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## **Disability and Employability: Professional categorisations and individual experiences at the boundaries of disability**

Handicap et employabilité. Catégorisations professionnelles et expériences individuelles aux frontières du handicap

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### **At the edges of disability**

If language is everywhere and always an instrument of action and power (Bourdieu, 1982), the vocabulary used in the domain of disability has particular importance. As a result, there is an abundance of conceptual definitions of and approaches to disability produced by individual researchers (Thomas, 2004; Ville, Fillion and Ravaud, 2014) and international institutions (UN<sup>1</sup>, WHO<sup>2</sup>, OECD<sup>3</sup>, INDCP<sup>4</sup>) aiming to clarify the variety of notions in use and draft a common framework. This is one of the roles of the WHO's international disability classifications, which are continuously updated and subject to endless debate (*Alter, European Journal of Disability Research*, 2013). Since the International Statistical Classification of Diseases (ICD) granted a specific branch for the field of disability with the creation of the International Classification of Impairments, Disabilities and Handicaps (ICIDH) in 1980, disability has become accepted as a complex and multidimensional notion integrating, at the minimum, organic, functional, and social aspects. The main disagreements have concerned questions of form (how to build a field that is not entirely defined by negative terms?) as well as fundamental questions, concerning in particular the inclusion of the surrounding environment in the very definition of disability. As others have aptly summed it

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<sup>1</sup> The United Nations

<sup>2</sup> World Health Organization

<sup>3</sup> Organisation for Economic Co-operation and Development

<sup>4</sup> International Network on the Disability Creation Process

up(Barnes, Mercer and Shakespeare, 1999), the individual model of disability (disability is fundamentally the consequence of a malfunction internal to the individual) and the social model (disability is fundamentally the consequence of a society that builds obstacles to social participation for certain categories of individuals) are in constant tension, although the former long seemed to be in a hegemonic position until it gave way to the accumulating assaults of the Quebecois classification (Fougeyrollas et alii., 1998) and international disabled persons associations (Davis, 2006).

These definition difficulties did nothing to facilitate the 20th century production of the field of disability, in both the social (through new social policies) and sociological (Bourdieu, 1985) senses of the term. Although there is a core where the variety of criteria applicable to disability overlaps, more surprisingly there are also a numerous situations with striking inconsistencies, and this among all the applied criteria. In France, the vast national study *Handicaps-Incapacités-Dépendance* (Handicaps-Incapacities-Dependency), conducted in the late 1990s, was partly conceived with the goal of tallying the number of disabled persons, but it only multiplied interrogations. As J.-F. Ravaud, A. Letourmy and I. Ville (2002) have shown, the percentage of disabled people in the French population ranges from 4% to 40%, depending on whether a narrow definition is applied, based on the official recognition of a disability, or a wide definition, based on the declaration of at least one impairment, with a variety of intermediary positions such as self-declaration of a disability (10% of the French population responds to this criteria, and this figure is the one most often chosen and cited in the press and scientific reports). As the rosettes of Jean-François Ravaud, Alain Letourmy and Isabelle Ville (ibid., p. 537 sqq.) suggest, disability may be represented by the form of a flower with a relatively tight centre (where all the defining criteria come together) and many petals, each representing conformity with a given criteria. A significant proportion of those declaring themselves disabled thus do not correspond to any objective

criteria allowing them to be counted in this category, while inversely, an equally significant proportion of people with official “handicapped” recognition do not declare themselves as disabled.

This special issue is devoted to the idea that approaching disability from the periphery has a heuristic value that allows an improved understanding of just what the field of disability is. By paying attention to borderline situations, by examining cases where disability merges into other qualifications (validity, illness, poverty...), by positioning ourselves on the boundaries shaping the field of disability, we learn as much, if not more, about its core as we would by addressing the most typical figures of disability head-on. Using Ravaud, Letourmy and Ville’s image of the rosette, one might say that our approach is focused not on the centre of the flower where the overlapping criteria (official disability recognition, presence of everyday limitations, self-designation as disabled person, etc.) make situations conceptually obvious, but instead on the petals, where the various dimensions of disability disconnect. From this angle, the domain of employment and the issue of the recognition of “handicapped workers” provide particularly interesting material for analysis.

The five contributions gathered in this issue thus address various borders of disability while sharing a common theme, the relationship to employment. The first two deal with the boundary between disability and illness; the first, (Jacques Rodriguez, “A course of treatment: Putting people with tuberculosis to work in England and France in the 1920s”), questions the place of work in the treatment of people suffering from tuberculosis in the early 20<sup>th</sup> century, when the category of disability was still only in its infancy but ripe for development in these early assemblies of sick people with irreversible physical effects (Ville, 2010); the second (Audrey Parron, “Autonomy issues for young adults dealing with psychic disorders”) focuses on mentally ill youths’ transition to adulthood, at the moment when the issues of their autonomy and a potential recognition of psychic disability, possible under

French law since 2005, take urgency. The third contribution (Samuel Neuberger, “Poverty as a situation of disability: Social workers’ reticence to back Active Solidarity Income (RSA) beneficiaries’ requests for Disabled Adults Allowance (AAH)”) also deals with programs for gaining autonomy and support for finding employment, but in this case focusing on people receiving social assistance, on the border between disability and social marginality. Lastly, the final two contributions address disabled persons more explicitly, questioning the boundary between disabled workers and disabled persons. The first (Louis Bertrand, Vincent Caradec and Jean-Sébastien Eideliman, “Situating disability. The recognition of ‘handicapped workers’ in France”) deals with the relative weight of social situations and individual characteristics in the recognition of “handicapped workers” in the French setting, while the second (TrudieKnijn and Frits van Wel, “Better at work: Activation of partially disabled workers in the Netherlands”) addresses the effects of new policies for the recognition of partial occupational disability on individuals in the Netherlands.

### **Between the right to work and the right to not work**

The origins of assuming political and social responsibility for disabled people are intimately connected to employment issues. In the history of disability in France, Henri-Jacques Stiker (1999) singles out historical efforts by the State, economically and socially liberal at the time, to assure a form of national solidarity with people injured at work (starting with the 1898 law on work accidents), disabled veterans (after World War I), and people ill with tuberculosis (following the epidemics of the late 19<sup>th</sup> and early 20<sup>th</sup> centuries). A pair of issues was raised from the very first measures addressing these populations: the occupational reclassification of individuals who fell victim to political and social processes (industrialization, war, urbanization) and the establishment of pensions and benefits. Put in

other terms, the right to work and the right to not work are jointly affirmed, the charge of determining who will benefit from which right being left to the institutions charged with administering these populations.

The term “right” used here contains a fundamental ambiguity, though. Is it really a matter of rights that individuals may assert, or is it instead a matter of injunctions that individuals might have trouble resisting? As Jacques Rodriguez shows in his commentary on two texts written by doctors, work combines some very different values in the first rehabilitation centres in France and England. Sometimes vaunted for its therapeutic values, sometimes advocated for giving social and economic utility back to disadvantaged individuals, the doctors behind these pioneering initiatives handle work as an instrument for governing the population. Although the English case gives greater emphasis to the economic value of work, a blend of moral, economic, and therapeutic values is found on both sides of the Channel.

There are as many histories of taking charge of disability as there are national histories (Woodill and Velche, 1995). Specific systems were gradually put in place for the employment of people who were not yet called disabled. Studies based on international comparisons (Velche, 2012; Oakes, 2005) put countries with established forms of affirmative action into opposition, primarily based on those with disabled-worker quotas for large businesses (such as Germany, Austria, Spain, France, Italy) and others that borrowed a page from the civil rights movement and targeted their legislation on fighting discrimination against disabled workers (including Canada, the United States, the United Kingdom, Sweden). The Netherlands is in an intermediate position, since it recently became possible for large companies to negotiate the establishment of quotas with social partners without any national obligation having been voted. These systems differ in many other ways, from the generosity of benefits to the relative focus of measures toward the most disabled people

(Velche, 2012), showing the diverse ways the right to work and the right not to work may be arbitrated in specific national contexts.

Beyond this national diversity, there are similarities to be found in how these arbitrations have developed. Once again, the Netherlands provides an interesting example, as TrudieKnijn and Frits van Wel show: while policies for disabled persons had long favoured a high rate of inactive people living off rather generous and widely granted disability pensions, there was an about-face in the early 2000s. In most cases disability pensions were replaced with income supplements or unemployment benefits, which vary according to the rate of disability recognized by the administration and are conditional on active efforts to find work. If the Netherlands's case is extreme, it dramatically demonstrates the trend that the right to work is gaining the upper hand over the right not to work. In the French case, for example, after the 1970s-1980s period when the establishment of the *Allocation Adulte Handicapé* (Handicapped Adult Benefit; AAH; created in 1975) allowed a certain number of people to develop a feeling of social utility outside of the sphere of the labour market while not compounding the already high unemployment figures (Ville, 2008), a variety of reforms in the field of disability sapped the justifiability of not making an effort to rejoin the workforce. In consequence, the opposition between AAH beneficiaries, who since 1975 had been considered at least temporarily exempt from looking for work, and beneficiaries of the *Reconnaissance de la qualité de travailleur handicapé* (Recognition of the Quality of Handicapped Workers; RQTH), who to the contrary were considered to be workers disabled in strength or in actions, faded away in the 2000s (Bertrand, 2013). Not only could AAH and RQTH henceforth be combined, but disability professionals had to examine the working capacities of all AAH claimants. In the name of disabled persons' right to work, an injunction to be as integrated as possible into the job market is gradually established, to the detriment of other forms of non-market occupational engagements (Ville and Winance, 2006).

## **Employability and autonomy**

Concomitant with these developments, the notion of employability experienced rapid success on both sides of the Atlantic in the latter part of the 20<sup>th</sup> century (Gazier, 1990). It was also used in the field of disability, which is unsurprising since disabled persons have a higher likelihood than others of being both less productive and more discriminated against on the employment market. But in addition to its descriptive character, the notion of employability is also a template orienting how one might view relationships with employment: thinking in terms of employability makes employment an unambiguously desirable good and transforms the opposition employable/unemployable (which in the field of disability could refer to the opposition between pensioned people unfit for work and disabled workers) into a continuum of degrees of employability. One could draw parallels with the notion of educatability, whose success in the sub-field of disabled childhood came with the idea that no child was uneducatable (as was thought and officially affirmed until the latter half of the 20<sup>th</sup> century) and that it was rather a question of finding the suitable pedagogy for each child (Chauvière and Plaisance, 2000) so that all might receive an education, perceived as an inalienable collective good. In this special journal issue, although employment appears to be a more or less distant possibility depending on the article concerned, it at least remains a horizon that orients support professionals' practices, and to a lesser extent their publics' as well. In the first articles this horizon seems unattainable (particularly for tuberculosis sufferers in the early 20<sup>th</sup> century, and to a lesser degree for youth suffering from psychic problems and beneficiaries of social assistance), while it seems distinctly closer, although challenging to attain, in the latter two contributions (for disabled workers in France and partially unfit workers in the Netherlands).

Considering this variety of situations through the lens of employment prompts us to look into the professional worlds that have developed around these publics in search of, or at least perceived as lacking, employability. There are many such worlds and they do not necessarily communicate easily amongst themselves. Naturally, there are some significant differences in employment support professionals' practices from one country to the next, as shown by the examples developed here of France (representing a hybrid case) and the Netherlands (more activationist) (Barbieret Ludwig-Mayerhofer, 2004), and from one sector to another as well. Yet people likely to be considered disabled frequently navigate between several sectors, especially the medical, social service, and medico-social. Employment is a concern in all these sectors, but it assumes different connotations for the various concerned professionals: doctors see it more as a vector of healing and moralization (see contributions by Jacques Rodriguez and Audrey Parron), social workers in terms of social integration and autonomy (Audrey Parron and Samuel Neuberg), and disability professionals as a path to normalization and social integration (Bertrand, Caradec and Eideliman; Knijn and van Wel).

For many of these professionals, doing one's work well consists of supporting their publics on their paths to employment – not necessarily bringing them to the destination, but getting them to move forward in what they think is the right direction. The quest for improved employability is thus often confused with the search for greater autonomy, which has become a cardinal value in contemporary societies (Ehrenberg, 2010). In the case of young adults with psychic problems, Audrey Parron clearly demonstrates that the professions supporting them (doctors and social workers) do not aim for just any form of autonomy, but pursue only what they consider “good autonomy,” which may in fact be strictly supervised by institutions. What is important is not that young adults be able to get by at any cost (which could lead to bad autonomy resulting in forms of social marginalisation), but that they

advance toward a responsible adult life in society, evaluated according to a given number of criteria for social integration (housing, employment, forming romantic partnerships...)

This perspective and these criteria are also found among the social workers that Samuel Neuberger studied. They also see the path to employment as a long and winding road, punctuated with way-posts and “impediments” that they work to remove one by one. These impediments often concern the same kinds of material elements (housing, cleanliness, transportation, child care...), which in this case serve as so many points for professionals to address hence giving themselves and their publics the feeling that things are moving in the right direction. In this context, disability is thought of as a particular sort of impediment that prevents employment and progress, to the point that disability benefit claims are perceived as a last resort that in a way indicate support’s failure.

Shifting now to the disability professionals’ side, as the last two articles do, we see that support in moving toward employment does not end with the establishment of a claim to benefits, since it is possible to combine benefits and employment according to different modalities in different countries. But here again, a significant proportion of professional practices are guided by a rationale of moving claimants toward the goal of increasing employability.

### **Administrative categories and experiences of disability**

These articles prompt us to think about categorization in the domains of handicap and employment conjointly, and to wonder what is at issue in these categories for professionals and individuals alike. As one might expect, the issues differ depending on which side of the counter you are on: articles addressing the professionals’ perspective (those by Jacques Rodriguez and Samuel Neuberger) reveal rationales quite different from those addressing their

publics' viewpoints (Knijn and van Wel). These differences are even more obvious in articles contrasting the two points of view (those of Audrey Parron and Louis Bertrand, Vincent Caradec and Jean-Sébastien Eideliman): professionals are situated in relation to the meanings their specific fields give the categories, so that a claim for disability recognition will have quite distinct meanings for those working in the domain of social assistance and those working in the field of disability. But for the individuals whose claims they process, these categorizations are part of a much broader universe of meaning that encompasses various spheres of their social lives: depending on their age, gender, and academic and occupational careers, the possibility of new job training, recognition of a degree of disability, or the evaluation of a degree of employability may have widely divergent meanings and consequences.

And yet one of the objectives of the movement toward the individualisation of social policy, which also touches the domain of disability (Bertrand, Caradec et Eideliman, 2012), is to reduce these gaps by making professionals study claimants' situations case by case, in relation to their needs and expectations. In the domain of disability, this is why professionals evaluating claims applications are required to take account of "Life Plans" that claimants may have formulated to back up their request (although it is optional). The article by Louis Bertrand, Vincent Caradec and Jean-Sébastien Eideliman shows that this desire to account for the particularities of claimants' situations does not stop professionals from comprehending these situations very differently than those who are experiencing them, who, when they call upon the disability sector, are often seeking some kind of protection from the pressures they are subjected to at a given moment in their life course.

In addition to highlighting the great diversity of motives behind recourse to support, this article also stresses that disability-related categorizations are not only the bases of rights and statuses, but are also elements of identification, in the sense of qualifications that

individuals may or may not integrate into their self-perception. Although there are a variety of forms of resistance to designation of the self or a loved one as a disabled person, expressions like “disabled worker,” “disability,” and “unfitness” hold strong meanings for people. In this vein, Trudie Knijn and Frits van Welsh show that the new disability policy in the Netherlands produces discernable effects on its beneficiaries, who react in varying ways during the conducted sociological interviews. Contrary to the authors’ expectations, individuals do little to challenge the system’s tendency to be stingy in attributing high degrees of disability and instead signal repeatedly that their occupational capacities are under-estimated, as manifest in what they find to be excessive degrees of disability. The evaluation is therefore an incident where an individual’s declassing is brutally objectified, even if it does open access to new rights. This is at the heart of the complexity of administrative instruments, which are simultaneously somewhat arbitrary quantifications caught up in politico-economic imperatives and qualifications that could have important subjective consequences. Disability in general is particular in how it is placed at the intersection of public health issues, social policy, and individual experience, making it fruitful for analysing contemporary social transformations.

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