

## Increasing symptoms, met and unmet needs in adults with cerebral palsy or meningomyelocele a longitudinal follow-up

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The aim of this study was to investigate how symptoms and personal assistance needs change over time among people with cerebral palsy (CP) or meningomyelocele (MMC), and to identify unmet needs. The study design was a longitudinal follow up, both cohorts starting as young adults while treated at the adult habilitation clinic. The participants were interviewed by telephone. Group (A) was studied in 1983 (n = 55), in 1997 (n = 42) and in 2009 (n = 28). Group (B) was studied in 1998 (n = 30) and in 2009 (n = 25). Perceived symptoms were aggravated in both groups in 2009 compared with 1997 (8), and significantly more aggravated in group A (older than group B). The number of participants needing practical assistance increased significantly in both groups between 1997–1998 and 2009. Most people in both groups had contact with health care professionals and many wanted more assistance, especially access to a specialized team. As a consequence of aggravating symptoms, the need for specialized health care continues into adulthood.

**Keywords:** activities of daily living; access to health care; cerebral palsy; health and social care; patient satisfaction; physical disabilities

### Introduction

According to the UN Convention 2006 on the Rights of Persons with Disabilities, signed by Sweden (Government bill 2008), measures to ensure access to health services (article 25) and to organize, strengthen and extend comprehensive habilitation services (article 26) for people with disabilities are to be performed.

Life expectancy of teenagers with severe cerebral palsy (CP), lacking basic functional skills such as feeding and mobility, has increased by approximately five years during the last 20 years, and the life expectancy of high-functioning adults with CP is close to that of the general population (Strauss and Shavelle 1998; Strauss et al. 2007). Before use of the cerebrospinal fluid shunts in the 1960s, most children with myelomeningocele (MMC) died in infancy (Oakeshott et al. 2010). Today 75–85% of children born with MMC are expected to reach their early adult years (Dicianno et al. 2008). Thus, more people with CP or MMC now live into adulthood and old age, thereby needing care and health services from a life span perspective. It is a clinical problem to ensure that all people with CP or MMC regardless of age are given continuous, age-appropriate care including high quality, multidisciplinary care comparable to that available for children (Binks et al. 2007). Chronic bodily pain

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often starts earlier in life among people with CP occurring in 1/3 of this population compared with 1/6 of the general population (Jahnsen et al. 2004a). Muscular-skeletal pain is the most common, primarily in the back, hips and lower extremities (Vogtle 2009). Locomotion often starts deteriorating in early adulthood (Andersson and Mattsson 2001; Jahnsen et al. 2004b). Other health problems at a higher-than-expected rate among people with CP include gastro-oesophageal reflux disease, bowel and bladder dysfunction, urinary tract infections, oral motor and dental disorders, osteopenia and fractures, fatigue and progressive musculoskeletal deformity and dysfunction (Liptak 2008). Adults with MMC have problems including varying degrees of mobility limitations, hydrocephalus, neurogenic bladder and bowel dysfunction, scoliosis and pain (Dicianno et al. 2008).

People with CP or MMC often need practical personal assistance in activities of daily life. In Sweden, a person with pronounced disability can get 'personal assistance' subsidized by the government (Barron, Michailakis, and Söder 2000). According to a US study mothers were more likely than other members of a family to become a caregiver (Rivera et al. 2006). A Swedish qualitative study (Whitaker 2008) showed that parents are caregivers even if their disabled children are adults and have personal assistants. A Dutch study (Nieuwenhuijsen et al. 2008) of adults (aged 16–40) with CP found that 52% of the whole group and 90% of those with a severe disability met with a rehabilitation physician regularly. Almost three quarters of the participants had used allied health care at least once in the past year. Of these, the most frequently used were the physical therapist (55%) and social services (32%). The unmet needs reported were mostly regarding information on complications, consequences and causes of CP (79%), mobility in terms of access to the community, driving a car and other peoples' willingness to help (66%) and health care in terms of physical therapy, in-patient rehabilitation and hospital specialists (66%) (Nieuwenhuijsen et al. 2008). A US study of 64 adults with CP found that the majority of the participants with chronic pain did not access health care providers for help in managing their pain and that CP-related pain is undertreated among adults (Engel, Kartin, and Jensen 2002).

In Sweden the care for adults with disabilities is organized in different levels. The first level being community habilitation and primary health care and the second level being a more specialized unit with multidisciplinary teams, called the adult habilitation unit. The municipalities are responsible for social services and transportation of the disabled, while the state organizes the social insurance office and the employment service. Little is known about experiences of middle-aged people with CP or MMC in relation to health care and other authorities in Sweden.

The aim of this study was to investigate how perceived symptoms and personal assistance needs change over time among people with CP or MMC. A second aim was to identify met and unmet needs in relation to health care professionals and other authorities.

## **Methods**

The project was approved by the Regional Ethical Review Board, Gothenburg.

The study is a follow up of studies that was conducted in 1983 and in 1997/8 and therefore the study design and the sample size were predetermined. Two groups of adults (19 to 33 years of age) with CP or MMC were involved in this study. A step wise follow up was undertaken at 14 years for the first group

recruited (1997–1998) and 12 years (2009) for both groups. The first group (A) was recruited in 1983 and interviewed three times, starting with 55 people with a mean age of 24; at the second interview they had a mean age of 38 and at the third interview they had a mean age of 50. In order to study differences with societal conditions over time a second group (B) was started at the time of the second interview of the first group. Group B comprising 30 people were included in 1998 with a mean age of 26; at the final interview they had a mean age of 38. The study design is shown in Figure 1. Mainly, this article describes changes in a 12 year period (between 1997/8 and 2009) but we have also used background data and information about education and practical personal assistance in school gathered in 1983 (group A). The main part of group A consists of people with CP, while group B is more of a mixture.

The inclusion criteria were; Swedish-speaking people with CP or MMC, aged 19–33, who lived in Göteborg and had ongoing contact with the adult habilitation unit at the Department of Rehabilitation Medicine, Sahlgrenska University Hospital in Göteborg, Sweden in 1983 (group A) and in 1998 (group B). There were probably people with CP or MMC in the community who did not attend the adult habilitation unit, it is unclear how many. Participants who no longer attended the adult habilitation unit at the time of follow ups were still included in the study. At the time of inclusion people with IQ below 70 were treated in another unit, and therefore all participants had an IQ above 70. All had attended regular schools. Some had

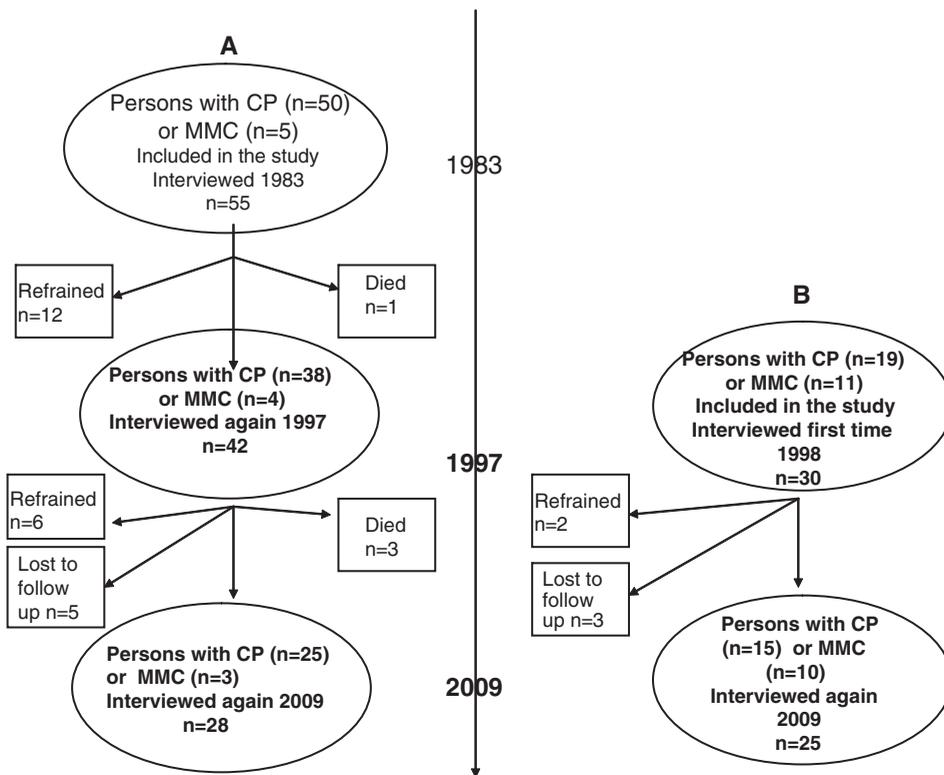


Figure 1. Study design

periodically attended special schools or special classes in regular schools for people with motor impairments or minor learning difficulties. People with communication problems were not excluded. Parents and personal assistants have in some cases helped to interpret what the person meant. When the study began in 1983, the non-Swedish speaking population in the community was very small, and there were no non-Swedish speaking patients attending the unit. The non-Swedish speaking population has increased since then, in Sweden as a whole as well as at this unit. In 1983, 10 people attending the adult habilitation unit declined to participate, it is unclear how many of those had either CP or MMC or a different diagnosis altogether. In 1998, nine people with CP and four people with MMC declined to participate. The design was a longitudinal follow up. The sample was not representative of the population, it was a convenience sample based on ongoing contact with the adult habilitation unit in 1983 or 1997. At the time of inclusion in 1983, five people were classified as having MMC. With the knowledge we have today about the cognitive deficits associated with MMC, two of these people would not have been included. They both have a spinal chord injury acquired in early childhood.

#### **Earlier data collection (1983 and 1997–1998)**

All participants were sent a letter describing the study and were asked to contact the medical social worker who would conduct the interview if they wanted to participate.

A scheduled appointment for the telephone interview was determined when the participants called. The interview varied between one and 1.5 hours. One interview was completed with the help of a close relative. Four were written by a close relative. The interviews were conducted with two different medical social workers in 1983 and 1997/8 respectively. In 1997, two participants were interviewed with a personal assistant and one together with a close relative. The medical social workers interviewed 11 participants from both groups in person because of difficulties with speech and concentration.

The questionnaires were designed specifically for this study in 1983 and somewhat modified in 1997/8 and 2009. Background factors were gathered in 1983 (A) and 1998 (B) regarding integration in compulsory and upper secondary school (two questions), technical devices while in school (one question), what kinds of teaching placements they had during school time; need for technical devices at teaching placements and whether they were content with their teaching placement (three questions), whether they were content with the school (two questions), what kinds of transports they used to get to school (two questions), whether buildings were accessible within school (two questions), need for assistance and what help they got while in school (four questions), whether and what kind of employment they had had during weekends or holidays (one question) and whether they had taken a university course (one question). As things were in 1983 and in 1997 (A) and in 1998 (B) regarding what kind of occupation they had and how much they worked (seven questions) whether they were content with their work (one question), whether they thought the labour market had changed and how (one question), whether the working-place was adapted for their needs (one question), the need for technical devices (one question), means of living (one question) and occupational plans for the future (one question). Information about the need of assistance from

personal assistants and home services was gathered for the first time in 1997 (A) and in 1998 (B).

Thirteen of the initial 55 participants included in group A were lost to follow up in 1997. In 1983 these 13 people did not differ in terms of mobility and need for assistance from the remaining 42 participants interviewed.

### **Final data collection (2009)**

Before the interviews, all participants were sent a letter describing the study and were again asked to participate and send a consent form to the researchers. After a number of weeks all participants were contacted by telephone and asked whether they wanted to participate or not. All of those who wanted to participate were given a scheduled appointment for the telephone interview. The interviews were conducted either by a lecturer (former medical social worker) or a rehabilitation physician, both with extensive clinical experience. Interviews varied between 45 minutes to 1.5 hours. They were conducted during the autumn of 2009. Communication with the interviewers was alleviated by personal assistants in one case. Two participants were interviewed in person. One participant wanted to fill in the questionnaire himself and send it back to the interviewers.

In 2009, 11 of the participants from group A in 1997 were lost to follow up. According to data from 1997, 81% of them were ambulators, compared to 74% in group A as a whole. There was no difference in the number who received practical assistance between the participants and the non-participants. In group B in 2009, 80% of the non-participants were ambulators compared to 70% of the whole group in 1998.

In the current data collection there was more emphasis on mobility (one question), needs for assistance in detail (three questions) and perceived bodily symptoms (two questions) due to ageing of the participants. Other themes were very similar to the earlier data collections; continued education during the period 1997/8—2009 (one question), educational plans for the future (one question), whether they had an occupation and how much they worked, if they had changed occupation (three questions), what kinds of help were needed in the work place (four questions), whether they had daily activities if not working (two questions), work satisfaction (Motivation for Change Questionnaire [Grahn and Gard, 2008]), means of living (one question) and experiences of accessibility (two questions) were gathered. We added two questions; participants were given an open question about spare time activities and if there was something they needed that they did not get from health care professionals and authorities.

During the interviews, the answers to the open questions were noted immediately or directly after the interview. The results of the open questions were assessed up by the lecturer experienced within qualitative research and the answers were categorized inductively. All participants answered all questions.

The study has a descriptive approach. Statistical analyses were performed with SPSS (Statistical Packages for Social Sciences, 18.0, SPSS Inc, Chicago, IL). The Wilcoxon signed rank test was used to compare the number of people in need of practical personal assistance within each group over time, and the Mann-Whitney U Test was used to compare level of perceived bodily symptoms between the groups.

## Results

### *Demographics of study sample*

The variables are shown in Table 1.

The amount of people working full-time in group A in 2009 has decreased and the number of people with full-time disability pension has increased. When comparing group A (1997) with group B (2009) at the same age, more people in group A were married and worked full-time. More people in group B had a higher educational background than in group A. No person without work were at home caring for young children, they were either unemployed or had a full pension. People with a university degree are shown in Table 1. There were also one person in group A and four people in group B, who had taken single courses at the university.

### **Perceived bodily symptoms over time**

In the 2009 data set 75% in the older group A (76% of those with CP and 67% of those with MMC) and 36% in the younger group B (60% of those with CP and 20%

Table 1. Demographics of study sample in 1997/8 and 2009.

	Group A (n = 42) 1997–1998	Group B (n = 30) 1997–1998	Group A (n = 28) 2009	Group B (n = 25) 2009
Age in years, mean	38	26	50	38
CP	38 (90.5%)	19 (63%)	25 (89%)	15 (60%)
MMC	4 (9.5%)	11 (37%)	3 (11%)	10 (40%)
Gender <i>n</i> (%)				
Male	22 (52%)	18 (64%)	15 (54%)	16 (64%)
Female	20 (48%)	12 (36%)	13 (46%)	9 (36%)
Marital status <i>n</i> (%)				
Married	13 (31%)	2 (7%)	11 (39%)	5 (20%)
Unmarried	21 (50%)	22 (73%)	12 (43%)	13 (52%)
Divorced	1 (2%)	0 (0%)	2 (7%)	2 (8%)
Cohabiting	7 (17%)	6 (20%)	3 (11%)	5 (20%)
Children <i>n</i> (%)				
Children	16 (38%)	6 (20%)	12 (43%)	8 (32%)
No children	26 (62%)	24 (80%)	16 (57%)	17 (68%)
Work <i>n</i> (%)				
Full-time	16 (38%)	7 (23%)	8 (28%)	6 (24%)
Part-time	15 (36%)	9 (30%)	10 (36%)	10 (40%)
No work	11 (26%)	14 (47%)	10 (36%)	9 (36%)
Contributions <i>n</i> (%)				
Disability pension (full-time)	8 (19%)	6 (20%)	8 (28.5%)	5 (20%)
Disability pension (part-time)	16 (38%)	11 (37%)	10 (36%)	9 (36%)
Other *contributions*	3 (7%)	9 (30%)	2 (7%)	4 (16%)
No contributions	15 (36%)	4 (13%)	8 (28.5%)	7 (28%)
Education <i>n</i> (%)				
Compulsory school			10 (36%)	1 (4%)
Upper secondary school			16 (57%)	19 (76%)
University degree			2 (7%)	5 (20%)

Note. \*Other contributions mean study contribution, social allowance or unemployment compensation.

of those with MMC) answered that their bodily symptoms had aggravated, when asked if their bodily symptoms had changed since they were interviewed in 1997 (8). There were more people in group A that experienced aggravation of symptoms than in group B ( $p < 0.02$ ) during the period 1997/1998–2009. The problems that had increased for those with CP were the same for both groups; stiffness, pain, problems with balance and fatigue. For those with MMC, urinary problems (group A) and weakness, scoliosis and stiffness (group B) were worse.

**Mobility over time**

In the 2009 data set there were relatively more people in group A (54%) who never used a wheelchair (Table 2) than in group B (32%), despite the fact that they were older. Group B contained more participants with MMC and among participants with MMC (group A + B) 62% and with CP (group A + B) 30% always used a wheelchair. In group A, the number of participants who always used a wheelchair increased in 2009 compared with 1997 and the number of participants who occasionally used a wheelchair had decreased. In 2009, 32% in group A and 44% in group B used assistive devices for walking in the community.

**Practical personal assistance over time**

For participants who remained in the study in 2009, their need for practical personal assistance in 2009 was compared with their data from 1983 and from 1997/8.

The participants were asked if they had needed practical personal assistance at school in 1983 (group A) and in 1998 (group B), 50% in group A and 80% in group B had needed this kind of support, such as carrying trays and books. They were assisted either by other pupils or by teachers and other staff members at school.

Table 2. Use of wheelchair and assistive devices over time.

	A (N:55) 1983	A (N:42) 1997	B (N:30) 1998	A (N:28) 2009	B (N:25) 2009
	Mean age 24 yrs	Mean age 38 yrs	Mean age 26 yrs	Mean age 50 yrs	Mean age 37 yrs
	CP N:52 MMC N:3	CP N:39 MMC N:3	CP N:19 MMC N:11	CP N:25 MMC N:3	CP N: 15 MMC N:10
Wheelchair always	CP 25% (13) MMC 33% (1)	CP 26% (10) MMC 33% (1)	CP 26% (5) MMC 36% (4)	CP 36% (9) MMC 67% (2)	CP 20% (3) MMC 60% (6)
Wheelchair partly	CP 21% (11) MMC 0% (0)	CP 18% (7) MMC 0% (0)	CP 26% (5) MMC 36% (4)	CP 8% (2) MMC 0% (0)	CP 33% (5) MMC 30% (3)
No wheelchair	CP 54% (28) MMC 67% (2)	CP 56% (22) MMC 67% (2)	CP 47% (9) MMC 27% (3)	CP 56% (14) MMC 33% (1)	CP 47% (7) MMC 10% (1)
Assistive devices always	CP 10% (5) MMC 0% (0)	CP 13% (5) MMC 0% (0)	CP 21% (4) MMC 27% (3)	CP 8% (2) MMC 0% (0)	CP 27% (4) MMC 20% (2)
Assistive devices partly	CP 23% (12) MMC 0% (0)	CP 18% (7) MMC 33% (1)	CP 16% (3) MMC 27% (3)	CP 24% (6) MMC 33% (1)	CP 20% (3) MMC 20% (2)
No assistive devices	CP 67% (35) MMC 100% (3)	CP 69% (27) MMC 67% (2)	CP 63% (12) MMC 45% (5)	CP 68% (17) MMC 67% (2)	CP 53% (8) MMC 60% (6)

Practical personal assistance at work in group A was used by 7% in 1983, by 14% in 1997 and by 21% in 2009. Practical personal assistance at work in group B was used by 4% in 1998 and by 16% in 2009.

In 2009, 71% in group A and 76% in group B needed practical assistance. When interviewed in 1997–1998, 32% in group A and 48% in group B had needed practical personal assistance. The increased number of people in need of practical personal assistance in 2009 compared with 1997–98 was significant in group A ( $p < 0.001$ ) and in group B ( $p < 0.025$ ). In group A there were only three people with MMC and all needed practical personal assistance in 2009 and one in 1997. In group B in 2009, 90% with MMC and 67% with CP needed practical personal assistance and in 1998, 70% with MMC and 33% with CP needed practical personal assistance.

In 2009, a majority of the participants (A + B) had help with cleaning their homes, a substantial part had assistance with buying food and cooking, while the least common form of assistance was help when eating and drinking. Considering practical assistance, a majority of the participants thought they received sufficient help (Table 3). In group A, two people said that they wanted more help from their personal assistants; one said that home care was too expensive and one needed help from home care and intended to apply. In group B, two people needed more personal assistance; one of them had fought for more assistance without getting it and one needed help from home care but had been denied.

In 2009, the most common caregivers (A + B) were ‘families’ and ‘transportation for the disabled’ and the most common combinations of caregivers were ‘families and transportation for the disabled,’ and ‘personal assistants and transportation for the disabled.’ Thus, 40% (A + B) were partly or entirely assisted by their family, 21% of these were mostly helped by their partner/spouse and 19% were mostly assisted by their mothers. About half of the entire group used transportation for the disabled. Only 18% had home care.

### **Contacts with professional health care and other authorities in 2009**

In group A 68% of the participants and 76% in group B had contact with health care professionals. The most common professional was a physical therapist, 34% of the whole group (A + B) had that kind of contact and the second most common professional used was a physician, 28% of the whole group had that contact. Other professionals are described in Table 3.

### **What help did they want but did not receive?**

In group A 68% and 32% in group B were not content with the professional support they received. Discontentment was most prominent regarding contact with the specialized adult habilitation unit in Göteborg, but it was also seen in contacts with primary health care and other authorities. The same kinds of comments emerged from both groups. Therefore, all of the answers to this open question from both groups are included below (most common answer given first).

### ***Health care from specialists and others***

One factor mentioned by 13 participants was that access to the specialized team was limited and they were upset about this. The most prominent wish was to have

Table 3. Practical assistance, caregivers and health care.

	Group A CP N = 25 (%)	Group A MMC N = 3 (%)	Group B CP N = 15 (%)	Group B MMC N = 10 (%)
Information from 2009				
Practical assistance:				
Clean home	16 (64%)	3 (100%)	10 (67%)	9 (90%)
Buy food	13 (52%)	1 (33%)	7 (47%)	7 (70%)
Cook	8 (32%)	1 (33%)	7 (47%)	5 (50%)
Hygiene	8 (32%)	1 (33%)	5 (33%)	2 (20%)
Go to toilet	6 (24%)	1 (33%)	3 (20%)	2 (20%)
Dress and undress	8 (32%)	1 (33%)	7 (47%)	3 (30%)
Eat and drink	5 (20%)	0 (0%)	4 (27%)	0 (0%)
Sufficient practical assistance*	14 (78%)	3 (100%)	7 (87%)	9 (100%)
Caregivers:				
Families	11 (44%)	2 (67%)	5 (33%)	3 (30%)
Transportation for the disabled	15 (60%)	1 (33%)	6 (40%)	7 (70%)
Personal assistant	6 (24%)	1 (33%)	4 (27%)	1 (10%)
Home care	2 (8%)	1 (33%)	1 (7%)	3 (30%)
Special contact	0 (0%)	1 (33%)	0 (0%)	0 (0%)
Neighbour	0 (0%)	0 (0%)	1 (7%)	0 (0%)
Companion service	1 (4%)	0 (0%)	1 (7%)	0 (0%)
Nursing staff	0 (0%)	0 (0%)	0 (0%)	1 (10%)
Health care providers:				
Physical therapist	11 (44%)	1 (33%)	2 (13%)	4 (40%)
Physician	5 (20%)	1 (33%)	5 (33%)	4 (40%)
Occupational therapist	2 (8%)	2 (67%)	0 (0%)	2 (20%)
Social worker	3 (12%)	0 (0%)	1 (7%)	1 (10%)
Psychotherapist	2 (8%)	1 (33%)	0 (0%)	0 (0%)
Project within employment services	0 (0%)	0 (0%)	1 (7%)	1 (10%)
Clinical psychologist	0 (0%)	0 (0%)	1 (7%)	0 (0%)
Speech therapist	1 (4%)	0 (0%)	0 (0%)	0 (0%)
Audiologist	0 (0%)	0 (0%)	1 (7%)	0 (0%)
Prosthetist and orthotist	0 (0%)	0 (0%)	1 (7%)	0 (0%)
Job coach	1 (4%)	0 (0%)	0 (0%)	0 (0%)
Masseur	0 (0%)	0 (0%)	0 (0%)	1 (10%)
Dietician	1 (4%)	0 (0%)	0 (0%)	0 (0%)
No contact with health care professionals	8 (32%)	1 (33%)	5 (33%)	1 (10%)
Not content with health care	18 (72%)	1 (33%)	5 (33%)	3 (30%)

Note. \*Percentage of those in need of practical help.

follow-up visits with specialists at the adult habilitation unit, once a year or less often in order to meet with physicians, physical therapists, occupational therapists and medical social workers. Participants whose disabilities were not severe enough felt rejected. They argued that the advantage of having an accessible specialized team would be that a person could always contact the team when having a health problem. Four people felt that being referred to primary health care was frustrating since there was a feeling that the primary care physicians were lacking in competence.

Nine people argued that they wanted specialized physical therapy. Two people perceived physical therapy within primary health care as insufficient since they often only offer eight sessions per year per person. Five people needed contact with medical social workers within the specialized team both for psychological support and for practical chores, such as help with applications for financial aid. Two people experienced difficulties getting in touch with an occupational therapist in the community when they had been rejected from the specialist team.

### ***Social services***

Three participants did not like being investigated by social workers employed by the municipalities in order to get home care. They described it as a bureaucratic process where the person in need is dependent on the decisions of others; they said that it should be the people needing the help who make the decisions. One participant argued that in a system with a more individual approach, family members might be employed by home services or married couples might get help with cleaning even if they are not both disabled. One participant needed home care but could not afford it. One participant argued that the social services should contact people with disabilities to offer assistance.

### ***Employment services***

Three participants said that there seems to be a lack of resources to provide work, especially to people with disabilities. Also, two people experienced attitude problems with some members of staff, where they had not considered that people with disabilities can also be part of the labour force. One thought that the organization of the labour market for people with disabilities should be improved, with more unemployment benefits, retraining and one thought that the employment security of people with disabilities should be improved. One argued that work opportunities within new markets should be provided for people with disabilities.

### ***Social insurance office***

Two people said that the disability pension was so low that it was difficult to manage the expenses of daily life. One said that it should be possible to try employment without losing the disability pension. Currently, if it turns out that the disabled person is not fit enough to cope with employment he or she has to apply for disability pension again, this process takes time and the application may not be granted. One argued that education about life conditions for people with disabilities should be given to employees of social insurance offices to make them understand the people they meet with and to improve attitudes among employees and to create a dialogue about decisions that treat people with disabilities unfairly. The importance of education and better economic conditions when studying was also mentioned. One participant said that a person with higher education does not have to perform manual labour and the body can last to the age of retirement, and one is not forced to apply for disability pension when middle-aged. Three said that personal assistance with basic needs was generally provided, but assistance on vacation, trips or with activities during spare time and in the evenings was not provided. One person had appealed for more hours of assistance but the decision was not altered.

### **Transportation**

Criticism from nine participants of the study concerning transportation dealt with the computerized system used for organizing trips for the disabled. They said that the trips took much too long; a 15 minute ride could take one hour, because other people were picked up and dropped off at different locations along the way. The need for improvement of accessibility to public transportation was mentioned by three people.

### **Discussion**

The aim of this study was to focus on how symptoms and practical personal assistance have changed over time for people with CP and MMC and to describe the current contacts they have with health care professionals and other authorities. Perceived symptoms aggravated within both study groups over time and significantly more people in group A experienced this change for the worse compared with group B. Group A is older and consists of relatively more people with CP. In both groups, the number of participants needing practical personal assistance increased significantly between 1997/8 and 2009 and the most common helpers were families and personal assistants. Most people in both groups had contact with health care professionals and a substantial part wanted more assistance from health care professionals, especially access to a specialized team.

In our study, 26% worked full-time and 38% part-time and in the general population in Sweden, the number of people working full-time in the age range 35–64 years was 60% and part-time was 21%. Thus, a considerable number of people in our study worked less compared with the general population in this age group (Statistics Sweden 2009). Regarding marital status amongst 44-year-olds, 30% in our study were married compared with 50% of the general population (Statistics Sweden 2010).

### **Perceived bodily symptoms over time**

One of the most striking results was the development of perceived bodily symptoms over time in participants of both group A and group B. Significantly more people in group A (average age of 50) reported aggravated problems such as pain, stiffness and balance problems in relation to CP compared with the situation 12 years earlier. Even though no longitudinal studies have been found, one survey study confirms this result; chronic pain is a pronounced problem among adult people with CP (Jahnsen et al. 2004a) and a review article about people with CP describes pain related to increasing age and inactivity (Vogtle 2009). Increasing urinary problems, scoliosis, stiffness and weakness were mentioned in relation to MMC in our study, and these problems are also mentioned in an earlier review article (Dicianno et al. 2008).

### **Mobility**

We described the mobility problems over time by stating whether the participants used wheelchairs always, occasionally or never. In group A and B in 2009, 70% of the participants with CP were ambulators with or without assistive devices compared with 78% in a Norwegian study (Jahnsen et al. 2004b) and 76% in a Dutch study

(Nieuwenhuijsen et al. 2008). People with intellectual disabilities were not included in any of these studies.

### **Practical personal assistance**

From this study it seems as if people with MMC in 2009 to a larger extent needed support with buying food and cleaning, but the increase over time is more pronounced in the CP population. Many of the participants of our study had always needed practical personal assistance from others, but they had more support at school than later on as young adults. Later in life, because of increasing pain and more pronounced mobility problems, they had to accept assistance from others, according to our study results. Elderly people in Sweden have practical personal assistance from their families (Barron et al. 2000) and according to our study so do middle-aged people with a disability. Almost half of the participants in this study were entirely or partly supported by their husbands, wives or mothers.

Only seven out of 53 people had home care; many more were assisted by family members. In order to get formal home service a person has to contact social services and be thoroughly investigated by care managers employed by social services in Sweden. These care managers are extremely loyal to the guidelines and policies of the organisation and make their decisions entirely in agreement with them (Dunér and Nordström 2006). Since the 1990s the proportion of formal home care has decreased and assistance from voluntary organizations and private enterprises have increased (Barron et al. 2000; Larsson 2004). It is especially difficult to get home care for household tasks if you have an able-bodied spouse.

Mothers played a key role for 10 people in our study. According to one author, ageing caregivers face problems with social isolation and declining resources, and they have lingering worries about who will care for their loved one when they are unable to do so (Braddock 1999). In our study, the participants were adults and their mothers were middle-aged or elderly. It is very demanding for parents with a grown-up disabled child, giving practical personal assistance, being responsible for their finances and managing contact with health care professionals (Whitaker 2008).

### **Contacts with professional health care and other authorities in 2009**

The majority of the participants in the two groups had professional contacts within the health care system but 32% of group A and one quarter of group B had no such contacts. Sixty-eight percent in group A and 32% in group B were not content with the professional support they received. According to our study and to Binks et al. (2007), a substantial proportion of the participants with CP or MMC wanted to belong to an adult habilitation unit. There it would be possible to get continuous age-appropriate care after the transition from child habilitation units (Binks et al. 2007).

### **What help did they want but did not receive?**

Our study showed that even though some people had fought for more hours of 'personal assistance,' most people were content with the assistance given. In order to obtain autonomy during journeys and outdoor activities, a few people stressed the importance of more hours of assistance. Most of the participants with pronounced

needs for ‘personal assistance’ seemed to get what they needed and wanted in this respect, and this is in accordance with an earlier state report (Barron et al. 1999).

Participation in society can be more difficult for people with a disability because they often have financial problems. Some of the participants in our study stressed that it is difficult for a person on a disability pension to pay for home care, transportation for the disabled and food, and this is in accordance with the results of another study (Munir 2006) which showed that extra expenses related to the disability and a lower income from the disability pension, put people with a disability in a more economically vulnerable situation. They are not in a position where they can choose to buy home help or treatment from a physical therapist, if they need more than what the state provides.

In this study, physical therapy was mentioned as the most wanted allied health care within a specialized team, but all other professional members of this specialized team also were wanted and needed. This result is in accordance with a Dutch study (Nieuwenhuijsen et al. 2008) which showed that in-patient rehabilitation, physical therapy and visits with hospital specialists were needed much more than were being offered within the Dutch system.

This study shows that adults with CP have increasing problems with balance, stiffness and pain, and that, not surprisingly, they wanted better access to health care providers. According to the Convention on the Rights of Persons with Disabilities, signed by Sweden (Government bill 2008), each state shall provide these health care services needed by people with disabilities. Each state shall organize, strengthen and extend the habilitation services which are available to people with disabilities. Each state shall also take effective and appropriate measures to enable people with disabilities to attain and maintain maximum independence and full participation in all aspects of life. The participants of our study group needed to have access to health care and habilitation units for assistance with physiological needs and to obtain a sense of medical security. In order to obtain full participation in society, physiological needs have to be taken care of first before getting a job and starting a family.

This study is non-experimental. We used a convenience sample and our target group was limited and cannot be seen as representative for all people with CP and MMC. However, in many ways the severity of the disability of the people included in our study population resembles those of other comparable studies (Jahnsen et al. 2004a; Nieuwenhuijsen et al. 2008). We interviewed a selection of people with CP or MMC referred to an adult habilitation unit. When the first study started with one of these groups (A) in 1983 one of the inclusion criteria was normal intellectual capacity to specifically investigate the influence of a bodily impairment in relation to societal conditions, this criteria has not been altered over time. The accessibility to health care and habilitation services is of course a local phenomenon, thereby reducing generalisability. Unfortunately, studies from the Netherlands, the US and Canada show that this local problem may be prevalent worldwide (Nieuwenhuijsen et al. 2008; Engel et al. 2002; Binks et al. 2007; Young et al. 2009; White 2002). The strength of this study is its longitudinal perspective, and the fact that it highlights an area where much more research is needed. However, the longitudinal approach has resulted in an ongoing use of non-validated questionnaires. Both health care professionals and health care planners and organizers need more information about adults with disabilities.

## Conclusion

In conclusion the most important findings of our study are that symptoms become aggravated over time and that there has been a significant increase in the number of people needing practical assistance over the last 11 to 12 years. Most people in our study were satisfied with the personal practical assistance they received, but felt that there was a lack of sufficient assistance from the adult habilitation unit in particular, and also from other health care professionals and authorities. In order for Sweden to adhere to the UN Convention on the Rights of Persons with Disabilities there is still work to be done. Among other things, the adult habilitation units must provide more assistance to a larger number of people with disabilities.

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