

Social integration of adults with cerebral palsy

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Social integration and independence is the ultimate goal of habilitation and social support for patients with cerebral palsy (CP). Having a partner and having children provide support for social integration of adults with or without a disability. We studied 416 participants with CP born between 1965 and 1970 (243 males, 173 females; mean age 32y 2mo [SD 2y]; age range 29–35y) and compared them with 2247 age-matched comparison individuals. Diagnostic subtypes of the 416 participants were: 31% hemiplegia, 49% diplegia, 11% tetraplegia, and 9% other types. The level of motor impairment, estimated in childhood, with regard to walking ability was 65% able to walk without assistance, 22% with assistance, and 12% not able to walk (for 1% of the participants their walking ability was not known). We found no sign of increased social integration over the past two or three decades in Denmark. Sixty-eight per cent lived independently, 13% lived with their parents, and 16% lived at an accommodation facility arranged by the county (institution). Twenty-eight per cent of the participants were cohabiting and 19% had children. The presence of epilepsy and the severity of physical or cognitive impairment as assessed in childhood predicted independent living and physical and cognitive impairment predicted cohabitation, but parents' socioeconomic position and region of living did not. Fifty-five percent of the participants, compared with 4% of the comparison group, had no competitive employment, cohabiting partner, or biological children. The remaining participants had at least one of these types of social contact, but this more optimally socially integrated half of the participants only combined all three types of social contact half as often as the comparison group. This could be due to cognitive difficulties or premature ageing.

Independent life and integration into society are as important for adults with cerebral palsy (CP) as they are for other people. We have previously described employment in adults with CP,¹ but accommodation and cohabitation are other important parts of independence and participation in society and are the ultimate goal of habilitation. Living independently and being employed might promote physical and financial independence; employment, cohabitation, and having children could support social participation. To ensure an optimal environment and habilitation for people with disabilities, social welfare authorities need information on the status of independence among people with disabilities today.

Previous studies on accommodation and cohabitation in CP were based on selected populations, included very young adults, or measured cohabitation according to marital status, which is very different from cohabitation today.^{2–6}

The present study analyzed accommodation, cohabitation, and children born to adults with CP compared with the comparison group from the general population matched for age and sex. Correlations between cohabitation, employment, and having children were also analyzed. The participants were born between 1965 and 1970 and were compiled from the Danish Cerebral Palsy Registry covering eastern Denmark.⁷ Changes in social integration were analyzed by comparing results with those from a previous Danish study that included adults with CP born between 1940 and 1945.^{8,9}

Methods

PARTICIPANTS

The materials and methods have been described in detail previously.¹ All 486 people born between 1965 and 1970 with congenital CP who were registered in the Danish Cerebral Palsy Registry on 31 December 1999 were enrolled in this study. The comparison group were people living in eastern Denmark born between 1965 and 1970 selected from the Civil Registration System, which covers all residents of Denmark. One comparison could not be traced, and after adjusting for deaths and emigrants the study population included 416 participants and 2247 comparison individuals. After studying parents' socioeconomic position only the 359 participants living with their parents at the age of 15 were included. After analysis of predictors of independent living, only the 377 participants with a known status of accommodation and severity of cognitive and motor impairment were included. Finally, after analysis of predictors of cohabitation, only the 283 participants with a development quotient (DQ) of more than 50 and with an ability to walk were included.

DATA SOURCES

Danish Cerebral Palsy Registry

The Danish Cerebral Palsy Registry is a population-based registry that contains cases of CP from the birth year 1925 and has reported the birth prevalence since 1950.^{7,10–12} The uptake includes 2.5 million people in eastern Denmark, about half the Danish population.

Registries in Statistics Denmark

Information on accommodation, cohabitation, children, education, employment, and income were obtained from registries kept by Statistics Denmark through linkage with the Civil Registration System. The data sources are schools, educational institutions, workplaces, and local authorities, which are all

obliged by law to deliver information to Statistics Denmark.

DEFINITIONS

Cerebral palsy

CP is an umbrella term covering a group of non-progressive, but often changing, motor impairment syndromes secondary to lesions or anomalies of the brain arising in the early stages of its development.¹³ Disability is measured by severity. The severity of motor impairment is measured by the ability to walk. The severity of cognitive impairment is measured by DQ. The DQ is estimated to be more than 85 when school was begun without help (excluding manual assistance) and between 85 and 50 for those needing more support at school. The third category is a DQ of less than 50. Epilepsy is registered if there are two or more unprovoked seizures after the neonatal period. Diagnosis, subtype of CP, DQ, ability to walk, and epilepsy, are estimated when the child is 6 years old.⁷

Accommodation

Accommodation is based on information from the Social Pensions Registry of the Danish Local Government Computing Centre, the Central Register of Buildings and Dwellings, and the Civil Registration System. The accommodation is categorized as living with parents, living in an accommodation facility arranged by the county, or living independently. In 1998 Denmark abolished the concept of 'institutions', and accommodation was separated into accommodation facility and personal assistance. Counties are especially obliged to ensure accommodation facilities to persons in need of care and treatment. Severely disabled persons often live in 'accommodation facility arranged by the county' (the concept closest to 'institutions'), where these services are present, but in contrast with the old institutions, inhabitants still receive their anticipatory pension and decide what to buy. As a consequence some people with severe disabilities might live in ordinary housing and receive substantial personal assistance.

Cohabitation

Cohabitation is based on the constitution of a family living at the same address. Persons can be single, single with children, cohabiting without children, or cohabiting with children. Cohabitation is measured both in participants and the comparison group and in parents of participants and the comparison group.

Table I: Accommodation among people with cerebral palsy (CP) aged 29–35 years versus comparison group

Accommodation type	%	
	CP (n=416)	Comparison group (n=2247)
Independent	68	92
With parents	13	5
Arranged by the county ^a	16	<1
Unknown	3	3

^aThis is close to the concept of an 'institution' that Denmark abolished in 1998. Accommodation facility and personal assistance were separated, and sheltered accommodation therefore does not exist. People living independently might receive substantial practical help to manage activities of daily living. $p < 0.001$.

Education

Education is grouped according to whether the highest education was beyond lower secondary school or not. The highest level of education of the parents is described on the basis of the parent with the highest level of education (biological or non-biological) living with the participant or comparison at the age of 15 years. Education is measured both in participants and in the comparison group and in parents of participants and the comparison group.

Employment

Competitively employed means working on equal terms with people who are not disabled. Employment is measured both in participants and the comparison group and in parents of participants and the comparison group.

Income

Household annual income is the sum of the pretax income of the parents (biological and non-biological) living with the participant or comparison at 15 years of age. Amounts from different calendar years were adjusted to 1980 equivalents. Any tax-free benefits received by participants or the comparison group are not included in annual income. Participants not living with any parents at the age of 15 years have their income defined as unknown. The households were divided into quintiles according to the annual income of the the comparison group.

Region of residence

Eastern Denmark is currently divided into seven counties and the City of Copenhagen. We converted these into four regions for this study, each region having about the same population density and distance from Copenhagen.

STATISTICAL ANALYSIS

Analysis was based on contingency tables and associated χ^2 tests. We analyzed the predictors and indicators of living independently and cohabitation by using multivariate logistic regression. The odds ratios are presented with 95% confidence intervals.

ETHICS

The Danish Data Protection Agency approved this study. The civil registration numbers of participants were delivered to Statistics Denmark, and each civil registration number was replaced by an identification number immediately after being linked to other registries. All analyses are based on this number, and identifying individual people is neither possible nor legal. Only Statistics Denmark knows the key between the civil registration number and the new identification number.

Results

CHARACTERISTICS OF THE STUDY POPULATION

The mean age for both participants and the comparison group born between 1965 and 1970 in this study was 32 years 2 months (SD 2y; age range 29–35y).

ACCOMMODATION

Table I shows that two-thirds of the participants aged 29 to 35 years were living independently. More participants than comparison individuals were living with their parents. Accommodation did not differ by sex between participants,

whereas significantly more males in the comparison group lived with their parents ($p=0.001$). We analyzed the type of accommodation facility for participants and found that 22% were living at nursing homes for elderly people, 45% were living at accommodation facilities for people with substantial impairment of physical or cognitive functioning, and 34% had an unknown type of accommodation facility.

Table II describes the severity of CP and parents' socioeconomic position according to type of accommodation. Few participants living independently had a DQ of less than 50 or were not able to walk, and only 10% had epilepsy. Nearly half the participants still living with their parents had a DQ of less than 50 or epilepsy. This is similar to the participants living in accommodation facilities arranged by the counties and very different from the percentages of participants living independently. Significantly fewer participants with no ability to walk lived with their parents than at an accommodation facility arranged by the county ($p<0.001$). Of the 77 participants with epilepsy, 30% lived independently as adults, 30% lived with their parents, and 36% lived at an accommodation facility arranged by the county (not shown). Corresponding numbers for the 83 participants with a DQ of less than 50 were 13, 30, and 52% and for the 49 participants with no walking ability they were 20, 20, and 55% (not shown).

DQ, presence of epilepsy, and severity of motor impairment significantly predicted not achieving independent living in adulthood (Table III). The subtype of CP significantly predicted independent living, but not in the multivariate

analysis. Parents' highest educational level, income, cohabitation, and region of residence when the participants were aged 15 years did not significantly predict independent living and were not included in the multivariate analysis.

COHABITATION

Twenty-eight per cent of the participants (compared with 69% of the comparison group) were cohabiting (Table IV); 11% of the participants and 19% of the comparison group had previously been cohabiting but were living alone at the age of 29 to 35 years ($p<0.001$, not shown). Slightly more participants than those in the comparison group had been divorced or previously cohabiting among the participants and those in the comparison group who had ever been cohabiting (not shown). Fifteen per cent of the participants and 42% of the comparison group were married, whereas 13% of participants and 26% of the comparison group were cohabiting without being married ($p<0.001$, not shown).

No participant assessed in childhood with a DQ of less than 50 or with no walking ability was living with a partner. Among the rest of the adults with CP, the severity of cognitive and motor impairment predicted cohabiting equally strongly (Table V). Epilepsy was included in the multivariate analysis despite no significance on the chosen 5% level, because it was nearly significant, and only four adults with epilepsy cohabiting resulted in a broad confidence interval. Parents' highest educational level, income, cohabitation, and region of residence when the participants were aged 15 years did

Table II: Severity of cerebral palsy (CP) and socioeconomic position of participants and parents according to accommodation in people with CP aged 29–35 years.

<i>Characteristic</i>	<i>Independent % (n)</i>	<i>With parents % (n)</i>	<i>Facility arranged by county % (n)</i>	<i>Unknown % (n)</i>
(<i>n=416</i>)	<i>n=284</i>	<i>n=55</i>	<i>n=65</i>	<i>n=12</i>
Severity of CP ^a (assessed in childhood)				
Epilepsy ^b	8 (23)	42 (23)	43 (28)	25 (3)
DQ<50 ^b	4 (11)	45 (25)	66 (43)	33 (4)
Not walking ^b	4 (10)	18 (10)	42 (27)	17 (2)
Highest educational level ^a				
Participant beyond lower secondary school ^b	50 (143)	13 (7)	0 (0)	8 (1)
Employment				
Participant competitively employed ^b	45 (128)	15 (8)	0 (0)	17 (2)
Parents' socioeconomic position when participant was aged 15y ^c				
(<i>n=359</i> ^d)	<i>n=267</i>	<i>n=54</i>	<i>n=30</i>	<i>n=8</i>
Highest education ^a				
Parents beyond lower secondary school	72 (192)	65 (35)	77 (23)	63 (5)
Cohabitation				
Parents cohabiting	81 (217)	80 (43)	87 (26)	88 (7)
Household income ^a				
Lowest 20%	21 (55)	33 (18)	23 (7)	25 (2)
Parents not living with their child at age 15y				
(<i>n=57</i> ^d)	<i>n=17</i>	<i>n=1</i>	<i>n=35</i>	<i>n=4</i>
Accommodation of participant aged 29–35y ^b	30 (17)	2 (1)	61 (35)	7 (4)

Results are percentages and numbers in three groups of accommodation with different characteristics. ^aSix per cent (26) of participants had an unknown severity of cognitive impairment, 23 lived independently; 1% (6) of participants had an unknown severity of motor impairment; 3% (13) of participants had an unknown highest education, 8 lived independently; 2% (8) of parents had an unknown highest education, 6 had children and were living independently; one set of parents had an unknown household income. ^bStatistical significant difference on a 5% level. ^cParents are adults living with participant, including both biological and non-biological parents. ^dOf 416 participants, 57 did not live with their parents when they were 15 years old, and data on parents socioeconomic position were not recorded; accommodation is reported separately for this group at bottom of table. DQ, development quotient.

not significantly influence cohabitation and were not included in the multivariate analysis. No effect modification of parents' highest education, parents' income, parents' cohabitation, or region of residence was found.

CHILDREN

Table VI shows that 19% of the participants had biological children, compared with 61% of the comparison group ($p < 0.001$). Twenty-seven per cent of the female participants and 13% of the male participants had children ($p < 0.001$), compared with 69% of females in the comparison group and 55% of males in this group ($p < 0.001$, not shown). Seventy-nine per cent of participants with biological children were estimated in childhood as having a normal DQ and 87% were assessed as being able to walk without assistance. No participant with a DQ of less than 50 or no walking ability had biological children. Eighty-five per cent of the participants and

91% of the comparison group with biological children lived together with their children ($p = 0.058$).

COHABITATION, BIOLOGICAL CHILDREN, AND COMPETITIVE EMPLOYMENT

Fifty-five per cent of the participants (compared with 4% of the comparison group) were not cohabiting, had no competitive employment, and had no biological children; 11% of participants and 46% of the comparison group had all three social contacts. Even among those with at least one of these social contacts, only one-quarter (44/186) of the participants had all three social contacts, compared with half of the comparison group (103/2149).

Discussion

VALIDITY

We consider the participants to be very close to a representa-

Table III: Predictors of not living independently for people with cerebral palsy (CP) aged 29–35 years (multivariate logistic regression)

Characteristic	<i>n</i>	OR (95% CI) ^b	OR (95% CI) ^c
Subtype of CP (estimated in childhood)		$p < 0.001$	
Hemiplegia	119	1	
Diplegia	181	2.49 (1.36–4.57)	
Tetraplegia	44	20.41 (8.52–48.89)	
Other	33	4.07 (1.70–9.75)	
DQ (estimated in childhood)		$p < 0.001$	$p < 0.001$
> 85	199	1	1
85–50	99	6.16 (3.15–12.05)	4.02 (1.96–8.24)
< 50	79	80.30 (34.55–186.58)	36.81 (14.89–91.08)
Epilepsy (estimated in childhood)		$p < 0.001$	$p = 0.013$
No	304	1	1
Yes	73	7.63 (4.34–13.41)	2.56 (1.23–5.36)
Motor impairment (estimated in childhood)		$p < 0.001$	$p = 0.015$
Walks without assistance	251	1	1
Walks with assistance	79	4.14 (2.37–7.23)	1.99 (0.99–3.99)
Not walking	47	18.04 (8.29–39.26)	3.82 (1.39–10.49)
Parents' highest education ^a		$p = 0.511$	
Beyond lower secondary school	233	1	
Lower secondary school	86	1.21 (0.69–2.11)	
Unknown	58	Not in analysis	
Parents' income ^a		$p = 0.121$	
Highest 80%	253	1	
Lowest 20%	72	1.58 (0.89–2.82)	
Unknown	52	Not in analysis	
Parents' cohabitation ^a		$p = 0.825$	
Partner	267	1	
Single	59	0.93 (0.48–1.80)	
Unknown	51	Not in analysis	
Region of residence ^a		$p = 0.151$	
Cities of Copenhagen and Frederiksberg and Copenhagen County	131	1	
Frederiksborg and Roskilde Counties	79	0.61 (0.31–1.21)	
Vestsjælland, Storstrøm, and Bornholm Counties	60	1.28 (0.65–2.50)	
Fyn County	41	0.52 (0.21–1.29)	
Moved outside Eastern Denmark or unknown	66	Not in analysis	

Results are for 377 people; 39 of 416 participants were excluded because of missing data: 27 lacked data on severity of cognitive or motor impairment (20 were living independently), 11 participants had unknown accommodation (and different level of severity of cognitive and motor impairment), and one participant lacked data on both cognitive impairment and accommodation. ^aParents' highest education, cohabitation, and income and the participants' region of residence were analyzed when participant was 15 years of age; 51 participants not living with their parents at age 15 years were not included in univariate analyses; in addition, seven parents of participants had an unknown highest education, one set of parents had an unknown income, and 15 sets of parents had moved outside Eastern Denmark. ^bControlled for age. ^cControlled for sex and other significant predictors. Only variables statistically significant on a 5% level in multivariate analysis were included. OR, odds ratio; CI, confidence interval; DQ, development quotient.

tive sample of young adults with CP in Denmark. However, some bias should be considered. Topp et al.¹⁴ studied the validity of the Registry in 1997 and found the number of people with CP born between 1979 and 1982 to be underestimated by 15%. The young adults with CP not registered did not differ from the registered hospitalized persons in the severity of impairment or clinical subtype. A possible selection bias compared with the CP participants of today is insufficient reporting of persons with mild CP who are either not diagnosed or have not contacted a paediatric department or special institution. This would probably overestimate the adverse social effects of CP. Twenty-eight participants lacked data on severity of cognitive and/or motor impairment and are not included in analyses on predictors of independent living or cohabitation. Fewer in this subgroup had epilepsy and they were often living independently and with a partner.

The data from the registries of Statistics Denmark are considered complete and valid, because the institutions are required to provide this information by law and have been delivering these data for 20 years. Data on education and accommodation were missing in about 3% of participants and the comparison group. Participants lacking data had various severities of cognitive and motor impairments.

ACCOMMODATION

Among adults with CP aged 30 years, born between 1940 and 1945 who were recorded in the Danish Cerebral Palsy Registry, 67% lived independently, 10% at an institution, 11% with their parents, 8% in foster care, and 4% in sheltered accommodation.⁸ This is very close to our results on participants born 25 to 30 years later. However, institution and accommodation facility arranged by the county might not be comparable. Institutions

Table IV: Cohabitation among participants with cerebral palsy (CP) aged 29–35 years compared with comparison group

Cohabitation	%	
	CP (n=416)	Comparison group (n=2247)
Single without children	71	26
Single with children	1	5
Couple without children	13	17
Couple with children	15	52

Results include both biological and non-biological children.
 $p < 0.001$.

Table V: Predictors of no cohabitation among participants with cerebral palsy (CP) aged 29–35 years (multivariate logistic regression)

Characteristic	n	OR (95% CI) ^b	OR (95% CI) ^c
Subtype of CP (estimated in childhood)		$p = 0.014$	
Hemiplegia	114	1	
Diplegia	150	2.00 (1.19–3.39)	
Other	19	3.11 (0.94–10.22)	
DQ (estimated in childhood)		$p < 0.001$	$p = 0.004$
>85	197	1	1
85–50	86	3.58 (1.92–6.67)	2.61 (1.36–5.01)
Epilepsy (estimated in childhood)		$p = 0.008$	$p = 0.071$
No	252	1	1
Yes	31	4.40 (1.47–13.19)	2.86 (0.91–8.94)
Motor impairment (estimated in childhood)		$p = 0.002$	$p = 0.020$
Walk without assistance	228	1	1
Walk with assistance	55	3.25 (1.56–6.78)	2.49 (1.16–5.37)
Parents' highest education ^a		$p = 0.890$	
Beyond lower secondary school	187	1	
Lower secondary school	69	1.04 (0.58–1.88)	
Unknown	27	Not in analysis	
Parents' income ^a		$p = 0.194$	
Highest 80%	206	1	
Lowest 20%	56	1.54 (0.80–2.96)	
Unknown	21	Not in analysis	
Parents' cohabitation ^a		$p = 0.973$	
Partner	213	1	
Single	50	1.01 (0.52–1.96)	
Unknown	20	Not in analysis	
Region of residence ^a		$p = 0.129$	
Cities of Copenhagen and Frederiksberg and Copenhagen County	105	1	
Frederiksberg and Roskilde Counties	64	1.25 (0.65–2.41)	
Vestsjælland, Storstrøm, and Bornholm Counties	45	1.85 (0.86–3.98)	
Fyn County	36	2.54 (1.06–6.09)	
Moved elsewhere in Denmark or unknown	33		

Results are for 283 people; 125 of 416 participants were excluded from this analysis: 28 had an unknown severity of cognitive or motor impairment (11 were living with a partner) and 105 participants had tetraplegia, a DQ of less than 50, or were not able to walk, and none in this group were living with a partner. ^aParticipants' region of residence was analyzed when participant was 15 years old. ^bControlled for age. ^cControlled for sex and other significant predictors. Only variables statistically significant on a 5% level in multivariate analysis were included, except for epilepsy, which was nearly significant. OR, odds ratio; CI, confidence interval; DQ, development quotient.

before 1980 were large and segregated from society, whereas today there are more small accommodation facilities in the local areas arranged by the county. We would have expected more people living in ordinary housing to be receiving substantial help compared with 25 to 30 years ago. One reason that the number of people living in institutions has not been reduced could be that we had more participants with severe CP than Glenting in the 1970s,⁸ because more children with severe CP probably survive to adulthood today. Glenting assessed severity of impairment in adulthood, whereas we have only had the assessment made at the age of 6 years. He found 12% of the 518 adults to be have a learning disability* and we found 20% of our 416 participants to have a DQ of less than 50.⁸

Other studies²⁻⁶ found that between 40 and 66% of adults with CP were living independently and between 13 and 58% were living with their parents. None of the studies was population based and selection criteria for study populations differed, making it difficult to compare results. Two important predictors of independent living and cohabitation, age, and degree of severity among participants, often differed substantially.

Women entered the labour market in Denmark between the 1940s and the 1960s. Since 1980, the idea of integrating people with disabilities in society has been advocated and this is now stipulated by law in Denmark. Despite the difficulty in making up the comparison group, we find it noteworthy that about the same percentage of adults with CP who were living as dependents on either parents or society in 1970 were also living this way 25 to 30 years later. The figure of 13% of the 29- to 35-year-olds living with their parents in Denmark seems to be lower than in the two studies from California^{4,5} and about the same as in the study in Sweden,² but the study populations are very different, so the exact influence of different social systems is hard to judge.

Denmark has accommodation facilities for people with severe disabilities as described, but one in five participants aged 29 to 35 years who were living at an accommodation facility arranged by the county lived at nursing homes for elderly people. Such homes are not meant to meet the needs of disabled young adults and must be considered an improvised, unsatisfactory solution. The similarity in severity between adults living with their parents and adults at an accommodation facility arranged by the county indicates that living with parents might be an alternative to such accommodation facilities. Besides a lack of suitable homes, other reasons that adults with CP live with their parents could be that parents resist letting go of their disabled children or the lack of social competencies among young disabled adults.^{3,6,15-17}

*North American usage: mental retardation.

Table VI: Biological children among participants with cerebral palsy (CP) aged 29–35 years compared with controls

<i>Nr of biological children</i>	<i>%</i>	
	<i>CP (n=416)</i>	<i>Comparison group (n=2247)</i>
None	81	39
One	9	27
Two	8	27
Three or more	1	7

$p < 0.001$.

Severity of epilepsy and cognitive and motor impairment predicted living independently, but region of living and parents' income did not. Our analyses included only participants living with their parents at the age of 15 years, resulting in the exclusion of, for example, a group of more severely disabled participants living at an accommodation facility arranged by the county from childhood. We do not know whether parents' socioeconomic position and region of living affected these participants' chance of living independently in adulthood.

COHABITATION

Cohabiting is a way of obtaining social contact, and this may be especially important for people with disabilities, who have more difficulty than people without disabilities in participating in social activities. Finding comparable studies on cohabitation is difficult. Many studies use marital status, but today many couples are not married in Denmark and many other countries. A study in Sweden² found 22% cohabiting. This is less than in our study, although the Swedish participants were older (mean age 36y, range 20–58y) and no participants with learning impairment or living in an institution were included. The study of people with CP born between 1940 and 1945 in Denmark⁹ found 32% currently married among people with CP aged 30 years. This is very close to our result on cohabitation, and we suspect that nearly all cohabitants in the 1970s would have been married.

As expected, we found that the severity of CP predicted cohabitation. This study did not include data on individual social competencies or ability to speak, but these are other important predictors of cohabitation. In Finland, social maturity (unrelated to the severity of disability) was reduced among people with disabilities (primarily those with CP) aged 19 to 26 years compared with people without disabilities.³ The Danish study of children with CP born between 1940 and 1945 found that normal speech was the most important predictor of getting married.⁹

CHILDREN

The presence of biological children is strongly correlated with age, and comparing the proportions of participants who have children does not make sense unless the study groups are of the same age. One study in California with participants aged 27 to 74 years⁴ found that 3% had children, but this was a selected group excluding participants at institutions and including few participants with mild CP. Among participants in Sweden with a mean age of 36 years (range 20–58y), 8% were living with children.² The study of people with CP born between 1940 and 1945 in Denmark found that 28% had biological children among 30-year-old people with CP, in comparison with our finding of 19% among participants 29 to 35 years of age. In general, however, people today become parents at an older age and have fewer children than they did 25 to 30 years ago.¹⁸

COHABITATION, BIOLOGICAL CHILDREN, AND EMPLOYMENT

Assuming that cohabitation, having children, and participating in the labour market are indicators of social integration in a society, we found it important to examine how these three types of social contact were associated with each other, in participants as well as in the comparison group. In a previous study based on data from the same population, we found that 33% of the 416 adults aged 29 to 35 years with CP were competitively employed. In the present study we found that 19% in this

age group had biological children and that 28% were cohabiting. Only 11% of the 29- to 35-year-old participants (compared with 46% of the comparison group) were cohabiting, had biological children, and were competitively employed.

In this study we measured only three types of social contact and did not include any other factors, such as non-competitive employment and leisure activities, that are important for social integration. Our previous study¹ showed that very few of the participants were in supported employment, but we did not look at sheltered workshops. In The Netherlands, young adults with CP were poorly integrated socially in education, employment, and sport activities despite a high level of independence in performing activities.⁶ An explanation for this could be a lack of social competencies, but this would not explain why adults who manage competitive employment or have a partner do not have both. Some publications have discussed specific cognitive or perceptual deficits of persons with CP.^{19–21} Esben²⁰ suggests that these specific cognitive deficits result in difficulty in concentrating and a reduced ability to combine, structure, and end tasks. Jahnsen et al.²² state that physical fatigue is a pronounced problem among adults with CP, and Kemp²³ describes how impaired people grow older faster and never reach the same maximum capacity as non-impaired people. These two problems might explain why we found that even the most optimally functioning adults had difficulty in succeeding in total integration concerning cohabitation and children, as well as the labour market. It would then be important to focus on, and intervene early in, cognitive training and continuing care and habilitation into adulthood. With such an initiative it should be possible to show improved social integration, especially among individuals with mild CP.

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References

- Michelsen SI, Uldall P, Kejs AMT, Madsen M. (2005) Education and employment prospects in cerebral palsy. *Dev Med Child Neurol* **47**: 511–517.
- Andersson C, Mattsson E. (2001) Adults with cerebral palsy: a survey describing problems, needs, and resources, with special emphasis on locomotion. *Dev Med Child Neurol* **43**: 76–82.
- Kokkonen J, Saukkonen AL, Timonen E, Serlo W, Kinnunen P. (1991) Social outcome of handicapped children as adults. *Dev Med Child Neurol* **33**: 1095–1100.
- Murphy KP, Molnar GE, Lankasky K. (2000) Employment and social issues in adults with cerebral palsy. *Arch Phys Med Rehabil* **81**: 807–811.
- O'Grady RS, Crain LS, Kohn J. (1995) The prediction of long-term functional outcomes of children with cerebral palsy. *Dev Med Child Neurol* **37**: 997–1005.
- van der Dussen L, Nieuwstraten W, Roebroek M, Stam HJ. (2001) Functional level of young adults with cerebral palsy. *Clin Rehabil* **15**: 84–91.
- Uldall P, Michelsen SI, Topp M, Madsen M. (2001) The Danish Cerebral Palsy Registry: a registry on a specific impairment. *Dan Med Bull* **48**: 161–163.
- Glenting P. (1981) *Social Prognosis of Congenital Cerebral Palsy. Cerebral Palsy Registry of Denmark Report No. V*. Copenhagen: The Danish Society for Cerebral Palsy. (In Danish)

- Glenting P. (1982) *Prognosis of Marital Status and Reproduction in Cerebral Palsy. Cerebral Palsy Registry of Denmark Report No. VI*. Copenhagen: The Danish Society for Cerebral Palsy. (In Danish)
- Glenting P. (1982) Cerebral palsy in Eastern Denmark 1965–1974. I. Decreased frequency of congenital cases. *Cerebral Palsy Registry of Denmark Report No. VII. Neuropediatrics* **13**: 72–76.
- Topp M, Uldall P, Langhoff-Roos J. (1997) Trends in cerebral palsy birth prevalence in eastern Denmark: birth-year period 1979–86. *Paediatr Perinat Epidemiol* **11**: 451–460.
- Topp M, Uldall P, Greisen G. (2001) Cerebral palsy births in eastern Denmark, 1987–1990: implication of neonatal care. *Paediatr Perinat Epidemiol* **15**: 271–277.
- Mutch L, Alberman E, Hagberg B, Kodama K, Perat MV. (1992) Cerebral palsy epidemiology: where are we now and where are we going? *Dev Med Child Neurol* **34**: 547–551.
- Topp M, Langhoff-Roos J, Uldall P. (1997) Validation of a cerebral palsy register. *J Clin Epidemiol* **50**: 1017–1023.
- Hill AE. (1993) Problems in relation to independent living: a retrospective study of physically disabled school-leavers. *Dev Med Child Neurol* **35**: 1111–1115.
- Stevenson CJ, Pharoah PO, Stevenson R. (1997) Cerebral palsy – the transition from youth to adulthood. *Dev Med Child Neurol* **39**: 336–342.
- Wynne ME, Rogers JJ. (1985) Variables discriminating residential placement of severely handicapped children. *Am J Ment Defic* **89**: 515–523.
- National Board of Health. (2004) *Birth Register 1973 to 2003*.
- Dorman C. (1987) Verbal, perceptual and intellectual factors associated with reading achievement in adolescents with cerebral palsy. *Percept Mot Skills* **64**: 671–678.
- Esben P. (2003) *New CP. Cerebral Palsy – Hold to the Light*. Copenhagen: The Danish Society for Cerebral Palsy.
- Goodman R. (1997) Psychological aspects of hemiplegia. *Arch Dis Child* **76**: 177–178.
- Jahnsen R, Villien L, Stanghelle JK, Holm I. (2003) Fatigue in adults with cerebral palsy in Norway compared with the general population. *Dev Med Child Neurol* **45**: 296–303.
- Kemp BJ. (2005) What the rehabilitation professional and the consumer need to know. *Phys Med Rehabil Clin N Am* **16**: 1–18, vii.

Appendix 1: Subtype and severity of cerebral palsy (CP) in people born between 1965 and 1970

Characteristic	At analysis (n=416)		At diagnosis (n=486)	
	n	%	n	%
Subtype of CP				
Hemiplegia	31	127	27	130
Diplegia 1	35	147	32	155
Diplegia 2	14	59	14	66
Tetraplegia	11	47	18	86
Ataxia	3	11	3	14
Hyperkinesia	5	19	6	28
Dystonia	1	6	1	7
Motor impairment				
Walks without assistance	65	270	58	282
Walks with assistance	22	91	21	103
Not walking	12	49	19	94
Unknown	1	6	1	7
Developmental quotient				
>85	49	203	43	208
85–50	25	104	24	116
<50	20	83	27	132
Unknown	6	26	6	3
Epilepsy				
No	81	339	77	374
Yes	19	77	23	112