Education and employment prospects in cerebral palsy

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Parents and paediatric neurologists need information on the long-term social prognosis of children with cerebral palsy (CP). No large population-based study has been performed on this topic. On 31 December 1999, to find predictors in childhood of subsequent education and employment, 819 participants with CP born between 1965 and 1978 (471 males; mean age 28y 10mo, SD 4y, range 21 to 35y) in the Danish Cerebral Palsy Registry were compared with 4406 controls without CP born between 1965 and 1978 (2546 males; mean age 28y 10mo, SD 4y, range 21 to 35y). Diagnostic subtypes of the 819 participants with CP were: 31% hemiplegia, 43% diplegia, 18% tetraplegia, and 8% other types. Level of motor impairment with respect to walking ability was: 62% able to walk without assistance, 21% with assistance, and 16% not able to walk (for 1% of study children walking ability was not known). Relevant information was obtained from Denmark's unique registries. Of the participants with CP, 33% vs 77% of controls, had education beyond lower secondary school (i.e. after age 15–16y), 29% were competitively employed (vs 82% of controls), 5% were studying, and 5% had specially created jobs. Excluding participants with CP with an estimated developmental quotient (DQ) of less than 50 or inability to walk at age 5 to 6 years, the odds ratios (multivariate analysis) for not being competitively employed were 1.9 for diplegia versus hemiplegia, 22.5 for DQ 50 to 85 versus DQ greater than 85, and 3.7 for those with epilepsy versus those without epilepsy. The severity of motor impairment among participants with CP able to walk had just a minor influence. Only half the participants with CP who had attended mainstream schooling were employed. In conclusion several childhood characteristics seemed to predict long-term social prognosis.

Cerebral palsy (CP) is the most common motor impairment affecting children. Recognized associated impairments include sensory defects, learning disability*, specific learning difficulties, behavioural disorders, and the presence of seizures. The severity of the symptoms varies substantially. During childhood, industrialized countries have various schemes to manage these disabilities in the best possible way. Many young people, however, experience difficulty in becoming liberated from their family and in achieving an independent life (Kokkonen et al. 1991). People with disability have the right to education and to work according to the International Covenant on Economic, Social and Cultural Rights (United Nations 1966), but discrimination and accessibility are problems in the labour market (Lindqvist 2002).

A few small studies have been published on education and employment among young adults with CP based on somewhat different methods (Kokkonen et al. 1991, O'Grady et al. 1995, Murphy et al. 2000, Andersson and Mattsson 2001). Murphy et al. (2000) included 101 specially selected individuals with CP in the US: 53% were competitively employed. O'Grady et al. (1995) included a self-selected cohort of participants by reviewing records from a CP clinic in the United States: 49% were working, with 38% of those full time. Kokkonen et al. (1991) studied 52 individuals with CP aged 19 to 26 years from the same hospital area in Finland: 38% were working. A study in Sweden (Andersson and Mattsson 2001) included 221 individuals with CP from the same county without documented learning disability who responded to a mailed questionnaire: 24% were working full time.

Parents understandably want a prognosis for their children with CP, including how they are expected to manage socially in adult life. Information on later education and employment opportunities, based on clinical assessment in early childhood, is important for paediatric neurologists and rehabilitation teams to have so that they can provide parents with reasonable expectations for their child and help them plan the management of their child. We have not found any large unselected population-based study that addresses the crucial question of the proportion and characteristics of children who achieve full social participation in adult life after rehabilitation.

This study analyzed the education, employment, and financial situation of young adults with CP (henceforth 'participants') according to clinical characteristics in early childhood compared with a group of young adults without CP (henceforth 'controls'). Participants were born between 1965 and 1978 and were compiled from the population-based Danish Cerebral Palsy Registry covering eastern Denmark (Uldall et al. 2001).

Method

PARTICIPANTS

All 948 people born between 1965 and 1978 with congenital CP registered in the Danish Cerebral Palsy Registry on 31 December 1999 were enrolled in this study. The controls were individuals living in eastern Denmark born from 1965 to 1978 selected from the Civil Registration System, which records every resident of Denmark. Five controls per participant were randomly selected with the same sex and age. Thirteen controls had CP and were removed, leaving 4727 controls. A total of 114 participants and 92 controls had died,

*US usage: mental retardation.

and 14 participants and 226 controls emigrated before 31 December 1999. Three controls could not be traced, and one participant was excluded because their civil registration number could not be found. This left 819 participants and 4406 controls for analysis. Permission to conduct this study was obtained from the Danish Data Protecting Agency

DATA SOURCES

Danish Cerebral Palsy Registry

The Danish Cerebral Palsy Registry is a population-based registry that contains a record of individuals with CP from the birth year 1925 and has reported birth prevalence since 1950 (Glenting 1982; Topp et al. 1997b, 2001; Uldall et al. 2001). The uptake includes 2.5 million people in eastern Denmark, which is roughly 50% of the population. Data were collected prospectively based on voluntary reports from physicians in all paediatric departments and special institutions for children with disabilities. A paediatric neurologist (Paul Glenting) had contact with the paediatric departments and special institutions, and he evaluated all case records or discharge notes before including or excluding individuals. Both registries in Statistics Denmark and the Danish Cerebral Palsy Registry are public registries and The Danish Data Protection Agency approved the study. Data were delivered with anonymous but unique personal identification numbers, enabling anonymous linkage between registries on an individual level. The project did not require approval by the regional committee on scientific ethics. Participants were not ascertained until age 6 years to ensure that those diagnosed late or with mild CP were included and that cognitive development could be reasonably estimated. Information on pregnancy, birth, neonatal period, impairments, and the civil registration number of the child and mother were recorded on punched cards (birth years 1965 to 1970) or in a standard form (birth years 1971 to 1978). The sub-classification of CP was modified according to the Swedish classification (Hagberg et al. 1975). Children who had hypotonia only without ataxia, dyskinesia, or spasticity, who were previously included as having CP in the Registry were excluded. One of the authors (PU) read the medical records for the birth years 1965 to 1970 and excluded 85 participants in the Registry. From the birth years 1971 to 1978 a further 20 participants with hypotonia only were excluded. A detailed description of motor function is currently not in the Registry, but in the future children will be classified according to the Gross Motor Function Classification System (Palisano et al. 1997).

Civil Registration System

The Civil Registration System has registered the resident population of Denmark since 1968. The existence of a unique civil registration number enables information to be processed and linked at the individual level. All residents alive in 1968 were included in the System.

Registries in Statistics Denmark

Information on education, employment, and economy was obtained from various registries kept by Statistics Denmark (Copenhagen, Denmark) through the civil registration number. The data sources are schools, educational institutions, workplaces, local authorities, and tax authorities, who are all obliged by law to deliver information to Statistics Denmark.

DEFINITIONS

CP

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 which arise in the early stages of its development (Mutch et al. 1992). The definition is based on one proposed by members of the Little Club in 1958 (Mac Keith and Polani 1958) and used by the various CP registries in the following years. The subtypes of CP are: spastic hemiplegia, spastic diplegia, spastic tetraplegia, ataxia, and dyskinesia (Hagberg et al. 1975). The last two subtypes are uncommon and are collectively labelled 'other types' in this study. Disability is measured by severity. The severity of motor impairment is measured by the ability to walk. The severity of cognitive or learning impairment was measured by a developmental quotient (DQ). In this study, few participants had taken a psychological test, and their level of cognitive development was mainly based on clinical assessment. DQ was scored as greater than 85 when a child began school without help (excluding manual assistance) and between 85 and 50 for those needing more support at school. The third category was DQ less than 50. Epilepsy is registered with two or more unprovoked seizures after the neonatal period. Diagnosis, including subtype, severity, and the presence of epilepsy, is registered when the child is 6 years old (Uldall et al. 2001).

School and education

In Denmark, primary and secondary schools are integrated in one school. Most children start school when they are six years old with one year led by early-childhood educators. Then they continue for nine years at the same school, but taught by schoolteachers. The 10th year of school is voluntary. After passing the examinations at the end of nine compulsory years of school, children can enter the educational system, choosing either vocational training or upper secondary school (age 16–19y), possibly followed by tertiary education. Information on education was collected from a registry on type of class in the last years of lower secondary school and from a registry on the individual's highest educational level attained. Both registries were based on routine reports from educational institutions. Lower secondary schools register in grades 8 to 10 (age 14–16y) if an individual is in a class where children are not divided by grade (age) or are at a special school. Normally children of the same grade are taught together, but in some classes children of different grades are taught together. Such classes are named 'not divided' classes. Virtually everyone in a 'not divided' class is in special education, but theoretically there may be a few children in mainstream classes in schools with too few pupils to create a class of each grade. In Denmark, schoolchildren who are able to follow mainstream education should have an IQ of roughly 85 or greater. Great efforts have been undertaken to integrate children into mainstream schools because since 1980 and a physical disability alone does not qualify a child for special education. Of the controls, 3% received special education. It is not registered if a child in a normal class receives some lessons in a special class.

Employment

Employment is described socioeconomically. Based on income sources in 1999, individuals are categorized as competitively

employed, not competitively employed, studying, or not employed. Competitively employed means equal terms for people with and without disability. Denmark has two types of non-competitive employment. (1) Flexible working arrangements are for individuals who are not receiving a disability pension. Employees work less than full time, and the workplace pays attention to special needs. Employees receive standard wages but the employers get a public wage subsidy. (2) Individuals receiving a disability pension have little ability to work and can be offered sheltered employment. The employee is given a wage and the employer receives a public wage subsidy.

Sector is classified based on the characteristics of the workplace using the standard classification of all employees in Denmark. The examples of jobs in each sector are based on the highest educational level acheived by the individual.

Disability pension

Denmark had three levels of disability pension in 1999: highest, intermediate, and ordinary. The highest level is for those unable to work because of health problems, the intermediate level is for individuals with only one-third of their ability to work because of health problems, and the ordinary level is for those with half their ability to work because of either health or social problems.

Income

The main income source is the largest income source of an individual in 1999. Annual income is the pretax income in 1999. Individuals with CP receiving a pension receive an additional fixed sum tax-free every month; the results include this in the annual income after accounting for taxes. Any other tax-free benefits received by participants or controls are not included in annual income. Government benefits as the main income source are mostly welfare or unemployment benefits.

STATISTICAL ANALYSIS

Most comparisons used the χ^2 test. The predictors of not being competitively employed or of receiving special education were analyzed using multivariate logistic regression. The odds ratios are given with 95% confidence intervals (CIs). Individuals lacking data in one or more categories are excluded from the multivariate analysis. Only variables significant in the multivariate analysis are included in the logistic regression.

Results

CHARACTERISTICS OF THE STUDY POPULATION

Mean age among the 819 participants with CP was 28 years 10 months (SD 4y, range 21 to 35y) and 471 males and 348 females participated. Controls were matched by sex and age

Table I: Education (%) in individuals 21–35 years old with cerebral palsy (CP) according to clinical subtype of CP, compared with controls

Education	*Hemiplegia (n=256)*	*Diplegia (n=347)*	*Tetraplegia (n=148)*	*Others (n=68)*	*CP total (n=819)*	*Controls (n=4406)*
Highest education						
Primary and lower secondary school, no examination pass	28	45	68	63	45	5
Primary and lower secondary school, examination pass	21	18	8	16	17	17
Upper secondary school	11	8	5	1	8	19
Vocational training	25	17	9	3	17	38
Tertiary education	14	8	3	6	9	20
Unknown	1	4	7	10	4	<1
Type of education						
Special	18	35	66	59	37	3
Mainstream	80	60	26	31	58	96
Unknown	2	4	7	10	5	1

Table II: Employment status (%) among individuals 21–35 years old with cerebral palsy (CP) according to clinical subtype of CP and compared with controls

Employment and income	*Hemiplegia (n=256)*	*Diplegia (n=347)*	*Tetraplegia (n=148)*	*Others (n=68)*	*CP total (n=819)*	*Controls (n=4406)*
Current employment status						
Competitively employed	46	26	12	10	29	82
Flexible working arrangements	2	3	<1	2	2	<1
Sheltered employment	4	4	1	2	3	<1
Student	7	4	3	3	5	7
Not employed	41	63	83	84	62	11
Main income source						
Income from employment	50	29	14	13	32	83
Educational benefit	3	1	2	0	2	6
Pension	33	58	79	81	56	2
Temporary benefit	13	9	5	4	9	8
Unknown	2	2	<1	1	2	2

(2546 males, 1860 females; mean age 28y 10mo, SD 4y, range 21 to 35y). Of the 948 cases at diagnosis, 114 (12%) died before data were collected on 31 December 1999. Appendix I shows the distribution of subtype and severity of CP in the study population and the participants who died before 1999. The subtypes with the most severe CP had the highest mortality.

EDUCATION

Table I shows the educational level obtained by participants and controls: 51% of participants obtained an education, but 45% of participants, compared to 5% of controls, never passed an examination in lower secondary school. Subtypes of CP differed substantially, but even among individuals with hemiplegia, only 50% had been educated beyond lower secondary school (i.e. after age 15–16y) compared with 77% of controls. Among those educated beyond lower secondary school, the distribution between upper secondary school, vocational training, and tertiary education was almost the same for participants and controls. Participants with education beyond lower secondary school often had mild CP: only 4% (n=11) had a DQ of less than 85, 19% walked with assistance or were not able to walk, and 3% (n=9) had epilepsy (based on clinical assessment in early childhood). Special education was received by 37% of participants (5% had no registered type of education) and 3% of controls (1% had no registered type of education). Predictors of receiving special education were analyzed in a multivariate logistic regression. As expected, the estimated DQ at age 6 had the highest odds ratio followed by the CP subtype and motor disability. Odds ratios for having received special education were 4.6 (95% 2.7 to 7.9) for DQ between 85 to 50 versus DQ greater than 85, 3.9 (95% CI 1.8 to 8.3) for diplegia versus hemiplegia, and 1.8 (95% CI 1.1 to 3.1) for walking with assistance versus walking without assistance. Parents' educational level had significant influence, whereas epilepsy was not significant when other significant factors were controlled for.

EMPLOYMENT AND MAIN INCOME SOURCE

Twenty-nine per cent of participants were competitively employed and 5% (n=38) studying (Table II). Among those 29 to 35 years old, 33% were competitively employed and 1% (n=6) studying. Participants with hemiplegia had the highest employment rate. Five per cent (n=42) were in flexible working arrangements or sheltered employment. Only four participants who had received special education were competitively employed. Participants and controls did not differ substantially according to sector. The five largest sectors in which participants were employed were health and social welfare institutions, e.g. nurses or early-childhood teachers, 19% (vs 15% among controls); commerce, e.g. offices and retail trade outlets, 17% (vs 19%); real estate, leasing, business services, and similar, e.g. office services and information technology, 13% (vs 11%); manufacturing, e.g. mechanics and technicians, 11% (vs 15%); and public administration, armed services, and social insurance, such as office employees 11% (vs 7%). Twenty-eight per cent of the employed participants and 33% of the employed controls changed workplace (including changes of function with the same employer and resuming employment) from 1998 to 1999. Participants did not change workplace as often as controls (rate ratio 0.93, 95% CI 0.88 to 0.98).

The main income source for 56% of the participants was a pension (Table II). Individuals with hemiplegia most often received their main income from employment, but relatively

Table III: Predictors of not being competitively employed among 513 individuals 21–35 years old with CP able to walk and who had an estimated developmental quotient ≥50 (multivariate logistic regression, adjusted for sex and age)

Characteristics	*n*	*Odds ratio (confidence interval), controlled for sex and age*	*Odds ratio (confidence interval), controlled for sex and age and other significant predictors*[a]
Subtype of CP		$p<0.0001$	$p=0.0014$
Hemiplegia	204	1	1
Diplegia	236	2.56 (1.71–3.82)	1.93 (1.20–3.08)
Tetraplegia	42	2.66 (1.25–5.65)	1.54 (0.66–3.62)
Other	31	5.77 (2.10–15.82)	5.55 (1.89–16.30)
Developmental quotient		$p<0.0001$	$p<0.0001$
>85	417	1	1
51–85	96	33.26 (10.16–108.88)	22.54 (6.80–74.73)
Epilepsy		$p<0.0001$	$p=0.00301$
No	462	1	1
Yes	51	4.25 (1.85–9.73)	3.69 (1.46–9.36)
Motor impairment		$p=0.0001$	$p=0.0439$
Walk without assistance	396	1	1
Walk with assistance	117	3.05 (1.83–5.08)	1.84 (1.01–3.35)
Parents' highest level of education		$p=0.0198$	$p=0.0547$
Education beyond lower secondary school	379	1	1
Primary and lower secondary school	134	1.66 (1.08–2.57)	1.60 (0.99–2.59)
Birthweight, g		$p=0.3144$	Not in analysis
>3500	124	1.22 (0.75–1.99)	
2500–3499	163	1	
<2500	226	1.39 (0.91–2.12)	

[a]Only variables significant in multivariate logistic regression are included.

more received social welfare or unemployment benefits than those with other subtypes of CP or controls. Seventy-seven per cent of participants on a disability pension received the highest level, 19% intermediate level, and 4% (n=18) ordinary level. Five per cent of participants receiving a disability pension (n=24) worked in sheltered employment in 1999, and 7% (n=32) in 2001.

PREDICTORS OF NOT BEING COMPETITIVELY EMPLOYED

Only three participants with severe motor impairment and none with DQ less than 50 (assessed in early childhood) were competitively employed; these were therefore excluded from the predictor analysis on employment. Table III shows the odds ratio of possible predictors of not being competitively employed. Among participants with an estimated DQ of at least 50 and ability to walk, significant predictors of not being competitively employed were the severity of cognitive impairment, subtype of CP, presence of epilepsy, and motor impairment (calculated using a multivariate analysis, controlled for sex and age). Individuals with diplegia and other subtypes of CP had a significantly higher risk of not being competitively employed compared with those with hemiplegia. Compared to controls, the odds ratio for not being competitively employed for participants with an estimated DQ of 50 to 85 versus greater than 85 was 22.5 (95% CI 6.8 to 74.7), whereas participants with epilepsy versus those without had an odds ratio for not being competitively employed of 3.7 (95% CI 1.5 to 9.4). Only seven participants with DQ 50 to 85 were competitively employed. The severity of motor impairment among participants able to walk had a minor influence. Parents' education did not significantly influence the risk of not being competitively employed, but their educational level was not known for 18%.

ANNUAL INCOME

Controls were divided into quintiles according to their annual income in 1999. Participants were then placed in their respective annual income groups (Table IV). Fifty-five per cent of participants were lower-middle income; few were in the two highest groups, 18% in the middle, and 15% in the lowest group. Most participants receiving disability pensions were in the lower-middle group. Participants and controls who were competitively employed differed slightly but significantly. More participants were in the middle-income group, whereas more controls were in the upper-middle or high-income group. Participants generally had a lower annual income than controls.

Discussion

VALIDITY

We consider the participants to be very close to a representative sample of young adults with CP in Denmark. Participants were recruited through close contact with paediatric departments and special institutions for children with disabilities, and data were collected from voluntary reports and copies of case notes. The same paediatric neurologist evaluated all reports and case notes, but some bias should be considered. The validity of the Registry was studied in 1997 (Topp et al. 1997a). The birth years 1979–1982 were re-evaluated, and the Registry was found to be only 85% complete before linkage to the National Patient Registry. Nevertheless, the participants with CP not registered did not differ from the registered hospitalized participants in the severity of impairment or clinical subtype. Compared with patients with CP of today, a possible selection bias in the 1979 to 1982 sample was insufficient reporting of participants with mild CP, who were either not diagnosed or had not contacted a paediatric department or special institution. This would have lead to an overestimation

Table IV: Annual income level in 1999 (%), divided into five categories, among individuals 21–35 years old with cerebral palsy (CP) compared with controls and according to subtype and severity of CP

Category	*Low*	*Lower-middle*	*Middle*	*Upper-middle*	*High*	*n*
Controls	20	20	20	20	20	4406
Participants	15	55	18	6	5	819
Participants in competitive employment	9	21	30	21	18	234
Controls in competitive employment	11	17	24	24	24	3609
Type of CP						
Hemiplegia	21	40	21	10	7	256
Diplegia	14	51	22	6	6	347
Tetraplegia	8	80	8	2	2	148
Other	9	75	9	4	3	68
Motor impairment						
Walk without aid	19	43	22	8	7	506
Walk with aid	11	64	18	5	2	176
Not walking	5	90	4	2	0	131
Unknown	0	33	17	0	50	6
Developmental quotient						
DQ>85	22	41	21	9	7	488
DQ 85–50	6	72	19	<1	2	142
DQ<50	2	90	8	0	0	154
Unknown	6	34	23	14	23	35
Epilepsy						
No	17	51	19	7	6	683
Yes	4	77	17	2	2	136

of the adverse social effects of CP.

Comparing the CP prevalence and trends of the Danish Cerebral Palsy Registry (Glenting 1982) with the registries in Sweden and Western Australia is reassuring (Hagberg et al. 1984, Stanley and Watson 1992). Trends from 1965 to 1974 and the birth prevalence are very similar. The distribution of subtypes of CP differs from that of Sweden's registry, probably reflecting individual variation in applying the rather vague definition of CP subtypes. The main difference is that hemiplegia was somewhat less often used than in Sweden's registry, but the distribution seems fairly similar to that of the Merseyside region of England (Pharoah et al. 1987). Comparing Danish children with CP born 1965 to 1978 with children born 1987 to 1990, we find an increased number with diplegia (Topp et al. 2001). The proportion of children with DQ less than 85 was 42% from 1965 to 1978 (population at diagnosis) and 58% from 1987 to 1990. The proportion of children who were non-ambulatory or not able to walk without assistance was 44% from 1965 to 1978 (population at diagnosis) and 45% from 1987 to 1990. These changes in the population with CP and changes in the Danish educational system in the past 30 years must be taken into account if interpreting the results of children with CP today.

Data from the registries of Statistics Denmark are considered complete and valid because the information is required by law and the reporting institutions have been delivering these data for 20 years.

EDUCATION, EMPLOYMENT, AND ANNUAL INCOME

The employment rate in other studies varied widely. It is obvious that it is not possible to compare these studies with ours because the study populations was small, non-population based, or used specially selected participants varying according to age, severity of impairment, and outcome measures.

A study of individuals with CP in Denmark born from 1940 to 1945 found that 52% were 'entirely socialized', defined as 'completely independent in supporting themselves financially' (Glenting 1981); these included married women without a disability pension. This study (and ours) found that DQ was the most important single personal factor for employment among individuals with CP.

We have found no other study performing a multivariate logistic regression analysis on predictors of employment. We believe that it is an important result that rather simple clinical characteristics in early childhood seem to predict future employment. It is thought-provoking that motor disability seems to be of rather minor influence, remembering that our rehabilitation efforts are focusing on physical training. The discussion on the relevance and value of the CP sub-classification into different CP syndromes has been going on for many years (Blair and Stanley 1985, Stanley et al. 2000). We have found that this classification is an important predictor of the long-term social prognosis for children with CP. The sample in our study comprises survivors; 74% of the participants who died had tetraplegia or hyperkinetic CP. Therefore, the surviving participants with CP of these two subtypes remaining for the predictor analysis therefore probably constitute the best functioning individuals. This is the key to examining predictors for being employed competitively and explains the rather small difference in odds ratio between diplegia and tetraplegia (Table III). We believe that our study supports the value of subclassification as defined by Hagberg et al. (1975).

It is unknown how many children in the present study received some special education outside a regular special class or special school. Despite this, an important finding is that only half of the participants with CP attending mainstream classes managed to get a job (47% competitively employed and 6% non-competitively).

IQ is well known to be a very crude estimate of intellectual capacity, but few have studied the specific cognitive or perceptual deficits of participants with CP with normal IQ (Dorman 1987, Goodman 1997, Esben 2003). Such deficits could be one explanation of why less than half of the participants with CP with mainstream schooling are competitively employed. More research into educational remedies to overcome the specific cognitive and perceptual deficits is needed. Further, environmental factors such as employment policies, accessibility, and attitudes towards individuals with CP in the labour market could be reasons for the low employment level in the CP population apart from the limitations of the impairment itself.

A third reason for the low employment rate might be that individuals with CP have problems with social interaction; we did not study this. Research shows that young people with CP are less socially active than young people without disability, and individuals with disabilities become increasingly socially isolated with age (Stevenson et al. 1997). The opposite applies to individuals without disability, who become more socially active after school age. Lack of ability to function socially is a very important factor associated with failure to obtain employment and difficulty in adapting for adults with and without disability (Wadsworth and Harper 1993).

The milder the degree of motor and learning impairment the higher the chances of participants being in the lowest income group, depending on social welfare or unemployment benefits. A reason for this could be that individuals with the mildest degree of CP are expected to compete in the labour market on equal terms, and that this is simply not possible.

Conclusion

A total of 29% of the 819 young adults with CP in eastern Denmark were competitively employed, 5% were in flexible working arrangements or sheltered employment, and 5% were studying. There were substantial differences according to subtype and severity. Several childhood characteristics seemed to predict long-term social prognosis. A total of 62% were outside the labour market. According to the UN Covenant on Economic, Social and Cultural Rights (United Nations 1966), which recognizes 'the right to work, which includes the right of everyone to the opportunity to gain his living by work which he freely chooses or accepts', the government of Denmark has not created enough job opportunities for individuals with disabilities. Of special concern are those with CP who have completed normal schooling, and in childhood were judged to have a normal intellectual capacity, yet by age 21 to 35 only half have gained employment. More research is needed on such factors as cognitive impairment associated with CP, social development, and environmental factors to reveal reasons for the high rate of young adults with CP outside the labour market.

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Appendix I: Subtype and severity of cerebral palsy (CP) in participants born between 1965 and 1978 in eastern Denmark

Characteristics	*At analysis (n=819)*		*At diagnosis (n=948)*		*Participants who died before 1999 (n=114)*	
	%	*n*	*%*	*n*	*%*	*n*
Subtype of cerebral palsy						
Hemiplegia	31	256	28	269	6	7
Diplegia 1	26	211	23	221	7	8
Diplegia 2	17	136	16	147	7	8
Tetraplegia	18	148	23	220	61	69
Ataxia	3	24	3	28	4	4
Hyperkinesia	4	36	5	52	13	15
Dystonia	1	8	1	10	2	2
Other	0	0	0	1	<1	1
Motor impairment						
Walk without assistance	62	506	56	530	14	16
Walk with assistance	21	176	21	196	14	16
Not walking	16	131	23	215	71	81
Unknown	<1	6	<1	7	<1	1
Developmental quotient						
DQ>85	60	488	54	509	10	11
DQ 85–50	17	142	17	162	16	18
DQ<50	19	154	25	238	71	81
Unknown	4	35	4	39	4	4
Epilepsy						
No	83	683	79	750	47	54
Yes	17	136	21	198	53	60

Diplegia 1, no motor impairment in upper extremities; Diplegia 2, some motor impairment in upper extremities.