

OUTCOME INDICATORS IN THE CARE FOR PEOPLE WITH A MENTAL HANDICAP

C. G. C. Janssen and G. J. Vreeke

Introduction

Quality control plays an important role in the care for people with a mental handicap. In the Netherlands, for instance, the National Inspectorate is responsible for monitoring care and investigating complaints. When errors, accidents or near-accidents are reported, national committees make recommendations on how to prevent a recurrence in the future. In addition, affiliated institutions occasionally organize evaluations by colleagues in other institutions. Moreover, umbrella organizations have drawn up a number of quality criteria to guide the quality control policies of institutions for the mentally handicapped. Care institutions are also subject to control from the government and health insurance companies, exercised by means of certification, visitations, and so forth.

In the future, every institution in the Netherlands must have its own system of internal quality control and control

from the government and health insurance companies will primarily take the form of supervision of the quality control systems itself ('supervising supervision'). The need for meticulous and systematic monitoring by external institutions is expected to diminish. In short, providing quality care requires self-regulation.

In this process of quality control valid and reliable measuring instruments are indispensable. These instruments should provide a solid foundation for quality control and ensure that quality can be evaluated. Comparisons of similar institutions or evaluations made at several points in time within a single institution are only possible if adequate measuring instruments can be used. Having realised the absolute necessity of adequate measuring instruments, the Dutch Association for Scientific Research (NWO) promoted

* Dr. C. G. C. Janssen,
Free University, Faculty of Psychology and Pedagogical Sciences, 1081 BT, Amsterdam.

Dr. G. J. Vreeke,
Free University, Faculty of Psychology and Pedagogical Sciences, 1081 BT, Amsterdam.

* For Correspondence

two studies surveying the effectiveness of these instruments:

A survey of measuring instruments for the *quality of the processes* in the care for the mentally handicapped (Staring *et al.*, 1993).

A survey of measuring instruments for the *quality of the outcome* of care for the mentally handicapped (Vreeke *et al.*, 1993).

This article describes the findings of this second study: a survey and an assessment of the instruments for measuring outcome of care.

We believe that measuring instruments can be used fruitfully in quality control if at least the following criteria are met:

The instruments assess outcome of care only or at least discriminate between outcome influenced by care and outcome influenced by other events in life.

The instruments provide a standard discriminating adequate care from inadequate care.

The instruments are valid and reliable.

Survey of instruments measuring the outcome of care

The outcome of care is the (intended or unintended) result of the care

process. The results, the outcome, sought in care provision for the mentally handicapped vary. In our view, these results can be divided into four general categories (Vreeke *et al.*, 1993):

1. achieving a certain level of *quality of life* for people with a mental handicap;
2. improving (or at least preventing the decline of) the *practical and social functioning* of mentally handicapped persons;
3. ensuring social *integration* and
4. ensuring that the clients (and their parents) are *satisfied* with the care provided.

1. Quality of life

The quality of life has increasingly come to be regarded as an important outcome of the care provided. It is sometimes thought that this concept will replace the concept of normalisation (Landesman, 1986; Schalock and Begab, 1990). The quality of life is considered to be the proper standard by which to assess the quality of care since care - especially when provided around the clock - is the factor determining the quality of life for many mentally handicapped people. The quality of life is a kind of umbrella concept which may cover all the major aspects of the lives of the mentally handicapped: friendships, health, relationships with the staff, freedoms, work, recreation etc.

The 'quality of life' concept is based on some common principles (Schalock and Begab, 1990):

First, the quality of life is considered to be the same for the mentally handicapped as well as the non-handicapped. They have the same basic needs and want to have the same responsibilities.

Second, the quality of life is basically socially determined, by both the nature and extent of interaction with other people. Thus, relationships with significant others should play an important role in defining the quality of life.

Third, the quality of life may be considered to be the result/outcome of the extent to which basic needs are fulfilled in the lives of the mentally handicapped.

Fourth, in the final analysis the quality of life is a matter of individual perception and evaluation. Clients should define quality of life for themselves.

We believe that in the Netherlands, as well as in other European countries, the concept of the quality of life 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 the quality of life. This trend is reflected in the increasing focus on the clients' satisfaction, the efforts to include a sense of 'togetherness' as a criterion in assessing the quality of care provision and the greater emphasis on the importance of small group homes and of social networks for the mentally handicapped.

One of the focal problems in studying the quality of life is how to define it. To date, professionals in the care sector for the mentally handicapped have been

unable to agree on a definition (Landesman, 1986; Dossa, 1989; Sinnott-Oswald *et al.*, 1991). There are three approaches towards defining the quality of life (Dossa, 1989; Schalock *et al.*, 1989; Parmenter, 1992):

- a. the social indicator approach (the so-called 'objective' approach).
- b. the psychological indicator approach (the 'subjective' approach) and
- c. the combined approach.

The social indicator approach consists of assessing the quality of life based on the adequacy of the individual's income, housing, recreational opportunities etc. The individual's own perception of these factors does not play a significant role. The quality of life is essentially determined *from the outside* (i.e. 'objectively'). The psychological (i.e. 'subjectively') indicator approach does take the individual's view of the quality of life into account. The individual's sense of satisfaction, happiness and well-being in his/her work, friendships, relationship and leisure activities, for example, are central issues. The combined approach derives from the idea that the quality of life is determined both by objective and subjective factors.

Related to these issues is the determination of the dimensions which can be ascribed to the quality of life. Although there is no consensus on this point, health, satisfaction, social relationships, friendships, involvement in and access to public life (integration) and leisure are the dimensions most commonly mentioned.

Many authors regard the magnitude and complexity of this concept as positive rather than negative. They feel that complex systems of the care provision require complex assessments (Schalock *et al.*, 1989). Furthermore, it has been established that the concept of 'the quality of life' offers a framework for an adequate understanding of human acts. The concept is suited to a democratic outlook on life, and consequently lends itself to an ideology and language that acknowledge and recognize the rights of, and opportunities for, the mentally handicapped (Goode, 1990). Opponents, however, consider the concept as too vague and too open for assessing the quality of care provision (Baroff, 1986). These opponents also point out that the quality of life is used as a criterion in determining the appropriateness of medical treatment (Luckasson, 1990).

Although instruments for measuring the quality of life have only been recently developed, the field is rapidly growing. A number of authors have developed theoretical models which connect the various aspects of, and factors determining the quality of life (Brown *et al.*, 1989; Schalock *et al.*, 1989; Goode, 1990; Parmenter, 1992). Assessment instruments have been developed, based on these models. Goode's theoretical model also provides guidelines for discussions between care providers, parents and mentally handicapped people on the quality of life, and can be used primarily for detecting problem areas in care provision (Myhrman and Ohman, 1989). Others have developed instruments that evaluate the mentally handi-

capped people's quality of life without explicitly using a theoretical model (Cragg and Harrison, 1986). In their efforts to measure the quality of life, other researchers have made eclectic use of existing questionnaires and scales which were not initially developed for this purpose (such as scales for adaptation and questionnaires on integration).

It should be pointed out that the instruments developed cannot simply be used as a means of controlling quality for several reasons:

- a. In most cases the instruments lack a standard on which to base conclusions about the quality of the care provision. Two of the instruments developed show promise. These instruments, at least, have some kind of standard: Schalock *et al.*, (1989) connect their instrument to an index, which can be used to indicate how high the mentally handicapped individual's quality of life is. However, the authors do not indicate the point at which the value is no longer acceptable. The instrument developed by Schalock *et al.* is best-known and most frequently used and it is adaptable to many situations in care provision. Three components evaluate the quality of life: the extent of the individual's control of his/her environment; the individual's use of public facilities; and the quality of his/her social relationships. Either the individuals themselves or two people very close to them answer the questions. Each aspect is covered by a number of questions.

- Another frequently used instrument is that of Cragg and Harrison (1986). This instrument is designed to determine the quality of life for mentally handicapped people living in a group home. Consequently, the instrument is not as broadly applicable as that of Schalock *et al.* The instrument consists of 70 items relating to the physical surroundings, integration, the staff's behaviour, decision-making, leisure, supervision and training. The instrument should be supported by observations and discussions with staff and the mentally handicapped. Although, from an evaluative point of view, this instrument is considered to be less sound than Schalock's, its standards were established in an interesting way. The authors postulate that the quality of the care provision is acceptable if the residents of a group home enjoy a quality of life that would be acceptable to most people in society. The standards for Cragg and Harrison's instrument have thus been based on a standard for quality of life that would also be acceptable to non-handicapped people. According to Cragg and Harrison, the quality of care for the mentally handicapped requires improvement when the values measured for the quality of life drop below that level.
- b. The quality of life may indicate the quality of care. However, the quality of care does not influence all aspects of the quality of life. Existing instruments fail to make a clear distinction between the aspects of the quality of life that can or cannot be influenced by the quality of care. The seriousness of the disability in particular correlates with the score on the instrument of Schalock *et al.*: people with serious mental handicaps generally score lower than those with milder handicaps. This would imply that the instruments require further refinement if they are to be considered valid and reliable indicators of the quality of care. It is worth noting, that instruments measuring the process of care will be needed in addition.
 - c. As far as we know, no instrument for measuring the quality of life for the mentally handicapped has been developed, adapted or established specifically for the Dutch/European situation.
 - d. Existing instruments, most of which are American, have rarely, if ever, been applied on behalf of people with serious mental handicaps. Indeed, these instruments are probably not suitable for them. Existing theoretical models could well be useful in developing instruments to evaluate the quality of life for this group.
 - e. Generally speaking, little is known about the validity and reliability of the existing instruments.
- In short, instruments are usually introduced as a way of measuring quality without being geared or being examined as such. Standards are lacking and usually no distinction is made between those aspects of quality of life which are influenced by care and those which are not.

2. Functioning

Aiming at improving the functioning of mentally handicapped people or - in many cases - fighting a decline, plays an important role in care provision. Various terms are used in the literature to characterise mentally handicapped people's functioning: coping, adaptation, adjustment etc. Many instruments for measuring the functioning of mentally handicapped people have been developed.

These instruments, however, do not all cover the same areas and they largely differ in scope and detail, because the number of aspects regarding the functioning of the mentally handicapped is in fact endless (Raynes, 1987). These aspects range from grasping a pencil to independently running a household.

Because every country developed their own instruments with specific norms, we will not mention all the Dutch instruments found.

Until recently, there was a lack of instruments to evaluate the functioning of very young children and people with a serious and profound mental handicap, a gap that has been filled to some extent over the past few years.

Although increasingly more attention is paid to older mentally handicapped people (their problems in aging, depression and dementia) we found a lack of instruments measuring their specific functioning. Instruments are lacking especially in home care and early intervention. This type of care is not only provided for the mentally handicapped, parents or care providers too are offered

help. As far as the parents/care providers are concerned, the objective of the provision of this type of care is twofold: on the one hand it relieves (or it reduces) stress and on the other it attempts to enlarge the parent's capability to handle their child's problematic behaviour or to stimulate their development (Van Berkum, 1992). Depending on the specific type of home care, the effects of this care will become apparent in a better functioning of the parents/care providers and/or in a better functioning of the child. For this type of care hardly any instruments have been developed which have the potential to measure these effects, however. In spite of the recent initiatives, home care is still an area with many voids as to appropriate measuring instruments.

It seems evident, that the many existing instruments measuring functioning of the mentally retarded are not always directly suitable for a system of quality control. The extent to which a mentally handicapped person is able to show his/her wants, shows interfering behaviour, adjusts, develops etc. can all be determined by means of these instruments, but this does not give us much direct information on the quality of care. Using these instruments to monitor quality, therefore, requires a special use. Based on these instruments objectives for intervention or training can be set or formulated (a particular level of coping, for instance); subsequently, a special programme or care plan is linked to this (ways to realise the intended level of coping). Thus, the instrument can function as a way to evaluate the outcome of

the programme/treatment. The results achieved show whether the intended objectives have been realised. The well-known Portage programme, for example, has adopted this procedure. Consequently, the instruments measuring functioning can in this way help to gain a better understanding of the quality of individual programmes (Gunzburg, 1992), but they have not been adjusted to structural and practical procedures of quality control. Because effective training programmes improving functioning in some situations can affect the quality of life (e.g. electroaversive-therapy in reducing self injurious behaviour), measurements of functioning can possibly better be integrated in procedures for assessment of quality of life. In short: In this area there are many measuring instruments but there is little understanding of the way in which these instruments may be of any help in a structural control-system of the quality of care.

3. Integration

The importance of integration as an objective of the various types of care provision for mentally handicapped people is increasing. Many institutions explicitly label the stimulation of integration as one of their top priorities. Integration can roughly be defined as the extent to which a mentally handicapped person is able to cope in society. Sometimes a distinction between three forms of integration is made:

- a. physical integration (mentally handicapped people live among non mentally handicapped people)
- b. functional integration (mentally handicapped people use the same social services as non mentally handicapped people) and
- c. social integration (mentally handicapped people relate to non mentally handicapped people).

The physical and functional integration can be taken as a *conditio sine-qua-non* for social integration.

The aspects of integration most often looked at are housing, recreation, education and work. Various instruments consider items relating to integration, such as do most of the instruments measuring quality of life (Schalock *et al.*, 1989). Sometimes (social) integration is a separate category in the instruments measuring satisfaction (Sands *et al.*, 1991). However, there are also instruments which focus on integration in particular (Malin, 1983; Flynn and Saleem, 1986; Jahoda *et al.*, 1990; Weidner and Schneider, 1994). These instruments were developed to determine the extent to which a specific group of people is integrated. Bersani and Salon (1988) have developed an instrument which focuses on semi-independently living mentally handicapped people in particular. This instrument requires filling in of a questionnaire by a good friend of the mentally handicapped person in order to see how that person's social integration is developing, if developing at all.

Most existing instruments do have many shortcomings:

- * the questionnaires often are extensive and have open ended questions.
- * usually most of the instruments are used only once. [The ICI, the *Index of Community Involvement* (Raynes *et al.*, 1979), is an instrument which is used in various studies.]
- * the instruments focus on integration in particular and the sub-scales of the other instruments do not have a standard. Thus, they have not been made fit to serve the purpose of quality control.

These shortcomings are the reasons for many of the voids in this field of study. We found the same problems mentioned for instruments measuring quality of life and functioning.

4. Satisfaction

The clients' satisfaction regarding care provision is an increasingly important outcome in this sector (Van Campen *et al.*, 1990). The clients' satisfaction will have to play an important role in the development of systems of quality control. Usually in most questionnaires about care and interventions the questions are about overall satisfaction, and sometimes there is an additional question as to a person's willingness to recommend the same kind of care to other people or to recommend returning to the institution in case the situation would deteriorate. Occasionally, there is a specific measuring instrument which assesses the level of satisfaction of a number of aspects of the

care provided for that person.

However, measuring satisfaction is quite complicated for several reasons:

- a. When clients are asked about their degree of satisfaction with the provision of care they often give answers which do not fit their true perception. Their assessments of the degree of satisfaction might well be influenced by response sets, such as the social desirability of the answers, gratitude, the Hawthorn effect, secondary benefits from illness, inclining to consent, the halo effect, etc.
- b. The connection between the satisfaction with care and the actual effect of care provision appear not always to be linear (Van Campen *et al.*, 1990). Clients often are satisfied with the care provided, even if it helped them very little to attain a reasonable quality of life (Kozleski and Sands, 1992).
- c. The care provided for mentally handicapped people is often permanent and around the clock. So, it is difficult for the mentally handicapped clients to distinguish between this permanent care and other non-care related events in their lives in the assessment of satisfaction. If a mentally handicapped person's satisfaction with care provision in general is desired, a 'quality of life' instrument would be more preferable (Lemmens and Donker, 1990).
- d. Regarding the provision of care, clients are often rather led by their personal feelings towards care, by their relationship with those providing care than by its quality and effects.

Based on these points, Lemmens and Donker (1990) and Van Campen *et al.*, (1990) state that instruments for the measurement of the degree of satisfaction should comply with the following requirements:

- * If possible, clients should be involved in listing all the relevant items and the relevant aspects of care for improving the validity of an instrument. Measuring (the degree of) satisfaction by means of superficial questions only would not be valid due to a 'is everybody happy effect'. By asking specifically about the satisfaction with the many aspects of care which are relevant to the clients, there should be hardly any influence of the above-mentioned distorting response sets, such as the inclination to consent, gratitude, etc., which will ultimately lead to a greater variance in response.
- * More neutral terms such as 'good care' and 'poor care' should be used rather than 'satisfaction' and 'dissatisfaction'. This will increase the variance in response and will rule out some response sets. That is why the use of Likert scales and z-scores is recommended. 'Ceiling effects' (i.e. too many satisfied people) and 'bottom effect' should also be avoided. Items should preferably be formulated in the first person rather than the third person.
- * An instrument which has yet to be developed should actually formulate a 'central core' of items in addition to field specific items. By doing so, a

cumulation of knowledge can be accomplished.

Some authors, however, feel that dissatisfaction as to quality control should play a more important role (Crocker, 1989; Vuori, 1991), because if clients are dissatisfied, care failed.

Seltzer (1981), Heal and Chadsey-Rusch (1985), Burchard *et al.*, (1990); Sands *et al.*, (1991), Kozleski and Sands (1992) have developed instruments, parts of which can be useful measuring satisfaction with care. The so-called *Consumer Satisfaction Survey* (CSS, Sands *et al.*, 1991) is the most reliable and valid instrument. The CSS is not restricted to a specific character of care, but rather the entire package of care which is used by mentally handicapped people in the state of Colorado (USA) in the fields of education, housing, employment, health care, transportation, counselling etc. However, this instrument is not a specific quality control instrument either, for standards are lacking. Kars and Janssen (1994) have developed a questionnaire for assessing the satisfaction of parents, which can be used in the institutions' care. They have also considered the aspects most often criticized in the instruments measuring satisfaction. In their instrument a true standard is also lacking. Van Campen *et al.*, (1990) feel that three instruments certainly are worth examining with respect to assessing satisfaction in the general health care: The Patient Judgement System (PJS, Nelson, 1989), The Patient Judgement of Hospital Quality (PJHQ, Meterko, 1990) and the Questionnaire

for Quality Assessment by Clients (QQA, Kooi and Donker, 1991).

It may be stated that instruments measuring the degree of satisfaction lack standards in particular. These instruments do not sharply indicate when the quality of care is inadequate. Furthermore, the instruments usually are too superficial and they have been developed for residential care only. Actually, there are no detailed satisfaction instruments for semi-residential and ambulant care that have been validated and found reliable.

Conclusions and recommendations

A great deal of research is carried out on measuring the outcome of the care provision for mentally handicapped people; the outcome can be measured by various instruments. However, this does not necessarily mean that real outcome indicators have actually been developed. It is often quite the opposite, because an outcome indicator requires standards. The importance of the development of standards should be emphasised in future studies. Consequently, institutions and care providers or other people who want to assess the quality of care will have to determine the minimum requirements for care; these minimum requirements can then be used to formulate standards. Developing appropriate standards for quality also requires a cooperation of all people involved in the provision of care, such

as care providers, clients and their parents, the government, the health insurance companies and researchers.

It is also important that future researchers either develop instruments or at least modify the existing instruments, so that they can clearly indicate if and how the measurements can be ascribed to care only or to other factors as well. This clear indication certainly is needed, for the current instruments often lack this clarity. In quality control instruments measuring outcome of care should be used in addition to instruments measuring the process of providing care.

Summary

The outcome of care provided to the mentally handicapped can be divided into:

1. offering a certain quality of life;
2. stimulating a certain development of social and practical functioning;
3. realising a certain degree of integration of mentally handicapped people; and
4. realising a certain extent of satisfaction for clients (mentally handicapped people and their parents).

The literature has been reviewed and it has been elucidated which measuring instruments or indicators have been developed in this field.

Generally, many instruments seemed to have the potential to measure the outcome of care, but current instruments

are hardly ever capable of providing a standard by which the care provided can be assessed. Most instruments are not capable of indicating either to what extent the measuring result is an immediate result of the care provided. Many instruments studying results do not check the other influencing aspects. However, there are various instruments measuring outcome of the care provided to the mentally handicapped which are essential for future studies.

Acknowledgement

This study was commissioned and subsidised by the *Nederlandse Organisatie voor Wetenschappelijk Onderzoek, Gebied Medische Wetenschappen* [the Dutch Organisation for Scientific Research, Department of Medical Sciences].

References

- Baroff, G. S. (1986). Maximal adaptive competency, *Mental Retardation*, 24, 367-368.
- Berkum, H.W. van (1992). *Stress bij ouders van een verstandelijk gehandicapt kind: evaluatie van thuiszorg*. (Stress of parents of a mentally handicapped child: evaluation of home care), Amsterdam: Swets en Zeitlinger.
- Bersani, H. and Salon, R. (1988). *Personal integration inventory*. New York: Syracuse University.
- Brown, R. I., Bayer, M. B. and MacFarlane, C. (1989). *Rehabilitation programmes: performance and quality of life of adults with developmental handicaps*. Toronto: Lugus Productions.
- Burchard, S. N., Gordon, L. R. and Pine, J. (1990). Manager competence, program normalisation and client satisfaction in group homes. *Education and Training in Mental Retardation*, 25, 277 - 285.
- Campen, C. van, Friele, R. D. and Kerssens, J. J. (1990). *Methods for assessing patient satisfaction with primary care. Review and annotated bibliography*. Utrecht: NIVEL.
- Cragg, R. and Harrison, J. (1986). *Living in a supervised home: a questionnaire on quality of life*. Birmingham: Birmingham Campaign for People with a Mental Handicap.
- Crocker, T. M. (1989). Assessing consumer satisfaction with mental handicap services: a comparison between different approaches. *British Journal of Mental Subnormality*, 35, 94 - 100.
- Dossa, P.A. (1989). Quality of life: individualism or holism? A critical review of the literature. *International Research of Rehabilitation Research*, 12, 121 - 136.
- Flynn, M. C. and Saleem, J. K. (1986). Adults who are mentally handicapped and living with their parents: satisfaction and perceptions regarding their lives and circumstances, *Journal of Mental Deficiency Research*, 30, 379 - 387.
- Goode, D. A. (1990). Thinking about and discussing quality of life. In: Schalock, R. L. and Begab, M. J. (eds.). *Quality of life: perspectives and issues*. Washington: American Association on Mental Retardation.
- Gunzburg, H. C. (ed.) (1992). *Despite mental handicap: learning to cope with adult daily life*. Stratford-upon-Avon: British Society for Developmental Disabilities.
- Heal, L. W. and Chadsey-Rush, J. (1985). The Lifestyle Satisfaction Scale (LSS): Assessing Individuals' Satisfaction with Residence, Community Setting, and Associated Services, *Applied Research in Mental Retardation*, 6, 475 - 490.
- Jaboda, A., Cattermole, M. and Markova, I. (1990). Moving out: an opportunity for friendship and broadening social horizons? *Journal of Mental Deficiency Research*, 34, 127 - 139.
- Kars, H. and Janssen, C. G. C. (1994). Parents' attitudes towards and their satisfaction with care in an institution for mentally handicapped people, *British Journal of Developmental Disabilities*, 40, 81 - 97.

- Kooi, R. en Donker, M. (1991), *Cliënten over de RIAGG. Ontwerp en afname van een vragenlijst voor kwaliteitsbeoordeling door cliënten*, [Development of a questionnaire for quality control by clients], Utrecht: NCGV.
- Kozleski, E. B. and Sands, D. J. (1992), The Yardstick of Social Validity: Evaluating Quality of Life as Perceived by Adults without Disabilities, *Education and Training in Mental Retardation*, 27, 119 - 131.
- Landesman, S. (1986). Quality of life and personal life satisfaction: definition and measurement issues. *Mental Retardation*, 24, 141 - 143.
- Lemmens, F. and Donker, M. (1990). *Kwaliteitsbeoordeling door cliënten. Een metastudie naar tevredenheidsonderzoek in de geestelijke gezondheidszorg. (Quality control by clients. A search for satisfaction research)*, Utrecht: NCGV.
- Luckasson, R. (1990). A lawyer's perspective on quality of life. In: Schalock, R. L. and Begab, M. J. (eds.). *Quality of life: perspectives and issues*. Washington: American Association on Mental Retardation.
- Malin, N. A. (1983). Group homes for mentally handicapped adults: residents' views on contacts and support. *British Journal of Mental Subnormality*, 28, 142 - 157.
- Meterko, M. (1990), Patient judgement of hospital quality, *Medical Care*, 28, 9, 1 - 56.
- Myhrman, A. and Ohman, A. (1989). Quality of life for mentally handicapped adults in Finland. *International Journal of Rehabilitation Research*, 12, 465 - 466.
- Nelson, E. C. (1989), The patient judgment system: reliability and validity, *Quality Review Bulletin*, 15, 185 - 191.
- 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. San Diego, California: Academic Press, Inc.
- Raynes, N. V. (1987). Adaptive Behaviour Scales. In: Hogg, J. and Raynes, N. V. (eds.), *Assessment in Mental Handicap*, London and Sydney: Croom Helm.
- Raynes, N. V., Pratt, M. W. and Roses, S. (1979). *Organisational Structure and the Care of the Mentally Retarded*. London: Croom Helm.
- Sands, D. J., Kozleski, E. B. and Goodwin, L. D. (1991). Whose needs are we meeting? Results of a consumer satisfaction survey of persons with developmental disabilities in Colorado. *Research in Developmental Disabilities*, 12, 297 - 314.
- Schalock, R. L., Keith, K. D., Hoffman, K. and Jaran, O. C. (1989). Quality of Life: Its Measurement and Use. *Mental Retardation*, 27, 25 -31.
- Schalock, R. L. and Begab, M. J. (1990). *Quality of Life : Perspectives and Issues*. Washington: American Association on Mental Retardation.
- Seltzer, G.B. (1981). Community residential adjustment: the relationship among environment, performance and satisfaction. *American Journal of Mental Deficiency*, 85, 624 - 630.
- Sinnott-Oswald, M., Gliner, J. A., and Spencer, K.C. (1991). Supported and sheltered employment: quality of life issues among workers with disabilities. *Education and Training in Mental Retardation*, 26, 389 - 387.
- Staring, M. A. T. M., Duterloo, C. M. and Horn, G. H. M. M. ten (1993). *Kwaliteitsmeting van Proceskenmerken in de Zwakzinnigenzorg. Overzichtstudie binnen het onderzoekprogramma Kwaliteit van Zorg. (Quality measurement of processes in the care for the mentally handicapped)*, Den Haag: Nederlandse Organisatie voor Wetenschappelijk Onderzoek.
- Vreeke, G. J. , Janssen C. G. C., Kars, H. and Schuurman, M. (1993), *Uitkomstindicatoren in de zorg aan mensen met een verstandelijke handicap. Overzichtsstudie binnen het onderzoeksprogramma Kwaliteit van Zorg. (Outcome indicators in the care for the mentally handicapped)*, Den Haag: Nederlandse Organisatie voor Wetenschappelijk Onderzoek.
- Vuori, H. (1991). Patient satisfaction - does it matter? *Quality Assurance in Health Care*, 3, 3, 183 - 189.
- Weidner, E. W. and Schneider, M. J. (1994). *Sociale integratie en het sociaal netwerk van bewoners van sociowoningen en gezinsvervangende tehuizen: een vergelijkend onderzoek. (Social integration and social networks of people living in small group homes)*, Amersfoort: 's Heeren Loo.