Definition of Disability

by

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This study has been produced under the European Community Action Programme to combat discrimination (2001-2006). This programme was established by the European Commission's Directorate-General for Employment and Social Affairs as a pragmatic support to ensuring effective implementation of the two Directives on "Race" and "Equal treatment in the workplace" (2000) emanating from Article 13 of the Amsterdam Treaty. The six-year Programme primarily targets all stakeholders capable of exerting influence towards the development of appropriate and effective anti-discrimination legislation and policies, across the EU-25, EFTA and the EU candidate countries.

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I. Introduction

This paper is about the issue of defining disability in European discrimination law context. It is based on the research and discussions which have been undertaken within the European Group of Disability Discrimination Experts. The paper reviews the definition of disability in disability discrimination laws of those EU countries which have transposed the Framework Directive 2000/78/EC by the end of 2003. The main question of this review is whether the various definitions of disability perpetuate the medical/individual model of disability or support the social model of disability. According to the medical/individual model of disability the problems disabled person face in their daily life are mainly caused by their impairment, whereas the social model locates the problems in societal and environmental barriers outside the individual disabled person. The paper examines whether impairment related definitions of disability in disability discrimination laws perpetuate the medical model of disability. Secondly, the paper discusses whether a definition of disability is necessary within the context of disability discrimination law.

Since the Framework Directive only deals with the area of employment and occupation, not all disability definitions in EU countries will be addressed. Some EU countries, such as Germany or Spain, have more disability discrimination laws outside the employment area at federal or regional level, that contain various definitions of disability. However these discrimination laws cannot be regarded as transposition laws with regard to the Framework Directive. Similarly, definitions of disability in other European laws outside the discrimination context are not covered.

II. Legal Definitions of Disabilities: Difficulties and Obstacles

Legal definitions of disability have been an issue of much debate in Europe and around the globe. Despite the efforts of the World Health Organisation which resulted in the new ICF, there is no international universal legal definition of disability, neither is there one in any EU country. A recent study on definitions of disability in various EU countries has shown that disability definitions vary from country to country but also inside each country. While there are similarities between the definitions of disabilities in some areas of social policy, legal disability definitions in each country differs with respect to income maintenance, employment measures or social assistance with daily life activities.

While legal definitions of other categories, such as sex, ethnic backgrounds, or sexual orientation also raise questions of demarcation, disability is even harder to define because it encompasses numerous conditions of mind and body and the boundary between ability and disability seems to be less clear. Well-known examples are visual and hearing conditions. When does a visual limitation constitute an impairment? When do we call a person who is hard of hearing a disabled person? In addition, definitions of disability change according to developments in medical science. New disabilities

1 Out of the old fifteen EU countries before May 2004.
emerge with new medical developments and discoveries. Genetic dispositions to certain diseases are recent examples.

Legal definitions of disability vary also in relation to different legal purposes. A social welfare law providing personal assistance benefits may have a different target group of disabled persons than a discrimination law. The distribution of social benefits has to be needs-based in order to be rational. Equal treatment as a right not a benefit should not be offered only to those in need but to all persons potentially affected by discrimination.

From a theoretical perspective disability definitions are challenged by the debate on what causes disability: medical conditions, environmental factors, social structures and/or individual or collective behaviors and attitudes. This debate about medical (individual) vs. social model of disability has had a large impact on European disability policy because it has led to the paradigm shift from charity-based to rights-based disability policy and it has helped to understand disability as a social construct.

III. Disability Discrimination Law: Endorsing the Social Model of Disability or Perpetuating the Medical / Individual Model

Discrimination Law has the purpose to prevent unequal treatment which is rooted in stereotypes and stigma. With respect to disability, neglect of disability as a human difference has been analyzed as the third source of disability discrimination. In the employment sector stereotypes about disabled persons range from the view that disabled persons are unable to work or unable to compete in the open labor market, to the opinion that a disabled worker disturbs the normal process of work in any enterprise, if not being a health and safety hazard to other employees.

Disabled workers are stigmatized as unproductive and economically undesirable. The fact that most work sites and work environments are inaccessible to many disabled employees is the result of neglect of disabled persons needs.

Disability discrimination law sends a powerful message to the general public. It is based on the assumption that discrimination is wrongful and a major problem for disabled persons. The latter are seen not as problems but as right holders. Disability discrimination law, thus endorses the social model of disability because it locates the problem of disability outside the individual person. Discrimination law neatly fits with an understanding of disability as a social construct. It can help to deconstruct the medical/individual model of disability and the stereotypes that come with it.

At the same time law is of course a tool to construct social reality in modern society. Thus, it is clear that every legal definition of disability takes part in the social construction of disability. The question then arises, whether legal definitions in discrimination law reinstate or perpetuate the individual model of disability? In Germany, where we had over twenty disability discrimination laws adopted over the course of the last decade, members of the disability movement often demanded that disability should not be defined as a medical condition, notably an impairment. Only non-medical definition, it was argued, could endorse the social model of disability. Similar debates took place in other countries and in international legal context. But the social model of disability does not give any guidance as

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how to legally define disability alternatively. While the various revised WHO definitions have been a valuable contribution to the discussion in that it seeks to combine what is true about the medical model and the social model of disability and produced the biopsychosocial model of disability, it seems to be less useful in the context of disability discrimination law. This is because the WHO notion of disability as a result of an interaction between an impaired individual and social environment mixes characteristics and treatment. A discrimination law has to separate these two things by saying which treatment is regarded prohibited discrimination against whom. Disability discrimination laws thus need to define discrimination as well as disability and it makes no sense to define disability as the outcome of discrimination.

Thus, it seems that the solution might not be to refrain from using medical terms or impairment terminology. Rather the opposite is true if we think about how disability discrimination actually works. Disability-based prejudice and stigma are always related to an actual or presumed abnormality called impairment or chronic illness. The view that a blind person cannot work as a bank accountant is based on the assumption that a bank accountant needs (full) vision capacity. The hotel manager who does not accept disabled guests, assumes that their impaired appearance distracts able-bodied guests. The impairment may be visible or invisible, it may be real existent or imputed, but it is always the reference of discriminative treatment. Neglect, the third source of disability discrimination works the same way. It is neglect of differences due to an impairment which results in discrimination. Neglecting that paralysed people move on wheels instead of on legs, or neglecting that blind persons read braille instead of black print leads to inaccessibility and exclusion.

Thus, definitions of disability in discrimination laws do not perpetuate the individual model of disability if they refer to impairment.

There are, however other pitfalls for the reinstatement of the individual model of disability in discrimination laws. One such pitfall are definitions which portray disabled persons as helpless and incapable with respect to a range of normal life activities. A recent OECD study on disability definitions has come to a similar conclusion by suggesting that disability should not be equated with employment incapacity. Those definition convey the very same stereotypes about disabled persons, discrimination law seeks to prevent. One of the core values of non-discrimination law in the context of disability is that it creates space for individual abilities despite any group membership. Such space can only be created if disability definitions are cleared of any assumptions about ability or incapability.

Another pitfall is to narrowly construe the definition of disability to persons who are severely disabled or substantially limited in a range of daily life activities. Jurisprudence on the American with Disabilities Act (ADA) has shown that such a definition screens out many disabled person who are victims of discrimination but do not match the “truly disabled” label. To protect only a certain category of disabled persons against discrimination is problematic for a number of reasons. In this paper I will only focus on how such a definition intersects with the medical/individual model of disability. Such a narrow definition of disability is based on the assumption that only severely disabled persons are in need for anti-discrimination measures. This in turn presumes that disability discrimination is actually and only invoked by a certain degree of impairment, which again locates the problem of disability discrimination inside the individual victim. The opposite is true: disability discrimination is the result of treatment, attitudes and social structures. Often the impairment of the victim does not matter at all, except for being a vent for prejudice and stigma. These are the cases,


8 http://www3.who.int/icf/icftemplate.cfm


when disability should not be taken into account at all may it be severe or less severe. A person with only one arm may be denied a job as a secretary even though she can perform all the essential functions of the job without any accommodations. Her disability should not matter at all. The same holds true for the applicant who misses only one finger. What is important is not the impairment but the reaction to it. By obscuring the cause of discrimination, narrow definitions of disability in discrimination laws indirectly purport the individual/medical model of disability.12

Another, yet similar indicator for the individual model of a disability definition is, if not all persons affected or threatened by disability-based discrimination are covered by the definition. This group is much larger than the group of persons with present disabilities, because discrimination may be based on past, present, future or assumed disabilities. The reasons for this indicator are similar to those already mentioned with relation to a “truly disabled” definition. In addition it can be said, that a definition that encompasses past, future and assumed disabilities as well as associates of disabled persons is a clear approval of the social model of disability because it is firmly based on a notion of disability as a social construct.

Finally a definition of disability in a discrimination law might create tensions with respect to other social welfare law definitions on disability. Again experiences from the US with respect to ADA implementation can be illustrative. Because disabled employees seeking protection under the ADA need to bring evidence that they are “otherwise qualified” for the particular employment, they might face the danger of losing out on disability benefits which require recipients to prove that they have reduced or lost work capacity.13 Similar conflicts between social welfare and discrimination law have been predicted for Europe14 While the tension between these two sets of laws might not first of all be a problem of different definitions, it should not be ignored in this context. People with disabilities might have to choose between anti-discrimination or social benefits. Or they might be forced to take up two roles. One in which they play the capable and qualified disabled employee, and another one in which they have to play the helpless and needy beneficiary. Such a result would perpetuate the individual model of disability.

IV. Definitions of Disability in Laws transposing the Framework Directive in various EU countries

Out of the fifteen EU Member States under review in our expert group, ten countries have disability discrimination laws in the area of employment at the time of this conference. These are: Belgium, Finland, Germany, Greece, Ireland, Luxembourg, the Netherlands, Portugal, Sweden, and UK. While a few countries, such as the United Kingdom, Sweden and Ireland already had these laws before the Framework Directive was adopted in November 2000, the majority of laws were adopted in order to transpose the Framework Directive. It seems that only four countries, namely Germany, Ireland, Sweden and the United Kingdom adopted disability discrimination laws which entail definitions of disability.15


14 Lisa Waddington, ibid, p. 256.

15 In France, a law has been adopted by the Senate in March this year, but the legislative procedure hasn’t been finalized at the time of the conference. For this reason, the disability definition in the French draft bill on “the Equal Rights and Opportunities, Participation and Citizenship of Handicapped People” will not be considered in this paper. The same holds true for other draft bills in EU countries, e.g. Austria.
Germany

In Germany, the legislators decided to transpose the Framework Directive within the context of the new rehabilitation law, which came into force in 2001. The Ninth Book of the Social Law Code (SGB IX) encompasses a prohibition for all employers to discriminate against severely disabled employees (§ 81 (2) SGB IX). According to § 2 SGB IX persons are disabled if their physical functions, mental capacities or psychological health are highly likely to deviate for more than six months from the condition which is typical for the respective age and whose participation in the life of society is therefore restricted. Severely disabled are persons whose degree of disability is at least 50 % and who either lawfully stay in Germany, have their ordinary (legal) residence or (legally) work in Germany. (§ 2 (2) SGB IX) The percentage of a given disability is determined according to a list of impairments and diseases and according to guidelines prepared by a group of medical and legal experts.

Ireland

In Ireland, disability discrimination is prohibited by two laws which are not disability specific, but cover several grounds. Employment discrimination is prohibited by the Employment Equality Act of 1998. Section 2(1) of the Act defines:

‘disability means-
(a) the total or partial absence of a person’s bodily or mental functions, including the absence of a part of a person’s body
(b) the presence, in the body of organisms causing, or likely to cause, chronic disease or illness,
(c) the malfunction, malformation or disfigurement of a part of a person’s body
(d) a condition or malfunction which results in a person learning differently from a person without the condition or malfunction, or
(e) a condition, illness or disease which affects a person’s thought processes, perception of reality, emotions or judgement or which results in disturbed behavior,
and shall be taken to include a disability which exists at present, or which previously existed but no longer exists, or which may exist in the future or which is imputed to a person.

Sweden

In Sweden a disability-specific law against employment discrimination was adopted in 1999. The “Prohibition of Discrimination in Working Life of People With Disability Act (Lag 1999:132). § 2 of the Act contains a short definition:

Disability means every permanent physical, mental or intellectual limitation of a person’s functional capacity that is a consequence of an injury or illness that existed at birth, arose thereafter or may be expected to arise.

United Kingdom

In the United Kingdom, employment discrimination against disabled persons is prohibited by the Disability Discrimination Act of 1995 (DDA) of which Section 1 provides:

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16 GdB/MdE-Tabelle zu Section 30 Bundesversorgungsgesetz.
17 Bundesministerium für Arbeit und Sozialordnung (Hg.) Anhaltspunkte für die ärztliche Gutachtertätigkeit im sozialen Entschädigungsrecht und nach dem Schwerbehindertengesetz (1996).
a person has a disability for the purposes of this Act if he has a physical or mental impairment which has a substantial and long-term adverse effect on his ability to carry out normal day-to-day activities.

A long term effect is considered to be a period of twelve months at least.

Section 2 (1) provides:

The provisions of this Part and Parts II and III apply in relation to a person who has had a disability as they apply in relation to a person who has that disability.

**Conclusion**

All of these definitions are impairment-related. While the general German definition of disability emphasises the deviation from a typical condition without referring to impairments, the definition of severely disabled persons\(^\text{18}\) does. The latter one is determined by a list of impairments. Accordingly, a person without four fingers (including a thumb) would be a severely disabled person. The same holds true for a person without one leg or a person with serious facial disfigurements. The German definition only covers persons who are presently disabled.\(^\text{19}\)

The Irish definition, too is impairment– and/or capacity related, but it does not require a certain severity of the impairment or of the functional limitation. It covers present, past, future and imputed disabilities.

The Swedish definition is focussed on functional limitations as the result of impairments, but again, does not require any severity or long lasting condition to be reached. It covers present and future disabilities.

The British definition is impairment–related and refers to a range of normal life activities and long term effects. The person’s functional limitations need to be substantial. It covers present and past disabilities.

None of the definitions in these four EU countries cover persons who are associated with disabled persons.

Case law in these four countries\(^\text{20}\) reveals that the British definition has been most problematic, because it installs a high threshold plaintiffs have to overcome in order to receive protection of the law. Similar to the US experiences with the ADA-definition, many plaintiffs loose their cases because they cannot prove that they belong to the group of the “truly disabled”.

Taking into account the guidelines for disability definitions described supra, the German and the British definitions clearly perpetuate the medical/individual model of disability for several reasons. Both definitions are narrowly construed towards the “truly disabled” person. They do not cover all persons affected by disability-based discrimination, i.e. not those who might have a future disability or who are presumed to be disabled. The German definition additionally ignores past disabilities.

The Swedish definition is less oriented towards the individual model of disability in that it covers a broad number of disabled people and covers future disabilities. Yet, it covers not all persons who are or might be victims of disability-based discrimination, because past and imputed definitions are not

\(^{18}\) And only to this group of disabled persons does the discrimination ban apply!

\(^{19}\) The SGB IX also covers „persons threatened by a disability” (§ 2 (1) SGB IX ), however the ban on employment discrimination does not.

\(^{20}\) Germany did only have one case so far, which did not involve questions on the definition of disability.
explicitly covered and plaintiffs need to provide evidence that they are somehow unable because of mental, physical or intellectual limitations.

The Irish definition seems to circumvent almost all the pitfalls described above. It does not portray disabled persons as helpless or needy, because it makes no assumptions about the effects of a given impairment or malfunction. It is not based on a “truly disabled” notion and it covers past, present, future and imputed disabilities. It thus can be regarded as truly endorsing the social model of disability.

As to the possibility of creating tensions with other social disability laws, it seems that it is too early to say anything about this subject relating to the four countries under review here. It might be predicted though, that the Irish definition will pose the least problems with respect to this issue.

V. Do we need a definition of disability in discrimination law?

Since not all EU countries which have adopted disability discrimination law have chosen to define disability in this context, the question arises whether this might be a possible solution to the problem. In other words: does disability discrimination law necessitate a legal definition of disability? The Framework Directive is silent on this issue. The issue of disability definition was deliberately left to the Member States in order to give leeway to use their own nationally developed disability definitions.

But the Framework Directive does not demand Member States to define disability in the context of employment discrimination and at least six EU members have chosen not to.

An argument for the need to define disability which has been put forward is that discrimination laws have the purpose to protect a distinct group which has historically been oppressed by another dominant group. The definition would then serve as a gatekeeper and clarify which group is to be protected by the law. Such a “subordination-approach” claims to ensure that only the members of the subordinated group have anti-discrimination rights. There are three counter arguments against this.

First, most discrimination laws do not only cover a distinct subordinated group, because they are symmetric. The ban on discrimination is based on a neutral category, such as race, religion, or sexual orientation which allows both groups, the members of the dominant as well as the members of the subordinated group to claim protection against discrimination. This of course is difficult with respect to disability which is an asymmetric category as such. Some authors have suggested to try to find a neutral symmetric category for disability discrimination, such as the term capabilities. However, to my view, this is not a neutral category and disability discrimination often has nothing to do with what the individual can or cannot do.

Secondly, any group definition bears the danger of making unfound assumption about each member of that group. This essentialist trap can be avoided by focussing on the act of discrimination instead of on the definition of the group. As Jerome Bickenbach and Robert Burgdorf have recently explained to our expert group, discrimination is an invidious and unjust response to disability, so our focus should be on the nature of that response and the disadvantages and inequalities that the complainant suffers as a consequence, rather than any physiological feature of the person themselves.

Thirdly, I agree with Gerard Quinn that the Framework Directive does not create space for groups but for individuals. Non-discrimination law focuses on the person rather than the group to which s/he

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22 Aart Hendriks, (2002), supra note 7, at 212.
23 For a fuller picture on what is meant see: Martha Minow, (1990), Supra note 3, at pp. 101
belongs. It creates space for the individual on the assumption that the individual does have the capacity to contribute. Thus, a definition of disability is not necessary in order to describe the group protected. Rather, the law should protect every one against disability based discrimination. Such an approach would ensure that persons would not first have to prove that they are disabled (enough) in order to receive protection against discrimination. The ADA and DDA jurisprudence in the US and in the UK has shown that in the employment area, the definition of disabled persons is often used as a device to disqualify the plaintiff without even debating the discriminatory treatment\(^{25}\).

No definition of the protected group might also be a solution to the possible tension between discrimination and other social disability laws.

However, to refrain from defining the group of disabled person does not solve the question, whether a definition of disability is necessary in the discrimination context. In order to outlaw a certain action, the prohibited action needs to be defined. Because disability in the discrimination context has a different meaning than in the social welfare context, a referral to other definitions in social laws of a Member State is not sufficient. Discrimination laws are related to stigma whereas social laws are related to need.

Thus, a disability definition is necessary but only with respect to the act of discrimination. In order to avoid the medical/individual model of disability such a definition should be tailored according to the guidelines I have stated earlier. The definition:

- should be related to impairment, chronic illness or malfunctions
- should not be based on a certain severity of disability
- should cover past, present, future and imputed impairments or chronic diseases and associates.

Since the Irish definition follows most of these guidelines, it could serve as a model definition for other EU Member States.

**VI. Conclusion**

The Framework Directive (FD) clearly endorses the social model of disability but provides no definition of disability. Out of the fifteen EU-Member-States under review, ten have laws, which are supposed to transpose the FD. Only four Members have adopted discrimination laws that contain definitions of disability. All of these definitions are impairment- or capacity-related, but this does not necessarily mean that the respective definition perpetuates the medical/individual model of disability. This is because disability-based prejudice and stigma are always related to an actual or presumed abnormality called impairment. Whether a definition in an anti-discrimination law perpetuates the medical or social model of disability depends on other indicators. The medical model of disability is perpetuated if the definition of disability only covers a certain group of “truly disabled persons” or - more generally speaking – if not all persons affected by disability discrimination are protected.

Disability discrimination laws need a definition of disability. But the definition should not describe the group protected under the law, but rather define the act declared prohibited. Thus, the definition should describe the term “disability-based”, rather than the term “disabled person”.

Such an approach is in line with the Framework Directive. According to Article 1 is the purpose of the Framework Directive not to protect certain groups but to combat discrimination on certain grounds. Only with respect to indirect discrimination (Article 2 (2) (b)), reasonable accommodation (Art.5) and positive action (Art.7) does the FD speak of disabled persons as a group. These are the instances when disability matters and the plaintiff may have to prove that s/he belongs to that group. In these instances, it would be sufficient to take recourse to the definition of disability – based discrimination.

\(^{25}\) See supra note 12 for analysis of US jurisprudence on the ADA definition.