Journal of Policy and Practice in Intellectual Disabilities
Volume 2 Number 3/4 pp 229–239 September/December 2005

Quality of Life Versus Quality of Care: Implications for People and Programs

Isabel De Waele*, Jos van Loon*, Geert Van Hove*, and Robert L. Schalock†
*Department of Orthopedagogics – Research Group Disability Studies, Ghent University, Ghent, Belgium; and †Hastings College, Hastings, Nebraska, and Life Span Institute, University of Kansas, Lawrence, KS, USA

Abstract The authors focus on the differences between a quality of care and a quality of life approach to services and supports for persons with intellectual disabilities. They distinguish between quality of care and quality of life program foci, present an example of how one large agency in the Netherlands converted from a quality of care to a quality of life-focused organization, and discuss the consequences of such a conversion. They note that organizations that have transitioned successfully to a quality of life emphasis focus on measuring person-referenced outcomes related to personal experiences and circumstances that reflect an increase in the person's independence, productivity, community integration, and satisfaction. The authors conclude that in the future more agencies and organizations will move from a quality of care to a quality of life-oriented service and supports system and suggest a number of fundamental principles and change strategies that could facilitate this transition process.

Keywords: discourse, management, quality of care, quality of life, supports paradigm

BACKGROUND AND OVERVIEW

The current emphasis on quality of life and program outcomes has resulted in a strong need among organizations to evaluate the primary focus of their organization and whether the services and supports they provide are aligned with current best practices. Historically, the major emphasis for programs servicing individuals with intellectual disabilities (ID) in Belgium and the Netherlands, as well as elsewhere, has been to provide a safe and secure environment, with educational and employment opportunities frequently provided but with less emphasis and importance. In this article, we refer to this emphasis as "quality of care." With the advent of the quality revolution, the reform movement, the supports paradigm, and the emphasis on consumer empowerment and community inclusion best practices throughout the world are now focused on insuring quality of life-oriented programs and valued outcomes for persons with ID.

From our experience and based on extensive research across the two program types and from the literature (e.g., De Waele & Van Hove, 2005; Schalock & Bonham, 2003; Van Hove, 1995; 1996; 2000; Van Loon, 2003; Van Loon & Van Hove, 2001), it is evident that if these quality of life-oriented and valued personal outcomes are to be achieved in organizations, these organizations need to incorporate the concept of quality of life as their primary focus. Such a focus would permit those organizations to incorporate better the related concepts of person-centered planning, individualized supports, self-determination, empowerment, community involvement, personal growth, outcome evaluation, and continuous program improvement.

Within this context, this article (1) distinguishes between a quality of care and a quality of life program focus; (2) presents an example of how one large organization, Arduin, in the Netherlands converted from a quality of care to a quality of life focus; (3) discusses the major consequences of such a conversion; and (4) outlines the key components to successful transitions from a "quality of care" to a quality of life-focused organization. Throughout the article we use the term discourse to refer to ways of thinking and producing meaning (Weedon, 1994).

QUALITY OF CARE VERSUS QUALITY OF LIFE: A DISCOURSE

The disability field is currently influenced significantly by the concept of quality. However, as evidenced in the following discussion, it can be manifested in at least one of two ways: a focus on quality of care and/or a focus on quality of life.

Quality of Care

In a quality of care discourse, people with ID are described as "consumers," that is, merely "clients" of a care system rather than

Received May 27, 2004; accepted August 1, 2005
Correspondence: Isabel De Waele, Researcher, Department of Orthopedagogics, Ghent University, Henri Dunantlaan 2, 9000 Gent, Belgium. Tel: +32 9264 63 65; Fax: +32 9264 64 91; E-mail: Isabel.DeWaele@ugent.be

citizens in a society. Perspectives of staff and facility are usually more influential than perspectives of these consumers. The types of results that are of importance in a quality of care system are often conceived in an easy-to-reach-and-measure way. This means that value-based evaluation is less popular. Although every service pretends to know what it is aiming at, the quality of care system gives no guarantee that existing knowledge about good predictors for quality of life, such as social inclusion, self-determination, and personal development, are implemented (Van Loon & Van Hove, 2001). Thus, one frequently finds an emphasis on impairment, categorization, homogenous grouping, health and safety, and control (De Waele & Van Hove, 2005).

The main concern for quality of care strategies is typically the process (Maes, Geeraert, & Van den Bruel, 2000). This focus on the process allows organizations to invest a considerable amount of time and energy in their own (management) structures and arrangements, always "being on the way." Sometimes this process-approach inhibits decisiveness and, in some cases, even covers the abandonment of principles. In addition, it has been our experience that quality of care discourses tend to remain within the borders of the existing care system, showing little or no interest or engagement in the deconstruction of the historical, political, or sociological context in which disability exists (Skrtic, 1995).

Quality of Life

In contrast to a quality of care model, the quality of life model is based on the quality of life construct that has emerged throughout the world (WHOQOL, 1995) and is currently being used as: (1) a sensitizing notion that gives us a sense of reference and guidance from the individual's perspective, focusing on the eight core domains (emotional well-being, interpersonal relations, material well-being, personal development, physical well-being, self-determination, social inclusion, and rights to a life of quality); (2) a social construct that provides a model for assessing the core quality of life domains; and (3) a unifying theme that provides a systematic framework to apply quality of life-oriented policies and practices (Schalock & Verdugo, 2002). Basic to an organization's commitment to a quality of life and individualized supports delivery model are the fundamental beliefs that: (1) the quality of life of people with disabilities is composed of those same factors (that is, core domains) and relationships that are important to all persons; (2) a person's quality of life is enhanced by empowering persons to participate in decisions that affect their lives; (3) quality of life is enhanced by the acceptance and full integration of persons into their local communities; and (4) a person's quality of life is enhanced through the provision of individualized supports (Brown & Brown, 2003; O'Brien & O'Brien, 1989; Schalock & Verdugo, 2002; Vreeke, Janssen, Resnick, & Stolk, 1998).

As a result of these beliefs and principles related to inclusion, equity, personal development, and self-determination, one finds a number of implications of a quality of life-focused approach to persons with ID at the micro, meso, and macrosystemic levels. Chief among these are:

- microsystem: active and valued members of a social network, learning by experience, empowerment, person-centered planning, and individualized supports;
- mesosystem: regular environments, flexible support, lifelong learning, and personal assistance;
- macrosystem: the premise of community life, natural supports, and human rights.

Fundamental Differences Between the Quality of Care and Quality of Life Models

The discourses of quality of care and quality of life are often confounded. Now that we have expounded some of their key aspects and implications, we will point out the key differences between the two. As summarized in Table 1, the two can be distinguished on the basis of perspective, interest, content, evaluation, and structures.

The differences summarized in Table 1 should not be construed to mean that safety and security needs are not part of a

TABLE 1
Essential differences between a quality of care versus quality of life focus

	Quality of care focus	**Quality of life focus**
Perspective	Provider	Person in his or her natural network
Interest	Process	Outcomes
Content	Management of care systems	Support and its effects on a personal life
Typical criteria for evaluation	Efficiency, cost-effectiveness, planning, consumer satisfaction	Long-term value-based outcomes on inclusion, personal development, and self-determination
Structures	Actual care systems only need improvement	Support needs to serve a persons case, even if this means that alternative structures have to be found

quality of life-oriented program or organization. Specifically, care or support needs to be of good quality, but the question is whether a system of quality of care is efficient enough for the realization of a personal life of good quality. The dominance of the quality of care discourse leads us to situations where control, health and safety, and impairment become central issues. These systems bring about outcomes that answer criteria of satisfaction, but not necessarily valid personal outcomes related to personal well-being and a higher quality of life. This means that an exclusive quality of care orientation frequently remains an empty box, without critical reflection on the context and the aim of long-term quality of life outcomes.

QUALITY OF LIFE DISCOURSE AND THE EXAMPLE OF ARDUIN

Arduin, an ID program in the Netherlands, will be used to demonstrate the processes and impacts of moving to a quality of life and individualized supports approach in services and supports for persons with ID. First established in 1969, up until about 10 years ago, Arduin functioned, under the name "Vijvervreugd," as a residential care institution, day nursery, and a day care center serving persons with ID. In 1994, it emerged as a new organization and came under new management. An independent study carried out at the time reached the conclusion that 35% of the inhabitants had fallen through the care net (Van Hove, 1995) and that the agency needed to change its focus.

Based on this study and other evaluations, the new Arduin became an independent, refocused organization. It immediately developed an action plan whose title was "*It Is Really Going to Happen Now*" (van den Beemt, 1995). This plan was based on a quality of life focus and the supports paradigm. Specifically, as a consequence of adopting a quality of life perspective, with the emphasis on inclusion, self-determination, personal development and support, Arduin was transformed from an institution to a new community-based organization, focusing on supporting each individual who determines what he/she needs. The separation between the three life spheres – accommodation, work/daily activities, and leisure – is fundamentally important in the process of deinstitutionalization and promotion of quality of life. With respect to the actual provision of support, the implications of the emancipation cornerstone were carried through consistently in all the resolutions made that structured Arduin's activities (van Loon & Van Hove, 2001). At present, Arduin serves about 600 persons: 394 for 24 h a day (living and work/daily activities), 11 who get support in their homes, 27 short stay (weekends and holidays), and 168 who come to Arduin for (support in) work/daily activities. People live in normal houses in the community, work full-time in a great variety of businesses or day centers, and are supported by support workers according to their needs. Specific strategies and techniques are discussed in the following two sections.

Quality of Life Focus

A focus on quality of life was continuous during the program changes. The importance of emancipation and self-determination of people with ID was stressed in order to secure the best possible quality of life. The concept of quality of life was operationally defined and implemented through the eight core quality of life found in the international quality of life literature (Schalock & Verdugo, 2002). From a large action research project we can now conclude that from these eight domains, inclusion, self-determination, and personal development were especially influential in the shift from "total care" – as organized within the traditional institutional care – to "support" (Van Loon & Van Hove, 2001).

In a program emphasis on quality of life, the individual is encouraged to develop from a position of dependence to one of self-determination. There is a clear focus on long-term person-referenced outcomes. This was accentuated in the decision to dismantle the institution, as well as in choosing a style of management directed toward autonomy and self-direction. The focus was clearly not on short-term outcomes such as consumer satisfaction, but on long-term person-referenced outcomes. There had to be a fundamental change in the personal experiences and circumstances of the individuals to such an extent that sometimes parents and staff found it difficult beforehand to believe it would be possible. In the following process, the opinions of the organization's clientele played an important role in structuring the new organization. At the start, they were interviewed regarding their wants, but actually more by way of the choices they make in the vacancy bank, the housing bureau, and the courses in the educational center. In this, individuals are supported by their personal assistant – this function is explained below (Van Loon, 2003).

Supports Paradigm

In an organization that wants to offer individualized supports to people with ID, the central function is definitely not housing, health, safety, or control, as mentioned above, but the supports in the life spheres that are chosen by the individual himself or herself as well as where and how he or she wants these supports. Supports in the concept of "supported living" are offered in first instance by the natural network of the person: parents, family, friends, neighbors, colleagues, and volunteers. It is only when the natural network is unable to offer sufficient support that the social "safety net," consisting of service professionals, comes into action. In many cases, it becomes evident that the natural network has to be reconstructed or reactivated.

Supports have to be offered flexibly as not every person needs support in the same areas or in the same amount. Thus, the "group thinking" is being abandoned. Within Arduin there is a wide variety, from people who need very intensive support to people who only need a couple of hours of support from a host.

Furthermore, the individual's need for supports may also vary from time to time. Therefore, the individuals are not asked on a once-only basis for their opinions, wishes, or needs, but are continually queried. People (whether with or without ID) need to have control of their own lives in order to experience a good quality of life. This results in inclusion, self-determination, and empowerment being built into the values and practices of the services offered to people with ID, because the focus of these services is on supporting people, instead of caring for people. As a result, one should not underestimate the implications of these factors on the needed conversion of an organization. It is, however, our conviction that people with ID themselves have the least problem in getting used to a system in which they have control of their own lives.

At Arduin, to fully implement individualized supports, strong leadership and good communication were indispensable. It became clear that the changeover of the whole organization from offering care to offering support meant that staff had to rethink their functioning. They now had to use their expertise to optimize supports in order to eliminate impediments for and in the individuals they were helping, so that the individuals developed their own abilities to manage their lives.

During the course of this transition, we observed that it was at times difficult for staff to work in this new role and in other circumstances as most staff members in Arduin were trained primarily in nursing for people with ID. As their training did not prepare them for these new roles and responsibilities, regular and additional training of the organization's workers was considered an important instrument for supporting the process of change. A large budget for additional training was developed and the emphasis during the first years of the transition was on changing attitudes and habits of the staff.

By focusing on providing supports, the services provided by the organization had to be adjusted accordingly, going through a transition from "providing a total care service" toward "offering the support that the individual desires" – no more, no less. A good system of communication within the organization was an important condition. In an institute with hierarchical lines, with all personnel on a campus, communication seemed easier than within an organization with many small parts spread over a large region. To solve this problem, Arduin looked to its extranet, a communication system by way of the Internet, which provided continuous and actual information for all parts of the organization and which allowed quick and easy communication by means of e-mail (van den Beemt, 2004).

EXEMPLARY CONSEQUENCES OF THE CONVERSION

The intent of this section is to show, based on the example of Arduin, how similar organizations and their service/support delivery system can expect a number of changes and consequences at the micro, meso, and macrosystems levels. The most important ones are described next.

The Macrosystem

Legislation in the Netherlands has helped the government formulate public policy that states that all people with disabilities have the right to a full life in Dutch society. With this as a framework, the government has encouraged the transition from large-scale care institutions to small-scale distributed services (Vliegenthart, 1999). This is reflected in the National Program on Community Care (Vliegenthart, 2000). In spite of this major shift in government policy, services in the Netherlands are generally still very traditional (Walsh, 1997). Arduin is an example of an exception; here the organization has implemented a new approach to services based on the quality of life concept and the supports paradigm (Van Loon & Van Hove, 2001). The rationale for this development is reflected in the definition of "mental retardation" as espoused by the American Association on Mental Retardation (Luckasson, 2002), and is found in the changing views of the international community on the nature of ID, advocacy coming forth from disability studies (Rioux, 1994), criticism of institutional care throughout the years (van Gennep, 1976; Goffman, 1962; O'Brien & O'Brien, 1993; Rosenberg, 1994; Vreeke et al., 1998), the Universal Declaration of Rights and the United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities (and preceding declarations), a focus on enhancing quality of life and person-referenced outcomes (Schalock & Verdugo, 2002), and the supports paradigm (Klein, 1994; Luckasson, 2002; O'Brien & O'Brien, 1993).

Inclusion: Meso and Micro Level

Each person should be able to choose where and how he or she wants to live and work. Thus, in the provision of supports, an organization needs to focus on maximizing inclusion. Under this notion, individuals are supported in finding ordinary, small-scaled homes in the regular housing market in the region. This applies to everyone with a disability regardless of the intensity of his or her need for supports. Thus, even people with intensive support needs can live in normal houses that are adapted to those needs. However, this means that there is a greater dependence on the informal social networks of the family, church, the community, and volunteers. In the case of children who cannot stay with their parents, it is the policy to look for a foster family in the first instance. Furthermore, each person can apply for work or day occupation of their own choice in a range of companies and day centers that are integrated with the local society (e.g., in a gift shop or a gallery in the town center and companies in ordinary industrial estates).

Self-Determination: Meso and Macro Level

The principle of self-determination should be emphasized for all people. However, in practice this is not always easy to realize.

Yet there is the belief that all people, regardless of their level of dependence, can function autonomously. To be able to sustain living arrangements under the principle of self-determination, a personal assistant is very important. Under this model, each individual has a personal assistant that he or she can call upon for support in a continuous dialog with the organization and in formulating care and support requests directed at the organization. The personal assistant sees that the agreed-upon personalized package of support is carried out in conformity with the wishes of the individual. The personal assistant also functions, when the situation calls for it, as an interpreter or translator of the wishes of the individual, but always explicitly from the role of assistant. The intensity and frequency of this support is totally dependent on the request of the individual (of course, within given financial margins of the organization). In our experience, on average, a personal assistant spends about three-quarters of an hour each week working on behalf a particular person.

The communication with the person is based on equality (De Baets, 1998). This is reflected in the "personal plan" that replaces the care plan and in which an ongoing dialog between the individual and his or her personal assistant is key. The personal assistant asks his or her client about what he or she wants, how he orshe wants it, whether he or she got what he or she wanted, and about what is happening. The assistant then helps the person in formulating his or her need of supports in the personal plan, and does this on an ongoing basis.

Personal choice is an important ingredient under this notion. One component of choice under the Dutch example we are using is the maintenance of a "vacancy bank." Such a bank permits individuals served by the organization to apply personally for a position in a work establishment or day unit. Work or day occupation is fundamentally important to quality of life; It is one of the fundamental rights in the Universal Declaration of Rights. Therefore, all agency clients, including also those with an intensive need for support, should be offered a full-time job or day occupation. Another component is the freedom to choose where one lives. Adults should be able to choose (sometimes with support of their personal assistant and/or their parents) where and with who they want to live. Under the Dutch example, the "board of placement," which decided where everyone should live, was dissolved. Thus, this action enabled more independent decision making and more people living where they wanted. Yet such freedom often entails a process of trial and error. At the heart of this process is the "housing bureau." In the Dutch example, this bureau every month issues over the agency's extranet an overview of dwellings associated with Arduin that are or will become available. In principle, there is an unlimited variety of ways of living. The offerings include housing that ranges from independent living with little support, living with a foster family, living on a farm, or in an estate or in the center of the town, to living in a small group home, and anything in between. Principles such as a homogeneous or heterogeneous group structure become irrelevant; What is important is individual choice.

Personal Development: Meso and Micro Level

Personal development is related directly to opportunities, experiences, empowerment, and personal decision making. That is why people are asked to make their own decisions (large or small) and thereby take control of their own lives. To gain skills in personal decision making, adults are offered a range of education and training opportunities. In the Dutch example, the Arduin organization offers over 50 courses that anyone can take. These courses cover areas such as social education, general development, occupational training, and creative development. These courses are prepared in compliance with the request of the agency's clients who want to know, for example, more about the new philosophy of personal supports, first aid, how to handle tools, how to use makeup, or how to use the telephone. The emphasis is always on learning to appreciate new information and learning how to make decisions that enable one to stand up for oneself. Often this learning exposes areas the participants never had a chance to learn about – a kind of catching up on knowledge areas that they should have learned about earlier in their lives.

The changes described above represent Arduin's transition from a quality of care focus to a quality of life focus, as illustrated in Table 2.

SUCCESSFUL TRANSITIONS FROM QUALITY OF CARE TO QUALITY OF LIFE

It has been our experience that moving from a quality of care to a quality of life discourse program requires commitment to five fundamental principles as well as the implementation of four key change strategies. The principles and strategies are summarized in Table 3 and discussed in more detail in this section of the article.

Fundamental Principles

First, focus on long-term person-referenced outcomes These outcomes, which reflect a change in personal experiences and circumstances, are different from either program outputs or short-term outcomes. This distinction is shown clearly in the "program logic model" used by human service agencies. This systems approach to services is characterized by the following five components (Schalock & Bonham, 2003): (1) resources that involve capital, staff, time, and expertise; (2) program process that includes services and supports provided, program components, staff utilization patterns, approach to service/support delivery such as the individual program/supports plan; (3) program outputs that pertain to quality of care, quality assurance objectives met, individual program/supports plan objectives met; (4) short-term outcomes such as subjective well-being (e.g., satisfaction or happiness), client placement/discharge; and (5)

TABLE 2
The quality of care versus quality of life focus in the case of Arduin

	Quality of care focus	**Quality of life focus**
Perspective	*Provider. For example:* • The provider offered from the perspective of the organization a limited and fixed number of places to live in and to have daily activities; The board of placement decided where a person could live and work; The person had to accept this and adjust to these (take it or leave it). • The staff wrote the care plan about the care they thought was necessary for the person and they wanted to deliver to the person.	*Person in his natural network. For example:* • The perspective is the person: what he wants, what support he needs, what he asks of the organization. There is an ongoing dialog with the person on this, starting with the intake. There is no more board of placement, but a housing bureau and a vacancy bank, where people can apply themselves. • A personal plan is written by the personal assistant with the person: what do you want, how do you want it, do you get what you want?
Interest	*Process. For example:* • The greater interest in organizational processes was reflected in the large overhead: far more people working in the administration and behind desks.	*Outcomes. For example:* • There is very little overhead. Most staff work directly in supporting clients. The focus is on the quality of life of every individual person, with emphasis on participation in the community, personal development, etc.
Content	*Management of care systems. For example:* • Giving care in an effective way induced an institutional way of organizing lives of people, grouping people together on the basis of similarities in intellectual functioning or physical disability, treating them all similar. People were seen as patients. Most of them lived in the institution. The food came from the large institutional kitchen. There was little work or daily activities as the focus was on care. In the ward where one lived, one of the nursing staff took special care for a person. All clients had one and the same doctor: the doctor of the institution. As to religion, there were sometimes special services for people with ID in the gym of the institution.	*Support and effects on a personal life. For example:* • Support is given on an individual basis, according to the needs for supports of the individual person. Much emphasis on participation in the community, personal development (schooling, courses), a normal life as citizen. Supports are flexible as not every person gets supports in the same areas or in the same amount. People live in normal houses scattered over the region. People are involved in preparing their own meals in their own kitchen as much as possible. Everyone has a full-time job or has full-time daily activities. Every person has a personal assistant who has an independent position and is not involved in the daily support or care for the person. The people have the same local general practitioner as the other people in the neighborhood (who can get support by a specialist). People go to their local church.
Typical criteria for evaluation	*Efficiency, cost-effectiveness, planning, consumer satisfaction:* The focus is on the organizational, bureaucratic, and administrative processes. Are the organizational processes running smoothly?	*Long-term value-based outcomes on inclusion, personal development, and self-determination:* The focus on continuous, ongoing, evaluation of the quality of life of every individual person is part of the method of the personal plan and part of the job of the personal assistant in dialog with his or her client. A quick scan on quality of life is one of the instruments.
Structures	*Actual care systems only need improvement. For example:* • The organization had a strong hierarchical structure, with many managers and middle managers as a result. • Communication went through these hierarchical lines. • Most staff were trained in nursing.	*Support needs to serve a person's case, even if this means that alternative structures have to be found. For example:* • A new organizational structure based on autonomy and self-direction of staff was introduced, with few hierarchies and the focus on coaching. The person who gets support always is point of reference. • Continuous communication and actual information for everyone on the extranet, by way of the Internet. • New education and additional training for staff was developed with the focus on support.

TABLE 3
Principles and strategies involved in organization change

- Principles
  - Ensure a life of quality for one's clientele
  - Focus on long-term person-referenced outcomes
  - Employ the supports paradigm
  - Empower staff and persons with ID
  - Be proactive and change-oriented
- Strategies
  - Know where you are going
  - Understand the experiences of successful organization and systems-level change
  - Measure outcomes
  - Manage for results
  - Be systems-oriented

long-term outcomes that involve changes in personal experiences and circumstances.

Organizations that have transitioned successfully to a quality of life emphasis focus on measuring person-referenced outcomes related to personal experiences and circumstances that reflect an increase in the person's independence (both in activities of daily living and instrumental activities of daily living, and residential status), productivity (i.e., employment status), community integration (what the person does, where it is done, and with who), and satisfaction (Schalock, 2001). Based on extensive research, it is known that organizational change requires the objective assessment of person-referenced long-term outcomes rather than short-term outcomes such as satisfaction or happiness (Schalock & Felce, 2004).

Second, employ the supports paradigm The supports paradigm focuses: (1) on using the pattern and intensity of a person's supports needs as the basis for agency and system planning and reimbursement patterns; and (2) on integrating the related practices of person-centered planning, personal growth and development opportunities, community inclusion, and empowerment. Areas of critical support assessment for adults include major life activity areas (e.g., home and community living, lifelong learning, employment, health and safety, social, and protection and advocacy) and exceptional medical and behavioral support needs (AAMR, 2003; Thompson et al., 2002). An inclusive supports model for people with ID can be found in Luckasson (2002). A commitment to the supports paradigm also requires incorporating the following support standards into one's service delivery system (Luckasson, 2002): (1) supports occur in regular, integrated environments; (2) support activities are performed primarily by regular people working, living, educating, or recreating within integrated environments; (3) support activities are person-referenced; (4) supports are coordinated through someone such as a supports manager; (5) outcomes from the use of supports are evaluated against quality indicators and measured based on individual values; (6) the use of supports can fluctuate during different stages of one's life; and (7) supports should be ongoing and should not be withdrawn unless the service or supports provider continues to monitor the person's current and future pattern and intensities of needed supports.

Third, empower both staff and persons with ID Organizations typically change from the bottom up, not from the top down. That is, regardless of the organization's mission statement and administrative directives, true organization change occurs only when persons with ID and staff act differently. Basic to this change in persons with ID and staff behavior are the concepts of self-determination and empowerment (Stancliffe, Abery, & Smith, 2000). At the most fundamental level, both concepts (which are considered synonyms in this article) are about power and the ability to make decisions, self-direct, dream, take risks, and exercise one's rights and responsibilities (Powers, 2002). As discussed by Deci and Ryan (1985), self-determination/empowerment consists of two critical components: (1) an attitude that leads people to define goals for themselves; and (2) the ability to take the initiative to achieve these goals. This attitude and ability are developed – in both persons with ID and staff – through the development of skills related to choice making, decision making, problem solving, goal setting, independence, self-observation, self-instruction, and self-advocacy. Developing and using these skills produce outcomes related to increased locus of control, positive attributions of efficacy and outcome expectancy, self-awareness, and self-knowledge (Wehmeyer & Schalock, 2001).

Fourth, be proactive and change-oriented The transition from a quality of care to a quality of life focused organization can occur only when the fundamental culture and values of the organization change. A critical part of that change is to shift one's focus to being a "learning organization" whose major characteristics include (Argyris & Schon, 1978; Newman, 2000; Senge, 1990): (1) an institutional process by which organizations and their members notice, interpret, and manage their experiences; (2) a process that changes beliefs, knowledge, and behaviors; (3) a belief that organizational learning enhances the organization's potential for innovation and growth; (4) a differentiation between "single loop learning" (i.e., focusing on maintaining the operations, policies, and objectives and detecting and correcting errors with this framework) and "double loop learning" (i.e., changing the organization and searching for new routines and practices); (5) an altering of organization routines that involve ideologies, strategies, systems, policies, and procedures; (6) a realization that the only way an organization can learn is through its individual members; and (7) an acknowledgment that management strategies are important because they provide the vessel for capturing and sharing learning and the mechanism through which learning is facilitated.

Key Change Strategies

The four principles discussed above relate to the concept of quality of life (person-referenced outcomes, the supports paradigm, the empowerment of staff and persons with ID, and a commitment to change) and provide the vision and motivation to enable a transition from a quality of care to a quality of life organization. However, as the Japanese proverb reminds us, "vision without action is a daydream" – that is, vision needs action and structure. Such an implementation framework can be outlined by the following five key change strategies.

First, know where you are going Experience with programs that focus on transitioning to a quality of life-focused organization has resulted in the identification of six common characteristics of this movement into the community. Schalock (2001) notes that such a process: (1) is progressive, usually starting with children and progressing to adults; (2) involves parents initially and then progresses to legislators, funding bodies, local governments, schools, agencies, and self-advocates; (3) begins in a facility-based service delivery system and then progresses to a community-based system; (4) involves a number of key roles including visionary, organizer, promoter, and a following of dedicated advocates; (5) includes a number of key concepts that drive the movement including inclusion, equity, empowerment, person-centeredness, quality of life, the supports paradigm, and the human potential model; and (6) is catalyzed ("moved") by principles such as normalization, the passage of public/national laws, the consumer movement, and the emphasis on systems, organization, and person-referenced outcomes.

Thus, strategic planning for transitioning from a quality of care to a quality of life organization needs to focus clearly on organizational goals and objectives, and operational plans related to the eight core quality of life domains, quality enhancement techniques, self-determination and empowerment of staff and persons with ID, and the measurement of person-referenced long-term outcomes. In addition, program administrators need to be certain that their programs are aligned both vertically and horizontally. Vertical alignment assures congruence between the organization's mission statement, and the organization's strategies and staff utilization. Horizontal alignment assures congruence among consumer needs, organization practices, and desired outcomes.

Second, understand the experiences of successful organization and system-level change A series of ongoing studies (see, for example, Schalock, 2001; Schalock & Bonham, 2003) of organization and systems change have identified both the characteristics of those organizations transitioning to a quality of life focus and the role that policy makers and funding bodies play in that transition process. Seven characteristics that have been identified as defining successful organization change include: (1) openness to risk taking; (2) shared values drive services; (3) ongoing process of self-evaluation; (d) linkages to external resources; (4) holistic focus on consumer needs; (5) direct staff roles in establishing organizational goals and decision making; and (6) emphasis on continuous improvement.

The support of policy makers and funding bodies is essential for these seven changes to occur. The five key roles that they play include: (1) flexibility and innovation, including individually directed funding and funding flexible community-based supports; (2) incentives to agencies to expand community living and community employment programs; (3) community support and advocacy; (4) systems-level goals and data collection, and a clear understanding by systems personnel that community living and employment are the preferred outcomes for consumers; and (5) implementation of outcome-based performance measures and desired person-referenced long-term outcomes.

Third, measure outcomes Transitioning to a quality of life-focused program requires shifting from an emphasis on process (i.e., quality assurance and quality of care) to one that incorporates both quality service and indicators of quality outcomes. There are many purposes for outcome data, including providing information, improving programs, and guiding judgments. Today's human service programs are being buffeted by two major movements related to outcome data: the "reform movement," which stresses accountability and measured performance; and the "quality revolution," which stresses valued, person-referenced quality outcomes. The integration of these two movements into a quality of life-focused organization can be accomplished by measuring one or more indicators from each of the following four outcome categories:

- individual performance outcomes, including physical well-being (health status and wellness indicators) and material well-being (employment status, residential status, and educational status);
- individual value outcomes, including emotional well-being, personal development, self-determination, interpersonal relations, social inclusion, and rights;
- organization performance outcomes, including service coordination, financial stability, health and safety, program data, and staff tenure or turnover;
- organization-value outcomes, including access to services, consumer satisfaction, reliability and responsiveness of services, appropriateness of services, and staff competencies.

Fourth, manage for results Managing for results requires three key changes in the way organizations operate and managers think. The first change relates to "right to left thinking" that involves focusing initially on the desired outcomes (such as those described above) and then asking the question, "what needs to be in place for these outcomes to occur?" Answering this question requires that the organization commit itself to embarking on evaluation efforts to determine the significant predictors of the desired outcomes. Once these predictors are identified, this information is "fed back" to all levels of the organization to ensure that

TABLE 4
The quality assurance process in quality of life-focused organizations

Quality of life domain	**Monitoring variables**	**Outcome indicators**
Emotional well-being	Increased safety, stable and predictable environments, positive feedback	Contentment, self-concept, lack of stress
Interpersonal relations	Foster friendships, encourage intimacy, support families	Interactions, relationships, supports received
Material well-being	Ownership, possessions, employment	Financial status, employment status, residential status
Personal development	Functional education/training, augmentative technology	Education status, personal competence, performance
Physical well-being	Health care, mobility, wellness, nutrition	Health status, activities of daily living, leisure, and recreation
Self-determination	Choices, personal control, decisions, personal goals	Autonomy, goals and personal values, choices
Social inclusion	Community role, community, activities, volunteerism	Community integration, community roles, social supports
Rights	Privacy, voting, due process, civic responsibilities	Human (e.g., respect), legal rights (e.g., access)

organizational learning occurs and change results. For example, if one knows that the significant predictors of clients' personal development primarily involve interpersonal relations, physical well-being, and opportunities for growth and development, then individualized supports and services can be directed at facilitating those three predictors.

The second required change involves how the concepts of quality assurance and monitoring are operationalized and implemented within the organization. In quality of care organizations, quality assurance equals a program output; Whereas in quality of life organizations, quality assurance is a process of monitoring quality enhancement techniques and evaluating quality outcomes. Key quality enhancement techniques and potential person-referenced outcomes can be monitored and evaluated through the quality assurance process (see Table 4).

The third required change involves commitment to "continuous improvement management," the goals of which are increased customer satisfaction, product quality, and organizational effectiveness and efficiency. The practice of continuous improvement management integrates the management literature related to total quality management with the utilization of outcome evaluation data. Key aspects of continuous improvement management include: (1) strong management and changing management strategies based on program evaluation; (2) consumer orientation; (3) data-driven decision making (i.e., use of evaluation information for programmatic change and improvement); (4) teamwork and providing a safe environment to discuss evaluation processes and outcomes; (5) focusing on vertical and horizontal alignment; (6) adopting an ecologic perspective; (7) stakeholder involvement in planning and implementation; (8) modifying data collection practices, as programs evolve, grow, and learn from experience; and (9) balancing feedback with program accomplishments and strengths.

Fifth, be systems-oriented One can neither overlook nor minimize the role that the external environment plays in either maintaining or changing an organization's mission, policies, and procedures. Indeed, organizations – just as people – live in multiple systems which can be conceptualized as micro (individual and family), meso (education and habilitation programs), and macro (larger society). Transitioning from a quality of care to a quality of life-focused organization requires sensitivity to each of these "systems" and the role that they play in the transitioning process. We have observed that the key roles and responsibilities that each has in the transitioning process included the microsystemic level, where agency service users and advocates (including staff) need to develop and express self-efficacy, internal local of control, self-determination, and empowerment; the mesosystemic level, where educators, practitioners, and program administrators need to focus on and implement person-centered planning, personal development (empowerment and self-determination), user-friendly and person-first language, prosthetics and technology, dimensions of quality service (reliability, responsiveness, empathy, extensiveness, and appropriateness), program-based quality enhancement techniques, collaboration, and the evaluation of person-referenced outcomes; and the macrosystemic level, where policy makers need to listen to service users and advocates, incorporate key quality of life concepts and principles into public policy, fund research and demonstration projects, and evaluate the effects and impacts of quality of life-related policies and practices.

CONCLUSION

In the last decade, considerable attention has been given to the concept of quality. This focus on quality has often led to overestimating the concept of quality of care. Quality of care on its own, however, is absolutely not a guarantee for quality of life. Quality of care has a completely different orientation and can even become counter-productive in terms of attaining a high level of quality of life. Key domains in quality of life, such as social inclusion, self-determination, and personal development, can be at risk if a program or agency focuses exclusively on quality of care, because the procedures associated with this discourse deal mainly with control, power, health, and safety and put a strong emphasis on defectology and categorization. In comparison, focusing on quality of life puts the primary emphasis on long-term person-referenced outcomes related to independence, productivity, and community inclusion and is based on the provision of individualized supports. This difference is important. It is our feeling that the future requires agencies and organizations to move from a quality of care to a quality of life-oriented service and supports system. Thus, the focus of this article has been to suggest a number of fundamental principles and change strategies to make this transition possible.

REFERENCES

American Association on Mental Retardation (AAMR). (2003). *Supports intensity scale*. Washington, DC: AAMR.

Argyris, C., & Schon, D. A. (1978). *Organizational learning: A theory of action perspective*. Beading, MA: Addison-Wesley Company.

van den Beemt. P. (Ed.). (1995). *Het gaat nu echt gebeuren. Visie, doelstellingen en organisatiebeschrijving.* Middelburg: Cluster Verstandelijk Gehandicaptenzorg Walcheren.

van den Beemt, P. (2004). *Arduin: Het model in de praktijk – Op weg naar zelfsturing*. Leuven-Apeldoorn: Garant.

Brown, I., & Brown, R. I. (2003). *Quality of life and disability: An approach for community practitioners*. London: Jessica Kingsley Publishers.

De Baets, K. (1998). *Respectvol bevragen opent toekomst: kwalitatief interviewen van mensen met een verstandelijke handicap als middel tot vraaggestuurde zorg*. Ghent: Ghent University.

De Waele, I., & Van Hove, G. (2005). Modern times: An ethnographic study on the quality of life of people with a high support need in a Flemish residential facility. *Disability and Society*, *20*, 625–639.

Deci, E. L., & Ryan, R. M. (1985). *Intrinsic motivation and self-determination in human behavior*. New York: Plenum.

van Gennep, A. (1976). *Het recht van de zwakste*. Meppel: Boom.

Goffman, E. (1962). *Asylums*. New York: Anchor.

Klein, J. (1994). *The principles of supported living.* Retrieved June 25, 2004, from http://www.allenshea.com/principles.html

Luckasson, R. (2002). *Mental retardation, definition, classification, and systems of supports* (10th ed.). Washington, DC: American Association on Mental Retardation.

Maes, B., Geeraert, L., & Van den Bruel, B. (2000). Development a model for quality evaluation in residential care for people with intellectual disability. *Journal of Intellectual Disability Research*, *44*, 544–553.

Newman, K. L. (2000). Organization transformation during institutional upheaval. *Academy Management Review*, *3*, 602–619.

O'Brien, J., & O'Brien, C. L. (1989). *What's worth working for? Leadership for better quality human services*. Syracuse, NY: Responsive Systems Associates.

O'Brien, J., & O'Brien, C. L. (1993). Unlikely alliances: Friendship and people with developmental disabilities. In A. N. Amado (Ed.), *Friendships and community connections between people with and without developmental disabilities* (pp. 9–40). Baltimore, MD: Paul Brookes Publishing.

Powers, L. E. (2002). Introduction to special issue. *Journal of Disability Policy Studies*, *13*, 1–2.

Rioux, M. (1994). *Disability is not measles: New research paradigms in disability*. North York, Ontario: Roeher Institute.

Rosenberg, R. R. (1994). Capitol people first: Self-advocacy and quality of life issues. In D. Goode (Ed.), *Quality of life for persons with disabilities: International perspectives and issues* (pp. 174–184). Cambridge: Brooklin Books.

Schalock, R. L. (2001). *Outcome-based evaluation*. New York: Kluwer Academic/Plenum Publications.

Schalock, R. L., & Bonham, G. S. (2003). Measuring outcomes and managing for results. *Evaluation and Program Planning*, *26*, 229–235.

Schalock, R. L., & Felce, D. (2004). Quality of life and subjective well-being: Conceptual and measurement issues. In E. Emerson, C. Hatton, T. Thompson, & T. Parmenter (Eds.), *International handbook of applied research in intellectual disabilities* (pp. 232–254). West Sussex: John Wiley & Sons.

Schalock, R., & Verdugo, M. A. (2002). *Handbook on quality of life for human service practitioners*. Washington, DC: American Association on Mental Retardation.

Senge, P. M. (1990). *The fifth discipline*. New York: Doubleday.

Skrtic, T. (1995). *Disability and democracy*. New York: Teachers College Press.

Stancliffe, R. J., Abery, B. H., & Smith, J. (2000). Personal control and the ecology of community living settings: Beyond living-unit size and type. *American Journal on Mental Retardation*, *105*, 431–454.

Thompson, J. R., Hughes, C., Schalock, R. L., Silverman, W., Tasse, M. J., Bryant, B., et al. (2002). Integrating supports in assessment and planning. *Mental Retardation*, *40*, 390–405.

Van Hove, G. (1995). *Rapport m.b.t. een "second opinion" over de kwaliteit van zorg binnen de cluster verstandelijk gehandicaptenzorg walcheren* (interne ortho-agogische rapporten n°4). Gent: Universiteit Gent, Vakgroep Orthopedagogiek.

Van Hove, G. (2000). *Het recht van alle kinderen*. Leuven: Acco.

Van Loon, J. (2003). Empowerment en de persoonlijk assistent. Het nieuwe werken in de zorg voor mensen met een verstandelijke beperking. *Praktijkboek Casemanagement*. 's Gravenhage: Reed Business Information.

Van Loon, J., & Van Hove, G. (2001). Emancipation and self-determination of people with learning disabilities and down-sizing institutional care. *Disability and Society*, *16*, 233–254.

Vliegenthart, M. (1999). *Standpunt over community care*. Den Haag: Ministerie van Volksgezondheid, Welzijn en Sport.

Vliegenthart, M. (2000). *Landelijk programma community care*. Den Haag: Ministerie van Volksgezondheid, Welzijn en Sport.

Vreeke, G. J., Janssen, C. G. C., Resnick, S., & Stolk, J. (1998). *Kwaliteit van bestaan van mensen met een verstandelijke handicap. Ontwikkeling van een meetinstrument voor woonvoorzieningen en de stand van zaken in nederlandse instellingen*. Amsterdam: Vrije Universiteit.

Walsh, P. N. (1997). Old world-new territory: European perspectives on intellectual disability. *Journal of Intellectual Disability Research*, *41*, 112–119.

Weedon, C. (1994). *Feminist practice and poststructuralist theory*. Oxford: Blackwell.

Wehmeyer, M. L., & Schalock, R. L. (2001). Self-determination and quality of life: Implications for special education services and supports. *Focus on Exceptional Children*, *33*, 1–16.

World Health Organization Quality of Life Group (WHOQOL). (1995). The World Health Organization quality of life assessment: Position paper from the World Health Organization. *Social Science and Medicine*, *41*, 1403–1409.