

## RESEARCH ARTICLE

# Work and Invisible Disabilities: Practices, Experiences and Understandings of (Non)Disclosure

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Invisible disabilities involve dilemmas that differentiate them from visible disabilities. However, little is known about the situation persons with invisible disabilities face at work, as empirical studies are scarce. The present article contributes in-depth knowledge of practices, experiences and understandings that affect the work situation for people with invisible disabilities in a Swedish context. The article draws on qualitative, in-depth interviews with 10 persons with invisible disabilities and seven persons who – in their professional work as employers, HR managers, medical doctors or psychologists in the occupational healthcare – regularly have dealings with persons with invisible disabilities. The analysis shows how practices, experiences and understandings regarding disclosure differ between the two groups of informants – differences that lead to dilemmas for the persons with invisible disabilities. These results indicate that persons with invisible disabilities are in a vulnerable position despite the fact that working life in Sweden is relatively well-regulated.

**Keywords:** disclosure; invisible disabilities; work; chronic illness; coming-out; disability

## Introduction

An invisible disability is 'one that is hidden so as not to be immediately noticed by an observer except under unusual circumstances or by disclosure from the disabled person or other outside source' (Matthews 1994: 7).<sup>1</sup> Persons living with invisible disabilities experience dilemmas that those living with visible disabilities do not, such as having to decide whether, when and what to disclose as well as to whom. In efforts to promote an inclusive working life for all, studies of invisible disabilities are of great relevance, as knowledge of the specific dilemmas associated with such disabilities may reduce impairment effects (Lingsom 2008). Moreover, studies of invisible disabilities at work have demonstrated certain experiences 'that are dislocated from the traditional expectations of how people should be at work' (Vickers 2003: 86). However, few empirical studies focusing on work and disclosure have been conducted (Santuzzi, Waltz, Finkelstein & Rupp 2014). The present article aims to contribute in-depth knowledge on the dilemmas persons with invisible disabilities face in the Swedish working life by drawing on results from a larger study. The article explores and identifies practices, experiences and understandings regarding disclosure of invisible disabilities at work that affect these persons' work situation. My theoretical understanding is that individuals' scope for action in his/her everyday life is influenced not only by his/her experiences, but also by interactions and social factors such as institutional practices and discourses (Norstedt 2015, 2017; Smith 2005, 2006) This requires focusing on persons with invisible disabilities *and* representatives from different workplaces who encounter people with invisible disabilities on a professional basis. Thus far, most previous studies on disclosure of invisible disabilities at work have concerned either the persons who have invisible disabilities or the attitudes of employers. As I will show, different understandings of disclosure existed between the two groups. These results need to be understood against the background of: 1) a changed working life globally as well as in Sweden and 2) laws aimed at protecting the rights of persons with disabilities.

### *The Swedish context of the study*

Compared to other countries, Swedish working life is relatively well-regulated (Allvin 2004). Nevertheless, global changes, both demographic and economic, have created new challenges for welfare states as well as new forms of employment (Germundsson & Runesson 2014) and production (Esping-Andersen 2003). These changes have involved

<sup>1</sup> Many other terms – such as episodic disabilities, hidden impairments, psychosocial disabilities, and contested illnesses – have also been used in the research to refer to non-apparent disabilities. A scoping literature review by Michael J. Prince (2017) offers a conceptual mapping.

new norms regarding for example, employability and flexibility (Garsten & Jacobsson 2004), norms worsen the already reduced work ability of persons with disabilities who, despite labour market and social policy efforts, remain far removed from the Swedish labour market (Larsson-Tholén & Danermark 2015).

In Sweden, the Discrimination Act (2008: 567) and the law regulating Support and Service for Persons with Certain Functional Impairments (LSS) (1993: 387) are laws meant to protect the rights of persons with disabilities. Further, the Employment Protection Act (1982: 82) requires employers to facilitate possibilities for a new work placement or other work accommodations within their organization before an employee can be dismissed for personal reasons, such as a long period of reduced work ability following illness. Moreover, the Work Environment Act (1977: 1160) and the Social Insurance Code (2010: 110) regulate the employer's responsibility to prevent unhealthy working conditions and to adapt the work environment to suit employees' needs. To meet these responsibilities, however, the employer must understand the employee's need for rehabilitation and how that need should be accommodated. Although the employee is required to present a medical certificate stating how his/her work ability is affected by impairment or illness, he/she is not required to specify a diagnosis. Interestingly, both the Sick Pay Act (1991: 1047) and the Public Access to Information and Secrecy Act (2009: 400) stipulate that the employer is bound by confidentiality and is not permitted to disclose information about, for example, an employee's illness or disability. This part of the law reinforces the notion that illness and disability are private concerns.

### ***Invisible Disabilities and Disclosure at Work***

The most characteristic aspect of invisible disabilities is that it is up to the individual to decide whether, how, when, and to whom to disclose. However, the privilege of passing as 'normal' (Goffman 1963; Goffman 1986), may also involve negative emotions, such as shame for not acknowledging who one is, thus causing an 'inner dissonance' (Samuels 2003: 239).

Given that people are categorized as able or disabled based on what is visible (Roman 2009; Samuels 2005), those with invisible disabilities are often met with distrust because they do not look disabled or ill (Lingsom 2008; Stone 2005; Åsbring & Närvänen 2002). Consequently, others often question the validity of the disability (Mullins & Preyde 2012). Passing as normal may also be associated with risks if an emergency situation occurs and people in the person's surroundings are unaware of the practical and medical measures that must be taken (Charmaz 2010), for example, in the event of an epileptic seizure (Eriksen & Næss 1998). Moreover, accommodations and support at work cannot be offered if the employer is unaware of an employee's needs.

Although aspects of invisible disabilities continue to be studied within disability studies, mainstream research on employment and disability seldom addresses disclosure of invisible disability to the employer (Prince 2017). The few studies that have been conducted, show how persons with invisible disabilities see more barriers to disclosure than do those with more apparent disabilities (Von Schrader, Malzer & Bruyère 2013; Wilton 2006). Von Schrader, Malzer and Bruyère (2013) have identified some of these barriers: the risk of not being employed or being fired, limited chances for promotion, concerns about losing health insurance, and being treated differently by colleges and employers. Several factors influence the decision to disclose, and have been identified as follows: whether the organization is perceived as 'disability friendly,' whether the disability is hidden or apparent, whether it is stigmatizing or the person has multiple simultaneous disabilities, and whether, and when, the person needs accommodations at work (Jans, Kaye & Jones 2012).

The choices of when, what and how to disclose have different consequences. In a study on the recruitment process, the employers' response depended on *how* the disability was disclosed, what kind of disability was being disclosed, and how much information about it was disclosed (Spirito-Dalgin & Bellini 2008). Hazer and Bedell's (2000) study showed that applicants who requested reasonable accommodation *before* getting a position received lower employment suitability ratings compared to applicants who did not seek accommodation.

Studies have also identified organizational aspects that engender disclosure, such as social support and colleagues' knowledge of chronic illness and invisible disabilities (Munir, Leka & Griffiths 2005). Thus, earlier studies on disclosure of invisible disabilities at work, cover a range of topics (for a scoping literature review, see Prince 2017).

### ***Institutional Ethnography, Surveillance and 'the Other'***

Studying work and disability, requires theories of power. According to Foucault, power exists 'everywhere.' Through its various institutions, the state exercises a controlling gaze so as to discipline the body (Foucault 1990). But this power over the population's bodies – *biopower* – is enabled by individuals' desire to live up to the norms of 'normality' and by their *self-surveillance* and practices of *self-discipline* (Foucault 1985). Scholars within disability studies have shown, in different ways, how the norms of 'normality' are closely connected to expectations of autonomy (Campbell 2009; Priestley 2003; Wendell 1989). In Western culture, where the body is idealized and presumed to be something one can control, persons with disabilities are rendered both *the other* and symbols of 'failure of control and the threat of pain, limitation, dependency and death' (Wendell 1989: 104). Wendell's concept of *othering* captures what happens in the interaction between people from different groups: 'If you are 'other' to me, I see you primarily as symbolic of something else – usually, but not always, something I reject and fear and that I project onto you' (Wendell 1989: 116).

Although the concepts of surveillance and othering are used in the present article, they are not the starting-point for the analysis. In my understanding, the social world is constituted through the activities of people. I therefore use

institutional ethnography (IE) as my theoretical and methodological approach (DeVault & McCoy 2006; Rankin 2017; Smith 1987, 2005, 2006; Teghtsoonian 2016). The point of departure of IE is always the experiences and activities of a group of people – here persons with invisible disabilities – whose lives are understood as ruled by the activities of individuals ‘in corporations, government, professional settings and organizations’ (Smith 2006: 18.). The goal of IE research is to explain how some forms of knowledge and interests are subordinated to other forms of knowledge and interests, and to do so by exploring ‘how people’s purposeful actions (their work) are linked into coordinated circles of activity that extend into distant places’ (Rankin 2017: 2). By ethnographically describing the interaction and coordination between individuals and institutional processes, traces of *ruling relations* can be discovered. The term *ruling relations* refers to ‘practices of governing that depend on selecting, categorizing, and/or objectifying aspects of the social world in order to develop facts and knowledge upon which to base decisions’ (Rankin 2017: 3). Identifying institutional practices requires an analytical shift from individuals’ experiences to professionals’ practices, decisions, use of discourses, and texts (such as the law, flow charts, work descriptions etc.) in different organizations (Norstedt & Paulsen Breimo 2016; Smith 2005).

Using IE can highlight the tensions between people’s knowledge in the everyday life and knowledge that is organized elsewhere. It can also contribute to disability studies by focusing on how social organization and practices – rather than the impairments per se – disable persons, but without neglecting individual experiences. In this way, IE offers a theoretical bridge between a social and an individual model of disability (Hughes & Paterson 1997; Priestley 1998).

## Method

The starting point for the present article is taken in the experiences, practices and understandings of persons with invisible disabilities. These informants were recruited in various ways. A description of the study and a call for participants was posted on a Facebook page for the national interest organization specialized on neurology: *Neuroförbundet*. Others either read about the study online or were informed by other informants. Thus, all the informants with invisible disabilities contacted the researcher themselves. The 10 informants were chosen to achieve as much variation as possible in disability type, age, education, workplace and occupation. Three men and seven women aged 30–50 years of age were interviewed. They had been diagnosed with multiple sclerosis, Parkinson’s disease, fibromyalgia, bipolar disorder, attention deficit hyperactivity disorder, depression and congenital vision impairment. The present focus is on the consequences of invisible disability they all share, both socially – when the disability cannot be seen by others – and as lived experiences – of extreme fatigue, pain and depression that sometimes affected work ability, but not always. Even though the informants’ respective diagnoses are commonly understood as chronic illnesses, I argue – in line with other disability researchers (Bertilsdotter Rosqvist & Katsuni 2009; Scambler 2012; Thomas 2007; Wendell 2001) – that they could be understood as disabilities, because persons with chronic illnesses also face ‘social exclusion, disadvantages as well as disableism’ (Thomas 2007: 50).

To focus on the experiences and practices of disclosure of invisible disabilities in working life, questions were posed concerning: the informant’s disability and its consequences, how the disability may affect the work, how the informants communicated or did not communicate his/her invisible disability at his/her current or previous workplace and which persons or actors have been important for the informant’s practices and decisions. Most of the informants had disclosed their respective disabilities to at least a few people at their current or previous workplaces. Only two of the informants had actively chosen *not* to disclose their disability to anyone at their current workplace.

In order to identify the institutional practices at work across different organizations, interviews were conducted with actors mentioned by the persons with invisible disabilities: five persons who handle issues such as sick leave, preventative health management, rehabilitation and recruitment – hereafter these professionals will be referred to as *employer representatives*. To include a variety of workplaces, both workplaces in the private and public sector were contacted within the fields of industry, management and education. Of the participating informants, two were from the Human Resources Department at a larger workplace focusing on public sector management; one Human Resource manager was from a larger workplace focusing on private sector industry and two executives (principals) were from two smaller workplaces: a private school and a municipal school. Because occupational healthcare was discussed in the interviews as an important actor for rehabilitation, additional interviews were conducted with a psychologist from a larger occupational healthcare organization and with a doctor from a small occupational healthcare organization.

These informants were asked to describe their work tasks and how they worked with disability issues, sick leave, work ability and rehabilitation. In the interviews, they referred to both real (anonymous) cases, as well as hypothetical cases. They were also asked to show and explain any documents, guidelines or models they used in their work.

Informed consent was obtained from all the informants in the study prior to the interviews. As the persons with invisible disabilities experienced negative consequences after disclosure, I chose not to interview employer representatives from the same workplaces so as to protect the identity of those with invisible disabilities (for further discussion, see Norstedt & Paulsen Breimo 2016). To preserve the informants’ anonymity, pseudonyms are used.<sup>2</sup>

<sup>2</sup> The study was approved by the Regional Ethical Review Board in Lund, Sweden (No. 2013/382).

### **Limitations of the study**

Because the persons were interviewed only once, the analysis cannot capture changes over time. Additionally, some of the disabilities discussed here are degenerative. Having multiple sclerosis or Parkinson's disease entails knowing that the disability may become visible in the future, in the form of balance difficulties or involuntary tremors for example. The analysis makes no claims as to the 'truthfulness' of the informants' reporting. However, the informants are not the objects of the analysis. Rather, it is the 'aspects of institutions relevant to people's experience' (Smith 2005: 38) that are the objects of the present study, as they have an impact on people's actions and choices, and thus have real consequences.

### **Analysis**

As a way to identify experiences and practices of disclosure at work, descriptions of institutional practices and texts (e.g., laws, flow-charts and contracts) as well as the informant's use of discourses were searched for in the interviews. Moreover, a thematic content analysis was conducted by identifying, comparing and categorizing the informants' talk about disclosure in the different interviews (Burnard 1991). The analysis revealed that the employer representatives and the persons with invisible disabilities had different understandings. The present focus will be on the following three themes, through in which practices, experiences and different understandings of disclosure became particularly evident: *stigmatizing disabilities*, *work ability* and *control*.

### **Stigmatizing disabilities**

Four persons in the study had disabilities that they explained as neuropsychological or psychological and that had led to depression, anxiety, hyperactivity or concentration problems. In contrast to the other informants, these four persons spoke more about experiences of being stigmatized connected with the disability itself. This became especially evident when describing an employment interview situation. Sofie revealed:

If somebody asks, because ... they will see this gap of five years, it's rather eye-catching. I'll say that I was ill during this period. And then of course, they'll ask me what kind of illness. And then I won't mention any diagnosis but rather say that I wasn't mentally well and went to therapy for many years and try to turn it into something positive. (Interview with Sofie)

The finding that psychological disabilities were experienced as stigmatizing corresponds with earlier studies showing how persons with psychological disabilities face certain barriers in working life due to the stigma connected to mental illness (Jans et al. 2012; Jones 2011). However, people with other invisible disabilities in the study also outlined strategies for what and how they disclosed to others. Some of the disabilities were experienced as stigmatizing by the persons with invisible disabilities because they were either considered as a 'women's disease,' had an invalid diagnostic label or both, as in the interview with Åke. He was diagnosed with fibromyalgia and experienced that he was being questioned by his co-workers and his manager: 'I got to know from my co-workers and team leader that I was an evader (*en smitare*), an old lady (*kärring*)' (interview with Åke). Moreover, his team leader questioned his back pain by using sexist comments and by questioning his will to work: 'She meant that we, well, should "wear skirts". [...] She didn't believe us. She had the idea that we thought [the work] was too hard – that we backed off' (interview med Åke). As a researcher, I cannot know whether this actually happened. However, the fact that Åke chose to tell me this in the interview shows that he experienced disclosure as stigmatizing; he had been characterized as feminine, weak, and unwilling to work by his co-workers and team leader. Fibromyalgia – along with chronic fatigue syndrome, irritable bowel syndrome and more – may be seen as a contested diagnosis, because some in the medical profession argue that it is not a 'valid diagnostic label and should not be used' (Madden & Sim 2006). In her interview, Anna also talked about the importance of a valid diagnosis. Being diagnosed with multiple sclerosis was a relief, she confessed. Having a valid diagnostic label prompted her to disclose as a strategy to distance herself from what she, at the time, perceived as a contested diagnosis in her female-dominated work sector: burnout syndrome. Whether or not a disability has a valid diagnostic label can influence not only disclosure, but also how disclosure is dealt with by others.

Whereas the persons with invisible disabilities mentioned several aspects of invisible disabilities as stigmatizing, the employer representatives argued that, because depression and burnout syndrome are more common today, there is greater openness about psychological disabilities in working life. Contradictory to what the persons with psychological disabilities experienced, the employer representatives felt that psychological disabilities were more socially accepted today.

Furthermore, one of the principals talked about disclosure of a stigma as something rather unproblematic:

I find that many employees think, when they suffer from an illness or suffer from a stigma, that they are completely alone and everyone else thinks it's disgusting or strange. It's a journey for the employee. And those who make that journey and eventually say 'I have this illness and that's why I can't do this or that,' they feel much better and many times are met with even greater understanding and sometimes even an admiration as well such as 'God, you're so strong that you dare to talk about this. When you told me, I also dared to tell.' So overall, it can contribute to a better psychosocial work environment. (Interview with principal, public school)



According to this understanding, disclosure of disabilities connected to stigma, not only leads to greater understanding from co-workers, but also improves the psychosocial work environment. Hence, disclosure is framed as a valued practice. At the same time, the two groups discussed how and if disclosure was dependent on work ability.

### Work ability

The concept of work ability is difficult to define, because different welfare organizations and actors use the term differently (Seing, Ståhl, Bülow, Nordenfeldt & Ekberg 2012). When the informants with invisible disabilities discussed their work ability, they were referring to their perceptions of their ability to complete the work tasks in their present job. All of them shared the view that if and when their work ability was affected, they would feel compelled to disclose their disability to their employer: 'As long as it didn't affect my daily work I felt like, "No, it's none of their business". But then, I noticed that now, now it affects my work' (interview with Helen). The notion that reduced work ability is the most important factor for disclosure is underpinned by the Work Environment Act (1977: 1160) and the Social Insurance Code (2010: 110), concerning the employer's responsibility for rehabilitation and accommodation. Although none of the informants with invisible disabilities referred explicitly to these laws, several of them had accommodations and adapted working time. For them, disclosure was necessary to gain access to this support and to maintain their work ability. However, in the interviews, an inherent tension associated with needing accommodations appeared, as seen in this statement by Anna:

I don't want to be the one coming to work and they think, 'Here's Anna, who's ill'. I want to function; I want them to treat me like normal – like everyone else. But at the same time, I want them to understand that I'm not always able. And that's really ... that balance is really hard. (Interview with Anna)

In order to be treated like 'everyone else,' Anna needs to pass as 'normal' (Goffman 1963; Goffman 1986), but when accommodations are made for her, she risks becoming *the other* (Wendell 1989). Moreover, Anna's co-workers sometimes questioned her new assignments and flexible hours. When they viewed her as being 'like everyone else,' that is as able, they were questioning her accommodations. Consequently, she has had to explain to them the agreement she has with their employer and the Social Insurance Agency.

Similarly, accommodations for Helen have allowed her to keep working, but have also put her at risk of being treated as *the other* (Wendell 1989):

There are positive and negative aspects of being different in some way. The positive thing ... what you can gain somehow, is that you get another kind of support and stuff like that, but the negative aspects can be that you get different treatment – that you get treated differently, and I was ill-used that way at my last workplace, so I'm scared of that. (Interview with Helen)

Like the persons with invisible disabilities, the employer representatives regarded reduced work ability to be the most important criterion for employees to disclose their invisible disability. Employer representatives claimed that disclosure gave employers the opportunity to offer rehabilitation and to adapt the work environment, thereby fulfilling their legal responsibilities. They added that disclosure is relevant only if the person's work ability is reduced. In one case, an informant referred to the Discrimination Act (2008: 567), claiming that employers in Sweden cannot discriminate against candidates for a position solely on the basis of illness or disability. This presents the argument that a job candidate should be able to disclose an invisible disability without reducing his/her chances of employment. However, another employer representative reported that, because of this law, employers might not ask anything about illness or disabilities in a job interview, fearing such a question would be perceived as discrimination if the job applicant did not get the position. Therefore, as with the first informant, the employer representative felt it was helpful if the person disclosed without the employer having to ask. This allowed them to evaluate whether the necessary accommodations could be made and to avoid employing the wrong person at the wrong place. One HR specialist stated:

If a person has a very obvious disability, which means that the work situation needs accommodation, it's tricky if the person doesn't tell about it because perhaps this work situation can't be adapted, and then it will probably end with dismissal one day...maybe the person ends up with a job they didn't want to do. So, it's more about oneself [the individual]. (Interview with HR, public sector)

According to this informant, there is a problem if the person is employed but cannot work in the position and is then transferred to another position that he/she is unhappy with. Based on this reasoning, disclosure is something the person with an invisible disability ought to benefit from. Thus, the interviews with the employers showed that disclosure was seen as desirable, not 'only if' work ability was reduced. Disclosure was valued regardless of whether work ability was affected, because it enabled the employer representatives to evaluate risks. Why a disability, in this case epilepsy, might be seen as a risk was made evident below when the employer representative suggested that the responsibility to disclose lies with persons with certain disabilities:

In a classroom where the pupils will see the adult fall down and behave in a way they perceive as grotesque... and this can happen at any time without warning...it's totally unacceptable, it's not okay. It's the wrong place to work and that should have been understood by the person who accepted the job. This is nothing to hold the employer responsible for. On the contrary, you have to take this responsibility yourself [as an employee with epilepsy]. Of course, it should be understood that this is not ok and no employer will accept it, nor will parents. You would not accept it yourself – that your children are in a class where pupils don't know if the teacher will function or not, when on school trips, as a guardian in the schoolyard, or as a classroom teacher. Of course, this kind of illness is easy to medicate nowadays. But there is, for example, a very big difference between office work, where you work by yourself, and an environment where you work with children. (Interview with principal, private school)

The argument the principal wished to make here is that work ability is relative to the work tasks. However, the quote reveals a number of understandings of both disclosure and of epilepsy. Though he ended by saying that today epilepsy can easily be medicated, he also suggested that a teacher who could have a seizure or pass out, thereby upsetting pupils, has a moral obligation not only to disclose, but to choose another profession altogether. The risk of passing out or having a seizure, however, could be applicable to several disabilities or acute illnesses. But rather than giving examples of how disclosure of epilepsy may facilitate certain accommodations or support at the workplace in order to maintain work ability, the principal suggested that a person with epilepsy should not even work as a teacher. Like the HR manager above, the principal referred to a discourse about 'the wrong person at the wrong place'. In order to avoid 'the wrong person at the wrong place', institutional practices of control were used in the different workplaces under study.

### Control

The persons with invisible disabilities said that if they were in a recruiting process at their workplace today, they would be forced to disclose their disability due to health controls and drug tests, which they perceived as standard hiring practices at their current workplace when hiring a new employee. Being in control of 'who knows what' was highly important to the persons with invisible disabilities, as this gave them control over their appearance and identity, and thus how others perceive them (Charmaz 1991; Goffman 1963; Goffman 1986). At her former workplace, and without her knowledge, Helen's diagnosis was disclosed to her colleagues by her manager. She experienced how colleagues began treating her differently than before: 'Some became incredibly good at achieving – really kind and handy and compliant. Others became almost mean' (Interview with Helen). This made Helen hesitant – or 'scared to death,' as she put it – to tell others at her new workplace about her disability. For her and other informants in senior management positions, disclosure was experienced as a risk in that it could undermine their professional role. This experience is reflected in the interview with Karen, who had previously worked as a manager:

The more I showed it [the impairment] and had this role –being a manager and to having, what should I call it, power [to have] a position of power and at the same time being dependent – it doesn't work well. I think that's where it's hard. /.../ It has something to do with not showing that you're to be vulnerable. (Interview with Karen)

Control is not only a matter of who knows what. The informants also controlled themselves and their own bodies. In one case where the person was determined not to disclose her invisible disability, she controlled her own behaviour and body, for example, by lifting heavy objects with her stronger hand:

My friends, who know I haven't told others at work, they say 'But Sarah, you're putting on an act every bloody day because you withhold information – isn't it hard?' The answer to that is yes, it's hard. Because if I need to grab a binder or something, I don't use this hand (shows me her weaker hand). I use the other one. (Interview with Sarah)

Controlling of one's own body can also be seen in the cases of Anna and Helen, as they chose to medicate over the weekends to be able to work more on weekdays.

The interviews with the employer representatives demonstrate how control was an institutional practice used in their respective workplaces. One way of putting into practice the employer's responsibility for preventing unhealthy working conditions and of adapting the working environment to employees' needs was by controlling short-term sick leave to allow the employer to make a preventive rehabilitation plan. Several of the workplaces in the study had computer applications that notified the HR manager or the manager about an employee after a certain number of short-time sick leave periods. In those cases, it was standard practice to arrange a meeting between the manager and the employee to ask about the underlying cause of repeated sick leave. Such institutional practices can be used as tools to engender an employee to disclose, but can also lead to a higher presenteeism if the employee does not wish to disclose his/her invisible disability (Munir, Yarker & Haslam 2008).

Yet another controlling practice became evident when the occupational healthcare service psychologist described how different contracts could be signed between the occupational healthcare providers and the employer. For example, some contracts stated that if the employee was planning to contact or receive any form of occupational healthcare,

he/she might be required to inform the employer first, while other contracts stipulated that an employee could receive occupational healthcare up to three times before the employer must be notified. These types of practices and uses of texts were realized differently across workplaces, but all were put into action and had legitimacy owing to the employer's responsibility for preventing unhealthy work conditions and for providing any accommodation needed.

Another way for the employers to engage with the occupational health service was through work ability assessments. According to the occupational healthcare service doctor, employers now asked her, more often than before, to evaluate the work ability of employees with a disability when a workplace reorganization was imminent. She gave the example of a work ability assessment of a woman who had had both a visual impairment and hearing impairment since childhood and who worked at a telephone switchboard:

She tells us what accommodation she has. We go to the company and I see that she can handle the resources. She is able to answer the phone, she hears everything, she has not made a single mistake during the time we have been there. And so I say to the company 'What do you think I should do here?' [the employer answered her:] 'Yes, but now we have a completely different equipment and we have training and tests to get ISO certified [...] She has made a number of mistakes, and if you cross this limit you can't handle it'. /.../ Something happens in the company and suddenly, such a person no longer fits in and then it should be a medical problem – something that has never been a medical problem before. (Interview with the occupational health service medical doctor)

Here, the occupational health service doctor argued that organizational or work task changes could lead to lowered work ability for a person with a disability and that employers – rather than asking what accommodations could help an employee keep his/her work position – instead referred to the impairment as the problem.

Regardless of intent, the practices of control in the different work places can all be understood as institutional practices that monitor the employees' work ability and limit their chances to decide if, when, to whom, and how to disclose. Moreover, this surveillance of work ability was internalized by the persons with invisible disabilities, as discussed above.

## Discussion

The present article has shown that control of short-term sick leave, employment interviews, and assessment of work ability by the occupational health providers are institutional practices that affect the work situation for persons with invisible disabilities. If the disability is experienced as stigmatizing or medically questioned and if the persons consider their work ability to be reduced, these situations have also been identified as experiences and discourses that affect their work situation. However, building on its double focus on employer representatives *and* on persons with invisible disabilities, the analysis has also revealed different understandings of disclosure, stigma, work ability and control:

- The employer representatives and the persons with invisible disabilities both understand the need for disclosure with reduced work ability, but have different views on the importance of disclosure in the recruitment situation.

Employer representatives viewed openness (about the disability) as important both to current employees and in the recruitment process. When the employer representatives report that disclosure is important 'only if' (interviews with HR manager and principals) work ability is reduced, but also frame disclosure in a recruitment situation as something positive, this can be understood against the background of the Discrimination Act (2008: 567) and the employer's legal responsibility to accommodate the work, as well as the Employment Protection Act (1982: 82). Disclosure can also be understood as allowing employers to calculate risks when employing such persons, for example, the risk of employing 'the wrong person at the wrong place'. In the present study, what were considered risks by the employer representatives were not evident to the persons with invisible disabilities in the study.

In regards their respective disabilities, the persons with invisible disabilities made a distinction between the need to tell their current employer and a potential future employer in a recruitment situation. They reported positive experiences of disclosure, as this had led to support from co-workers and employers and to accommodations being made. Despite such positive experiences and despite their knowledge of the Discrimination Act (2008: 567), they all expressed uncertainty about whether they should disclose their disability to a future employer. This was due to their concern that a potential employer might not want to hire them. Worry and insecurity about a future employer's attitude may lead to 'job lock' for persons with an invisible disability, resulting in them remaining with their present employer (regardless of whether the employer knows about the disability). Previous studies in the US have shown that employees with chronic illness stay at their present workplace to avoid losing their health insurance (Beatty 2012). Although the employment context is different in Sweden, where employees' rights laws are relatively strong, the present results indicate that there may be a similar risk of job lock, as the persons with invisible disabilities reported feeling insecure about not knowing how a new employer would act upon a disclosure, or even if they should disclose in a job interview. Such insecurity concerning a potential new employer's attitudes towards hiring a person with disabilities may cause persons to decide to remain at their present workplace.

However, as the interviews with the persons with higher positions in their respective organizations showed, staying at one's present workplace meant dealing with co-workers and employers' assumptions that persons with invisible disabilities cannot handle challenging work or soon will leave work (Beatty 2012). Such assumptions about the work ability of persons with disabilities may mean that they are not given challenging opportunities that could help them develop new skills (Wilson-Kovacs, Ryan, Haslam, Alexander & Rabinovich 2008).

- The employer representatives saw less risk for stigma associated with certain invisible disabilities compared with the persons with invisible disabilities, who experienced having been treated differently by employers and co-workers after disclosure.

Because burnout syndrome has become common and because there is a greater openness about psychological disabilities such as depression, several of the employer representatives believed that there is now less stigma associated with such invisible disabilities. However, the persons with invisible disabilities had another perspective. Stigma was still associated with certain psychological disabilities, but also with contested diagnoses. Additionally, no matter the disability, they experienced their reduced work ability to be stigmatizing because it caused co-workers and managers to treat them like *the other* (Wendell 1989). The dilemma at hand here – needing accommodation in order to have a certain work ability, but then being seen as less able – is framed by Whitt, Cawley, Yonker and Polage (2014); they connect (dis)ability, accommodation and job performance as follows: 'Despite legislation seeking to open opportunities for those with disabilities, there remains the stigma that if one has a disability, he or she is a less productive member of the team, a perceptual stigma seemingly reinforced by the need for special accommodations in order to be a productive member of the workforce' (Whitt et al. 2014: 266). Being seen as less productive is only one of many job performance stereotypes applied to persons with disabilities (Santuzzi et al. 2014). This view of the disabled body as *the other* has bearing on who is seen as an able worker and who is not. In some cases, the making of *the other* becomes part of the institutional practices, for example when occupational healthcare providers are asked to assess the work ability of employees with disabilities before or after a workplace reorganization.

The stereotypical connection between work performance and disability, together with experiences of being constructed as *the other* (Wendell 1989) in working life, can help us understand people's unwillingness to be seen as the disabled. Moreover, it may explain the sense of hesitance the informants reported having concerning disclosure. Another cause of stigmatization is when others perceive the disability as illegitimate, thus questioning the person's will to work or need for accommodations. Several of the informants reported experiencing such a stigmatization. Santuzzi et al. (2014) argue that the experiences of stigma connected to job-performance and illegitimate disabilities is: 'an experience that is unique to workers with invisible disabilities' (Santuzzi et al. 2014).

- Controlling practices in workplaces can help the employers prevent illness and disabilities among the employees. However, the persons with invisible disabilities experienced these practices as limiting their control over disclosure.

The controlling practices identified in the analysis can be understood as being performed at different workplaces and by the persons with invisible disabilities themselves. Control of short-term sick leave and evaluating work ability are institutional practices that can be used by employers not only to live up to their responsibility for making accommodations and preventing unhealthy working conditions, but also for governing the employees' work ability. No matter the intention of these controls, they limit a person's control over how, when and to whom an invisible disability is disclosed (Munir et al. 2008). Further, persons with invisible disabilities internalize these institutional practices, because they control their own body and work ability while deciding whether or not to disclose. Such self-surveillance practices can be understood as part of a person's strategies to maintain in control over his/her identity (Charmaz 1991) and to pass as 'normal'. Paradoxically, these attempts to achieve normality create the risk of reproducing norms implying that the ideal worker is the able worker (Foster & Wass 2013).

These tensions between different understandings caused a number of dilemmas for the persons with invisible disabilities. Although they experienced disclosure as an uncertain balancing act between positive and negative consequences, they could not be certain of these consequences prior to disclosure. Still, most of the persons had disclosed their disability to their employer. This suggests that persons with invisible disabilities are aware of the employers' preference for disclosure, which encourages them to disclose despite the potential negative consequences and negative experiences. Thus, the knowledge of everyday life among persons with invisible disabilities is subordinated the knowledge and interests organized elsewhere (Rankin 2017).

## Conclusion

With respect to disability studies and working life research, the present article contributes with critical perspectives on disclosure by showing that, despite employee protection laws and the rather well-regulated working life in Sweden, persons with invisible disabilities are in a vulnerable position in the workplace. It shows how disclosure can involve



gaining more understanding from co-workers and saving persons with invisible disabilities the distress of being 'caught' or having to 'lie' (to use the informants' own words). However, persons with invisible disabilities fear losing their job and not being able to get a new job. The persons in the present study who had disclosed their invisible disabilities felt that they had been met by and treated differently than their co-workers. This result is in accordance with international studies showing that respondents who reported disclosure experienced negative long-term consequences in their work life, although fewer reported that their immediate experience of disclosure was negative (von Schrader et al. 2014).

Building on its double perspective on employer representatives and persons with invisible disabilities, the article contributes with new knowledge by showing that these two groups have different understandings of disclosure. In the interviews the employer representatives referred to 'ideal' institutional practices and understandings in line with laws and guidelines, while the persons with invisible disabilities based their understandings of disclosure on their past experiences. The tension between the different understandings indicate that employers need a greater knowledge of the dilemmas persons with invisible disabilities face in working life and of how disclosure affects their work situations.

Another important contribution of the present article is the understanding that a person's (non)disclosure should not be reduced to personal traits such as honesty/dishonesty. Rather, we need to understand non-disclosure as one of a person's set of strategies to maintain control over his/her identity and as a struggle for normality, in this context strongly associated with work ability and participation in working life.

### Competing Interests

The author has no competing interests to declare.

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