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QUALITY OF LIFE OF PEOPLE WITH MENTAL RETARDATION - RESIDENTIAL VERSUS COMMUNITY LIVING

C. G. C. Janssen, G. J. Vreeke, S. Resnick and J. Stolk

Introduction

Quality control plays an important role in the care for people with mental retardation. By law, every care facility in the Netherlands has to develop its own system of internal quality control. Control by the government primarily takes the form of supervision of the quality control systems themselves ('supervising supervision'). In this process of internal quality control valid and reliable measuring instruments are indispensable. Quality of Life (QOL) is considered to be a proper standard by which to assess the quality of care. After all, care - especially when provided around the clock - is the main factor determining QOL for many mentally retarded people (Janssen and Vreeke, 1995)

The concept of QOL is based on some common principles (cf, Schalock and Begab, 1990). First, QOL is considered to be

the same for the mentally retarded as well as the non-retarded. They have the same basic needs (for optimal housing, optimal relationships, optimal physical and mental health, etc.) They all want to be responsible as much as possible and they share the right for optimal self-determination (people with profound mental retardation included). Second, QOL is basically socially determined by the nature of, and the extent to which there is interaction with other people. Thus, relationships with parents, other family members, friends and caretakers should play an important role in defining QOL. Third, QOL is a reflection of the extent to which basic needs are fulfilled in the life of the mentally retarded. Fourth, in the assessment of QOL clients' own evaluations should play an important role and if they are not able to evaluate QOL themselves, a proxy evaluation by close relatives is needed.

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In the Netherlands, as well as in other European countries, the concept of QOL plays only a minor role in quality control. Nevertheless, it is worth noting that the increasing attention for quality control has prompted more explicit attention for the aspects of care affecting QOL. Nowadays, one of the most important aspects of care in the Dutch situation which is urged by the Dutch government, is de-institutionalisation and the development of small-scale facilities in the community. A decisive question in this respect is to what extent these small-scale facilities in the community bring about improvements in the QOL of the people with mental retardation.

In this study an instrument for measuring QOL is developed and used in Dutch care facilities. Theoretical issues in defining and constructing the instrument, and its reliability and validity, will be discussed. We will use our instrument to make a comparison between the QOL of people living inside residential care facilities and those living in the community, both groups with moderate and mild mental retardation. As a result ways of improving the quality of care are discussed.

Theoretical issues: dimensions of QOL

Vreeke *et al.* (1977) in using the international literature (Donegan and Potts, 1988; Borthwick-Duffy, 1990; Schalock and Begab, 1990; Parmenter, 1992; Felce and Perry, 1993; Goode, 1994) defined QOL in a four-dimensional way as (1) a judgement from different perspectives (objective and subjective), to what extent a person with mental retardation realises in (2) certain domains of life (health, relations etc.) (3) certain goals in life (safety, freedom, etc.) that finally meet (4) certain norms of life (normalisation, personalisation).

Dimension 1: A combined approach: objective and subjective perspectives. QOL can be seen from an objective or outsiders perspective. Outsiders can judge QOL by considering: a) the extent to which basic needs are realised. In this objective or outsiders-perspective 'basic' should be minimally defined by the criterion of 'harm': a basic need that is not realised, produces harm to an individual. This 'harm-criterion' is defined to prevent endless discussions about what is basic and what is not; besides, there is a second additive objective component or outsiders-component: b) the extent to which a person can achieve specific intersubjectively determined valuable goods and things. The criterion of intersubjectivity is used because each culture will make its own list of valuable goods/things. Therefore, there should be agreement among those involved in the care for people with mental retardation about what is valuable. This is only a part of the definition, because QOL can be felt by the individual himself as inadequate even if outsiders say otherwise. The QOL of a very depressed and structurally dissatisfied individual can hardly be seen as adequate, even if he has enough food and shelter and has access to all important goods and things from an outsiders point of view. And vice versa. This indicates that a mere outsiders-perspective is not sufficient and subjective components must be added to the definition. In defining QOL from the inside, the individual himself considers: c) the extent to which he experiences pleasure and happiness and d) the extent to which he can realise personal and rational wishes and aspirations in life. 'Rational' is added to the definition because QOL can be adequate even if a person cannot 'reach the stars' he or she desires.

It can be seen, that a mere subjective perspective is not sufficient either. One

can be completely satisfied with life even if this life has no quality from an objective/ outsiders point of view, for example because one “does not know better”, because of life-long institutionalisation or because one values a very profitable criminal life. Each of these two perspectives is additive to the former:

Dimension 2: domains of life. In studying the literature we found a number of ways to define domains of life (Flanagan, 1978, 1982; Landesman, 1986; Dossa, 1989; Schalock *et al.*, 1989; Borthwick-Duffy, 1990; Edgerton, 1990; Schalock and Begab, 1990; Parmenter, 1992; Felce and Perry, 1993; Reiter and Bendov, 1996). We categorised all the domains defined in the literature into the 7 domains and 19 subdomains mentioned in FIGURE 1. Life can be exhaustively subdivided into these (sub)-domains, if they are maximally specified.

Dimension 3: Goals in life. We completed the study of the aforementioned literature with Mansell and Ericsson (1996) and Van Gennep (1997) and combined it with a thorough study of the ‘grey field’ of mission-statements of care facilities and parent organisations and with a study of (Dutch) instruments for measuring aspects of quality of life and quality of care. These studies made clear that all the goals in life and in care mentioned could be categorised into 5 main goals: development, freedom (self-determination), integration, physical and emotional safety and a general quality of life goal related to specific domains of life and not associated to these four goals (see FIGURE 1).

Dimension 4: Norms in life. In the attempt to reach these goals in all the domains of life, the new paradigm in the modern care for the mentally retarded is an adequate combination of personalisation and normalisation. Mere normalisation is not enough, according to Mansell

and Ericsson (1996). In answer to the question of how much development, how much integration, freedom and safety should be facilitated, these authors respond: “as normal as possible but appropriate to the personal needs of the individual concerned”. So, we developed our 4-dimensional model as shown in FIGURE 1.

Method

The instrument. By using the aforementioned literature we tentatively operationalised the concept of QOL by filling in the 105 cells in FIGURE 1 with plausible items. We asked a group of experts with different perspectives on care (parents, professional caretakers, management and a representative of the governmental inspectorate) to systematically discuss these items, to reach intersubjective agreement and to complete our operationalisation of QOL. This group completed the formulation of items for the 105 cells by using the concepts of our model. Thus, we ended up with a very detailed instrument: two parallel questionnaires both with approximately 300 items, an ‘objective’ or outsiders version and a ‘subjective’ counterpart.

The ‘objective’ or outsiders version has to be answered by the personal caretaker of the person with mental retardation. This personal caretaker is asked to make judgments *of the adequacy of the circumstances in care regarding the needs of the resident*. The ‘subjective’ counterpart is completed by the persons with mental retardation. If they are not able to do so, it is answered by their parents for them. In the ‘subjective’ counterpart *resident’s satisfaction with circumstances* is asked.

Aben and Van den Bergh (1998, an unpublished thesis in Dutch, available on

FIGURE 1
4-dimensional model of QOL: 2 perspectives x 21 (sub-)domains x 5 goals x 2 norms

QUALITY OF LIFE	1. PERSPECTIVES:		OBJECTIVE AND/PLUS SUBJECTIVE			
		3. GOALS:				
2. DOMAINS:	SUB-DOMAINS	GENERAL	SAFETY	FREEDOM	INTEGRATION	DEVELOPMENT
PHYSICAL	HEALTH	4. NORMS: PERSONALISATION NORMALISATION				
	FITNESS					
	EAT DRINK					
	MOBILITY					
	SEXUALITY					
PERSONAL	MENTAL HEALTH					
	IDENTITY					
	RELIGION					
MATERIAL	HOUSING					
	PROPERTIES					
	HOUSE-KEEPING					
	ENVIRONMENT					
	TRANSPORT					
RELATIONAL	CARE-TAKERS					
	FAMILY					
	OTHERS					
RECREATIONAL						
WORK, SCHOOL, ACTIVITIES	WORK					
	SCHOOL					
	ACTIVITIES					
PARTIC. SOCIETY						

demand from the authors of this article), using this resident/parent version of our instrument, compared the judgements of parents with the judgements of the mentally retarded themselves (using in-depth interviews). They found “. . . that parents can speak for their child. In general, they can make adequate judgements of their child's opinions”. According to Aben and Van den Bergh, and comparable with the results of Reiter and Bendov (1996), parents do have some difficulties in adequately matching their child's dissatisfaction with respect to freedom in daily activities (e.g. refusing dinner, having own belongings at one's free disposal) and with discontinuity and instability in the team of caretakers.

An example of an item based on our 4 dimensional model: 1. perspective: objective/outside (= version personal caretaker); 2. domain: eating/drinking; 3. goal: freedom; 4. norm: personalisation and normalisation:

“Is this resident able to show preferences in some way concerning eating/drinking? (if not, go to the next question). If yes: *This resident has an adequate say about the daily menu*”. Caretakers answer by means of a 5-point-scale, from “fully realised” until “not realised at all”.

In the resident/parent version (subjective perspective) the parallel item is: “Are you/is your son or daughter able to show preferences in some way concerning eating/drinking (if not, go to next question). If yes: *I have an adequate say about the daily menu*”. The person with mental retardation, or his parents, answer by means of a 9-point-scale, from “yes, sure” until “not at all”.

We did a pilot study in a random group of 355 people with mental retardation living in three different residential facilities (mean age 38, sd. 15, with a range from 4 to 81; 62% male, 38% female; 16%

profoundly, 22% severely, 52% moderately, 10% mildly retarded; mean number of people in group home 10 with a range from 2 to 14). This pilot study showed that our instrument was valid and reliable: factoranalysis showed the a-priori-clusters of our 4-dimensional model; in the resident/parent version of our instrument we found high and significant correlations between the specific items and some general judgements of QOL made by residents/parents; as to the caretakers-version of the questionnaire we did a study of the interrater-reliability: for 62 residents two caretakers completed the caretakers version; we found high agreement: only a few differences more than 1 score point between the respondents. In a study with 668 residents we tried to reduce the amount of data by developing scales. We found 17 reliable and valid scales for the caretakers version and 20 scales for the resident/parent version. TABLES I and II show these scales and the high internal consistencies. The scales all largely match our a priori theoretical model.

The respondents. In this follow-up study a representative group of 7 residential facilities (each with 200-400 residents) with highly educated caretakers (3-4 years of professional training after finishing high school) participated: a random group of 668 residents (mean age 38, sd. 15, with a range from 4 to 89; 59% male, 41% female; 14% profoundly, 17% severely, 53% moderately, 16% mildly retarded; mean number of people in group home 9 with a range from 1 to 18). We distinguished 6 subgroups with increasing needs for care. In the group of 668 residents significant differences in QOL were found between the 6 subgroups: QOL appeared to be more adequate in the more independent groups. For this paper we selected two subgroups from this larger group of residents. The first subgroup (n=80) is a

TABLE I
Internal consistency of the 17 scales of the caretakers' version

scale	Crohnbach's alpha	n of items
<i>JUDGEMENT OF ADEQUACY OF CIRCUMSTANCES IN CARE:</i>		
physical domain	.92	28
adapted housing	.94	6
acceptance sexual activities	.96	2
care for identity	.90	15
care for vision on life and religion	.91	2
general housing	.89	16
care for own property/belongings	.98	9
housekeeping	.87	9
relationship with caretaker	.83	24
relationship with others	.94	5
recreation	.86	14
daily activities	.97	14
safety	.80	14
freedom	.95	29
training/development	.92	14
integration	.89	15
general care	.94	55

TABLE II
Internal consistency of the 20 scales of the resident/parent version

scale	Crohnbach's alpha	n of items
<i>SATISFACTION OF RESIDENT WITH:</i>		
care for physical health	.79	16
care for fitness	.80	9
freedom in eating and drinking	.73	10
care for mental health	.82	17
care for identity	.90	13
religious activities	.78	2
housing	.92	15
care for own property/belongings	.96	12
independence in housekeeping	.90	12
living environment	.89	7
quality of treatment by caretakers	.87	12
relationship with family	.80	5
freedom in relations with others	.87	5
quality and quantity of recreation	.85	18
daily activities	.97	15
safety	.85	21
freedom	.90	18
training/development	.83	8
integration	.79	16
general care	.96	64

random group of moderately and mildly retarded residents that live in houses on the edge of the care facilities. This first group still makes use of the many services of the facility (e.g. central kitchen, house cleaning services, recreational utilities). The second subgroup (n= 119) of the same level of functioning, lives outside the care facility in group-homes in the community and does not use the facilities of the mother organisation to a great extent. The type of care given in both groups is called: 'normalised living with guidance by caretakers, who facilitate activities'. Persons in both groups require approximately the same amount of care. A description of these two groups is given below. We did not find significant differences in these descriptive variables between the two groups.

	group homes on edge care facility	group homes in community
mean age	34(sd.9,range 10-68)	38(sd.13, range 8-74)
ratio male/female	57% / 43%	56% / 44%
profoundly retarded	-	-
severely retarded	5%	8%
moderately retarded	61%	45%
mildly retarded	34%	47%
mean number home mates	9 (range 1-15)	8 (range 2-15)

These are two comparable subgroups, who only differ in their living environment; community versus residential facility. Both the personal caretaker and the residents (or the parents for him/her) completed the questionnaires.

Results

As can be seen in TABLE III, the mean scores for quality of life of those living in the community is, according to the caretakers, for almost all scales *significantly* better. In other words, quality of life for those

still living on the edge of the care facility is worse in all the domains of life, especially concerning the following:

*In the assessment of the caretakers almost 30% of the residents living on the grounds/edge of the care facility do not receive adequate care in the physical domain (for those living in the community: 6%). Specifically: they have less freedom to participate in physical activities, to choose with respect to eating and drinking, mobility to visit others; they receive less training in self care and in transportation and less integration related activities.

*In the assessment of the caretakers 23% of the residents living on the grounds/edge of the care facility do not receive adequate care in the identity domain (versus \pm 3% in the community group): e.g. they have a less structured living situation; they receive less preparation for changes and they do not always have a special private place in the house; they receive less training in handling emotions, handicaps and problems; less chances to decorate their own room, to own a key of the house.

*In the assessment of the caretakers 22% of the residents of the care facility do not receive adequate care in the house-keeping domain (versus 7% in the community group): e.g. less self-determination and training in housekeeping.

*In the assessment of the caretakers 47% of the residents of the care facility do not receive adequate care in relationships with others (versus 18% in the community group): e.g. less training opportunities in social skills and less freedom in relating to and meeting others/friends.

*In the assessment of the caretakers 27% of the residents of the care facility do not receive adequate care in recreation

TABLE III
Mean, standard deviation, and percentage people for whom (according to the caretakers) adequate quality of care is realised on the scales of the instrument in both groups: answers on a 5-point-scale.

ADEQUACY OF CIRCUMSTANCES IN:	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
	**	**	**	**	**	**	**	**	**	**	**	**	**	**	**	**	**
LIVING IN GROUP HOMES ON THE EDGE OF THE CARE FACILITY																	
Mean	4.19	4.33	4.77	4.26	4.40	4.41	4.34	4.29	4.28	3.99	4.15	4.28	4.39	4.07	4.08	4.06	4.39
N	77	16	42	77	54	77	75	77	77	70	77	63	77	77	77	77	77
StdDev	.34	.66	.40	.38	.63	.44	.48	.39	.35	.80	.48	.60	.33	.39	.47	.49	.30
<4	29.9%	18.8%	2.4%	23.4%	14.8%	15.6%	18.7%	22.1%	18.2%	47.1%	27.3%	20.6%	7.8%	41.6%	40.3%	40.3%	11.7%
LIVING IN GROUP HOMES IN THE COMMUNITY																	
Mean	4.53	4.61	4.88	4.55	4.67	4.70	4.70	4.59	4.51	4.43	4.51	4.50	4.61	4.45	4.34	4.53	4.64
*n	109	13	68	109	83	109	109	109	105	109	109	88	109	109	109	109	109
StdDev	.33	.42	.40	.30	.50	.23	.27	.43	.30	.58	.40	.41	.25	.37	.49	.42	.22
<4	6.4%	0%	2.9%	2.8%	7.2%	1.8%	.9%	7.3%	7.3%	18.1%	11.0%	12.5%	0%	13.8%	19.3%	10.1%	0%

(* significant differences between means of the 2 groups: ANOVA. P < .01)

KEY:

- 1 Physical Domain
- 2 Adapted Housing
- 3 Acceptance, Sexual Activ.
- 4 Identity
- 5 Vision/Religion
- 6 Housing
- 7 Property/Belongings
- 8 Housekeeping
- 9 Relation Caretaker
- 10 Relation Others
- 11 Recreation
- 12 Daily Activities
- 13 Safety
- 14 Freedom
- 15 Training
- 16 Integration
- 17 General Care

(versus 11% in the community group): e.g. they have less frequent recreational activities in and outside the house; less freedom to participate in recreational activities; less training in and stimulation of hobbies/talents.

*In the assessment of the caretakers almost 21% of the residents of the care facility do not receive adequate care in daily activities (versus 12% in the community group): e.g. they receive less training opportunities and suitable guidance; less freedom of choice.

In sum, in the assessment of the caretakers the residents living on the grounds/edge of the care facility do not receive adequate care with respect to self-determination/freedom (almost 42% versus almost 14%), with respect to training/development (40% versus 19%) and with respect to integration (40% versus 10%): for specific examples see above.

As can be seen in TABLE IV, according to the residents themselves (or as perceived by their parents), the mean quality of life of those living in the community is slightly better for almost all scales. According to the residents/parents, living on the grounds/edge of the care facility means enjoying *significantly* less quality of life in the following areas:

*21% of the residents lack adequate freedom in general (community group: 15%): e.g. less freedom in choosing the menu; less freedom in relationships with non-residents.

*11% of the residents lack adequate opportunities for training and development in general (community group: \pm 3%): e.g. less chances to develop talents, to develop skills for handling new situations.

*21% of the residents lack adequate opportunities for integration in general (community group: 8%): e.g. less chances to make contact with others in the direct vicinity; less opportunities to visit shops etc.; less opportunities to invite guests to the house. These results match the results of the caretakers in many respects: the residents who live in the community have more freedom of choice, receive more training and are more integrated, not only physically but also socially in comparison to those who live in the care facility.

Discussion

The need for de-institutionalisation is often motivated by ideology instead of empirical research data. This study shows a discrepancy in QOL scores between people living inside and people living outside the care facilities. Living in the community without using the residential facilities of the mother organisation to a great extent appears to be an important condition for a better quality of life for people with mental retardation.

In general, the mean scores on the scales indicate that QOL is reasonably good in both subgroups, but these mean scores covered up dissatisfaction for large groups of residents. One is reminded that the QOL scores are seen as indicators and as outcomes of the quality of care, that people receive. Which specific aspects of care ought to be changed, is still not always clear. Thus, an analysis ought to be made to determine which relevant aspects of care determine the discrepancies in QOL scores. We tentatively try to find some relevant aspects in the following:

* Freedom and self-determination seem to be more self-evident in a community context. Problems in freedom and self-de-

TABLE IV
 Mean, standard deviation, and percentage of dissatisfied residents (according to their parents) on the scales of the instrument: answers on a 9-point-scale.

SATISFACTION WITH	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
*																				
LIVING IN GROUP HOMES ON THE EDGE OF THE CARE FACILITY																				
Mean	7.01	7.26	6.52	7.40	7.40	7.17	7.38	7.10	7.18	7.38	7.34	7.31	7.11	6.86	7.10	7.27	6.49	7.08	6.64	7.39
n	47	47	47	47	47	32	47	43	46	47	47	47	43	46	39	47	47	46	47	47
StdDev	.91	1.06	.99	.75	.83	1.09	.74	.81	.79	.91	.82	1.08	1.20	.97	.92	.69	.82	.93	1.10	.69
<6	14.9%	0.6%	23.4%	2.1%	4.3%	9.4%	2.1%	4.7%	0%	6.4%	2.1%	8.5%	14.0%	17.4%	12.8%	4.3%	21.3%	10.9%	21.3%	2.1%
LIVING IN GROUP HOMES IN THE COMMUNITY																				
Mean	7.16	7.32	6.95	7.56	7.62	7.22	7.57	7.34	7.29	7.46	7.59	7.44	7.38	7.17	7.16	7.43	6.87	7.39	7.09	7.54
n	71	71	70	71	71	47	71	67	71	70	71	70	66	71	54	71	71	71	71	71
StdDev	.89	.83	.90	.71	.74	1.03	.75	.92	.84	.90	.75	1.01	.77	.93	.75	.73	.83	.81	.86	.67
<4	11.3%	4.2%	12.9%	0%	1.4%	8.5%	1.4%	7.5%	5.6%	5.7%	2.8%	4.3%	4.5%	8.5%	7.4%	5.6%	15.5%	2.8%	8.5%	2.8%

(** significant differences between means of the 2 groups: ANOVA, $P < .01$; *significant: $p < .05$)

KEY:

- 1 Care Physical Health
- 2 Care Fitness
- 3 Freedom in Eating/Drinking
- 4 Care Mental Health
- 5 Care Identity
- 6 Religious Activities
- 7 Housing
- 8 Care Properties
- 9 Independent Housekeeping
- 10 Living Environment
- 11 Treatment by Caretakers
- 12 Relation with Family
- 13 Freedom/Relations with Others
- 14 Quality and Quantity Recreation
- 15 Care Daily Activities
- 16 Safety
- 17 Freedom
- 18 Training
- 19 Integration
- 20 General Care

termination are frequently mentioned by the caretakers and by the residents/parents for those people living on the edge of the care facility. In their comments these caretakers indicate shortage of staff and the size of groups (too large), that are set by administration and management, as the main excuses for these problems. Indeed, to allow residents to experience more freedom (of choice) and self-determination, staff time is needed to make their choices reality. However, because of the similarity of the two groups in our research as to group size and number of staff, we believe that the attitude of caretakers can account for the differences in freedom given. Caretakers who work on the grounds/edge of the care facilities often seem more inclined to give wrong answers to the questions: 1) who is the host and who is the guest? and 2) who has priority: the individual or the group? Caring for people in the community probably urges caretakers to treat people with mental retardation as hosts with more respect for their individual potential in handling freedom and self-determination. They appear to care for individuals and not for a group of people.

*The same can be said about the given opportunities for training and development. The lack of opportunities for training and development induces permanent dependence on care. Any investment in training and development of the residents (or reducing deterioration of skills) will give caretakers more future prospects for other urgent matters in care. Caretakers in group homes in the community seem to be prone to pay more attention to the fit between the resident and the community. So, they also provide more training opportunities in such a way that the residents can meet community demands. Our data do not show in what way the caretakers are also involved in adjusting the community to the residents.

*By definition physical integration is better when living in the community. We found this to be true for social integration too. People have more chances to meet others and will profit from their physically integrated situation.

*As to safety no big differences are found between the two subgroups in our research. This is explained by the history of institutional care. Safety has always been a main issue in care and quality of life and safety were seen to be identical. Our detailed results can be used to make the above mentioned analysis of urgent changes in the quality of care. When focusing on the large groups of residents who lack adequate care in the many domains of life one can zoom in on the heart of the matter more quickly. Our bird's-eye view suggests some urgent organisational changes:

Decentralisation of services. When living on the grounds/edge of the care facility food is prepared by a central kitchen, repairs are done by a central service, budgets are centrally laid down etc. This centralisation of services influences chances for freedom and self-determination to a great extent and in many ways.

Self-employment in groups. In addition to decentralisation more services should be provided in a personalised way in the very group homes adjusted to the needs of the individual residents.

Client-centred budget. An individual budget based on the problems in QOL should be introduced. The lower the QOL, the higher the budget.

De-institutionalisation. As yet, de-institutionalisation can be seen as an unpolished summary of the above mentioned inevitable organisational changes.

Development of community group homes into private housing. In this context of de-institutionalisation a serious risk is the development of community group homes

as micro-institutions. We found community group homes to provide a better QOL for the residents compared to the institution. We argued that the community context is responsible for this. This does not necessarily mean that we should build group homes in the community. In The Netherlands, as elsewhere, we are also building or renting homes for individuals or couples, not for groups. We are looking forward to compare QOL in community group homes with QOL of people in private houses in the community.

Summary

The present study examined the differences in quality of life (QOL) between people with mental retardation living in group homes in the community and a comparison group living on the grounds/edge of residential facilities. Using two parallel versions of an extensive QOL questionnaire, one completed by the personal caretaker (the outsiders perspective) and one by the residents and/or his parents (the insiders perspective), we found QOL to be significantly better in the community group homes. Living in the community probably is an important condition that forces caretakers to provide more freedom, more chances for training and development and for integration. As a result, issues related to de-institutionalisation are discussed.

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References

- Borthwick-Duffy, S. A.** (1990). Quality of life of persons with severe or profound mental retardation. In: Schalock, R. L. (Ed.). *Quality of Life: Perspectives and Issues*. Washington: American Association on Mental Retardation, 177-189
- Donegan, C. and Potts, M.** (1988). People with mental handicap living alone in the community. A pilot study of their quality of life. *The British Journal of Mental Subnormality*, 34, 10-22
- Dossa, P. A.** (1989). Quality of life: individualism or holism? A critical review of the literature. *International Journal of Rehabilitation Research*, 12, 121-136
- Edgerton, R. B.** (1990). Quality of life from a longitudinal research perspective. In: R. L. Schalock (Ed.). *Quality of life. Perspectives and issues*. Washington DC: AAMR
- Felce, D. and Perry, J.** (1993). *Quality of Life: A Contribution to its Definition and Measurement*. Wales Applied Research Unit, University of Wales, College of Medicine
- Flanagan, J. C.** (1978). A research approach to improving our quality of life. *American Psychologist*, 33, 138-147
- Flanagan, J. C.** (1982). Measurement of quality of life: Current state of the art. *Archives of Physical Medicine and Rehabilitation*, 63, 56-59
- Gennep, A. Th. G. van,** (1997). *Paradigma-verschuiving in de visie op zorg voor mensen met een verstandelijke handicap*, (change in paradigm in the care for people with mental retardation). Inaugral address, Universiteit Maastricht
- Goode, D. A.** (1994). *Quality of life for persons with disabilities*. International perspectives and issues. Cambridge: Brookline Books
- Janssen, C. G. C. and Vreeke, G. J.** (1995). Outcome indicators in the care for people with a mental handicap, *The British Journal of Developmental Disabilities*, XLI, 79-90
- Landesman, S.** (1986). Quality of life and personal satisfaction: definition and measurement issues. *Mental Retardation*, 24, 141-143
- Mansell, J. and Ericsson, K.** (1996). *De-institutionalization and community living*. London: Chapman and Hall

- Parmenter, T. R.** (1992). Quality of life of people with developmental disabilities. In: Bray, N. W. (Ed.). *International Review of Research in Mental Retardation*, 18, 247-287
- Reiter, S. and Bendov, D.** (1996). The self concept and quality of life of two groups of learning disabled adults living at home and in group homes, *The British Journal of Developmental Disabilities*, XLII, 97-111.
- Schalock, R. L. and Begab, M. J.** (1990) *Quality of Life: Perspectives and Issues*. Washington: American Association on Mental Retardation
- Schalock, R. L., Keith, K. D., Hoffman, K. and Karan, O. C.** (1989). Quality of life: its measurement and use. *Mental Retardation*, 27, 25-31
- Vreeke, G. J., Janssen, C. G. C., Resnick, S. and Stolk, J.** (1977). The quality of life of people with mental retardation. In search of an adequate approach. *International Journal of Rehabilitation Research*, 20, 289-302