COMPARABILITY OF QUALITY-OF-LIFE STUDIES OF THE GENERAL POPULATION AND PEOPLE WITH INTELLECTUAL DISABILITIES

By Leena M. Matikka

Abstract: The study on the comparability of the quality of life of persons with intellectual disabilities to the quality of life of members of the general population was based on data from a number of Finnish research projects. Although people with intellectual disabilities were generally found to be equally as happy with their lives as the overall Finnish population, it seemed that they experience more physical violence and more stress. One of the central problems in comparing the quality of life of different groups is the great diversity of their circumstances and, consequently, their life experiences. This problem is exacerbated by the fact that comparability of research results is impaired by modifications and variations in the survey instruments used in different studies. Finally, in interpreting comparative results it is vital to consider the potentially diverse array of meanings that certain life domains hold for different groups of people.

Introduction

In recent decades efforts have been made in Western countries to improve the quality of life of people with intellectual disabilities. The notion of disability politics is based on the equalisation of the opportunities of all people, all of whom share the right to have a good life (cf. United Nations, 1994). In order to assess just how successful the resulting policies have been, we need to assess whether the quality of life for people with intellectual disabilities is as good as that of the general population. Over the years many studies have tried to define and describe the quality of life of people with intellectual disabilities. Researchers have often argued that the quality of life of people with intellectual disabilities has to be defined by using the same criteria as those used to measure the quality of life of the general population (Goode, 1994; Schalock, 1990; 1996; 1997). However, it has been found to be difficult to successfully carry out research projects that compare the quality of lives of such diverse groups. For example, national
surveys usually focus on the general population, thereby omitting marginal groups (cf. Statistics Finland, 1995). The aim of the present study is to use available data in order to investigate to what extent a meaningful comparison between the quality of life of people who have intellectual disabilities and that of members of the general population is at all possible.

The Concept of Quality of Life
In the field of disability research, the concept of quality of life is vague, and it has been variously defined by different researchers. Many stress its multidimensional nature (Felce & Perry, 1995; Parmenter & Donelly, 1997; Schalock, 1996). These dimensions are often divided into two approaches: the objective and subjective quality of life (see e.g. Cummins, 1997). The objective quality of life is similar to the concept of ‘living conditions’, while the subjective aspect closely resembles the concept of ‘satisfaction with life’. ‘Quality of life’ is also understood to consist of several - usually six to eight - life domains, which may be measured objectively and/or subjectively. In reviews of the literature written on the quality of life Hughes and Hwang (1996) identified 44 definitions of the quality of life of persons with or without disabilities spanning the years 1970 to 1993. They aggregated these definitions into 15 dimensions that best represented and summarised quality of life.

In this comparative study, “quality of life” is understood as a multidimensional social construct. Restrictions in the scope of the quality-of-life concept are due to data available for comparisons rather than theoretical definitions of those who are doing the research.

The Comparative and Context-Bound Nature of Studies on the Quality of Life of People with Intellectual Disabilities
The first studies on the quality of life of people with intellectual disabilities were conducted at approximately the same time as when the social and health care authorities started to close down institutions and place those residing there in smaller housing units, such as group homes and flats located within the community. The main arguments in favour of this change were related to the assumed improvement in quality of life. These studies intended to determine whether the quality of life of people with intellectual disabilities had actually improved following those changes. Comparisons were then made among a group of people with intellectual disabilities. As a consequence, the concept of ‘quality of life’ has carried significant health and socio-political meaning (cf. Schalock, 1996; 1997). Quality of life of a group of students with intellectual disabilities has also been examined in several studies on the transition from school-age to adulthood (Halpern, 1994).
As the aim of the studies on the quality of life of people with intellectual disabilities was to discover which service model produced a better quality of life for its clients, certain criteria were required in order for the researchers to compare the outcomes. Criteria specifically designed for this purpose underline the special circumstances where persons with intellectual disabilities usually live. A close connection between the life of persons with intellectual disabilities with the service system and the life style that it enables formed a special context for quality-of-life outcome measures. Crystallising the concept of the quality of life into a series of questions further serves to underline the special nature of the living conditions of people with intellectual disabilities (cf. Tössbro, 1998). This is why using the very same standards for studying the quality of life of the general population is very difficult, if not impossible. Comparisons can therefore only be made with regard to certain individual, concrete questions.

From the Standard of Living to the Perceived Quality of Life in Studies on the General Population

Numerous studies on the standard of living, or living conditions, of entire nations have been carried out in order to monitor the success of various measures of the welfare state. Information was needed on problem areas that affected all people, such as livelihood, housing, employment, and so on. The success in attaining common goals was first monitored by social indicators in national and international comparative studies (Allardt, 1998; Johansson, 1970).

At first, the main focus was placed on living conditions, because those could be manipulated by national mechanisms. Subjective experiences were ignored, as they emphasised mental factors that were considered impossible to influence directly by social measures.

The concept of "quality of life" was introduced to Finnish social politics when researchers sought to extend the study of well-being to cover people's

European Community, have supported these activities (Glatzer, 1991). Similarly, people's happiness has been studied - not so much in order to make comparisons between nations, but to compare groups of people of varying ages living in varying environments and conditions (see the meta-analytic study by Veenhoven, 1984).

The institution of the welfare state was based upon the notion that the citizens' well-being is society's shared responsibility. This made it necessary to gather research data related to the conditions of the many groups of people. It was assumed that the feedback could be used to guide various social measures and efforts. Thus, information was needed on problem areas that affected all people, such as livelihood, housing, employment, and so on. The success in attaining common goals was first monitored by social indicators in national and international comparative studies (Allardt, 1998; Johansson, 1970).
personal experiences (Allardt, 1975; 1993; 1998; Karisto, Takala & Haapola, 1988). The average Finnish citizen’s well-being has been studied extensively. In the 1990’s, the life of the Finnish people has been studied with particular emphasis given to the impacts of the recession and the structural changes taking place in society (Ahlqvist & Ahola, 1996; Huuhka, Lahelma, Manderbacka, Mattila, Karisto & Rahkonen, 1996). It seems that psychological factors have been given more weight in research projects. Such concepts as: coping, perceived control, sense of control, self-efficacy, sense of coherence, and autonomy have emerged to accompany the notion of living conditions (see e.g. Marski, 1996; Statistics Finland, 1995). This new way of approaching research provides descriptive information as to what life is like in a particular country, how it has changed, and what the inter-relationships between different life domains are. Livelihood, employment and housing continue to be important objects of study, but researchers are now paying increasing attention to how individuals subjectively experience their lives.

Possibilities for Comparing the Quality of Life of People with Intellectual Disabilities to that of the General Population
Comparative studies of the possible differences between the quality of life of people with intellectual disabilities and of the general population have not been made in Finland. Comparisons can be made on the basis of available data. It is possible to select certain individual interview questions from several empirical studies and compare the answers given by people with intellectual disabilities to those given by other populations. In the latter case, the questions dealt with should be as concrete as possible so that they might at least remotely carry the same meaning for persons with intellectual disabilities as for other people. It is possible that questions selected using such criteria will not, however, represent the most important aspects of the lives of both groups.

When following the experiential approach, the subjects’ personal preferences should be considered. As persons with intellectual disabilities may have different preferences than others, it is not enough to make comparisons on the level of questions alone; instead, the lives of both groups should be viewed more holistically, emphasising the importance of some particular issue for a particular group of respondents.

The Purpose of the Study
The purpose of the present study was (a) to investigate to what extent a meaningful comparison between the quality of life of persons with intellectual disabilities and that of members of the general population is
possible, and (b) to analyse and discuss the problems encountered in comparing the quality-of-life survey data of these groups. The quality of life was defined by including both objective and subjective aspects, and assessed using both overall descriptions and comparative data of specific life domains.

**Method**

The quality of life of people with intellectual disabilities was examined both in a large national survey of people with intellectual disabilities, and by using the national database gathered in order to assess the quality of services provided for people with intellectual disabilities. The quality of life of the general population was described on the basis of research reports from two large surveys carried out by Finnish administrative and statistical authorities together with the survey data of a small group interviewed by questionnaire, including some of the questions presented to the interviewees with intellectual disabilities in the quality-of-life survey run by the Finnish Association on Mental Retardation (FAMR).

*Research Data on the Quality of Life of People with Intellectual Disabilities FAMR-QOL study.* The extensive interview data obtained by the FAMR Research Unit’s quality-of-life research project were gathered during the years 1990-91, and so far it has been used in some two dozen research reports (cf. Autio, 1992a; 1992b; 1993a; 1993b; Henriksson, 1992; Matikka, 1993; 1994; 1996a; Matikka & Vesala, 1997; Vesala, 1992; Öhman, 1991, 1992). The objective of that study was to depict the quality of life of persons with intellectual disabilities in different service units, both in Finland’s various regions and throughout the entire country. The structured questionnaire included more than 200 questions related to residential circumstances, work, financial subsistence, leisure time, social relationships, individual psychological factors, awareness of one’s disability and access to information (Matikka, 1993).

The general method of the FAMR-QOL study was to survey a nationwide random sample of adults with intellectual disabilities receiving residential services or participating daily activities in Finland in 1990 and to gather background information about them. Sampling was conducted in two major stages: service unit sampling and service consumer sampling. The whole sample consisted of 46 group homes, 9 big institutions, 4 foster families, 22 sheltered workshops, and 16 day care and activity centers. Service consumer sampling was performed in the unit sample. The objective was to include from each unit some 5 to 10 people. In all, the sample encompassed 822 persons with intellectual disabilities from throughout Finland. The sampling method, representativeness of the
sample and procedure are documented in detail by Autio (1992a). In considering the representativeness of the sample, comparisons with statistical data published by National Board of Social Welfare were made. The interview results may be generalised for the population of Finnish people who use special services and have either mild or moderate intellectual disabilities. Acquiescence, a possible threat to the validity of the interview data, was not found to have distorted the results (Matikka & Vesala, 1997).

A total of 619 adults with intellectual disabilities were interviewed. Their mean age was 36.9 years (SD = 10.9; with the youngest age 18 and oldest age 69). About one half (51%) of the subjects were male. 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 subjects (31%) lived with their parents or relatives; 13% had their own flats; 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.

**FAMR-SWB data.**

The experiences and results of the quality of life studies were utilised when the FAMR Research Unit started to develop tools for the assessment of the quality services for people with intellectual disabilities, which include, among other criteria, a scale for the assessment of subjective well-being (SWB) (Matikka, 1999a; Matikka, 2000). The SWB scale includes eight sub-scales: self-determination at home, safety, activity, social inclusion, happiness, freedom from stress, work, and social exchange. The database of the scales is continuously increasing. For the present study the results of 297 subjective well-being interviews were utilised. The sample was not randomly drawn from service units, but was composed by the units, which had ordered an evaluation of their services and this being the case had indicated interest to develop their service quality. Comparisons to the national statistical data of people with intellectual disabilities (Matikka & Aaltonen, 1998) showed that the database included more persons aged 30-39 years and relatively fewer persons aged 50 years or over. Due to the research method consisting of interviews, the study group included relatively more people with mild than severe intellectual disabilities. According to background information people included in the study group represented fairly well the group of consumers with mild intellectual disabilities using special services in Finland. This group often works in sheltered workshops and resides in group homes for more than five people (for more detailed information see Matikka, 2000).

The mean age of the subjects was 40.2 years (SD=12.1; with the youngest age 18 and oldest age 74), and 50% were
men. Most had either moderate (38%) or mild (33%) mental retardation, and 7% were diagnosed as having average or borderline intelligence. The data were gathered during the years 1994-96 (Matikka, 2000).

Research Data on the Quality of Life of the General Population
Several large surveys have been conducted in order to examine the quality of life, living conditions and the well-being of the general Finnish population. Because the context of life is shaped by both time and local conditions, the studies used here were selected because their data had been gathered throughout the whole country and as close to the time of the FAMR studies (1990 to 1991 and 1994 to 1996) as possible. The studies chosen for most comparisons were ‘The Living Conditions Study’ run by Statistics Finland (Statistics Finland, 1995) and the well-being studies run by the Social Insurance Institution, Finland (Marski, 1996).

Statistics Finland - Living Conditions Study.
The data supporting this study were obtained from a sample of 12,093 Finnish citizens over 15 year old. A total of 8,650 (71.5%) persons were interviewed in 1994, of which 48% were men. Sixteen percent were aged 15 -24 years, 38% were from 25 to 44 years, 30% from 45 to 64 years old, and 17% were aged 65 years or older (Statistics Finland, 1995; more detailed in Ahola, Djerf, Heiskanen & Vilkki, 1994).

This postal survey was designed to obtain responses representative of the Finnish population in the age group 18-74. The number of questionnaires returned was 3,025 (73%). Data were gathered during the year 1995. (Marski, 1996).

FAMR – Comparative QOL Study.
In this small comparative study 42 people without intellectual disabilities were interviewed using some questions that were asked to people with intellectual disabilities in the FAMR-QOL study with regard to: hobbies, happiness, stress and a positive view on life. The original purpose of the study was to find out possible differences in acquiescent responding and to test the extent to which questions designed for people with intellectual disabilities could work in a survey targeted to ordinary Finnish people participating in working life. The sample was drawn from two small enterprises in Helsinki and interviews were made by a female student in 1993. The mean age of the subjects was 40.4 years (the youngest was 23 years, and the oldest 63 years old). Nine were men. This group had a higher level of education than people in Finland normally have, and all of them were employed. The 80 questions chosen for this group from the
Interview questionnaire originally planned for persons with intellectual disabilities were presented in exactly the same format as had been used for people with disabilities. Finding the questions for this study was not an easy task. Many of the original questions had to be abandoned because of their disability-specific nature and wording (Matikka, 1999c).

Analyses

The comparisons between the quality of life of persons with intellectual disabilities and that of members of the general population were made in the following two ways:

- Individual dimensions and life domains found in separate previous studies were compared; and
- Selected quality of life domains of both groups have composed by using results from the study that employed the very same interview questions for both of the groups.

Results

Comparing the Quality of Life in Various Life Domains

In order to focus comparisons of specific areas of life, individual dimensions and life domains were isolated. The quality of life of persons with intellectual disabilities and the general population was compared in the following life domains: livelihood and subjective poverty, security, work and hobbies, and happiness and stress. These particular life domains were selected for this study because they were used in recent Finnish studies (Table 1).

Table 1. The quality-of-life domains of the studies used in comparisons.

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>*livelihood</td>
<td>*standard of living</td>
<td>*livelihood</td>
<td>*choices and self-determination at home</td>
</tr>
<tr>
<td>*housing</td>
<td>*employment</td>
<td>*housing</td>
<td>*safety</td>
</tr>
<tr>
<td>*security</td>
<td>*autonomy of agency</td>
<td>*social relations</td>
<td>*social relations</td>
</tr>
<tr>
<td>*human relations</td>
<td>*sense of coherence</td>
<td>*working life</td>
<td>*work</td>
</tr>
<tr>
<td>*work</td>
<td>*political participation</td>
<td>*leisure time</td>
<td>*activity</td>
</tr>
<tr>
<td>*leisure time</td>
<td>*values and priorities</td>
<td>*health</td>
<td>*stress</td>
</tr>
<tr>
<td>*health</td>
<td></td>
<td>*psychological factors</td>
<td>*happiness</td>
</tr>
<tr>
<td>*everyday life</td>
<td></td>
<td>*awareness of disability</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>*information on society</td>
<td></td>
</tr>
</tbody>
</table>

Table 1 continued...

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Standard of Living and Subjective Poverty

Comparing poverty and subjective poverty of persons with intellectual disabilities with that of the general population is rendered more difficult by the fact that these two aspects of life are generally studied by surveying people's household and private economy. As many persons with intellectual disabilities live in institutions or group homes and are not responsible for their own household, this concept is inapplicable.

In the study undertaken for the Social Insurance Institution, Marski (1996) discussed standard of living on the basis of various livelihood indicators and accumulating welfare gaps. Marski suggests that as the resources are generally scarce, a system of 'scarcity management' is needed for their allocation. Additionally, 'pleasure management' is needed. It is crucial to distinguish one's needs from one's desires. Subjective poverty or dissatisfaction with one's standard of living may simply be due to the fact that one's needs and desires substantially exceed one's existing resources. Regarding subjective experiences, individual respondents may be greatly dissatisfied with their standard of living irrespective of their income level. Table 2 illustrates poverty as measured by various livelihood indicators.

Table 2. Indicators of livelihood and responses in percentages (n=3025) (Marski, 1996, p. 63).

<table>
<thead>
<tr>
<th>Indicators of livelihood</th>
<th>% of all respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Living allowance client</td>
<td>6.2</td>
</tr>
<tr>
<td>Dissatisfaction with current standard of living</td>
<td>5.3</td>
</tr>
<tr>
<td>Special hardships related to livelihood</td>
<td>8.4</td>
</tr>
<tr>
<td>Insufficient provision of basic necessities (food)</td>
<td>3.7</td>
</tr>
<tr>
<td>Subjective poverty</td>
<td>8.9</td>
</tr>
<tr>
<td>Experienced over-indebtedness</td>
<td>10.3</td>
</tr>
</tbody>
</table>

In the FAMR studies nearly all respondents with intellectual disabilities would have been categorised as poor, had they been living in their own private household (Table 3). Nevertheless, only 10% of the respondents in the years 1990-91 and in 1994-96 stated that they did not have enough money at their disposal (Table 4). Compared to the research data from the Social Insurance Institution study, it seems that the experience of subjective poverty was equally common among persons with intellectual disabilities and the general population. In the Social Insurance Institution study, 8.9% of the respondents stated that they were poor (Table 2).
Table 3. Income of people with intellectual disabilities (n=619) (FAMR-QOL study, Autio, 1992b, p. 44).

<table>
<thead>
<tr>
<th>Monthly income/FIM</th>
<th>Yearly income/FIM</th>
<th>% of all respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than 2000</td>
<td>Less than 24000</td>
<td>36%</td>
</tr>
<tr>
<td>Less than 3000</td>
<td>Less than 36000</td>
<td>10%</td>
</tr>
<tr>
<td>More than 3000</td>
<td>More than 36000</td>
<td>3%</td>
</tr>
<tr>
<td>Unable to say</td>
<td></td>
<td>51%</td>
</tr>
</tbody>
</table>

Note that the table presents the personal income of persons with intellectual disabilities, not the total income of the household.

Table 4. Experiences of persons with intellectual disabilities regarding the sufficiency of their income.

<table>
<thead>
<tr>
<th>Do you have enough money? (FAMR-QOL study, n=619)</th>
<th>Do you have enough money? (FAMR-SWB data, n=297)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Sufficient</td>
<td>Yes</td>
</tr>
<tr>
<td>Adequate</td>
<td></td>
</tr>
<tr>
<td>No answer</td>
<td>No answer</td>
</tr>
<tr>
<td>10%</td>
<td>10%</td>
</tr>
<tr>
<td>38%</td>
<td>86%</td>
</tr>
<tr>
<td>45%</td>
<td></td>
</tr>
<tr>
<td>7%</td>
<td>4%</td>
</tr>
</tbody>
</table>

Security

In the Statistics Finland study on living conditions (Statistics Finland, 1995, p. 81), the respondents’ security was measured by using questions concerning the occurrence of direct physical violence or threats of physical violence. In spring 1994, 1% of the respondents stated that they had experienced serious violence (violence that had resulted in visible marks on the body) over the past 12 months. The proportion of victims of mild violence was 2% and victims of serious threats 5%.

In the FAMR studies the occurrence of violence was measured using a set of questions that did not differentiate between serious and mild violence. According to the FAMR studies, 18% of the respondents had experienced violence over the past 12 months (Table 5). Additionally, the proportion of rape victims (4%) was alarmingly high.
Table 5. Physical violence and threats experienced by persons with intellectual disabilities (n=297) (FAMR-SWB data).

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
<th>No answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Has someone acted violently towards you during the past year?</td>
<td>18%</td>
<td>79%</td>
<td>3%</td>
</tr>
<tr>
<td>Has someone threatened you during the past year?</td>
<td>20%</td>
<td>76%</td>
<td>3%</td>
</tr>
<tr>
<td>Were you raped during the past year?</td>
<td>4%</td>
<td>79%</td>
<td>17%</td>
</tr>
<tr>
<td>Has someone made disturbing advances toward you during the past year?</td>
<td>11%</td>
<td>76%</td>
<td>13%</td>
</tr>
</tbody>
</table>

Social Relations

The Statistics Finland study on living conditions charted the respondents' human relations by asking about the number of close friends, and confidential relationships with others than family members, as well as sources of financial aid, advice and emotional support. In 1994, 7% of the respondents stated that they had one close friend; 34% had 2-3 close friends and 51% had more than four close friends (Statistics Finland, 1995, p. 204).

Again, the FAMR studies used a different set of questions (Table 6), but based on rough estimates, the number of friends is approximately the same with persons with intellectual disabilities in the FAMR-QOL study and the rest of the population. However, it seemed that the meaning of the concept 'friend' differed in those groups. People with intellectual disabilities often considered staff members as well as family members to be their friends. Living circumstances of persons with intellectual disabilities differed from members of the general population in that the former very seldom lived in an intimate relationship. Ninety-two percent of the respondents to the FAMR-QOL study had never been married or lived in an intimate relationship, and 30% of the adults still lived with their parents (Autio, 1992a). Who one considers to be one's friends demands respondents' subjective evaluation. The comparison between the two FAMR studies rendered similarities in responding even if questions' wording and consequently the alternatives in answering differed. To the question used in FAMR-SWB study 'Do you have at least three good friends?', 28% persons responded negatively, when they only had two alternatives (yes/no) in answering. A total of 25% of persons interviewed in FAMR-QOL study similarly said that they had less than three friends.

The result indicated that because of differences in social relations of people with and without intellectual disabilities...
as a whole, the meaning of friendship differs among the two groups and without putting the results into a broader interpretative frame, comparing amounts of friends is not relevant. Furthermore, comparability of the two studies employing self reports of the groups with intellectual disabilities seemed reasonable instead of differences in questions’ wording.

Table 6. Number of friends of persons with intellectual disabilities.

<table>
<thead>
<tr>
<th>How many friends do you have? (FAMR-QOL, n=619)</th>
<th>Do you have at least three good friends? (FAMR-SWB data, n=297)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>No 28%</td>
</tr>
<tr>
<td>1</td>
<td>9% Yes 61%</td>
</tr>
<tr>
<td>2</td>
<td>10%</td>
</tr>
<tr>
<td>3+</td>
<td>72% No answer 10%</td>
</tr>
<tr>
<td>No answer</td>
<td></td>
</tr>
</tbody>
</table>

Work and Hobbies

Work accounts for a large proportion of our use of time, and thus it plays a significant role, especially in the lives of persons of working age. It could be assumed that persons with intellectual disabilities have a different view of the significance of work than other people; for people who do not have intellectual disabilities, work provides for their livelihood and it also guarantees resources for an independent leisure time. On the other hand, the main source of income for persons with intellectual disabilities is the disability pension, which guarantees them a minimum livelihood. Nevertheless, according to the FAMR-QOL study (Autio, 1993a), work seemed to be very important to persons with intellectual disabilities. For most, sheltered work gave them the feeling of actively participating in working life. When asked ‘What, in your opinion, is the most important aspect of your work?’ in the FAMR-QOL study, 41% (N=586) replied ‘good salary’, 31% replied ‘nice colleagues’, 15% replied ‘varying tasks’, and 5% ‘I can make decisions concerning my work’ (Autio, 1992a). In a follow-up study of persons with intellectual disabilities who had received vocational training in Perttula Special Vocational school between 1976 and 1983 the later living conditions, employment and self-concepts of the former trainees were studied. Data were gathered from the group twice after leaving the school: in 1983 and 1993. Their arguments for job satisfaction were somewhat different. The most important considerations were ‘nice colleagues’ (56% in 1993; 31% in 1983) and ‘varying work’ (25% in 1993; 24% in 1983). Only a small minority thought that salary was important (11% in 1993; 8% in 1983).
(Korhonen & Matikka, 1991; Matikka, 1996b). Certain studies indicate that the importance of salary is emphasised by those respondents who have low-paying jobs (see Autio, 1992a, p. 15).

In the study on living conditions (Statistics Finland, 1995, pp. 130-132) the role of work was either interpreted as instrumental or content-oriented. With regard to the group of respondents as a whole (n=4107), the significance of the content of work had increased from 78% in 1986 to 84% in 1994. Generally, the content of work was considered to be important by elderly respondents as well as by female and highly educated respondents. Those respondents who had been categorised as workers based on their socio-economic status considered work to have an instrumental meaning more often than other respondents.

Because of differences in main source of income in the groups with and without intellectual disabilities, it seemed contradictory to compare subjective views on an instrumental or content-oriented meaning of work. In order to compare these views the context of work has to be taken into account. For example comparisons should be done between the groups having and not having a pension for their livelihood.

In the FAMR-QOL study, the number of hobbies and participation in them was charted through a list of 29 hobbies. This comparative study of 42 people without intellectual disabilities indicated that persons who did not have intellectual disabilities had more hobbies than persons with intellectual disabilities; they also participated in such activities more often than persons with intellectual disabilities. The former were more active in swimming, visiting art exhibitions, going to the library, the theatre and to concerts; they also ate out more often, were more active in photography and reading, and travelled more both in Finland and abroad. On the other hand, persons with intellectual disabilities were more active in singing in choirs and attending Sunday services and other religious events. Both groups (80% of the persons with intellectual disabilities and 86% of the other group) felt that they had enough leisure activities (Matikka, 1999c).

Happiness, Stress and a Positive View on Life

Happiness, stress and a positive view on life were examined in a small comparative study in which data from the FAMR-QOL study were compared to data on a group of 42 persons without disabilities.

In order to compare the perceived quality of life of persons with intellectual disabilities and that of other adults, three previously developed subscales were used: happiness, stress and a positive view on life (for more, see the precise description in Matikka,
The persons without intellectual disabilities reported more happiness and less stress than persons with intellectual disabilities. No significant differences between the two groups were found in connection with positive view of life. (Matikka, 1999c).

Content of Life

According to the Study on Living Conditions, work was the main source of pleasure in life for every fourth employed respondent. For 60%, the main source of pleasure in life was the family. Thirteen percent felt that their main source of pleasure consisted of leisure activities (Statistics Finland, 1995, p. 48).

As part of the FAMR-QOL study the respondents were asked to name the best aspect of their lives. The alternatives were: work, hobbies, home and friends. Thirty-six percent of employed persons with intellectual disabilities felt that work was the best thing in their life; for 33% the best thing in life was friends, for 21% home, and for 10% hobbies. Older respondents found work more important than younger respondents; for young respondents friends were more important than for older respondents (Autio, 1993a). That home was the most important thing in the lives of only 21% of the respondents may well be seen as an example of the differences between the lives of persons with intellectual disabilities and the general population. Starting a family was extremely rare among people with intellectual disabilities, although it was a dream for many (Matikka, 1996b).

Because of different response alternatives, the data of the two studies were only roughly comparable. The main problem, however, was that the lives of the both groups obviously differ and consequently appraisals are given from within different contexts.

Discussion

The main purpose of this study was to investigate the extent to which it is possible to compare the quality of life of people with intellectual disabilities to the quality of life of members of the general population. Comparability was studied by using available data. The study was conducted in the 1990s - at a time when Finland was experiencing a great recession. The groups were then living in the same cultural and geographical area at the same economically defined period of time.

The aim of socio-political measures has been to guarantee equal conditions and opportunities in life for all citizens. Thus, the purpose of quality of life studies has often been to discover to what extent the social political measures taken have succeeded. The main argument to shift the focus from 'standard of living studies' to 'quality of life studies' was the priority of
emphasising subjective experiences. It was considered to be important trying to find out whether people were satisfied with their living conditions rather than just describing these per se.

It was soon discovered that subjective experiences of satisfaction are not necessarily closely linked with actual living conditions. People strive to sustain a sufficient level of satisfaction through adaptation processes regardless of what other people may think of their living conditions (see Helson, 1964; Diener, 1994; Taylor & Brown, 1988). Consequently, the study of happiness seeks explanatory factors in psychological processes in people’s minds rather than in the environment in which they live (e.g. Veenhoven, 1984).

These psychological processes of evaluating life satisfaction are often seen to include cognitive, emotional and value components. According to the definition of intellectual disability, people in this category have cognitive difficulties that affect their judgements of life domains and overall life satisfaction. In interpreting the data on the quality of life of the two groups, it is important to consider whether differences in cognitive processes in the groups may lead to differently weighted responses.

Another problem caused by cognitive difficulties regards the structure and wording of questions and response alternatives used in quality of life surveys. In studies of the general population for example, Likert scales are often used to reveal as much variation as possible in participants’ responses. On the other hand, in the studies of people with intellectual disabilities, yes/no responses have been found to be more reliable (Matikka & Vesala, 1997). The wording of questions must also be very simple and, for example, time references have to be avoided. Inconsistencies in these approaches are the reason why the results of the separate previous studies were difficult to compare.

Drawing conclusions based on comparisons is difficult in many ways, particularly with regard to considering each subject’s individual assessments and preferences. Whereas hopes and dreams lend themselves to the construction of a multidimensional average image of an ideal life; comparing the concrete life of an individual to this general image does not provide information as to how removed the reality of an individual is from his or her own ideal image. Research is rendered even more difficult by the fact that the target group should construct images to serve as a bases for reflection on their current life situation, when constructing such images is far too demanding a task for many persons with intellectual disabilities.

It is hard enough to study the subjective quality of life of people with mild
intellectual disabilities. Those who have severe difficulties in understanding or responding to interview questions cannot be interviewed at all. Some researchers have solved this problem by using proxies. By doing so, they have abandoned the idea that subjective assessments can only be produced each person her/himself. Some have restricted their studies to living conditions, preferring the idea of a coherent group of people with intellectual disabilities; others have restricted their studies to a group of people who only have milder cognitive difficulties, preferring the idea of the subjectivity of assessment. In this study the latter strategy was chosen. Consequently, when interpreting the results it should be remembered that the group of people with intellectual disabilities in this study represents people who do not have very severe cognitive difficulties.

It is even more difficult to find out if both groups attribute equivalent meanings to the same interview questions. Even if the concepts were understood in the same way, putting these concepts into the broader life context might give them diverse meanings. An example of this was the concept of 'work', which had different meanings for the different groups.

In which direction, then, should we develop comparative studies on the quality of life of people with intellectual disabilities and other groups of people? An even more crucial question is: why do we need these comparisons? In many cases, comparative studies on living conditions alone could provide us with a great deal of new information. If we prefer to study subjective experiences of life, we should need to carefully consider all results of comparisons between subjects or groups. It might be useful to start by presenting qualitative overall descriptions of the quality of life of the groups and let people draw their own conclusions. In addition, involving persons with intellectual disabilities in the planning and carrying out of quality of life studies would reveal new objects of study of great importance to them (cf. Nummelin, Matikka & Vesala, 2000; Trigler, 1998). This way we would be able to confirm the validity of quality-of-life studies concerning groups that might have different cultures and priorities than those of the general population.

In order to describe the quality of life of different groups it is crucial to study: (a) actual living conditions and resources available; (b) people's activities in these conditions; (c) their subjective assessments with regard to their living conditions and resources; and (d) their views on life in general as well as how they experience their own life. In spite of all the difficulties in making comparisons between the quality of life of the two groups, a rough and preliminary picture emerges...
that can provide useful input for further studies.

Differences were found in the actual living conditions and available resources. The sphere of life of people with disabilities seemed to be more restricted than it was among people comprising the general population. A large proportion of persons with intellectual disabilities lived in residential collectives and were not engaged in paid employment.

Activity in life domains obviously varies according to an individual’s participation within these domains. If one is not involved in working life, one’s daily activities are more occupied by leisure or home-oriented activities than are those of people who are employed. Daily routines obviously played a large part in the lives of persons with disabilities because they only rarely used their time to deal with, for example, child care, household tasks and work. Both groups had a lot of hobbies that differed only slightly.

Subjective assessments with regard to living conditions and resources were studied in some life domains. Differences were not found in subjective poverty and social relations. On the other hand, experiences related to safety differed considerably. Persons with disabilities experienced more threats of violence than people representing the general population. It is of interest to ask whether falling victim to violence is linked to the fact that they were intellectually disabled, or to the environment that was provided to people with intellectual disabilities by society? Do other groups in a similar position find themselves objects of violence in our society? What is the situation for refugees, convicts or persons with mental problems, for example, compared to people who have intellectual disabilities? Examining these questions would enhance studies of comparisons of the quality of life across marginal groups.

The overall views on life in the group of persons with intellectual disabilities did not greatly differ from the views of others. Persons with intellectual disabilities valued the same things as persons of the general population. Their life was, however, more stressful.

The substantial results of this study serve in directing further studies on lives of people with intellectual disabilities. Comparisons to the quality of life of the general population seem adequate only in applying a broader frame of reference for depicting living conditions of the group of people with intellectual disabilities in a society. In order to understand differences and similarities in subjective appraisals of life as a whole, investigations on evaluative processes that individuals with intellectual disabilities use in constructing their worldviews and self-concepts in the context of their living conditions are needed.
References


COMPARABILITY OF QUALITY-OF-LIFE STUDIES OF THE GENERAL POPULATION AND PEOPLE WITH INTELLECTUAL DISABILITIES


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