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QUALITY OF LIFE AND PROBLEMS EXPERIENCE BY THE MENTALLY RETARDED PERSONS, BOTH INSTITUTIONALIZED AND LIVING IN THE COMMUNITY

ABSTRACT

In this article are discussed differences between subjective feeling in quality of life and problems experience by two groups of the people with mental retardation in Poland. One group consist inhabitation of the Institution, where there is not any day activity program, another individuals who live in the community with full access to the day programs.

In the conducted research were utilized two methods: Quality of Life Questionnaire by R.L. Schalock and K.D. Keith and Scale - LNU by T. Witkowski.

The results show evidently that the community based rehabilitation of the individuals with mental retardation is the best way to achieve high quality of live by them.

INTRODUCTION

The past nine years that followed 1989 brought to Poland, the country undergoing a vivid political, social, and economic transformation, significant changes in all aspects of social life as well as sharpening of social awareness concerning problems both of the healthy people and people with disability. During that time the following important legal acts had been laid down: *The Rehabilitation and Employment of People with Disability Bill* (1991), *The protection of Mental Health Bill* (1994), additionally *The Governmental Plan of the Support of Individual with Disability* (1993) had been prepared as well as amendments added to *The Social Support Bill* (1997) and to *The Anti-Unemployment Bill* (1994) - all of them reflect-

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ing clear tendencies toward changes in the *Social Welfare* policy of the Polish government that have constituted totally new legal circumstances for the action to be taken by and on behalf of the person with disability in Poland.

Changes in the functioning of *Social Welfare System* vary, however, in respect to different groups of the disabled depending on the type of disability. The scope of this article allows only a limited analysis of the phenomenon, therefore I will concentrate on the group of the person with mental retardation.

Comparing the range of *Social Support* services available for the individual with mental retardation before and after 1989, it must be stated that indeed revolutionary changes have occurred in some at least areas of life of the above mentioned group of people. Revolutionary character of those changes flows not only from the fact that great efforts have been made in order to increase and improve the *Social Welfare* system in general, but also from exposing all sorts of negligence of the previous social policy with regard to the persons with mental retardation.

The so-far mentioned legal acts together with the amendments to the already existing ones not only give equal access for various governmental and local administrative authorities as well as nongovernmental organizations to the social funds, but, what is more important, they clearly describe standards of particular services for which the funds are to be used so that refundation could be allowed. The procedure proves an effective means of promoting initiative, guarantees protection against squandering of social money and ensures proper standards of services.

Standardization of social services remains a vital condition of any successful social policy, which is proved by experience of many a country, still in itself it cannot be seen as sufficient solution to particular problems of the person with mental retardation and their families (Butterworth, Steere, Whitney-Thomas, 1997).

Standardization depicts and refers solely to objective life conditions and were we to consider these only, we would overlook the important factors of subjective well-being and personal satisfaction of the persons with mental retardation themselves (Borthwick-Duffy, 1996; Felce, 1997).

It becomes necessary, therefore, to collect and compare subjective opinions of the person with mental retardation alongside the consolidation of standardization of social services.

The idea of measuring quality of life of the person with mental retardation (and attention to the problems that ones individual stressed), so widely discussed in scientific literature, seems to be a suitable solution that can be easily applied also in Polish conditions. The application of the ratio of quality of life as a means of evaluation of social services for the individuals with mental retardation brings into closer attention the richness of theoretical and practical achievement in this field.

From among many important publications that appeared in English and to which I have had access I would like to distinguish works published by *American Association on Mental Retardation* edited by Robert L. Schalock (1990; 1996; 1997)

which comprehensively deal with the question of quality of life and comprise full documentation of the applied methods.

Similarly, Polish publications also reveal numerous theoretical findings and some research on quality of life issue. I shall return to the above point further in the article.

In order to analyze the question of quality of life and its practical implications as understood and applied in Polish circumstances I will first present the scientific output of Polish researchers in the subject, then define the notion of quality of life and conclusively I will present the results of the research I have done on differences in quality of life among persons with disability, those living in open community and attending Day Activity Centers as well as those who live in Institutions without any occupational activity/therapy.

SOME EXAMPLES OF THE RESEARCH ON QUALITY OF LIFE IN POLAND

Speaking about the Polish research on quality of life I will concentrate on these works only which directly use the term. I intend to exclude from my attention all the scientific literature which thematically refers to the subject in question but does not apply the term.

The criterion used here entails a limited focus, i.e. mostly on the recent works from before 3-5 years. The theoretical research will be presented in chronological order and as preceding a short discussion on empirical works, that latter being far less abundant than the former ones.

Initially, theoretical research on quality of life was conducted by two Polish university sites: in Poznan by professor Stanislaw Kowalik and professor Augustyn Banka and in Czestochowa by professor Romuald Derbis. The joint interest of the two centers resulted in the conference on *Possibilities of Psychology and Pedagogic in Examining and Shaping the Feeling of Quality of Life* in 1993. Not only did the conference gathered Polish scientists in the field, but it also delineated main tendencies for future research. Details can be found in the materials entitled *Psychological and Pedagogical Dimensions of Quality of Life* edited by A. Banka and R. Derbis (1994).

As far as further theoretical research is concerned attention should be drawn to works by Stanislaw Kowalik analyzing psychological dimensions of quality of life (1993), temporal conditions of quality of life as well as theoretical controversies on the subject (1995).

Equally important seems the research of Jerzy Brzezinski on methodological and ethical aspects of quality of life (1994) and Augustyn Banka's treatment of quality of life in terms of concepts of man and the work (1994).

As a distinct group of theoretical research emerges the examination of quality of life in the light of responsible freedom (Derbis, 1994) and man's creative activity (Pufal-Struzik, 1994).

Another branch of theoretical thought concentrates on the analysis of quality of life as seen through the prism of human suffering (Maciuszek, 1994), spiritual life of the dying (Stelcer, 1997) and focuses on differences in quality of life among people terminally ill (Stelcer, 1994; Surdyka, 1997; Jackowska, 1997).

Some of the above mentioned works merge theoretical thought with empirical findings (the latter being still insufficient) to which I will presently turn.

Zbigniew Zabor (1997) initiated empirical research examining residents of Institutions of Poznan province using Campbell's *Scale of Quality of Life*. The only criterion applied in his work was that of being a resident of an Institution with disregard of the age of the people under examination (whether a child, a teenager or an adult) and type of disability (whether physical, sensory or developmental).

Considering the results of his research on quality of life, the evaluation of the institutional living conditions and personal satisfaction by the examined proved quite unexpectedly positively high.

Research on quality of life among persons with disability from one local community became of foremost interest for Andrzej L. Juros (1997 pp. 302-303) who investigated a group of 152 persons with disability chosen randomly from Leczna area applying *Quality of Life Questionnaire* (QLQ) by Robert L. Schalock and Kenneth D. Keith (1993) (translated and adjusted to Polish conditions by Andrzej L. Juros).

In Juros research from among the examined people the following subgroups were singled out: people with mental retardation (N=35), with physical disability (N=38), with heart disease (N=27), with psychiatric disorder (N=23) and with SM (N=16).

Comparing the final result of the examination of the people with mental retardation with those achieved in respective subscales of QLQ and referring them to the same category of research done by Kenneth D. Keith (1996 pp.79), Juros concluded that Polish results are much below average as compared with Keith's equivalents.

Additionally, Juros pointed at a number of interesting interdependencies among results achieved within separate subgroups of the examined sample.

As a complementation to the above I would like to present my own research concerning differences in quality of life among the persons with mental retardation living in open community and attending Day Activity Centers as well as among those who live in Institutions without any occupational activity/therapy.

**DIFFERENT LIVING ENVIRONMENTS AND THERE IMPLICATION ON
QUALITY OF LIFE AND PROBLEMS EXPERIENCE
BY THE MENTALLY RETARDED PERSONS**

According to the statistics in the middle of the 90 's about 70 thousand people in Poland have been estimated to be residents of Institution. Within that group at most 18% refers to persons advanced in years, i.e above 74, further reasons for residing in Institutions include: illness, disability (of various kind also mental retardation), social maladjustment, drug or alcohol addiction, mental disease. In addition to the above mentioned one should emphasize the fact of prolonged residence in Institutions of 9 thousand of people and the number of successive 17 thousand awaiting vacancies owing to social factors (Wisniewska, 1997, pp.124-127).

The statistics may sound alarming especially if viewed through the prism of earlier and recent investigations on the differences of quality of life among persons with mental retardation in particular, those institutionalized and those living in community (Bachrach, 1981; Ashbaugh, Blaney, 1994; Bruinninks, 1981; Butterworth, 1993; Kowalik, 1981, 1987, 1997; Koscielska, 1987; Minnen, Hoogdui, Peeters, Smedts, 1993; Minnen, Hoelsgens, Hoogduin, 1994; Mrugalska, 1987; Olechnowicz, 1987, Otrebski, 1992, 1993a, 1993b; Schrenberger, 1981; Witkowski, 1987).

Unquestionably Institution emerges as necessary evil rather than a positive social phenomenon for both the persons institutionalized and the whole society that sustains the institutional system. Were we to consider the financial aspect solely the institutional system still proves a much too expensive form of rehabilitation and care of people with mental retardation. The social and individual expenses that the institutional system entails are comprehensively dealt with in the precited literature.

It is widely agreed that the most beneficial form of care and rehabilitation for an individual person as well as the entire society is the one that relies on the resources of a local community, in which case a person with mental retardation may remain in a familiar for herself/himself environment and avail oneself of civilizational opportunities in due measure to his/her needs and requirements.

The category of quality of life in regard to the persons with developmental disabilities appears to be the most thoroughly depicted scientific domain in the aspects of theory, methodology, research practices and supported with broad practical application (Felce, 1997; Hughes in all, 1995; Schalock, 1996, 1999) .

Taking into account the immense advantages that the application of the category of quality of life provides for remodeling the rehabilitation and care services for people with developmental disabilities I have joined the efforts of adapting the Questionnaire of Quality of Life actively participating in research on the group of people with mental retardation.

Having analyzed earlier investigation in the field and having considered my own experience I have posed the following question: **Is there a vital difference in the perception of quality of life and the intensivity of experience problems between the persons with mental retardation living in Institutions and those living in community?**

In order to examine the problem thus formulated I have conveyed a research on two groups of people with mental retardation living in two different environments. The outcome of the investigation and its analysis follows beneath.

THE EXAMINED GROUP

The examination was carried on the group of 81 mentally retarded persons. From among all the examined two subgroups were singled out: **subgroup A** - comprising 41 persons (23 men and 18 women), staying either with families or in group homes and actively participating in occupational therapy led by Day Activity Centers; **subgroup B** - consisting of 40 persons (30 men and 10 women), residents of Institutions for people with mental retardation in which no occupational therapy was offered. The average age of the subgroup A was 27.92 and for the subgroup B 39.90 (Table A).

Table. A. Description of groups A and B by gender and age

Environment	Gender			Age		
	M	F	Total	M	F	Total
Institution	30	10	40	39.37	41.50	39.90
Shelter Workshop	23	18	41	27.96	27.89	27.92

THE METHOD

To measure and evaluate the quality of life of people with mental retardation specially constructed *Quality of Life Questionnaire* (QLQ) by Robert L. Schalock and Kenneth D. Keith was used, translated and adjusted to Polish conditions, with the authors consents, by Andrzej L. Juros.

In adjusting the Questionnaire to Polish conditions particular attention was paid to linguistic and cultural differences treated as important factors influencing research over the people with mental retardation (Keith, 1996).

The Questionnaire enables establishing a general level of quality of life as assessed by a person with mental retardation and gives us its detailed description in terms of Satisfaction; Competence/Productivity; Empowerment/Independence; Social Belonging. Each of the four subscale comprises 10 items that can be evaluated according to a threefold scale: 1, 2, 3, the minimal result being for each of the subscale 10, and the maximal 30. The total result respectively 40 as minimal and 120 as maximal.

To look at the problems the examined group face the *Scale - LNU* by Tadeusz Witkowski was applied. The *Scale - LNU* is one of the five and was constructed based on the Handicap Problems Inventory (HPI) by the G.N. Wright and H.H. Roomers as the results received after application of the HPI to the Polish population (over 1000 people).

The Scale - LNU consists of 60 items (potential problems) assessed on the 6 points scale from 0 as not appear through 1 - very low intensity; 2 - low intensity; 3 - middle intensity; 4 - high intensity, up to 5 - very high intensity. The 60 items are grouped in to 4 spheres (15 items each) consider different aspects such as:

I - personality; II - family; III - social; IV - occupational. The minimum score in the sphere is 0 and maximum 75 but the minimum total score is 0 and maximum 300.

Assessing the own problems person with mental retardation in order to make this easier first has to decide if the particular problem appears or no in his/her life, than if yes the person has to assess the intensity.

THE PROCEDURE

The examination was carried by a team of specialists employed in *Institutions* and *Day Activity Centers* or *Shelter Workshops* and possessing a thorough knowledge of the applied methods. The subjects were being individually examined and asked to either choose the answer themselves or to point at it. All the examined persons were verbal.

RESULTS

In order to establish potential statistical differences in quality of life and the experienced problems between the two groups under examination mean and standard deviation has been worked out and the test of significance of differences ap-

plied. The above procedures have been referred both to the results achieved in particular subscales or sphere and to the total score (table 1 - 6).

Tab. 1. Mean Score on the *Quality of Life Questionnaires* and the significance level of differences between the main group

	Institution		Shelter Workshop		p.
	M	SD	M	SD	
Satisfaction	20.43	4.62	21.56	4.01	no signif.
Competency/Productivity	12.75	3.96	21.68	6.32	0.000
Empowerment/Independence	20.88	2.93	19.73	3.32	no signif.
Social Belonging	18.40	3.54	21.78	5.06	0.001
Total Score	72.55	9.51	83.73	15.79	0.000

Tab. 2. Mean Score on the *Quality of Life Questionnaires* and the significance level of differences between the subgroups (male)

	Institution		Shelter Workshop		p.
	M	SD	M	SD	
Satisfaction	20.57	4.92	21.56	4.01	no signif.
Competency/Productivity	12.70	4.56	22.87	6.03	0.000
Empowerment/Independence	21.07	2.96	20.22	3.01	no signif.
Social Belonging	18.50	3.66	23.04	5.51	0.002
Total Score	73.07	10.51	86.61	17.06	0.002

Tab. 3. Mean Score on the *Quality of Life Questionnaires* and the significance level of differences between the subgroups (female)

	Institution		Shelter Workshop		p.
	M	SD	M	SD	
Satisfaction	20.00	3.80	20.83	3.80	No signif.
Competency/Productivity	12.90	0.88	20.17	6.52	0.000
Empowerment/Independence	20.30	2.91	19.11	3.68	No signif.
Social Belonging	18.10	3.35	20.17	4.00	No signif.
Total Score	71.00	5.72	80.05	13.59	0.021

The analysis of the outcome acquired through the application of *Quality of Life Questionnaire* to the survey of the two groups *A* and *B* indicates that the persons with mental retardation living in community possess a higher level of quality of life than those living in Institution ($p < 0.000$).

Statistically important discrepancies emerge between the investigated groups also in further subscales of the Questionnaire: *Competence/Productivity* ($p < 0.000$) and *Social Belonging* ($p < 0.001$). This clearly proves that persons with mental retardation living in community and having access to various daily activities (group *A*) enjoy a higher degree of being competent and indispensable as well as possess

a stronger feeling of belonging to the community they live in as opposed to the persons living in Institution (group B).

Talking about the subgroup of the women and men it is important to underline that similarly significant differences, concerning quality of life, appear among the men coming from the different environments regarding the total score ($p < 0.002$) and the subscales (approximately $p < 0.000$, $p < 0.002$). The subgroup of the women shows the significant difference in total score of the *Quality of Life Questionnaire* ($p < 0.021$) and the subscale *Competence/Productivity* ($p < 0.000$).

Tab. 4. Mean Score on the *LNU – Scale* and significance level of differences between the main groups

	Institution		Shelter Workshop		p.
	M	SD	M	SD	
I	37.60	11.05	40.71	12.03	no signif.
II	31.70	9.75	38.00	10.03	0.005
III	43.58	8.66	42.32	10.29	no signif.
IV	42.48	10.70	45.05	10.40	no signif.
Total Score	155.35	30.87	164.30	37.78	no signif.

Description of the tab. : I – personality sphere; II – family sphere; III – social sphere; IV – occupational sphere.

Tab. 5. Mean Score on the *LNU – Scale* and significance level of differences between the subgroups (male)

	Institution		Shelter Workshop		p.
	M	SD	M	SD	
I	37.60	11.26	41.52	10.98	no signif.
I	30.86	10.47	39.96	10.79	0.003
III	44.50	7.65	43.57	10.89	no signif.
IV	43.50	10.74	47.04	8.53	no signif.
Total Score	156.47	30.73	168.91	36.97	no signif.

Description of the tab. : I – personality sphere; II – family sphere; III – social sphere; IV – occupational sphere.

Tab. 6. Mean Score on the *LNU – Scale* and significance level of differences between the subgroups (female)

	Institution		Shelter Workshop		p.
	M	SD	M	SD	
I	37.60	10.98	40.71	12.03	no signif.
II	34.20	7.00	35.50	8.61	no signif.
III	40.80	11.18	40.72	9.54	no signif.
IV	39.40	10.49	42.50	12.18	no signif.
Total Score	152.00	32.71	158.39	39.03	no signif.

Description of the tab. : I – personality sphere; II – family sphere; III – social sphere; IV – occupational sphere.

The analysis of the outcome acquired through the application of *Scale - LNU* to the survey of the two groups *A* and *B* indicates the middle intensity of the experienced problems among the both examined group regarding the total score of the scale as well as the scores in the spheres. The only significant difference between the group appear in the sphere II concerning **family problems** ($p < 0.005$). Persons with mental retardation living in community faced more intensively problems with the family of origin as well as more fears with the future own family.

Looking at the scores of the subgroups women and men living in two difference environment we can say that the level of intensity of the faced problems is similar to those reached by the main group. Within the men subgroup there is also a statistically significant difference in the sphere II (family problems) between examine environment. There is not any significant difference in the women subgroup.

DISCUSSION

The acquired results of the survey I have conveyed put into question Z. Zabor's (1997) standpoint previously presented claiming a beneficial influence of Institution on its resident, furthermore, they reveal the urgency of reorganizing the system of rehabilitation and care as well as services rendered for the people with mental retardation (Schalock 1999).

The reorganization should enable a greater number of people with mental retardation to live in the community they belong to, provide a broader range of daily routines and fulfill their needs. Only then will the full development of the all potential a person with mental retardation possesses be possible and the normalization of his/her life conditions ensured. This in turn is bound to raise the level of quality of life of this group of people (Otrebski, 1996, 1998).

The Polish norms corresponding to the category of quality of life have not been yet established, therefore one may, in the interest of pure comparison, add that according to the research by A Juros (1997, pp.302) and the one I have carried out people with mental retardation in Poland acquire a lower score on the Quality of Life Questionnaire than those examined by K. Keith (1996, p.79).

The above comparison, in my view, proves an irrefutable argument in favor of change in the system of services for the persons with mental retardation.

CONCLUSIONS

Conclusively it should be stated that the scientists in Poland approach the question of quality of life multidimensionally. Not only do they thoroughly analyze

theoretical, methodological and ethical aspect in question but also broadly apply this new category of description of reality in empirical research.

It is of foremost importance therefore to either establish or adopt methods in order to gather information and depict objective factors and subjective evaluation of quality of life of an individual person or a social group.

The necessity of accepting the category of subjective assessment of quality of life as the main factor of measuring and evaluating the standard of care and rehabilitation services concurrently with the introduction of organizational changes could be therefore duly recognized and paid attention to.

Achieving organizational outputs and personal outcomes appear as a great challenge to the local communities and they authorities when they are going to work on the new structure of the human services system as a one of the consequences of the administrative reform in Poland.

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