Social consequences of cerebral palsy

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Preface

Cerebral palsy is defined as a permanent but not unchanging disorder. Nevertheless, paediatricians are the only medical specialists and they are in charge of the rehabilitation teams providing treatment and support for children with cerebral palsy and their families. Adult neurologists have no tradition of taking care of cerebral palsy in adulthood.

Traditionally, treatment has focused on the physical achievements of the child, and physical therapy is offered through special schools and hospital departments of paediatrics. Neuropaediatricians and orthopaedics follow the physical, mental and social development of the children. But when they grow into adolescents and adulthood, traditionally a difficult period for even nondisabled people, they are left alone.

I wondered why care is not provided for adults with cerebral palsy. What happens to the disabled adolescents when they become adults? Are they integrated in society and living life like any nondisabled adult using compensating aids? Or are they isolated and strongly dependent on their parents? And what happens to the parents when their disabled child gets older? Do the parents manage to continue with the same level of social integration as before the child was born? Do parents put their societal participation on hold for some years and then become active again when the child grows older? Or are they isolated with their disabled adult son or daughter?

This was my motivation to study the social consequences of cerebral palsy in both adults with cerebral palsy and parents to a child with cerebral palsy.

The PhD dissertation is based on the following three papers.

Paper I
Michelsen SI, Uldall P, Kejs AMT, Madsen M. (2005) Education and employment prospects in cerebral palsy. *Dev Med Child Neurol* 47: 511-517.

Paper II
Michelsen SI, Uldall P, Hansen T, Madsen M. Social integration of adults with cerebral palsy. *Accepted for publication in Developmental Medicine and Child Neurology.*

Paper III
Michelsen SI, Uldall P, Hansen T, Madsen M. A cohort study of parents' social situation after the birth of a child with cerebral palsy. *Manuscript.*

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- the children and adults with cerebral palsy I met during my work in the Cerebral Palsy Centre and the parents of children with cerebral palsy I met at a focus group discussion in the European research project SPARCLE, who all contributed to putting faces and real stories behind all the registry data;
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Contents

Abstract English

Cerebral palsy (CP) is a common impairment affecting children and includes motor impairment and, for some people, mental impairment, epilepsy and sensory defect as well. Young adults with CP, parents of children with CP, paediatric neurologists, the social welfare administration and politicians need to know to what degree people with CP achieve social integration and independence. Optimising the support to parents with a disabled child requires knowledge on employment, income and cohabitation and if these factors change after the child is born and later in life.

The aim of this PhD study was to analyse the societal participation of adults with CP and of families with a CP-afflicted child.

People with CP, registered in the Danish Cerebral Palsy Registry were compared with a gender and age-matched sample of controls from the general population. The parents of children with CP and control children were identified and studied as well. Information on school, education, employment, income, accommodation, cohabitation and having children was obtained from registries in Statistics Denmark.

School, education, employment and income among adults with cerebral palsy
A total of 819 subjects born between 1965 and 1978 (age 21–35 years) were studied and compared with 4406 controls. Twenty-nine percent were competitively employed (versus 82% of controls), 5% had specially created jobs and 5% were studying. A total of 37% of adults with CP received special education and they were later not employed. Only half the subjects who had attended mainstream school were later competitively employed. Childhood characteristics assessed when the children were 6 years old (severity of mental and motor impairment and presence of epilepsy) and parents' highest education independently predicted long-term social prognosis.

Accommodation, cohabitation and having children among adults with cerebral palsy
A total of 416 adults with CP born between 1965 and 1970 (age 29–35 years) were studied and compared them with 2247 controls. Sixty-eight percent lived independently, 13% lived with their parents and 16% lived at an accommodation facility arranged by the county (institution). Twenty-eight percent of the subjects were cohabiting and 19% had children. The presence of epilepsy and the severity of physical and mental impairment as assessed in childhood predicted independent living and cohabitation, but parents' socioeconomic position and region of living did not. Fifty-five percent of the subjects versus 4% of the controls had no competitive employment, cohabiting partner or biological children.

Employment, cohabitation and having additional children among parents to a child with cerebral palsy
Parents of 1824 children with CP and parents of 9153 controls born 1965 to 1990 were studied. The follow-up period started in 1980 and ended in 1999. We found most parents in Denmark employed and no change in employment frequency for parents of control children and fathers of children with CP after giving birth to a child. Ten percent of mothers to a child with CP left the labour market after birth of the child. Results indi-

cated that half of these women never re-employed. Mothers of children with CP more often worked part time and particularly not employed mothers had a lower income, compared with mothers of controls. The majority of children with CP had siblings and they lived with their parents just as often as other children.

Conclusion

The poor social integration of adults with CP necessitates providing a care for them. Action is needed to improve education and to increase the low proportion of disabled adults on the labour market. Too few are in supported employment, and society needs to create more job opportunities suitable for disabled people. Most adults with CP live independently, but it is unacceptable that some adults with CP live in nursing homes for elderly people. We need to ensure that suitable accommodation facilities are available to severely disabled adults. Reinforcing individual resources, such as cognitive and social competencies from early childhood, might improve social integration more than having the focus on the motor impairment. With no higher risk of parents' divorce, the majority of CP children having siblings and only ten percent of the mothers leaving the labour market after the birth of a child with CP we find that the Danish welfare system has succeeded on these issues. But we do recommend focus on the minor group of mothers disadvantaged according to employment, awareness of the income level of mothers to disabled children and further studies to describe psychological well-being and health of adults with CP as well as parents and siblings to disabled children.

Dansk resumé

Cerebral parese (spastisk lammelse, CP) er et hyppigt motorisk handicap blandt børn og for nogle involverer det tillige indlæringsvanskeligheder, epilepsi og sansedefekter. Unge voksne med spastisk lammelse, forældre til børn med spastisk lammelse, børneneurologer og andre faggrupper fra de tværfaglige handicapteams, samt politikere har brug for at vide i hvilken grad voksne med spastisk lammelse er socialt integreret i samfundet. For at optimere støtten til forældre med et handicappet barn er der behov for viden om erhverv, indkomst og samliv samt om disse faktorer ændres efter barnet bliver født og senere i livet.

Formålet med denne ph.d. var at beskrive de sociale konsekvenser af spastisk lammelse i voksenalderen, samt at analysere belastningen på en familie med et handicappet barn.

Personer med spastisk lammelse registreret i Cerebral Parese Registret blev sammenlignet med et udtræk af kontroller fra den generelle danske befolkning, ”matched” på køn og alder. Forældre til børn med spastisk lammelse og kontroller blev identificeret og deres sociale situation analyseret. Information om skole, uddannelse, erhverv, indkomst, bolig, samliv og børn blev indhentet fra registre i Danmarks Statistik.

Ph.d. afhandlingen er baseret på tre artikler omhandlende:

Skole, uddannelse, erhverv og indkomst blandt voksne med spastisk lammelse
Et samlet antal af 819 voksne med spastisk lammelse født 1965-1978 (alder 21-35 år) indgik og blev sammenlignet med 4406 kontroller. Niogtyve procent var i arbejde på almindelige vilkår (sammenlignet med 82% af kontrollerne), 5% var i skåne- eller flexjob og 5% studerede. Syvogtredive procent af de voksne med spastisk lammelse havde modtaget specialundervisning (gået i specialklasse og/eller på specialskole). Kun halvdelen af de voksne med spastisk lammelse, der havde været integreret i en almindelig folkeskole var i arbejde på almindelige vilkår. Karakteristika i barnealderen, vurderet da barnet var 6 år gammel (indlæringsvanskeligheder, epilepsi samt sværhedsgrad af motorisk handicap) samt forældres højeste uddannelse, prædikterede den sociale langtidsprognose.

Bolig, samliv og børn blandt voksne med spastisk lammelse
Et samlet antal af 416 voksne med spastisk lammelse født 1965-1970 (alder 29-35 år) indgik og blev sammenlignet med 2247 kontroller. Otteogtres procent boede uafhængigt i samfundet, 13% boede hos deres forældre og 16% boede i amtslige boformer. Otteogtyve procent boede med en partner og 19% havde børn. Indlæringsvanskeligheder, epilepsi samt sværhedsgrad af motorisk handicap, men ikke forældres socio-økonomiske position og bopælsregion prædikterede den social integration som voksen i form af uafhængig bolig og samliv. Femoghalvtres procent af de voksne med spastisk lammelse og 4% af de voksne kontroller var hverken i arbejde på lige vilkår, boede med en partner eller havde børn.

Erhverv, samliv og andre børn blandt forældre til et barn med spastisk lammelse
Forældre til 1824 børn med CP og forældre til 9153 kontroller født 1965-1990 blev studeret. Opfølgningsperioden startede i 1980 og sluttede i 1999. Flertallet af forældre i Danmark var i arbejde. Vi fandt ingen ændring i erhvervsfrekvensen for fædre til CP og kontrolbørn eller for mødre til kontrolbørn, efter fødslen af barnet. Ti procent af mødre til et barn med CP forlod arbejdsmarkedet efter at have født et barn med CP. Resultaterne indikerede at halvdelen af disse mødre aldrig kom i arbejde igen. Mødre til børn med CP arbejdede oftere deltid og særligt mødre udenfor arbejdmarkedet havde en lavere indkomst, sammenlignet med mødre til kontrolbørn. De fleste børn med CP havde søskende og de boede med begge deres forældre lige så ofte som andre børn.

Konklusion
Som følge af den dårlige sociale integration er det nødvendigt at etablere en tværfaglig indsats overfor voksne med spastisk lammelse. Tiltag mod det lave antal voksne med spastisk lammelse på arbejdsmarkedet er nødvendige. Der er for få i flex- og skånejob, og samfundet bør etablere flere jobmuligheder for handicappede. Ved at forbedre individuelle kompetencer, f.eks. ved træning af kognitive funktioner og sociale kompetencer fra tidlig barndom, vil vi forvente at den sociale integration bedres. Flertallet af voksne spastisk lammede boede uafhængigt, men det er uacceptabelt at nogle boede på plejehjem. Vi er nødt at sikre, at egnede boliger er tilgængelige for svært handicappede voksne. En ikke højere risiko for at forældre levede hver for sig, samt det at fleste CP-børn havde søskende, og at flertallet af mødre med børn med spastisk lammelse var i arbejde, mener vi er et tegn på, at det danske velfærdssystem på dette område virker. Men vi anbefaler et fokus på den mindre gruppe af mødre, der ikke er i arbejde, på det generelle indkomstniveau for mødre til handicappede børn og yderligere studier, der kan beskrive den psykiske trivsel, samt helbred af såvel voksne med CP som forældre og søskende til handicappede børn.

1. Introduction

1.1 Cerebral palsy

Cerebral palsy (CP) is a common and severe disability of childhood. Definitions of CP have changed somewhat over the last five decades in the epidemiology of CP, and in 2000 by the European network of CP registries, in which Denmark's registry participates [43]. All definitions are based on clinical assessment and agree that CP covers a group of permanent but not unchanging disorders arising from injury to the immature brain [35;38]. It always involves a motor impairment: 45% cannot walk unassisted among children age 5-6 years in Denmark with CP born from 1987 to 1990. Common associated impairments, however, can be as disabling as the motor impairment. These include epilepsy (31% among this same group of children), impairment of mental functioning (58%) and cognitive, sensory or speech defects [54]. Most recently a group of experts have made a new proposal for a definition including the term "activity limitation" and "disturbances of sensation, cognition, communication, perception, behaviour and epilepsy" [3]. People with CP have varying numbers of impairments and are affected very differently by these impairments. Few live a life without limitations; many are affected in some areas of daily life, but few depend on help 24 hours a day.

Most cases of CP are congenital, which is defined in Denmark as an injury occurring before day 28 of life. Cases occurring later but before the brain has stopped developing are called post neonatal. The percentage of post neonatal cases varies between countries. Denmark has no recent numbers for post neonatal cases, but 5–7% of the cases in Sweden are post neonatal [48].

CP is classified into three main groups according to motor impairment: spastic (85% among children in Denmark with CP born from 1987 to 1990, either bilateral or unilateral (hemiplegia)), ataxic (3%) and dyskinetic (11%) [43;54]. The severity of impairment varies both between and within the three groups.

In Denmark, as in other countries, the birth prevalence of CP has been changing. It declined from 2.2 per 1000 live births in the late 1960s to 1.7 per 1000 in the early 1970s. This increased to 3.0 in the 1980s, probably because more preterm babies survived, and declined in the late 1980s to 2.4, perhaps due to better neonatal care [14;54;55].

1.2 Disability

Ignorance, neglect, superstition and fear have historically isolated people with disabilities. Until the 1950s, a handicap was considered an individual problem or weakness. In the 1960s, organizations of people with disabilities started to formulate a new concept of disability. They acted against the medical approach, which ignored the deficiencies of the surrounding society [36;60].

In 1980 the International Classification of Impairments, Disabilities and Handicaps (ICIDH) stated that impairments were the damage to the body, disability the resulting reduce in function and handicap the loss or limitation of opportunities to take part in the life of the community on an equal level with others. Again in 1993, United Nations Standard Rules underlined that handicap is a relationship between disabled people and their environment. In 2001 the International Classification of Function, Disability and Health (ICF), a revised version of the ICIDH, was published. This no longer describes the consequences of disease but merely the components of health. The ICF classifies health according to individual factors (body function and impairment), activities (individual actions) and participation (involvement in life situations). In addition, it classifies the context, describing facilitators or barriers in the environment. By describing health from a biological, individual and social perspective, the ICF is combining two models of disability. One is the old medical model of disability, viewing disability as a personal problem caused by diseases and to be treated by health care. Another is the social model of disability, stating that society creates disability and that environmental changes are needed to achieve full participation and integration in society [60;64].

Views differ on how to address people in terms of disability. Some find it correct to say “people with disabilities”, implying that the society created the disability, instead of saying “disabled people”, since it is the environment that is disabled and not the people. Others prefer “disabled people”, implying that society disables these people. I do not think it is fair to categorise these opinions into groups of different views on disability but merely as different personal preferences. Since I am attempting to integrate the biological, individual and environmental perspectives on disability, I have decided to alternate between these two terms in this publication. Some parts use the term “subjects”, not to dehumanise the participants but to simplify explanations of empirical data.

For most people with CP, the impairment leads to more or less severe disabilities. Sillanpää [45] found that impairments of the nervous system are more disabling and handicapping (based on the terms used in ICIDH) than non-nervous system impairments, such as diabetes.

1.3 Rights of people with disabilities

The position of disabled people in society has been discussed internationally for many years. No international convention deals solely with the rights of people with disabilities, but the principles related to equality and non-discrimination in the general human rights conventions also apply to disabled people. “Equal before the law” means that disabled people may require special treatment to achieve equality with other citizens (Article 26 of the International Covenant on Civil and Political Rights) [57]. According to the International Covenant on Economic, Social and Cultural Rights [58], everyone has the right to education that enables them to participate effectively in a free society and the right to work, which includes the right to the opportunity to earn a living by work (Articles 6 and 13).

The year 1981 was the International Year of Disabled Persons, with the theme of equalising opportunities and full participation. To ensure effective follow-up, the United Nations adopted the World Programme of Action Concerning Disabled Persons in 1982[59]. This defined handicap for the first time as a function of the relationship between disabled people and their environment.

In 1993 the United Nations adopted the Standard Rules on the Equalization of Opportunities for Persons with Disabilities [60]; these are not are legally binding, but they are politically and morally binding. The United Nations appointed a Special Rapporteur, Bengt Lindqvist, from 1994 to 2002 to monitor the implementation of the Standard Rules in cooperation with governments, the United Nations and nongovernmental organizations. Bengt Lindqvist concluded that a majority of countries had a welfare approach to disability, meaning that they mainly emphasize rehabilitation and prevention and pay less attention to accessibility and non-discrimination. He further stated that the present policies throughout the world fail to create equal job opportunities, even though Standard Rule 7 on employment together with the Vocational Rehabilitation and Employment (Disabled Persons) Convention of the International Labour Organization (ILO) [26] gives clear guidance as to how to do this. Sheikha Hessa Khalifa bin Ahmed al-Thani was appointed as the Special Rapporteur on Disability for 2003 to 2005. She concluded in her first report that "despite the commitments shown by Member States to the promotion and protection of the rights and dignity of persons with disabilities and to the equalization of opportunities for full participation, most have not matched that commitment with a financial one" [1].

The United Nations is currently working on a text of an international convention on the rights of people with disabilities building on existing human rights norms and interpreting those in the context of disability.

1.4 Danish disability policy

The description of Danish disability policy is mainly based on information from Michelsen et al. 2004 and the Danish Disability Council 2002 [36;52].

Many national-level public tasks were decentralised during the 1970s in Denmark. In 1980, the responsibility for caring for people with disabilities was allocated to counties and municipalities. The approach towards people with disability was then dominated by integration and normalisation. Many large institutions for disabled people were closed; people with disabilities moved to smaller accommodations closer to their family and began to participate in activities in local communities. In 1980, the Danish Disability Council was established with an equal number of representatives of disabled people and of public authorities. The Council monitors the situation of disabled people in society and acts as an advisory body to the government and the Folketing (parliament) on disability policy.¨

In 1993, the Equal Opportunities Centre for Disabled Persons was established at the request of the Danish Disability Council. The Centre collects information on the equalisation of disabled people and non-disabled people and draws attention to areas of problems in equalisation. Moreover, the Centre's task is to publish information on equal opportunities for disabled people in Denmark.

Disability policy in Denmark is based on three principles. First, the environmentally based perception of disability implies that a person may present a disability, but the environment creates the handicap. Second, the principle of compensation means that society tries to remove or reduce the consequences of a disability by offering help. This can be achieved by generally adapting the environment for disabled people or by offering individual aids or financial support. The compensation is free of user charges and granted irrespective of income. Third, the responsibilities of the sectors establish that all sectors of society and not only the public social sector in Denmark are responsible for ensuring that people with disabilities acquire equal opportunities. Organisations of disabled people (mainly the umbrella organisation, the Danish Council of Organisations of Disabled People) are involved in political decision-making processes through both formal boards and committees and informal contacts.

Denmark's social legislation was comprehensively reformed in 1998, with the main aim of giving individuals better opportunities for self-determination and for getting assistance according to individual need. Three acts govern compensation for disabled people: the Act on an Active Social Policy and the Act on Social Services administered by the municipalities and the Compensation for Disabled People in Employment Act administered by the public-sector employment centres. The municipalities have most responsibilities, and the counties have a few.

Education
One step towards integration in society is education. A fundamental principle in Denmark is that everybody meeting the formal admission requirements has access to an educational programme.

All children, disabled as well as non-disabled, have a right and duty to at least nine years of basic school education. The municipalities are responsible for making any compensatory measures available, such as special education or special aids. Teachers must be qualified to teach all children, including disabled children. The counties are responsible for special education. The Act on Special Education for Adults provides education for severely disabled young people who are not capable of completing a youth education in the normal educational system. The counties provide this in practice but have no guidelines, and offers vary in duration, content and objectives. The individual higher education institutions are responsible for granting measures to compensate for handicaps. Young people (disabled or non-disabled) are entitled to financial support when they are enrolled in a programme of youth or higher education. If disabled students are not able to supplement this support with employment, they may receive a rehabilitation allowance if the municipality finds the employment plan realistic.

Denmark has a system for continuing and advanced occupational training. It includes people in and outside the labour market. Financial support for the cost of living may be granted but not any measures to compensate for handicaps. However, disabled people in work can obtain personal assistance for a continuing and advanced occupational training programme that is closely related to their present employment. In addition, disabled people may receive compensatory special education to compensate for the consequence of functional impairments (such as learning how to use certain tools or methods).

Employment

Employment is a way to achieve financial independence and social integration. Denmark has decided to strive to achieve a labour market open for everyone: an inclusive labour market. The conditions in Denmark's labour market are regulated through collective agreements between employers and employees. In these agreements, social provisions allow people with less than full work capacity to work fewer hours and get paid less than the collective agreement otherwise determines.

Despite laws that ensure disabled people compensation for their handicap, they may have difficulty in getting a job. Various arrangements are made to facilitate disabled people entering the labour market. To reduce prejudice against disabled people, they have "preferential access" to public jobs according to law. This means that they are entitled to a job interview if they have the necessary qualifications, and if they are as qualified as the other applicants they should be offered the job. In 1994, the employment centres appointed special handicap consultants to help disabled people with the opportunities available for assistance in getting employed. At the same time, the Icebreaker Scheme was created to give newly educated disabled people work experience, since they often did not have work experience relevant to their studies as other students had. The disabled people are hired on normal terms, but the employer gets reimbursed. Another way of compensating for the disability is to get a personal assistant, who is allowed to help with practical tasks but not allowed to do the job for the disabled employee.

If a disabled person cannot get employment despite these arrangements, the municipality can provide different arrangements. Social rehabilitation is job-oriented activities, with financial support, to improve chances of employment. When all attempts to attain competitive employment are exhausted, people may be employed under special working conditions (flexjobs). The municipality approves a disabled person for a job with special working conditions and pays a wage subsidy to the employer, who pays the disabled person like every other employee. During the period when this employment is being approved and implemented, the disabled person receives unemployment compensation.

People with a permanently reduced capacity to work who cannot support themselves and that are not eligible for old-age pension are entitled to disability pension. The capacity to work is assessed as the ability to meet the requirements of the present labour market. Since the basic principle is that everybody should be able to lead an independent, active life with participation in the labour market, all possibilities of employment should be ruled out before disability pension is granted. Sheltered employment is for people receiving disability pension. Special attention is paid to the reduced capacity to work, and the municipality arranges the sheltered employment and pays the employee a wage subsidy. Disabled people who cannot meet the demands of sheltered employment can be offered work at a sheltered workshop. Income from a sheltered workshop is very low.

The number of people in flexible working arrangements or sheltered employment in Denmark increased from 1999 to 2004. Among people 16–34 years old, 11,000 were employed under these schemes in 1999 and 37,500 in 2004. In this age group the proportion of people in flexible working arrangements increased from 53% in 1999 to 74% in 2001. The numbers for disabled people only are not available, and there are no statistics on sheltered workshops [50].

Accommodation

In 1998, Denmark abandoned the concept of institutions. Accommodation for severe disabled people is today separated into accommodation facilities and personal assistance. Counties are especially obliged to ensure accommodation facilities for people who need care and treatment. Severely disabled people often live in accommodation facilities arranged by the county, where these services are present. In contrast to the old institutions, the residents still receive a disability pension and decide what to buy.

Families with a disabled child

As a consequence of the principle of compensation, families with a disabled child are generally entitled to be granted the extra expenses they have due to the disability of their child. Many families with a child with substantial impairment of physical functioning need a special car to get around. All extra expenses for making the car disability-friendly are granted, and the parents may be granted a loan to buy a car. Parents who forego employment to take care of their child can be paid a salary. In some cases, a personal helper can assist in the house and the disabled child can be placed in a foster family for a weekend to relieve the parents and any siblings for a while.

Very few evaluations or reports have been published on the effect of the new initiatives since 1980.

In 2007, Denmark's counties will be abolished and instead five large regions will be constructed. Municipalities will be amalgamated, and a minimum population size will be instituted. This will influence services for disabled people. It is hoped that it will improve the legal rights of individuals and minimise the differences in the level of services the municipalities provide today. The Danish Disability Council recommends that each municipality develop a disability policy and it has recently been decided that municipalities are obligated by law to establish a disability council.

1.5 Support for adults with cerebral palsy

In Denmark, health care for children with CP is coordinated through hospital departments of paediatrics. Rehabilitation teams have paediatric neurologists, orthopaedics, physiotherapists, occupational therapists, speech therapists and social workers. Psychologists are often not part of the teams, but psychological assessment can be requested. A child with CP typically consults the paediatric neurologist twice a year, and other experts are consulted when needed. As soon as children become 15–18 years old, they will no longer consult the department of paediatrics and services are no longer provided, and the provision of health care for adults with CP seems inadequate [47]. Neurologists who treat adults do not follow patients with CP if they do not have other co morbidities like epilepsy. The child-oriented approach to CP is the same in other countries, such as Italy and the Netherlands [5;61]

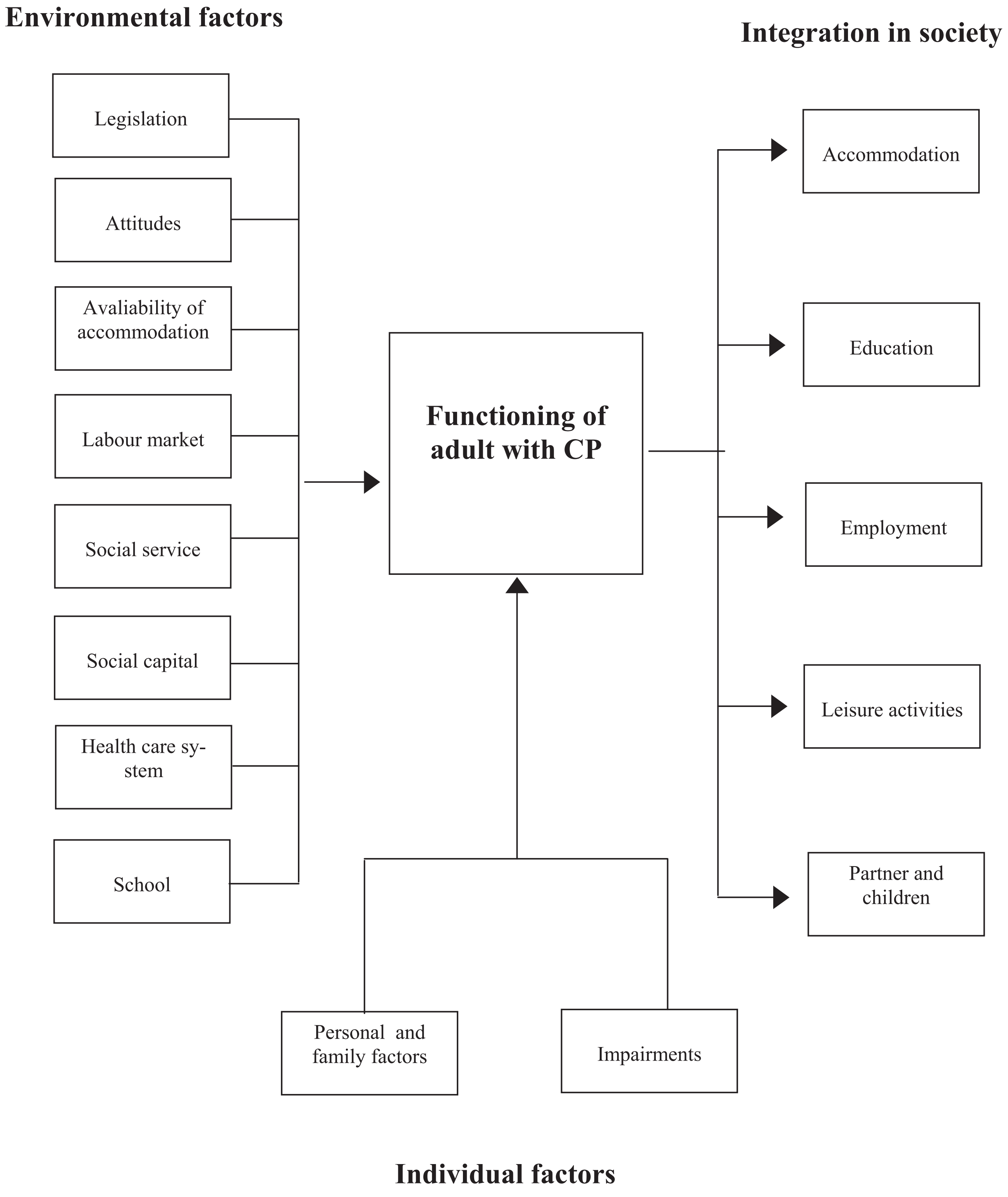
1.6 Integration in society

The concept of equality of opportunity is linked to full participation in society. Integration into and participation in society are as important for disabled people as they are for everyone else. Developing a healthy identity requires being an active, independent part of society. The Danish Disability Council states that accommodation, "home" and employment are the most identity-creating factors in everyone's life [10].

Integration into society can include physical, financial and social aspects. Independent living supports physical integration, in contrast to living in an institution segregated from non-disabled people. Disabled adults living with their parents can participate in society through their parents, but they may lack independence. Competitive employment provides people with disability both financial and social integration. Building a family, living with a partner and having children greatly support social integration.

Within the terms used by the ICF, factors potentially affecting the integration of disabled adults in society might be described by functioning (capacity to perform activities) and contextual factors. Internal contextual factors are individual factors (impairment and personal factors) and external contextual factors are environmental factors. Integration into society is then described by participation in different social settings (Figure 1).

Figure 1 Integration of adults with disability in society



Families with a disabled child might have difficulty in participating in society as well. Figure 1 shows the factors affecting the integration of a family by replacing “adult with CP” with “family with CP”. For many parents, the outcome measures of integration are already determined before the child with CP is born, and the ability to sustain these participation factors should be assessed instead. The strain on the family could make it difficult to stay employed and have the same time and energy for leisure activities. New accommodation might be needed and marital problems might occur.

1.7 Literature

Literature on employment and accommodation of adults with CP was searched in Medline from 1980 to March 2005. The search terms were “cerebral palsy” in combination with “social”, “vocational”, “employment”, “income”, “independent living” and “housing”. A total of 662 references were found and titles or abstracts read. In addition, some references were found through list of references in papers. Quantitative processing of the social outcome variables and a study population of at least 50 people were selected. Study populations solely with people with CP were preferred, and when people with other disabilities participated, identifying separate outcome for the group of people with CP was important. One reference describing a mixed population of adults with CP and spina bifida was selected since the numbers of participants with spina bifida were very small. The studies in which the population is a mixture of adults and young adults were included. Only literature written in English and from countries in the Western Hemisphere was included. An exception was publications written in Danish with important figures on the social situation of adults with CP in Denmark. Eight articles were selected to describe the social situation of adults with CP. In addition, several articles were selected to describe the social situation using a qualitative view.

Literature on employment, income and cohabitation of the parents of a disabled child was searched in Medline as well (from March 2005). The search terms were “cerebral palsy” in combination with “parent”, “family” and “mother”. A total of 605 references were found and titles or abstracts read. In addition, some references were found through lists of references in papers. Quantitative processing of the social outcome variables was preferred in the selection process. Since there were few articles on the parents of children with CP, studies involving children with chronic illness or other disabilities were included. Studies older than 1980 were included as well. Only literature written in English and from countries in the Western Hemisphere was included. An exception was publications written in Danish with important figures on the social situation of adults with CP in Denmark. Six articles were selected to describe the social situation of the parents of a disabled child. In addition, some references were selected with qualitative data on the social situation of families with a disabled child.

Literature from other countries is reported initially here and studies in Denmark are mentioned at the end of each paragraph, since they are the most obvious to compare with our study later in the discussion.

Employment in cerebral palsy (table 1)
The definition of being employed varies in the literature. Possible indicators are working full time or part time, being competitively employed or non-competitively employed, paid work or unpaid work and open employment versus sheltered employment. Countries have different regulation of and schemes for supported and sheltered employment. This and differing selection criteria make comparing studies difficult. The proportions of study subjects, who are competitively employed, employed full time or working in open employment were searched, assuming that these would be the most comparable outcome measures. Seven studies [2;33;37;40;46;61] showed that 20–53% are working under these conditions. van der Dussen et al. [61] found the lowest percentage among subjects 21–31 years old in the Netherlands, whereas Murphy et al. [37] found 53% competitively employed in a self-selected population living in the community in California. In Denmark, Glenting [13] found 52% completely independent in supporting themselves financially (including married women without an disability pension).

Accommodation in cerebral palsy (table 1)
Studies outside Denmark [2;33;37;40;61] find 40–66% living independently and 13–33% living with their parents. The selection criteria of the study population differ, making comparing results difficult. The severity of CP and the age of the subjects seem to be substantial predictors of living independently and living with parents. A study in California with a self-selected population living in the community with no learning disability [37] found the highest percentage living independently. The studies with young adults have the lowest percentages. Van der Dussen et al. [61] found 40% of the 21- to 31-year-old subjects living in homes not with their parents and not classified as institutions or sheltered homes. Kokkonen et al. [33] found that 35% of 19- to 26-year-old subjects were living alone or with a partner versus boarding or living with parents. None living in institutions are included in this study. A study from 1981 based on the Danish Cerebral Palsy Registry and subjects 30 years old [13] found 67% living independently. A study in Sweden of people living in the community and without learning disability [2] found a low percentage of subjects living with their parents; a 1991 study from Finland with the youngest participants [33] found the highest percentage.

Partner and children (table 1)
Some studies only measured the percentage married [37;40] and others only the percentage cohabiting [2;61]. Kokkonen et al. [33] found 8% married and 24% married or cohabiting in the same population of 19- to 26-year-old subjects with CP or spina bifida. Recent studies have found lower percentages cohabiting. Van der Dussen [61] found 13% of 21- to 31-year-old people with CP living with a partner, and Andersson & Mattsson [2] found 14% living with a partner among subjects living in the community and with no learning disability. Few studies report on the children of subjects with CP. The percentages are 4–8% [2;37]. The older study based on the Danish Cerebral Palsy Registry and subjects born from 1940 to 1945 found 32% married and 28% with children [15].

Social situation of parents of disabled children (table 2)

Education, employment, income and cohabitation among parents with disabled children were searched for. No differences were reported in educational level between the parents of subjects and the parents of controls [6;63], and the only study specifically reporting on the employment rate of fathers [34] found 93% of fathers employed among both subject and control parents in the Nordic countries. Mothers of disabled children, however, are more often outside the labour market [6;34]. In Sweden, Westbom [63] found no mothers with severely disabled children working full time versus one third of the mothers to mild and moderately disabled and mothers of controls. In Canada, Brehaut et al. [6] found that more caregivers of CP children had a lower annual income than caregivers of controls. In Ohio, Breslau et al. [7] found that child disability negatively affected maternal labour force participation in low-income two-parent families. In contrast, Lie et al. [34] found no difference in the financial situation of Nordic families with a child with spina bifida versus controls, except that the Danish fathers of a disabled child were less often in the high-income group than controls. The results on cohabitation and ending cohabitation (divorce) diverge. Some studies [34;63] report no increase in the number of parents divorced or separated in families with disabled children versus control families, whereas other studies [29;51] report an increased risk of divorce among the parents of disabled children.

Table 1 Quantitative studies of the social situation of adults with CP

Reference	Study population	Results			Comments
		Employment	Accommodation	Cohabitation and children	
Van der Dussen et al. Netherlands 2001	80 (of 130) subjects with CP known to a rehabilitation clinic completed a mailed questionnaire in 1996; born 1965–1974: 21–31 years old	20% competitive market employment 16% sheltered employment	30% living with parents 40% living in home with or without adaptation and assistance	13% with partner 33% alone	74 subjects were not included due to unknown address
Andersson & Mattsson Sweden 2001	221 (of 363) subjects with CP living in Stockholm County born before 1979 and with no learning disability completed mailed questionnaire	24% full-time employment	13% living with parents	14% with partner 8% with partner and children	None living in institutions or with a documented learning disability included
Murphy et al. California, USA 2000	101 volunteer participants 27–74 years old through a local United Cerebral Palsy Affiliate (Oakland) with CP were examined, interviewed and completed a questionnaire	53% competitively employed 18% sheltered employment	66% independent	4% married 4% with children	Self-selected population, few with mild CP and none living in institutions included
O'Grady et al. California, USA 1995	117 (of 810) individuals with CP visiting the Cerebral Palsy Clinic of the University of California, San Francisco from 1951 to 1974 completed a questionnaire	38% work >20 hours per week	31% living with parents 48% independent 20% board and care or institution	10% married 8% divorced or separated	Subjects with IQ <69 and not registered in the California Department of Developmental Services were not searched; respondents more often had functional speech
Kokkonen et al. Finland 1991	52 (of 59) adults born from 1963 to 1968 (19–26 years old) with CP or spina bifida from the catchments area of Oulu University Central Hospital attended follow-up examinations	36% work full time	58% living with parents 9% boarding or other 35% alone or with partner	8% married 24% married or cohabiting	None living in institutions included. 4 of 52 subjects had spina bifida not CP
Sillanpää et al. Finland 1982	86 patients with CP from an outpatient unit of the Department of Paediatrics, University of Turku, at least 15 years old in 1981 were followed and completed a questionnaire in 1981	12% open employment 31% >19 years in open employment 7% <19 years in sheltered work			Young population with 45% in comprehensive school (7% of the population above 19 years old)
Glenting Denmark 1982	518 patients born from 1940 to 1945 with CP in the Danish Cerebral Palsy Registry were examined after the age of 30 years			32 % married 3% divorced or separated 28 % children	Subjects with very mild CP might not be included
Glenting Denmark 1981	518 patients born from 1940 to 1945 with CP in the Danish Cerebral Palsy Registry were examined after the age of 30 years	52% completely independent in supporting themselves financially (including married women without an disability pension)	11% living with parents 8% foster care 67% living independently 10% living in an institution 4% living in sheltered accommodation		Subjects with very mild CP might not be included

Table 2 Quantitative studies of the social situation of parents with children with CP

Reference	**Study population**	**Control population**	**Parents education, employment and income**	**Parents cohabitation**	**Comments**
Brehaut et al. Canada 2004	Caregivers (468 of 632) of children with CP from rehabilitation centres in Ontario: primary caregivers (95% parents, 94% women)	National representative samples of the Canadian population	No difference in education; 66% of the caregivers of CP children had paid employment versus 81% of controls. 25% of caregivers had an annual household income <CAD 30,000 versus 16% of controls		The control population is based on all of Canada
Joesch & Smith USA 1997	7246 once-married mothers from the 1988 National Health Interview Survey (15 with CP)	7246 once-married mothers from the 1988 National Health Interview Survey		Mothers of children with CP have a higher risk of marital disruption (rate ratio = 2.83, confidence interval 0.73–10.94) controlled for demographic, marital, and reproduction measures and for mothers' and siblings' health	Women who remarried and women with children who have died are not included; 15 children with CP
Lie et al. Nordic countries 1994	527 (of 630) children born from 1966 to 1980 with myelomeningocele from hospitals and rehabilitation centres in Denmark, Finland, Norway and Sweden; data collected in 1984	A representative sample of 11,196 children of the same age sampled randomly by their civil registration number in four Nordic countries	93% of fathers worked or studied full time in both subject and control families. 66% of mothers of subjects and 77% of mothers of controls were employed or studied full time. More single mothers worked. In Denmark, 46% of the subject families were high-income compared with 57% of control families	84% of the subjects versus 87% of the controls lived in two-parent families; 14% of couples was separated in both subject and control families	No CP children
Westbom Sweden 1992	98 (of 183) chronically ill children in Dalby primary care district age 4 to 14 years.	168 (of 199) non-chronically ill children in Dalby primary care district age 4 to 14 years.	Parental education level did not differ. Chronic ill children more often had parents with manual work (33% of the subjects versus 19% of the controls). No mothers with severely disabled children worked full time versus one third of the others	The parental situation was unchanged in 85% of the families; 11% of the subjects had single mothers versus 5% of controls	The number of children with CP (if any) is unknown
Breslau et al. Ohio 1982	369 (of 460) families with a 3- to 18-year.old disabled child (cystic fibrosis, CP, myelodysplasia) from paediatric speciality clinics in Cleveland	456 of 530 randomly selected families with 3- to 18-year-old children from the same geographical area. A child was randomly selected in each family	Child disability negatively affects maternal labour force participation in low-income two-parent families		The income of families with a disabled child was estimated; the number of children with CP was unknown
Tew et al. 1977 UK	144 families with children with neural tube malformation born from 1964 to 1966	General population in England and Wales 20–34 years old		The divorce rate of parents of a living spina bifida child was 10.3% versus 3.5% of bereaved parents and 1.1% of the general population	No children with CP. 86 of the 144 children had died. The control population is based on all of England and Wales

2. Aims

The aim of this PhD study was to analyse the societal participation of adults with CP and families with a CP-afflicted child. The study had three sub goals:

- to analyse the education, employment and income of adults with CP compared with a control group of adults without CP;

- to analyse accommodation, cohabitation and having children among adults with CP compared with a control group of adults without CP, as well as the correlations between cohabitation, employment and children; and

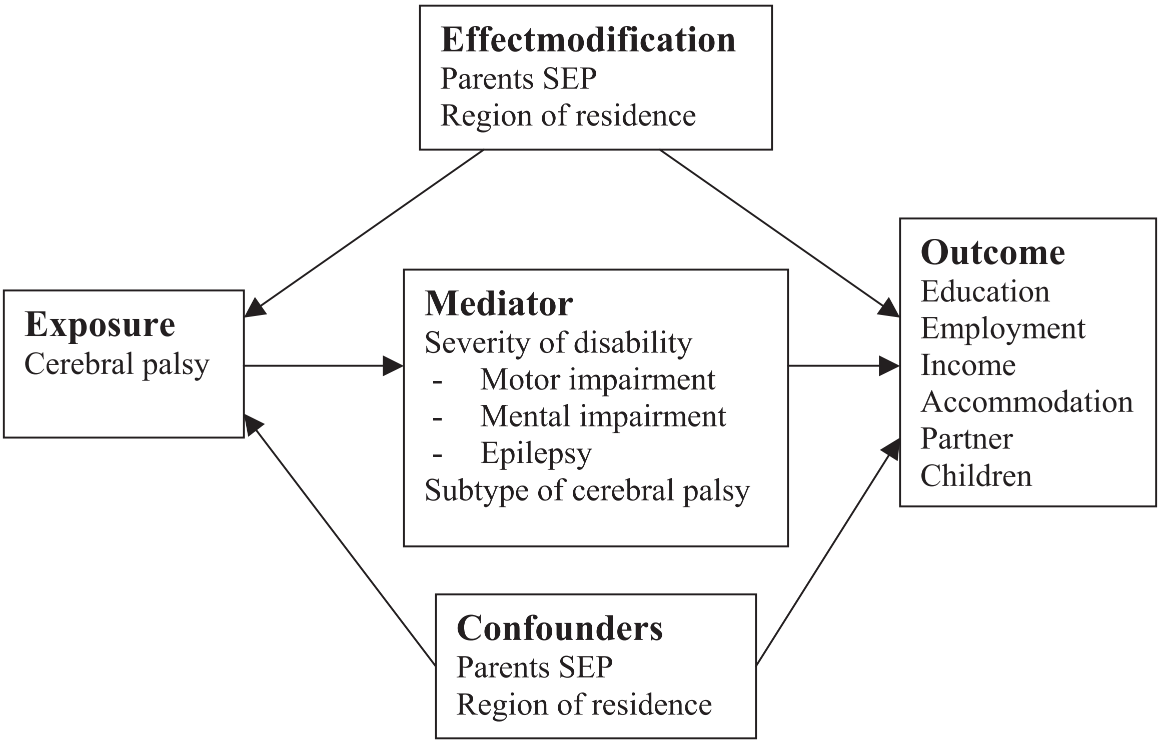
- to analyse employment, income, cohabitation and having additional children among parents with a child with CP compared with a group of parents to children without CP; and to analyse changes in social situation after having a child with CP.

3. Methods

3.1 Model and study design

This study is designed as a historical follow-up study of children with cerebral palsy and their parents. Children and their parents were followed from birth of the children to 31 December 1999. Cohorts of CP children were compared with cohorts of controls matched by gender and age. Cohorts of parents to children with CP were compared to cohorts of parents of controls. Figure 2 shows a model of the study.

Figure 2 Model of study



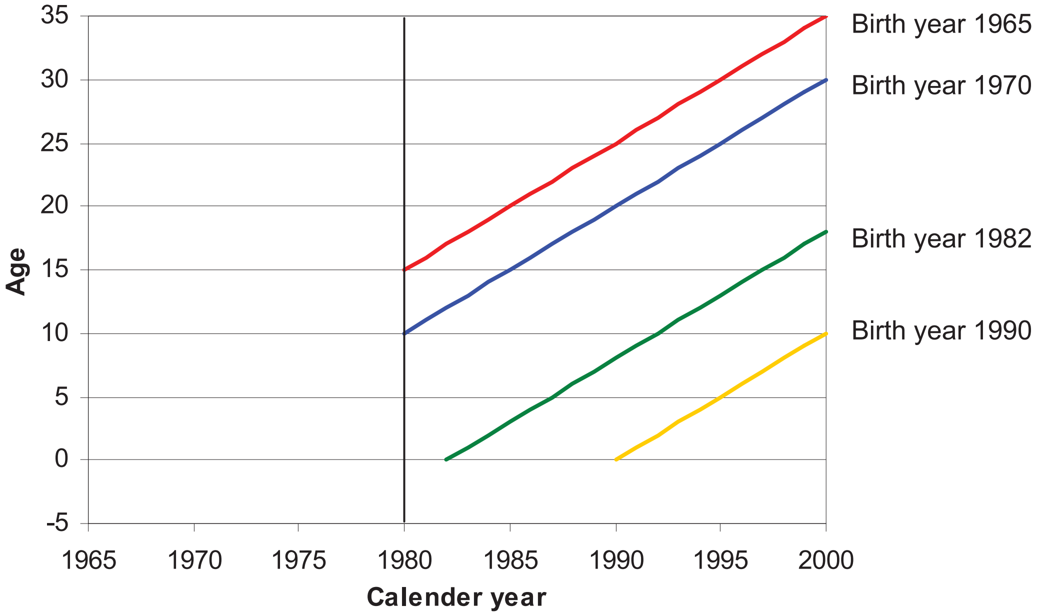
The model is developed from the model in Figure 1 and is based on the ICF. The model shown is for children with cerebral palsy; a similar model could be drawn for parents with a disabled child, replacing the listed confounders and effect modifiers with "parents socioeconomic position (SEP) before the child was born" and "region of residence before the child was born". Exposure is the brain dysfunction; the CP. Outcome is integration or participation in society and is measured by accommodation, education, employment, income, cohabitation and having children in adults with cerebral palsy as well as parents to a child with cerebral palsy. The mediator of the effect of CP (regardless of whether the effect is studied on subjects or parents) is the severity of disability or subtype of CP. Walking ability; development quotient and presence of epilepsy all assessed in childhood are proxy measures of functioning.

Personal or familial factors and environmental factors are confounders, since they potentially affect both presence of CP and later social integration. Environmental factors and family factors are possible effect modifiers of later social integration as well.

Functioning as a mediating factor was measured when the child was six years old, while outcome measures were collected every year from the beginning of the registries in 1980 and to the end of follow-up in 1999.

Figure 3 shows the cohorts of children and which calendar years data is available for.

Figure 3 Cohorts



3.2 Study population

The Danish Cerebral Palsy Registry registers children with congenital CP. All subjects born between 1965 and 1990 who were recorded in the registry were included in the study. Diagnose of cerebral palsy is verified by a neuropediatrician before inclusion in the Danish Cerebral Palsy Registry. Birth years 1965 to 1978 were included by the registry's former paediatric neurologist, Paul Glenting, and birth years 1979 to 1990 by the present paediatric neurologist, Peter Uldall. To ensure that the inclusion criteria for the children were the same from1965 to 1990, special attention was paid to the oldest subjects born between 1965 and 1978. For the birth year period 1971–1978, Peter Uldall excluded 20 subjects with the diagnosis of hypotonia. Peter Uldall read the medical records for subjects born between 1965 and 1970, and 85 subjects were excluded due to a non-CP diagnosis, mainly hypotonia.

To describe the social situation of adults with congenital CP, we enrolled all 948 subjects born between 1965 and 1978 from the Danish Cerebral Palsy Registry. The civil registration number of one subject could not be found. A total of 114 subjects had died and 14 subjects had emigrated, leaving 819 subjects for analysis on 31 December 1999. These were the subjects of Paper I. For analyses on accommodation, cohabitation and children (Paper II), only the 416 oldest subjects born between 1965 and 1970 were included (Figure 4).

To describe parents' social situation, the biological parents of the 1856 subjects born between 1965 and 1990 were searched for in the Fertility Database of Statistics Denmark; 119 parents could not be found, leaving 3593 parents of subjects for analysis in Paper III (Figure 5). For 32 subjects, neither mother nor father was identified, and analyses were based on the parents of 1824 children with CP. The parents of subjects or controls who died or emigrated before 31 December 1999 were included, and parents who died before follow-up ended on 31 December 1999 were censored at the time of death.

We selected a group of controls from the Civil Registration System, which included all residents of Eastern Denmark. Five controls were randomly selected per subject and matched for gender and age; in total 9280 controls. For analyses of adults; thirteen controls already included as subjects, 92 controls dead before end of analyses, 226 controls who emigrated and two subjects not traceable were excluded, leaving 4406 subjects born between 1965 and 1978 for analyses (2247 of these was born 1965 to 1970) (Figure 4). For analyses of parents 23 adult controls already included as subjects was initially excluded, leaving parents of 1824 children with CP for analyses. The biological parents of controls were searched for in the Fertility Database of Statistics Denmark. For 104 neither mother nor father could be identified and analyses was based on 9153 children without CP. 532 parents could not be found, leaving 17.982 parents of controls for analysis (Figure 5).

Figure 4 Study populations of adults with cerebral palsy

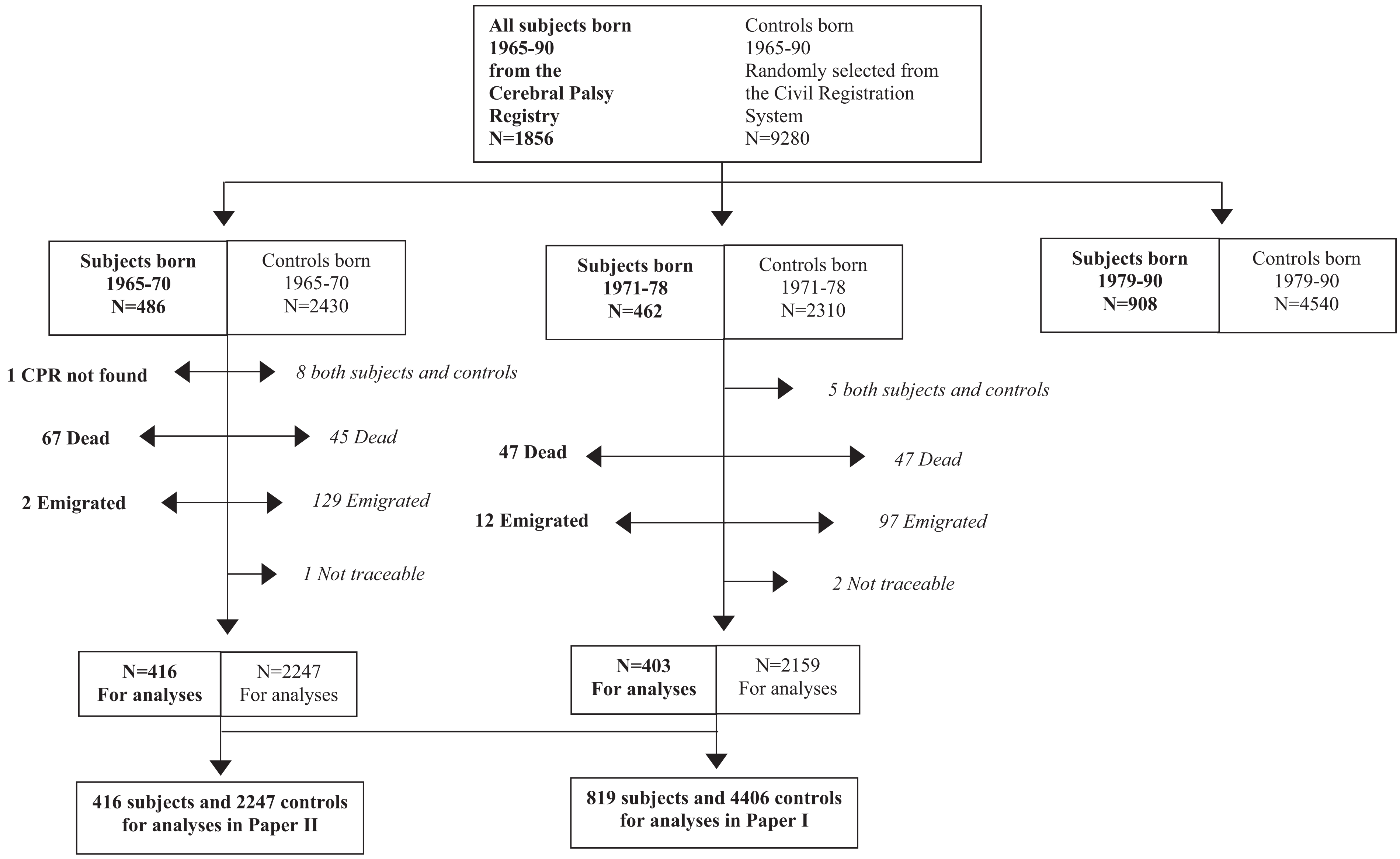
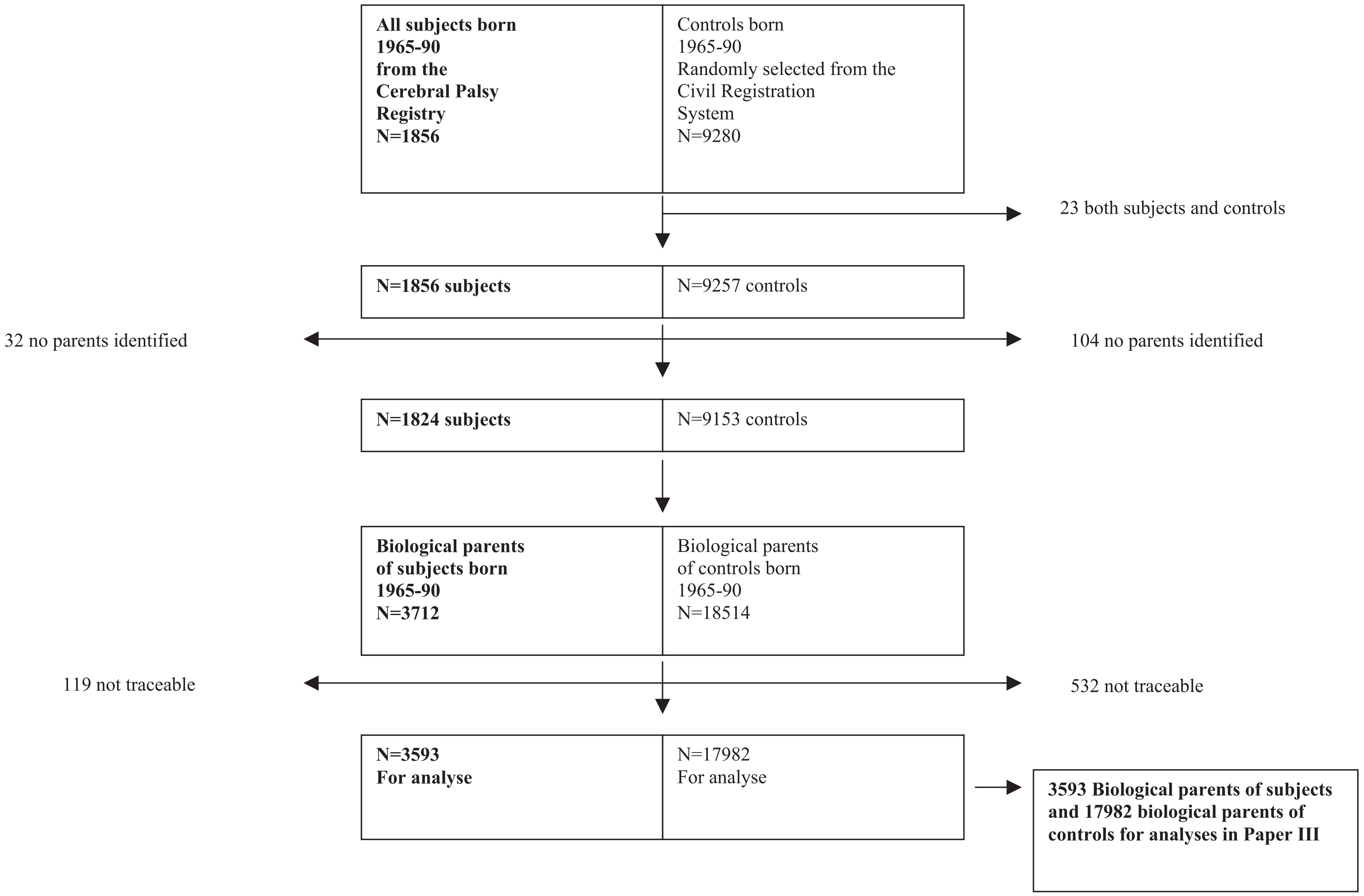


Figure 5 Study populations of parents to children with cerebral palsy



3.3 Data sources

All data are register data. Subjects with CP are identified in the Danish Cerebral Palsy Registry and controls are identified in the Civil Registration System. Parents and siblings of subjects and controls were identified in the Fertility Database of Statistics Denmark.

The Danish Cerebral Palsy Registry

The Danish Cerebral Palsy Registry is a population-based registry that contains subjects with CP from the birth year 1925 and has reported birth prevalence since 1950 [14;54-56]. The catchments area includes 2.5 million people in eastern Denmark, about 50% of the population of Denmark. Two paediatric neurologists included all the subjects in the Registry from 1950 and until today (Paul Glenting for those born from 1950 and Peter Uldall for those born from 1979). Since birth year 1965, data have been collected prospectively. Case records from paediatric departments and special institutions are sent to the registry and evaluated and information on pregnancy, birth, neonatal period and impairments is registered. Subjects are not ascertained until 6 years of age in order to ensure that the mild and late-diagnosed cases are included and that mental development is reasonably estimated. Children who died before 1 year of age are not included. To complete the registration, children born since 1983 have been linked with the National Patient Registry. Children, who have been in contact with a hospital (with a diagnosis of CP) are identified, and if they are not already in the Danish Cerebral Palsy Registry, inclusion is considered based on case records from paediatric departments. From birth year 1979, the Swedish classification of CP has been used [19], and in practice, the diagnostic criteria today used today are similar to those adopted by the Surveillance of Cerebral Palsy in Europe [44]. The severity of mental impairment is described by a development quotient. The development quotient is assessed to be > 85 when school is begun without help (excluding manual assistance) and between 85 and 50 for those needing more support at school. The third category is development quotient < 50. Motor impairment is classified according to ability to walk. The Registry does not currently contain a detailed description of motor function, but in the future children will be classified according to the Gross Motor Function Classification System [42]. Epilepsy is registered following two or more unprovoked seizures after the neonatal period. The obstetric data are from birth year 1983 and are coded by an obstetrician. The Registry covers all of Denmark, from birth year 1995, and is thus probably the first nationwide CP-registry in the world.

The Danish Cerebral Palsy Registry provided information on the severity of motor impairment, severity of mental impairment, presence of epilepsy, subtype of CP and birth weight in this study.

Registries in Statistic Denmark

Statistics Denmark keeps various registries with socioeconomic data. The data sources are schools, educational institutions, workplaces, local authorities and the tax authorities, which are all obligated by law to deliver information to Statistics Denmark. In this study, we used data from the following registries:

- Integrated Database for Labour Market Research (IDA): education, employment, disability pension, income, cohabitation and region;

- Integrated Student Registry (Det integrerede elevregister): type of school and class and degrees;
- Registry of Employment under Special Working Conditions (Flexjobs) and Sheltered Employment: supported employment;
- Database of Children: Main income source;
- Central Register of Buildings and Dwellings (BBR), the Civil Registration System and Social Pensions Registry: accommodation.

The Danish Cerebral Palsy Registry contains the civil registration number of the subjects. The Danish Civil Registration System was founded in 1968, and all living residents were allocated a civil registration number. Subjects in the present study who were born between 1965 and 1967 were sometimes only registered with their name and date of birth but could be identified in the Civil Registration System and their civil registration number was thus included. Data on 1856 people in the Danish Cerebral Palsy Registry were delivered to Statistics Denmark, which identified parents and controls, and linked the information to other registries in Statistics Denmark using the civil registration number.

3.4 Variables

Exposure variable
In comparing subjects and controls, exposure is measured by the presence or absence of CP. In comparing children with CP with each other, exposure is measured by severity or subtype of CP.

Mediating variables
Disability, described by severity of mental impairment, severity of physical impairment and presence of epilepsy was included from the Danish Cerebral Palsy Registry as mediating factors, when comparing subjects with CP with controls, and are listed in Appendix A. All measures of severity were mediators of the relation between exposure and social situation of adults with CP, as well as the social situation of parents to a child with CP, when comparing with controls

The number of variables describing the disability in the Danish Cerebral Palsy Registry has increased from children born between 1965 and 1970 and children born between 1971 and 1978 and again to children born between 1979 and 1990. Only variables present for all the birth year cohorts were included in this study. Data on subjects born from 1965 to 1970 were on punched cards, while for subjects born from 1971 to 1978 and from 1979 to 1990 data were recorded on two different standard forms. All information was recoded to fit the newest standard form. Disability is assessed when the child is six years old. Severity of physical and mental impairment is unknown when information in the medical papers is too sparse. Epilepsy is never unknown. If an episode of seizures is not recorded in the case notes before or at the neuropediatric evaluation at 6 years of age, epilepsy is considered unlikely.

In addition, school and education were analysed as mediating factors of later employment.

Outcome variables
Variables describing the social situation of adults with CP, as well as parents to a child with CP were identified from the registries in Statistics Denmark. For each variable a careful research of possible variables were conducted.

School, education, employment and income
The only available variables to describe schooling were type of school and class in grades 8 to 10. Attendance in special class was not registered, but attending a class with pupils of different ages was chosen as a proxy for special class. Passing all school leaving examinations was not possible to register, therefore passing at least one examination was chosen as a measure of school performance. Highest educational level was chosen to describe education for adults with CP.

Employment among adults with CP was described by different variables; a group of variables described employment by dividing people according to type of labour market status (competitive employment, supported employment, under education, outside the labour market) and a variable described employment from financial stance, dividing people according to main income source (employment, educational benefit, temporary benefit and pension).

People with disabilities are in different kind of employment (Figure 6). Three types of supported employment exist: flexible working arrangements, where the employee lives of his/her salary; sheltered employment where the employee receives a disability pension as well as salary; and sheltered workshop where the employee receives a disability pension as well as a very low salary. The last is not included in the registries and we were not able to study this kind of employment.

Figure 6 Types of employment

Employment	Terms	Pension	Salary	Included in analyses
Competitive	Equal	No	Normal	Yes
Flexible working arrangement	Special	No	Means of living	Yes
Sheltered employment	Special	Yes	Municipalities pays half the salary (a maximum exists)	Yes
Sheltered workshop	Special	Yes	Very little, only by effort	No

Annual pre-tax income was chosen to describe financial situation.

Schooling was only used as an outcome variable amongst adults with CP, while education, employment and income were used as outcome variables amongst parents to a child with CP as well. During maternity leave, the mothers were regarded as working.

Accommodation

Type of accommodation could not be derived from one register and persons living in accommodation provided by the county were particularly difficult to identify. One variable available in the Integrated Database for Labour Market Research (IDA) had been constructed to describe this, but was found to be invalid. Adults living in accommodation provided by the county are registered in the Social Pension Registry, but Statistics Denmark suspected, that the sensitivity of the variable was low. In the Central Register of Buildings and Dwellings type of accommodation was registered according to address code and substantially more persons were living in accommodation provided by the county according to this register then were identified in the Social Pension Registry. We decided to use both registers. The Social Pension Registry was regarded as having the highest specificity, since type of accommodation arranged for by the county was registered for all persons receiving a social pension. The Central Register of Buildings and Dwellings was considered to have high sensitivity since all persons in Denmark have address code and all addresses are associated with a type of accommodation. A comparison of address codes allowed for identification of adults who were living with their parents. Type of accommodation was only used as outcome variable for adults with CP.

Marital partnership and children

To describe people who were in a relationship, we decided to use cohabitation, since many people today live a family life without being formally married. Parents not living together are in this study called divorced. Variables based on address codes were used as outcome variables for adults with CP as well as parents to a child with CP. Biological children of adults with CP and biological children of parents to a child with CP were identified in the Fertility Database. Cohabitation and having children was used as outcome for adults with CP and parents to a child with CP.

Confounding variables

Socioeconomic data are well defined in registries and are chosen to describe family background. Variables describing socioeconomic position varied somewhat throughout the study. When analysing employment in adults with CP (Paper I), we used parents' highest educational attainment at the end of follow-up 31.12.1999. At that time (writing Paper I) we did not yet have access to longitudinal data on parents and educational level was chosen as a relatively time-stable variable compared with income, employment and cohabitation. To analyse accommodation and cohabitation (Paper II) we used parents' highest education, income and cohabitation, when the child was 15 years old, as this was considered an age which was close to adulthood, but nevertheless before the child left home. Analysing parents' employment, income and cohabitation situation, we consequently used parents' highest educational attainment and cohabitation in the year before the child was born. In addition, employment the year before the child was born was found relevant when analysing employment status. Number of siblings the year before the child was born, was found relevant to analyse cohabitation.

Analyses of education, employment, accommodation and cohabitation were controlled for age and gender of the child, while analyses on parents' employment, income and cohabitation were controlled for age and gender of the child and birth year of child.

Region of residence at age 15 was included as a confounder in analysing accommodation and cohabitation, but we found no effect of this at all and decided to leave it out in the more complicated analyses of parents’ social situation. At our first analyses in Paper I we had not yet constructed the variable “region of residence at age 15” since this involved longitudinal data.

Variables from Statistics Denmark are listed in Appendix B according to the social situation that they describe and the registry from which they originate. Content of the variables are described and values used in this study are listed.

3.5 Statistics

Most univariate comparisons used a chi-squared test for homogeneity in two-dimensional contingency tables. More elaborate analyses of binary outcomes like independent living, cohabiting and being competitively employed and also outcomes related to parents' status used multivariable logistic regression models. In the multivariable models we investigated effect modification of the variables listed in Figure 2 on either exposures (CP-status) or mediators regardless of whether confounders/effect modifiers were univariately statistically significant. Region of living were however only included in the analyses on living independently and cohabitation as explained in 3.4.

In analyses on parents we additionally used multivariable proportional hazards models to examine time to divorce and time to subsequent (younger) children following the birth of the CP/control child. Lastly, parents' log yearly income were analysed longitudinally using standard multivariable growth curve modelling for normally distributed outcomes.

In all analyses a 5% level of statistical significance was used.

4. Ethics

The Danish Data Protection Agency approved this study. The civil registration numbers of subjects are delivered to Statistics Denmark, and an identification number replaces each civil registration 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. The Danish Cerebral Palsy Registry became a public registry in 1992, and linkage to other public registries is permitted for the purpose of research.

5. Results

5.1 Characteristics of the study population

The mean age of the 819 children with CP who were born between1965 and 1978 was 28 years and 10 months (range 21 to 35 years). Fifty-eight percent were males. This group was used to describe education, employment and income. Only the oldest children born between1965 and 1970 were included in analyses on accommodation, cohabitation and having children. The mean age for this subgroup was 32 years and two months (range 29-35 years). Fifty-eight percent were males. 4406 controls born between 1965 and 1978 were matched by gender and age. 2247 controls were born between 1965 and 1970.

Subtype of CP and severity of impairment were assessed in childhood and distribution in the two groups is shown in table 5.

Table 5 Characteristics of children with CP at age 6 years alive 31.12.1999.

Characteristics	819 children born 1965 to 1978		416 children born 1965 to 1970	
	%	N	%	N
Subtype of CP				
Hemiplegia	31	256	31	127
Diplegia	42	347	50	206
Tetraplegia	18	148	11	47
Other	8	68	9	36
Motor impairment				
Walk without assistance	62	506	65	270
Walk with assistance	21	176	22	91
Not walking	16	131	12	49
Unknown	<1	6	1	6
Development quotient				
DQ>85	60	488	49	203
DQ 85-50	17	142	25	104
DQ<50	19	154	20	83
Unknown	4	35	6	26
Epilepsy				
No	83	683	81	339
Yes	17	136	19	77

The majority of the 114 children who died before 1999 were severely impaired (not shown).

The mean age of the 3593 biological parents of subjects with CP (N=1824) did not differ from that of the 17982 biological parents of controls without CP (N=9153). However parents of the younger cohort of children born between 1982 and 1990 were older when their child was born (mothers 28 years and fathers 31 years) than were the parents of the older cohort born between 1965 and 1970 (mothers 25 years and fathers 29 years).

5.2 School, education, employment and income

(described in Paper I)

In lower secondary school 37% of adults with CP had received special education compared with 3% of controls. Severity of mental impairment and subtype of CP were the most important predictors of having received special education, followed by motor impairment. OR of having received special education were 29.8 (14.0-63.3) and 4.6 (2.7-7.9) for children with a DQ between 50 and 85 and a DQ<50 respectively compared with children with a DQ>85. Parents' highest education was controlled for and parents' highest education did not modify the effect of motor or mental impairment on receiving special education.

Forty-five percent of adults with CP never passed an examination in lower secondary school, compared with five percent of controls (Table 6). We found that 34% subjects were educated beyond lower secondary school, compared with 78% of controls.

Table 6 Education (%)

Highest educational level	CP (n=819)	Control (n=4406)
Lower secondary school, no examination	45	5
Lower secondary school, examination	17	17
Upper secondary school	8	19
Vocational training	17	38
Tertiary education	9	20
Unknown	4	<1
	P<0.0001	

Excluding adults with no education beyond lower secondary school; we found no differences in the distribution of the different levels of education - upper secondary school, vocational training and tertiary education between adults with CP and controls (not shown).

Subjects in the age group 21–35 years with CP were significantly more often outside the labour market than controls, and few were in supported employment (Table 7).

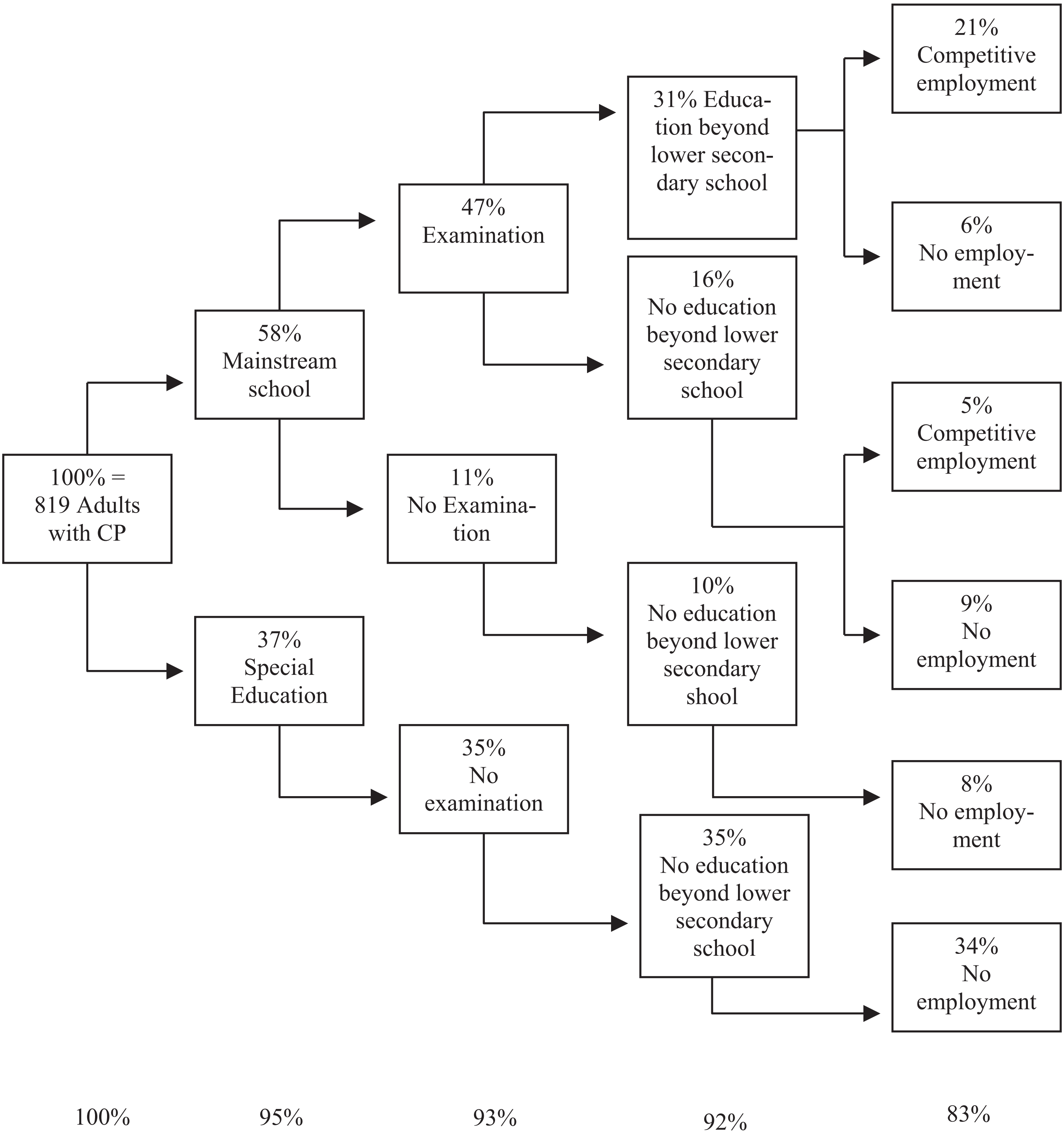
Table 7. Employment (%)

Employment	CP (n=819)	Control (n=4406)
Competitively employed	29	82
Flexible working arrangements	2	<1
Sheltered employment	3	<1
Student	5	7
Not employed	62	11
	P<0.0001	

The severity of mental impairment and presence of epilepsy at the age of 6 years greatly influenced the chances of competitive employment in adulthood, whereas the severity of motor impairment had only a minor, but significant effect. Only three adults with severe motor impairment and no adults with an estimated development quotient < 50 were competitively employed. Excluding these most severely affected adults, the odds ratios (multivariate analysis) for not being competitively employed were 22.5 (6.8–74.7) for children with a DQ between 50 and 85 versus children with a DQ > 85 and 3.7 (1.5–9.4) for children with epilepsy versus children without epilepsy. Parents' highest education had a minor significant effect and was controlled for. No effect modification of parents' highest education was found.

Figure 7 shows the history of schooling, higher education and employment in this population. The percentages are all based on the whole population of 819 subjects, and boxes with less than 5% of the population are not drawn, since the purpose of the figure is to provide an overview of the role of school and education in the chances of obtaining employment. Below the figure, the percentage of the total population described at the different levels is shown; this percentage is decreasing, since groups comprising less than 5% of the population are continuously excluded. People in supported employment or studying comprise less than 5% of the population and are therefore not reported here. All subjects who were studying had attended mainstream school and had passed examinations, whereas the group of subjects in supported employment was more mixed. Examination after lower secondary school means passing one or more examinations at the end of lower secondary school.

Figure 7 Schooling and education as predictors of chance of employment
(the percentages are all of the total population of 819 persons)



The main results were as follows. More than one third of the population had been in special schools or special classes. They did not pass any examinations in lower secondary school and they did not achieve any educational degree or employment. Fifty-eight percent were in mainstream school, and most passed one or more examinations. Half of these subjects were later competitively employed, the majority after education beyond primary school.

In a multivariate analysis on employment status of both adults with CP and controls we found a higher OR of not being competitively employed among adults with CP compared with controls. We found no effect modification of parents' highest education. Highest educational level (including passing examinations in lower secondary school) however modified the effect of CP on employment. Among CP-adults with no examination in lower secondary school OR of not being competitively employed was 24.2 (12.0-56.1) compared with controls. Among CP-adults who passed one or more examination in lower secondary school OR was 7.1 (4.6-11.1) compared with controls, among CP-adults with upper secondary school or vocational training OR was 3.3 (2.4-4.7) and among CP-adults with a tertiary education OR was 3.0 (1.4-6.0).

We found more subjects in the lower-middle income group and fewer in the upper-middle and upper income groups compared with controls. Competitively employed subjects and competitively employed controls were more similarly distributed among the income groups, but controls were still more often in the upper-middle and upper income groups.

In conclusion, few adults with CP were in competitive or supported employment, and severity of CP in childhood predicted the long-term chance of employment. Only half the subjects who attended mainstream school were later employed. Passing examinations in lower secondary school and attaining further education increased the chance of employment.

5.3 Accommodation, partner and children

(described in Paper II)

The majority of 29-35 year-old adults with CP lived independently (Table 8). Subjects living independently might receive substantial practical help. More subjects than controls were living with their parents.

Table 8 Accommodation (%)

Accommodation	CP (n=819)	Control (n=4406)
Independent	68	92
Accommodation arranged by the county	16	<1
With parents	13	5
Unknown	3	3
	P<0.0001	

Type of accommodation was analysed amongst 65 adults living in accommodation facility arranged for by the county. Forty-five percent were living in accommodation for people with substantial physical or mental impairment. 22% were living at nursing homes for elderly people and 34% had an unknown type of accommodation provided by the county.

The severity of impairment at 6 years of age predicted independent living as young adults. Severity of mental impairment was the strongest predictor, OR for living independently was 4.0 (2.0-8.2) and 36.8 (14.9-90.1) for adults with a DQ 50-85 and a DQ<50 respectively. The possible confounders; parents' highest education, income, cohabitation and region of residence (when the child was 15 years old) had no effect on independent living and we found no effect modification of living independently by parents' highest education, income, cohabitation or region of residence.

Twenty-eight percent of the adults with CP (versus 69% of controls) were living with a partner and 19% had biological children (versus 61% of controls).

No subject with a DQ<50 or no ability to walk was living with a partner and after excluding this group in a multivariate analysis, the severity of mental and physical impairment and epilepsy equally strongly predicted cohabitation. Parents' highest education, income, cohabitation and region of residence (when the child was 15 years old) had no effect on cohabitation and we found no effect modification of living with a partner by parents' highest education, income, cohabitation or region of residence.

Both female and male subjects had children; eighty-five percent of the subjects and 91% of the controls lived with their children (P= 0.0577).

We combined the results from Paper I on employment and the results from Paper II on cohabitation and found differences in the social integration of subjects and controls (Figure 8 and 9). Forty-five percent of subjects versus 96% of controls had at least one of the following social contacts: cohabiting partner, children or competitive employment. In this most optimally integrated group, subjects more seldom combined employment and cohabitation than controls.

Figure 8 Cohabitation, biological children and/or competitive employment among 29- to 35-year-old subjects n *(%)*

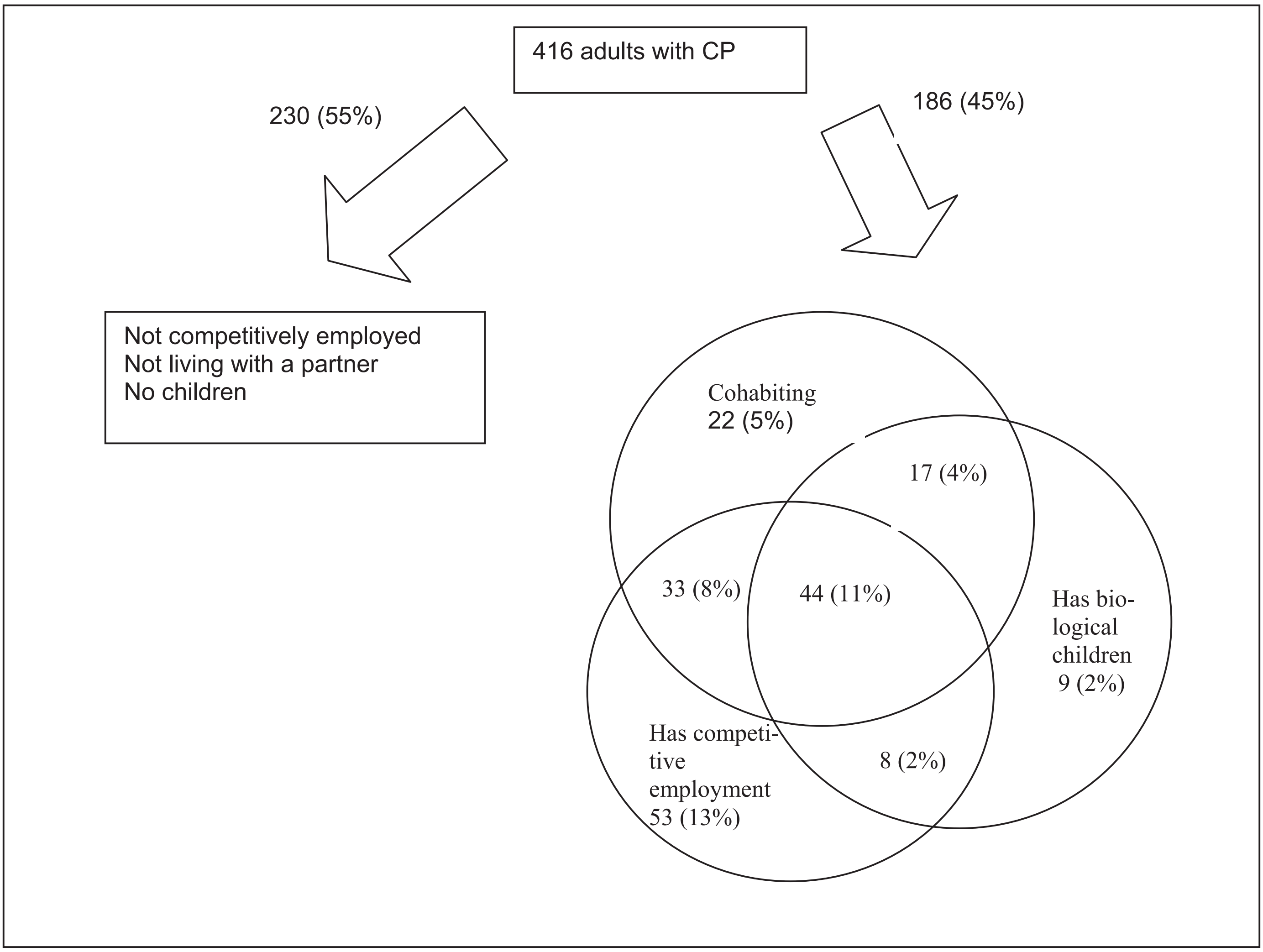
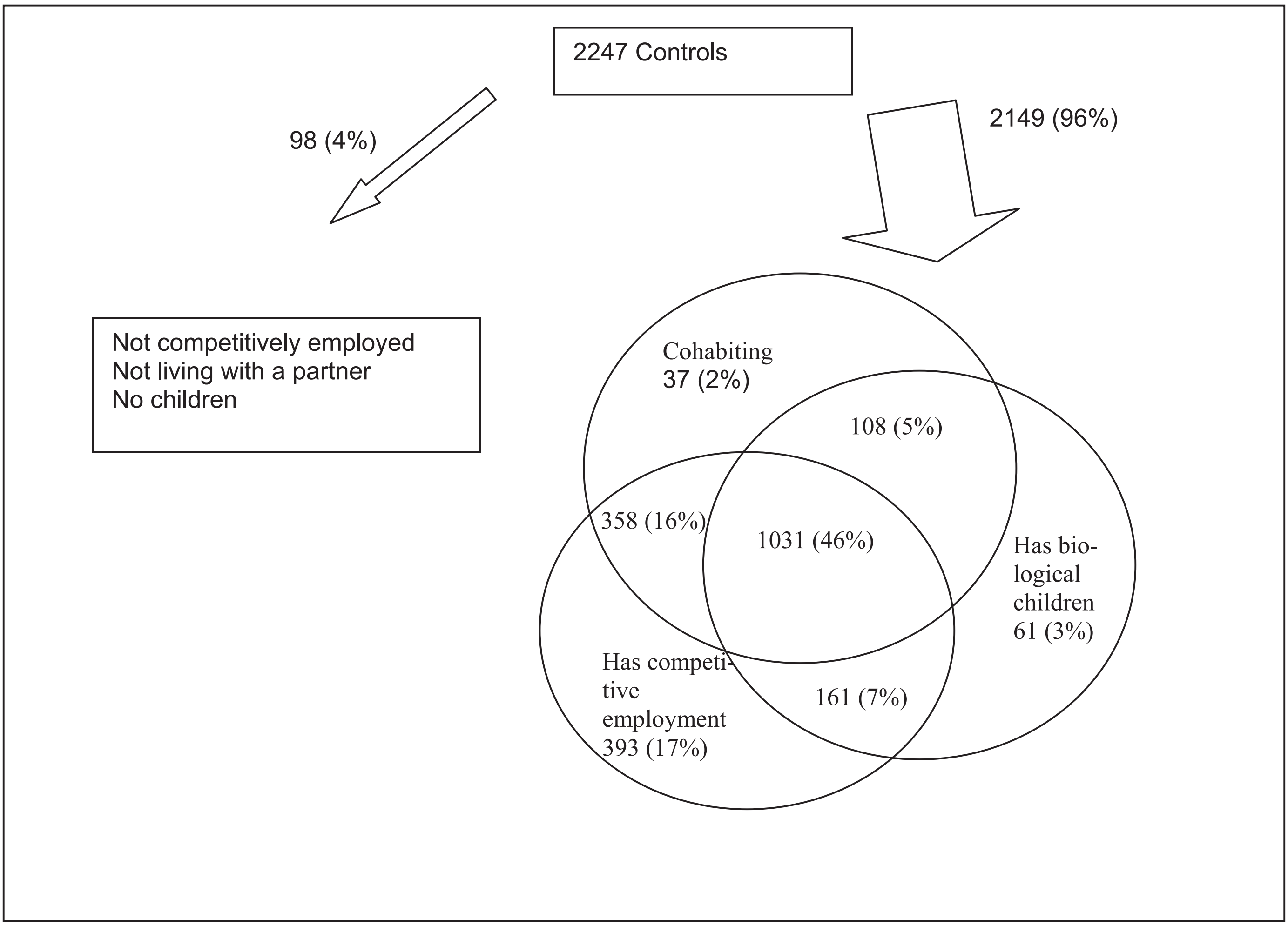


Figure 9 Cohabitation, biological children and/or competitive employment among 29- to 35-year-old controls n *(%)*



In conclusion, most adults with CP lived independently and a minority cohabited and had children. Independent living and having children were largely determined by the severity of CP and not by parents' socioeconomic status or region of residence. Adults with CP seldom combined employment, cohabitation and having children.

5.4 Social situation for families

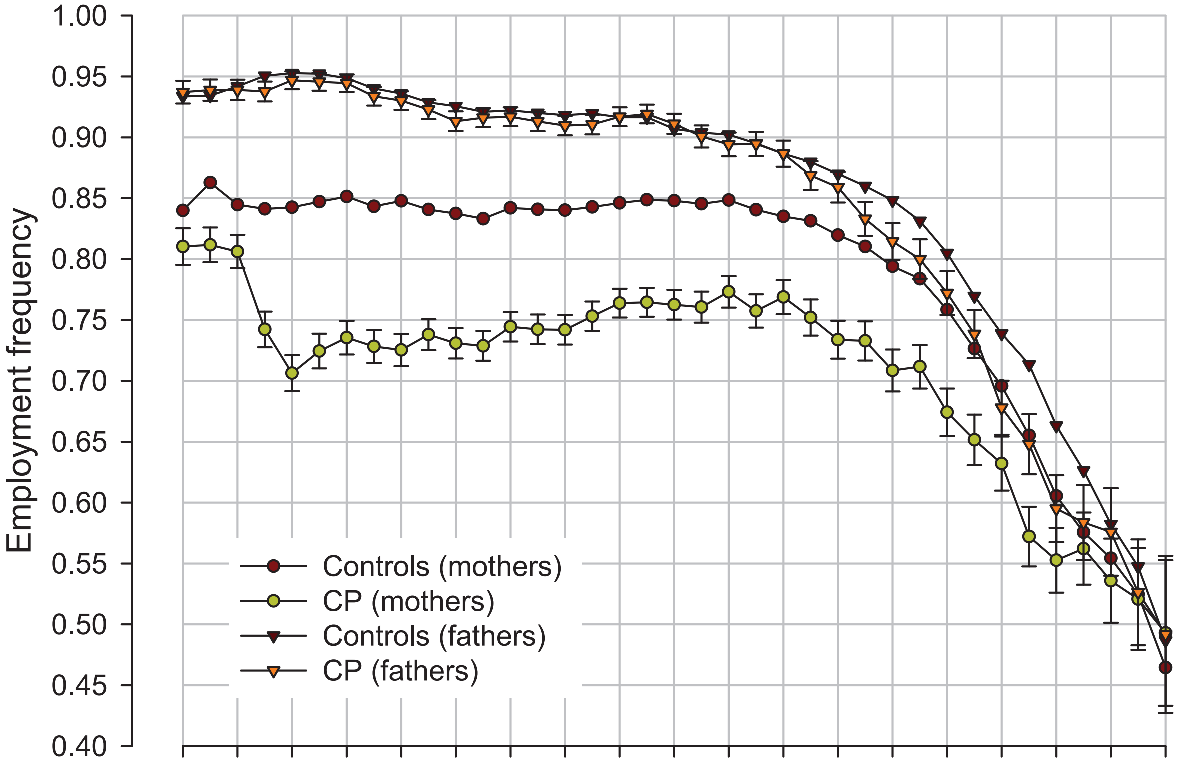
(described in Paper III)

Parents of subjects and controls did not differ in terms of age at which they had the child, but parents of the younger cohort born between 1982 and 1990 (mothers 28 years and fathers 31 years) were older when their child was born than were the parents of the older cohort born between 1965 and 1970 (mothers 25 years and fathers 29 years).

Significantly fewer mothers and fathers of children with CP had an education beyond lower secondary school compared with mothers and fathers of controls (not shown). This was evident both before and after the child with CP was born. When the child was 5 years old, 32% of the fathers and 43% of the mothers of a child with CP had no education beyond lower secondary school versus 30% and 39% of mothers and fathers of controls.

Figure 10 is based on cross-sectional analyses on employment frequencies of parents at different ages of their children.

Figure 10 Employment frequencies of mothers and fathers



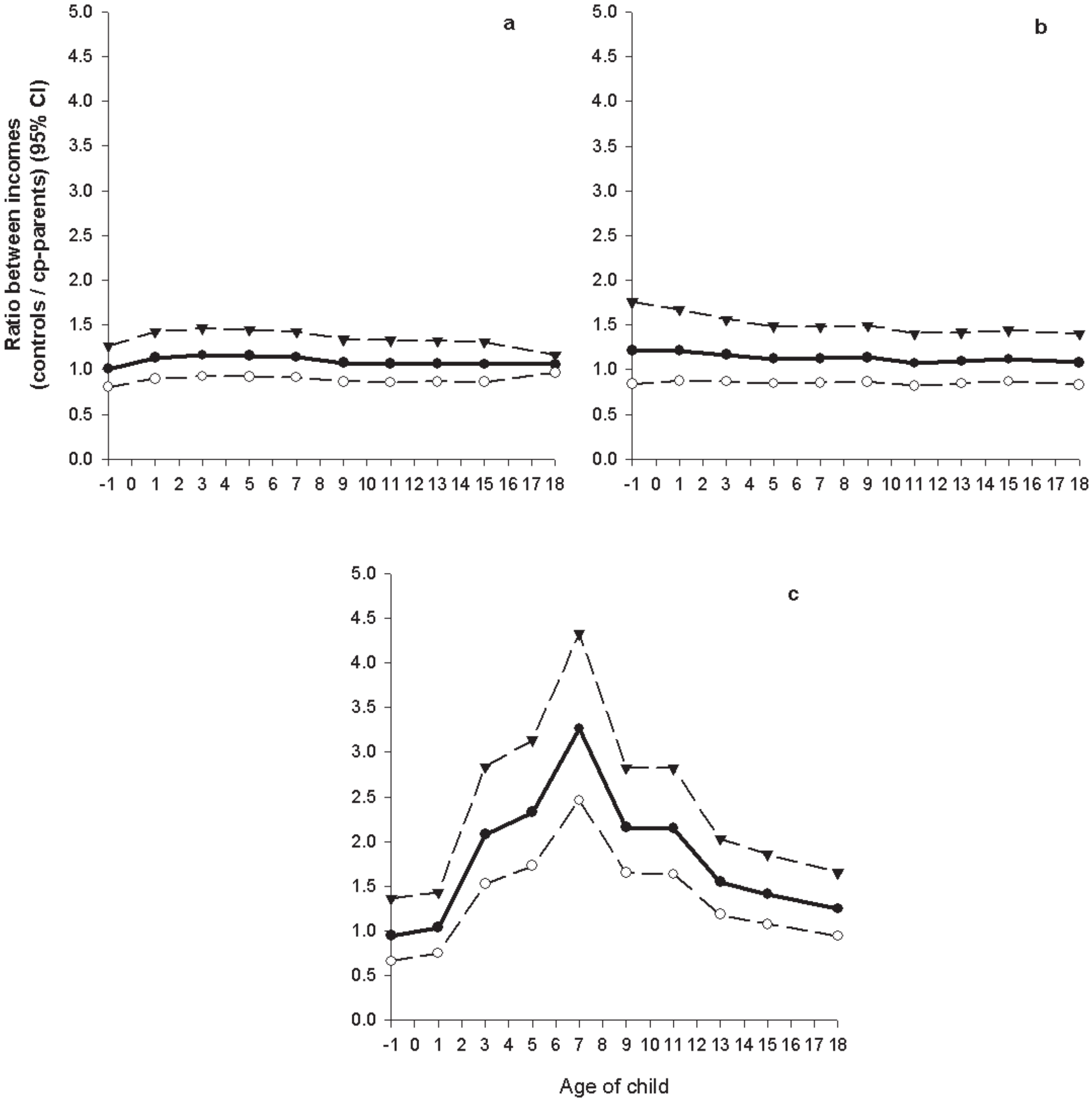
The first observation was in 1980 and the last one in 1999. Parents only contribute to the figure during a certain period, and the same parent might pass in and out of the labour market during follow-up.

Most mothers of children with CP were employed after the birth of the child, but the employment frequency decreased by ten percent after birth of the child and only half of the decrease was later reversed. Mothers of children with CP were more often outside the labour market when the child was five years old, compared with controls, OR 2.2 (1.7-2.7). The higher OR of not being employed was mediated by severity of impairment. Highest education, employment status and cohabitation before the child was born were controlled for. No effect modification of the confounders was found on CP versus control. One in three mothers with a severely disabled child, one in four mothers with no education beyond lower secondary school and more than half of the single mothers were outside the labour market when the child with CP was five years old.

Among employed mothers to children with CP; 27% worked part time, 62% worked fulltime and 11% worked an unknown numbers of hours when then child was 5 years old. Amongst employed mothers of controls 18% worked part time, 74% worked full-time and 9% worked an unknown numbers of hours. One percent of employed fathers of children with CP and controls worked part time.

Mothers of children with CP had a lower pre-tax annual income than controls, after controlling for parents' age, birth year of the child and parents' cohabitation. When the child was 5 years old mothers of controls earned 72% more than mothers of children with CP. This was mainly due to not employed mothers to children with CP having a lower income than not employed mothers of controls, rather than to hours worked a week (Figure 11).

Figure 11 Pre-tax incomes in mothers according to level of attachment to the labour market



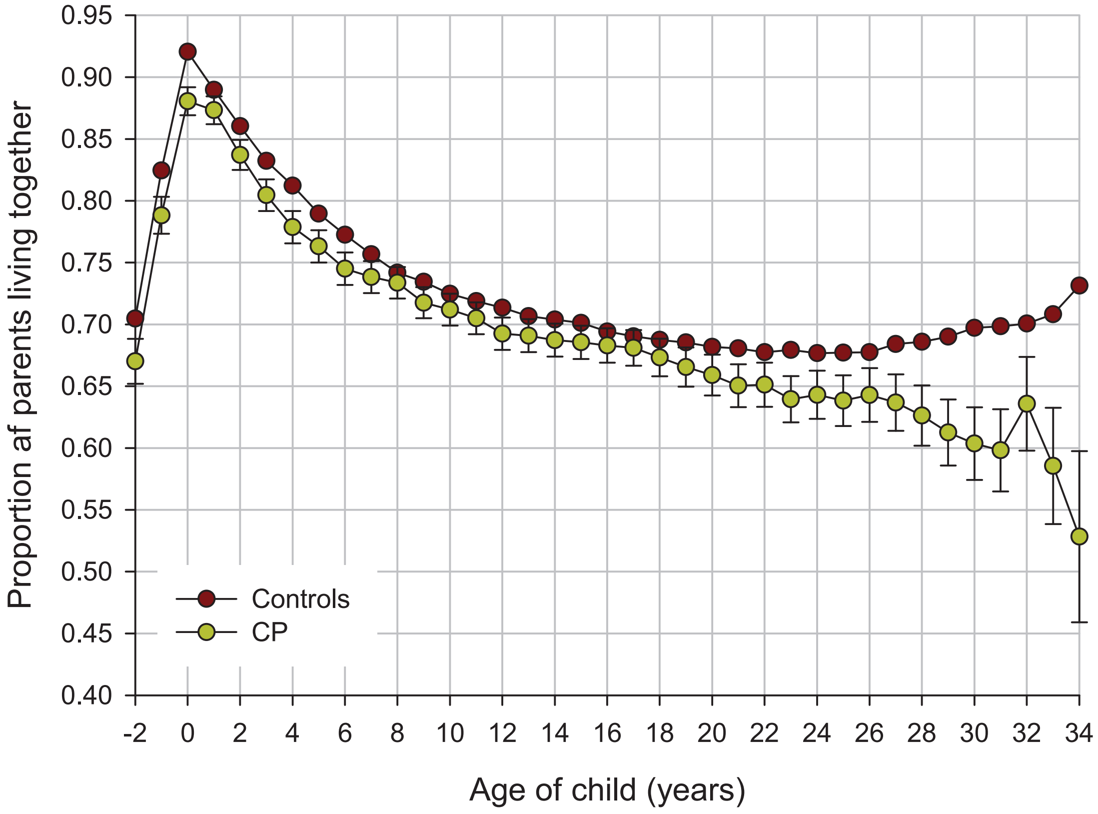
Ratio between control-mothers and CP-mothers in three groups of different labour market attachment, with curves showing the 95% confidence interval.

a= mothers working fulltime
b= mothers working part-time
c= mothers not employed

No overall differences in income between fathers of children with CP and fathers of controls were found.

The OR of divorce was not increased among the parents of children with CP when the child was 5 years old, after controlling for birth year and gender of the child, the age of the parents, the highest educational level of the mother and father and number of siblings the year before the child was born, OR 1.08 (CI 0.87-1.33). No effect modification of parents' cohabitation was found, when studying CP versus controls. The proportion of parents cohabiting differed slightly between the parents of children with CP and the parents of controls during the first years of the child's life, but the difference was the same as before the child was born (Figure 12).

Figure 12 Cohabitation of parents.

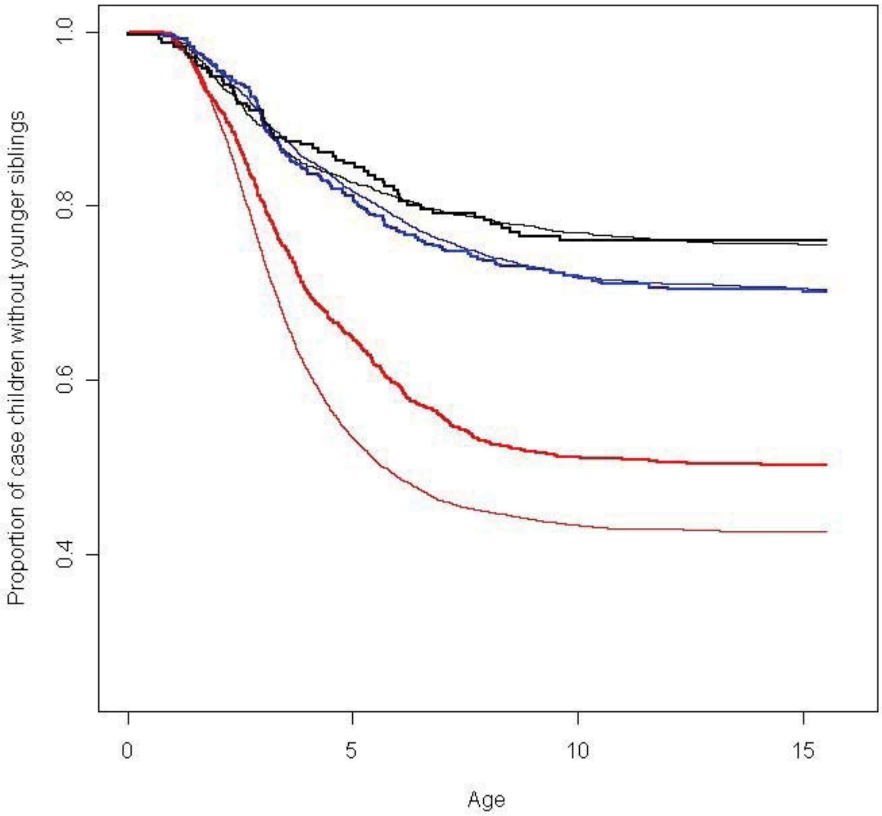


The first observation was in 1980 and the last one in 1999. Parents only contribute to the figure during a certain period, and parents might end cohabitation more than once during follow-up.

More parents with adult CP children were divorced than parents with adult children without CP, but there were few parents with adult children. In an analysis of "time to divorce" of parents with children aged 0-17 years we also found no overall difference in proportion of parents that divorced (P=0.1937).

The analysis of "time to subsequent children following birth of a CP/control child" showed that parents of CP children tended to either postpone or completely desist from having subsequent children, hazard ratio 0.852 (0.79-0.92). The CP-status, however, interacted with number of older siblings (0, 1 or >=2) and the entire difference in postponement/abstinence lied within the group of parents where the CP/control child was the first child. Thus, parents who had a CP child following older siblings (41% of children with CP and 46% of controls had older siblings at birth) were not more prone to postpone or desist from having subsequent children than parents of control children (P=0.9196) (Figure 13). If the CP child was the parents' first child, parents of CP children more often desisted from having subsequent children, hazard ratio 0.77 (0.71-0.85). Among parents where the CP/control child was their first child we found 48.7% of CP parents with only one child when the child was 15 years old compared with 41.8% of control parents (Figure 13).

Figure 13 Younger siblings.



Top curves are children with two or more older siblings, middle-curves are children with one older sibling and bottom curves are children with no older siblings. Bolded curves are children with CP.

Distribution of siblings at age 15 years is shown in Table 9.

Table 9 Siblings (%)

Siblings	CP (n=1824)	Control (n=9153)
No siblings	28.8	22.7
Only older siblings	27.5	32.1
Only younger siblings	30.4	31.6
Both older and younger siblings	13.4	13.5
Unknown	<0.1	<0.1
	P<0.0001	

In conclusion, all fathers and the majority of mothers continued to work after giving birth to a child with CP. Mothers of children with CP were more likely to work part-time and particularly not employed mothers had a lower annual pre-tax income. Most children with CP had siblings and they lived with both their parents just as often as other children.

6. Discussion

6.1 Societal participation of adults with CP

Participation in school and education
Denmark supports the idea of an inclusive school. We have studied a group of children with the same diagnosis, but with very different type and severity of disability. One third of this group attended special schools or special classes in childhood. It is reasonable to let the most severely disabled people attend schools which focus on and accommodate their disability and where they are surrounded by like-minded people. Nevertheless, our results indicate that this type of education does not result in either competitive or supported employment. On the other hand, it could qualify people for sheltered workshops, probably the most realistic possibility for adults with a severe impairment. The registries did not enable sheltered workshops to be studied; these could be an important source of social input in the daily life of adults who are unable to work. In terms of participation and integration, sheltered workshops could be regarded as a special school for adults that segregates the disabled adults from non-disabled adults.

Fifty-eight percent had attended mainstream school and socially integrated among non-disabled children. However, of these mild to moderately impaired children, some never passed an examination in lower secondary school and half never attained an education beyond lower secondary school. We know that the most important predictor of education is mental function and a relevant concern is that some children do not actually participate in mainstream schooling and later education, but are just physically and perhaps socially integrated. A recent benchmarking analysis between five countries (Denmark, Sweden, Netherland, UK and USA) places Denmark lowest when comparing the level of education among disabled and non-disabled people, this is despite the factor that we in Denmark has the highest expenditure on special educational support per recipient [11].

Participation in employment
Our employment rate of 29% could be in accordance with the literature, since other studies find an employment rate between 20% and 53%. Our material was population-based and includes mildly as well as severely impaired adults in contrast to studies which excludes either people living in institutions or people with low IQ [33;37;40] and found very high employment rates. In 1981 however, Glenting [13] found in a population of children born between 1940 and 1945 in the Danish Cerebral Palsy Registry that 52% were completely financially independent in supporting themselves (including married women without an disability pension). We would expect Glenting's population to comprise fewer subjects with mild CP than our population, which would result in a lower employment rate than ours. On the other hand, there are probably more subjects with severe CP who survive into adulthood today. It is difficult to compare Glenting's outcome measure with our measure of competitive employment, but certainly no improvement in employment rate was seen.

As early as 1966, Klapper et al. [31] pointed out that adults with CP who are potentially employable and capable of social activity, are typically unemployed and socially isolated. We also found few adults with CP in employment, including in supported employment. Why is this? Supported employment was a relatively new arrangement at time of analysis in 1999, and the number of people in supported employment in Denmark has generally increased since. Specific numbers on disabled people are however not available however, and additional analyses showed that in our population, only a slightly higher proportion were in supported employment in 2001 compared with 1999. Data only represent Eastern Denmark and numbers for persons in supported employment could be different in Western Denmark, however the principle of an inclusive labour market does not seem to work fully for this group of people. A particular focus on people with disabilities supports chance of employment and social integration. Wehman et al. [62] showed that supported employment is a way of employing people, and Owen & Garetz [41] that a training programme resulted in improved education, employment, dwelling situation, mobility and activities of daily living. In addition, according to the principle of responsibilities of the sectors; employing people with disabilities must be shared between different sectors and should not only lie on the public sector.

Adults with CP generally had a lower annual income than controls. If this financial disadvantage is a consequence of their disability, this indicates that the principle of compensation is not fully implemented. It is a societal responsibility to adapt the environment, offering individual assistance or financial support to remove or reduce the consequence. Our study supports the statement of the Special Rapporteur on Disability about how most countries do not match the promotion of equal opportunities with a financial commitment.

Participation by place of residence

The majority of adults with CP lived independently (68%). Since the new social service system in Denmark separates accommodation and practical help, we do not know how much help this group receives in their homes. Other studies [2;33;37;40;61] find between 40% and 66% of adults with CP living independently and between 13% and 58% living with their parents. None of these studies are population based and selection criteria for study populations differ, making comparison of results difficult. Two important predictors of independent living and cohabitation, age and degree of severity among subjects, often differ substantially. In Denmark, Glenting [13] found nearly the same distribution of type of accommodation as the present study with the exception that fewer subjects lived in institutions. This could be due to a greater share of subjects having a severe impairment today.

One in five of the 29-35 year old adults with CP in Denmark who lived in an accommodation facility provided by the county, lived in a nursing home for elderly people. Nursing homes are not designed to meet the needs of young adults with CP. In Chicago, Heller et al. [22] found that adults with severe CP benefited from moving from nursing homes to community-based settings. Although accommodation facilities might not be comparable between the United States and Denmark, this is also what we would expect.

Our study showed that adults living with their parents are severely disabled and receive a disability pension. An explanation for adults with CP living with their parents could be that the parents have difficulty in letting go of their children. Hill [24] found that parents feel their children should not live independently, and Wynne & Rogers [65] found that parents' feelings about institutionalisation predicted whether the child later lived at home or in a community-based setting. Parents might not consider the available accommodation acceptable for their grown-up children. But adults with severe CP who live with their parents have an insecure future. They might very well outlive their parents.

Participation in family life

Only a few adults with CP lived with a partner and had children compared with controls. Glenting [15] found that 32% of his subjects were married and assuming that nearly all couples cohabiting at that time in Denmark were married, this finding is similar to the results of the present study. Like Glenting we found mental impairment to be the most important predictor of cohabitation; it is however remarkable that even a mild motor impairment results in a tripled odds of no cohabitation in adulthood.

Functioning

Functioning is described by extent of disability. The severity of CP is however only described in childhood. This is relevant and important to predict the social consequences of CP from a neuropaediatric view. But conducting assessment in adulthood would have been informative in describing groups of adults with different levels of social participation. A more recent and detailed description of disabilities would be required, especially when considering personal factors as causes of poor integration.

Given the lack of psychological test results, the severity of mental impairment is registered by a development quotient, based on a neuropaediatric assessment of whether a child is able to start school without help or not and if the development was less than 50% of normal. This is a very general measure and does not sufficiently take into account the cognitive deficits of children and adults with CP. When we used it in the different analyses, however, this parameter was the most predictive factor with very high odds ratios. Specific cognitive defects have been highlighted recently. It is suggested that these are often present and have substantial implications for every day life [12]. Goodman [16] states that these cognitive difficulties make even mildly affected children more liable to specific learning difficulties. In addition studies found that children with hemiplegia have a substantially higher rate of psychiatric disorders and that the children did not soon grow out of these psychiatric problems[17;18]. Koch found that Danish children surviving a CNS tumour had a reduced level of educational attainment and establishing cohabiting relationships compared with controls or children surviving non-CNS cancers. [32]. We need more detailed information on the mental impairment of the children to be able to fully understand the influence of this impairment on the later education and employment.

Years ago the life expectancy for children with CP was short, but today most children with CP grow into adulthood and many grow old as well [25;39]. Some studies have looked at the health of adults with CP. CP is a permanent, but not unchanging disorder according to old and new definitions, and this seems to be very true. Research shows that despite the focus on physical training, deterioration in locomotion skills is a significant problem for people with CP from an early age [27] and that physical fatigue is a pronounced problem in adults with CP [28]. In California, Kemp [30] even mentions a "post-impairment syndrome" and describes how impaired people age more rapidly and never reach the same maximum capacity as non-impaired people.

Vision and speech are other impairments describing functioning of children or adults with CP. Both could affect the social situation and demand specific aid and training. Glenting [15] found normal speech to be the most important predictor of getting married.

Internal contextual factors

Family factors like parents' socioeconomic position were studied in the analyses, but had no effect on cohabitation and accommodation and only minor effect on employment. We found that parents' highest education did not influence chance of employment different in adults with CP and controls.

Personal factors like psychological well-being, behaviour and social competencies are other possible predictors of education, employment, accommodation and cohabitation. They could also be related to the brain dysfunction and actually affect functioning through the impairment and not mainly as an isolated personal factor.

These factors as well as ethnicity are not included in our study.

External contextual factors

Region of residence was the only variable studied to illuminate the effect of environment on integration in society. The region of residence did not have any bearing on accommodation or cohabitation. The regions we used were large, since our data material is far too small to measure differences at the level of municipalities. Our factor was geographically based on the counties, the distance from Copenhagen and population density. The Danish Disability Council states that the differences of the level of services between municipalities in Denmark are unacceptable, and Hammal et al. [21] found regional differences in participation among children with CP in northern England. In spite of our rather crude environmental factor it is reassuring to the Danish welfare system that it had no influence at all. Effect of environment on participation of children with CP is currently studied much more precisely in a large European study, SPARCLE (see 8.3 Research)

Attitudes in the general population and in the labour market, legislation and physical accessibility are other important environmental factors that could enhance or aid the integration of disabled people in, for example employment. We would expect physical accessibility (for example access for wheelchairs and use of computer technology when compensating for a handicap) to have improved during the last 25 years, resulting in an increased employment rate amongst disabled people, however attitudes in the labour market might be less tolerant due to a higher pace and demand for effectiveness and this could result in a lower employment rate amongst disabled people. Possible environmental explanations for the low number of adults with CP living with a partner could be general attitudes towards disabled people or limited access to social activities for young people and adults with CP.

6.2 Societal participation of parents to a child with CP

Participation in employment

Remarkably few mothers of children with CP remained not employed when their children grow up. We consider part-time work amongst mothers of children with CP together with granting mothers temporary leave from their jobs to enable them to cope with the disabled child to be optimal solutions. But not employed mothers of children with CP seemed to earn significantly less than not employed mothers of control children and as is the case for adults with CP, we need to consider whether these women are satisfactory compensated. A possible explanation for the comparatively better financial situation of not employed mothers of controls could be that they more often received unemployment benefit, which is higher than other temporary benefits.

The birth of a child does not affect a father's employment frequency or level of income, but fathers of children with CP do leave the labour market earlier than fathers of controls. The reason could be that their lower educational level and more frequent employment in manual work reduce their incentive to stay in the labour market in the long term.

Participation in family life.

We found little difference in cohabitation frequency between the parents of subjects and the parents of controls and find it positive that parents apparently cope well in terms of their own relationship after the birth of the disabled child. The fact that the parents of adults with CP were more likely to be divorced is difficult to interpret, and the effect of different cohorts needs to be taken into account. Only parents of the oldest children are followed that far into their children's adult life, and we can not therefore conclude that the parents of younger children will split up when their children grow up. On the other hand, an explanation could be that after the child has moved from the parents' home (and Paper II shows that only 13% of the 29 to 35 year old adults with CP lived with their parents), parents no longer need to protect the child and feel free to do what they like.

We note that the majority of children with CP had siblings and among the first-born children; the difference of only 7 percent points in number of children being only children is considered small. It is positive that children with CP had siblings but implies that in providing support to families with a disabled child, attention needs to be paid to non-disabled siblings and their needs as well.

Functioning

As with regard to the social situation of adults with CP, a more detailed description of functioning of children with CP is needed. A child's cognitive function, behaviour, speech and social competencies are possible mediators of the effect of having a CP-child on parent's level of social integration.

Internal contextual factors

Parents' socio-economic position before the child was born (the social inequality in CP) was studied. But we had no information about other potential individual confounders like psychological function, social competences and behaviour of the children.

External contextual factors
We did not include any measures of region of residence when studying parents' social situation. Our reservations concerning our constructed regions are explained above and we feel the impact of the environment should be analysed in a later study using other measures. Attitudes in society, legislation and accessibility are contextual factors influencing the social integration.

6.3 Discussion of the results within the frame of ICF

The theoretical model of the study was based on the ICF focusing on participation. Some components of the ICF were well described within the registries and others were not. Within the component describing functioning and disability loss of body function in terms of impairments were included, but no positive aspects of functioning were studied. For example, social competencies might influence both possibility of employment and cohabitation. Participation in terms of education, employment, accommodation and cohabitation and thereby social functioning is also well described. But the individual level in between which describes activities of the disabled adults is not included in this study. Within the component describing contextual factors, personal factors in terms of parents socioeconomic position were fairly well described, whereas environmental factors were only vaguely included. Personal factors such as psychological well-being and behaviour did not exist in registries, but is regarded significant to the social outcomes. Only a very broad measure of region of residence was included as environmental factor, while other important factors like attitudes, accessibility, availability of accommodation, social service and labour market situation were excluded due to lack of information in registries. Schooling was included as a measure of participation in education, but also as a mediator of later employment. To fully implement this model, data other than register data are needed, but as shown in the general discussion of results it is still possible to discuss the results in view of the ICF.

6.4 Methodological considerations

Strength of the study
This is the first large population based study with a longitudinal design on CP. Selection and information bias is considered to be limited and confounding is largely controlled for. People with cerebral palsy have both physical and mental impairments, as well as epilepsy and the results of the present study are therefore probably applicable to a wide range of disabled people. The study is to a large extent able to describe the social consequences of disability for adults as well as for parents to a disabled child.

Selection bias
We consider the subjects to be very close to a representative sample of young adults with CP in Denmark. The validity of the Danish Cerebral Palsy Registry was studied in 1997. The birth years 1979–1982 were re-evaluated, and the Registry was found to be

85% complete before linkage to the National Patient Registry. The CP subjects not registered did not differ from the registered hospitalised subjects in the severity of impairment or clinical subtype [53].

Missing data in the registries occurred but this is not considered a significant bias mainly because the number of children with missing data is small. Closer analysis was performed for two groups of adults excluded from analyses due to missing data. Adults missing data on severity and children not living with their parents at age 15 years. (Appendix C)

Most children lacking data on severity of impairment were in the oldest age groups where information on the children was somewhat sparse. Only 37 (5%) children of the 819 children born between 1965 and 1978 were missing data in one or more categories of severity and were therefore excluded from the analyses on predictors of not being competitively employed. The excluded children were mixed according to employment status and educational achievements, but they were more likely to be employed than the whole group and as a result the estimated OR of not being employed might be a little too high. Twenty-eight (7%) of the 416 children born between 1965 and 1970 lacked data on severity and were excluded from the analyses on predictors of not living independently and no cohabitation. The excluded children were mixed according to status of cohabitation and living, but they were more likely to be living independently and slightly more likely to live with a partner than the whole group and again the estimated ORs might be a little too high.

The SEP of the parents was measured when the child was 15 years old. This age was chosen as an age close to adulthood, but an age at which few children have left home. For the 57 subjects, an explanation for not living with their parents could be that they lived in an accommodation facility arranged by the county. Accordingly 61% later lived in an accommodation facility arranged by the county, the majority later received disability pension and nearly none were employed. A greater share of the 53 controls not living with their parents at age 15 years were living in an accommodation facility arranged by the county than were all the adult controls. But more than half were later employed and living with a partner. Some subjects in this group might have been living in residence halls or living abroad the year they turned 15 years old. Highest educational attainment, annual income and cohabitation of parents when the child was 15 years old were analysed as potential confounders in the analyses of independent living and cohabitation. They had no significant effect and were not included in the multivariate analysis. The 57 subjects not living with their parents were excluded from the analyses. Since these subjects were more often severely impaired this could bias the results. But level of parents highest educational attainment was not found to vary significantly between subjects with different levels of CP-severity in the total population of adults with CP born between 1965 and 1970 (frequency tables with severity of mental impairment, severity of motor impairment and epilepsy versus parents' highest education, income group and cohabitation at child age 15 years, chi-square test). Together with the fact that the excluded subjects were a heterogeneous group according to the outcome measure, in that 30% lived independently and 11% cohabited, we do consider it unlikely that the estimates would have shown an effect of parents' socioeconomic position, even if this group could have been included.

Information bias

Data from the Danish Cerebral Palsy Registry are considered valid. The same two neuropediatricians evaluated all case notes and CP birth prevalence's and trends are in accordance with other registries in the world [20;49].

Our study relies on data from numerous registries in Statistics Denmark. Generally these registries are considered complete and valid since the provision of information is required by law and the reporting institutions have delivered these data for 20 years. But nevertheless, some problems have occurred.

Data on special education are limited since registries do not directly indicate the type of education. In lower secondary schools, the registries indicate whether a person is in a class that is "not divided" by age or at a special school for grades 8-10. Children in the same grade are usually taught together (and thereby are in a class "divided" by age), but in some classes children in different grades are taught together. Such classes are referred to as "not divided". Virtually all students comprised in a "not divided" class are in special education, but theoretically a few could be in a mainstream class at a small school with too few pupils to form a class for each grade. The registries do not indicate whether a child in a normal class receives some lessons in a special class. In our study, a person has received special education if the person is registered in a special school or in a "not divided" class at any time in grades 8–10. We consider this to be a valid measure of extensive special education, but we have no measure including all levels of special education and suspect that the subjects receive substantially more of this unmeasured special education than controls. Solely measuring the type of education in the last grades of lower secondary school is acceptable, since people who can follow normal education in grades 8–10 are not likely to have received extensive special education in earlier grades. Passing an examination after lower secondary school is registered as having passed one or more examinations or not. This is inconvenient, since people who have passed one or more examinations constitute a very heterogeneous group. Our data showed that many adults with CP did not even pass one examination, but it would have been interesting to determine the effect of number of examinations passed on later employment.

Accommodation is measured by combining three different registries (the Social Pensions Registry of the Danish Local Government Computing Centre (KMD A/S), the Central Register of Buildings and Dwellings and the Civil Registration System), since none contained all the information needed. People in accommodation facilities were particularly difficult to identify. The Social Pensions Registry includes everyone receiving a disability pension, and in practice this would mean everyone living in an accommodation facility arranged by the county. But the categories only comprise the type of accommodation facility arranged by the county, and there is no category for not living in an accommodation facility. These persons are in the group of "unknown" accommodation facility. Some persons in this group are however registered as living in a building used as an "institution" and are therefore included in our study as living in an accommodation facility arranged by the county. Finally, the changes in legislation in 1998 mean that we cannot be sure that the group living independently is actually independent in everyday activities, since they might receive substantial help from the municipalities. However, the group of people receiving substantial help in an independent living setting is probably not large in our study, since most severely impaired people lived in an accommodation facility arranged by the county or with their parents and not independently. In addition, we consider this not to be very important, since independence is achieved by being a master of your own home: deciding for yourself.

A final concern regarding the registry data is the cohabitation status of the parents. Parents are defined as cohabiting when they live at the same address. If they are not living at the same address and have different addresses in Denmark they are defined as living separately. Cohabitation status changed more than once during the follow-up study for a small group of parents. We cannot be sure that brief periods of not living at the same address are the same as cohabitation ending, since they could just reflect a father moving for one year to another part of Denmark to take a job, or parents could report different addresses to receive more public benefits. We do not consider this bias significant.

Confounding
Possible confounders and inclusion in the present study are already discussed in details in sections 6.1 and 6.2.

Overall, we do consider confounding widely controlled for in the analyses, but in some areas we lack register data on relevant confounders.

Personal confounding factors such as age and gender are controlled for, but other personal factors like psychological and social competencies as well as ethnicity are not controlled for at all. The frequency of these factors is very likely to vary between CP and control groups and between persons with different levels of functioning.

Family factors such as parents' socioeconomic position are well-described and controlled for.

Some environmental factors could be expected to be confounders as well and we have hardly been able to control for these except for region of residence.

7. Conclusion

The employment frequency of adults with CP was low. A particular concern is that only half of those completing normal schooling were competitively employed. Too few were in supported employment, especially given the political goal in Denmark of achieving an inclusive labour market. Most adults with CP lived independently. Thirteen percent, mainly severely disabled people lived with their parents. This might hinder the independence of the adults with CP. It is unacceptable that some adults with CP lived in nursing homes for elderly people. A minority of the adults with CP lived with a partner and had children, and we found adults with mild CP less integrated in society than could be expected since they more seldom combined employment with cohabitation and children, compared to age matched controls. We found no sign of an increased integration over the past two or three decades in Denmark. Mental impairment was the most important predictor of later social integration and focus on this aspect of cerebral palsy is needed. The addition of disturbances of sensation, cognition, communication, perception, behaviour and epilepsy in the recently proposed new definition of CP seems very appropriate[3]. Studies on health and psychological well-being of adults with CP are needed to fully describe the situation of adults with CP in Denmark.

Remarkably few mothers in Denmark are not employed and this is also the case for mothers of children with CP. Special attention needs to be paid to single mothers, mothers with a low educational level and mothers with severely disabled children, who are at highest risk of being marginalized form the labour market. Children with CP lived together with both their parents just as often as controls and the majority had siblings. The Danish welfare system seemed to have succeeded overall on these issues, but we have not studied the psychological well-being or health of parents or siblings to a child with CP.

In conclusion the title of the thesis “Social *consequences* of cerebral palsy” seems to be highly relevant for adults with cerebral palsy. Although the disability model framed by the ICF has left consequences to the benefit of participation and activities, I consider the term consequences important to emphasise that a considerable group of disabled people in Denmark experience vast negative social consequences of the disability and are not active participants in society.

8. Implications for the future

8.1 Clinical work with children with cerebral palsy

Traditionally, the neuropediatric focus has been on the motor disability both in terms of evaluation, training and treatments (physiotherapists, orthopaedics and antispastic medication). Our study revealed that mental impairment is the strongest predictor of not being socially integrated in adulthood. Currently the mental impairment of a child with CP is not always well described and it is necessary to monitor this aspect of CP better. It would be advisable to have all pre-school CP-children assessed by a psychologist, to be able to support the children optimally, even before school age.

Knowledge about chances of education and employment according to different CP subtypes and severity of CP could, in combination with a clinical judgment of the child, make it easier for the neuropediatricians to inform parents about later social prognosis. Knowing the social situation for families with a child with CP, the neuropediatrician could focus on the employment situation of the mother and provide more precise information about the known risk of leaving the labour market.

8.2 Disability politics

Given the poor social integration of adults with CP, care services need to be established for adults. Ending neuropaediatric care without offering further care is not acceptable and providing health care for adults with CP is a specialised task which should be carried out. Adults with CP have problems in very different specialised fields and care should be carried out by multi-specialised teams. Different experts in the teams caring for adults with CP should improve their societal participation, but often issues in adult and child care will overlap, stressing the need for a strong cooperation between adult and child care. For example, adult social integration might be improved by re-enforcing individual competencies, such as by training cognitive functions and social competencies, but this need to be done from early childhood. Studies suggest that health status deteriorates between youth and adulthood[2;5] and it is important to recognise that adolescence is a difficult time for disabled young people and stable care with special staff is particularly needed in this period. Some matters like premature aging might be mainly an issue for adult care, stressing the need for continuous supervision of their motor function and allowing for intervention with physiotherapists.

Simultaneously, the environment needs to be improved to give disabled people equal standing in society and to fulfil the International Covenant on Economic, Social and Cultural Rights, which claims a right for all people to “an education that enables them to participate in a free society and the right to earn a living by work”. In Denmark, we are supposed to have an inclusive labour market, but we need to ensure that potentially employed people really are employed. Establishing a multi-specialised care for adults

CP would provide a good basis for identifying disabled people in need of a job and to ensure that they are employed.

From 2007, when counties will no longer exist in Denmark, it is to be decided whether to offer this type of care in the five large regions or at the level of municipalities. It is strongly advisable to gather some expertise of disabilities in every municipality, but also to establish links to specialist centres in the respective regions. Local knowledge on disability is necessary to support optimal school integration, education and later employment and it is a positive sign that local disability councils were recently made obligatory.

A report on the principle of responsibilities of all sectors in Denmark concluded that disabled adults do not regard the labour market as inclusive in opposition to the arena of spare time activities. Networks of for example local disability councils to implement the principle of responsibilities of all sectors are recommended[4].

Schooling and later education are the basis for future employment. Focus on disabled children in school is needed. Both national and international policies aim at integrating children with disabilities in mainstream schools. We need to be sure this is done with the greatest effort and to the highest benefit of the disabled children. Our results showing that only half of the children attending mainstream school were employed later, and the recent benchmarking analysis[11] both suggest that school integration is not currently satisfactory. This emphasises the urgency of improving education for disabled children in mainstream and special schools as well.

Disabled adults, whether employed or not earn less than non-disabled adults. Two political issues need attention. First, is the current level of disability pension reasonable for a severely disabled person, who is forced to live by this throughout life? Secondly, could we increase the income level of mildly disabled adults on the competitive labour market, by optimising support and training to this often self sufficient group?

It is positive that most disabled adults lived independently, this needs to be sustained in the future regions. But our results on accommodation suggest that the capacity of suitable accommodation for adults with severe CP is too low. If this is the case it needs to be changed. It is unacceptable that some adults lack something as basic as a suitable place to live. In addition, optimal accommodation facilities for this group might have a positive effect on the psychological and social well-being of families to a growing child with CP. Often, these families are concerned about the future possibilities for their child, for example in terms of employment and independent living.

A less well-defined problem in the environment is social attitudes, but when even a mild motor impairment leads to tripled odds of no cohabitation, it appears to be an area that needs attention. Maybe a more visible acknowledgement of people with disabilities would be beneficial for social attitudes in general. Disabled people are still referred to the back entrances in different social venues due to poor accessibility and daily social arenas such as shops and supermarkets are often poorly accessible.

As mentioned we think the Danish welfare system overall succeeds in supporting the families to a disabled child. But mothers, and thereby families to a child with CP are affected economically. Special attention must be paid to the few mothers leaving the labour market and individual advice of the families is important in order to ensure the return of the mothers to the labour market should they so want. A successful project in this area has been conducted and evaluated in Western Denmark[23]. Additionally the financial situation of not employed mothers of children with CP must be evaluated to position them equally in income with employed mothers of control children, who might have easier access to unemployment benefits.

8.3 Research

Register based follow-up studies are ideal to describe long-term consequences of a disease. We only described the social situation in adulthood, but describing the adult health-status and use of health system would be informative as well. In addition, this study population had a maximum age of 35 years. Employment situation and health might change substantially for this group over the next ten or twenty years and it would be important to know how the disability will affect the adult over the following years. Studying health and use of health systems amongst parents compared to controls before and after birth of CP would be interesting. Similarly, studying siblings of disabled children in relation to health, education, employment, leaving parental home and creating a family would improve our understanding of how a disabled child affects a family.

With register data we have quantitatively described the social situation of adults with CP and of families with a child with CP. Some causal pathways are clear, for example severity of CP affects chance of employment, but other pathways are not well understood. For example; how does the environment affect chance of employment in adults with CP or why does severity of CP affect social integration? In order to answer these questions, other data sources are needed. Some answers would be given through other quantitative methods, for example questionnaires and other would require qualitative methods like interviewing. High level of participation is in our study used as a proxy for “a good life for adults with CP”, but studies with a more subjective measure, like quality of life would be important to consider before drawing conclusions on optimal surroundings for disabled people. It would be crucial to assess the psychological well-being of parents and siblings in evaluating the Danish welfare system.

Information on effect of environment on participation and quality of life is necessary to plan an ideal service for disabled children and adults. An ongoing large European Study is looking into environment, quality of life and participation in 8-12 year-old children with CP[8]. Families have been visited and parents and children completed a wide range of questionnaires about quality of life, participation, environment and family characteristics. Data are currently being analysed. A similar study on participation and quality of life in adults would be able to inform families, politicians and clinicians on the optimal environments of adults with CP.

Reasons for the low employment rate should be revealed. First, we need to identify more predictors for not being competitively employed among mildly CP-affected adults. Studies on cognitive defects, psychiatric disorders, premature ageing, social competencies and schooling would be important. The latter should describe how children with CP function in mainstream schools and how their cognitive problems could be alleviated most efficient. Secondly, reasons for the low number of adults with CP in supported employment arrangements should be revealed. To fully describe the social situation of the moderately to severely disabled adults, we need information on sheltered workshops. Ideally data on sheltered employment workshops were made available in registries like supported employment. To evaluate whether Denmark fulfils the covenant on rights of all people to participate and work in society these data would be necessary. In this context information on how the sheltered workshops are integrated in the society would be important as well.

Our study revealed some information about where adults with CP in Eastern Denmark live today. But questions are left unanswered. Why do young adults with CP live in nursing homes for elderly people? How is their daily life and how do they and their families evaluate the offer of accommodation? Why do adults with CP live with their parents? Is it a free choice made by the parents or does the parents lack acceptable alternatives? These questions can not be answered only by register data, but must be answered by for example questionnaires or interviews.

Disabled ethnic minority children or adults constitute a vulnerable group at high risk of poor social integration and this is a group of concern in Denmark [9]. Special attention needs to be paid to this group and knowledge of their social situation is important in order to provide optimal support to future generations.

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10. Appendices

Appendix A. Variables from the Danish Cerebral Palsy Registry

Category of impairment or disability	Content of variable	Values	Variable name
Diagnose	Subtype of cerebral palsy	01= diplegia 1 02= diplegia 2 03= hemiplegia 04= tetraplegia 05= ataxia 07= hyperkinesia 08= dystonia 70= other	DIAGNOSE
Severity of physical impairment	Walking ability	1= walking without assistance 2= walking with assistance 3= not walking 9= unknown	MOTORISK
Severity of mental impairment	Development quotient	1= DQ>85 2= DQ 85-51 3= DQ<50 9= unknown	IQ
Epilepsy	Seizures after neonatal period (28 days)	1= never 2= yes, now or previously	EPILEPSI
Birth weight	Birth weight	Birth weight in grammes 9999=unknown	VAGT

Appendix B. Variables from registries in Statistics Denmark

Category of social situation or environment	Registry	Content of variable	Values relevant for this study	Variable name
School	Integrated Student Registry	Type of educational institution (identify children in special schools)	3 digit code 126,128= special school	ityp2
		Type of and level of school class (identify children in classes with pupils of different age as a proxy for special classes)	4 digit code 1208, 1209 and 1210= class with pupils of different age	udd
		Status of examinations at end school year	1=one or more examination passed 2=no examinations passed	eks
Education	Integrated Database for Labour Market Research (IDA)	Highest achieved education	8 digit code, using the two first digits 10=primary and lower secondary school 20=upper secondary school 35=vocational training 40, 50, 60, 65,70= tertiary education (short, moderate, bachelor, long, research)	hffsp
Employment	Integrated Database for Labour Market Research (IDA)	Socio-economic classification based on main occupation the year in question (1995 to 1999)	1-3 digit code 1= employed 2= unemployed 3= outside the labour market (31= student, 321=disability pension, 322 old age pension, 323=early retirement pension)	socio
		Socio-economic classification based on main occupation the year in question (1980 to 1994)	2 digit code 10-47= employed 51= outside the labour market or student 54= pension	asocio2
		Change of workplace compared with the year before	T1-T2= changed workplace within the sane company T3-T4= changed workplace between companies T5-T7= from unemployment, early retirement pension or leave U= unchanged at the same workplace	ansxtilb
		Sectors of work	4 digit code, using the two first digits 15-37= manufacturing 50-52= commerce 70-74= real estate, leasing and business services 75= public administration, armed services and social insurance 85= health and welfare	bran4
		Extent of attachment to the Labour market based on type of insurance	1-3= working more than 30 hours a week (insured and not insured) 4-5= unemployed (insured and not insured) 6= working 20-29 hours a week 7= working 10-19 hours a week	hdtid2

			8= working 0-9 hours a week	
	Registry of employment under special working conditions	Sheltered or supported employment	130= supported employment 131= sheltered employment	foranst
Disability pension	Registry of Coherent Social Statistics	Type of permanent benefit	2= highest level of disability pension 3=intermediate level of disability pension 4= ordinary level of disability pension	slartv
Income	Database on Children	Main income source the year in question	1-3= salary 4= Educational benefit 5= Temporary benefit 7= Pension	hvind
	Integrated Database for Labour Market Research (IDA)	Pre-tax income	Income en Danish currency (DKK)	brindk2
Accommodation	Central Register of Buildings and Dwellings		3 digit code 160= institution	f307
	Social Pension Registry	Accommodation facility arranged by the county	3 digit code 001, 002, 052 = nursing homes 008, 007, 057, 058= accommodation facilities for people with substantial impairment of physical or mental functioning	insttyp
Cohabitation and children	Integrated Database for Labour Market Research (IDA)	Number identifying the family (family is based on addresses)	xx digit code	cnr
		Type of family (family is based on addresses including both biological and non-biological children)	01= single without children 02= single with children 11, 21, 31, 41= couple without children 12, 22, 32, 42= couple with children	ctype
Region of living	Integrated Database for Labour Market Research (IDA)	County and municipality	3 digit code of municipality and thereby county 101, 141= Copenhagen and municipality 151-189= Copenhagen County 201-237= Frederiksborg County 251-271= Roskilde County 301-345= West Zealand County 351-397= Storstrøm County 401-411= Bornholm County 421-499= Funen County 501-861= Jutland Counties	kommune

Appendix C. Missing data

Below the problem with missing data is quantified and analysed.

Data from the Danish Cerebral Palsy Register:
All 819 children with CP have a diagnosis of subtype and a registration of epilepsy, but 37 children lack assessment of motor or mental impairment. Four children lack information on motor impairment and development quotient, two lack information on motor impairment only and 31 lack data on mental impairment only. Social situation and CP characteristics of these children are shown in table 9.

Table 9 Characteristics of children with missing data on severity (%)

Characteristics	Subjects		Controls	
	Born 1965 to 1978	Born 1965 to 1978 and missing data on severity	Born 1965 to 1970	Born 1965 to 1970 and missing data on sever
N	819	37	416	28
Mean age (range)	28y 10m (21-35)	31y 2m (26-35)	32y 2m (29-35)	32y 4m (29-35)
Diagnose				
Hemiplegia	31	19	31	21
Diplegia	42	57	50	71
Tetraplegia	18	22	11	4
Other	8	3	9	4
Severity of motor impairment				
Walk without assistance	62	49	65	54
Walk with assistance	21	22	22	25
Not walking	16	14	12	0
Unknown	<1	16	1	21
Epilepsy				
No	83	95	81	96
Yes	17	5	19	4
Type of education				
Mainstream	58	84	59	89
Special	37	16	37	11
Unknown	5	0	3	0
Highest education				
Lower secondary school	62	41	61	39
Beyond lower secondary school	33	59	36	61
Unknown	4	0	3	0
Employment status				
Competitively employed	29	49	33	54
Supported employment	5	8	6	11
Student	5	3	1	4
Not employed	62	41	60	32
Accommodation				
Independent	62	89	68	86
With parents	17	5	13	7
Accommodation arranged by the county	17	3	16	4
Unknown	5	3	3	4
Cohabitation				
Single	78	57	72	61
Couple	22	43	28	39
Biological children				
No	83	81	75	78
Yes	17	19	25	21

Most of the children for whom data on severity of CP were lacking are in the oldest age groups and 28 of the 37 children belong to the oldest cohort of children born between 1965 and 1970. The mean age of all children born between 1965 and 1970 is close to the mean age for the children born in this period, for which data on severity is missing. More children with diplegia and fewer with hemiplegia were in the group of children lacking data on severity compared with all children with CP. A similar proportion in the group lacking data had a mild motor impairment compared with all the children (when excluding children with unknown severity of motor impairment). Fewer children in the group had epilepsy than all the children with CP. Children for whom data on severity is missing are more integrated in society as adults, than all children with CP. They are more likely to have attended mainstream school, are more likely to be educated beyond secondary school level are and competitively employed. Additionally they are more likely to live independently and with a partner.

Data from registries in Statistics Denmark
For some variables missing data do not occur, as categorisation is based on an exclusion criterion. For example “status of employment” where a possible value is “other persons outside the labour market” or “cohabitation” where a person is “single” if not living with anyone.

For other variables missing data may occur. As shown in table 6 the percentage of missing data is rather constant around 3-5%.

To analyse information on parents when the child was 15 years old, the child had to be living with at least one parent at the time. Fifty-seven subjects and 53 controls born between 1965 and 1970 were not living with either of their parents at the age of 15. Social situation and CP characteristics of these children compared with social situation and CP characteristics of all controls and subjects born between 1965 and 1970 are shown in Table 10.

Table 10 Characteristics of children not living with their parents at age 15 (%)

Characteristics	Subjects		Controls	
	Born 1965 to 1970	Born1965 to 1970 and not living with parents at age 15	Born 1965 to 1970	Born 1965 to 1970 and not living with parents at age 15
N	416	57	2247	53
Mean age (range)	32y 2m (29-35)	32y 6m (29-35)	32y 3m (29-35)	32y 9m (29-35)
Diagnosis				
Hemiplegia	31	18		
Diplegia	50	39		
Tetraplegia	11	30		
Other	9	14		
Development quotient				
DQ>85	49	11		
DQ 85-50	25	32		
DQ<50	20	54		
Unknown	6	4		
Severity of motor impairment				
Walk without assistance	65	33		
Walk with assistance	22	28		
Not walking	12	37		
Unknown	1	2		
Epilepsy				
No	81	65		
Yes	19	35		
Type of education				
Mainstream	59	9	96	64
Special	37	77	3	13
Unknown	3	14	1	23
Highest education				
Lower secondary school	61	84	22	40
Beyond lower secondary school	36	4	78	53
Unknown	3	12	<1	8
Employment status				
Competitively employed	33	4	86	58
Supported employment	6	2	<1	0
Student	1	0	2	6
Not employed	60	94	11	36
Accommodation				
Independent	68	30	92	79
With parents	13	2	5	4
Accommodation arranged by the county	16	61	<1	8
Unknown	3	7	3	9
Cohabitation				
Single	72	89	32	40
Couple	28	11	68	60
Biological children				
No	75	88	30	38
Yes	25	12	70	62

Children with CP who were not living with their parents at the age of 15 were more often severely impaired, in relation to epilepsy, mental and motor impairment. More than half lived at an accommodation facility arranged by the county as adults and fewer lived with a partner or had children. Controls that were not living with their parents at 15 years of age were more likely to be living in accommodation arranged by the county in adulthood as well.

Paper I

Education and employment prospects in cerebral palsy

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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,

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*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.

Paper II

Social integration of adults with cerebral palsy

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Social integration of adults with cerebral palsy

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Summary

Social integration and independency is the ultimate goal of habilitation and social support for participants with cerebral palsy (CP). The society needs to know to what degree this is achieved. Partnership and having children support the social integration of disabled as well as non-disabled adults. We studied 416 participants with CP born between 1965 and 1970 (243 males; mean age 32y 2 mo, SD 2y, range 29 to 35y) and compared them with 2247 age-matched controls. Diagnostic subtypes of the 416 participants were: 31% hemiplegia, 49% diplegia, 11% tetraplegia, and 9% other types. Level of motor impairment with respect to walking ability was 65% able to walk without assistance, 22% with assistance, and 12% not able to walk (for 1% of study children walking ability was not known). We found no sign of increased integration over the past two or three decades in Denmark. Sixty-eight percent lived independently, 13% lived with their parents and sixteen percent lived at an accommodation facility arranged by the county (institution). Twenty-eight percent 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 versus 4% of the controls 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 controls. This could be due to cognitive difficulties or premature aging.

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 cerebral palsy[12], but accommodation and cohabitation are other important parts of independence and participation in society and the ultimate goal of habilitation. Living independently and being employed might promote physical and financial independence, while employment, cohabitation and having children could support social participation. To ensure an optimal environment and habilitation for disabled people, social welfare authorities need information on the status of independence among disabled people today.

Previous studies on accommodation and cohabitation in CP are based on selected populations, include very young adults or measure cohabitation according to marital status, which is very different from cohabitation today [1;11;13;16;22]

This study analysed accommodation, cohabitation and children born to adults with CP compared with age and gender matched controls from the general population. Correlations between cohabitation, employment and having children were analysed as well. The participants were born from 1965 to 1970 and were compiled from the Danish Cerebral Palsy Registry covering eastern Denmark [21]. Changes in social integration were analysed by comparing results with results from a previous Danish study including adults with cerebral palsy born 1940 to 1945 [4;6].

Methods

Participants

The material and methods have been described in details[12]. All 486 people born between 1965 and 1970 with congenital CP registered in the Danish Cerebral Palsy Registry on 31 December 1999 were enrolled in this study. The controls were people living in eastern Denmark born from 1965 to 1970 selected from the Civil Registration System, which covers all residents of Denmark. One control could not be traced, and after adjusting for deaths and emigrants the study population included 416 cases and 2247 controls. Studying parents' socio-economic position only the 359 children living with their parents at age 15 were included. Analysing predictors of independent living only the 377 children with a known status of accommodation and severity of cognitive and motor impairment were included. And analysing predictors of cohabitation only the 283 children with a DQ>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 [5 20 19;21]. 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 that are all obligated 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[14]. 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 a development quotient (DQ). The DQ is assessed to be > 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 DQ < 50. Epilepsy is registered if there were 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[21].

Accommodation. Accommodation is based on information from the Social Pensions Registry of the Danish Local Government Computing Centre (KMD A/S), the Central Register of Buildings and Dwellings and the Civil Registration System. The accommodation is defined 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 for care and treatment. Severe disabled often live in "accommodation facility arranged by the county" (the concept closest to "institutions"), where these services are present, but in opposition to the old institutions inhabitants still receive their anticipatory pension and decide what to buy. As a consequence some severe disabled 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 in both participants/controls and parents of participants/controls.

Children. Two groups of children are included. Biological children and children living with the parents.
Education. Education is grouped as to whether the highest education is beyond lower secondary school or not. The highest level of education of the parents is described using the parent with the highest level of education (biological or non-biological) living with the participant or control at the age of 15 years. Education is measured in both participants/controls and parents of participants/controls.

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

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

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

Statistical analysis

Analysis was based on contingency tables and associated chi-square tests. We analysed the predictors and indicators of living independently and cohabitation using multivariate logistic regression. The odds ratios are presented with 95% confidence intervals (CI).

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 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 controls born 1965-70 in this study was 32 year and two months (range 29–35).

Accommodation
Table 1 shows that two thirds of the 29- to 35-year-old participants were living independently. More participants than controls were living with their parents. Accommodation did not differ by gender among participants, whereas significantly more men among the controls lived with their parents (p=0.0010). We analysed the type of accommodation facility and found 22% were living at nursing homes for elderly people, 45% at accommodation facilities for people with substantial impairment of physical or cognitive functioning and 34% had an unknown type of accommodation facility.

Table 2 describes the severity of CP and parents' socioeconomic position according to type of accommodation. Few participants living independently had a DQ<50 or were not able to walk and only 10% had epilepsy. Nearly half the participants still living with their parents had a DQ<50 or epilepsy. This is rather similar to the participants living in accommodation facilities arranged by the counties and far 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<0.0001). Among the 77 children 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 children with a DQ<50 were 13%, 30% and 52% and for the 49 children 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 3). Subtype of CP significantly predicted independent living, but not in the multivariate analysis. Parents’ highest educational level, income, cohabitation and region of residence at the age of 15 years did not significantly predict independent living 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.

Cohabitation
Twenty-eight percent of 29–35 years old participants with CP versus 69% of the controls were cohabiting (Table 4). Eleven percent of the participants and 19% of the controls had previously been cohabiting but were living alone at the age of 29–35 years (p<0.0001, not shown). Slightly more participants than controls tended to have been divorced or previously cohabiting among the participants and controls who had ever been cohabiting not shown). Fifteen percent of the participants and 42% of controls were married, while 13% of participants and 26% of controls were cohabiting without being married (p<0.0001, not shown).

No participants assessed in childhood with a DQ<50 or no walking ability were living with a partner. Among the rest of the adults with CP, the severity of cognitive and motor impairment equally strongly predicted cohabiting (Table 5). Epilepsy was included in the multivariate analysis despite no significance on the chosen 5% level, since 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 at the age of 15 years did 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 6 shows that 19% of the 29- to 35-year-old participants had biological children versus 61% of the controls (p<0.0001). Twenty-seven percent of the female participants and 13% of the male participants had children (p=0.0002), compared with 69% of the female controls and 55% of the male controls (p<0.0001, not shown). Seventy-nine percent of participants with biological children were assessed in childhood as having normal DQ and 87% as being able to walk without assistance. No participants with a DQ<50 or no walking ability had biological children. Eighty-five percent of the participants and 91% of the controls with biological children lived together with their children (p-value= 0.0577).

Cohabitation, biological children and competitive employment
Fifty-five percent of the participants versus 4% of the controls were not cohabiting, had no competitive employment and had no biological children. Eleven percent of participants and 46% of controls had all three social contacts. Even among those with at least one of these social contacts only one fourth (44/186) of the participants compared to half of the controls (1031/2149) had all three social contacts.

Discussion

Validity
We consider the participants to be very close to a representative sample of young adults with CP in Denmark. Some bias should however be considered. Topp, 1997 studied the validity of the Registry in 1997 and found the number of people with CP born between 1979 and 1982 underestimated by 15%.The CP participants not registered did not differ from the registered hospitalised participants in the severity of impairment or clinical subtype[18]. A possible selection bias compared with the CP participants of today is insufficient reporting of participants 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 lack 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, since the institutions are required to provide this information by law and have been delivering these data for 20 years. Data on education and accommodation was missing in about 3% of participants and controls. Participants missing data had various severities of cognitive and motor impairments.

Accommodation

Among 30-year-old adults with CP born from 1940 to 1945 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 [4]. This is very close to our results on participants born 25–30 years later. But institution and accommodation facility arranged by the county might not be comparable. Institutions before 1980 were big and segregated from the society, while today more small accommodation facilities in the local areas arranged by the county exist. We would have expected more people living in an ordinary housing receiving substantial help compared with 25-30 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, since more children with severe CP probably survive to adulthood today. Glenting assessed severity of impairment in adulthood, while we have only the assessment made at age 6. He found 12% og the 518 adults to be mentally retarded and we found 20% of our 416 children with a DQ<50[4].

Other studies [1;11;13;16;22] find between 40% and 66% of adults with CP living independently and between 13% and 58% living with their parents. None are population based and selection criteria for study populations differ, making comparing results difficult. Two important predictors of independent living and cohabitation, age and degree of severity among participants, often differ substantially.

Women entered the labour market in Denmark from the 1940s to the 1960s, a marked change. Since 1980, the idea of integrating people with disabilities in society has been advocated and is now stipulated by law in Denmark. Despite the difficulty in comparing, we find it noteworthy that about the same percentage of adults with CP were living dependent on either parents or society in 1970 and 25–30 years later. The 13% of the 29- to 35-year-olds living with their parents in Denmark seems to be a lower number than in the two studies from California (Murphy et al. 2000, O'Grady et al. 1995) and about the same in the study in Sweden (Andersson & Mattsson 2001) [1;13;16], but the study populations are very different, so the exact influence of different social systems is hard to judge.

Denmark has accommodation facilities for severely disabled people as described, but one in five 29- to 35-year-old participants living at an accommodation facility arranged by the county lived at nursing homes for elderly people. Nursing homes for elderly people 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. Beside lack of suitable homes, other reasons 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 [8;11;17;22;23].

Severity of epilepsy, cognitive and motor impairment predicted living independently. But the decision on whether independent living is chosen did not depend on the availability of accommodation facilities arranged by the county as well as the parents' income. Our analyses only included children living with their parents at age 15 years, resulting in exclusion of for example a group of more severe disabled children living at an accommodation facility arranged by the county from childhood. We do not know if parent's socioeconomic position and region of living affects these children's chance of living independently in adulthood.

Cohabitation

Cohabiting is a way of getting social contact, and this may be especially important for disabled people, who have more difficulty in participating in social activities than non-disabled people. 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 Sweden [1] found 22% cohabiting. This is less than in our study, although the Swedish participants were older (mean age 36 years, range 20–58) and no participants with learning impairment or living in an institution were included. The study of children with CP born from 1940 to 1945 in Denmark [6] found 32% currently married among 30-year-old people with CP. This is very close to our result on cohabitation, and we suspect that nearly all cohabitants in the 1970s would be 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 disabled (primarily CP) people 19–26 years old compared with non-disabled people [11]. The Danish study of children with CP born from 1940 to 1945 [6] found that normal speech was the most important predictor of getting married.

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 at the same age. One study in California with participants 27–74 years old [13] found that 3% had children, but this was a selected group excluding participants at institutions and with few participants with mild CP. Among participants in Sweden with a mean age of 36 years (range 20–58), 8% were living with children [1]. The study of children with CP born from 1940 to 1945 in Denmark found that 28% had biological children among 30-year-old people with CP versus our finding of 19% among participants 29–35 years old. People, however, in general today become parents at an older age and have fewer children today than they did 25–30 years ago[15].

Cohabitation, biological children and employment
Assuming that cohabitation, having children and labour market participation are indicators of social integration in a society, we found it important to examine how these three types of social contact intervened in participants as well as controls. In a previous study based on data from the same population, we found that 33% of the 416 adults with CP aged 29–35 years 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 versus 46% of controls were cohabiting, had biological children and were competitively employed.

In this study we only measured 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 study [12] 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 both in education, employment and sport activities despite a high level of independence in performing activities[22]. Why is this? An explanation could be 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 CP participants [2;3;3;7]. Esben (2003) suggests that these specific cognitive deficits result in difficulty concentrating and reduced ability to combine, structure and end tasks. Jahnsen 2003 states that physical fatigue is a pronounced problem among adults with CP [9]and Kemp 2005 describes how impaired people grow older fast and never reaches the same maximum capacity as non-impaired people[10]. These two problems might explain why we found that even the most optimally functioning adults had difficulty in succeeding total integration concerning cohabitation and children as well as the labour market. A focus on and early intervention in cognitive training and a continuing care and habilitation into adulthood would then be important. Such an initiative should be possible to show improved social integration especially among the mildest cases of CP.

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Table 1. Accommodation among 29- to 35-year-old people with CP versus controls (percent)

	CP *n* = 416	**Controls** *n* = 2247
Accommodation		
Independent	68%	92%
With parents	13%	5%
Accommodation arranged by the county*	16%	<1%
Unknown	3%	3%
P-value < 0.0001		

*This is close to the concept of 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.

Table 2. Severity of CP and socioeconomic position of participants and parents according to accommodation in 29- to 35-year-old people with CP (percentage and number in three groups of accommodation with different characteristics)

	Independent living	**With parents**	**At an accommodation facility arranged by a county**	**Unknown accommodation**
	% (*n*)	% (*n*)	% (*n*)	% *(n)*
n= 416	*n* = 284	*n* = 55	*n* = 65	*n*= *12*
Severity of CP ** **(assessed in childhood)**				
Epilepsy*	8% (23)	42% (23)	43% (28)	25% (3)
DQ < 50*	4% (11)	45% (25)	66% (43)	33% (4)
Not walking*	4% (10)	18% (10)	42% (27)	17% (2)
Highest educational level **				
Participants with an education beyond lower secondary school*	50% (143)	13% (7)	0% (0)	8% (1)
Employment				
Participants competitively employed*	45% (128)	15% (8)	0% (0)	17% (2)
Parents’ *** **socioeconomic position when the CP child was 15 years old**				
n= 359****	*n* = 267	*n* = 54	*n* = 30	*n*= *8*
Highest education **				
Parents with an educational level 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 **				
Lowest 20%	21% (55)	33% (18)	23% (7)	25% (2)
Parents’ not living with their child at age 15				
n = 57****	*n* = 17	*n* = 1	*n* = 35	*n*= *4*
Accommodation of child at age 29-35 years*	30% (17)	2% (1)	61% (35)	7% (4)

* Statistical significant difference on a 5% level.

** 6% (26) of participants had an unknown severity of cognitive impairment, 23 lived independently. One percent (6) of participants had an unknown severity of motor impairment. Three percent (13) of participants had an unknown highest education, 8 lived independently. Two percent (8) of parents had an unknown highest education, 6 had children and were living independently. One set of parents had an unknown household income.

*** Parents are adults living with the participant, including both biological and non-biological parents.

**** 57 of 416 participants did not live with their parents when they were 15 years old and data on parents socio-economic position were not recorded. Accommodation is reported separately for this group at the bottom of table 2.

Table 3. Predictors of not living independently among 377* people 29–35 years old with CP* (multivariate logistic regression)

	n	**Odds ratio (confidence interval), controlled for age**	**Odds ratio (confidence interval), controlled for age and other significant predictors*****
Subtype of CP		$p < 0.0001$	
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)	
Development quotient (DQ)		$p < 0.0001$	$p < 0.0001$
> 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		$p < 0.0001$	$p = 0.0125$
No	304	1	1
Yes	73	7.63 (4.34–13.41)	2.56 (1.23–5.36)
Motor impairment		$p < 0.0001$	$p = 0.0151$
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**		$p = 0.5113$	
Education beyond lower secondary school	233	1	
Lower secondary school	86	1.21 (0.69–2.11)	
Unknown	58	Not in analysis	
Parents' income**		$p = 0.1213$	
The highest 80%	253	1	
The lowest 20%	72	1.58 (0.89–2.82)	
Unknown	52	Not in analysis	
Parents' cohabitation**		$p = 0.8253$	
Partner	267	1	
Single	59	0.93 (0.48–1.80)	
Unknown	51	Not in analysis	
Region of residence**		$p = 0.1506$	
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	

* 39 of 416 participants were excluded due to missing data: 27 lacked data on severity of cognitive or motor impairment (20 were living independently), 11 participants had an unknown accommodation (and different level of severity of cognitive and motor impairment) and one participant lacked data on both cognitive impairment and accommodation.

** Parents' highest education, cohabitation and income and the participants' region of residence were analysed when the participant was 15 years old. 51 participants not living with their parents at the age of 15 years were not included in the univariate analyses. In addition seven parents of participants had an unknown highest education, one set of parents had an unknown income and 15 set of parents had moved outside Eastern Denmark.

*** Only variables statistically significant on a 5% level in the multivariate analysis were included.

Table 4. Cohabitation among 29- to 35-year-old people with CP compared with controls (percent)

	CP *n* = 416	**Controls** *n* = 2247
Cohabitation		
Single without children*	71%	26%
Single with children*	1%	5%
Couple without children*	13%	17%
Couple with children*	15%	52%
P-value < 0.0001		

***Biological and non-biological children**

Table 5. Predictors of no cohabitation among 283* people 29–35 years old with CP (multivariate logistic regression)

	n	**Odds ratio (confidence interval), controlled for gender**	**Odds ratio (confidence interval), controlled for gender and other significant predictors*** **
Subtype of CP		*p* = 0.0143	
Hemiplegia	114	1	
Diplegia	150	2.00 (1.19–3.39)	
Other	19	3.11 (0.94–10.22)	
Development quotient (DQ)		*p* < 0.0001	*p* = 0.0041
> 85	197	1	1
85–50	86	3.58 (1.92–6.67)	2.61 (1.36–5.01)
Epilepsy		*p* = 0.0081	*p* = 0.0712
No	252	1	1
Yes	31	4.40 (1.47–13.19)	2.86 (0.91–8.94)
Motor impairment		*p* = 0.0017	*p* = 0.0198
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**		*p* = 0.8896	
Education beyond lower secondary school	187	1	
Lower secondary school	69	1.04 (0.58–1.88)	
Unknown	27	Not in analysis	
Parents' income**		*p* = 0.1938	
The highest 80%	206	1	
The lowest 20%	56	1.54 (0.80–2.96)	
Unknown	21	Not in analysis	
Parents' cohabitation**		*p* = 0.9732	
Partner	213	1	
Single	50	1.01 (0.52–1.96)	
Unknown	20	Not in analysis	
Region of living**		*p* = 0.1286	
Cities of Copenhagen and Frederiksberg and Copenhagen County	105	1	
Frederiksborg 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		

* 125 participants of 416 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, DQ < 50 or were not able to walk and none in this group were living with a partner.

** The participants' region of residence was analysed when the participant was 15 years old.

** Only variables statistically significant on a 5% level in the multivariate analysis were included, except for epilepsy that was nearly significant.

Table 6. Biological children among 29- to 35-year-old people with CP compared with controls (percent)

	CP *n* = 416	**Controls** *n* = 2247
Number of biological children		
None	81%	39%
One	9%	27%
Two	8%	27%
Three or more	1%	7%
P-value < 0.0001		

Appendix: Subtype and severity of CP in people born between 1965 and 1970

	At analysis *n* **= 416**		**At diagnosis** *n* **= 486**		**Participants dead before 1999** *n* **= 67**	
	%	***n***	**%**	***n***	**%**	***n***
Subtype of CP						
Hemiplegia	31	127	27	130	1	1
Diplegia 1	35	147	32	155	10	7
Diplegia 2	14	59	14	66	10	7
Tetraplegia	11	47	18	86	58	39
Ataxia	3	11	3	14	4	3
Hyperkinesia	5	19	6	28	13	9
Dystonia	1	6	1	7	1	1
Motor impairment						
Walks without assistance	65	270	58	282	13	9
Walks with assistance	22	91	21	103	18	12
Not walking	12	49	19	94	67	45
Unknown	1	6	1	7	1	1
Development quotient (DQ)						
> 85	49	203	43	208	3	2
85–50	25	104	24	116	18	12
< 50	20	83	27	132	73	49
Unknown	6	26	6	30	6	4
Epilepsy						
No	81	339	77	374	49	33
Yes	19	77	23	112	51	34

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Paper III

A cohort study of parents' social situation after the birth of a child with cerebral palsy.

Manuscript.

A cohort study of parents' social situation after the birth of a child with cerebral palsy

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Summary

Optimising the support to parents with a disabled child requires knowledge of employment, income and cohabitation and if these factors change after the child is born and later in life. We studied a population-based cohort of parents of children with cerebral palsy (CP) born from 1965 to 1990. Cohorts of control children were matched by gender and age. In total, parents of 1,824 children with CP and parents of 9,153 control children were included. The follow-up period started in 1980 and ended in 1999. We found most parents in Denmark employed and no change in employment frequency for parents of control children and fathers of children with CP after giving birth to a child. Ten percent of mothers to a child with CP left the labour market after birth of the child. Results indicated that half of these women were never re-employed, and not employed mothers to a CP child earned less than not employed mothers of controls. The parents of a child with CP were not more often divorced (living separate) compared with parents of a control child and most children with CP had siblings. The Danish welfare system has succeeded in this area, but we have not studied the psychological well-being or health of parents or siblings.

Having a child with cerebral palsy (CP) changes the life of the parents. Speculation on the future of the child and on how CP will affect everyday life is inevitable. Mothers might prolong their maternity leave and constantly support the child to ensure optimal development. The resources allocated to the child might be substantially more than expected. Less time and energy are left for marital activities. The coping process is lifelong for people with a disabled child.

Studies [1;3;4;7] have explored how a disabled child affects the social situation for parents at a specific time, including children of different ages.

The strain a disabled child places on parents might change during childhood and adolescence. This population-based cohort study analysed education, employment, income, cohabitation and having additional children, among parents of a child with CP and among parents of control children. Socio-economic data on the parents were analysed before the children were born, during childhood and in early adulthood. The effect of having a child with CP on employment, cohabitation and having additional children was analysed. The children with CP were born from 1965 to 1990 and were compiled from the population-based Danish Cerebral Palsy Registry covering eastern Denmark, Uldall et al.(2001). In two recent papers, we have described the long-term outcome of these children[5]. This paper describes the short- and long-term outcome for their parents.

Methods

Participants

Parents of children with CP were identified through their children being in the Danish Cerebral Palsy Registry, which registered 1,856 children born from 1965 to 1990 with congenital CP. The controls were children born and living in eastern Denmark at the age of six. Five controls per child were randomly selected with the same gender and age from the Civil Registration System, which covers all residents of Denmark. Twenty-three controls were subjects as well and were excluded as controls. Biological parents were identified through the Fertility Database in Statistics Denmark. A total of 119 parents of subjects and 532 parents of controls could not be identified in the registries of Statistics Denmark, leaving 3,593 parents of subjects and 17,982 parents of controls for analysis. No parents were identified for 32 subjects and 104 controls. The analysis was therefore based on the parents of 1,824 children with CP and 9,153 children without CP.

Data sources

Danish Cerebral Palsy Registry
The Danish Cerebral Palsy Registry is a population-based registry with cases of congenital CP. Children born from 1925 are registered, and since 1965 data have been collected prospectively based on reports from physicians in paediatric departments and special institutions. It covers eastern Denmark, which has 2.5 million inhabitants, or about half the population of Denmark [8].

Registries in Statistics Denmark
Parents and siblings were identified in the Fertility Database. Information on cohabitation, education, employment and income was obtained from registries kept by Statistics Denmark through linkage with the Civil Registration System. The data sources are educational institutions, workplaces and local authorities obligated by law to deliver information to Statistics Denmark.

Study design

The study was a cohort study of parents of children born from 1965 to 1990. Information was obtained each year from the start of the registries in 1980 to the end of follow-up December 31, 1999. Parents of all children, whether they were dead, emigrated or lived in Denmark, participated. Parents who died or emigrated before the follow-up ended were censored at the time of the event. The entire cohort with children born from 1965 to 1990 was analysed, but since no children were followed from before birth to the age of 35, we decided to follow two fixed cohorts as well. A younger cohort of parents of children born from 1982 to 1990 was followed from two years before the children were born and up to the age of ten (n = 707). An older cohort of parents of children born from 1965 to 1970 was followed when the child was 15–30 years old (n = 486).

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 [6]. Disability was measured by severity. The severity of motor impairment was measured by the ability to walk. The severity of mental impairment was measured by a development quotient (DQ). The DQ was assessed to be >85 when school was begun without help (excluding manual assistance) and between 85 and 50 for those who needed more support at school. The third category was DQ<50. Epilepsy was registered if there are two or more unprovoked seizures after the neonatal period. Diagnosis, including subtype, severity and the presence of epilepsy, was registered when the child is six years old [8].

Control children
Control children were children not having cerebral palsy, but we did not know if they had other impairments. In multivariate analyses, we assumed they had a DQ>85, were able to walk unaided and had no epilepsy.

Education
The highest educational level of the parents was described in four categories: lower secondary school, upper secondary school, vocational training and tertiary education.

Employment
Information on employment was obtained from the Integrated Database for Labour Market Research (IDA) in Statistics Denmark. Based on the main income source for the year in question, parents were categorised as either employed or not employed. Attachment to the labour market was described on four levels measured by a combination of status of employment

and hours worked a week: Working full-time (<30 hours a week), working part-time (9-30 hours a week), working unknown hours, not working.

Income

Income was based on the annual pre-tax income. Amounts from different calendar years were adjusted to 1980 money. Any tax-free benefits received by the parents of subjects or controls were not included in annual income. The annual family income was the total pre-tax income of the parents living together. The income of controls was divided into quintiles, and subjects were then placed in the groups of their respective income.

Siblings

Siblings were children with the same biological mother and father as the child.

Cohabitation

Cohabitation was measured by comparing address codes of parents. Parents not living together are in this paper called “divorced”. The address codes were anonymous and were obtained from Statistics Denmark.

Statistical analysis

Most univariate comparisons used a chi-squared test for homogeneity.

Parents' risk of not being employed and parents' risk of divorce (both outcomes assessed at the child's fifth year) were analysed using logistic regression models.

We analysed parents' income longitudinally at fixed time points (-1, 1, 3, 5, 7, 9, 11, 13, 15 and 18 years after the birth of the child) comparing the group of parents with CP children and the group of parents of non-CP children. Yearly income was analysed, log-transformed and controlled for calendar year of birth, ages of parents at the year of birth of the child, the number of adults in the household and the parents' affiliation to the labour marked (full-time job, part-time job and no job). Correlations among consecutive measurements of log income were controlled by using an unstructured covariance matrix to model residual correlations.

For each pair of parents we defined time until divorce as the time from child birth to the year when the parents did not share same physical address or to the child's 18th birthday whichever came first. Pairs of parents living together throughout the first 18 years of the case child's life were regarded as censured. Using child age as the underlying time scale, we modelled time to divorce/censorship using Cox's proportional hazards model. The analysis of divorce was controlled for birth year, parents' job-status (time-dependent variables indicating whether or not parents have jobs) and parents' income (time-dependent variables indicating whether or not parents' income is in or above the 20 percentile of the income distributions). Note that since we only had information on parents from 1980 through 1999, the analyses were conditioned by either the parents living together in 1980 (for children born before 1980) or on the children being born after 1980. Parents whose children were born before 1980 and who were not living together in 1980 were not at risk for divorce from 1980 and onwards and hence not included. Moreover, a delayed entry approach was used for parents whose children are born before 1980 because the time scale of the model was child age (0-18 years of age).

Finally, we analysed whether parents of CP children tended to postpone or desist from having children following their CP-child using Cox's proportional hazards model. We used time from birth of the CP/control child to birth of the next subsequent child of the same two parents or December 31, 2000 whichever came first. The model included ages of both parents at the time of birth of the CP/control child and the number older full siblings.

For all analyses, we used a 5% level of statistical significance.

Ethics

The Danish Data Protection Agency approved this study. The civil registration numbers of subjects were delivered to Statistics Denmark, and an identification number replaced each civil registration number immediately after being linked to other registries. All analyses were 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

Study population
The ages of the parents of subjects and controls did not differ. But the parents of the younger cohort born from 1982 to 1990 were older when their child was born (mothers 28 years of age and fathers 31 years of age) than the parents of the older cohort born from 1965 to 1970 (mothers 25 years of age and fathers 29 years of age).

Education
Significantly fewer mothers and fathers of children with CP had an education beyond lower secondary school compared with mothers and fathers of controls. This was evident both before and after the child with CP was born. When the child was five years old, 32% of the fathers and 43% of the mothers of a child with CP had no education beyond lower secondary school versus 30% and 39% of mothers and fathers of controls.

Employment
The social situation of parents at various ages of their children is shown in Tables 1 and 2. Fig. 1 shows the changes in employment frequencies for the mothers and fathers of children born from 1965 to 1990. Most mothers of children with CP stayed employed after birth, but ten percent left the labour market and only half of these later seem to be re-employed. The birth of a child did not affect the employment frequencies of the fathers of children with CP or the parents of controls, but the fathers of children with CP left the labour market earlier than the fathers of controls.

The employment frequency of mothers, but not of fathers, differed according to the severity of mental and motor impairment (Table 3), and this continued into adulthood (not shown). When the children were five years old, one third of the mothers of severely disabled children were outside the labour market. The employment frequency differed according to the highest educational level among both the parents of children with CP and the parents of controls (Table 4). The higher the educational level, the higher the proportion of parents employed. Significantly more mothers of children with CP who had a shorter education were outside the labour market compared with controls. Significantly more single mothers compared with mothers living with a partner were outside the labour market when the child was five years old. This was evident for both mothers of children with CP and mothers of controls (Table 4).

The OR of being outside the labour market when the child was five years old was twice as high among mothers of children with CP versus mothers of controls, after adjusting for the birth year and gender of the child, mother's age, educational level, employment status and cohabitation of the mother the year before the child was born (Table 5). No effect modification of educational level, employment status or cohabitation was found on CP versus control. The severity of impairment predicted the mothers' chance of employment. The OR of fathers of CP-children being not employed was not higher than that of the fathers of control children, and the severity of impairment did not predict their chance of employment (not shown).

Mothers of children with CP more often worked part-time than mothers with control children. When the child was five years old, we found 27% working part-time, 62% working full-time and 11% working unknown hours among employed mothers to children with CP. Figures for employed mothers of controls were 18% working part-time, 74% working full-time and 9% working unknown hours. One percent of employed fathers of children with CP and controls worked part-time.

Income

The mothers of children with CP were more often in the lowest income group than controls, but the fathers of children with CP were not. The difference was evident before the birth of the children and during childhood more families were in the low-income group compared with controls (Table 1). Mothers of children with CP had a lower pre-tax annual income than controls controlled for mothers age, birth year of the child and parents' cohabitation. When the child was five years old, mothers of controls earned 72% more than mothers of children with CP. This was mainly due to not employed mothers to children with CP having a lower income than not employed mothers of controls and not due to hours worked a week (Figure 2). No differences were found in income between fathers of children with CP and father of controls.

Cohabitation

The OR of divorce was not increased among the parents of children with CP when the child was five years old, adjusting for birth year and the gender of the child, the age of the parents, the highest educational level of the mother and father and the number of siblings the year before the child was born, OR 1.08 (0.87-1.33) (Table 6). No effect modification of parents' cohabitation was found on CP versus controls. The proportion of parents cohabiting differed slightly between the parents of children with CP and the parents of controls during the first years of the children's lives, but the difference was the same as before the child was born (Figure 3). More parents with adult CP children than parents with adult control children lived separately, but there were few parents with the oldest children. The analysis of time until divorce showed no overall difference in divorce rate between the parents of CP children compared to parents of non-CP children (P = 0.1937) though the controlling variables were significant (not shown).

Siblings

The analysis of time until subsequent children following birth of a CP/control child showed that parents of CP children tended to either postpone or completely desist from having subsequent children, hazard ratio 0.852 (0.79-0.92). The CP-status, however, interacted with number of older siblings (0, 1 or >=2) and the entire difference in postponement/abstinence lied within the group of parents where the CP/control child was the first child. Thus, parents who had a CP child following older siblings (41% of children with CP and 46% of controls had older siblings at birth) were not more prone to postpone or desist from having subsequent children than parents of control children (P=0.9196) (Figure 4). If the CP child was the parents' first child, parents of CP children more often desisted from having subsequent children, hazard ratio 0.77 (0.71-0.85). Among parents where the CP/control child was their first child we found 48.7% of CP parents with only one child when the child was 15 years old compared with 41.8% of control parents. At the age of 15 years; 13% of all children with CP had both older and younger siblings, 30% had only younger siblings, 27% had only older siblings and 29% were only children versus 14%, 32%, 32% and 23% of all controls (P<0.0001).

Discussion

Validity
At least one parent was identified for 98% of the subjects and 99% of the controls. Both parents were identified for 92% of the subjects and 94% of the controls. The reasons a parent was not identified could be adoption or that references between registries were incomplete for the oldest subjects or controls. We considered the parents of children with CP included to be close to a representative sample of parents in Denmark whose children have CP and are 0–35 years old.

The strength of our study is the follow-up design, which enables reporting changes in socio-economic position from before birth and during childhood and into adulthood. Since the participants in the younger and older cohorts are not the same parents, we cannot truly describe the changes in socio-economic status through the whole period, but separately in two periods, and Fig. 1 and 2 are approximations. Children in the oldest cohort were born before 1980 when major state institutions were responsible for caring for people with disabilities. After 1980 (the younger cohort), a new law aimed at increasing the integration and normalisation of disabled people, and this might have had implications for the social situation of parents. The transition was, however, gradual. If the parents of the older cohort more often had children institutionalised, they might have less practical work with the child during the day, and more mothers could then be employed. Nevertheless, more mothers were homemakers at that time, although many women in Denmark were already participating in the labour market in the 1960s.

Employment and income
Our finding that mothers of children with CP are more often not employed and more often in a low-income group than mothers of controls is in accordance with other studies. Brehaut et al. (2004) studied the caregivers (nearly all mothers) of children with CP and found that 66% had paid employment versus 81% in a population survey [1]. The figures in our study were a bit higher, and this could reflect the high employment rate among women in Denmark, but the difference is difficult to interpret since the data from Canada were all collected in 2001–2002 whereas our data were based on a cohort study with results from 1980 to 1999. Brehaut et al. (2004) found more caregivers to be in the low-income group, and we found this too [1]. A Swedish study in 1992 [9] found an effect of the severity of impairment on employment like we did, but while Westbom found no mothers of severely chronically ill children working, we found around one third of the women to children with a severe disability working. A Nordic study on children with myelomeningocele [4] found 66% of the mothers with disabled children working or studying full-time versus 77% of the mothers of controls. It is remarkable that the social welfare systems in the Nordic countries and Canada seem to succeed in keeping the employment frequency of mothers very high even after giving birth to a disabled child. It would be interesting to compare with data from other Western countries.

Lie et al. (1994) found that in Denmark fewer families with a disabled child were in a high-income group than controls. In Sweden, Norway and Finland, Lie et al. found no differences in income between subject and control families [4]. In our study, we found not employed mothers to children with CP having a dramatically lower income than not employed mothers of controls. Lie et al. found, as we did, that nearly all fathers of disabled and control children were employed. Breslau et al. (1982) found in Ohio that child disability negatively affected the maternal labour force participation among low-income two-parent families, but not among low-income single mothers [2]. We found more single mothers than cohabiting mothers outside the labour market. This difference in outcome could reflect differences in the economic support provided to single mothers in Ohio and Denmark.

Most mothers of children with CP in our study were employed. The mothers of a disabled child who are outside the labour market in Denmark have a legal right to be paid a public subsidy instead of receiving income by employment. We do consider it to be an optimal solution letting the mother leave her job for a while to enable her to cope with the disabled child. Nevertheless, being aware of mothers' social situation as well and supporting their return to the labour market again, if desired, are important.

Social inequality as cause of birth prevalence of CP or social effects of CP?
Differences in socio-economic position of parents with a CP child with compared to parent of controls can be due to social differences in the prevalence of CP or differences as result of having a disabled child, or both. The first would have implications for the causation of CP, and the relationship between socio-economic position and the birth prevalence of CP has been studied for years, with diverging results. This study did not focus on social inequality as a cause of birth CP prevalence, but on the changes in social situation for the parents of a disabled child. We found, however, a social disadvantage in parents' educational level and mothers' employment before the child was born, but also a change in employment frequency of mothers after having a child with CP.

Cohabitation and siblings
We found no differences in parental cohabitation between parents with CP children and parents with control children, assuming that parents with different addresses have ended their relationship. This is in accordance with some others studies [4;9], but results of studies on the divorce of the parents of a child with CP or another disability are inconsistent. In a nationwide survey in the United States, Joesch et al. (1997) found a higher risk of divorce or separation among the mothers of children with CP than among the mothers of healthy children. The study examined 15 different health conditions in a large material, and 15 women were mothers of children with CP. In England, Tew et al. (1977) found a higher divorce rate among parents living with a child with spina bifida (10.3%) than in the local population of parents (1.1%). The strain was diminished by a child's early death (divorce rate 3.5%), and Tew et al. (1977) concluded that a handicapped child added greatly to the strain on a marriage [7]. Our result that parents of adults with CP more often lived separately (Figure 3) is difficult to interpret, and the effect of different cohorts needs to be taken into account. It is positive that the 41% of CP-children with older siblings have younger siblings just as controls. Among the first born children, we consider the difference of only 7 percent points in number of children being only children at the age of 15 small.

Conclusion

All fathers and the majority of mothers continue to work after giving birth to a child with CP, and the majority of children with CP have siblings. The Danish welfare system seems to have succeeded in this area, even though we have not studied the psychological well-being or health of parents or siblings. Special attention needs to be paid to single mothers, mothers with a low educational level and mothers with severely disabled children, who are at highest risk of being outside the labour market. Paediatricians and social workers need to be aware of the long-term consequences of a mother taking care of her child during the day and support their re-entering the labour market, if desired.

Acknowledgements

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Table 1. Socio-economic status among parents according to the age of the child among children born from 1982 to 1990

Age of child (years)	–2	–1	2	5	10**
Number of children CP (control)	707 (3572)	707 (3527)	707 (3527)	707 (3527)	630 (3143)
Fathers not employed					
CP	6%	6%	5%	8%	12%
Control	7%	7%	5%	7%	11%
Mothers not employed					
CP	19%	19%*	30%*	29%*	28%*
Control	16%	14%*	15%*	16%*	18%*
Fathers in lowest income group					
CP	18%	21%	20%	26%*	24%*
Control	20%	20%	20%	20%*	20%*
Mothers in lowest income group					
CP	23%	24%*	37%*	38%*	33%*
Control	20%	20%*	20%*	20%*	20%*
Families in lowest income group* **					
CP	20%	23%	34%*	32%*	32%*
Control	20%	20%	20%*	20%*	20%*
Fathers living without a partner					
CP	31%*	20%*	14%	18%	19%
Control	27%*	17%*	12%	16%	18%
Mothers living without a partner					
CP	29%	21%*	17%	21%*	20%
Control	27%	18%*	14%	18%*	20%
Parents divorced					
CP	33%	21%*	17%*	25%	29%
Control	30%	18%*	14%*	22%	29%

* Statistical significant difference between CP and controls group on a 5% level.

** A total of 77 children with CP and 384 controls were only nine years old and are not included in this analysis.

*** Parents living separately are not included in this analysis.

Table 2. Changes in the social situation of parents according to the age of their child among children born from 1965 to 1970

Age of child (years)	15	20	25	30**
Number of children	486	486	486	426
CP (control)	(2422)	(2422)	(2422)	(2122)
Fathers not employed				
CP	4%	8%	18%	41%*
Control	5%	9%	15%	34%*
Mothers not employed				
CP	26%*	22%*	28%	45%
Control	16%*	14%*	19%	39%
Fathers in lowest income group				
CP	18%	22%	23%	23%
Control	20%	20%	20%	20%
Mothers in lowest income group				
CP	31%*	31%*	29%*	26%*
Control	20%*	20%*	20%*	20%*
Families in lowest income group* **	26%*	27%*	26%*	22%
CP	20%*	20%*	20%*	20%
Control				
Fathers living without a partner				
CP	19%*	20%	22%*	22%
Control	14%*	17%	17%*	17%
Mothers living without a partner				
CP	18%	24%	29%*	31%*
Control	18%	21%	22%*	25%*
Parents divorced				
CP	30%*	34%*	38%*	40%*
Control	24% *	28%*	30%*	30%*

* Statistical significant difference on a 5% level.
** A total of 60 children were only 29 years old and are not included in this analysis.
*** Parents living separately are not included in this analysis.

Table 3. Parents employed according to the severity and subtype of CP when the child is five years old (N=1,105 children with CP)

	Father	Mother
Motor impairment		
Walks without assistance	94%	80%
Walks with assistance	93%	67%
Not walking	92%	61%
P	0.5415	<0.0001
Development quotient		
>85	96%	81%
50–85	90%	73%
<50	92%	61%
P	0.0097	<0.0001
Epilepsy		
No	94%	74%
Yes	92%	68%
P	0.3783	0.0615
Subtype		
Hemiplegia	95%	87%
Diplegia	93%	70%
Tetraplegia	95%	64%
Other	90%	72%
P	0.2219	<0.0001

Table 4. Parents employed according to the parents' highest educational level and cohabitation when the child is five years old (N=1,105 CP-children and 5,513 controls)

Highest education	**Lower secondary school**	**Upper secondary school or vocational training**	**Tertiary education**
Father			
CP	89%	95%	98%
Control	89%	96%	98%
Mother			
CP	59%*	80%*	92%
Control	75%*	88%*	95%
Cohabitation	**Living without a partner**	**Living with a partner****	
Father			
CP	83%	96%	
Control	82%	96%	
Mother			
CP	53%*	78%*	
Control	72%*	87%*	

* Statistical significant difference on a 5% level.
** A partner can be a biological parent or another partner.

Table 5. Mothers' risk of not being employed when the child was five years old calculated using multivariate logistic regression

	Odds ratio (Confidence interval)		*P*
Control children	1		
Children with CP	2.17	(1.72–2.70)	<0.0001
Diagnosis			
Diplegia	1.77	(0.99–3.29)	0.062
Tetraplegia	5.58	(2.69–11.85)	<0.0001
Others	2.39	(1.16–5.02)	0.02
Controls	0.91	(0.54–1.61)	0.72
Hemiplegia	1		
Mental impairment			
DQ>85	1		
DQ50–85	1.59	(0.99–2.48)	0.047
DQ<50	3.72	(2.68–5.12)	<0.0001
Motor impairment			
Walks with assistance	2.86	(1.81–4.42)	<0.0001
Not walking	4.27	(2.97–6.09)	<0.0001
Walks without assistance	1		
Epilepsy			
Yes	2.52	(1.62–3.87)	<0.0001
No	1		
Gender of child			
Female	0.97	(0.80–1.18)	0.78
Male	1		
Age of mother (per ten year)	1.21	(0.98–1.50)	0.082
Birth year of child (per year)	1.14	(1.10–1.18)	<0.0001
Mothers' highest educational level the year before the child was born			
Lower secondary school	5.37	(3.82–7.70)	<0.0001
Upper secondary school	2.68	(1.70–4.23)	<0.0001
Vocational training	2.13	(1.48–3.11)	<0.0001
Tertiary education	1		
Mothers' cohabitation status the year before the child was born			
Living without a partner with children	1.50	(1.13–1.99)	0.005
Living without a partner without children	1.79	(1.23–2.60)	0.002
Living with a partner and children	0.78	(0.62–0.98)	0.036
Living with a partner, no children	1		
Mothers' employment status the year before the child was born			
Not employed	7.03	(5.62–8.82)	<0.0001
Employed	1		

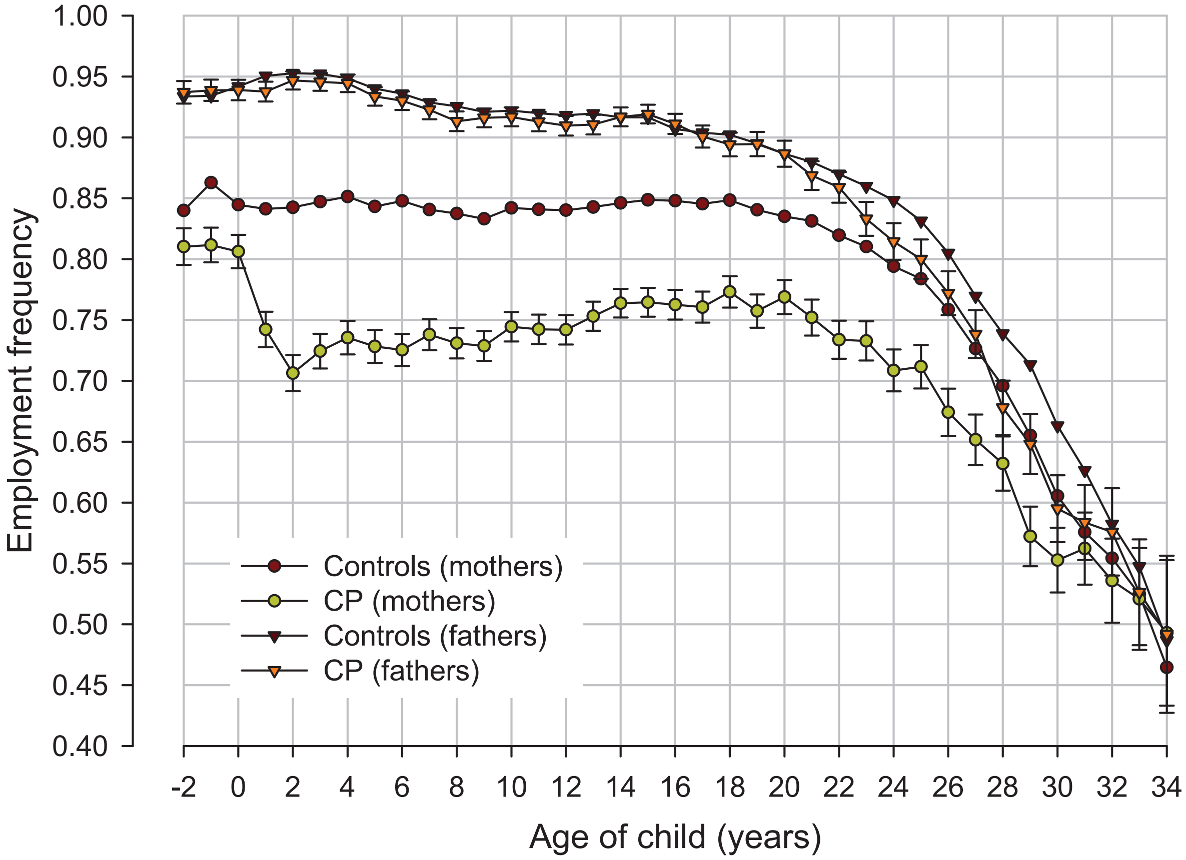
The analyses included child gender, age of mother, childbirth year and mothers' highest education, employment status and cohabitation, the year before the child was born. The effects of CP status, diagnosis, mental- and motor impairment and epilepsy status were analysed separately adding each of these variables to the fore mentioned model. All possible two-way effect modifications were studied in all multivariate regression analyses. These were in all cases not statistically significant and hence neither shown nor discussed any further.

Table 6. Parents' risk of divorce when the child was five years old calculated using multivariate logistic regression

	Odds ratio (confidence interval)		*P*
Control children	1		
Children with CP	1.08	(0.87-1.33)	0.48
Diagnosis			
Diplegia	1.08	(0.64–1.90)	0.78
Tetraplegia	1.67	(0.82–3.41)	0.16
Others	2.00	(1.05–3.87)	0.04
Controls	1.16	(0.73–1.92)	0.55
Hemiplegia	1		
Mental impairment			
DQ>85	1.20	(0.79–1.79)	0.39
DQ50–85	1.26	(0.91–1.74)	0.16
DQ<50	1		
Motor impairment			
Walks without assistance	1		
Walks with assistance	1.19	(0.76–1.83)	0.43
Not walking	1.14	(0.78–1.63)	0.50
Epilepsy			
Yes	1.24	(0.81–1.88)	0.31
No	1		
Gender of child			
Female	1.00	(0.85–1.18)	0.98
Male	1		
Age of parents (per ten year)			
Mother	0.56	(0.44–0.72)	<0.0001
Father	1.08	(0.90–1.30)	0.39
Birth year of child (per year)	1.02	(0.99–1.05)	0.30
Fathers' highest educational level the year before the child was born			
Lower secondary school	2.09	(1.57–2.81)	<0.0001
Upper secondary school	1.55	(1.06–2.24)	0.022
Vocational training	1.57	(1.19–2.08)	0.002
Tertiary education	1		
Mothers' highest education the year before the child was born			
Lower secondary school	1.60	(1.22–2.10)	0.001
Upper secondary school	1.26	(0.88–1.80)	0.21
Vocational training	1.00	(0.76–1.32)	0.99
Tertiary education	1		
Cohabitation the year before the child was born			
Parents divorced	3.55	(2.96–4.25)	<0.0001
Parents living together	1		
Number of siblings the year before the child was born	1.12	(1.06–1.19)	<0.0001

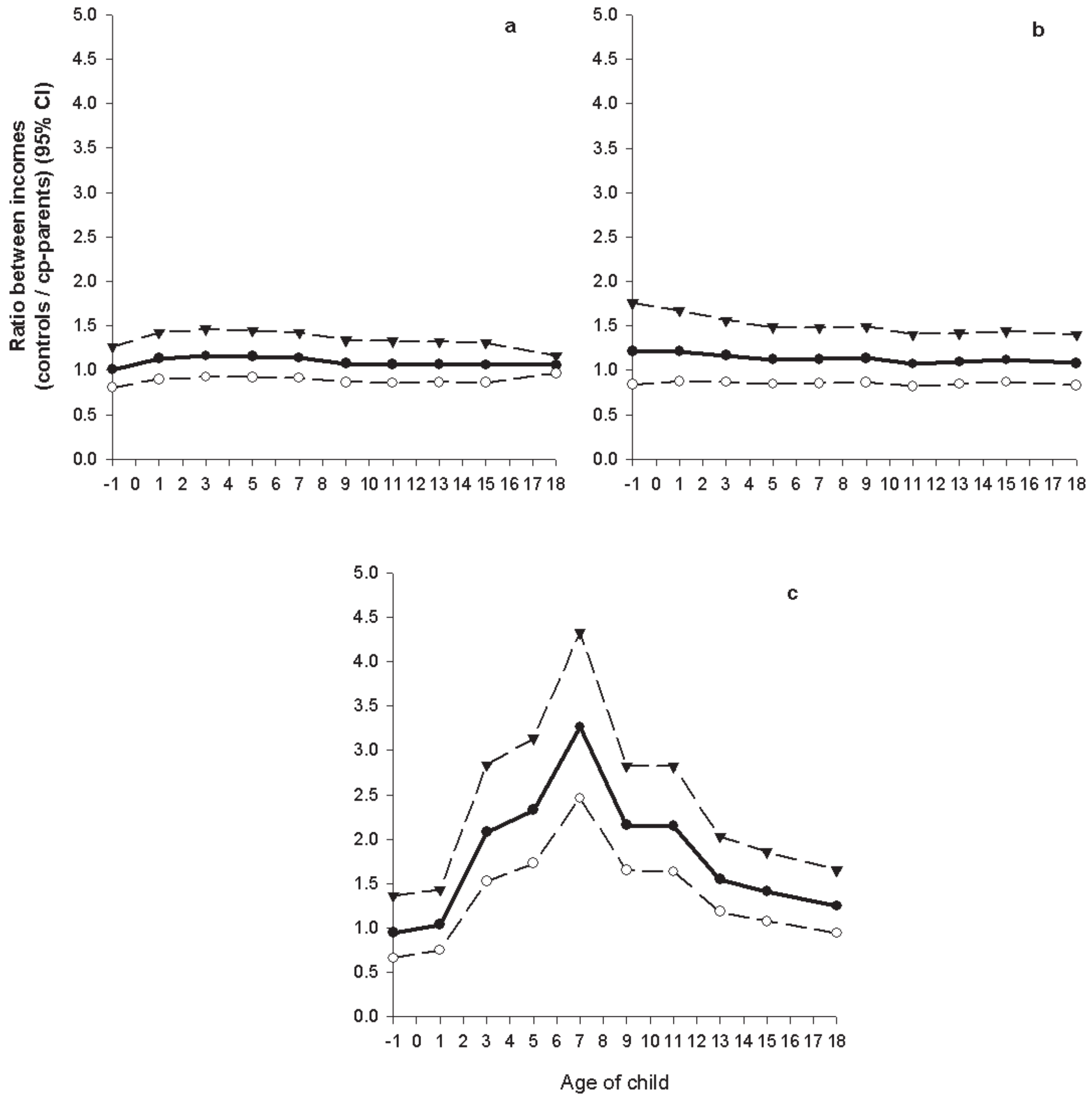
The analyses included child gender, age of mother, childbirth year and mothers' highest education, cohabitation and number of siblings, the year before the child was born. The effects of CP status, diagnosis, mental- and motor impairment and epilepsy status were analysed separately adding each of these variables to the fore mentioned model. All possible two-way effect modifications were studied in all multivariate regression analyses. These were in all cases not statistically significant and hence neihter shown nor discussed any further.

Figure 1. Employment frequency of parents of children born from 1965 to 1990.



The first observation was in 1980 and the last one in 1999. Parents only contribute to the figure during a certain period, and the same parent might pass in and out of the labour market during follow-up.

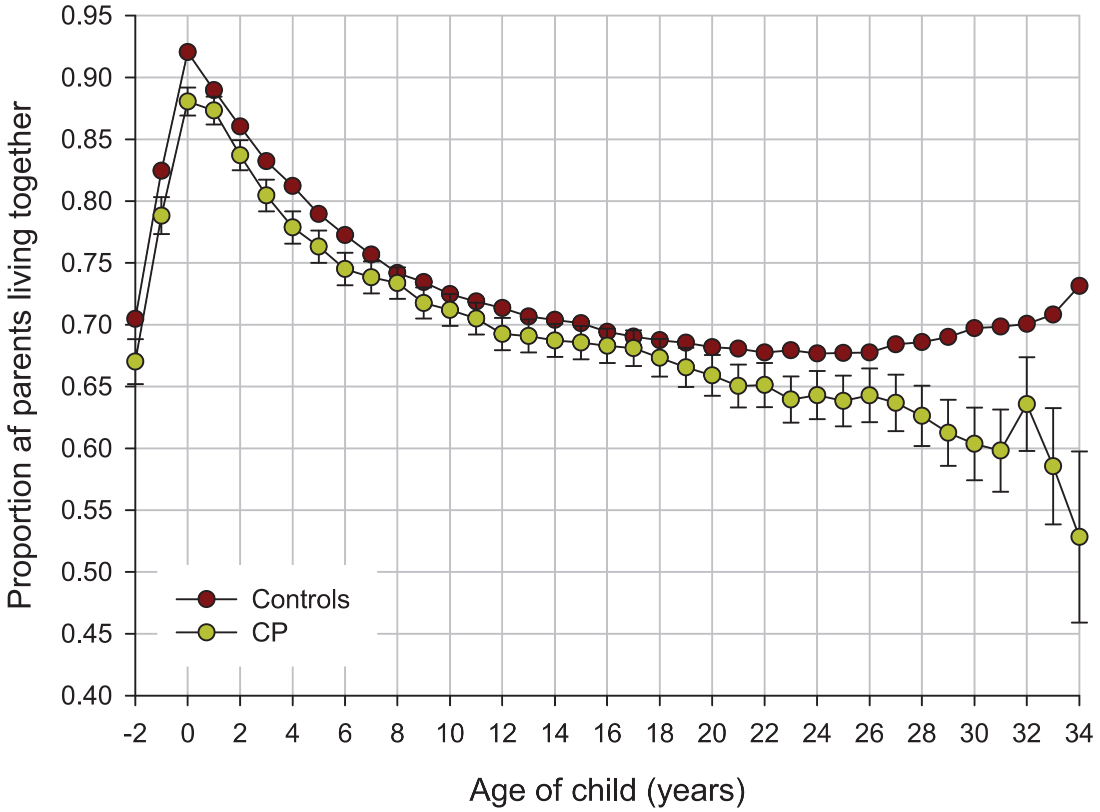
Figure 2. Pre-tax income in mothers according to level of attachment to the labour market



Ratio between control mothers and CP mothers in three groups of different labour market attachment, with curves showing the 95% confidence interval.

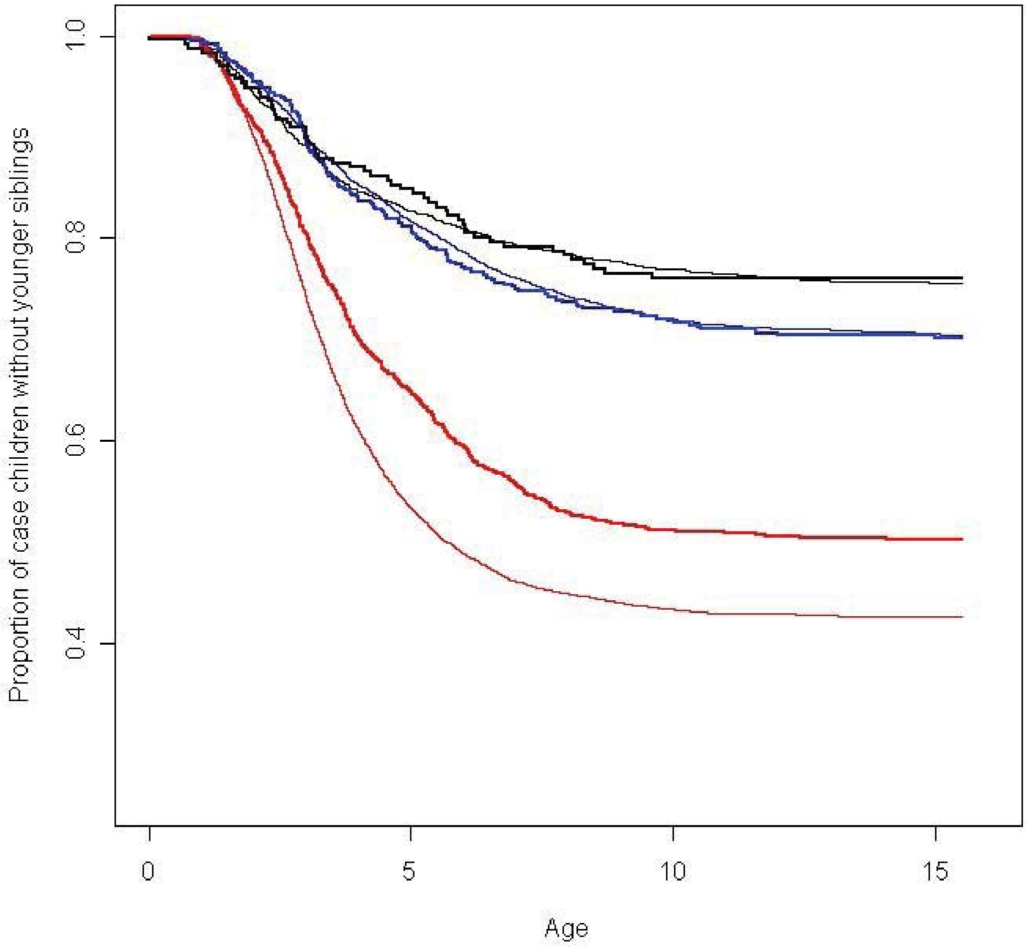
a= mothers working full-time
b= mothers working part-time
c= mothers not employed

Figure 3. Cohabitation among parents of children born from 1965 to 1990.



The first observation was in 1980 and the last one in 1999. Parents only contribute to the figure during a certain period, and parents might end cohabitation more than once during follow-up.

Figure 4. Younger siblings.



Top curves are children with two or more older siblings, middle-curves are children with one older sibling and bottom curves are children with no older siblings. Bolded curves are children with CP.

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Cerebral palsy is a common impairment affecting children. What happens when the disabled children become adults? Are they integrated in society and living life like any non-disable adult - using compensating aids? Are they employed and maybe living with a partner?

How does having a child with cerebral palsy affect the social integration of parents? Do mothers of disabled children leave the labour market and do parents of children with cerebral palsy divorce more often?

This PhD thesis gives some answers to these questions in relations to the social situation of 21–35 year-old adults with cerebral palsy. Parents of children with cerebral palsy were followed before the child was born and into their child's adulthood.

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