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**The quality of life of people with intellectual developmental disabilities:
Implementation of a participatory action research approach**

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Abstract

This article describes a pioneering evaluation of services for people with intellectual developmental disabilities (IDD) in Israel based on the principles of the participatory action research approach. This approach was carried out in an organization that provides housing, employment, and leisure services to people with IDD in Beer Sheva. The aim of the evaluation was to examine the tenants' level of satisfaction with the services received. Participants in the evaluation included 46 tenants and 20 staff members. The evaluation tool focused on the quality of their lives in general as well as on specific domains. Furthermore, the caregiving staff's perceptions of their own quality of life (QOL) and that of the tenants were examined. The evaluation tool used to assess the tenants' quality of life was based on Schalock & Keith's (1993) model, which underwent adaptations and changes by focus groups of the tenants. The tenants took an active part in the evaluation process, from the stage of adapting the tool through interpretation of the findings.

The level of QOL was generally rated high by the tenants, though the "control/independence" domain received low scores. The findings indicated significant differences between the tenants' reports and those of the staff relating to their perceptions of the components of QOL and their prioritization. In addition, when dividing the tenants into groups according to level of functioning and support required, differences were found in the perceptions of the components of QOL and their rank order. The main finding showed a tendency among the higher functioning tenants to display less satisfaction with the level of independence in their lives.

Introduction

The de-institutionalization movement and principle of normalization (Nirje, 1980; Wolfensberger, 1972) emphasized the rights of people with disabilities to full, quality lives in a non-limiting environment that allows choice. To date in Israel, the implementation of this principle has not been examined among people with intellectual developmental disabilities (IDD), particularly not in terms of how they define the components of their quality of life (QOL). The normalization principle has also had implications for research methodology involving people with disabilities, for example the People First movement operating under the logo “Nothing about us without us,” followed by “No longer researching about us without us” (Walmsley & Johnson, 2003). This approach is meant to include the voices of those who belong to weakened and excluded groups as active partners in the research process with knowledge and life experience relevant to the subject of the evaluation. This type of evaluation methodology is pluralistic, and most of the collection and analysis of data is done in a qualitative manner (Barnes, 2003). Use of this approach allows for direct learning about the complexity of the lives of people with disabilities.

This evaluation aims to explore the QOL of tenants with IDD in an organization that operates a chain of municipal housing, employment, and leisure services. The evaluation was conducted on the basis of the participatory action research approach in which representatives of those being studied were partners in developing the guidelines for the evaluation, defining the topics to be examined, adapting the evaluation measures, and translating the evaluation findings and practical recommendations into actions directed at improving their QOL.

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Participatory action research among people with IDD

During the last three decades, there has been a move away from conventional methodological research approaches as a result of the worldwide struggle of people with disabilities to relate to disability as a political issue (Cample & Oliver, 1996; Charlton, 1998). The socio-political interpretation of disability provided a new conceptualization for the social model of disability, which identifies disability as social oppression (Hunt, 1981; Oliver, 1992). A new approach of emancipatory research (Oliver, 1992) was developed on the basis of reciprocity between the researchers and the subjects, and as such represents a reversal of the traditional researcher-subject hierarchy.

Shortly after the concept of emancipatory research was proposed, the participatory action research approach emerged (Keirnan, 1999; Whitney-Thomas, 1997) and has since been implemented among people with disabilities in various places, including the European Union (Priestley, Waddington, & Bessozi, 2010; 2011). The participatory action research approach is not satisfied with a description of the situation, but rather strives to change it. Its roots are in the applicable evaluation model. The main aspect of this concept is to produce maximum cooperation from the participation of the subjects as partner researchers, from the stage of creating the evaluation/ research questions through analysis and interpretation of the evaluation findings (Robinson & Krause, 2003). Participatory action research encourages real involvement and contributes to the development of a community and cultural identity (Ramcharan, Grant, & Flynn, 2004).

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Principles of the participatory action research/evaluation

1. The evaluation question topic is brought before or selected by the group.
2. The researchers and the participants with disabilities work together on all stages of the evaluation.
3. An alliance is created between the participants with disabilities and the researchers, with the purpose of bringing about change in intervention programs and policies.
4. A process of joint learning takes place in participatory action research as the participants with disabilities are empowered during the evaluation (Jurkowski, 2008).

It has been suggested that this approach be called “inclusive research” (Walmsley, 2001).

However, conducting inclusive research among people with IDD requires the involvement of professional researchers and a greater degree of adaptation, support and involvement than required among people with non-intellectual disabilities. Indeed, much of the literature on inclusive research does not refer to people with IDD.

As with all models, the participatory action research approach has its limitations and has been subject to criticism (Mercer, 2002). These have been detailed in a previous paper discussing participatory action research among people with disabilities (Roth, 2009). The current paper describes a pioneering evaluation of services for people with IDD in Israel based on the principles of the participatory action research approach, in which the knowledge was created together with the participants (the subjects of the evaluation). We aimed not only to promote change and improvement in the services, but also to empower the participants by broadening and documenting our understanding of their life experiences.

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Measuring QOL among people with IDD

QOL is a broad concept that relates to the individual's basic needs and desires and their association with social expectations and level of support received. In the last two decades, there has been a significant change in the way that society relates to social services in general and the services provided to people with disabilities in particular. Schalock (1999) noted that this trend is particularly noticeable in three areas: 1) a perception of the recipients of the service as customers; 2) a greater focus on the outputs, rather than the inputs, of the system and their implications for the customers' QOL; and 3) a reduction in the customers' dependence and development of their empowerment. Over the years, both objective and subjective perceptions have been used to measure QOL (Borthwick-Duffy, 1996; Felce, 1997; Perry & Felce, 2002; Schalock, 1999). Perry & Felce (2002) claim that QOL is derived from the objective evaluation of an individual's living conditions and a subjective evaluation of the measures of physical well-being (e.g., health and mobility); material well-being (e.g., quality of housing and financial state); social well-being (e.g., interpersonal relationships and involvement in community life); growth and productivity (e.g., independence and employment); and emotional well-being (e.g., positive mental health and fulfillment). Schalock and colleagues (Schalock, Bonham, & Verdugo, 2008) identified three domains as central to the concept of QOL: independence; social involvement and well-being; and emotional and material well-being. Schalock & Verdugo-Alonso (2002) argued that an ecological model should be adopted in understanding an individual's QOL. Such a model would include the individual's immediate social framework, such as family, residence, and peer

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group; the community, the neighborhood, and agents of various social services; and the local culture and socio-political environment at large.

Many studies that have tried to examine the QOL of people with disabilities in various contexts have deliberated over the question of whether the measures of QOL for the general population are also valid for special populations. Perry & Felce (2002) delineated the numerous challenges encountered by researchers when measuring the QOL of people with IDD:

- In many cases, the QOL is reported by family members or the staff working with the subjects of the evaluation, rather than directly by the subjects themselves.
- Often the subjects' communication skills are limited.
- Because of their cognitive disability, subjects with IDD may exhibit difficulty in understanding the study questions, and consequently the data may be only partially reliable.

People with IDD tend to consistently select a particular answer (the first or last). Schalock (1997) lists 10 core principles that relate to the QOL of people with IDD:

1. QOL of people with disabilities rests on the same measures as that of the general population.
2. QOL is experienced when a person's basic needs are met and equal opportunities are provided to achieve one's aims within the framework of housing, community, education and employment settings.
3. QOL is a multi-dimensional perception that is likely to be reported according to the different points of view of many parties, including the individual himself, family members, advocates, professionals and service providers.

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4. QOL is reinforced by empowerment of the individual and encouragement to be an active partner in making decisions relevant to one's life.
5. QOL will be achieved by acceptance and full integration of the individual in the community of residence.
6. QOL is an organizing concept that can be implemented in various contexts, such as measuring the QOL of the individual and the compatibility of available services.
7. Evaluation of QOL requires thorough familiarity with the population being studied and its perceptions of the components of QOL.
8. QOL must be measured by a variety of methods.
9. The variables relating to QOL must be expressed in the evaluation programs.
10. The findings of the evaluation of QOL are important in the development of resources and support for people with disabilities and their families.

In comparing the QOL of people with IDD with that of the general population, it is found that they experience lower levels of QOL and choice, have less autonomy, and make fewer decisions relating to their daily lives (Sheppard-Johns, Prout, & Kliener, 2005). This is more notable as the degree of severity of the disability increases. The more the person is disabled the lower his or her QOL, the less autonomic, and they make fewer decisions regarding their lives (Chubon, Clayton, & Vandergrift, 1995; National Organization on Disability, 2000). Studies have indicated that where there are programs in place for personal empowerment and choice in daily activities, even if small, an increase in the physical and emotional QOL of individuals is observed, and existential satisfaction is reported (Wallhagen, Strawbridge, Kaplan, & Cohen, 1994; Wells & Taylor, 1991).

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Duncan-Myers and Huebner (2000) found a correlation between the ability for choice among people with IDD and their reporting of satisfaction with life in all areas of daily activities, particularly with choices related to eating and personal hygiene. Mandler & Neon (2001) argued that support of the caregiving staff in fostering independence constitutes an important component in the QOL of tenants with IDD in residential settings.

The evaluation process

Aims

The current evaluation examined the satisfaction and QOL of people with IDD living in the Agudat Ami residential setting in Beer Sheva, Israel³ and receiving leisure and employment services through the organization. The aim of the evaluation was to identify the organization's strengths and weaknesses as the basis for improving the service. Three specific aims were defined:

1. Examination of the satisfaction and QOL of the tenants of the residential setting.
2. Comparison of the important components of the tenants' QOL, as perceived by the staff and by the tenants themselves. Compare the staff's perceptions of the components that tenants will define as important to their QOL versus the tenants' actual perceptions.
3. Recommendations for future therapeutic and practical aims and goals based on the findings of this evaluation.

³ The management of "Agudat Ami" consented to identifying the organization by name in this paper.

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Ethical approval

The organization contacted the legal guardians of all the participants and received their written informed consent to participate in this evaluation.

Method

The evaluation was conducted in the participatory action research approach. This methodology is based on the participation of people with IDD as representatives of the “subjects” in each stage of the evaluation that concerns them. The representative researchers also participated in data analysis, which utilized both quantitative and qualitative methods. The staff participated in a similar, shorter process, where they were asked to complete questionnaires assessing their perceptions of their own QOL, as well as that of their clients.

Evaluation stages

1. Focus groups - staff and tenants (separately)
2. Adaptation and creation of the evaluation tool
3. Data collection
4. Data analysis
5. Joint analysis, discussion and recommendations (with the tenant researchers)

Tenant representative researchers

The first stage of the study consisted of a discussion with a group of tenants, the tenant representative researchers, with the aim of bringing into focus the components of QOL as

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perceived by them. Eleven tenants with mild to moderate IDD participated in the group, which was co-chaired by two researchers. One documented the main themes that were discussed, using visual aids; the other focused on supportive, inclusive, adapted guidance. The session was recorded for purposes of analysis at a later stage. Additionally, central themes that were discussed were written on a board throughout the session.

The tenant representative researchers were asked to describe what they perceived as important to their QOL. Next they were asked to indicate with which elements of the residential setting they were satisfied and unsatisfied. After the components of QOL described by the focus group were written on the board, a vote was held to determine the rank order of these components. This information was to be used later in the qualitative data analysis and compared to the perceptions of staff members on the same topic. Later in the discussion, Schalock and Keith's questionnaire (1993) was presented to the group, and participants were asked to indicate which questions were less relevant to them and what important questions were missing and should be added. A revised version of the research questionnaire was created on the basis of these comments.

Completion of questionnaires

Initially, a pilot study was conducted among the tenant representative researchers to test the reliability of the evaluation tool and the clarity of the items. Prior to the completion of the questionnaires, the organization's management filled out a socio-demographic questionnaire for each participant. Following a short introductory session in which the researcher explained the term QOL and the study aims, data collection was done in a group setting where each participant completed the questionnaire with varying levels of assistance from the researchers. The method of completing the questionnaire was also

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adapted to the needs of the study population. The questions were projected in a large font and read out loud by one of the researchers or the participants. Once the researchers were convinced that everyone understood the content of each question, the participants marked their answers in pencil in order to allow for any necessary corrections. After all the participants finished answering each question, the researchers moved on to the next item. The group setting was found to be an effective method, and the entire study questionnaire was completed in this manner.

It is important to note that Agudat Ami and the management did not take part in determining the content of the evaluation or in collecting the data. They did allocate space and equipment, as needed by the researchers, in order to enable optimal objective reporting by the subjects. The organization's staff did not participate in the discussion of the findings, and the data collection process was not held within the residential setting.

The tenant sample

The sample consisted of 46 of the 106 tenants of Agudat Ami's residential setting in Beer Sheva (43.3%), including 29 males and 17 females with IDD. Half of the tenants who were determined by the organization to have the cognitive and communicative skills needed to participate in the study were represented in the sample. Duration of residence in the setting ranged from one to 21 years (mean=10.27 years). Thirty-seven participants were secular, five were traditional, and four were religious. Thirty participants were diagnosed with mild IDD and 16 with moderate IDD. The management characterized the level of support required by the tenants, as defined by the American Association on Mental Retardation (AAMR, 1997) and adopted by the Israeli department of care and service for people with IDD and their families, as follows: four required continuous

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support, two limited support, and 22 intermittent supports, while 18 tenants were independent. Twenty-two participants had good health, 22 had good health but required ongoing medical treatment, and two had a severe illness that impaired their functioning.

The staff sample

Similar to the discussion with the tenants, staff members were also asked how they perceived their own QOL and that of the tenants to whom they provide services.

Twenty-one staff members participated in the group discussion, including 11 counselors, 3 house mothers, 3 apartment supervisors, one evening coordinator, one personal advancement manager, one recreational manager, and one nurse. Duration of work in the organization ranged from 3 months to 15 years.

Evaluation instrument


Tenant research questionnaire


The evaluation tool was based on Schalock & Keith's QOL questionnaire (1993). This measure, designed for people with mild to moderate IDD, assumes that QOL is a subjective construct. The questionnaire was translated to Hebrew by Benedov & Reiter (1997) and has been used in previous studies in Israel (Reiter, Goldman, & Lieblich, 1997). The questionnaire's internal consistency, as previously reported, is 0.87. The questionnaire assesses four domains: satisfaction and happiness (sense of fulfillment); productivity (sense of competence); control and independence (sense of empowerment); and social belonging / community integration. The current evaluation was based on a version of this questionnaire used by Almosni (2001) to examine the effects of physical education teaching strategies on the QOL of young adults with mild to moderate IDD.


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The questionnaire is composed of 40 items (10 per domain). Responses are rated on a Likert scale ranging from 1 (disagree) to 3 (strongly agree).

The questionnaire was adapted to suit the cognitive abilities of the study population, as expressed during the focus group that aided the development of the evaluation tool. Items were added and removed from the questionnaire on the basis of the two-hour discussion within the focus group. As a result, a total of 24 items were selected, with 6 per domain. All items were worded in a positive manner. In order to simplify the response scale, a face was attached to each response to represent different expressions for different emotions:

1=disagree - sad face 

2=slightly agree and slightly disagree - neutral face 

3=strongly agree - smiley face 

This method is commonly used for the assessment of pain (the Wong-Baker faces pain rating scale) among children under eight years old or people with dementia.

Once the QOL questionnaire was adapted for purposes of this study, with the help of the tenant representative researchers, a pilot was conducted. The questionnaire was found to have good internal consistency (Hatcher& Stepanski, 1994), with Cronbach's $\alpha=0.7$. In the current study, when analyzing the responses of all the participants, the questionnaire showed moderate internal consistency ($\alpha=0.57$). Twenty-two items were used for data analysis, as two items were found to be unsuitable for analysis.

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As previously mentioned, the organization's management completed a socio-demographic questionnaire for each participant based on personal acquaintance and on the data that appeared in their personal files.

Staff research questionnaire

The staff's perceptions of their own QOL and that of the tenants were also examined.

Given that staff members act as agents and take part in shaping the QOL of the tenants, it is interesting to compare their perceptions of the components of QOL and the priorities of these components to those perceived by the tenants. Staff members were introduced to theoretical perspectives on QOL and then asked to answer questions that were drafted on the basis of the focus group's discussion. Staff members who participated in the focus group did not take part in the evaluation. The staff met the researchers in a group session, though questionnaires were completed individually in writing. Staff members did not have access to all the questions, but rather viewed each question separately and answered when instructed to do so by the researchers. The questions were:

- State your position, number of years with the organization, and cognitive profile of the population with whom you work.
- State four components that are important to your QOL.
- State four components that you think are important for the QOL of the tenants.
- State four components that you think the tenants would indicate are important to their QOL.

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Data analysis

Once the questionnaires were completed by the staff and the tenants, and the socio-demographic information was provided, the data were coded using SPSS 19. Statistical analyses are detailed in the results section. Qualitative data collected from the staff and tenants were also analyzed.

Results

The findings of this study are presented in several stages: 1) tenants' satisfaction with the service, based on their responses to the research questionnaires; 2) a summary of the qualitative findings regarding important components of QOL, as defined by the staff and tenants, based on the questions presented to staff members; and 3) a comparison of the components of tenants' QOL, as perceived by the staff and as defined by the tenants in the focus group.

Findings from the tenant questionnaire

The association between the formal cognitive diagnosis of the tenants' intellectual impairment and the level of their required day-to-day support, as defined by the organization's management in the socio-demographic questionnaire, was examined prior to data analysis. This resulted in a significant negative correlation ($r=-0.62$, $p=0.034$), suggesting that higher levels of cognitive functioning are associated with lower levels of required support.

QOL of the tenants

The findings regarding QOL among all the participants, based on individual items (see Table 1), subscale scores and total scores, indicate overall high life satisfaction ($\bar{x}=2.69$, $SD=.61$); high mean productivity ($\bar{x}=2.71$, $SD=.55$); moderate mean control and

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independence ($\bar{x}=2.15$, $SD=.76$); and high mean social belonging/community integration ($\bar{x}=2.67$, $SD=.68$). Regarding control and independence, two items scored particularly low (less than 2 on a 1-3 scale): “To what extent do you decide for yourself what to do?” and “Do you have a key to your residence (flat/ room /personal closet)?” Likewise, one item scored low on social belonging/community integration: “How much control do you have over choosing your roommates?”

Insert Table 1 here

The means of each domain are depicted in Figure 1.

Insert Figure 1 here

The tenants were divided into three groups based on the level of support they required: independent, intermittent support, and enhanced or continuous support. This categorization was used to examine the differences between the groups in the main study variables. Analysis of variance (ANOVA) suggests that the following significant differences were found between the groups (see Table 2):

- Participants requiring intermittent support reported higher levels of satisfaction with their accommodations (item 3), as compared to independent participants.
- Minor significant differences ($p<0.001$) were observed between the groups on the way in which they were treated by their friends in the residence (item 4), though all groups reported high satisfaction on this item.
- Participants requiring enhanced or continuous support reported higher levels of satisfaction with the way in which they were treated by the residence staff (item 10), as compared to participants in the other two groups.

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- Independent participants reported that they did not earn enough money at work to buy what they wanted (item 12) to a greater extent than participants requiring intermittent support.
- Independent participants reported more control over decisions about what to buy (item 13) and what to do (item 15) than participants in the other two groups. Despite these significant differences, the mean score of control over decisions about what to do was relatively low (1.4) among independent participants, suggesting that they too were not satisfied with this domain.
- Participants requiring enhanced and continuous support were visited most often by friends (item 22).

Insert Table 2 here

The means and significant differences between the groups according to their level of required support are presented in Figure 2.

Insert Figure 2 here

The first stage of the study included a focus group with the “tenant representative researchers,” in which their perceptions of the most important components of QOL were defined. Next, these components were ranked according to importance. A similar process was done with the staff members by addressing the issue of QOL both in a focus group and in the research questionnaires. The evaluation questionnaires completed by the staff

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members were used to compare their perceptions of the components of QOL with those of the tenants.

Main components of QOL as perceived by the staff and tenants

The main components of subjective QOL, as perceived by the staff (regarding their own lives) and the tenants, were compared (see Table 3). The staff members attributed great importance to work and livelihood (75%), family (70%), health (65%), and joy and happiness (25%). The tenants attributed great importance to social life (73%), attitude of the caregiving staff (73%), trust in the staff (73%), sense of competence (73%), intimate relationships (63%), and privacy and independence (45%).

Insert Table 3 here

Main components of the tenants' QOL as perceived by the staff and tenants

The components perceived by the staff members as important to the QOL of the tenants were very different from those defined by the tenants themselves (see Table 4). The staff members defined health as being the most important component in the QOL of the tenants, while the tenants themselves did not refer at all to health in their perceived components of QOL. Attitude of the caregiving staff was ranked similarly by both the staff and the tenants, though the percentages of endorsement of this item differed between the groups. Likewise, the rankings of independence (by the staff) and competence (by the tenants), two similar concepts, were similar between the groups, though again the percentages of endorsement of these items differed (20% of the staff and 73% of the

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tenants). No further similarities were observed between the groups. The overall percentage of endorsement of the various components was higher among the tenants than among the staff members.

Insert Table 4 here

Staff perceptions of QOL components ranked by the tenants

The staff's responses to the question "which components do you think the tenants would indicate are important to their QOL?" were very different from the components defined by the tenants themselves (see Table 5). The staff assumed that the tenants' main components would concern concrete items such as food (55%), whereas the tenants actually ranked social life as the most important component in their QOL (73%).

Acceptance and willingness to listen (35% of the staff) and sense of trust in the staff (73% of the tenants) were ranked third by both groups, though the percentages of endorsement differed between the groups. Both groups viewed the relations with the caregiving staff as an important component of QOL. The fifth ranked item among the staff members was family relations (25%), while among the tenants it was intimate relationships (63%).

Insert Table 5 here

Discussion

The first part of this section will discuss the researchers' analysis of the findings of the QOL questionnaire from the focus group, as well as the process that relied, *inter alia*, on issues that arose in the focus group. Themes were discussed in the focus group according to the order of the domains evaluated. The second part will address the

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components of QOL and their ranking according to priority among the group of tenants, as compared with the group of staff.

Discussion on the findings of the QOL questionnaire among the tenants

The findings indicated that the group of tenants, both in general and at all levels of support, ranked the control and independence domain low relative to the other three areas that were examined, which were ranked between 2.5 and 3 (the maximum score). The control and independence domain relates to independent decisions made by the tenants in various areas of life, such as shopping, choosing who will be sharing with them their apartment, and determining the look of their room. Significant differences between the groups were found in some of the items. As a trend, the independent group displayed less satisfaction concerning the issues of visits by friends, the amount of money accessible for purchases to fulfill their personal desires, the attitudes of the counselors and the housemother, and the apartment accommodations. However, this group expressed clear satisfaction in deciding what to buy, as well as in the area of relationships between friends in the apartment. Tenants in the “intermittent support” category rated higher satisfaction relating to the amount of money available to them for the purchase of personal items and satisfaction with the accommodations. Relative to the other two groups, tenants in the “enhanced and continuous support” category indicated high satisfaction with the issues of friends visiting the apartment, as well as with the attitudes of the counselors and the housemother. Nevertheless, a particularly low score was found, in comparison with the other two groups, on the extent to which they were able to decide what to do and what to buy.

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When the control and independence domain was presented to the focus group, it became clear that some of the tenants were experiencing ambivalence between the desire for independence and the need for various levels of support from a permanent, available person. As one of the members of the group stated: “If the house mother decides whether we bring friends over and go out, sometimes she says no – but it is like a mother. Sometimes it is yes and sometimes it is no”. This conflict was expressed throughout the discussion. On the one hand, the tenants with lower levels of functioning and in need of higher levels of support exhibited understanding and sympathetic attitudes towards the figures of authority in their surroundings, probably because these individuals met their needs and induced a sense of security. On the other hand, the tenants with a higher level of functioning expressed the expectation for increased autonomy and self-determination.

The researchers sought to organize the views that arose in the discussion and asked the participants what the advantages were of their dependence on the staff members and where this dependence limited their independence. The responses indicated a good ability to differentiate and define the advantages and disadvantages of their reliance on accompanying and supporting figures of authority. They recognized that while “the rules and regulations protect us,” at the same time “it is important for us to learn things in order to succeed, for example how to be independent and pay bills.” People with IDD tend to experience over-protection from their primary and secondary sources of support (Levy-Shiff & Shulman, 1998), which may have implications for an individual’s self-image. It is possible that individuals needing relatively greater support tend to view directing and accompanying figures as sources of security and dependence and are therefore characterized by an external “locus of control” (Rotter, 1966). In

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contrast, as the individuals' levels of functioning increase, a greater sense of autonomy and competence is established, fostering a more internal locus of control over their lives.

In the field of social belonging and community integration, the general score showed relatively high satisfaction ($\bar{x} = 2.67$). However, in a question relating to opportunities allowed for creating intimate relationships, disappointment was expressed among the tenants with higher levels of functioning. One of them suggested different sets of rules for the independent and for the problematic individuals, rather than keeping the rules the same for everyone. This approach would establish the need for a differential perception between the tenants who need higher levels of support and dependence on the environment, as compared to the more independent tenants with a greater internal locus of control (Levite-Bernstein, 2011).

The productivity domain, which refers mainly to the tenants' employment, showed high satisfaction at all levels ($\bar{x} = 2.71$). Nevertheless, lower satisfaction was reported on the items relating to independence in using their money. The tenants explained that the counselors determined for them what to purchase with their money, and they expressed the desire to have more freedom regarding what to buy and when. When it was suggested to the tenants that they be allowed to buy whatever they wanted with a weekly amount of NIS 20 (\$5.00), and only above this amount would approval of the counselors be required, they indicated that this solution would satisfy them.

The tenants' general satisfaction with life and the services provided to them in the residential setting received a high score, with the exception of the item on satisfaction with the freedom to choose their food in the apartment. Thus, it appears that despite satisfaction with personal well-being and general QOL among the tenants in most of the

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domains examined, the issue of control and independence requires re-examination. The researchers observed two trends among the members of the focus group. The tenants with high independent functioning abilities reported a desire to change the existing framework, while the tenants with relatively low levels of functioning saw the various figures of authority around them as a source of support, direction and security that they needed.

Comparison of the evaluation of QOL components between the groups of tenants and staff

A comparison of the frequency of central themes in the components of QOL in the eyes of the staff and the tenants revealed meaningful differences between the two groups in the components of QOL, as well as in the frequency of endorsement of various items. The results indicate that the staff members viewed work, livelihood and family as the central components of their QOL, while the tenants considered society and caregiving figures to be the center of their QOL. It appears that these findings attest to the gap between the expectations of subjects found in the normative circle of life and those of subjects with IDD, who are in earlier stages of maturity and development. It should be noted that based on our knowledge of the two research groups, the distribution of the chronological age of the members in both groups was similar.

The most significant gaps were observed in a comparison of the components of QOL that the staff thought the tenants would define as central in their lives versus those actually defined by the tenants as such. According to the staff, the tenants were focused on very concrete and primal needs in their lives, whereas the tenants revealed entirely different expectations of QOL. The most notable example was the staff's perception of

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food and health as the central and most important component of the tenants' QOL, while the tenants themselves reported that social life was actually more important to them.

Furthermore, the staff members estimated that relations with the families were a central component of the tenants' QOL. Yet, the tenants noted that one of the main components of their QOL was actually the creation of intimate relationships.

It is worth noting that the organization allowed the process of examination to take place without any intervention on its part. There is a dynamic process in participatory action research of this kind that obligates the researchers to be flexible and creative and to respond to unexpected events with which they have to cope – a phenomenon that is generally not required in the process of a standard evaluation. However, despite the challenges in such a process, this appears to be the preferred model for conducting evaluations on the QOL of people with disabilities in general and those with IDD in particular.

Main Recommendations

This evaluation raises a number of central issues that should be translated into direct actions for the improvement of the QOL of tenants in residential settings, as follows:

1. In the determination of the procedures of residential settings for their tenants, it is fitting that the process of their formulation be done in a personal, rather than a collective, manner according to the tenants' level of functioning and the level of protection and support that they require.
2. It is recommended that guidance be provided to help the tenants develop self-acceptance and achieve fulfillment in their lives according to a realistic perception of

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their strengths and abilities, particularly those with the highest levels of functioning who have not yet internalized and come to terms with their group of belonging.

3. It is recommended that social sexual guidance be provided, according to the level of functioning, for those tenants who express the desire for intimate relationships and that appropriate opportunities be given to those tenants for establishing such relationships.
4. Regarding the use of money, it is recommended that a policy be determined to allow the independent use of an amount set by the management together with representatives of the tenants, beyond which approval from the counselors would be required.
5. It is recommended that residential settings find a way to provide an appropriate private space for each tenant, such as a private closet with a lock.
6. Given the gaps between the way in which staff members perceive the important components of the tenants' QOL and the way in which the tenants themselves perceive the components of their own QOL, it is fitting to consider the establishment of a tenants' committee within the residential setting in order to promote constructive dialogue between the clients and the service providers.

It is worth noting that the findings of the study were presented at a seminar organized by Agudat Ami for policymakers and the professional community and that the group of tenant representative researchers presented the process and the personal insights gained during the evaluation. As required in participatory action research, Agudat Ami implemented the study recommendations by holding meetings with the tenants and the

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staff members in order to start a dialogue to define the central issues, coordinate expectations, and chart the way to creating a new reality through changes in policy.

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Table No. 1 - Means and Standard Deviations of the QOL Questionnaire

Item	Area	Question	Mean	Standard Deviation
1.	General satisfaction with life	How much fun and enjoyment do you get out of life?	2.71	0.65
2.		How well do you cope in the apartment?	2.73	0.57
3.	General mean 2.69	How satisfied are you with the accommodation in your apartment?	2.65	0.67
4.		How do your friends in the apartment treat you?	2.69	0.55
5.		To what extent do you feel socially accepted?	2.67	0.63
6.		**How satisfied are you with the food in the apartment?	2.67	0.63
7.		**How do the apartment's counselors and housemother treat you?	2.76	0.58
8.	Productivity	How successful do you think you are, compared to your friends?	2.84	0.36
9.	General mean 2.71	How good do you feel you are at your job?	2.7	0.64
10.		How do the counselors and friends at work treat you?	2.80	0.45
11.		How satisfied are you with things you have learned to do at work?	2.82	0.48
12.		Does your job provide you with enough money to buy the things you want?	2.39	0.83

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Item	Area	Question	Mean	Standard Deviation
13.	Control / Independence	To what extent do you decide what to buy?		
14.	General mean 2.15	**How much are you taken care of when you are ill?		
15.		To what extent do you decide for yourself what to do?		
16.		How much can those you love visit your apartment?		
17.		Do you have a key to your home / personal closet?		
18.		**To what extent can you decide how your room / apartment will look?		
19.		Social belonging/ Community integration	To what extent do you participate in leisure activities and extra-mural activities in the community?	2.84
20.	General mean 2.67	How satisfied are you with these extra-mural activities and leisure activities?	2.89	2.89
21.		To what extent does the framework allow you to meet, and maintain contact with, a partner?	2.89	2.89
22.		Do friends visit you at your apartment?	2.78	2.78
23.		To what extent do you feel you	2.85	2.85

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Item	Area	Question	Mean	Standard Deviation
		belong to, and are a part of, your family?		
24.		** To what extent do you decide who your roommates will be?	1.77	1.77

** Items added by the focus group that were not in Schallock's original questionnaire

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Table No. 2: ANOVA - Significant differences between the groups of tenants according to level of support required

Grade	Independent (N=18)	Intermittent Support (N=22)	Enhanced and continuous support (N=6)	Level of Significance
3. How satisfied are you with the accommodation in your apartment?	2.55	2.86		0.029
4. How do your friends in the apartment treat you?	2.78	2.72	2.75	0.015
10. How do the counselors and friends at work treat you?	2.72	2.82	3	0.000
12. Does your job provide you with enough money to buy the things you want?	2.27	2.63		0.040
13. To what extent do you decide what to buy?	2.65	1.73	1.5	0.005
15. To what extent do you decide for yourself what to do?	1.44		1	0.034
22. Do friends visit you at your apartment?	2.5	2.95	3	0.028

* Note: The places where there are no values in the column relating to enhanced and continuous support are a possible product of the low number of participants in this group (N=6)

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Table 3: Comparison of frequency of central themes in the components of QOL in the view of the staff and the tenants

Grade	Staff Group		Focus Group - tenants	
	Personal QOL components of the staff members themselves	Frequency of endorsement	QOL components as defined by the tenants	Frequency of endorsement
1.	Work and livelihood	75%	Social life	73%
2.	Family	70%	Attitude of the caregiving staff	73%
3.	Health	65%	Sense of trust in the staff (attention, relating to desires with respect)	73%
4.	Joy and happiness	40%	A sense of capability	73%
5.	Friendship	25%	Intimate relations	63%
6.	Love and good intimate relations	20%	Privacy	45%
7.	Security	15%	Independence	45%
8.	Gratification, QOL, fulfillment, accommodation conditions	10%	Personal budget	18%

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9.	Human relations, raising an animal, a garden, respect, personal time, independence, food	5%	Physical accommodation conditions, security, leisure, love and support, family, popularity	Low reference (less than 2%)
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Table 4: Comparison of frequency of central themes in the components of tenants' QOL as viewed by the staff and as defined by the tenants themselves

Grade	Staff Group		Focus Group - tenants	
	Important QOL components for the tenants in the view of the staff	Frequency of endorsement	QOL components as defined by the tenants	Frequency of endorsement
1.	Health	45%	Social life	73%
2.	Social life, work, attention, and attitude of the caregiving staff	35%	Attitude of the caregiving staff	73%
3.	Food	30%	Sense of trust in the staff (attention, relating with respect to desires)	73%
4.	Independence, intimate relations, extra-mural activities and leisure	20%	Sense of competence	73%
5.	Good living conditions, fun, love, warm home, joy and happiness	15%	Intimate relationships	63%

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6.	Acceptance by society, getting along with roommates, security	10%	Privacy	45%
7.	Sports, clothes, money for luxuries, satisfaction with life, family, gratification, cleanliness and aesthetics	5%	Independence	45%
8.			Personal budget	18%
9.			Physical living conditions, security, love and support, family, popularity	Low reference (less than 2%)

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Table 5: Components of QOL that the staff thought the tenants would define compared with those actually defined by the tenants

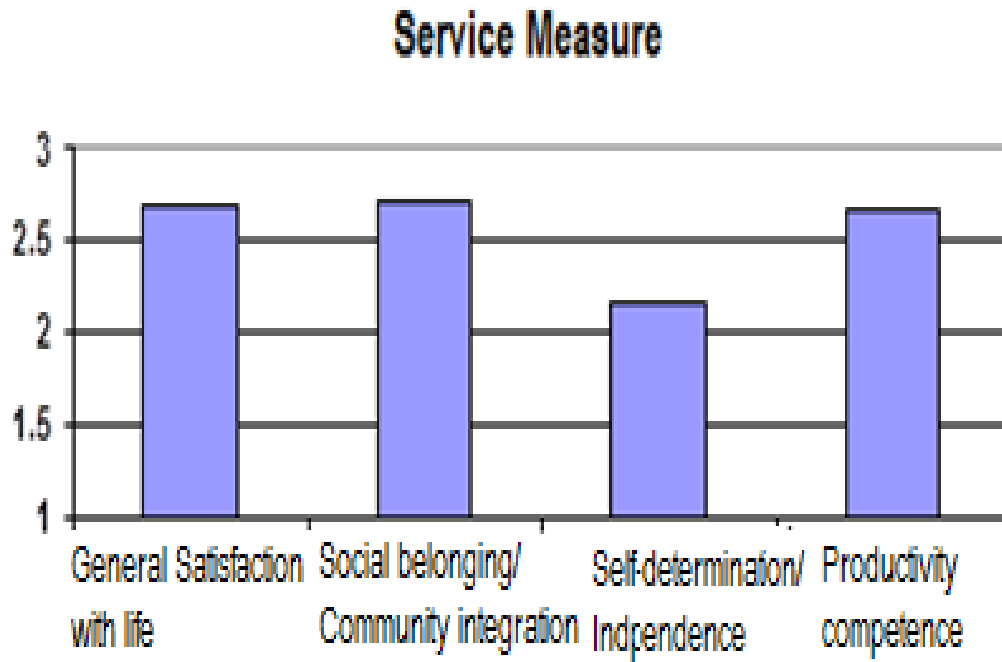
Grade	Staff Group		Focus Group - tenants	
	QOL components - tenants' perspective by the staff	Frequency of endorsement	QOL components as defined by the tenants	Frequency of endorsement
1.	Food	55%	Social life	73%
2.	Extra-mural activities and leisure	45%	Attitude of the caregiving staff	73%
3.	Acceptance and a willingness to listen	35%	Sense of trust in the staff (attention, relating with respect to desires)	73%
4.	Friendships, health	30%	Sense of capability	73%
5.	Family relations	25%	Intimate relationships	63%
6.	Clothing, entertainment, fun and trips, warm home and accommodation, happiness	20%	Privacy	45%
7.	Love, success at work	20%	Independence	45%

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8.	Security, intimate relations	10%	Personal budget	18%
9.	Money, gratification, accumulation of personal property, independence	5%	Physical living conditions, security, love and support, family, popularity	Low reference (less than 2%)

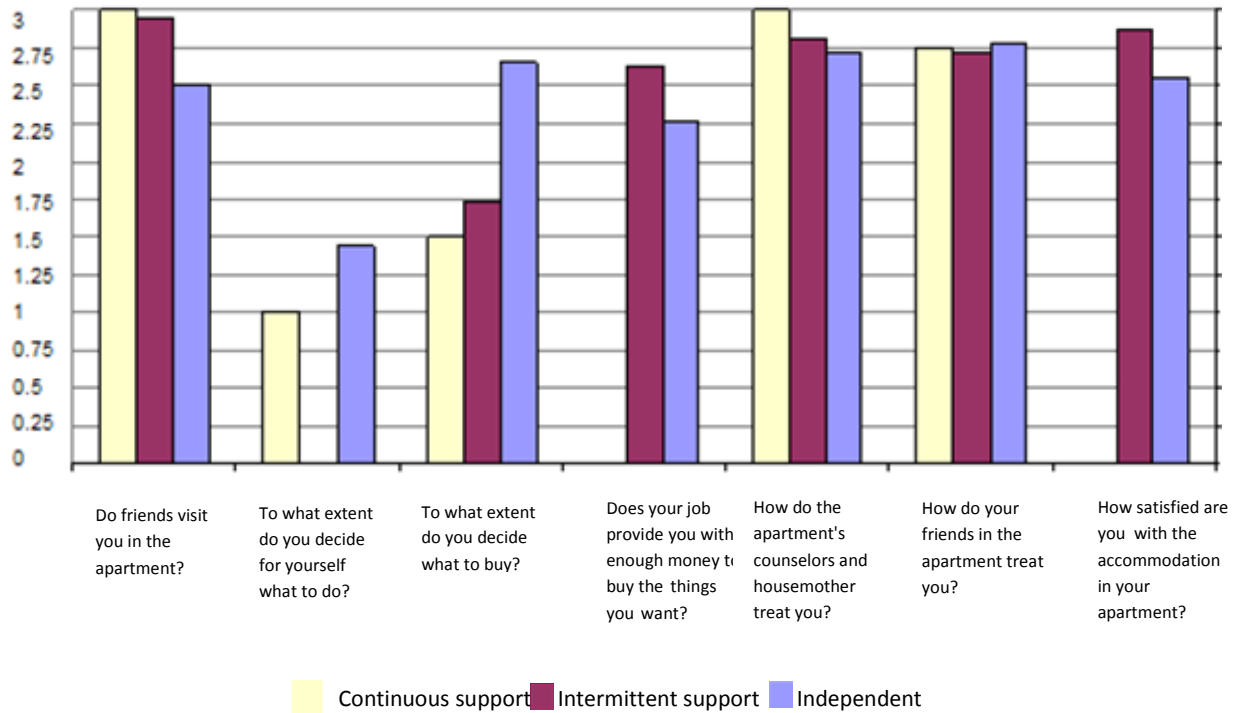
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Graph 1: Means of domains of tenants' QOL measures






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Graph 2: Significant differences in means between groups of tenants according to the level of support required






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Appendix 1. Adapted QOL questionnaire

Item	Area	Question			
1.	General satisfaction with life	How much fun and enjoyment do you get out of life?	1	2	3
2.		How well do you cope in the apartment?	1	2	3
3.		How satisfied are you with the accommodation in your apartment?	1	2	3
4.		How do your friends in the apartment treat you?	1	2	3
5.		To what extent do you feel socially accepted?	1	2	3
6.		*How satisfied are you with the food in the apartment?	1	2	3
7.	Productivity	How successful do you think you are, compared to your friends?	1	2	3
8.		How good do you feel you are at your job?	1	2	3
9.		How do the counselors and friends on your job treat you?	1	2	3
10.		*How do the apartment's counselors			

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Item	Area	Question			
		and housemother treat you?			
11.		How satisfied are you with things you have learned to do at work?	1	2	3
12.		Does your job provide you with enough money to buy the things you want?	1	2	3
13.	Control / Independence	To what extent do you decide what to buy?	1	2	3
14.		*How much are you taken care of when you are ill?	1	2	3
15.		To what extent do you decide for yourself what to do?	1	2	3
16.		How much can those you love visit your apartment?	1	2	3
17.		Do you have a key to your home / personal closet?	1	2	3
18.		*To what extent can you decide how your room / apartment will look?	1	2	3
19.	Social belonging/	To what extent do you participate in leisure activities and extra-mural	1	2	3

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Item	Area	Question			
	Community	activities in the community?			
20.	integration	How satisfied are you with these extra-mural activities and leisure activities?	1	2	3
21.		To what extent does the framework allow you to meet, and maintain contact with, a partner?	1	2	3
22.		Do friends visit you at your apartment?	1	2	3
23.		To what extent do you feel you belong to, and are a part of, your family?	1	2	3
24.		*To what extent do you decide who your roommates will be?	1	2	3

Based on the work of Almonsi (2001), items were adapted as follows:

In the domain of general satisfaction with life:

- Items 3,4,7 were removed
- Items 8,9,10 were grouped into one question enquiring about social acceptance
- One new question was added, as suggested by participants in the focus group: "How satisfied are you with the food in the apartment?". The remaining items

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from the original questionnaire (1,2,5,6) were reworded, for instance: the original question "How satisfied are you with your current home or living arrangement?" was changed to "How well do you cope in the apartment?"

In the domain of productivity:

- Items 12,16,17,19,20 were removed
- Items 11,13,18 were included
- Items 14,15 were reworded

In the domain of Control / Independence:

- Items 23,24,27,28,29,30 were removed
- Items 21,26 were included
- Items 22,25 were reworded
- Two new questions, determined to be relevant by the focus group, were added:
"How much are you taken care of when you are ill?" and "To what extent can you decide how your room/ apartment will look?"

In the domain of Social belonging/ Community integration:

- Items 33,34,38,39,40 were removed
- Items 31,32,35,36,37,38 were included though their wording was slightly adjusted
- One new question was added by the participants of the focus group: "To what extent do you decide who your roommates will be?"