Disability and Shame
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Three Dimensions in the Register of Shame

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Abstract: This article highlights the ways in which people with disabilities who have recently been involved in programs set up by the Swiss compulsory Disability Insurance (DI) refer to the register of shame in their discourse. It pinpoints three dimensions of this register: social position, social judgment and mirror-effect and shows that while referrals to shame do not constitute a direct challenge of ableist hierarchies, they do displace the meanings attached to disability.

Keywords: Swiss Disability Insurance; Shame; Vocational Rehabilitation

Introduction

Shame. It does not scream. It brings on a chill

—Henri Michaux, Difficultés, 1930

He had joined the brigade of the damned, he told himself, and from now on he would be looked upon as one of those crippled, distorted people who no longer counted as full-fledged members of the human race.

—Paul Auster, 4 3 2 1, 2017

Persons who receive welfare state benefits often publicly display feelings of shame, unease, guilt or embarrassment (de Gaulejac, 1996; Tabin, Frauenfelder, Togni, & Keller, 2010), such as in the context of dealings with welfare state agents (Driessens, 2010). As researchers in the domain of social sciences, we have regularly heard such discourses during the interviews we conducted with persons having to deal with the Swiss Disability Insurance (DI). This government agency assesses whether an applicant is disabled, partially disabled or able to seek employment, and decides if rehabilitation measures will be proposed.¹

From a sociological point of view, the fact that feelings within the register of shame are displayed by persons whose earning capacity is diminished because of a health impairment—this being the legal definition of disability in Switzerland—is not particularly surprising. On the one hand, contemporary societies are built around a logic that gives value to ability, and that then devalues persons who cannot perform (Stiker, 2005). Ableist ideas
and practices put these people in a position of inferiority (Campbell, 2009; Goodley, 2014), and persons who fail to meet ableist expectations concerning ‘performance’ are systematically described in negative terms as incapable, infirm or as not able-bodied. In prevailing discourses, this vocabulary conveys negative judgments and conjures pejorative narratives of loss and lack, of being broken, less worthy and less human. It is thus hardly surprising that terms such as these have an effect on the persons concerned, people with disabilities. References to shame, unease, guilt or embarrassment on their part is an expected reaction, all the more so, when they are interacting with people who view themselves as able-bodied.

On the other hand, numerous recent changes in Swiss disability policies, with its litany of pronouncements on the abuse of social benefits by recipients (Ferreira & Frauenfelder, 2007), have emphasized the people accessing social services, are individually responsible for their own recovery, increasing their employability, accessing a greater range of professional opportunities, and/or ceasing to rely on disability benefits (Probst, Tabin, Piecek-Riondel, & Perrin, 2016). Such moral framing of people with disabilities, prevalent in Western liberal democracies’ discourse on social protection, has been pivotal in the implementation of active employment programs aimed at rapidly moving recipients into the labor market (Parker Harris, Owen, Fisher, & Gould, 2014; Yates & Roulstone, 2013). These policy tools, all based on the regulation of individual behavior, are defined as means for “overcoming disability benefit culture” (OECD, 2009, p. 17), and as central drivers for resolving social problems. Applicants for disability benefits are thereby not seen as victims of socio-economic insecurity linked to structural disadvantages, but as financial risks for social insurance schemes. As Skeggs (2004) observes, “[under liberal policy frameworks], those who cannot perform their state-defined ‘duty’ are thus morally suspect” (p. 82). In this context, DI applicants and recipients are pressured to take on the classical posture demanded of the ‘worthy’ poor—that of being ashamed rather than proud (Castel, 2003; Geremek, 1987; Sassier, 1990). Thus, the people we met, unsurprisingly spoke primarily of the negative emotions they had experienced.

A closer analysis reveals, however, that the choice to call upon the register of shame—whether individuals truly felt ashamed or not is not the concern of the present article—is more complex than it might seem. This paper argues that while referrals to shame do not constitute a direct challenge of ableist hierarchies, they do displace the meanings attached to disability. We intend to shed light on this issue through an analysis pinpointing three dimensions of the register of shame: social position, social judgment and mirror-effect. But first, we begin with a brief overview of the scientific literature on shame and present the research methodology we used.

**Theoretical Context**

During the last decade, the scientific literature pertaining to shame has considerably widened in scope, within the context of what some authors have called the ‘affective turn’ in social sciences (Clough & Halley, 2007; Lordon, 2013). The broad range of work on this topic, inspired by different perspectives, often stands at the crossroads between psychological and sociological theories.
Shame, as an object of categorization within the field of social sciences, may be defined in more or less specific ways. While some authors are intent on distinguishing it specifically from other notions, particularly those of guilt, humiliation and embarrassment (Biddle, 1997; Probyn, 2005), others emphasize the overlapping nature of emotional experiences. These scholars warn against the risk of a reification of categories, due to overly circumscribed definitions (Barrett, 2018). According to the latter, emotions coexist and dynamically blur into one another depending on the context of on-going interactions (Munt, 2008; Sedgwick, 1993). For Scheff (2000), shame is thus, “a large family of emotions that includes many cognates and variants, most notably embarrassment, humiliation, and related feelings such as shyness, that involve reactions to rejection or feelings of failure or inadequacy” (p. 96). We adopt this definition in the present article.

From a sociological standpoint, shame is an affect that is linked to individuals’ social position and to the experiences that stem from it (Loveday, 2016; Skeggs, 1997). In Bourdieu’s (2000, 2001, 2014) terms, it’s one of the dimensions of a habitus that becomes embodied in a hexis. It has been fashioned not only by history and culture, but also by dominant norms and values. Thus, as Ahmed (2004) states, it may be understood as “the affective cost of not following the scripts of normative existence” (p. 107). The experience of individuals we met who are dealing with DI falls within this understanding of shame, to such an extent that DI only intervenes for adult workers whose confirmed physical, psychological or mental impairments are liable to compel them to permanently abandon gainful employment. For all recipients, there is thus a deviation from the expected course of existence, such incapacities being socially acceptable only in old age—in 2018, the economic activity rate of the population aged 15 to 64 is 84.2 % in Switzerland (Federal Statistical Office, 2019). We shall analyze later how this deviation is experienced.

Other perspectives can allow us to further nuance our understanding of shame. The interactionist perspective (e.g. Goffman, 1959), for example, emphasizes the reflexive and interpersonal nature of this affect. It highlights that shame is connected both with self-judgment and with the image reflected in the eyes of others, and even with the anticipation of this image; implying not only an awareness of social norms, but also of judgment by others. Therefore, it stems from a moral appreciation, through which the person imagines the disqualifying gaze—real or imagined, present or absent—focused on him or her by people. In other words, social actors respond to the situations they experience, not only in terms of social interactions, but also in terms of anticipation or projections. In a context characterized by recurring political debates about DI, extensively relayed by the media, over the past two decades (six major legislative revisions set in motion, including three actually implemented), applicants and recipients of DI know that their situation is viewed by others in a disqualifying way. Indeed, persons viewed as disabled have been designated since the mid-1990s as responsible for the increase in the costs of DI (Probst, Tabin, & Courvoisier, 2015).

Shame is tied to this designation because the social discourse about individuals considered as disabled, like the discourse about the poor, tends to explain their situation through the notion of personal failings. Within this context, the argument of deservedness gets
conjugated with discourse about parasitism: recipients are defined by the media, the general public, politicians and welfare institutions as ‘shirkers,’ ‘scroungers,’ ‘apathetic’ or ‘wasters.’ This process legitimizes the tightening of controls, for example the introduction of systematic reviews of pension benefits and of the requirement for all insured persons “to take all necessary measures in order to avoid having to resort to insurance benefits” (Despland, 2012, p. 77). As the Swiss government stated, “[since] January 1st 2008, DI has implemented an active battle … against abuses in this insurance … that can be divided into four phases: identification of suspicious cases, inquiries and in-depth testing, surveillance … and finally the recourse to insurance legislation and to the penal code” (Conseil fédéral, 2017, p. 4). Swiss authorities have therefore contributed to spreading the idea that a potentially significant number of people receive, or attempt to obtain, benefits to which they are not entitled, thus discrediting all DI recipients. This goes some way towards explaining the climate within which links are necessarily created between shame and DI, and the context in which our interviewees refer to the register of shame.

Shame is thus not only an affect, it is a ‘moral tool’ (Chase & Walker, 2013). Like ‘politics of resentment’, it “forms an exclusionary emotional and social framework that traps minority identities and people experiencing multiple deprivations in its belief system and practices” (Hughes, 2015, p. 996). In this way, shame, humiliation and disgust maintain the boundary between social constructions of ‘normal’ and ‘abnormal’ and reconstitute the categories of what is acceptable and unacceptable, as Moore (2016) shows using the example of the shaming process of individuals who have transgressed gender norms. These politics of emotions (Ahmed, 2004) confer value on some while denying it to others.

From that standpoint, shame then becomes a pattern of social regulation that reflects and maintains social hierarchies and inequalities. It is a subtle form of power, that promotes the self-regulation of behaviors and the normalization of conducts (Baker, 2013; Creed, Hudson, Okhuysen, & Smith-Crowe, 2014). Thus, Walker (2014) suggests that it “might be better described as cement reinforcing structures of inequality and perpetuating poverty” (p. 191). Shame, in a way, naturalizes social stratification as it leads to “experiencing in the mode of original sin and of essential indignity differences that … are the product of social conditioning” (Bourdieu & Delsaut, 1975, p. 36). As a result, individuals who experience these processes, “contribute to their own domination by tacitly accepting the limits imposed” (Bourdieu, 2001, p. 38). It is the ‘sense of one’s place’ that is being experienced: the shame of the person who is feeling out of place or the ease associated with the feeling of being in one’s place (Bourdieu, 2000). Being ashamed thus reflects the awareness that individuals have of their social position, shame being “an embodied sense of self-judgment” (Barrett, 2018, p. 39).

In short, shame is one dimension of a habitus, associated with a position in social space. It arises in relation to social judgment, thus requiring a context that views some social positions as inferior. When this judgement is interiorized by the very persons occupying devalued social positions, shame becomes a powerful tool for the reproduction of hierarchies. However, post-structuralist research has shown that because shame also structures the
individual as a subject (Fullagar, 2003; Munt, 2008), it could also lead to the questioning of social roles. Shame, from this standpoint, is not simply a ‘negative’ (Chase & Walker, 2013), or even a ‘debilitating’ (Weiss, 2010) emotion; it affects self-representation in more ambiguous ways.

**Methodology**

This article is founded upon the discourse of 33 persons who were, or had been, involved in rehabilitation programs run by Swiss DI. This data was collected between February 2016 and January 2017, within the context of the research project “Living under the new paradigm of Swiss disability insurance” supported by the Swiss National Science Foundation. The goal of the study was to better understand the way in which recipients experienced the recent reforms introduced to DI.

Our project aimed at collecting a wide range of rehabilitation experiences in order to meet the principles set out for the selection of qualitative multiple case samples (Glaser & Strauss, 1967; Pires, 1997). During the process of recruiting participants, we contacted close to a hundred organizations—disease-specific associations, foundations, support groups, unions, psychosocial residential structures, social services—and asked them, respecting all standard ethical criteria, to relay requests for interviews. Despite the number of contacts initiated, we encountered some difficulties in recruiting participants. Refusals stemming from particularly difficult personal situations (in terms of health or of conflict with DI), or from fear that information could get back to DI agents, were reported.

We met 13 women and 20 men aged between 20 and 64 (13 were under 40 years of age, 20 between 40 and 64 years of age). They experienced a broad range of impairments (e.g. hearing impairment, chronic pain, depression, cancer, professional burnout, nervous breakdowns). These persons were at various stages of their contacts with DI: some were involved in rehabilitation measures and others were not; some had returned to employment and others had not. The duration of their involvement with DI ranged from a few months to over 20 years.

A semi-structured interview schedule was designed to focus on the evaluation of the interventions of DI, in order to avoid reproducing the structure of DI questionnaires concerned with health impairments and professional experience. Although none of the questions explicitly focused on emotions, 11 persons explicitly used the term “shame” when describing their experiences and 29 interviewees referred to this affect through the use of words such as “stigmatizing,” “hard,” “difficult,” “painful,” “humiliating” or of metaphorical expressions such as, “It is not something you would shout about from the rooftops.”

All interviews were recorded, transcribed and anonymized. We were able to identify three specific dimensions in the register of shame that we will detail below (social position, social judgment and mirror-effect). At least one of these three dimensions appears in 29 of the 33 interviews we conducted. A majority of interviewees, 17 persons, referred to two of these dimensions, eight persons referred to three, and four interviewees referred to only one.
interviewees who gave a positive assessment of DI intervention in their case, as well as those who viewed it as unhelpful or even deleterious to their health, reported experiencing shame. Among those who actually referred to all three dimensions of the register of shame, we found a majority of women, six persons out of eight. Ten out of 11 people who were in work at the time of the interview did not refer to the third dimension of shame, the mirror-effect. Other biographical elements such as age, level of education or type of impairment were not associated with any specific type of discourse about shame.

The First Dimension of Shame: Social Position

The individuals we met describe having been fearful about having dealings with DI because of the social re-positioning that becoming a DI recipient implies. During a typical life course progression, the vast majority of people never come into contact with the DI system—except insofar as they compulsorily pay into it as contributions are deducted from their salaries. To have to be confronted with this institution is an experience we have often heard interviewees describe as “impossible,” “inconceivable” or even “shocking.” That is what Martine (nurse, 47) explains, “In the beginning, I didn’t want to go because I said to myself: ‘I have nothing to do with disability, I only had a burnout, I just need a bit of time to get over it’.” Ivana (in a retraining program in the administration sector, 34) confirms that having to be confronted with DI put her social worth into question, “It did not sit well with me. I felt useless…. It seemed like I was worth not quite nothing, but almost.” Frequently described through descending spatial metaphors (i.e. falling, tumbling down, falling back, landing), this repositioning, sometimes brutal, to a lower rung on the social ladder carries with it a powerful symbolic charge. As Probyn (2005) emphasized, the shame that is derived from it, “puts one’s self-esteem on the line and questions our value system” (p. x).

But entering into contact with DI is also an encounter with a locus of state power (Bourdieu, 2014). The official instances with its agents acting on behalf of the state hold the monopoly of providing titles, categorizing and judging, and thus consecrating and maintaining the symbolic and social order. People know that they are confronted with an institution, that alone, is endowed with the power of placing them on a disability scale. They also understand that this encounter will have a lasting influence on their social position and may—or may not—give them access to certain social services and financial support without which their basic quality of life would be threatened.

Potential recipients of DI are at a double disadvantage in this confrontation. Firstly, they have no choice, in view of their new position in terms of work capacity, but to turn to DI in order to obtain the means to survive outside the labor market—a pension from DI can enable a person to reach minimum income levels—or to regain an earning capacity through rehabilitation measures. “Now well, I am required to do it … I just have to,” states Ivana (in a retraining program in the administrative sector, 34). As Brigitte (intern in a secretarial pool, 55) points out, “Nobody wants to be on DI … it’s part of a treatment, like insulin if [we] have diabetes.” Secondly, DI applicants are systematically made to feel that they are individuals deprived of power facing an institutional system. For instance, the classifications used by DI are not communicated to them, and barely explained. The letters from DI are written in legal
jargon and other obscure language terms. Also agents change, and offices are difficult to get a hold of on the phone. Marie (waiting for a DI decision, 48) describes how her shame has built up, “Since 2012, there’s no one there. Nobody is in charge of my file…. And that’s really terrible. You feel that you don’t exist anymore. You aren’t good for anything.”

Over and above the concrete confrontation with state power, going to the DI office signifies, for our interviewees, the institutional confirmation of their drifting away from standards of normalcy. It means losing the status of an ‘adult involved in productive work,’ and thus no longer being able to consider oneself independent, capable and endowed with the physical and mental capacities that enable one to meet the requirements of the labor market. While being dependent on an employer is perceived as ‘normal,’ financial ‘dependency’ on the state brings with it feelings of shame and a sense of rejection by society as a whole (Fraser & Gordon, 1994; Young, 2003). This difference probably stems from the fact that whilst DI can exempt an individual of working age from the requirement of being employed through the provision of a pension, it simultaneously institutes a status experienced as being of lesser social value. As Jérôme (in training as a salesperson, 46) puts it, it is “a bit difficult to say right, now you’re on DI, that you are … lowered a bit if you want.” Brigitte (intern in a secretarial pool, 55) points out that, “to find oneself there, on DI, it’s horrible,” while Marie (waiting for a DI decision, 48) explains, “When I see myself now, nobody could imagine I was a nurse…. Can you imagine how low I have fallen? It’s terrible.” Hence, exemption from the requirement to be employed, granted when one is awarded the status of DI pension recipient, is not experienced as freedom from the constraints of the work world, but as a sad fate. Jean, 48, who previously worked as a nurse’s aide and is now a DI pensioner, states it clearly:

I was very upset when they put me on full disability benefit. I was angry…. [The DI agent] explained that it was for my own good … and … that there was no shame in it…. He doesn’t realize how it can weigh on my children … labels, they stick … labels can be very heavy.

Moreover, this social repositioning is tied to shame because dealing with DI also involves a complex process of exposure. During the course of the DI inquiry, individuals must demonstrate that their health impairments diminish their earning capacity. Having to present oneself through one’s limitations is a source of shame. This is for example the experience that Helmut (waiting for a DI decision, 25) talks about:

I really explained everything to [my DI counselor], everything, all of it, all of it. And even that in order to be at the office at 8 am, I have to get up at 5 am…. I explained to him what I have to do to go the bathroom, when one is half paralyzed you can’t go the toilet in 5 minutes, it takes 40 minutes every morning. It was a bit embarrassing to talk about it … that I had to massage my abdomen to stimulate my intestinal tract.

Under the scrutiny of the medical gaze, Helmut’s body is measured in terms of efficiency. The disabled body has been socially constructed as monstrous, excessive, contaminated, malign and helpless (Davis, 1995; Mitchell & Snyder, 2000; Shildrick, 2002), and applicants are
forced to identify with that ‘disabled body’ and expose it in order to be eligible for DI benefits. The act of describing and acknowledging the ways in which their activity is constrained by their physical or mental state force people confronted with assessment instruments to objectify their bodies and re-construct themselves as disabled (Reeve, 2012). Moreover, those state redistributive policies contribute to the construction of the body as ‘abnormal,’ deviant and shameful because the disability certification processes are based on a classification of bodies as ‘productive’ on the one hand and ‘unproductive’ and therefore ‘risky’ on the other. A person with disabilities’ work capacity is assessed by the extent to which they diverge from the reference point of the ‘normal’ or ‘ideal’ body defined by social policies. Such processes are an integral part of the conception and implementation of social policies founded upon identifying, categorizing, measuring and eliminating the ‘abnormal.’ However, as eligibility criteria have narrowed over the last fifteen years in the context of austerity narratives, such as in the United Kingdom (Goodley, Lawthom & Runswick-Cole, 2014), participants’ obligation to prove that their bodies are unproductive and diverge from the norm has been exacerbated.

This identification to a dominated status in a system that places value on abilities has multiple consequences because it can affect one’s capacity to play other social roles, for instance those associated with being a parent or conforming to male gender roles. Olivier (special-needs technical instructor, 46) describes what was left of his ability to be a desirable partner:

I was 28 when I started to collect a DI pension … not married, I thought: ‘But wait, what woman is going to fall in love with me?’… I brought myself down right off the bat with ideas like, ‘… You are washed up, you are of no value now.’

In the 27 interviews we conducted, we heard similar references to the first dimension of the register of shame: the assignment to a social position perceived as lower. As we emphasized in the theoretical part of the present article, this perceived social ‘demotion’ also refers to a sense of having deviated from a life course viewed as normal. Beyond this, however, our data shows that this dimension is also connected to the power held by the state to categorize individuals, and to the ways in which state agents carry out this task. It is thus, a reaction to the subordinate position to which individuals are assigned.

The Second Dimension of Shame: Social Judgment

The second dimension of the register of shame, referred to in 20 of the interviews, pertains to the ubiquitous discourse about the abuse of DI benefits we mentioned earlier. Aline (child-care center assistant, 32), for example, says that when she contacted DI, she was “guilt-tripped.” Sonia (DI pensioner, 46) explains “to have this feeling: yes, I am dishonest, I’m taking advantage of the system. Yes, to be a crook,” just like Ivana (in retraining in the administrative sector, 34), who has, “this feeling that people are looking at you in a slightly weird way. You have this feeling that you are, like, a profiteer.” Martine (nurse, 47) brings up a similar experience, “Well now, I arrived in Switzerland in 2013, I found myself having a burn-out, and there, here I am on DI…. But what are they going to think about me?” These
experiences result from the state’s moral framings of people with disabilities as defrauding the welfare system as mentioned at the beginning of this paper. The conduct on which that rhetoric about abuses focuses is dishonesty, as it pinpoints behaviors such as dissimulation of relevant elements and simulation, in aid of a supposed lifestyle choice of idleness. It is thus, not very surprising that our interviewees express the shame they feel to be suspected of belonging to such a group.

Further, just like the individuals interviewed by Chase and Walker (2013), the persons we met do connect their feelings of shame with the shaming practices they have had to undergo in various social contexts. As Yann (DI pensioner, 24) explains, “Right away we are labelled as profiteers and all that, as leeches on society.” For Gabriel (communication manager, 41), “If you say ‘DI ’… the suspicion of abuse … is pretty strong.” Antonio (special-needs technical instructor, 36) expresses a similar opinion, “You quickly get to prejudices, it quickly becomes short-cuts: ‘Ha, you’re on DI? You don’t want to do anything then!’” Aline (child-care center assistant, 32) states that she has been “labelled as lazy.”

The shaming of DI recipients is largely based on challenging the impact of the health problems they are experiencing on their work capacity. Mario (in training as a building-site manager, 56) talks about what he went through as follows, “People, they don’t believe you. Right away, the guy who wants to be on DI, he doesn’t want to do anything!… Even my girlfriend … didn’t believe me.” Thus, discourses sometimes go as far as questioning the very existence of the illness, particularly in the case of psychological impairment. For some people, this questioning takes the form of attributing responsibility for the illness to the DI recipients themselves, “When you suffer from mental illness, it’s almost as if you are responsible for what happened to you” (Dominique, bookstore employee, 43). The DI process itself confronts applicants with a similar attitude, in which individuals have to prove that the health impairments they are experiencing affect their work capacity—even the opinion of their doctor about their illness can be challenged by DI experts. Probably in reaction to this social judgment, our interviewees frequently felt the need to stress the genuine character of the health problems from which they suffer.

The people we encountered also used other strategies of self-presentation during the interviews, which could be seen as attempts to become a subject again. One such strategy we observed involves demonstrating awareness of the social solidarity on which the benefits they are receiving—financial or in the form of programs financed by DI—are founded, since DI is financed by taxes. Individuals say they feel they “owe” (Laurent, in training as a salesperson, 45) or that they have “a debt” (Pierre, social care worker, 50). If this posture—humble and grateful— recalls the historical image of the ‘worthy poor’ mentioned above, it also provides a way to become a subject who is capable of analyzing and interpreting his or her position in the world. A second strategy is founded upon attempting to distinguish oneself from the group of ‘benefit abusers’ through one’s active participation in feeding the discourse about abuses. Jérôme (in training as a salesperson, 46) best illustrates this situation when he states:

If people need it, if they really can’t work anymore … and they get a DI pension, that’s
OK but people who can work and who get on to DI, who are always trying to get on it, to get benefits and then to do nothing afterwards, I don’t find that normal.

This distinction strategy entails an enunciation of the truly disabling character of the speaker’s own health impairment. Florent (bank employee, 60) explains that, “without trying to profit from it, because that’s not at all the kind of thing I would do … it’s a recognition, actually, of my work incapacity that’s taking place now.”

In daily life, the shame of being labeled as a profiteer leads some of our interviewees to resort to passing by concealing their status (Cooper 2016; Siebers, 2004). They do not mention the fact they are DI applicants or recipients. Carlos (mechanic, 26) explains it as, “[People] often would ask me: ‘Yes but what are you up to? What are you looking for?’ And most times I would lie, I would say: ‘I’m looking for work.’” Gabriel (communication officer, 41) says, “I still had a contract with my employer … I could use a bit of a ruse, say I still had a contract … that made it easier to conceal the DI side of things, let’s say. At the same time, it’s rather hard to say ‘to conceal’.”

Yet being a DI recipient is not only shameful because of the discourse about abuses of the social security system, it also carries shame because of the ableist social norms (Campbell, 2009; Goodley, 2014) that prevail in contemporary societies. The fear of being judged as disabled or perceived as sick and incapable becomes combined with that of being labeled as a profiteer. For instance, Aline (child-care center assistant, 32) and Martine (nurse, 47) explain that they did not disclose the fact that they had received benefits from DI when they looked for work compatible with their state of health, because they feared they would not be deemed ‘competent.’

In this context, interviewees who tell us that they have learned to “accept” their status and that they no longer feel shame are those who are able to successfully justify being a DI recipient. This means that they have accepted—at least for a time—their disability status. Brigitte (intern in a secretarial pool, 55) explains:

I’m not saying I’m happy about it, not at all. But I told myself: ‘But actually, it’s social insurance, I paid into it…. It’s a disability I have, it’s a frailty.’… You have to learn to accept you own limitations.

Aline (child-care center assistant, 32) states that, “I tell myself: ‘OK, I can’t anymore.’… That’s what the system is there for.” Yet, this acceptance process is fraught with difficulties, as Jean-Michel (quality control agent, 56) states, “In the beginning it was difficult … I had to work on my own self…. You have to admit that you can be tired, that others won’t see you the same way anymore.” A few people, like Paul (social worker, 33), take on a more provocative stance, that also reflects that accepting this status requires overcoming some resistance, “Now I say it with pride.’… ‘I have just gone through DI, so what?’”

As Despret (2005) suggests, emotions “are a way through which we negotiate our relationship to ourselves, to the world, and to others” (p. 283) and our interviewees’ discourse
about shame is a clear illustration of this point. Our data also highlights some of the mechanisms of the social production of inferiority, particularly the fact that being made inferior causes resistance. The ways in which participants in this study referred to the register of shame thus not only reflect a process of internalizing one’s own social position, in Pierre Bourdieu’s words quoted earlier, but may also constitute an attempt to counter the degradation of one’s social status by becoming a subject again.

The Third Dimension of Shame: The Mirror-Effect

When they have been involved in DI rehabilitation programs within the context of professional retraining (i.e. internships, training for a new occupation) or preparing to retrain via work preparedness measures, 15 interviewees brought up a third dimension of the register of shame. This dimension is associated with the concept of vocational rehabilitation implemented by DI, particularly within the context of encounters with other persons taking part in rehabilitation measures. In their interactions, while taking part in such measures, they must confront what we call a mirror-effect, which gives concrete expression to their sense of deviating from ableist norms.

This effect is first of all related to the impression of going back to a previous stage of one’s life, as Mario (in training as a building-site manager, 56) explains, he finds it difficult to “go back to sitting in school with 19-year olds.” Marie (waiting for a DI decision, 48) states, “Can you imagine? I’ve had to take written arithmetic tests. Just like the kids, they made me do grammar.” Sonia (DI pensioner, 46) also expresses her revolt against these requirements, “You can’t ask a person … 45 years old, with at least 20 years of professional experience, to go back to regular school, to take a leap backwards of 20 years.” These persons thus experience not a mere deviation from a norm but a form of regression within their life-course, a step backward in the hierarchy of ages.

Indeed, this “leap backwards” Sonia talks about is not merely temporal; it also pertains to status. It is a return to the status of ‘trainee.’ We must bear in mind that age is not a natural category or a mere item of classification but a social relationship (Jenny, 1995; Perriard, 2017). Social norms are closely associated with age groups instituted by the State and governing the relationship to employment, i.e. to the dominant norm for individuals between 25 and 64 years of age in Switzerland. Within a standard life-course, comprised of a sequence from childhood, to education or training, to employment and then to retirement:

The dominant position is occupied by the person in employment, … other social positions being conceptualized on the basis of this dominant position: for children and youth, it is a goal to be attained later; retirement benefits are justified because one has previously occupied it (Tabin & Perriard, 2014).

The dominant position of ‘adult worker’ confers status, authority, money and (a relative) autonomy. The rehabilitation process brings this position into question, relying as it does on training and education, which people see as corresponding to an earlier phase of the standard life-course.
The inferiority of their new status is confirmed by the description of the interactions with DI. Brigitte (intern in a secretarial pool, 55) explains it this way:

What was a bit difficult as well, was to tell myself I was an intern at 55 after having worked for 38 years. Intern, and not to be able to go to a job interview by myself…. It is a [DI] coach that goes along with us.

Attributes associated with adulthood, such as autonomy, are brought into question in the context of vocational rehabilitation. Julie (commercial employee, 27) describes it as “infantilizing,” with agents assessing activities carried out and saying things like, “‘Right, that’s good. This isn’t quite as good. You should do it like so.’ And that, it didn’t sit well with me…. It’s really this aspect that is a bit infantilizing sometimes. Others are speaking for me.” In her case, an assessment had to be filled out that included a question about “appearance and personal hygiene.” Here, Julie’s feeling of shame is derived from being assessed on competencies that have to do with basic education, and are thus associated with child-rearing.

The mirror-effect is also a function of finding oneself in contact with other individuals defined as needing rehabilitation. Their situations are often seen by our interviewees as impossible to compare to theirs, and they try to distinguish themselves from them. Laurent (in training as a salesperson, 45) thus explains that he spent some time in a structure that was “for drug-addicts and all those kinds. But me, I was there because I had to get myself together and because I was on pretty strong medication after my burn-out … it wasn’t easy.” Carlos (mechanic, 26) says, “The sheltered workshops they were proposing to me … people there were having a lot more difficulties than me, they were in wheelchairs…. Why did they want to put me in there?” and Marie (waiting for a DI decision, 48) puts it this way, “I found myself with people, asylum seekers and unemployed people, who did not give a shit about being there.” The mirror-effect causes shame and is a site of resistance for persons trying to counter stigmatic associations with sickness and bodies that deviate from a norm. But the negative views of ‘other’ people are also aimed at distancing oneself from them.

The mirror-effect may also be associated with the activities included in these programs. Our interviewees mentioned tasks such as “sorting used clothing, can you imagine your self-esteem after all that?” (Marie, waiting for a DI decision, 48), or activities viewed as meaningless and without any use, “It was really a waste of time…. The whole week you sat in front of a computer supposedly to learn how to use it a bit.” (Mario, in training as building-site manager, 56).

While they were involved in rehabilitation programs, our interviewees thus experienced various types of deviations from normalcy. Examples ranged from discrepancies in terms of the ‘normal’ age for being in training, to mismatches with other participants in the program and to the—in their view—inappropriate nature of activities proposed within the programs. The way interviewees refer to shame therefore appears, especially when displaying the mirror effect dimension, to be an attempt to regain the status of subject.

Does it challenge classification schemes? When our interviewees express their
criticism of the actions of DI and their resistance to the classifications made by DI agents, we interpreted their discourse as a way of trying to reconstruct themselves as subjects. But it also reflects an internalization of “the ideology of ability”, as Siebers (2011, p. 8) calls it, or internalized ableism (Campbell, 2008), because of the way in which recipients distance themselves from others that they define as “more disabled,” “more sick,” or belonging to other subordinated social groups (i.e. asylum seekers, unemployed people).

Conclusion

Our discourse analysis has shown that persons whose work capacity is challenged by an impairment spontaneously refer to shame, supporting the results of previous scientific studies highlighting the role played by shame in the reproduction of social hierarchies. Our results confirm the central social value of work capacity and show that shame functions as a force that maintains social divisions.

A more detailed analysis brings to light that shame comes in a variety of shades. In some cases, shame is experienced in reference to the new social position to which individuals are assigned; it is thus linked to the way they experience their contacts with DI. Shame stems from the ableist hierarchy that compels persons to interiorize a status defined as inferior, that of disabled person or of person at risk of being labeled disabled, in order to be eligible for benefits. In other cases, shame is associated with the fear of social judgment. Since moral discourse about abuses tends to generalize the suspicious manner in which the disabled people are viewed, shame in this case is also the result of an actual shaming process. Finally, shame may be a consequence of the mirror-effect resulting from involvement in rehabilitation programs. It is then associated with discrepancies with standards of normalcy—be it the ‘normal’ age for being a trainee, the confrontation with other individuals deemed incapable of working, or the type of tasks to be carried out—and it becomes concrete proof of the mismatch they perceive with regard to ableist dominant norm.

However, shame is not merely a negative emotion, the antonym of which would be pride. Our analysis of the ways in which shame is defined, nuanced and referred to in participants’ discourse enables us to bring to light more complex uses of that emotion, and to see them for example as possible strategies for association with the dominant group – i.e. that of persons able to work. Unlike individuals involved in collective action such as Disability Pride in the German-speaking regions of Switzerland (see Disability Pride Zurich, n.d.), the persons we met do not directly challenge ableist hierarchies when they refer to shame. Rather, they displace meanings attached to disability, and highlight the violent character of identity reassignments stemming from dealings with DI. The way they refer to shame may thus be considered as part of a process in which they realize that no individual should be seen as inferior because s/he is defined as disabled or at risk of becoming disabled. Shame then takes its place in the dual register of emotions described by Despret (2005), “of what we make and of what makes us” (p. 244). Shame, among other emotions, “then actively participates in the creation of the social world” (Despret, 2005, p. 246), and can therefore perhaps be considered a force contributing to a reconfiguration of normalcy.
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References


### Endnotes

1. Like the American Social Security Disability Insurance and the Vocational Rehabilitation system.

2. In accordance with the editorial policy, the authors we use the term “people with disabilities,” i.e. people-first phraseology (for a discussion, see Titchkosky, 2001). The authors would like to point out that some interviewees emphasize that they do not conceive of themselves as people with disabilities.

3. In this article we use interchangeably the terms affect and emotion (for a discussion see Goodley et al. (2018) and Gorton (2007)).

4. See [http://p3.snf.ch/project-156131](http://p3.snf.ch/project-156131)

5. In order to ensure anonymity, fictitious names have been used. The occupations indicated are those the interviewees practiced at the time of interview.

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