

## Everyday challenges for mothers with Spinal Cord Injury: a qualitative study

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The aim of this study was to explore how women with traumatic spinal cord injury (SCI) manage their daily lives after becoming mothers and if they experienced barriers in society. Five women were interviewed, aged 25–40 years, who had incurred a traumatic SCI two to twenty years previous to their first child being born. All the participants expressed a wish to carry out infant care tasks and to take part in their children's activities. The participants used welfare arrangements to manage certain tasks. They faced challenges in the form of physical barriers in their surroundings, as well as various degrees of struggle related to social services. Statements from five Norwegian women with SCI point to unique practical and emotional experiences of becoming mothers. Their reports also elucidate the lack of knowledge among professionals related to motherhood and SCI.

**Keywords:** Spinal Cord Injury; mothers with SCI; mothers with disability; mothering

### Introduction

The prevalence of women with traumatic spinal cord injury (SCI) has been far below that of men who incur SCI, i.e. 20–25% of the total SCI population. Consequently, the knowledge of the consequences of SCI, gained through clinical experience and research, has principally involved men. However, recent research indicates that the number of women with SCI is increasing (Wyndaele and Wyndaele 2006).

SCI causes sensory and motor disturbances below the lesion level. The level and the extent of the spinal cord lesion correspond to the neurological consequences of the SCI, i.e. paralysis in the lower limbs (paraplegia) or in all four extremities (tetraplegia) (Bromley 1998).

Since a relatively high proportion of those who incur SCI are young, familiarisation seems to be a relevant topic. Limited research exists on parents with disabilities including SCI, and on mothers in particular (Sørheim 1998; Grue and Lærum 2002; Alexander, Hwang, and Sipski 2002; Olsen and Clarke 2003).

During pregnancy and as parents, women with SCI have unique experiences and challenges such as the need for practical arrangements and limitations related to participation. In Norway, the cultural expectations of mothering include playing with the child at the playground, and participation in various activities in kindergarten and at school. The environmental design influences the opportunity

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to participate in these activities. In everyday life, a mother with SCI may need assistance from service providers to manage tasks such as childcare, transportation, looking after a toddler who is playing outside the house, for housekeeping and so on. As the child ages, their demands change, and the mothers' need for support and technical aids is likely to become different (Rogers, Tuleja, and Vensand 2004). These are examples indicating that mothers with SCI often need to depend on several people who provide public services.

Being a parent is usually seen as valuable and as having profound personal meaning (Farber 2000). However, research claims that society does not necessarily expect women with disabilities to become or to be mothers (Sørheim 1998; Grue and Lærum 2002; Olsen and Clarke 2003). Pregnant women with disabilities risk other people, including health professionals, disapproving of or questioning their ability to care for a child. Even though parents with disabilities need support in the same way as other parents, such as 'adequate income, secure and accessible housing, a network of informal support, access to leisure facilities among other things,' these sources of support are harder to access because of 'inaccessible environments and negative attitudes' (Olsen and Clarke 2003, 37). Maternity wards have been found to be inaccessible for those who use wheelchairs, and the ward staffs often lack knowledge about mothers with disabilities (Lærum and Grue 2003).

Why is this the case? One explanation, which often appears in the literature, is that society leans on attitudes based on a medical view of people with disabilities; i.e. as patients and therefore passive recipients of care, rather than caregivers (Thomas 1997; Grue and Lærum 2002; Olsen and Clarke 2003). Dated literature on parents with disabilities focused on deficits rather than coping skills, and concluded that children were negatively affected by their parents' disability. Today, these studies are regarded as problematic because of their methodologies (Farber 2000). However, during the last 10–20 years, research results have been positive with regard to how people with disabilities handle their parental responsibilities. Westgren and Levi (1994) conducted a quantitative study that included 26 Swedish mothers who had given birth after a SCI. The purpose was, among others, to evaluate parental ability and the quality of family life. The results showed no reason to question the women's ability to be competent mothers, and the participants and their families seemed to be well integrated in the community. A study by Rintala, Herson, and Hudler-Hull (2000) compared parenting styles and concerns between parents with and without SCI. The results supported the findings by Westgren and Levi. Alexander, Hwang, and Sipski (2001, 2002) concluded that mothers with SCI or other physical impairments did not have a negative impact on their children's development.

The mentioned studies have mainly discussed the social and psychosocial aspects of mothering with a SCI or other physical disabilities. However, they do not address the practical challenges of having physical limitations when raising children. Rogers, Tuleja, and Vensand (2004) stress the importance of early intervention from health professionals to carry out infant care tasks with the mother in order to help her gain confidence in her own skills and conserve energy by using proper equipment and techniques. Practical advice can be found on the Internet; 'Through the looking glass', [www.lookingglass.org](http://www.lookingglass.org) and <http://www.dppi.org.uk/>.

Mothers with disabilities may experience limitations with participation. It is also likely that cultural, social and personal expectations as well as environmental factors influence their performance in raising children. Mothers with SCI relate to their surroundings and public services in order to fulfil their tasks as mothers. In doing so,

they might face negative attitudes and physical barriers. Models of disability can enable us to understand why these challenges occur and how they can be faced. Thus, a relational understanding of disability was chosen, and will be described below.

### *The relational model of disability*

*The traditional medical model of disability* takes an individual perspective based on diagnoses and considers the impairment as the main cause for a person's problems in society. In contrast, *the social model of disability* distinguishes between impairment and disability, and draws attention to physical and attitudinal barriers in society as the real hindrance to participation, not the person's impairment (Söder 2009). Thus, to increase participation by persons with disabilities, reducing barriers in society rather than making individual adjustments is emphasized (Barnes, Mercer, and Shakespeare 1999). According to Tøssebro (2010) and Gustavsson, Tøssebro, and Traustadottir (2005), the Nordic approach to the social model is often referred to as a relational understanding of disability. The Norwegian government draws on a *relational model* in order to achieve a more accessible society for all citizens. White Paper No. 40 (Norwegian Government, Det kongelige Sosialdepartement, 2003) defines disability as a gap between a person's functional ability (due to impairment) and the demands of the physical and social environment. This gap is not static, but changes during life and with the undertaking of new roles.

The Norwegian welfare system aims at providing basic needs, individual adjustments and economic support to persons with disabilities to ensure inclusion and participation. Necessary technical aids, transportation, home nursing and personal assistance are subsidized in order to help the individual live as independently as possible. There are also general arrangements in order to support citizens during particular periods of life such as parental benefits at birth, loans and grants for students, sickness allowances and unemployment benefits. Parental leave at birth is linked to the mother's employment status with 100% payment of salary for 47 weeks or 80% of salary for 57 weeks.<sup>1</sup> The Anti-discrimination and Accessibility Act (2009) focuses on the universal design of the environment in order to ensure participation in society. However, public services officers often lack expertise about the laws and regulations (Norwegian Government, Det kongelige Sosialdepartement, 2003). Grut, Kvam, and Lippestad (2009) underline the idea that persons who need public services are better off if they are knowledgeable about these systems and can claim their rights.

According to Christensen (2009), services must be flexible and accessible when required. Norwegian organizations for disabled people argue that user-controlled personal assistance (Personal Assistance Services-PAS) is the best way to gain independence and control in one's life (Fleiner 2010). PAS was implemented as a social service in 2005 (Christensen 2009), and it is often recommended to persons with SCI who need help in daily activities or want to return to school or work. It can also be used if they need assistance to take part in social activities. However, even though municipalities are obliged to offer PAS, they may offer traditional nursing and domestic help services instead. The individual may, therefore, have to argue why PAS is appropriate to fill his or her needs.

It is apparent from clinical experience in meetings with women with SCI that they have questions related to motherhood. The literature on the subject seemed to be limited, and there was a need to gain more knowledge on mothering with SCI. The

purpose of the present study was to explore how women with SCI manage their daily lives after becoming mothers.<sup>2</sup> Furthermore, the Norwegian Directory of Health requested information on the experience of barriers among people with disabilities. This article will communicate the everyday challenges as reported by five Norwegian mothers with SCI.

## **Materials and methods**

### ***Participants***

Five women participated in the study. They were known from initial rehabilitation and follow-up at a SCI rehabilitation hospital and were recruited using a request mailed to them at their home. They all accepted the request. One important criterion for participation in the study was the experience of living with SCI previous to motherhood. To protect the participants' privacy, only a minimum of demographic data and little detail about the women's impairments are presented.

The participants were ethnic Norwegians with similar socio-economic middle-class backgrounds and lived in municipalities in the eastern (central) part of the country. They were between 25–40 years old and had one or two children aged 18 months to nine years at the time of the interviews. Their employment status varied from full-time job to full disability benefits. Four of the women lived with their children's father, and the families owned the house or apartment they lived in.

The participants had SCI due to injuries. They had upper- and lower extremity paralyses or lower extremity paralyses. Their daily activities were influenced by the use of a wheelchair, poor walking ability and/or reduced strength in arms and hands. Four participants were assisted in personal care, infant care tasks or household activities. They had lived with SCI for two to twenty years before their first child was born.

### ***The research interview***

A semi-structured interview was chosen. The qualitative approach provides opportunities to gain knowledge about a field that has not been previously investigated very thoroughly, thus contributing to a new understanding and also probably revealing a need for further research (Malterud 2003). An interview guide was developed containing demographic information about the participants and with a few headlines like 'The prospect of having children after the accident' and 'How is it to be a mother'. Furthermore, the questions were open ended such as: 'Tell me about everyday life: what you do with the child, and what kind of assistance or help you need.' The participants were asked about what they regarded as important in order to take care of children. They were also asked how family, friends and other people reacted when they told them they were pregnant. Five women participated and each woman was interviewed independently for about an hour and on one sole occasion. The interviews started with a clarification of the study's purpose and the participants' rights. With the women's permission, the interviews were tape recorded. The author conducted the transcriptions.

### ***Data analysis***

The material was analysed with an interactionist perspective taking into account the fact that human beings create identity and meaning through interaction with others.

In this approach, empiric material from an interview cannot be viewed as objective fact because the meaning is embedded in cultural and social definitions. The interviewer's profession and background and the interviewee's expectations and position will influence both the questions and the answers (Järvinen and Mik-Meyer 2005). The author, who is an occupational therapist, interviewed the participants. Their experiences with that profession were related to daily activities and technical aids, which were the first themes that came to their mind in the interviews.

The eclectic form of generating meaning described by Kvale (2002) was used to systematize the material. The interviews were read to get an overall impression and then re-read. The main themes from each interview were put into tables and given headlines such as 'assistance,' 'challenges,' 'technical aids,' 'aspects of pregnancy,' 'attitudes of others,' etc. The next step was to find patterns within the categories. The desire for participation in their children's activities was designated as the main category, and this overarching category was divided into themes that influenced the mother's capability to participate: 1) *preparation and arrangements for infant care*; 2) *employment status and disability benefit*; 3) *access to flexible and appropriate assistance services* and 4) *universal design of public areas*.

### ***Ethical considerations***

The number of women who have given birth after SCI in Norway is small. The Privacy and Data Protection Office, Oslo University Hospital granted permission to send a request to five women known from one rehabilitation hospital. In order to maintain participant anonymity, information is presented carefully regarding details of the individual impairments and daily functioning. The Regional Ethics Committee of South-East Norway and the Privacy and Data Protection Office of Oslo University Hospital approved the study.

### **Results**

Persons with SCI may have various degrees of impairments, and, as such, a potentially wide range of everyday challenges. Therefore, two cases were drawn from the empiric material to illustrate different life situations: difficulties that may occur and how problems can be solved. Central topics will then be addressed for further reflection and discussion.

### ***Anne***

Anne is a 33-year-old married woman with a three-year old son. She sustained a SCI from an accidental fall when she was a teenager, and the injury caused paralysis in both upper and lower extremities (tetraplegia). She needs help in personal care including toileting, dressing and transferring from the bed to the wheelchair. She has used different services from the municipalities and today she receives help from a personal assistant. She propels a manual wheelchair in the house, but uses a robust electric wheelchair on shorter distances outdoors. Anne also has a car, which her husband or the assistant drives. She receives disability benefits. The following quotation describes the prospects of having children:

I always wanted to have children. Early after the accident, I asked if having my own children still would be possible. I got a positive answer. It took some years until I met my husband. At that time we were both ready to start a family.

Since Anne needed help with infant care, the authorities allowed her husband to go on parental leave the first year after their son was born. He did the practical infant care tasks while Anne interacted with the baby through eye contact and talking. She was handed the baby for feeding, playing and comforting. When her husband returned to work, the assistant took over some of the childcare, but Anne decided what tasks were to be done. As the child grew older and became more self-reliant, tasks were easier for Anne to perform herself:

Now it is so much easier. We are going out on our own and do things together. And it seems that he understands that he must behave differently with me than with his father.

The child started in kindergarten when he was three years old. Anne brought him there with the electrical wheelchair herself. She still preferred to have a person with her when she was shopping or going places where she felt it was hard to keep the child safe.

### ***Kate***

Kate is 35 years old, married and has two daughters, aged 18 months and five years. At the age of 20, she was involved in a car accident causing paralysis from the waist down (paraplegia) because of a spinal cord lesion. During initial rehabilitation she gained a high level of independence, managing all daily activities. For mobility, she mainly uses a manual wheelchair, but she has an electric wheelchair for longer outdoor distances. She drives an adapted car. Kate likes to be outdoors and has some adapted sports equipment. She used to work full time until she became a mother, and she then stayed home the first year with the advantage of parental benefits. During her first pregnancy she contacted the SCI rehabilitation hospital and started planning for the baby's birth. The occupational therapist helped her with applications for adaptive infant care equipment, a change of car and PAS.

It is important to get the adapted equipment in time. We got a special baby crib that was too big and that made me afraid that we wouldn't have another crib on time. But that was sorted out.

The basic infant care equipment was delivered before the baby was born, but she had to wait for the new car. Her application for PAS was denied. Her husband stayed with her at the maternity ward and took care of the baby there, and he also spent the first few weeks at home with her. She learnt to manage infant care tasks, but she still needed help to get the baby in and out of the car or take the pram out. The wheelchair did not function with the adapted baby seat. Kate also needed some help with housekeeping since her self-care, in addition to the infant care, demanded a great deal of time and effort. After a time consuming process she was allocated PAS.

After a year, Kate returned to her fulltime job and her daughter attended kindergarten. She thought she did not need an assistant any longer. After a few months she realized that the situation of having a SCI, being a mother and

having a full-time job was too exhausting. She applied for disability benefits in combination with part time work. This arrangement turned out to be manageable and satisfying:

I have more time to spend now; I used to get home from work at 5.30 pm. Then we had dinner and our son was put to bed. I don't have to prove that I can manage everything, working full-time, children and all . . .

When the first child became more active and the second child was born, Kate realised that she needed a new assistant and she also had to find smarter ways of doing things.

Several topics that arose in the interviews are illustrated through the cases of Anne and Kate. All the mothers in the study mentioned a desire to participate in infant care tasks and in their children's activities. Four issues that influenced their ability to participate are presented below:

- *preparation and arrangements for infant care;*
- *employment status and disability benefits;*
- *access to flexible and appropriate assistance services;*
- *universal design of public areas.*

#### ***Preparation and arrangements for infant care***

The study participants said that the regular birth preparation courses did not seem relevant to them, stating, '*It's different with us*', or that they were not invited to join such courses at all. After delivery, these mothers stayed in the maternity ward from one to several weeks due to complications. They were asked about their hospitalization experiences and they addressed problems such as appropriate access to showers, toilets and access to adapted/suitable infant care equipment. The main issue seemed to be a lack of guidance in infant care tasks from the staff at the maternity ward. Since the mothers lacked experience with infant care, they expected the ward staff to help them to find practical solutions. Instead of guiding the mothers in infant care, the staff often performed the tasks themselves or focused on teaching the father. The following story underlines the importance of enabling the mothers:

I spent a lot of energy during pregnancy wondering how I would manage. Would I only be a voice to the child while other people cared for her? After our daughter was born they (the nurses) were teaching my husband about infant care, but one day a nurse came in and asked if I wanted to try to change the diaper. She found a suitable table. When I managed to change the diaper I was so relieved and happy! I didn't dare to ask, you know – I was so afraid I would not manage.

The statement illustrates the mother's vulnerability and her low expectations of her capability, but also her relief when she was met by the nurse's supportive approach. The nurse sensed the post-natal woman's insecurity, and helped her to find effective techniques and useful equipment. This increased the mother's confidence in her own skills. Another quotation elucidates the woman's frustration over being helped instead of enabled:

They (the nurses) were not coming home with me. I needed them to help me practise in order to manage on my own—not that they helped by doing everything.

Mothers with SCI or other disabilities are used to finding problem-solving strategies to overcome difficulties in their daily lives. One participant said:

We have met a lot of challenges from the day we entered into this situation (sustaining SCI). However, this is a good challenge, a positive challenge.

She referred to hard training during initial rehabilitation and the use of compensatory techniques in daily life activities to cope with SCI. Becoming a mother added new challenges, which she found mostly positive. She also said; *'You can't read about it in a book; we have to find our own ways of doing infant care tasks.'* This statement indicates why these mothers did not ask for help. It seems as if they had an understanding that they would have to cope on their own, because they had no references or sources of comparison. Also, in the interviews, the mothers revealed their fear of being regarded as inadequate. One participant reported that during pregnancy she was anxious that child welfare would come for a home visit after the baby was born to see if she managed childcare properly. Another said that she knew a woman with a lesser degree of impairment than herself who was denied adoption: *'Is that how society looks upon us? As if we are not good enough to be mothers?'* A third participant described how she tried to be a perfect housewife in order to dispel potential doubts regarding her competence. However, all the interviewed mothers expressed that today they feel confident about managing parenting as well as everybody else. And, just as other parents, they were more confident with the second child.

### ***Employment status and disability benefit***

All of the participants wished to work, and three of them were able to do so. Mothers with SCI are likely to spend more time and effort doing practical activities than able-bodied mothers. Thus, two participants considered part-time work to be the best solution:

When I went back to work, I worked full time. After six months I was exhausted and received sickness benefits for a while before I applied for sharing work with disability benefits. Now, I work part time, 50%, and feel much better and less tired.

The opportunity to share employment with disability benefits made their lives more manageable. Part-time work also provided them with the privilege of staying in touch with their children more closely:

I pick him up from school even though I don't have to, and it seems as his friends also find it nice to talk to me and I enjoy spending some time with them.

One participant, however, had worked full time since her child was two years old and found that satisfactory.

The parents' ability to receive parental benefits at birth are linked to the mother's employment status. Two participants, who had disability benefits, transferred the parental birth benefits to their spouse so both parents could be home during the first year. One father received wages from the municipalities for a year since neither

parent had the right to parental benefits. One participant worked full time until her child was born and then received parental leave for a year.

### *Access to flexible and appropriate assistance services*

In addition to time consuming routine infant care, mothers with SCI must attend to their own complex personal care and daily activities. They have to plan and prioritize most carefully to avoid burnout. The participants and their spouses had taken advantage of different opportunities offered by the parental birth benefits. One participant described how she chose otherwise with the second child:

It was very convenient that my husband stayed at home with the first child and me, since I was insecure and didn't know how to manage on my own. It also gave me the opportunity to finish my studies. With the second child I had learnt from experience, and we had found some practical solutions at home. Then it was important for me to prove that I could manage by myself. But I had a personal assistant a few hours in the middle of the day for the first year. After that our daughter attended kindergarten.

She felt confident that she could manage infant care, and she also realised that she needed an assistant some of the time. As the child ages and becomes more active, keeping a toddler safe can be a challenge for a mother with SCI:

He is a toddler now and very active, and I don't dare to take him out of the house alone. My husband works a lot at the moment, so my parents are often here on weekends. Then I have someone to look after him when we go out.

This woman expressed that she was primarily on the terrace or in the house when she was alone with her son. She got valuable support from her parents in order to take him out. Other strategies were to have a fence around the garden or to rely on a personal assistant, neighbours or friends outdoors.

Personal assistants were used on a short or long term basis. The following section will focus on why four of the participants considered PAS appropriate. Attention is also given to their experiences with how local authorities sometimes consider an application for PAS.

One woman received help from PAS for a few hours during weekdays for the year she spent at home with the youngest child. The assistant did practical tasks, while the mother spent the time and effort on infant care. One woman used several hours of PAS every week for housekeeping. Those participants did not report problems with being allocated the hours of assistance they needed. The other two told of long processes being necessary to get consent for PAS. One of them needed permanent help with personal care and housekeeping after sustaining a SCI and said:

The first one and a half year after the accident I had nursing services. About 30 different people helped me during one week. Then I made an arrangement with fewer people before I got PAS. But after some time the local authorities decided that they wanted me to have nursing services again and I struggled for a year before I got PAS back.

The flexibility with PAS also ensured help with the infant care tasks that she could not do herself. The fourth participant had not used PAS or other services from the municipality before. Since she would have parental leave and be at home alone with the child during the day, she thought carefully through the difficulties to come.

She applied for an assistant who could help her take the baby out in the pram or in the car, shopping, housekeeping or babysitting when she was in the bathroom or had physiotherapy. The local authorities refused her application:

The child was born in October and I got an assistant in April. First they (the local authorities) wanted me to wait until the baby was born, then they refused my application twice and gave me some sort of a contact person. Later on I received a positive answer from the County Governor and was allocated all the hours of PAS I had applied for when I was pregnant.

The local authorities had argued that she could wait to take a shower, shop and exercise until her husband came home from work. They did not recognise that since she was unable to take the baby out, she would be isolated at home. She said she felt as if *'my life was put on hold'*. Another participant described the difference from other mothers: *'I feel that the main difference is that I cannot just take the baby and go out; I always have to plan and have someone with me'*.

### ***Universal design of public areas***

Many public buildings in Norway, including kindergarten, schools and sport halls are not accessible for people with physical limitations.

Norwegian children often begin kindergarten at the age of one when the parental birth benefits stop and the parent goes back to work. Parents bring and pick up the children. They are also expected to meet their children's teacher(s) and join different activities during the year.

All the participants expressed the importance of taking part in their children's activities: *'I join his activities. Even though I can't play football I can be there to encourage him,'* or *'It was important to bring and pick her up in the kindergarten myself.'* Four out of the five mothers in the study had experiences of having children in kindergarten. One of them had chosen an outdoor kindergarten, because she wanted to give her child the opportunity to join outdoor activities that she herself could not take part in. She was satisfied with the help she received from the staff or other parents when she attended activities. The fifth woman's son was about to begin kindergarten in a few weeks and she reported that she sought out possibilities and took action to ensure access to the kindergarten:

There are several kindergartens in the neighbourhood. I added in the application that I use an electric wheelchair and that I need access to the kindergarten, because I am the one to bring him there in the morning and pick him up in the afternoon. And he is starting in a brand new kindergarten nearby, so that will not be a problem.

While parents can choose kindergartens by the activities or facilities they offer, the community area determines schools. Children may therefore attend a school with physical barriers that make them inaccessible for a parent with disabilities. One participant mentioned that sport arenas were difficult to attend with the wheelchair. Her children played handball and volleyball, and matches were played all over the county. Recently, she had to search for a backdoor and find someone to let her into a brand new sports hall. She said that she was tired of making compromises; she wanted to enter through the main doors like everybody else.

## **Discussion**

In this qualitative study, five women with SCI described their experiences with preparing for motherhood and being mothers of young children. In the following section the results will be discussed in order to get a better understanding of why difficulties might occur.

The results of the current study show that during pregnancy, the participants were worried about their own capability to perform infant care tasks. They considered general birth preparation courses to be of little relevance in their cases. This points to a need for an individual approach from midwives and other health professionals in the municipality in the case of pregnant women with SCI. Experiences from the maternity ward were both positive and negative, and seemed to depend on the personal characteristics of individual health professionals. According to Rogers, Tuleja, and Vensand (2004), a professional 'can-do attitude' and early intervention are essential to strengthen the mother's confidence and involvement in infant care. Intervention includes assessing the mother's motor function related to the coming tasks, suggesting and training relevant techniques, applying for adapted infant care equipment and suggesting appropriate physical training.

The participants brought forward thoughts about mothering ability that can be based in societal attitudes towards people with disabilities. As discussed by Grue and Lærum (2002), these attitudes can be interpreted as regarding women with SCI or other disabilities as incompetent mothers, especially if they ask for help. However, these thoughts were obviously most prevalent among the study participants in the early phase of motherhood. From their statements, it seems as if personal progress took place over time, and at the time of the study, they seemed to be confident about motherhood and to regard themselves as 'normal' mothers. Corresponding results are seen in other studies of women with SCI (Westgren and Levi 1994; Alexander, Hwang, and Sipski 2001, 2002; Farber 2000). Holum (2007) points to mothering activity as complex and with continuous adaptation to the child's needs. Time and experience make the mother confident and in this personal process, mothers with SCI seem to be similar to other mothers.

This study gives examples of the advantages of the Norwegian welfare system and how five women with SCI used its possibilities in order to take care of their families. Representatives from the municipalities and the Norwegian Labour and Welfare Services play important roles with helping to find the best solutions to meet the individual's needs. The gap between the study participants' physical ability to care for their children, the cultural demands and these mothers' wish to participate in their children's activities, were reduced by a combination of benefits, PAS and adapted aids. The participants also valued employment, and the potential for adequate income and housing should not be disparaged as they are essential elements to family functioning (Olsen and Clarke 2003). Education is important in order to obtain employment, and studies can be made possible by providing personal assistance and economic support to mothers with SCI.

The statements from the studied women portray parents with disabilities as a group who need flexible assistance services. Their comments elucidate PAS as an appropriate way of organizing these services. Assistance services are often related to residential and self-care activities such as washing, dressing, eating, housekeeping, etc. (Christensen 2009). Thus, the need that SCI mothers have for practical assistance to take care of their responsibilities as mothers can be ignored. Representatives in the municipality who deal with applications for assistance services relate to laws and

regulations, but are also given autonomy when considering the needs. Women with SCI, who previously managed without any assistance, may have difficulties with being approved to receive practical help with the baby. Families are expected to manage by themselves without interference from social services, and municipalities may be reluctant to offer services related to childcare when the child is healthy. Participants in the study stated that they had to fight to receive appropriate assistance services. This finding is well known in the literature (Grut, Kvam, and Lippestad 2009; St.meld.40 (2002–2003)). People with disabilities in general regard independence as the possibility of having assistance when required, and that the offered services should contribute to more control and choices (Christensen 2009). Four of the five participants in the present study emphasised the need for flexible assistance provided by the municipalities, in addition to informal support from family and friends in order to take care of young children.

The collected information points to public areas where universal design is essential for mothers with SCI. The participants in the study experienced lack of access to buildings and activities relating to their children. The requirements of universal design are a step towards easier access to activities in kindergarten, schools and other arenas. Owners of public buildings are obliged to comply with The Anti-Discrimination and Accessibility Act. However, it will take a long time before, for example, all schools are accessible for all citizens.

### **Methodological considerations**

The small sample and the qualitative design of the present study limit the study with respect to generalization. The participants are to some extent homogenous and their experiences may not cover the experiences of parents from other ethnic or socio-economic backgrounds. Still, issues that these mothers have dealt with are important and interesting. Scandinavian women with SCI, and especially those who have become mothers, may recognize topics discussed by the study participants.

### **Conclusion**

In this qualitative study, five women with SCI confirm a variety of experiences of motherhood. They all needed time to adapt to the new situation to optimize daily life with their young children. Their experiences indicate a lack of knowledge among health professionals, both at the maternity ward at hospitals and in the community about the needs of mothers with SCI. The study brings forward insight into the situation of five mothers with SCI, and may serve as a reference for young women with SCI and their partners, health-care professionals, disability policy makers, and disability support professionals in general. Their experiences can probably also serve as relevant references for other women with physical impairments and their spouses.

There are topics related to parenting that this study did not include, for example medical issues in SCI and pregnancy. The participants in the study requested more research and information on pregnancy within the context of SCI. Future research should also include the perspective from fathers with disabilities and how family roles may change when one parent has a disability. Also, studies on the organization of health services for parents with disabilities would be of interest. Due to the lack of research on parenting with a SCI or other disabilities, there is a need for both quantitative and qualitative investigations.

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## Notes

1. For more information, please see [www.nav.no](http://www.nav.no).
2. The study was conducted as a part of the master programme at University of Oslo, Section for Health Science. The master thesis was published in Norwegian in DUO (digital publishing at UiO) in 2009. Aune, G. 2009. English title: 'To focus on possibilities. Women with spinal cord injury share their stories as mothers living with young children.'

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