

Brief Report

# Work participation among middle-aged persons with cerebral palsy or spina bifida – a longitudinal study

Marie Törnbom, Ph.D.<sup>a,b,\*</sup>, Ulrica Jonsson, M.D.<sup>a</sup>, and Katharina S. Sunnerhagen, M.D., Ph.D.<sup>a,c</sup>

<sup>a</sup>Research group for Rehabilitation Medicine, Institute of Neuroscience and Physiology, Sahlgrenska Academy, University of Gothenburg, Sweden

<sup>b</sup>Department of Social Work, University of Gothenburg, Sweden

<sup>c</sup>Sunnaas Rehabilitation Hospital, The Medical Faculty, Oslo University, Norway

## Abstract

**Background:** Most studies of work participation among persons with cerebral palsy (CP) or spina bifida (SB) have focused on young adults, little is known about older adults.

**Objective:** The aim of this study was to compare work participation in 2009 with 1997 (98).

**Methods:** Two groups of persons with CP or SB in Gothenburg, Sweden with an IQ above 70 were interviewed using a structured questionnaire regarding work participation. 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 ( $n = 25$ ). In this study, the persons interviewed in 2009 were compared with their own data from 1997 (8), with a non-parametric test.

**Results:** Work participation had significantly decreased ( $p < 0.004$ ) since 1997 (8); more persons worked part time or had stopped working. Thirty-eight percent had continued their education during 1997 (8)–2009, most of them worked. Of 34 persons working in 2009, 56% had wage subsidies, an increase from 42% in 1997 (8). Of the persons who worked and had continued their education, 37.5% had wage subsidies while, among persons without continued education, 72% had this support. Transportation to work functioned but not as well as in 1997 (8). More persons used transportation for people with a disability in 2009 than in 1997 (8) and criticism was expressed about the transportation system.

**Conclusions:** Results showed that work participation for middle-aged persons with CP or SB without intellectual disability decreased with age but continued education and wage subsidies facilitated work participation. © 2014 Elsevier Inc. All rights reserved.

**Keywords:** Cerebral palsy; Spina bifida; Work; Employment; Education

Studies indicate that persons with cerebral palsy (CP) or spina bifida (SB) have difficulty obtaining competitive employment. In a Norwegian and a Danish study with adults with CP without intellectual disability 33%<sup>1</sup> and 29%<sup>2</sup> were competitively employed, respectively. In a Swedish study about adults with CP with no documented learning disability, 47% were employed but without information how many that

had wage subsidies.<sup>3</sup> In a Dutch study of CP with IQ above 70, 24% had a regular employment.<sup>4</sup> Mitchell and colleagues<sup>5</sup> investigated the roles of aging and disability on lifespan employment status among 262 people with disabilities not having a cognitive impairment and 115 people without disability aged 23–64 years. CP was one of the six impairment groups studied. Those who had some college education among persons with disability reported a 49% employment rate versus 23% among those with high school or less in their 20s and 30s, but higher education did not prevent significant employment loss by their 40s. The group with disabilities reported faster and earlier declines in employment in a lifespan perspective than those without disabilities.<sup>5</sup> A Swedish study of adults with SB showed that 17% were competitively employed and 23% were employed with wage subsidies. A higher educational level increased work participation.<sup>6</sup> In a British study of adults with SB, 24% were competitively employed.<sup>7</sup> In a Canadian study about CP or SB, one explicit hindrance for working seemed

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Parts of the contents have been presented at national conferences in 2010 and 2011.

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\* Corresponding author. Sektionen för klinisk neurovetenskap och rehabilitering, Rehabiliteringsmedicin, Per Dubbsgatan 14, 3 tr Sahlgrenska universitetssjukhuset, 413 45 Göteborg, Sweden. Tel.: +46 31 3423343.

E-mail address: Marie.Tornbom@neuro.gu.se (M. Törnbom).

to be transportation barriers.<sup>8</sup> Contextual factors, such as affirmative action or wage subsidies, personal assistants and other kinds of societal support might facilitate work participation in people with disabilities. In Sweden, wage subsidies for individuals with disabilities have been used for several decades and have been considered an efficient method.<sup>9</sup>

Earlier data collections in this project showed that 82% of the young adults (A) involved in 1983 worked or studied. Most of them worked or studied in 1997 and two thirds of a newly recruited group of young adults in 1998 (B) worked. They all worked significantly more often part time in 1997 (8) compared with those studied in 1983.<sup>10</sup> Bodily symptoms were aggravated in group A and B in 2009 compared with 1997 (8) and significantly more in A than in B.<sup>11</sup> Our clinical experience was that work participation among adults with a disability declined over time. The aim of the present study was to describe changes in work participation and facilitators and hindrances for working between 1997 and 98 and 2009. The study involved persons with CP or SB without an intellectual disability in Gothenburg, Sweden.

## Methods

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

The study is a follow-up of studies that were conducted in 1983 and in 1997 (8) in Gothenburg, Sweden, and the study design was the same as the previous data collections.<sup>12,13</sup> Two groups of young adults (19–33 yrs) with CP or SB were included in this study. A follow-up was undertaken at 14 years for the first group recruited (1997–1998) and at 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. 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, 30 people, were included in 1998; their mean age in that year was 26. The study design is shown in Fig. 1. This paper describes changes in a 12 year period (between 1997 (8) and 2009). The main part of group A consisted of persons with cerebral palsy, while group B contained more with SB.

The inclusion criteria were as follows: all persons who had CP or SB and ongoing contact with the adult habilitation clinic at the Department of Rehabilitation Medicine, Sahlgrenska University Hospital in Gothenburg, Sweden, in 1983 (group A) and in 1998 (group B) were asked to participate. There were people with CP or SB in the community who did not attend the adult habilitation clinic; it is unclear how many this might be. Participants who no longer attended the adult habilitation clinic at the time of the follow-ups were still included in the study. In 1983, ten people attending the adult habilitation clinic declined to participate; it is unclear how many of those had either

CP or SB. In 1998, nine persons with CP and four persons with SB declined to participate. At the time of inclusion, their ages were 19–33, they lived in Gothenburg and could communicate in Swedish. All of the participants had either CP or SB, had attended regular schools, some had periodically attended special schools or special classes in regular schools for persons with motor impairments or minor learning difficulties, all had an IQ above 70. At that time, persons with an IQ below 70 were treated in another unit. 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 clinic in 1983 or 1997.

Data collections in 1983 and in 1997/8 have been published in earlier studies (Törnblom et al, 2011 and 2012).<sup>12,13</sup>

## 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 wished to participate. All 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. The questions were structured and asked the same way regardless of interviewer. They were conducted during the autumn of 2009. All answered for themselves. In 2009, 14 participants from group A and five from group B in 1997 (8) did not participate. Of persons lost to follow-up in group A, five worked full time, six worked part time and three had a full time pension in 1997. Non-participants did not differ in terms of work participation compared with the whole group in 1997.<sup>13</sup> In group B, four had a full time pension and one studied half time.

Themes of questionnaires were similar to those in earlier data collections: continued education during the period 1997 (8)–2009, educational plans for the future, whether they had an occupation and how much they worked, whether they had wage subsidies, whether they had changed occupation, what kinds of help were needed at the work place, means of living and experiences of accessibility.

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 persons working (group A + B) in 1997 (8) in comparison with the same persons in 2009.

## Results

The demographics of the study sample in 2009 are shown in Table 1.

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