Disability and the Disabled - Issues, Laws and Programs

Women, Disability, and Culture

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Women, disability and culture

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Introduction

This book will provide an overview of women with disabilities by examining the topic from a cultural viewpoint, as well as from other angles. The contributions of several scholars from different countries will provide a framework of analysis of the current situation of women with disabilities in various different environments.

The book is divided into three parts, based on three types of analysis: the first part offers an overview of disability and health, the second examines the specific aspect of being female and having a disability and the third looks at the inclusion of women with disabilities in their cultural surroundings.

The concept of disability is commonly immediately associated with health and health-related issues. In Part I, scholar Anna Siri provides a different conceptualisation of disability, starting with the original interpretation as a personal health issue, later as a social concept and finally with its insertion into the social contest. A long theoretical path led to the classification of disability at an international level by the World Health Organisation and this is analysed in a specific chapter. Part I concludes with a reference to the topic of disability contained in the UN 2030 Agenda for Sustainable Development.

Part II looks at disability from the viewpoint of gender, focusing on women. Together with a contribution by Anna Siri on the importance of the codification, collection and organisation of data on disability, scholar Cinzia Leone provides an intersectional interpretation of discrimination and an introduction to feminist disability studies in this part, which is then examined in greater detail in part III by scholar Rita Bencivenga.

Following the change in attitudes towards disability at the start of this century, the UN Convention on the Rights of Persons with Disabilities was approved and this has resulted in a different approach to disability and to social disadvantage within the EU, analysed here by Cinzia Leone.

Despite the work done, disability continues to be viewed today as somehow a negative condition and this forms the basis of Part III, focused particularly on the aspects of women with disabilities in their socio-cultural environment.

The role of non-disabled researchers in conducting research into disability and the birth of feminist disability studies is analysed by Rita Bencivenga.

Moreover, thanks to the contribution by Cinzia Leone, this book also examines the concepts of disability from a cultural viewpoint with specific reference to Italy.

Diversity and diverse environment are investigated by scholar Sonja Bezjak, who has done field work to shed light on women with disabilities living in rural areas, looking at a combination of gender, disability and place of residence.

The last contribution in Part III is made by scholar Darja Zaviršek, who discusses the mostly unexplored topic of women with disabilities and independent living and the right to make intimate decisions, including those associated with motherhood and sexuality in general.

Throughout the book, reference is also made to the work of scholars who have already studied these issues, in order to clarify the persisting grey areas.

First Chapter

Concepts of disability and health: a theoretical excursus

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Abstract

The chapter aims to provide an overview of the different conceptions of disability that have marked the scientific and social debate in the last century, trying to capture its main aspects through the evolution of the main models of disability. Attempts to propose definitions of disabilities that integrate different dimensions and interactions can be understood in the light of this evolution. What we call "disability" today has always been a cause for fear and debate. For a long time, the main question has been to what extent different beings, in body or mind, belonged to humanity. In ancient times they were considered "superhuman" beings close to the gods, then, in the classical centuries, as "infrahuman" beings, intermediaries between humanity and animality. Now that finally the condition of humanity of "disabled people" is fully recognized, the debate has moved mainly on their social condition.

Keywords: disability; health; disease; model

1.1 Introduction

The concepts of health, disease and disability are the result of an elaborate review process that has taken place over time. Since the early decades of the 20th century, many causes have led to a reflection on the concept of health and disease, which, thanks to the World Health Organization (WHO), has become a subject shared throughout the world. Care for man, the meaning of "person" and the relationship between doctor and patient are some of the elements that have played a crucial role in the transition from the concept of "disease" to that of "health".

What we now call "disability" has always aroused fears and questions. For a long time, the main problem was to determine to what extent different beings, in their bodies or minds, belonged to humanity. They were later considered "superhuman" beings close to the gods during antiquity, then, in the classical centuries, as "infra-human" beings, intermediaries somewhere between the human and the animal (Stiker, 2001). With the condition of humanity now fully recognized, the debate mainly concerns the social condition of people defined as "disabled".

Disability is a multifaceted physical and/or mental manifestation of the human being that hardly lends itself to a unified and univocal definition.

Its definition is as complex (never static, but dynamic and subject to the scientific and social evolutions of the community over time) as there are questions about its contextualization in today's society. According to the Global disability action plan 2014-2021 by WHO, both health and disability are complex, dynamic and multidimensional issues, and that these issues cannot be comprehensively addressed without support and assistance from a wide range of other sectors such as education, employment and social welfare, and stakeholders including development organizations, service

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providers, academic institutions, disabled people’s organizations, communities, and people with disabilities and their families.

Disability is socially constructed. Each physical, mental and/or emotional limitation has a meaning and shapes a person's life situations based on the local resources and structures, attitudes and belief system and values of the community to which they belong. As Trent (1994) pointed out, disability is a construct whose change of meaning is shared by administrative policies, programmes and practices, as well as by the social context to which these individuals must respond.

An interesting study by Goerdt (1984) shows how within a social organization based on the connection between individuals and mutual help: "...the unity of the group depends not only on the contribution of each member, but also on the willingness to accept the help of others": it is the limitation in social interactions that makes the person a disabled person.

Disability is a transcultural phenomenon, in the sense that it is found in every society. What varies between societies are the individual characteristics by which a person is identified as disabled, and how these characteristics affect the possibility of playing a certain social role.

Today there are few companies that are not affected by the globalized representations of disability determined by the consolidation of an idea of person whose substance performative is focused on the ability to work, the circulation of dominant biomedical knowledge, and the affirmation of commercial empires such as the pharmacological one.

Transcultural anthropological research on disability shows that in many non-western cultures the "disabled" are not recognized as a category and that people are not named according to their individual characteristics: the blind, the deaf, the dumb, the lame, and so on.

In the west, on the contrary, people are regularly grouped according to common individual characteristics and therefore categorized according to a dichotomous model: man/woman, foreign/native, normal/disabled, etc. Western society usually distinguishes between the "normally able-bodied" and the "disabled", following the common idea of a "normal level of ability" on which the assumption of a certain role in social life is based. The limitation of capacities is the result of a dysfunction of the body or mind, according to a biopsychological meaning; from here, we see how the culturally determined notion of disability is defined in clinical terms within a biomedical discourse that enshrines the perfect function, psychology and physiology of the development of normal and non-normal individuals. In Western culture, based on the autonomy of the individual, disability is conceptualized in terms of dependency based on the level of inability to perform certain tasks of daily living. However, major differences remain.

In the twentieth century, there was an important theoretical reflection on health, disease and its consequences on the life of the person, which led to the formulation of different conceptual models. The focus and common point of arrival of some of these models is the so-called "disablement" process. While in the first models this process is seen as deriving from the characteristics of the person (pathology and impairments), in the later models there is a progressive recognition of the role of the environment (in its physical and social aspects). While in the early models an indissoluble link between pathology and absence or reduction of work possibilities and life opportunities was hypothesized, thereafter an attempt was made to analyse the complex dynamics that can be created between these variables, and progressively the role of environmental factors in improving the lives of people with disabilities was also included and analysed. Among the models that have been elaborated, some have had a greater relevance at international level and are better known, others have spread mainly at national or local level.

This chapter aims to provide an overview of the different conceptions of disability that have animated the scientific and social debate in the last fifty years and aims to capture the evolution and articulation of the main models of disability, at national and international level.

1.2 The evolution of theoretical models of disability

The concepts of disability and the way in which human societies have dealt with this phenomenon have changed throughout history.

Before engaging in reflections on disability, we need to know the main approaches that have shaped and shape people's perceptions and ideas about people with disabilities. This is important because, as Smart (2004) points out, such models provide:

- definitions of disability and explanations on the allocation of causes and responsibilities;
- based on (perceived) needs, can guide policy formulation and implementation;
- not being value neutral, they shape the self-identity of people with disabilities and can cause prejudice and discrimination;
- provide information on which academic disciplines they study and learn about the disabled.

There are currently two main models of disability that coexist in Western societies: the individual or medical model and the social model. Both are based on the same approach to disability, i.e. a long-term health problem that limits the person's ability to perform activities that would be considered as “normal”. A third model developed in the 1980s tends to reconcile the two prevailing models, taking into account both individual and environmental aspects of disability. Then, on the basis of the criticisms of the prevailing models, others have developed that have had and still have an impact on the way people perceive people with disabilities.

Although these are not the only models of disability that can be found in our time, they are now the most widespread and dominant models and it is important that those who approach disability know their existence and assess the influence on their way of thinking about people with disabilities.

The model of charity or moral model: the disability to be protected

This is the oldest approach to disability, framed within the sphere of caring and protection, this initially in terms of protecting the vulnerable "other", but in reality the need to protect the economic and social order by controlling, through segregation, the "deviant members" of society (Braddock & Parish, 2001). The construction of dedicated structures has been a fundamental response to this point of view. Often large, imposing, containing cavernous dormitories and located within a vast park away from urban centers, these structures are a clear manifestation of the institutional nature of the model of charity of disability. Usually less impressive from an architectural point of view than work houses (Higginbotham, 2018) and asylums, but not necessarily better located in terms of social services nearby, segregated schools for the "blind and deaf" were also common.

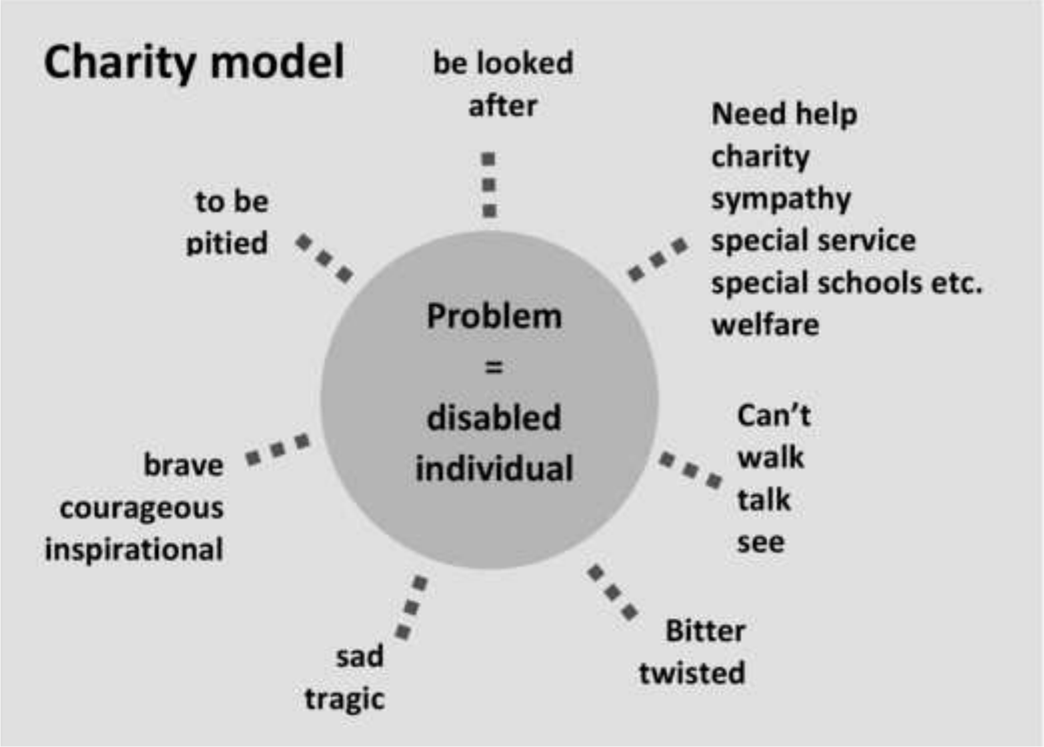

Figure 1: The moral/charity model of disability

Historically, therefore, significant proportions of the population, not only "disabled", but also people with "mental disorders", "elderly" and "defective" children, have been grouped into institutional care facilities at a distance, both geographically and culturally, from society in general (Wolfensberger, 1969; Barnes and Mercer, 2003). A rather inevitable consequence of the invisible segregation of the charity model of people with disabilities.

This model has traditionally been applied to fundraising for people with disabilities. While it is praiseworthy in many respects, there are many criticisms motivated by the view that it represents a danger. From tragedy and pity comes a cultural "cure". Critics argue that it causes discrimination. In fact, the many charities that support people with a particular type of disability are referred to from a medical point of view, institutionalizing segregation in some way. Not only that, from a personal point of view, the idea of being recipients of charity lowers the self-esteem of people with disabilities and, on the other hand, charity brings with it an expectation of gratitude from donors and the risk of imposing a series of conditions on the recipient (e.g. imposing a limit on choices). Critics of the model invoked the need to educate charity managers and other professionals to review their way of working. By reviewing their way of working they could ensure that funds are directed to promote the empowerment of people with disabilities and their full integration into society as equal citizens who demand respect but not compassion.

Religious/Moral Model of Disability

The religious model considers disability as a punishment inflicted on the individual or the family. It may be due to crimes committed by the disabled person, someone in the family or community, or by their predecessors. Sometimes the presence of "evil spirits" is used to explain differences in behaviour, especially in conditions such as schizophrenia. Acts of exorcism or sacrifice may be performed to expel or appease the negative influence or recourse to persecution or even death of the individual who is “different”.

In some cases, disability stigmatizes an entire family to the point of total social exclusion. Or it is seen as a necessary affliction to be suffered before a future spiritual reward.

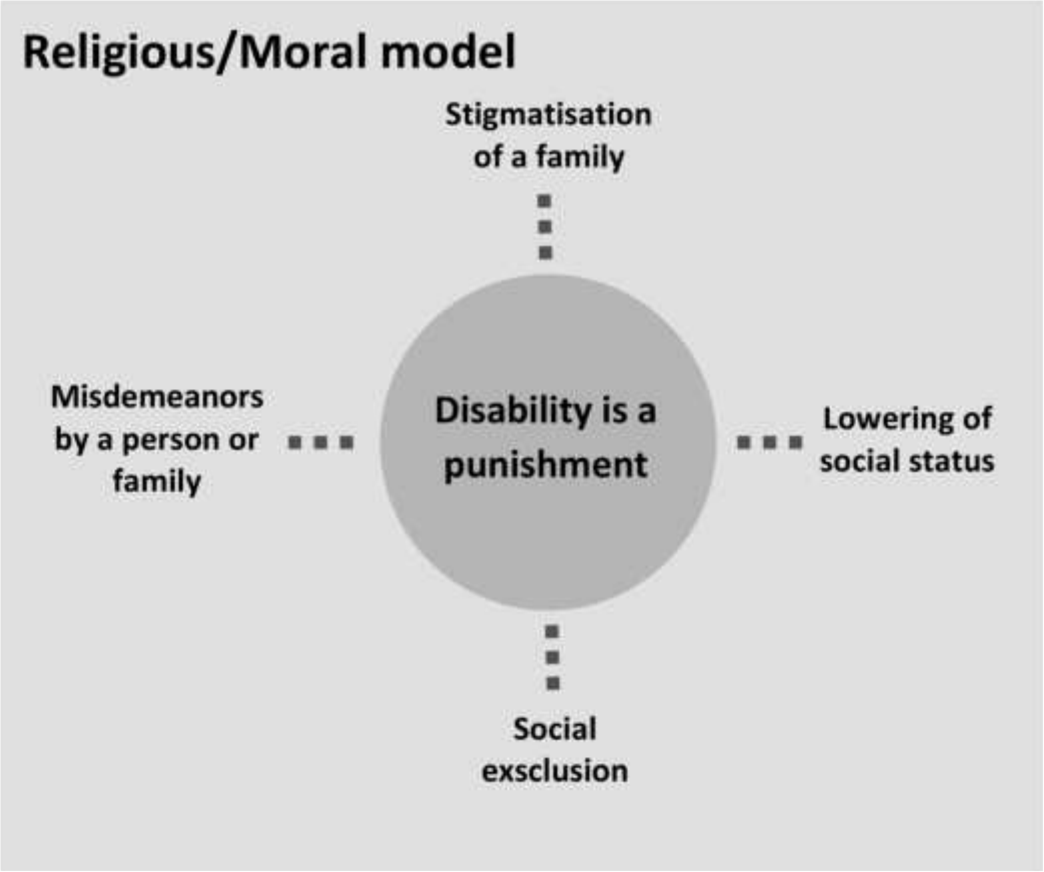

Figure 2: The moral/charity model of disability

The individual or medical model: disability as a disease

The individual model is based on a medical approach and considers disability as an intrinsic reality of the individual. From the mid-1800s onwards, the medical (or biomedical) model of disability began to gradually replace the moral and/or religious model, in relation to significant advances in medical science. Disability is an individual medical problem of a person whose body has a permanent physical, mental or psychological impairment that prevents him from performing the acts of daily life and that limits his social participation (Olkin, 1999).

This model follows a cause-effect logic: a disease or trauma causes an organic and functional disability; it results in a disability for the person; this disability results in a social disadvantage or disability. Disability is therefore clearly the result of the individual's disability. The proposed interventions are of a curative nature and ultimately aim to cure the person or at least rehabilitate him in society as it exists for the "normally-abled". The "impairment" of a person can be diagnosed, treated, or at least rehabilitated by modern medicine and/or medical technology with interventions provided by omniscient professionals (Oliver 1998; Scotch 2000; Pfeiffer 2003).

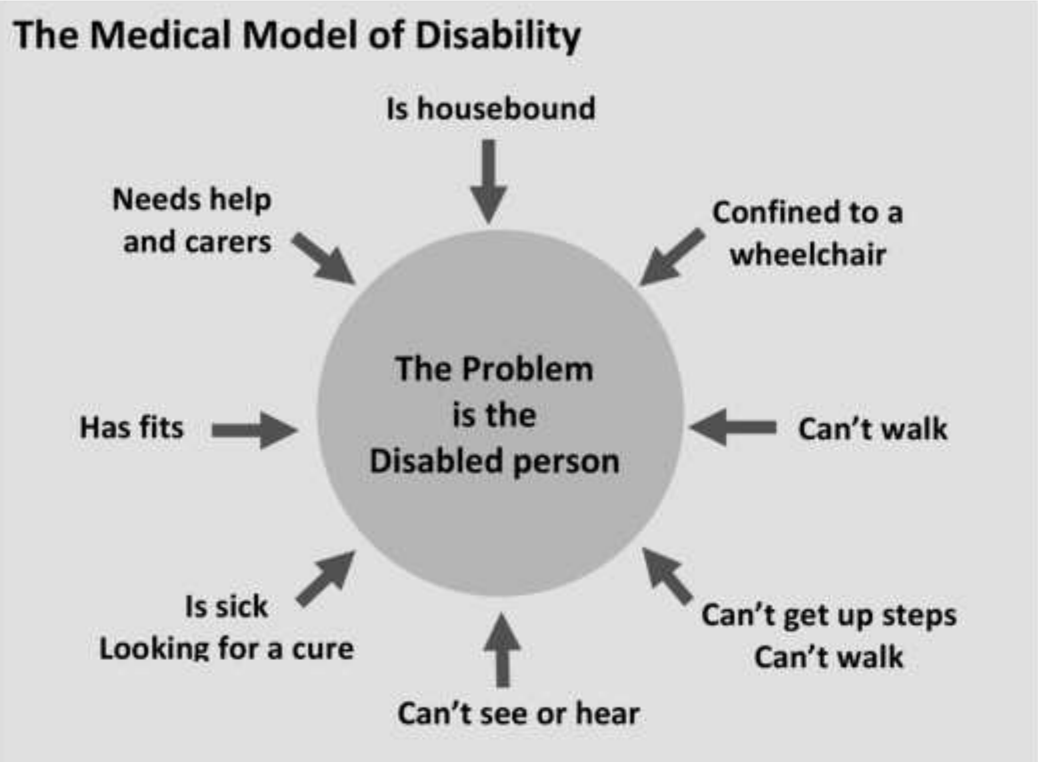

Figure 3: The medical model of disability

The model places the origin of the problem on the disabled person and concludes that solutions can be found by focusing on the individual. According to the model, the main need of people with disabilities is medical services in the form of hospitals, specialist doctors, nurses, therapists, etc.. The medical model of disability is sometimes also referred to as a model of "personal tragedy" (Thomas & Woods, 2003), because it defines disability in a fundamentally negative way, as a pitiful condition, "a personal tragedy for both the individual and his family, something to prevent and, if possible, cure" (Carlson, 2010). As Carlson points out, this negative conception of disability has contributed to some of the questionable medical treatments performed on disabled people, including, for example, involuntary sterilization and euthanasia.

Doctors who follow the medical model tend to treat people as problems to be solved, often not taking into account the various aspects related to the life of the person as a whole (Thomas & Woods 2003; Kasser & Lytle, 2005).

The medical model of disability assigns enormous power to health professionals who diagnose people using criteria developed from the point of view of what is considered "normal" in society (Thomas & Woods, 2003). Parsons (1951) described in a discerning way the basic characteristics of the "role of the sick" in any social context in which the medical model prevails, for example the person "in need of help" is expected to be exempted from normal social obligations or from certain responsibilities.

Disabled people should adequately play the "role of the sick" for the biomedical paradigm, if they wish to receive continuous help and support. However, the "role of the patient" approach does not take into account the vital distinction between disability and disease, as highlighted by Llewellyn et al. (2008). Many disabled people are not ill, but rather have permanent disabilities that do not present themselves as daily health problems.

At a legislative and policy level, the proposed solutions use compensation systems, such as invalidity insurance, which assesses invalidity in terms of loss of earnings due to personal invalidity. The critical view is interesting as expressed by Stiker (1999) of our society, which argues that the scheme is not a scheme of equality, but of identity. The distance between identity and equality is enormous. We are a society that seeks the same thing in inequality, while others have claimed the difference in inequality and we hope for equality in difference.

The social model: disability as a socially constructed phenomenon

The biomedical model, for which there was the slogan "a cause, a disease, a treatment", in force after the Second World War, came less and less with the appearance of significant transitions in public health: two of particular importance were the epidemiological transition and the "demographic transition" (Ravaud, 2001).

The idea of re-education therefore underwent significant growth with the aim of normalizing people, adapting them to society as it exists, in order to reintegrate them into it. Hence the need to introduce accessibility standards. In 1965, the first international conference on architectural barriers was held in Stresa, Italy. Sanchez (1997) identified in this evolution a radical paradigm shift: "disability is shifted towards environmental factors and the new model of integration will aim to think and promote the adaptation of society, its openness to physical or mental differences to the norm". During this period in the UK, two British researchers of disability activists and great theorists, Finkelstein and Hunt, developed their theory concluding that the social exclusion of people with disabilities was a result of the 'materialistic landscape of the industrial age' making them economically unprofitable (Hunt 1966; Finkelstein 1993; Finkelstein 2001). The design of factories and workplaces, schools, public transport systems and infrastructures has been strongly influenced by the demands of the designers' clientele, unaware of the effect on the results of accessibility.

Through this further passage from the idea of rehabilitation to that of accessibility, the passage from the medical model to the social model of disability is clearly perceived.

The social model, developed at the end of the 1960s in a context marked by the action of numerous disability movements[1], considers disability as a social product, as a result of the inadequacy of society to the specificities of its members.

It is not a real theory that can explain the multitude of phenomena related to disability but rather a holistic approach explaining which specific problems are experienced by people with disabilities, taking into account all the environmental and cultural factors that make them disabled (Covelli, 2016). The philosophy of this model appears to be in clear contrast with the dominant medical approach (D'Alessio 2011): it is the society "that disables people with disabilities, and therefore any significant solution must be directed towards social change rather than individual adaptation and rehabilitation" (Barnes et al., 2010). The medicalized view of disability, which describes people as "sick" and "deviant", as a burden on their families and society and dependent on charity, encourages the development of negative attitudes towards them and deprives them of their fundamental rights.

During the 1970s, there was a significant increase in mobilisation on disability issues and these activist movements undoubtedly played a very important role in the development of the social model of disability, as Ravaud pointed out (2001).

Made up of people with disabilities, these movements consider people with disabilities first and foremost citizens, and then as consumers of health, rehabilitation or social services, with equal rights to social participation, self-determination and control over their daily lives. The crucial points can be summarised as follows:

- Only people with disabilities know what is best for them, so it is up to them to propose better solutions, organise themselves politically and defend their individual and collective rights (advocacy).
- People with disabilities should be able to choose their service providers and the people who assist them. In order to be able to manage their daily lives, they must receive the necessary financial support from the government (empowerment).

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[1] Disabled students at the University of Berkeley in California received personal assistance from their university in the late 1960s, enabling them to complete their studies. After graduation, with the help of the authorities, they set up a new programme of "personal assistance" that allowed them to live independently in society. The Berkeley Centre grew rapidly and many Independent Living Centres were created in the United States and then in the rest of the world (Ravaud, 2001, p.58).

- Support among disabled people who have experienced a similar situation is more effective and useful than professional interventions; it allows the analysis of their own situation, the assumption of responsibility for their own life and the development of coping strategies (peer-counselling).

The underlying philosophy is to ensure an independent life, which does not mean that people with disabilities should or want to do everything themselves and that they do not need anyone or want to live in isolation. Independent living means having the same choice and control in everyday life that non-disabled people take for granted.

Fundamental to the social model of disability is the concept that disability is ultimately a socially constructed phenomenon.

One of the most important documents for the development of this approach is the policy document of the Union of the Physically Impaired against Segregation (UPIAS), Fundamental Principles of Disability (1976).

UPIAS also draws an important conceptual distinction between the terms "impairment", defined as “lacking part of or all of a limb, or having a defective limb, organ or mechanism of the body” and "disability", defined as the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities.

From this point of view, disability is a socially constructed disadvantage, which is “a particular form of social oppression” (UPIAS 1976).

In the 1980s, a British scholar and disability activist, Oliver (1983, 1998, 2013), developed the social model of disability, challenging the approach to the medical model (Oliver 1983; Scotch 2000; Pfeiffer, 2003). Oliver shifts the focus from the individual (to be treated) to society (to dismantle the barriers that build disability). Disability stems from barriers within an "oppressive and discriminatory society" rather than from disability *per se* (Oliver, 1990; Barnes, 1992, 2012; Soder 2009). To this, Barnes (2012) adds, cultural discrimination is driven by the media through negative images that devalue people with disabilities.

Figure 4: The social model of disability

The social model of disability has had a profound influence on how disability is understood in our times (Giddens, 2006) and has played a crucial role in the definition of social policy towards disabled people, not only at the national level but also at the international level.

To sum up, the origin of the disability for the social model is external to the individual, it is up to society to evolve so that people with health problems are no longer "disabled" or, more precisely, "in a situation of disability", but with the same rights and opportunities as people whose bodies function normally. It is about adapting the environment and services, making them accessible and usable for people with physical or mental disabilities. This conception is clearly opposed to the one underlying the medical model. The type of interventions proposed changes. The social approach abandons the ideal of care and promotes the development of the person's residual capacities to make him or her autonomous in his or her daily life (logic of empowerment). Disability therefore leads to everything that imposes restrictions on people with disabilities, whether it be individual prejudice, institutional discrimination, inaccessible public buildings, unusable means of transport, segregation education, work organisations that generate exclusion, etc. Anti-discrimination and equality legislation is based on this model. The concept of equality, of equal opportunities is central here, and that is why this model has spread widely on the basis of the notion of human rights.

Some variants of the social model: the identity model and the human rights model

Closely related to the social model of disability is the identity model (or affirmation model) of disability, which differs to the extent that it "claims disability as a positive identity" (Brewer et al. 2012). This model shares the understanding of the social model that the experience of disability is socially constructed, but, as highlighted by Brewer, deviates from the approach of the social model because it is more interested in forging a positive definition of disability identity based on experiences and circumstances that have created a recognizable minority group called 'people with disabilities'. According to the identity model, disability is an indicator of belonging to a minority, such as gender or race.

The identity model has influenced many in the disability community, inspiring disabled people to adopt a positive self-image celebrating the "pride of disability" (Darling & Heckert, 2010).

Swain et al. (2000) define the identity model of disability as "the model of affirmation", which shapes the identity of disabled people in several ways: by motivating disabled people to be part of a group to develop a collective identity; by making them aware that there is nothing wrong with having an "outsider" identity, but that they should have the right to be "insiders" if they prefer; by stimulating them to seek "revolutionary visions of change, often under the banner of "civil rights" and "equal opportunities".

Even the identity model is not without criticism. For some critics this approach seems to force individuals to identify with a specific group culture, for others it seems to deny the struggle for redistribution, not paying sufficient attention to the reality of the economic inequalities that disabled people are constantly confronted with (Fraser, 2003).

Another model similar to the social model is the human rights model of disability.

The disability model for human rights did not appear spontaneously, but evolved within a continuum of rights-based approaches (Quinn et al. 2002; Degener 2016). Not all scholars agree to see distinctions between this model and the social model, but the position of Degener (2017) is interesting, instead highlighting a number of important differences between them. While the social model stimulates us to understand the social factors that underlie our understanding of disability, the human rights model goes beyond explanation and offers a theoretical framework for a disability policy that emphasizes the human dignity of disabled people. In addition, the human rights model "includes a range of human, civil and political rights as well as economic, social and cultural rights" (Degener 2017). Unlike the social model, the human rights model respects the fact that some disabled people are actually faced with extremely difficult and painful life situations and argues that these factors should be taken into account in the development of appropriate theories of social justice (Degener

2017). Last but not least, the human rights model "offers space for minorities and cultural identification", which is not considered at all by the social model (Degener 2017). The human rights model also recognises the fact that a public health policy aimed at preventing impairment, if properly formulated, can be considered an example of human rights protection for the disabled (Degener 2017). Finally, Degener (2017) highlights the constructiveness of the human rights model, which does not attempt to explain why so many disabled people live in poverty, but offers constructive proposals to improve their life situation.

A first sign towards the human rights model of disability is the United Nations Universal Declaration of Human Rights adopted in 1948, shortly after the end of World War II (Berghs et al., 2016) in response to established power imbalances that limit the ability of marginalized and/or minority groups to participate fully in all aspects of society.

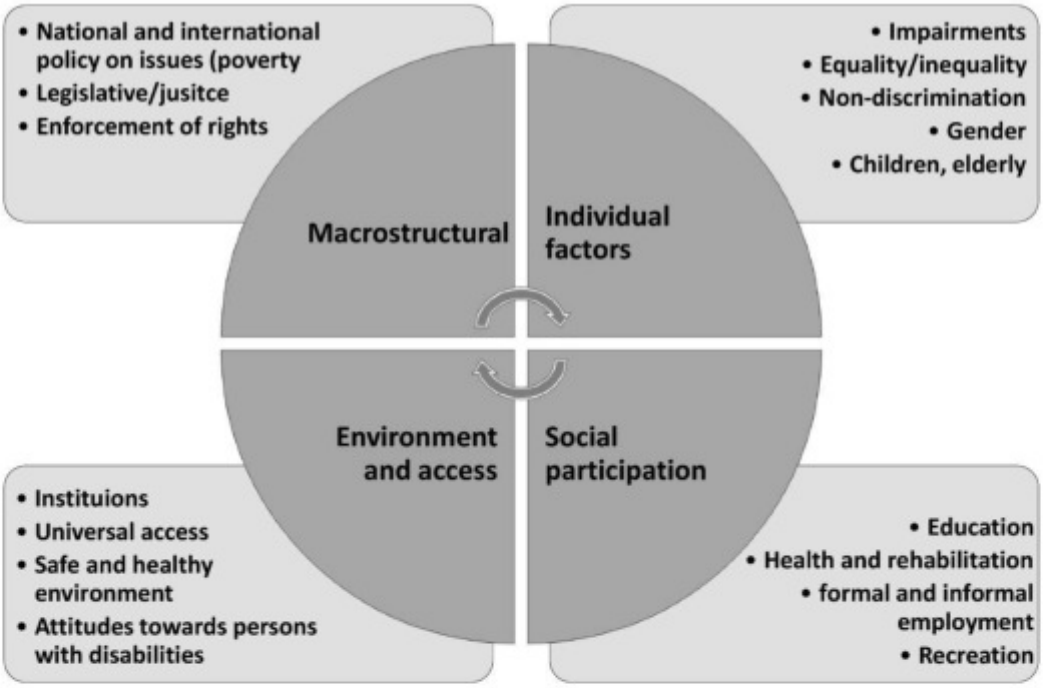


Figure 5: United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)

The Human Development Model-Disability Creation Process (HDM-DCP or MDH-PPH in French language): a model that does not place the responsibility of disability on the person

A model designed to reconcile the two prevailing perspectives of disability, individual and environmental, is the model developed by Fougeyrollas and his team at the end of the 1980s (Fougeyrollas, 1998, 2001, 2010).

The HDM-DCP conceptual model is based upon the Quebec Classification: Disability Creation Process (1998), which is a scientific classification that provides definitions, taxonomies and measurement scales for life habits, environmental factors and personal factors conceptual domains. This classification system help to identify, appreciate and follow the observed changes in these three conceptual domains in a given period.

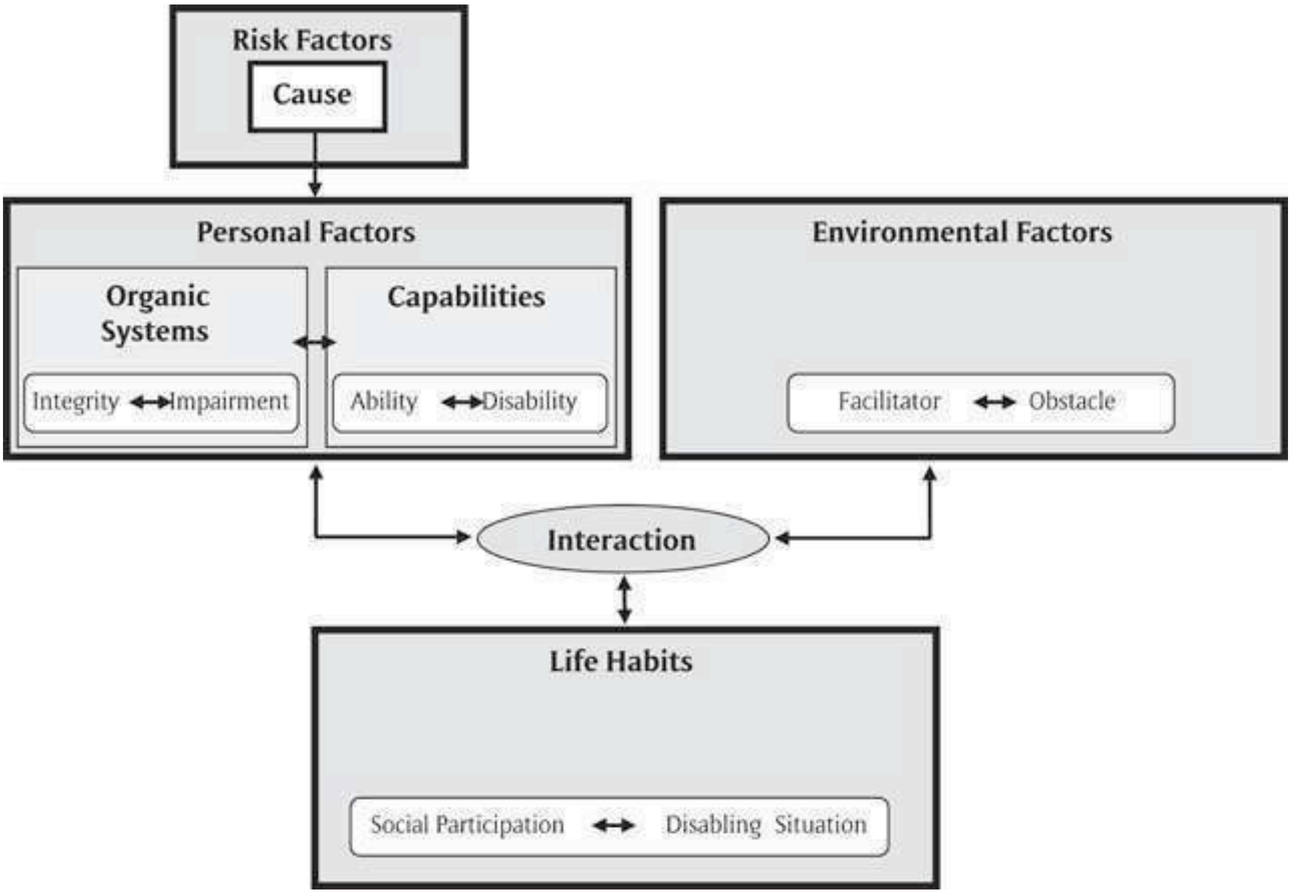


Figure 6: HDM-DCP conceptual model based upon the Quebec Classification: Disability Creation Process (Source: Fougeyrollas et al., 1998)

As pointed out by Borioli & Laub (2005), the model is built on the basis that the person carries out his daily life activities in continuous interaction with his physical and social environment. This permanent interaction between the person and the surrounding environment produces activities related to food, personal care, travel or interpersonal relationships.

The basis is an anthropological and pedagogical model of human development that applies to all (Fougeyrollas, 2001).

The original version of the human development model uses three determining factors: personal factors, personal factors and life habits.

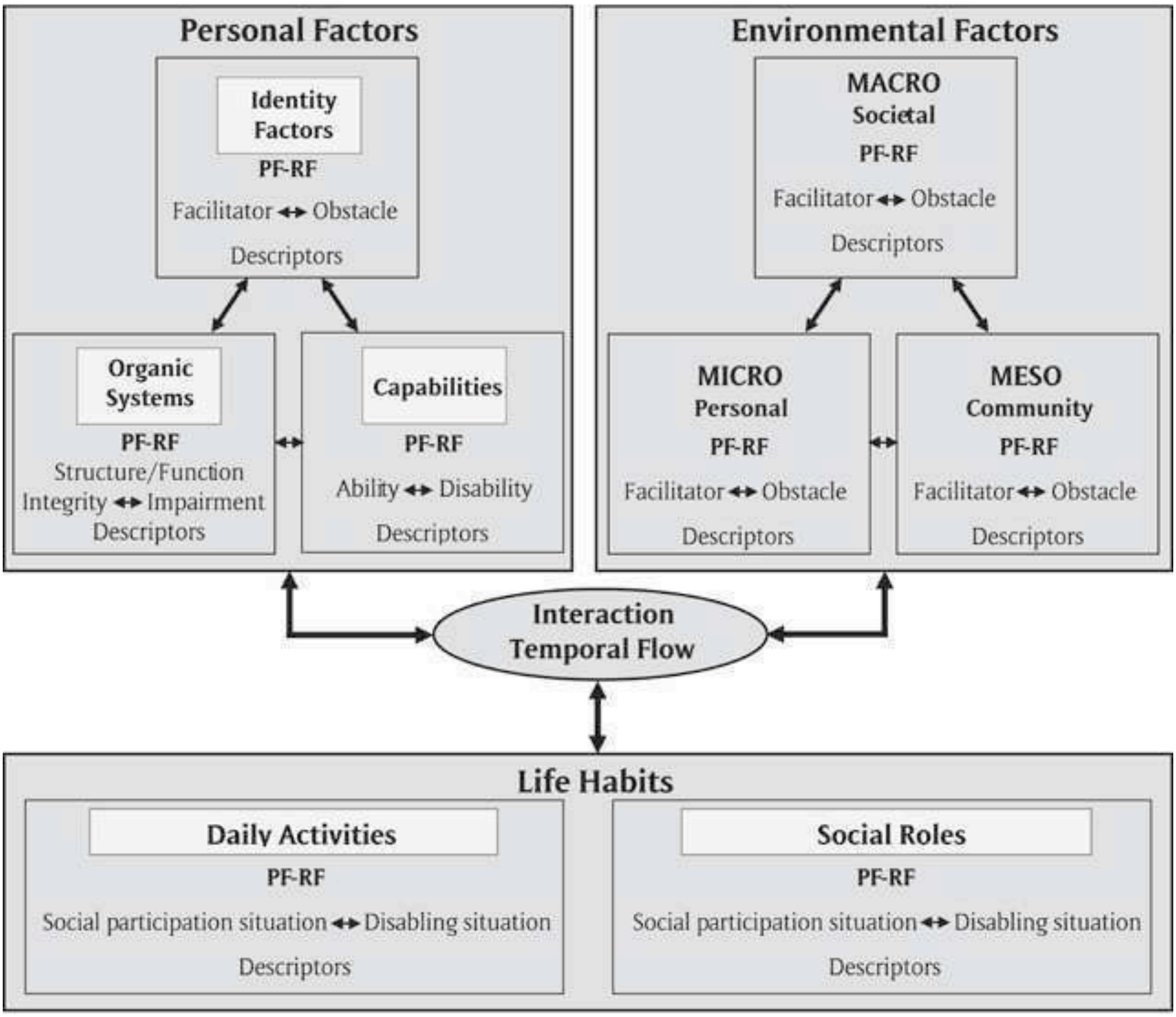
More specifically:

- Personal factors correspond to intrinsic characteristics of the person, such as age, gender, socio-cultural identity, organic systems, skills, etc.. The model focuses mainly on the latter two features. An organic system is considered as "a set of body components aimed at a common function" that can be evaluated along a continuum that goes from integrity to complete damage, and “ability” means "the ability of a person to perform a physical or mental activity", measured on a scale that goes from optimal ability to complete disability (Fougeyrollas, 2001).
- Environmental factors are defined as the social or physical dimensions that determine the organisation and context of a society. They are expressed in a continuum that goes from the facilitator (who promotes the realization of life habits when interacting with personal factors) to the complete obstacle (which hinders life skills).

- A life habit is defined as a current activity or a social role evaluated by the person or his socio-cultural context according to his characteristics. The quality of achieving a life habit is measured on a scale ranging from full social participation to total disability" (Fougeyrollas, 2001).

The following diagram illustrates these different factors and their components. We also see the central place occupied by the interaction between factors.

"The process of producing disability is not an autonomous reality and separate from the general model of human development; it is only a variation of possibilities in relation to the biological, functional and social norm whose production process we are trying to clarify" (Fougeyrollas, 2001).



Legend: PF-RF: Protective Factor – Risk Factor.

Figure 7: HDM-DCP2 conceptual model (Source: Fougeyrollas et al., 2010)

The HDM-DCP sees disability as a variation of human development, i.e., a difference in the level of achievement of life habits or in exercising human rights. Making disability a completely separate reality from human development is based on a dichotomy in perception, which far too often differentiates between people with disabilities having abnormalities and so-called “normal” or valid people.

According to the HDM-DCP, disability is not necessarily a permanent and static state for everyone. Since everything depends on personal factors or the environment in which a person lives, people may see the quality of their social participation improve or deteriorate over time.

1998 was the year of birth of the HDM-DCP, after several years of research. This conceptual model differed from other human development models because it covers the idea of “risk factors”, “organic systems” and “capabilities”. According to this version of the HDM-DCP, risk factors are behind the shortcomings in organic systems and the disabilities related to capabilities for the person or population.

The HDM-DCP model differs from the previous one in that it includes the concept of risk factors, linked to both organic aspects and attitudes. The model is based on the hypothesis that the type of help required coupled with the level of realization of the life habits of people or populations reveal their degree of participation or social exclusion in everyday life (Parè et al., 2013).

This model introduces the idea that environmental factors related to the context of a person's or a population's life may facilitate or hinder the implementation of daily activities or social roles. "One risk factor is an element belonging to the individual or coming from the environment which can cause illness, trauma or other damage to the integrity or development of the person. These risk factors may result from real causes leading to disease, trauma or any other harm to the integrity or development of the person” (Fougeyrollas & Charrier, 2013).

There is therefore a conceptual difference between a person's ability to perform a physical or mental activity and its possible use in an activity of daily life or in a social role, always defined within a given context of life.

The HDM-DCP also aims to ensure that social players are more aware of and better accept their responsibilities towards people with disabilities and their families, with the ultimate aim of developing an inclusive society (Griffo, 2012).

The HDM-DCP also allows for the evaluation of the models of organization of services and projects, as well as the adoption of social policies able to guarantee equal opportunities and the exercise of the rights of disabled people and able to really respond to their expectations and needs.

In the recent years, many tools were developed to facilitate the use of the HDM-DCP by the organizations, the professionals, the researchers and the activists advocating for the human rights of people with disabilities:

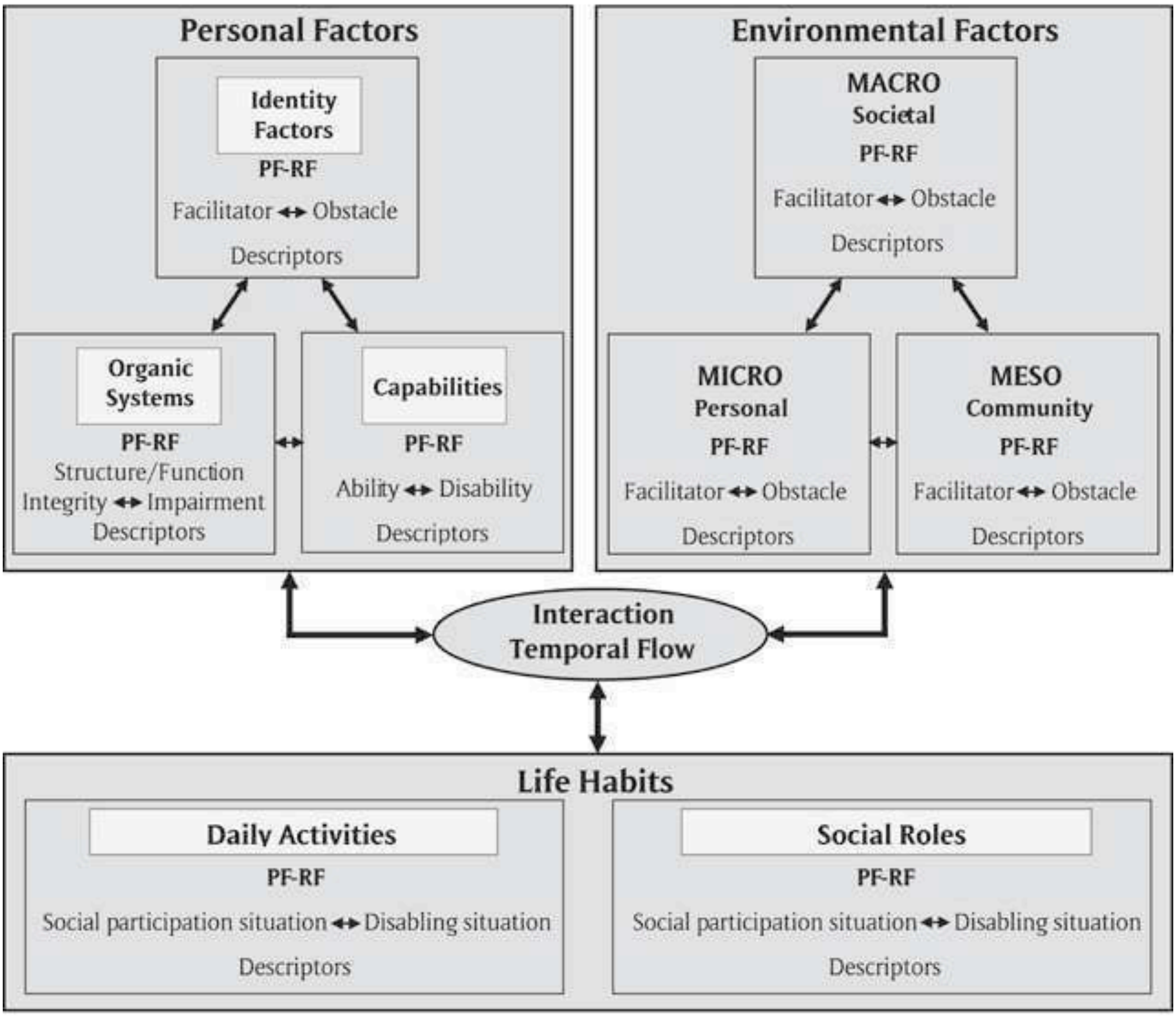
- Le Processus de production culturelle du handicap; Contextes sociohistoriques du développement des connaissances dans le champ des différences corporelles et fonctionnelles (1993) ;
- Disability Creation Process poster (1998);
- Quebec Classification: Disability Creation Process (1998);
- La funambule, le fil et la toile : Transformations réciproques dans le champ du handicap (2010) ;
- LIFE-H and MQE assessment tools;
- HDM-DCP poster (2010).

In 2018, the international classification of the HDM-DCP model reaffirms its anchorage in an anthropological reading of the cultural construction of human beings and repositions itself in a broader perspective that is not limited to health problems. The classification highlights its relevance to the evaluation of the implementation of the United Nations Convention on the Rights of Persons with Disabilities (UN, 2006).

The International Classification: Human Development Model - Disability Production Processes (2018) includes the conceptual framework of the HDM-DCP, the conceptual domain definitions "lifestyle", "environmental factors" and "personal factors" and their different nomenclatures.

First, the International Classification integrates the elements of the 2010 HDM-DCP scheme published in "La funambule, le fil et la toile". In addition, some definitions of identity factors have been improved. Environmental factors are now subdivided according to micro-meso-macro-environments, including examples of each domain for each environmental level.

The International Classification contains about 80 more pages than the International Classification, most of which are more detailed and in-depth than the 1998 Classification. This new tool is therefore more precise and complete.



Legend: PF-RF: Protective Factor – Risk Factor.

Figure 8: Human Development Model - Disability Production Processes (2018) (Source: Fougeyrollas et al., 2018)

The HDM-DCP model presents several key elements of interest for policy and service development, as well as for the human rights respect. As highlighted Feuo..., one of the crucial point is the incorporation of a diachronic perspective, which assumes that people’s life situations change over time and allows evaluation of the impact of interventions or programs by measuring changes between periodic synchronic snapshots of the components of the model.
Moreover, the explicit focus on risk factors that may affect or complicate the development of a person and their impairments over time, and on the factors of protection that may be introduced to assist people living with disabilities is another key issue of this model.

It is also important to underline that the possibility to assess disability and human development, not just at the personal level but also at the population level providing a robust framework that is adaptable to new understandings as they emerge.
Finally, the HDM-DCP model development shares a common history with the development of WHO's ICIDH and ICF classifications that will be explored in more detail in the next chapter.

The cultural model: disability as culture

The cultural model of disability has developed in the North American context, where many scholars of social sciences and humanities have addressed the issue of disability in an interdisciplinary way (Michalko 2002; Titchkosky 2007). The primary characteristics of the cultural model were outlined by Junior & Schipper (2013), in particular in terms of differentiation from the medical model and the social model. The cultural model, in fact, in its approach to disability focuses on a number of cultural factors and this approach radically differentiates it from the medical and social models. These factors may include medical and social factors, but are by no means limited to these factors. Consequently, the cultural approach does not seek to define disability in a specific way, but rather focuses on the way in which the different concepts of disability and non-disability operate within a specific culture. Schipper (2006) also highlights the critical importance of the distinction between impairment and disability in different cultures; while an impairment is universally constant (for example, the inability to conceive children), the extent to which this impairment has socio-political consequences shifts from culture to culture, for example, the inability to conceive children can be more "disabling" in the ancient cultures of the Near East than in the western industrialized cultures.
The social model is particularly concerned with addressing "barriers to participation" experienced by people with disabilities as a result of various social and environmental factors in society (O'Connell, Finnerty & Egan, 2008; Purtell, 2013).
A key role in shaping the theoretical contours of the cultural approach to understanding disability was played by Snyder and Mitchell (2006) who argue that disabled people are often placed, often against their will, in "cultural places of disability".
The main problem of these places of production is constituted by the modernist assumptions that support them, in particular by the strategy of classifying and pathologizing human differences (now known as disabilities) and then managing them through various institutional locations (Snyder & Mitchell, 2006). Such places could have a real meaning if they transmitted "authentic cultural ways of understanding disability", which are necessary and important for understanding disability (e.g. the disability rights movement, the culture of disability, the movement for independent living).
It is a cultural model of disability increasingly accepted in the disability community (Lewis 2007; Holcomb 2013), although not without critical points.

The model of limits: limits as a common aspect of the human being

According to the model of limits, a theological model of disability developed by Creamer (2009), it is important that people accept the fact that all human beings experience a certain level of limitation in their daily lives and that these limits are experienced to varying degrees throughout all phases of our lives. Using "limit-ness" neologism, Creamer argues that, instead of being something alien to human experience, limits are in fact a common aspect of the human being, which is not surprising at all. Human limits should not (should) be seen as negative or as something not to be done, but rather as an important part of the human being. And they go far beyond the labelled ones: some, in fact, are seen as more normal (I cannot fly) than others (I cannot see).
The model of disability limits has profound implications for the understanding of disability. First, it tries to avoid categorizations such as "disabled", "able", "abnormal body" or "normal body"; second, it tries to focus on the importance of "a network of related experiences" that for example recognizes that a legally blind person may have more in common with someone wearing glasses than with a wheelchair user.

No less important is the attempt to avoid over-determining the situation of the disabled with respect to the population in general, since every human being lives on limits (Mawson, 2013).
While recognizing the key to understanding the social model that disability is primarily social in nature, the model of limits differs from it, allowing us to consider that not "all limits are necessarily “normal” or even “good” (Creamer, 2009).

Other models of economic, organisational and welfare nature

In addition to the main models described above and those that revolve around them or tend to mediate between the two positions, individual and environmental, there are also other models that mostly fit into a particular theoretical context and that respond to rather pragmatic considerations (ref.). One of these is the economic model that sees disability as a productivity challenge. The economic model focuses on the effects of disability on a person's abilities, particularly on work and employment skills (Armstrong et al., 2006), underlining original. It requires an assessment of the economic model of the capacity to work and contribute to the economy, factors such as respect for and civil rights of persons with disabilities (Smart, 2004). It is widely used by governments in formulating disability policy (Jordan, 2008), but has been strongly criticised for framing disability almost exclusively in terms of cost-benefit analysis (Aylward et al., 2013; Smart, 2004), leading to the dehumanisation of the person with disabilities (Stone cited by Smart 2004).

Figure 9: The economic model of disability

The administrative model frames disability in relation to its recognition, which occurs when a person receives benefits from an administrative body (public or private) due to a long-term health problem. Anyone who receives such benefits is therefore invalid.

More recently, the need for assistance model refers to the services that society provides to help people with disabilities or activity limitations. According to this model, disability arises when a person with health problems needs the help of others to carry out the normal activities of a human being (getting up, dressing, eating, studying, moving, working, etc.). This model is generally referred to when it comes to organising performance systems to meet specific care needs, such as a home care service or a leisure offer adapted to wheelchair users. This model generally refers to informal help, provided by relatives (relatives, neighbours, acquaintances), and organised help, provided by specialised services (association, home care service, etc.). The need for assistance therefore partly overlaps with the administrative model. It is also a variant of the social model, as it focuses on measures to be taken in the social environment so that people with health problems can function as normally as possible.

1.3 The Biopsychosocial Model: an holistic approach

The application of medical and social models proved to be only partially effective, since they only took into account a part of the universe of health and disease: the former focused more on the biological aspects of the disease, while the latter tended to examine the responsibility of the physical and social environment in determining the process of disability.

The crisis of the two prevailing paradigms, biomedical and social, has paved the way to a wider consideration of the factors involved in the concept of health, to identify a model that can take into account the multifactorial nature of the causes that act on health and disease and the undifferentiability of the mind and body in influencing the health condition of an individual (Braibanti, 2002).

In 1977, American psychiatrist George Engel challenged medicine to abandon the biomedical model and adopt a new systemic orientation. He described a model which he called "biopsychosocial", and which has become commonly understood at the international level, representing a framework for the application of theoretical thought to the clinical practice of treatment (Cigoli & Mariotti, 2002). The biopsychosocial model integrates these two dichotomous paradigms, considering together the biological, psychological and social variables involved in the processes of health and disease.

Engel (1977) believed that the crisis in the biomedical model was due to its adherence to a model focused exclusively on disease, which was inadequate in capturing all the influential aspects in the processes of health and disease. Defining the disease only in terms of somatic parameters, he completely neglected the psychosocial aspects.

Engel emphasized the fact that the biochemical defect, taken into account by the disease-centred approach, was just one of many factors whose complex interaction could culminate in an active disorder or an established disease. These factors were considered by the author to be the cause of the subjective variability of the clinical manifestation of the disease. Moreover, the biomedical model, favouring technical procedures and laboratory measurements, left little room for the patient's verbal report. He overlooked the need to analyse the meaning of the patient's report in psychological, social and cultural terms as well as in anatomical, physiological and biochemical terms (Engel, 1997). In his studies, Cassel (1964) has shown higher rates of disease among populations exposed to inconsistency between the demands of the social system in which they were living and their own culture. For Engel, it was a demonstration of the importance of the role of psychosocial variables in the manifestation of disease in humankind. The biochemical defect could determine some characteristics of the disease, but not necessarily the moment when the person fell ill or accepted the role of being a “sick” person (Engel, 1977). Another criticism that Engel made of the biomedical model was its dualistic nature, with its separation of mind and body, and the rigidly reductionist orientation of medical thought. He sensed that it was not possible to study a system from within and to take a position of full objectivity. In this way, he provided a logical basis for including the human dimension of the physician and the patient as the legitimate focus of the scientific study. Embracing the system theory, Engel recognized that mental and social phenomena depended on, yet did not necessarily have to be limited to, the most basic physical phenomena (Borrell-Carriò et al., 2004). Engel's work promoted an approach to health and disease that combined micro (interactional), meso (community and organizational) and macro (ecological-social) levels, considering them as predictors of clinical and social outcomes (Schultz & Gatchel, 2005). The author started out from these assessments to develop a model able to take into account the patient, its social context, the role of the doctor and the health system.

The biopsychosocial model thus provides a broad understanding of the processes of the disease, simultaneously considers multiple levels of functioning and every aspect involved in the process of treatment, from diagnosis to treatment (Frankel et al., 2003).

Explicit in this model is the reference to the concept of "system" developed by Von Bertalanfly (1968), understood as a dynamic entity in which the components are in continuous and reciprocal interaction, so as to form a unit or an organic whole (Braibanti, 2002).

Since the 1960s, medicine has found itself faced with the need to take greater account of the subjectivity of patients, under increasing pressure from both society and the market. Indeed, around those years there was a growing demand for qualitatively adequate care in the population and for cultural instruments of judgement, criticism and bargaining (Engel, 1977).

The systemic option involves both the specificity of each level of organisation and the need to indicate precisely the nature of the relationships and interdependence between the levels of interaction (Braibanti, 2002). The Von Bertalanffy systems theory approach considers a set of related events as a system that manifests specific functions and properties depending on the level at which it is placed compared to a larger system that includes it. This means that the family and the territory, the health organization, the operators and the patients are all involved in a dynamic and incessant exchange and that the change of one of the levels involved necessarily corresponds to a repositioning of all the others and the entire system.

The relationships between the different levels of organization are defined as transactions, since they bring changes to all levels of organization involved; they are therefore not classed as interactions, where the emphasis is placed more on effects than processes (Braibanti, 2002).

The theory of systems can be seen as a global ecological model in which the human organism is better understood if represented as a system that is part of larger systems, such as the relevant family, community, socio-economic state, profession, cultural context and living environment: thus all living structures can be described as included in larger systems and made up in turn of subsystems in constant mutual interaction. The idea of the "living system as a machine", made up of different parts with their own essential characteristics, begins to undergo a change, going towards the idea of the "living system as a network of relationships". The analysis of any subsystem always takes place within the context of the relationship of that subsystem with other systems (Cigoli & Mariotti, 2002). The ecosystem vision has profound implications when applied to the area of individual health and society (Mengheri, 2003).

Thus, the adoption of system theory could provide medicine with a theoretical approach suited to the study of disease and medical care as related processes, not only to the biopsychosocial conception of disease (Engel, 1977).

Unlike the biomedical approach of identifying characteristics, categorizing symptoms and making the correct diagnosis, in the biopsychosocial model the lenses that guide the investigation are the interactions, bonds and relationships. Those who act according to this model collect information on living systems, their systemic and procedural properties, formulating approximate descriptions of the condition within the context. Through this process data is obtained both on the process of disease and on the relationships at different levels (Cigoli & Mariotti, 2002).

Since 1948, the WHO has defined health as more than just the absence of disease, thus conceived as a state of complete physical, mental and social well-being. An innovative key to understanding the concept of health was beginning to emerge and was later adopted by the biopsychosocial model. In fact, this model has moved away from the rigidly dichotomous definition of health and disease proposed by the biomedical paradigm, which saw the dimensions of health and disease as very much separately defined aspects and, moreover, mutually exclusive. The biopsychosocial model promotes a different conception of these two dimensions: health is considered within a continuum of well-being and illness that is structured along the space delimited by two extremes, death and quality of life. The health of an individual is in a position along this continuum; however, this position is not static, but is influenced by the positive or negative effects experienced in daily life.

Health is no longer considered as a direct consequence of the absence of the disease but is recognized in its intrinsic evolutionary nature and positive meaning. In addition, individuals are acknowledged as having the ability to change their lifestyle in order to improve their health.

The biopsychosocial model sees the disease in relation to the individual experience of the person. The disease becomes a subjective measure of the disorder, in contrast to the strictly objective indices of the medical model, such as body temperature or cholesterol level. Moreover, the development of the disease is not limited to biological imbalance, but rather is influenced by psychological and social factors, which can modify the patient's reaction to his health conditions (Deep, 1999). The "good quality of life" and well-being require opportunities and possibilities to reach the maximum of personal autonomy to be used as a tool for interaction with the environment; they also require the creation of mediations between the subject and the environment and mutual adaptations to reduce disadvantages.

The biopsychosocial model takes a holistic view not only of health, but also of disease. It embraces an integrated and multifactorial concept of suffering. The model recognizes the complexity of the relationship between suffering, physical and psychological impairment, and functional and social disability. Suffering includes several components: biological, which includes the physiological and neurological functioning at the cellular, organic and systemic levels; physical functioning, which includes the ability to perform daily activities; psychological, which consists of cognitive and emotional processes, such as anxiety, enthusiasm, mood and hopes for the future; and social functioning, which includes the individual's interactions in society, the ability to occupy social roles, such as work and interpersonal relationships, within a certain socio-cultural environment. Suffering is seen as resulting from the interaction between these interdependent components (Schultz & Gatchel, 2005). The vision of the biopsychosocial model considers disabilities as one of the variations of human functioning, which originate from the interaction between intrinsic characteristics of the individual and characteristics of the physical and social environment (Ustun et al., 2001). The biopsychosocial model also differentiates between impairment and disability: the first is defined as the loss or damage of any part, system or body function, while the second is conceived as the contextualization of the impairment.

Organic pathology is not considered a reliable predictor of impairment and disability: psychological and socio-cultural factors play a fundamental role in defining suffering and in mediating the individual's reaction to harm and consequent disability (Schultz & Gatchel, 2005).

Another peculiarity of the biopsychosocial model is the adoption of a circular causality model. Engel opposed the traditional linear cause-effect model to describe clinical phenomena, considering clinical reality much more complex. Few pathological conditions could in fact be interpreted as originating from nature "a microbe, a disease": instead, there were usually many interacting causes and contributing factors. The biopsychosocial model adopts a circular causality, which describes how a series of circular counterreactions support specific patterns of behaviour. This is an attempt to understand these complex recursive properties of systems, and to find interrelated proximal causes that could be changed with the right program of interventions (Borrell-Carriò et al., 2004). Interference in the interaction of systems can give rise to processes that alter the basic organization; such interference can result from stress, which occurs when the demands of the context exceeds the ability of a particular system to meet the demands.

Another characteristic of the biopsychosocial model is the adoption of the lifespan perspective, in which the understanding of the processes of health and disease is contextualized according to a temporal perspective that covers the entire life span. The levels of organisation involved in the bio-psychosocial system are, in fact, dependent on the changes that characterise development. The very representation of health and disease changes dramatically throughout life, as do basic biological processes, emotional, cognitive and personality dynamics, social norms, activities and the level of participation in relational life. The evolutionary dimension involves all the relationships that specify the relationship between person and context (Braibanti, 2002).

The biopsychosocial approach therefore implies an evolutionary dimension, i.e. that the transactional relationships that specify the relationship between person and context change along a time line through dynamic processes that can be characterized by personal and social development, personal and social skills and competences, and cognitive and metacognitive skills. The biopsychosocial model tries to account for how the relationships between the levels of organization change along the time line.

One of the key concepts of the biopsychosocial model pays close attention to the humanity of the doctor-patient relationship. Engel's thesis on the relationship between practitioners and patients believed that the doctor's need to understand and know should be combined with the ability to make the patient feel understood and known (Smith & Strain, 2002). To assure a correct diagnosis was only part of the physician's task: he also had to insist on interpreting health and disease from an intersubjective perspective, giving the patient the right space to voice his concerns, finding out about his expectations, and making a commitment to the effect that the health profession would show the patient a human side. Such an approach represented the movement towards an equal relationship, in which the physician is aware and careful in the use of his power (Borrell-Carriò et al., 2004). Within the biopsychosocial model, observation, introspection and dialogue were the basis of the methodological triad for clinical studies and for the interpretation of scientific data related to the patient (Fava & Sonino, 2008).

Engel's proposal is for an approach that emphasizes human warmth, understanding, generosity and care (Borrell-Carriò et al., 2004).

With the advent of the biopsychosocial model, we have therefore moved from a compliance relationship to a concordance relationship, which is, from a paternalistic approach, characteristic of the biomedical model, to an approach centred on the patient, characteristic of the biopsychosocial model (Leonardi, 2012). Compliance presupposed trust, understood as an absolute act of delegation to the expert in decisions concerning one's own health, since he believed that the patient did not have the physiopathological knowledge, technical skills, tools and psychological capacity to deal with situations deriving from the pathology that afflicts him. While this model proved to be quite effective for acute diseases, it was not as effective for chronic disorders. In the face of this evidence, a culture of empowerment has been increasingly strengthened, with the aim of involving the patient in decisions regarding their own health and in the management of chronic conditions. The expert in this vision has the task of encouraging the organization of a knowledge structure capable of enabling the patient to identify their goals, take their actions and experience their power. While traditional education offers information and technical skills, self-management education teaches problem-solving skills with a person-centred approach. A fundamental characteristic of the approach to empowerment therefore presupposes a combined work between doctor and patient, aimed at the development of an individual action plan. Each action plan must be adapted to the individual taking into account culture, age, health status and personal aspirations. The challenge of helping patients develop individualized care plans is assigned to the entire care team, with the patient representing the most important member, the one who will perform the actions (Wagner, 1998). The patient is considered to be the only true expert of his illness, in his own cultural and social context, both from an organic and functional and emotional point of view. By paying close attention to "humanity", the bio-psychosocial model creates a wide network, in which there are a number of applicants and paid positions. If the exact aetiology is unknown, clear compensatory guidelines could be formulated, such as interdisciplinary guidelines, which could direct the interaction to individual factors, such as medical condition, physical ability and work tolerance, with the physical and psychological needs of the work in the context of individual psychological functioning and coping ability. In the biopsychosocial model, the patient is an active participant in the rehabilitation process, while health professionals simply facilitate this process: in this way, the rehabilitation objectives are more easily achieved (Schultz & Gatchel, 2005).

The biopsychosocial model considers individuals to be largely responsible for their own health, and health professionals are seen as valuable human resources to be drawn upon in conditions of need.

The biomedical model, on the other hand, teaches that the operator must heal the disease. In the biopsychosocial model, healing, when possible, is more desirable; however, in an era of chronic diseases, the chances of healing are less frequent. The process of treatment involves providing people with the means to deal with these aspects of the experience of the disease. Care attempts to create a context in the patient-operator relationship to give meaning to current experiences and to produce changes in other relationships, in order to strengthen the sense of control and the bonds. The transfer of attention from healing to treatment also requires other shifts. The professional no longer focuses mainly on the disease, but the goal becomes to optimize the general welfare and health promotion (Cigoli & Mariotti, 2002).

Within such a healthy paradigm, fundamental importance is attached to the quality of life of the individual. Revicki et al. (2000) define quality of life as a wide range of human experiences related to overall well-being. With reference to quality of life, health is defined as a subjective assessment of the impact of disease and treatments on the domains of physical, psychological, social and somatic functioning and well-being.

Life satisfaction is often measured within the same domains as quality of life, but with the distinction that this concept focuses on the individual perception of the difference between subjective reality and needs or desires (Börsbo, 2008).

Considering the person with disabilities as part of a quality of life project means giving them back their main status, which is first and foremost that of being a person, with their own identity and subjectivity; it means going beyond the labelling that places the person with disabilities within an undifferentiated category and offering them the opportunity to implement the potential and skills that characterize them. The quality of life of people with disabilities is influenced by their psychological-emotional, physical, material and social wellbeing, as well as by the possibility of using their own abilities and being able to express themselves in an environment in which social attitudes and values favour their integration and identity.

The new meanings of health and health promotion, understood as attention to the well-being and quality of life of the person, have ended up redefining the concept of disability.

Disability is no longer the prerogative of a group of well-characterized people, but can involve any human being, affected by a more or less serious (or more or less temporary) loss of health and placed in an unfavourable environmental context (Leonardi, 2012). The term "quality of life" focuses on the need to consider the person with a disability within a broader horizon, within which the whole life span is assessed as potentially evolutionary (WHO and World Bank, 2011).

According to WHO, the biopsychosocial model is the one that best represents the circular and no longer linear process of interventions in the field of disability and that helps to modify the conceptual framework of reference. There is a shift from a conception of disability as quantitative and measurable in statistical terms, to a consideration that looks rather at adaptive functioning, and therefore the need to always think in relation to a context. Disability is no longer a consequence of an illness, but a problem created by society in terms of the full integration of people within it. It is also necessary to support at all levels the promotion of rights and the active participation of citizens in the programming of interventions of general interest.

Most quality of life measurements pay marginal attention to organic and bodily functioning, while they focus more on the consequences of impairment at the level of personal activities and social roles (Wunderlich et al., 2002).

It is a relatively recently-acquired school of thought that the subject with a disability, after having passed the phase of the curative moment (diagnosis, therapy and intensive rehabilitation, etc.), needs a network of services to ensure his "care", i.e. that active and professionally qualified attention that allows him to face the daily life of his condition in the concrete perspective of reintegration into the dynamics of society.

The biopsychosocial model integrates the concepts of disease and disability of the medical model and the social model. In fact, illness and disability are considered both a problem that affects the person in his or her individuality, and a problem that affects society, which with its limitations and barriers prevents it from participating in community life. Disability is conceived from a systemic point of view, taking into account the multiple factors involved in a person's disability conditions: attention is focused not only on the biological factors, which determine the disease on a physical level, but also on the psychological factors, related to the individual's psychological conditions and reactions and strategies for dealing with his situation, and on the social factors, with reference to the external and community environment, which can act as facilitators (such as social support) or, on the contrary, in a disabling way, due to physical and cultural barriers. Therefore, the biopsychosocial approach does not focus only on the individual's biological problems or disabling environmental characteristics, but also on how people live in relation to their physical, psychological, historical and cultural context, and how such conditions can be improved by the concrete possibility of achieving a satisfactory life at a social and productive level (Leonardi, 2012).

It is, therefore, a shift in the focus of the analysis that moves with a global and holistic approach, in order to analyse three conditions: impairments related to body functions and structures, limitations related to activities, and restrictions related to participation.

From this perspective, rehabilitation interventions aim not only to improve cognitive and physical abilities, but also to formulate a comprehensive rehabilitation project that, taking into account contextual, personal and environmental factors, pursues the aim of improving the quality of life of that person both through the enhancement of residual skills and the improvement of the level of functioning, through interventions that act on the context.

In addition to individual treatment, the biopsychosocial model also provides a process of social action, which can make the person "skilled" within society, thus facilitating its process of integration and improvement of living conditions. Moreover, care practices must not remain separate from the existential context and outside the networks of relationships, but must harmonize care and the necessary resources, using as much as possible the natural contexts and bringing together different needs apparently distant.

Within the services for people with disabilities, paying attention to the social network can mean recognizing the complexity of interventions for the care and qualification/rehabilitation and paying attention not only to the places of intervention formally deputies, but also to the places where the path of life is concretely carried out. From this perspective, it is therefore essential not to keep care and qualification/rehabilitation separate from the context of life and to approach the person considering the totality of his health, psychological, social and moral needs, designing integrated paths to ensure not only the right to health and quality of relationships, but also the recognition of citizenship as a right to live, work, social participation, supporting mediation processes to increase dialogue and communication. It becomes essential to support the social network to be able to broaden as much as possible the relational contexts, to further develop the initiatives of support and collaboration between institutions, families and associations.

This approach to disability allows us to broaden and support the social context that sometimes supplants and sometimes strengthens the family context, experimenting with forms of integration between the formal system of care, made up of initiatives of specific services, to an informal system of help, formed by those initiatives that also make available the resources of the community.

The medical model considered as the only opportunity the professional help of medical staff towards the sick individual, while the social model considered fundamental an individual and collective responsibility; the biopsychosocial model combines both perspectives, considering fundamental the specialized care, to which it combines the importance of individual and collective responsibility, i.e. the society in which the individual lives, in improving the response to treatment.

Society must take on disability not as a sectoral issue, but as a structural issue of life and development. Inclusion is a process to be experienced in communities through inclusive development that involves the direct participation of the excluded (Griffo, 2012). It is therefore necessary to act both on the person with disabilities, making them better able to be “integrated” into the community, and on the social context, in order to make them more "inclusive". The training actions and interventions focused on empowerment are primarily interventions that aim to strengthen the power of choice on the part of individuals and this strengthening is not only aimed at a therapeutic-reparative character, but must also be understood in a political-emancipatory sense. A fundamental characteristic of this term denotes a constant and progressive growth of the potential of the individual, accompanied by a corresponding growth in autonomy and assumption of responsibility.

Only through cross-sectoral collaboration and an integrated approach can solutions be identified that reduce the disability of a population (Leonardi, 2012).

The bio-psychosocial model considers to be of fundamental importance not only health and welfare interventions, but also those related to the human rights of the person, which consider the individual with disabilities discriminated against by society and aim to include it, facilitating the expression of its capabilities and potential.

In this conception, disability is considered a condition from which to start facing difficulties, not an insurmountable limit to living an autonomous life. The value of human dignity plays a fundamental role in this approach, which considers non-discrimination, equal opportunities, the development of non-discrimination legislation and mainstreaming policies to be important.

Despite the indubitable cultural revolution and the many advantages brought about by the introduction of the biopsychosocial model, it has also received numerous criticisms, in particular on the lack of detailed specification of the interactions between systems and between the different levels and the overly difficult language.

The fact remains that the biopsychosocial model, unlike the other models, has managed to grasp the dynamic and reciprocal nature of the individual's interactions in its own environment, overcoming the cause-effect perspective, and considering for the first time in a holistic way the biomedical, psychological and socio-environmental aspects.

A person who experiences an alteration of the functional or structural levels of his body, is no longer defined as "disadvantaged" in a static and rigid sense, but, interacting with the environment, can live two conditions: a loss or limitation of their levels of activity and participation in life contexts, if the environment is hostile or indifferent because of barriers, or a good performance in activities and participation in life contexts, if the environment is characterized by facilitating elements. In these conditions, the adoption of an interdisciplinary strategy is of fundamental importance, which does not remain only theoretical but which is transformed into real practice. According to Cigoli & Mariotti (2002), it must not simply be a patchwork of guidelines or competences, which continue to proceed separately, but rather an articulation and integration of multiple points of view.

1.4 The social-oriented recovery vision for mental illness

A separate study and reflection should be devoted to social approaches to mental illness. Traditionally, the mental health scenario is extremely influenced by the medical model, where severe mental illnesses are observed as chronic. Instead of employing the traditional medical model which emphasizes on problems and failures in people with mental disabilities, the social-oriented *recovery*[2] vision is presented as it deserves special consideration (Thornton, 2010). In recent years, in the social approaches, the increasing attention to mental health and illness is for instance reflected in the establishment of the Social Perspectives Network (Tew, 2005; Tew et al., 2006; Beresford, 2002, 2004; Beresford et al., 2010), a coalition of service users/survivors, carers, policy makers, academics,

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[2] It is important to differentiate between ‘personal’ recovery and recovery in the sense used by doctors – sometimes called ‘clinical’ recovery. Clinical recovery is a psychiatric term involving the mitigation of symptoms, restoration of social functioning and a return to what is considered “normal”. In this contribution, the author refers to the personal recovery as described by William Anthony (1993) as “a deeply personal, unique process of changing one’s attitudes, values, feelings, goals, skills, and/or roles. It is a way of living a satisfying, hopeful and contributing life, even within the limitations caused by illness.”

students, and practitioners interested in how social factors both contribute to people becoming distressed, and play a crucial part in promoting people's *recovery*.

Globally, mental illness is one of the leading causes of disability and social exclusion (Lasalvia et al., 2013; GDB, 2016; GBD, 2018). People with mental illness suffer from limitations in social life and stigma that can also have implications for their ability to work (Scheid, 2005; Thornicroft, 2009; Williams, 2016).

Recent studies have also shown that in low- and middle-income countries people with mental illness have higher rates of stigmatisation, impairment of social functioning and unemployment compared to the general population (Semrau et al., 2015; Mutiso et al., 2018).

The stigmatisation of mental illness has a strong ancestry, as mentioned here in the first chapter, and from the earliest times, it has been connected with deviations from the "normal" and from "normative" prescriptions of conventional states of being for self and others.

It manifests itself much more in high-income countries, through both overt and covert actions (Williams, et al. 2016; Hanisch et al., 2017) and is essentially divided into two types.

It is internal (self-stigma) when sick people believe they are worth less than others and are ashamed of themselves. Internal prejudices also arise from experiences of helplessness, despair, loneliness and segregation experienced after the onset of the disease (Cavelti et al., 2012; Hofman, 2016; Vrbova et al., 2017; Isaksson et al., 2017). On the contrary, stigmatisation is external when others impose it, i.e. when society reinforces the experience of inferiority perceived by the sick, when economic, cultural and political ideologies keep these people in a state of inferiority, not recognizing any chance of improvement (Hofman, 2016).

Although refuted by numerous scientific evidence, the prejudices remain even among health workers, as several studies have highlighted (Pinfold et al., 2005; Nordt et al., 2006; Szeto & Dobson, 2010; Gabbidon et al., 2013; Hansson et al., 2013; Morgado et al., 2013; Eissa et al., 2020).

Moreover, a pattern of gender discrimination, with women encountering superior rates of anticipated discrimination than men, was highlighted by researchers (Farrelly et al., 2014; Koschorke et al., 2014).

Besides, people with (severe) mental illness experience high levels of suffering that can often be exacerbated by coexisting physical health problems. These disadvantages have a substantial impact on social participation and consequently affect human rights. According to Mascayano et al. (2015), addressing this problem is important because it represents a still neglected social issue, especially in low-income countries with little research on mental illness.

The rehabilitation process must consider both internal and external stigma because only a comprehensive view of this problem can lead to its overcoming.

The relationship between disease and environment, the quality of the relationship between the patient and the context in which they live, as well as the perception that the patient has of themselves and that others have of them are all elements that studies have highlighted as factors capable to affect both the course and the outcome of the disease (Harding et al., 1992; Tew et al. 2012).

These perspectives brought essential consequences: first of all, the shift of the focus from the disorder to the person (principle of personhood), considered capable of recovering personnel energies to improve basic functional levels (Moxley & Mowbray, 1994; Farkas et al., 1997; Carozza, 2006) and of elaborating and adopting new behaviours to lead a satisfying and productive life, despite the continuing limitations of the disease (Anthony, 1993). "*There is an important aspect that medicine is losing sight of: the subjectivity of the sick person, seen as an object of treatment more and more*", this wrote Franca Ongaro Basaglia (2012) in the years of "deinstitutionalisation of the disease", as well as of the places that contained and objectified the sick persons. "*If healing takes place, it is the healing of a body unaware of itself, of its needs, of its illnesses and of its health, deprived of any possibility of participating and fighting for it [...]. A different cure cannot that to move in this direction, by offering a therapy as a stimulus to a re-appropriation of the self [...]. The only premise for a possible cure for human being's illness is a different, subjective, participatory relationship in the life and, therefore, in the illness"* "(p. 27).

Thanks to the development of treatments aimed at social and occupational reintegration and also thanks to the contribution of critical longitudinal studies (Huber et al., 1980; Ciompi & Muller, 1984; Harding et al., 1987; De Girolamo, 1996), the approach to mental illness has changed. An important contribution has also been made when, following the recognition of mental illness as a disability, all the rights and responsibilities of community membership guaranteed to people with physical disabilities have been extended to people with these illnesses.

Several studies found out that the trajectories of mental illness are heterogeneous and have different courses and outcomes (Leucht & Lasser, 2006; Zipursky, 2014; Emsley et al., 2011; Van Eck et Al., 2017) and that *recovery* is a much more common phenomenon than initially thought (Vita & Barlati, 2018).

This longitudinal research constituted the scientific foundation for the birth of the concept of *recovery*, first appeared around the 1980s in the testimonies of patients who "recovered" (Anthony, 1993).

It should not be forgotten that fundamental was also the contribution offered by the spread of socio-political movements in defence of the rights of people with mental disabilities and the enactment of regulations aimed at overcoming their marginalisation and neglect (for example, in Italy, the Basaglia law of 1978 provided for the closure of asylums, again giving dignity and value to the patients who were locked up there).

The message of social recovery lies in need to include the social context in understanding, analysis and response to people's mental health difficulties (Ryan et al. 2012).

Although the word “healing” could represent the highest aspiration of those, who suffer, whatever the disease, this can be misleading in the field of mental health, mainly when used biologically. It is a complex, non-linear and multidimensional process. And above all, it is an individual construct, a personal issue, and therefore, in this sense, a highly subjective concept, both in its constitutive elements and in its explanatory models, where the person is the determining factor.

The concept of *recovery* has been defined and translated in many ways, but in no sense coincides with the disappearance of the disease (restitutio ad integrum), rather it reflects the development of skills lost with the disease and the recovery of an active and satisfactory role within society (Warner, 2004; Carozza, 2006; Tew, 2013).

Patricia Deegan (1988) referred to the term *recovery* for the first time as a journey rather than a destination, pointing out that it is about the process and not necessarily the outcome. The author described it as: “[…] *the lived or real life experience of people as they accept and overcome the challenge of the disability… they experience themselves as recovering a new sense of self and of purpose within and beyond the limits of the disability*"(p.11).

One of its most common definitions is the following by Anthony (1993): “*a deeply personal, unique process of changing one’s attitudes, values, feelings, goals, skills and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with limitations caused by the illness. Recovery involves the development of new meaning and purpose in one’s life as one grows beyond the catastrophic effects of mental illness. Recovery from mental illness involves much more than recovery from the illness itself”(p.17)*.

Moreover, for Liberman and Kopelowicz (2005), “the absence of symptoms is not a proxy for a return to wellness. Therefore, a definition of recovery from any serious mental illness should include participation in work or school and in social, family, and recreational activities as well as achieving symptom remission." (p. 739). Recovery is intended then "a process of change through which the individual improves their health and wellness, live a self-directed life, and strives to reach their full potential" (SAMHSA, 2012, p. 3).

However, for all of the cited scholars, the central meaning is *to live a meaningful life in the community and strive to achieve your potentials*.

As highlighted, among others, by Canadian psychiatrist and philosopher Abraham Rudnick (2012, preface), “*It is only in the past 20 years that the concept of 'recovery' from mental health has been more widely considered and researched. Before then, it was generally considered that 'stability' was* *the best that anyone suffering from a mental disorder could hope for. But now it is recognised that, throughout their mental illness, many patients develop new beliefs, feelings, values, attitudes, and ways of dealing with their disorder. The notion of recovery from mental illness is thus rapidly being accepted and is inserting more hope into mainstream psychiatry and other parts of the mental health care system around the world. Such recovery - particularly in relation to serious mental illness such as schizophrenia - is often not about cure and can mean different things to different people. For example, it can mean symptom alleviation, ability to work, or the striving toward mental well-being (with or without symptoms)*".

Figure 10: The concept of recovery

Source: own elaboration based on the publication of the Australian Health Ministers' Advisory Council (2013). A national framework for recovery-oriented mental health services: Policy and theory. Online ISBN: 978-1-74186-013-9

Since some years, the paradigm of *recovery* has been extraordinarily widespread in the languages of health policy, service practices and research in the field of mental health. Alongside the biomedical meaning, in terms of clinical outcome, result of treatment and remission of symptoms, we speak of *"personal" recovery*, i.e. the "awakening" of a positive identity, in which the mental disorder is considered as only one aspect of the person as a whole. Mental illnesses cannot be reduced to their symptomatologic manifestations exclusively; they cannot remain confined to the biomedical domain and be the object of a technological approach, waiting for the supposed "chemical imbalance" to be repaired. As Franco Basaglia[3] framed already, mental illness is experienced by the subject. It manifests itself in the human environment above all through its "double", i.e. as a profound and catastrophic erosion of a sense of self, dignity and self-efficacy. It must be considered that no one, healthy or sick, can face and overcome the incessant demands and challenges that life poses if they do not feel they can bring back choices, decisions, responsibilities, to an internal, personal, unique dimension, reinforced by own choices. Though with the best intentions, it is precisely this exercise of self-determination, which is subtracted or compromised in the presence of psychic discomfort.

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[3] Franco Basaglia (Italian; 11 March 1924 – 29 August 1980) was an Italian psychiatrist, neurologist, professor who proposed the dismantling of psychiatric hospitals, pioneer of the modern concept of mental health, Italian psychiatry reformer, charismatic leader in Italian psychiatry, figurehead and founder of Democratic Psychiatry architect, and principal proponent of Law 180 which abolished mental hospitals in Italy. He is considered to be the most influential Italian psychiatrist of the 20th century.

Therefore, first of all *recovery* represents the attempt to give back this possibility to the subject. And in this sense, healing processes cannot be understood only as a struggle against the symptoms of the illness, but they must be supported by the effort to restore control over one's own life.

Recovery can be understood as a multidimensional concept, since it is an individual path, referring to the way a person manages their disorder, living independently within society.

What is meant by *recovery* in the field of mental health is, therefore, a profoundly and authentically personal process, a "recovery of self", a new assumption of responsibility to oneself, illness, society. The redefinition of oneself as a person, i.e. the development of a new perception of self and identity, implies, in turn, the redefinition of the mental problem as an integral part of one's life, therefore the acceptance of illness. In other words, recovery is a re-appropriation of one's life beyond illness, notwithstanding the illness, that means despite the suffering and limitations caused by psychic discomfort.

The focus on the social model of health in the field of mental health allows us to grasp important social innovations, aimed at particularly vulnerable members of society.

The application of the social model of health to the field of mental health led to an understanding of mental illness as not only oriented towards clinical deficits but also built on two strengths: abilities and desires of the individual. It is therefore based on a commitment to recovery and care, so that individuals can live at the best their lives, as members of a community.

The focus on the social model of mental health and *recovery* embraces the issues of integration and inclusion because it involves at the same time professionals, institutions, people with mental disabilities and the whole community. In recovery-oriented practices, then, it plays a fundamental role the "shared" dimension with family members, friends, operators or peers on the one hand, and on the other hand, the construction of projects with citizens, oriented to: the fight against external and internal stigma, the inclusion in the local community, and the promotion of the subjectivity of citizens with mental distress. Conversely, the recognition of the protagonism of the sick people and of experiential knowledge, as precious as the professional one, involves an important redefinition of the operative model itself by the side of professionals.

Two approaches are very important for the implementation of Recovery: training of social skills (Liberman, et al., 1998; Bellack, et al., 2003; Granholm, et al., 2005; Liberman & Kopelowicz, 2009; Galderesi, et al., 2010; Kalil, 2012) and stigma reduction.

The first is aimed at strengthening individual, cognitive and emotional skills (e.g., problem-solving, decision making, emotion and stress management), as well as relational and psychosocial skills (e.g., interpersonal conflict management, effective communication, correct expression of desires and needs), generally lacking in people with psychiatric disabilities. The theme of skills fits and assumes importance with the development of the Bio-Psycho-Social Model oriented to the study of the person as a complex system. Thus, from a passive education, without motivation and proposing pre-packaged solutions, there has been an approach to education based on empowerment and assumption of responsibility by the individual.

To reduce stigma, it is essential to fight and overcome the internal and external prejudices that are at the origin of the problems experienced by people with mental illness, such as lack of work, inability to live independently and to manage the disease, weak or absent social relationships.

Many theories attempt to operationalise the concept of *recovery*. It is crucial to conceptualise key theoretical perspectives on the recovery process and the creation of recovery-oriented environments using the perspective of people who have experienced it.

In recent years, mental health services and programs worldwide have adopted different models for helping staff to understand personal recovery practises and how they might support personal recovery. There are many similarities among the various models, although each one also has unique elements. Everyone agrees that mental health recovery is a process rather than a destination. It is not possible to identify the "best" model in terms of its explanatory power and operational efficacy, because models can help guide ways of working but do not have to stifle the creativity and flexibility (Glover, 2012).

HOPE[4] is a simple model of recovery developed by Penumbra, an innovative Scottish mental health charity that supports people by applying a person-centred model of *recovery.* HOPE stands for home (somewhere that is safe and comfortable), opportunity (education, leisure, recreation, volunteering or working, etc.), people (friends, confidantes and supporters, etc.) and empowerment (always being involved in any decisions that affect own life). As Penumbra states it: "These for us are the fundamental aspects of day to day life that enable people to regain confidence and to move forward to their desired future" (Penumbra).

A quite recent review of *recovery* practices in mental health in the United Kingdom identified five processes (CHIME framework[5]) as central to recovery (Nelson et al., 2001; Mancini et al., 2007; Leamy et al., 2011; Tew et al., 2012): Connectedness (peer support, support from others, etc.); Hope and optimism about the future; Identity; Meaning in life (Meaning of mental illness experiences, Spirituality, Quality of life, etc.); Empowerment (personal responsibility, control over life, self-efficacy, etc.). According to Tew and colleagues (2012): "Recovery may involve a journey both of personal change and of social (re)engagement - which highlights the importance of creating accepting and enabling social environments within which recovery may be supported" (p.2). This recovery model values the importance of the social within multidisciplinary mental health practice (Ramon, 2009) and the crucial relevance for mutual support approaches.

The Psychological Recovery Model captures both the internal processes (the components in CHIME) and the stages of progression to recovery (Andrersen et al., 2003, 2006, 2011). This model was described as falling between the rehabilitative model (mental illness is incurable but manageable) and the empowerment model (mental illness can be overcome through understanding, optimism and empowerment). It identifies four psychological processes to recovery (hope, identity, meaning, responsibility/control) over five steps of recovery (moratorium, awareness, preparation, rebuilding and growth).

Similar to the previous models, Glover (2012) introduces the Self-Righting Star Model for emphasizing personal responsibility and control. Glover describes the Self-Righting Framework as "a simple five point structure that attempts to articulate the efforts that individuals undertake in their processes of self-righting/recovery". It is organised into five steps (passive to active, hopelessness to hope, others' control to personal control, alienation to discovery and disconnectedness to connectedness).

The Socioecological Model indicates that mutual support works as a driver of change in seven ways (correcting attachment difficulties, exhibiting altruism, developing socialisation, using imitation and adaptive learning, maintaining group cohesiveness and suffering (White & Madara, 2002; Finn, 2007; Loat, 2011).

The Ladder of Change Model presents an explicit model of the steps that individuals need to take to successfully make the journey to mental health recovery, as active agents in their own lives (stuck, accepting help, believing, learning and self-reliance). Therefore, programs or services are required to create change by engaging the motivation, understanding, beliefs and skills of the individuals (MacKeith, 2011).

Empowerment, choice and recovery become the goals and mutual support the channel for the Critical Learning Model that allows individuals to re-interpret the external medicalisation of their mental problems and internalised stigma. Mental health services and supports often focus on figuring out "what's wrong" and "fixing" it. In other words, people begin to understand change and learning not as an individual process but rather one where they continuously construct knowledge from actions and reactions, conversations and the on-going building of consensus. Rather than thinking about personal symptom reduction, they are talking about social change. The new version of "help" offers people the possibility of establishing true mutual empowerment (MacNeil & Mead, 2003).

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[4] For further information, please see: http://www.penumbra.org.uk/how-we-will-work-with-you/ (accessed May 2020).

[5] For more in-depth information, visit the page here: https://www.therecoveryplace.co.uk/chime-framework/ (accessed May 2020).

The usefulness of Stress Vulnerability Coping Model lies in the identification of the risk and protective factors; that is, the factors that either make it more likely that mental illness symptoms will emerge and those that inhibit the emergence of symptoms. Originally developed to explain the onset of schizophrenia, this model is now used to understand many mental severe disorders such as bi-polar disorder, depression and psychosis (Zubin & Spring, 1977; Goh & Agius, 2010).

The evidence framework emerging from this review offers numerous stimuli on where social inputs can make a difference to the recovery of people with mental illness, with a primary emphasis on empowerment, relationships and social inclusion.

Because there is a strong link between the recovery process and social inclusion (i.e. involvement in society through work, education, culture and leisure activities), services have a key role which is to support people to regain their place in the communities where they live and enable them to participate in activities and opportunities (Levin, 2004; Anghel, Ramon, 2009; Tew, 2011; Slade, 2014).

Taking a more proactive role in enabling people to realise their social aspirations and address the potentially negative impact of stigmatisation and discrimination, shifts the focus from the individual towards a dual-track approach, that involves not only service users, but also families, social systems and communities.

Unfortunately, however, in many countries, the responses still offered by traditional mental health policies of most services still appear unsatisfactory, unbalanced on the hospital-residential side instead of on the social inclusion side, and far from enhancing the subjectivity of people with mental disabilities.

1.5 Conclusion

Disability, disablement, and impairment are universal. They know no national, societal, or cultural confines. Anyone can become disabled—regardless of age, class, race, or gender—through birth, accident, illness, war, poverty, or advanced age. In some countries disability is a condition of everyday life, such that disability and impairment are not simply the experience of a minority group but rather the normal condition of humanity. From that point of view, distinctions between disabled and nondisabled persons become difficult. When all persons are included, whether because they are frail, limited, or mortal, there is no distinct identity.

The previous paragraphs have outlined the main models of disability that continue to have an impact on the way people perceive people with disabilities. They are not the only models of disability that can be found in our time, but they are today the most dominant models of disability.

Disability models are tools to define disability and ultimately to provide a basis for governments and society to develop strategies to meet the needs of people with disabilities.

They are often treated with scepticism because they are thought not to reflect a real world, are often incomplete and encourage limited thinking, and rarely offer detailed guidance on what to do. They are essentially designed by people who turn to other people and provide an understanding of the attitudes, conceptions and prejudices of the former and their impact on the latter.

However, they are a useful framework for understanding disability issues, and also the perspective of those who create and apply models.

The models are influenced by two fundamental philosophies: the first perceives people with disabilities as people who depend on society. This can result in paternalism, segregation and discrimination. The second recognizes the disabled as customers of what the society has to offer.

This leads to choice, emancipation, equality of human rights, integration and inclusion.

We do not have to look at the models as a series of exclusive options.

Their development and popularity provides us with a constantly evolving historical-geographical-cultural picture of attitudes towards disability. Models change as societies change and the influence of the most recent social theories such as the feminism, the post-modernism and the post-structuralism must be taken into account when identifying other models.

Understanding disability culture offers several possibilities for future thinking, research studies, and practices. Those possibilities embrace the study of changes in the way disability and difference are defined and understood, the changes in thinking about disability identity in relation to society as a whole as well as in relation to disability movements, and the changes in the ways that people think about and develop supportive communities.

References

Andresen, R, Oades, LG and Caputi, P (2003). The experience of recovery from schizophrenia: towards an empirically validated stage model. Australia and New Zealand Journal of Psychiatry. Vol. 37. Pp 586-594.

Andresen, R, Oades, LG and Caputi, P (2011). Psychological recovery: beyond mental illness. West Sussex, UK: Wiley-Blackwell.

Andresen, R., Caputi, P., & Oades, L. (2006). The Stages of Recovery Instrument: Development of a measure of recovery from serious mental illness. Australian & New Zealand Journal of Psychiatry, Vol. 40. Pp. 972-980.

Anghel, R., Ramon, S. (2009) Service Users and carers' involvement in social work education: lessons from an English case study. European Journal of Social work, 12,2, 185-200.

Anthony WA. Recovery from mental illness: the guiding vision of the mental health system in the 1990s. Innovations and Research 1993; 2: 17–24.

Anthony, W.A. (1993). Recovery from mental illness: The guiding vision of the mental health service system in the 1990 s. Psichosocial Rehabilitation Journal, 16, 11-23.

Armstrong, S., Noble, M. & Rosenbaum, P. (2006). Deconstructing barriers: The promise of socio-economic rights for people with disabilities in Canada, in R. Howard-Hassmann & C. Welch (eds.), Economic rights in Canada and the United States, pp. 149–168, University of Pennsylvania Press, Philadelphia, PA.

Aylward, M., Cohen, D. & Sawney, P. (2013). Support, rehabilitation, and interventions in restoring fitness for work', in K. Palmer, I. Brown & J. Hobson (eds.), Fitness for work: The medical aspects, 5th edn., pp. 69–87, Oxford University Press, Oxford.

Barnes, C. (1992). Disabling Imagery and the Media: An Exploration of Media Representations of Disabled People. Belper: The British Council of Organisations of Disabled People.

Barnes, C. (2012). Re-thinking Disability, Work and Welfare. Sociology Compass. 6. 10.1111/j.1751-9020.2012.00464.x.

Barnes, C., Mercer, G. & Shakespeare, T. (2010). The social model of disability, in A. Giddens & P. Sutton (eds.), Sociology: Introductory readings, 3rd edn., pp. 161–166, Polity Press, Cambridge.

Basaglia Ongaro, F (2012). SALUTE / MALATTIA. Le parole della medicina. Einaudi

Bellack, A., Mueser, K. T., Gingerich, S., Agresta, J. (2003). Social Skills Training per il trattamento della schizofrenia. Torino: Centro Scientifico Editore.

Beresford P, Nettle M, Perring R (2010) Towards the social model of madness and distress? Exploring what service users say, Joseph Rowntree Foundation.

Beresford, P. (2002) 'Thinking about "mental health": towards a social model', Journal of Mental Health, Editorial, Vol. 11, No. 6, December, pp. 581–84.

Beresford, P. (2004) 'Madness, distress, research and a social model', in C. Barnes and G. Mercer (eds), Implementing the Social Model of Disability: Theory and Research. Leeds: Disability Press, pp. 208–22.

Berghs, M., Atkin K, Graham H, Hatton C, and Thomas C (2016). Chapter 3 Scoping models and theories of disability. In Implications for Public Health Research of Models and Theories of

Disability: A Scoping Study and Evidence Synthesis. Southampton: NIHR Journals Library, Public Health Research, No. 4.8.

Borioli, J., Laub, R. (2005). Le handicap en territoires : le cas des personnes en fauteuil roulant à Lausanne. Mémoire de licence ès Lettres, Université de Lausanne, Suisse.Borrell-Carriò et al., 2004.

Börsbo, 2008 Doctoral thesis: Relationships between Psychological Factors, Disability, Quality of Life and Health in Chronic Pain Disorders. Linköping University, Department of Clinical and Experimental Medicine, Rehabilitation Medicine. Linköping University, Faculty of Health Sciences.ORCID iD: 0000-0002-4385-428X.

Braddock, D., & Parish, S. (2001). Disability history from antiquity to the Americans with Disabilities Act. In G. L. Albrecht, K. D. Seelman, & M. Bury (Eds.), Handbook of disability studies (pp. 11-68). Thousand Oaks, CA: Sage.

Braibanti P. (2002). Pensare la salute: orizzonti e nodi critici della Psicologia della Salute, Franco Angeli, Milano.

Brewer, E., Brueggemann, B., Hetrick, N. & Yergeau, M., 2012, ‘Introduction, background, and history’, in B. Brueggemann (ed.), Arts and humanities, pp. 1–62, Sage, Thousand Oaks, CA.

Carlson, L., (2010). The faces of intellectual disability, Indiana University Press, Bloomington, IN.

Carozza, P. (2006). Principi di riabilitazione psichiatrica. Milano: FrancoAngeli.

Carozza, P. (2006). Principi di riabilitazione psichiatrica. Milano: FrancoAngeli.

Cassel, J. (1964). Social science theory as a source of hypotheses in epidemiological research. American Journal of Public Health, 54, 1482–1488. doi:10.2105/AJPH.54.9.1482.

Cavelti, M., Kvrgic, S., Beck, E.M., Rüsch, N., & Vauth, R. (2012). Self-stigma and its relationship with insight, demoralization, and clinical outcome among people with schizophrenia spectrum disorders. Comprehensive Psychiatry, 53(5), 468-479

Cigoli V., Mariotti M. (2002), Il medico, la famiglia e la comunità. L’approccio biopsicosociale alla salute e alla malattia. Franco Angeli, Milano;

Ciompi, L., Muller, C. (1984). The life course and aging in schizophrenia: A catamnestic longitudinal study into advanced age, by E. Forstberg for the Vermont Longitudinal Research Project.

Covelli, A.(2016).Verso una cultura dell’inclusione. Rappresentazioni mediali della disabilità. Roma: Aracne.

Creamer, D., 2009, Disability and Christian theology: Embodied limits and constructive possibilities, Oxford University Press, Oxford.

D’Alessio, S., 2011, Inclusive education in Italy: A critical analysis of the policy of *integrazione scolastica*, Sense Publishers, Rotterdam.

Darling, R.B. & Heckert, D.A. (2010). Orientations toward disability: Differences over the lifecourse’, International Journal of Disability, Development and Education 57(2), 131–143.

De Girolamo, G. (1996). WHO Studies on Schizophrenia: An overview of the results and their implications for the understanding of the disorder, The Psychotherapy Patient,9 (3-4), 213-223.

Deegan, P.E. (1988). Recovery: The lived experience of rehabilitation. Psychosocial Rehabilitation Journal, 11(4), 11-19.

Deep P. (1999). Biological and Biopsychosocial Models of Health and Disease in Dentistry. Journal of the Canadian Dental Association, vol. 65, n. 9, pp. 496 497.

Degener, T. (2017). A new human rights model of disability’, in V. Della Fina, R. Cera & G. Palmisano (eds.), The United Nations convention on the rights of persons with disabilities: A commentary, pp. 41–60, Springer, Cham, Switzerland.

Eissa, A.M., Elhabiby, M.M., El Serafi, D. et al. Investigating stigma attitudes towards people with mental illness among residents and house officers: an Egyptian study. Middle East Curr Psychiatry 27, 18 (2020). https://doi.org/10.1186/s43045-020-0019-2.

Emily A. Hennessy (2017) Recovery capital: a systematic review of the literature, Addiction Research & Theory, 25:5, 349-360, DOI: 10.1080/16066359.2017.1297990

Emsley, R., Chiliza, B., Asmal.L, LehloenyaK. (2011). The concepts of remission and recovery in schizophrenia. CurrOpinPsychiatry, 24:114 – 121.

Engel G.L. (1977). The need for a new medical model. A challenge for biomedicine. Traduzione a cura di Clerici C.A., Albasi C., Verrastro S., (2006), AeR Abilitazione e Riabilitazione, Anno 15, n. 1, pp. 13-32.

Engel G.L. (1997). From biomedical to biopsychosocial. Being scientific in the human domain. Psychosomatics, vol. 38, n. 6, pp. 521-528.

Farkas, M., Gagne, C., Anthony, W. (1997). Rehabilitation and recovery: A paradigm for the new millennium, Boston, MA: Boston University, Center for Psychiatric Rehabilitation.

Farrelly S, Clement S, Gabbidon J, Jeffery D, Dockery L, Lassman F, et al. Anticipated and experienced discrimination amongst people with schizophrenia, bipolar disorder and major depressive disorder: a cross sectional study. BMC psychiatry. (2014) 14:157. doi: 10.1186/1471-244X-14-157.

Fava G.A., Sonino N. (2008). The Biopsychosocial Model Thirty Years Later. Psychotherapy and Psychosomatics, vol. 77, n.1, pp. 1–2.

Finkelstein, Vic. (1993). Disability: A social challenge or an administrative responsibility? In Disabling Barriers, Enabling Environments. Edited by John Swain, Vic Finkelstein, Sally French and Mike Oliver. London: Sage.

Finkelstein, Vic. (2001). A Personal Journey into Disability Politics. Presentation Held in Independent Living Institute Library Collection. Available online: www.independentliving.org/docs3/finkelstein01a.html.

Finn, L, Sparrow, N and Bishop, B (2007). Mutual help groups: an important gateway to wellbeing and mental health. Australian Health Review. Vol. 31 (2). Pp. 246-55.

Folgheraiter F. (1998), Teoria e metodologia del servizio sociale. La prospettiva di rete, Franco Angeli, Milano.

Fougeyrollas P. & F. Charrier (2013). Modèle du Processus de production du handicap. EMC. Kinésithérapie – Médecine physique – Réadaptation. 9(3) : 1-8.

Fougeyrollas, P. (2001). Le processus de production du handicap : l'expérience québecoise. In R. de Riedmatten (Ed.), Une nouvelle approche de la différence : comment repenser le « handicap » (pp.101-122). Genève : Médecine et Hygiène.

Fougeyrollas, P. (2010). La funambule, le fil et la toile: transformations réciproques du sens du handicap. Presses de l'Université Laval Québec.

Fougeyrollas, P., Normand Boucher, Geoffrey Edwards, Yan Grenier and Luc Noreau (2019). The Disability Creation Process Model: A Comprehensive Explanation of Disabling Situations as a Guide to Developing Policy and Service Programs. Scandinavian Journal of Disability Research, 21(1), 25–37. DOI: https://doi.org/10.16993/sjdr.62.

Fougeyrollas, P., and Yan Grenier. 2018. Monitoring Disability Policies and Legislation towards Effective Exercise of Rights to Equality and Inclusive Access for Persons with Disabilities: The Case of the Quebec Model. Societies 8(2): 41. DOI: https://doi.org/10.3390/soc8020041.

Fougeyrollas, P., Noreau, L., Bergeron, H., Cloutier, R., Dion, S., St-Michel, G. (1998). Social consequences of long term impairments and disabilities: Conceptual approach and assessment of handicap. International journal of rehabilitation research. Internationale Zeitschrift für Rehabilitationsforschung. Revue internationale de recherches de réadaptation. 21. 127-41. 10.1097/00004356-199806000-00002.

Frankel R.M., Quill T.E., McDaniel S.H. (2003). Introduction to the Biopsychosocial Approach. In “The biopsychosocial approach: past, present, and future”, Boydell & Brewer, Rochester, New York.

Fraser, N. (2003). Rethinking recognition: Overcoming displacements and reification in cultural politics, in B. Hobson (ed.), Recognition struggles and social movements, pp. 21–34, Cambridge University Press, Cambridge.

Gabbidon J, Clement S, Nieuwenhuizen AV et al (2013) Mental illness: clinicians’ attitudes (MICA) scale. Psychometric properties of a version for students and professionals in any healthcare discipline. Psychiatry Res 205:81–87.

Galderesi, S., Piegari, G., Mucci, A.,Acerra, A., Luvciano, L., Rabasca, A. F., Santucci, F., Valente, A., Volpe, M., Mastantuono, P., Maj, M. (2010). Social Skills and neurocognitive individualized training in schizophrenia comparison with structured leisure activities, Eur Arch Psychiatry Clin Neurosci 260:305-315.

Giddens, A. (2006). Sociology, Polity, Cambridge.

Global Burden of Disease - GBD (2016). Global, regional, and national incidence, prevalence, and years lived with disability for 310 diseases and injuries, 1990–2015: a systematic analysis for the Global Burden of Disease Study 2015. Lancet. (2016) 388:1545–602. doi: 10.1016/S0140-6736(16)31678-6).

Global Burden of Disease - GBD (2018). Disease and Injury Incidence and Prevalence Collaborators. Global, regional, and national incidence, prevalence, and years lived with disability for 354 diseases and injuries for 195 countries and territories, 1990–2017: a systematic analysis for the Global Burden of Disease Study 2017. The Lancet. 8 Nov 2018;392:1789–858. doi: http://dx.doi.org/10.1016/S0140-6736(18)32279-7.

Glover, H (2012). Recovery, Life Long Learning, Social Inclusion and Empowerment: Is a new paradigm emerging? In P. Ryan, S Ramon and T Greacon. Empowerment, lifelonglearning and recovery in mental health: towards a new paradigm. Palgrave Publishers.

Goerdt, A. (1984). Physical Disability in Barbados: A Cultural Perspective. Ann Arbor: University Microfilms.

Goh, C and Agius, M (2010). The Stress-Vulnerability Model: How Does Stress Impact on Mental Illness at the Level of the Brain and What are the Consequences? Psychiatria Danubina. Vol. 22 (2). Pp 198-202.

Granholm, E., et al. (2005). A Randomized, Controlled Trial of Cognitive Behavioral Social Skills Training for Middle-Aged and Older Outpatients With Chronic Schizophrenia, Am J Psychiatry,162:3,520-529.

Griffo G. (2012). Persone con disabilità e diritti umani, in Th. Casadei (a cura di), Diritti umani e

Hanisch SE, Wrynne C, Weigl M. (2017). Perceived and actual barriers to work for people with mental illness. J Vocat Rehabil. (2017) 46:19–30. doi: 10.3233/JVR-160839.

Hansson, L., Jormfeldt, H., Svedberg, P., & Svensson, B. (2013). Mental health professionals’ attitudes towards people with mental illness: Do they differ from attitudes held by people with mental illness? International Journal of Social Psychiatry, 59(1), 48–54. https://doi.org/10.1177/0020764011423176.

Harding, C.M., Brooks, G.W., Ashikaga, T., Strauss, J.S., Breier, A. (1987). The Vermont longitudinal study of person with severe mental illness: methodology, study Sample and overall status 32 years later, American Journal of Psychiatry, 6, 718- 726.

Harding, C.M., Zubin, J., Strauss, J.S. (1992). Chronicity in Schizophrenia: Revisited, British Journal of Psychiatric, 161, 27-37.

Higginbotham, P. (2018). The Workhouse. Available online: http://www.workhouses.org.uk.

Hofman, G.D. (2016). The Burden of Mental Illness Beyond Clinical Symptoms: Impact of Stigma on the Onset and Course of Schizophrenia Spectrum Disorders. American Journal ofPsychiatryResidents’ Journal, 11(04), 5-7.

Holcomb, T. (2013). Introduction to American deaf culture, Oxford University Press, New York.

Huber, G., Gross, G., Schuttler, R., Linz, M. (1980). Longitudinal studies of schizophrenic patients, Schizoph Bull, 6(4): 592-605.

Hunt, P. (1966). A critical condition. In P. Hunt (ed.), Stigma: The Experience of Disability, London: Geoffrey Chapman, 145-59.

Isaksson A, Corker E, Cotney J, Hamilton S, Pinfold V, Rose D, et al. Coping with stigma and discrimination: evidence from mental health service users in England. Epidemiol Psychiatr Sci. (2017) 27:577–88. doi: 10.1017/S204579601700021X.

Jordan, B. (2008). Welfare and well-being, Policy Press, Bristol.

Junior, N. & Schipper, J. (2013). Disability studies and the Bible', in S. McKenzie & J. Kaltner (eds.), New meanings for ancient texts: Recent approaches to biblical criticisms and their applications, pp. 21–37, Westminster John Knox Press, Louisville, KY.

Kalil, A. (2012). A Community Based Treatment: Impact of Social Skills training Program on Improving Social Skills among Schizophrenic Patients. World Applied Sciences Journal 18 (3): 370-378.

Kasser, S. & Lytle, R. (2005). Inclusive physical activity, Human Kinetics, Champaign, IL.

Koschorke M, Padmavati R, Kumar S, Cohen A, Weiss HA, Chatterjee S, et al. Experiences of stigma and discrimination of people with schizophrenia in India. Soc Sci Med. (2014) 123:149–59. doi: 10.1016/j.socscimed.2014.10.035.

Lasalvia A, Zoppei S, Van Bortel T, Bonetto C, Cristofalo D, Wahlbeck K, et al. (2013). Global pattern of experienced and anticipated discrimination reported by people with major depressive disorder: a cross-sectional survey. Lancet. (2013) 381:55–62. doi: 10.1016/S0140-6736(12)61379-8.

Leamy M, Bird V, Le Boutillier C, Williams J, Slade M A (2011). Conceptual framework for personal recovery in mental health: systematic review and narrative synthesis. British Journal of Psychiatry. Vol. 199 (6). Pp 445-452 http://bjp.rcpsych.org/content/199/6/445.long.

Leonardi M. (2010). Nuovi paradigmi della definizione di salute e disabilità. La classificazione ICF e la Convenzione ONU dei diritti delle persone con disabilità, in A. Pessina (a cura di), Paradoxa. Etica della condizione umana, Vita e Pensiero, Milano 2010, pp. 11-35.

Leucht S., Lasser R. (2006). The concepts of remission and recovery in Schizophrenia, Pharmacopsychiatry, 39 (05), 161-170.

Levin, E. (2004) Involving service users and careers in social work education. London: Social Care Institute for Excellence.

Liberman, R.P., Kopelowicz, A. (2009). Training Skills for illness, self-management in the rehabilitation of schizophrenia. A Family-assisted Program for latinos in California. Salud Mental,31:93-105.

Liberman, R.P., Wallace, C. J., Blackwell, G., Kopelowicz, A., Vaccaro, J.V., Mintz, J. (1998). Skills Training Versus Psychosocial Occupational Therapy for Person Whit Persistent Schizophrenia, Am J Psychiatry,155:1087-1091.

Llewellyn, A., Agu, L. & Mercer, D. (2008). Sociology for social workers, Polity, Cambridge, UK.

Loat, M (2011). Mutual Support and Mental Health. London: Jessica Kingsley.

MacNeil C. & Mead S. (2003). Understanding What Useful Help Looks Like: The Standards of Peer Support. http:// akmhcweb.org/Articles/PeerSupport.pdf.

Mancini, M (2007).The role of self-efficacy in recovery from serious psychiatric disabilities. Qualitative Social Work. Vol. 6 (1). Pp 49-74.

Mascayano F, Armijo JE, Yang LH. Addressing stigma relating to mental illness in low-and middle-income countries. Front Psychiatry. (2015) 6:38. doi: 10.3389/fpsyt.2015.00038.

Mawson, M., 2013, ‘Subjectivity and embodied limits: Deborah Creamer’s disability and Christian theology’, Journal of Religion, Disability & Health 17(4), 409–417. https://doi.org/10.1080/15228967.2013.840962.

Mengheri M. (2003). Dalla prevenzione alla promozione della salute. Sentieri, Itinerari di psicopatologia-psicosomatica-psichiatria, vol. 3, n. 1-2, Edizioni ETS, Pisa.

Michalko, R. (2002). The difference that disability makes, Temple University Press, Philadelphia, PA.

Morgado P, Oliveira A, Machado D et al (2013) Stigmatizing attitudes towards mental ill patients among medical students and professionals. Eur Psychiatry 28:1.

Moxley, D.P., Mowbray, C. (1994). Consumers as providers: Forces and factor legitimizing prole innovation in psychiatric rehabilitation, in C. Mowbray, D. Moxley, C. Jasper e L. Howell (Eds.), Consumers as providers in psychiatric rehabilitation, Columbia, MD.

Mutiso V, Pike K, Musyimi C, Rebello T, Tele A, Gitonga I, et al. (2018). Feasibility of WHO mhGAP-intervention guide in reducing experienced discrimination in people with mental disorders: a pilot study in a rural Kenyan setting. Epidemiol Psychiatr Sci. (2018) 28:156–67. doi: 10.1017/S2045796018000264.

Nelson, G, Lord, J and Ochocka, J (2001). Empowerment and mental health in community. Journal of Community and Applied Social Psychology. Vol. 11. Pp 135-42.

Nordt C, Rössler W, Lauber C (2006). Attitudes of Mental Health Professionals Toward People With Schizophrenia and Major Depression, Schizophrenia Bulletin, Volume 32, Issue 4, October 2006, Pages 709–714, https://doi.org/10.1093/schbul/sbj065.

O’Connell, C., Finnerty, J. & Egan, O. (2008). Hidden voices, Combat Poverty Agency, Poverty Research Initiative, Dublin.

Oliver M (1983). Social Work with Disabled People. MacMillan, Basingstoke.

Oliver M (1990). The Politics of Disablement MacMillan, Basingstoke Oliver M (1996) Understanding Disability: From Theory to Practice. MacMillan, Basingstoke.

Oliver M, Barnes C (1998). Disabled People and Social Policy: From Exclusion to Inclusion. Addison.

Oliver, M (2013). The social model of disability: Thirty years on. Disability & Society, 28.

Olkin, R. (1999). What psychotherapists should know about disability, Guilford Press, New York.

Parsons, T. (1951). The social system. New York: Free Press.

Pfeiffer, D. (2003). The disability studies paradigm’, in P. Devlieger, F. Rusch & D. Pfeiffer (eds.), Rethinking disability: The emergence of new definitions, concepts and communities, pp. 95–110, Garant Uitgevers, Antwerpen.

Pinfold, V., Byrne, P., & Toulmin, H. (2005). Challenging Stigma and Discrimination in Communities: A Focus Group Study Identifying UK Mental Health Service Users’ Main Campaign Priorities. International Journal of Social Psychiatry, 51(2), 128–138. https://doi.org/10.1177/0020764005056760.

Purtell, R. (2013). Music and the social model of disability, in J. Williams (ed.), Music and the social model: An occupational therapist’s approach to music with people labelled as having learning disabilities, pp. 26–32, Jessica Kingsley, London.

Quinn, G., Degener, T. (2002). Droits de l’homme et invalidité : l’utilisation actuelle et l’usage potentiel des instruments des Nations Unies relatifs aux droits de l’homme dans la perspective de l’invalidité. New York et Genève : ONU.

Ramon, S (2009). Adult mental health in a changing international context: The relevance to social work.

Ravaud, J. F. (2001). Vers un modèle social du handicap : l'influence des organisations internationales et des mouvements de personnes handicapées. In R. de Riedmatten (Ed.), Une nouvelle approche de la différence : comment repenser le « handicap » (pp.55-68). Genève : Médecine et Hygiène.

Revicki DA, Osoba D, Fairclough D, Barofsky I, Berzon R, Leidy NK, Rothman M. (2000). Recommendations on health-related quality of life research to support labeling and promotional claims in the United States. Qual Life Res. 2000;9(8):887-900.

Rudnick A, ed. Recovery of People with Mental Illness: Philosophical and Related Perspectives. Oxford, UK: Oxford University Press; 2012. https://oxfordmedicine.com/view/10.1093/med/9780199691319.001.0001/med-9780199691319. Accessed May 1, 2020.

Ryan, P., Ramon, S., Greacen, T. (2012) Empowerment, Lifelong Learning and Recovery in Mental Health: Towards a new paradigm. Basingstoke: Palgrave Macmillan

Sanchez, J. (1997). Enjeux concrets et symboliques de l'accessibilité. In J. F. Ravaud, J. P. Di-dier, C. Aussilloux & S. Aymé (Eds.), De la déficience à la réinsertion, recherches sur les handicaps et les personnes handicapées (pp.139-146). Paris: INSERM.

Scheid TL. (2005). Stigma as a barrier to employment: mental disability and the Americans with Disabilities Act. Int J Law Psychiatry. (2005) 28:670–90. doi: 10.1016/j.ijlp.2005.04.003.

Schipper, J. (2006). Disability studies and the Hebrew Bible, T & T Clark, New York. Seale, J., 2006, E-learning and disability in higher education, Routledge, London.

Schultz, I. Z. & Gatchel, R. J. (Eds.) (2005). Handbook of Complex Occupational Disability Claims: Early Risk Identification, Intervention and Prevention. New York, NY: Springer Publishing Ltd.

Scotch, R. K. (2000). Models of disability and the Americans with Disabilities Act. *Berkeley Journal of Employment & Labor Law, 21*, 213-222.

Semrau M, Evans-Lacko S, Koschorke M, Ashenafi L, Thornicroft G.(2015). Stigma and discrimination related to mental illness in low-and middle-income countries. Epidemiol Psychiatr Sci. (2015) 24:382–94. doi: 10.1017/S2045796015000359

Slade, M., Amering, M., Farkas, M., Hamilton, B., O'Hagan, M., Panther, G., … et al. (2014). Uses and abuses of recovery: implementing recovery-oriented practices in mental health systems. World Psychiatry, 13(1), 12-20.

Smart, J. (2004). Models of disability: The juxtaposition of biology and social construction', in T. Riggar & D. Maki (eds.), Handbook of rehabilitation counseling, pp. 25–49, Springer, New York.

Smith G.C., Strain J.J. (2002). George Engel's contribution to clinical psychiatry. Australian and New Zealand Journal of Psychiatry, vol. 36, n. 4, pp. 458–466.

Snyder, S. & Mitchell, D. (2006). Cultural locations of disability, University of Chicago Press, Chicago, IL.

Soder, M. (2009). Tensions, perspectives and themes in disability studies, Scandinavian, Journal of Disability Research, 11 (2) 67- 81.

soggetti vulnerabili, Giappichelli, Torino 2012, pp. 143-163.

Stiker, H. J. (1999). A History of Disability. Michigan: University of Michigan Press.

Stiker, H. J. (2001). De l'exposition des infirmes à la classification des handicaps : quelle éthique? In R. de Riedmatten (Ed.), Une nouvelle approche de la différence : comment repenser le « handicap » (pp.15-19). Genève : Médecine et Hygiène.

Substance Abuse and Mental Health Services Administration - SAMHSA (2012). New working definition of 'recovery' from mental disorders and substance use disorders. ScienceDaily. ScienceDaily, www.sciencedaily.com/releases/2012/01/120105154653.htm (accessed May 2020).

Swain, J. & French, S. (2000). Towards an affirmation model of disability', Disability & Society 15(4), 569–582. https://doi.org/10.1080/09687590050058189.

Szeto A, Dobson K (2010) Reducing the stigma of mental disorders at work: a review of current workplace anti-stigma intervention programs. Appl Prev Psychol 14:41–56.

Tew J, Ramon S, Slade M, Bird V, Melton J, Le Boutillier C (2011) Social factors and recovery from mental health difficulties: a review of the evidence, British Journal of Social Work, 2(3):443-460.

Tew J, Ramon S, Slade M, Bird V, Melton J, Le Boutillier C (2012). Social Factors and Recovery from Mental Health Difficulties: A Review of the Evidence, The British Journal of Social Work, Volume 42, Issue 3, April 2012, Pages 443–460, https://doi.org/10.1093/bjsw/bcr076

Tew J. 2013. Recovery capital: what enables a sustainable recovery from mental health difficulties? Eur J Social Work. 16:360–374.

Tew, J. (ed) (2005) Social Perspectives in Mental Health: Developing Social Models to Understand and Work with Mental Distress. London: Jessica Kingsley.

Tew, J., Gould, N., Abankwa, D., Barnes, H., Beresford, P., Carr, S., Copperman, J., Ramon, S., Rose, D., Sweeney, A. and Woodward, L. (2006) Values and Methodologies for Social Research in Mental Health, National Institute for Mental Health in England and Social Perspectives Network, in association with the Social Care Institute for Excellence. Bristol: Policy Press.

Thomas, D. & Woods, H. (2003). Working with people with learning disabilities, Jessica Kingsley Publishers, London.

Thornicroft G, Brohan E, Rose D, Sartorius N, Leese M, Group IS. (2009). Global pattern of experienced and anticipated discrimination against people with schizophrenia: a cross-sectional survey. Lancet. (2009) 373:408–15. doi: 10.1016/S0140-6736(08)61817-6

Thornton T & Lucas P (2010). Tim Thornton e Peter Lucas. J Etica Med 2011;37:24e28. doi:10.1136/jme.2010.037234.

Titchkosky, T. (2007). Reading and writing disability differently, University of Toronto Press, Toronto.

Trent, J. (1994). Inventing the Feeble Mind: a history of mental retardation in the United States, Berkeley, University of Califomia Press.

UPIAS (1976). Fundamental principles of disability, Union of the Physically Impaired against Segregation, London.

Üstün, T. B., Chatterji, S., Bickenbach, J. E., Trotter II, R. T., & Saxena, S. (2001). Disability and Cultural Variation: The ICIDH-2 Cross-Cultural Applicability Research Study. In T. B. Üstün, S. Chatterji, J. E. Bickenbach, R. T. Trotter II, R. Room, J. Rehm & S. Saxena (Eds.), Disability and Culture: Universalism and Diversity (pp. 3-19). Seattle, WA, US: Hogrefe & Huber.

Van Eck R.M., Burger T.J., Vellinga A, et al. (2017). The relationship between clinical and personal recovery patients with schizophrenia spectrum disorders: a systematic review and meta-analysis. Schizophr Bull.

Vita, A.& Barlati, S. (2018). Recovery from schizophrenia: is it possible? Current opinion in Psychiatry, 31(3), 246-255.).

Von Bertalanffy, L. (1968). General System Theory. Foundations, Development, Applications. New York: George Braziller.

Vrbova, K., Prasko, J., Ociskova, M., Kamaradova, D., Marackova, M., Holubova, M., Latalova, K. (2017). Quality of life, self-stigma, and hope in schizophrenia spectrum disorders: a cross-sectional study. Neuropsychiatricdisease and treatment, 13, 567.

Wagner, E. H. (1998). Chronic disease management: what will it take to improve care for chronic illness? *Effective Clinical Practice, 1*(1), 2-4.

Wesley Longman, Harlow Oliver M, Sapey B (1999). Social Work with Disabled People. 2nd ed. MacMillan, Basingstoke

White, BJ and Madara, EJ (eds) (2002).The Self-Help Group Sourcebook: Your Guide to Community and Online Support Groups (7th edition). Denville, NJ: American Self-Help Group Clearinghouse.

Williams AE, Fossey E, Corbière M, Paluch T, Harvey C. (2016). Work participation for people with severe mental illnesses: an integrative review of factors impacting job tenure. Austr Occup Ther J. (2016) 63:65–85. doi: 10.1111/1440-1630.12237

Williams AE, Fossey E, Corbière M, Paluch T, Harvey C. (2016). Work participation for people with severe mental illnesses: an integrative review of factors impacting job tenure. Austr Occup Ther J. (2016) 63:65–85. doi: 10.1111/1440-1630.12237.

Wolfensberger, W. (1989). Human Service Policies: The Rhetoric Versus the Reality, in Barton, L. (ed.) Disability and Dependency, Lewes: Falmer.

World Health Organisation - WHO (2016). Global disability action plan 2014–2021: Better health for all people with disability. Geneva.

Wunderlich, G. S. Dorothy P. Rice and N. L. Amado (eds.) (2002). The Dynamics of Disability: Measuring and Monitoring Disability for Social Security Programs National Academy Press, Washington, D.C.

Zipursky, R.B. (2014). Why are the outcomes in patients with schizophrenia so poor? ClinPsychiatry, 75 (2 Suppl): 20 – 24.

Zubin, J and Spring, B (1977). Vulnerability: a new view of Schizophrenia. Journal of Abnormal Psychology. Vol. 86. Pp 103-126.

Second Chapter

The universal nature of disability

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Abstract

The chapter firstly presents the International Classification of Diseases (ICD) and the system for classifying impairments, disabilities, and handicaps (ICIDH) published by the World Health Organization with the purpose of improving information on the consequences of disease and setting the scene for the forthcoming revision process. The consequences of diseases and disorders at the level of the body (impairment), the person (disability), and the person as a social being (handicap) are defined and described. In 2001, the International Classification of Functioning, Disability and Health (ICF) was approved by the World Health Organization (WHO). In this classification, functioning and disability are viewed as a complex interaction between the health condition of the person and the contextual factors of the environment as well as personal factors. The image produced by this combination of features and dimensions is of "the individual in his/her world".

Keywords: disease; impairment; disability; handicap; international classification

2.1 Introduction

Health, which is the basis of a nation's development, must be measured and described. For this reason, over time, several organisations have tried to develop reference tools that use a common language and shareable, in order to guide research, policies and social health interventions for an adequate and effective use of resources.

Since its establishment in 1947, the WHO (World Health Organization) replaced the notion of health as the absence of disease with the new definition of health as "a state of complete physical, mental and social well-being", believing that health is a state of human functioning relative to the person as a whole and also to the society in which he lives.

This vision was reinforced in 1986 by the Ottawa Charter for Health Promotion, which, while considering health as a characteristic of the person, considered that the promotion and achievement of health necessarily involved the whole experience of the person in his or her environment. In fact, the Ottawa Charter contains the following definition of health promotion:

"*Health promotion is the process of enabling people to increase control and improve their health. To achieve a state of complete physical, mental and social well-being, a person or group must be able to identify and realize aspirations, meet needs, change or cope with the environment. Health, therefore, is seen as a resource for everyday life, not a life goal. Health is a positive concept that emphasizes personal and social resources, as well as physical abilities. Therefore, health promotion is not only the responsibility of the health sectors, but goes beyond healthy lifestyles, towards well-being*".

As mentioned above, before the establishment of the WHO, health was defined as "absence of disease": it was enough not to be sick, in the physical sense, to be considered healthy. The new definition is much more articulated and takes into account not only physical health but also mental

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health and social integration. If only one of these components is not adequate the individual cannot be considered healthy. It is a definition that does not evaluate the individual per se but considers him or her in a dynamic and interactive relationship with the environment around him or her.

Therefore, three very important aspects of the new concept of health emerge:

- Health does not concern the individual organs (lungs, heart, etc.) but is a state of full efficiency of the whole person.
- Health is essentially linked to human functioning at all levels: biological, personal and social.
- Health cannot be separated from the context in which the person lives. Health impacts on the environment and the environment impacts on health.

What changes have occurred to justify this profound cultural change? Certainly important changes in epidemiological terms. Diseases used to be predominantly acute: either one died rather quickly or survived them and the survivors still had a low probability of long-term survival. The states of chronicity or disability were relatively few due to the simple fact that medical and social progress was not such that a person with important chronic-degenerative diseases survived for a long time. Another important change is related to the lengthening of the average age with the prevalence of older age groups where the phenomena of disability and chronicity are more frequent.

This change in the epidemiological-demographic scenario has had an inevitable impact on the way health services are conceived, prioritising the need to organise care pathways capable of guaranteeing continuity of care, and not just assistance during the acute phases.

At global level, the WHO has also had to adapt its reading instruments to the new concept of health. Health care needed diagnostic information on the underlying disease (signs and symptoms) to be supplemented with information on the consequences of the health condition on a person's life.

This made it necessary to supplement the classifications used with a classification of the state of operation using a common international language to describe it. A standard language was also required to compare data from the different tools for assessing functioning status, which were commonly used in the medical, care and rehabilitation fields.

At the same time, people with disabilities stated that their needs were not fully taken care of by simple medical and rehabilitation interventions: in fact, the impact of the environment on their functional state and disability could definitely aggravate the disease condition.

The understanding of the health of an individual or population and the planning of effective interventions require reliable data, throughout the life cycle, on the effects of people's health conditions, on their ability to perform activities, whether they are simple actions of personal autonomy or more complex activities of participation in community life.

The following paragraphs detail their evolution and their current structure.

2.2 Concepts of functioning and disability

In 1893, with the approval of the Conference of the International Classification of Causes of Death by the International Institute of Statistics, the indicator deemed suitable for assessing health was the cause of death.

Subsequently, in 1946 with the International Classification of Diseases (ICD) by WHO, a new detector represented by the disease took over.

In this classification the diseases are ordered for statistical purposes and in correlated groups; the medical terms in which the diagnosis of the disease is formulated and the diagnostic and therapeutic procedures are indicated with alphanumeric codes. The ICD system is based exclusively on disease and diagnosis according to the aetiology-pathology-clinical manifestation sequence and is periodically reviewed.

A version of ICD-11 was released on 18 June 2018 to allow Member States to prepare for implementation, including translating ICD into their national languages. ICD-11 will be submitted to the 144th Executive Board Meeting in January 2019 and the Seventy-second World Health Assembly in May 2019 and, following endorsement, Member States will start reporting using ICD-11 on 1 January 2022.

As mentioned in the previous chapter, in the 1950s an important theoretical reflection on health and disease began at world level, which began to give greater prominence to the consequences of the latter on people's lives. This was mainly due to the change in the healthcare scenario, marked by the transition from acute, infectious and chronically evolving diseases. There were therefore economic and health needs, which required a better allocation of resources in order to bridge the gap between what health services actually offered and the emerging needs (ability-capability gap).

On this basis, in May 1976, the XXIX World Health Assembly approved the International Classification of Impairments, Disabilities and Handicap. A manual of classification relating to the consequences of disease (ICIDH), published in 1980 as the International Classification of Impairments, Disabilities and Handicap (ICIDH-1 or ICIDH-80). It was designed by British physician Philip Wood, not to replace, but rather to complement, the ICD classification.

It is not a guide to the classification of people with disabilities, but instead attempts to identify circumstances that may lead to disadvantage some people compared to others on the basis of an alleged normality. It introduces the consequence of a pathological or chronic state. It is the first attempt to highlight the social consequences of a disease, shared internationally and translated into 13 languages.

This new classification was intended above all as a cultural and operational tool aimed at promoting valid feedback and an acceptable recording of impairments and the consequent states of disability and existential disadvantage. It was proposed to focus on the consequences of diseases and their interdependencies, allowing to clear the field from the old clinical baggage, to focus, instead, on the targeted and individual recovery of existing potential, both at the level of impairments, and, above all, of disabilities and handicaps.

The ICIDH was therefore conceived as complementary to the ICD and able to provide a broader and more indicative picture of the state of health of the person, allowing the integration of data on the disease with information on the consequences it produces on daily life and relationships: the phenomenological sequence of the ICD aetiology-pathology-clinical manifestation is integrated with the sequence of the ICIDH impairment-disability-handicap. The words “impairment,” “disability,” and “handicap,” are often used interchangeably. They have very different meanings, however.

In the classification ICIDH 1 or ICIDH 80:

- Impairment is defined as “any loss or abnormality of psychological, physiological or anatomical structure or function”.
- Disability, in the context of health experience, is “any 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”.
- Handicap is instead “a disadvantage for a given individual, resulting from an impairment or a disability, that limits or prevents the fulfilment of a role that is normal (depending on age, sex, and social and cultural factors) for that individual” (WHO 1980).

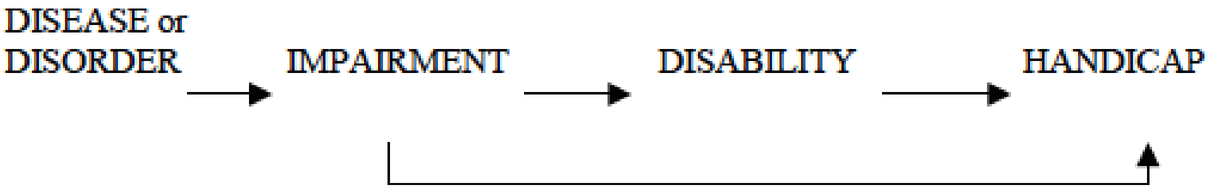


Figure 1 - Classification of Impairments, Disabilities and Handicap

According to the WHO document published in 1980, therefore, the impairment is permanent, the disability depends on the activity that the individual has to perform and the disability indicates the disadvantage that the individual has in relation to the so-called “normally-abled”. From this distinction it follows that a single disability may give rise to different disabilities and may involve more than one disability.

The conceptual elaboration of ICIDH, surely, served to put order in a field in which at least in terms of classification there was an absolute semantic anarchy.

However, it lent itself to criticism concerning in particular:

1. the linear logic of the sequence of impairment-disability-handicap;
2. the absolute connection between the three levels. The sequence, in fact, is not always so linear, a disability can give rise to problems in social relations; the disability can occur without the mediation of disability (for example, a disfiguring scar that does not cause disability can cause disability);
3. the ambiguity that in ICIDH is associated with the definition of disability, which the Authors themselves describe as follows: "Whether the same awareness, or the altered behaviour or performance that this activates, can put the individual at a disadvantage compared to others, this is the socialization of experience. This plan reflects the response of society to the experience of the individual, expressed in attitudes, such as stigma activation, or in behaviours that may include specific tools such as legislation. These experiences represent handicap resulting from impairment and disability".

Disability practitioners have used this classification mainly as a common language, while associations of people with disabilities have been able to appreciate its underlying conception, i.e. a more functional and less medicalised view of disability.

At the same time, at the international level, a strong debate was taking place, stimulated mainly by people with disabilities, who were beginning to become aware of the fact that, due to their conditions, they were excluded from the recognition of human, social and working rights.

In England, Disabled Peoples' International (DPI) was created, and in America la Society for Disability Studies (DPS), which in turn gave rise to the Union of the Physically Impaired Against Segregation (UPIAS).

The UPIAS opposed ICIDH by judging the approach too individualistic and on a purely medical basis. In fact, it stated that only on the basis of medical and health decisions were people with disabilities deprived or relegated to secondary roles within society. One of the main flaws of ICIDH 80, however, was that it did not take into account the role of the physical and social environment in the genesis of disability and, consequently, this classification could not be used to describe, and even less to measure, the effects of an environment unsuitable for people's lives. ICIDH 80 considered, in fact, the physical and social world as fixed and immutable, and did not recognize either the presence of environmental/social barriers, or the absence of environmental/social facilitators, factors that are at the origin of disability.

UPIAS, with the publication of an official document entitled Fundamental Principles of Disability, as described in the previous chapter, challenged the hitherto prevailing "medical model", a "social model" of disability, attributing a great responsibility to society, which "makes disabled people who have disabilities [...] disability is something that is imposed on our impairments by the way we are isolated and excluded, in a way not necessary by full participation in society".

This introduced a new concept, disablement, or the "creation of disability". In the wake of these ideas, organizations and movements were born all over the world with the aim of overcoming social segregation and promoting the integration of people with disabilities.

Under this impetus, WHO began the revision of ICIDH 80 in 1996, with the help of Wood himself.

The new model was intended to provide a standard and unified language of reference for the description of functioning and disability; to replace the negative terms of impairment, disability and handicap with more neutral and positive expressions; to consider disability as an expression of the interaction between the person and the environment understood as a restriction of participation in all areas and aspects of human life.

During the revision process that took place from 1996 to 1999, several drafts of the new ICIDH were drawn up on the basis of the results of field trials by international centres.

The new classification was to be hinged on five conceptual principles:

1) Universality: disability seen as a universal aspect of humanity; not as a definition of characteristics of some minority group.
2) Environment: the environmental factors included as part of the classification scheme.
3) Neutral Language: a positive classification of the levels of human functioning, not an exclusive classification of the functioning problems. An essential objective of the review was to avoid any negative terminology.
4) Equality: the classification of all human functions, without reference to the cause of the problem.
5) Biopsychosocial Model: greater attention to the analysis of the personal, social and physical context.

It should also be:

- functional to the needs felt in the different countries, sectors and health disciplines.
- useful for practice, i.e. to identify health and social care needs and to prepare intervention programmes (e.g. prevention, rehabilitation, social actions).
- able to provide a coherent view of the processes involved in the consequences of health conditions, so that the process of compromise consisting of dimensions, which are distinct from diseases/disorders, could be objectively evaluated and recorded.
- sensitive to cultural differences (being translatable and applicable in different cultures and health and social care systems).
- able to be used in a complementary way to the WHO family of classifications.
- enriched by further schemes concerning Contextual Factors (external-environmental factors and internal-personal factors) which constitute important components of the disability process.
- applicable in a transcultural way so as to spread the principles of universality.
- used to develop training and presentation materials.

The fact that in the last twenty years a concept of health protection, understood as attention to the "well-being" and the "quality of life" of the individual, has become more and more established has contributed to this result. Above all, the concept of "social participation" and "use of the environment" have begun to be understood as fundamental parameters against which to measure any intervention objective.

The latest version of ICIDH-2, the Beta 2 draft version, was published in 1999 under the name of the International Classification of Impairments of Activities and Participation and was to have experimental value and then be revised in 2001.

ICIDH-2 is structured into three dimensions:

- body functions and structures (former impairments): loss or abnormality of the body structure or of a physiological psychological function;
- activity (previous disability): whatever a person performs at any level of complexity, i.e. more or less simple activities that may be limited in nature, duration and quality;
- participation (ex-handicap): interaction between alterations in body functions and structures, activities and contextual factors in all areas and aspects of human life, which may be restricted in nature, duration and quality.

The three dimensions are influenced by:

- environmental factors: physical, social or attitudinal; organised in an order that goes from the closest environment to the person to the most general one;
- personal factors that are related to the individual's personality and characteristics.

It is a model of functioning of disabilities whose constituent elements are all in dynamic interaction and able to influence each other.

This tool, while preserving its diagnostic value and giving increasing emphasis to environmental factors, proposes the approach of the "biopsychosocial model".

The experimentation of the ICIDH-2 Beta 2 draft version by various international centres ended in September 2000.

In May 2001, the World Health Assembly approved the final text as the International Classification of Functioning, Disability and Health (ICF). He recommended its use in the Member States as a substitute for ICIDH for research, surveillance and statistics, and supported its use with the ICD-10, with periodic reviews.

After approval, the ICF became part, together with the ICD-10, of the WHO Family of International Classifications (WHO-FIC), as mentioned in the previous paragraph.

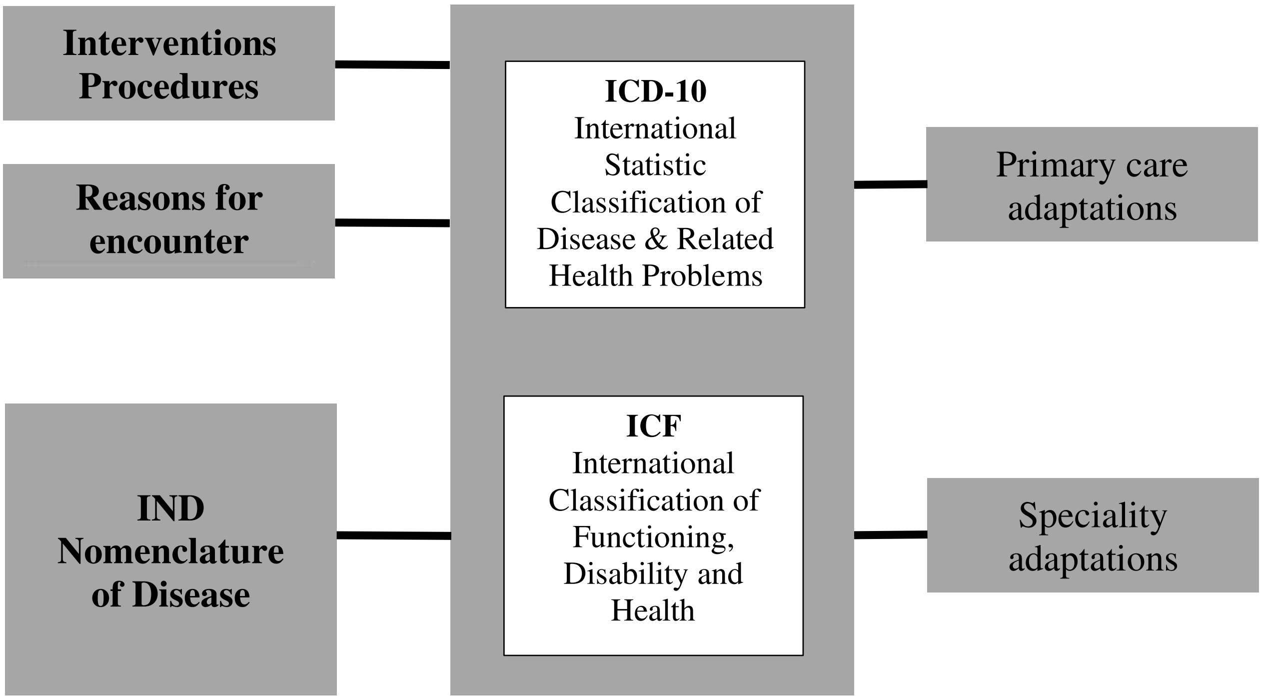


Figure 2 - WHO Family of International Classifications (WHO-FIC)

The two classifications are complementary and WHO recommends joint use where possible.

The principles underlying the ICF classification are universalism, integrated approach, interactive and multidimensional model of functioning and disability.

Currently widespread and used in 191 countries around the world, the ICF defines health conditions and the states associated with them. Health conditions include "acute and chronic diseases, disorders, damage and trauma" but also "other circumstances such as pregnancy, aging, stress, congenital abnormalities or genetic predispositions" (WHO, 2001). To analyse health conditions and states related to health, he refers to two umbrella terms: disability and functioning.

The term ‘disability’ in the new ICF is thus defined as follows: “an umbrella term for impairments, activity limitations and participation restrictions. It denotes the negative aspects of the interaction between an individual (with a health condition) and that individual’s contextual factors (environmental and personal factors)” (WHO, 2001:213).

Disability represents the interaction between the individual, with his health conditions and the environment (in the negative aspects), while the functioning represents the same interaction in positive terms. The ICF depicts human functioning and its reductions as the product of the dynamic interaction between health conditions and contextual factors (WHO, 2001).

To do this, domains are analysed and described from the perspective of the body, the individual and society: body functions and structures, and activity and participation respectively.

Body functions are defined as "physiological functions of body systems (including psychological functions)".

Body structures are defined as "anatomical parts of the body such as organs, limbs and their component parts". Alterations in body structures and functions are referred to as impairments.

The model also classifies activities and participation. An activity is defined as "the performance of a task or action by the individual"; participation is referred to as involvement in life situations. Both can then encounter problems that are referred to respectively as limitations in activities ("difficulties an individual may have in performing activities") and restrictions in participation ("problems an individual may experience in engaging in life situations"). The distinction drawn between activity and participation is one of the unclear aspects of this new model as the classification is unique for both, although several options for distinction are suggested to the encoder.

This specification removes some of the ambiguity concerns the distinction between capacity and performance.

Capacity is defined as "the ability of an individual to perform a task or action with the construct intended to indicate the highest probable level of functioning that a person can achieve in a given domain, at a given time. To assess the full ability of the individual, one would need a standardized environment that neutralizes the impact of different environments on the individual's ability. In this way the ability reflects the ability of an individual, adapted according to the environment in which it is measured. On the basis of this distinction it would be possible to assess the capacity of people who belong to different places and cultures and are possible international comparisons.

Performance means "what the individual does in his or her current environment. Since this current environment includes social contexts, performance can be understood as an involvement in "life situations" or "the experience" lived by the person in the real context in which he lives". Once again details are given about the context "this context includes environmental factors, all aspects of the physical, social and attitudes that are encoded in the environmental factors component".

The gap between capacity and performance represents the impact of the environment and can provide useful information about the action that can be taken to change the environment in order to improve performance.

So far, domains of health conditions related to the person are listed, but as mentioned above, the ICF model analyses the relationship between the person and the environment. In the second part of the ICF the contextual factors that are distinguished into personal and environmental are indicated.

Contextual factors are defined as "the complete background of the individual's life and living" (WHO, 2001). Environmental factors mean "the physical and social environment and attitudes in which people live and conduct their experiences".

These factors represent everything that surrounds the person and that can have an influence on the functioning of the individual, accordingly on his body structures and functions, on his capacity (as an individual or as a member of a social group). These influences can be positive or negative, depending on whether these factors act as facilitators or barriers (and this is how they are described in the ICF model).

As already mentioned, the ICF defines disablement as the result of the interaction of the body, person and environment domains. The theoretical contribution at the base of the ICF has certainly received direct and indirect influences from the other models that have been described so far and is the most recent (as well as being the most widespread).

This new document indicates from the beginning a change of perspective in the conceptual definition of disability. It should be noted that, compared to the previous document, the link between the concept of disability and that of health is immediately highlighted. The ICF covers all aspects of human health, distinguishing the various functions indicating the health status of an individual (see, hear, walk, learn and remember) from different indicators concerning the social life of the individual (mobility, education, participation in social life, etc.). Another significant innovation is that the term “disability” is no longer used and its meaning is extended to indicate both the restriction of activities and the limitation of participation.

With the ICF, therefore, we are witnessing a real reversal of the terms from negative to positive: we no longer speak of impediments, disabilities, handicaps, but of functions, structures and activities.

From this point of view, disability no longer appears as a mere consequence of the physical condition of the individual, but arises from the relationship between the individual and the conditions of the outside world.

Another major innovation in the perspective introduced by the ICF is that it is not specifically concerned with people with disabilities, but rather has universal use and value, as it is based on the idea that every human being, at some point in his life, can find himself living a state of health that, in a negative environment, becomes a disability: there is a widespread misunderstanding that ICF is only about people with disabilities; in fact, it is about all people. In other words, ICF has universal application.

This approach therefore represents a fundamental change of perspective in the definition and perception of disability, due to the fact that the focus shifts from the causes of disability to the impact on the activities of the individual. From this point of view, disability is the interaction between a non-inclusive society and an individual, between his or her state of health and environmental factors.

The ICF defines disability as a health condition in an unfavourable environment. From this point of view, it represents an overturning of logic in that it proposes the quality of life as central. The ICD-10 describes mortality and morbidity, while the ICF describes the full range of health conditions, as represented in the Figure 3.

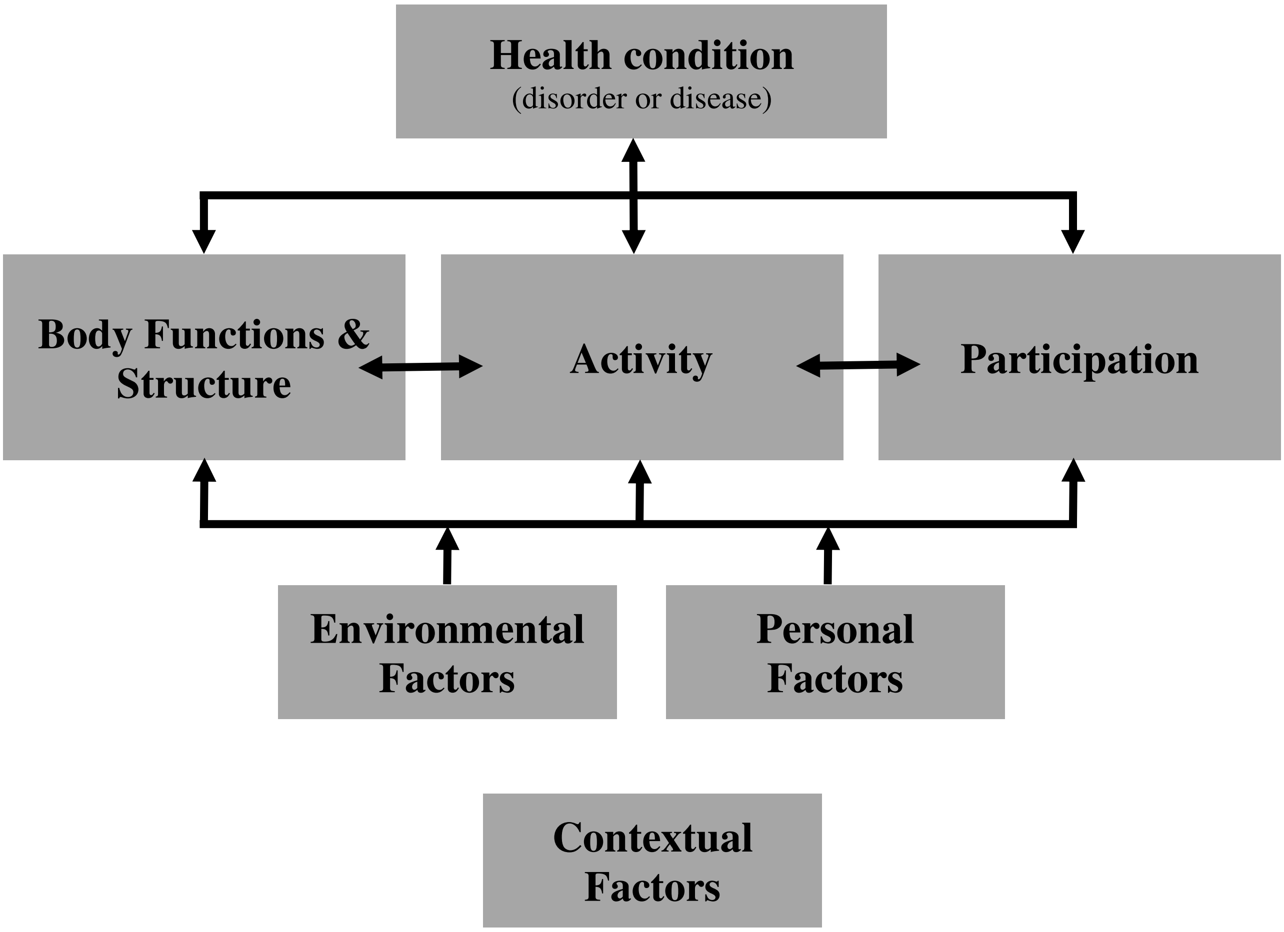
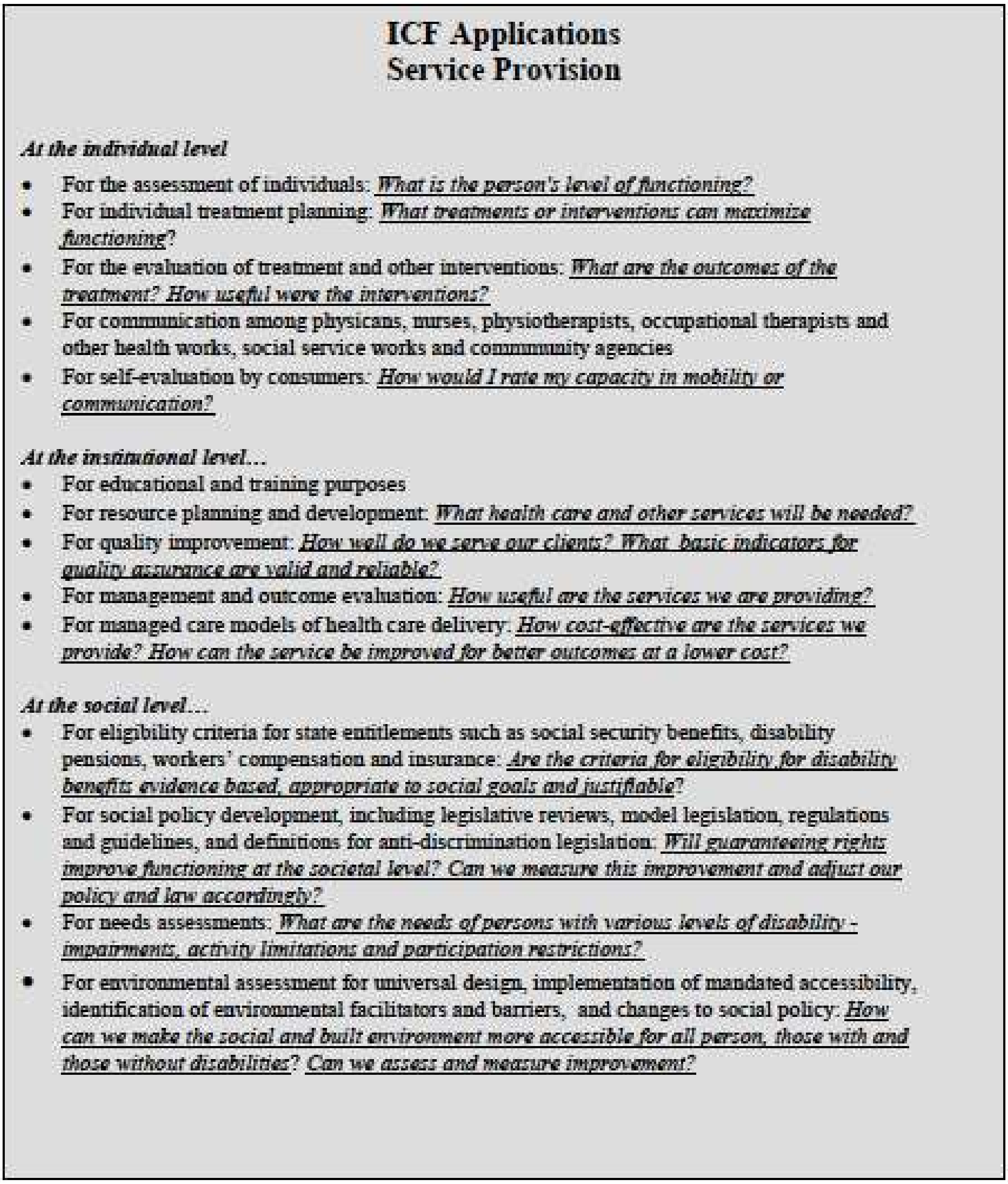


Figure 3 – Towards a Common Language for Functioning, Disability and Health (WHO, 2002)

Body functions are the physiological functions of body systems including psychological functions, while body structures are the anatomical parts of the body, such as organs, limbs and their components.

In this context, the term "impairment" in the previous classifications is to be interpreted as a problem (from limitation or alteration to loss) of a body function or structure. The activity is the execution of a task or action by an individual, participation is the involvement in a life situation. Environmental factors are the attitudes, physical and social environment in which people live and lead their lives. There are two versions of the ICF: the full version for up to four-level coding and the short version for two-level coding.

Because of its flexible framework, the detail and completeness of its classifications and the fact that each domain is operationally defined, with inclusions and exclusions, it is expected that ICF is used for a myriad of uses to answer a wide range of questions involving clinical, research and policy development issues. In the box below, specific examples of practical issues and uses of ICF in the area of service provision are addressed.



ICF Applications
Service Provision

At the individual level

- For the assessment of individuals: *What is the person's level of functioning?*
- For individual treatment planning: *What treatments or interventions can maximize functioning*?
- For the evaluation of treatment and other interventions: *What are the outcomes of the treatment? How useful were the interventions?*
- For communication among physicans, nurses, physiotherapists, occupational therapists and other health works, social service works and commmunity agencies
- For self-evaluation by consumers: *How would I rate my capacity in mobility or communication?*

At the institutional level…

- For educational and training purposes
- For resource planning and development: *What health care and other services will be needed?*
- For quality improvement: *How well do we serve our clients? What basic indicators for quality assurance are valid and reliable?*
- For management and outcome evaluation: *How useful are the services we are providing?*
- For managed care models of health care delivery: *How cost-effective are the services we provide? How can the service be improved for better outcomes at a lower cost?*

At the social level…

- For eligibility criteria for state entitlements such as social security benefits, disability pensions, workers' compensation and insurance: *Are the criteria for eligibility for disability benefits evidence based, appropriate to social goals and justifiable*?
- For social policy development, including legislative reviews, model legislation, regulations and guidelines, and definitions for anti-discrimination legislation: *Will guaranteeing rights improve functioning at the societal level? Can we measure this improvement and adjust our policy and law accordingly?*
- For needs assessments: *What are the needs of persons with various levels of disability - impairments, activity limitations and participation restrictions?*
- For environmental assessment for universal design, implementation of mandated accessibility, identification of environmental facilitators and barriers, and changes to social policy: *How can we make the social and built environment more accessible for all person, those with and those without disabilities*? *Can we assess and measure improvement?*

Figure 4 – How can ICF be used? (WHO, 2002)

The ICF introduces, therefore, the innovative concept of the classification of the state of health of the person, shifting the focus of the problem on life, on how people live in relation to their physical, psychological, historical, cultural and how these conditions can be improved or hindered by the concrete possibility of being able to achieve a satisfactory life at a social and productive level. Consequently, any process aimed at improving the situation and promoting the integration of people with disabilities would require social action and society at large would be required to implement the behavioural and environmental changes necessary to enable these people to participate fully at all times in life. From the point of view of disability, we must reflect on the capacity of the environment to guarantee people an adequate level of health, safety and accessibility, both in terms of quality and quantity.

2.3 The cultural revolution of the IFC model

The ICF is a classification that has different purposes and can be used in different disciplines and sectors. Its main aims can be summarised as follows:

- to provide a scientific basis for understanding and studying health, conditions, consequences and related determinants;
- to establish a common language for describing health and health-related conditions with the aim of improving communication between different users, including health professionals, researchers, policy makers and the general public, including people with disabilities;
- to make it possible to compare data collected in different countries, health disciplines, services and at different times;
- to provide a systematic coding scheme for health information systems. These aims are interrelated, since the needs underlying the ICF and its applications require the creation or availability of a meaningful and practical system that can be used by various consumers for health policy, quality assurance and performance evaluation in different cultures.

Since the ICF is a classification of health and health-related states, it is also used in sectors such as insurance, social security, labour, education, economics, legislation and environmental change.

As such, the ICF is the appropriate instrument for the implementation of national and international actions in defence of human rights. It provides a conceptual framework for the organisation of information that is applicable to personal healthcare - including prevention and health promotion - and to the improvement of participation through the removal or reduction of social barriers and the promotion of social support actions. It also applies to the study of healthcare systems for policy evaluation and formulation.

In a discussion of health and disability, we cannot ignore the fact that a new approach to health and disease has been in place for some time now. Research, at an international level, is, in fact, moving, albeit with difficulty, from an approach based on disease to an approach based on the patient, on the person. We are moving away from a compliance report and towards a concordance report, i.e. from a paternalistic approach to an approach based on a "therapeutic agreement" model.

Usually the doctor/person relationship is unbalanced on the paternalistic model (compliance), in which the doctor alone decides what is good for the care of the person. Now, as mentioned earlier, we are confronted with diseases with which we can live for many years, with diseases that are not directly fatal, but that cause great disability. In these situations a new agreement is developed in which the principle applies that the doctor, who fails to heal, must, however, take care of the person and must establish, together with the patient, the stages of care that can ensure the best possible quality of life. This is the new mentality, the strategy of concordance, which should be created in the health sector, and also in the social sector, but which still finds us, dramatically, unprepared. The ICF can help a lot in this because it introduces and defines, in scientific terms, the areas in which one can influence the quality of life of the person. This is a very delicate and very difficult step: it involves a new rethinking of the same profession as the doctor and the same profession as all health workers and social workers.

The ICF stimulates new reflections because it brings health and disability issues back to the level of people's real problems, needs, functions and activities. What role does research play in this attention to the person as a whole?

What does it mean and what does it involve to open a debate on medical science and experimental sciences, using instruments that do not belong only to the domain of sciences?

2.4 Conclusions and perspectives

The growing need for information on population mortality, morbidity and non-fatal outcomes of diseases has highlighted the need to describe the health of the population in such a way that both expectations and health deficits are outlined. Hence the need to use measurement tools to compare the level of health between different populations in a longitudinal perspective. This is the only way to identify priorities for action. Diagnosis alone does not allow for the provision of data and information relevant to adapting the needs of services, nor does it make it possible to understand what performance is at work or at school, nor does it provide information on the social integration of the person.

This means that if you use the diagnosis in isolation, you lack some of the information needed to properly plan a person's real needs.

Allocating resources for health, especially when they are scarce, requires an assessment of the importance (or impact) of the disease on the population.

The use of mortality as a health indicator has resulted in a drastic limitation of the attention threshold for those diseases which result in low mortality but which involve a high disability and have a high prevalence. The use of traditional indicators has, in fact, led to a serious underestimation of chronic disabling diseases such as, for example, neurological diseases, or psychiatric diseases, since these have a low mortality rate, although they cause major disabilities. The mortality of a population does not tell us anything about the outcomes of a non-fatal disease, nor does the prevalence data alone account for the severity or duration of a disease. The shift from a scenario with a prevalence of communicable diseases to one with a prevalence of chronic non-communicable diseases, coupled with the general ageing of the population, have further increased the difficulties for those who need to assess the overall health and disability of populations.

These programming needs, combined with the general scarcity of resources and the changing health landscape of populations, have increasingly highlighted the need for instruments and measures to address these problems, at least in part.

One of the mandates of the World Health Organization (WHO) is to publish and update the International Classifications of Health and Disease. The International Statistics Classification of Diseases and Related Health Problems (ICD 10) and the International Classification of Functioning, Disability and Health (ICF) are the two classifications that make up the WHO Family of International Classifications/WHO-FIC.

The main purpose of the WHO-ICF is to ensure the comparability of health information in and between countries, between users and professionals. The general criteria underlying the classifications are mainly three: scientific validity, which ensures a conceptualization of the different domains, a comparability of information and a good transcultural applicability, which ensures its international relevance. For these reasons, the classifications of the WHO-ICF are closely related and are structured in such a way as to provide a standard and unified language, so that they can serve as a reference model for the description of the different aspects of human health and allow communication, in the field of health and healthcare, within the various sciences and disciplines, in ways that can be shared and approved at the international level.

The ICF recognises that every human being can have a health problem and clarifies the fundamental role of the environment in determining disability, allows us to measure and classify the health and related health statuses of the person. Disability is an event that can affect anyone. The ICF is therefore a reference tool for mainstreaming the disability experience and recognises it as a universal human experience.

It is a real revolution in the definition and perception of health and disability. Highlighting the importance of an integrated approach, for the first time, environmental factors are taken into account and systematically classified. The new classification takes into account the contextual aspects of the person, and allows for a correlation between health status and environment, thus arriving at the definition of disability as: "a health condition in an unfavourable environment". This approach introduces the concept of person.

The fundamental passage was the passage from the notion of "handicapped" to that of "person with disabilities". In thus doing, we have come out of the mental scheme for which there are separate groups for which we do special things. People with disabilities are all of us who have, or may have in the future, more or less serious operating problems. We can no longer think of laws for "separate groups", because with the ICF we talk about ourselves and, therefore, we introduce a universal model. We are therefore talking about rights and, in particular, about the right to health, but we are also talking about discrimination based on different health conditions, that is to say, on what I see, on the body, on what the person is. Many people, all of us perhaps, have some impairment, some disability, but disability is part of life.

If it is true that we can all have a condition of health and the functioning of a person can be determined at the three levels systematized by the ICF: at the level of the body, the person and society. Therefore, solutions for the person should also be identified on these same three levels.

Moreover, this classification, with its various components, serves to provide a scientific basis and to create a common language and allows data to be compared, being heavily inserted in a major medical, social and political debate. Politically, in fact, accepting the ICF approach has significant consequences: we cannot divide the person into a "medical part" and a "social part".

The ICF therefore allows us to answer the question "what does disability actually consist of", but do we know how many people have disabilities? We need reliable and comparable data to build targeted policies.

References

World Health Organization - WHO (1980). ICIDH - International Classification of Impairments, Disabilities and Handicaps. Geneva.

World Health Organization - WHO (1986). The Ottawa Charter for Health Promotion. Geneva, Switzerland.
Available from: http://www.who.int/healthpromotion/conferences/previous/ottawa/en/index.html.

World Health Organization - WHO (1989). ICD-10 - International Statistical Classification of Diseases and Related Health Problems: Tenth revision. Geneva.

World Health Organization - WHO (1995). Constitution of the World Health Organization. Geneva. Available from: http://apps.who.int/gb/bd/.

World Health Organization - WHO (2001). International Classification of Functioning, Disability and Health: ICF. Geneva: WHO, 2001.

World Health Organization - WHO (2013). How to use the ICF: A practical manual for using the International Classification of Functioning, Disability and Health (ICF). Exposure draft for comment. Geneva. Available from: http://www.who.int/classifications/drafticfpracticalmanual.pdf

World Health Organization - WHO (2018). ICD-11 International Classification of Diseases for Mortality and Morbidity Statistics: reference guide. Geneva. https://icd.who.int/browse11/content/refguide.ICD11_en/html/index.html

Third Chapter

The 2030 Agenda for sustainable development by, for and with persons with disabilities

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Abstract

"Persons with disabilities" are specifically mentioned in the 2030 Agenda for Sustainable Development, that has thus opened doors for their participation and recognition as active contributing members of society. Persons with disabilities should be recognized as equal partners: they must not face any discrimination and exclusion or be left out or behind. The chapter investigates how the people with disabilities are taken up in the new 2030 Agenda architecture at the international level with a closer look at the sustainable development goals (SDGs).

Keywords: Disability; Agenda 2030; Human Rights

3.1 Introduction

The cultural and technical innovations brought about by the UN Convention on the Rights of Persons with Disabilities (CRPD) have substantially influenced the international debate and policies for the protection of the rights of this population group, which represents one billion according to the WHO, i.e. 15% of the world's population). The Convention emphasises respect for human rights and clarifies how disability is a condition that manifests itself in relation to the relationship between the individual with his or her particular characteristics and the physical and social environment.

Figure 1: Disabling world

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The CRPD has been ratified by 90% of the member countries of the United Nations (181 countries out of 193), which have thus taken as standard the bio-psycho-social model of disability, based on respect for human rights. At the same time, States are committed to monitoring its implementation, through the periodic drafting of a report on its implementation, also with respect to specific areas of intervention, such as women with disabilities, non-discrimination, inclusive education and independent living).

The European Union has consolidated its commitment to European citizens with disabilities (around 80 million) by defining a disability strategy (2010-2020)[1] based on the elimination of all types of barriers to the exercise of their rights. The EU has identified eight main areas for action: accessibility, participation, equality, employment, education and training, social protection, health and external actions including both international cooperation and humanitarian aid[2].

During 2015, the European Council adopted the document "Council conclusions on disability-inclusive disaster management"[3] which defined the actions of the States and the European Commission to ensure the inclusion of the needs of people with disabilities among emergency interventions.

In 2016, then, the new 2017-2023 Strategy of the Council of Europe was approved: "Human rights: a reality for all", launched during the Nicosia Conference in March 2017. The Strategy includes five priority areas for action: equality and non-discrimination, awareness raising, accessibility; equal recognition before the law, combating violence and abuse, and considers five cross-cutting themes, such as participation, cooperation and coordination; universal design and reasonable accommodation; gender equality; multiple discrimination; education and training. At Italy's suggestion, there are also references to social responsibility and development objectives.

The United Nations has progressively included the issue of disability in the most important initiatives of recent years. In 2015, the “Sendai framework for risk disaster reduction”[4] has foreseen the need to include this issue within the prevention, first aid and reception actions, actively involving organizations of people with disabilities in all phases of the emergency.

In May 2016, on the occasion of the Humanitarian Summit, the "Istanbul Charter for the inclusion of people with disabilities in humanitarian activities"[5] was approved.

In September 2015, Agenda 2030 on sustainable development objectives gave the issue of disability a new focus in international development strategies.

The concept of sustainable development is first introduced in the Our Common Future Report (known as the Brundtland Report), produced in 1987 by the World Commission on Environment and Development (WCED) of the United Nations Environment Programme (UNEP). The document defines sustainable development as "development that meets the needs of the present without compromising the ability of future generations to meet their own needs". The notion of sustainability is linked to the compatibility between the development of economic activities and environmental protection; and the question of equity is introduced, not only intergenerational, but also within the same generation.

The principle of sustainable growth requires that the richest countries adopt production processes and lifestyles compatible with the biosphere's capacity to absorb the effects of human activities and that

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[1] European Commission (2010). European Disability Strategy 2010-2020: A Renewed Commitment to a Barrier-Free Europe. Website: http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=COM%3A2010%3A0636%3AFIN%3Aen%3APDF (accessed: March 2020)

[2] These areas have been identified according to their potential contribution to the overall objectives of the Strategy and the CRPD, the relevant documents of the EU institutions and the Council of Europe, the results of the EU Disability Action Plan 2003-2010 and public consultations with Member States and stakeholders.

[3] General Secretariat of the Council (2015). Draft Council conclusions on disability-inclusive disaster management – Adoption. Website: https://www.consilium.europa.eu/register/en/content/out/?&typ=ENTRY&i=ADV&DOC_ID=ST-6450-2015-INIT (accessed: March 2020)

[4] United Nations Office for Disaster Risk Reduction (2018). Monitoring the Implementation of Sendai Framework for Disaster Risk Reduction 2015-2030: A Snapshot of Reporting for 2018. Website: https://www.undrr.org/ (accessed: March 2020)

[5] World Humanitarian Summit (2016). Charter on Inclusion of Persons with Disabilities in Humanitarian Action. Website: http://humanitariandisabilitycharter.org/ (accessed: March 2020)

developing countries can grow in demographic and economic terms at rates compatible with the ecosystem.

From this moment on, we begin to think about a social agenda that considers the relations between development and the environment on a global scale, paying particular attention to political and economic aspects. The principle of sustainable development is associated with topics such as population, food security, species extinction, energy, industry, urban issues, which represent 'collective challenges'. These issues can only be addressed through 'joint efforts'.

In 1992 the United Nations Conference on Environment and Development (UNCED) in Rio de Janeiro, the Earth Summit, consolidated the concept of sustainable development. The two fundamental elements around which the reflection is articulated are the environment, as an essential dimension of economic development, and the intergenerational responsibility in the use of human resources. The Conference is attended by 172 governments, 108 Heads of State and 2,400 representatives of non-governmental organisations that approve Agenda 21, a global programme of action to be undertaken at national and local level in all areas of sustainable development. In addition to this agreement, which focuses on the environment, economy and society, two other agreements have been signed: the Rio Declaration on Environment and Development, which incorporates the standards set at the Stockholm Conference and sets out the 27 principles on the rights and responsibilities of nations in pursuit of development and human well-being, and the Declaration of Principles for the Sustainable Management of Forests, which sets out the standards for their sustainable management, conservation and use. In order to ensure an effective follow-up to the United Nations Conference on Environment and Development, the Commission on Sustainable Development (UNCSD) is established, subsequently replaced by a political forum appointed in 2012 by the United Nations Conference on Sustainable Development.

Progress achieved five years after the definition of Agenda 21 is assessed in 1997 at the 19th United Nations General Assembly, Earth Summit. On this occasion, the growing interest in everything related to sustainable development is underlined, but at the same time the continuing disparities in the achievement of the objectives set are highlighted. This delay is attributed to the phenomenon of globalisation, which has led to an imbalance between those countries where poverty levels have been reduced and others where socio-economic conditions have deteriorated. Indigence, low levels of social development, inadequate infrastructure and lack of capital have prevented these less developed countries from benefiting from globalisation. As a result, their move towards sustainable development requires international support.

The need to work in a spirit of partnership in order to extend the benefits of globalisation to all countries is also confirmed by the Millennium Declaration.

It sets out eight Millennium Development Goals (MDGs), which commit the 193 signatory states to achieving them by 2015: eradicating extreme poverty and world hunger; making primary education universal; promoting gender equality and empowering women; reducing child mortality and maternal mortality; combating AIDS, malaria and other diseases; ensuring environmental sustainability; and building a global partnership for development.

In 2002, the World Summit on Sustainable Development (WSSD), meeting in Johannesburg, reaffirmed the focus on the new challenges to be faced in order to achieve sustainable development: a model of development that combines economic, social and environmental aspects, capable of ensuring a more equitable and prosperous society, with respect for future generations.

Twenty years after the Earth Summit, the United Nations Conference on Sustainable Development (UNCSD), Rio+20, is being held in Rio de Janeiro in 2012, with the aim of renewing the political commitment to sustainable development, monitoring the state of implementation of the international responsibilities assumed over the last two decades and channelling the efforts of governments and civil society towards common goals and new challenges to be faced.

In this context of global action concerning the implementation of the values linked to sustainable development, the definition of the Agenda 2030 for Sustainable Development will take place in 2015.

In September 2015, the United Nations General Assembly adopted the 2030 Agenda for Sustainable Development, which sets out the global guidelines for activities in the coming years (UN Resolution A7RES/70/1, New York September 2015).

In the same year, consistent with Agenda 2030, the Paris Climate Agreement (UN decision 1/CP.21, adoption of the Paris Agreement) and the Sendai Framework for Disaster Risk Reduction (adopted at the Third UN World Conference on Disaster Risk Reduction in Sendai, Japan) were also adopted.

The 17 Sustainable Development Goals (SDGs) that make up Agenda 2030 refer to different areas of social, economic and environmental development that must be considered in an integrated way, as well as the processes that can accompany and foster them in a sustainable way, including international cooperation and the political and institutional context.

As indispensable components, there are numerous references to the well-being of people and to a fair distribution of the benefits of development.

The 2030 Agenda for Sustainable Development is therefore the United Nations' global plan of action for people, the planet and prosperity, which takes into account the need to support universal peace, freedom and the eradication of poverty in all its forms and dimensions, achieving a sustainable transformation of society, the economy and the environment by 2030, including in terms of security, well-being and justice.

The global plan needs concrete policies and also appropriate monitoring and evaluation of progress towards the objectives of the Agenda. To this end, the United Nations Statistical Commission has set up the Inter Agency Expert Group on SDGs (IAEG-SDGs), which has proposed a set of periodically revised indicators, some of which are used to monitor more than one goal (for a total of 247)[6].

A comprehensive review of the indicators is planned in 2020 and another one in 2025.

Also in the context of the implementation of the SDG indicators, the urgency of strengthening the statistical capacity of national statistical systems has been reiterated. For all countries, in fact, the development of technical-scientific activities in this respect is required, as well as an effort in terms of knowledge sharing and dedicated investment. In addition to strengthening the statistical information production of existing National Statistical Systems, Agenda 2030 also requires the use of data that are complementary to official statistics and the use of innovative technologies and methods (Data Revolution)[7].

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[6] The official indicator list below includes the global indicator framework as contained in A/RES/71/313, the refinements agreed by the Statistical Commission at its 49th session in March 2018 (E/CN.3/2018/2, Annex II) and 50th session in March 2019 (E/CN.3/2019/2, Annex II), and the changes from the 2020 Comprehensive Review (E/CN.3/2020/2, Annex II) and annual refinements (E/CN.3/2020/2, Annex III) from the 51st session in March 2020.

For further information, please see the United Nations Statistics Division website: https://unstats.un.org/sdgs/

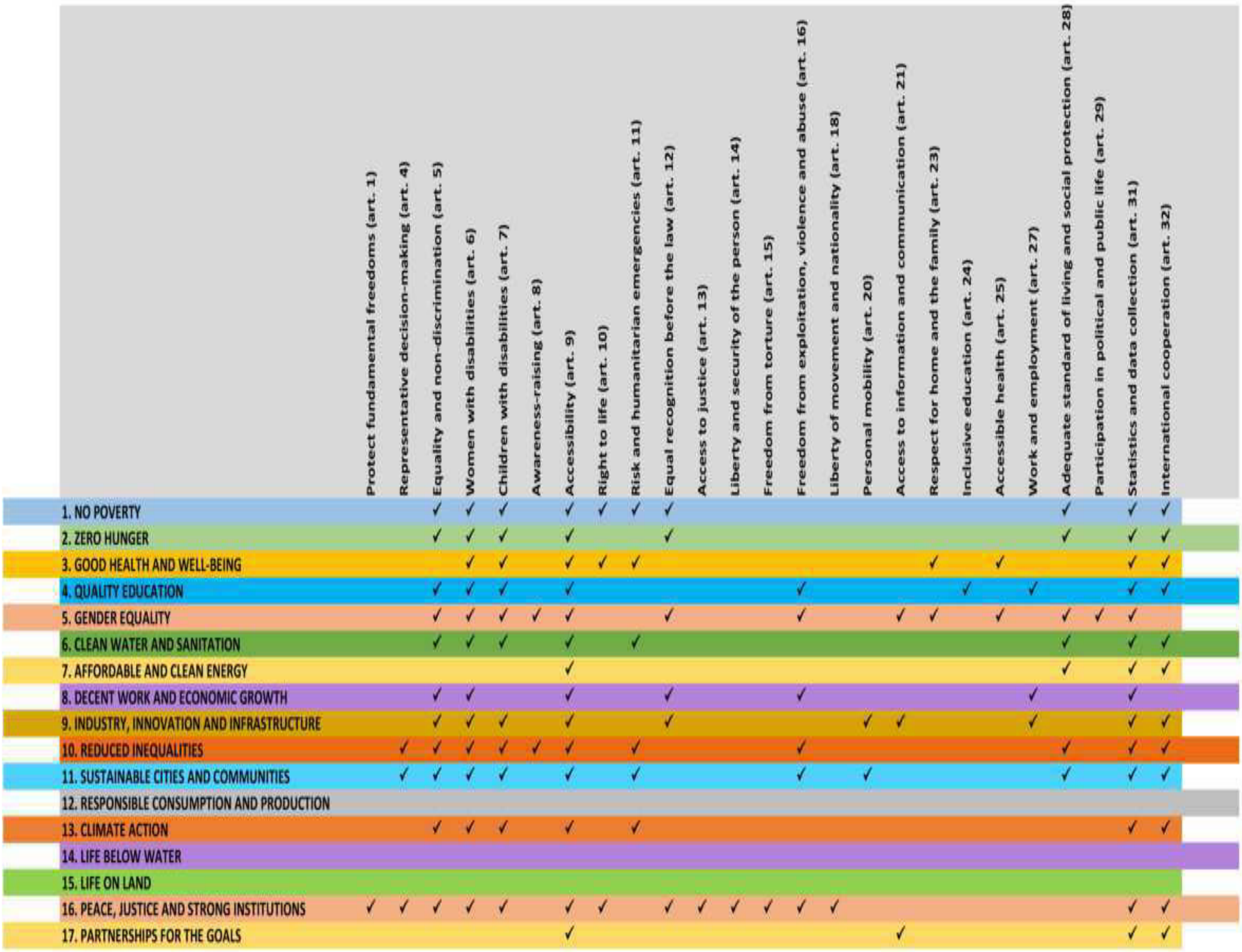
[7] On the importance of how data is counted, please see: Golden, C. Washington Group Meetings, Processes and Milestones. In International Measurement of Disability. Purpose, Method and Application; Altman, B.M., Ed.; Springer International Publishing: Geneva, Switzerland, 2016; pp. 29–52. Washington Group on Disability Statistics. Available online: http://www.washingtongroup-disability.com/ (accessed on March 2020).

In light of this, to understand the data quality of currently available disability data, we suggest the review report authored by Leonard Cheshire in which existing nationally representative datasets within 40 countries are analysed (.

Altman, B.M. (Ed.) International Measurement of Disability. Purpose, Method and Application; Springer International Publishing: Geneva, Switzerland, 2016.

Groce, N.E.; Mont, D. Counting disability: Emerging consensus on the Washington Group questionnaire. Lancet Glob. Health 2017, 5, e649–e650.

Madans, J.H.; Loeb, M.E.; Altman, B.M. Measuring disability and monitoring the UN Convention on the Rights of Persons with Disabilities: The work of the Washington Group on Disability Statistics. BMC Public Health 2011, 11 (Suppl. 4), S4.



	Protect fundamental freedoms (art. 1)	Representative decision-making (art. 4)	Equality and non-discrimination (art. 5)	Women with disabilities (art. 6)	Children with disabilities (art. 7)	Awareness-raising (art. 8)	Accessibility (art. 9)	Right to life (art. 10)	Risk and humanitarian emergencies (art. 11)	Equal recognition before the law (art. 12)	Access to justice (art. 13)	Liberty and security of the person (art. 14)	Freedom from torture (art. 15)	Freedom from exploitation, violence and abuse (art. 16)	Liberty of movement and nationality (art. 18)	Personal mobility (art. 20)	Access to information and communication (art. 21)	Respect for home and the family (art. 23)	Inclusive education (art. 24)	Accessible health (art. 25)	Work and employment (art. 27)	Adequate standard of living and social protection (art. 28)	Participation in political and public life (art. 29)	Statistics and data collection (art. 31)	International cooperation (art. 32)
1. NO POVERTY			✓	✓	✓		✓	✓	✓	✓												✓		✓	✓
2. ZERO HUNGER			✓	✓	✓		✓			✓												✓		✓	✓
3. GOOD HEALTH AND WELL-BEING				✓	✓		✓	✓	✓									✓		✓				✓	✓
4. QUALITY EDUCATION			✓	✓	✓		✓							✓					✓		✓			✓	✓
5. GENDER EQUALITY			✓	✓	✓	✓	✓			✓				✓			✓	✓		✓		✓	✓	✓	
6. CLEAN WATER AND SANITATION			✓	✓	✓		✓		✓													✓		✓	✓
7. AFFORDABLE AND CLEAN ENERGY							✓															✓		✓	✓
8. DECENT WORK AND ECONOMIC GROWTH			✓	✓			✓			✓				✓							✓			✓	
9. INDUSTRY, INNOVATION AND INFRASTRUCTURE			✓	✓	✓		✓			✓						✓	✓				✓			✓	✓
10. REDUCED INEQUALITIES		✓	✓	✓	✓	✓	✓		✓					✓								✓		✓	✓
11. SUSTAINABLE CITIES AND COMMUNITIES		✓	✓	✓	✓		✓		✓					✓		✓						✓		✓	✓
12. RESPONSIBLE CONSUMPTION AND PRODUCTION																									
13. CLIMATE ACTION			✓	✓	✓		✓		✓															✓	✓
14. LIFE BELOW WATER																									
15. LIFE ON LAND																									
16. PEACE, JUSTICE AND STRONG INSTITUTIONS	✓	✓	✓	✓	✓		✓	✓		✓	✓	✓	✓	✓	✓									✓	✓
17. PARTNERSHIPS FOR THE GOALS							✓										✓							✓	✓

Figure 2: Comparing the 2030 Agenda Sustainable Development Goals (SDGs) and the Millennium Development Goals (MDGs)

In many Objectives we find direct references to people with disabilities, in particular n. 4 (education), n.8 (employment), n.10 (inequalities) and n.11 (sustainable cities), all closely linked by the human rights approach.

It is important to highlight the interdependence of the objectives and related targets with particular reference to education, health, violence, especially gender-based violence, emergency, accessibility and training.

3.2 Development goals for persons with disabilities

Disability-inclusive development is an essential condition for a sustainable future, because of its bidirectional link to poverty. Disability may increase the risk of poverty, and poverty may increase the risk of disability.

The eradication of poverty and hunger represents key commitments under Sustainable Development Goals 1 and 2.

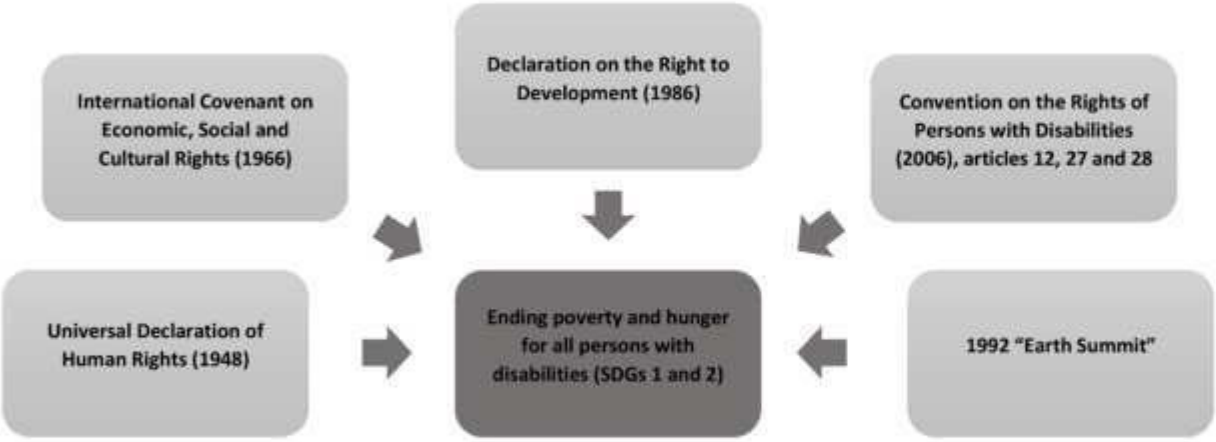


Figure 3: International normative frameworks relevant for the achievement of SDGs 1 and 2 for persons with disabilities (Source: own elaboration based on UN, 2019)

Poverty is a concern under article 28 of the Convention on the Rights of Persons with Disabilities, in which States parties recognise the right of disabled persons to an adequate standard of living for themselves and their families and commit to guaranteeing access by people with disabilities, in particular women and girls with disabilities and older persons with disabilities, to social protection programmes and poverty reduction programmes.

Guaranteeing a healthy life and promoting well-being represent crucial points under Sustainable Development Goal 3. Article 25 of the Convention on the Rights of Persons with Disabilities provides for the same quality and level of healthcare services and programmes to be provided to persons with disabilities at affordable prices as to other persons, while Article 26 provides for the strengthening of comprehensive certification and rehabilitation services and programmes.

Figure 4: International normative framework for people with disabilities relating to the achievement of SDG 3 (Source: own elaboration based on UN, 2019)

Access to health services remains a challenge for people with disabilities, who are three times more likely than people without disabilities not to be able to receive healthcare when they need it. Barriers include the lack of financial resources and public transport, as well as the presence of inaccessible facilities.

In addition, people with disabilities are a heterogeneous group with a wide range of impairments and identity traits such as race, colour, sex, sexual orientation, gender identity, language, religion, national, ethnic, indigenous or social origin and age. The interaction of these traits produces further health and health-care inequalities and barriers. For example, communication barriers are particularly high for migrants, refugees and asylum seekers with disabilities, and financial barriers are especially problematic for certain groups, such as Roma and indigenous persons with disabilities[8].

The current legal framework does not recognise that factors such as those cited above can interact to create multiple or intersectional disadvantage. This situation leaves the most disadvantaged members of society, unable to challenge the discrimination they experience.

Women with disabilities have consistently less access to health-care services and programmes than women without disabilities and men with disabilities.

They also experience worse health care and preventive care. Likewise, they are more likely to be subjected to violence, abuse and neglect and to experience human rights violations in the exercise of their sexual and reproductive health and rights. Women with severe impairments have higher chances of facing unmet needs and human rights violations in health-care settings.

The right to health is recognised in various international and regional human rights instruments, as highlighted in the figure below.

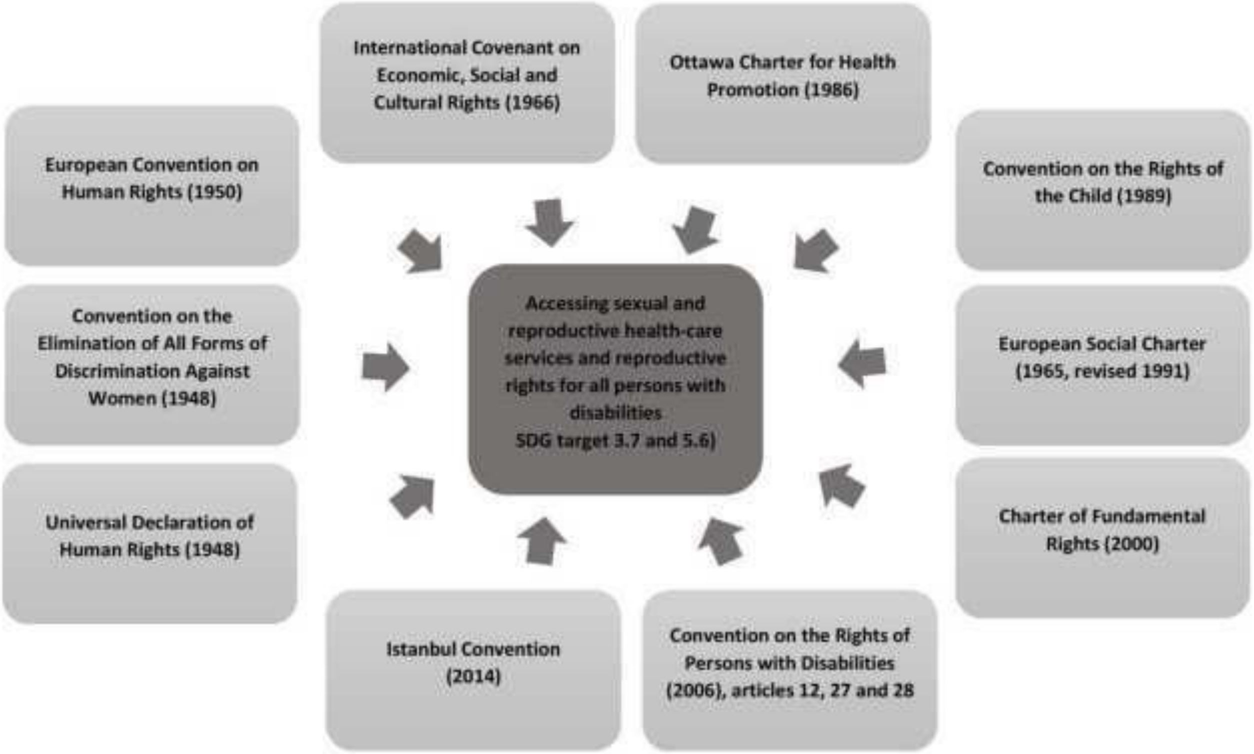


Figure 5: International normative framework for people with disabilities relating to the achievement of SDGs 3 and 5 (Source: own elaboration based on UN, 2019)

Ensuring quality, fair and inclusive education, is a central topic under Sustainable Development Goal 4.

Education is considered a fundamental human right and a necessary condition for improving individual development and effective participation in society. The Universal Declaration of Human Rights (1948) states that everyone has the right to education (art. 26). This guarantee was strengthened following the adoption of the Convention against Discrimination in Education (1960), which outlines the fundamental elements of the right to education and is the first legally binding international instrument. Article 24 also states that States shall recognise the right of persons with disabilities to education and Article 9 commits to ensuring the elimination of obstacles and barriers to accessibility in schools. Sustainable development objective 4 calls for inclusive and

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[8] European Union Agency for Fundamental Rights (FRA), *Inequalities and multiple discrimination in access to and quality of healthcare* (2013), pp. 47–51.

quality education for all, ensuring equal access to all levels of vocational education and training for people with disabilities, and the construction and modernisation of disability-sensitive educational facilities.

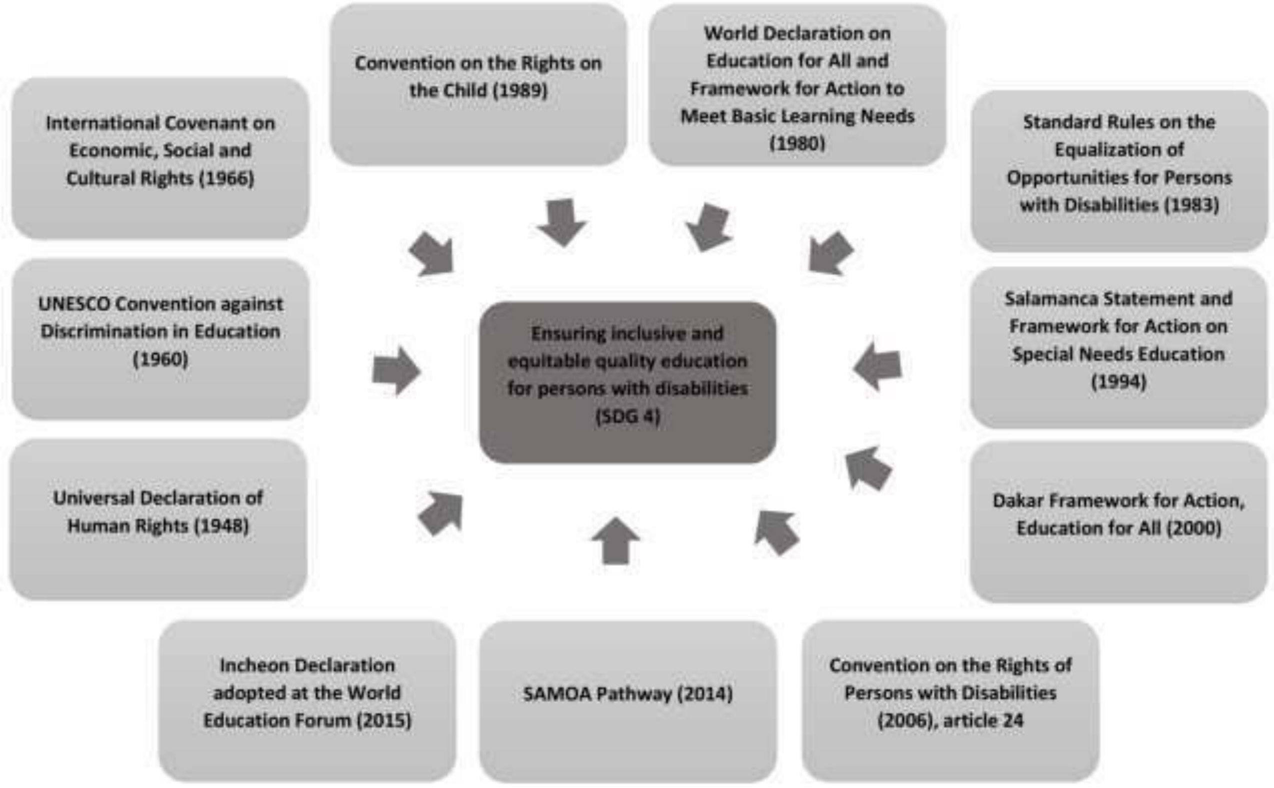

Figure 6: International normative framework for people with disabilities relating to the achievement of SDG 4 (Source: own elaboration based on UN, 2019)

People with disabilities are less likely to attend school and complete primary education and are more likely to be illiterate. In 2010, on average, only 77% of disabled people aged 15-29 years had attended school, compared to 87 percent of non-disabled people of the same age.

Many countries have worked to strengthen national legal frameworks and develop policies to ensure better access to education for people with disabilities. Of the 193 Member States, 34 guarantee in their constitutions the right to education for people with disabilities or provide protection against discrimination on grounds of disability in education. In terms of inclusive education, while in 2013 students with disabilities attend the same class as other students in only 44% of Member States. In 5% of the countries, children with disabilities do not receive any additional support in public education to meet their needs. However, progress has been made in recent years. In 2017, an increasing number of countries provided adequate materials (41% of countries), adequate human resources (33% of countries) and physical environments (33% of countries) for students with disabilities in schools. Out of more than 30,000 school facilities surveyed in various countries (mostly developed countries), only 47% were considered wheelchair accessible.

Measures to encourage the inclusion of students with disabilities range from free and compulsory education for students with disabilities, to financial assistance, the provision of teaching materials, the continuous training of teachers and the education of students without disabilities on disability.

The objective of sustainable development requires the achievement of gender equality and the empowerment of all women and girls to promote the full enjoyment of human rights and fundamental freedoms, including by persons with disabilities, as underlined in Article 6 of the Convention on the Rights of Persons with Disabilities.

Figure 7: International normative framework for people with disabilities relating to the achievement of SDG 5 (Source: own elaboration based on UN, 2019)

Women with disabilities are often subject to multiple forms of discrimination, on account of their gender and disability status, and continue to be disadvantaged in most areas of society and development (United Nations Department of Economic and Social Affairs, 2019). Compared to men without disabilities, women with disabilities are three times more likely to have unmet health needs; twice as likely to be unemployed or inactive on the labour market; three times more likely to be illiterate; and four times less likely to work in senior roles. In addition, women with disabilities are four times more likely to experience sexual violence.

Objectives 6 and 7 set as objectives the availability of water and sanitation, as well as electricity, respectively.

In the context of sustainable development objective 6, States undertake to ensure universal and equitable access to safe and affordable drinking water for all. The need to pay attention to people in vulnerable situations, which implies the inclusion of people with disabilities, is underlined in Objective 6.2.

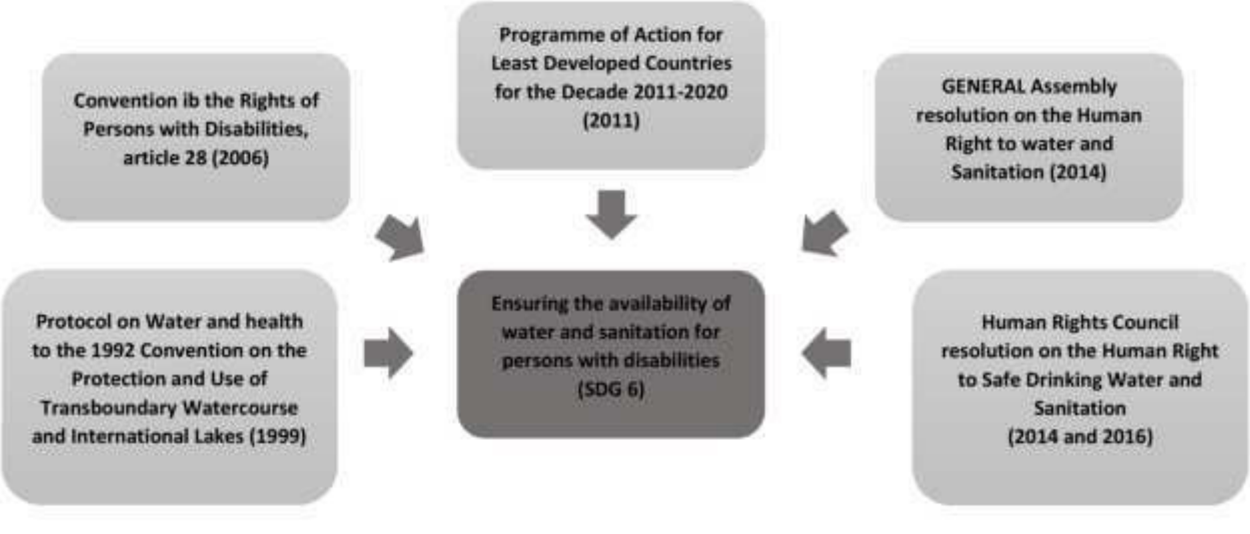

Figure 8: International normative framework for people with disabilities relating to the achievement of SDG 6 (Source: own elaboration based on UN, 2019)

Accessibility and inclusive design are increasingly becoming the norm in many countries, but people with disabilities, particularly those living in developing countries, face barriers in access to water, sanitation and hygiene, including physical, institutional, social and attitudinal barriers. The call for access to energy for all, which implicitly includes people with disabilities, was formulated in the final document of the United Nations Conference on Sustainable Development, entitled "The future we want", as well as in Objective 7, which recognizes the critical role that energy plays in the development process. Of the 50 priority assistance products identified by the WHO, almost half require the use of electricity.

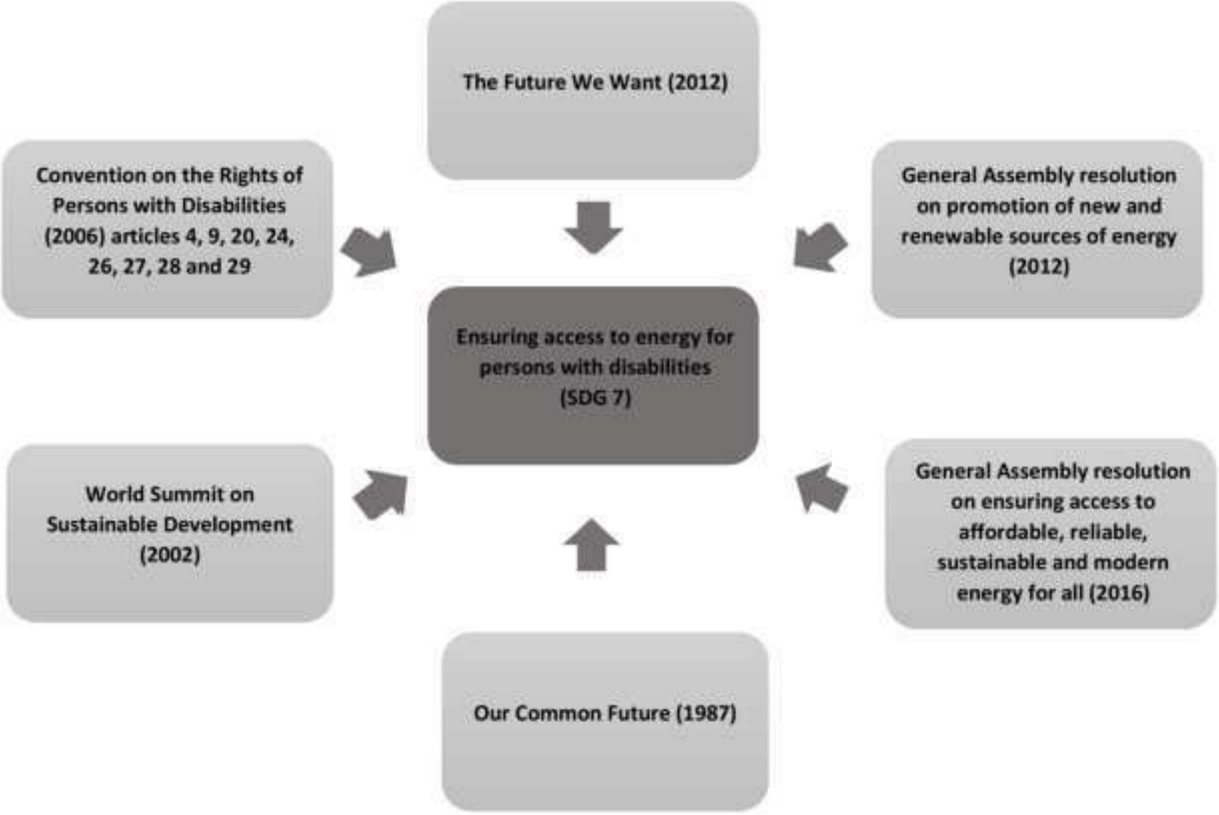

Figure 9: International normative framework for people with disabilities relating to the achievement of SDG 7 (Source: own elaboration based on UN, 2019)

The promotion of inclusive and sustainable economic growth and decent work for all is crucial and is the target of Objective 8. Persons with disabilities are explicitly mentioned as persons to be included in the objective of achieving full and productive employment and decent work for all.

Despite the requirements of the Convention on the Rights of Persons with Disabilities, as reflected in Council Resolution 22/3 on the employment of persons with disabilities, lower employment rates for persons with disabilities are consistently observed. Based on 91 countries, the employment/population ratio of people with disabilities aged 15 and over averages out as 36%, while the ratio of people without disabilities is 60%.

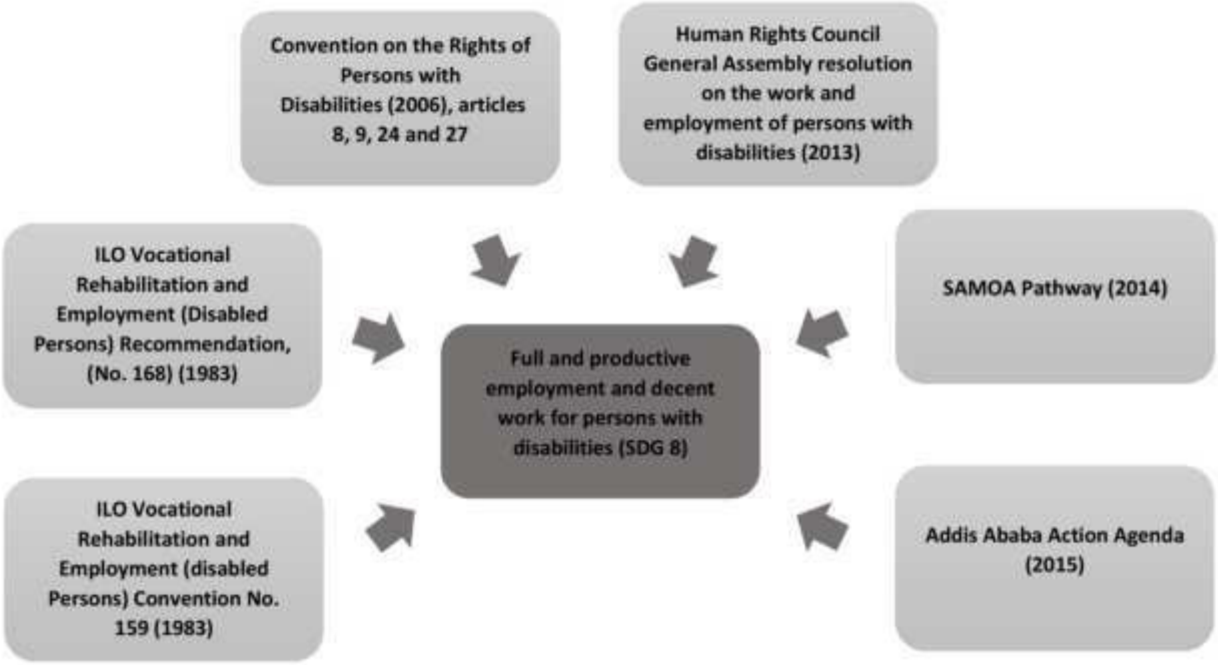

Figure 10: International normative framework for people with disabilities relating to the achievement of SDG 8 (Source: own elaboration based on UN, 2019)

Women with disabilities are less likely to be employed than men with disabilities, but the average gender gap in the ratio of employment to population of people with disabilities aged 15 and over is 11%, compared to 20% of people without disabilities.

People with disabilities in employment tend to earn lower wages than people without disabilities. A positive action measure frequently used by countries to promote the employment of people with disabilities is a quota system, which obliges employers to employ a certain number or percentage of people with disabilities. More than 100 countries have established such quota systems, with quota levels varying mostly between 1% and 15%. 57 The most effective quota systems include the payment of a levy by the defaulting company for each position not held by a disabled person. These levies generally contribute to a special fund used to finance measures to promote the employment of people with disabilities.

The need to increase the use of information and communication technologies and to provide universal access to the Internet at affordable prices is underlined in sustainable development objective 9.

Despite regulatory calls and state commitments, there remains a significant gap between people with and without disabilities in the use of the internet.

Observing that the assistive technology enables and promotes the inclusion, participation and engagement of persons with disabilities[9] and that this has a significant adverse impact on the education, livelihood, health and well-being of individuals, and on families, communities and the whole society, the United Nations Convention on the Rights of Persons with Disabilities adopted a resolution on improving access to assistive technology for everyone and everywhere[10]. Other major international instruments even call for promoting access to technology[11,12] and for

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[9] WHO, Assistive technology fact sheet (18 May 2018), www.who.int/en/news-room/fact-sheets/detail/assistive-technology.

[10] World Health Organization, resolution 71.8 of 26 May 2018, entitled "Improving access to assistive technology", available at http://apps.who.int/gb/ebwha/pdf_files/WHA71/A71_R8-en.pdf.

[11] T. Shakespeare, T. Bright and H. Kuper, "Access to health for persons with disabilities", discussion paper commissioned by the Special rapporteur on the rights of persons with disabilities (2018), pp. 21–26. Available at http://disabilitycentre.lshtm.ac.uk/resources/.

[12] WHO and World Bank, *World Report on Disability* (2011).

investing in accessible and affordable technology for persons with disabilities, as showed in the figure 11 below.

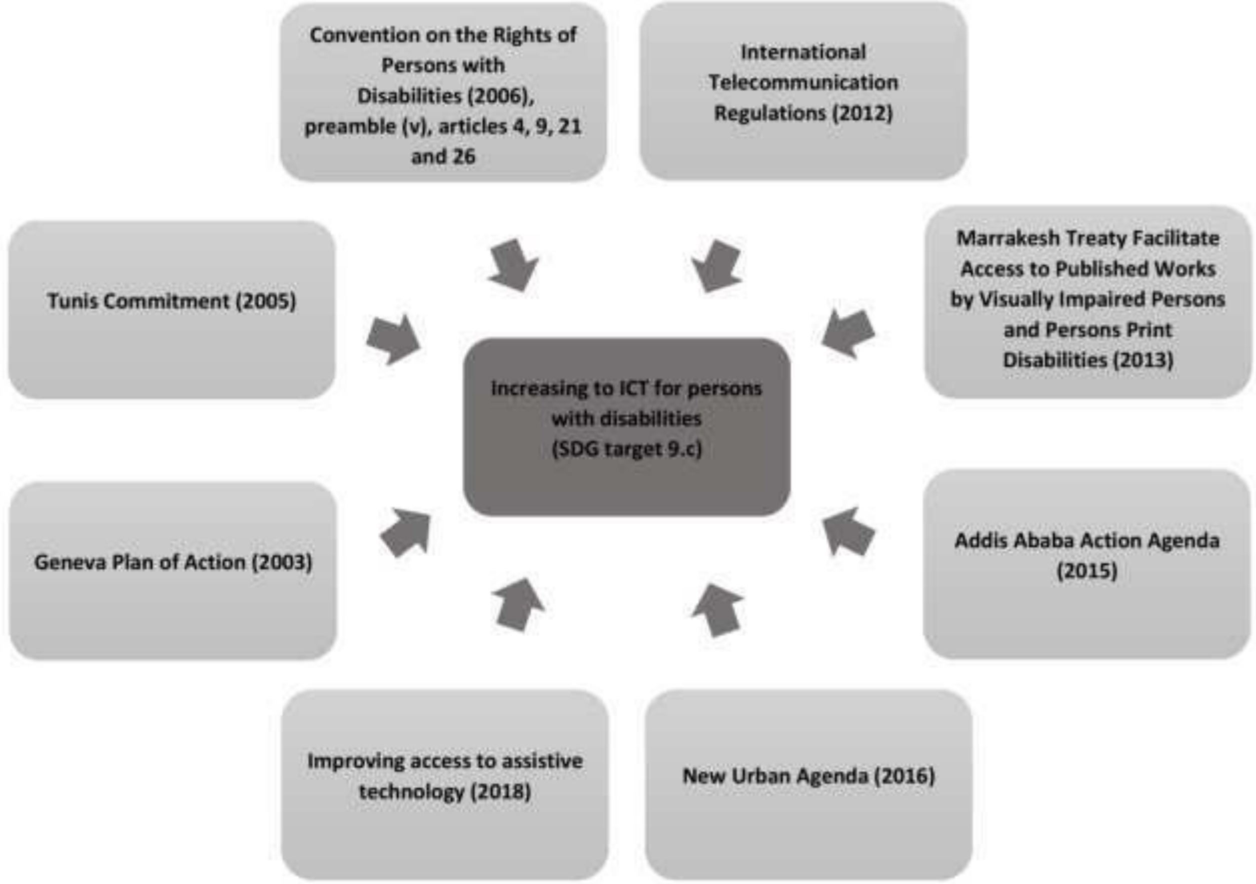

Figure 11: International normative framework for people with disabilities relating to the achievement of SDG 9 (Source: own elaboration based on UN, 2019)

Even with regard to objective 10 of sustainable development, which aims to reduce inequalities, persistent inequality for people with disabilities remains. In all areas covered by the sustainable development objectives, there is a clear gap between people with and without disabilities, and people with disabilities who are systematically disadvantaged. Although the gaps vary from country to country, in some countries the gaps are wide. Although most countries have ratified the Convention on the Rights of Persons with Disabilities and much progress has been made over the last decade in adopting national laws in line with the Convention, some countries still have discriminatory laws and policies, particularly in the areas of education for persons with disabilities and political participation. Again, greater inequalities are typically observed for women with disabilities, as also emerges from the analysis of Objective 5, for indigenous people with disabilities and for people with intellectual and psychosocial disabilities.

Figure 12: International normative framework for people with disabilities relating to the achievement of SDGs 10 and 16 (Source: own elaboration based on UN, 2019)

People with disabilities face a number of barriers that prevent them from exercising their right to live independently and in the community, their right to adequate housing, the use of accessible means of transport and access to public facilities and spaces. Sustainable development objective 11, which calls for cities and human settlements to be made inclusive and sustainable, with a particular focus on ensuring access for all to adequate, safe and affordable housing and basic services, is also far from being achieved in many countries.

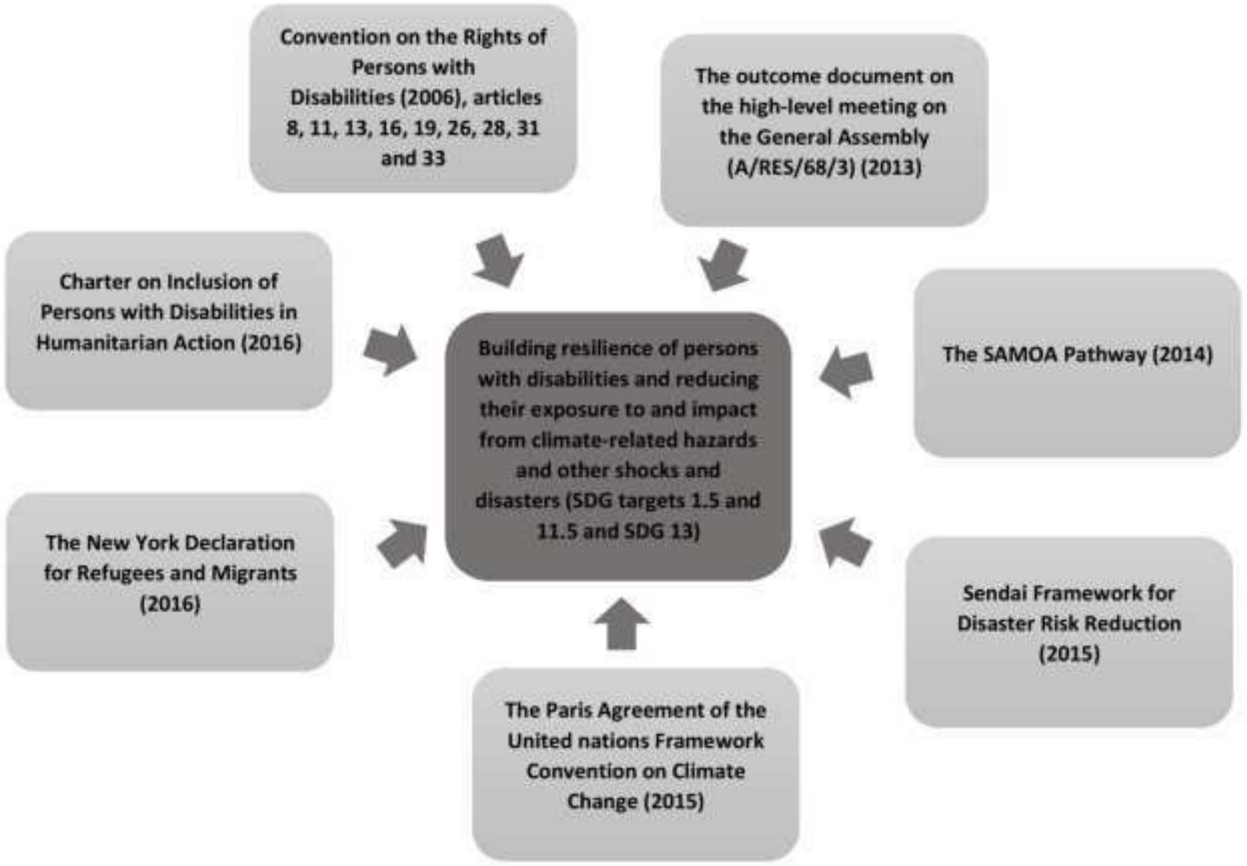

Figure 13: International normative framework for people with disabilities relating to the achievement of SDGs 1, 11 and 13 (Source: own elaboration based on UN, 2019)

Objective 16 of sustainable development also pays attention to people with disabilities. The objective requires the promotion of inclusive societies in which all persons, including persons with disabilities, have access to information, justice and responsible public services and participate in public decision-making at all levels. For people with disabilities, several subobjectives of Objective 16 are essential to ensure their full inclusion and participation: they take up the demands of the Convention on the Rights of Persons with Disabilities for equal recognition before the law, access to justice and freedom from exploitation, violence and abuse.

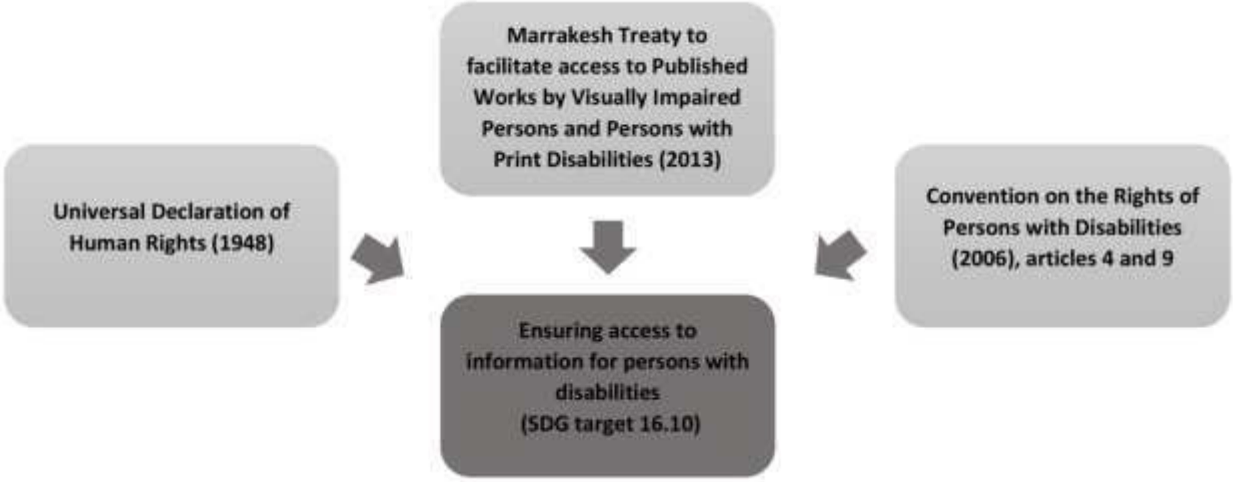

Figure 14: International normative framework for people with disabilities relating to the achievement of SDG 16 (Source: own elaboration based on UN, 2019)

Monitoring progress, ensuring that no one is left behind and providing essential information for policy guidance require high quality, timely and reliable, disaggregated data. This is Objective 17 of sustainable development. Much is being done by international bodies, such as WHO, UNICEF and ILO, but there is still a long way to go to make people with disabilities visible.

3.3 Mainstreaming disability into Sustainable Development Goals

People with disabilities are at a disadvantage compared to most of the sustainable development objectives, as can be seen from the analyses mentioned in the previous paragraph. Furthermore, despite progress in laws and policies in line with the Convention on the Rights of Persons with Disabilities, progress in implementing these measures has been slow. Discriminatory laws still exist in many countries. In order to achieve the objectives by 2030, international and national development programmes will need to prioritise inclusive development. In particular, concrete actions are needed to make people with disabilities and their situation visible in policy-making and to build fair and inclusive societies.

The inclusion of disability will require international efforts and effective partnerships. Indeed, while there are excellent examples of organisations that have inclusive development policies and programmes, there are many other organisations that do not understand and are not aware of the problems of disability.

The key issues causing the exclusion of people with disabilities need to be addressed urgently: discriminatory laws and policies, lack of accessibility to physical and virtual environments, negative attitudes, stigma and discrimination, lack of access to assistive technology and rehabilitation and lack of measures to promote independent living of people with disabilities. Removing these barriers requires capacity building in countries.

All national legal and policy frameworks should reflect the rights of persons with disabilities and be aligned with the Convention on the Rights of Persons with Disabilities, in particular by eliminating discriminatory legislation and language. Accessibility is best pursued through regulations and guidelines at EU level and by thematic area, in accordance with national laws and accountability mechanisms. Negative attitudes are often the result of a misunderstanding of disability and the potential of people with disabilities as a contribution to society. Education systems and the media, given their wide dissemination, can contribute to the effective combating of stereotypes.

The United Nations General Assembly in its report "United Nations 2018 flagship report on disability and development: realization of the Sustainable Development Goals by, for and with persons with disabilities" (2018), summarizes the key points on which the international community and individual states must act to ensure an inclusive society also for people with disabilities: “In many countries, essential services for persons with disabilities lack funding, are of poor quality or are unavailable. Although mainstreaming disability into all Sustainable Development Goals will be essential for the achievement of the Goals, there are fundamental areas needing urgent action to catalyse progress, namely access to social protection, education, employment and basic services. When designing and implementing social protection systems, States should ensure a flexible combination of income security and disability-related job support to promote the economic empowerment and employment of persons with disabilities. In education, special education systems for persons with disabilities should be discouraged and educational opportunities within the mainstream system provided instead. Increasing access to health for persons with disabilities will require accessible health services and training of health professionals on ways to adequately care for persons with disabilities. To provide inclusive access to water and sanitation, emphasis on accessible designs, including accessible toilets, water points, water carriers, bathing places and handwashing facilities, is needed.

Monitoring and evaluation of progress are also crucial for success in the implementation of the Sustainable Development Goals for persons with disabilities. Many relevant global and country indicators are still not disaggregated by disability status. It is therefore necessary for disability disaggregation to become standard in all relevant monitoring systems of Governments and civil society organizations, to inform the development of disability-inclusive national policies and programmes”.

1.5 Practical implication

The UN Convention on the Rights of Persons with Disabilities, as mentioned in the previous paragraphs, aims to "promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities and to promote respect for their inherent dignity". It reflects the major change needed in global understanding and responses to disability. Everyone must have the most correct information available on disability in order to understand, appreciate and contribute to improving the lives of people with disabilities and to facilitate the implementation of the objectives of the Convention.

Unfortunately, there are still too few disability movements actively working to improve the living conditions of people with different abilities, and this is even more true in developing countries. Still too often, people with disabilities are part of vulnerable groups, weakly represented in civil society or, even worse, completely marginalised, and if they are women, this is even more true.

It follows, unfortunately, that the concepts of marginalisation, suppression and repression are still prevalent when it comes to the needs of people with disabilities.

Only knowledge can generate mutual respect and understanding and contribute to a truly inclusive society.

Gathering information on knowledge, beliefs and attitudes towards disability can help to identify gaps in public understanding and these gaps can be filled mainly through education and public information. Therefore, it is vital to improve public understanding of disability, address negative perceptions and represent disability equally. One of the drivers of inclusiveness is certainly the school authorities who must ensure that schools are inclusive and promote an ethos of valuing diversity.

Everyone, individuals and organizations, must see the great link between disability and personal talent development, a link that is often overlooked.

Educational programmes must be geared towards the development of talent in each individual, whether skilled or not. In addition to education, the skills of human resources working in all areas responsible for the management of people with disabilities should be regularly enhanced. A review of staff knowledge and skills in relevant areas can provide a starting point for developing appropriate measures.

Attitudes and knowledge of people working, for example, in education, health care, rehabilitation, social protection, employment, law enforcement and media are particularly important to ensure non-discrimination and participation.

Together with education, governments, voluntary organisations and professional associations should pay special attention to the possibility of conducting social marketing campaigns that can change attitudes on stigmatised issues such as mental illness and other forms of disability. Media involvement is vital to the success of these campaigns and to ensure the dissemination of positive stories about people with disabilities and their families.

The planned recognition by society is another crucial point to ensure that this group of people is properly positioned in society, to ensure that their concerns are addressed in a conscious and appropriate way.

References

European Commission (2010). European Disability Strategy 2010-2020: A Renewed Commitment to a Barrier-Free Europe. Website: http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=COM%3A2010%3A0636%3AFIN%3Aen%3APDF (accessed: March 2020)

European Union Agency for Fundamental Rights – FRA (2013). Inequalities and multiple discrimination in access to and quality of healthcare (2013), pp. 47–51.

General Secretariat of the Council (2015). Draft Council conclusions on disability-inclusive disaster management – Adoption. Website: https://www.consilium.europa.eu/register/en/content/out/?&typ=ENTRY&i=ADV&DOC_ID=ST-6450-2015-INIT (accessed: March 2020)

Shakespeare T, Bright T and Kuper H (2018). "Access to health for persons with disabilities", discussion paper commissioned by the Special rapporteur on the rights of persons with disabilities, pp. 21–26. Available at http://disabilitycentre.lshtm.ac.uk/resources/.

United Nations (1972). Report of the United Nations Conference on the Human Environment (A/CONF.48/14/REV.1), Stockholm, 5-16 June 1972, New York 1973, http://www.un.org/ga/search/view_doc.asp?symbol=A/CONF.48/14/REV.1.

United Nations (1987). Report of the World Commission on Environment and Development: Our Common Future (A/42/427), 4 August 1987, https://sustainabledevelopment.un.org/content/documents/5987our-common-future.pdf.

United Nations (1992). Conference on Environment and Development (UNCED), Earth Summit, Rio de Janeiro, Brazil 3-14 June 1992, https://sustainabledevelopment.un.org/milestones/unced.

United Nations (1993). Resolution adopted by the General Assembly on the report of the second Committee (A/47/719), 29 January 1993, http://www.un.org/documents/ga/res/47/ares47-191.htm.

United Nations (1997). Programme for the Further Implementation of Agenda 21, A/RES/S-19/2, 19 September 1997, http://www.un.org/en/ga/search/view_doc.asp?symbol=A/RES/S-19/2.

United Nations (2000). Millennium Declaration, Resolution adopted by the General Assembly, 8 September 2000, http://www.un.org/millennium/declaration/ares552e.htm.

United Nations (2002). Johannesburg Declaration on Sustainable Development, World Summit on Sustainable Development, A/CONF.199/29, 4 September 2002, http://www.un-documents.net/jburgdec.htm.

United Nations Office for Disaster Risk Reduction (2018). Monitoring the Implementation of Sendai Framework for Disaster Risk Reduction 2015-2030: A Snapshot of Reporting for 2018. Website: https://www.undrr.org/ (accessed: March 2020).

United Nations General Assembly (2018). United Nations 2018 flagship report on disability and development: realization of the Sustainable Development Goals by, for and with persons with disabilities. Website: https://www.un.org/development/desa/disabilities/news/news/new-un-report-on-disability-sdgs.html (accessed: March 2020).

United Nations (2019). Conference of States Parties to the Convention on the Rights of Persons with Disabilities. Twelfth session, New York, 11–13 June 2019. Website: https://www.un.org/development/desa/disabilities/conference-of-states-parties-to-the-convention-on-the-rights-of-persons-with-disabilities-2/cosp12.html (accessed: March 2020)

United Nations Department of Economic and Social Affairs, (2019). Achieving gender equality and empowering all women and girls with disabilities (Goal 5), in Disability and Development Report 2018: Realizing the Sustainable Development Goals by, for and with Persons with Disabilities, UN, New York, https://doi.org/10.18356/26e82c95-en.

United Nations (2020). Global indicator framework for the Sustainable Development Goals and targets of the 2030 Agenda for Sustainable Development, adopted by the General Assembly (A/RES/71/313), annual refinements contained in E/CN.3/2018/2 (Annex II), E/CN.3/2019/2 (Annex II), and 2020 Comprehensive Review changes (Annex II) and annual refinements (Annex III) contained in E/CN.3/2020/2. Website: https://unstats.un.org/sdgs/indicators/Global%20Indicator%20Framework%20after%202020%20review_Eng.pdf

World Health Organization-WHO & World Bank (2011). World Report on Disability. ISBN-13: 978-92-4-156418-2

World Humanitarian Summit (2016). Charter on Inclusion of Persons with Disabilities in Humanitarian Action. Website: http://humanitariandisabilitycharter.org/ (accessed: March 2020).

World Health Organization-WHO (2018). Assistive technology fact sheet, www.who.int/en/news-room/fact-sheets/detail/assistive-technology.

World Health Organization-WHO (2018). Resolution 71.8 of 26 May 2018, entitled “Improving access to assistive technology”, available at http://apps.who.int/gb/ebwha/pdf_files/WHA71/A71_R8-en.pdf.

Third Chapter

Does everybody count? The case of women with disabilities

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Abstract

The codification, collection and analysis of consistent information about health and disability are crucial to build and implement policies for promoting the rights of persons with disabilities. Data on disability, in general, and on women and girls with disabilities, in particular, are not gathered in a consistently way also since there are different definitions of disability across countries. The inclusion of people with disabilities among vulnerable people in Agenda 2030 makes their status more relevant and recognises the unique challenges that people with disabilities face in the fight for their rights. This commitment can only be achieved if the global community is able to develop evidence-based policies, assess progress towards their implementation, and understand the remaining challenges.

Keywords: disability; women; indicators; data

1.1 Disability is not a gender-neutral condition

Women and girls with disabilities are constantly faced with multiple and intersectional discrimination due to their gender and disability (UNCRPD, 2016; European Disability Forum, 2019).

At the "Counted and visible: Global conference on the measurement of gender and intersecting inequalities"[1], held in New York on February 2020, several international experts from UN Agencies, government officials, leaders from private foundations, and civil society organizations, explored four crucial topics: The importance of measuring gender and intersecting inequalities and its theoretical foundations; Multi-level data disaggregation and gender-responsive monitoring of the SDGs; Innovations in data collection, analysis, dissemination and communication, including use of technology for measuring intersecting inequalities; The policy and programmatic uses of data on gender and intersecting inequalities.

Sandra Fredman provided attention to the SDGs and human rights relationships:

> *"The 2030 Agenda and its Sustainable Development Goals (SDGs) broke new ground with their explicit commitment to protect human rights. Yet the relationship between human rights and the SDGs remains contentious and underdeveloped. Whereas the SDGs measure success through the improvement of collective welfare, human rights focus on the intrinsic value of each human being and on securing individual rights. These different strengths need to work together if we are to achieve the Agenda's promise to empower all women and girls and leave no-one behind. […]*
> *For the SDGs to be truly transformative for women and girls, they must reflect a transformative understanding of gender equality – one that goes beyond seeking the same treatment for women as men."*

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[1] For more information about the "Counted and Visible: Global conference on the measurement of gender equality, leave no one behind and intersecting inequalities", please see the website: https://data.unwomen.org/news/counted-and-visible-global-conference-measurement-gender-and-intersecting-inequalities (accessed on March 2020).

Not only does the intersection of disability and gender with race, ethnic origin, social background, age, sexual orientation, nationality, religion, refugee or migrant status, and others, have a multiplier effect that reinforces the discrimination they face every day in the world. Women with disabilities do not enjoy equal opportunities to participate, on similar terms with others, in all aspects of society. Still, they are all too often excluded from education, employment, access to poverty reduction programmes, access to adequate housing and participation in political and public life.

> *"[...] a four-dimensional framework of substantive equality, requiring simultaneous attention to the need to: redress disadvantage (the redistributive dimension); address stereotyping, stigma, humiliation and violence (the recognition dimension); facilitate voice and agency (the participative dimension); and transform structures (the transformative dimension). The four-dimensional concept has recently been incorporated by the Committee on the Rights of Persons with Disabilities in its General Comment on equality and disabled persons. It casts particular light on intersectionality, where inequality is intensified but often invisible."*

Besides, certain legislative acts prevent them from making decisions about their lives, including their sexual and reproductive rights (European Disability Forum, 2011 and 2018).

There are also several obstacles to the exercise of their rights as citizens (European Parliament, 2018). This discrimination stems from the way people construct their identities, failing to recognise diversity as a value, as discussed in previous chapters, and tending to have a uniform view of women with disabilities in all social spaces. Many states around the world have discriminatory laws, policies and practices. They are far from adopting robust and far-reaching legislation to protect women with disabilities from intersectional discrimination in all aspects of life (UNCRPD, 2016).

Discrimination against women and girls with disabilities can take many forms not only in the public sphere but also in the private field, for example, within the family. Regardless of the form, it takes, and where it takes place, the impact of discrimination violates the rights of women with disabilities.

It may be direct when women with disabilities are treated less favourably than another person in a similar situation. For example, it occurs when the testimonies of women with intellectual or psychosocial disabilities are rejected by the policy or in court proceedings, thus denying these women justice and effective remedies as victims of violence[2] (UNHCHR, 2012; European Union Agency for Fundamental Rights, 2014; Inclusion Europe, 2018).

Discrimination can be indirect when laws, policies or practices that appear a priori neutral have a negative impact on women with disabilities. An example of this is the inaccessibility of health care facilities to carry out prevention and control examinations that are fundamental for women. Often women who play a caring role suffer discrimination by association; this is even more evident if the woman is disabled.

There is also a type of discrimination (structural or systemic) that is reflected in hidden or overt patterns of discriminatory institutional behaviour, discriminatory cultural traditions and discriminatory social norms and/or rules. Harmful gender and disability stereotypes, which can lead to such discrimination, are linked to the lack of specific policies, regulations and services for women with disabilities. For example, due to stereotypes based on the intersection of gender and disability, women with disabilities may face barriers when reporting violence, such as disbelief by police, prosecutors and courts.

With that in mind, Sandra Fredman (2016) argued

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[2] All these acts and practices constitute serious violations of their fundamental rights and should be condemned and effectively sanctioned. The ratification by the EU and all its Member States of the Council of Europe Convention on preventing and combating violence against women and domestic violence ("Istanbul Convention") 21 is particularly required. More information about the Istanbul Convention is available on the website of the Council of Europe, here: https://www.coe.int/en/web/istanbul-convention/.

> “ […] *for a four-dimensional framework of substantive equality, requiring simultaneous attention to the need to: redress disadvantage (the redistributive dimension); address stereotyping, stigma, humiliation and violence (the recognition dimension); facilitate voice and agency (the participative dimension); and transform structures (the transformative dimension). The four-dimensional concept has recently been incorporated by the Committee on the Rights of Persons with Disabilities in its General Comment on equality and disabled persons. It casts particular light on intersectionality, where inequality is intensified but often invisible.”*

Lack of awareness, education and policies to prevent harmful stereotypes about women with disabilities by public officials, be they teachers, health service providers, police officers, judges, and the general public, can often lead to the violation of rights.

Women with disabilities remain on the margins of society: not only is their condition worse than that of non-disabled women, but it is also worse than that of men with disabilities (European Disability Forum, 2011 and 2018).

This situation requires that all countries take measures to ensure the full and equal enjoyment by women with disabilities of all human rights and fundamental freedoms.

As stated by CRPD Committee in the General Comment No. 3 on women and girls with disabilities (2016), paragraph 16:

> *“Intersectional discrimination recognises that individuals do not experience discrimination as members of a homogenous group but rather, as individuals with multidimensional layers of identities, statuses and life circumstances. It means acknowledging the lived realities and experiences of heightened disadvantage of individuals caused by multiple and intersecting forms of discrimination, which requires targeted measures with respect to disaggregated data collection, consultation, policymaking, enforceability of non-discrimination and provision of effective remedies.”*

Other institutions, such as the Committee on Elimination of Discrimination against Women, these multiple and intersectional forms of discrimination are increasingly taken into account. They should be recognized as crucial and addressed by policy-makers and legislators worldwide.

These forms of multiple and intersectional discrimination require the adoption of targeted political and social measures, but to identify and adopt effective remedies, it is first necessary to collect individual statistical data and detailed information.

1.2 The disability and gender-related global indicator framework for Sustainable Development Goals

Including people with disabilities in the definition of vulnerable people in Agenda 2030 makes their status more relevant and recognises the unique challenges that people with disabilities face in the fight for their rights. This commitment can only be achieved if the global community can accompany this effort through the development of evidence-based policies, the assessment of progress made, and the identification of remaining challenges. The lack of robust and disaggregated data for people with disabilities exacerbates vulnerabilities and limits the international community's ability to understand the discrimination and exclusion of people with disabilities.

There is still a severe lack of robust knowledge of the difficulties faced by individuals with disabilities. These limitations of existing data and information reflect the lack of relevance that disability has historically received within the global community. As a result, there has also been little political commitment to recognise and address the real situation of people with disabilities and the resource implications that this implies. When data are lacking, the political determination to address inequalities is always limited, and budgetary constraints ultimately steer policy towards other priorities.

As outlined in the United Nations report (2017),

> "*The lack of sound disaggregated data for many of these vulnerable groups -including children, youth, persons with disabilities, people living with HIV, older persons, indigenous peoples, migrants, refugees and those internally displaced- exacerbates vulnerabilities by masking the extent of deprivation and disparities. What's more, a lack of rigorous evidence and comprehensive data has long compromised the ability of governments and the international community to accurately document the discrimination faced by various groups.*
>
> *As a result, planning and budgeting for necessary services along with effective policymaking have suffered. Children living outside of family care, persons with disabilities and older persons, for example, have largely fallen off the statistical "map". While innovative approaches for bringing these hidden populations into focus have begun to emerge, more resources and capacity-building efforts are needed to ensure that vulnerable groups receive their long-overdue place in the development agenda.*"

SDGs progress can only be monitored and implemented through accurate and timely, sufficiently disaggregated, relevant, accessible and user-friendly data and statistics.

Data availability and quality have steadily improved over the years, but need to be strengthened. This requires coordinated efforts by data producers and users of multiple data systems. An innovative approach is also required to produce and apply critical data and statistics in addressing the multi-faceted challenges of sustainable development.

The disaggregation of data, not only for disability but also for other characteristics such as gender and socio-economic status, can detect essential elements for effective planning and to address the needs of those who are most marginalised. The disaggregation of data allows this result to be achieved, highlighting where inequalities exist and removing the invisibility of marginalized groups.

Agenda 2030 objective 17.18 also states that in order not to leave anyone behind, in particular it points out that "Sustainable Development Goal indicators should be disaggregated, where relevant, by income, sex, age, race, ethnicity, migratory status, disability and geographic location, or other characteristics, in accordance with the Fundamental Principles of Official Statistics" (General Assembly Resolution 68/261).

The introduction of SDGs has therefore increased the political drive for improving disability data that started with the adoption of the Convention on the Rights of Persons with Disabilities (CRPD) in 2006, but much remains to be done (WHO, 2015).

The table in the Annex contains the updated tier classification, made by the Inter-agency and Expert Group on SDG Indicators (IAEG-SDGs). This tier classification is expected to change as methodologies are developed, and data availability increases. Also reflected in the document are the possible custodian agencies for the indicators.

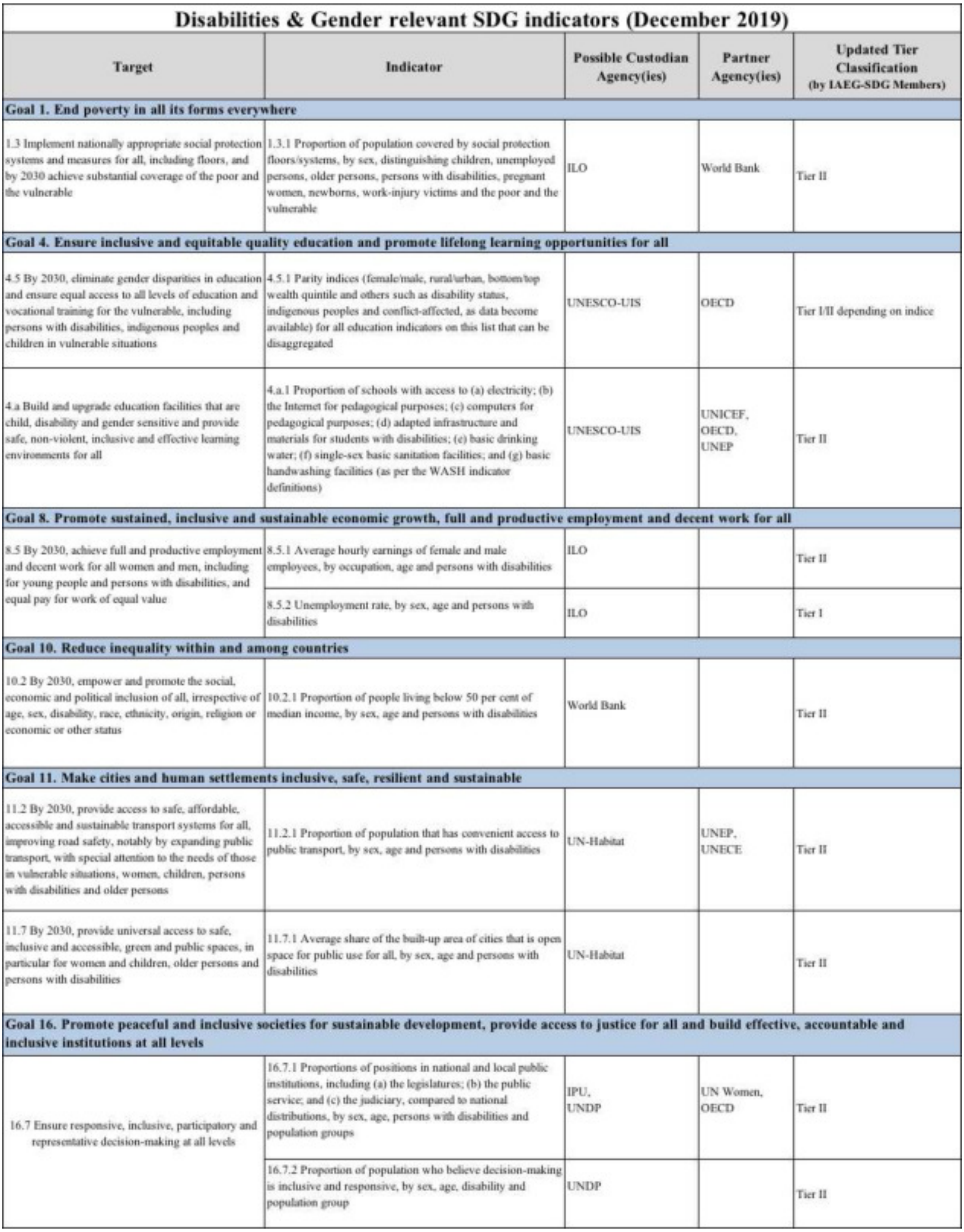
In order to facilitate the implementation of the global indicator framework, all indicators are classified by the IAEG-SDGs into three tiers based on their level of methodological development and the availability of data at the worldwide level (UN, 2020), as follows:

> *Tier 1: Indicator is conceptually clear, has an internationally established methodology and standards are available, and data are regularly produced by countries for at least 50 per cent of countries and of the population in every region where the indicator is relevant.*
>
> *Tier 2: Indicator is conceptually clear, has an internationally established methodology and standards are available, but data are not regularly produced by countries.*
>
> *Tier 3: No internationally established methodology or standards are yet available for the indicator, but methodology/standards are being (or will be) developed or tested.*

All indicators are equally relevant, and the tier system is intended exclusively to support in the development of global implementation strategies. For tier I and II indicators, the availability of data at the national level may not necessarily in line with the global tier classification and countries can create their own tier classification for implementation.

As indicated on the UN website, the updated tier classification (December 2019) contains 116 Tier I indicators, 92 Tier II indicators and 20 Tier III indicators. In addition to these, 4 indicators have multiple tiers (different components of the indicator are classified into different tiers).

In the table below, the SDG indicators that are relevant for both disability and gender are presented. The table shows for each target the indicators and where to find the data, as well as whether the data is regularly collected at national level or there are no standard methodologies.



Disabilities & Gender relevant SDG indicators (December 2019)

Target	Indicator	Possible Custodian Agency(ies)	Partner Agency(ies)	Updated Tier Classification (by IAEG-SDG Members)
Goal 1. End poverty in all its forms everywhere				
1.3 Implement nationally appropriate social protection systems and measures for all, including floors, and by 2030 achieve substantial coverage of the poor and the vulnerable	1.3.1 Proportion of population covered by social protection floors/systems, by sex, distinguishing children, unemployed persons, older persons, persons with disabilities, pregnant women, newborns, work-injury victims and the poor and the vulnerable	ILO	World Bank	Tier II
Goal 4. Ensure inclusive and equitable quality education and promote lifelong learning opportunities for all				
4.5 By 2030, eliminate gender disparities in education and ensure equal access to all levels of education and vocational training for the vulnerable, including persons with disabilities, indigenous peoples and children in vulnerable situations	4.5.1 Parity indices (female/male, rural/urban, bottom/top wealth quintile and others such as disability status, indigenous peoples and conflict-affected, as data become available) for all education indicators on this list that can be disaggregated	UNESCO-UIS	OECD	Tier I/II depending on indice
4.a Build and upgrade education facilities that are child, disability and gender sensitive and provide safe, non-violent, inclusive and effective learning environments for all	4.a.1 Proportion of schools with access to (a) electricity; (b) the Internet for pedagogical purposes; (c) computers for pedagogical purposes; (d) adapted infrastructure and materials for students with disabilities; (e) basic drinking water; (f) single-sex basic sanitation facilities; and (g) basic handwashing facilities (as per the WASH indicator definitions)	UNESCO-UIS	UNICEF, OECD, UNEP	Tier II
Goal 8. Promote sustained, inclusive and sustainable economic growth, full and productive employment and decent work for all				
8.5 By 2030, achieve full and productive employment and decent work for all women and men, including for young people and persons with disabilities, and equal pay for work of equal value	8.5.1 Average hourly earnings of female and male employees, by occupation, age and persons with disabilities	ILO		Tier II
	8.5.2 Unemployment rate, by sex, age and persons with disabilities	ILO		Tier I
Goal 10. Reduce inequality within and among countries				
10.2 By 2030, empower and promote the social, economic and political inclusion of all, irrespective of age, sex, disability, race, ethnicity, origin, religion or economic or other status	10.2.1 Proportion of people living below 50 per cent of median income, by sex, age and persons with disabilities	World Bank		Tier II
Goal 11. Make cities and human settlements inclusive, safe, resilient and sustainable				
11.2 By 2030, provide access to safe, affordable, accessible and sustainable transport systems for all, improving road safety, notably by expanding public transport, with special attention to the needs of those in vulnerable situations, women, children, persons with disabilities and older persons	11.2.1 Proportion of population that has convenient access to public transport, by sex, age and persons with disabilities	UN-Habitat	UNEP, UNECE	Tier II
11.7 By 2030, provide universal access to safe, inclusive and accessible, green and public spaces, in particular for women and children, older persons and persons with disabilities	11.7.1 Average share of the built-up area of cities that is open space for public use for all, by sex, age and persons with disabilities	UN-Habitat		Tier II
Goal 16. Promote peaceful and inclusive societies for sustainable development, provide access to justice for all and build effective, accountable and inclusive institutions at all levels				
16.7 Ensure responsive, inclusive, participatory and representative decision-making at all levels	16.7.1 Proportions of positions in national and local public institutions, including (a) the legislatures; (b) the public service; and (c) the judiciary, compared to national distributions, by sex, age, persons with disabilities and population groups	IPU, UNDP	UN Women, OECD	Tier II
	16.7.2 Proportion of population who believe decision-making is inclusive and responsive, by sex, age, disability and population group	UNDP		Tier II

Source: own elaboration based on SDG Indicators (https://unstats.un.org/sdgs/iaeg-sdgs/tier-classification/)

Even today, however, despite the efforts and progress made in data collection, the system is still not able to fully and comprehensively answer these questions. Significant information gaps remain, linked both to the lack of indicators capable of adequately capturing the phenomenon and to the unavailability or poor dissemination of data of an administrative nature.

It is difficult while acknowledging the attempts made, to prepare, as required by the Convention on the Rights of Persons with Disabilities, statistical tools capable of going beyond the health aspect and assessing the real level of participation and inclusion of persons with disabilities. This implies indicators capable of measuring the "interaction between person and environment" to which the Convention refers. According to the Convention, disability is not a characteristic of the individual inherent in pathology or impairment. Still, it is the interaction with a social organization that restricts the activities and opportunities for participation of people with disabilities, placing environmental barriers and hostile attitudes in their path.

Conditions of exclusion and territorial inequalities in terms of e.g. levels of education, access to employment, poverty affect disability and health conditions.

There is a strong need for an assessment of disability that is not limited to bodily structures and functions, but that includes a detailed description of environmental factors, taking into account territorial differences, such as, among others, the presence of health services, prevention and care in the territories of reference.

If it is known that disability is one of the first determinants of impoverishment, it should be investigated whether the inverse can also be supported, i.e. that poverty has a decisive influence on driving people towards a dimension of disability.

The challenge of the Group on Sustainable Development Goal Indicators (IAEG-SDGs), and more generally the world of research, is therefore to provide the information and data needed to support governments in identifying problem areas on which to focus their economic planning, and in assessing the outcomes of the measures taken, with respect to the welfare conditions achieved.

1.3 Current approaches to data collection on disability and gender-related condition

Counting disability is one of the biggest challenges, first and foremost, because there is no universal definition (UIS, 2017). Moreover, there is no unambiguous key question that can fully capture the correct number of people with disabilities. In fact, asking an individual if he or she "has a disability" usually generates inaccurate data, not only because each individual interprets disability in his or her own way, as we said before, but also because people often do not reveal their disability because of shame and stigmatization. That's why there are still no solid and comparable data.

Current approaches to data collection vary globally. This makes it difficult to understand the asccurate scale of these gaps. Some studies, for example, may not capture a representative sample of people and be equally extended to the whole population with the consequence of underestimating the phenomenon.

Without qualitatively valid and reliable data on disability, it is also more challenging to drive the policy agenda, it becomes difficult to accurately monitor the progress and demands of people with disabilities for change without concrete evidence and statistics remain weak and often disregarded.

To track the reduction or dismantling of barriers to the inclusion of people with disabilities according to a human rights-based approach, data are essential.

We know that there are inequalities and disadvantages for people with disabilities when it comes to access to fair and equal employment, education, health care and social support. Still, we need to have more and better information to act more effectively on barriers and disparities.

One of the most intense discussions currently taking place at international level concerns the use of disaggregated data in identifying the needs of the most marginalised, i.e. how these data should be used, and the expectations and dangers that new data sources can bring. From a purely technical point of view, we can disaggregate and not finish, but if we look at this issue from a political point of view, we must first take into account why we need this information and have a dialogue with civil society organisations or policymakers who understand what information is needed to make a dent in the policy.

Information at the national or regional level, at the group level, and so on, actually comes from the dialogue between producers and users to identify the data needed in relation to the policies to be pursued and the ways in which it can be found. Sometimes it is not a question of disaggregating data already available, but of collecting new data.

It is also essential to reflect on the human rights principles necessary to ensure that data does not cause harm. But also, what partnerships between National Statistical Institutes, non-governmental organisations and policymakers are needed so that they can be taken and used for awareness-raising purposes to inform policy. This is also to rationalise resources and avoid waste. Producers are often also consumers of data. So it is crucial to observe the same quality standards when producing data, making sure that they are not competing, but can be used to complement what each group (public or private) is doing.

To meet data needs at the local and national level, for example, in measuring poverty, employment, skills and learning of inclusive education, food security, access to health services and public services, discrimination and violence, household surveys have always played a crucial role. They are also essential in monitoring gender, class and disability inequalities and other indicators of disadvantage, which are essential for observing progress towards the Sustainable Development Goals (SDGs). Furthermore, household surveys are a valuable source of data for behavioural and attitudinal measures that cannot be collected through administrative data systems. About one-third of all SDG indicators, covering 13 different objectives, can be derived from household surveys.

Despite their crucial role in national statistical systems in recent decades, household surveys now face many challenges about their usefulness and adaptability to this era of a constantly changing data landscape. They are too often framed as obsolete when compared and contrasted with other data sources such as Big Data and administrative data.

The question then arises as to whether household surveys are still relevant in the changing data landscape and how their full potential can be used to add value to other data sources. How to improve the effectiveness of household surveys and their contribution to the implementation of the 2030 Sustainable Development Agenda, how to develop innovative approaches in countries and how to disseminate best practices so that all countries benefit equally from them are yet to be explored.

1.4 Conclusion

Data on women and disabilities are essential to deepen intersectional inequalities and to understand the double discrimination they suffer. Women are at greater risk of becoming disabled due to continuing gender inequalities due to inequalities in economic and educational status and access to health care, and women live on average longer than men, which may put them at greater risk of age-related functional limitations (Wheaton & Crimmins, 2016). Violent partners also increase the risk of becoming disabled (Barrett et Al., 2019), just as their vulnerability rises in case of early pregnancy. Besides, numerous studies show that women with disabilities find themselves having to break down unique and individualised barriers compared to non-disabled people or men with disabilities. Finally, women and girls with disabilities are vulnerable to forms of abuse, such as forced marriage (Clawson & Fyson, 2017) and sexual abuse (Balogh et Al., 2001; Bretherton et Al., 2016), and people with disabilities have more difficulty in obtaining support if they report abuse to the authorities. Understanding how inequality affects women with disabilities is key to designing effective prevention strategies to generate autonomy and reduce the risk of marginalisation. All these are important considerations to take into account when examining the reasons for inequality and what specific interventions are needed to overcome exclusions at the intersection of gender and disability.

The measurement of any phenomenon using indicator systems expressed only at national level leads to the non-detection of - often relevant - inhomogeneities within individual countries. The policies implemented by central governments are often ineffective unless they are designed to take account of these territorial differences. From this observation, in recent decades, there has been a growing

awareness of the need to approach the study of disability issues in the various countries through regional analyses. This approach must address many problems that have not yet been solved.
There are very few contexts in which statistically representative data are available at the national level and even less so at the regional level on the theme of gender inequality and disability, a complex issue which, if analysed at regional level, must address at the same time economic, social, demographic, cultural, infrastructural and environmental aspects.
The indicators considered at the moment remain unbalanced on economic well-being and labour as a source of income. Still, they do not yet take sufficient account of the different forms of inequality that remain at the country level. A strong commitment is therefore needed to identify and measure indicators additional to those currently envisaged, and to start, also with the involvement of the social partners and advocacy organisations ("legal protection"), a process of construction and implementation of indicators additional to those currently surveyed by official statistics.
Obviously, the thought goes to the definition of indicators that are consistent with the UN Convention on the Rights of Persons with Disabilities, and that therefore allow appropriate monitoring of existing inequalities, on which to intervene, and of the conditions to be removed in order to increase the well-being of all members of the community.
Unfortunately, our statistical systems - despite some timid attempts often limited to surveys - have not yet systematically adopted in a stabilized manner indicators useful to outline, quantitatively and qualitatively, disability and, therefore, inequality. In a country where it is not known, for example, what the actual unemployment rate of people with disabilities is, or which has not revised the criteria for the recognition of the condition of disability itself, to hope for the adoption of effective indicators in this sense unfortunately remains a chimera.
Estimating invaluable is an ethical question.
To make an informed decision, it is necessary to know the contexts and evaluate what results are to be achieved within the available resources. Therefore, a monetary evaluation is not enough; it is also necessary to assess human life, suffering, pain, quality of life, well-being, etc. The intangible costs are not unquantifiable. An imprecise estimate is better than an absence of valuation.

References

Balogh, R., Bretherton, K., Whibley, S., Berney, T., Graham, S., Richold, P., Firth, H. (2001). Sexual abuse in children and adolescents with intellectual disability. J. Intellect. Disabil. Res. 2001, 45, 194–201.

Barrett, K.A.; O’Day, B.; Roche, A.; Carlson, B.L. (2019). Intimate Partner Violence, Health Status, and Health Care Access among Women with Disabilities. Women’s Health Issues 2019, 19, 94–100.

Bretherton, K.; Berney, T.; Javate, K.R.; Castaldelli-Maia, J.; Torales, J.; Ventriglio, A. (2016). Child sexual, physical and emotional abuse and intellectual disability. Int. J. Cult. Ment. Health 2016, 9, 438–441

Clawson, R.; Fyson, R. (2017). Forced marriage of people with learning disabilities: A human rights issue. Disabil. Soc. 2017, 32, 810–830.

European Disability Forum (2011). 2nd Manifesto on the Rights of Women and Girls with Disabilities in the EU, 2011, pp. 18 and 34.

European Disability Forum (2018). Report on ending forced sterilisation against women and girls with disabilities, 2018, p. 49.
European Disability Forum (2019). Ensuring the rights of persons with disabilities to equality and non-discrimination in the European Union, Editor: Catherine Naughton. An accessible PDF and Easy

to Read version of this report is available on EDF's website: www.edf-feph.org (accessed on March 2020).

European Parlament (2018). Opinion of the European Economic and Social Committee on — The situation of women with disabilities. Exploratory opinion requested by the European Parliament. (2018/C 367/04)

European Union Agency for Fundamental Rights (2014). Survey on Violence against women, p. 186. Luxembourg: Publications Office of the European Union. ISBN 978-92-9239-273-4

Fredman S (2016). Substantive equality revisited, *International Journal of Constitutional Law*, Volume 14, Issue 3, July 2016, Pages 712–738, https://doi.org/10.1093/icon/mow043

Inclusion Europe (2018). Report of Inclusion Europe on Life after violence (2018), available here: https://inclusion-europe.eu/wp-content/ uploads/2018/11/LAV-Publication_web.pdf (accessed on March 2020).

United Nation Committee on the Rights of Persons with Disabilities - UNCRPD (2016). General comment No. 3 (2016) on women and girls with disabilities. Website: https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/3&Lang=en (accessed on March 2020).

UNESCO Institute for Statistics - UIS (2017). (2017). "Education and Disability." UIS fact sheet no. 40. Montreal: UIS. http://uis.unesco.org/sites/default/files/documents/fs40-education-and-disability-2017-en.pdf (accessed on March 2020).

UNHCR (2012). Thematic study on the issue of violence against women and girls and disability, Report of the Office of the United Nations Commissioner for Human Rights, UN Doc. A/HRC.20/5.

United Nation (2017). The Sustainable Development Goals Report. New York, NY, USA. Website: https://unstats.un.org/sdgs/files/report/2017/thesustainabledevelopmentgoalsreport2017.pdf (accessed on March 2020).

United Nations General Assembly (2015). Transforming Our World: The 2030 Agenda for Sustainable Development (A/RES/70/1). United Nations: New York, NY, USA.

Wheaton, F.V.; Crimmins, E.M. (2016). Female disability disadvantage: A global perspective on sex differences in physical function and disability. Ageing Soc. 2016, 36, 1136–1156.

Resources for information and data by international organizations in the area of disability and gender-related statistics

Here are some additional resources that may also be helpful for obtaining disability information and data for gender assessments:

- United Nations Statistics Division: https://unstats.un.org/home/
- Economic Commission for Latin America and the Caribbean (ECLAC): https://www.cepal.org/en/datos-y-estadisticas
- Economic and Social Commission for Asia and the Pacific (ESCAP): https://www.unescap.org/research
- Economic and Social Commission for Western Asia (ESCWA): https://data.unescwa.org/

- World Health Organization (WHO), the Global Health Observatory: https://www.who.int/data/gho
- World Bank, Open data: https://data.worldbank.org/
- Washington Group on Disability Statistics: http://www.washingtongroup-disability.com/
- UNICEF Data: https://data.unicef.org/
- International Labour Organization – ILO: https://www.ilo.org/global/statistics-and-databases/lang--en/index.htm
- UNESCO Institute for Statistics (UIS): http://uis.unesco.org/
- Disabled Persons Organizations (DPOs)
- Disability Data Portal: https://www.disabilitydataportal.com/
- USAID Disability: https://www.usaid.gov/reports-and-data
- United Nations Gender Statistics: https://genderstats.un.org/
- United Nations Women: https://data.unwomen.org/
- Women in data: https://www.womenindata.org/
- WomanStats Database: http://www.womanstats.org
- Global Partnership for Sustainable Development Data: http://www.data4sdgs.org/about-gpsdd
- International Disability Alliance, Diasability Data Advocacy Working Group: http://www.internationaldisabilityalliance.org/content/disability-data-advocacy-working-group

Conclusions

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The widely known slogans 'Nothing about us without us' and 'Nobody shall be left behind' tell us how the world is intertwined in relation to current understanding of disability and rights of people with disabilities in the last decade. Such understanding is a result of numerous disabled and non-disabled scholars' and disability activists' civil movements who advocated for equal treatment of disabled people and demanded that the existence of disabled individuals should no longer be constantly threatened. The pledge for social and recovery models of disability favoring humanizing policies and practices such as self-determination, independent living, barrier-free environments, the needs-based as well as the rights-based approaches, have become common knowledge and shared vision worldwide. Recognitional justice, to recall the work of Nancy Fraser (2009), inevitably calls for diversity and heterogeneity as part of everyday life in place of seeing disabled people as the 'exception' from the norm. Undoubtedly, the UN CRPD put a lot of pressure on governments and policy makers to become swift and more efficient in recognizing the universal human rights and needs of persons with disabilities across the world.

This book was written before the global lockdown due to the outbreak of the SARS-CoV-2 virus in early 2020. Since then, several new problems occurred. Economic crisis for communities and individuals; the rise of unemployment; the increase in numbers of precarious workers worldwide; the global geostrategic interdependencies and their re-positioning. Some issues are closely related to the rights of persons with disabilities, for example housing and institutional living; access to health services; the exponential increase in domestic violence across the globe; reduced access to information; fear of unjust, selective treatment as the numbers of infected people are on the rise, to name only a few.

Social scientists know all too well that social inequalities do not disappear by themselves. As shown by two acclaimed thinkers, Noam Chomsky (2016, 2017) and Naomi Klein (2007, 2014), each crisis exposes and sheds light on hidden inequalities that are suppressed, poorly visible and overlooked in times of prosperity. In a crisis, people who are most devalued and discriminated against – the disabled are among them - usually suffer the most (Marmot, 2015a, b).

Let us recall the rise of global neoliberalism in the 1980s and 1990s when people with disabilities lost their 'institutional safety'; however, instead of granting them the right to community living, many became homeless or were criminalized after the gentrification of areas where they were rehoused and the increase of rent prices which people were not able to pay, anymore. In the process of disintegration of the Soviet state, people with disabilities lost their pensions, health insurance and other socially granted rights; many ended up homeless or a 'family burden' in societies with a 'family-centered social policy', as was the case in most post-socialism countries. In the time of global economic crisis and austerity policies following 2008, the right to personal assistance in some Western European countries with most successful policies of de-institutionalization was threatened. In post-socialism European countries, the lack of funding was one of the excuses for keeping large state-run institutions unchanged. Thousands of people with disabilities were locked up in them for life. The present pandemic crisis showed that those countries which were reluctant to invest into public health and essential services and kept underfunded all networks of good quality, community-based residential homes for physically ill elderly and disabled experienced the highest loss of lives. Hundreds of thousand fear that the infection will spread out of control. Apparently, some countries like Germany and Scandinavian countries with a universal public health system, and good quality, community-based services implemented the least draconian measures of quarantine, and suffered the least in terms of human lives, people's mental health, and general feelings of safety.

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However, not only public health and care systems are of crucial importance during the pandemic crisis. The issues of human rights implemented by politicians, policy makers, and professional workers are equally important. Do all lives really matter? Are people really asked about their needs? Is it true that nobody is left behind? The current crisis triggered the debates on protecting large populations either through coercive care or by democratic negotiations and responsible behavior of all. We are reminded that people with least socioeconomic and symbolic power - among them many people with disabilities - suffer the most and are easily forgotten. The Guardian reported about a teenage boy with cerebral palsy, immobile and unable to speak, who died in his bed after having been left alone for six days. After the authorities quarantined his relatives, the only thing his father could do was to post messages on the social media asking people to help his son.[1] The question that inevitably comes to mind is: was the boy's death related to his disability? Did he die because his life was not seen as equally important as the lives of non-disabled people who needed to be rescued at the same time? Such tragedies could also happen in other countries with a large rural population and under-developed public health services.

In Slovenia, over 75% of all deaths related to Covid-19 (86 persons by 27 April 2020) were among the residents of large nursing homes for the elderly with different impairments. This did not come as a surprise. Long-term institutions with large numbers of residents (from 250 up to 1000 persons, counting residents and staff) faced a crisis of poorly paid and inadequately educated personnel, and a lack of medical staff over a long period of time. Large nursing homes accommodate about 17.000 residents; among them are young people with disabilities due to the lack of housing policy and community care living opportunities.[2] Disregarding Article 19 of the UN CRPD, nursing homes which have been promoted as the places of 'safety' and 'protection' for the elderly and the disabled became places of danger and death. Similar outbreaks of infection and death happened also in smaller residential homes for elderly in France and even in private nursing homes in Sweden and the UK.

On 13 March 2020, The European Disability Forum wrote an open letter to the EU and Member States' leaders in order to draw attention to the 'disability-inclusive response' to the pandemic. They offered several recommendations on equal treatment of disabled people, and emphasized that people with disabilities are disproportionately impacted by the spread of SARS-CoV-2 virus.[3] At the beginning of the quarantine measures, most families and individuals tended to stock up large quantities of food; many people with disabilities who face either economic disadvantage or physical restrictions could not stock up. Many disabled persons depend on public transport which was mostly closed down. In some countries, almost no health professionals and health facilities were available for health problems other than Covid-19. Many people with disabilities did not have proper access to information, as the news were not communicated in the easy-read format or in sign language. Many persons with disabilities were left without care staff. Those who live alone in inaccessible housing with irregular support became even lonelier. Some countries showed an impressive number of volunteers supporting people who live in self isolation (750.000 in the UK for example), but not all. In some countries, special schools, day centres and sheltered workshops were locked down entirely; children, young people and adults had to return to their families, relatives or guardians. Neither family members and other caregivers, nor people with disabilities - especially women who were in danger of emotional, physical and sexual violence, restrictions of movement or material deprivation - got any support. People with disabilities who reside in large long-stay institutions and nursing homes were in some places not allowed to leave their rooms and could not see the relatives and visitors for weeks. Such restrictions were clearly against the recommendations of the European Disability Forum.

During the pandemic, social Darwinism, eugenics and disposability were words often used by critical writers in relation to the elderly with different impairments. In some instances, triage was

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[1] Standaert, M. (2020). Disabled teenager in China dies at home alone after relatives quarantined. *The Guardian. 30 January 2020*. https://www.theguardian.com/world/2020/jan/30/disabled-teenager-in-china-dies-at-home-alone-after-relatives-quarantined (Accessed 30.04. 2020).

[2] See the detailed analysis in this book.

[3] European Disability Forum, 13 March 2020, http://edf-feph.org/newsroom/news/open-letter-leaders-eu-and-eu-countries-covid-19-disability-inclusive-response. (Accessed 30.4.2020).

implemented in the form of deciding who lives and who dies[4] because the medical personnel were unable, as stated by the European Disability Forum, 'to provide the same level of care to everyone due to lack of equipment and underfunding of the healthcare sector.' Persons with disabilities feared to be discriminated. The Bioethics Committee of the San Marino Republic issued guidance specifically for Covid-19. It stated that triage must be based solely on the criteria of clinical appropriateness and proportionality of the treatments: "Any other selection criteria such as age, gender, social or ethnic affiliation, disability is ethically unacceptable, as it would implement a ranking of lives only apparently more or less worthy of being lived, constituting an unacceptable violation of human rights."[5]

All these difficult issues point to the importance of research redressing cultural prejudices towards disabled people, especially women who face even greater danger of exploitation and discrimination than men do. This timely book hopes to add to other academic and practice-based activities that are carried out in the area of disability studies and activism and to inspire them for the future to come.

REFERENCES:

Chomsky, N. (2016). *Who Rules the World?* New York: Henry Holt and Co.

Chomsky, N. (2017). *Optimism over Despair: On Capitalism, Empire, and Social Change* (with C.J. Polychroniou). London: Penguin Press.

Fraser, N. (2009) *Scales of justice: reimagining political space in a globalizing world*. New York: Columbia University Press.

Klein, N. (2007). *The Shock Doctrine: The Rise of Disaster Capitalism*. Toronto: Knopf Canada.

Klein, N. (2014). *This Changes Everything: Capitalism vs. the Climate*. New York: Simon & Schuster.

Marmot, M. (2015). *The Health Gap: The Challenge of an Unequal World*. New York: Bloomsbury.

Marmot, M. (2015). *The Status Syndrome: How Social Standing Affects Our Health and Longevity*. New York: Bloomsbury.

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[4] Merrick, R. "Coronavirus: NHS Doctors to Be Given Guidelines to Decide Which Victims Go on Ventilators." *Independent. 20 March 2020*. Retrieved March 29, 2020. (https://www.independent.co.uk/news/uk/politics/coronavirus-boris-johnson-uk-doctor-victims-intensive-care-ventilator-italy-a9415356.html (Accessed 30.4.2020).

[5] National Bioethic Committe Republic of San Marino, Answer to the requested urgent opinion on ethical issues regarding to the use of invasive assisted ventilation in patients all age with serious disabilities in relation to Covid-19 pandemic. 16. March 2020. http://www.google.si/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&ved=2ahUKEwjjp--NiJHpAhVns4sKHcYcBmgQFjAAegQIARAB&url=http%3A%2F%2Fwww.sanita.sm%2Fon-line%2Fhome%2Fbioetica%2Fcomitato-sammarinese-di-bioetica%2Fdocuments-in-english%2Fdocumento2116023.html&usg=AOvVaw2DNRpG2ZqMjF4sAaw4Y8ql (Accessed 30.4.2020).