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Perceived Quality of Life among Adults with Severe Intellectual and Physical Disabilities, Family Members and Caretakers

Author(s): Orly Gat and Shira Yalon-Chamovitz

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Orly Gat, Shira Yalon-Chamovitz

Key words: Quality of life, intellectual disability, physical disability, supported living, adults, client-centered therapy

Abstract

The current study compares the perceived quality of life of adults with severe intellectual and physical disabilities living in residential facilities with those living in a family residence. Their perceptions are further compared with those of family members and caregivers. The Cross Cultural Survey of Quality of Life questionnaire (Vardugo & Schalock, 2001) was completed by 30 adults with severe intellectual and physical disabilities, 24 family members and 30 caregivers (n=84). No differences were found in perceived QOL of adults living in different types of residences, but there were differences between their perceptions and those of family members and caregivers. Overall, it appears that one can't ascertain which residential environment will provide better QOL for adults with intellectual disabilities. Rather, it is imperative to apply client-centered principles by relating to the needs and desires of each individual with regards to all aspects of his or her life.

Orly Gat - OT, MSc. At the time this article was written, Gat was an occupational therapist at Alin-Beit Noam, Kiryat Ono. The research was conducted as part of the MSc program in the Department of Occupational Therapy, Hebrew University in Jerusalem. orlygat@gmail.com

Shira Yalon-Chamovitz, Ph.D. OT, Chair, Department of Occupational Therapy, School of Health Professions, Ono Academic College. E-mail: shirayc@ono.ac.il

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Introduction

Quality of life (QOL) is gradually becoming recognized as a major emphasis of occupational therapy (OT) along with well established client-centered approaches (Christiansen, Baum, & Bass-Haugen, 2004; Creek, 2006; Yalon-Chamovitz, Sachs, Weintraub, Nota, & Mazor et al., 2006). Nonetheless, when dealing with a population of adults with severe intellectual and physical disabilities substantive questions arise regarding the implementation of these two central approaches: how can we, as therapists, know what the client's desires are? How can we be certain that the choices made by clients are truly their own? How can we ascertain whether clients are content or satisfied with their life? How can we know how clients perceive their quality of life?

QOL refer to people's perception of their situation in life, in the context of their culture and values and with reference to their goals, expectations and other factors that they consider important (WHO, 2001). It is a broad and inherently subjective concept that is influenced by the person's physical and emotional condition, level of independence, social relationships, beliefs, and, to a large extent, by his or her environment (Schalock et al., 2005).

Research findings regarding people with cerebral palsy (CP) have demonstrated lower QOL than the general population in some, but not all, aspects of QOL. However, no correlation was found between QOL levels and functional factors such as mobility or gross motor function within the CP population (Livingston, Rosenbaum, Russell, & Palisano, 2007). QOL research among people with intellectual disabilities emerged in the 1970s, and was aimed mainly towards examining whether or not QOL characteristics in the general population are valid measures of QOL among people with intellectual disabilities (Mendler & Neon, 2001). Non-conclusive findings led to the establishment of a special research group in 2004, under the auspices of the International Association for the Scientific Study of Intellectual Disabilities (IASSID). This group formulated three principles related to QOL: a) QOL is multidimensional and influenced by personal and environmental factors and the relationships between them; b) QOL is built of the same components for all people; and c) QOL is improved by self-determination, resources, having goals in life and a sense of inclusion (Bramston, Chipuer, & Pretty, 2005). In addition, Schalock and Verdugo (2002), leading scholars in QOL research of people with intellectual disabilities, identified eight core QOL domains: a) emotional well-being, b) interpersonal relations, c) material well-being, d) personal development, e) physical well-being, f) self-determination, g) social inclusion, and h) rights.

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One of the major issues that the concept of QOL is currently applied to is the debate regarding appropriate residential options for people with intellectual and physical disabilities. A review of the literature suggests that community residence is more highly correlated to increased participation in daily activities, utilization of services, improved connection to caregivers, family members and friends, and better acceptance in the community, than is institutional residence (Mendler & Neon, 2001). Nonetheless, very few studies compared living in a family residence with living in a supported-living facility and the literature considers both of these frameworks "community residences." The concept of QOL replaced the normalization principle as a guideline for decision making regarding choice of residential facilities for people with intellectual disabilities. QOL is supposed to reflect a degree of correlation between the person's desires, aspirations and abilities and the person's residential situation, by relating to the person's desires and needs, and steering clear of setting general rules that a particular type of residence is correct for all (Reiter & Bendov, 1996; Schalock & Verdugo, 2002).

Various studies have been conducted in Israel and internationally to evaluate the QOL of people with intellectual disabilities (Chan, Krupa, Lawson, & Eastabrook, 2005; Janssen, Schuengel, & Stolk, 2004; Jenaro et al., 2005; Lyons, 2005; Otrebski, 2005; Schwartz & Rabinovitz, 2003; Reiter & Bendov, 1996; Schalock et al., 2005; Verdugo, Schalock, Keith, & Stancliffe, 2005; Xu, Wang, Xiang, & Hu, 2005). Most studies utilized proxies to provide the subjective perspective of people with intellectual disabilities regarding their QOL (Lyons, 2005). However, the reliability and validity of these methods is questionable, as studies that compared self-reporting with caregiver reporting regarding QOL of adults with intellectual disabilities indicated frequent discrepancies (Schwartz & Rabinovitz, 2003). Therefore, there is a growing consensus that a person with intellectual disabilities needs to be involved directly in evaluating his or her QOL and that a proxy should be used only when communication is significantly limited (Verdugo, Schalock, Keith, & Stancliffe, 2005).

The purpose of the current study was to compare perceived QOL of adults with intellectual disabilities with family members and caregivers' perceptions of the participants' QOL. In addition, the correlation between these perceptions and type of residential facility among adults with intellectual disability was examined by comparing those living in a family residence with those living in supported-apartments in the community.

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Methods

Participants

The supported community living group included 13 adults with severe intellectual and physical disabilities living in a residential (supported-living) facility in the community, 9 of their family members and 13 caregivers. The family residence group included 17 adults with severe intellectual and physical disabilities living in a family residence, 15 of their family members and 17 caregivers. This convenience sample was retrieved from Alin-Beit Noam, a day center for adults with severe intellectual and physical disabilities. Of the 70 recipient of services in Alin-Beit Noam, all who met the inclusion criteria were invited to participate in the study, and 30 gave their consent. Inclusion criteria were: age 21 and over, severe intellectual and physical disability as reported in the medical record and sufficient verbal communication abilities to enable interviewing. For family members, inclusion criteria included being first-degree family members of the adult participant and ability to read and write Hebrew or English. Inclusion criteria for caregivers included working for Alin-Beit Noam daycare center; non-professional training, and ability to read and write Hebrew or English.

All participants were diagnosed with severe intellectual disability. Of the 13 participants in the supported living group, 12 had a dual diagnosis of CP and 1 participant was diagnosed with a progressive degenerative disease. All participants were young adults (average age 30.3 years), 7 were males and 6 were females. Of the 17 participants in the family residence group, 12 had a dual diagnosis of CP and 1 participant was diagnosed with a progressive degenerative disease. All participants were young adults (average age 30.4 years), 10 were males and 7 were females. Data regarding the physical condition of participants is provided in Figure 1.

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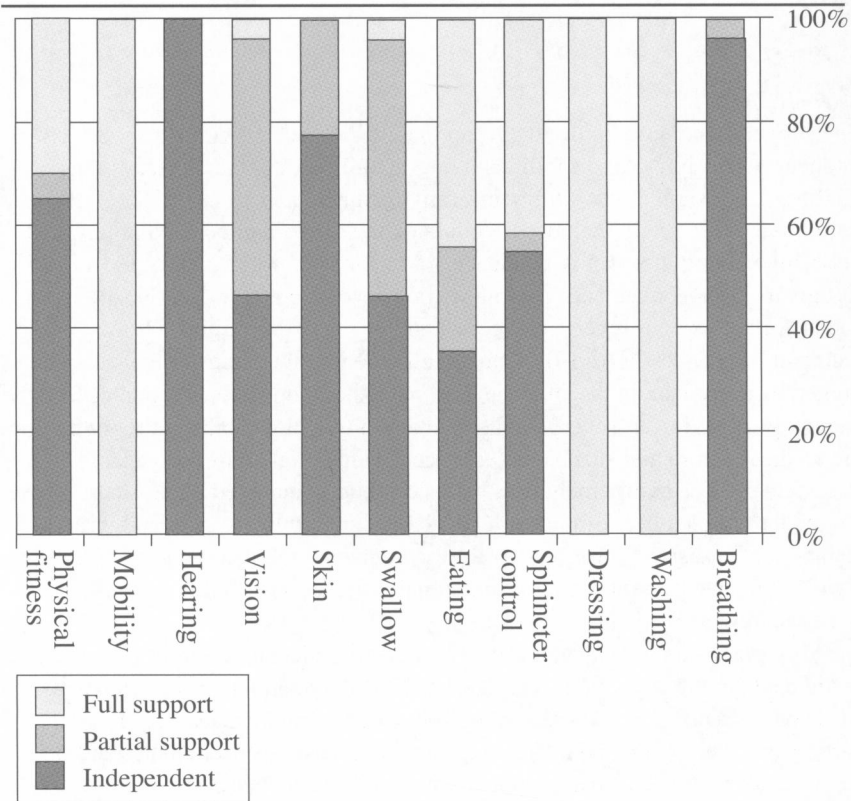


Figure 1. Physical condition of the participating adults with intellectual disabilities

Of the 30 family members who gave their consent to participate in the study, 6 did not complete the questionnaire for various reasons.

Instruments

Cross-Cultural Survey of Quality of Life was developed by Schalock and Verdugo (2002). A measure developed to provide culturally valid information regarding perceived QOL among adults with intellectual disabilities, their family members and caregivers. The measure includes three questionnaires: a participant questionnaire, a family member questionnaire, and a service provider questionnaire. This measure was developed based on Schalock and Verdugo (2005) model of QOL, such that all three questionnaires include eight

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core QOL domains: a) emotional well-being, b) interpersonal relations, c) material well-being, d) personal development, e) physical well-being, f) self-determination, g) social inclusion, and h) rights. Each domain is further characterized by three indicators. For example the indicators for emotional well-being are a) contentment, b) self-concept, and c) lack of stress. All factors and indicators are measured across two dimensions: a) Importance and b) Emphasis. Importance is tapped by the question, "How important is this indicator for people with intellectual disabilities" and is measured on a scale of 1-4, from "not important at all" (1) through "very important" (4). Emphasis is tested using the question "How much is this indicator used in services/supports received or delivered?" and was measured on a scale of 1-4, from "not at all emphasized" (1) through "emphasized strongly" (4).

Family members and caregivers usually complete these questionnaires independently in approximately 30 minutes. The questionnaires for participants with intellectual disabilities are often completed by interviewing the participant.

While originally developed in English, it had since been translated into many languages including Spanish, Mandarin, Polish, French, and Chinese, and used in numerous studies (Jenaro et al., 2005; Schalock et al., 2005). The questionnaires were translated using a translation-retranslation process and found to be highly consistent with the original language (Schalock et al., 2005). In the current study, language compatibility was insured using a translation-retranslation process. The translation into Hebrew was done by an occupational therapist working with people with intellectual disabilities and the re-translation into English was done by a professional translator. No cultural adaptation was required.

Reliability of the questionnaire was assessed by the Cronbach internal consistency test and the split-half test. Alpha Cronbach ranges were found to range between 0.92 and 0.95 with an average of 0.94 (SD= 0.01). On the split-half test, the range was between 0.84 and 0.92 with an average of 0.89 (SD = 0.03). These results indicate that the questionnaires' reliability is good (Schalock et al., 2005). Validity was tested via a variety of tests, including factor analysis and profile analysis. These tests provided information regarding both Importance and Emphasis dimensions, and confirmed the structure of the eight core QOL domains (Schalock et al., 2005).

Demographic questionnaire. A questionnaire developed to collect demographic data such as age or level of physical support needs in the current study. Most of the data was retrieved from participants' medical records.

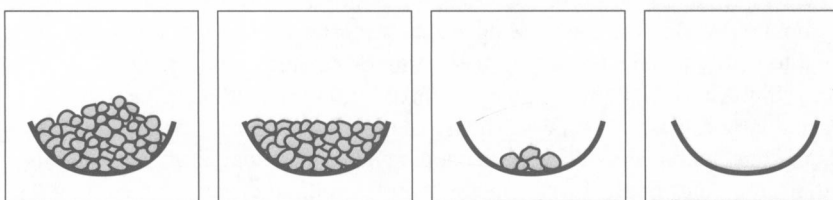
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Research process

Research was conducted in cooperation with Alin-Beit Noam, after receiving approval of the Institutional Review Board ("Helsinki Committee"), signed consent forms from caregivers and family members, and oral consent from adults with intellectual disabilities.

A pilot study was conducted, mainly to explore required adaptation of the questionnaire to the study population. The pilot study was conducted with 4 adults with intellectual disabilities who met the research criteria but whose family members did not meet the criteria. The purpose of the pilot study was to check potential graphic representations of responses, which were created to adapt the response scale to participant cognitive levels. Since many of the participants in the study communicated using Boardmaker symbols, the scale was processed using symbols that would be familiar to them. Two variations of the scale were tested alternately (see Figure 2). All of the participants in the pilot study preferred scale A for answering questions from the Cross-Cultural Survey of Quality of Life, therefore, Scale A was used in this study.

Scale A:



Scale B:

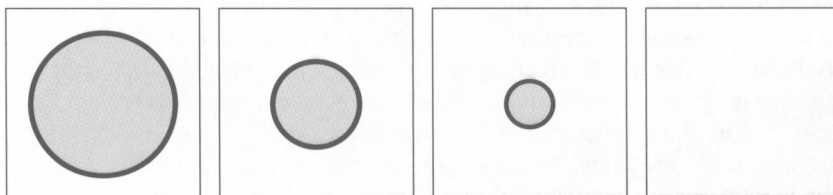


Figure 2. Adapted response scale using Boardmaker symbols

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Next, data was collected from adults with intellectual disabilities, members of their families and caregivers, using the participants' questionnaire, family members' questionnaire and caregivers' questionnaire, respectively.

1. Adults with intellectual disabilities were interviewed at Alin-Beit Noam, using the adapted scale A as described above. The interviews were conducted during the center's ordinary activity times. In order to minimize compliance effect, interviews were conducted by a person who does not work at Alin-Beit Noam and who was previously unknown to the participants.
2. Family members were sent questionnaires and a cover letter. In families in which the adult with intellectual disabilities lived in the family residence, the participants themselves delivered and returned the questionnaires. In families in which the adult with intellectual disabilities lived in a residential facility, the questionnaires were sent by mail and included a stamped, pre-addressed return envelope. Telephone follow-ups were conducted by the first author to monitor the completion of the questionnaires and two questionnaires were completed by a telephone interview with family members who found it difficult to complete the questionnaire independently.
3. Caregivers were requested to complete the questionnaires independently during work hours. Each caregiver completed the questionnaire for a predetermined participant. A researcher handed the forms and cover letter directly to the caregivers and they were returned in like manner.

Data Analysis

All statistical analyses were conducted using SPSS - 14, with the level of significance set at $p \leq 0.05$. T-test for independent samples was used to explore between-groups differences in perceived QOL. Wilcoxon test was further applied to explore differences in the family members' perceptions. Pearson's correlation coefficient was employed to explore the relationship between the perceived QOL of adults with intellectual disabilities and their family members' and caregivers' perceptions.

Results

T-test for independent samples was used to explore the perceived QOL of adult with intellectual disabilities in residential facilities as compared to that of those in family residences. No differences were found between the groups for either

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the Importance or Emphasis dimensions. However, it is important to note that the perceived QOL of adults in both groups was relatively high (see Figure 3).

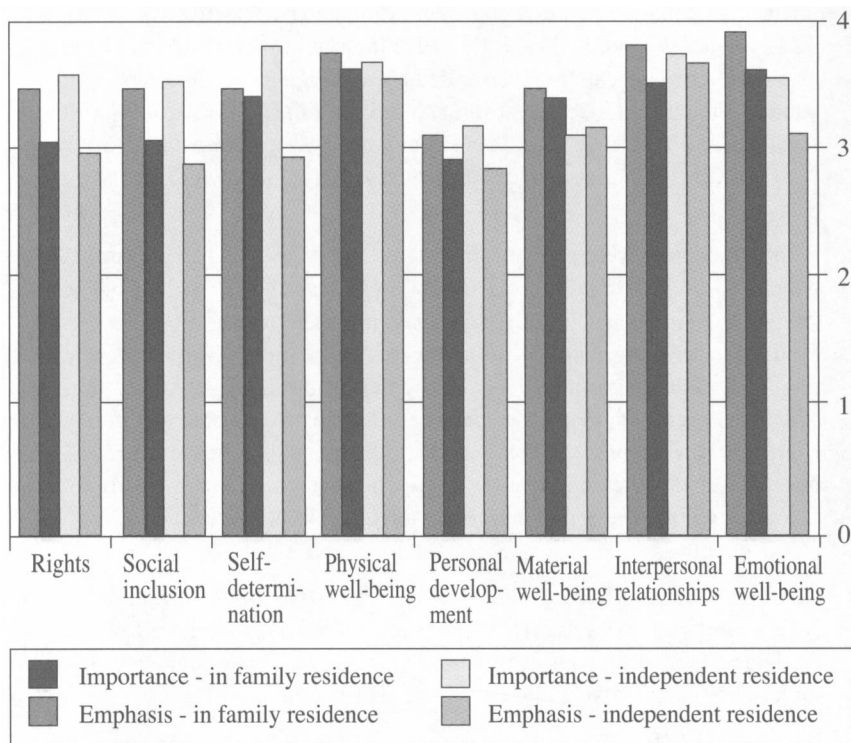


Figure 3. Average scores for Importance and Emphasis (adults with intellectual disabilities)

In addition, the T-test for independent samples revealed no overall difference between family members' perception of the QOL of adults with intellectual disabilities living in residential facilities versus that of those in family residences (see Table 1). However, it was found that family members of adults living in a residential facility perceived a higher QOL for their relative in the "self-concept" domain, than did family members of adults living in the family residence ($t = -3.75, p < 0.005$). The average score for "self-concept" given by family members of adults living in a residential facility was 3.79 (SD=0.24),

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which was higher than the average score given by family members of adults living in the family residence (average 2.98, SD=0.74). These findings suggest that family members of adults with intellectual disabilities living in residential facilities ascribed significantly greater importance to expressions of independence and control, working on personal goals and values, and the opportunity to choose, than did family members of adults with intellectual disabilities who lived in the family residence (see Table 1).

Table 1. Difference between how family members of adults with intellectual disabilities perceive the adults' QOL, divided by residence

	Family members family residence		Family members residential facility			
	Average	SD	Average	SD	T	W
Emotional well-being	3.31	0.87	3.67	0.44	-1.30	156.50
Interpersonal relations	3.64	0.56	3.78	0.37	-0.70	183.00
Material well-being	3.31	0.77	3.24	0.72	0.22	103.50
Personal development	2.81	0.97	3.22	0.69	-1.19	150.50
Physical well-being	3.48	0.70	3.59	0.46	-0.48	167.00
Self- determination	2.98	0.74	3.79	0.25	-3.75*	123.00*
Social inclusion	2.92	0.84	3.59	0.66	-2.09	122.50
Rights	3.04	1.23	3.67	1.00	-1.35	146.00

Pearson's correlation coefficient was employed to explore the correlation between family members' perception regarding the QOL of adults with intellectual disabilities and the way the adults themselves perceived their own QOL. No correlation was found for the Importance dimension. With respect to

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the Emphasis dimension, correlations were found in all domains except for "personal development" and "rights". In both of these domains, adults with intellectual disabilities perceived their own QOL to be higher than the perception of family members (See Figure 4).

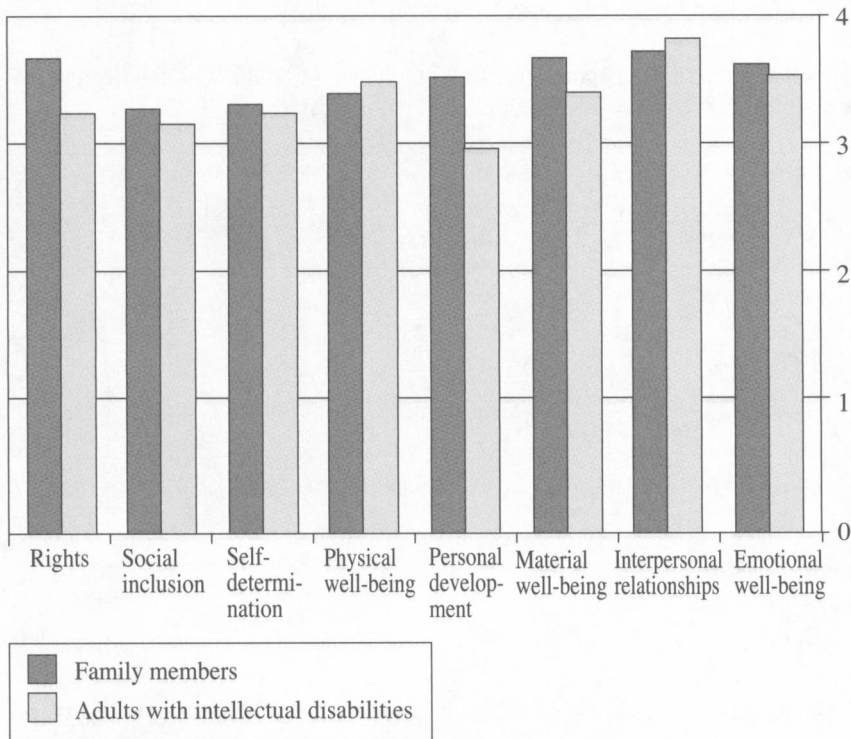


Figure 4. Comparison of average values for adults and family members, on the Emphasis dimension

Pearson's correlation coefficients were also used to explore the correlation between the caregivers' perceptions regarding the QOL of adults with intellectual disabilities and the way the adults themselves perceived their QOL. No correlation was found with respect to the Emphasis dimension. In contrast,

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a significant correlation was found with respect to the Importance dimension ($r=0.54$ with $p\leq 0.002$) between the adults and the caregivers for the "rights" domain alone (see Figure 5). Both caregivers and adults regarded rights as an important detriment of QOL for adults with intellectual and physical disabilities.

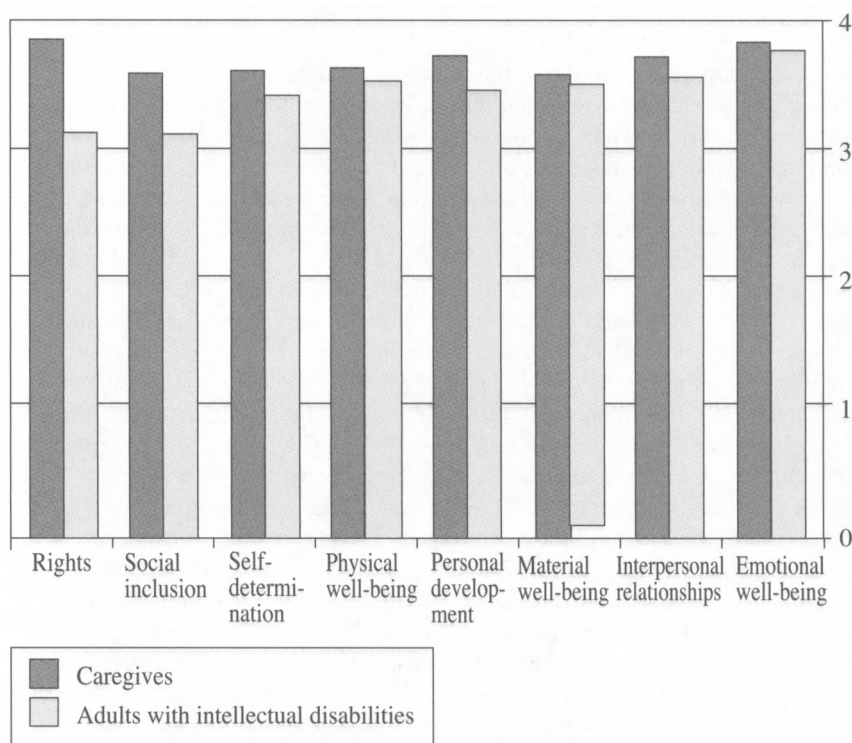


Figure 5. Comparison of average values for adults and caregivers members, on the Importance dimension

Discussion

The purpose of the current study was to compare the perceived QOL of adults with severe intellectual and physical disabilities with those of their family members and caregivers, and to examine the correlation between these

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perceptions and place of residence. Some differences were found in specific domains and values among family members of adults living at home and those living in supported residential facilities. In addition, some correlations were found between the way family members or caregivers perceive the adults' QOL and the adults perceived QOL. However, no differences were found between the perceived QOL of adults with intellectual disabilities living in supported-living facilities and those living in the family residence; the perceived QOL of both groups was relatively high.

These findings are similar to the findings of a study that explored QOL among adults with learning disabilities in Israel, in which no differences were found between perceived QOL of adults with learning disabilities living in a supported-community residence and those living in a family residence. Both groups demonstrated positive self-concept and were content with their QOL. The researchers concluded that QOL can be high in both community-residential facilities and in family residences, and that adults with learning disabilities can have a positive self-concept in either residential environment (Reiter & Bendov, 1996). Our study suggests that this might also be the case for adults with severe intellectual and physical disabilities.

However, other studies yielded unequivocal findings, revealing both advantages and disadvantages in QOL for adults with intellectual disabilities living in a family residence (for review see Selzer & Krauss, 2001). It appears that adults with intellectual disabilities living with their family have close family relationships, characterized by mutual support and emotional involvement, which contribute to high QOL for them as well as their family members. On the other hand, it seems that living at home often limits the social networks of adults with intellectual disability to a small number of friends of the same age group. This translates into a disadvantage with regards to their perceived QOL (Braddock, Emerson, Felce, & Stancliffe, 2001; Chou et al., 2007; Marcus & Rommel, 2006).

Overall, it appears that one can't ascertain which residential environment will provide better QOL for adults with intellectual disabilities. Rather, it is imperative to apply client-centered principles by relating to the needs and desires of each individual and take all aspects of his or her life into account when deciding between residential options. Family members and professionals alike must take the necessary steps to ensure that they are attentive to the perception of adults with intellectual disabilities when making substantive decisions concerning their lives. This awareness needs to be accompanied by the knowledge that they must learn to accept the fact that these adults' perceptions will not always be consistent with the perceptions of others.

Nonetheless, we did find a correlation between family members' perception of QOL of adults with an intellectual disabilities and the way these adults perceive their own QOL. Interestingly, family members of adults in the residential facility group ascribed significantly greater importance to expressions of independence and control, working on personal goals and values, and the opportunity to choose, than did family members of adults in the family residence group. An extensive search of the literature revealed no research as to the differences in approach between family members of adults with intellectual disabilities living in the community and those living in the family residences (Marcus & Rommel, 2006). Obtaining information from professionals and family members is helpful for understanding some of the underlying factors with regards to self-perception of QOL among adults with intellectual disabilities. Parents have a continuing role in children's life even after the child have matured or left home. Therefore, it is generally assumed that parents' attitudes and expectations influence the way their children perceive themselves, and consequently their QOL (Schwartz & Rabinovitz, 2003). Caregivers' perspectives regarding the QOL of a person with an intellectual disability may also influences the way the adult perceives his or her own QOL (Schalock et al., 1990 quoted in Schwartz & Rabinovitz, 2003). However, given our findings, it is important to ensure that the caregiver's perspective does not replace those of the client when considering whether or not action is taken to change or improve support systems or residential choices available to people with intellectual disabilities (Janssen et al., 2004).

Recommendations for future research

The relatively small convenience sample from a single facility obviously limits the generalizability of our findings. Future research with a larger, more representative sample would enable us to further explore issues such as potential demographic variables that might influence the decision making process, as well as a more deliberate exploration with regards to the correlation between service providers' attitudes and perceptions and clients' QOL perceptions.

Among the general public, there is a tendency to assume that QOL of individuals with severe intellectual and physical disabilities is lower than that of the general population. Furthermore, lay persons and professionals alike tend to assume that people with intellectual disabilities are suffering or unhappy with their lives. These unestablished assumptions often lead to either pity or withdrawal. Our results clearly demonstrate that unlike the accepted

perception, adults with severe intellectual physical disabilities perceive their own QOL as good, as do their parents and caregivers. Acknowledging this information might contribute to alleviating prejudices regarding people with intellectual and developmental disabilities and ensure that they be treated as equals.

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