

## Occupations and means of living in adults with cerebral palsy or meningomyelocele during two decades in Sweden

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The aim of this study was to focus on education, work and means of living during two decades in two groups of people with cerebral palsy (CP) or meningomyelocele (MMC) within the framework of social policies. Two groups of patients at an adult habilitation unit were interviewed by telephone – Group A (n = 55) in 1983 and again in 1997 (n = 42), and Group B (n = 30) in 1997. All but one subject in Group B had attended upper secondary school (1997), compared with 61% in Group A (1983). In 1983, a majority of Group A worked or studied. In 1997, most of them still worked or studied, compared with only two thirds of the 1997 Group B, but both the A and B groups worked part-time significantly more often in 1997 compared with Group A in 1983. Of those who worked, about one third of Group A and more than half of Group B had wage subsidies from the state in both 1983 and 1997. The majority of Group A thought that over the period from 1983–97 the labour market had generally become harder, which had affected people with disabilities in general in a negative way. Almost all in Group A in 1983 and Group B in 1997 were content with their work tasks and work environment, but one third of Group A had problems within these areas in 1997. Significantly more people had disability pensions, of varying amounts, in 1997 (A and B groups) than in Group A 1983. In conclusion, it seems as if social policies have managed to integrate these people into the regular educational systems and support them financially, but have failed to stimulate the labour market to offer them work, especially regular and permanent work without wage subsidies.

**Keywords:** occupations; means of living; working conditions; disability history; marginalization; cerebral palsy; non-experimental clinical study; meningomyelocele

### Introduction

The purpose of the present study was to focus, analyze and compare the living conditions of people with cerebral palsy (CP) or meningomyelocele (MMC) within the framework of social policies regarding educational level, work and means of living. Data was collected about a group in 1983 (Group A) and two in 1997 (Group A and Group B). Gaining knowledge of the experiences and thoughts of the people

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in Group A about developments in the labour market during the period 1983–97 was also an important aim. We know very little about the labour market situation and other social conditions for people with CP or MMC, especially in Sweden.

### **Previous research**

At the Department of Rehabilitation Medicine, Sahlgrenska Academy at University of Gothenburg, Sweden, several studies have been carried out about young adults with CP or MMC. One study showed that activity limitations were less pronounced for vocation-related tasks compared to household tasks and transportation (Andrén and Grimby 2004a). Another study showed that, over a period of five years, increased dependence in daily activities was observed, which may reflect diminishing capacity (Andrén and Grimby 2004a).

Chronic pain, especially back pain and neck pain, was reported in a study in Norway among one third of people with CP, especially among males 40 years of age or older. Compared with a reference group, bodily pain seemed to start earlier in life among people with CP (Jahnsen et al. 2004).

The educational level of people with CP or MMC has been the subject of a large number of studies. One problem encountered when comparing these studies is that some have included people with mental impairments while others have not. A study in Finland that included 52 people (12 with mental impairment who attended auxiliary school) found that half of the study group had completed all their elementary education in regular schools. The remaining group of 14 people had attended special schools for the disabled (Kokkonen et al. 1991). Michelsen et al. (2005), in a Danish study, found that 33% of 819 participants with CP (including people with mental impairment) aged 21–35 years had an educational level above lower secondary school; that is above the age of 15–16 years. In a Dutch study, it was found that of 103 participants with CP and without a learning disability 73% had low or medium education, while the rest had high level of education (Donkervoort et al. 2007).

In terms of working ability in the 1980s, it was found among 86 CP patients 15–27 years of age in Finland that 72% were able to work, and were either working, unemployed or attending school. Four people were involved in sheltered work and one fifth was unable to work due to their disability. Ability to work was more common in people with a spastic syndrome than in people with a dyskinetic or ataxic syndrome (Sillanpää, Piekkala, and Pisirici 1982). Another study of 222 adults (18–26 years of age) with Spina Bifida in the UK reported that 81% were unemployed. When asked why, 57% reported that they had not found suitable work, 24% that no jobs were available and 19% made some mention of their disability. The study concluded that people with MMC had lower work potential and poorer work attitudes than other physically handicapped young people (Lonton et al. 1984).

With regard to work ability, a study of 52 disabled young adults with CP in Finland found that 38% were currently working, compared with 66% of a control group. Only three people were considered too severely disabled for work (Kokkonen et al. 1991). An American study found among 117 respondents with CP that 38% worked more than 20 hours per week and that 10% worked less than 20 hours every week (O'Grady, Crain, and Kohn 1995).

More recently an American study including 101 subjects with CP with a mean age of 43 years, found 53% were in regular employment. It was also shown that education

beyond high school was the most significant factor in achieving regular employment, especially for individuals whose physical disability was severe (Murphy, Molnar, and Lankasky 2000). On the other hand, only 20% of 80 young adults with CP were employed on the ordinary labour market in a Dutch study; other occupations were sheltered labour (16%), voluntary work (14%) and activities at day centres (41%) (van der Dussen et al. 2001). A Swedish study of 221 respondents with CP reported that 24% worked full time and 13% worked part time and had a part-time disability pension (Andersson and Mattsson 2001). In a Danish study it was found that among 416 adults with CP 45% had regular employment compared with 96% in an age-matched comparison group (Michelsen et al. 2006). In a Swedish study of 48 people with MMC, 38% worked, and it was shown, as in the above study (Murphy et al. 2000), that work participation increased with educational level (Valtonen et al. 2006).

Findings most relevant to this study include that bodily pain and reduced capacity are hindrances for work among ageing people with CP (Andrén and Grimby 2004b; Jahnsen et al. 2004), and that educational level differs between countries, probably due to contextual factors and whether the individuals have mental impairment or not. Work participation increased with educational level, as does the probability of regular employment both for CP and MMC (Murphy, Molnar, and Lankasky 2000; Valtonen et al. 2006). The proportion of people with CP engaged in regular employment differed between countries, ranging between 20–53%, lowest in a Dutch study (van der Dussen et al. 2001) and highest in an American study (Murphy, Molnar, and Lankasky 2000). It should be noted that some studies only report full-time regular employment while others include part-time employment. Also, cultural and contextual factors might contribute to different procedures and political decisions to facilitate work participation for people with disabilities.

The Swedish Social Insurance Administration in Stockholm (2007) made available to us data for people with diagnoses of CP and MMC. The number of people with disability pension for this group has increased sharply in recent years from 45,289 in 1980, to 49,237 in 2000 and to 60,308 in 2005.

### **Disability context**

In recent years labour market policies have changed a great deal in many parts of the world (Bergskog 2001). During the 1990s political goals in many countries were to minimize dependency on benefits and raise the level of employment among people with physical disabilities. A Swedish study of a total of 21 OECD countries shows that Norway, Austria and Sweden have more physically disabled citizens involved in different state-run labour market programmes than the other countries that were examined. The study also indicates that disabled people in Sweden are primarily recruited to employment positions with wage subsidies in the public sector. Furthermore, the study showed that countries with a large number of disabled people involved in labour market programmes also have a large number of individuals on disability pension. New Zealand, Great Britain and Australia have relatively few people on disability pensions, while the Czech Republic, Poland, Sweden, Portugal and Ireland have a relatively large number of people with disability pensions (Bergskog 2001).

In Sweden it is common for the state to financially compensate employers who are willing to hire someone with reduced capacity. Employees hired in this way are meant to receive the same wages and employment benefits as people covered by collective

bargaining agreements in the industry in question or by comparable agreements. The size of the subsidy is based on labour costs and employee work capacity. Initially, a wage subsidy may not run for more than one year, but may be extended for a maximum of four years (Swedish Institute 2005).

In order to be granted wage subsidies, employers and representatives of the employment office must reach an agreement concerning the level of the subsidy; for example, employers may pay 35% of the total wage and the state 65%. In discussions of a possible extension of wage subsidies, the ambition is that the employer pays a larger amount of the salary than during the initial period.

According to this report (Swedish Institute 2005) one problem with this state support is that plans for reduced wage subsidies are seldom formed in cooperation with employers and their employees. While the state sometimes contributes a rather large amount of money to wage subsidies at first, these benefits can suddenly be withdrawn and this may have a negative influence on the disabled person and the employer. The limitations of wage subsidies can be considered an obstacle to finding new employment for individuals that need this support. The report also pointed out that employers adjust the salaries they pay to the subsidies. This will result in lower pay for the employees (Betänkandet Arbetskraft 2003, 95).

### **Marginality and social exclusion**

According to Svedberg (2003), individuals in the labour market can be located on a continuum between integration and exclusion. The concept of integration is used for individuals with a secure position in the labour market and the concept of exclusion for individuals who have lost their footing in the labour market. In this continuum marginalized people occupy a position in the middle. Despite of the risk of exclusion the individual or the group has a possibility to turn the marginal position towards integration into the labour market again. According to Svedberg (2003) marginality might be looked upon as a relative and not an absolute concept, which means that individuals may be more or less marginalized.

The concept of social exclusion has French roots and implies a lack of participation in society. The extent to which people are excluded from the societal context is related to the ideas of fraternity and equality (Duhaime 1996). In a Swedish context social exclusion might be looked upon as a summarized term for the processes through which certain categories of people are marginalized socially, economically or politically. One basis for social exclusion is 'race' or 'ethnic origin'. The term social exclusion has a wider meaning, including processes of exclusion that influence many disadvantaged categories in society, such as disabled people, sexual minorities and unemployed people (Westin et al. 1999).

Individuals and groups can be part of a process where they partly participate within different 'areas of life' in society. Social exclusion can be defined as a process where it is possible to be excluded from different 'areas of life', for example the labour market, social relationships or political participation (Edgren-Schori 2000). According to one study, experience of long-term unemployment, severe disability problems, economic difficulties, negative attitudes from employers and a poorly adapted physical environment will increase the risk of marginalization (Munir 2006).

From both qualitative and quantitative studies in Sweden Munir (2006) has pointed out three main consequences of the marginalized socio-economic position in society of people with motor disability. First, people with motor disabilities have

difficulties in finding work and supporting themselves. Second, people with motor disabilities have difficulties with their finances, because they have extra expenses related to their disability; and third, they have generally less income through the Social Insurance Office than people earning their income from employment (Munir 2006).

How to define and use the concepts of marginalization and exclusion in relation to people with disabilities is probably an open question. It seems more accurate to talk about marginalization. Even though a substantial number of disabled people are excluded from the labour market, they might be included in society in other ways, with relationships to friends, relatives and are involved with different societal and voluntary organizations and authorities.

### **Material and methods**

In this study, two groups of individuals with CP or MMC were involved ( $n = 85$ ). Group A ( $n = 55$ ) was interviewed by telephone in 1983 at an average age of 24 (the range being 20–33 years) and again in 1997 ( $n = 42$ ) at an average age of 38. Group B ( $n = 30$ ) was interviewed by telephone in 1997 at an average age of 26 (the range being 18–30 years). Group A consisted of 50 individuals with CP and 5 with MMC in 1983 and 38 people with CP and 4 with MMC in 1997. Group B consisted of 19 with CP and 11 with MMC. The study groups were presented with a semi-structured interview. In Group A, questions were formulated about developments in relation to work opportunities (opportunities in the labour market) in 1983 and 1997. When subjects were interviewed for the first time (both in groups A and B), questions were asked about background factors such as their earlier education and need for assistance, as well as occupation, situation on the workplace and means of living. When interviewed the second time (Group A), we focused on education, occupation, situation on the workplace, need of assistance and future plans.

Our inclusion criteria in this study were the following: When interviewed, all the subjects in the present study were patients in an adult habilitation unit at the Department of Rehabilitation Medicine, Sahlgrenska University Hospital in Göteborg, Sweden, lived in Göteborg or nearby and could speak Swedish. At the age of 18 they had all been referred to this adult habilitation unit from paediatric habilitation in Göteborg. All the subjects had motor impairments and regular intellectual capacity and had attended regular schools. Some results regarding these subjects have been reported earlier in Swedish (Jespersen, Bähr, and Grimby 2002a, 2002b).

In this study we interviewed Group A twice and Group B once about their present and earlier living conditions. The study design has the character of being a non-experimental study (Figure 1).

When Group A was interviewed in 1983, 55 people with CP or MMC participated. Group A in 1997 consisted of 42 individuals, born in 1950 or later. The 13 people in Group A who did not participate again in 1997 had an average age of 25 (the range being 19–33 years); eight of them were dependent or partly dependent on a wheelchair and seven had work, while four studied and four had some level of disability pensions. This group of non-participants does not seem to differ very much compared with the group interviewed according to the variables mentioned in the earlier sentence, except that more people were dependent or partly dependent on wheelchairs.

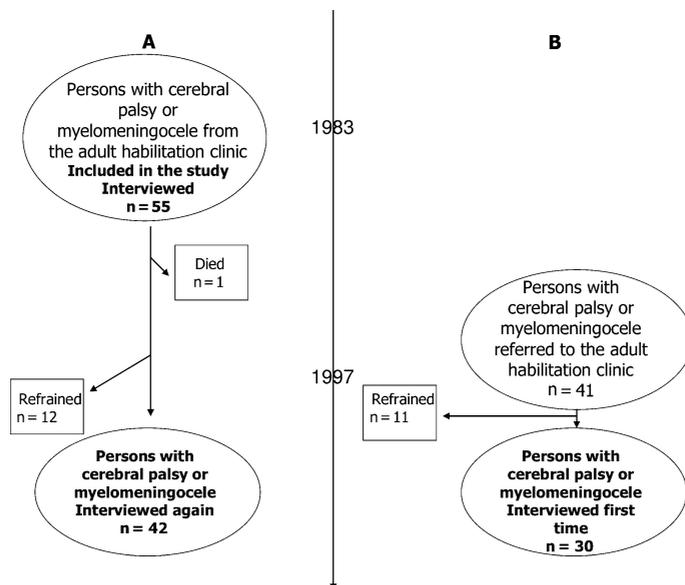


Figure 1. Data collections.

When Group B was invited to participate in 1997, 11 people declined to be part of the study and in total 30 people were interviewed. From patient records we found that the people who did not participate had an average age of 25 (the range being 21–31 years), six of whom were dependent or partly dependent on a wheelchair and at least three had some kind of work while two studied, three had disability pensions, one was unemployed and in two cases there was no information about these factors. Among the people who declined, fewer people seemed to be entirely or partly dependent on wheelchairs. No reasons for not participating were given.

In Group A, 14 people were totally dependent on a wheelchair in 1983, and this decreased to 11 people in 1997. In Group A, 11 were partly dependent on a wheelchair in 1983, and seven in 1997. The remaining participants in Group A did not need a wheelchair (30 people in 1983 and 24 in 1997). In Group B, nine people were dependent on a wheelchair at all times, 15 were partly dependent and six did not use a wheelchair. This indicates that Group B had more pronounced mobility problems than Group A.

Before the interviews, all the subjects were sent a letter describing the study and were asked to contact the medical social workers who would conduct the interview. After some weeks the subjects were reminded about the study if they had not already called the medical social worker. An appointment for the telephone interview was scheduled when the subjects called. During the interview, no one wanted to interrupt the procedure. The interview varied between one to one-and-a-half hours. One interview was completed with help of a close relative. Four were transcribed by a close relative. In 1997, two subjects were interviewed with the help of a personal assistant and one together with a close relative. The medical social workers interviewed 11 subjects from the A groups in person because of difficulties with speech and concentration.

Chi-square analysis has been used when comparing the A groups with Group B. Wilcoxon Ranks Signed Test has been used when comparing the A groups.

The project was approved by the Ethics Committee at the Faculty of Medicine of Sahlgrenska Academy.

## **Results**

### *Education*

All respondents had completed compulsory school (7–15 years of age). The population of people who had attended upper secondary school (16–19 years of age) was higher in Group B, where all but one had attended, than in Group A, where only 61% had. Also, seven people in Group A had interrupted upper secondary school, but no one in Group B had.

More than one third of Group B had attended upper secondary school for three years, compared with less than 10% in Group A. In Group A most people had attended upper secondary school for at least two years. The number of those who had studied at university was larger in Group B than in Group A, one third compared with 21%.

The subjects in Group A were asked during the telephone interview about whether they felt their educational possibilities had improved or had become worse during the period from 1983–97.

Only 17 subjects out of 42 gave such comments. Seven said that the possibilities for pursuing an education had not altered during the period. Three said that the possibilities for education had improved thanks to the availability of personal assistants. Six said that they did not know whether possibilities for education had improved or become worse. One pointed out that in order to get another job if he or she became unemployed they would have to get an education.

### *Work*

Socio-economic status and the number of people working and studying in Group A in 1983 and 1997 and in Group B in 1997 are given in Table 1.

A majority of the subjects in groups A and B were working or studying in 1983 and in 1997. It can be seen in the table that most subjects who worked were lower grade officials or workers. The most common type of work among the subjects in Group A was office work: in 1983, 15 people and in 1997, 17 had this occupation, while in Group B only four had clerical work. Among the higher grade officials, most in Group B were involved in IT.

The main part of Group A worked or studied both in 1983 and 1997, while two thirds of Group B worked or studied. However, the differences were not significant. The number of subjects working or studying part time is significantly higher in Group B (p-value <0.05) and Group A 1997 (p-value <0.08) than in Group A 1983. In the 1983 Group A, 32 subjects worked or studied full time, while 13 worked or studied part time. In Group A in 1997, 17 people still worked or studied full time and 16 worked or studied part time. In Group B in 1997, eight people studied or worked full time, while 13 worked or studied part time. Only one person in Group B was employed full time and did not have temporary work.

A considerable number of the subjects were helped by wage subsidies, as seen in Table 2.

Table 1. Socio-economic status and number of people working or studying in Group A (1983 and 1997) and in Group B (1997) (CP+MMC).

Socio-economic group	Group A				Group B	
	1983		1997		1997	
	n	%	n	%	n	%
Employers	0		0		1	3
Higher grade officials	4	7	2	5	5	17
Lower grade officials	15	27	17	40	4	13
Workers	16	29	12	29	6	20
Students	10	18	2	5	5	17
Not working or studying	10	18	9	21	9	30
Total	55	100	42	100	30	100

Note: A (1983), A (1997) and B (1997) respectively, according to working or studying and not working or studying: A (1983) vs A(1997) not significant, A (1983) vs B (1997) not significant, A (1997) vs B (1997) not significant.

The table shows that 13 people in Group A in 1983 and 12 in 1997, and 10 subjects in Group B had wage subsidies. About half of the people in both groups worked part time.

In Group A in 1983, 37% of the employed subjects and, in 1997, 39% of the employed subjects had wage subsidies. In Group B, 63% of the employed subjects had wage subsidies in 1997.

The subjects in Group A were given a question in 1997 during the telephone interview about how they thought that their possibilities had improved or become worse in relation to access to work during the period from 1983–97.

Of the 42 people in Group A in 1997, 30 subjects said that it had become more difficult to get work. All said in different ways that the labour market had become harder and had had an effect on everyone in society but that it had contributed especially to making the situation difficult for people with disability.

Seventeen subjects, more than half, added that employers primarily want to recruit healthy people with a satisfactory work capacity and a good education. Seven said that not having an education or a higher education had contributed to a poorer situation in the labour market for them, and five also said that being older and/or

Table 2. Wage subsidies in Group A 1983 and 1997 and Group B 1997 (CP+MMC).

Category	Group A				Group B	
	1983		1997		1997	
	n	%	n	%	n	%
Work with subsidies: 100%	6	11	6	14	4	13
50–75%	6	11	4	10	6	20
25%	1	2	2	5	0	
Work with no wage subsidies	22	40	19	45	6	20
Not working	20	36	11	26	14	47
Total	55	100	42	100	30	100

having a disability also played a role. One said that his earlier social problems could influence an employer's willingness to include him in his staff.

Of the remaining 12 people, three said it would be easy to get work, one because of his IT education and the others because the labour market was favourable in their specialities. Two said that the situation had improved because of the support they received from AMI (a special state section dealing with individuals with different kinds of work-related disabilities), including state wage subsidies to employers. One said that a new disability, added to an old one, could worsen problems in getting work.

Two people indicated that the possibility of getting personal assistants had improved their situation; it was possible to get help to come to work and to manage tasks at the work place. One said that the situation had become neither better nor worse for people with disabilities in terms of getting work. Three people said they did not know how to evaluate the development.

Two subjects said that it was easier to get work if the person had contacts in the labour market and that it otherwise might be difficult.

In Group A, one question was asked about experiences of work in 1983, that is, whether the subjects were content, partly content or not content (Table 3).

The table shows that most of the people seemed to be content with their work experiences. Some made comments in relation to the question.

One person thought he had to keep to office work because of his disability, while one thought this type of work was exciting. The physical disability sometimes hindered the person from working, one spoke about his speech defect and two talked about neck pain. Two people described the sedentary work that they had and that it posed a strain on their bodies.

Two people wanted to be transferred to another workplace, one because of neck pain and one because he felt lonely. One was not content with a transfer to another workplace. Two people did not want to leave their work because of difficulties in the labour market and one talked about financial problems because he had a low-wage occupation.

Table 4 shows the experiences of the subjects in Group A and Group B in 1997 as to whether they were content, partly content or not content with work tasks, work environment and social support in the workplace. All subjects in Group A who were employed and the 16 subjects in Group B that worked responded to the question. About two thirds of the subjects were content with their work tasks and work environment in Group A while one third was not content. In Group A, over 90% of the subjects were content with the social support they received. In Group B, two thirds of the subjects experienced the work environment as acceptable, but one third

Table 3. Experiences in Group A regarding employment in 1983 (CP+MMC) among subjects working.

Category	1983	
	n	%
Content	26	74
Partly content	8	23
Not content	1	3

Note: 20 subjects in Group A did not work in 1983.

Table 4. Experiences about work in the Group A and Group B in 1997 (CP+MMC).

Category	Group A		Group B	
	n	%	n	%
<i>Work tasks:</i>				
Content	22	71	15	94
Partly content	0		0	
Not content	9	29	1	6
<i>Work environment:</i>				
Content	20	65	10	63
Partly content	0		1	6
Not content	11	35	5	31
<i>Social support:</i>				
Content	28	90	15	94
Partly content	0		1	6
Not content	3	10	0	

Note: 31 subjects of 42 worked in 1997 (Group A) and 16 subjects of 30 (Group B) worked in 1997.

was partly content or not content. A majority of the subjects in Group B were content with their work tasks and their social support.

The most common problem related to the work environment was poor ventilation, mentioned by nine individuals. One sensed that there was mould in his room. One thought that the workplace should be renovated and two thought that the room was very small. Three people experienced a high noise level. Four individuals said that the tasks were monotonous, and one said he could not use the knowledge he had. One said that the work was difficult in a physical and psychological sense, two felt stress and one of these added a threat of being robbed. Two felt lonely, two did not get along with one of their fellow workers and one did not obtain the help needed from his fellow workers with work tasks. One worked alone and had no experience of fellow workers.

### *Financial means*

Different pensions and subsidies from the state or community are shown in Table 5.

As seen, almost all of the subjects of Group B and more than half of Group A had different kinds of economic support from the state. Significantly more people received welfare contributions from society in Group B compared with Group A 1983 (p-value <0.01) and Group A 1997 (p-value <0.05). Also, significantly more people had disability pensions of varying amounts, in Group A 1997 and Group B compared with Group A 1983 (p-value <0.01 and p-value <0.05 respectively).

In Group A, 19 people in 1983 and 27 in 1997 had disability pensions or different levels of sick leave. Further, one studied and one was unemployed with no pension or subsidy in 1983. In 1997 one person was employed part-time with no state subsidy. More than half of the subjects in Group B had a disability pension or were on different levels of sick leave. Two people were unemployed and received subsidies from the social services. One person was unemployed with no subsidy or pension at all and one person received no support for 25% of the level of unemployment.

Table 5. Levels of disability pension and other contributions from the state or community in Group A, 1983 and 1997, Group B in 1997 (CP+MMC).

Category	1983		1997		1997	
	Group A		Group A		Group B	
	n	%	n	%	n	%
Sick-leave 100%	2	4	0		0	
Sick-leave 25–50%	0		3	7	1	3
Disability pension 100%	4	7	8	19	6	20
Disability pension 25–75%	13	24	16	38	11	37
Study contribution 50–100%	7	13	0		5	17
Unemployment benefit 50–100%	2	4	0		1	3
Social service 50–100%	1	2	0		2	7
Missing	3	5	1	2	0	
No contribution	23	42	14	33	4	13
Total:	55	100	42	100	30	100

Note: A (1983), A (1997) and B (1997) respectively, according to contribution from state or community and no contribution from state or community: A (1983) vs A(1997) not significant, A (1983) vs B (1997)  $p < 0.01$  A (1997) vs B (1997)  $p < 0.05$ . According to disability pension and no disability pension A (1983) vs A (1997)  $p < 0.01$ , A (1983) vs B (1997)  $p < 0.05$  and A (1997) vs B (1997) not significant.

## Discussion

The aim of the study was to focus on education, work and financial situation within the framework of social policies regarding people with CP or MMC in Sweden. The character of the study can be called a non-experimental study and telephone interviews were performed in 1983 (Group A) and in 1997 (A and B groups). There are several limitations with this study. First, the sample is small and it is not possible to generalize the results and secondly, a qualitative approach might have given a more profound perspective.

In 1983 and 1997, the majority of the subjects in our study were working, but often with wage subsidies and not full time. A Danish study (Michelsen et al. 2006) reported that more than half of the people with CP did not have regular work compared with 4% in an age-matched group. We found in our study in 1983 that 75% of Group A worked or studied full time and, in 1997, about 40% still worked full time. In Group B (1997) one third worked full time. Consequently, there seems to be many obstacles for people with CP or MMC to get and keep regular work, at least with full time work.

A substantial part of the two groups worked part time, more than one fourth of Group A in 1983, almost half of Group A and over 60% of Group B in 1997. Thus, in 1997 both Group A and Group B worked significantly more often part time than Group A in 1983. Our findings in Group A in 1983 agree with those of another Swedish study, which showed that almost one fourth of a population of 221 subjects with CP worked part time (Andersson and Mattsson 2001). All part-time workers in our study combined part-time employment with part-time disability pension or sick leave. In the study by Andersson and Mattsson (2001) 10% held part-time employment with no disability pension.

In Sweden, more than half a million work opportunities disappeared from the labour market during the 1990s, and this had an effect on various groups, among them young people. The number of young people seeking work doubled (Fritzell, Gähler, and Neramo 2007). We are not surprised that people with disabilities have had a difficult time finding work in this societal situation. During their time in upper secondary school, pupils are given opportunities to work for a few weeks in real jobs. Although the participants in one study were not given exactly the 'practice jobs' they wanted, most of them, 85%, were content with their practice jobs (Jespersion, Bähr, and Grimby 2002a). This and the fact that most of the subjects had attended upper secondary school should indicate that the subjects would have qualifications for gaining employment.

About one third of the people in Group A who worked had wage subsidies, while more than half of those in Group B who worked had this support. The use of employment subsidized by the state is common in Sweden (Bergeskog 2001) and is confirmed by this study. Another interesting perspective can be that, in this study, wage subsidies seem to be an extended support given by the state to the employer, which is not in agreement with the four years stipulated in a Swedish report (Swedish Institute 2005). Every four years the level of wage subsidies from the state is negotiated with employers and should decrease over time and vanish if the employees perform better. Several subjects in Group A had wage subsidies both in 1983 and 1997.

However, the majority of Group A said that it had become harder in general to enter the labour market and that this especially had an impact on people with disabilities. More than half added that employers primarily want to recruit healthy people with a good education.

Our study shows that, compared with the people of the same age in Group A, the individuals in Group B had lower labour market participation, especially in the regular labour market. Is it possible that young people with disability have experienced a tougher labour market over time, as was expressed by the people in Group A during 1983 up to 1997? Most people in Group A were included in the labour market in 1983, and 45% of them worked full time; while 10% of Group B worked full time in 1997. One plausible explanation for this difference is that one third of Group A had clerical work while only 13% of the people in Group B had this kind of work. The clerical tasks offered to these people have successively disappeared from the labour market. Generally, the harder working conditions might contribute to a worse situation for the people in our study. They were in different positions regarding integration into the labour market; they might have been integrated but they are so to a lesser extent over time, more often socio-economically marginalized or excluded from the labour market. This result is in accordance with the findings of Lindqvist (2007). During the period 1975–1985, the labour market included more persons with disabilities. After 1985, the situation has got worse for people with disabilities and they have problems finding work (Lindqvist 2007). From our study it cannot be concluded that the subjects are in a position where they have been able to turn their marginal position towards integration into the labour market over time as described by Svedberg (2003). On the contrary, in relation to the labour market both Group A and Group B are in more marginalized positions in 1997 than Group A was in 1983; both groups are significantly more dependent on disability pensions of varying amounts.

Of course, it is important to note that medical problems can complicate living conditions. Physical status might be affected by pain, contractures or a reduced capacity, and these problems will become worse with age (Andrén and Grimby 2004b; Jahnsen et al. 2004). However, if it had been possible to adapt workplaces, influence employers' attitudes, lower the working tempo and create adapted tasks, more of these people might have been working. Therefore, it seems important to consider and work more intensively with environmental factors, such as those to which the social model points (Barnes, Mercer, and Shakespeare 1999). It is hard to tell to what extent physical pain on one hand and labour market policies on the other influence the study groups; regarding access to work, there seems to be a complicated interaction between the two dimensions.

For the individuals who are active in the labour market, the personal experiences in the workplace are mainly positive, both in 1983 and 1997. The majority of the subjects in the two groups in 1997 were content with their work tasks, work environment and social support, and these results are in line with the findings in another study where 80% of respondents with MMC and with traumatic spinal cord injury thought that their current work situation was rather good or very good (Valtonen et al. 2006). This is at the same level as is found in the Swedish population in general, in which the corresponding proportion is commonly about 75% (Torgén et al. 2001). In this study, nine respondents were not content with their work tasks because their tasks were monotonous and stressful, and 11 subjects referred to negative factors in the work environment, such as poor ventilation and high noise levels. These concerns about tasks and the environment seem to be negative, worrying experiences.

Our results showed that the education level in the group studied had improved over time, as it has on a national level. Almost all (98%) had completed a period of three years in upper secondary school by 1997 but it was more common with two years in upper secondary school in 1983 (SCB 2009). All but one in Group B had completed upper secondary school (16–19 years), compared with 60% of Group A. A study published in Swedish showed that, of 56 people with severe mobility disorders, all but two had completed upper secondary school (Vander Hart 2000).

This indicates that a high proportion of subjects had a relatively high level of education in 1997 in comparison with other studies. In other Nordic studies of disabled people, one showed that 33% had a level of education beyond lower secondary school (Michelsen et al. 2005), another reported that 50% had completed all elementary years in regular schools (Kokkonen et al. 1991) and a third found that 57% continued their education beyond 16 years of age (Andersson et al. 2001).

Eighteen percent of Group A and 20% of Group B had full disability pensions in 1997, which agrees with another study carried out in Stockholm (Andersson et al. 2001). In the long run, economic problems may arise for these subjects because of extra expenses related to their disabilities and lower incomes than regular work would give (Munir 2006).

Our target group is a limited one and cannot be seen as representative for all people with CP or MMC in Sweden. We interviewed a selection of people with CP or meningomyelocele referred to an adult habilitation unit. Perhaps not all people with these diagnoses came to the child habilitation unit and probably not all came to the adult habilitation unit.

It seems as if social policies have managed to integrate these people into the regular educational system and support them financially, but have failed to stimulate

the labour market to offer them work, especially regular and permanent work without wage subsidies. We consider of crucial importance that all people in society, who want to and can contribute to the labour market, should be able to do so.

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