Do persons with intellectual disability have a social life? The Israeli reality

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Abstract

Living in the community does not, in and of itself, guarantee social integration and inclusion for persons with intellectual disability. Social life and leisure participation can indicate the beginning of such a process and its impact on the quality of life. The present study investigated the social life quality of persons with intellectual disability who live in community settings or with foster families and its impact on their quality of life. The sample consisted of 85 adults with intellectual disability, ranging in age from 18 to 55 years. Forty-five of them lived in community residential settings and 40 lived with foster families in Israel. Five questionnaires were used: I) a demographic questionnaire; 2) Quality of Life Questionnaire; 1 3) the Revised UCLA Loneliness Scale;² 4) Social Relationships List;3 and 5) Leisure Activities List.3 The main findings showed no significant differences between the two groups in social life or feelings of loneliness. Foster residents were more involved and more independent in their leisure activities than were those who lived in community residences. An association between social life and quality of life was partly confirmed. The need for intervention programs and leisure education programs is discussed.

Key words: social life; leisure activities; quality of life; lonelines; Israel

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Resumen

El hecho de vivir en una comunidad no garantiza, por sí mismo, ni la integración ni la inclusión de los discapacitados intelectuales. Las amistades y la participación en actividades recreativas pueden ser indicadores de que tal proceso comienza a darse y de su impacto en la calidad de vida. El presente trabajo investigó la calidad de vida social de personas con discapacidad intelectual que viven en residencias comunitarias y con familias adoptivas y su impacto en cuanto a calidad de vida. La muestra consistió de 85 adultos con discapacidad intelectual de edad entre 18 y 55 años. Cuarenta y cinco de ellos viven en áreas comunitarias residenciales y 40 con familias adoptivas en Israel. Se utilizaron cinco cuestionarios: 1) un cuestionario demográfico; 2) el Cuestionario de Calidad de Vida; 13) la Escala de Soledad Revisada de la UCLA; 24) el Catálogo de Relaciones Sociales; y 5) el Catálogo de Actividades Recreativas.³ En general no se encontraron diferencias significativas entre los dos grupos en lo referente al número de amistades o en cuanto a los sentimientos de soledad. Los residentes con familias adoptivas tendieron a involucrarse más y a ser más independientes en sus actividades recreativas que los que vivían en residencias comunitarias. Se confirmó en parte una relación entre vida social y calidad de vida. Se discute la necesidad de programas de intervención y educación de la recreación.

Palabras clave: vida social; actividades recreativas; calidad de vida; soledad; Israel

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Over the last 25 years, there has been a significant change in the lives of people with intellectual disability. Many more people live in the community now, either with family members, in foster homes, or in a supported living arrangement.^{4,5} A growing body of literature documents the broad range of community experiences and increasing opportunities for inclusion of people with disabilities.⁵⁻¹¹

Living in the community does not, in and of itself, guarantee that individuals with intellectual disability have a real opportunity to be part of the community. One of the most important factors associated with the failure to adapt to community living is the inability of persons with intellectual disability to use their free time in a personally satisfying manner and to build meaningful social relationships. It was found that many of them suffer from loneliness, boredom, and anxiety brought on by an abundance of unstructured free time and a lack of the knowledge and skills required to take control over their own leisure participation. ¹²⁻¹⁴

Staff efforts are often found to be directed toward preparing people with intellectual disability to adjust to a life in the community. While they focus on vocational training and independent living skills, they often fail to recognize the importance of leisure and social relationships and the necessary training needed for utilizing leisure opportunities and resources. The neglect of relevant leisure programming and services for persons with intellectual disability is particularly unfortunate because appropriate participation in recreation activities has been identified as an important factor in successful community adjustment and high quality of life. 13,15,16

Studies on leisure activities of people with developmental disabilities reveal that people with intellectual disability engage in leisure activities less often than do people without disabilities, and that they often lack the skills essential to social interaction and self-determination. ^{17,18} Recreation has an important role in the facilitation of friendship for people with intellectual disability. Therapeutic recreation services promote and encourage friendship through recreation between people with and without disabilities. A life with no friends can lead to feelings of social isolation, loneliness, reduced self-esteem, depression, and emotional maladjustment. ¹⁹⁻²¹

There is scholarly agreement that friendship is characterized by mutual, reciprocal, enjoyable, supportive, and dynamic relationships. ^{22,23} For persons with intellectual disabilities, as well as for those without disabilities, friendship is an essential component in their quality of life. Friendship relationships provide life-affirming anchors that enhance many facets of being human. Psychologists and sociologists have identified

a number of qualities that characterize friendships and differentiate them from other types of social relationships. These include a high frequency of interaction, stability in interaction over time, reciprocity, exchange of positive behaviors, and well-developed negotiation and conflict resolution strategies. ²⁴⁻²⁶

The nature of friendship changes significantly over time as the individuals involved develop and mature. A wide variety of social relationships would appear to be necessary for the development of feelings of inclusion. Experiencing a feeling of inclusion is dependent not only on the affiliations that one has with other persons, but also on the relationships that these individuals have with each other. A general lack of friendship with persons other than professionals and family members has been found to characterize the lives of individuals with intellectual disability, whether they live in community-based settings or at home with their families.^{4,27-30} Research further suggests that when individuals with intellectual disability do establish social relationships with typical members of the community, they often experience a difficult time maintaining those relationships.24,31

Person-specific variables (such as level of functioning, number of disabling conditions) were not found to significantly predict such difficulties in either establishing or maintaining social life in the community. However, the specific residential site was found to be a powerful predictor of the level of community integration and social inclusion.³² Deficits in social skills and insufficient ability to successfully access environments in the community within which friendships are made, have long been considered as the primary reason that persons with disabilities lead socially isolated lives.^{33,34} Although people with cognitive impairments are not likely to be self-determined during their free time, there is evidence that they can learn to make choices.^{35,36}

Research examining the effectiveness of intervention on the acquisition of social skills relevant to leisure participation showed that participants were able to maintain many social skills for years following intervention, including increased initiation of leisure activities, increased feelings of control in leisure, and increased independence in leisure. 14,37-39

The purpose of the present study was to explore the social life and level of quality of life among adults with intellectual disability in two different residential settings: foster homes and community living arrangements. Three hypotheses were examined:

 Persons with intellectual disability who live with foster families have more social relationships than do those who live in community residential settings. ARTÍCULO DE REVISIÓN

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- Persons with intellectual disability who live in community residential settings are more involved in leisure activities than are those who live with foster families.
- The more social life one has, the higher is the quality of one's life.

Material and Methods

The sample consisted of 85 adults with intellectual disability, ranging in age from 18 to 55 years, from three major geographic areas of Israel. Forty-five of them live in community residential settings and 40 live with foster families. All of the participants were diagnosed as having mild to moderate level of functioning by the Ministry of Work and Welfare, which is the government agency for persons with intellectual disability. All had verbal but no mental problems.

The participants from the foster families were collected from the list of foster care service agencies throughout the country, according to the criteria described above. The group from the community residential settings was randomly sampled from the three major geographic areas –Haifa and the north; Tel-Aviv and the center; Jerusalem and the south– with 15 participants from each area.

Instruments

The demographic questionnaire includes variables such as gender, age, duration of stay in the program, level of functioning, employment status, health status, relationship with the biological family, and quantity of visits.

The Quality of Life Questionnaire¹ measures four aspects of life: Life satisfaction and happiness; Competence and creativity; Control and independence; Community involvement and social belonging. Each aspect consists of 10 questions, and the total score is the sum of the four sub-scales. The validity of the four sub-scales ranges from .67-.90 and for the general scale is .90. The Hebrew version was done by Ben-Dov and Rieter⁴⁰ in a study on persons with intellectual disability in community settings. In our study, only three aspects are used, as the fourth one on "community involvement and social belonging" was measured as an independent variable and was studied in depth. The internal validity of the three sub-scales was α =.64 for Life satisfaction; α = .87 for Competence and creativity; and α = .87 for Control and independence. The general validity was α =.77 (M=59.24, SD= 7.68). A higher score means a higher quality of life.

The Revised UCLA Loneliness Scale² measures the loneliness variable, which is defined as the major aspect

Table I

Demographic, Health and Employment Characteristics

OF THE SAMPLE POPULATION WITH INTELLECTUAL

DESABILITY, ACCORDING TO RESIDENCE FRAMEWORKS

Variable	Foster N	care %		nunity ential %	Z-Difference
Gender					
Male	20	50	22	49	.10
Female	20	50	23	51	
Level of intellectual disabil	ity				
Low	18	45	25	55	1.52
Medium-low	8	20	13	29	
Medium	14	35	7	16	
Residence					
Urban	31	77	45	100	_
Province/rural	7	18	_	_	
Else	2	5	-	-	
Geographic region					
North	16	40	15	33	_
Central	10	25	15	33	
Jerusalem	8	20	15	34	
South	6	15	-	-	
Previous residence					
Biological family	17	42	32	71	2.65**
Governess	14	35	I	2	(family compared
Institute	5	13	12	27	to all other)
Else	4	10	-	-	
Health problems					
Yes	20	50	16	36	1.34
No	20	50	29	64	
Employment					
Open market	7	18	17	38	3.37**
Supported	2	5	15	33	(Working compared
Sheltered	12	30	Ш	25	to not working)
Not working	13	32	2	4	2.06*
Student	6	15	-	-	(Regular compared to all the rest)
* p<.05 ** p<.01					

of social relationships. It consists of 20 statements, with 10 positive and 10 negative ones, scored on a four-point Likert scale. The validity was α = .96 for the revised version and α = .80 for the Hebrew version of the revised scale. ⁴¹ In our study α = .87, with M=38.56 and SD=10.25.

The range of the scoring was between 80-20, with a higher score meaning more loneliness.

The Social Relationships List³ is based on other scales on social relationships. 28,42,43 Fifteen questions were chosen according to the Israeli reality and tested on 120 adults with intellectual disability in community settings. A higher score means more meaningful social relationships.

The Leisure Activities List³ measures the level of participation and independence in leisure activities. It consists of 12 active and passive activities, such as going to the movies, swimming, shopping, or watching television; it measures the frequency of each activity in the last month on a five-point Likert scale. The independence component is measured on a four-point Likert scale, such as "can not go by oneself", "does not want to go", "will go only with friends", "can go by oneself". In the Shwartz study the α = .68, whereas in our study the α = .74, with a range of 1-4, M= 2.10, and SD=.37. A higher score means more participation and independence in leisure activities.

With the permission of the governmental service for persons with intellectual disability, a letter was sent to the foster families and the community residential settings requesting their agreement to take part in the research. Those individuals who agreed to participate in the study were interviewed by the researchers in their homes with a guarantee of confidentiality.

Results

Social relationships

In the two studied groups, most of the participants have some friends (between 4-5). Two major differences were found between the two groups: First, those who live in residential settings meet with their friends at home (Z=3.92, p<.001) more than those who live with foster families, and they participate more often in group activities in the community (Z=3.39, p<.01). Second, those who live in foster homes have more normative social relationships (Z=2.68, p<.01) and have better relationships with their families than those who live in residential settings (Z=3.83, p<.001).

Loneliness

In general, feelings of loneliness were found to be in correlation with friendships: that is, the more friends, the less feeling of loneliness. Satisfaction with social relationships, however, was not found to be correlated with loneliness (table II).

Leisure activities

For the two studied groups, leisure activities included segregated programs or trips in the neighborhood or in the parks, but not with the general population. Significant correlations were found between all the variables of social relationships and involvement in leisure activities: Those who had more friends and met with their friends more often participated in leisure activities (table III).

Differences and correlations between social relationships, leisure activities and quality of life and demographic variables were assessed. In general, no significant differences were found in the study variables according to the demographic characteristics. The only significant difference was in quality of life and employment status: Those who work have a higher quality of life than those who do not work. Given that only 18% of the participants in the study do not work and that employment status seems to follow type of residency, the two hypotheses were analyzed while controlling for duration of residency and level of functioning. Di-

Table II **CORRELATION BETWEEN PARTICIPANTS' FRIENDSHIPS** AND THEIR FEELING OF LONELINESS. ISRAEL

	All of the sample	Foster care	Community residential
Number of friends	40***	23	46**
Amount/ frequency of friendships	30**	40*	28
Satisfaction	01	16	08

^{*} p<.05

Table III **CORRELATION BETWEEN PARTICIPANTS' FRIENDSHIPS** AND THEIR INVOLVEMENT IN LEISURE ACTIVITIES. ISRAEL

	All of the sample	Foster care	Communal accommodation
Number of friends	.32**	31	.42**
Amount of friendships	.36**	.52**	24
Satisfaction	.21*	.14	23
Loneliness	25*	20	30*

^{*} p<.05 ** p<.01

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fferences were found according to level of functioning and duration of residency in the different settings.

Hypothesis no. 1: Persons with intellectual disability who live in foster homes have more social relationships than do those who live in community residential settings. A multivariate analysis of variance (MANCOVA) was conducted while controlling for duration of residency and level of functioning. No significant differences were found between the two groups (table IV).

Hypothesis no. 2: Persons with intellectual disability who live in residential settings are more involved in leisure activities in the community than are those who live with foster families. Analysis of covariance (ANCOVA) was conducted while controlling for duration of residency and level of functioning. A significant difference was found in the level of involvement in leisure activities $[F(1,81)=4.48,\ p<.05]$: The average level of involvement in leisure activities among persons who live with foster families was significantly higher than among those who live in community residential settings.

Hypothesis no. 3: Persons with intellectual disability who have more social relationships and are more involved in leisure activities will have a higher quality of life. A multiple hierarchical regression analysis of quality of life was conducted as follows: first step with demographic variables and second step with social relationships and leisure activities (table V).

As table VI illustrates, demographic variables do not contribute significantly to the general quality of life. The higher one's involvement in leisure activities and the lower one's feeling of loneliness, the higher the quality of one's life.

A multiple hierarchical regression was conducted in the same way on satisfaction with life, first with demographic variables and second with social relationships and leisure activities (table VI).

Table IV

MULTIPLE ANALYSIS OF VARIANCE (MANCOVA)

OF FRIENDSHIPS AND LONELINESS ACCORDING TO

RESIDENCE'S TYPE. ISRAEL

	Foster care		Community residential			
Variable	М	SD	М	SD	F (1,80)	
Number of friends	4.41	2.62	5.00	5.22	1.14	
Amount of friendships	3.97	1.16	4.11	1.15	.004	
Satisfaction from friendships	.67	.48	51	.51	15	
Loneliness	37.82	7.54	39.29	12.25	.29	
* p<.05						

Table V
HIERARCHIC MULTIPLE REGRESSION OF QUALITY OF LIFE
ON DEMOGRAPHIC CHARACTERISTIC, FRIENDSHIPS
AND LEISURE ACTIVITIES (N=84). ISRAEL

Variable	В	SE B	β
First step			
Age	07	.08	10
Gender	1.08	1.60	.07
Level of functioning	2.20	1.61	.14
Accommodation duration	06	09	06
Second step			
Number of friends	04	21	02
Loneliness	23	.08	31**
Leisure involvement	4.88	2.24	.24*

^{*} p<.05 ** p<.01

N.S. for first step R²=.07 *** p<.01 for second step Δ R²=.17 F(7,76)=3.42,

** p<.01,Total R²=.24

Table VI

HIERARCHIC MULTIPLE REGRESSION OF LIFE SATISFACTION
ON DEMOGRAPHIC CHARACTERISTIC, FRIENDSHIP
AND LEISURE ACTIVITIES (N=84). ISRAEL

Variable	В	SE B	β
First step			
Age	07	.03	21*
Gender	28	.67	.04
Level of functioning	94	.68	.14
Accommodation duration	.07	04	17
Second step			
Number of friends	10	09	.12
Loneliness	16	.04	46***
Leisure involvement	75	.94	.19

* p<.05 **p<.01

****p<.001

* p<.05 for first step R²=.12 *** p<.001 for second step Δ R²=.24 F(7,76)=6.06 ***p<.001, Total R²=.36

As indicated in table VI, 36% of the differences in satisfaction with life can be explained by the demographic variables and the feeling of loneliness. Specifically, young persons with a lower feeling of loneliness were

found to be more satisfied with their life. Thus, the major factor impacting on satisfaction with life was found to be the feeling of loneliness, rather than the level of involvement in leisure activities.

In sum, quality of life is significantly explained by the feeling of loneliness and involvement in leisure activities. Results show that the more social relationships one has, the less lonely one feels, and the more involved one is in leisure activities, the higher is one's quality of life. Furthermore, satisfaction with life is higher for young persons and for those who live with foster families.

Discussion

Although a significant change has been occurring over the last 25 years, and more people with intellectual disability are now living in the community, they still have limited opportunities to be part of the community. The results of this study show that although persons with intellectual disability live in varied living arrangements in the community (foster homes and community settings), there are no significant differences in their feelings of loneliness or in the extent of their social relationships. It seems that their lack of social skills and their limited social network generate too much unstructured free time, leading to loneliness, boredom and sometimes anxiety.^{28,44}

One's social competence seems to relate to personal characteristics, such as age, gender, and level of functioning, rather than type of living arrangement. The fact that people live together in the same setting does not guarantee a richer social life. Hayden and colleagues⁴⁵ compared the social contacts of persons with intellectual disability in different settings (foster homes, private group homes, and governmental group homes) and found no differences between them. In Lunsky and Benson's study, 46 the social support received from family, workers, friends and partners was related to the type of living arrangement, but not significantly so. In another study, ⁴⁷ the findings showed that persons with intellectual disability who lived in foster care had a higher level of involvement in community activities and a richer social life. Thus, it would seem that personal characteristics play a major role in the ability to form satisfying social relationships, while the setting with the appropriate leisure education programs can support and contribute to the development of these social skills.

In our study, the feeling of loneliness was found to be related to the social relationships of the studied groups insofar as a richer social life reduces the feeling of loneliness. The more extensive the social skills of persons with intellectual disability, the more they are socially accepted and the less lonely they feel. These results provide support for the findings of other studies, including Ben-Dov's⁴⁸ research on students with learning disabilities in different living areas (urban vs. rural) and Avrahami's⁴⁹ study on adolescents with mild mental retardation. In other studies⁵⁰ on students with and without intellectual disability, the feeling of loneliness was found to be negatively related to their social acceptance.

The fact that persons who live in foster homes are more involved in leisure activities and are more independent in these activities was surprising. In different studies, such as those of Hayden and coworkers⁴⁵ and Chen and coworkers, 47 it was found that persons who lived in group homes and community settings were more involved in leisure activities than were those who lived in foster homes. It seems that the differences are a result of the nature of the settings. People tend to enjoy their social life more in settings that encourage freedom of choice and offer an unstructured and independent way of life. 13 Leisure is defined as activities in which people engage for the primary reasons of enjoyment and satisfaction. ¹⁷ Although the community settings may encourage engagement in leisure activities, it is done in a more structured and less free way. The lifestyle in foster homes is characterized by a more normative way of life involving participation in the social activities of the foster family. Having more freedom to choose their own social activities, these individuals tend to be more involved in integrative leisure activities of the community.⁵¹

In Ben-Dov and Rieter's⁴⁰ study on quality of life and self-esteem of persons with learning disabilities who lived at home or in community settings, those who lived at home were found to be more independent and more satisfied with their life than were those who lived in community settings. Similar results were obtained in another study,⁵² in which persons with intellectual disability who lived at home were more self-determined and more satisfied with their life than were those who lived in community settings. The explanation of the authors was that the lifestyle in community settings is too structured and that there is not enough emphasis on freedom of choice and self-determination. Studies on the daily life of persons with intellectual disability in community-based settings show that most of their free time is spent on housework and other assigned chores, as compared to those who live in foster or natural homes and who enjoy more freedom of choice.^{3,28}

The high correlations between social contacts and involvement in leisure activities underline the importance of leisure programs and education. Studies examining the effectiveness of these programs^{37,38,53} have all shown that those who participated in the programs successfully acquired social skills and were able to maintain these

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skills years later. Results of such programs include increased initiation of leisure activities, increased feelings of control in leisure, and increased independence in leisure. 14,39,54

It is clear that unless effective programs to facilitate the establishment and maintenance of supportive relationships and leisure activities are developed and implemented, the goal of full inclusion in the community will remain unrealized. The neglect of relevant leisure programming for persons with intellectual disability is a major barrier to empowerment, self-determination, and successful community adjustment. Leisure education programs and social skills should receive a higher priority in policy making and service development. Service workers must facilitate the establishment of informal sources of support and social relationships and explore ways of interweaving informal and formal modes of social support.

The positive results of the foster care service reveal that foster care is an important alternative to natural homes and provide a normative way of life in the community. Therefore, human service workers can adapt multiple strategies to promote the use of foster care. The limited sample of foster families in this study is a result of neglect of efforts from policy and service workers to promote the use of this service.

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