Evaluating quality of support from the perspective of persons with intellectual disabilities: a review

By Bea Maes

Abstract: Increasing importance is attached to the involvement and participation of persons with intellectual disabilities in planning and evaluating support and services. This can be explained by the changed relationship between clients and professionals and by the shift to a person-centred approach of services that aims to provide responsive support to assist people in achieving valued 'quality of life' outcomes. Different strategies of quality evaluation from the perspective of persons with intellectual disabilities are discussed, including methodological issues concerning satisfaction research and the proxy-approach. An overview is given of studies in which persons with intellectual disabilities were questioned about the quality of their life and supports. Specific attention is paid to the association of quality of life outcomes with type of service provision and support characteristics. Finally, some future challenges are indicated to promote user involvement in quality evaluation, from the perspective of researchers, service providers and persons with intellectual disabilities themselves.

Introduction

The theme of 'quality' has been receiving a great deal of attention in services and policy for persons with disabilities, and significant trends can be noticed during recent decades with regard to quality management, quality standards, and quality evaluation procedures.

In the eighties and nineties the principles of Total Quality Management spread to social services (Schalock, 1996a). Services became responsible for an evidence-based, continuous and systematic evaluation, optimisation and assurance of the quality of the supports they provide. The model of the European Foundation of Quality Management assumes that three groups of factors are of importance in the quest for quality: the results (from the perspective of the consumers, the staff, the facility, and society), the processes used to obtain certain results, and the organisational context in which this is to be achieved.
The pursuit of quality is not value-free. It has to do with the extent to which actual support meets specific quality standards. These standards are never definite; they evolve over time and differ from one culture to the next. In the disability field, new quality standards have been put forward, and this has been attributed to the paradigm shift to social and support models of disability (Bradley, 1994; Luckasson et al., 1992).

Increasing importance is attached to the involvement and participation of persons with disabilities in evaluating the quality of support and services they are using (cf. Ward, 1998; Whittaker, 1995). Quality of support and indicators that are used to measure it, are increasingly being determined by the service user rather than by the service provider. Following on from that, there has been a shift from quality evaluations that are directed at organisational and procedural characteristics of services to evaluations of person-referenced outcomes (Gardner, Carran & Nudler, 2001; Schalock, 1996a). Since the overall purpose of services is to enable people with disabilities to have a meaningful life that they enjoy and value, general quality norms make way for individualised outcomes that have been derived from the person’s aspirations and lifestyle.

The intention of this article is to give a state of the art concerning quality evaluations of support and services from the perspective of persons with intellectual disabilities. First, we will clarify the background of this theme, more specifically the changes in the position of the client in relation to professionals and the quality of support-standards that contribute to quality of life outcomes. The next parts will focus on the practical implementation of quality evaluation from the clients’ perspective and on the results of studies in which persons with intellectual disabilities were questioned about the quality of their life and support. Finally, some future challenges concerning user involvement in quality evaluation will be presented and discussed.

Theoretical and ideological backgrounds

Changes in the relation between persons with intellectual disabilities and professionals

Persons with intellectual disabilities are no longer considered to be passive and dependent consumers of care that has been planned and designed by experts. They are capable and have the right to direct their own lives and to make choices with regard to the support that they need (cf. Ward, 1998; Pedlar, Haworth & Hutchison, 1999). They are more and more empowered to express their opinions, make choices and control their life situation as well as to seek resources and take actions that are necessary for realising their personal goals in life.
For services this implies a shift from system-centred care to person-centred support (Butterworth, Steere & Whitney-Thomas, 1997; Holburn & Vietze, 2002). The question is no longer how to fit groups of persons with intellectual disabilities into a predefined array of residential, employment or educational settings. Persons with intellectual disabilities should instead be supported in identifying and achieving their personal lifestyle and in becoming valued community members. Their aspirations, preferences, strengths and needs must be directive for the support that they are given. This is impossible without an increasing involvement and participation of persons with intellectual disabilities and their family in planning and evaluating their support program. For they alone can judge to what degree support answers their needs, preferences and choices, and enables them to realise their personal goals in life.

The contribution of persons with intellectual disabilities to planning, developing and reviewing support and services implies a collaborative partnership between clients and professionals (Dale, 1996; Dunst, Trivette & Johanson, 1995). Clients must be informed in an accessible, accurate and comprehensible way. Their perceptions, values and visions need to be heard and respected. By consultation and negotiation, different perspectives can be turned into mutually agreed-upon goals. Persons with intellectual disabilities and their allies must play a central part in, and contribute actively to, all plans and decisions that have an impact on their well-being. Open communication and continuous dialogue discussing expectations and experiences are essential here. They should also have opportunities to make choices and decisions concerning their life and support.

In recent research we have found that this equal position of clients and professionals has not yet been fully realised (Maes et al., 2001; Maes, Bruyninckx & Goffart, 2003). In focus groups and interviews with persons with intellectual disabilities and parents, several bottlenecks were revealed. The support system and the regulations connected with it (with regard to structure, admission criteria, and modalities) are not clear, transparent and unequivocal to them. They lack information and help in their search for desirable support arrangements. Their participation in the process of determining support that is most adequately geared to their needs is too limited. Many of them have negative experiences with support workers who showed no respect and appreciation for their views or preferences. In their opinion, service systems are not flexible enough in adapting support to their specific needs. Services rather than clients still control the way in which support is provided.
Quality evaluation from the clients' perspective

Quality of support-standards that contribute to quality of life-outcomes

Quality of support and services has becoming increasingly linked to quality of life issues (Goode, 1994; Gardner et al., 2001; Schalock et al., 2002). Quality of life is a focal point of service delivery and program development and evaluation for people with intellectual disabilities. The assignment of a service system is to provide responsive support that assists people in achieving and maintaining valued quality of life-outcomes. Clients evaluate then to what degree and in which ways services contribute to, or on the contrary, are impeding these outcomes. Quality of life outcomes pertain to different domains of life (Felce & Perry, 1996; Keith, 2001; Schalock et al., 2002): emotional well-being, interpersonal relations, material well-being, personal development, physical well-being, self-determination, social inclusion and civic rights. These broad domains are assumed to have general applications, which are then further broken down into a variety of indicators or outcome measures.

Quality of life experienced by people with intellectual disabilities and their family is to a significant degree influenced by the way they are supported and given opportunities. For this reason, it is still important to evaluate the degree to which service and support meet specific quality standards (Bradley, 1994; Schwartz, Jacobson & Holburn, 2000; Holburn & Vietze, 2002). We have developed a set of quality standards for services for persons with a disability (see table 1) (Maes, Geeraert & Van den Bruel, 2000). These were based on current theories regarding quality of life and support, on a consensus between persons with disabilities, parents, support workers, policymakers and researchers in Delphi-discussion-rounds, and on a questionnaire for care providers and clients in all Flemish facilities.

Table 1: Quality standards in supporting persons with intellectual disabilities

| Person-centeredness: Each client is acknowledged as an individual with unique potentialities and needs. Support is individualised and person-centered. It is adequately tailored to the wishes and needs of the client and builds on his capacities, preferences and goals. |
| Involvement and participation: Clients and persons important to them are fully involved in planning and evaluating their life conditions and the support and services they receive. There is an exchange of information and consultation with all those concerned. |
| Choice and control: Clients are given every opportunity and support to express their preferences, to make their own choices and decisions and to exercise control. This pertains to important choices related to their living conditions, work, leisure time, relations etc., but also to opportunities for choices and decision making as part of the person's everyday routine. |

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Dignity and respect: Support is given in respect for the integrity and the personal lifestyle of each person. Clients can fulfil respected and valued roles in their family, school, work or community. They are treated with respect by others and protected against all kinds of violence, abuse and neglect. Their rights are not violated and promoted actively.

Atmosphere: The living or working environment is adapted to the function under consideration and to the clients’ characteristics. This pertains to material as well as to interpersonal components.

Relations: Clients have secure and stable relationships and commitment to family, friends and acquaintances. Support is directed at extending, maintaining and strengthening this relational network. The relationship between support workers and clients is characterised by concern, trust and respect.

Development and engagement in activities: Support is aimed at a harmonious development of the person’s potentialities. Clients are stimulated to develop new competencies and skills. They are actively supported to participate in meaningful activities that are in accordance with their interests and choices. In doing so they may gain a large range of valued life experiences.

Autonomy: Clients are encouraged to act as the primary causal agent in their life and to achieve personal goals. Support is directed at raising a person’s confidence in his own strengths, abilities and competencies. Clients are stimulated to carry out the activities and (parts of) actions that they are able to perform by themselves.

Structure and flexibility: The organisation of the living or working situation and the daily routine is clearly structured. The degree of structure depends on the clients’ individuality and on the context.

Full participation in community life: Clients must be able to participate in social life as full citizens. Support is inclusive and community-based. It is directed at full and active participation in community-based activities and at interactions involving people with and without disabilities. The person makes as much as possible use of generic resources in the community.

Perspective: Clients are supported to make plans for the future. They pursue short and long term goals. Actual events are situated in the course of their life.

Methodical action: Individual plans are written for each client. Professionals from different disciplines, clients and/or parents mutually agree on the assessment of and the perspective for an individual. Long-term goals are set by team consensus, while short-term goals are drawn up and carried out by specific disciplines. Every plan explicitly specifies the activities that are needed to reach the goal. The plan is implemented in a well-considered way. Any action that is undertaken by support workers can always be answered for. At regular intervals the goals and activities are evaluated systematically and corrected. Evaluation on previously defined moments generates new information which makes it possible to resume in a cyclical way the different phases of assessment, goal setting, implementation and evaluation.
Practical applications of client involvement and participation in quality evaluation

Different strategies can be used to involve persons with intellectual disabilities in evaluating the achievement of quality of life outcomes and the implementation of quality of support standards. Although those formats are not specific for persons with intellectual disabilities, the specific characteristics of the target group are a challenge to their practical implementation.

Subjective and objective evaluations

Persons with intellectual disabilities can be involved in objective as well as in subjective evaluation of the quality of their life or support. In the first case, they are asked for de facto information about their living circumstances or support arrangements. In the subjective experience of persons, several interrelated aspects can be differentiated: their satisfaction with certain aspects of their living conditions and the support they are getting; the value and relative importance they attach to these aspects; the degree to which individual needs and wants are met, to what extent personal objectives and aspirations are the aim, and the degree to which they have the feeling that change or improvement is possible (Felce & Perry, 1996; Renwick & Brown, 1996; Schalock et al., 2002).

Life satisfaction is frequently used as a measure of quality of life and as an outcome measure in service evaluation. Cummins (1995) reviewed a number of unrelated studies of satisfaction in different groups, and found that, despite significantly different life conditions, life satisfaction in all the groups amounts to a mean of about 75%. Satisfaction scores tend to be consistently high, most people rating themselves satisfied above average on all domains of life. In addition there is a remarkably weak relationship between a person’s subjective perception of well-being and the objective living conditions (Perry & Felce, 2002). Therefore, a fundamental debate has started concerning the use of subjective quality of life measures to assess service quality (Hatton, 1998; Hatton & Ager, 2002). Satisfaction may not be the most sensitive or appropriate measure to assess the quality of service provision. Subjective well-being appears to be relatively stable across the life span, and may reflect especially temperament, self-regulation and adaptation. A high degree of satisfaction may be the consequence of low hopes, of gratitude, of having difficulties in expressing criticism or of limited knowledge of the alternatives (Sands & Kozleski, 1994; Gregory et al., 2001; Hensel et al., 2002). Different authors therefore argue in favour of a combination of objective measures of life conditions, subjective appraisals of satisfaction, weighted by personal
values (Felce & Perry, 1996; Cummins, 1997; Schalock et al., 2002).

**Individual and group methods**

The most widely used methods of involving persons with intellectual disabilities in evaluating quality of life and support are (semi-)structured interviews and questionnaires. Many standardised instruments have been developed in the last ten years (for an overview see Keith, 2001). Some are general quality of life-scales, encompassing different domains of life. Others focus more specifically on certain aspects such as choice, self-determination, community participation, etc. Interviews provide an opportunity for in-depth exploration of subjective issues and attitudes, thereby potentially improving the comprehensiveness and validity of findings (Atkinson & Zibin, 1996). On the basis of a qualitative analysis of interviews taken from persons with intellectual disabilities, Antaki, Young & Finlay (2002) however point out several interviewer traps such as negative expectations, evaluating what the interviewee says, suggesting improvements or offering advice, shepherding the respondent’s answer into a more acceptable official shape, and offering alternative answers.

For persons with profound and/or multiple disabilities, one can identify expressions of (dis)satisfaction or (dis)like by (participatory) observation in the individual’s own natural settings (Hogg et al., 2001; Maes, Petry & Demuynck, 2003). An individual relationship with the participant seems to be necessary in order to open the observer up to the idiosyncratic expressions of the person with profound and/or multiple disabilities. Identification and verification of a person’s subjective experience in different situations and from different sources of information is called for in order to confirm the interpretations.

**Strategies of person-centred planning**

are based on teams consisting of a focus person, people that are important in the life of that person (‘circles of support’) and a facilitator, meeting regularly to help the focus person to achieve a better lifestyle (Butterworth et al., 1997; O’Brien & O’Brien, 2002). After the development of a personal profile and a vision of the person’s desirable future lifestyle, the team undertakes actions to identify and mobilise strategies and resources in order to achieve the desired goals. By systematically following up and continuously evaluating the plan, an appraisal is made of the degree that support contributes to the assumed objectives. In response to unresolved or new issues, new actions are developed. This is a collaborative and recurring process, characterised by long-term-commitment, creative and flexible problem-solving processes, and respect for the input and experience of all team members.

Several methods of systematic preference assessment have also been developed.
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They deal with important life questions such as accommodation, job, relations (Davis & Faw, 2002), but also with everyday preferences and interests in activities (Reid & Green, 2002). Persons with intellectual disabilities need sufficient information and experience to get to know the possible alternatives and to be able to express preferences and make choices. This may be done by means of information and training sessions, (virtual) visits, job or housing exhibitions. Situational assessments involve having people experience different situations and closely observing how they respond to each situation (Reid & Green, 2002).

Turning next to strategies on the individual level, several examples of group participation are found. User involvement is accomplished in house meetings, resident committees or user boards (Whittaker, 1995). Mixed groups consist of service users, relatives, advocates, service providers and/or policy makers to keep an eye on the quality of services. This can take the form of regularly meeting quality action groups (Allen, 1995) or interactive focus groups (Wheeler, 1996; Maes et al., 2000). Questions and statements on quality of life or support are discussed and elaborated upon. Group interactions generate new ideas and reactions to information.

Benjamin, Capie & Nossin (1997) have described audit-teams of persons with disabilities, relatives and professionals. These teams assess the quality of a service they themselves have no connection with. In pre-training sessions, they get to know each other, the evaluation criteria, and the method. During a visit of several days, they have interviews with all those who are concerned (clients, family, direct support staff, managers) and make direct observations of the service. In team meetings, an attempt is made to reach a consensus in the evaluation of the service’s quality and specific recommendations for improvement are made.

Diverse sources of information

Persons with intellectual disabilities are the primary source of information, especially when measuring subjective satisfaction and personal values. They can be assisted by a coach or advocate. Functional limitations in relation to communication, comprehension and/or affective state interfere however with self-report measurement (Atkinson & Zibin, 1996). Frequently mentioned problems are acquiescence (the tendency to say yes to questions regardless of their content), social desirability (the tendency to give the answer that is expected), and recency (the tendency to choose the last option offered in response to an either/or question or a multiple choice question) (Antaki & Rapley, 1996; Heal & Sigelman, 1996; Finlay & Lyons, 2001; Perry & Felce, 2002). Strategies to reduce those response biases include: using concrete
and simple structured questions, screening for biases in pre-tests, visualising topics, questions and/or answering categories, choosing a quiet, private and comfortable place, and gearing the pace to personal abilities.

Working with respondents who are well-acquainted with the focus person ('proxies') is then an alternative. They may be family-members, friends or staff. The literature however yields conflicting results concerning the value of the proxy-approach. Some studies find little agreement between persons with an intellectual disability and proxies on questions regarding the quality of their life or support (Heal & Sigelman, 1996; Stancliffe, 2000), while others find a greater concordance (McVilly et al., 2000). The concurrence between subject and proxy ratings seems to be more of a problem in evaluations of emotional experiences and personal preferences, than for more objective issues (Perry & Felce, 2002). Next to the nature of the issues under consideration and their degree of observability and specificity, the proxy’s relationship and familiarity with the target person may also be important mediators of the concurrence between persons with intellectual disabilities and proxies (McVilly et al., 2000). It seems best to consider the perspective of proxies as a complement rather than as a substitute for the perspective of the persons with intellectual disabilities themselves (Stancliffe, 2000).

**Research data on evaluation of quality of life and quality of support**

**Users' perspectives on quality of life and support**

Several researchers have questioned persons with intellectual disabilities about how they perceive the quality of their life and the quality of the support they are getting (cf. Sands, Kozleski & Goodwin, 1991; Wehmeyer & Metzler, 1995; Neumayer & Bleasdale, 1996; Gregory et al., 2001; Larsson & Larsson, 2001; Forrester-Jones et al., 2002).

In general the majority of the clients approve of all mapped aspects of their support and appear to be satisfied with their life situation. It is nevertheless obvious that their lifestyle conditions and preferences are not always fully met or addressed by services. Work is of great importance for persons with intellectual disabilities, but many think that they do not get enough employment opportunities and that their interests are not taken seriously for job placement. It is difficult for them to know what is available in terms of leisure-time activities or they have transport problems to access recreations. Lack of meaningful and varying activities is also frequently mentioned. Clients indicate that they do not have many friends, and that they are dependent on staff members for social and emotional support. They do not have enough independence and freedom of choice to do the things they want to do. They do not have enough
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information and support to make adequate choices. They point out that there are limited opportunities for consultation and user meetings. In such areas, the level of expressed satisfaction may be considered to be far from optimal. Those experiences probably contribute to the observation that many respondents consider their current living situation to be temporary and think something better will come along in the future.

Different factors have been identified that appear to be associated with higher levels of expressed satisfaction (Gregory et al., 2001). Positive factors include being independent, participation in domestic tasks, privacy and pleasant surroundings. Negative factors are lack of money, incompatible co-residents, isolation and harassment in local communities, institutional constraints on preferred lifestyles, and poor quality food.

Association of quality of life-outcomes with type of environmental setting

In the last decade, researchers took up the question of how different residential settings influenced the well-being of persons with intellectual disabilities. In a series of studies by different research groups in Europe, Australia and North America, quality of life outcomes were compared in different living or working situations of persons with intellectual disabilities (Tøssebro, 1995; Emerson & Hatton, 1996; Griffin et al., 1996; Stancliffe, 1997; Felce, 1998; Felce et al., 1998; Young et al., 1998; Howe, Horner & Newton, 1998; Stancliffe, Abery & Smith, 2000; Stancliffe & Keane, 2000; Emerson et al., 2000a, 2000b, 2001; Gregory et al., 2001; Kim, Larson & Lakin, 2001; Wehmeyer & Bolding, 2001; Heller, Miller & Hsieh, 2002).

Different service provisions were compared regarding living (supported living in the community, living in dispersed, small and community-based group homes, village communities and institutions or nursing homes) and working (supported working in the community, sheltered employment settings and specific day programs). Those services differ as to the number of people with intellectual disabilities who are living or working together (alone, with 1 or 2 companions, in a small group up to about 7 people, in large groups from about 8 people), the level of expected independence of the person with disabilities (drop-in support for a few hours a week, part-time support, 24 hour support) and the degree of being embedded in the local community (service in the community, in campus-style villages, in segregated facilities). In some studies, quality of life outcomes and quality of support characteristics of groups of clients that were matched on individual characteristics (such as level of social adaptation) were compared in different environmental settings. In others, changes were measured in a within-
individual design when individuals moved to a more community-based and less restrictive environment. The studies differed a great deal with regard to methodological approach. In some studies, only objective data were collected by means of questionnaires and interviews of members of the clients' support team, combined with observations of environmental characteristics. In others, a combination of objective and subjective variables was measured, and persons with a disability themselves or their proxies were an important source of information.

The results of the above mentioned studies differ a great deal depending on the measurement of subjective life satisfaction or objective life conditions. Few statistically significant differences are found between the rated life satisfaction of participants from different environments. Clients tend to express high levels of satisfaction with their current service, irrespective of actual environmental conditions. The majority of users who had been resettled from institutions into small community-based homes however clearly prefer their new support arrangements.

There is abundant evidence based on objective indicators that environmental factors and support arrangements positively affect quality of life outcomes for service users. In general, the results are equivalent or consistently better in the more individualised support programs than in the community-based group homes, and equivalent or consistently better in the community-based group homes than in traditional institutions. This has been established with regard to choice-opportunities, self-determination and autonomy, adaptive behaviour skills, participation in community-based activities, self-esteem and engagement in preferred activities.

Yet a more carefully balanced appraisal is due here. In the first place, the changes in community-based support are disappointing with regard to some variables such as challenging behaviour, social networks, friendships and choice in life-defining issues. Although community activities are more frequent, there is little evidence of their impact on social status and community acceptance (Emerson, 1999). Friendships do not seem to grow the longer the clients are staying in community-based provisions. In the study by Gregory et al. (2001) on the contrary, greater satisfaction with friendships and relationships was associated with the proportion of people with an intellectual disability in the users’ networks.

Secondly, people with an intellectual disability are still disadvantaged when compared to their peers who do not have a disability (Newton et al., 1994; Sands & Kozleski, 1994; Wehmeyer & Metzler, 1995; Stalker & Harris, 1998; Keith, 2001; Robertson et al., 2001; Hensel et al., 2002). This is especially the case for indicators such as income, participation in health care, productivity,
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and community participation. They also have fewer opportunities to choose and less autonomy, when compared to age-peers without disabilities. The social networks of people with intellectual disabilities are very limited with regard to friendships and are likely to involve very few meaningful relationships with people who do not have a disability, are not relatives, and are not paid to support them.

Finally, people with profound intellectual and multiple disabilities seem to be the most vulnerable group. Personal disability was the single most powerful predictor of variation in the quality of outcomes experienced (Hatton et al., 1996; Stancliffe & Lakin, 1998; Felce et al., 2000). These studies report a consistently strong positive correlation of individual outcomes with the individual’s adaptive behaviour. People with significant intellectual disabilities achieve fewer personal outcomes, on average, than people with milder intellectual disabilities. They have fewer chances of living in typical community environments, not so much variety in day-time and leisure activities, less choice, fewer chances of social participation, a less active lifestyle and not as much participation in community-based activities.

Association of quality of life-outcomes with support characteristics
In the first wave of studies, the superior quality of life outcomes in community-based alternatives were credited to structural reforms: the size being small, the resemblance with home, the community location, etc. Recent research however has demonstrated that these aspects may be necessary for the promotion of quality of life outcomes, but that they are in themselves not sufficient to guarantee it. The setting’s structural characteristics do not automatically lead to good quality of life outcomes.

The relationship between quality of life outcomes and the environmental context is mediated by the staff’s attitude and working methods, the organisational procedures and the service policy and culture (Felce, 1998; Stancliffe et al., 2000; Gregory et al., 2001; Robertson et al., 2001; Wehmeyer & Bolding, 2001; Heller et al., 2002). An important factor is staff competence to encourage independence, to facilitate the expression of personal preferences, to promote choices, and to support and enable clients to participate and engage in activities they are interested in. Other relevant support characteristics are staff practices such as the degree of individualised planning of structured day-activities and support arrangements, the degree of staff attention, the degree and quality of assistance, and support by direct care staff.

Research by Vlaskamp (1993) and Felce, Jones & Lowe (2002) has demonstrated the positive effects of systematic and individualised planning,
monitoring and evaluation of goals and activities for clients, in addition to training staff to actively support clients and provide effective assistance. Staff were better able to understand the meaning of their clients’ behaviour and felt more competent in their professional work. Actual staff support was characterised by more and better assistance for, and communication with, the clients. The ‘active support’ approach was also associated with higher levels of client participation in everyday activities, more opportunities for self-determination, and higher levels of user-satisfaction. Finally, with regard to the organisation, there was more continuity and interdisciplinarity in working with the clients.

Challenges to facilitate user involvement in quality evaluation of support and services

From the researchers’ perspective
Research should focus on the specific contribution of different sources of information and methods to identify subjective feelings and preferences of persons with intellectual disabilities. Specific attention should be paid to the requirements of reliability and validity. It is also necessary to develop procedures that have more consideration for the individual limitations of people with intellectual disabilities. Research and experience show that too many questionnaires are geared to the group of people who are socially more adapted and verbally proficient (Perry & Felce, 2002). It remains a real challenge to develop procedures and communication strategies, if persons with more communicative and cognitive limitations are to be involved in quality evaluation in ways that are valid.

Quality evaluation from the clients’ perspective in different settings can make it possible to identify more specifically the characteristics of service and support practices that are associated with positive quality of life outcomes. Pursuing the ideas of emancipatory disability research, persons with intellectual disabilities and their advocates must have more opportunities to contribute to research on the quality of services (Barnes & Mercer, 1997; Walmsley, 2001).

From the services’ perspective
Quality evaluation from the client’s perspective sets out a clear purpose related to better organisational policies and procedures (Taylor, Bogdan & Racino, 1991; Wheeler, 1996; Schalock, 1996b; Dean & Mank, 1997; Schwartz et al., 2000; Becker et al., 2000; Amado & McBride, 2002; Reid & Green, 2002). To promote user involvement and participation, changes are required in the organisational context. Too often agencies pay ‘lip-service’ to innovations in service, but undermine the change process because they do not provide the support and system changes that are necessary to make innovations work.
Quality evaluation from the clients’ perspective

First of all, the aims and values that are the service’s foundation should be articulated in clear mission statements and well-defined quality of support standards and quality of life outcomes. All professionals should be committed to support individuals with intellectual disabilities and their family in order to obtain the outcomes that they have chosen. Support staff must try to better understand what is fulfilling in an individual’s life and to support activities that are guided by these understandings, and in this way respect the individual’s lifestyle. Job descriptions and staff orientation should reflect this person-centred approach.

Service providers should implement strategies and establish procedures for consultation, involvement and participation of people with intellectual disabilities and their advocates in planning and appraising the service, and in monitoring and evaluating the effects of the service on the quality of their lives. Support staff also need practical training and supervision in communicating with clients, in involving clients in planning and evaluation of support and in providing opportunities. Quality evaluation from the client’s perspective must not be a once-only event, but something that regularly takes place.

Service systems should progress to outcome and evidence-based methods of meeting the needs of persons with intellectual disabilities. Therefore, monitoring systems should be implemented to gather information about valued outcomes and standards. This information must lead to decisions and concrete actions that improve the quality of support and advance the quality of people’s lives. Each team member is responsible for optimising the quality of support provided. This presupposes cohesive and self-directing teams, characterised by self-assessment, continuous learning, and expanding possibilities.

The organisation must be flexible and open to creative solutions and innovative thinking. There must be a willingness to take risks. Re-allocation or flexible use of resources is sometimes needed to implement new methods. Research by Felce et al. (1998) has shown that resource allocation is scarcely related to the needs that have been defined on the basis of adaptive behaviour skills and problem behaviour. The relationship between resource input, quality of support, and quality of life outcomes seems to be very weak.

From the perspective of persons with disabilities
People with intellectual disabilities should be sensitised regarding their role in the evaluation of valued quality of life outcomes and quality of support standards. They can actively participate in planning and reviewing support when they are given the right support and learning opportunities. Support
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must be made available for them to develop confidence and skills that enable them to express their needs and preferences and to put forward their views. There should be programs to teach persons with intellectual disabilities decision-making skills and effective self-advocacy strategies. These programs serve both as a support system and as a means of providing technical assistance, information sharing and a source of empowerment (Zirpoli et al., 1994; Capie & Ahrens, 1996).

Self-advocacy groups should be developed and expanded in each region. Core components of self-advocacy are clear knowledge and information about one’s rights and ability to express one’s opinions and wishes, to make choices and decisions and to undertake actions in order to realise changes and valued quality of life-outcomes (Ward, 1998; Goodley, 2000). Other forms of advocacy include: citizen advocacy (the advocate is a member of the local community), paired advocacy (the advocate is another person with intellectual disabilities), circles of support (groups of people who are personally committed to a focus person), and facilitators or support brokers (a professional who is independent of services). All these people may help persons with intellectual disabilities to clarify their wishes and support needs, to put forward individual goals, and to negotiate accommodation, aids, services, supports and funds required to realize these goals. Direct payments could give persons with disabilities and their family more control and authority over the nature and the modalities of the support they want (Lord & Hutchison, 2003).

People with disabilities and their advocates finally should have political power to deal with environmental and social factors that negatively affect the quality of their lives (Cowger & Snively, 2002). They must be able to participate on a large scale in democratic decision-making processes that directly affect their life and well-being. In this connection, constant pains should be taken to make a policy of equal opportunities more sensitive and responsive to the differences that have been observed in quality of life between people with and without a disability.

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