Participation in the workforce is lower among people with disabilities worldwide. In this study we explore how people with disabilities perceive their inclusion in working life. Twenty women and men were interviewed. The sample comprises a group of working people experiencing different kinds of physical and sensory disabilities. The employment barriers found were related to accessibility, cooperation among welfare agencies, technical aids and welfare services. We named them as follows: the environmental participation barrier, the jungle of devices, the catch 22 situations, and, the inflexibility of welfare services. According to our interpretation these external barriers hinder people with disabilities from engaging in work and civic life to the extent that they want. Most interviewees in our sample were well-educated and successfully employed, nevertheless they all had experienced barriers in relation to remaining in work. Although the intentions in Sweden and most welfare states is to include people with disabilities in working life there are several obstacles in implementation of this intention.

Keywords: employment; social services; equal' rights; work barriers

Introduction
Work is generally good for health and well-being and minimises the harmful physical, mental, and social effects of long-term sick leave. It also promotes full participation in society, and is central to individuals’ social roles and social status (Waddell and Burton 2006). People with disabilities have throughout history faced discrimination and negative attitudes that have impact on productivity and employment (Kilbury, Bordieri and Wong 1996). In 1938, the deaf, blind, and “crippled”, as well as those with tuberculosis, were defined as a disadvantaged group with reduced work capacity in a minimum-wage agreement between the employer organisation (SAF) and the trade union for manual workers (LO) (Blomqvist 2001). This was the first time that a classification was made of people experiencing disability and reduced work capacity in Sweden. In this classification, disability was defined in terms of impairments. Today, work disability is mainly considered a result of conditions at work such as job demands and possibilities to adapt one’s work related to experienced health status (Ilmarinen 2008; Johansson and Lundberg 2004).

The number of people with disabilities is increasing, and the proportion of people worldwide in the adult population is estimated to 14% in low income countries and 12% for countries with high income (Mitra & Sambamoorthi 2014). In 2015 in Sweden, 15, 8% among those aged 16 to 64 reported experiencing disability. Among these, 68, 5% reported that disability reduced their work ability (Statistics Sweden, 2016). The United Nations “Convention on the Rights of Persons with Disabilities” (CRPD) states the right of persons with disabilities to work on an equal basis. Several laws in Sweden strengthen labor participation among people with disabilities. According to the Work Environment Act (1977: 1160) Swedish employers must make allowances for employees’ specific needs at work by modifying the working conditions or taking other appropriate measures to facilitate work for people with disabilities http://www.government.se/government-policy/labour-law-and-work-environment/19771160-work-environment-act-arbetsmiljolagen/.

According to the Discrimination Act (2008: 567), an employer may not discriminate against someone with a disability that is employed, is inquiring about or applying for work, apply for or perform internships or perform work as temporary or borrowed labour http://www.government.se/information-material/2015/09/discrimination-act-2008567/. Despite these acts, the employment figures are lower globally for people with disabilities (WHO 2011). In Sweden in 2015, 84% of the population aged 16–64 belonged to the labour force (Statistics Sweden, 2016). Comparable figure for people with disabilities are 68% which is identical to the figures from 2004 (Statistics Sweden 2005).
Studies indicate that people with disabilities value work and are as likely as others to want a job (Dag and Kullberg 2010; Ali et al. 2011). However, Kaye (2009) reported that even after taking in account average educational attainment, workers experiencing disabilities appear to be disproportionately relegated to entry-level occupations. In a study from 2011 Kaye and colleagues found three reasons for employers’ reluctance to employ people with disabilities. These are: (a) lack of access, (b) misconceptions about disabilities, (c) discrimination, and (d) overprotection in labour law. In the report it is stated that more research is needed of barriers for inclusion of people with disabilities in the labour market. However, the barriers outlined in the WRD are based on national reports and a few peer-reviewed and published studies, mainly of single-disability groups. Research from the Nordic countries is almost entirely unrepresented in the WRD (WHO 2011). A review of Swedish research on disabilities and employment found that few disability studies were focused on employment (Rönnberg et al. 2012). Nordic countries have from a European perspective been successful in minimising spatial inequality for people that otherwise would be trapped within disability benefits through increased labour market participation and solidarity supported by the social democratic model (Danson et al. 2015). Although new inclusion policies and approaches to improve work participation such as supported employment have been developed in the Nordic countries the scope and degree of governmental support are questioned (Spjelkavik 2012). Debated is also to what degree labour market approaches for vulnerable groups really enhance equal opportunities related to participation in workforce (Halvorsen and Hvinden 2014). Moreover, if chosen by the individual the right to work should also include the possibility to work throughout the life cycle. In Sweden the pension system is based on that people are supposed to work until retirement of age (Laun and Wallenius 2013) and if not their economic situation decreases drastically. In the present study we invited people that were already included in the workforce to talk about their experiences in order to understand more about the barriers experienced in remaining work active.

**Aim and research question**

The aim was to explore how people with different types of disabilities perceive working life and the possibility of continue to be work active.

The research question was:

What are the barriers faced by people with disabilities to remain in the workforce?

**Methods**

In this inductive interview study we included participants having experience from a permanent employment. We recruited the participants through the organizations in the Swedish Disability Federation (HSD) by informing about the project via e-mail, two organisations answered the call: The Association of Hard of Hearing People (HRF), and the organisation for people with mobility impairments (NHDR). In the next step, snowball sampling was used in order to find more participants. One of the participant advertised the call for research participants to a web site for people with disabilities (www.funktionshinder.se). Moreover, the Swedish Association of the Visually Impaired (SRF) approach the researcher during a seminar 2006, requesting to be included in present study.

Twenty participants were recruited in total, nine men and eleven women, all of which had work experiences for a variety of work places; NGOs, public agencies, and private companies. The disabilities included were physical impairments, sensory impairments (visual and hearing), mobility impairments, neurological impairments, and multiple impairments. Sixteen of the participants were actively employed, while four were out of work at the time of the interviews, but had been employed previously. The interviewees ranged from 30 to 59 years of age. Twelve were born with a disability, while four had developed disability during childhood and four in adulthood. The majority of the interviewees had post-secondary education or higher (17 out of 20), Table 1.

**The interviews**

The first author conducted the interviews. An interview guide with the following themes was used: experiences of education, the labour market and work life, structural, social and individual conditions at work, and the interviewees’ future plans. The interviews were taped with permission and had the length of 1–2 hours. The tapes were transcribed by a professional firm. The excerpts were slightly improved to increase readability by editing repeated words and speech fillers (e.g. “ah,” “um,” “you know?”) without changing the intended meaning of the utterances.

We analysed the data by thematic analysis. This is a method for identifying, analysing and reporting patterns (themes) within data (Braun & Clarke 2006). In the analysis we sought to find the patterns and variety in data. The prevalence of instances in the themes was therefor not of importance. First, the transcripts were read and the tapes were listen to see if anything were missing and to get familiar with the text, then preliminary codes were given. After this, patterns were identified and reviewed by the second author and through discussions, narrowed down furthermore focusing on to retention in the work life. In the analysis we followed the guidelines outlined by Braun and Clarke (2006): familiarization with data, generating initial codes, searching for themes among codes, reviewing themes, defining and naming themes, and producing the final report.
When presenting quotes in the result section, the interviewee’s age group, level of work participation, and type of disability are provided.

**Ethical considerations**

Ethical considerations have been part of every phase of the research process. First, in designing the study and working out where it was possible to access an appropriate sample. That is, people with disability who have experience working. Second, when making contact with possible participants, informing them about the aim of the study, the fact that participation was voluntary, and that participants could quit at any time during the research process without any consequences. The information was given in order to give possible participants knowledge of their rights as research participants, as well as of the study, in order for them to be able to make a conscious choice in terms of participating. Third, when conducting the interviews, each individual was given enough space and time to share their experiences to achieve valid data shaped by the participants’ perspective. Fourth, in presenting the results, so that no details that could be connected to a particular individual were revealed. This helped to preserve each respondent’s anonymity. Fifth, the reflexivity of the researcher’s own position during the process was maintained by discussing with colleagues and presenting the manuscript in conferences and seminars. To add to this, a second author was invited to contribute to reflexivity, and the analysis and formation of manuscript. Finally, this data has been used for research purposes alone, as was communicated to the participants. This use of data is also part of the rights of the research participants, which has been preserved throughout.

**Results**

The interviewees in this sample are well-educated and integrated in the working force (Table 1), however, they worried about having to face early exit from the workforce. The received self-fulfillment through working and a possible bad economic situation in the future, were factors underpinning their worries. The major barriers described to retain in the work force were; Environmental participation barrier described as the social, communicative and physical difficulties to attend public places and workplaces. Another barrier experienced was the “catch 22 situations” related to the lack of coordination among the rules, regulations and goals of different welfare authorities. The “jungle of devices” describes the lack of coordination concerning the devided responsibilities related to the deliverance of assistive devices. A described barrier was related to “inflexibility of welfare services” which refers to how health-, rehabilitation-, home- and transport services are not coordinated with being a worker and having scheduled shifts at daytime.

**The environmental participation barrier**

The environmental participation barrier found in the study encompassed physical, social, and communicative difficulties experienced in relation to work. One interviewee working full time described how the reduced accessibility of being confined to a wheelchair complicated things, preventing him from starting his own business or changing jobs. Even though he had received offers from another company, the inaccessibility of the buildings stopped him. Working as a consultant, or performing similar tasks that involve visiting clients, might be impossible if you do not know what kind of work environment you will face. Interviewees with hearing impairments described that meetings sometimes had to be stopped due to the bad hearing environment, and that new dates and places to meet had to be chosen and

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<tr>
<th>Category</th>
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these repeated changes and miscalculations made the person angry and lose faith in others' caring or willingness to understand or adapt. The interviewees also described having experienced a lack of communicative accessibility in public places when attending meetings and engagements related to work. Accommodations were even worse when working abroad. It was almost impossible to take part in research conferences or international meetings with a hearing impairment. Another interviewee working full-time said that he had to turn down an offer for an international position, since suitable accommodation simply were not available and because it would be impossible to attend meetings where different languages were used.

One interviewee working part-time reported that following her sick leave and rehabilitation, her manager showed no interest in her return-to-work process and gave her no feedback on how things were going. Nor did the manager turn up at the scheduled rehabilitation meeting with the social insurance officer. This interviewee said that she always had to struggle a bit more in every situation, and that this took the energy away from her. A similar view was expressed by another interviewee who reported that her tiredness was a result of the combination of the lack of accessibility and the disability.

1. I never view myself as sick or disabled ... I see myself as a woman; that's how I view myself. I have physical limitations that hinder me sometimes, but it isn't actually the disability that holds me back; it's things around me that are hindrances. Of course the disability means that I tire rather quickly. (Age 40–49, working part-time, mobility impairment)

The environmental participation barrier require strength to overcome when one's body does not function at 100%. Some of the interviewees had been forced to take sick leave after putting too much pressure on themselves to work at full capacity. The attentiveness to the environmental circumstances was tiring and demanding for the individual, and this participation responsibility was not often shared with others according to the interviewees.

**The jungle of devices**

Some interviewees described being unsure of whom to turn to when technical devices or adjustments of the work environment were needed. Coordinating the welfare services and communicating with the various professionals, including procuring the right devices, are often left to the individual. For every workplace or school, new aids must be procured and devices used in previous settings must be returned. This can become even more complicated when moving between regions because of the differing priorities, economic situations, and understanding of devices in different parts of Sweden. One interviewee described this fragmentation of disability services and its lack of coordination in relation to assistive devices as a “jungle”.

II. The problem is that when you leave upper-secondary school and go to university or look for a job, you don’t know where to turn. The natural place is the health service, but they seldom offer technical support. You can get it at the employment office, social insurance office, or the university, depending on what you are going to do. If you enter higher education you sometimes can borrow portable devices from them [university], or you can borrow them from the health-care office. When entering the workforce, the first year you are supposed to receive work-related technical devices from the employment office. [After] one year then you should turn to the social insurance office for the same devices. If you have a wage subsidy then you should turn to the employment office. As you can see, there’s a jungle of devices. (Age 30–39, working full time, sensory impairment)

According to the interviewees, these uncertainties about technical tools make it extra difficult to compete for temporary employments lasting shorter periods, and to change accommodation. The interviewees argued that a possible solution would be if technical devices followed the individual. The interviewees also talked about how county counsils in parts of Sweden prioritised differently in relation to new hearing devices for the users.

**The catch 22 situations**

Rules concerning various provisions may be incompatible and put people in a catch 22 situation. Rules on compensation for rehabilitation from the social insurance may allow some activities and not others. The interviewees had experienced that involvement in non-governmental organisations, may lead to sickness benefits being withdrawn. Another regulation concerned the number of hours an individual is allowed to work while receiving benefits. Two of the interviewees, both unemployed at the time of the interviews, wanted to work ten hours a week. However, this was impossible in conjunction with the regulations requiring a work capacity of at least 17 hours a week to be eligible for support from the employment service.

III. It is hard to know your individual work capacity if you have a neurological disease. It varies over time, but after listening to my neurologist I have understood that it is around 10 hours a week, maybe a little less sometimes, or maybe a little more. I believed that I would be able to continue working after my period of sick leave last spring. Thinking about what I might do, I contacted the Unemployment Benefit Fund, and I found out that...
it was not possible. You have to have a work capacity of at least 17 hours a week to be eligible for help from the employment service... being unemployed I have problems with the Social Insurance Office [if I'm working]; it really feels like a "Catch 22 situation". (Age 50–59, unemployed, neurological impairment)

An apparent lack of cooperation between authorities was also experienced with regard to retain employment or going back to work. Experiences that the individuals themselves were responsible for both making contacts with the authorities and keep them informed was described. Moreover, cooperation was often lacking between the employer, the social insurance office, or the employment agency. Lack of coordination also arose through organizations had different goals with their activities and therefore had different focus in rehabilitation and return to work (RTW). At one point in his rehabilitation, one interviewee felt stuck between authorities with competing goals during the RTW process. The employment agency’s objective was education, while that of the social insurance office was to push back to work.

**The inflexible welfare services**

Some participants in the study received assistance in terms of transportation and home care. Routines of home care and transportation service may be incompatible with the requirements of the presence required at the work place. The interviewees described needing to leave work in the middle of the day due to home-help needs.

IV. I have home help every Monday. I’d have liked to have it on another weekday, but it’s been decided: Monday at one o’clock. They come to my place and I can’t have anything else planned, since I never know when they’ll arrive. It’s all up to them. It’s not that it doesn’t work, but it isn’t easy when you are an active, employed person. (Aged 40–49, working part-time, mobility impairment)

The problem of having to be absent from work was also related to rehabilitation and health care, since these services are provided only during the day and therefore require taking time off, which ended up reducing the number of working hours. Transportation to work was also problematic for some of the interviewees. One interviewee working full time explained that the mobility service was not an option for those with jobs, because you could not count on arriving on time. According to her, you had to live close to your job to get there on time.

**Discussion**

In the present study we have focused on barriers of retaining and remaining in work for people experiencing physical disabilities such as mobility, hearing, or sighted problems. Four barriers were identified: a) the environmental participation barrier which encompass social, communicative and physical hinder to take part on equal terms; b) the jungle of devices; c) the catch-22 situations which relates to conflicting rules and goals of welfare agencies and; d) the inflexibility of welfare services, which describes difficulties in combining demands from work with organisation from other assisting agencies (Figure 1).

![Figure 1: Four barriers that people with disabilities may meet when working.](image-url)
Not surprisingly, environmental participation barriers were described as a hindrance to retaining and remaining in the workforce, which also have been found in an interview study of work active people with disability from Brazil (Toldra & Santos 2013). Barriers within the workplace such as physical and communicative hinders are, according to Work Environment Act (1977: 1160), the responsibility of the employer. However, there are also barriers that occur outside the workplace, such as lack of accessibility to public spaces where work-related activities take place. Even though employers cannot be held responsible for such barriers, these obstacles may hinder people with disabilities from performing certain work-related tasks, which may in turn adversely affect their career or prevent them from getting a new position. A physical disability may have non-motor symptoms such as tiredness or fatigue (Khedr et al. 2013; Feldthusen et al. 2013; Varekamp et al. 2013). In addition to providing direct obstacles to participation in working life, attending participation barriers may also contribute to this tiredness and fatigue. Clayton et al. (2012) found that engagement from employers were important for successful return to work among people with disabilities. Our results indicate that such engagement may be directed to the environmental participation barriers the employees face.

The interviewees in this sample were well-educated (Table 1) and active in keeping their employment and fear having to leave the workforce early facing lesser economic circumstances. The Swedish pension creates large incentives for continued employment for older workers and labour supply behaviour (Laun and Wallenius 2013). This pension system increases the difficulties to keep the economic welfare for people experiencing disability.

The barrier jungle of devices put several people with disabilities in the insecure situation of not knowing whom to turn to when one’s situation changes. The quality of assistive devices also depended on where you lived; not all municipalities had the same economic resources or enough knowledge about new technical advances. This violates the goal of equal rights for people with disabilities (Swedish Agreements 2008: 26). According to the interviewees in our study a possible solution would be for technical devices to follow the person rather than the organisation or workplace.

Another perceived barrier that was described was “catch 22 situations” that make it difficult for individuals to remain in the workforce. Research in Sweden has shown that the social insurance offices and employment agencies have difficulties cooperating and also have different goals (Eriksson et al. 2008). Stähl et al. (2009, 2010) found that collaboration between stakeholders in the return-to-work process was obstructed by divergent perspectives on the cooperative work, which can be a result of institutional preferences and self interest or, as reported in the our study, when welfare authorities have different foci and goals. Laws aiming to protect the right of people with disabilities to employment and equal participation will be ineffective if they are not coordinated and if collaborations between stakeholders do not function. Furthermore, welfare authorities have to improve their understanding of how to create anti-discriminatory practices, instead of individualising discrimination by viewing it as connected to the individual’s identity rather than unjust aspects of the welfare system (Dominelli 2008).

Lastly, the barrier inflexibility of welfare services can have a major influence on the employment prospects of those in need of the services. It was almost impossible for someone with service needs to work full-time because services are only delivered during daytime. We are not aware of any research on how welfare services are delivered to employed people experiencing disabilities or other employed groups in need of such services. Because inadequate delivery of welfare services to employed persons experiencing disabilities may violate the intention of civil rights and discrimination legislation, it is an important area for further studies.

**Limitations of the study**

Since this study used an open mail call and snowball sampling it may have attracted people more willing to discuss their work experience. Those who do not want to put experienced disability and it’s consequences out in the open may face hinders in relation to work that we missed. Another limitation in our study is that it is restricted to those experiencing physical disabilities. We therefore do not know from this study what barriers people experiencing e.g. chronic pain or psychiatric disorders may face in working life (see eg. Santuzzi et al. 2014).

We are aware that positive changes might have risen in the last ten years for people with disabilities in relation to participation in the labour force. However, statistics and interviews unfortunately paint a similar picture of problems related to work participation for people with disabilities, the differences are still there (Statistics Sweden 2005; Statistics Sweden 2016).

**Conclusion and implication**

Although the intentions in Sweden and most welfare states is to include people with disabilities in working life there appears to be several obstacles in implementation of this intention. We need to learn more about such obstacles in different groups and develop strategies to minimize such obstacles. Such strategies may be directed to the employers. But this does not seem to be sufficient. Organization of other welfare services have to be altered in order to make working life more accessible for people with disabilities.

**Competing Interests**

The authors have no competing interests to declare.


**Laws and agreements**

