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LITERATURE REVIEW

Disability, Human Rights, and the International Classification of Functioning, Disability, and Health Systematic Review

ABSTRACT

Aluas M, Colombetti E, Osimani B, Musio A, Pessina A: Disability, human rights, and the international classification of functioning, disability, and health: systematic review. *Am J Phys Med Rehabil* 2012;91(suppl):S146–S154.

This literature review focuses on the literature on disability from the ethical and human rights perspective in the light of the International Classification of Functioning, Disability, and Health in the period from January 1, 2008, to June 30, 2010. This article identifies and examines studies that deal with the subject of disability with reference to rights, ethical issues, and justice. A total of 42 articles and 33 books were selected. The subject most frequently dealt with in studies on disability is that of human rights (76% of the articles and 79% of the books examined), followed by topics relating to welfare (52% of articles and 64% of books), International Classification of Functioning, Disability, and Health (38% of articles and 45% of books), justice (24% of articles and 48% of books), education (21% of articles and 61% of books), and work (19% of articles and 39% of books). The subject of disability is dealt with in various fields of study and various disciplines. Most of the studies are based on the legal approach. It is to be hoped that there will be an increase in the philosophical and ethical study of disability, which has only recently entered the European debate.

Key Words: Biopsychosocial, Human Rights, Justice, Ethics, ICF

In the public perception, disability has always been thought of as an exclusively medical problem. It was believed, therefore, that the study of disability was the task and responsibility of those working in the field of health problems. But in the last 20 yrs, thanks both to technologic and scientific progress and to political and cultural developments, there have been a number of cultural changes in the concepts of health, treatment, functioning, and disability. In May 2001, the World Health Organization adopted the International Classification of Functioning, Disability, and Health (ICF), and in October 2007, it published the ICF for Children and Youth, specifically directed to children and adolescents. What is new about these classification instruments is the shift in focus toward the individual and his/her real needs rather than focusing purely on the causes of disease. These

TABLE 1 Key words used for PubMed search

Disability & justice	0	Disability & justice & ICF	0
Disability & ethics	0	Disability & ethics & ICF	0
Disability & rights	24 (2)	Disability & rights & ICF	0
Disability & work	1 (0)	Disability & work & ICF	0
Disability & education	2 (0)	Disability & education & ICF	0
Disability & welfare	0	Disability & welfare & ICF	0

Figures in parentheses indicate the number of articles selected.

ICF, International Classification of Functioning, Disability, and Health.

classifications show that it is essential that the definition of the state of health include the influence of the environment on people's health.¹

According to the ICF's classification, disability is an outcome of the negative aspects of the interaction between the individual (with a health condition) and his/her environmental and personal factors²: "The need to raise the subject of disability as a relationship between environment and pathological condition (or impairment) derives from a single fact: the changes in the living conditions in Western societies resulting from scientific and technological progress made it possible for an ever increasing number of people to live with their disease, with their impairments, and it is therefore crucial to think of the treatment relationship as a question of justice."³

On December 13, 2006, the United Nations (UN) General Assembly adopted the Convention on the Rights of Persons with Disabilities as a UN international human rights instrument designed to protect the rights and the dignity of people with disabilities. The Convention defines persons with disability as "those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others" (Article 1.2).

Thanks to these changes in perspective, and the new reinterpretation of the concept of disability introduced by these documents, in recent years, the topic of disability has become an area of investigation for philosophers, anthropologists, jurists, and others.

The objective of the present work was to identify studies (documents, books, journals, or individual articles) that deal with disability with reference to justice and rights, in the light of the ICF. An attempt was also made to assess in statistical terms the presence of these topics in research on disability during the period January 1, 2008, to June 30, 2010.

In the light of the changes referred to above, and on the basis of a Multidisciplinary Research

Network on Health and Disability in Europe⁴ research project, it is interesting to note the following issues in the literature on these topics: fields of research in which the subject of disability is examined; the presence of studies problematizing disability from the philosophical, ethical, or bioethical perspective; references made by these studies to the ICF and the biopsychosocial model in the approach to disability; the vocabulary used in the specific literature; and the terms used when discussing disability or persons with disabilities.

METHODS

The bibliographical search was conducted bearing in mind the following criteria:

1. The linguistic criterion: The material was examined in the following languages: English, French, Italian, Spanish, and Romanian.
2. Key words used: *ethics/moral, work/employment/labour market, right /human rights/law, welfare/wellbeing/disability policies, justice/equality/social inequality, ICF*, and their equivalents in the above languages.

Eligible material was determined in two stages: first, the identification of literature on disability, ethics, and human rights according to titles, abstracts, key words, and presentations of studies; second, the selection and analysis of studies relevant to our research.

TABLE 2 Statistics on the journal sample

	<i>n</i>	%
ICF	16	38
Work	8	19
Welfare	22	52
Education	9	21
Rights	32	76
Justice	10	24
Total articles	42	

ICF, International Classification of Functioning, Disability, and Health.

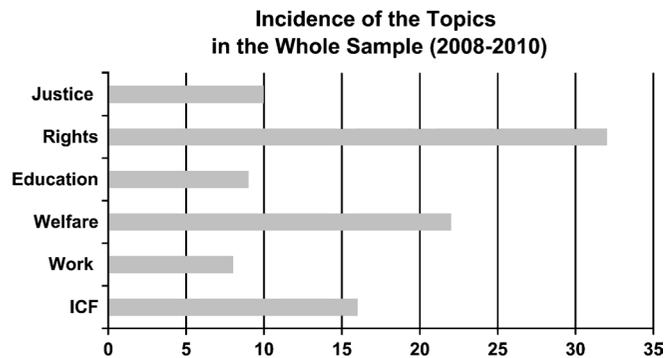


FIGURE 1 Incidence of the main areas of study in the collected sample. ICF, International Classification of Functioning, Disability, and Health.

The search proceeded along two paths:

- (a) Search for key words in PubMed, with the following criteria:

Publication date: January 1, 2008, to June 30, 2010

Search field: title and abstract

Table 1 shows the results of the search, for each combination of words.

- (b) Exploratory search was done by the identification of authors and research centers or groups dealing with disability issues from the ethical and human rights point of view. From the publications found by this screening process, we moved on to their bibliographical references, conducting a sort of recursive search. In this way, further authors were identified, and some of them were contacted to expand the bibliography by using their specific expertise.

3. European research: Taking these two criteria (linguistic and key words) into account, we made a preliminary selection that comprised 91 articles and 42 books. We then introduced a “geographical” criterion, because our focus was on bibliographies on disability, ethics, human rights, and the ICF in Europe. Consequently,

the material was restricted to contributions by European authors, authors describing the situation in European Union countries, or the relevance of the topic discussed to the debate in Europe. The bibliographical search concentrated on contributions concerning the relationship between disability and ethical issues in the light of the ICF. Research results will be presented in a descriptive fashion.

RESULTS

After this selection, a total of 42 articles⁵⁻⁴⁸ and 33 books⁴⁹⁻⁸² dealing with the topics concerned came within our criteria.

The statistical summary based on the sample selected shows that in the period 2008–2010 (Table 2), the topic most frequently discussed in studies on disability is that of human rights: 76% of the articles selected dealt with this topic (it has to be remembered that some studies address issues relating to more than one of the topics within the same article or book).

The graph in Figure 1 shows the predominant position of human rights in the articles selected.

TABLE 3 Incidence of the different topics in the sample per year

Topic	Year					
	2008		2009		2010	
ICF	6	67%	8	36%	2	18%
Work	3	33%	4	18%	1	9%
Welfare	3	33%	13	59%	6	55%
Education	3	33%	3	14%	3	27%
Rights	7	78%	16	73%	9	82%
Justice	2	22%	4	18%	4	36%
Total articles	9		22		11	

ICF, International Classification of Functioning, Disability, and Health.

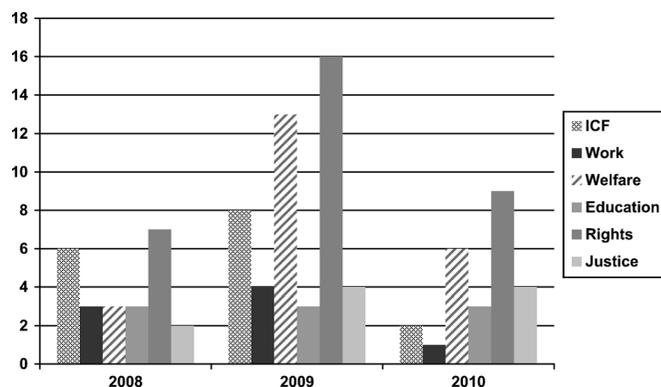


FIGURE 2 Incidence of the different topics in the sample per year. ICF, International Classification of Functioning, Disability, and Health.

Temporal analysis of the data shows that this trend change from one year to the next (the literature examined for the year 2010 is limited to the period from January 1 to June 30). According to Table 3, the number of publications in 2009 is more than the double of that from 2008. A hypothesis of this significant increase in the number could be the adoption of the ICF for Children and Youth by the end of 2007, which led to commentaries that appeared only in 2009.

The graph in Figure 2 shows the same data visually.

It can be observed, moreover, that the topic of human rights is connected to the ICF in 39% of the articles analyzed (Table 4).

In terms of where the articles were placed, 29% were published in various specialist disability journals, whereas 71% were published in journals devoted to other topics (sociologic journals, bioethics journals, legal studies, economics, and philosophy journals) (Table 5).

Descriptive statistics regarding the books are shown in Table 6.

The topic of human rights is connected to the ICF in 46% of the papers examined (Table 7).

The books sample, unlike the journals sample, is comparatively well balanced between the ICF and rights group and the rights-only group.

DISCUSSION

This literature review on disability, ethics, and human rights enables us to state that studies dealing with disability are to be found in a number of different fields of study, such as health, health services, rehabilitation, welfare; education, teaching, and work; rights and justice; philosophy, ethics, and bioethics; accessibility and transport; housing arrangements; and technology.

Most of the texts examined dealt with disability from the rights perspective, perhaps because in the last few years, the approach based on equality of rights has been prevalent in European Union countries. In recent years, disability policy at the European level has changed from “a formerly disregarded branch of traditional social policy into a modern policy formation which comprises not only social protection and labour market integration, but also equal rights and non-discrimination.”³⁷

Within this subject area, we can distinguish studies promoting the UN Convention on the Rights

TABLE 4 Percentage of articles dealing with rights issue with and without reference to ICF

	2008	2009	2010	Total	
ICF and rights	3	6	2	11	39%
Rights only	2	11	6	19	68%
				28	

ICF, International Classification of Functioning, Disability, and Health.

TABLE 5 Distribution of the papers in specialized vs. nonspecialized journals

	2008	2009	2010	Total
Papers published in disability journals	0	13	1	14
	0%	54%	9%	29%
Papers published in other journals	9	11	10	30
	100%	46%	91%	71%
	9	24	11	42

TABLE 6 Incidence of various topics in the books sample per year and in the total period

Topic	Year							
	2008		2009		2010		2008-2010	
ICF	6	50%	6	38%	3	60%	15	45%
Work	5	42%	7	44%	1	20%	13	39%
Welfare	8	67%	9	56%	4	80%	21	64%
Education	8	67%	9	56%	3	60%	20	61%
Rights	8	67%	13	81%	5	100%	26	79%
Justice	5	42%	8	50%	3	60%	16	48%
Total books	12		16		5		33	

ICF, International Classification of Functioning, Disability, and Health.

of Persons with Disabilities; texts problematizing topics such as citizenship and the relationship between rights and cultural traditions; and other texts that link the ICF to the UN Convention to highlight disability-related issues and suggest valid instruments for assessing disability.

The UN Convention has been described as a great landmark in the struggle to reframe the needs and concerns of persons with disability in terms of human rights and has been perceived as an instrument that has at last empowered the “world’s largest minority”⁹ to claim their rights and to participate in international and national affairs on an equal basis with all others. This document is described as the “first human rights treaty” that contemplates the possibility that not only states but also regional organizations may become parties, and the first human rights treaty that the European Union has signed and ratified. Ratification of the Convention commits countries to “higher standards of non-discrimination with respect to persons with disability.”^{44,83} Some authors describe it as the first human rights treaty adopted by the UN in the 21st century, which makes the transition “from welfare to rights in the context of disability”⁶³ to ensure equal and effective enjoyment of

human rights for the approximately 650 million persons with disability in the world, of whom about 50 million (1/10) are in the countries of the European Union.⁵³

Because the rights-based approach has frequently been criticized for being exclusively Western and for being insensitive to non-European traditions and cultures,⁸⁴ Bickenbach¹⁶ argues that this “conflict between universalism of rights and cultural sensitivity exists only if these positions are expressed in extreme forms: rights absolutism and cultural relativity.” And that “the realisation of human rights will always be a matter of political negotiation, and that a social commitment to equality demands that we ensure that only transparent, fully-informed and fully-participatory procedures, respectful of difference [are employed].”¹⁶

With regard to the spread throughout the world of laws and debates on disability, the positive role played by globalization has been stressed. Thus the protection of the rights of persons with disabilities as envisaged in the Americans with Disabilities Act (1990) in the United States has led to a revision of the meaning of discrimination in national and regional legislations in Europe and Latin America. With the drafting, adoption, and impact of the UN Convention on the rights of persons with disabilities, through information shared thanks to globalization, it is hoped that “disability rights (as well as other civil rights) advocates may continue to influence the global development of law in their respective fields.”³⁵

Citizenship is another topic to be found in studies on disability. It is considered the key concept in the sociologic and political study of contemporary society since the latter half of the 20th century and grants access to citizen status in purely formal terms. The fact that there are people excluded from the public space of participation, such

TABLE 7 Percentage of books dealing with rights issue with and without reference to ICF

	2008	2009	2010	Total	
ICF and rights	4	5	3	12	46%
Rights only	4	8	2	14	54%
				26	

ICF, International Classification of Functioning, Disability, and Health.

as persons with disabilities, is a proof that there are situations of inequality as a result of structural and symbolic barriers within the social environment⁴³ and, therefore, that these people are unable to exercise all their rights. A person can be considered a full citizen only if he/she is in possession of all three types of rights, civil, political, and social, and belongs to a social class.⁸⁵

The UN Convention and the ICF may be used together to ease the way toward change and reform, in order not to consider disability merely as a problem for some people but as a given aspect of the human condition that concerns all citizens.^{44,83} There are some studies⁸⁶ that suggest using the ICF to monitor the Convention, because the ICF is the only worldwide standard of acknowledged validity and reliability that can be trusted when collecting and processing data on disability. The Convention as a tool is necessary but not sufficient to reinforce disability-related rights, and it should not be seen as a panacea for ending discrimination against persons with disability.²⁵

It would be interesting to monitor whether this trend, which is presumably conditioned by the promulgation of the Convention on the Rights of Persons with Disabilities, will be confirmed in the future.

A problem stressed by some authors²⁴ is the lack of solid empirical data on the disadvantages faced by persons with disabilities. This point is important in the field of rights and public health policies. Even though the Convention states explicitly in Article 31 that responsibility for data collection lies with member states, the same authors argue that the planning of this data collection and of adequate instruments of analysis remains a complex and heterogeneous process, on account of the variety of conceptual paradigms that define disability.

One proposal for the empirical study of disability could be the use of the ICF together with Sen's capability model.¹⁷ The capability approach deals with what people are able to achieve in a given context. But the sum of capabilities of a person with disability covers not only what that person actually does but also his/her potential functioning. The issue to be addressed is how to reduce the environmental barriers that increase disability to develop capabilities and enable the person to live the sort of life that he/she desires.¹⁹

In the field of humanistic studies, the topic of disability is addressed from the sociologic, pedagogic, psychologic, legal, historical, or political analysis point of view. The philosophical and ethical

perspectives take up comparatively little space: Of a total of 33 books and 42 articles considered in the literature review, 6 books^{61,68,74,78,81,87} and 6 articles^{7,10,15,21,22,38} include philosophical, ethical, or bioethical discussions of disability. With regard to the philosophical study of the ICF and of the biopsychosocial model of disability, Sticker⁷⁸ attempts to link the components of the ICF to Arendt's⁸⁸ dimensions of active life: labor, work, and action. Labor is the economic dimension because people have to feed themselves, dress themselves, and look after themselves. Work is the anthropologic dimension, the way in which persons inhabit the world. Action is the ethical and political dimension, the way in which humans construct themselves in relations with others. The ICF refers to three components: the bodily functions and structures that make up the individual; activity, in other words, the level on which action takes place; and participation, which concerns social relationships and the building of the city. According to this view, persons with disability must not only be guaranteed the first level (bodily functions and structures) but must also be recognized "as creators and citizens," and in this sense, Arendt's philosophy can be a useful point of reference.

Another point that emerges from this research is the use of a number of different terms to indicate disability and persons with disability. In the literature of the French-speaking world, expressions like *handicap* and *personnes en situation de handicap* (people living under conditions of handicap) are used. However, in recent years, this term has been strongly disputed and has been replaced with *disability*. Although it derives from the French word *dishabile*, the term *disability* has no literal equivalent in French, and so the notion of *situation de handicap* (handicap condition) or *handicap de situation*⁸⁹ (context-dependent handicap) is referred to. Anglo-Saxon authors, especially those working in the social sphere, use expressions such as *disabled people* and *disablement*¹² because people find themselves in this situation as a result of external circumstances, because of the society that makes them disabled.⁹⁰ In the Spanish literature, the expressions *las personas con diversidad funcional* (people with functional diversity) and *la discapacidad*¹³ (incapability) are used, and the concept of *diversidad funcional* has been used in the debate around the right to make decisions and to overcome the marginalization that persons with disability have experienced over the years. This concept, devised as a way of overcoming negative definitions (disability, handicap), is linked to the idea of

independent life philosophy, which claims the right to full recognition of the dignity of these persons, as a possible single expression of numerous forms of diversity.⁴⁹ In studies written in Italian, we can find the following expressions: *persone con disabilità* (persons with disability), *diversamente abili* (otherwise able), and *i disabili* (handicapped). It has also been argued that anyone referred to as *handicappato* (handicapped), *disabile* (disabled), *diversamente abile* (otherwise able), or *diversabile* (otherwise able) is branded with a mark that devalues and excludes him/her.⁷⁵

In terms of the type of language used by authors, three linguistic registers can be identified: Some texts use academic scientific language, others are written in “militant” language,⁷⁸ and others make use of direct testimony.

In conclusion, this literature review could be seen as a map of the most important topics in the European disability debate and could provide a basis for further study.

The data that have emerged show that interest in the subject of disability in philosophical study is fairly recent in Europe and that it needs to be expressed, even though this may seem a difficult task in view of the complexity of the concepts and the different situations to which they refer in different cultures, religions, and customs.

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