

INTRODUCTION

French Disability Studies: Differences and Similarities

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ABSTRACT *In the introduction to this special issue on French disability studies, the authors – guest editors for this issue – examine the gradual development of the field of disability in France, the heritage of a long history. According to the authors, the vitality of disability research in France is camouflaged by a certain number of particularities. Two hypotheses are put forward to explain the weak development, in France, of a research area specifically dedicated to disability research. The first hypothesis is based on the conception of equality under French republican universalism; the second is based on the particular way that research is organized in France. The terminological problems and the difficulties of translating the term “handicap” are also discussed. The introduction ends with a presentation of the various articles that make up this special issue.*

“Disability studies” essentially emerged in Anglo-Saxon and Scandinavian countries to constitute a specific disciplinary field. The situation is different in France, but even if disability research is not organized in an autonomous manner and has not pervaded the international arena to such a great extent (mainly for linguistic reasons), it has nevertheless developed with some similarities and also some specific differences (compared to the north-American, English or Scandinavian traditions) that stem just as much from history as from a political concept of equality or from the way that research is organized in France.

The Gradual Development of the Field of Disability in France: Heritage of a Long History

It is impossible to understand the public policies at work in the field of disability, any more than the social practices developed by the various social actors, without examining how this field has gradually developed throughout

history. Interest shown in international comparisons allows one to observe huge variations in the way in which different countries, including within Europe, conceive disability, deal with it, and implement appropriate policies. But the significance of disability in other cultures, the understanding of the social situation of disabled persons in different societies and the nature of their rights within different systems of social policies can only be properly understood by putting them in the context of each country's individual history.

Certain historical events have had a determining effect on most European countries. This is particularly true of the two World Wars, which led to such a large number of wounded in Europe that they had a huge effect on these countries' relations with disability. Before the wars, successive waves of industrialization had led to most concerned countries dealing with the consequences of work-related accidents, albeit not all at the same rhythm. Other historical events particular to each individual country – such as the Revolution in France – might also have had an effect on national policies.

The field of disability was built relatively recently. In France's case it goes back to the second half of the 20th century. But its heritage goes back much further. It was thus built in successive strata by unifying situations which until then had had little to do with one another. Prior to the construction of this field there had been no disabled persons, but war victims on the one hand and victims of work-related accidents on the other, further categories being children suffering from the after-effects of poliomyelitis, maladjusted children, etc. These different pre-existing categories distinguished people in terms of the origin of their impairments, and this tended to camouflage the common nature of their experiences.

The era of rehabilitation was the opportunity to unify the field of disability. Above and beyond the origin and nature of their impairments and disabilities, via rehabilitation the people concerned were offered solutions that aimed to allow them to return to ordinary life. Physiotherapy and re-education techniques, technical aids and vocational rehabilitation policies laid the stress on the common characteristics of people whose impairments had very different origins.

Whilst international debates about the term “handicap” and its definition were extremely heated, the unity of this field was less problematic than that which defined it. As an alternative, the social model thus proposed an approach of restricting participation in social life due to physical or social barriers. It is this community of experience which then served as a reference. The accessibility of the city, the struggle against obstacles of all types, the adaptation of social and political rules, all of these became preferred means of action with which the various sub-populations could identify.

Whilst the social construction of the field of disability met historical necessities, we might now wonder about its future in France, and in particular, we might wonder how the French republican tradition is going to be able to integrate or to adapt to international changes.

Equality: French Republican Universalism

The approach in terms of rights and non-discrimination which is gradually gaining ground at international level raises a certain number of questions on the evolution of public disability policies in France. Indeed, whilst there may be consensus on the principles, there is continued debate on their implementation.

The divergences between certain Anglo-Saxon culturalist approaches and the French egalitarian approach give us clues as to the cultural differences in defining and recognizing disability and to understanding the different systems of social protection. Whilst it is now standard procedure to compare the issue of ethnic minorities with that of multiple differences (gender, sexual orientation, traditions), these particularist orientations continue to come up against the republican egalitarian ideal (Wieviorka 1997, 2001), and thus divide French opinion.

First of all, since the French Revolution, equal rights have been one of the cornerstones of the French republic. Article 1 of the 1789 Declaration of the Rights of Man and of the Citizen states: “Men are born and remain free and equal in rights. Social distinctions may be founded only on the general good”. This Declaration was placed at the beginning of the first constitution of 1791. Since then, the attachment to these principles has been repeated in all successive constitutions and constitutes the preamble to the current French constitution. The first consequence of this postulate is that any discriminatory policy would be contrary to the constitution, whether it is based on race, religion or disability. It infers a model of assimilation which is founded upon a certain number of major principles that are considered to be ideals (secularism, equal rights, public education), and is based on a process of normalization, each citizen having to accept to live in accordance with these common rules. One fine example is primary education – which was made obligatory by Jules Ferry in 1882 – in state schools in which all of the nation’s children, whatever their origin and social milieu, were to be treated in the same way, differences being hidden by the fact that everyone wore the same school smock. In return for this republican universalism, differences could not be expressed in public and had to be restricted to the private sphere.

One of the strengths of this system is that it offers protection against any temptation to grant different rights to different citizens in line with any given characteristics they might have. Its weakness is that equal rights do not mean equal situations – as the continued social inequalities between groups shows with acuity. This system thus has the advantages of strong integration, but can become “blind to differences” (Ravaud & Stiker 2001).

The second consequence is that in such a political system, it is (in theory) not necessary to create legislative devices to guarantee rights relating to gender, race, religion or whatever, because given that equality is a principle, a part of the constitution, these criteria do not discriminate between citizens. Coming up with anti-discrimination policies in the French political system is therefore not a simple matter. In the same way, approaches in terms of positive discrimination, quota policies in particular, remain difficult to

integrate into this type of thinking, which essentially considers their risk of stigmatization and marginalization. Yet above and beyond the principles, the observation of situations which highlight the persistence of social inequalities remains the only political lever with which to fight against discrimination that resides not in rights but in facts (Ravaud, Madiot & Ville 1992). This is why France recently created a high authority to fight against discrimination and for equality (HALDE: Haute Autorité de la Lutte contre les Discriminations et pour l'Égalité).

We thus find a tension between two approaches to disability policies that we might qualify as differentialist and universalist; the former demanding the right to a difference, to a specificity, even to a minority group identity; the latter referring to the universality of human rights and rejecting any particularism (Bickenbach, Chatterji, Badley & Ustün 1999). This tension is not without consequence on the social situation of disabled persons. The first approach sows the seeds of segregation, the second the seeds of social inequalities.

The Specificities of Research Organization in France

When one looks at disability research in France, one has to look at both its strengths and its weaknesses. This is not the place to talk about the debate on critical disability studies and their relation to traditional disciplines and political activism (Priestley 2002); let us simply agree here to call disability studies a set of works of research in the field of human and social sciences, distinct from biomedical approaches that relate to rehabilitation sciences (Linton 1998). As we have said, in France disability studies do not constitute an autonomous discipline with the same development that they might have in other countries.

The republican universalism mentioned above is probably one of the reasons for the reticence to develop specific fields of research, something which is not in fact proper to disability studies, and which can also be found in gender studies and cultural studies.

But another specificity relates to the French system of research and teaching. This is characterized by a relatively original situation with the coexistence of two different systems: universities where researcher-lecturers work, and national research institutes, among the biggest of which are the National Centre for Scientific Research (CNRS: Centre National de la Recherche Scientifique) and the National Institute for Health and Medical Research (INSERM: Institut National de la Santé et de la Recherche Médicale) with their full-time researchers. With the notable exception of the National Academy of Arts and Trades (CNAM: Conservatoire National des Arts et Métiers), there is no higher education establishment with a chair explicitly dedicated to disability. It is therefore hard for “disability” as an academic subject to find its place in the organization of higher education and research in France (Albrecht, Ravaud & Stiker 2001). Intellectual activity on disability nevertheless exists. There are both formal and informal initiatives.

Among the initiatives backed by the ministry of research, the *Institut Fédératif de Recherche sur le Handicap* (Federative Research Institute on Disability) is a network of research teams working on disability throughout France. These teams belong to various research organizations and also to several universities. Their activity relates to three axes: research in public health and human and social sciences, research in rehabilitation sciences and technological research. In some ways, this network is the French equivalent of the Nordic Network for Disability Research. One of the objectives of this issue is to encourage exchanges between these two networks and, more generally, between French and Scandinavian scientific communities doing research on disability.

As another example, the association ALTER (International Society for the History of Impairments, Social Problems, Disabilities) recently launched a European journal of disability research with the same name.

So as we can see, there are signs of vitality. Numerous actors would like to create a sector of research specifically dedicated to disability, made up of experts in the field – the only means, in their opinion, with which to ensure its development. Indeed, in 2005 these debates justified the creation of a National Observatory for Training, Research and Innovation on Disability (ONFRIH: Observatoire national sur la formation, la recherche et l'innovation sur le handicap).

The current situation has the advantage of avoiding French disability research from becoming isolated. The fact that the main currents of social science thinking might traverse it, through the interest, however occasional, of researchers who ordinarily work in other areas, is undoubtedly a source of opening and enrichment.

Comparison with international scientific literature on disability would seem to bring out two main themes in France, with on the one hand a marked interest for socio-historical analyses, and on the other a former involvement in the approach to social representations of disability.

About the Terminology: Translation Difficulties

An introductory comment is needed with regard to the vocabulary used, in order to avoid any misunderstanding with regard to language. One of the linguistic problems relates to use of the word “handicap”. First and foremost, it is important for Scandinavian readers to understand that whilst the term has more or less the same meaning in English and in French, it is not at all used in the same way in the two cultures. In French, the word “handicap” does not have any pejorative connotations and social actors, politicians and academics have no qualms about using it, unlike their counterparts in Anglo-Saxon countries where it is generally considered to be politically incorrect. In practice, the traditional use of the word “handicap” in French is far closer to that of the English term “disability”, i.e. a generic meaning which covers all the lesional, functional and social consequences of impairment or the consequences of environmental barriers, depending on whether one adopts the medical model or the social model. But whereas the English language uses

two terms – “handicap” and “disability” – and differentiates them, the French language only uses one – “handicap”. One might therefore, without having any impression of contradicting oneself, speak in French of the social model of handicap.

It is important to note that the authors asked to take part in this issue are all aware of the international debates on terminology. They all respect the unanimous wish not to use any terminology that might be considered offensive. If the word “handicap” is used in this issue, it is with a view to remaining as close as possible to the French use of “common sense”. It should be considered as a compromise between the difficulties of translation and the desire to reflect the practice of the French language. The authors have also tried to restore as closely as possible the terminological uses existing in the different periods of history concerned.

Presentation of the Issue

This special issue, devoted to French disability studies, was made possible through a partnership between the *Nordic Network for Disability Research* and the *Institut Fédératif de Recherche sur le Handicap*, a French network of research teams in the field of disability. These exchanges are part of a broader wish to federate disability studies at a European level.

This issue aims to provide a representative though not exhaustive panorama of traditions for French disability research in the field of human and social sciences. This introduction is followed by seven articles by authors of different institutional backgrounds.

The first article presents the contribution made by leading French intellectuals to the understanding of disability. Rather than setting out a comprehensive panorama of French works on the subject, Henri-Jacques Stiker highlights the main lines to have marked the field over recent decades. In particular, he mentions authors such as Michel Foucault, Georges Canguilhem, Marcel Gauchet and Robert Castel, whose works have inspired thinking on disability and are still capable of enriching it. He discusses their epistemological and conceptual contributions and their relation to thinking on alterity and exclusion.

The article by Myriam Winance, Isabelle Ville and Jean-François Ravaud examines disability policies in France. Using a socio-historical approach, the authors look at the origins of current French policy. They discuss the main periods to have marked this long history, show the changes that have occurred and the tensions that still run through existing policy. They identify three types of approach – category-based, universalist and personalized – each with a different history, but all affecting the debates which surrounded the renewal of French disability policy, through the introduction of the law of 11 February 2005, referred to as the “law on equal rights and opportunities and the participation and citizenship of disabled persons”.

The next two articles examine representations of disability, though with a different approach.

Marcel Calvez, using an ethnographic work on relationships between neighbours, carried out in a small Brittany town on the social participation of mentally disabled persons, presents an analysis of disability as representation which is both pragmatic and cultural. By using Mary Douglas's typology of forms of social organization, he is able to lead up to a generalization in order to show that representations of disability are based on principles which differ in accordance with the forms of organization of social relations.

Alain Giami, Jean-Louis Korpes and Chantal Lavigne approach the question of representations, this time from a symbolic angle, enlightening the significations of the notion of disability in France. Taking a qualitative study carried out in particular among people who are *a priori* "not concerned" by disability, they show the polysemic nature of the term "handicap" and the metaphorical function of "mental handicap", a central notion which condenses the multiple aspects of this field of representations and points to a situation that would be beyond possible effective social response.

The associative movement is one of the main actors in the field of disability. Catherine Barral's article examines associations in the field of disability in France in their relationships with disabled persons and with the State. She sets out the gradual historical structuring of this movement since the creation of the 1901 French statute governing associations. She describes the public-private nature of the partnership between managing associations and the State that is so typical of the French situation, and to end, discusses the Europeanization of associative actors and the related reorientation of public policies.

Serge Ebersold looks at the relationship between social participation and citizenship. After showing that access to the social goods and the needs-centred approach are necessary but not sufficient conditions for a full social participation, he links the notion of participation to its affiliating nature, which then leads him to consider perspectives of identity and the relationship between citizenship, social recognition and the feeling of existing.

In their approach to the ethical questions surrounding selective management of births, Danielle Moyse and Nicole Diederich highlight in an original way the issue of prenatal screening. Using two works of research on different populations – disabled persons and prenatal diagnosis experts – they explore both the way in which disabled people perceive medical practices relating to birth selection and the way in which these practices (foetal ultrasounds in particular) are developing within the context of the judicialization of medical risk.

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References

- Albrecht, G. L., Ravaud, J.-F. & Stiker H.-J. (2001) L'émergence des *disability studies*: état des lieux et perspectives (The emergence of *disability studies*: current situation and future directions, abstract available in English), *Sciences Sociales et Santé*, 19(4), pp. 43–73.
- Bickenbach, J., Chatterji, S., Badley, E. M. & Ustün, T. B. (1999) Models of disablement, universalism and the international classification of impairments, disabilities and handicaps, *Social Science & Medicine*, 48, pp. 1173–1187.
- Linton, S. (1998) Disability studies/not disability studies, *Disability & Society*, 13, pp. 525–540.
- Priestley, M. (2002) Why we need to work together in the European Year of Disabled People, *Disability & Society*, 17(7), pp. 845–849.
- Ravaud, J.-F., Madiot, B. & Ville, I. (1992) Discrimination towards disabled people seeking employment, *Social Science & Medicine*, 35(8), pp. 951–958.
- Ravaud, J.-F. & Stiker, H.-J. (2001) Inclusion/Exclusion: An analysis of historical and cultural meanings, in: G. Albrecht, K. Seelman & M. Bury (Eds), *Handbook of Disability Studies*, pp. 490–512 (Thousand Oaks & London: Sage Publications).
- Wieviorka M. (1997) Déficience, différence et égalité (Impairment, difference and equality), in: A. Blanc & H.-J. Stiker (Eds) *L'insertion Professionnelle des Personnes Handicapées en France (The Professional Insertion of Disabled Persons in France*, not available in English), pp. 23–37. (Paris: Desclée de Brouwer).
- Wieviorka M. (2001) *La Différence: Identités Culturelles: Enjeux, Débats et Politiques (Cultural Identities, Stakes, Debates and Policies*, not available in English) (Paris: Balland).