

Article

# Vulnerable Rights: The Incomplete Realization of Disability Social Rights in France

Anne Revillard

Observatoire Sociologique du Changement (OSC)—Laboratoire Interdisciplinaire D'évaluation des Politiques Publiques (LIEPP), Sciences Po, 27 Rue Saint-Guillaume, 75337 Paris CEDEX 07, France; anne.revillard@sciencespo.fr

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**Abstract:** While disabled people embody a classical figure of vulnerability, this paper shifts the focus of attention to the vulnerability of their social rights. I address this question normatively and empirically. From a normative point of view, a common framing of disability rights as civil rights, under the influence of the Americans with disabilities Act (ADA), has tended to impede the discussion on disability social rights. By re-asserting that social rights are fundamental human rights, the United Nations' Convention on the Rights of Persons with Disabilities (CRPD) contributes to bringing them back to the forefront of disability research. However, the realization of disability social rights also needs to be empirically assessed. Based on theories of social rights as well as on Weberian sociology of law, I point to two major ideal-typical characteristics of social rights: they are expected to reduce uncertainty, especially regarding the evolution of one's autonomy, and to foster a sense of citizenship. I then study the reception of two types of disability benefits in France, the Adult disability benefit (AAH) and the Disability compensation benefit (PCH), to assess to what extent these promises of social rights translate into the experiences of disabled citizens. My analysis is based on 30 biographical interviews with people with either visual or mobility impairments, conducted between 2014 and 2016. The results show the persistent vulnerability of disability social rights in France, pointing to the importance of the procedural dimension of rights realization.

**Keywords:** disability; social rights; social policy; disability compensation; policy reception; qualitative methods; biographical interviews

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Disabled people are one of the classical figures of vulnerability (Satz 2014); as such, they have been the object of a form of protection which was initially granted on religious and charitable grounds. "Rights, not charity!": through this slogan, the disability rights movement internationally expressed their rejection of this traditional form of intervention towards disabled people, marked by paternalism and pity; at the same time, the slogan conveyed the trust put into rights as an alternative basis for public policy and ground for citizenship (Fleischer and Zames 2011; Scotch 2001). However, beyond the slogan, the actual transformation of the meaning of public intervention towards disabled people has been and remains difficult, both normatively and empirically (Buton 2009; Hirschmann 2016). This is particularly the case in the field of social welfare. Therefore, in this paper, I suggest shifting the focus of attention from the vulnerability of disabled people to the vulnerability of their social rights<sup>1</sup>. How are these rights vulnerable?

Their vulnerability first appears, from a normative point of view, in the framing of part of disability rights literature which, under the international influence of the Americans with disabilities

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<sup>1</sup> The two perspectives are compatible. The concept of vulnerability, especially when apprehended as universal rather than categorical, is a fruitful basis for the definition of human rights (Fineman 2008; Satz 2008).

Act (ADA), has been focusing more on antidiscrimination than on welfare (Heyer 2005; Vanhala 2011; Waddington and Diller 2002). Within a broad opposition between a social welfare model and civil rights model of disability policy, welfare has tended to be portrayed as opposed to rights, making it difficult to think of disability social rights as rights. By re-asserting that social rights are fundamental human rights, the United Nations' Convention on the Rights of Persons with Disabilities (CRPD) contributes to bringing them back to the forefront of disability research.

Taking social rights seriously means asking what distinguishes them, as rights, from previously existing charitable interventions. Based on theories of social rights as well as on Weberian sociology of law (Weber 2013), I point to two major ideal-typical characteristics of social rights: they reduce uncertainty, especially regarding the evolution of one's autonomy, and they foster a sense of citizenship. This theoretical discussion leads to an empirical question: to what extent do disability social rights reduce uncertainty and promote a sense of citizenship among their recipients?

Indeed, disability social rights are also vulnerable in practice, in the sense that many obstacles stand in the way of their full realization. This is the case even in a country with a strong social policy tradition, such as France. In France, the connection between social rights and citizenship was at the heart of the major reform of disability which took place in 2005 with the Law «on the equal rights and opportunities, the participation and the citizenship of disabled persons». As its name indicates, this law aimed at promoting the participation and citizenship of disabled persons, while reinforcing social rights, notably with the creation of a new disability compensation benefit.

Since this reform was implemented, several studies have documented the insufficient funding and human resources of the bureaucracy in charge of the allocation of disability social rights, the *Maison départementale des personnes handicapées* (MDPH), operating at the local level of departments (the French territory is divided into 101 departments). These entail restrictions in allocation and strong territorial inequalities, as well as long delays in the processing of individual applications (Baudot et al. 2013; Borelle 2015; Perrier 2013; Revillard 2017b). As a complement to these works describing the institutional sources fueling this vulnerability of disability social rights, this article analyzes how this translates into recipients' perceptions. To what extent do French disabled citizens perceive the social rights they are eligible to as rights—and as a corollary, to what extent do they consider themselves as right holders in this respect? I provide elements of answer to these questions based on biographical interviews with 30 persons with either visual or mobility impairments.

The first section of the article makes the case for considering, in line with the CRPD, the potential of social rights as fundamental human rights, rather than envisioning them *a priori* as an imperfectly modified form of charity. The second section presents the French context of the 2005 reform, the two types of benefits under study here (the Adult Disability Benefit—AAH and the Disability Compensation Benefit—PCH), and the methods. The last two sections develop the main results of this study with regards to the two dimensions of rights underlined above, their capacity to reduce uncertainty and to foster a sense of citizenship. The analysis of the interviews points to a vulnerability of disability social rights in France following these two dimensions. Based on these results, the conclusion stresses the importance of the procedural aspect of rights realization.

## 1. Disability Social Rights as Fundamental Human Rights

Within the context of US-based political mobilization, lawyers and political scientists have first and foremost conceptualized disability rights as civil rights. The Americans with disabilities Act (ADA) of 1990, which “mandates equal opportunities, integration, and accommodation for difference”, epitomizes this conception (Heyer 2005, p. 241). The US political context and the legacy of the civil rights movement contribute to explaining this framing. However, this focus on civil rights also derives from their affinity with the “paradigm shift” (DeJong 1979, p. 442) at play in the collective mobilization by disabled people since the 1970s. At the heart of this mobilization was a shift in the perception of disability, from being synonymous to individual impairment to being the consequence of social and environmental obstacles (Hahn 1985; Oliver 1990). Under different

vocabularies, this same aspiration was expressing itself on both sides of the Atlantic in the second half of the 1970s. Describing the Independent Living movement paradigm in the US in 1979, Gerben DeJong argued that “the theory of causation implicit in the Independent Living paradigm asserts that environmental barriers are as critical as, if not more so than, personal characteristics in determining disability outcomes” (DeJong 1979, p. 443). At the same time, in the United Kingdom, the Union of the Physically Impaired Against Segregation defined disability as “the disadvantage or restriction of activity caused by a contemporary social organization which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities” (UPIAS 1976). By focusing on social and environmental barriers, this “social model” of disability (Oliver 1990) pointed to barrier removal as a political strategy: making the environment accessible, banning discrimination, promoting equality between disabled and non-disabled people (Shakespeare 2013; Swain et al. 2013). In the US, civil rights were a prominent legal tool from this perspective, in keeping with the influence of the civil rights movement.

However, and especially in the US context, this focus on civil rights has tended to fuel a theoretical opposition between the notion of “rights” (reduced to civil rights) and that of “welfare” (viewed as synonymous to charity) (Waddington and Diller 2002; Kimberlin 2009; Heyer 2005; Ellis 2005; Scotch 2001). For example, comparing US and European policies towards disabled people in employment in the beginning of the 1990s, Lisa Waddington noted that “disability policy in Europe continues to be shaped, for the most part, by a welfare (or charity) model of people with disabilities, rather than a civil rights model” (Waddington 1994, p. 393). Here again, the connection to contrasted models of disability helps explain this theoretical opposition. By contrast with the civil rights model which primarily sees disability as the result of social and environmental barriers, the social welfare model is rooted in a medical vision of disability, according to which the issue lies in the individual, whom is viewed with “pity” and “charity”, if not “stigma” and “shame” (Heyer 2005, p. 239). This legitimizes various forms of segregation (special schools, sheltered workshops) in the name of addressing the “special needs” of disabled people. Ideas such as segregation, pity and charity seem hard to reconcile with the notion of rights. Moreover, these works, under the influence of ADA activism, have tended to conflate civil rights with rights in general, to the detriment of a consideration of other forms of rights. Therefore, this opposition between the social welfare model and the civil rights model has suggested an incompatibility between welfare and rights.

This idea is both descriptively and normatively problematic. Welfare is not necessarily synonymous with charity and paternalism. The very idea of social rights, since the XIXth century, has been to disentangle the former from the latter, and to ground welfare on legal criteria of eligibility rather than good will. As defined by T.H. Marshall in 1950, social rights include “the whole range from the right to a modicum of economic welfare and security to the right to share to the full in the social heritage and to live the life of a civilized being according to the standards prevailing in the society” (Marshall 1950, p. 11). In many countries, disability social rights were not only the first form of disability rights, but also one of the first forms of social rights. France here provides a case in point: the first legally ensured social right adopted under the Third Republic at the end of the XIXth century, which is also recognized as the birth certificate of the welfare state, is the creation of a social insurance scheme providing pensions for injured workers in 1898 (Ewald 1986; De Blic 2008). Even in the US where this opposition between civil rights and welfare was mainly theorized, disability civil rights have always coexisted with social security provisions. In fact, social rights have been the subject of renewed attention in view of the limits of antidiscrimination as a redistributive strategy for disabled people (Bagenstos 2009; Satz 2008). In this context, several authors who had initially relied on the opposition between civil rights and welfare have later questioned it and pointed to alternative conceptualizations of disability rights which include social rights. In 2002, Lisa Waddington and Matthew Diller argue in favor of a social justice model that goes beyond the initial opposition between welfare and civil rights (Waddington and Diller 2002). In her 2015 book, Katharina Heyer distinguishes between the civil rights model promoted by the ADA and the more encompassing human rights model

embodied by the United Nations Convention on the Rights of Persons with Disabilities (CRPD), which notably includes social rights (Heyer 2015).

Human rights as promoted by the CRPD indeed are not limited to non-discrimination. In compliance with the way human rights have been defined at the international level throughout the second half of the XXth century, they include a broad array of “substantive” socioeconomic rights. These for example relate to education, healthcare, rehabilitation, work, the right to live independently and to be included in the community, and the right to an adequate standard of living and social protection (Harpur 2012; Degener 2016; Pinto 2011). The CRPD thus frames these issues as human rights issues rather than domains of charitable interventions.

More specifically, how do welfare rights differ from welfare provided under the form of charity? Two key elements can be stressed: sense of citizenship and reduction of uncertainty. First, social rights may foster a sense of citizenship (Jenson and Phillips 1996; Lister 1997). Defined by T.H. Marshall as the “status bestowed on those who are full members of a community” (Marshall 1950, p. 28), citizenship is of interest to us here in its subjective dimension, in the extent to which this status indeed is felt as such by those it is bestowed upon. Under a charity regime, a person is granted welfare based on the purveyor’s good will. The allocation is both arbitrary and infused with moral connotations. It is often conditioned upon a moral characterization of the recipient. It turns beneficiaries into obliged persons who should be grateful for benefiting from the purveyor’s generosity (Castel 1995). Under a social rights regime, the recipient becomes a subject of rights rather than an object of charity. Entitlement is depersonalized in the sense that it follows legally encoded criteria which are—at least theoretically—devoid of moral connotations and indifferent to the moral characteristics of both purveyor and recipient. Allocated by the state (or a local government), social rights are one of the ways by which a government signals to their citizens their belonging to the nation. As citizens, they are entitled to a right of protection, along with several other fundamental rights. They exist as political subjects also by means of claiming and being granted these rights.

The second dimension through which rights differ from charity is the reduction of uncertainty. Within a formal-rational legal system as defined by Max Weber, legally defined rights, provided they are efficiently implemented, have the potential to stabilize individuals’ time horizon, favoring predictability and rational anticipation (Coutu 1995; Stryker 2003; Weber 2013). In other words, they decrease uncertainty regarding a certain number of life circumstances, such as the availability of education, healthcare, or a minimum income. What is key in this Weberian perspective is the trust individuals put into these rights. This subjective dimension is the leverage through which rights are incorporated into individual anticipations and behavior. Social rights, in this respect, are even more efficient since they are perceived as stable and perennial. This anticipated stability in time can also be characterized in space. Indeed, by being legally enshrined within the context of a nation-state, rights also spur an anticipation of homogeneity in their allocation throughout the national territory. One expects to be entitled to the same rights no matter where one is located within this perimeter.

Thus, as legally defined rights, social rights are potential vectors of both predictability and a sense of citizenship—two characteristics that distinguish them from the provision of welfare based on charity. In the field of disability, this basic distinction between charity-based and legally-enshrined forms of welfare has tended to be blurred by the framing of disability rights as civil rights opposed to welfare. Admittedly, there are strong empirical reasons, both historical and contemporary, for such blurriness. Historians have shown how in many instances, the development of publicly provided social welfare had built upon preexisting private charitable initiatives (Castel 1995). Sociological research on the provision of welfare has shown how old patterns deriving from the previous charity regime have persisted and been re-actualized at the front-line of contemporary bureaucracies. Nancy Hirschmann stresses that welfare can be “extremely discretionary, subjecting the individual to intense state surveillance and arcane bureaucratic requirements that seem designed to make applicants feel shame and humiliation”. She concludes that “welfare is thus linked much more to notions of charity [ . . . ] than to rights” (Hirschmann 2016, p. 46). While such tendencies indeed are a risk

in the implementation of welfare policies, they should not be considered a necessary implication thereof—even more since variations have been documented between programs and across publics (Soss 1999; Siblot 2006). Therefore, to what extent recipients indeed experience social rights as rights should be a subject of empirical investigation.

Given how fundamental they are for disabled people, disability research needs to bring social rights back at the core of its sociopolitical analysis. If social rights indeed empirically struggle to be fully considered as rights, this should not lead us to consider them theoretically or normatively as analogous to charity. On the contrary, keeping in mind the promise these rights may hold as full-fledged rights (notably in terms of reducing uncertainty for individuals and contributing to their sense of citizenship and entitlement), empirical research is needed to analyze to what extent this promise is kept or not. The aftermath of the 2005 disability policy reform in France provides a fruitful opportunity to do so.

## 2. The 2005 Reform and the Promise of a Virtuous Circle between Social Rights, Participation and Citizenship

Disability-related social rights typically include various financial provisions and services. The two types of French benefits under study in this paper are the Adult disability benefit (*Allocation aux adultes handicapés*, or AAH) and the Disability compensation benefit (*Prestation de compensation du handicap*, or PCH).

Created in 1971, the Adult disability benefit (AAH) is a welfare benefit, ensuring a minimum income to disabled people who have no other (or very limited) sources of income. This means-tested benefit is allocated based on the medical recognition of a certain level of “incapacity”. People who are recognized a level of incapacity comprised between 80% and 100% get the full amount of the benefit. The current monthly amount for a single individual without a child is 819€. By comparison, the other existing welfare benefit which is not connected to disability, the “Active solidarity income” (*Revenu de solidarité active* or RSA), is 550€. The poverty line is around 1000€, and the net full-time minimum wage is 1150€.

The Disability compensation benefit (PCH) was created in 2005 to compensate for some of the costs entailed by disability, in terms of technical equipment, renovations to favor accessibility, personal assistance, support animals . . . Before 2005, another provision permitted a partial compensation for personal assistance, the “Third party compensation benefit” (*Allocation compensatrice de tierce personne*, or ACTP), but this benefit was means-tested and of more limited scope than the PCH. Unlike this benefit and unlike the AAH, the PCH is conceived as a “universal” benefit, in the sense that it is not means-tested. It operationalizes the recognition, in the 2005 law, of a new disability related social right (Winance et al. 2007).

Drawing on the literature on social rights, these benefits can be analyzed as potential vectors of autonomy. Sociologically, individual autonomy can be defined within a system of interdependence (Elias 1984). In the context of social rights in general, autonomy has traditionally been defined mainly as economic autonomy, characterized in terms of an alleviation of dependence towards the market (demarketization) and the family (defamilialization) (Esping-Andersen 1990; Lister 1997). These dimensions are crucial in the case of disability. A classical definition of disability as inability to work indeed has historically legitimized the allocation of pensions or benefits freeing people from the need to sell their (deemed inexistent or too limited) labor force on the market, while limiting their economic dependence on family ties. By providing for a minimum income and compensating for part of the extra costs entailed by disability, the AAH and the PCH contribute to limiting the individual’s dependence on other sources of income such as the labor market or family solidarity. These benefits play a major role as a safety net for disabled people. While social benefits represent 6% of the income of people of working age on average in France (15–64 years old), this proportion reaches 18% for people who are administratively recognized as disabled (Levieil 2017, p. 5). Even with such provisions, this

population's median income is 21% lower than the median income of people without a disability.<sup>2</sup> Hence disability social rights are an essential, if not sufficient, source of economic autonomy.

However, the experience of disability also draws attention to another dimension of autonomy aside from financial independence. For disabled people, autonomy also means the capacity to do things on their own, or to control by whom, how and when things are done to or for them (Vernon and Qureshi 2000; Kelly 2014). Here again, as stressed by the rich philosophical discussions on disability and care, autonomy needs to be reframed within a framework of interdependence (Kittay 2011; Winance 2016). Moreover, autonomy refers to the choice of residence and the possibility of independent living, against institutionalization. Social rights are instrumental to this dimension of autonomy as well. In France, one of the main improvements brought by the PCH in comparison with the previously existing benefit, the ACTP, is the possibility it offers to fund personal assistance for people who need it on a 24-7 basis (which is the case, for example, of many people with quadriplegia). The compensation provided for 24-7 personal assistance opened the possibility of independent living for people who previously had been constrained to remain in institutions for this precise financial reason (Beyrie 2015). The PCH may also compensate for renovations and technical devices (ex. a ramp, an electric wheelchair) enabling disabled people to do things on their own instead of relying on personal assistance.

While reinforcing the AAH and creating a new type of social right with the PCH, the 2005 law aimed at connecting the realization of social rights to the "participation and citizenship" of disabled people. The promise of such connection was embodied by a new institution created to allocate disability rights at the level of departments, the *Maison Départementale des Personnes Handicapées* (MDPH). This new institution was conceived as a "one stop shop" for the allocation of all disability-related benefits, statuses, and services. It replaced two main preexisting institutions, the *Commission Technique d'Orientation et de Reclassement Professionnel* (COTOREP) and the *Commission Départementale d'Education Spéciale* (CDES), in charge of social rights targeting respectively adults and children. On the one hand, the MDPH oversees defining individual eligibility to disability benefits such as the ones studied here, the AAH and the PCH. It thus plays a key role in the realization of social rights (Baudot and Revillard 2014). On the other hand, this new institution was conceived as a welcoming institution, where users would be put "at the heart of the device" (Perrier 2013). This notably translated into procedural rights allotted to users and their representatives, such as guarantees in terms of timing of the answer to individual applications, or the possibility for individuals to come and argue in favor of their application in front of the decision-making committee within the MDPH, the Disabled People's Rights and Autonomy Committee (*Comité des Droits et de l'Autonomie des Personnes Handicapées*—CDAPH). Finally, disability organization representatives were granted a third of the seats in these committees, which was also seen as a way of promoting the "participation" of users in the process (Revillard 2017b). The sense of citizenship that accompanies right-bearing thus was likely to be enhanced in this institutional context. Was it the case in practice?

Several studies have explored the obstacles impeding the realization of social rights by studying the institutional level of the MDPHs. The relative autonomy and unequal resources of governmental agencies at the departmental level result in strong territorial inequities in levels of compensation, processing delays, bureaucratic routines in the processing of cases, types of expertise relied upon (Baudot et al. 2013; Perrier 2013; Baudot and Revillard 2014) . . . Beyond this geographical variation which is a democratic issue in itself, studies converge in identifying general trends which are detrimental to a full realization of disability social rights. Excessive delays in processing and lack of information of claimants regarding their procedural rights (especially the right to present their case in front of the committee) notably have been documented in several studies (Borelle 2015; Baudot et al. 2013).

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<sup>2</sup> 15,200€ per year as opposed to 20,500€ (Levieil 2017, p. 4).

As a complement to these studies at the institutional level, this paper offers an insight into how social rights and the administration in charge of their allocation are perceived by their individual targets. In line with the Weberian conception of rights outlined in the previous section, my aim is to adopt a comprehensive/interpretative perspective on individuals' relationship to these social rights. In sociolegal research, such qualitative microsociological perspective on the realization of rights at the individual level has been developed by studies of rights consciousness inspired by legal consciousness studies (Engel and Munger 2003; Marshall 2005; Fleury-Steiner and Nielsen 2006). This approach is also used in disability research, where it has been revived within the framework of CRPD monitoring initiatives (Lawson and Priestley 2013; Pinto 2011; Shah and Priestley 2011).

In line with these works, the present analysis is part of a broader research project on the reception of disability policy in France (Revillard 2017a). I have conducted biographical interviews with 30 persons with either visual or mobility impairments. Participants include 13 men and 17 women from diverse social backgrounds, aged 23 to 75. All live in urban or suburban areas. I contacted them using a combination of different intermediaries, such as specialized websites and service providing non-governmental organizations. I avoided institutional intermediaries to prevent being identified with the MDPH, as well as activist networks, with the aim to reach more "ordinary", not necessarily politicized people. Participants gave their consent orally to the interviews (there are neither Institutional review boards nor written consent procedures in French academic sociology), and I sent them individually the full research report as well as an executive summary, in order for them to provide comments if they wished, and check if they had any issues with the modalities of anonymization (the names of participants were modified, as well as the names of locations, except for the Parisian area).

The topics of social rights and the relation to the MDPH were part of a broader interview guide. The semi-structured interviews also included accounts of the person's family background, experience of schooling, employment, and professional career when applicable, everyday life, experiences of mobility and political participation. The interviews were all conducted in person except for two which were conducted by phone. A majority took place at the participant's home. They lasted 1 h 35 min on average.

Within the broader framework of this project I combined different techniques of qualitative analysis to work on the interview transcripts (Revillard 2017a), but to analyze the issues of social rights and the perception of the administration I mainly relied on a thematic content analysis using Atlas.Ti. This software enables a very open-ended coding approach, in line with a grounded theory perspective (Glaser and Strauss 1967). While I had initially defined a minimal number of codes based on the themes of the interview guide, I have added several others throughout the coding process. The way I have built my theoretical analysis after the coding stage (even though the analysis always emerges to some extent parallel to coding) follows a grounded theory approach. I read the list of interview excerpts corresponding to all codes and defined the first hypotheses based on this. I followed with a second reading of the citations actively looking for negative cases that contradicted my initial theory;<sup>3</sup> this helped me refine the initial hypotheses. The results of this research will be developed in two sections, focusing on the two ideal-typical characteristics of rights previously presented: their potential to foster a sense of citizenship, and to reduce uncertainty. In both cases, I will stress how the interview data generally points to an incomplete realization of these rights.

### 3. "Participation and Citizenship" through Social Rights?

To what extent has the creation of a new institution in charge of social rights allocation, the MDPH, fostered a sense of "participation and citizenship" among disabled citizens, to quote the 2005 law's title? Given the age-range and the disability histories of the interviewees, most of them had been in contact with the preexisting institution in charge of social rights for adults, the COTOREP, before

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<sup>3</sup> Such negative cases will be mentioned below in the analysis of participants' perception of the MDPH, for example.

they interacted with the MDPH as of its creation in 2005. Given the (past and present) geographical locations of research participants, their accounts cover 10 different MDPHs.

Despite the political discourse conveying the idea of the creation of the MDPH as a radical innovation, most interviewees did not experience this institutional change as a major one. None of them made spontaneous mention of it, and when I asked them directly about it, most commented on the change in neutral or negative terms. Only one person, Lucien Remo, provides an account of the change as a very positive one, precisely regarding the switch from a charity-inspired to a rights-based vision of welfare. Unlike the experiences of his mother and his sister, who had become disabled before him and had to “go through hell” and “beg” the COTOREP for help, he appreciates that the MDPH treats him as “a user, [ . . . ] a normal human being”:

*My mother and my sister went through hell with the COTOREP. I had the feeling they spent their time begging. Asking for charity. Whereas here, you feel like, you fill in a form . . . You are not considered as a beggar. You are considered as a user. As a normal human being. In addition, society has a duty towards us, to allow us to access to things as other people do. I find this very good. I like this state of mind. I don't feel like I am a beggar. Which I am not, actually.* (Lucien Remo,<sup>4</sup> 56-year-old man with mobility impairment, January 2015)

Lucien Remo however is the only respondent to develop such comment. Laetitia Roger also mentions she was optimistic when the MDPH was created, only to stress that she was even more disappointed by the fact that it does not really “solve issues” but just “handles paperwork”:

*I idealized the MDPH. It meant “Departmental house for disability”, so I told myself: “this surely is going to solve a lot of issues”. But it doesn't. It just handles paperwork.* (Laetitia Roger, 40-year-old woman with mobility impairment, November 2014)

Only five of the 30 participants have a positive opinion of the MDPH, describing a fluid administrative process and a feeling of being well treated as users. All other evocations have a negative tone, to various extents. One of the main reproaches levelled at the MDPH is a feeling of objectification, of being considered as an object rather than a rights-bearer. Referring to the medically-defined percentage of incapacity which serves as the basis to define eligibility to the AAH, Lydie Sonnet (73-year-old woman with mobility impairment) comments: “60%, 80%... We are not cheese!”. Leila Saddi (31-year-old woman with mobility impairment) feels being reduced to “paperwork”: “We are not paperwork”. Daniel Morand (58-year-old man with visual impairment) expresses the feeling that case-workers “do not give a damn”: “that they care so little, it is unacceptable. [ . . . ] You do not feel like telling them your story because you very well know that they couldn't care less”. For him, this perception is reinforced by his experience of the lack of accessibility of his MDPH, where the ticket-based waiting system in the waiting room is not vocalized:

*“They give you a ticket at the welcome desk and they ask you to go sit, to wait your turn. But to know when your turn is, how do you do? Well, you need to read a digital panel up above the wall. [As a visually-impaired person], you could wait there a long time . . . ”* (Daniel Morand, 58-year-old man with visual impairment, November 2014)

As mentioned earlier, two provisions of the 2005 law particularly embodied the aim to foster “participation and citizenship” in the MDPH: the inclusion of a third of disability organization representatives in the CDAPH and the possibility for claimants to come and defend their application in front of this committee. The former was never referred to in the interviews, and my attempts at more direct questions on the topic turned out irrelevant to the research participants: they either had

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<sup>4</sup> All the names of research participants have been modified.



no knowledge of this participation of associations in the MDPH or had no comment to make about it. This does not mean that this participation has no effect—a topic I have explored in previous research (Revillard 2017b)—but at least one can conclude that this provision did not give these claimants a feeling of participation.

Comments on the possibility of defending one's application in front of the Committee are even more revealing regarding the limit of the MDPH's capacity to foster a sense of citizenship among its target population. Legally, the MDPH is supposed to inform claimants, 15 days ahead of time, of the date their application will be discussed by the CDAPH, as well as their right to come and argue their case on this occasion.<sup>5</sup> Fieldwork conducted on the actual institutional functioning of various MDPHs show unequal (and sometimes illegal) practices regarding this information. Notably because the decision-making process takes much longer in cases of hearings, some MDPHs do not inform the claimants of this right, or only do so very discreetly. Céline Borelle describes "a form of non-take-up embedded in institutional functioning" (Borelle 2015, p. 218). My interviews confirm this situation of a massive absence of recourse to a legally enshrined procedural right: only two participants have exerted this right.

The others, in many cases, had heard about this possibility. Elise Bastien argues she does not go, as well as many visually impaired people she knows, because of public transportation accessibility issues:

*"We have the right to attend the Committee meeting. [ . . . ] But for visually impaired people, going to [the city where the MDPH is], taking the bus, the train, the subway . . . it is the end of the world. It is a place we don't know, so someone in this department, apart from people who live in [the city where the MDPH is], nobody will go . . . and defend their application"* (Elise Bastien, 47-year-old woman with visual impairment, January 2015)

Several other research participants understood this procedural right as a right for the Committee to summon the claimant, rather than a right for the claimant to argue their case. Dora Moleiro gives the example of a colleague who was recently "summoned":

AR: [ . . . ] *Did the MDPH inform you of the possibility to be heard?*

DM: *No. Now I know that some people, when they ask for benefits . . . A colleague of mine, she was in an economic lay-off, and they asked that she apply for reclassification because her vision had decreased, she couldn't work on the same type of position anymore, she had to submit an application to the MDPH, and then she was summoned. Because for 25 years she had work, and then all of a sudden, she was applying for disability benefit [AAH]. So she was summoned and she went in front of a committee.*

AR: *But you, has it ever happened to you?*

DM: *No. I think when it is cases of . . . a long time ago [when you have been disabled for a long time, they don't summon you]. But maybe one day we will have to go?* (Dora Moleiro, 47-year-old woman with visual impairment, February 2015)

Dora's perception of a possibility to be "summoned" refers to an actual MDPH practice, which is situated at an earlier stage of file processing. Before applications are reviewed by the CDAPH for a final decision, they are processed by case-workers and by a "pluridisciplinary team", who may indeed resort to calls to claimants, auditions or in-home assessments if deemed necessary. The right to be heard by the CDAPH therefore chronologically follows an obligation of accountability to other MDPH personnel in the previous stages of application processing. This coexistence of obligations and rights contributes to blurring the status of this "possibility" to be heard by the CDAPH, as illustrated by the way Daniel Morand accounts for it:

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<sup>5</sup> Décret No. 2005-1589 du 19 décembre 2005 relatif à la CDAPH, Art. R. 241-30.

AR: Were you informed of the possibility to be heard by this committee?

DM: I know that there are possibilities of hearings, but I think . . . I had been informed that if they deemed it necessary, we could be auditioned, but I was not the one . . . I could not attend the committee meeting if they did not deem it necessary. I think. (Daniel Morand, 58-year-old man with visual impairment, November 2014)

The fact that a right may be commonly understood—and possibly feared—as an obligation reveals its vulnerability (understood here in terms of its limited capacity to foster a sense of citizenship and entitlement). These interview excerpts show how this vulnerability derives from a perception of the institution in charge of rights allocation as a source of social control rather than a place of empowerment. Even though user “participation” is formally invited, users in fact often do not feel welcome. Hence, although the benefits at stake make an objective difference in people’s lives, the process of their allocation (at least partially) fails to nurture a sense of citizenship among their recipients. These rights also only partially achieve their function of reduction of uncertainty.

#### 4. A Situation of Uncertainty

Benefits such as the AAH and the PCH only fully achieve their function as social rights if their allocation fosters a sense of trust, among recipients, regarding the stability of their eligibility and of their receiving these benefits, both in space and time: certainty that they will continue to receive these benefits in the future if needed, and certainty that these benefits will be the same wherever they move on the French territory. As opposed to this image of stability, certainty and trust, comments on these social rights throughout the interviews are marked by expressions of fear, uncertainty, and anger. This derives from the uncertainty which characterizes the relation to the MDPH, regarding the time frame of institutional answers to individual claims, and the stability of eligibility in time and space.

Delays in file-processing are a major source of user complaints towards the MDPH. At the national level, these delays are a structural issue for the institution, even though the reduction of delays had been one of the goals of the 2005 reform (Baudot et al. 2013, p. 245). While the 2005 law mandates that MDPHs provide answers to claimants within a 4-month delay, average file-processing delays in 2014 for adult applications were above 4 months in half of the MDPHs, reaching 6 to 12 months in 10 of them<sup>6</sup> (CNSA 2014, p. 8).

In compliance with these aggregated results, many research participants have faced major delays in the processing of their application. In one instance, the file was lost. This happened to Daniel Morand regarding a PCH claim to cover the cost of computer-based assistive technology:

*They lost the file I had submitted, with all the documents. They couldn't find it anymore. As part of the application, they force you to go through a series of medical exams. In addition, these medical exams are only valid for 3 months. So a lost file, if it takes 6 months [to realize the file is lost], it means you have to go through the medical exams all over again. So no, this drove me furious. I told them there was no way I was going back . . . Because on top of this, these medical exams are done in hospitals where you need to wait 6 months in order to get an appointment. So it is a dead end. I told them there was no way I was going to do the exams again, that I would give them a copy, because thankfully, I had made sure to keep a copy of the whole file. Otherwise it would be a dead end. In addition, many people suffer from this, from the MDPH. So maybe there is not enough staff, or that they are insufficiently trained. Maybe they lack funding. But it is unacceptable.* (Daniel Morand, 58-year-old man with visual impairment, November 2014)

Daniel’s comment on disabled people “suffering from the MDPH” provides a good illustration of the relevance of the social model of disability. Indeed, in the field of disability, the idea of “suffering”

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<sup>6</sup> Moreover, these figures should be taken with caution given the frailty of the information system they are based on, and the high political stake surrounding this key measure of institutional efficacy (Baudot 2015).

most often is associated to impairment: nondisabled people commonly hold the belief that disabled people suffer from their impairment. While this is true in some cases (Wendell 2001), the social model points to another source of suffering, namely the social and environmental barriers disabled people face. The allocation of social rights theoretically should contribute to the alleviation of these barriers. Indeed, the PCH, when obtained, increases Daniel's autonomy. However, the process through which the benefit is allocated represents a source of suffering in itself, introducing obstacles in the process of barrier-removal. This excerpt also shows Daniel's awareness of the institutional constraints (the lack of personnel, training, and funding) that lead to such an "unacceptable" situation.

In a previous research, I showed how these institutional constraints have been interiorized by disability organization representatives taking part in the CDAPH, who negotiate their role as disability rights advocates within the limits of these constraints (Revillard 2017b). The present research shows that these institutional constraints, in this case the lack of resources leading to excessive delays in file-processing, are also to some extent interiorized by disabled citizens themselves. Through personal experience and peer socialization, claimants learn to adapt their expectations to the reality of administrative practices rather than to legal promises. One typically expects a PCH application to take one year to be processed. This anticipation of delays is manifest in benefit renewal claims, which the more experienced or informed claimants submit a year in advance. Dora Moleiro proceeds this way:

*You need to get ready for the application one year in advance. [ . . . ] Before, [with the COTOREP] you could count on an answer within 3 or 4 months . . . Now you get it a year after.* (Dora Moleiro, 47-year-old woman with visual impairment, February 2015)

These long delays are particularly problematic for applications that cannot be anticipated, such as when a deteriorating health requires an immediate increase in the number of daily hours of personal assistance, or when a new technical equipment is promptly needed. Indeed, the PCH cannot cover already engaged expenditures: one needs to get PCH approval before buying the equipment or service. Claudine Durand humorously points to the fact that her hearing aid had not warned her of its upcoming failure 6 months in advance:

*When I changed my hearing aid, I wrote to the MDPH to get some refund. But this is really absurd: the first aid stopped working, I had no choice but to buy a new one immediately. So I write to the MDPH, I explain it all to them, and they say: "Now that you have the new aid, we can't do anything, you had to warn us before you purchased it". But the old aid had not warned me, telling me "In six months, I will stop functioning, and I will have to be replaced" . . .* (Claudine Durand, 56-year-old woman with mobility impairment, November 2014)

In this case, Claudine tried to apply for the PCH and her request was turned down. However, the need to wait for MDPH approval before spending also results in non-take-up: when they can, some people prefer to pay for the needed equipment on their personal budget to obtain it quickly, rather than having to go through the PCH application process and the delay it entails. After having been denied the PCH on a previous occasion because she was deemed "not disabled enough" ("I am in between"<sup>7</sup>), Léa Martin describes the "fatigue" that leads her to fund disability-related equipment on her personal budget:

*I should ask again, but then, you are fatigued. You don't do it anymore because it takes two years just for file-processing, and still, you don't know if it is going to be accepted. So . . . A wheelchair, you need it now! An adapted bathroom, you need it now!* (Léa Martin, 28-year-old woman with mobility impairment, January 2015)

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<sup>7</sup> Léa has a mobility impairment which entails important difficulties walking and stepping over obstacles. She was refused PCH funding for the renovation of her bathroom, where in order for her to be able to take her shower by herself, the bathtub needed to be replaced by a walk-in shower. Following PCH refusal, she paid for personal assistance on her own budget to have someone help her take her shower.

Yet, people often cannot rely on personal resources, especially for personal assistance expenses which can rapidly reach important amounts. Following a delay in her PCH renewal, Leila Saddi, a 31-year-old quadriplegic woman, was in such payment backlog that the company providing her personal assistant services threatened to suspend the service. Such threat puts the person either at vital risk, or at risk of institutionalization. Philippe Tain, a 47-year-old visually impaired man, feared eviction when he was faced with delays in the renewal of his AAH at a time when he was out of employment: “Go and explain this to your landlord!”, he comments. Uncertainty in file-processing delays thus entails serious consequences, first because of the material risks at stake, financial and sometimes vital, but also due to the anxiety these risks provoke. Social rights, to the opposite of their expected function of stabilization and predictability, become sources of uncertainty. Following an interiorization of institutional constraints, claimants develop tactics (such as submitting applications a year in advance) that result in reintroducing some forms of predictability in this uncertain environment.

However, as we have seen, not all hazards can be covered in this way. Moreover, even when they engage in such tactics, disabled citizens express worries regarding the continuation of benefits: either the continuation of their individual eligibility, the maintenance of existing criteria of entitlement, or of the benefit in general, in times of budgetary constraints. The main concern is the stability of individual eligibility. Even when their eligibility to a benefit (AAH or PCH) has been recognized once, many people fear that this eligibility may be questioned at the time of renewal application. More specifically, some fear that they may not be recognized the same level of “incapacity” (the basis for AAH allocation), or that their compensation needs assessment may change, resulting in a decrease in PCH level. This fear sometimes results from individual experience. In the 1990s, Philippe Tain (whose residual sight was decreasing at the time) suddenly underwent a reduction of his AAH from a 100% to a 60% “incapacity” basis, and only succeeded to have the evaluation reversed after a two-year judicial proceeding at the administrative Court. Even when they have not had such personal experience, many research participants express fears regarding the stability of their social rights, invoking the economic context and the idea that norms of evaluations become more restrictive. Maryse Cloutier, a 72-year-old woman with mobility impairment, “trembles each time [she] needs to reapply”. Marie Germain, a 60-year-old blind woman, worries about the renewal of her PCH, noting that “things have changed, economically, in the past 10 years”, and that “many things are being questioned”. Elise Bastien, a 47-year-old woman with visual impairment, refers to acquaintances who “fall into a depression, are under stress, do not sleep at night in the renewal period”. Here again, expressions of suffering (trembling, stress, depression, insomnia) are connected to the bureaucracy rather than to the impairment.

This uncertainty regarding the stability of benefits in time also unfolds in space. The territorial instability of rights appeared in two ways in the stories told by research participants. First, several of them have experienced suspensions or modifications of their rights when moving from one department from the other. Jérôme Ricordeau, a 28-year-old blind man, notes that unlike the transfer of his other administrative files (health care, housing etc.) which was rather smooth, it took one year for his disability file to be transferred from one MDPH to the other when he had to move for professional reasons. He analyzes this episode as revealing the administration’s perception of disabled people as anchored in a given location: “they do not know that disabled people can move”. Jean-Marc Sernin, a 61-year-old blind man, underwent a substantial restriction of the amount of ACTP he was allotted (the benefit was divided by three) when he moved departments: “I did not understand why, I mean, I thought the criteria were harmonized”. Unlike this reaction of surprise, several other interviewees allude to this territorial inequality as common knowledge:

*We know that [in this town] it is OK. Because you know, it is the Departments that pay for the benefits [ . . . ] so it depends on their piggy bank. If you go to [names a neighboring department] you will not have any PCH because they have no money” (Nicolas Barut, 40-year-old blind man, January 2016)*

This territorial inequity not only is a source of uncertainty for people when they move, but also affects their sense of citizenship, given that being treated equally throughout the national territory is part of the expectations of nation-state-based citizenship. From both points of views of citizenship and predictability, the benefits under study here fail to fulfil their full potential as social rights.

## 5. Conclusions

Arguably, semi-structured interviews provide a very subjective and limited account of rights realization, based on recipients' perceptions. Other aspects in need of empirical investigation include the institutional workings that favor or impede rights allocation, as well as the material effects of social rights in people's lives, independently from the way they are perceived. Yet this subjective dimension should not be taken as a pale approximation of what social rights "really" do to their beneficiaries, in view of the criteria under study here. Part of the potential of social rights is to foster a sense of citizenship and to limit uncertainty, and their effectiveness in this respect can only be measured by taking people's subjectivities seriously. No matter how well intended institutional interventions may be, citizens' subjectivities are the relevant judge of rights effectiveness in this respect.

As shown in the last two sections, the interviews I have conducted generally point to a vulnerability of disability social rights, in the sense that, for many research participants, these rights fail to foster a sense of citizenship and to limit uncertainty. The main sources of distrust identified through the interviews (social control rather than participation, delays, territorial inequities) are in compliance with the results of research conducted on the institutional side of MDPH functioning (Baudot et al. 2013; Borelle 2015; Revillard 2017b).

However, this bleak picture of disabled people's relation to their social rights needs to be qualified, methodologically and theoretically. The reliance on semi-structured interviews introduces a bias in accounts of rights realization: people tend to talk more about problematic situations than about all the other occurrences in which the realization of their rights goes more smoothly, and beneficiaries who have gone through administrative difficulties may be more eager to answer a call for participants in a policy-related research project. This may lead to an overestimation of the difficulties encountered. Moreover, this study would need to be complemented by other investigations, on broader samples and including other types of impairments than those under study here, to show if and to what extent the trends identified here are confirmed on a larger scale. The other aspects of rights realization listed above, pertaining to MDPH functioning (funding, staffing, decision-making process, delays, etc.) and to the more material effects of social rights (measure of take-up, impact on poverty level, actual role in compensation) are also in need of further investigations.

From a theoretical standpoint, it is crucial not to confound the negative comments made by research participants on the process of rights allocation, with what would be a negative perception of these benefits as such. On the contrary, obstacles to their allocation are even more harshly felt since these social rights make a significant difference in people's lives. When their scope is substantially restricted, as is the case in the current context of austerity in the United Kingdom, it results in increased poverty and a strong risk of re-institutionalization. In other words, the gloomy assessment developed in the last section of this paper should not feed into the previous normative estrangement of social rights described in the first one. Rather, my goal is to point to some sources of vulnerability of social rights, based on their experience by disabled citizens, in view of a better understanding of how these rights could more fully realize their potential. In this respect, the research shows the importance of the procedural aspects of rights realization.

At the opposite of the virtuous circle the 2005 law hoped to put into place between the creation of new social rights and the promotion of "participation and citizenship" via the MDPH, institutional practices and citizens' relation to the institution, as described by several users in this study, seem to undermine the emancipatory potential of these rights. Even if they end up being allocated and making a substantial difference in people's lives (these benefits do favor individual autonomy), the process by which these rights are "made real" (Epp 2009) limits their scope. While measures of

rights effectiveness often are limited to quantitative indicators (amounts spent, number of recipients, estimation of non-take-up), this conclusion also calls for a more systematic qualitative evaluation of the realization of rights, from the viewpoints of their bearers.

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