

## Research Article

### Swedish Citizens with Cerebral Palsy or Spina Bifida – Perceived Experiences of Social Life and Employment

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**Abstract:** This article offers insight into the ways in which people with cerebral palsy and spina bifida reflect upon their experiences of participation in relation to social life and employment. The qualitative method was used to explore experiences of participation among adults with CP or SB, using semi structured interviews. Participants expressed a desire to make a contribution to the labor market, to have sustainable relationships and to be accepted by others.

**Keywords:** Disability, Participation, Employment

## Introduction

Participation is important to human health and is crucial for psychosocial development. The International Classification of Functioning, Disability and Health define participation as involvement and engagement in a life situation ([WHO, 2001](#)). It states the level of social engagement and the ability to accomplish goals in life are important factors that influence a person's perceived participation ([Salter et al., 2005](#)). When the ICF is used for rehabilitation, full participation in society is considered a key concept for people living with a chronic disability ([AlHeresh & Keysor, 2015](#); [Shakespeare, 2013](#)).

In today's Sweden, the political climate is dominated by the social model of disability. This means that disability is defined as socially and politically influenced discourse around interpretation of physical differences ([Byrne, McLaughlin, Byrne, & McLaughlin, 2007](#); [Shakespeare, 2013](#)). According to the social model, impairments exist but how they are viewed is socially constructed. Therefore the social model makes a fundamental distinction between impairment and disability, where the latter means constraints of activities caused by a current social organization, which might exclude people from social contexts in society ([Goodley, 2001](#)). In this study, disability is understood in terms of socially created disabling barriers that prevent people with disabilities from participating in society on equal terms with others. However, unlike the more traditional social model, this view does not exclude an understanding of disability as significant in some people's lives, for example because of chronic pain from a specific impairment ([Shakespeare, 2013](#)).

From a Swedish historical perspective, disability has been a factor in discrimination and exclusion from large parts of society and the present disability policy is the result of developments over the last two hundred years ([Kjellberg & Hemmingsson, 2013](#); [Schaap](#)

[Williams, 2013](#)). Ignorance, disregard, superstition and fear are societal factors that have hindered persons with CP and SB and complicated their struggle for participation in society ([Edwards, 2008](#); [Riddle, 2013](#)). However, recent international social policies have been formulated to promote acceptance, integration and inclusion for this group. Despite these policies, participating in today's society requires physical skills and people with CP or SB might be in need of personal assistants or assistive devices in order to participate on equal terms ([WHO, 2001](#)).

Internationally, The United Nations Convention on the Rights of Persons with Disabilities (2011) recognizes the right of people with disabilities to have equal opportunities in the labor market and to participate in an open, inclusive and accessible work environment. The CRPD also emphasizes the importance of employment as one of the means of reaching full participation. However, according to Kaye et al. ([2011](#)) and Barnes and Mercer ([2005](#)) employers still generally have negative attitudes toward people with disabilities. Employers were reported to have difficulties with costs, legal liability and ignorance when it came to hiring and retaining a person with a disability ([Kaye et al., 2011](#); [Roach, Short, & Saltzman, 2011](#)).

In Sweden the work participation rate among adults with CP or SB is high when compared internationally, with a previous study ([2014](#)) showing a 66% participation rate as a result of the system of wage subsidies ([Törnbom et al., 2014](#)). This means that the employer reaches an agreement with the state about what percentage of the wage they each are willing to pay ([Törnbom, Lundälv, Jespersen, Sunnerhagen, & Grimby, 2011](#)). A Swedish study presented that 19 persons working full or part time had wage subsidies and the others were competitively employed ([Marie Törnbom et al., 2014](#)).

Through participation, people can learn abilities and competencies, associate with others and find a new purpose in life. However, previous research suggests that the presence of cerebral palsy (CP) or Spina Bifida (SB) might lead to participation that is less varied and involves fewer social relationships ([Stewart et al., 2012](#); [Marie Törnbom et al., 2014](#); [Yeung, Passmore, & Packer, 2008](#)).

People diagnosed with CP or SB and their experiences of living in today's Swedish society have not yet been widely explored. People with disabilities in general, and with CP and SB more specifically, should be able to take part in society under the same conditions as others. Therefore, it's very important to uncover issues and areas of inequality in society for these groups ([Shakespeare, 2013](#); [Van De Ven, Post, De Witte, & Van Den Heuvel, 2005](#)).

The purpose of this article is to describe experiences and perceptions about participation of adults with CP or SB with regards to their social life and employment.

## Methods

A qualitative method was used to collect views held by adults with CP or SB about

participation and to examine phenomena that have not been widely explored before. To explain issues from the perspective of the participants' own experiences, perceptions and interpretations of events, in-depth interviews were chosen ([Cope, 2014](#); [Patton, 2002](#)). Content analysis was used to achieve a better understanding of the individuals' perceptions by asking them to describe their lived experiences and to describe and analyze the subjects that were brought up by the researchers ([Graneheim & Lundman, 2004](#); [Kondracki, Wellman, & Amundson, 2002](#)). The study was approved by the Regional Ethics Review Board in Gothenburg and all participants gave written informed consent.

### Participants

All persons invited to participate had been patients at an adult habilitation unit at the Department of Rehabilitation Medicine, Sahlgrenska University Hospital, Gothenburg. In a previous interview that took place in 2009, the patients from the adult habilitation unit were asked if they would like to participate in an upcoming in-depth interview. Twenty patients agreed to participate, aged 35-55, 9 females, 8 with SB and 12 with CP. Civil status; 8 were cohabiting and 6 of them were married, 12 lived alone.

All had completed year 9 of secondary school and 16 had completed upper secondary school. All were Swedish speaking and lived in Gothenburg. Twelve always or occasionally used a wheelchair, 4 were in need of crutches and 3 were walking independently. Eight were employed full time and 7 part time; 9 had wage subsidies and 6 were competitively employed. Four had full time disability pension and one was unemployed.

### Data Collection

In line with a qualitative approach, the aim was to elicit thoughts and feelings about experiences of importance for the participants. Before the interview started, all participants were given a letter with information about the study and their right not to participate or to refrain from answering any of the questions. One of the authors conducted the semi structured interviews of 45-75 minutes at a location preferred by each participant. The questions were directed to the participant's experiences within the following themes of employment and social life ([Cope, 2014](#)). These themes were chosen in accordance with the current political debates in Sweden about persons with disabilities and their conditions in the labor market, as well as their ability to lead a social life (Socialstyrelsen, 2010). These themes were also chosen beforehand to ensure clear boundaries and to avoid an immense amount of data ([Patton, 2002](#)). Participants were asked to think about their experiences of participation within each theme.

In-depth interviews were chosen to encourage explanatory answers and two-way communication. To yield important insights in the themes, we used open ended and follow-up questions that varied depending on the answers, for example: "Can you tell me more about that job?" ([Kondracki et al., 2002](#)). To increase the validity of the interview process, themes and ideas were reflected back to the participants, to make sure that we understood the responses correctly ([Cope, 2014](#)). The interviews were audio taped with the participants'

knowledge. Anonymity and confidentiality concerning the collected material was assured.

### Data Analysis

All interviews were transcribed verbatim and the analysis began with two authors reading the transcripts of all interviews several times, to attain a sense of the whole. Two members of the research team developed a coding scheme based on key concepts that appeared in the material and were related to the research questions. This coding scheme was revised in an ongoing process as new transcripts were read and discussed by members of the research group ([Graneheim & Lundman, 2004](#)).

In accordance with the conventional content study design, the interview material contained narratives within each theme ([Graneheim & Lundman, 2004](#); [Kondracki et al., 2002](#)). Conventional content analysis (CCS) was appropriate to use in this study to help describe experiences and thoughts where existing theory or research literature is limited. In line with the CCS we allowed categories and names for categories to flow from the data, which is an apparent advantage with this method ([Hsieh & Shannon, 2005](#)). This assisted in delving deeper into the data to allow new insights to appear, also described as inductive category development ([Patton, 2002](#)). In this case, participants spoke a lot about themselves, aside from their experiences within the labor market and their social life. This resulted in an additional theme that was labeled; “personality and characteristics”.

## Results

The results are presented under the following major themes that emerged from the interviews: employment, social network and personality and characteristics. Supporting quotes from the participants are provided to represent different perspectives and to exemplify each theme.

### Employment

#### Being Valuable

At the time of the interview, 10 people had employment and 7 were unemployed. Participants who were employed felt pride and satisfaction from working. Relationships with co-workers were mainly described as valuable. Several said that it was important for them to contribute to and to feel needed in society. All participants stated explicitly that they wanted to be like “everyone else” and to have the right and ability to support oneself:

“I’m happy at my job! I know that I’m needed here and that I can accomplish things ... it’s fun being somewhere where things happen ... ah where you see that you’re doing something useful”(4).

The participants wished to perform something they had competence in doing or felt good at:

“Yes, it’s probably because I have a job that I can do, I’m good at my job. And we have nice colleagues, it’s a good (working) environment. It’s okay if you make a mistake. Ah, in other words, it’s a really good job”(12).

Most participants were working within the field of computers but held different views of what impact the disability had had in choosing their field of interest:

“That I’m interested in computers is only because I saw this as a possible occupation for me. I wasn’t a computer nerd to start out with, I’ve become one. But it is also my biggest interest”(3).

“It’s a meaningful interest that I didn’t choose because of my handicap. Sure, it’s very easy to sit in front of a computer with my kind of handicap. But for me ... this was a passion, which I would have had even without my handicap. I’m convinced of that”(4).

Several participants explained that they had been encouraged by their parents or by someone from school to develop computer skills. This was often said to be an appropriate interest for someone with a physical disability:

“Yes, I realized that I can’t manage a job where you have to move around a lot. What I need to do is to sit still in a chair and write”(12).

### Being Unemployed

The unemployed participants were not content with their situation and the most common reason for this was that they wanted to make a contribution to society and they found this difficult as people who were unemployed. Several participants also felt bored on a daily basis and in some cases merely observers of society:

“I was there for five years, until I couldn’t stay any longer ... and I was probably going to get a permanent position but then they realized that they couldn’t afford to have me there. It was something about their funding... it was the best work I’ve ever had... otherwise I’ve mostly been unemployed”(9).

Several participants said they had lost their position because of economic circumstances at their workplace and the procedure of being dismissed was described as irregular or even illegal in some cases. A shared experience was being fired from a job that they liked, without an opportunity to get a reallocation and with difficulty in finding a new job:

“I became redundant, as they call it... But can you reallocate me? I asked. To another department or something... but that wasn't possible. There was no position! So I had to go! And they thought that I should go into early retirement. And that was all there was for me. But I'm only 37! So that was really sad for me”(13).

Participants articulated sadness at the loss of employment and a growing emptiness in their new life. How they would spend their days was not predictable anymore:

“When I had a job I felt meaningful because, like, I came there every day. And knew what I would do. And there wasn't any uncertainty, like I think now; ‘what should I do today?’ I was active in a completely different way and everything was easier”(9).

Several of the job-seekers assumed that employers would focus on their limitations and difficulties and that this would affect their employability negatively. The participants reported that a general negative attitude among employers came out of ignorance and thought that the employers were not used to dealing with people with disabilities. One factor for employers to avoid hiring someone with disabilities was thought to be a fear of increased expenses:

“I can't like... go into a shop and look for a job like normal people... because they would see right away that... ‘he's handicapped!’ And then I'm not even considered. It's too expensive for them to have me”(2).

It was common for the unemployed to be aware of how others would react to their appearance. Being educated beyond high school and having contacts on the labor market were seen as important factors for getting an attractive job despite their disability:

“My dream was to come out into the regular labour market, but it doesn't work the way things are today... or it would work, with the right kind of help...if they're open and want to put effort into having me there, but the truth is that this can be very difficult”(1).

Out of the participants who had a job, all except one had education beyond high school, i.e. the Swedish equivalent of upper secondary school. Participants without education beyond high school said they would like a higher level of education, if that would give them better opportunities for getting a job.

## Social Life

Participation in society was described as being part of a social context in which you are valued in a positive way. Having social support and sustainable relationships were considered key elements for a wider experience of participation. Examples of how participants defined the meaning of participation:

“This is when you are around people, who want you there ... when you feel welcomed. I am wanted here (at work), I am needed at home and with my friends”(7).

“That is when someone asks for my opinion ...and wants me to be involved in something that we share”(3).

The presence or absence of relationships affected how participants spoke of their experienced level of participation.

### Characteristics of Social Life

Almost all participants claimed to have fewer social relations compared to what they had had during childhood and adolescence. The former period was often filled with leisure activities, along with which came acquaintances and friends. In this sense, participants experienced a growing emptiness when they reached adulthood and were no longer a part of a compulsory activity schedule.

A majority of the participants met regularly with their family and a few close friends. It was also common for the participants to describe their personal assistant as a close friend. Some participants wanted more friends and others felt content with a small social life. Most of the participants socialized with friends in someone's home, by making dinner together, or watching TV.

### Getting Out and Meeting New People

Several participants expressed difficulty in finding contexts where they could form new relationships. It was also hard to find the courage to participate in social activities. In addition, a few said that they were dependent on personal assistants to mediate social relationships and some feared that stereotypical assumptions about disabilities could get in the way of forming new relationships. Three participants said they had difficulties talking to new people in general:

“I'm a loner, so there isn't too much of seeing other people. But sometimes I want to meet and talk with other people, even though it's hard to talk to them. I like that, exchanging thoughts. And hanging out with close friends”(1).

A lack of energy, shortage of money or too few hours with transportation services or a personal assistant were factors that the participants highlighted as barriers to participating socially as much as they wanted to. Two participants felt very isolated and considered their opportunities to get out and socialize to be strictly limited:

“If I’d had more (assistance) hours I would have lived like an ordinary 42-year-old...I wouldn’t think that the minutes are ticking away and I’ll probably have to go home now. You shouldn’t have to think like that...Being at home; it’s worse than a prison actually! In my opinion, everyone should have the right to go out and meet other people”(2).

### Social Media

For many participants, experiences of social interaction were not limited to social contacts face-to-face, but included communicating over social media. All participants had friends and other contacts online. A majority had found close and meaningful relationships this way. Being engaged in a social life online was considered to be a clever tool for making new friends. Two participants spoke about the advantage of not having to explain or deal with questions about their disability in the process of forming new friendships:

“I’ve met new people there (on Facebook) so it’s really fun...even if you haven’t met someone in person it feels like you’ve known each other for a long time...and I don’t always have to present myself as someone who is disabled, and that I don’t consider lying, it gives me an opportunity to withhold the truth when I want to focus on other aspects of myself...and I get in a really bad mood when the internet is down and I can’t speak to them”(13).

Others did not enjoy this form of social interaction:

“I like to speak to people that I can see and who are real. It’s so weird for me to be friends with someone I haven’t actually met in real life...I meet many, many people face-to-face every day at work and that means a lot to me”(12).

The employed participants tended to be more negative towards having social relationships online, whilst this type of social interaction was more common among the unemployed.

### Personality and Characteristics

Participants who considered themselves to be engaged in, and content with, their lives also communicated a positive view of themselves and of people around them. Certain characteristics that appeared in relation to these narratives were: a constant struggle to solve everyday problems, positive thinking in general, being tolerant in the case of failures and an ability to trust oneself and others:



“I’ve never seen myself as an outsider or a person who’s not welcomed. If I’ve felt that this doesn’t work, I never think that this isn’t for me... instead I try to find a solution so that I can participate... I believe that if you look happy and extrovert, and if other people can see that, you’ll be met in a positive way”(15).

“Yes, well, everyone can have an influence. It’s just that you have to try... I’ve never felt that I can’t do this or that, I’ve probably had just as much fun and dealt with about the same difficulties as everyone else”(16).

### Being Involved in Different Activities

Those who expressed a greater feeling of participation commonly expressed a feeling of being able to cope in everyday situations and an ability to enjoy most days in life. Several participants also used a strategy of putting a minimum focus on their disability and the pain that followed. To make that easier, participants got involved in different projects, such as work and leisure activities; for example swimming, floor hockey or family and friends. These activities had enabled them to feel engagement in their lives. A mental strength and an ability to find alternative solutions in difficult situations were also articulated in these narratives:

“I think that all people have obstacles, it doesn’t have to do with whether you sit in a wheelchair or not. I’ve always known that I can do things... for me it hasn’t been a question of whether I can do something or not. It’s about when I’ll do it!”(3).

### Feelings of Insecurity or Resignation

Some participants felt ambiguous about their social skills and their ability to participate in daily life. Several said they wanted to take part in an activity, for example: singing in a choir or attending swimming classes, but did not have the confidence or emotional strength to put this into action. An uncertainty about how they would be met by others stopped them from trying:

“by others stopped them from trying; And other days I can feel that I’m just a burden. Like last fall I just felt like a burden all the time ... it was hard for me even to go out and shop for milk. It was like everyone was watching me in a negative way”(13).

One participant said that her poor financial situation made her feel ashamed in social situations and sometimes like a second-class citizen, which in turn held her back from being socially active:

“Sometimes I notice that people don’t even want to look at me, and don’t talk to me. I feel that I’m probably an inconvenience for people. That other people see it like that. But it also has to do with my social situation... If I’d had nicer clothes and a nice car, people would take me more seriously”(9).

Several participants were conscious about the future, and their personal financial

situation was described as unpredictable. A tougher political climate in Sweden was brought up as a cause for worry:

“It’s harder now and you don’t know how it’s going to be in the future. And if I really face the truth, I don’t think that there are going to be any improvements in my case. I probably won’t ever get a job... I only hope that it won’t get worse”(14).

Some participants articulated that they had been overprotected or that they had missed support in general during childhood. Participants expressed how their upbringing had had an influence on their self-esteem:

“No, they (my parents) stopped me all the time, they never supported me in anything...and they’ve been very overprotective and they still are today. In fact, they didn’t want me to get a driver’s license, so they stopped me getting it. They told me that I could never do it. And in the end I believed them, and I cancelled my driving lessons”(13).

Participants who seemed more positive and confident participated to a greater extent than those who said they felt insecure. Therefore, the participant’s expressed attitudes towards themselves in relation to others, played a vital role for their level of participation.

## Discussion

To our knowledge this is the first study to explore experiences of social life and employment perceived by adults with SB and CP.

Participants described social and psychological consequences that they had experienced as a consequence of being unemployed for a long time. The results showed that the most important area of participation, according to the participants, was to have a job. Furthermore, participants who were content with their social relationships felt included and engaged in everyday life to a greater extent than those who had fewer friends or felt isolated. Access to a social life was thus important to achieve an experience of participation.

### Employment

Participants explained how they wanted to feel valuable and able to contribute to society. Some participants thought of having a job as the equivalent of being like anyone else, which had a high priority. This is similar to another study which argued that participants gave priority to being independent and contributing to society ([Yeung et al., 2008](#)).

In this study, participants who were unemployed did not have an education beyond high school, whereas a majority of those who were employed did. Michelsen et al. ([2005](#)) found that the most significant factor in achieving employment in their study was education beyond high school. In addition, several previous studies showed that the frequency of higher education beyond high school is lower in participants with CP or SB than for the average population ([Bjornson, Kobayashi, Zhou, & Walker, 2011](#); [Frisch & Msall, 2013](#)). This is

presented for both developed and developing countries ([Andersson & Mattsson, 2001](#); [Michelsen et al., 2005](#); [Tornbom, K., Tornbom, M., & Sunnerhagen, K. S., 2013](#)).

A number of the participants had been fired from a job. According to the participants, this was due to their employers' financial situation and discrimination against disabled people in general. These findings are similar to those described by Kaye and colleagues ([2011](#)), who found that people with disabilities thought that ignorance and increasing costs were the main reasons for employers not to employ or to keep an employee with disabilities. It is also shown that prejudices and discrimination against people with disabilities sometimes have an impact on the labor market ([Chacala, McCormack, Collins, & Beagan, 2014](#); [Verhoef, Bramsen, Miedema, Stam, & Roebroek, 2014](#)). Previous studies have found that (part-time) paid work is one of the three most frequently identified problems among young adults with CP and that they consider problems with work to be very important ([Livingston, Stewart, Rosenbaum, & Russell, 2011](#); [Nieuwenhuijsen, Donkervoort, Nieuwstraten, Stam, & Roebroek, 2009](#); [Verhoef, Bramsen, Miedema, Stam, & Roebroek, 2014](#)). The Central Bureau of Statistics in Sweden states in a report that the possibilities of gaining employment after many years away from the labor market, and having a disability, are relatively low in Sweden (Central Bureau of Statistics, 2016).

The right for people with CP and SB to have and retain employment is of great value for their feelings of participation in society ([Cope et al., 2013](#); [Tornbom, Jonsson, & Sunnerhagen, 2014](#)). However, this is not so much a question of the moral standards of citizens and politicians in general, as it is about what each employer considers profitable for business. Employers that are frightened of increasing costs or other problems are more likely to employ someone without a known disability ([Kaye et al., 2011](#)). Nevertheless, the way employers interpret the value of hiring someone with a disability is highly dependent on laws and general attitudes and prejudices about people with disabilities that exist in society ([Barnes & Mercer, 2005](#); [Shakespeare, 2013](#)).

### **Social Life**

According to the narratives of this study, a great majority of the participants had a small circle of friends and acquaintances, while some felt isolated or alone. These findings are similar to those of Jonsson and colleagues ([2008](#)) concerning adults with CP and their social life. Having a very small number of friends or not being part of a context in which you can form new relationships might result in feelings of isolation. Previous research has also shown that strong social support networks and community ties help people with disabilities to reduce negative stress and enhance their self-esteem ([Tornbom, Tornbom, & Sunnerhagen, 2013](#)).

Participants who said to be content with their social relationships felt included and engaged in everyday life to a greater extent than those who had few friends or felt isolated. These findings are confirmed by Yeung et al. ([2008](#)) who found that meaningful, social relationships increased feelings of inclusion and participation, while isolation and loneliness led to the opposite. For this reason, a person needs to be appreciated and accepted by others in

order to fully participate in society ([Livingston et al., 2011](#)).

A previous study concerning young adults with CP and social participation has identified different supports that helped the participants in becoming more socially active ([Stewart et al., 2012](#)). Highly valued characteristics in this study were having social skills and a social personality. Additionally, the authors argued that these qualities might not be developed enough among participants who spent a lot of time by themselves ([Stewart et al., 2012](#)). Insufficient social skills, as a cause of loneliness, might therefore discourage people with CP and SB from taking initiative to create new relationships ([Sawin & Bellin, 2010](#); [Shakespeare, 2013](#)).

#### Having a Few, But Important, Relationships

Half of the participants said they had a few close and meaningful relationships, although they did not see themselves as active members of society. A previous study about loneliness and friendship showed that some participants with CP explained that their current living situation did not support the development of friendships. Participants said they did not participate in social contexts where they could find new relationships ([Ballin & Balandin, 2007](#)). Yeung et al. ([2008](#)) pointed out another aspect of the social life among persons with CP. In order to participate in society, it is important to have the abilities and opportunities to form relationships on your own, without being dependent on, or getting too much help from someone else i.e. a personal assistant. In addition, only associating with a few assistants and your immediate family can result in a way of living in which a person feels comfortable in these contexts, although not participating in public spheres in society ([Yeung et al., 2008](#)).

#### Having a Social Life Online

In this study, being engaged in a social life online was considered a clever tool in creating new friendships and this form of socialization was mostly performed by the unemployed participants. These participants reportedly appreciated that they could be anonymous in social interactions online. Being able to avoid or not having to explain, or expose one's disability was seen as liberation by some participants.

#### Personality and Characteristics

According to several studies, the severity of a disability is not a predictor for the perceived level of participation or quality of life ([Albrecht & Devlieger, 1999](#); [van der Slot et al., 2010](#)). Nor did this study show a correlation between the extent of the disability and the experienced level of participation. However, we did find a correlation between the level of participation and personal characteristics that are presented in the results.

Van der Slot et al. ([2010](#)) showed that self-esteem can correlate with participation. The authors showed that a higher level of self-esteem was associated with enhanced participation among young adults with a disability, including young adults with CP. Our results indicate a similar phenomenon. Even though we did not measure the participants' level of self-esteem, we did notice that the participants who spoke more about their abilities and competencies also

perceived a higher level of participation in their own lives. Our study also showed that participants who carried out and took pleasure in their current roles and were intellectually aware of their achievements, in comparison to what they could expect from their physical functions, experienced participation to a higher extent than those who found this more difficult.

Sorenson ([2007](#)) has investigated different variables associated to the nature of social experiences among persons with disabilities, such as; self-esteem and activity participation, which had a positive correlation to social participation. Additionally, according to Abraham et al. ([2002](#)) community participation appears to be related to a higher self-esteem in adults, or older participants, and it seems that participation also enhanced self-esteem in this group. These findings strengthen the line of argument that personality plays a vital role, when it comes to the experience of participation.

## Conclusions

Participation in society was, by the participants, described as being part of a social context in which you are valued in a positive way. Having social support and sustainable relationships were considered key elements for a wider experience of participation. Furthermore, employment was important for the participants in this study to feel as though they were participating in society. Several participants described being fired from a job in an unusual way, without the possibility of reallocation or reemployment elsewhere. How the participants felt about themselves in relation to others also played a vital role for their experience of participation.

According to the Swedish government, the main goal is to create a social community based on diversity; a society designed to allow disabled people of all ages full participation in society. The foundation of the Swedish disability policy is that all people have equal value and equal rights ([Lundalv, Larsson, Tornbom, & Sunnerhagen, 2012](#)). However, it is important to keep in mind that equality not only stands for formal rights. It also means having equal opportunities in taking on various societal roles such as; employee, friend, student or member of an association. To reach these goals, society must take action and work against ignorance, negative attitudes and values on different levels ([Yeung et al., 2008](#)).

## Limitations

A number of the participants in this study were members of a disability organization or politically active, which may lead to them being not entirely representative of the wider CP or SB population, as they were likely more able to communicate their opinions effectively. As researchers in the field of social work and rehabilitation, we may have brought our own professional perspectives to the research process. We recognize our subjectivity as inevitable and acknowledge that it might have influenced the way in which we conducted this study.

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**Karin Törnbom:** PhD student within the field of disability studies. My thesis is about people with disabilities and their experienced participation in society. I have used qualitative and quantitative research to study persons with cerebral palsy, Spina Bifida and stroke, with respect to integration and participation in society.

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