepsy, neurological conditions (polyneuropathy, myopathy), orthopedic conditions, mental retardation, hematological diseases, vascular diseases – peripheral arteriopathy, Parkinson disease, ophthalmological problems, rheumatoid Arthritis, multiple sclerosis, coronary diseases, obstructive pulmonary disease, renal disease (failure) and psychiatric disorders.

The **training tools** were essential for the process of changing the disability assessment system. Two guides were required. The first was the **ICF Assessor's Guide** with two parts: one with the basics of the ICF and a second part presenting the main tools used to implement ICF in Cyprus, namely the focused protocols and guidelines for medical and rehabilitative professionals for evaluating disability, both medically and functionally. The second was the ICF Train-the-Trainer Guide which was used with medical and rehabilitative professionals as a study guide for them to use to make their own presentations for training sessions they would themselves conduct. This Guide contains sections on the philosophy of ICF, international practice, basic concepts, coding instructions, assessment mechanism and work flow, focused protocols, vignette and holistic report, designing and applying practical exercises and also guidelines of behavior during assessment for children, adolescents and adults.

Finally, the **basic training package** was based on a five day program that combined theoretical discussions and practical exercises (see below). The goal was to get health professionals (physicians and rehabilitators), many of whom are assessors in the current system, to understand the ICF, the disability assessment system and ICF's role in reforming the system.

<b>DAY 1</b>
<b>Getting to know the trainees: ICF Philosophy.</b> <i>General principles of the Classification, its difference from other medical models, its scope, principles, aims and applications</i>
<b>International Practice in the use of ICF</b> <i>Description of the disability classification systems, other countries' experience of the Classification</i>
<b>DAY 2</b>
<b>Linking – coding instructions</b> <i>Theoretical and methodological background of evaluating strategies, coding, qualifiers</i>
<b>Assessment mechanism:</b> <i>Application for assessment, preparation stage, vignette formation, assessment stage, completion of assessment , holistic report</i>
<b>Focused protocols:</b> <i>Development of focused protocols, rationale, aims and utility</i> Practice in coding
<b>DAY 3</b>
<b>Linking – coding instructions</b> <i>Theoretical and methodological background of evaluating strategies, coding, qualifiers</i>
<b>Catch up with basic principles and coding</b>
<b>DAY 4</b>
<b>Case study: tutorial</b> <i>Presentation of completed vignettes</i>
<b>Case study: interactive</b> <i>Presentation of incomplete vignettes</i>
<b>Case study</b> <i>Group practical exercise</i>
<b>DAY 5</b>
<b>Coding: test</b>
<b>Assignment of evaluation test</b> <i>A significant final trial for the evaluation of the understanding and assimilation of the unified system.</i>

## **Annex 4: A Note on Disability Policy and Disability Assessment in the United Kingdom**

Ola abu Alghaib and Tom Shakespeare<sup>1</sup>

### **Abstract**

*This paper first discusses the background to and political context for disability benefits payments in the UK, and then outlines the main disability benefits currently available. Next, it presents the Work Capability Assessment (WCA), the test for receiving Employment Support Allowance (ESA), the main work substitution benefit for disabled people, and discusses the main criticisms which have been made of WCA and the Employment Support Allowance regime, before finally drawing conclusions about the difficulties encountered in changing the patterns of social assistance and employment for disabled people.*

### **1. Introduction**

Over the last 30 years, the United Kingdom (UK) – like many countries has seen a dramatic rise in the share of the working age population receiving sickness and disability benefits (hereafter disability benefits): According to the Department for Work and Pensions (DWP) (2013b), the UK government spent 2.4 percent of its Gross Domestic Product (GDP) on disability benefits, a fifth more than the European average, and significantly more than Germany, France, Italy, and Spain and increased spending by a third between 2005 and 2009.

In the context of austerity, and with the election of a government committed to shrinking the size of the public sector, spending on disability is vulnerable to cuts. Given that the Coalition government had committed to no cuts in spending on health and education and pensions, this adds to pressure on the disability budget.

Traditionally, disability is considered to be something unfortunate and undesirable which is outside an individual's control. Therefore, there has been widespread public support for state expenditure on disability benefits. Disability rights perspectives challenge this charitable and individualized approach, and argue that disabled people are disadvantaged less by any limitations of their bodies and brains, and more by discriminatory barriers in society. If people are unable to work, it is due to lack of access to education, inaccessibility of transport and workplaces and prejudice on the part of employers, rather than to their impairments.

In the United Kingdom, successive legislation is perceived to have been successful in removing discriminatory barriers. Most public buildings and transports systems are now accessible, and law protects disabled people from unfair discrimination. This makes it possible for governments to highlight the apparent equality between disabled and non-disabled people. In this rhetoric, if disabled people are not working, it is now their own fault, and no longer explained by their bodies and minds, or disabling barriers. Research shows that newspaper and policy pronouncements on disability have become increasingly framed in terms of disability benefit fraud. A distinction is

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drawn between 'genuine' disabled people, and those thought to be fraudulently claiming disability benefits (Strathclyde Centre for Disability Research/Glasgow Media Unit 2013). This political rhetoric has underpinned a harsher regime, where entitlement to benefits has been tightened, and public spending on disability reduced. Assessment of disability is therefore a highly contentious issue, with disability rights organizations and charities in conflict with government.

## 2. Development and evolution of disability benefits in the UK

The history of state support for persons with disabilities in the UK dates back to the 17<sup>th</sup> century (Stone 1986): The *Poor Law* of 1601 stipulated taxes for the 'necessary relief of the lame, impotent, old and blind'. Charitable support for poor persons with disabilities was considered an important means for the rich to secure salvation. Yet, from its inception, claimants faced popular suspicion that their conditions were faked, and the Tudor welfare legislation fostered the distinction between "deserving and undeserving" poor.

During the second half of the 18<sup>th</sup> century such concerns were compounded by increasing pressure on parochial resources. As a consequence, the receipt of welfare assistance for persons with disabilities was based on firmer medical principles and charitable initiatives focused more on returning sick persons and those with disabilities to the workforce (Turner 2012). Yet, by the early nineteenth century, war and a rapid population growth have put this welfare system under severe strain.

The *Poor Law Amendment Act* of 1834, also called the "New Poor Law", established the principle of less eligibility, whereby reliance on the public purse should be made an undesirable situation. Measures to classify sick persons and those with disabilities, together with the expansion of institutional care for blind, deaf and mentally impaired persons both furthered the separation of this group from the mainstream society.

Successive welfare laws during the late nineteenth- and early twentieth century included the introduction of compensatory benefits (e.g. war pensions), compensation for injured or disabled workmen and unemployment and health insurance in 1911 (including temporary disability benefits). The latter expanded the support systems for persons with disabilities beyond the *Poor Law*. Yet, it also promoted anxieties about a 'crisis of malingering' (Turner 2012) and to date, most disability benefits are still based on its principle of 'less eligibility'.

While the 1970s and 1980s saw the expansion and improvement of earnings-replacement benefits, the rise in disability benefit expenditure and recipients became a major concern for the government of the late 1970s. The growth in welfare spending was considered to encourage rather than reduce dependency which led to a major policy review of disability benefits from the 1980s onwards: It included the Fowler reforms which targeted mainly income replacement benefit, the attachment of all long-term benefits to prices rather than earnings and the conversion of short-term sickness benefits from earning-related to a flat-rate (Burchardt 1999).

Besides the 'compensatory' benefits like the Industrial Injuries benefit, 'extra costs' benefits' like the Disability Living Allowance (DLA) have become an increasingly significant component of the UK benefit basket for persons with disabilities: DLA together with the Social Security Act 1992 that underpinned it were a response to the findings of a number of disability surveys in the mid-1980s that established that persons with disabilities had significant unmet needs despite the above benefits (Roulstone & Prideaux 2012). The increase in numbers claiming income replacement

benefits between 1970-1985 has been explained in terms of the normal lag before a newly introduced welfare benefit reaches stable levels, followed by the widening of access to Invalidity Benefit in 1984 (Burchardt 1999). Changes in employment rates/benefit claim rates for disabled people have not coincided with major changes in social security rules and procedures (Berthoud 2011).

The continued growth in spending throughout the 1980s and 1990s<sup>2</sup> was followed by a contraction and by the late 1990s, resistance had formed against further growth in welfare spending. This led to the biggest reviews of a range of disability-related benefits since the establishment of the welfare state under the Blair government from 1997 onwards. The 'moral panic' (Roulstone & Prideaux 2012) was particularly fuelled by the growing numbers in receipt of DLA, an increasing albeit legal overlap of IB and DLA recipients (Beatty et al. 2009) and the limited success of getting persons with disabilities off income replacement benefits. Despite the 1994 Social Security (Incapacity for Work) Act which was to stem the numbers of recipients of disability income replacement benefits, claimant numbers continued to grow.

In social policy terms, the 1990s brought a new dawn of social and legal entitlements: Under pressure from the disability rights movement, the 1995 Disability Discrimination Act (DDA) was passed. While it recognized some social components in discrimination against persons with disabilities, it has received criticism, especially from the disability movement for its limited anti-discrimination stance due to restrictive definitions and qualifying conditions and its orthodox view of disability (Gooding 2000). The 2005 Disability Discrimination Act had a wider and stronger remit, although the 2010 Equality Act saw a reduced impact for the Equality Duty.

Garthwaite et al. (2014) argue that the considerable reforms of the UK's disability benefit system since the 1980s rather brought about a decrease in benefit levels and duration of support, a greater focus on compulsory participation in welfare to work schemes and a tightening up of eligibility criteria. Particularly in the context of latter, the Employment & Support Allowance (ESA)—a reformulation of earnings replacements benefits in 2008 which involves a lengthy assessment protocol (see sections 4 & 5 below)—has been widely criticised. Prevailing public and policy assumption in the UK that many recipients are not sufficiently sick or disabled to 'deserve' welfare benefits—claims that have been made in the absence of empirical data on the health of recipients (Garthwaite et al. 2014)—show that the focus on 'sturdy beggars' in the early *Poor Law* has never fully disappeared (Roulstone & Prideaux 2012). Governments rather seem to have shifted the disability category and who counts as having a disability over time to fit policy and fiscal targets, and reforms have made welfare claiming a perilous activity (Roulstone & Prideaux 2012).

Since coming to office in 2010, the current Government has pursued an extensive programme of 'welfare reform' that seeks to introduce "...greater fairness to the welfare and pensions systems by making work pay and reinvigorating incentives to save for retirement...while protecting the most vulnerable – disabled people and pensioners" (DWP 2013a, p.3). The current overhaul of disability benefits aims at simplifying the system. Besides the replacement of the Disability Living Allowance with **Personal Independence Payments (PIP)**, a number of working-age benefits (six of

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<sup>2</sup> In the 1990s, the number of disability benefit recipients increased by 54% in Great Britain, and disability benefit expenditures' share of the GDP increased from 0.88% in 1990 to 1.27% in 1999 (eds. Honeycutt & Mitra 2005)



the main means-tested benefits and tax credits) will be merged into a single payment called **Universal Credit**. This controversial new benefits system is to be introduced by 2017/18.

### 3. Overview of available benefits for persons with disabilities in the UK

For persons with disabilities, there are a number of benefits to claim that can be grouped in four types (Burchardt 1999): These include compensatory benefits (for example, industrial injury and war disablement benefits); earnings replacement benefits to provide an income for individuals unable to earn as a result of disability (for example Employment and Support Allowance (ESA)); and extra costs benefits to support the extra costs of persons with disabilities. And in addition, persons with disabilities may access a number of available means-tested mainstream benefits to top-up their income: for example, Income Support but also Housing or Council Tax Benefits.

The main available disability-specific benefits will be presented in more detail below<sup>3</sup>:

#### **Employment and support allowance - partially taxable, partially contributory, partially means-tested**

ESA replaced the previous Incapacity Benefit (IB) in October 2008. There are two forms of ESA:

- Contributory ESA is only paid to claimants who meet the National Insurance conditions.<sup>4</sup>
- Income-related ESA is paid to claimants who have not satisfied these contribution criteria but have passed a means test.<sup>5</sup>

To be entitled to ESA, applicants must

- be aged 16 or over but under Basic State Pension age
- have a limited capability to work due to an illness or disability
- be present in Great Britain and satisfy the 'habitually residence test'
- not be receiving Jobseeker's Allowance, Statutory Sick Pay or Statutory Maternity Pay and not be in or have returned to work

To be entitled to contributory ESA, applicants must also pass a contributory test while the eligibility for income-related ESA requires passing of a low income test.

The main change from the previous IB is that the old Personal Capability Assessment (PCA) was replaced with the Work Capability Assessment (WCA), which the government claims to give a better view of the claimant's ability to undertake work: Applicants must go through an 'assessment phase', which usually lasts for 13 weeks after the claim is made. During this phase, they undergo the WCA which involves two separate assessments: The *limited capability for work assessment* measures a person's ability to perform certain activities relating to physical, mental, cognitive and intellectual function and determines whether the individual can be awarded ESA or

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<sup>3</sup> The information is largely based on most recent information provided on the homepage of the DWP <https://www.gov.uk/browse/benefits/disability> and Disability Rights UK factsheets (2014).

<sup>4</sup> Contributory ESA requires the passing of a contributory test verifying that the applicant paid enough national insurance contributions in specific tax years.

<sup>5</sup> Needs (and those of the partner, if you have one) are compared with the available money (e.g. income and savings) to determine the income-related ESA rate. It can be paid on its own (if the claimant is not entitled to contributory ESA) or as a top-up to contributory ESA (if he/she is). Income-related ESA can include amounts to help towards mortgage interest payments and some other housing costs.

should apply for Jobseeker's Allowance instead. The *limited capability for work-related activity assessment* determines the rate of ESA that will be paid after the first 13 weeks and whether the claimant will be required to undertake any work-related activity as a condition of entitlement (more information on the WCA in section 4 and 5).

Those judged via WCA as unable to work or with limited work capacity receive a higher level of benefit and are placed in the Support Group with no conditionality, i.e. they will not have to undertake work-related activities. Those who are deemed 'sick but able to work' are placed in the work-related activity group and receive a lower rate of ESA than those in the support group. There is a one-year limit on contributory ESA for those in the work-related activity group, including the 13-week assessment phase. Claimants placed in either the support or the work-related activity group receive 'main phase' ESA. This includes either the 'work-related component', which is conditional on attending work-focused interviews, or the 'support component', for those deemed unable to work. Applicants deemed fit for work are moved onto Jobseekers Allowance (JSA) (paid at a lower rate than ESA and means-tested after six months).

After the assessment phase, one of two additional components on top of the basic allowance is provided: Claimants in the support group receive the 'support component' and those in the work-related activity group receive the 'work-related activity component'.

Some key changes to ESA are currently underway: Between 2013 and 2017 the income-related ESA will be abolished and be paid as part of the universal credit (UC) - a new benefit to be introduced over the period 2013 to 2017 (see section on UC below). Contributory ESA will remain outside UC, yet a time limit of one year maximum claim has been introduced before people are moved onto Income-related (i.e. means tested) ESA (UNISON 2013). Furthermore, ESA is included in the list of benefits to which the 'benefit cap' applies which limits the total weekly benefits that can be claimed. There are some exceptions, for example, the cap does not apply for those placed in the 'support group' (UNISON 2013).

As at the end of February 2012, ESA had around 991,190 claimants and 921,250 beneficiaries. The total expenditure on ESA rose sharply from £1.3 billion in 2009–10 to around £3.6 billion in 2011–12 (Browne 2012).

#### **Attendance allowance - Non-taxable, non-contributory, non-means-tested**

Attendance Allowance (AA) is the alternative to DLA or PIP for people aged over 64 with care or supervision needs. There are two rates of payment, a lower rate and a higher rate, depending on care or supervision needs during the day or night.

To qualify for AA, the claimant must:

- be aged 65 or over
- pass at least one of the disability tests: The lower rate is paid if the claimant has day or night needs, i.e. requires frequent help or constant supervision during the day, or supervision at night. The higher rate is paid if claimants require help or supervision throughout both day and night, or are terminally ill.
- satisfy the relevant disability conditions for a period of six months before the award
- pass the residence and presence tests and not be subject to immigration control.

Assessment is done based on the application form and sometimes a medical examination is requested to determine eligibility.

AA does not have a mobility component and is not counted as income when calculating entitlements to means-tested benefits such as income-related ESA.

In February 2012, approximately 1.7 million people were entitled to AA at an estimated cost of just over £5.3 billion in 2011–12 (Browne 2012).

### **Carer's Allowance - Taxable, non-contributory, means-tested**

Carer's Allowance (CA) is a weekly benefit for persons who regularly look after someone with substantial caring needs.

To qualify for CA, the claimant must:

- be aged 16 or over
- spend at least 35 hours a week caring for someone
- not earn more than currently £102 per week after tax, national insurance contributions and half of any pension contributions have been taken into account or be in full-time education
- live in England, Scotland or Wales, or abroad as a member of the armed forces
- take care of a person that already receives one of following benefits: Personal Independence Payment (PIP) daily living component, Disability Living Allowance - the middle or highest care rate, Attendance Allowance, Constant Attendance Allowance at or above the normal maximum rate with an Industrial Injuries Disablement Benefit, or basic rate with a War Disablement Pension or Armed Forces Independence Payment

As of February 2012, CA was claimed by 594,860 people, with expenditure in 2011–12 totalling around £1.7 billion (Browne 2012).

### **War pensions and AFCS - Non-taxable, non-contributory, non-means-tested**

Individuals who have suffered injury or disability as a result of service in the Armed Forces before 6 April 2005 are entitled to war pensions and after 6 April 2005 to benefits and payments from the Armed Forces Compensation Scheme (AFCS). Illness and injuries are graded into 15 tariff levels, depending on the severity of the conditions. Pensions are also available to widows, widowers and dependants of those killed in service.

As of 31 March 2012, there were almost 135,000 claimants of the War Disablement Pension in the UK (Browne 2012).

### **Industrial injuries benefits - Non-taxable, non-contributory, non-means-tested**

Industrial injuries benefits are payable to individuals who have suffered injury in an industrial accident, or who have contracted a disease<sup>6</sup> while at work, and, as a result are consequently considered to be at least partially disabled. The main benefit is the *Industrial Injuries Disablement Benefit (IIDB)*. Additional benefits might be paid as increases to IIDB - the most important being

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<sup>6</sup> The scheme covers more than 70 diseases, including asthma, chronic bronchitis or emphysema, deafness

the Constant Attendance Allowance (CAA) and Exceptionally Severe Disablement Allowance (ESDA).

To qualify for Industrial Injuries Disablement Benefit (IIDB), the applicant must have acquired the illness or disability

- from an accident or disease that occurred while on employment
- while on an approved employment training scheme or course the work accident or event that caused your illness or disability happened in England, Scotland or Wales.

The amount of benefit depends on the level of disability which will be assessed by a 'medical advisor' on a scale of 1 to 100 percent. Normally you must be assessed as 14% disabled or more to get the benefit.

Eligibility is decided upon based on the application form, relevant evidence from the employer or witnesses and a medical examination.

During the period 2011-12, over £850 million was spent on industrial injuries benefits (including Reduced Earning Allowance) in 2011–12 (Browne 2012).

### **Disability living allowance for children - Non-taxable, non-contributory, non-means-tested**

Disability Living Allowance (DLA) for children provides financial support with the extra costs of looking after a child with disabilities.

To qualify for DLA, the child must:

- be under 16 years of age
- have difficulties walking or require more looking after than a child of the same age without a disability. They must have had these difficulties for at least 3 months and they are expected to last for at least 6 months, except if they are terminally ill.
- have lived in Great Britain for 2 out of the last 3 years if over 3 years old
- habitually reside in the UK, Ireland, Isle of Man or the Channel Islands

DLA has two components: the care component, which has three rates of payment and the mobility component which has two rates of payment. Depending on the needs, a child can be paid one or both components.

#### **Care component**

- For the lowest rate of the care component, the child must need attention in connection with their bodily functions for a significant part of the day (which can be during one or more periods) for some of the day or night.
- For the middle rate, the child must require another person to give them frequent attention throughout the day in connection with their bodily functions; or require prolonged or repeated attention during the night in connection with their bodily functions; or require continual supervision throughout the day in order to avoid substantial danger to themselves or others; or require, another person to be awake for a prolonged period or at frequent intervals at night, for the purpose of watching over them in order to avoid substantial danger to themselves or others.

- For the highest rate, the child must require one of the day conditions *and* one of the night conditions for the middle rate care component above or be terminally ill.

### **Mobility component**

- For the lower rate of the mobility component, the child must need guidance or supervision with walking on unfamiliar routes because of the mental or physical disablement. He or she must need substantially more guidance or supervision than a child of the same age who is in normal physical or mental health. The child cannot receive the lower rate of the mobility component until they reach the age of five.
- For the highest rate, the child must be unable or virtually to walk, have had both legs amputated (or missing from birth) at or above the ankle, qualify for the highest rate of the DLA care component, be severely mentally impaired and show disruptive behaviour, have a severe visual impairment *or* be both blind and deaf and need assistance to move.

The higher rate of the mobility component cannot be applied for until the child reaches the age of three.

Eligibility is determined through evaluation of the completed application form, and supporting evidence / documentation from the applicant's doctor. The DWP responsible for DLA claims may also decide that a face- to-face medical with a health care professional is needed which is subcontracted to a company.

For people of working age (i.e. aged 16 and over), DLA has been replaced by the personal independence payment (PIP) (see below). Those of working age who are already on DLA, will be asked to claim PIP rather than DLA at some point in the future.

In February 2012, over 3.2 million people were receiving DLA and related costs amounted to approximately £12.6 billion in 2011–12 (Browne 2012).

### **Personal independence payment – Non-means tested, non-contributory, non-taxable**

The Personal Independence Payment (PIP) is a benefit for people aged 16 to 64 to help with extra costs caused by a long-term (one which is expected to last 12 months or longer) health condition or disability. It is gradually replacing the Disability Living Allowance (DLA), except for children under 16, being introduced in stages from 2013 to 2017. Most people will be affected in 2015.

To qualify for PIP, applicants must:

- be aged 16 to 64
- have a long-term health condition or disability and difficulties with activities related to 'daily living' and or mobility
- be resident in Great Britain when claiming (with some exceptions) and have been in Great Britain for at least two of the last three years

PIP is made up of two parts, the daily living component and the mobility component. People may be able to get one or both components.

An applicant may be eligible for the daily living component if he/she needs help with:

- Preparing food

- Taking nutrition
- Managing therapy or monitoring a health condition
- Washing and bathing
- Managing toilet needs or incontinence
- Dressing and undressing
- Communicating verbally
- Reading and understanding signs, symbols and words
- Engaging with other people face to face
- Making budgeting decisions

An applicant may be eligible for the mobility component of PIP if he/she needs help with:

- Planning and following journeys
- Moving around

Claimants must have met the disability conditions for a 'qualifying period', i.e. 3 months prior and at least nine months after the application, except in cases of terminal illness.

Each component is paid at two different levels: A 'standard rate' and an 'enhanced rate'. The rate to be paid depends whether the applicant's ability to carry out daily living or mobility activities is 'limited' or 'severely limited' which is tested under the PIP assessment: It is points-related and based on the applicant's ability to perform above 12 activities related to daily living needs and mobility. Thereby, PIP does not separate day and night-time needs. The number of scored points will determine eligibility for either component and at which rate. Within each activity is a series of descriptors with scores ranging from 0 to 12. The descriptors explain related tasks of varying degrees of difficulty and an applicant scores points when assessed as unable to complete a task 'reliably'. The sum of highest descriptor score from each activity makes up the points for each component. To be entitled to the standard rate, a score of at least 8 points under the daily living or mobility activities is required, for the enhanced rate a score of at least 12 points.

The DWP is responsible for the PIP. Most claimants will need to undertake a 'face to face consultation' with a health professional who will assess their ability to carry out key activities of daily living and mobility. These assessments have been contracted out to ATOS Healthcare and Capita Health and Wellbeing, depending on the location. The DWP will decide about a claim based on the results of this assessment, the application and any supporting evidence that the applicant submitted. If approved, there are no conditions as to how to spend the benefit. Successful claimants will be regularly reassessed.

As of March 2014, 50 percent of applicants for PIP were being awarded the benefit (Personal Independence Payment: Official Statistics, GB, published 5 June 2014)<sup>7</sup>.

## Universal credit - Means-tested

<sup>7</sup> [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/317425/pip-statistical-release-june-2014.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/317425/pip-statistical-release-june-2014.pdf)

**Universal Credit** is a new welfare benefit in the United Kingdom that the government plans to introduce over the period 2013 to 2017. It will replace six of the main means-tested benefits and tax credits:

- child tax credit;
- housing benefit;
- income-related employment and support allowance;
- income-based jobseeker's allowance;
- income support;
- parts of the social fund; *and*
- working tax credit

Other benefits (e.g. disability living allowance and personal independence payment) will remain largely unchanged by the new system. Like ESA, claims can be submitted at the local Jobcentre Plus. All people receiving ESA and those being moved onto or applying for universal credit will be assessed in addition to the application form with the WCA as to which group they will go in: (1) limited capability for work or (2) limited capability for work and work-related activity (WRAG) or (3) fit for work (see description of ESA above and chapter 4 for more information on the WCA).

The results of the WCA will be used by the universal credit adviser to decide what conditions and work related requirements or activities people must meet to receive Universal Credit.

The maximum amount is made up of a '*standard allowance*' and five '*elements*', paid to cover different needs, including:

- child element;
- housing costs element;
- limited capability for work elements;
- carer element; *and*
- child care costs element.

The previous Working Tax Credit (WTC) will not be available under Universal Credit (UC) for anyone assessed as 'fit for work' under the Employment Support Assessment (ESA) work capability assessment apart from those who qualify as 'not fit for work'.

### **Personal budget – Means-tested**

In 2010, the Department of Health set out its vision for Adult Social Care with a commitment to the personalisation of care. Direct payments and personal budgets are a central part of the 'personalization' agenda to give people choice and control over the care services which they receive from adult social care funding by self-directing their own support.

Persons with disabilities may be eligible for support under this scheme towards community care services which they have been assessed as needing. In order to apply for a personal budget (or individual budget in some regions), the applicant is required to complete the local authority Self-Assessment Questionnaire (SAQ). This assessment will identify the applicant's needs, looking at life aspects that are affected by the impairment, such as personal care needs, health and safety, social inclusion etc. Furthermore, the applicant will be requested to fill in a financial assessment. After submitting these to the local authority, social services will decide on an Indicative Personal Budget, i.e. an estimate of the amount needed to meet the requirements which will enable

development of a support plan. The plan will list the types of support required to meet the needs identified in the initial assessment and how the budget will be spent to meet those needs. It recognises that there are other issues in addition to medical needs that can impact on a person's health and well-being.

People can either take their personal budget as a direct payment (while still choosing how their care needs are met and by whom) or leave the Council / social services with the responsibility to buy the services on their behalf. People can also choose to go with a combination of the two. The payments must only be spent on the services identified in their support plan.

As part of this Self Directed Support (SDS) persons with disabilities can get different funding streams and resources other than those from Social Services. These include for example Disabled Student Allowance or **Access to Work** which is a benefit to meet additional costs incurred by people in employment, for example extra costs of travel to work or workplace adaptations caused by having an impairment, or a support worker in the workplace.

## **4. The Work Capability Assessment (WCA)**

### **4.1. History of disability assessments in the UK and rationale for the introduction of the WCA**

The economic restructuring in Britain's industrial communities in the 1980s resulted in rising unemployment which over the medium-term contributed to increased numbers of claimants for Invalidity Benefits and subsequently Incapacity Benefits (Sissons 2009): The number of working-age recipients of Incapacity Benefit more than doubled from 1.2 million in 1984 to 2.5 million by 1997 and reached 2.8 million in 2003 (Sissons 2009). This continued an upward trend which began in the 1970s and accelerated through the 1980s and much of the 1990s (Beatty, et al. 2009) - a concern to both Conservative and Labour governments over the past two decades (Grover & Piggott 2009).

In this context, welfare reforms focused on increasing the 'employability' of persons with disabilities and reducing the caseloads and costs of incapacity-related benefits (Clayton 2011, Roulstone & Prideaux 2012): In 1995, Invalidity Benefit was replaced by the less generous Incapacity Benefit as the main income replacement benefit. While before 1995, eligibility was largely determined by the claimant's GP, the introduction of the Incapacity Benefit came along with the 'All Work Test' which assessed general capacity to work through a series of 'descriptors' but marginalised evidence from the claimant's GP.

In 1997, the then Labour government started adopting active labor market policies (e.g. the New Deal for Disabled People, Pathways to Work) to support the return of people with health and disability-related barriers to employment. In 2000, the All Work Test was succeeded by the Personal Capability Assessment (PCA) - a more rigid medical eligibility test in order to reduce claimants of benefits that did not require active job search and provide a more objective assessment of functional limitation. The PCA again focused on what a person was able to do and how they could be supported back into work involving self-administered questionnaire and if needed face-to-face examination. The administration of the PCA was contracted out to a company called SchlumbergerSema which was taken over in 2004 by the now Atos Healthcare and its employees assessed the claims, using the Logical Integrated Medical Assessment computer system. Yet, these evaluations proved unreliable and the number of successful appeals against



decisions skyrocketed. In 2003, the DWP introduced 'Pathways to Work', in which claimants had to undertake a work-focused interview with a personal advisor. If not screened out, they would go on to mandatory monthly interviews where they would be encouraged to return to work.

Still, in 2006, the welfare reform Green Paper 'A new deal for welfare - Empowering people to work' criticised that "almost nothing is expected of [incapacity] claimants – and little support is offered" (DWP 2006a, p. 4). In 2007, a report commissioned under the previous Labor government concluded that some two thirds of those receiving Incapacity Benefit were indeed capable of work. As a response to this criticism, continuing reforms saw in 2008 the replacement of the Incapacity Benefit with the Employment Support Allowance (ESA) (Franklin 2013). As part of the ESA, the Welfare Reform Act 2007 established the more stringent Work Capability Assessment (WCA) to determine a claimant's eligibility for Employment and Support Allowance (ESA) - although the Government argued during the introduction of ESA that the existing Personal Capability Assessment (PCA) was 'already recognised by the OECD as being one of the toughest in the world' (Secretary of State for Work and Pensions 2006). As such, the introduction of ESA and the WCA was embedded in the 'moral panic' over fraud although it has never been substantiated, the more conditional welfare context of the late 1990s and 2000s and an increased shift to conditionality, means testing and reduced take-up of IBs (Roulstone & Prideaux 2012). Between 2000 and 2011, the number of disability benefit claimants fell from 7.4 percent of the working age population to 6.5 percent (Jones and Wass 2013).

The introduction of the ESA presented a central element in the government's efforts to increase employment rates, reduce on-flows to sickness benefits and increase off-flows in the medium term. Thereby, the arguments for the introduction of ESA and the WCA can be summarised as follows (Grover & Piggott 2010): IB was considered as not targeted enough upon 'genuinely' sick people and / or those with disabilities. It was specifically argued that the way IB was structured made access to the scheme too easy and encouraged beneficiaries to remain on it for long periods (Secretary of State for Work and Pensions 2006). Furthermore, the receipt of IB has become framed by popular concerns that the majority of claimants are fraudulently claiming IB or abusing its lax administration – despite the lack of evidence to support this belief (Grover and Piggott 2009, 2010). Lastly, the introduction of ESA was put forward in the context of a 'support' discourse, i.e. ESA as a mechanism to support people who experience health or disability-related barriers to work in accessing employment and thus, address socio-economic disadvantages that they face (see, for example, Secretary of State for Work and Pensions 2006).

The WCA was designed to provide a functional assessment, based on the premise that eligibility for ESA should not be determined by the description of a person's disability or health condition but rather by how their ability to function is affected (Litchfield 2013). As such it was designed to look at the effects of a condition rather than the condition itself since the focus is on function, reflecting at least nominally the WHO's ICF. It is to present a means of distinguishing people who cannot work due to health related problems from those who are fit for some work or could, with support, eventually return to employment. If assessed as able to undertake work related activities, claimants receive a lower level of benefit than those judged unable to work. As such, it is as a social policy mechanism that classifies the claimants into administrative categories (Litchfield 2013, Grover & Piggott 2010). Grover and Piggott (2010) argue that this process of sorting was central to address the governments' argument of the gateway onto IB being too lax and the existing Personal Capability Assessment not discerning enough: The WCA was designed to ensure that only the most 'needy' (those who are assessed to have the most limiting health conditions) and the most 'deserving' (those who are judged compliant and fully engaged with

requests) claimants can access the highest amount of ESA. It does this by placing paid work, more specifically, efforts to develop or maintain a relationship to it, at the centre of its qualifying criteria. As such, it also reflects an increasingly sharper shift in policies for people who are sick and/or have disabilities towards a return to work focus and work-related solutions to their socio-economic problems (Grover and Piggott 2010).

For the time being, up to 1.5 million of IB claimants still needs to be assessed under the WCA for their eligibility for ESA and it is not yet fully clear how this process will interact with the conversion of ESA claimants to universal credit (see section 3) (UNISON 2013).

#### **4.2. Procedures and mechanisms of the WCA**

All people receiving ESA and those being moved onto Universal Credit will be assessed with the work capability assessment (WCA). Thus, the WCA plays an important role in determining entitlement to various benefits where claimants' current health condition or disability must be found to restrict their ability to work. As such, this section will have a closer look at how the WCA as the central assessment procedure operates in practise.

The DWP (2013c) describes the **Work Capability Assessment** as the process of gathering information and evidence, which may include a face to face assessment, in order to determine whether a claimant has limited capability for work, and if so, whether they have limited capability for work-related activity. *Limited capability for work* is thereby understood as the extent to which a claimant's health condition or disability affects their capability for work (DWP 2013c). *Limited capability for work-related activity* as the extent to which a claimant's health condition or disability affects their capability for work-related activity (DWP 2013c).

The WCA should be completed within the first 13 weeks of claiming benefit (unless a person is terminally ill in which case the assessment does not apply). During this period, claimants receive the assessment rate. The WCA has two components:

**1) Limited Capability for Work test** to help determine benefit entitlement based on the extent to which their health condition or disability affects their capability for work.

**2) Limited Capability for Work-Related Activity test** to determine whether the claimant can be placed into the *Support Group* where she/he will not have to undertake work-related activities or the *work-related activity group (WRAG)* where she/he will be expected to adhere to work-related conditions in order to continue receiving the benefit in full (e.g. attendance of work focused interviews as part of Pathways to Work/The Work Programme) and receive a lower benefit rate than if placed in the support group.

In some cases a DWP decision maker may be able to decide on limited capability for work based on the information in the application form. The WCA recognises a number of special circumstances in which a claimant may be treated as having limited capability for work: These include for example terminal illness, awaiting, receiving or recovering from cancer treatment by way of radiotherapy and / or chemotherapy, undergoing medical or other treatment as a patient in a hospital or similar institution where they have been advised by a health care professional to stay for 24 hours or longer, or which is a day of recovery from that treatment etc. (DWP 2013c). In practise, most cases are referred to an external subcontractor—currently ATOS—who implements the WCA.

Once a claim has been referred to the external subcontractor, they will send the claimant a self-assessment questionnaire – ESA 50 – to complete. Claimants normally have four weeks to fill out the questionnaire. It seeks the claimant’s views on the effects of their disabling condition in each of the functional areas in the assessment. The claimant will be asked to identify (by a tick in a box) the descriptor in each affected area which best describes the effect of their disabling condition, and to give any further information or supporting evidence from other sources (e.g. the GP) that they think should be taken into account.

The **limited capability for work test** is points related and assesses the applicant’s ability to carry out a range of physical and mental, cognitive and intellectual activities.

The physical descriptors are grouped into ten types of activity (DWP 2013c):

1. Mobilising unaided by another person with or without a walking stick, manual wheelchair or other aid if such aid is normally, or could reasonably be worn or used
2. Standing and sitting
3. Reaching
4. Picking up and moving or transferring by the use of the upper body and arms
5. Manual dexterity
6. Making oneself understood through speaking, writing, typing, or other means which are normally or could reasonably be, used, unaided by another person
7. Understanding communication by (i) verbal means (such as hearing or lip reading) alone, (ii) nonverbal means (such as reading 16 point print or Braille) alone, or (iii) a combination of (i) and (ii), using any aid that is normally, or could reasonably be used, unaided by another person.
8. Navigation and maintaining safety, using a guide dog or other aid if either or both are normally, or could reasonably be used
9. Absence or loss of control whilst conscious leading to extensive evacuation of the bowel and/or bladder, other than enuresis (bed-wetting), despite the wearing or use of any aids or adaptations which are normally, or could reasonably be worn or used
10. Consciousness during waking moments

Thereby, the assessment takes into account the abilities when using any aid or appliance the applicant would normally, or could reasonably be expected to use.

The descriptors of the mental, cognitive and intellectual activities are grouped into seven types of activity (DWP 2013c):

1. Learning tasks
2. Awareness of everyday hazards (such as boiling water or sharp objects)

3. Initiating and completing personal action (which means planning, organisation, problem solving, prioritising or switching tasks)
4. Coping with change
5. Getting about.
6. Coping with social engagement due to cognitive impairment or mental disorder
7. Appropriateness of behaviour with other people, due to cognitive impairment or mental disorder

As an example, within the first activity on 'Mobilising' there are five descriptors (DWP 2013a):

(a) Cannot either:

(i) mobilise more than 50 metres on level ground without stopping in order to avoid significant discomfort or exhaustion; or

(ii) repeatedly mobilise 50 metres within a reasonable timescale because of significant discomfort or exhaustion.

(b) Cannot mount or descend two steps unaided by another person even with the support of a handrail.

(c) Cannot either:

(i) mobilise more than 100 metres on level ground without stopping in order to avoid significant discomfort or exhaustion; or

(ii) repeatedly mobilise 100 metres within a reasonable timescale because of significant discomfort or exhaustion.

(d) Cannot either:

(i) mobilise more than 200 metres on level ground without stopping in order to avoid significant discomfort or exhaustion; or

(ii) repeatedly mobilise 200 metres within a reasonable timescale because of significant discomfort or exhaustion.

(e) None of the above apply.

Within each type of activity is a list of 'descriptors' explaining related tasks of varying degrees of difficulty with fixed scores ranging from 0 (not applicable) to 15 (Cannot at all). Though more than one descriptor may apply, the applicant can only pick up one score from each type of activity; in each case whichever scores the highest. If the claimant scores 15 points in any physical and/ or mental activity or a total of 15 or more points from a combination of activities, then the criterion for limited capability for work is met for benefit entitlement purposes.

The **limited capability for work-related activity test** has a further sixteen activities and descriptors, relating to both physical and mental, cognitive or intellectual functions which are considered to determine if a claimant who has limited capability for work also has limited capability for work-related activity (DWP 2013c):

Mobilising unaided by another person with or without a walking stick, manual wheelchair or other aid if such aid is normally, or could reasonably be worn or used
Transferring from one seated position to another
Reaching
Picking up and moving or transferring by the use of the upper body and arms (excluding standing, sitting, bending or kneeling and all other activities specified in this Schedule)
Manual dexterity
Making oneself understood through speaking, writing, typing, or other means normally, or could reasonably be, used, unaided by another person
Understanding communication by hearing, lip reading, reading 16 point print or using any aid if reasonably used
Absence or loss of control whilst conscious leading to extensive evacuation of the bowel and/or voiding of the bladder, other than bed-wetting, despite the wearing or use of any aids or adaptations which are normally, or could reasonably be, worn or used.
Learning tasks.
Awareness of hazard
Initiating and completing personal action (i.e. planning, organisation, problem solving, prioritising or switching tasks)
Coping with change
Coping with social engagement, due to cognitive impairment or mental disorder
Appropriateness of behaviour with other people, due to cognitive impairment or mental disorder
Conveying food or drink to the mouth
Chewing or swallowing food or drink

Again, the assessment takes into account the abilities when using any aid or appliances.

As an example, within the first activity on 'Mobilising' are two descriptors (DWP 2013c):

Cannot either:

(a) mobilise more than 50 metres on level ground without stopping in order to avoid significant discomfort or exhaustion; or

(b) repeatedly mobilise 50 metres within a reasonable timescale because of significant discomfort or exhaustion.

If at least one descriptor is satisfied, the claimant will be placed in the support group. If none is satisfied, they will be placed in the work-related activity group.

In most cases, applicants will also be asked to attend an assessment carried out by a health care professional from the external provider. At such face-to-face assessment they will identify whether or not the applicant's account in the questionnaire corresponds with their findings, asking a series of questions relating to physical and mental, cognitive or intellectual capabilities and may give a physical examination. The healthcare professional (usually a doctor or a nurse) may ask the claimant about a normal day and not necessarily the same questions that are on the ESA50 form. The healthcare professional may also consider that further information from the claimant's doctor or other sources is required. In the case of persons with most severe levels of

disability, the approved healthcare professional may consider all available evidence on the claim and give advice to the decision maker without a face-to-face assessment.

The decision on whether or not an applicant has a limited capability for work and a limited capability for work-related activity will not be taken by the health care professionals from the external provider. The healthcare professional conducting the assessment will complete a report of the assessment to a DWP decision maker with a recommendation, for the purposes of determining entitlement, on whether a claimant can be considered to have limited capability for work. The DWP decision maker will then decide based on the report, the applicant's application form and a statement of fitness for work from the claimant's own doctor. If the DWP decides that the claimant has limited capability for work and is eligible for ESA, they then have to decide whether she/he also has 'limited capability for work related activity' for which they look at the results of the set of descriptors under the Limited Capability for Work-Related Activity test. In practise, this assessment is usually carried out at the same time as the limited capability for work assessment.

The healthcare professional will also make recommendations as to when the claimant should be re-assessed under the WCA.

## **5. Experience with the WCA to date and related criticism and developments**

While earlier independent reviews concluded that the WCA is conceptually right (Harrington 2010, 2011 & 2012), it has generated a range of criticisms from disabled people's organisations (DPOs) and governmental and non-governmental and academic commentators alike since its inception in October 2008.

One of the main concerns revolves around the perception that the WCA is heavily weighted towards a medical model (e.g. National AIDS Trust 2013, Grover & Piggott 2010). Designed as a functional assessment of how someone's condition affects their work capability, critics claim that the assessment by a health care professional forms the dominant part of the evidence base used by DWP decision makers without sufficiently taking into account the psycho-social factors that influence a person's capability for work in the decision-making (e.g. NAT 2013, Grover & Piggott 2010). Nearly half the claimants for Employment Support Allowance have mental health problems.

Likewise, the latest independent review (Litchfield 2013) observes the great reliance on information from medical records which however, rarely describe capability. This leads to assumptions about capability being made on the basis of diagnoses which may not only undermine the policy intent but also reinforces the stigma that persons with disabilities face in accessing employment. The review underpins above concern that additional non-medical evidence (e.g. information from support workers, carers) which might be more useful in constructing a full picture of capability is not sufficiently sought and given appropriate consideration (Litchfield 2013).

In social policy terms, there has been some recognition of the social model of disability, reflected e.g. in the adoption of the DDA in 1995 and the Equality Act in 2010 or in government documents on the ESA which recognize to some degree that persons with disabilities face a range of barriers. However, there are concerns that the current approach disregards the social model: The process of sorting into either a 'support' or an 'employment' group that the WCA involves is considered

to reinforce division and exclusion along the lines of deserving public support and capability to engage in work – a contradiction to the government’s argument for the changes in income replacement benefits to be concerned with the inclusion and equality of persons with disabilities (Grover and Piggott 2010, Garthwaite 2014).

As such, the ESA with the WCA is seen to continue the tradition of the medicalisation of disability. For example, Grover and Piggott (2010) highlight how the majority of members of the technical working groups involved in the transformation of the previous PCA (IB) to WCA (ESA) were from medical backgrounds. Moreover, the focus of the working groups was on:

“proposals for transforming the Personal Capability Assessment (PCA) from an incapacity-based tool for determining entitlement to Incapacity Benefit, to a more positive assessment incorporating assessment of capability and of health-related interventions which would contribute to overcoming health-related barriers preventing people with disabilities engaging in work” (DWP 2006b, p.2).

As such, commenters conclude that the review of the PCA failed to challenge the ‘medicalisation’ of sickness and impairment, but rather redrafted the medical test, introducing greater conditionality and more stringent eligibility criteria (e.g. Grover and Piggott 2010, Garthwaite 2014).

Yet another concern with the WCA is the influence of ‘statistical norms’, or expectations on the decision as to who will be granted benefit: Franklin (2013) collected evidence from the original contract between Atos and DWP, Atos employees and Freedom of Information requests which indicates that outcomes for ESA claimants are not only driven by the severity of their condition or the nature of their disability but seem to be geared by the imposition of ‘statistical norms’ towards a desired result. The previous test for Incapacity Benefit, the Personal Capability Assessment, was criterion-based, awarding points based upon how a person scored against certain criteria. For example, those who could walk less than 50 metres were awarded more points than those who could walk less than 200 metres. If the person scored the number of points the criteria demanded for benefit receipt then they would be entitled to the benefit. The WCA in contrast uses a norm-referenced system. People must score the number of points required for benefit receipt and also fall within the proportion of people the norms system will allow to receive the benefit. In practice this means there is a finite number of claims the assessment system will allow to be awarded the benefit (Franklin 2013).

Franklin (2013) found that Atos monitors the performance of their assessors by using a computer system which compares the average results for each practitioner with those of other practitioners in the same region and nationally. These criteria for the audit system are set by the DWP and the numbers for the ‘norms’ were given to Atos by the DWP, based on the percentage of cases the DWP expects to fall into each category. As such, DWP specified in the original contract with Atos that it expects 11 percent of claimants to fall within the support group—the figure rose to 16 percent in 2011 following the first independent WCA review by Professor Harrington (2010). Although described as ‘statistical norms’, in practice this system operates like a de facto target system: It guides the outcome of the entire process and constrains assessors to ensure all descriptor choices fall within the margin of the norms permitted by the DWP.

In addition, the audit system uses the estimated national trends to also audit the performance of regions and individual assessors. As such, it fails to account for variation in terms of the frequency

of conditions an assessor gets to assess each day yet, also demographic variations in health and levels of disability. This places both those claiming in areas where levels of sickness and disability are considerably higher than others and the assessors working in those areas at a significant disadvantage.

In the above context, protest by the public and DPOs against the WCA is sparked particularly by widespread dissatisfaction with the outcome of the assessment: The number of successful appeals against ESA/WCA decisions continues to rise (e.g. Jeory 2013, Franklin 2013). According to the Ministry of Justice, 327,961 appeals were received for the period 2012 – 13. 225,236 appeals were heard, of which approximately 43% were decided in favour of the claimant (Franklin 2013). In June 2014, an investigation of [illegal.org.uk](http://illegal.org.uk) into DWP statistics relating to the Work Capability Assessment revealed that of 1,287,323 ESA appeals, at least 567,634 claimants have had the original DWP ESA refusals overturned in their favor.<sup>8</sup> These figures challenge previous claims of the DWP that the initial Work Capability Assessment outcomes are a valid measure of the claimant's ability to work and only a relatively low number of decisions have been overturned. An article in the Express in 2013 warns that rising unemployment, a large backlog and confusion over the reforms and controversial WCA mean that the figure is forecast to hit nearly £1billion by the end of this Parliament in 2015 (Jeory 2013).

These findings add to the call of DPOs and disability campaigners to scrap the WCA. Besides the above questions concerning the reliability of the decision making process, such groups further question the following key aspects of the assessment process:

- The failure of the WCA to recognise invisible, mental and intermittent fluctuating conditions. This has historically been a problem, which disability organisations attribute for example to poorly designed mental health descriptors which do not reflect the full range of issues experienced by those with mental health disorders and the “snapshot” problem of the face-to-face assessment.
- Organisations like MIND or Rethink Mental Illness also criticise that the WCA substantially disadvantages people with mental health conditions. In 2013, a tribunal panel ruled that the DWP had failed to make reasonable adjustments to ensure people with mental health problems were treated fairly by the system. The judgment agreed with the arguments of charities (e.g. Mind, Rethink Mental Illness etc.) that people with mental health problems struggle with the assessments because they could be confused by their symptoms, be unable to accurately explain how the condition affects them or have difficulty in understanding the questions while assessors may fail to understand the complexities of such conditions (Gentleman 2013).

As a result, the court said that it is especially important for the DWP and Atos assessors to take medical evidence from applicants’ community health professionals, and that unless the system was adapted to take such medical evidence into account at the early stages of the process it is unfair to people with mental health problems. Following the judgement, the DWP considers that no procedural changes need to be made: “The Upper Tribunal did not direct us to make specific changes to the WCA process, and the Court of Appeal’s judgment does not change this direction. It will be business as usual for DWP Operations. Individuals will apply for ESA and undergo the

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<sup>8</sup> (<http://illegal.org.uk/thread/8640/release-staggering-numbers-overturned-secrecy?page=1&scrollTo=21759>)



WCA in the normal way. Those currently on Incapacity Benefit will be reassessed as planned” (Disability Rights 2013).

- The scope of the evidence taken into account in assessing the eligibility for benefits more generally.
- The impact of the WCA and the reassessment on persons with disabilities and the impact on perceptions of the benefit system. Litchfield for example notes in his review of the WCA that “length and complexity of the process contributes to dissatisfaction and negative perceptions surrounding the assessment” (Litchfield 2013).

The legislation (Welfare Reform Act 2007) provided for an independent assessment review of the WCA in its first five years of operation. As such, the WCA has evolved since its introduction and as the last review states will continue to evolve as circumstances change (Litchfield 2014). Changes during the past years of operation relate both to the process and the management of the WCA:

- The previous Government appointed in 2008 Atos Healthcare as the sole provider for carrying out Work Capability Assessments. Atos was frequently alleged to be the cause of the problem. In 2013, a Public Accounts Committee concluded that the WCAs resulted in too many wrong decisions being overturned (see above). In view of mounting evidence that a significant number of applicants have been wrongly judged to be fit for work and ineligible for government support, the DWP announced in March 2014 a settlement for Atos to exit the contract (DWP 2014a). The plan is for the new contract to be awarded late 2014, with a view to the new provider taking responsibility for delivery of Work Capability Assessments by 2015. The DWP also considers moving to multiple providers in the longer term to increase competition (DWP 2014a).
- Largely in response to the recommendations of the independent reviews, some of the descriptors have been removed, the questionnaire formats were changed to allow claimants to explain in their own words how their condition affects them, a personal statement intended to explain to the claimant why they have or have not been allocated the benefit was added, a number of special circumstances that ensure both limited capability for work and limited capability for work-related activity were added. Audio recording of the assessments is also theoretically permitted, but in practice prevented by lack of equipment (Franklin 2013).
- Between 2008 and 2010 a work-focused health-related assessment was included in the WCA to identify the kind of work a claimant who received the work-related activity component could do and identified ways of improving their capacity for work. The assessment was abolished from July 2010 as a result of the planned introduction of the Work Programme.
- Following the 2013 independent review measures included enhancing the capacities of the external Atos health care professionals to conduct the WCA, i.e. retraining and re-evaluating all Atos healthcare professionals, with those not meeting the required standard having their work audited or their approval to carry out assessments withdrawn (DWP 2013d).

However, Franklin (2013) notes that such changes are minor and presentational, rather than substantial. It remains to be seen whether changing the provider without revising the process may bring about greater public acceptance of the WCA.

In March 2014, in its response to the latest independent review of the WCA, the DWP announced 'that there is no evidence that changes to the WCA descriptors would significantly improve the overall assessment' (DWP 2014b). Dr Litchfield made a total of 32 recommendations to the DWP in his review concerning implementation of previous recommendations, effectiveness and perceptions of the WCA, decision-making, simplifying the process and mental health. The majority of recommendations were accepted and as a result DWP committed among others to 1) carry out a full impact assessment into the alternative approach to the decision making process as outlined by Dr Litchfield; 2) continue work already begun to develop a new form for healthcare professionals to use for the collection of further medical evidence and 3) review all letters and forms used in the WCA process – including the Limited Capability for Work Questionnaire (ESA50) (DWP 2014c).

Yet, it has to be noted that critic of assessment procedures to determine eligibility for disability benefits extends also to other assessments such as the one for PIP which has recently been described as an assessment nightmare which forces persons with disabilities routinely to undergo a barrage of evaluations.

## **6. Conclusion**

In January 2015, UK Employment Minister Mark Harper MP heralded a 2.5 percent increase in the disability employment rate, with a quarter of a million more disabled people in work since the previous year (Harper 2015). This was explained because more efforts had being made to help people into work through one-to-one employment support and through the Access to Work benefit. However, an alternative explanation could be that this rise reflects the general rise in employment in 2014-15: the UK employment rate of 73.2 percent was at the highest level since statistics began and overall unemployment declined to 5.7 percent (ONS 2015).

At the same time, Deaf people were complaining that they were at risk of being excluded for work because of restrictions to how sign language interpretation costs would be compensated by Access to Work (Deaf ATW). The percentage of people receiving secondary mental health services in paid work fell from 8.8 percent in 2012-13 to 7.1 percent in 2013-14. The proportion of learning disabled people known to social care who were in paid employment fell slightly from 7 percent to 6.8 percent over the same period (Department of Health 2014). Scope's analysis suggests that more disabled people are leaving the work force than are entering it (Trotter 2014). The Department of Work and Pensions found that 7 out of 10 disabled people were not receiving any support to find work (DWP 2013e).

Despite the earlier-than-planned replacement of one Work Capability Assessment operator, Atos, by Maximus (DWP 2014a), the test has not been changed, and continues to cause considerable concern. In 2014, the retiring head of the appeals tribunal said that the WCA had undergone 'virtual collapse' (Siddique, 2014). The removal of legal aid funding for advice and assistance on welfare rights, together with 'sanctioning' (temporary removal of benefits) has meant further difficulties for claimants. Scope's analysis of Department of Work and Pensions data indicates that a total of 120,000 disabled people have had their benefits suspended since November 2012 (Trotter 2014).

The problems with Employment Support Allowance and the Work Capability Assessment have caused considerable hardship to disabled people. Media coverage of welfare reform has generated a hardening of attitudes towards disabled people claiming benefits (Strathclyde Centre for Disability Research/Glasgow Media Group 2012). From reviewing the evidence, our conclusion would be that a punitive approach to reducing disability benefit claimant levels is more effective in causing misery than in raising employment rates, leads to a high level of appeals, and consequently creates a political backlash. Prior to recent welfare benefit changes, the UK welfare benefit system was already regarded as being relatively strict (OECD 2003), which suggests that cutting welfare benefits for disabled people was seen as politically expedient by the 2010-2015 Coalition government, which had already pledged not to reduce spending on older people's pensions, the National Health Service, and foreign aid.

Promoting work for disabled people is clearly a good thing, both for school leavers with existing health conditions, and older people developing health conditions which lead them to leaving the workforce. This requires investment in appropriate vocational rehabilitation and return to work strategies (Anderson et al 2012, Edwards 2014, Tompa 2008, van Stolk et al 2014), and a flexible and fair welfare benefit system. Evidence shows that one third of disabled people in work, and two thirds of disabled people out of work, have health conditions which limit the type and/or amount of work they can do. These individual limitations, together with realistic assessment of the possibilities for a disabled individual to find work in a particular employment market, need to be taken into account if the human rights of disabled people are to be respected.

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## Annex 5: Mandatory Disability Insurance Systems Overview<sup>1</sup>

The report analyses the challenges that disability insurance systems face in terms of costs and beneficiary identification, especially as disability insurance has been opened up to new medical conditions; and it discusses reforms that have been introduced to contain an expansion of the system and its costs.

### Background

*Disability insurance*<sup>2</sup> protects the insured against drops in income due to loss of productive capacity because of health problems that make it difficult for the person to work at his or her regular job, or any job. In their basic form, disability plans are public schemes managed by public agencies and financed on a pay-as-you go basis out of payroll taxes, sometimes supplemented with general budget transfers.<sup>3</sup> Disability plans pay defined benefits, usually at least 70 percent of recent wages.

Spending on public and mandatory private disability benefits in OECD countries stretches from less than 1 percent to almost 6 percent of GDP, with an average of 2.6 percent. Public spending on disability is around 10 percent of all social spending. Beneficiaries vary from less than 1 percent to 9 percent of the working age population. This range in spending and beneficiaries partly reflects variations in social security coverage between countries, and in part differing design features of the disability plan that make it more or less attractive to apply for disability benefits.

The profile of applicants and beneficiaries has changed over time. Originally, disability insurance was intended for people with well-defined chronic illnesses, but increasingly, disability plans have been opened up to more difficult-to-define conditions with a more uncertain impact on disability, and their prevalence among applicants and beneficiaries has ballooned. Currently, muscular-skeletal (in particular low-back pain) and mental health conditions constitute over half of all new entrants; and while the risk of disability is strongly and positively correlated with age, with the new medical conditions, the inflow of young disability beneficiaries has been growing rapidly.

This change in health conditions leading to disability has occurred as the approach to disability has shifted from a purely medical one to one that emphasizes the applicant's ability to function in the workplace, either through rehabilitation or (often subsidized)

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<sup>1</sup> This overview was prepared by Hjalte Sederlof, a consultant to the World Bank. It is a summary of a much longer background paper prepared by Estelle James, a consultant to the World Bank, for the study on disability assessment.

<sup>2</sup> In this document, "insurance" will denote contributory payroll-funded as well as non-contributory budget-funded schemes.

<sup>3</sup> In a few cases, private plans also exist, tied to an employer, occupation or pension plan.



employment; and a participatory role for the private sector. Such approaches increase the likelihood that benefits accrue to the genuinely disabled, while at the same time reducing system costs.

The report looks at contributory disability insurance financed by (formal sector) employers and workers, focusing on key assessment and governance processes. It does not directly address the broader issue of disability beyond those in formal employment, and that is financed exclusively from budget resources. Such interventions form part of social assistance, albeit targeted at persons with disability. Still, many the issues raised in the report also are valid for the social assistance-based disability schemes.

### **Issues in disability insurance**

As disability insurance has opened up to new medical conditions, the determination of disability based on impairment has become more difficult and selection problems have arisen. At the same time, high wage replacement rates have made disability an attractive option when compared to other safety net mechanisms, or even work.

**Assessing disability:** As understanding of disability has changed towards the interaction of a person with a health condition and his / her environment and it pertains to all health conditions, not only those related to physical health, it has become more difficult to observe and measure it, define its severity and determine work capacity of a person with a health condition using traditional impairment or functional limitation approach. Hence the errors of assessment have increased – some beneficiaries are wrongly included (errors of inclusion-false positive), while others are wrongly excluded (errors of exclusion-false negative). In countries where this has been studied, one third or more of all decisions about claims are estimated to be wrong.

**Screening procedures:** The tightness of screening procedures – years of work needed for eligibility, the waiting period before the benefit can begin, the extent of capacity loss required, and the qualifications and generosity of gatekeepers – determine the rate at which applicants are accepted or denied. And it affects the behavior of potential applicants, introducing elements of self-selection when higher denial rates discourage individuals from applying and more lax ones encourage application.

**Replacement rates:** Irrespective of screening procedures, benefit generosity may encourage more applications – with high replacement rates, individuals with poor health are more likely to stop working when they qualify for a benefit; and they are less likely to seek alternative benefits that may be less generous, such as social assistance, unemployment benefits and sick leave. And some countries (Austria, Netherlands, and Sweden) have explicitly used disability as an alternative to unemployment compensation or early retirement, especially for older workers.

**Disability insurance design may discourage work.** In OECD countries, disabled persons have employment rates that are only 60 percent of non-disabled ones and their

unemployment rates are twice as high. When the disabled work, it is likely to be part-time and at low wages. The picture is even worse for disability beneficiaries: only one-third work and their incomes are less than the (often low) earnings threshold that is allowed for benefit recipients. This is due to health problems impeding their work, but it also reflects design features in the disability insurance system itself that discourage individuals from using their remaining work capacity - working makes individuals ineligible for insurance benefits. To receive the benefit, applicants must exit employment; and once receiving a benefit, it will stop if the person resumes employment. In the US it will cease if a person works beyond a threshold - that is, there is an implicit tax on work that might be as high as 100 percent. And the return to work becomes more difficult, the longer the time out of work. As a result, once people qualify for disability benefits, they tend to remain on disability until retirement (or death).

### **Reform strategies**

Faced with these challenges, a number of reforms to disability insurance are being introduced that seek to contain program costs while raising accuracy and work. Some reforms are parametric, changing design features such as eligibility and screening, periodic reassessment of eligibility, and better coherence between disability and substitutes to disability within the safety net. Others place the emphasis on drawing disabled into jobs wherever possible by providing subsidies for working instead of benefits for not working. And still others attempt to move responsibilities onto private sector agents, such as employers, insurance companies and service providers.

#### **1. Parametric reforms.**

In considering parametric reforms, key questions in considering adjustments to design features are the following:

**Eligibility.** Normally, eligibility extends to formal sector workers who contribute through payroll taxes. *Should eligibility extend beyond contributors to the system?* Some countries have introduced flat benefits for persons with disability, regardless of work experience, and in some instances they have linked this to means-testing. For those with a work history, decisions have to be made concerning the length of the contribution period before eligibility is established; the circumstances under which full and partial benefits are granted; and the emphasis to be placed on job search assistance and unemployment benefits.

**Benefit amount and replacement rate.** The benefit amount and the replacement rate should seek to strike a balance between benefit generosity and costs, including both direct and indirect costs. Relatively high replacement rates are found in most countries – generally above 70 percent – but evidence about the adverse effects of high replacement rates on claim applications and labor force participation suggest caution in setting rates.

**Screening.** Screening—assessing the degree of disability—involves finding the right balance of stringency. That determines the number of errors of inclusion (lax screening) and of exclusion (stringent screening). The most common indicator of stringency is the denial rate, with a median of 45 percent of applicants in OECD countries. Rather than stringency, accuracy might be emphasized – introducing more unbiased information into the screening process. This would include drawing on external experts hired by the medical insurance system, and private sector parties such as employers acquainted with the applicant, or vocational counselors with understanding of the links between medical impairment and ability to work. System procedures that raise the cost of applying, such as application fees or waiting times, may discourage marginal applicants. Intensified screening and counseling during sick leave, including job counseling and job search assistance, can be a means of reducing so-called disability traps that are created when easy eligibility and high replacement rates for extensive sick leave make re-entry into the work force difficult.

**Periodic Reassessment of eligibility.** Once on the disability rolls, exits before reaching retirement age are rare. This is at odds with the fact that a person’s medical condition can improve, and treatments evolve; and it argues for periodic reassessment. But it needs to be weighed against the costs of periodic reassessment of beneficiaries and challenges of labor market reinsertion after long periods of inactivity. Recent reforms treat many disabilities as temporary conditions that periodically should be re-evaluated, while permanent disability is reserved for a small proportion of the disabled that have little chance of improvement.

**Disability as part of the safety net system.** When unemployment, early retirement, and social assistance plans are reformed, disability rolls may grow, and conversely, when the disability program is reformed, other social programs may grow. Therefore, changes in individual programs should take into account their effects on the demand and costs for other programs.

## **2. Increasing work incentives.**

Keeping disabled people in the labor force, and getting them back to work have become key elements of reform to disability insurance. The main levers include setting *earnings thresholds*, introducing *trial work periods*, *eliminating the implicit tax*, making use of *wage supplements and subsidies*, and *anti-discrimination legislation, workplace accommodations and employment quotas*.

**Thresholds and trial work periods.** An increasing number of countries allow individuals to earn up to a threshold amount without loss of eligibility or benefits. Thresholds are generally low, which may limit the opportunity for full-time work and deter some individuals from entering the labor force. Sometimes recipients are allowed trial work periods with earnings above the threshold, without losing their benefit and having to reapply. However, in practice, neither the introduction of thresholds or trial work periods have proven very effective in enticing beneficiaries back to work. In many instances, their

disability may be too severe; in others, information flows may be weak, or the benefit may be competitive with the potential wage.

***Eliminating the implicit tax.*** Eliminating the implicit tax simply means that the benefit is not lost if the person works. The financial disincentive to work is removed, and the work decision is guided by the replacement rate, as well as the capacity and willingness to work.

***Wage subsidies and supplements.*** Some countries are experimenting with replacing benefits by wage subsidies or supplements for partially disabled individuals. The combination of a wage and a subsidy reduces system costs per recipient by the amount of the wage, and allows fewer people to be designated as fully disabled. However, more people are likely to apply for benefits and cut down on work if they can keep their partial wage in addition to their partial benefit, and more individuals will qualify if partial disability is the criterion and the gatekeeper is lax.

***Anti-discrimination legislation, workplace accommodation and employment quotas.*** Attempts to encourage work by disabled individuals would have little effect if employers were allowed to discriminate against them in hiring and firing or refused to make simple workplace accommodations to compensate for disability. Such measures may be subsidized by the Government. In many countries, firms also face mandatory employment quotas for disabled workers, usually comprising some 3 to 6 percent of a firm's employees.

### **3. A Larger Private Sector Role**

The past two decades have seen movement toward a greater private role in providing information about applicants, insurance, finance and services -- although the gatekeeper role continues to be carried out by public officials. The systems are structured so as to give participating private entities incentives to keep costs under control by shifting beneficiaries into work rather than into benefits.

In the **Netherlands**, much of the costs of the system have been shifted onto private employers. Private employers pay for up to two years of sick leave and make reasonable workplace accommodations, and contract with private providers for rehabilitation and vocational counseling. With sick leave being the major pathway to disability benefits in many European countries, the objective is to get persons with short and medium-term illness back to work before they enter the disability rolls. If the individual still claims to be disabled, (s)he is sorted into full, part-time or no-disability categories. Partly disabled remain the responsibility of the employer for a period of ten years, receiving the same services as during sick leave, and if working, the state provides a wage supplement. Periodic reassessment of eligibility is undertaken. The system provides efficiency gains in terms of better information on the worker/applicant, and hence improved gatekeeping; it discourages unnecessary applications, and it facilitates movement back into work.

In **Denmark**, too, applicants are sorted into the three categories, and partially disabled get a wage supplement. But responsibility for running the program is vested in municipalities rather than employers. Until recently, municipalities were reimbursed by the central government for two thirds of their expenditures, and so had few incentives to encourage the partly disabled to work. There was, moreover, no periodic reassessment: once given, the benefit becomes permanent. Facing high application rates, the system recently has been modified to improve work incentives, by reducing reimbursements to municipalities and subsidies to workers, and by increasing reimbursements for employer- and employment-oriented measures.

In **Australia**, disability benefits go only to those who are permanently unable to work more than 15 hours a week. The remainder are evaluated and assigned to a private, competitively selected, service organization for training and personal support. They receive unemployment benefits for a limited time, and are required to engage in job search.

In **Chile**, workers contribute to retirement savings accounts. Pension funds purchase disability insurance policies where the premium is dependent on the previous claims experience of the fund. Full and partial disability is covered, partly from the worker's own retirement account, (which may discourage claims); and the remainder through a top-up financed with a group insurance policy purchased by the pension fund. Thus, workers, pension funds and insurance companies all have an interest in controlling disability claims. Initial claims are evaluated by regional medical boards, and medical protocols spell out the criteria granting partial or full disability. Pension funds and insurance companies can participate in the assessment process, present information, contest claims and bring appeals. This contrasts with the previous system, where decisions were made by regional medical boards based on information provided by the individuals own doctor.

So far, results of reforms introducing a greater role for the private sector have been mixed. In the Netherlands, inflows into disability benefits per 1000 working age population shows a decline from over 11 to 4 between 2000 and 2008; while spending as a percentage of GDP over the 2000-2005 period dropped from some 4.6 percent to 4 percent. Denmark saw an increase in inflows into disability benefits from 4 to 5 percent, while spending rose from 3.8 percent to 4.4 percent of GDP between 2002 and 2005. Reforms in Australia also saw inflows fall, albeit slightly, from 6.2 to 6.1 percent, while spending a share of GDP fell from 3.5 percent to 3 percent of GDP over the 2000-2005 period.

## Endnotes

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<sup>vi</sup> Convention on the Rights of Persons with Disabilities, G.A. Res. 61/106 (2007). Accessible at <http://www.un.org/esa/socdev/enable/rights/convtexte.htm>.

<sup>vii</sup> OECD. 2010. *Sickness, Disability and Work: Breaking the Barriers. A Synthesis of Findings across OECD Countries*. Paris, OECD.

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<sup>ix</sup> In this report we stayed away from disability assessment in children, because of its specificity and particularity. As it happens, most people develop poor health during adulthood either from work or non-work related injuries and non-communicable diseases or simply because of the ageing process. The likelihood of a person experiencing poor health increases with age. Adults who have acquired disability in childhood, either because they were born with a health condition or acquired a health condition before the age of 18, make up only a small share of the overall population with disability. Issues of education and labor market participation for this population are different from those faced by adults whose health deteriorates after they have reached adulthood. It should also be noted that a number of people who would report experiencing disability in households or other population surveys would always be several times higher than a number of people assessed as disabled based on countries criteria for disability (see WHO and the World Bank, 2011, *supra*).

<sup>x</sup> The 2012 OECD report on work and mental health issues documents the challenge the high cost arising from mental ill-health poses to the labor market. See OECD. (2012). *Sick on the Job? Myths and Realities about Mental Health and Work*. Paris, OECD.

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<sup>xii</sup> This strategy is used in the Dutch disability insurance reforms, which has made the Netherlands one of the very few countries that has managed to significantly cut inflow into disability benefits. One element of the reform was the extension of a paid sickness leave to 104 weeks, which put pressure on the worker, the social insurance agency and its disability assessment arm, the employer and other social services to work together to ensure full return to work. Disability assessment criteria were changed as well and today they are quite close to the full application of the ICF approach to disability assessment. See, Van Sonsbeek, J.M. and Gradus, R. 2012. Estimating the effects of recent disability reforms in the Netherlands. *Oxford Economic Papers* 2012, 1 of 24. Oxford University Press. De Yong, P.R. (2012). *Recent Changes in Dutch Disability Policy*. University of Amsterdam and Aarts and APE. Amsterdam. Geurts, S., Kompier, M. and Gründemann, R. 2000. Curing the Dutch disease? Sickness absence and work disability in the Netherlands. *ISSR* 53(4): 79-103.

<sup>xiii</sup> OECD, 2010, *supra*.

<sup>xiv</sup> Autor, D. and Duggan, M. 2006. *The Growth in the Social Security Disability Rolls: A Fiscal Crisis Unfolding*. NBER Working Paper No. 12436.

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- <sup>xvii</sup> Van Sonsbeek Gradus, *supra*.
- <sup>xviii</sup> See in general Brage, S., Konrathsdottir, A.D. and Lindenger, G. Work disability evaluation. In Escorpizo, R., , Brage, S., Homa, D. and Stucki, G. (eds.) 2015. *Handbook of Vocational Rehabilitation and Disability Evaluation*. New York: Springer, pp.107-140.
- <sup>xix</sup> It is argued that situation in the labor market is one of the factors taken into account in deciding on whether a claimant is disabled or not in the US Social Security Disability Insurance system. See: Autor, D. and Duggan, M. 2006. The Growth in the Social Security Disability Rolls: A Fiscal Crisis Unfolding. Working Paper 12436. Cambridge, Massachusetts: NBER and Autor, D. 2011. The Unsustainable Rise of the Disability Rolls in the United States: Causes, Consequences and Policy Options. MIT and NBER. November 2011.
- <sup>xx</sup> See in general, Bickenbach, J. 2012. Ethics, Law and Policy. Vol 4 of the SAGE Reference Series on Disability: Key Issues and Future Directions. Thousand Oaks, CA: Sage Publications.
- <sup>xxi</sup> For the most exhaustive and regularly updated source on social security programs around the world, including information on disability benefits provided through country specific social security systems see: Social Security Programs throughout the World. <http://www.ssa.gov/policy/docs/progdesc/ssptw/>. Very few countries would not have any disability related provisions. See also a background paper on UK disability benefits and assessment prepared for this study by Ola abu Algaib and Tom Shakespeare from the Faculty of Medicine and Health, University of East Anglia presented as Annex 1 to the study.
- <sup>xxii</sup> Because of the many levels of reconsiderations and appeals, the US Social Security Administration's disability evaluation process may take years to complete, and so is one of the most costly to administer in the world: Stobo, J.D., McGeary, M. and Barnes, D.K (eds). 2007. Improving the Social Security Disability Decision Process. Washington DC: National Academic of Sciences, Chapter 4.
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- <sup>xxiv</sup> Bickenbach, *supra*, p. 30.
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