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Leena M. Matikka

**Service-oriented Assessment of Quality of Life
of Adults with Intellectual Disabilities**

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SUMMARY

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The aims of this study were 1) to examine which factors define and affect quality of life of people with intellectual disabilities, 2) to construct a scale for measuring quality of life in the context of assessment of quality of residential services for this group, and 3) to describe the quality of life of these people in Finland.

The study employed survey data from 616 persons and data from 421 persons interviewed for assessment of the quality of the services provided in the residential units where they lived. During the research process, a subjective well-being (SWB) scale containing eight domains of life and a scale of acquiescence was constructed. The eight domains crucial in determining quality of life of people with mild intellectual disabilities were choices related to home, safety, activity, social relationships, happiness, health and stress, work and mutual support.

Perceived quality of life was found to be affected more by psychological factors than by living conditions. Despite of their intellectual disability, reliable measurement of the quality of life of these people was found to be possible when scales were designed to take into account difficulties in understanding and responding to questions and in dealing with some situational factors. Comparisons of quality of life of the group with intellectual disabilities and the general population of Finland are problematic because of differences in ways of life. Although people with intellectual disabilities were found to be equally as happy with their lives as the overall Finnish population, the data indicate that they experience more physical violence and more stress.

Key words: quality of life, subjective well-being, intellectual disability, mental retardation, quality of services

TIIVISTELMÄ

Matikka, Leena M. (2001). **Service-oriented Assessment of Quality of Life of Adults with Intellectual Disabilities** [Kehitysvammaisten elämänlaadun arviointi palvelujen laadun kontekstissa].

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Tavoitteena oli 1) tutkia, mitkä tekijät määrittelevät kehitysvammaisten elämänlaatua, 2) kehittää sellainen asteikko kehitysvammaisten elämänlaadun arvioimiseksi, jota voidaan käyttää arvioitaessa kehitysvammaisille järjestettyjen asumispalvelujen laatua sekä 3) kuvata suomalaisten kehitysvammaisten elämänlaatua.

Tutkimusaineiston muodostivat 616 kehitysvammaisen elämänlaatuhaastattelut sekä 421 kehitysvammaisen subjektiivista hyvinvointia käsittelevät haastattelut, jotka oli tehty palvelujen laadunarvioimiseksi niissä asumisyksiköissä, joissa vastaajat asuivat. Tutkimusprosessin aikana konstruoitu Subjektiivisen hyvinvoinnin (SWB) asteikko sisältää kahdeksan elämänalueen osa-asteikkoa sekä myöntyvyyttä mittaavan asteikon. Kahdeksan aluetta, jotka olivat oleellisen tärkeitä lievästi kehitysvammaisten elämänlaatua määriteltäessä olivat: Kotielämään liittyvät valintamahdollisuudet, turvallisuus, toiminta, sosiaaliset suhteet, onnellisuus, terveys ja stressi, työ sekä vastavuoroinen tuki.

Koettuun elämänlaatuun vaikuttivat enemmän psykologiset tekijät kuin elinolosuhteet. Elämänlaatua kyettiin arvioimaan luotettavasti huolimatta haastateltavien intellektuaalisista vaikeuksista, kun varmistettiin erät haastattelun tilannetekijät ja otettiin huomioon vastaajien vaikeudet ymmärtää kysymyksiä ja vastata niihin. Kehitysvammaisten ja muun suomalaisväestön elämänlaadun vertailu osoittautui ongelmalliseksi, koska näiden ryhmien elämäntavat poikkeavat huomattavasti toisistaan. Vaikka kehitysvammaiset ilmaisivat olevansa yhtä onnellisia kuin muutkin, he kokivat elämässään enemmän fyysistä väkivaltaa ja stressiä.

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Helsingissä 1.8.2001

Leena Matikka

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List of Original Publications

This study is based on the original publications listed below. Taken together, they constitute the doctoral dissertation of the author.

- Study I Matikka, L. M. (1994). The quality of life of adults with developmental disabilities in Finland. In D. Goode (Ed.), *Quality of life for persons with disabilities: International perspectives and issues* (pp. 22-38). Cambridge, MA: Brookline Books.
- Study II Matikka, L. M. (1996a). Effects of psychological factors on the perceived quality of life of people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 9, 115-128.
- Study III Matikka, L. M. & Vesala, H. V. (1997). Acquiescence in quality-of-life interviews of adults who have mental retardation. *Mental Retardation*, 35, 75-82.
- Study IV Matikka, L. M. (2000a) Comparability of quality-of-life studies of the general population and people with intellectual disabilities. *Scandinavian Journal of Disability Research*, 2 (1), 83-102.
- Study V Matikka, L. M. (2000c). *Subjektiiivisen hyvinvoinnin asteikon kehittäminen kehitysvammapalvelujen arvioimiseen [Development of the Subjective Well-being Scale for the assessment of services provided for people with intellectual disabilities]* (Valtakunnallisen tutkimus- ja kokeiluyksikön julkaisu 79). Helsinki: Kehitysvammaliitto.

In the text the publications are referred to by number (I - V).

I Introduction

Pursuing better quality of life became an important issue in the late 1990s, when it was seen as a goal of the welfare society. According to the philosophy of equal opportunity (United Nations, 1994), all citizens came to be considered to have an equal right to a good quality of life. The services needed in order to secure a good quality of life for people with intellectual disabilities were defined. The extent to which this goal has been reached was to be evaluated by comparing the quality of life of people with intellectual disabilities to the quality of life of people without disabilities. In order to conduct this evaluation it was (and remains) important to determine what we really mean by the concept of quality of life, how it can be assessed, and which kind of measurements are needed to compare the quality of life of these groups. As the quality of life of persons receiving special services

became a crucial measure of the success of the special services, it became necessary to determine what level of quality of life then would suffice in order to say that the quality of the service provided was good enough.

As a Nordic welfare state, Finland has built a service system that makes the local municipal authorities responsible for providing social welfare and health care to all citizens. These services are almost totally financed by taxes gathered by the state and municipalities. The Nordic welfare state model is characterized by its comprehensiveness, its universality and its emphasis on equality and solidarity, and it is known as a social democratic type of welfare state model (Esping-Andersen & Korpi, 1987; see also Hanssen, Sandvin & Söder, 1996 and Sipilä, 1996). A total of 448 municipalities in Finland are able to provide these services by organizing

them on their own, or by buying them from joint authorities of municipalities or from private organizations. In order to produce special services for people with intellectual disabilities the country has been divided into 16 special care districts including every municipality. Today, of the total population about 5.2 million about 28 000 (0.5%) people are defined as having mental retardation and are entitled to a pension or subsidy. About two thirds of these utilize special services, while the rest only use general services for all people. In Finland, monitoring quality of services provided for people with intellectual disabilities has developed according to the paradigm shift from a service- or program-centered ideology to an

individual- or customer-centered approach. This paradigm shift affected the whole social and health care sector in 1990s. For more information, see Study I, pp. 22-23.

In this study the concept of quality of life is related to the context of intellectual disability and quality of services provided for people with intellectual disabilities. This means that it was necessary, first, to define quality of life, second, to link the concept of quality of life with intellectual disability in order to define special aspects that have to be investigated, and third, to relate quality of life to quality of service. The core area of this study is represented by the area in Figure 1 where these three aspects overlap.

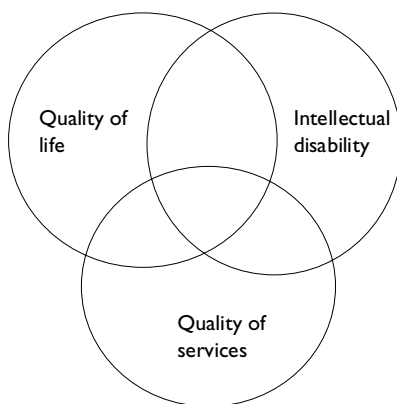


Figure 1. Overlapping of Quality of Life, Intellectual Disability and Quality of Services.

Philip Seed and Greg Lloyd (1997) state that “quality of life” in everyday terms includes the following: personal indulgence, luxury, a pleasurable sensory experience, privilege, choice and chance, access, universal opportunity, shared goals, social responsibility, effective communication, give and take, devotion, and sacrifice.

Various discourses employing the concept of quality of life have given it different meanings according to the context in which it is used. Some of these discourses appear in philosophy (good life), in politics (human rights, social politics, economics, disability politics), in the field of health and social services (quality of services), and in psychology (happiness and subjective well-being).

Quality of life of people with intellectual disabilities needs to be studied by taking the special characteristics and needs of this group into account. This entails a definition of intellectual disability. We can say that people with intellectual disabilities have difficulties in their cognitive functions, and they need support and services in leading their lives in communities or in institutional or residential settings. The more complicated our society becomes, the more support these people will need from the rest of the population. When we speak of quality of life in the context of quality of services provided for this special group of people, we need to limit the scope of

the concept of quality of life. If we evaluate quality of services in terms of the quality of life of people receiving these services, our research serves a practical purpose. This connection also justifies and motivates the study of quality of life of a special group of people with disabilities.

Why issues of quality of life have been increasingly applied to persons with intellectual disabilities is a question that leads to an examination of the history of the concept of quality of life and of the changing service paradigms that have been developed in efforts to address these issues.

An important issue in all various quality-of-life discourses seems to be the need to achieve consensus as to what quality of life entails. In the following, I will deal specifically with the concept of quality of life in the context of intellectual disability research and with the identification of characteristics of intellectual disability that affect measurement of the quality of life of people with intellectual disabilities. I will then outline the ongoing changes in services provided for this group in Finland.

In order to understand the debate about the definition of quality of life, it is useful to look at the history of the concept and to describe its development in various disciplines and its emergence on the agenda of such international organizations as the World Health Organization and the United Nations.

In order to illustrate different meanings that quality of life has in different contexts, I apply the figure introduced by Jarl Wahlström (1992; Figure 2). As the concept of quality of life varies according to the discourse

in which it is used, it cannot be determined in absolute terms. Instead, its flexible use in several discourses suggests that it is a practical and useful concept for various purposes.

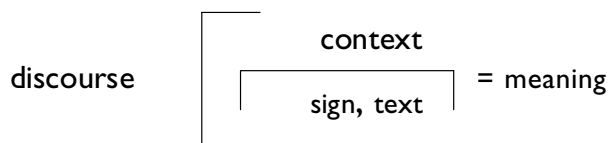


Figure 2. The Construct of Discourse, Context and Text According to Wahlström (1992, p. 58).

2 Discourses and definitions of quality of life

The main discourses of quality of life are found in philosophy, in international human rights policy and in the social politics of nation-states. In psychology, happiness and subjective well-being are often seen as being closely related to subjective quality of life.

These discourses have their origins in Classical philosophy, and they later differentiated with the gradual proliferation of scientific and societal practices. After discussing these trends on the general level, I will then focus on quality-of-life discourses as they relate to intellectual disability.

2.1 Quality-of-life discourses based on philosophy

The origins of quality-of-life discourses date back to Classical antiquity. In Greek philosophy the

ideal setting of life is discussed, and ideas of the “good life” are presented. In Plato’s view, the protected life, where man lives beyond the reach of destiny and chance, is the only worthwhile existence. According to Plato, reason dominates all human activity, and man should behave like the gods, rising as far as possible above human feelings and perspectives (Lindström, 1994). Aristotle, on the other hand, wanted human beings to be engaged in human perspectives and to take the risk of emotional engagement. Mankind has to live with conflicting sets of values, even when this involves personal risk-taking. Aristotle (trans. 1962) concluded that more than anything else, people seek happiness, and while happiness itself is sought for its own sake, every other goal is valued only because we expect that it will make us happy.

According to George von Wright (1963) there are at least three

well-known accounts of the happy life: (a) The Epicurean idea that happiness consists in having (as opposed to doing), along with the Lockean idea that property is the foundation and means of happiness (materialism); (b) the utilitarian view that happiness is essentially contentedness — equilibrium between needs and wants on the other hand and satisfaction on the other; and (c) Aristotle's concept of *eudaimonia*, which equates happiness with creative activity. Happiness is thought to come from the fulfillment of one's capacities by doing what one is keen on (Shin & Johnson, 1978).

Amartya Sen (1993) took a *capability approach* to a person's quality of life. Capability is concerned with evaluating a person's actual ability to achieve various valuable functionings as a part of living. Functionings represent parts of the state of a person — in particular, the various things that he or she manages to do or be in leading a life. The capability of a person reflects the alternative combinations of functionings the persons can achieve and from which he or she can choose a collection. This approach is based on a view of living as a combination of various doings and beings. Quality of life is then assessed in terms of the capability to achieve valuable functionings. Sen also states that the Greek word *dumanin*, used by Aristotle to discuss an aspect of the human good and sometimes translated as “potentiality,” could also be translated as “capability of existing or acting.”

Happiness also had a moral aspect. Only a moral person who was functioning as a responsible member of a community was defined in philosophical discourse as a happy person.

2.2 From social indicators to quality of life

Social indicators were developed in order to monitor economic and social trends and impacts and to provide a system of “early warning” of growing imbalances, social disbenefits, dissatisfactions and emerging social needs. Coherent and valid policy conclusions were thought to be made by utilizing information drawn from social indicators (OECD, 1973). Frank Andrews and Stephen Withey (1976, pp. 1-4) characterized social indicators as having normative interest and of having duration. These characteristics allow comparisons over an extended period which, in turn, permit one to grasp long-term trends as well as sharp fluctuation rates. Social indicators could also be seen as quantitative measures of social conditions that were designed to guide choices at several levels of decision making.

In America, the first major study of the quality-of-life experience, based on a probability sample of population, was carried out in 1957 by Gerald Gurin, Joseph Veroff, and Sheila Feld (1960). Their study had a mental-health orientation and it

included a single question, asking the respondent to report how “happy” he was — very happy, pretty happy, or not too happy. Later on, Norman Bradburn and David Caplovitz (1965) used as a basic measure of well-being the Gurin-Veroff-Feld question “Taking all things together, how would you say things are these days — would you say you are very happy, pretty happy, or not too happy these days?” Where one was on this measure was found to be related to the “relative balance of two independent conditions: positive and negative feeling states.” Angus Campbell, Philip Converse and Willard Rodgers (1976, p. 6) considered Bradburn’s theory of psychological well-being being to be based on a notion of emotional balance rather than on differences in the type of needs an individual has.

In Nordic countries, the first level of living surveys were conducted in the 1960s and 1970s by Sten Johansson (1970) in Sweden and by Erik Allardt and his colleagues in Finland and other Nordic countries (Allardt, 1973, 1975; Erikson, 1993). Allardt (1975) defines the concept of quality of life in relation to the concept of welfare. According to him the word “welfare” refers to the state of need-satisfaction in a national population, and it is usually studied and described by some system of social indicators. Indicators of welfare are explicitly value-oriented and as such are concerned with quality of life. The basic problem concerns the source of

these values. According to one view, welfare values or dimensions should be established by studying objective facts and thus established by researchers irrespective of whether they work in collaboration with the people studied or not. According to another view the welfare values have to be established by studying the subjective perceptions and attitudes of the people. The second problem is concerned with the question of whether one should focus on material or impersonal resources by which people presumably can master their living conditions, or whether one should emphasize values which are ends in themselves, or in other words, the satisfaction of all basic needs. Allardt highlights the implications of the two conceptual distinctions in a fourfold table (Table 1).

Robert Erikson and Hannu Uusitalo (1987) described the origin of the Scandinavian welfare studies by looking at the trends of social sciences and behavioral sciences. They concluded that quality-of-life research was affected by the Scandinavian level-of-living research, sociology, and psychology. The Scandinavian level-of-living research was in turn affected by the economics of welfare, macro-oriented level-of-living research, and British sociopolitical research. Antti Eskola (1985, pp. 164-175) described the particular Finnish paradigm shift from research on level of living to studies of quality of life, and eventually to research on way of

Table I. Two Basic Distinctions in Conceptualizing Welfare in The Comparative Scandinavian Study (Allardt, 1975, p. 4).

	Welfare	Happiness
Level of living	Needs for which satisfaction is defined by having or mastering material and interpersonal resources	Subjective evaluations and perceptions of how satisfied an individual is with his material living conditions
Quality of life	Needs for which satisfaction is defined by human relations or by how the individual relates to other people and society	Subjective evaluations and perceptions of how satisfied an individual is with his human and social relations

life. According to J. P. Roos and Tommi Hoikkala (1998) Finnish social sciences are placing more emphasis on “life politics” (cf. Giddens, 1991).

Typically, welfare studies operate at the level where socio-political decisions are made, and these studies still have connections to economics. Quality-of-life studies are, on the other hand, more involved on the micro level of human life, where social services and people meet and where the subjective life experiences of people are core issues. However, both traditions now stress subjective evaluations.

2.3 Human rights — international quality-of-life discourses

In an international framework, the idea of quality of life has been found useful in combining the efforts of organizations of people with disabilities. The Declaration on the Rights of Mentally Retarded Persons (United Nations, 1971) and the

Declaration on the Rights of Disabled Persons (United Nations, 1975) adopted by the United Nations were the first tools for improving the rights of people with disabilities. These declarations have not been given as much legal power as international covenants, but they have been useful in political discourse.

Perhaps the most important aspect of the philosophy of the international movement to guarantee the rights of disabled persons is the concept of the equalization of opportunities, which means the process through which the various systems of society and the environment, such as services, activities, information and documentation, are made available to everyone, particularly to persons with disabilities (Degener, 1995) on an equal basis. The United Nations General Assembly adopted the Standard Rules on the Equalization of Opportunities for Persons with Disabilities in 1993 (Resolution 48/96). Although the Standard Rules are not compulsory, they can become international

customary rules when they are applied by a large number of states with the intention of respecting a rule in international law (Newman, 1995).

Human rights can be seen as the foundation of quality of life. From this point of view, discourses of human rights can serve as starting points in investigating common values behind quality of life. The fact that we have general agreement about the most fundamental human rights and the international tools to promote these rights lays the basis for agreement on international values of quality of life. We can say that human rights are the universal part of quality-of-life issues. The viewpoint of human rights emphasizes the responsibilities of a community towards its members. Rights are the property of every individual person, but responsibility for them is bound to the community.

Two main lines in quality-of-life discourses are collective and individualistic approaches. The debate concerning the use of subjective versus objective measures is linked to these discourses, as well. In the human rights context, the collective approach prevails, and objective instruments are needed to evaluate the quality of life of individuals and groups that might live in vulnerable situations.

2.4 Health-related quality of life — a biomedical approach to social life or a developing health concept?

A significant change in health studies began when the World Health Organization (1948, p. 1) defined health as “a state of complete physical, mental and social well-being and not merely the absence of disease.” Although the concept of positive health has been discussed since then, consensus concerning its definition has not yet been reached. According to Lamb, Brodie and Roberts (1988) positive health can be described as the ability to cope with stressful situations, the maintenance of a strong social-support system, integration in the community, high morale and life satisfaction, psychological well-being, and even levels of physical fitness, as well as general physical health. Social health has also been conceptualized as a separate component of health status and defined in terms of the degree to which people function adequately as members of the community (Donald et al., 1978; Greenblatt, 1975; Renne, 1974).

There is increasing acceptance for the notion that health is more than an absence of disease; it is a result of a complex mix of social, economic, political and environmental factors, all of which reflect complex issues of power, status and

resource distribution. As public health has broadened from its focus on medical and behavioral paradigms to incorporate a socio-environmental approach, the questions asked by public health researchers have become more complex. Traditionally epidemiological methods have not been able to cope with the complexities of this subject (Baum, 1995).

In general terms quality of life in relation to health is a broader concept than personal health status, and it also takes social well-being into account. It is becoming fashionable to equate all non-clinical data with quality of life (Bowling, 1997). The health-related indicators of quality of life have been used both as dependent (outcome) and as independent variables in studies, and the concept of quality of life has received the role of a bridge between scientific and everyday discourses. Interestingly, many studies in the field of public health have, however, employed a research methodology based on the functionalistic-objective paradigm. The result is that quality of life now has the nature of an individual characteristic that can be measured, just as intelligence or adaptive skills, for example, can be.

The WHOQOL Group (1994) in the World Health Organization has defined quality of life as “individuals’ perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.”

Many health-related quality-of-life instruments are used in economic evaluations. Mark Deverill, John Brazier, Colin Green and Andrew Booth (1998) assessed the state of the art in using Quality-Adjusted Life-Year (QALY) measures and other quality-of-life measures in this context. They recommended that researchers should consider the credibility and validity of their studies more carefully. Some QALY-type measures have been criticized for lacking sensitivity to changes in health state, thus possibly leading to incorrect conclusions.

The development of QALY-type measures has also meant that so-called medicalization is assuming a threatening role in discussions of disability. In reaction to this prospect, it has been suggested that the term quality of life be abandoned as “death making” and hopeless (Wolfensberger, 1994). Ruth Luckasson (1990; 1997) has pointed that the subject of quality of life is raised as an issue only when attempts are being made to deny something to people with disabilities: life, medical care, supports, opportunities. The debate about the ethics of utilizing quality-of-life measures in evaluation and decision making concerning an individual’s treatment and services continues unabated. This controversy makes it plain that new paradigms in fields that have different research traditions may be misunderstood and misused in a way that could lead negative consequences, especially for people who

find it difficult to consider these issues (for further discussion see Matikka, 1999a).

2.5 Psychological approaches to quality of life

Happiness has often been understood in three different ways. For some the term refers to a feeling, which is usually of short duration, to short-term moods of gaiety, and elation, the presence of pleasure and absence of pain. For them happiness is a hedonic concept. A second use is one in which a person is “happy with” or “happy about” something. These expressions mean being “satisfied with” or “contented with.” Thirdly, the term “happy” is often evaluative, in that it makes an appraisal of one’s overall quality of experience rather than making a statement of the fact, as in the case of the second use. Being happy means that we have a happy life, a life in which all of our objectives form a harmonious and satisfying whole. When assessing our life we take into account various aspects of our condition and circumstances, as well as how we feel about them (Allardt, 1975; Andrews & Withey, 1976; Bradburn, 1969; Campbell et al., 1976; Shin & Johnson, 1978; Veenhoven, 1984).

Some researchers equate quality of life and happiness. Most, however, define quality of life as a composite of several components or domains of life. Doh Shin and D. M. Johnson (1978) suggested that happiness means an overall assessment of the quality of life and consists of the possession of resources; the satisfaction of needs, wants and desires; participation in self-actualizing activities; and comparisons with others and past experience.

Mihaly Csikszentmihalyi (1992, pp. 2-6) explained that happiness is not something that happens; it does not depend on outside events, but rather on how we interpret them. Moreover, people who learn to control their inner experiences will be able to determine the quality of their lives, which is as close as any of us can come to being happy. To clarify why some things we do are more enjoyable than others, he used the concept of “flow” and especially “conditions of the flow experience.” He defined “flow” as the way people describe their state of mind when consciousness is harmoniously ordered and they want to pursue whatever they are doing for its own sake.

In Finnish studies, happiness has been defined in the same way as in mainstream happiness studies (Argyle, 1987; Diener, 1984, 1994;

Diener & Diener, 1996; Diener et al., 1995; Diener et al., 1991; Diener et al., 1999; Diener et al., 1995; Myers & Diener, 1995; Veenhoven, 1984, 1988, 1989, 1991, 1994). The Finnish studies stress inner experience, and their interpretations of living circumstances are found to be crucial

in explaining happiness or subjective well-being of people (e.g. Matilainen & Helkama, 2000). Markku Ojanen (1997) criticized the Western notion of happiness, which stresses satisfaction and hedonism instead of inner peace and contemplation of the meaning of life.

3 Quality of life as a promising new paradigm in the field of intellectual disability

3.1 Changes in defining intellectual disability

Our understanding of intellectual disability has changed over the years. Mark Burton and Helen Sanderson (1998) have described four relatively distinct traditions in work with people with intellectual disability: ordinary living/normalization, functional, behavioral, and developmental. The normalization tradition emphasizes social integration, positive social roles, commitment to community, dignity, autonomy and growth (Nirje, 1969, 1985; Race, 1999; Wolfensberger, 1972, 1983). The functional or skill-based perspective emphasizes two domains: the functional activities of the person and practical ways of supporting the person in personally relevant acts (Gunzburg, 1968; Jones, 1993; Nietupski & Hamre-Nietupski,

1987; Peck & Hong, 1988; Whelan & Speake, 1979).

The recent behavioral approaches have stressed the analysis of behavior in real-life settings (Emerson, 1993; Zarkowska & Clements, 1994). Robert Hodapp, Jacob Burack and Edward Zigler (1990, pp. 4-9) have identified six assumptions of classical developmental approaches: (a) the organism is active, (b) change is directed toward a specifiable end point, (c) behavior is evidence of underlying schemes, (d) change can be both qualitative and quantitative in nature, (e) development is not a synonym for the amount of time the child has lived, and (f) development involves progressive increases in “differentiation, articulation, and

hierarchical integration” defined by Heinz Werner (1957, p. 126). These different paradigms can often be complementary when brought to bear on efforts to support people with significant intellectual disabilities. One special characteristic of these paradigms is that they focus on the individual.

One dimension that could be used in comparing paradigms is the extent to which personal characteristics are stressed compared to ecological or social environmental characteristics or to interactive processes where people with intellectual disabilities are involved. Early attempts to describe disability as a process were made by WHO in the ICDH classification (World Health Organization, 1980). Nowadays, more and more emphasis is being placed on contextual factors and on the participation of the disabled persons themselves in assessing disability (Luckasson et al., 1992; World Health Organization, 2001).

The adaptive behavior criterion was added to the definition of mental retardation nearly 40 years ago in response to the criticism that the IQ criterion was not sufficiently contextualized. According to Stephen Greenspan (1999) the most recent classification manual of the American Association on Mental Retardation (AAMR) (Luckasson et al., 1992) may be considered to include contextual elements: (a) an emphasis on human plasticity reflected in the optimistic statement that people with mental retardation

can grow out of their status; (b) an emphasis on the modularity of functioning in the view that one can have mental retardation and still be relatively competent, even normal, in numerous areas of functioning; and (c) a presentation of disability severity in terms of extent of needed supports (i.e. adapted contexts) rather than in terms of decontextualized deficiencies. In spite of these elements, the reliance on IQ as the primary criterion for defining mental retardation prevails both in the AAMR (Luckasson et al., 1992) and the American Psychologist Association (APA) (Jacobson & Mulick, 1996) manuals.

The following definition of mental retardation or intellectual disability adopted by the American Association on Mental Retardation (Luckasson et al., 1992) is widely accepted, and it is also used in Finland.

Mental retardation refers to substantial limitations in present functioning. It is characterized by significantly subaverage intellectual functioning, existing concurrently with related limitations in two or more of the following applicable adaptive skill areas: communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure, and work. Mental retardation manifests itself before age 18.

Marcia Rioux (1997) divided social and scientific formulations and treatment of disability into two main parts: individual pathology, including a biomedical approach and a functional approach; and social pathology (structural), including an environmental approach and a human rights approach. She stated that social responsibility has diverse contents in these approaches. In the biomedical approach the focus is on eliminating and curing disability, in the functional approach it is on amelioration and providing comfort, in the environmental approach the focus is on eliminating systematic barriers, and in the human rights approach it is on providing political and social entitlements.

Valerie Bradley (1999) stated that developments in the field of intellectual disability have recently ushered in a decade of self-determination. This is close to the human rights and environmental approaches that Rioux stressed some years earlier. The quality-of-life paradigm differs from them in combining several approaches and in being more focused on self-determination and on providing alternatives to persons with intellectual disabilities. This emphasis has also placed more value on the ideas of those who are directly affected by the assessment. Accordingly, new research strategies that allow them to participate in research processes have become more popular.

3.2 Enhancement of quality of life — a target of services in the field of intellectual disability

The ecological approach is now shaping disability politics. In the field of rehabilitation, formerly dominated by medical and psychological models, there is a shift from an emphasis on the individual to a concern with the wider social system (Cottone, 1986; Mercer, 1992).

The “World Programme of Action Concerning Disabled Persons” (United Nations, 1982) focuses on two targets: the full participation of people with disabilities, and equalization. “The Standard Rules on the Equalization of Opportunities for Persons with Disabilities” (United Nations, 1994) also includes the equalization of opportunities as a goal. The goals of the both of these programs can also be seen in Sen’s (1993) definition of quality of life. This definition stresses a capability approach. Core issues of quality of life involve people’s opportunities to act and modify their way of life as they want. Opportunities to create and to modify their own living conditions and own way of life as well as the freedom to make choices are important to everyone’s personal development (cf. Holzkamp, 1983). In the context of improving the quality of life of people with intellectual disabilities, empowerment of these people has become a parallel target.

Changes in ideology have promoted changes in service delivery as well. During the fifteen years between 1967 and 1982, the number of retarded people in U.S. state institutions declined by over one third from 194 659 to 119 335 (Hill et al., 1984). Since the beginning of the deinstitutionalization movement after 1960, 153 large state mental retardation facilities (housing 16 or more people) have closed (44% of the total number operating since 1960). The rate of the closures peaked between 1992 and 1995, with an average of 12.3 closures per year, and it has been declining since then. In 1999 the population of large state facilities totalled 48 496 (Anderson et al., 1999). This rapid change in service philosophy and service practices also signified a change in research concerning service quality. An emphasis on individually-based service planning was accompanied by quality management and the tendency to evaluate service quality from the viewpoint of clients (Bradley & Bersani, 1990; Gardner, 1996; Gardner & Nudler, 1998).

In Finland, the change from a centralized model to an inclusion model in service provision has meant that services organized by joint authorities have last years decreased and services organized by municipalities and private local organizations have increased. The number of people with intellectual disabilities residing in large institutions did not decline as rapidly as in the United States. In 1990, 4267 persons lived in institutions run by joint authorities of municipalities, and in 1996 the number of these people was 2818 (Matikka, 1998).

Recently, however, more emphasis has been put on quality of services and studying changes of service philosophy and their effects on the structure of service system (Matikka, 1998; Mäki, 1998; Nouko-Juvonen, 2000). The governmental strategy for quality assurance in Finland as well as in the other Nordic countries was guiding the process by information and supporting local voluntary development projects (Ministry of Social . . . , 1999).

4 Conceptualization of quality of life of people with intellectual disabilities

4.1 Conceptual models of quality of life

There has been considerable confusion about what quality of life means. As a postmodern concept it obviously can be seen as a social construct that is continuously being shaped in various discourses and negotiated in groups that are seeking consensus in particular fields. Involving all the people who are interested in quality of life in these negotiations promises an open forum and possibilities for empowerment. For scientists, however, this means big problems. If quality of life can be defined in several ways, it is necessary to explain the content of the concept precisely in every single study and consider the context of the concept in every single group that is a target of the study. Several preliminary decisions must be made before a

researcher can explicate the concept of quality of life that underlies his or her study.

Depending on the aim and the strategy of the research, the concept of quality of life is presented as a starting point or as a result of the study. In both cases researchers have utilized hypothetical reasoning or previous empirically produced results in developing their quality-of-life models. Conceptual models then serve as a framework of the study, or the models can be tested by applying multivariate statistical analyses. Typically, the models consist of main concepts and their relations. Additionally, main concepts are divided into terms and consequent lists of variables. When quality of life is defined as a multidimensional

concept, several dimensions are often seen together as domains of life or other kinds of subgroups.

Quality-of-life research in the field of intellectual disability is most commonly based on Anglo-American studies on quality of life in the general population. This tradition has labelled discourses in the direction that emphasizes an individually focused conceptualization of the term "quality of life." Finnish quality-of-life studies, however, have their roots in Scandinavian welfare studies as well.

4.1.1 Quality-of-life models for the general population

The origin of many checklists of quality-of-life indicators is said to be found in Abraham Maslow's (1954) "hierarchy of needs": (a) physiological needs, (b) safety, (c) affiliation and affection, (d) esteem, and (e) self-actualization.

In "The Comparative Scandinavian Study" (Allardt, 1975), the primary emphasis was on objective measures of welfare. A rationale for this decision was based on both conceptual and empirical arguments. Referring to von Wright (1963, pp. 87-88) Allardt stated that welfare, based on objective measures, and happiness, based on subjective measures, have very different relationships to time and causality. Happiness can be assessed without considering its causes and consequences, whereas welfare judgements are always permeated with causal

assumptions. He fitted welfare values (having, loving, and being) and welfare attitudes (dissatisfaction attitudes and satisfaction attitudes) into a four-fold table (see Table 1) in a manner presented in Table 2. According to Allardt, in many respects dissatisfaction attitudes are orientated toward external conditions of level of living, whereas the satisfaction attitudes measure general feelings or states of mind related to elements of quality of life, such as social relationships and self-esteem.

Norwegian researchers have regarded "quality of life" as a psychological indicator of welfare, in contrast to "level of living" which they have seen as a socio-economic indicator of welfare (Naess, 1987). They have defined quality of life as follows: "A person enjoys a high quality of life (or well-being) to the degree that that person (1) is active, (2) relates well to others, (3) has self-esteem, and (4) a basic mood of happiness" (Naess, 1987, p. 14).

Frank Andrews and Stephen Withey (1976, pp. 10-18) defined well-being indicators occurring at several levels. The most global indicators are those that refer to life as a whole. In order to obtain evaluations of well-being at the global level, one could ask for example "How do you feel about your life as a whole? How happy are you these days? and Is your life better, worse, or about same as that of other people?" At a more specific level are general evaluations of what they called life "concerns." Concerns are

Table 2. Having, Loving and Being as Indicators of Welfare (Allardt, 1975, p. 20).

	Welfare	Happiness
Level of living	(1) Having - Income - Housing - Employment - Health - Education	(4) Dissatisfaction attitudes - Perceived antagonism - Perceived discrimination - Perceived unjust privileges - Income satisfaction
Quality of life	(2) Loving - Community attachment - Family attachment - Friendship patterns (3) Being - Personal prestige - Insubstitutability (uniqueness) - Political resources - Doing	(4) Satisfaction attitudes (needs satisfaction) - Perceived happiness - Perceived needs satisfaction

aspects of life about which people have feelings. Examples of questions that assess well-being at the concern level are “How do you feel about your house or apartment? How do you feel about your marriage? and How do you feel about what you are accomplishing in your life?” Andrews and Withey divided concerns into two types: “domains” and “criteria” (or “values”). Domains of life are places, things, activities, people and roles. Criteria are values, standards, aspirations, goals, and ways of judging what domains of life afford. This two-dimensional conceptual model of domains and criteria with evaluations of well-being at three levels of specificity served as the framework of their empirical study.

John Flanagan (1978) asked nearly 3000 people to identify expe-

riences and behaviors that they found to be particularly important or satisfying in their lives. They then classified the answers into 15 quality-of-life components under five general headings: (a) physical and material well-being (material well-being, financial security, health, and personal safety); (b) relations with other people (relations with spouse; having and raising children; relations with parents, siblings, or other relatives; and relations with friends); (c) social, community, and civic activities (helping or encouraging other people and participating in public and governmental affairs); (d) personal development and fulfillment (intellectual development, personal planning and self-understanding, occupational role, and creativity and personal expression;

and (e) recreation (socializing, passive recreation, and active recreation).

Psychological interest in studying people's quality of life has recently focused more clearly on subjective well-being (SWB). Subjective well-being is defined by three correlated but distinct factors: the relative presence of positive affect, absence of negative affect, and satisfaction with life (Myers & Diener, 1995). At the cognitive level, SWB includes a global sense of satisfaction with life, fed by specific satisfaction with one's work, home life and other domains. At the affective level, people with high SWB feel primarily pleasant emotions, thanks largely to their positive appraisal of ongoing events. People with low SWB appraise their life circumstances and events as undesirable, and therefore feel unpleasant emotions such as anxiety, depression and anger.

When the SWB is adapted for use with people with intellectual disabilities it might be asked whether its components lend themselves to similar evaluations. As people with intellectual disabilities obviously have fewer cognitive skills at their disposal, the affective level might have a more prominent role in producing SWB in people with intellectual disabilities.

4.1.2 Quality-of-life models for people with intellectual disabilities

It is commonly believed that quality of life should be conceptualized similarly for individuals with and without disabilities (Goode, 1988b, 1994a; Heal et al., 1996). If quality of life has a status as a measurable psychological construct, it must obviously have similar meaning for the entire range of mental ability. If it is considered as a social construct, it is as obvious that it should be relevant for all people, including those who have disabilities. Nevertheless, Flanagan (1982) proposed that quality of life for people with disabilities should be evaluated within the context of individual physical, mental, or emotional disabilities (Heal et al., 1996). It is interesting to see how models of quality of life developed for the general population differ from those models applied to people with intellectual disabilities.

Sharon Landesman (1986) suggested that there are two separate phenomena: quality of life and satisfaction with life. Quality of life is the sum of a range of objectively measurable life conditions experienced by an individual. Subjective response to such conditions, on the other hand, is the domain of personal satisfaction of life.

David Goode (1990) took an ecological approach in arguing that quality of life is something experienced in particular settings and is highly responsive to the social relationships the individual with disabilities has in those settings.

Trevor Parmenter (1988, 1992) approached quality of life from a symbolic-interactionist / ecological theoretical perspective, including three components of quality of life in his model. According to him, the first pertains to an individual's perception of self (i.e. cognitive, affective, and personal life-style); the second to the individual's behavior in response to ecological domains that might affect him or her (i.e. functional behaviors like social interactions, occupational/material well-being, accommodation and access); and the third to responses the settings might produce in the individual (i.e. societal influences, including attitude, values, economics, political views etc.).

Sharon Borthwick-Duffy (1992) presented three perspectives on quality of life. Quality of life defined as (a) the quality of one's life conditions that have an impact on an individual's personal satisfaction (Edgerton, 1990; Landesman, 1986), (b) satisfaction with life conditions that are not part of quality of life but have an impact on it (Stark & Goldsbury, 1990; Taylor & Bogdan, 1990), and (c) a combination of both life conditions and satisfaction (Schalock et al., 1990).

David Felce and Jonathan Perry (1996) also attempted to make a synthesis of several conceptualizations of quality of life presented in the field of intellectual disability (Borthwick-Duffy, 1992; Brown, 1988; Goode, 1988c, 1994b; Schalock, 1990b) and in the literature concerning other groups and society as a whole (Bigelow et al., 1991; Campbell et al., 1976; Parmenter, 1988). Their formulation comprised a model in which personal values, life conditions and personal satisfaction interact to determine quality of life. By doing this they added the element of personal value to the three perspectives presented by Borthwick-Duffy (1992). Based on a review of the literature (Felce & Perry, 1995) they suggested a five-way categorization of life domains: physical well-being, material well-being, social well-being, development and activity, and emotional well-being. Based on these five categories, they developed a model of quality of life.

Robert Schalock, who has edited several books dealing with quality of life of people with intellectual disabilities and conducted many empirical studies on quality of life (1990a, 1990c, 1992, 1994, 1996b, 1997a; Schalock et al., 2000), developed his model of quality of life in several stages using conceptual and empirical analyses. As a result, his latest model (Schalock et al., 2000) includes life satisfaction affected by subjective well-being

(including dignity, work, independence and integration) that, in turn, are affected by predictor variables like respondent characteristics and services received.

At least two types of models can be found: (a) Simple additive models of quality of life describe domains of life and items included these domains. A quality-of-life index could then be calculated by summing up the domain scores, and quality-of-life profiles could be composed for every single domain of life; (b) Causal models of quality of life indicate the effects of certain characteristics and domains of life on the other domains of life that are defined to express a person's overall quality of life (outcome measure). As quality of life is seen as a concept that has no meaning apart from what a person feels and experiences (Taylor & Bogdan, 1990), it is obvious that the process through which the quality-of-life appraisal of a person is produced includes evaluative processes of the person and that these processes vary from person to person.

There seems to be more consensus about objective indicators of quality of life than subjective indicators. Felce follows Robert Cummins in suggesting that subjective indicators could be defined as satisfaction with objective life domains, and personal values could serve as weights to these domains. Later, this construct was strongly criticized by Alastair Ager and Chris Hatton (1999), among others.

Hatton (1998) stated that although the specifics of particular quality of life models differ, there appears to be broad agreement about what constitutes quality of life and the purpose of measuring quality of life in services for people with mental retardation. Referring to Canadian, Australian, British and U.S. studies (Brown, 1997a; Cummins et al., 1994; Felce & Perry, 1995; Goode, 1994a; Heal et al., 1996; Heal & Sigelman, 1996; Schalock, 1990b, 1996a, 1996b, 1997b) Hatton presents three components of this emerging consensus: (1) Quality of life is multidimensional, yet summable, (2) Comprehensive quality of life assessment must include objective and subjective components, and (3) Quality of life should be used as the ultimate yardstick of service quality.

International collaboration in order to find consensus in conceptualizing, measuring and applying quality of life in the context of intellectual disability has been organized by The Quality of Life Special Interest Group of The International Association for Study of the Scientific Intellectual Disabilities (IASSID). This group has recently suggested (IASSID, 2000) that quality of life might best be viewed as a sensitizing concept (rather than the definitive one) relevant to public policy determination, evaluation of services, and development of innovative local, national and international programs. However, it remains a notion rooted

in individual perceptions and values and is capable of contributing to the identification of necessary supports and services. Individual perceptions and values — the subjective views of individual persons — are recognized as a key facet of quality of life by virtually all present-day researchers.

The concept of quality of life was discussed from two perspectives: (a) core ideas and principles; and (b) implications, which then lead to measurement and application issues. The core ideas were: domains of well-being; inter- and intra-personal variability; personal context; life span perspective; holism; values, choices, and personal control; perception; self image; and empowerment. In addition, a number of core quality-of-life conceptualization principles have emerged in the international literature of quality of life that provide the framework for measurement and application. Quality of life was seen primarily as:

- composed of those same factors and relationships for people with intellectual disabilities that are important to those without disabilities
- experienced when a person's needs are met and when one has the opportunity to pursue life enrichment in major life settings
- having both subjective and objective components, although it is

primarily the perception of the individual that reflects the quality of life he/she experiences

- based on individual needs, choices, and control
- a multidimensional construct influenced by personal and environmental factors such as intimate relationships, family life, friendships, work, neighborhood, city or town of residence, housing, education, health, standard of living, and the state of one's nation.

This consensus paper (IASSID, 2000), as such, illustrates the discursive nature of quality of life.

4.2 Quality-of-life models in scientific paradigms or in separate discourses

Gibson Burrell and Gareth Morgan (1979) presented a typology of four fundamental scientific paradigms organized according to notions of the nature of reality and notions of the nature of society. Quality-of-life models could be described in this kind of framework, as well.

The nature of society can also be seen as recognition of the state of cultural diversity. Homogenous and consensus notions are evidence of a society which has unified values. For example Robert Edgerton (1990) pointed that this is not true in the

U.S. or in the world generally. It would be an interesting task for quality-of-life research to investigate the extent to which we share values behind several quality-of-life scales. Are there some issues that we all could accept as an inevitable part of the concept of quality of life that we are trying to cover with these scales, or should we totally abandon the idea of a normative quality-of-life concept? In order to illustrate this problem, a tentative mapping of quality-of-life models in the context of Burrell and Morgan's typology is presented in Figure 3.

To conclude this summary of the discourses of quality of life in the field of intellectual disability, it seems obvious that seeking consensus on its conceptualization and measurement will continue in the context of quality of services, and scales will be constructed for the purpose of evaluation. However, the time of large population-based surveys of quality of life in people with intellectual disabilities seems to be over.

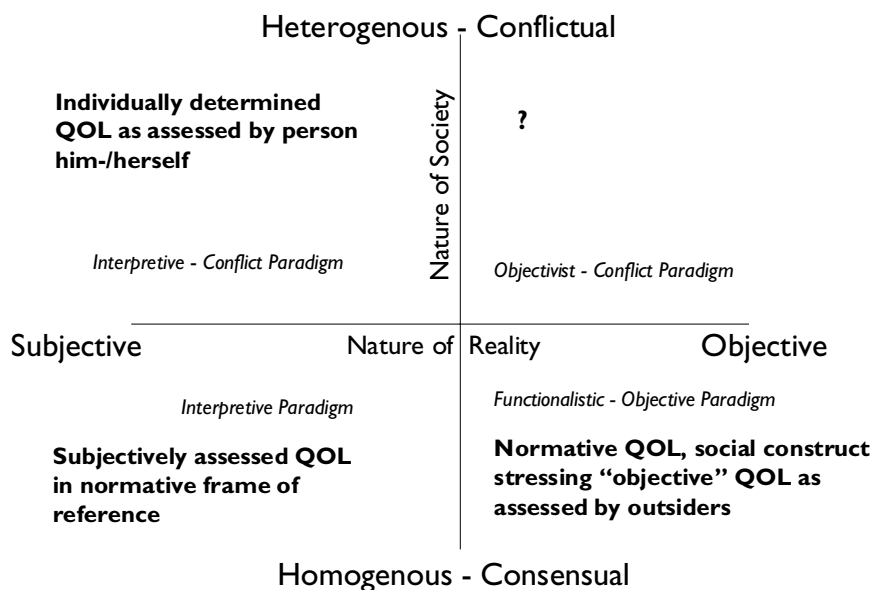


Figure 3. A Tentative Mapping of Quality-of-Life Concepts Applying the Typology of Burrell and Morgan (1979).

5 Measurement of quality of life of people with intellectual disabilities

5.1 Is quality of life measurable?

Steven Taylor and Robert Bogdan (1990) argued that as no single instrument is likely to capture quality of life as actually experienced by people, it is better to think of quality of life as a sensitizing concept. They pointed out that the distinction between sensitizing concepts and definitive concepts was made by the sociologist Herbert Blumer (1969, pp. 147-148) as follows:

I think that thoughtful study shows conclusively that the concepts of our discipline are fundamentally sensitizing instruments. Hence, I call them "sensitizing concepts" and put them in contrast with definitive concepts . . . A definitive concept refers precisely to what is common in a class of objects, by the aid of clear

definition in terms of attributes or fixed bench marks. This definition, or the bench marks, serve as a means of clearly identifying the individual instance of the class and the make-up of that instance that is covered by the concept. A sensitizing concept lacks the specification of attributes or bench marks and consequently it does not enable the user to move directly to the instance and its relevant content. Instead, it gives the user a general sense of reference and guidance in approaching empirical instances. Whereas definitive concepts provide prescriptions of what to see, sensitizing concepts merely suggest directions along which to look.

Since the publication of Taylor and Bogdan's chapter, quality of life as a sensitizing concept has been widely referred to in the field of intellectual disability (e.g., IASSID, 2000). The discussion of the concept could be connected to a broader discussion of the measurement of quality of life or discussions of qualitative and quantitative methods. It seems to me that researchers who stress the sensitizing nature of quality of life do not accept using trials in order to develop scales for measuring quality of life, and those who have been developing quality-of-life scales base their scales on a rather narrow conceptualization of quality of life.

5.2 Objective and subjective indicators

The words "objective" and "subjective" are not entirely clear and unambiguous in quality-of-life research. According to Allardt (1993) objective refers to reports of factual conditions and overt behavior, whereas subjective stands for measurement of attitudes. In using subjective indicators, one is in fact studying people's wants. The objective indicators, however, sometimes refer to needs and sometimes to wants. The main point is that they are designed by experts who may think of both the needs and the wants of people in deciding what should be recorded about people's living conditions. When objective

indicators are used, respondents are not asked to evaluate whether their living conditions are good or bad. They are simply asked to report their living conditions or overt behavior according to some given measures.

Subjective measures are often understood as satisfaction felt about domains of objective indicators (Allardt, 1993; Andrews & Withey, 1976; Campbell et al., 1976; Cummins, 1997a). Emergence of subjective indicators has meant that individual appraisals were given more value than in the early days of measuring living conditions of populations. Dividing indicators into two categories was not accepted without criticism. Allardt (1993) preferred using both objective and subjective indicators as a practical solution in order to diminish the conservatism usually attached to the sole use of subjective indicators, while avoiding the undue dogmatism resulting from the use of objective indicators only.

Andrews and Withey (1976, pp. 5-6) regarded a division between objective and subjective indicators as spurious and suggested instead that three other dimensions of the phenomena that are being indicated be considered: (a) the extent to which people agree on how to characterize a given phenomena, (b) the degree to which the same sensory or neural input at some level of the nervous system is available to co-observers, and (c) the extent to which different people can take similar action in response to a

phenomenon. They concluded that it may be more helpful and meaningful to consider the individualistic or consensual aspects of phenomena, the private or public accessibility of evidence, and the different forms and patterns of behavior needed to change something, rather than to cling to the more simplistic notions of objective and subjective.

Roy Brown (1997b) argues that the dichotomy of objectivity and subjectivity employed in quality-of-life studies is confusing and arbitrary. He refers to Andrews (1974), who pointed out that people respond to their perceptions rather than to more objective data. As personal views can be presented orally or registered non-verbally, they represent an externalization of personal and internal processes in forms that are measurable and replicable. They represent a system of data which we can value, not as expressions of belief or objective understanding, but as objective measures of perceived phenomena. It is the denial of the "reality" of these stated perceptions which has caused scientists to ignore such phenomena, arguing they are not measurable. We cannot understand behavior in its social context unless we are willing to accept quality of life as measurable scientific concept. If personal perceptions differ from those of others or from external data arising from other sources, this does not make them more correct or incorrect. It simply means that they represent another useful data source.

The WHOQOL Group (1994), at the World Health Organization, developed their WHOQOL-100 scale on the bases of the definition of quality of life as a person's perception of his/her life circumstances within the context of the culture and value systems in which he/she lives and in relation to his/her goals, expectations, standards and concerns. The multidimensional nature of quality of life is reflected on a scale consisting of four domains (physical health, psychological, social relationships and environment) and several facets of these domains. When health-related quality of life was used as an outcome measure, a question arose about who should measure quality of life. The wide discrepancies between doctors' and patients' assessments led the researchers to conclude that outcome measures should take individuals' self-assessments into account (Slevin et al., 1988).

Edgerton (1990) cited Mark Schneider (1976) in stating that "providing improved objective standards of living does not necessarily increase people's sense of well-being because, although the quality of life can be measured by objective criteria, it is experienced subjectively." After studying the life courses of persons with disabilities Edgerton depicted differences between quality of life and sense of well-being. In his view, quality of life is a normative and measurable multidimensional concept that is assessed by "other people," whereas

sense of well-being is close to happiness or subjective well-being and is assessed by each person. He also pointed out that people living in conditions that could be evaluated as miserable by most of people might still feel satisfied with their lives (cf.

Allardt, 1976). In his examples those people had good social networks or some aspect of their life that they appreciated a lot, and they had freedom to choose among alternatives.

6 Previous studies of quality of life of people with intellectual disabilities

Previous studies in this area can roughly be divided into studies employing quantitative methods and those employing qualitative methods. Qualitative approaches to quality-of-life issues were prominent especially in the United States (Edgerton, 1967; Goode, 1988a, 1988c, 1994a; Taylor & Bogdan, 1990). The advantages of this approach lie in a deeper understanding of the phenomena and evaluation of the ecological and social validity of the concept. A disadvantage is the lack of numerical information that is often expected by politicians.

Previous empirical studies using quantitative methods to study the quality of life of people with intellectual disabilities can be grouped according to the purposes of the studies: (a) surveys depicting quality of life of people with intellectual

disabilities, (b) longitudinal studies depicting changes in quality of life in various phases of people's life courses, (c) comparative studies searching for differences in quality of lives of people with intellectual disabilities living in diverse settings, (d) comparative studies searching for differences between quality of life of people with intellectual disabilities and that of the general population, and (e) studies developing or evaluating scales designed to measure quality of life.

6.1 Surveys

Studies depicting quality of life use diverse methods, both quantitative and qualitative. An important issue in evaluating these studies would be to investigate how well the study sample represented the target popu-

lation. Analogous to nationwide well-being surveys of the general population, the studies targeted to people with disabilities could employ the framework of a nation or other culturally coherent sub-region or that of a sub-group.

Nationwide studies might have good opportunities to reveal bad conditions and defects in the lives of the groups surveyed and consequently help to improve welfare service systems and their legislative basis in a particular country. A disadvantage of surveys employing interviews is that the results reflect the conditions of the time of investigation and follow-up studies are not often possible because of the substantial expenses of data gathering. Nationwide or large regional surveys where people with intellectual disabilities themselves were interviewed (not their proxies) were, however, not reported until the publication of the research that was done for this dissertation.

6.2 Longitudinal studies

Numerous studies of happiness, subjective well-being and quality of life have showed that personal satisfaction with life is quite stable in the long run (Diener, 1984; Diener et al., 1999; Myers & Diener, 1995). According to Edgerton (1990), the pattern that emerges repeatedly in people with intellectual disabilities is that people who were happy and hopeful 10, 20 or even 30 years ago

remain so no matter what ill-fortune they suffer, and those who were sad or negative about life do not change even if their environment improves significantly. Changes in mood or emotional state are rapid, and expressions of dissatisfaction or satisfaction with life are often linked to experiences in the immediate past. Many have endured the death of loved ones, have been the victims of such crimes as rape or robbery, or have lost their jobs, and have still remained satisfied with their lives and optimistic about the future. Others, despite finding better jobs, making new friends, and winning increased respect from friends and relatives, continue to complain about everything and express the fear that the future will be as bad, if not worse.

Nationwide, population-based, longitudinal quality-of-life studies are rare. A Finnish group studying the life course of people with intellectual disabilities was sailing in uncharted waters when it started its own multidisciplinary follow-up study from 1962 to 1998 (Matikka et al., 2000; Vesala & Matikka, 2000). On the other hand, some longitudinal studies where the subjects come from a special geographical area or from special institutions or schools have been reported (e.g., Conroy & Bradley, 1985; Edgerton, 1967; Edgerton & Bercovici, 1976; Edgerton et al., 1984). In Finland, Ulla Lahtinen started a follow-up study on the development of functional ability of young people

with intellectual disabilities living in diverse settings in the 1970's and continued the study with her colleagues in the 1990's (Lahtinen, 1986; Romar et al., 1998). Marketta Korhonen and Leena Matikka have followed up students with intellectual disabilities after their special vocational education since 1980, focusing on living circumstances and changes in self-concept (Korhonen & Matikka, 1991; Matikka, 1996b).

6.3 Comparative studies and scale construction

Quality-of-life scales were developed in order to compare conditions of people living in different settings that had been designed to support these people. A main argument for closing institutions and establishing community-based services was to improve the quality of life of service recipients. The substance of the scales was then determined from this viewpoint. The scales needed to be sensitive in differentiating satisfaction and qualities of residential settings and supportive services (Heal & Chadsey-Rusch, 1985; Schalock et al., 1990). This practical approach started to dominate other perhaps more theoretical approaches in quality-of-life studies applied to people with intellectual disabilities. Quality of life was put into the context of intellectual disability and the special needs of people with

intellectual disabilities and, consequently, into the context of services provided for this special group of people. It became an important outcome measure of services provided for these people.

At the time the first scales were developed for this purpose, the normalization principle was the dominating ideology in the field. That is why the theoretical background of most scales and quality-of-life studies rests on a conception of what makes for an ordinary normal life. For example, the Swedish Mental Retardation Project combined the idea of normalization with the ideas of quality of life defined by Siri Naess (Hjärpe, 1984; Kebbon et al., 1981; Kebbon et al., 1982; Sonnander & Nilsson-Embros, 1984). Later, a more person-centered view was adopted and such issues as satisfaction, empowerment, personal control, self-esteem, and self-reported health were included in the scales (Cummins, 1992, 1997b; Schalock, 1988; Schalock et al., 1990; Wehmeyer & Schwartz, 1998). It is difficult to say whether this development was a consequence of adopting ideas from the mainstream of happiness studies or a consequence of a paradigm shift in the field of intellectual disability. At any rate, happiness was taken as a part of quality of life scales, along with personal control and self-determination.

The history of the development of quality-of-life scales indicates that in the field of intellectual disability quality of life has become a social construct that changes its scope according to changes in service paradigms. Attempts to use quality of life as a psychological construct

were not very successful. Heuristic models have inspired research in developing questionnaires to assess quality of life, and several reviews of these have been made. Nevertheless, these models have seldom been tested in ambitious, large-scale studies.

7 Purpose of the Study

The three-fold purpose of this study was (1) to examine what constitutes quality of life of people with intellectual disabilities and which factors affect quality of life of people with intellectual disabilities, (2) to construct measures of quality of life which could be used in assessing the quality of residential services provided for people with intellectual disabilities in order to enhance their quality of life, and (3) to depict the quality of life of adults with intellectual disabilities living in Finland in 1990s.

The study addresses the following questions:

1. How can the quality of life of people with intellectual disabilities be conceptualized?
 - 1.1. Which life domains must be included in a definition of quality of life of people with intellectual disabilities? (Studies I & V)
 - 1.2. Which factors affect quality of life? (Study II)
 - 1.3. How is quality of life related to the personal characteristics and living conditions of persons? (Study II)
2. How can valid and reliable measures of the quality of life of people with intellectual disabilities be constructed?
 - 2.1. Do persons with intellectual disabilities exhibit acquiescence and naysaying in quality-of-life surveys to such an extent that their self-reports can not be used to determine their quality of life? (Study III)
 - 2.2. How can a quality-of-life scale be constructed to assess quality of residential services? (Study V)
3. What was the quality of life of Finnish adults with intellectual disabilities in the 1990s?

The research focused on defining quality of life, on testing its construct and related factors, and on depicting the lives of subjects. This was done

to improve our understanding of the concept, measurement and application of quality of life.

8 Methods

8.1 Outline of the present study

The present study draws on the findings of two projects of the FAMR Research Unit that investigated the quality of life and quality of services provided for people with intellectual disabilities. The projects involved several researchers and were supervised by the author.

The main purposes of the FAMR-QOL project were (a) to depict the quality of life (QOL) of adults with intellectual disabilities (ID) nationwide, in the country's various regions, and in individual care units, (b) to investigate factors affecting to the QOL of persons with ID, (c) to develop methods for studying the QOL of the persons with ID, and (d) to develop methods to help enhance the QOL of persons with ID. The general method was to survey a nationwide random sample of adults with intellectual disabilities receiving residential services or participating in daily activities in

Finland in 1990 and to gather background information about them. In the present study only the interview data obtained from people with mild intellectual disabilities were utilized. For more information concerning data and reporting, see the Appendix.

The aim of the FAMR-Assi project was to develop an assessment model for evaluation and developmental work targeted to improve residential services provided for adults with ID. The name "Assi"—a Finnish girl name—was given to the product that FAMR Research Unit created for the assessment of the quality of residential services of people with intellectual disabilities. The core of the product is the Assi data bank, which was established in order to gather norm data for the assessment scales developed that would allow the results of an individual facility to be compared to

national averages. The assessment of services was based on four kinds of data: (a) interviews of individual recipients using the Subjective well-being (SWB) scale, (b) postal questionnaires on living conditions and services of individual recipients; these were filled in by their direct care workers, (c) background information on the personal characteristics of the individual recipients, and (d) information on the culture, working practices, and services of the units. In the present study, the interviews of people with ID were utilized in order to develop a scale of subjective well-being.

8.2 Participants

8.2.1 Sampling of the FAMR-QOL Survey

The sampling of the FAMR-QOL study was conducted in two major stages: service unit sampling and service consumer sampling. Basic and supplemental sampling were done in September 1989. The initial sampling was a systematic cluster sampling. The first step in this process was to select a location in the catalogue's national alphabetical directory at the National Board of Social Welfare. Every fortieth unit following this location was incorporated into the sample. Inasmuch as some new group homes were not included in the catalogue, it was necessary to augment the basic sample. In co-operation with

Finland's special-care districts, a catalogue of small group homes was assembled. The sample drawn from it (sampling interval, 20) was then added to the basic sample.

For the supplemental sampling, the same catalogue was used to create district-by-district catalogues. From these, additional units (sampling interval, 6) were incorporated into the sample. These formed the supplemental sample, in which the districts were allowed to propose changes. The entire sample consisted of 46 group homes, 9 institutions, 4 foster families, 22 sheltered workshops, and 16 day care and activity centers. With the exception of the Åland district, all of Finland's special care districts were represented in the sample (Autio, 1992b). For several practical reasons, the original sample was not finalized exactly according to the plan. Some of the units in the supplemental part of the sample did not participate and were replaced by other units from the same region.

Service consumer sampling was done on the basis of a service unit sample. The objective was to include from each unit some 5 to 10 people working or living together. Since there were several groups of this sort in some units, one of them was chosen at random. In all, the total sample encompassed 822 persons with intellectual disabilities throughout Finland.

This sampling method and the representativeness of the sample are documented by Autio (1992b). In examining its representativeness, the

entire research sample was treated as a whole, combining the data for persons with mild and severe intellectual disabilities. Comparisons were made with statistical data published by National Board of Social Welfare regarding persons who have received special care services. The most recent data of this sort date from 1986. Comparisons were made with respect to age, gender, level of intellectual disability, special care district and place of residence. In terms of age and gender distribution, the sample corresponds fairly well to the national data for persons who were older than 17 years with intellectual disabilities. However, the sample is skewed to some extent toward those with mild intellectual disabilities. This is also visible as an underrepresentation of persons living in institutions.

In considering the impact of the representativeness of the sample on its suitability for generalized findings, it should be noted that the studies on persons who could be interviewed and those whose quality of life was studied by postal questionnaires sent to proxies produced separate data sets, and the results are presented separately. Only those interviewed are subjects of the present study.

The original size of the survey sample was 822 persons, but 43 (5%) refused to participate or could not be contacted. Of the remaining 779 persons, 163 (21%) were excluded at different phases of the study: (a) 89 persons were not interviewed be-

cause the interviewer or staff did not feel that they had the necessary interactive and/or communicative skills; (b) 35 other persons began the interview but did not complete it because they were unable to answer most of questions, got tired, or, in the opinion of the interviewer, did not understand the questions. Interviews of an additional 39 individuals were later rejected because the interviewers considered the answers unreliable. Most of these 163 persons had profound or severe mental retardation (70%) and lacked sufficient communication skills to participate in an interview (70%).

A total of 616 adults with ID were studied. They ranged in age from 18 to 69 years (mean = 36.9, standard deviation [SD] = 10.9), and 51% of them were men. Most had either mild (44%) or moderate (39%) mental retardation, 5% were diagnosed as having average or borderline intelligence, and 6% had severe mental retardation. Nearly one third of the interviewees (31%) lived with their parents or relatives; 13% had their own apartments; 35% lived in group homes; 13% lived in institutions or group homes where staff were present around the clock; and 5% lived in foster-family care. The mother tongue of 94% of subjects was Finnish, of 5% Swedish; of 1% the mother tongue was not known (Matikka, 1994).

8.2.2 Sample of the Assi project

The subjects targeted for the present study were 421 recipients of 71 agencies providing services for people with ID. Of the recipients, 50.1% were men. The mean age of the subjects was 40.1 years (SD=11.8, range 18-74 years). Comparisons to the national statistical data of the people with intellectual disabilities (Matikka & Aaltonen, 1998) showed that the present study group included relatively more persons aged 30-39 years and relatively fewer persons aged 50 years or over. Due to the use of interviews

as a research method, the study group included relatively more people with mild than severe intellectual disabilities. For more detailed background information of the study group, see the original publication (Study V).

The demographic characteristics of the samples are presented in Table 3.

Table 3. Demographic Characteristics of the Samples in Studies I - V.

Study	Sample characteristics	Study period	Number of subjects	Age (Mean)	Age (SD)	Age (Range)	Gender, % males	Level of intellectual disability
I FAMR- QOL study	Sample of persons with intellectual disabilities who received special services	1990-1992	762	35.9	11.0	18-69	50.5	normal/borderline 4% mild 37% moderate 35% severe 12% profound 5% unknown 7%
II FAMR- QOL study	All participants in the FAMR-QOL study who could be interviewed (communication was good enough with 81.2%)	1990-1991	619	36.9	10.9	18-69	51.0	normal/borderline 5% mild 44% moderate 39% severe 5% unknown 7%
III FAMR- QOL study	All participants in the FAMR-QOL study who were successfully interviewed (80.8%)	1990-1991	616	36.9	10.9	18-69	51.0	normal/borderline 5% mild 44% moderate 39% severe 5% unknown 7%
IV	Same persons as in studies II and III, plus 297 persons with intellectual disabilities who were interviewed for assessment of the quality of services they used (Assi data bank)	1994-1996	297	40.2	12.1	18-74	50.0	normal/borderline 7% mild 33 % moderate 38% severe 6 % unknown 16%
V As si data bank	Persons with intellectual disabilities who were interviewed to assess the quality of services they used	1994-1999	421	40.1	11.8	18-74	50.1	normal/borderline 7% mild 36% moderate 40% severe 5% unknown 12%

8.3 Procedure

The FAMR-QOL Survey. The nationwide survey was conducted in 1990-1991. Participants were interviewed individually in their residences or work places; in a few cases (3%) there was a third person present (usually a parent or a staff member). The duration of the interviews varied from 30 minutes to 7 hours 25 minutes. Most interviews (66%) took 1 to 3 hours, and 23% took longer than 3 hours. Sometimes the interview was interrupted and continued after a short rest or on another day. There were 81 interviewers. Seventy-one female interviewers interviewed 544 persons, and 10 male interviewers interviewed 72 persons. Most were employees of special-care agencies for people with mental retardation. However, no interviewer questioned subjects from their own units. A few interviews were conducted by social work or health care students. Interviewers were trained by the researchers, and written instructions (Autio, 1991, Appendix 3) were given to all of them. Beforehand, information about the research and ethical issues concerning it were distributed to the sample units and in simplified language to the persons who were included in the research.

The Assi project. The data was gathered beginning in 1995 from the service units that ordered the evaluation of their services. From 1995 to 1999 a total of 421 persons from 71 service units were interviewed. The sample was not randomly drawn

from service units, but was determined by the units, which were interested in improving their work and service quality. With respect to the interviews, principles similar to those used the FAMR-QOL survey were followed in recruitment of interviewers and in practical issues of data gathering.

Ethical considerations. All the participants were informed that their participation was voluntary and that their responses would be confidential. Informed consent was obtained from all participants before an interview, and interviewers were instructed to interrupt an interview immediately if a respondent became upset. Most survey questions dealt with the subject's everyday life and were designed to have little or no effect on the emotional state of the individual respondent. However, it was possible that some respondents might become angry or upset by certain questions such as those dealing with areas of their life in which they were not content or which they were not willing to discuss. Interviews were usually conducted at the respondent's home or work place, which guaranteed the support of close persons who were available if needed.

On the whole, respondents cooperated well and were very satisfied with the interview situations. They expressed joy at being given the chance to present their ideas about life. Some questions, however,

evoked bad memories. It was also difficult for some respondents to understand the nature of research as an independent situation that did not have a direct effect their living circumstances. For these reasons it was important to carefully discuss with them many issues concerning the research.

8.4 Measures

Quality-of-life questionnaire (Studies I, II, III, IV). The questionnaire consisted of 189 questions about quality of life, 31 about individual characteristics and living conditions (e.g., age, gender, level of mental retardation, education, and residential circumstances) and 5 that the interviewers answered about the interview situation and their evaluation of it (Matikka, 1993a).

Quality-of-life questions were designed using results of the group discussions (Öhman, 1991) and the theoretical framework of previous Nordic welfare studies (Allardt, 1975; Allardt & Uusitalo, 1977; Naess, 1987). The content of the questionnaire was also affected by American quality-of-life studies on persons with intellectual disabilities (e.g., Schalock, 1988; Schalock et al., 1989) and by the Swedish Mental Retardation Project (Fager, 1982; Hjärpe, 1984; Kebbon et al., 1981; Kebbon et al., 1982; Sonnander & Nilsson-Embros, 1984).

Most of the questions were in a "yes/no" format and many were

followed by a supplementary question in an effort to quantify the response. Pictogram cards were used in order to help interviewees answer questions and clarify answer categories. The questionnaire was originally drafted by Antero Myhrman and Pentti Kolari and further developed and piloted by Tiina Autio and Anneli Öhman under the supervision of Jarkko Hautamäki. Sari Toivonen and the author assessed its reliability and validity in a postal questionnaire sent to the interviewers in 1991 (Matikka, 1993a).

Quality-of-life questions were grouped according to domains of life as follows: Residential circumstances, work, financial subsistence, leisure time, social relationships, psychological factors, awareness of one's disability and access to information. On the bases of 189 quality-of-life questions, three summed variables depicting perceived QOL were constructed: happiness, a positive view of life, and stress. The reliability of the sum scores was tested by using Cronbach alpha coefficients and was found to be acceptable (varying from .46 to .87) with the exception of happiness (.46) (Table 1, Study II, p. 120). These sum scores were used in the analyses for Study II and Study IV.

Subjective well-being scale (SWB) (Studies IV, V). The subjective well-being scale was developed in several phases by item analysis, explorative factor analyses and by investigating the internal

consistency of the sub-scales. The first field test version (SWB0) contained 146 items mostly in a “yes/no” format. It also included twelve oppositely worded question pairs planned to measure acquiescence. In order to choose the best items for further development of the scale, the data of 297 interviews were first analyzed by exploring item frequencies, “don’t know” answers, missing values, acquiescence, and comments of interviewers.

Acquiescence measured by using oppositely worded question pairs varied according to an item pair from 9% to 43%; the mean was 23%. Based on the results of item analyses, 74 items were chosen for further analyses.

Test-retest procedure was used to study reliability. A total of 47 persons were interviewed by another interviewer after three weeks of the first interview. Phi coefficients of the items varied from 0.02 to 1.00 (in SWB3 version: from 0.18 to 1.00).

In order to study the construct of the SWB scale, explorative factor analyses were conducted with 65 items of the SWB0 version (N=297) and with 45 items of the SWB1 version (N=353) excluding items dealing with work, because these items were not addressed to all subjects, and some items because their distributions were skewed. SWB with eight sub-scales was developed on the bases of the six factors that were extracted by factor analysis and the items dealing with happiness and work that were not

included in the factor analysis. The internal consistency of the scale was investigated by Cronbach alpha coefficients. The number of items was further reduced in order to increase the values of the alpha coefficients of the eight sub-scales.

Convergent and divergent validity of the SWB scale was tested by the Multitrait Multimethod Matrix (Campbell & Fiske, 1959, referred to by Spector, 1992, p. 53) using ComQOL-ID (Cummins, 1993) as a parallel scale (N=53). The results indicated that both scales measured quite different constructs (for more detail information, see Study V, pp. 55-57).

The SWB scale was further developed for the Finnish Life Course Study (Nummelin et al., 2001) and for the survey of People First conference in Alaska (Trigler, 1998), and data drawn from these studies were used for SWB scale analyses (Study V, pp. 58-63).

As a result of the analyses of SWB0, SWB1, and SWB2 versions as well as of two English versions, SWB3 was constructed from 65 structured and 8 open ended questions. The SWB3 scale was divided in eight sub-scales. The internal consistency of the sub-scales was satisfactory. Cronbach alpha coefficients varied from .51 to .86. See Table 4.

Table 4. Cronbach Alpha Coefficients of the SWB3 Sub-Scales (Study V, p. 64).

Sub-scale	n	alpha
1. Choices related to home	307	.62
2. Safety	343	.68
3. Activity	267	.52
4. Social relationships	344	.51
5. Happiness	348	.54
6. Health and stress	324	.86
7. Work	83	.57

In the sub-scale of mutual support, n was too small for evaluation.

The correlations between the sub-scales were mostly positive; cf. Table 6.

9 Main results

9.1 The quality-of-life construct in persons with intellectual disabilities

One purpose of the present research was to find out how the quality of life of people with intellectual disabilities can be conceptualized. In order to do this, the context of the quality of life had to be determined. Two contexts were chosen: first, the context of the everyday life of people with intellectual disability in diverse settings indicating the special nature of their lives, and second, the quality of services provided for this group of people. The process of conceptualization continued through the whole study process — from the FAMR-QOL survey (Study I), to the construction of the SWB scale (Study V), to comparative studies of the quality of life of people with and without intellectual disabilities (Study IV).

9.1.1 Core dimensions of the quality of life of people with intellectual disabilities

In designing survey questions for the FAMR-QOL study, two lines of thought were followed. First, a pilot study was conducted, in which groups of people with intellectual disabilities discussed the quality of their lives and determined which domains of life were important to them. This pilot study was instrumental in designing the interview questions and the structure of the questionnaire in the FAMR-QOL survey. Second, researchers utilized previous studies and theories in operationalizing questionnaire items to cover domains of life taken into account in previous studies.

The procedure used did not allow us to test whether the domains of life chosen were the right ones — whether some were missing or unnecessary ones included. In addition, the decision to exclude

some domains obviously limited the scope of the study: no other domains could be tested in the sense that some other issues might or might not have been important regarding the quality of life of the study group. The same was true also in subsequent investigations where summed variables were developed from the original items. However, it was possible to study the relationships between variables representing diverse domains of life in the group, and it was possible to draw conclusions concerning the coherence of the concept of the quality of life based on these associations. See section 9.1.2.

The survey questionnaire of the FAMR-QOL study (Matikka, 1993a) included the following eight domains of life: residential circumstances, work, financial subsistence, leisure time, social relationships, psychological factors, awareness of one's disability and access to information.

It was found that people with intellectual disabilities experienced their lives individually and were able and willing to express their opinions and evaluations on the quality of their own lives. Because those with mild intellectual disabilities experienced life much differently than those with severe intellectual disabilities, the same concrete questions about everyday life could not be utilized with the both groups. The meaning of domains of life also differed between these two groups. Consequently, in assessing quality of life of people living in different

environments, living conditions, or settings, the importance of domains of life varied, and the quality of life could not be assessed by same criteria in diverse situations and in diverse groups. It appeared to be necessary to investigate whether there are domains of life that are assessed to be important to all people and that have the same meaning to all groups of people in spite of differences in intellectual level or functional capacity and settings (or conditions), where they lived.

In the present study not all people with intellectual disabilities could be interviewed. This circumstance raised an important issue, as it was self-evident that the opportunity to communicate with one's environment had to be a very crucial issue in assessing quality of life. Usually communication is not included in quality-of-life scales where the subjects themselves are interviewed, because such studies can only be carried out with people who are able to communicate with researchers. Because of these limitations, the group of people whose quality of life was going to be studied had to be restricted with respect to life spheres and capability to express one's own ideas about life.

The next phase involved the construction of the SWB scale. Here, the focus was put on subjectively perceived quality of life instead of an objective perspective. This decision was made for practical reasons. So-called objective facts were considered to be easier to obtain from

proxies, and subjective evaluations of people themselves were viewed as being more important and challenging to study because of the small body of prior research. As the total project progressed, it proved possible to combine both areas of knowledge in order to depict the quality of life of the group.

Domains of life that were included in subjective well-being varied according to the stage of development of the SWB scale. Its first version (SWB0) included the following domains: (1) home as physical environment, (2) home as social environment, (3) safety, (4) activity/leisure time, (5) social relationships, (6) freedom, dignity, and rights (7) opportunities, future (8) happiness, (9) health and stress, and (10) work. The domains of the latest version (SWB3) were: (1) choices related to home and residing, (2) safety, (3) activity, (4) social relationships, (5) happiness, (6) health and stress, (7) work, and (8) mutual support (Study V). One remarkable difference between the first and last versions lay in the domain of choices which indicate self-determination, and in the operationalization of this scale as concrete everyday life situations at home.

The developmental process of the SWB scale confirmed the view that the quality of life of people with intellectual disabilities must be operationalized as concrete life events and circumstances understood by these people. Domains that

demand more abstract conceptualization and events not familiar to the group in its everyday life do not have a common meaning for the group or are not perceived important by some people. For example, political activity seemed to be far from the everyday life of these people. However, inclusion and possibilities to make choices in more common issues, such as choices concerning whom to associate with, roommate, decoration and clothes were understood and appreciated by people with intellectual disabilities (Study I, p. 34; Study V).

The context of quality of services further influenced the selection of domains of life. In order to compare units providing services for people with intellectual disabilities, criteria or norms of good quality of life were needed. It was not possible to ground these on the use of individual preferences in defining quality of life. Instead, universal yardsticks were necessary (Study V). For this purpose, a consensus about quality of life had to be taken as a basis of measures in order to give legitimacy to the criteria of quality. The idea of a universal and a unique part of quality of life was developed (Study V; Matikka, 2000b).

The results of surveys reveal something about the usefulness of the items chosen. The range and variance of domain dimensions tell which of them are important to take into account in constructing scales of the quality of life to measure outcomes of services. If there is little

or no variability, the dimension is not very useful for the purpose. In this case the group is homogenous, which probably indicates special features of the group, especially if the same homogeneity is not found in the general population. However, for the purpose of depicting the quality of life of people with intellectual disabilities such variables might also be adequate, because they indicate the level of quality of life in the group compared to general population or to other special groups. Consequently, it is not possible to consider which domains of life are important

in determining the quality of life of people with intellectual disabilities only by examining the survey results of this group. The life domains used in different phases of the study are shown in Table 5.

The heuristic models of quality of life list relatively separate life domains, which are, taken together, said to constitute quality of life. This implies that there is no need to find high positive correlations between domains of life included in the quality of life construct. On the other hand, the domains of life chosen might vary both in importance and

Table 5. The Domains of Life Used in Different Phases of the Study.

FAMR-QOL survey	SWB scale, version 0	SWB scale, version 3
Residential circumstances	Home as physical environment Home as social environment	Choices related to home and residence
Work	Work	Work
Financial subsistence		
Leisure time	Activity/ leisure time	Activity
Social relationships	Social relationships	Social relationships Mutual support
Psychological factors		
Awareness of one's disability		
Access to information	Safety Freedom, dignity, rights Opportunities, future Happiness Health and stress	Safety Happiness Health and stress

in level of scale values, but any causal relations between domains are not assumed. The correlations between domains-of-life scores are, however, assumed to be positive because they intend, taken together, to measure quality of life. The use of self-reports was also expected to result in positive correlations. The correlations of sub-scales (domains of life) of the latest version of the SWB scale (SWB3) are shown in Table 6.

How the sub-scale scores relate to each other and how they correlate with a total score of the quality of life scale says something about the structure of the quality-of-life concept. Almost all correlations were positive, indicating coherence of the construct of quality of life. This also hints that behind of these domain-specific assessments of life

there might be an overall attitude toward life that colors all of a person's assessments of quality of life.

When studying quality of life in the context of service quality, one important criterion of defining quality of life has to be taken into account: most people have to subscribe to the concept of quality of life that the study is to be based on. We need consensus about this definition, and that consensus must be based on internationally accepted values in order to confirm common interpretations and evaluations of quality of life. Attempts to determine these common definitions, and consequently the goals of services, were reported by such international agencies as the United Nations. If only private, individual preferences were used as criteria of quality of life,

Table 6. Correlations Between Quality-of-Life Sub-Scales in SWB3 (Study V, p. 65).

Sub-scale	n	1.	2.	3.	4.	5.	6.	7.	8.
1. Choices related to home	421								
2. Safety	412	.03							
3. Activity	419	.29***	-.25***						
4. Social relationships	420	.15**	-.20***	.45***					
5. Happiness	405	.17***	.08	.17***	.14**				
6. Health and stress	417	.02	.54***	-.18***	-.23***	.18***			
7. Work	343	.12*	.39***	.00	-.09	.17**	.49***		
8. Mutual support	54	.18	-.20	.44***	.52***	-.00	-.48***	-.20	
9. Total score	421	.45***	.51***	.39***	.39***	.49***	.58***	.59***	.28*

*** p<.001, ** p<.01, * p<.05

the rights of so-called weak groups could not be guaranteed. This finding (see Study V) implies that in order to compare quality of life in diverse settings, we need normative measures that allow comparisons using same yardsticks in all settings evaluated. The problem is that this solution does not take into account the subjective nature of quality of life in the sense that every individual could determine quality of his or her life in his or her own way and evaluate the quality of his or her life by very individualistic and specific criteria (Study V; Matikka, 2000b).

A main result of this study is the conceptualization of the perceived quality of life of people with mild intellectual disabilities as a construct of eight relatively separate domains of life: choices related to everyday life, safety, activity, social relationships, happiness, health and stress, work and mutual support (Study V).

9.1.2 Factors affecting quality of life

If the goal is to improve quality of life, it is important to know which factors affect it and to try to make changes in these factors. In order to find out whether these factors are same in the people with intellectual disabilities as in the general population, the model adapted from Ruut Veenhoven's (1984) meta-analyses of happiness studies was tested in Study II. In this model the idea is that quality of life (happiness)

is affected by both the environmental circumstances and the psychological characteristics of a person. The model was originally designed by Veenhoven as a general model for all people. In the present study, variables of disability and awareness of disability were also included.

Quality of life was redefined, and variables were divided into three groups: perceived quality of life, objective environmental characteristics and psychological characteristics. In this phase, my definitions of perceived quality-of-life variables were based on previous studies (Study II). As a result, three summed variables measuring perceived quality of life were formed: happiness, a positive view of life, and stress experienced by a person. On the basis of previous studies, satisfaction with specific domains of life would be the fourth issue in the list. It was not, however, possible to utilize satisfaction in the analyses of the present study because of very low variation of satisfaction expressed in the responses to the survey items.

Standard multiple regression analyses (SAS Institute Inc., 1988) were performed to examine the extent to which individual characteristics or factors associated with living conditions had an impact on perceived quality of life. The regression analyses were performed on two sets of data for the FAMR-QOL study group and separately for men and women.

The first set of predictor variables consisted of individual (personal) characteristics (i.e., sense of autonomy, desire for autonomy, others' view of self, self-esteem, self-image, impression on impacts of disability, impression of equal treatment, recognition of own disability, and information about own disability). The regression analyses indicated that the more positive a self-image and "other's view of self" the interviewees had, the happier they were (Beta = .26, $r = .40$, $p < .001$; Beta = .17, $r = .33$, $p < .001$, respectively). Greater self-esteem, a better self-image, a more positive sense of the others' view of self, and a greater sense of autonomy predicted a more positive view of life (Beta = .29, $r = .46$, $p < .001$; Beta = .21, $r = .43$, $p < .001$; Beta = .19, $r = .36$, $p < .001$; Beta = .15, $r = .19$, $p < .001$, respectively). The subjects experienced more stress if their self-esteem was low, if they exhibited a desire for autonomy and if they felt their disabilities affected their lives (Beta = -.34, $r = -.48$, $p < .001$; Beta = .21, $r = .19$, $p < .001$; Beta = .17, $r = .27$, $p < .001$, respectively). Independent variables explained 22% of the variance of happiness, 36% of the variance of the positive view of life, and 32% of the variance of stress (Study II, Table 2).

The second set of predictor variables consisted of background variables and variables associated with living conditions (i.e., age, level of disability, education, gender, employment, spouse, children/

childlessness, number of friends, frequency of contact with parents, and frequency of contact with other relatives). The results indicated that only gender contributed significantly to the prediction of perceived quality of life, especially stress (Beta = .22, $p < .001$; $r = .21$, $p < .001$).

Differences between men and women were not found in terms of happiness and a positive view of life. However, a significant difference was noted in stress, as women felt more stress than men ($t = -5.42$, $p < .001$).

9.2 Measurement of quality of life

The way we measured quality of life was studied in order to identify crucial issues in interviewing people with intellectual disabilities, and as a consequence, in order to construct a valid and reliable instrument for measuring the quality of life of these people.

9.2.1 Acquiescence and naysaying in quality-of-life interviews

An average of 25% of the respondents gave acquiescent responses (Study III, Table 1). This was roughly half of what was expected on the basis of earlier studies of acquiescence among people with mental retardation. Furthermore, the proportion of respondents showing blatant acquiescence (i.e. those who answered acquiescently to three or

four question pairs and who did not show the opposite effect) was 8% (Study III, Table 2). As expected, the opposite effect, naysaying, occurred less frequently.

The cross-tabulation of the number of acquiescent and the number of naysaying responses revealed that 344 respondents (55.8%) contradicted themselves in an acquiescent manner on one or more items, and 150 respondents (24.4%) contradicted themselves in a naysaying manner on one or more items (Study III, Table 2). However, 76 respondents (12.3%) showed no clear tendency in responding to some items with “yes/yes” answers and to other items with “no/no” answers, which indicates that contradictory answering is not always a sign of a tendency toward acquiescence or naysaying.

Contrary to our expectations, all the correlations between variables related to intelligence (i.e., the level of mental retardation and the sum score of communicative ability), and the measures of acquiescence and naysaying were near zero.

Respondents who were living in group homes (supervised living) gave more “yes” answers to all questions than did the other respondents, $F(4, 605) = 5.29, p < .001$. Respondents who were evaluated as willing to express themselves a lot also gave more “yes” answers to all questions than did those who were less so, $F(2, 598) = 12.58, p < .001$.

Women responded more acquiescently than did men to oppositely worded question pairs, $t(614) = 2.75, p < .01$. When the interviewer was a woman, female participants gave significantly more acquiescent responses, $t(539) = 3.37, p < .001$; when the interviewer was a man, male participants gave more acquiescent responses, though not to a statistically significant degree. The gender combination analyses indicated that the essential difference was between situations of same gender and opposite gender: Acquiescent responses were more frequent when the respondent and the interviewer were the same gender, $t(614) = 3.60, p < .001$.

9.2.2 Subjective well-being scale

The subjective well-being scale (SWB) was constructed in order to measure quality of life of people receiving diverse residential services. Quality of life was viewed as an outcome of residential services.

As a result, the third version of the subjective well-being (SWB) scale was constructed. This latest version (SWB3) includes eight sub-scales that are organized according to domains of life and an acquiescence index constructed by oppositely worded question pairs. Additionally it was possible to produce a total score as a mean of sub-scale scores.

The sub-scales were constructed through item analyses and

explorative factor analyses. However, the final structure was determined keeping the purpose of the instrument in mind. As evaluation and developmental work in residential units was the context of measuring, the sub-scales needed to be defined to support feedback discussion and plans to improve the services. The domains considered to be important in everyday life of people with intellectual disabilities were stressed in constructing the scale.

SWB3 includes eight open-ended questions and 65 questions connected to eight domains of life. The sub-scales are as follows: choices related to home and residing, safety, activity, social relationships, happiness, health and stress, work, and mutual support. The internal consistency of the sub-scales was evaluated using Cronbach alpha coefficients. These were not very high, but they were satisfactory, varying from .51 (social relationships) to .86 (health and stress) (Table 4; Study V, Table 10, p. 64).

The correlations between the sub-scales were in many cases statistically significant, as well as the correlations between the sub-scales and the total score (Table 6). Some correlations were negative, indicating the contradictory nature of the SWB construct. For example “safety” correlated negatively with “activity” and “social relationships,” and “social relationships” with “health and stress.” It could be speculated that especially in the group of people with intellectual disabilities meeting

other people and participating in lots of activities may increase the risk of feeling unsafe, and social contacts may also be stressful.

There were no statistically significant differences between gender groups in the sub-scales and in the total score. The correlations between age and the sub-scales and age and the total score were non-significant, except for “activity,” indicating that younger people were more involved in activities.

9.3 The quality of life of Finnish adults with intellectual disabilities in the 1990s

The results of the FAMR-QOL study, which represent the situation in the whole country, provide a detailed description of the quality of life of Finns with mild intellectual disabilities. They are presented and discussed in numerous reports and articles elsewhere (see Appendix for a review) and summarized in Study I, pp. 27-30. In general, issues important to people in general were also important to people with disabilities. Additionally, they were generally satisfied with their lives, but wanted possibilities for self-determination, choices in everyday life, more independence in residential services, more influence over their work, and more opportunities to establish couple relationships. The results indicate that in describing

quality of life of people with intellectual disabilities, domains of life that have special importance for people with intellectual disabilities need to be taken into account in addition to those of general interest.

The survey method used here permitted me to address numerous, relatively separate questions and to study how answers to them differed according to gender, age, level and type of disabilities, residential arrangements, living area, etc. In order to have an accurate picture of the quality of life of the whole group studied, a comprehensive notion had to be drawn from the large body of data, and this notion had to be reviewed in the context of quality of life of the general population.

For reasons stated above and reported in Study IV, direct comparisons were meaningful or possible only in very few cases. The biggest problem was that the lives of both groups differed so much that comparisons of quality of life between them were meaningless. The life of people with intellectual disabilities compared to that of the general population can best be compared on the basis of data gathered in the FAMR-QOL study. The fundamental differences can be summarized as follows. See also Autio (1992b) and Matikka (1999b):

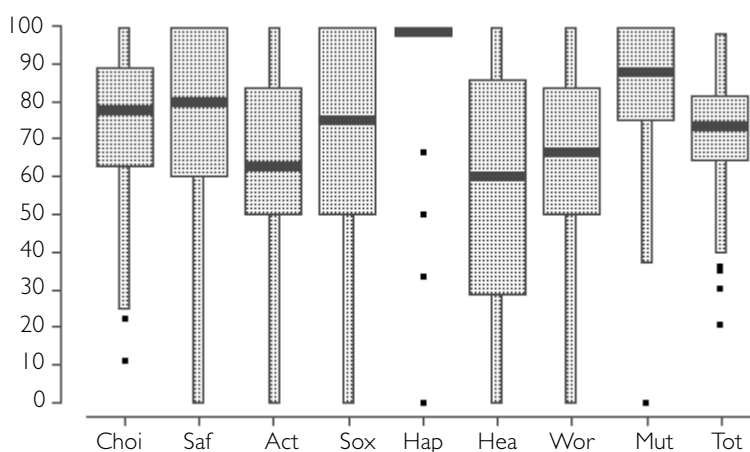
- About 30% of the adults with intellectual disabilities continued to live with their parents. Most (92%) were single and had never lived in a couple relationship.

Almost half lived in group homes, institutions or some other kinds of group settings. Most, however, would have preferred to live independently or supported in their own apartment with their loved ones.

- The source of basic livelihood for most people (95%) with intellectual disabilities was a pension instead of a salary. However, most (96%) spent their day at sheltered work.
- Human relations of people with intellectual disabilities were characterized by obligation on the one hand (paid helpers that one could not choose), but also by closeness on the other hand (staff members were considered to be friends). Friendships were very often limited with the other people with intellectual disabilities and direct care workers.
- People with intellectual disabilities had practically no political influence whatsoever. Obtaining information about what was going on in society was very difficult, since many persons with intellectual disabilities had inadequate reading skills, and TV channels did not have special newscasts for viewers with intellectual disabilities.

The sub-scales and the total scores of SWB were constructed on a scale from zero to one hundred, with the higher number reflecting a better rating of quality of life. The average scores on SWB sub-scales ranged from 58.4 to 93.1, and the total score was 72.3 on average (Study V, Table 13, p. 70). The biggest variance was found in health and stress (SD=33.4)

46-50). All of the distributions are negatively skewed. The total score of subjective well-being was on average 72.3, which is in the range of the “golden standard” for judgement of life satisfaction (70-80 percent of the scale maximum) reported in several studies of normative samples drawn from Western populations (Cummins, 1995;



Choi = Choices related to home, Saf = Safety, Act = Activity, Soc = Social relationships, Hap = Happiness, Hea = Health and stress, Wor = Work, Mut = Mutual support, Tot = Total score

Figure 4. Distributions of the Sub-Scales of Subjective Well-being in People with Intellectual Disabilities in Finland.

and the smallest in happiness (SD=19.4). Distributions of the SWB sub-scales are shown as box plots in Figure 4.

In Figure 4 the vertical line in the middle of a box marks the median or 50th percentile. The lower and upper edges of a box mark the quartiles, or the 25th and 75th percentiles (SAS Institute, 1993, pp.

Mellor et al., 1999). See also Ojanen (1997; 2001a; 2001b; 2001c).

Quality of life of people with intellectual disabilities and that of the general population were compared over the four domains of life: livelihood and subjective poverty, security, work and hobbies, and happiness and stress. Nearly all respondents with intellectual disa-

bilities would have been categorized as poor had they been living in their own private household. Nevertheless, only 10% of the respondents stated that they did not have enough money at their disposal. The experience of subjective poverty was equally common among persons with intellectual disabilities and the general population (Study IV, pp. 91-92).

Over the previous 12 months, 18% of the respondents with

intellectual disabilities had met violence, and 4% had been raped. This is more than in the general population, 1% of which had experienced serious violence, 2% mild violence and 5% serious threats (Tilastokeskus, 1995 p. 81). Although people with intellectual disabilities were generally found to be equally as happy with their lives as the general Finnish population, it seems that they have experienced more stress (Study IV).

10 Discussion

This study had three aims: first, to examine which factors (or domains) determine quality of life of people with intellectual disabilities and which factors affect quality of life of people with intellectual disabilities; second, to construct a scale for measuring quality of life in the context of assessment of quality of residential services for this group; and third, to describe the quality of life of people living in Finland.

The lives of people with intellectual disabilities are in many ways different from those of people in general. This means that the substance of assessment differed between the groups. Evaluation methods used with persons with intellectual disabilities to obtain appraisals of their life and its quality also differed from those most often used for studying the general population. However, the level of subjective well-being (subjective quality of life) of persons with

intellectual disabilities did not differ very much from that of the general population.

10.1 Methodological considerations

Of the two basic research paradigms — quantitative and qualitative — the former was chosen for this study. According to John Creswell (1994, pp. 1-16) paradigms in the human and social sciences help us to understand phenomena: they advance assumptions about the social world, how science should be conducted, and what legitimate problems, solutions, and criteria of “proof” consist of. The following discussion rests on the context of the quantitative paradigm assumptions based on Creswell (1994) and Tapani Alkula (1995).

The quantitative approach comes from the empiricist tradition,

whereas the qualitative paradigm is termed constructivist or naturalistic, or possibly postpositivist. The ontological, epistemological, axiological, rhetorical and methodological assumptions of the quantitative paradigm differ from those of the qualitative paradigm. Problems associated with remaining faithful to a given paradigm are not rare in multidisciplinary research areas, where methodologies are immature. In these cases, methodological pluralism might promote knowledge. In quality-of-life research, methodological pluralism includes the use of personal appraisal and functional assessment strategies (Schalock et al., 2000). Logic requires a researcher to remain faithful to the paradigm selected. This was not an easy task, as throughout the research process the desire to use the qualitative paradigm intervened and sometimes led to new studies reported elsewhere (i.e., Matikka & Korhonen, 1999). In the following I would like to shed some light on these contradictions.

With regard to the ontological issue of what is real, the quantitative researcher views reality as “objective,” “out there,” independent of the researcher. Accordingly, a researcher can measure quality of life objectively by using a questionnaire or an instrument like a well-being scale. For the qualitative researcher, the only reality is that which is constructed by the individuals who are involved in the research, be they the researchers themselves, the individuals being

studied, or the reading audience when interpreting the study. The quality of life literature reflects confusion in defining the concept of quality of life, and the debate over the proper components of quality of life and who has right to determine them is still going on. When the subjective approach to quality of life is stressed, it may be difficult or even impossible to determine it as a phenomenon that is “out there” and just waiting to be found. Instead, it seems to be more like a social construct that is constantly changing in various discourses and is constantly being negotiated by all concerned (cf. IASSID, 2000).

My solution to this problem was to include those aspects of quality of life that were found to be important to people with intellectual disabilities in a pilot investigation, and to test questionnaires developed in the Assi project by groups of people with intellectual disabilities. This solution meant the partial abandonment of the quantitative paradigm according to which the concepts or the terms of a study have to be drawn from theories or from previous studies and that these theories are then tested against empirical observations organized into operationalized concepts. When doing this, it was not possible to test any theory in this study unless its concepts happened to have the same content as the theories and the discourses of people with intellectual disabilities. Only in Study II was the model developed from previous

studies tested by using the data of the present study. The concepts used in Study II, however, are based on the author's operationalizations, and they may differ from the meanings that respondents with intellectual disabilities give them.

With respect to the epistemological question of the relationship between the researcher and that being researched, the quantitative paradigm assumes that the researcher should remain distant and independent from what is being researched. In collecting survey data, attempts were made to control for bias by selecting systematic random samples and by being "objective" in measuring situations. In order to control for response bias, acquiescence was studied and found to be within acceptable ranges. Minimizing the distance between researcher and those being researched is an important aspect of the qualitative paradigm. This was recognized in the FAMR-QOL survey, where the gender differences between an interviewer and an interviewee were found to be related to acquiescence. Further studies of this phenomenon using people with intellectual disabilities as interviewees are now underway (Nummelin et al., 2000). On the whole, data collection "objectivity" was fairly well achieved in our study. However, in some cases the responses of subjects could have benefited from further clarification by the respondents. A compromise between

a deeper understanding and standardized alternatives has to be made in these kinds of studies, where comparisons between groups are being made. The questions have to be kept simple if they are to mean approximately the same thing to all respondents (cf. Antaki & Rapley, 1996; cf. Rapley & Antaki, 1996).

It is an axiom of the quantitative paradigm that research is value-free and unbiased. Quality of life is, however, a value-laden concept in the sense that definitions and evaluations of it are based on culturally varying values and that we purposefully pursue good quality of life for all people. Nevertheless people have diverse ideas as to what good quality of life means. Whose ideas, then, are legitimate? My solution here was to legitimate the concept by using information given by groups of people with intellectual disabilities that expressed their ideas about quality of life. However, this does not mean that their views are accepted by all those people whose quality of life was studied and will be studied in the future, for example using the SWB scale. Whether there exist universal core dimensions or whether there are only individually varying ideas about quality of life is still under debate. In this study, the quantitative paradigm was followed and the researcher's personal views on quality of life did not play a prominent role. The difficulty of operationalizing the concept of quality of life remained unsolved

because of confusing and contradictory theories and models of quality of life developed in previous studies.

As the quantitative paradigm uses deductive logic, theories and hypotheses are tested in a cause-and-effect order. The intent of such studies is to develop generalizations that contribute to the theory and that enable one to better predict, explain and understand the phenomenon studied. The generalizations are enhanced if the information and instruments used are valid and reliable. This strategy was specially important in this study, where better quality of services was pursued by developing instruments to assess quality of life of recipients.

It could be stated that the results of the present study can be generalized to the group of people with mild intellectual disabilities using special services provided for them in Finland. The samples studied were drawn from a large pool of service units and are representative with respect to such demographic characteristics as gender, age, residential settings and regions of the country in the FAMR-QOL survey. In the Assi project the same is true in all demographic respects excluding age — the age group of 30-39 years were slightly over-represented in the study group. Correlations between age and the subjective well-being sub-scales were, however, significant only in the sub-scale of activity, indicating that younger persons participated in more

activities than the older ones. The data of some other studies employing the SWB scale also confirmed the results of the present study (Study V).

10.2 The concept of quality of life

Quality of life was at first considered in the context of previous models developed by empirical studies on quality of life of the general population (Allardt, 1975; Naess, 1987; Veenhoven, 1984). Later, it was put into the context of intellectual disability, and finally into the context of quality of service. These contexts have guided the conceptualization of quality of life. Throughout the research process the definition of quality of life was reconsidered and further developed.

The distinction between subjective and objective components developed especially by Cummins (1997b) and suggested by several researchers (e.g., Felce, 1997) is abandoned here. In his view, subjectivity is equal to personal appraisal (satisfaction and importance) of objectively addressed domains of life. In the present study, subjectivity is seen as an approach in which the persons themselves tell about their life and give their own personal appraisals of life. Their personal appraisals were both comprehensive and domain-specific. People with intellectual disabilities seemed to have big problems in

assessing specific domains of life when they were questioned about their satisfaction with various aspects of their life. For this reason, measures of satisfaction with specific domains of life could not be used reliably to assess quality of life. The result was that only overall satisfaction with life was included among the instruments developed and used here. These data were supplemented by people's responses to specific questions concerning their living circumstances, activities and feelings.

The concept of quality of life of people with intellectual disabilities was defined differently than in several previous studies because of the difficulties in measuring satisfaction with diverse categories. Whether this was due only to limitations imposed by measurement techniques or also to the limited ability of persons with intellectual disabilities to conceptualize remains open. In other words, we do not know whether people with intellectual disabilities have a more diffuse concept of quality of life than other people have.

In studies of the general public, quality of life was closely related to the terms "happiness" and "distress," which in turn were not found to relate closely to so-called objective living conditions or circumstances. Instead, psychological factors predicted these overall appraisals (Diener et al., 1995; Diener et al., 1999; Glatzer, 1991). This was also found to be true in the present study

concerning people with intellectual disabilities.

In taking the context of quality of residential services into account, more concrete life conditions or domains had to be included into the concept of quality of life. It was necessary to find factors that affect the quality of people's life and which could be influenced in order to improve people's quality of life. Because the goal was to improve people's "objective" living conditions, not to change their ideas about their life (cf. Csikszentmihalyi, 1992), living conditions and social relationships were considered. There were two reasons for abandoning subjective or personal definitions of quality of life in the context of service quality; first, the above-mentioned difficulties associated with using these people's personal appraisals of satisfaction with diverse domains of life, and second, the impossibility of comparing quality of life in different groups if subjective definitions of quality of life are utilized.

The result was that in the context of service quality, the concept of quality of life had to be defined as a social construct that was legitimated by negotiations with people whose quality of life was being measured, as well as by the general population. When criteria were not available, norm data gathered from Finnish service agencies were used in developing an instrument (the SWB scale) for assessing quality of life of

people with intellectual disabilities. It was then possible to draw comparisons with average conditions of people with intellectual disabilities in Finland instead of on the basis of criteria accepted by negotiations with the people involved or by political bodies.

Quality-of-life discourses do not differ from other discourses. According to Émile Durkheim (1982) discourses are not subjective viewpoints, but social facts that can be studied like other social phenomena. Quality-of-life discourses are not implements in the sense that we are able to decide how to manage them. On the contrary, they are part of our common social reality that we produce by communication (cf. Eskola, 1999; Gergen, 1985; Wahlström, 1992). For this reason, it is necessary to study diverse quality-of-life discourses and to identify the criteria of quality of life produced in these discussions. The result of these studies might be that we can never define only one quality-of-life concept with only one meaning, and that the meanings of quality of life in every discourse are constantly changing.

In this study the discourse of quality of life was specified by the contexts of intellectual disability and quality of service, which made it possible to take a more practical approach to conceptualization, measurement and improvement of quality of life. Restrictions, on the other hand, may lead to an exces-

sively narrow description of quality of life and to endless discussions on differences in quality of life of people with intellectual disabilities and that of the general population.

In summary, the quality of life of people with intellectual disabilities was conceptualized in the context of service quality as follows: quality of life is a multidimensional, discursive concept that focuses on domains of life that are important to the majority of the target group. In the group of people with mild intellectual disabilities the most important domains of life are nowadays as follows: self-determination and dignity (choices in everyday life); safety; activity; social inclusion and mutual support; work; happiness; and freedom from stress.

Quality of life was evaluated by the subjects themselves and by other people. In arranging these self-evaluations, it was possible for us to use a subjective approach to measuring quality of life that would allow quality of life to be determined by the subjects themselves. On the contrary, when other people are evaluating quality of life of this group, it is not possible to include the subjective appraisals of the persons. In this case, quality of life had to be defined in a different way which takes limitations in research methodologies into account. Living conditions, ability to function in one's environment, access, etc. are stressed more in conceptualizing. For example, the quality of life of people

with severe communicative problems cannot be studied using the strategy of personal appraisals. Consequently, two definitions of quality of life are needed in order to reconcile varying quality of life discourses in the field of intellectual disability.

Quality of life can be determined in continuous discussions with the target group and in discussions with general populations. These discussions produce a social construct of quality of life which can

also serve as a starting point for developing criteria for evaluative studies on living conditions and service quality. When applying the idea of social construct to quality of life discourses, another distinction is necessary: on the one hand, a subjective perspective and appraisals that respect everyone's own unique views about their lives and, on the other hand, universal constructs about what is considered good for all people (Matikka, 2000b). See Table 7.

Table 7. Subjective and Objective Discourses of Quality of Life Defined According to Contexts, Texts and Meanings.

QOL discourse	Context	Meaning	Latent variables (sign, text)	Concrete variables (sign, text)
SQOL (subjective perspective on quality of life)	individuals	SWB (subjective well-being)	overall positive perception of life	happiness, overall satisfaction, absence of stress and negative attitudes toward life as a whole
OQOL (objective perspective on quality of life)	individuals	Universal social construct in assessing human life in diverse cultures	domains of life which are important for all people	human rights livelihood security health housing education work services hobbies social relations
OQOL in context of ID (objective perspective on quality of life of people with intellectual disabilities)	individuals with ID using special services	Local or community-based social construct of QOL of people with ID	domains of life which are important for all people, and domains of life which are important for people with ID	variables mentioned above, plus self-determination empowerment inclusion mutual support special services and support

10.3 Measuring quality of life in people with intellectual disabilities

When studying a group of people with intellectual disabilities, one important issue is whether the group is homogeneous enough or whether it is futile to try to depict the quality of life of the whole group in the same way. It is useful to consider what intellectual disability means in the context of quality of life. In this study it seemed important to limit the study group according to level of intellectual disability for two reasons. Conceptions of what aspects of life should be included also differed a lot between the groups of people with severe and mild intellectual disabilities, and consequently the contents of the concept of quality of life differed. Second, the same methods could not be used to investigate the quality of life of these groups.

In previous studies the problem that the same methods could not be used in studying people with severe and mild intellectual disabilities is often solved by abandoning interviews with the target group itself. In cases where personal interviews could not be conducted, proxies were used as informants (e.g., Schalock & Keith, 1993) or so-called objective measures were preferred (Tössebro, 1998).

Studying the quality of life of people with intellectual disabilities is difficult because of limitations based on the cognitive difficulties of

the study group. These difficulties may additionally affect differences in evaluative processes that people use in assessing their lives. Emotional components may dominate their aspirations. Norbert Schwarz and Fritz Strack (1991) studied a model used to assess subjective well-being in the general population and stressed issues that are well-known among people with intellectual disabilities and that were also encountered in interviews done for this study: Information that is cognitively more accessible at the time of the happiness report affects the subjects' appraisals. Additionally, the communicative context of a conversation or research interview may induce individuals to disregard highly accessible information under some conditions.

Perceptions of what life entails are important determinants of perceptions about quality of life, because quality of life is realized in how people live. Compared to the general population, people with intellectual disabilities usually do not work for pay and they have less money to spend on travel and cultural events, which means that their life experiences are more limited. They usually are not married and have no children, which means that their family life as adults differs substantially from that of other adults. Although their way of life is different, is that because of their intellectual disability and are they less or more happy with their life because of these differences? If

comparative quality-of-life studies take into account only those domains of life that can be measured by the same variables in both groups, the scope of quality of life is too narrow and does not capture the domains of life that are important to the groups. The only way to compare their quality of life with that of general population is to compare overall appraisals of life as a whole in both groups.

It is probably more difficult to choose the frame of reference for evaluating persons' opinions concerning their future life. According to Allardt (1975) people may be able to say what they want here and now, but they are often unable to say what they would want in the future if the conditions were altered or improved. This idea played an important role in designing and developing interview questionnaires for people with intellectual disabilities. Allardt stated that the worse people's living conditions are, the less they are able to say what they would want if the situation were different. Approaching the issue in this way would then easily lead to fruitless conservatism, but on the other hand a complete disregard of expressed wants and wishes easily leads to inhuman dogmatism. See also W. G. Runciman (1966, pp. 27-35, mentioned by Allardt, 1975, p. 6).

In this study, only those whose communication skills were assessed to be adequate were included in the study group. Acquiescence was not

found to be as frequent as in some previous studies (Heal & Sigelman, 1990, 1996). However, in the subjective well-being scale developed in this study as an outcome measure of the quality of services, an acquiescence scale of oppositely worded question pairs was included in order to improve the reliability of the measurement.

The wording of items included in quality of life questionnaire was developed and improved through the study period. The need for simplified language was obvious in order to offer stimuli that could be understood well and in the same way by all the respondents. In addition, response alternatives also had to be limited. The alternatives "yes," "no" and "don't know" were used in order to create response alternatives that were understandable to as large a group of respondents as possible. By doing this, people who had difficulties in responding to Likert scales with three or more alternatives could also be included into the study group. The fact that this technique did not allow for much variation limited the number of usable statistical analyses. However, this strengthened the reliability of the scale.

It is often stated that mood or situational circumstances can disturb interviews or produce bias in interviews of people with intellectual disabilities. In the repeated interviews of the first version of SWB scale, some items had very low

reliability coefficients. It was not possible to confirm whether this was due to difficulties in understanding questions or to changed opinions.

The gender of the interviewer was also found to affect the responses to the extent that the subjects tended to experience more stress when an interviewer and an interviewee were the same gender. Further studies are needed in order to explain these findings.

All the difficulties in designing study instruments revealed how important it is to carefully consider the methods used when interpreting results of quality of life studies of people with intellectual disabilities. Besides ensuring that reliable methods are used to gather data, attention has to be given to possible differences in cognition between people with and without intellectual disabilities. Here, more studies are necessary, as well.

10.4 Quality of life as an outcome of quality of services

In the present study, one application of quality-of-life research was the development of a scale of subjective well-being. The SWB scale was designed to serve as an outcome measure of the quality of residential services provided for adults with intellectual disabilities. Because the model of the whole assessment process included another scale in

order to measure the living conditions of recipients of these services, there was no need to measure quality of life as a whole, but only those aspects on which data were gathered by interviewing people with disabilities. While designing this instrument, it became obvious that quality of life could be measured in two ways depending on the strategies used in data gathering: one part consisting of subjective evaluations that were elicited from the subjects themselves by interviewees and another part concerning living conditions and resources provided by service agencies from data gathered from proxies, direct care workers or family members. This strategy confirmed the idea that quality of life can be measured as a composite of subjective appraisals and notions shared by the community where people are living or working together.

The ability of the SWB scale to serve as an outcome measure of service quality will be studied later by testing the whole Assi model developed for the purpose. Development toward more and more individualized strategies in service provision demands discussions about subjective vs. universal criteria in evaluating services and, consequently, in evaluating the quality of life of the recipients.

10.5 Concluding remarks

Quality of life is an important issue for everyone on a personal level. When subjective appraisals are valued, the people themselves have to be used as informants. In this subjective approach to quality of life, individual preferences, cognitive (evaluative) processes, individual frames of reference including culturally adopted values and selection of reference group as well as adaptation to environmental demands and own aspirations are playing important roles. More psychological investigations are needed to reveal how people in general and especially people with intellectual disabilities build their ideas of quality of their lives and which strategies are successful in pursuing better quality of life.

One widely used way to measure the quality of a person's life is to sum up scores from diverse subscales of domains of life. This is not enough. In the future, more emphasis should be placed on psychological factors and their interrelations. Especially high rates of perceived stress together with high rates of satisfaction with life indicate complexity in experiencing life and warn one against oversimplifying measurement of subjective quality of life. In order to feel happy, people need dreams and aspirations and they have to struggle to achieve their goals. This is hardly ever possible without any stress.

Quality of life of people with severe intellectual disabilities who don't have adequate communication skills to permit interviews cannot be studied using a subjective approach. A knowledge of living conditions and of the resources available to them is nevertheless important in order to obtain a comprehensive picture of their quality of life. These aspects can also be studied in people with severe disabilities. An important issue is, however, to keep a subjective approach apart from the external evaluations of quality of life.

The possibility to define and evaluate one's own quality of life is highly appreciated in Western countries, where quality of life is considered from a customer-centered point of view in terms of quality of services. With respect to public services that are based on a generally accepted idea of what constitutes good quality, quality of life is conceptualized as a social construct in which human rights and criteria approved in political discussions are more valuable than individual preferences. Differences in defining quality of life in diverse discourses indicate that its content must be established before the scope and implications of research in this field can be clarified and translated into actions designed to help people with intellectual disabilities.

Both individual and social aspects of quality of life are important for people with intellectual disabilities, and these persons have only recently been considered as experts on their own lives. Quality-of-life discourses have, on the whole, brought them opportunities for empowerment and personal growth. Despite difficulties in eliciting their ideas about life and specifying their assessments of their own lives, it is to be hoped that every effort will be made to benefit from their direct input in future quality-of-life research.

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Appendix:

Additional information concerning the FAMR-QOL study

Data collected in the FAMR-QOL study

The FAMR-QOL study was based on seven sources of data:

- structured group discussions (Henriksson, 1992; Öhman, 1991)
- structured interviews of persons with mild intellectual disabilities (Autio, 1991; Autio, 1992a; Autio, 1992b; Autio, 1993a; Autio, 1993b; Matikka, 1993b; Matikka, 1993b; Matikka, 1993c; Matikka, 1993d; Matikka, 1993e; Matikka, 1993f; Matikka, 1993g; Matikka, 1996a; Matikka, 1999b; Matikka, 2000a; Matikka & Vesala, 1997; Vesala et al., 1993; Vesala, 1992; Öhman, 1992)
- background data of the sample gathered from personnel (Autio, 1992b)
- a postal survey of parents of persons who had severe intellectual disabilities (Qvist, 1992; Vesala, 1992; Öhman, 1993)
- a postal survey of direct care workers of persons who had severe intellectual disabilities (Qvist, 1992; Vesala, 1992; Öhman, 1993)
- observations of persons with severe intellectual disabilities
- a postal survey of the interviewers (Matikka, 1993a)

Research reports from the FAMR-QOL study

Reports on the study published in articles and monographs during years 1991 to 2000 are as follows:

Monographs

- Autio, T. (1991). *Kehitysvammaisten elämänlaatutietoa. Haastatteluvaiheen tuloksia taulukoina* [The quality of life of the mentally retarded. Interview results in tabular form] (Kehitysvammaliiton julkaisuja No. 2). Helsinki: Kehitysvammaliitto.
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