Living Conditions of People with Intellectual Disabilities

A Study of Health, Housing, Work, Leisure and Social Relations in a Swedish County Population

ÖIE UMB-CARLSSON
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Abstract

The general aim of this thesis is to describe mortality, health and living conditions in an administratively defined county population of people with intellectual disabilities born between 1959 and 1974 (N=213). The living conditions of persons with intellectual disabilities were compared with those of the general population. Moreover, the reports of relatives and staff were compared on the living conditions of people with intellectual disabilities. Information on the living conditions of persons with intellectual disabilities was provided by proxy (relative and staff) questionnaire reports and national welfare statistics conducted by Statistics Sweden (SCB). Medical examination and medical case records were used to obtain data on health and medical services.

People with intellectual disabilities lived in the community and took part in numerous common recreational and cultural activities. However, the comparison with the general population indicated clear differences in living conditions, particularly regarding employment and social life. In contrast, surprisingly little variation in living conditions was found in people with intellectual disabilities, despite varying ages and a wide range of level of disabilities. In addition, gender related differences of persons with intellectual disabilities were few when compared with those found in the general population. A wide range of physical and mental health problems were identified in the group with intellectual disabilities.

Although a majority of persons with intellectual disabilities had access to a family doctor and attended regular health checks, a number of needs of specialist examinations were identified indicating shortcomings in the quality of health care.

Analyses indicated differences in the reports of relatives and staff on living conditions of most domains included in the questionnaire. In general, disagreement was higher on subjective than on objective items. Relative and staff responders contribute dissimilar information that is related to varying viewpoints and different types of information.

Keywords: intellectual disabilities, living conditions, health conditions, mortality, associated disabilities, gender, comparative study, proxy responding

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There are days
when everything makes sense
Days when you get peace of mind
and no one is watching
and checking
to see what you have done is good
or not

There are days
when you can fly
Days when you get to do it your way
and someone whispers - You are good!
And no one is counting
or watching
to see if what you did was wrong
or not

There must be days
when everything becomes brighter
Days when only you are important
When you get to show your way of living
And it is allowed and good
that you exist.

*Maud Deckmar*

To Lina, Marcus, Sanna
and Leif
List of Papers

This thesis is based on the following papers, which will be referred to in the text by their Roman numerals:


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Abbreviations

SLC  Survey of living conditions
SCB  Statistics Sweden
CNS  Central nervous system
Introduction

The living conditions of people with intellectual disabilities in Sweden have radically changed during the past century. In the early 20th century, service and support were institution-based and people with intellectual disabilities did not take an active part in community life. When normalization and integration were introduced as guiding principles for service and support in the late 1960s (Nirje, 1969), the institutional era subsequently ended and was replaced by community-based services and support. According to Ericsson (2002), this change can be characterized as a shift in focus from a clinical perspective emanating from the institutional tradition to a citizen perspective emphasizing that persons with intellectual disabilities should be entitled to normal life conditions in the community.

Today, community services and support are linked to the equality-inequality discourse and persons with intellectual disabilities share public, generic social and health services with others in the Swedish population. In addition, they are eligible for complementary special social services and support typically provided by local governments. These special resources cover group homes and daily activities as well as personal assistance, companion service, contact person and personal counseling that are provided by, e.g., social welfare officers, psychologists, psychotherapists, speech therapists and dieticians.

The shift from total institutions to community life for persons with intellectual disabilities is not unique to Sweden, but common to many Western countries and has been the subject matter of numerous studies. Typically, research has been evaluative, focusing primarily on the outcome of deinstitutionalization (Emerson, 1985; Ericsson, 2002; Mansell & Ericsson, 1996) and different service models in terms of quality of life (Benjamin, Capie, & Nossin, 1998; Matikka, 2001; Perry, & Felce, 2003; Schalock, Bonham, & Marchand, 2000). Some quality of life studies have compared people with intellectual disabilities and the general population (Cummins et al., 1996; Matikka, 2000; Verri et al., 1999). No studies, however, have explicitly followed up a total population of children with intellectual disabilities describing health and living conditions in adult age.

In 1974, 213 children born between 1959 and 1974 in Uppsala County were registered at the former Board for Provision and Services to the Mentally Retarded. Of these, 122 children assessed with severe intellectual disabilities were medically examined in 1975-1976 (referred to hereafter as
medical examination I) and the magnitude and distribution of etiologic and pathogenetic factors were analyzed (Gustavson, et al., 1977). The study makes possible a 25-year follow-up of these children. Such longitudinal research on health conditions of people with intellectual disabilities is rare.

The definition of intellectual disability

Intellectual disability is commonly characterized by sub-average intellectual functioning existing concurrently with limitations in adaptive functioning and manifested during the developmental period before adulthood (APA, 1994; Lucasson et al., 2002; WHO, 1992).

Since the beginning of the 20th century, intellectual functioning has been the primary criterion of intellectual disability. Intellectual functioning is described as general mental capability, including reasoning, planning, problem solving, abstract thinking, comprehending complex ideas, learning quickly and learning from experiences and represented by intelligence quotient (IQ) scores (Gustafsson, 2003). The criteria for diagnosis is an individual score based on standardized intelligence tests of two or more standard deviations below the population mean score, i.e. IQ ≤ 70. The adaptive behavior criterion was added in the 1960s and refers to conceptual, social and practical skills in applicable areas (e.g., communication, self-care, housing and social skills) and is related to the individual’s background, cultural group and age (Gustafsson, 2003; Matikka, 2001).

The administrative definition includes all persons assessed with intellectual disabilities and receiving special services and support. Ever since the middle of the 20th century, special social services and support in Sweden has been regulated in a number of special legislations. The allocation of resources and the judgment of who should be eligible for such services and support are connected with sociopolitical policies and bureaucratic procedures and are thus heavily influenced by the cultural and historical context (Sonnander, Emanuelsson, & Kebbon, 1993). In 1977, at the time of medical examination I, 0.4% of the Swedish population, across all age groups, was provided special services and support, and thus administratively defined with an intellectual disability (SCB, 1981). Of those, an estimated majority (75%) were judged to have moderate or severe intellectual disabilities (Grunewald, 1979, 1997).

Legislation and service

In order to grasp the life circumstances of people with intellectual disabilities it is necessary to locate the discussion historically. The meaning of intellectual disability has differed in different periods and is reflected in the socio-
political value system underpinning legislation and societal service and support (Lewin, 1998; Söder, 1981).

Special service and support for people with intellectual disabilities in Sweden can be traced back to the 1860s when private institutions for care and education were established. In the subsequent period a comprehensive system of public and private total institutions was set up throughout Sweden (Tøssebro, Aalto, & Brusén, 1996).

It was not until 1954 that the first Act comprising all persons with intellectual disabilities was implemented. The Act on education and care of some mentally subnormal (SFS, 1954:483) prescribed that, in addition to institutionally based services, community-based schooling and sheltered workshops should be developed for children and adults with mild intellectual disabilities living in larger towns. The majority of people with intellectual disabilities were, however, still referred to total institutions. A county council authority, “the Board for Provision of Services to the Mentally Retarded”, was introduced to identify and register all persons with intellectual disabilities and obliged the main responsibility for special service and support. Bureaucratic decision-making processes were introduced and professionals selected services considered most suitable to the person in question. The individual and her or his family had no influence on the choice of service and support.

During the 1950s and 1960s, changes within the institutional structure were gradually implemented: living conditions were improved and more attention was paid to the quality of care. The institutions were modernized and made more homelike, with smaller units and one or two residents per bedroom. Education, daily activities and leisure activities were provided not only for persons with mild intellectual disabilities but also for those with more severe intellectual disabilities. An intention was that the institution should represent a miniature of the average municipality (Ericsson, 2002). Yet, it was questioned whether total institutions could promote personal development. In this context it has been suggested that segregation in general and institutions in particular may violate human rights and human values (Söder, 1993). Nevertheless, in the sociopolitical model institutions were still considered an undesired but necessary alternative (Tossebro, Aalto, & Brusén, 1996).

In the late 1960s, sociopolitical ideas emphasizing integration and normalization were introduced as guiding principles for services and support and the first step towards the dissolution of the total institutions was initiated (Sandvin, 1992; Söder, 1981). Normalization was described as “making available to the mentally retarded patterns and conditions of every day life which are as close as possible to the norms and patterns of the mainstream society” (Nirje, 1969, p. 181). The new paradigm was underpinned by a shift from a person-oriented perspective of disability towards a relative model and implemented in the 1967 Act on special services for some mentally retarded
Community-based group homes and daily activities in occupational centers became increasingly available. Adults with severe intellectual disabilities were, however, principally still referred to total institutions. Another feature of the Act was that all school-aged children were entitled to education, which would reject the idea that children with severe intellectual disabilities were “uneducable”. Compulsory schooling and a system of family support made it possible for most children to grow up with their families.

In the 1980s, general legislation marked a shift in public responsibility in that all citizens, including people with intellectual disabilities, got access to generic social and health services regulated in the Social Services Act (SFS, 1980:620) and in the Health and Medical Services Act (SFS, 1982:763). In addition, education for all children was regulated in the general Act on Schooling (SFS, 1985:1100). Contrary to previous legislations, which were based on the need of special arrangements for people with intellectual disabilities, the new policy was to make general service and support arrangements available for all citizens. The view of looking at people with intellectual disabilities changed from a competence perspective emanating from the institutional tradition to a citizen perspective focusing the social role of a citizen (Ericsson, 1996). Additional to generic services and support, people with intellectual disabilities were eligible for complementary special services and support regulated by the 1985 Act on special services for mentally retarded and others (SFS, 1985:568). The purpose of this act was to strengthen the individual’s citizenship by a “special-rights law” (Lewin, 1998). The special services were specified and covered five categories that included housing and daily activities as well as staff support in everyday life and personal counseling provided by, e.g., dieticians, speech therapists, psychologists and social welfare officers. Total institutions were no longer recognized as a special service. Consequently, the dissolution of total institutions was endorsed and the connection between extensive need for service and support and total institutions was discontinued. Another feature of the 1985 Act was that service and support should be provided optionally on the request of the person concerned (personally or through a trustee) and that it was possible to appeal against a decision in the county administrative court.

Current legislation, the 1993 Act on support and services for persons with certain functional impairments (SFS, 1993:387) formally transferred the responsibility for all special services and support to people with intellectual disabilities, except personal counseling, from county council authority to local authority level. Furthermore, the demands for the dissolution of total institutions were intensified. The sociopolitical policy was to ensure people with intellectual disabilities equal living conditions and the same possibilities and opportunities as other citizens (SOU, 1991: 46).
The special services and support for adult people with intellectual disabilities regulated in the Act of 1993 cover similar special services as the Act of 1985; however, the number of categories has been increased to 10 specified services. The Act applies to people with severe disabilities and needing help in fundamental areas of daily life, which includes persons with other disabilities as well. Personal assistance is probably the kind of staff support given most attention. A personal assistant is chosen and controlled by the person with a disability in order to provide a personal form of support (Ericsson, 2002).

Corresponding to the act of 1985, the right to self-determination, influence and privacy is emphasized. One central aim is to empower the individual and strengthen his or her position in relation to professionals assessing the extent of the incapacity and deciding services and support (Sandvin, & Söder, 1996). Furthermore, the Act of 1993 prescribes that “The activities pursuant to this Act shall promote equality in living conditions and full participation in the life of the community” (SFS, 1993:387, section 5).

In the late 1990s, a Swedish Governmental Bill (Regeringens Proposition, 1999/2000:79) stated that disability policy is a question of democracy. The emphasis on a democracy perspective has been underpinned by ethical positions on human rights, shifting the focus from equality and solidarity to freedom and choice (SOU, 1991:19).

Welfare

In the late 1940s, the platform for the welfare state in Sweden was established, although its roots can be traced back to the late 19th century (Hanssen, Sandvin, & Söder, 1996). In addition to economic growth, it is characterized by integration between social policy and labor-market participation and a comprehensive system of social programs (Korpi, 1990). Full employment and the abolition of poverty are central objectives for the social policy developed. At the individual level, employment is considered necessary for people’s experience of health and well-being, as well as in constructing self-identity (Grape, 1998; Jansson, 2003). However, despite the work-oriented approach, an important feature of the welfare state is its decommodifying nature (Esping-Andersen, 1990) with a system of generic social insurance introduced to ensure economic and social security to all citizens including people with severe disabilities (Korpi, 1990). Consequently, disability legitimates distribution of resources without diminishing the ideological primacy of work.

The social programs are largely financed by the public sector through general taxation and have been characterized during the past decade or so by its emphasis on equality and solidarity (Hanssen, Sandvin, & Söder, 1996). For example, in the late 20th century, despite problems in national finances,
the Swedish Parliament gave economic priority to the rights of people with severe disabilities. In 1993 to 1997, the public sector increased the expenses for services and support to people with severe disabilities with about 40% (SOU, 2000:3).

A large body of research exists on people’s welfare representing different disciplines and approaches: economy, labor market, social problems, empowerment, quality of life, living conditions etc. Some studies focus objective conditions, whereas others emphasize individual satisfaction with these conditions. Within the field of intellectual disabilities, the quality of life approach has been employed in a number of studies.

An unpublished overview by the author (using the words mental retardation, intellectual disabilities and learning disability combined with the concepts of quality of life and living conditions) based on about 300 publications between 1977 and 2001 found in databases (Allied and complementary medicine, CINAHL, International Bibliography of the Social Sciences, Institute for Scientific Information, Medline, PsychInfo, and Libris) and reference lists of highly relevant studies indicates that domains and variables included in scales of quality of life are typically included in Nordic studies of living conditions of people with intellectual disabilities as well. The main difference is that the purpose of the former is to grasp both objective and subjective variables (including the individual experience of well-being), whereas the latter focuses on objective variables. The research literature has reported a lack of correlation between objective variables and subjective ones, indicating that an alleged high subjective quality of life does not always imply good living conditions, and vice versa (Cummins et al., 1997; Edgerton, 1990; Matikka, 2001; Taylor, 1994; Tideman, 2000).

In Anglo-Saxon countries quality of life research has been conducted since the early 1980s. A large number of scales have been developed from this research. In Sweden and other Scandinavian countries, only a few quality of life studies on people with intellectual disabilities have been reported (Holm et al., 1996; Matikka, 2001; Sonnander, & Nilsson-Embro, 1984).

Matikka (2000) studied the comparability of the quality of life of people with mild intellectual disabilities with that of the general population. The author points to difficulties in comparing subjective assessments of quality of life of the two groups because of cognitive limitations in people with intellectual disabilities and diversities in preferences and frame of reference that are due to different life circumstances.

Living conditions
In the middle of the 20th century, typically employed monetary measures, such as the gross national product (GNP), were considered insufficient measures of welfare. Thus, economic growth as the sole indicator of welfare was questioned. It was suggested that a set of different components was
needed to give a description of welfare of citizens (Erikson, 1993; Johansson, 1970; Tøssebro, & Kittelsaa, 2004). This position was the general background for a Swedish governmental study of living conditions in 1968 known as the “Level of Living Survey” (Fritzell, & Lundberg, 2000; Johansson, 1970), which has been followed by a number of similar studies. The theoretical underpinning is influenced by the English sociologist Richard Titmuss’ writings on welfare and by reports of the United Nations (Johansson, 1970). Level of living has been defined as

The individual’s command over resources in the form of money, possessions, knowledge, mental and physical energy, social relations, security and so on, through which the individual can control and consciously direct his living conditions. (Erikson, 1993, p. 72)

The definition implies a view of the individual as a conscious actor striving for aspirations according to her or his own beliefs and preferences (Fritzell, & Lundberg, 2000). Level of living is operationalized as a person’s actual living conditions in a variety of social domains regarded relevant for social and economic policy. The list of domains is based on pragmatic considerations but also linked to theoretical ideas and has a close resemblance to Sen’s writings (1992) on welfare, well-being and the concept of capabilities. The list is a mix of actual living conditions (e.g., housing, work) and resources by which conditions desired can be achieved (Fritzell, & Lundberg, 2000). The good life and people’s needs are not defined but left to each individual to decide. Accordingly, the Swedish surveys of living conditions focus on objective living conditions and resources rather than on people’s needs and subjective assessments of these conditions. It is argued that there is no common yardstick through which all components could be merged into one single level of living index and, consequently, each domain is described separately (Erikson, 1993).

Since 1974, Statistics Sweden (SCB) has conducted annual “Surveys of living conditions of the general population, SLC” (SCB, 1999a) by interviewing a random sample of about 7 500 persons aged 16–84 years. The objectives are (1) to describe the adult population’s living conditions over time, (2) to uncover social problems and (3) to compare various socio-demographic groups (family, gender, age, socio-economic groups and living area) (Erikson, 1993; SCB, 1999a, 2004).

The SLC measure has been developed stepwise. The first survey included five social domains: health, education, housing, employment and working environment and finances. Questions tapping leisure and culture were added in 1976 while transportations, safety and political resources were included in 1978. A set of questions is asked every year, whereas other questions recur perennially.
Domains included in surveys of living conditions are considered essential for most adults in a period and cultural context (Fritzell, & Lundberg, 2000) and are also considered valid for people with intellectual disabilities. Accordingly, the living conditions approach will allow for comparisons between people with and without intellectual disabilities. However, Tøssebro (1998) argues that there are a number of problems in using a traditional living conditions approach in studies of people with intellectual disabilities and suggests that the following adaptations are necessary:

- Adaptations because of “the theoretical underpinning of living conditions surveys” (p.28). In questionnaires of living conditions of the general population resources (e.g., education, occupation and income) people use when realizing their personal preferences are considered the most important underpinning, whereas the focus in questionnaires regarding people with intellectual disabilities needs to be on the elimination of socially unacceptable living conditions, i.e. on results (e.g., housing).
- Adaptations because of “aspects of everyday life which we take for granted but which cannot be taken for granted in this population” (p.28). Autonomy and empowerment are issues of significance in most domains of the everyday life of people with intellectual disabilities but are only regarded as potential problems with regard to work and politics for the general population.
- Adaptations because of “the atypical life circumstances of many people with intellectual disabilities” (p.28). To reflect the life circumstances of people with intellectual disabilities many items have to be rephrased or given new response alternatives. For example, to capture work conditions items regarding employment have to include different types of occupation such as sheltered employment and daily activities.

In the past decades an increasing number of studies of health and living conditions of people with disabilities have been carried out in a number of countries, including the UK, the USA, New Zealand, Norway and Denmark (Tøssebro, & Kittelsaa, 2004). In Sweden, people with disabilities are included in the SLC surveys just like anyone else, i.e. they are selected on a random basis. They may be distinguished by items regarding health and impairment and have been separately accounted for in a few reports (e.g., SCB, 1992; SOU, 2001:56); however, living conditions of people with intellectual disabilities have not been presented separately. The disabled population is a heterogeneous group and it is therefore important to study conditions of groups with different types of impairment separately (Baldwin, 1999; Schmidt, Hayward, & Kay, 1999).

In addition to general surveys of living conditions, numerous countries have conducted special surveys of people with disabilities (Tøssebro, & Kittelsaa, 2004). Of those, the majority are designed to measure living condi-
tions of people with disabilities in a “different-life-circumstances” way (p. 34) instead of an environmental understanding of disability and environmental barriers.

The outcome of social reforms has been evaluated according to a living conditions perspective (Tideman, & Tøssebro, 2002; Tøssebro, 1996). The Swedish “KOM-UT” project employed a modified version of the SLC questionnaire to evaluate the transferral of responsibility of services and support to people with intellectual disabilities from county to local community authorities (Kebbon et al., 1992; Kebbon et al., 1998; Tideman, 2000). Tideman (2000) compared health and living conditions of adults with intellectual disabilities residing in the county of Halland in 1991 (pre-reform) and 1995 (post-reform) to that of the general population. Analyses were also made across gender. Data of people with intellectual disabilities were obtained by self-reports (independently or assisted by a relative or a staff) and by proxy responders, treating these sources as interchangeable. Apart from the Tideman study, there are no Swedish studies comparing the living conditions of people with intellectual disabilities with those of the general population. Thus, there is a need of surveys to describe the living conditions of people with intellectual disabilities as compared with those of the general population.

No follow-up studies are found of children assessed with intellectual disabilities in early childhood right up to early maturity regarding mortality, health and additional disabilities.

Proxy responding

Several studies have shown that there are problems inherent in obtaining information using self-reports from people with intellectual disabilities because of cognitive difficulties, limited communicative abilities and response bias (Heal, & Sigelman, 1995; Matikka, & Vesala, 1997; Perry, & Felce, 2002). Response bias (e.g., acquiescence, nay saying, idealization and socially desirable responding) is reported to occur more frequently among people with intellectual disabilities than among people without intellectual disabilities. Even though measures are modified and sign language, symbols and communication technology are used to facilitate communication, experience has shown that many persons are not able to provide information themselves (Perry, & Felce, 2002; Tøssebro, 1990).

In studies involving people with intellectual disabilities relatives and staff members (proxies) are typical sources of information (Cummins, 2002; Furenhed, 1998; Rapley, Ridgway, & Beyer, 1997; Schalock, Bonham, & Marchand, 2000; Schalock, & Jensen, 1986; Tideman, 2000; Tøssebro, 1996). There is reason to believe that all people communicate basic emotions (i.e. joy, loathe, interest, surprise) rather alike. People who cannot communi-
cate with spoken language usually develop their own expressions to communicate in addition to sign language, symbols and communication technology. This form of communication can provide relatives and staff with a good enough base for interpretation of how the individual experiences her or his living conditions (Goode, 1994; Favell, Realon, & Sutton, 1996; Furenhed, 1998; Tøssebro, 1990). Despite this, it has been shown that proxies do not always provide the same answers as would the person with intellectual disabilities (Cummins, 2002; Stancliffe, 1995, 1999). However, the validity of proxy responses seems to be acceptable if data are predominantly objective and represented by observable circumstances and behavior (Cummins, 2002; Perry, & Felce, 2002; Rapley, Ridgway, & Beyer, 1997; Schwartz, & Rabinovitz, 2003; Stancliffe, 1999; Tøssebro, 1990, 1996). For some persons, proxy information can even be more reliable than self-reports concerning actual living conditions in that proxies control the everyday life conditions and survey the comprehensive situation (Tøssebro, 1990). In contrast, proxy responding is questioned on subjective issues, such as level of satisfaction and well-being (Cummins, 2002; Perry, & Felce, 2002; Rapley, Ridgway, & Beyer, 1997; Stancliffe, 1995, 1999; Schwartz, & Rabinovitz, 2003).

There are few studies comparing reports provided by different proxies. The literature presents conflicting results and demonstrates significant correlations (Stancliffe, 1999) as well as lack of concordance (Gaudet et al., 2002). Little attention has been paid to whether proxy responding is influenced by proxy characteristics (e.g., gender, age and level of education), the nature of the relationship with the person with intellectual disabilities (e.g., family ties or the relationship between the caregiver and care receiver) and proxy frame of reference (e.g., people in general or persons with intellectual disabilities). Responders are treated as a homogenous group and a little guidance is available in the choice of proxies as data sources.

Health

Over the last 30 years there has been a considerable increase in the life expectancy of people with intellectual disabilities and research indicate that younger adults (Fisher, 2004) and people with mild intellectual disabilities (Patja et al., 2000) are expected to live as long as their peers without intellectual disabilities. However, people with severe impairments still have lower life expectancy than the general population, particularly in the earlier years. For example, in a follow-up of people after 35 years Patja and colleagues (2000) observed a proportion of expected life lost of > 20% among people with profound intellectual disabilities, serious neurological deficits and severe additional disorders. It may be noted that the survival rate for women and men differed less than in the general population across all levels of impairment.
The transition of people with intellectual disabilities from institutional to community life included a shift of medical responsibility towards primary health care services (district nurses and general practitioners). People with intellectual disabilities are a group identified as particularly vulnerable to health disparities and it is commonly acknowledged that they often have special health problems additional to their general health problems (Barr et al., 1999; Kerr et al., 2003; Lennox, & Kerr, 1997; van Schrojenstein Lantman-De Valk et al., 2000).

Down syndrome is the most common known causative factor to intellectual disabilities (Bower, Leonard, & Petterson, 2000; Leonard, & Wen, 2002; Stromme, & Hagberg, 2000). In comparison with people with other causative factors, research indicates a higher prevalence of overweight in people with Down syndrome (Hove, 2004; Rubin et al., 1998) as well as hypothyroidism, nonischemic heart disorders, visual impairment and dental problems (Barr et al., 1999; Kapell et al., 1998).

Researchers have expressed concern that medical conditions in people with intellectual disabilities are often undetected and insufficiently treated, indicating shortcomings in the quality of health care (Barr et al., 1999; Cumela, & Martin, 2004; Fisher, 2004; Kerr et al., 2003; Ryan, & Sunada, 1997; Smiley et al., 2002). Infrequent contact with people with intellectual disabilities makes it difficult for general practitioners and practice nurses to develop clinical experience, which implicates a lack of knowledge of characteristic morbidity patterns and diagnosing symptoms in people with intellectual disabilities (Fisher, 2004; Lennox, Diggens, & Ugoni, 1997; Phillips, Morrison, & Davis, 2004; van Schrojenstein Lantman-De Valk et al., 2000). In addition, a number of obstacles in providing adequate health care are suggested in the literature: consultation time restrictions, inadequate anamnesis, communicative difficulties, unacquaintance with physical examination and screening procedures and mobility problems (Barr et al., 1999; Lennox, & Kerr, 1997; Lennox, Diggens, & Ugoni, 1997; Melville et al., 2005; Ryan, & Sunada, 1997; van Schrojenstein Lantman-De Valk et al., 2000). Other hinders to adequate health care commonly mentioned are the nonfeasibility of screening and diagnostic instruments (Barr et al., 1999; Gustafsson, 2003; Ryan, & Sunada, 1997; van Schrojenstein Lantman-De Valk et al., 2000). It is important that people with intellectual disabilities receive assessment and adequate treatment in accordance with their varied health problems and needs.

Gender

It is suggested that a gender perspective is essential in understanding the meaning of social relations and processes (Alvesson, & Due Billing, 1999). However, research has traditionally neglected to explore the influence of gender in the lives of women and men with intellectual disabilities (Barron,
Michailakis, & Söder, 2000; Scior, 2000; SOU, 1998:138; Thompson, Caruso, & Ellerbeck, 2003). The feminist movement has been criticized for not considering the issues facing women with disabilities in general and women with intellectual disabilities in particular (Traustadottir, 1990). Nor has research on men taken into account men with disabilities (e.g., Connell, 2005).

Not until the late 20th century have studies in the disability field addressed the role of gender (Barron, 1997; Helmius, 1993; Hendey, & Pascall, 1998; Riddell, Baron, & Wilson, 2001; Thompson, Caruso, & Ellerbeck, 2003; Traustadottir, 1990). These studies cover various areas, including abuse and violence (Lewin, 2002), cognitive differences (Kittler, Krinsky-McHale, & Devenny, 2004), employment (Julius, Wolfson, & Yalon-Chamovitz, 2003; Levy et al., 1994; Olson et al., 2000), health (Davies, & Duff, 2001; Lunsky, 2003; Rubin, et al., 1998; Thompson, Caruso, & Ellerbeck, 2003), identity, social positions and roles (Barron, 2002) and living conditions (Tideman, 2000).

Aside from a survey by Tideman (2000), there are no Swedish studies comparing living conditions of women with intellectual disabilities with that of men with intellectual disabilities. Internationally, the picture is very much the same and comparative studies of living conditions from a gender perspective are rare.

People with intellectual disabilities are typically treated as a homogenous group that is largely categorized by the level of disability. Women in the general population have been found to have worse welfare than men (Palme et al., 2002). Further, women with disabilities are one of the most vulnerable and marginalized groups in society, being at a further disadvantage because of the combined discrimination based on disability and gender (Traustadottir, 1990). Yet, the focus in research has generally been on the impairment and little attention has been paid to the role of sex and gender differences (SOU, 1998:138; Thompson, Caruso, & Ellerbeck, 2003). Because biological conditions and role expectations differ between women and men, it is necessary to study the living conditions of women and men with intellectual disabilities separately.
Aims of the thesis

The principal aim of the present thesis was to describe mortality, health and living conditions of people with intellectual disabilities in a Swedish county. A further aim was to compare staff and relatives’ responding to the living conditions of people with intellectual disabilities.

Specific aims were

- to compare living conditions of adult persons with intellectual disabilities in a Swedish county with living conditions of the general Swedish population in corresponding age groups (Paper I)
- to compare relative and staff reports on a questionnaire of living conditions of adult persons with intellectual disabilities (Paper II)
- to examine whether proxy characteristics (gender, age and level of education) influenced proxy responding on living conditions (Paper II)
- to follow-up people with severe intellectual disabilities medically examined in 1975-1976 regarding mortality and additional disabilities (Paper III)
- to describe mortality, etiology, physical and mental health, additional impairments and medical health care for a selected population of adults with intellectual disabilities (Paper III)
- to compare people with Down syndrome and people with other causal factors to intellectual disability regarding physical and mental health (Paper III)
- to compare living conditions of women and men with intellectual disabilities in a selected population and to relate the results to similarities and differences between women and men in the general population of corresponding age groups (Paper IV)
Method

Research participants

The study population included all persons (N=213) with intellectual disabilities born between 1959 and 1974 in Uppsala County and registered at the Board for Provision and Service to the Mentally Retarded in 1974. Uppsala County, with 228,680 inhabitants in 1974, includes urban as well as rural areas.

At the time of the study, a number of persons were deceased or had moved abroad (Figure 1). All persons residing in Sweden (n=154) were invited by letter (including an easy-to-read version). Of these, 112 persons (73% of 154) gave their informed consent (personally or through a trustee) to participate in the study. Participants and nonparticipants with intellectual disabilities are presented in Figure 1.

![Figure 1. Participants and nonparticipants with intellectual disabilities in Papers I, II, III and IV. The number of individuals is given in brackets.](image-url)
Living conditions (*Papers I and IV*)

Of those persons with intellectual disabilities that accepted to participate in the studies (n=112), two persons were excluded because of missing information (no questionnaire was returned). Thus, the sample in these studies comprised 110 persons (43 women and 67 men).

Information about the general Swedish population was obtained from the SLC 1999 survey conducted by SCB (unpublished data made to order). The SLC 1999 survey gathered information on living conditions of residents in Sweden from a random sample of about 7 500 adults. Data from a subsample of persons born between 1959 and 1974 (n=1 600) were employed as a reference group.

Relative and staff reports (*Paper II*)

Of those proxies invited to provide information about living conditions (*Papers I and IV*), 96 relative-staff pairs were identified and constituted the sample in the study. Ninety-six percent (91 relatives and 94 staff) completed a questionnaire about living conditions, of which 89 relative-staff pairs were found. The analyses were based on these 89 pairs of relative-staff reports.

Mortality and health conditions (*Paper III*)

Twenty-nine of the 112 persons with intellectual disabilities that gave their informed consent to participate had moved to other counties and, of these, 24 persons were excluded from the study for practical and economic reasons. The remaining 88 persons were invited by telephone to medical examination II. Of these 88 persons, 82 participated in the study.

Measures

A questionnaire was compiled to obtain information from proxies on the living conditions of adults with intellectual disabilities. The questionnaire was based on the SLC questionnaire 99 (SCB, 1999a) and questionnaires employed in earlier studies about living conditions of people with intellectual disabilities in Sweden (Kebbon et al., 1992) and Norway (Tøssebro, 1990).

A pilot study was conducted to test the face validity of the questionnaire. Fourteen persons participated, including persons with intellectual disabilities, staff in housing and daily activities, professionals in habilitation services, trustees and relatives. Following the outcome of the pilot study, minor adjustments were made to the response alternatives in the questionnaire.
The final version of the questionnaire consisted of 233 items of which 93 items (40%) corresponded to the items included in the SLC questionnaire (SCB, 1999a). Papers I and IV were based on these 93 items. Paper II was based on all 233 items. Finally, in Paper III 58 items were used to tap information on socio-demographic characteristics.

The 233 items were grouped into the following 10 domains:

- **Education**: 14 items regarding type of education
- **Housing**: 53 items regarding type of housing, privacy markers, participation in everyday matters, neighbors and guests (of which 13 items corresponded to the SLC questionnaire)
- **Employment and daily activities**: 12 items regarding type of occupation and working conditions (of which 8 items corresponded to the SLC questionnaire)
- **Finance**: 18 items regarding income and financial situation (of which 5 items corresponded to the SLC questionnaire)
- **Transportation**: 7 items regarding public transportation and mobility service (of which 5 items corresponded to the SLC questionnaire)
- **Recreation and culture**: 39 items regarding holiday trips and recreational activities (of which 27 items corresponded to the SLC questionnaire)
- **Family and social relations**: 66 items regarding family circumstances, contact with family and friends and professional support (of which 30 items corresponded to the SLC questionnaire)
- **Personal safety**: 8 items regarding bullying, violence, threats and fear (of which 2 items corresponded to the SLC questionnaire)
- **Community participation**: 6 items regarding association activities, voting and being informed of news (of which 3 items corresponded to the SLC questionnaire)
- **General items**: 10 items regarding influence, well-being and happiness.

The response alternatives were in fixed format on a yes/no (25%), 3- (18%), 4- (20%), 5- (19%), 6- (13%), or 10- (5%) point scale.

Most items were objective (69%). Subjective items were included in 8 of the 10 questionnaire domains: housing (21 items), employment and daily activities (7 items), finance (4 item), transportation (3 items), recreation and culture (4 items), family and social relations (20 items), personal safety (6 items) and general items (8 items).

In addition, eight items were used to estimate limitations in functioning: understanding language (verbal, sign or alternative communication), use of language, managing to read and write, telling time, need of assistance at meals, need of assistance with personal care, need of assistance when dressing and need of assistance outside the home. A ninth item asked the proxy to summarize the level of disabilities on a five-point scale from no disabilities to very severe disabilities.
Finally, the questionnaire included information on proxy characteristics (age, gender and level of education) and type, length and frequency of personal contact with the person with an intellectual disability.

Medical examination II was performed (Paper III) to provide information on health. A checklist was used that included the following items: health condition, functions of the neuromuscular system, associated CNS disabilities in the form of epilepsy, cerebral palsy and other motor disorders, impairment of vision and hearing, heart failure, level of intellectual disability (severe, mild) and pharmacological treatment.

Procedures

Living conditions (Papers I, II and IV)

Professionals at the Uppsala County Habilitation Services were asked to rate if persons with intellectual disabilities (n=81) could respond in a satisfactory manner to a questionnaire on living conditions. Of these 81 persons with intellectual disabilities, 71 were considered unable to respond autonomously. Consequently, it was not possible to obtain information based only on the self-reports of individuals with intellectual disabilities. Systematic differences between proxy responding and self-reports are reported, indicating that they are not interchangeable (Perry, & Felce, 2002; Stancliffe, 1999). Thus, the choice of procedure was to ask proxies to provide all information sought.

An immediate family member was asked to recommend one relative and one staff member to provide information for each of the 112 persons who accepted to take part in the studies. The criteria for their choice were that proxies should have extensive direct contact with the person with an intellectual disability and should be well acquainted with her or his living conditions. For 21 persons, no relative was known and for 11 of them a trustee was considered equal to a relative. Six persons had no regular contact with staff. Thus, in 2001 to 2002, a questionnaire was mailed to 208 proxies (102 relatives and 106 staff members) with instructions to fill it in and return it in a self-addressed and prepaid envelope.

For each person with an intellectual disability, a data record based on one report for each item was prepared (Papers I and IV). For those persons for whom two completed questionnaires were returned (one from a relative and one from a staff member), the following procedure was used to choose responses for the data record: (1) Assessment of limitations in functioning and level of disabilities were based on staff reports; (2) relative reports were chosen for questions on education and finances; (3) for persons living independently or in a group home, reports on all other questionnaire domains were based on staff responses; and (4) for persons living with parents, re-
ports by staff in daily activities were chosen for questions on daily activities, whereas parental reports were used as data for the remaining domains.

For the comparison of relative reports and staff reports (Paper II), a data record based on two reports (one from a relative and one from a staff member) for each item was prepared.

Information on living conditions of the general population was obtained from the SLC 1999 survey conducted by SCB (unpublished data made to order). The sample from the SLC survey was age-matched (i.e., all persons were born between 1959 and 1974) with the sample of people with intellectual disabilities. Data collection by SCB continued throughout the year 1999 (personal interviews in combination with telephone interviews) and results were expressed as an average for the year of the sample of the general population.

Mortality and health conditions (Paper III)

Using a checklist, pediatricians conducted medical examination II in 1999 to 2000 (n=12) and in 2002 to 2003 (n=70) at the Uppsala County Habilitation Services. A relative or a staff accompanied the person with an intellectual disability. School records and medical case records were examined. In the event of unknown cause of the intellectual disability and suspicion of a new etiology specific cytogenetic and molecular diagnostic studies were done.

Information on socio-demographic characteristics and service utilization was obtained by a mailed questionnaire to relatives and staff (described above) and by case files at the Uppsala County Habilitation Services.

Statistical analyses

All data were analyzed using the Statistical Package for the Social Sciences (version 11.5 for Windows, SPSS, Inc. Chicago, IL, USA). Non-parametric tests (McNemar Test and Pearson’s chi-square test with Yates correction or Fisher’s exact test when the smallest expected frequency was less than 5) were used for the analyses, with the significance level set at p < 0.05 (Papers I, III and IV). All comparisons were two-tailed. In Paper IV, an unpaired t test was used for the comparison of participants and nonparticipants with intellectual disabilities across age.

Living conditions of people with intellectual disabilities and the general population were compared separately for each item (Papers I and IV). Analyses in the sample of persons with intellectual disabilities were conducted across age, gender and level of disabilities: no, minor and moderate disabilities (referred to as minor disabilities) and severe and very severe disabilities (referred to as severe disabilities).
Items were categorized in *Paper II* according to the type of information asked for. Sixty-nine percent of the items described objective circumstances (e.g., type of housing, occupation, income and leisure time activities). The remaining 31% of the items were categorized as subjective, as they asked for proxy opinion or asked the proxy to estimate the opinion of the person with an intellectual disability. Responses to objective and subjective items were analyzed separately. In order to correct for differences in response alternatives, relatives and staff respondents were treated as agreeing on items with a 10-point response scale if the observed difference was only one step.

Percent agreement and Cohen’s kappa statistics (Cohen, 1960) were used for the comparison of the reports of relatives and staff (*Paper II*). The labeling of agreement of Cohen’s kappa was set at < 0.20 (poor agreement), 0.21-0.40 (fair agreement), 0.41-0.60 (moderate agreement), 0.61-0.80 (good agreement) and 0.81-1.00 (very good agreement) (Taube, 1995). Comparisons were made across characteristics of proxies (gender, age and level of education), characteristics of the persons with intellectual disabilities (age, level of disabilities and level of communicative ability) and the frequency of personal contact and type of relation (relative ties or caregiver-care receiver) with the person with an intellectual disability.

In *Paper III*, analyzes were calculated across etiology, additional impairments, diagnose (Down syndrome and other diagnoses) and level of intellectual disability (mild: IQ 50-69 and severe: IQ < 50).

**Ethical considerations**

Each person with an intellectual disability and each proxy were informed about the aim of the studies, confidentiality, voluntary nature of the study and the possibility to withdraw at any time. Each person with an intellectual disability was invited to participate in the studies by letter (including an easy-to-read version). Informed consent (personally or through a trustee) was obtained in writing though telephone replies were accepted occasionally.

Service providers in Uppsala County and the Association for people with intellectual disabilities (FUB) were informed of the study in meetings and in writing. People with intellectual disabilities, family members and trustees were informed by a letter (including an easy-to-read version). The proxies who were asked to complete the questionnaire on living conditions were informed by both letter and telephone.

The study was approved by the Ethical Committee at the Faculty of Medicine at Uppsala University.
Results and Discussion

Characteristics of the sample of persons with intellectual disabilities

All participants with intellectual disabilities were born between 1959 and 1974 in Uppsala County. These participants were identified by a register and included all persons receiving special services (i.e. an administrative definition of intellectual disability was adopted). Proxies estimated 60 persons (20 women and 40 men) as having minor disabilities and 50 persons (23 women and 27 men) as having severe disabilities (Papers I and IV). Twenty-four persons (7 women and 17 men) were assessed with a mild or moderate intellectual disability and 58 persons (24 women and 34 men) with a severe intellectual disability (Paper III).

A majority of the participants were single and had no children. They lived in ordinary residential areas in the community, where 81 persons resided in Uppsala County while 29 had moved to another Swedish county. All persons except one were provided community-based service and support. Socio-demographic characteristics of participants with intellectual disabilities (Papers I, III and IV) are presented in Table 1. The Chi-square test and Fisher’s exact test revealed no association between socio-demographic characteristics and gender and level of disabilities.
Table 1. Characteristics of the persons with intellectual disabilities (Papers I, III and IV)

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Papers I and IV n=110 (%)</th>
<th>Paper III n=82 (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Women</td>
<td>43 (39.1)</td>
<td>31 (37.8)</td>
</tr>
<tr>
<td>Men</td>
<td>67 (60.9)</td>
<td>51 (62.2)</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>34.8 (4.3)</td>
<td>35.3 (4.3)</td>
</tr>
<tr>
<td>Range</td>
<td>27-42</td>
<td>27-42</td>
</tr>
<tr>
<td><strong>Housing</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Independent living</td>
<td>17 (15.5)</td>
<td>10 (12.2)</td>
</tr>
<tr>
<td>Parent’s home</td>
<td>21 (19.1)</td>
<td>12 (14.6)</td>
</tr>
<tr>
<td>Group home</td>
<td>72 (65.5)</td>
<td>60 (73.2)</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Basic education for pupils with intellectual disabilities aged 7-16 years</td>
<td>46 (41.8)</td>
<td>34 (41.5)</td>
</tr>
<tr>
<td>Basic education and special upper secondary education for pupils with intellectual disabilities</td>
<td>51 (46.4)</td>
<td>38 (46.3)</td>
</tr>
<tr>
<td>No education</td>
<td>5 (4.5)</td>
<td>3 (3.7)</td>
</tr>
<tr>
<td>No information</td>
<td>8 (7.3)</td>
<td>7 (8.5)</td>
</tr>
<tr>
<td><strong>Occupation</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Labor market</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Sheltered employment</td>
<td>2 (1.8)</td>
<td>2 (2.4)</td>
</tr>
<tr>
<td>Daily activities</td>
<td>103 (93.6)</td>
<td>77 (93.9)</td>
</tr>
<tr>
<td>No occupation</td>
<td>5 (4.5)</td>
<td>2 (2.4)</td>
</tr>
<tr>
<td>No information</td>
<td>0</td>
<td>1 (1.2)</td>
</tr>
<tr>
<td><strong>Formal support</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Housing</td>
<td>98 (89.1)</td>
<td>73 (89.0)</td>
</tr>
<tr>
<td>Work, daily activities</td>
<td>104 (94.5)</td>
<td>78 (95.1)</td>
</tr>
<tr>
<td>Contact person, companion service</td>
<td>73 (66.4)</td>
<td>56 (68.3)</td>
</tr>
<tr>
<td>(in leisure time)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Trustee</td>
<td>95 (86.4)</td>
<td>69 (84.1)</td>
</tr>
<tr>
<td>Personal counselling</td>
<td>59 (53.6)</td>
<td>56 (68.3)</td>
</tr>
</tbody>
</table>

*Thirteen had adult education. *Eleven had adult education. *Ten had adult education. *Seven had adult education. *Production, such as industrial tasks, handicraft, work at a café, farming, forestry and gardening, and sensory experiences. *Provided by the Uppsala County Habilitation Services (e.g., nurse, speech therapist, physiotherapist, psychologist, social welfare officer and recreational staff).

Characteristics of the general population sample

The sample of the general population (n=1 600) included 51% women and 49% men. Three percent of the participants lived with their parents, 70% cohabited with a partner and 20% lived alone. Fifty-six percent co-habited with children and 6.3% had children they did not live together with. No information was available for the age group in 1999 regarding personal income, education and level of unemployment. However, in 2001, 9% of the
women and 12% of the men had a compulsory education, 52% of the women and 54% of the men had upper secondary education, and 36% of the women and 30% of the men had a higher education (SCB, 2001). Further, in 1999, 5.7% of the women and 5.6% of the men born between 1960 and 1974 were unemployed (SCB, 1999b).

Characteristics of proxy responders

The majority of proxy responders in Paper II were women (Table 2). Relatives were found to be significantly older than staff. Most of the relatives were parents (79%) and most staff responders provided support in housing (80%).

<table>
<thead>
<tr>
<th></th>
<th>Relatives n= 89 (%)</th>
<th>Staff n= 89 (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Women</td>
<td>70 (78.7)</td>
<td>74 (83.1)</td>
</tr>
<tr>
<td>Men</td>
<td>19 (21.3)</td>
<td>15 (16.9)</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>57.1 (10.2)</td>
<td>41.9 (11.0)</td>
</tr>
<tr>
<td>Range</td>
<td>31-77</td>
<td>21-64</td>
</tr>
<tr>
<td>No information</td>
<td>2 (2.2)</td>
<td>4 (4.5)</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Compulsory education (&lt; 10 years)</td>
<td>29 (32.6)</td>
<td>15 (16.9)</td>
</tr>
<tr>
<td>Upper secondary education (10-12 years)</td>
<td>30 (33.7)</td>
<td>53 (59.6)</td>
</tr>
<tr>
<td>Higher education (&gt; 12 years)</td>
<td>30 (33.7)</td>
<td>19 (21.3)</td>
</tr>
<tr>
<td>No information</td>
<td>0</td>
<td>2 (2.2)</td>
</tr>
</tbody>
</table>

A comparison of the living conditions of adults with intellectual disabilities in a Swedish County and in the general population (Paper I)

People with intellectual disabilities lived and spent their time in the community like other citizens. Yet the analysis demonstrated differences in living conditions between the two samples, particularly regarding employment and social life. Whereas most people in the general population had paid employment, the majority of people with intellectual disabilities were provided supported daily activities and their main income source was a disability benefit from the social insurance system. This finding is consistent with the
results of other studies (Eurofound, 2003; Tideman, 2000) and indicates that disabilities decrease employment opportunities.

Although living in the community and taking part in a number of common recreational and cultural activities, people with intellectual disabilities typically lived in a more restricted social environment and had a social life that was more limited than the general population. Living with a partner and having children were common features in the general population but not in people with intellectual disabilities. On the other hand, to live with parents was more common in people with intellectual disabilities than in the general population.

Typically, the social network of people with intellectual disabilities was built on family ties (parents and siblings) and caregiver-care receiver relationships. This result is in agreement with other Nordic studies and suggests that the social network of people with intellectual disabilities only to a limited extent consists of chosen friends (Gustavsson, 1996; Tideman, & Tøssebro, 1996; Tøssebro, 1996). Proxies estimated that about one in five of the persons with intellectual disabilities preferred a more lively social life, which can be compared with about 1 in 10 in the general population.

On the remaining domains, differences between the two groups were observed on a number of items. For example, the homes of people with intellectual disabilities had a less private character than the homes of the general population, in leisure people with intellectual disabilities less frequently practiced activities that required active involvement and considerably fewer persons with intellectual disabilities voted in the 1998 election to the Swedish Parliament. The present results, which are in accordance with those of earlier studies, suggest dissimilarities in living conditions between people with intellectual disabilities and the general population (Matikka, 2000; Tideman, 2000). However, despite having a lower gross income, proxies estimated a majority of people with intellectual disabilities to have an average or above average financial situation. It may be noted that the living conditions of people with intellectual disabilities revealed only a few differences that could be associated with level of disability.

In conclusion, the results indicate that while living in the community, people with intellectual disabilities still tended to live in a highly restricted social environment. It is suggested that the way in which help and support is provided by professionals using the special and generic help system may actually prevent or restrain individuals with an intellectual disability from influencing their own life course and contribute to social marginalization.
A comparison of reports by relatives and staff on living conditions of adults with intellectual disabilities

(Paper II)

Relative and staff responders differed regarding age and level of education (Table 2). Yet, the analyses revealed no association between proxy responding and proxy characteristics. Item comparison revealed no systematic response pattern between the ratings of relatives and staff when their reports differed. Furthermore, proxy reports were not related to the communicative ability of the person with an intellectual disability.

Analyses of nonresponses and “don’t know” responses indicated that relatives and staff responders were familiar with different aspects of the living conditions of the person they rated. For example, more staff gave nonresponses or made a “don’t know” response on objective items regarding education and finances. The reports of relatives demonstrated more nonresponses and “don’t know” responses on items regarding employment and daily activities. This may reflect that staff providing support in adult age have limited knowledge about the background of the person with an intellectual disability and thus lack information about previous education. Response patterns on items regarding finance may be related to relatives carrying the main responsibility of the finances, whereas staff are only familiar with economic every day matters. Correspondingly, relatives may be less involved in and thus less knowledgeable about work conditions.

Case-by-case comparisons between reports of relatives and staff indicated differences for most of the domains investigated, with moderate kappa values for objective items and fair kappa values for subjective items. The mean percentage agreement across all 233 items was 71% though the level of agreement varied across item domain and item category. High agreement (> 78%) on objective as well as on subjective items was evident in three domains (housing, transportation and personal safety) though values of kappa < 0.40 were observed on subjective items regarding housing and personal safety. Analyses indicate that this paradox resulted from a limited variability of responses (cf. Feinstein, & Cicchetti, 1990).

Low percentage agreement (< 66%) and fair values of kappa (< 0.40) were found on both objective and subjective items regarding recreation and culture and family and social relations. A possible explanation is that the person with an intellectual disability may consider some issues private and consequently choose not to share them with all proxies. Individual proxies may also differ in how interested they are in the private life of the person with an intellectual disability. Furthermore, relatives and staff may have used different reference groups (people without disabilities and people with intellectual disabilities, respectively) in making their ratings (c.f. Stancliffe, 1995).
In general, the agreement was higher on objective items than on subjective items. In addition, the “don’t know” response alternative was more frequently chosen on subjective items by both relatives and staff. These findings are consistent with other studies and question the reliability of proxy judgments about subjective preferences and experiences (Cummins, 2002; Perry, & Felce, 2002; Rapley, Ridgway, & Beyer, 1997; Schwartz, & Rabinovitz, 2003; Stancliffe, 1995, 1999).

In conclusion, relative and staff proxies seem to contribute dissimilar information that is related to varying viewpoints and different types of information. Thus, it is suggested that information provided by these proxies should not be treated as being interchangeable but complementary.

A follow-up study of mortality, health conditions and associated disabilities of people with intellectual disabilities in a Swedish county. (Paper III)

In accordance with previous research (Forsgren et al., 1996), the results indicate an increased mortality in the people with intellectual disabilities (27%) compared with the general population (2%). The increase was especially pronounced in younger persons with severe intellectual disabilities (c.f. Patja et al., 2000). Most persons died before the age of 21 years (mean 13.5 years, SD 10.7).

Of the 47 persons medically examined twice, tendencies were noted of an increased rate of additional impairments in adulthood as compared with the rate in childhood. However, the differences were not statistically significant with the exception of epilepsy together with cerebral palsy (21% vs. 8%).

Medical examination II identified a wide range of additional impairments of varying degrees of severity (epilepsy, cerebral palsy, vision impairment and hearing impairment), other health problems (skeletal and/or muscular abnormalities, overweight, underweight and thyroid disorder) and mental health problems (behavioral, conduct, affective, obsessive or organic disorder, autism and autistic features).

Twenty-nine persons (35% of 82) were diagnosed with Down syndrome, which was the most common causative factor to intellectual disability. Epilepsy and cerebral palsy were less frequently observed in people with Down syndrome than in people with other causative factors, whereas the reverse pattern was found regarding hearing impairment and overweight. No association was found between causative factors and mental health problems.

A majority of the participants had access to a family doctor and attended regular health checks. Yet, at medical examination II a number of needs of specialist examinations were identified, a finding that is in accord with previous research (Barr et al., 1999; Jansen et al., 2004; Kerr et al., 2003;
Smiley et al., 2002), and indicates the potential risk that physical and mental problems may go unidentified and inaccurately treated. In conclusion, the present findings illustrate the need for specific education and training of medical students, practice nurses and doctors in the field.

Living conditions of adults with intellectual disabilities from a gender perspective (Paper IV)

Surprisingly, fewer differences were found between women and men with intellectual disabilities when compared with the differences found in women and men of the general population.

Persons with intellectual disabilities were not part of the labor force, but were provided supported daily activities. Despite this, a similar gender pattern of occupation was identified in both samples, with women working in traditional female sectors (e.g., restaurants and cafes) and men working in traditional male jobs (e.g., industrial production). This observation supports earlier findings (Julius, Wolfson, & Yalon-Chamovitz, 2003; Levy et al., 1994; Olson et al., 2000; Tideman, 2000) and indicates that, regardless of the form of occupation, the choice follows traditional gender roles. In the present study the majority of the persons with intellectual disabilities had not chosen occupational tasks themselves. Consequently, those who decide service and support may have stereotyped them into traditional female and male occupational roles. Such stereotyping would lead to limited autonomy in the sense of organizing everyday life according to individual preferences and views (cf. Barron, 1997).

Women and men with intellectual disabilities participated to about the same extent in recreational and cultural activities. In fact, significant differences were observed in only four of the 19 activities listed in the questionnaire. Differences in 13 activities were observed in women and men in the general population. With the exception of women more frequently visiting the library and reading books, there were no corresponding gender-related differences in the two samples.

For the remaining domains, no differences were observed between women and men with intellectual disabilities, which contrasted sharply with the differences found between women and men in the general population. With the exception of women having a richer social life than men, women in the general population were disadvantaged as compared with men in a number of items included in the comparison (e.g., working conditions, financial situation and experience of personal safety when leaving the house). A similar gender pattern was not found in women and men with intellectual disabilities.
In conclusion, proxy reports demonstrated few differences between women and men with intellectual disabilities. Thus, concerning living conditions, it appears that having an intellectual disability is a more important determinant than gender. This finding indicates that service and support were provided without considering differences in outcome of service and support for women and men and that people with intellectual disabilities were treated as gender-neutral persons rather than as women and men with different desires and needs.
General Discussion

The present study is one of only a few attempts to describe mortality, health and living conditions of a total population of children with intellectual disabilities (N=213) born in a Swedish county. The living conditions of persons with intellectual disabilities are compared with those of the general population in corresponding age groups.

Methodological considerations

In order to make a comparison with SLC data, the questionnaire was based on the SLC measure that has been annually used since the 1970s and is thus well established. However, some methodical limitations need to be considered when the living conditions of persons with intellectual disabilities are the focus of the study. The SLC questionnaire is formulated to describe living conditions of the Swedish adult population with items covering domains and features relevant for the great majority of people. However, it may be questioned if such general measures cover items relevant for people with intellectual disabilities. Are the life circumstances of people with intellectual disabilities and the general population too disparate (cf Matikka, 2000)? It has been suggested that issues regarded essential for a good life by most people are also significant for people with intellectual disabilities (Cummins, 1997; Tøssebro, 1996; Tøssebro, & Kittelsaa, 2004). However, some features are taken for granted for Swedes in general and not included in the SLC questionnaire but are particularly relevant to people with intellectual disabilities (Tøssebro, 1998). The choice was to design a questionnaire that, in addition to items corresponding with the SLC questionnaire, included items of specific relevance to the life situation (e.g., influence in choice of work, social relations with staff and access to formal service and support) of people with intellectual disabilities. In addition, response categories were added (e.g., group-home and daily activities were added regarding type of housing and type of work, respectively). The approach made it possible to (1) monitor the living conditions of people with intellectual disabilities as compared to the living conditions of the general population and (2) mirror features of specific importance for people with intellectual disabilities (e.g., special service and support and contact with professionals and staff personnel).
Financial resources facilitate the ability to choose among alternative lives. The reverse is also true, i.e. a lack of financial resources may inhibit an individual from choosing alternative lifestyles. Sen (1992) suggests that financial resources cannot be judged independently of individual possibilities of converting income and resources into capability to function and well-being. It is common knowledge that disability causes expenses that may reduce the level of living conditions and well-being (Mercer, 2004; Sen, 1992). Thus, level of income may provide a deceptive picture of the finances of people with disabilities. Therefore, economic hardship was chosen as a measure of the financial situation in the present study.

Face validity was tested in a pilot study. Strengths of the study were the high response rate and the low frequency (< 15%) of nonresponses on questionnaire items. These findings indicate that proxies may have perceived the features included in the questionnaire relevant for the living conditions of people with intellectual disabilities.

A questionnaire with fixed response alternatives runs the risk that the proxies could answer a question without having any information. Internal consistency checks were therefore carried out by comparing proxy responses on related issues, such as whether the person with an intellectual disability had staff in housing, frequency of contact with staff in housing and the importance of the relation with staff in housing. Agreement in responding was found to be satisfactory.

In the field of disability living conditions measures have been criticized because they do not capture accessibility and environmental barriers. This problem was also true for the present questionnaire, which included such issues to only a limited extent. Furthermore, a questionnaire of living conditions does not capture subjective experiences and satisfaction of the persons concerned and may thus not identify barriers and problems in living conditions that persons with intellectual disabilities experience. However, it is well recognized that the association between actual living conditions and satisfaction with these conditions is a rather week one. With respect to these limitations and the aim of this study, the ambition here was merely to catch and describe a slice of the living conditions of people with intellectual disabilities rather than provide a holistic picture.

Questions tapping health conditions were not included in the questionnaire. It has been suggested that proxies may have difficulty in identifying health problems in people with intellectual disabilities (Kerr et al., 2003; Tossebro, 1990). Thus, in order to optimize the possibilities to obtain reliable information data were collected through medical examination II and medical records. However, medical and school records only occasionally provided detailed information on diagnostic assessment procedures employed regarding the level of intellectual disability and mental health disorders. Thus, caution must be advised in the reliability of these particular aspects (Paper III).
Statistical analyses

The advantage of doing a chi-square test is that it adjusts for the sample size, with smaller samples needing larger percentage differences to reach statistical significance. A reason only few significant differences were found in relation to level of disability (Paper I) and gender (Paper IV) may be that statistical power was reduced because of the sample size (n=110). When statistically significant percentage differences were detected between women and men, they were in the order of at least 16.2% in the sample of persons with intellectual disabilities and 4.2% in the general population (Paper IV). Consequently, it is reasonable that the chances of finding statistically significant differences in the larger general population were higher because it was a substantially larger sample (n=1 600). Smaller magnitudes of differences may therefore be detected in the general population as compared with the sample of persons with intellectual disabilities.

A high percentage of agreement in conjunction with a moderate to very good value of kappa indicates sufficient agreement, and correspondingly, a low percentage of agreement and a low value of kappa indicate disagreement. However, interpretation becomes more difficult when there is a high percentage agreement and a low value of kappa. Symmetric imbalanced marginal totals of a concordance table may convert high percentage agreement into a low value of kappa. Such paradoxes may occur when responses are concentrated to one or few response categories, indicating sufficient agreement between reports by different proxies (Feinstein, & Cicchetti, 1990). In Paper II, contradictory mean values of percentage agreement and kappa were found, particularly for objective items. In addition, for 19% of the objective items and for 38% of the subjective items, responses were concentrated to one response alternative, suggesting that calculating the value of kappa would not be meaningful. These findings support the claim that the value of kappa depends not only on the two reports to be compared but also on the structure of the data. Nevertheless, an advantage of the kappa coefficient is its applicability for nominal scales and its correction for agreement that can be expected by chance.

Proxy responding

It was assumed that relatives and staff were familiar with different aspects of living conditions of the person they rated. The proxies considered most well-informed were chosen as a source of information in Papers I and IV. The results of Paper II confirmed this assumption. The choice of proxy is therefore important.

Differences in opinion between relatives and staff (Paper II) may reflect the views of relatives versus staff on the person with an intellectual disabil-
ity; however, and perhaps more importantly, they may be related to the social organizational contexts of relatives and staff, the family and the service organization. It therefore seems appropriate to consider the type of information sought when choosing the most suitable type of proxy as the data source. The finding is important because it seems likely that proxies will continue to be required as a source of information for a number of individuals who are unable to respond satisfactorily to questionnaire and interview questions. Unless proxy responses are used, people with severe intellectual disabilities are at risk of being excluded. Nevertheless, we need to be aware of the fact that proxy responding cannot be used as a replacement for self-reports.

Living Conditions

One way of considering the results of the present study is to discuss the gap between the living conditions of people with intellectual disabilities and the general population from a citizen perspective. A citizen perspective on people with intellectual disabilities entails that the rights and obligations that apply for people without disabilities are equally applicable to persons with disabilities (Ericsson, 1996). Though physically integrated in the community and gaining access to generic and special services and support, the present results demonstrated limitations in living conditions of people with intellectual disabilities. This observation indicates that people with intellectual disabilities only to a limited extent exercised social citizenship as formulated by Marshall (1964). Examples of areas of restriction include private areas and possessions in housing, living with a partner, inclusion in the labor market, voting in general elections and social relations. It may be suggested that a discrepancy exists between the socio-political ideology of equality in living conditions and reality on an individual level. Despite that persons with intellectual disabilities typically evidenced a lower gross income, proxies estimated that a majority of people with intellectual disabilities have an average or above average financial situation, which may exemplify a “good-enough for people with disabilities” attitude (Ekensteen, 1996).

Some similarities between the two groups were also observed. For example, the results indicate that people with or without intellectual disabilities practiced the same recreational and cultural activities, although the rate of occurrence of these activities differed between the groups. However, it was not known whether people with intellectual disabilities participated in activities in public cultural life or activities arranged particularly for people with intellectual disabilities.

It is reasonable to expect that the living conditions of people with minor intellectual disabilities only marginally differ from the living conditions of the general population whereas the living conditions of people with severe
disabilities show considerable differences from the general population. Surprisingly, in this study only limited variation across the sample of people with intellectual disabilities was found. It seems as though having an intellectual disability is a powerful and stigmatizing identity that overrides other social identities (cf. Burns, 2000). In consequence of such homogeneity in the group of persons with differences in gender and age and varying level of disabilities, it is reasonable to assume that environmental factors greatly impact on people’s living conditions. Tøssebro and Kittelsaa (2004) suggest a link between the living conditions approach and the disablement process and define disability as “negative living conditions outcomes of impairment-environment interactions” (p. 27).

Historically, special services and support for people with intellectual disabilities have segregated and restricted the lives of the individuals. For example, total institutions represented a miniature of the average municipality with its own culture, traditions and rules (Ericsson, 2002; Goffman, 1961). In the sample of persons with intellectual disabilities limited variations in living conditions may intimate that features of the institutional structure are being transferred to community living (cf. Mallander, 1999; Sandvin, 1996).

Persons with intellectual disabilities that participated in this study were provided staff support. Barron (2001) discusses two positions when providing service and support: support versus control. Support assumes that staff will provide help and support for the purpose of increasing individual control over everyday life. Control emanates from a view of the staff having a superior position of control, classifying people with intellectual disabilities as passive recipients with restrictive autonomy and influence. A similar discussion is found in Tucker and Johnson’s (1989) concepts of competence promoting and competence inhibiting support for mothers with intellectual disabilities and with the way Jarhag (2001) analyses and describes empowerment versus attitudes of paternalism in planning processes at the municipal, group and individual level. The complex interactions between the person with an intellectual disability and significant others are suggested to be a crucial factor when developing citizenship (Kjellberg, 2002). The limited influence regarding choice of work and financial matters in the present study may suggest that people with intellectual disabilities were deprived of normal social adult status and responsibility (Barron, 2002; Riddell, Baron, & Wilson, 2001; Wehmeyer, & Metzler, 1995).

The pattern of homogeneity in living conditions in the sample of people with intellectual disabilities can also be interpreted as a consequence of the implementation of the normalization principle. Normalization puts emphasis on equality in living conditions for people with or without intellectual disabilities, viewing life of people without disabilities as the norm. However, the approach is not unproblematic. Emphasizing the life of nondisabled people as the norm may warrant exercising power and control over people with intellectual disabilities in an effort to accomplish “normality”. Subjective
experiences of the living conditions of persons with intellectual disabilities were not included in this thesis and thus it is not known if these individuals desired changes in living conditions (e.g., employment on the labor market and increased social relations with people without intellectual disabilities).

Further, the normalization principle emphasizes the importance of independence and consideration for choices, wishes and desires of the individual. The results demonstrated that people with intellectual disabilities received support in their every day life, though no specific information was sought on amount and content of service and support. The limited variability in living conditions across the sample indicates a focus in general needs shared by all persons with intellectual disabilities. Service and support may thus have been stereotyped and not tailored to individual choices and wishes. It is not known to what extent individual choices with respect to dependence vs. independence determined the service and support provided by local governments. In certain situations, due to the actual context, an individual can choose to be dependent (cf Kjellberg, 2002). Kjellberg suggests the need to problematize the demand for independence and emphasizes the importance of giving the individual the opportunity to choose the level of dependency in everyday life.

To be characterized with an intellectual disability is often used as a dominant category concealing the ability of the individual (Riddell, Baron, & Wilson, 2001). For a number of persons with intellectual disabilities in the present study, the exclusion from the labor market may have been a function of their general marginalization within society (cf Jenkins, 1991) and the design of service and support rather than the absence of ability. There is broad agreement that work creates social identities and facilitates social relationships that extend beyond the workplace. It is suggested that such features as exclusion from the labor market (Sandvin, 1996) limit the opportunities to be included in the regular social life of the community. Special services, such as daily activities, while providing support, limit spontaneous meetings between people with intellectual disabilities and people without intellectual disabilities, and paradoxically, may contribute to social marginalization and segregation. In the present study this possibility was indicated by the social network of people with intellectual disabilities typically being built on family ties and caregiver-care receiver relations, with only a few chosen friends. Integration and physical nearness can contribute to decrease the social stigmatization process that marks out groups such as people with intellectual disabilities and identifies them as deviant and by that increase social relations between people with or without intellectual disabilities (Edgerton, 1967; Gustavsson, 1992).
Representativeness and generalizability

The sample of persons with intellectual disabilities, all of whom were born in one Swedish county, included more men (59%) than women, which corresponds with national proportions for this age group (SCB, 1981). In the general population sample, however, there was no difference in the number of men and women. Apart from year of birth (Paper I) and gender (Paper IV), the comparison between people with intellectual disabilities and the general population did not control for sample characteristics. Consequently, it cannot be ruled out that the present results were affected by differences in sample characteristics and individual circumstances.

In 1974, the prevalence of intellectual disabilities in Uppsala County was 0.42%, which closely corresponds with the national figure in 1977 (SCB, 1981). No statistics were available on gender and level of intellectual disabilities in age-matched groups in the Swedish population of people with intellectual disabilities. However, the proportion of women, in the county population in question for this study was slightly lower compared with the proportion in the nationwide population of people with intellectual disabilities in 1974 (41% vs. 44%) (SCB, 1981).

The study population of people with intellectual disabilities included all children born between 1959 and 1974 in Uppsala County and that were registered at the Board for Provision and Services to the Mentally Retarded and receiving special services in 1974. However, the register had limitations that may have affected the results. In comparison with national statistics, children with severe intellectual disabilities were overrepresented in the study population in 1974 (57%). One explanation is that mild intellectual disability is not evident in early childhood, and consequently, some of these children were not likely identified in 1974. On the other hand, the prevalence of severe intellectual disability (3 per 1 000) was as expected and corresponds with studies in other Swedish counties (Hagberg, & Kyllerman, 1983). The relative understanding of disabilities means that people with intellectual disabilities do not constitute a stable population. Other methods of selection might include other persons that may have an impact on the results.

Concerning the study population, information on living conditions was provided for 51% of the individuals and information on health conditions was obtained for 38%. Thus, it seems appropriate to discuss the dropout rate in this study. At the time of the study, 27% (n=57) were deceased and 1% (n=2) had moved abroad. The mortality rate was especially high in the younger ages and among persons assessed with severe intellectual disability. Of those persons refusing participation, few reported the reason. When the reasons were given, they included such responses as lack of interest, lack of time or inconvenient moment and not identifying oneself as having an intellectual disability. Although there might be limitations in the possibilities of generalizing the results to the Swedish population of people with intellectual
disabilities in corresponding age groups, the results make visible the differences between people with intellectual disabilities and the general population and could promote the further development of social services and support.

Statistical analyses did not reveal any significant differences between participants and non-participants on age, gender and level of intellectual disability as assessed in 1974. There is therefore good reason to expect that the sample is representative of the study population, which is representative of the whole country regarding proportion of the population, gender and prevalence of severe intellectual disabilities. Nonetheless, it cannot be ruled out that the results may have been influenced because the people with intellectual disabilities were all born in the same county.

Implications for future research and practice

The thesis lends support to the importance of including environmental and disabling barriers as well as environmental facilities when describing living conditions of people with intellectual disabilities. In line with the Governmental disability policy (Regeringens Proposition, 1999/2000:79) focusing freedom and choice it would be relevant to include issues tapping the opportunities to influence everyday life as well as one’s own life course. In practice, the results point to the importance of utilizing the opportunities in legislation and organization in order to enhance the development of social citizenship. A critical factor is to gain further knowledge of whether people with intellectual disabilities have access to personal support, how service and support are implemented and the way in which environmental knowledge is integrated into service and support.

Participation in community life for persons with intellectual disabilities requires a well adapted help and support system. What needs to be considered when planning services and support is that the individual with an intellectual disability, his or her family and the provider are all likely to attend to a different aspect of the situation. This is important to consider in order to provide individually tailored support. Furthermore, the findings in Papers I and IV indicate possible contradictory staff positions when providing service and support; support versus control. How does staff problematize these contradictory positions?

Because parents have a lifelong relationship with the person with an intellectual disability, the use of a life cycle approach is feasible. Longitudinal surveys can monitor the development of living conditions, including service and support, and describe any changes that occur over time.

It is commonly known that the relationship between objective living conditions and people’s satisfaction with these conditions is weak. Both are necessary to represent the construct of life quality. To understand the experiences of living conditions and well-being of people with intellectual disabili-
ties a dialogue with individuals would be required. In this respect, a necessary task is to develop methods and strategies so that information via self-reports can be obtained from as many people with intellectual disabilities as possible.

The present findings point to several shortcomings in health care for people with intellectual disabilities and demonstrate the need for training and specific education of medical students, practice nurses and doctors in the field. The content of medical health care could be studied for people with intellectual disabilities.

The results indicate the importance for practice as well as for the research community of acknowledging the gender of people with intellectual disabilities so that emasculation and de-individualization can be avoided. If participation in society and citizenship is to be reached for people with intellectual disabilities this requires individualized service and support.
Conclusions

People with intellectual disabilities in the sample studied all lived in the community. Yet, the comparison with the general population indicates clear differences in living conditions, particularly regarding employment and social life. Persons with intellectual disabilities were not included in the labor force and tended to live in a highly limited social environment. In contrast, surprisingly limited variation in living conditions was found across the sample of individuals with intellectual disabilities despite different gender and age groups and a wide variation in level of disability.

The results indicated that relative and staff proxies appear to contribute different information related to varying viewpoints and types of information. A difference was observed between relatives and staff on age and level of education, although the analyses revealed no association between proxy responding and proxy characteristics.

An increased mortality was observed in the people with intellectual disabilities as compared with the general population. The medical examination identified a wide range of physical and mental health problems in the sample of people with intellectual disabilities. A majority of these persons had access to a family doctor and attended regular health checks. Yet, at the medical examination a number of needs of specialist examinations were identified, indicating several shortcomings in the health care of this sample.

Fewer differences in living conditions were found between women and men with intellectual disabilities compared to those found between women and men of the general population. This finding suggests that people with intellectual disabilities were treated as gender-neutral persons rather than as women and men with individual preferences and needs. Thus, it appears that having an intellectual disability is a more important determinant than gender regarding the living conditions of women and men with intellectual disabilities.
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