

Enhancing Personal Outcomes: Organizational Strategies, Guidelines, and Examples

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Abstract Education and rehabilitation programs in the field of intellectual disabilities are developing specific strategies related to demonstrated personal outcomes, quality of life (QOL)-related services and supports, evidence-based practices, and quality improvement. The purpose of this article is to summarize key aspects of these strategies within a two-component framework: the concept of QOL and systems thinking. Based on our collective experiences and published literature, four specific strategies are presented and discussed: mental models, assessment, service delivery practices, and quality improvement (QI). Essential guidelines for the successful implementation of these strategies are then presented, along with an exemplary application of each strategy. Each example shows the significant role of the consumer, the organization, and the larger system in organizational change, QI, and the enhancement of personal outcomes.

Keywords: assessment, mental models, personal outcomes, quality improvement, quality of life, services delivery practices, systems thinking

INTRODUCTION AND OVERVIEW

Current education and rehabilitation program for persons with intellectual disabilities (ID) are operating within an environment that is characterized by a focus on personal outcomes and evidence-based practices. At the same time, over the last 3 decades, we have seen significant changes in organization and systems-level policies and practices reflected in a movement towards a quality of life (QOL) framework for the delivery of services and supports, community-based individualized support systems, participative management, the development of internal evaluation systems, and the use of quality assessment and improvement methodologies.

The purpose of this article is to summarize a number of strategies, guidelines, and examples that have been developed across a wide variety of organizations, systems, and countries to adapt successfully to these changes, and at the same time enhance personal outcomes. Based on our collective experiences and published literature, we use the *concept of QOL* and *systems thinking* to establish the parameters for the proposed implementation strategies and guidelines.

The concept of QOL provides the framework to integrate the increased demands for quality services, personal outcomes, quality improvement, and program accountability. The concept is

also increasingly becoming an agent for change as it encompasses the following aspects of current thinking and best practices in the field of ID: individual supports are the vehicle for an enhanced quality of life; the community is the context of a life of quality; organizations need to view themselves as bridges to the community; service delivery practices include person-centered planning, individualized supports, and consumer involvement in service delivery planning and evaluation; and evidence-based practices involve assessing personal QOL-related outcomes and using that information for quality improvement (QI) (Fantova, 2005a, 2005b; Schalock, Gardner, & Bradley, 2007; Verdugo, Schalock, Keith, & Stancliffe, 2005; Walsh et al., 2006).

Systems thinking provides the framework for seeing inter-relationships among the individual, organization, and larger service delivery system. It thereby provides the basis for organizations to implement strategies that respond effectively to an increasingly complex service delivery system, the need for evidence-based practices, and the focus on enhanced personal outcomes (Bronfenbrenner, 1979; Gardner, 1985; Senge, 2006).

ORGANIZATIONAL STRATEGIES

The two-component process of QOL and systems thinking provides the rationale and framework for developing four specific QOL-related implementation strategies: mental models, assessment, service delivery, and quality improvement. These four strategies are based on current program logic models (Andrews, 2004; Kaplan & Garrett, 2005; McLaughlin & Jordan, 1999;

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Schalock & Bonham, 2003), program evaluation theory (Donaldson & Gooler, 2003), and our personal experiences in public policy, service delivery practices, management strategies, quality-of-life research, and outcomes-based evaluation.

- Mental models are deeply ingrained assumptions, generalizations, and images we have to understand the world (Senge, 1990; 2006). They form the vision and culture of an organization and serve as the basis for leadership, values training, service delivery, outcomes evaluation, and quality improvement.
- Assessment is the foundation for evidence-based practices and quality improvement. Assessment involves the measurement of personal outcomes, performance indicators, and individual support needs.
- Service delivery practices include the services and supports that are provided to persons with ID. Their use involves the alignment of resources and strategies to produce enhanced personal outcomes through best practices.
- QI represents an organization or system’s capacity to improve performance and accountability through systematically collecting, analyzing, and synthesizing data, and implementing action strategies based on this process. The QI strategies presented are based heavily on the concept of organization learning that has been developed to promote change within bureaucratic organizations, which by their very nature have regulation or policy-defined structures that limit the consideration of new ideas (Cohen & Austin, 1994; Orthner, Cook, Sabah, & Rosenfeld, 2006).

MENTAL MODELS

In the field of ID, a number of mental models have historically inhibited change. Chief among these are: (1) models of disablement that focus on personal defectology rather than human potential and the ameliorating effects of environmental factors (Devlieger, Rusch, & Pfeiffer, 2003; Schalock, 2004); (2) an over-emphasis on quality of care that focuses on control, power, health, safety, defectology, and categorization as opposed to QOL that focuses on social inclusion, self-determination, personal development, community inclusion, and the provision of individualized supports (DeWalle & Van Hove, 2005; DeWalle, Van Loon, Van Hove, & Schalock, 2005); (3) organizations as mechanistic entities rather than organizations as self-organizing systems that reinforce thinking and doing, creativity, coordination, priority setting, and communication patterns (Schalock et al., 2007); and (4) built-in obstacles to change, including legacy monitoring systems, decentralized substate authorities, political consequences of transparency, lack of infrastructure, divided accountability, and potential litigation (Spector & Davidsen, 2006).

It is important to identify and understand these four inhibiting mental models because they are frequently the limiting factors to change. As stated by Senge (2006, p. 100), “to change the behavior of a system requires that one identify and change the limiting factor(s) and thereby increased one’s leverage.” Furthermore, we need to bring mental models to the surface, challenge them, and in the process bring about changes within a culture that promotes inquiry and personal awareness regarding the fol-

lowing three mental models that form the basis for organizational strategies and guidelines to enhance personal outcomes: QOL principles, learning organization, and ethics.

QOL Principles

Individuals with ID and the organizations that serve them need to understand the concept of QOL as reflected in the core QOL domains and indicators listed in Table 1. The interested reader can find similar QOL domain listings in Cummins (1997); Felce and Perry (1996); Gardner and Carran (2005); Human Services Research Institute (HSRI) (2006); and Renwick, Brown, and Raphael (2000). In this regard, QOL domains are factors composing personal well-being and reflect the range over which the QOL construct extends (and thus defines “quality of life”), and QOL indicators are domain-specific perceptions, behaviors, and conditions that give an indication of a person’s well-being and are the basis for assessing QOL-related personal outcomes.

Understanding the concept of QOL involves both an appreciation for the core domains and indicators summarized in Table 1 and an awareness of the following core QOL conceptualization, measurement, and application principles (Brown, Keith, & Schalock, 2005; Schalock, 2005; Verdugo et al., 2005):

- *Conceptualization:* QOL is multidimensional; composed of the same domains for all people; influenced by personal and environmental factors and their interaction; and enhanced by self-determination, resources, inclusion, and purpose in life.
- *Measurement:* QOL measurement involves the degree to which people have life experiences that they value; reflects

TABLE 1
Core quality of life domains and indicators

Domain	Literature-based indicators
Emotional well-being	Contentment, self-concept, and lack of stress
Interpersonal relations	Interactions, relationships, and supports
Material well-being	Financial status, employment, and housing
Personal development	Education, personal competence, and performance
Physical well-being	Health and health care, activities of daily living, and leisure
Self-determination	Autonomy/personal control, goals and personal values, and choices
Social inclusion	Community integrations and participation, community roles, and social supports
Rights	Human (respect, dignity, equality) and legal

Source: Schalock and Verdugo (2002).

domains that contribute to a full and interconnected life; considers the context of physical, social, and cultural environments that are important to people; and includes measured experiences common to all humans and those unique to individuals.

- *Application:* QOL application enhances well-being within cultural contexts and should be evidence-based; QOL principles should be the basis for interventions and supports; and QOL principles should take a prominent place in professional education and training.

Learning Organizations

Learning organizations are essential to the enhancement of personal outcomes. An effective learning organization has a culture or system of values (such as QOL) that supports learning, and a structure enabling processes that integrate new information and facilitate change. More specifically, a learning organization's *culture* is characterized by innovation, safety of inquiry, and goal setting; whereas its *structure* is characterized by collaboration, planfulness, and diffusion (Orthner et al., 2006; Tamarit, 2005).

Ethics

A recent review (Schalock & Luckasson, 2005) of the *ethical principles* published by a number of organizations identified five common ethical principles: exhibits competence, exhibits professional and scientific responsibility, shows respect for peoples' rights and dignity, exhibits concerns for others' welfare, and contributes to community and society. These five principles describe a system of moral behavior, and the rules and conduct recognized in respect to a particular class of human actions. They also establish the parameters for QOL-related services and supports wherein all persons are fundamentally equal as human beings, with the primary purpose of intervention being to enhance personal outcomes and ensure that people can be effective participants in the community (Dekecki, 1992; Reinders, 1999).

ASSESSMENT

Assessment involves the measurement of personal outcomes, individual support needs, and performance indicators. Assessment data provide information central to an internal evaluation system.

Personal Outcomes

Personal outcomes are person-defined and valued aspirations that are measured in reference to core QOL domains and indicators, such as those shown in Table 1. Personal outcomes can be analyzed at the level of the individual and/or aggregated at the organization level, and used for multiple purposes that include organization reporting, quality improvement, monitoring social inclusion, and reducing inequalities and injustices.

Selecting which personal outcomes to assess depends on the question(s) asked and the intended use of the assessment information. There is a general agreement in the QOL literature that the following eight criteria should guide the selection of personal outcome measures, those that: reflect what people want in their lives, are based on a validated QOL model, have utility for quality improvement, are psychometrically sound, the provider has some control over, are related to current and future policy concerns, can be easily understood and readily communicated, and are comprehensive (Schalock et al., 2007; Walsh et al., 2006).

The assessment of personal outcomes needs to be based on a QOL model in which domains and indicators have demonstrated factor structure and factor stability (Bonham et al., 2004; Jenaro et al., 2005; Schalock & Verdugo, 2002; Schalock et al., 2005; Verdugo, Gomez, Arias, & Martin, 2006). Furthermore, their assessment can involve both subjective and objective measures, but the QOL literature is very clear that objective measures are better to use for organizational change and QI (Felce & Perry, 2006; Schalock & Felce, 2004).

A critique of current QOL measurement approaches can be found in Cummins (2005a; 2005b), Schalock and Verdugo (2002), Verdugo et al. (2005), and Walsh et al. (2006). Across measurement approaches, Likert-type rating and attitude scales are used most frequently, followed by various forms of questionnaires. Suggested guidelines regarding the use of Likert-type scales for assessing attitudes and behaviors of persons with ID include pictorial representation of response alternatives, a single set of one- or two-word response descriptors, clarifying questions, and pretests (Hartley & MacLean, 2006). Furthermore, best practice guidelines stress that the measurement of quality indicators/personal outcomes should be a guide for personal, programmatic, or policy evaluation and enhancement, rather than for the classification of individuals or organizations (Schalock et al., 2007).

Supports Needs Assessment

Individualized supports are the vehicle through which an enhanced QOL is achieved. Thus, the assessment of the profile and intensity of supports needs is a necessary strategy to enhance personal outcomes. There is a difference between the assessment of adaptive behavior and the assessment of support needs. An adaptive behavior instrument assesses the adaptive skills that a person has learned, whereas a supports need scale assesses the extraordinary supports that a person needs in order to participate successfully in life activities. As one example of an instrument based on best practices, the *Supports Intensity Scale* (Thompson et al., 2004) evaluates the pattern and profile of needed supports in six life activity areas (home living, community living, lifelong learning, employment, health and safety, and social activities), protection and advocacy activities, and exceptional medical and behavioral support needs. As with personal outcomes, support assessment data can be used at the individual level (e.g., for the development and implementation of an Individual Support Plan [ISP]), and aggregated at the organization level for establishing staff utilization patterns and necessary staff competencies and training, and developing resource allocation models.

Performance Indicators

Performance indicators are a comprehensive set of indicators at the organization and system levels that typically include aggregated personal outcomes and other indicators such as staff turnover, annual medical/dental exams, mortality rates, incident/injury rates, staff stability and competence, case management, and family indicators (HSRI, 2006). The importance of organization and systems-level performance indicators has emerged as community systems continue to mature and become more complex—as the notion of community inclusion and individual empowerment has become broadly embraced and as the expectations of individuals and families to be involved in performance monitoring has occurred. The emphasis on personal outcomes and performance indicators represents a change from professionally dictated, programmatic models of oversight to a more democratic approach to quality that places the experience of the individual at the center of the analysis. A primary purpose of the analysis is to determine the discrepancy between personal outcomes and community-based social indicators (Cummins, Baxter, Colquhoun, & Monteath, 1996; Diener & Suh, 1997; Emerson, 2005; Matikka, 2000; Murrell & Norris, 1983; Schalock & Jensen, 1986; Schneider, 1976; Umb-Carlsson & Sonnander, 2005). As discussed later, one of the primary purposes of QI is to reduce this discrepancy.

Internal Evaluation System

The measurement of personal outcomes, individual support needs, and performance indicators provides the basis for an organization-level *internal evaluation system*. The advantages of such a system are that it: (1) leads to organization learning; (2) enhances the ability to manage program quality and sustain efficiency; (3) provides the basis for a theory of change that becomes the guide whereby the organization structures its daily activities to achieve its strategic goals and objectives; and (4) provides the framework within which each organization can examine what works and what does not work within its own programming and manage performance for continuous improvement (Hunter, 2006; Schuh & Leviton, 2006).

Our observation is that the development of such a monitoring system will take time for many organizations, and that five key factors should guide the process. First, to prevent information overload and to provide meaningful information, the measures used to assess personal outcomes need to meet those eight selection criteria previously mentioned. A related factor is that using more measures does not guarantee better information, and therefore data systems should be parsimonious and conceptually clear. Second, the selection of particular indicators and their measurement depends on their intended use. For example, for application and QI, both subjective and objective indicators can be used; however, there are few demonstrated predictors of subjective outcomes (e.g., satisfaction) and numerous predictors of objective outcomes (Felce & Perry, 2006; Walsh et al., 2006). For research, the indicators should involve objective measures of what one is focusing on (e.g., physical well-being, employment, and social inclusion) and the determination of the predictors

of those outcomes. Third, interviewers need to be competent, and the indicator measures used need to be both reliable and valid. Fourth, the organization assumes responsibility to collect and analyze the data and to use it for QI. Fifth, collecting data, monitoring outcomes, and using that information for QI are viewed as a partnership among all key stakeholders.

SERVICE DELIVERY

Throughout the world, service delivery systems for persons with ID are changing significantly and increasingly focusing on the assessment of personal outcomes and QI (Fantova, 2005a, 2005b; ISO, 2003; MTAS, 2005; Nabaskues, 2003).

This change is occurring within the context of service delivery systems becoming more complex, decentralized, and less formal. According to Schalock et al. (2007), the successful management of this transition from formal, centralized service systems to more individualized and dispersed support systems requires constant attention to—and balancing of—opposing processes, such as (1) delegating authority requires that direct support staff are well trained in the conceptualization, measurement, and application of the QOL concept and empowered to develop and implement individualized support plans; (2) decentralizing authority requires local capability and local autonomy to monitor and evaluate individual and organizational outcomes; (3) offering people choices results in fewer adherences to defined procedures and greater variability of employee performance; (4) integrating the values and content of personal QOL-related outcomes requires management and leadership styles that emphasize managing for results, individualized supports provision, participatory management and research, community leadership, and cultural directorship; and (5) providing the community context for a life of quality requires organizations to redefine their roles as bridges to the community, become brokers of social capital and natural support systems, and increase their collaboration and partnering. Successfully adapting to these requirements necessitates systems thinking beyond the level of the individual or the organization. Indeed, they demonstrate the need of the service delivery system to involve consumers, to provide values training to all stakeholders, to provide individualized supports, and to access social capital.

Consumer Involvement

The essential organizational strategy here involves incorporating consumers in meaningful roles. More specifically, the essential question to ask is, to what degree are consumers involved in the development and implementation of their ISPs, the selection of valued personal outcomes and their assessment, management and leadership roles and decisions, and program planning and change? Consumer empowerment and self-advocacy are not only an essential component of QOL, they underlie the attainment of personal outcomes. Thus, the culture of the organization should support self-advocacy and consumer involvement.

Values Training

Values training is essential not only to the development of positive and proactive mental models across systems levels, but also to the success of movements, such as normalization and mainstreaming (Wolfensberger, 2002). The proposed content and parameters for a systems-wide values training program were previously discussed in reference to the key aspects of mental models (QOL principles, learning organization, and ethics) and will be discussed more fully under "Implementation Guidelines."

Individualized Supports

The development and implementation of individualized supports facilitates the attainment of personal outcomes. There is an emerging consensus that individualized supports are characterized by their being (A. Aznar & D. Castanon, personal correspondence, April 5, 2006): (1) person centered (i.e., based on the person's interests, preferences, needs, and natural support network); (2) responsive (i.e., based on a dialog between the person and those involved in the supports plan); (3) flexible across the life span; (4) proactive (i.e., equalizing opportunities with fellow citizens, empowering the person, generating effective social inclusion, and increasing social/community participation); and (5) based on data (i.e., based on the pattern and intensity of support needs and evaluated in terms of facilitating personal outcomes).

Social Capital

Social capital refers to the connections among individuals, social networks, and the norms of reciprocity and trust. The international literature indicates that social capital has a direct effect on social, economic, and individual development (Gardner & Carran, 2005; Putnam & Feldstein, 2003; Schalock et al., 2007). Social capital is assessed through community partnerships and collaboration. It integrates systems thinking and requires engaging others and learning through knowledge exchange. Many authors (e.g., Hayden & Nelis, 2002; McConkey & O'Toole, 2000) explain how social capital can be accessed through three groups: (1) community volunteers and family members who provide emotional and practical support by acting as advocates, providing community education, and using their social networks and contacts to provide opportunities to join in community events; (2) local resource centers or Web-based information on providers that share information regarding their services, supports, and anticipated outcomes; and (3) self-advocacy groups that foster self-advocacy, empowerment, and involvement.

QUALITY IMPROVEMENT

The approach to QI presented in this section of the article relies heavily on the principles underlying the learning organization (Orthner et al., 2006; Senge, 2006), program logic models (Andrews, 2004; Kaplan & Garrett, 2005; McLaughlin & Jordan,

1999; Renger & Hurley, 2006), and QOL implementation strategies (Keith & Bonham, 2005; Schalock & Bonham, 2003; Schalock & Verdugo, 2002). As a key organization strategy to enhance personal outcomes, QI involves four fundamental processes: leadership, learning teams, evidence-based practices, and self-evaluation.

Leadership

Leadership within the QI framework sets the organization's direction, encourages learning and change, and reinforces efforts and outcomes. In the process, QI-focused leaders demonstrate the following five leadership characteristics: (1) communicate a shared vision that answers the question, "what do we want to create?"; (2) encourage and support the power of personal mastery so that people can grow and develop insight and skills (Senge, 2006); (3) stress a systems perspective that involves action feedback (Richardson, 1990); (4) promote a community life context for quality of life, emphasizing the bridging role of organizations (DeWalle et al., 2005; Schalock et al., 2007; Walsh et al., 2006); and (5) focus on measuring personal outcomes and ensuring the transfer of knowledge throughout an entire organization to examine and understand ways that the organization can achieve these desired outcomes (Orthner & Bownen, 2004; Orthner et al., 2006).

Learning Teams

Learning teams are based on the concept of synergy that is enhanced by being self-directed, setting and focusing on challenging new goals, and thinking insightfully about complex issues (Isaacs, 1999; Lick, 2006). Learning teams foster co-mentoring in the group; utilize learning resources such as research, literature, internal/external expertise, relevant learning models, and professional development; integrate knowledge; create potential solutions; and coordinate actions, apply potential solutions, and assess the results and share the findings from the attempted solutions. These activities require time to produce both first-order change (that involves the establishment of goals and the enactment of solutions) and second-order change (that involves changes in rules and roles that allow innovation and promote change).

Evidence-Based Practices

The essential idea in evidence-based practices is that personal outcomes should be used to guide organizational change and improvement (Gambrell, 1999). One of the advantages to evidence-based practice is that it is consistent with recent advances in theory-driven approaches to evaluation and utilization-focused evaluation. A *theory-driven approach to evaluation* explains how program inputs, processes, and external factors potentially impact outcomes. In addition to helping one understand how programs work, a theory-driven approach also identifies and prioritizes evaluation questions and aligns evaluation methodology to answering those questions (Donaldson & Gooler, 2003; Patton, 1996). *Utilization-focused evaluation* stresses that evaluation should not focus solely on outcomes, but also on the structure and causal entities that produce the

outcomes; learning organizations can use evaluation for programmatic change and improved personal outcomes, and quality indicators/personal outcomes information should be used to modify or change the structures of causal entities (Felce & Perry, 2006; Patton, 1996; Schalock et al., 2007).

In addition, evidence-based practices lead to *right-to-left thinking*, which is characterized by determining desired personal outcomes and then asking, “what needs to be in place within the organization, system, or community for these outcomes to occur?” Evidence-based practices also fulfill the requirements of the reform movement with its focus on outcomes rather than inputs, goals rather than rules and regulations, persons with ID as customers rather than as clients, and decentralized and empowered organizations rather than overly regulated entities (Mawhood, 1997; Nolan, 2001).

Self-Evaluation

The movement toward the development of internal evaluation systems and organization-based QI require thinking beyond external monitoring and evaluation, which has historically been the case, focusing instead on an internal information collection and utilization process that provides the basis for organization development and QI. This evolution requires a joint partnership between organizations and systems-level agents in which personal outcomes are clearly articulated and delineated, such as those shown in Table 1, a standardized method is developed by all stakeholders for their assessment, and an agreed upon plan for their publication and use is implemented (Keith & Bonham, 2005; Schalock et al., 2007).

In summary, these four strategies (leadership, learning teams, evidence-based practices, and self-evaluation) provide the conceptual basis for quality improvement. However, the integral role that personal outcomes and QI play in both organizational strategies and program accountability also necessitates the use of practical and useful *evaluation and reporting standards*. Three useful standards, as noted by Schwartz and Magne (2005), are (1)

product quality (i.e., well-defined scope, systematic [logical and sequential], accurate data, sound analysis, and impartial/objective findings and conclusions); (2) process quality (i.e., involvement of key stakeholders, transparent, and an ongoing part of the provision of services and supports); and (3) usefulness of the information (i.e., timeliness [information is produced at a time when it can make a difference in improving the organization’s performance], the right scope [the information is relevant to the issues of the day], and clarity [the information is understandable by the intended audiences]).

IMPLEMENTATION GUIDELINES

Our experiences suggest that if these four organizational strategies are going to result in enhanced personal outcomes for persons with ID, the following four important implementation guidelines need to be followed.

Systems Thinking

Systems thinking not only provides the framework for seeing interrelationships among the individual, organization, and larger service delivery system (and society), it also allows us to see patterns of interdependency and see into the future. Figure 1 shows these patterns of interrelationships and reflects how the four organizational strategies have parallels at the individual and systems levels. These are discussed further in Schalock and Verdugo (2002), Gardner and Carran (2005), HSRI (2006), and Schalock et al. (2007).

Public Policy Reflects QOL Principles and Desired Personal Outcomes

Public policy needs to be aligned with both QOL principles and the more specific goal of enhanced personal outcomes. The

Implementation Level	Mental Model	Assessment	Service Delivery	Quality Improvement
Individual	Consumer Empowerment Consumer Involvement QOL (Concepts and Components)	Personal Outcomes (QOL Domains and Indicators) Assessment Methods	Consumer Involvement Consumer Equity & Empowerment	Shared Vision Involvement Self-Advocacy
Organization	QOL Principles Learning Organization Ethics	Supports Needs Assessment Performance Indicators Internal Evaluation System	Values Training Individualized Supports Provision Social Capital	Leadership Learning Teams Evidence-Based Practice Self-Evaluation
System	Training & Organization Development Activities (to support above models)	Organization Based Evaluation Manage for Results	Systems Thinking Flexibility and Innovation Incentives to Change	QOL Framework QI Methodology Evaluation-Reporting Standards

FIGURE 1
Multisystem implementation strategies.

following four guidelines can facilitate that alignment: (1) all key stakeholders need to be involved in planning, implementation, and evaluation; (2) a funding mechanism and process needs to be in place that permits individualized supports and community-based alternatives; (3) there needs to be a requirement for systems-wide “managing for results” that includes the measurement of personal outcomes and the use of that information for reporting and QI; and (4) technical and financial supports need to be provided to organizations to implement QOL-related program practices.

Stakeholder “Buy In”

Concerns are frequently expressed about evaluation and organization change due to a history of regulatory and external reviews. To overcome these concerns, one needs to build on the following three stakeholder “buy in” guidelines: (1) *the movement from uncertainty to interest* among stakeholders requires a vision, a hope, and potential answers to how to handle pressing concerns and policy issues; (2) *the movement from interest to commitment* among stakeholders requires a QOL framework, anticipated institutional support, and personal involvement in the process of change; and (3) *the movement from commitment to action* requires understanding specific strategies, seeing the value of change, and developing a sense of personal mastery to affect change.

QI Becomes the Mechanism for Organization Change

QI, which begins with the measurement of personal outcomes and performance indicators, provides the mechanism for organization change. Four implementation guidelines are suggested. First, values training is basic to QI and includes those components summarized under “mental model” in Figure 1. Second, staff training involves frontline managers observing staff and providing feedback regarding what type of life the person with ID is living, how engaged the person is with his/her life, and whether lifelong learning opportunities are being provided. The purpose of this training is to enhance personal mastery and provide the expertise for direct support personnel to be key players in learning teams. Third, organizations need to redefine their roles and functions in terms of being bridges to the community, implementing organization-based evaluation systems, developing partnerships among all stakeholders, and advancing “research/evaluation mentality” rather than a “bureaucratized monitoring mentality.” Fourth, organizations need to have an internal evaluation system that includes measures of personal outcomes, individual support needs, and performance indicators. This information provides the basis for evidence-based practices and QI.

IMPLEMENTATION EXAMPLES

Many organizations and larger service delivery systems are embracing both the concept of QOL and the goal of enhanced personal outcomes. In addition, they are incorporating one or more of the four organizational strategies summarized in Figure 1 related to mental model, assessment, service delivery, and quality improvement. Although brief, the following four

examples reflect both strategies and implementation guidelines. Each example also shows the significant role played by the consumer and the organization/system’s commitment to using the concept of QOL as a change agent.

Mental Models

The FEAPS (Federación de Organizaciones en favor de Personas con Discapacidad Intelectual [Spanish Confederation of Organizations in Favor of Persons with Intellectual Disabilities]) program in Spain reflects the transition to a service delivery model that emphasizes QOL principles, ethics, and quality management as one approach to a learning organization. FEAPS was created in 1964 and includes 17 federations, 793 associated nonprofit entities, and over 2,600 centers and services. The FEAPS Quality Model is based on three components: the concept of quality of life, ethics, and quality management (Etxeberria, 2004; FEAPS, 2001).

FEAPS adheres to the paradigm of ID based on the supports that a people need to improve the conditions of their lives and to achieve their dreams. As a result, a QI plan (including ethical values) was adopted in 1996 based on the eight core QOL domains shown in Table 1. *Good Practice Manuals*, which were developed based on this model, are used in all service components. In addition, FEAPS, in collaboration with Universidad de Salamanca (Institute for Community Inclusion) and Universidad Ramon Llull (Gine, 2004), has promoted a system to assess the impact of an organization’s services on the QOL of people they support, and to provide training and post-graduate training in QOL and QOL-related areas such as self-determination, person-centered planning, and supporting people with dual diagnosis (Tamarit, 2005).

Assessment

The *Ask Me! Project* demonstrates the value of systems thinking and the key role that consumers, organizations, and the larger system (i.e., in the state of Maryland in the USA) play in the collection, interpretation, and use of assessment information (Bonham et al., 2004; Bonham, Basehart, & Marchand, 2005; Schalock & Bonham, 2003). The following example also illustrates how assessment activities are moving away from external monitoring and process assessment to a clear focus on promoting internal assessments systems that include personal outcomes and performance indicators that are used to manage for results and implement QI processes.

The *Ask Me! Project* involves having consumers with developmental disabilities (who have been trained in QOL survey procedures) administer a QOL Survey based on the eight core QOL domains summarized in Table 1. The implementation of the *Ask Me!* survey in 2002 represented the combined efforts of people with disabilities and their advocates, community provider agencies, and the state government to develop consistent and reliable information across agencies for multiple purposes. For example, each community provider agency needed as large a sample as possible to guide its QI efforts. In addition, the interests of state government required an annual scientific sample (sample size was increased each year over a 4-year cycle) of the people it supported

to address its Managing for Results requirements (Maryland Developmental Disabilities Administration, 2004).

Two types of Managing for Results goals were established based on the assessed personal outcomes: (1) at the organization level, maintaining threshold percents of people who report positive QOL in the eight domains; and (2) at the aggregate/state-wide level, increasing the average QOL reported in at least one domain (in this case, personal development). Results to date have generally supported these two goals, with increased efforts expended in those domains not showing improvement at the organization level. Based on the successful systems-wide results and the Project's acceptance, the average QOL scores/personal outcomes have been published for all community agencies (Bonham et al., 2005).

Service Delivery

As organizations redefine their service delivery roles within the context of QOL, it is important for them to understand what we know about the characteristics of successful organizational change. Three such characteristics are that successful organizations (Schalock, 2001; Schalock et al., 2007): use systems thinking, are flexible and innovative, and provide incentives to change. The Arduin Program in the Netherlands reflects these three characteristics and demonstrates the processes and impacts of moving to a QOL and individualized supports approach to services and supports for persons with ID. First established in 1969, Arduin emerged in 1994 as a new organization based on a number of internal evaluations that indicated that they needed to improve both financially and programmatically. It developed an action plan that embodied the principles of inclusion, self-determination, personal development, and individualized supports. Implementing that plan allowed them to transform themselves from an institution to a new community-based organization that currently serves about 600 persons in a wide variety of locations and support systems. People live in normal houses in the community, work full time in a wide variety of businesses or day centers, and are supported by support workers according to their needs. Four specific strategies have guided the transition (DeWalle et al., 2005; Van Loon, 2006; Van Loon & Van Hove, 2001): (1) the program focused on QOL that was defined operationally in terms of the eight core domains listed in Table 1; (2) there was a clear focus on long-term personal outcomes as reflected in personal experiences and circumstances; (3) QI focused on how to structure the organization so that personal outcomes occur; and (4) supports were individualized.

Quality Improvement

Measuring and reporting personal outcomes has been the basis for QI in the State of Nebraska in the USA since 1998, when the Nebraska developmental disabilities system began publishing an annual *Provider Profile* for use by individuals with ID and their families (Nebraska Department of Health and Human Services, 2006). The intent of the Profile is to provide consumers and their families a source for choosing an appropriate developmental disabilities service provider based on the choices expressed by the person and a profile of relevant information on which to base a

decision. All certified developmental disabilities services providers contracting with the state provide the following eight data sets that are updated annually: general agency information, number of persons served, supports/services provided, number of employees, type and amount of annual training provided to the employees, quality enhancement (i.e., QI) activities, quality assurance activities, and aggregated QOL scores for all service/supports recipients. Two sets of QOL scores are published: the average score per QOL domain (see Table 1) for consumers in service and the average score in the same domain areas for persons without disabilities living in the same locale.

CONCLUSION

Friedman (2005), in his 2005 book *The World Is Flat*, suggests that when the world moves from a vertical (command and control) to a horizontal (connect and collaborate) model, it does not just affect how business gets done, it affects everything . . . and that the most common disease of the flat world is a multi-identity disorder. Organizations and systems throughout the world are not only becoming more horizontal and experiencing multi-identity disorders, they are also implementing organizational strategies to enhance personal outcomes. Adapting to these changing realities clearly demands new ways of thinking and operating, and developing new capacities for continual learning, innovation, and adaptation.

Ultimately, two realities will provide the context and motivation for implementing strategies such as those four discussed in this article. The first is that "the organizations that will truly excel in the future will be the organizations that discover how to tap people's commitment and capacity to learn at all levels of the organization" (Senge, 2006, p. 41). The second reality is that as we move from the old to the new way of thinking about persons with ID and doing "their business," the transition will be based less on power and force and more on the mental models we have of persons with ID and the services and supports that will enhance their QOL through the achievement of personal outcomes.

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REFERENCES

- Andrews, A. B. (2004). Start at the end: Empowerment evaluation product planning. *Evaluation and Program Planning, 27*, 275-285.
- Bonham, G. S., Basehart, S., Schalock, R. L., Marchand, C., Kirchner, N., & Rumenap, J. M. (2004). Consumer-based quality of life assessment: The Maryland Ask Me! Project. *Mental Retardation, 42*, 338-355.
- Bonham, G. S., Basehart, S., & Marchand, C. B. (2005). *Ask me! FY 2005: The quality of life of Marylanders with developmental disabilities receiving DDA funded supports*. Annapolis, MD: The Arc of Maryland.

- Bronfenbrenner, U. (1979). *The ecology of human development*. Cambridge, MA: Harvard University Press.
- Brown, I., Keith, K. D., & Schalock, R. L. (2005). Quality of life conceptualization, measurement, and application: Validation of SIRG-QOL consensus principles. *Journal of Intellectual Disabilities Research, 48*, 451.
- Cohen, B. J., & Austin, M. J. (1994). Organizational learning and change in a public welfare agency. *Administration in Social Work, 18*, 1–19.
- Cummins, R. A. (1997). *Comprehensive quality of life scale intellectual/cognitive disabilities manual* (5th ed.). Melbourne, Australia: Deakin University, School of Psychology.
- Cummins, R. A. (2005a). Instruments assessing quality of life: Characteristics and functions. In J. H. Hogg & A. Langa (Eds.), *Approaches to the assessment of adults with intellectual disabilities: Part I: A service provider's guide* (pp. 118–137). Oxford: Blackwell.
- Cummins, R. A. (2005b). Issues in the systematic assessment of quality of life. In J. H. Hogg and A. Langa (Eds.), *Approaches to the assessment of adults with intellectual disabilities: Part II: Assessment instruments: Characteristics and functions* (pp. 9–22). London: Blackwell.
- Cummins, R. A., Baxter, C., Colquhoun, D., & Monteath, C. (1996, August). *Comparing the life quality of people with and without an intellectual disability who are living in the community*. Paper presented at the 10th World Congress of the International Association for the Scientific Study of Intellectual Disability, Helsinki, Finland.
- Dekecki, P. R. (1992). Ethics in mental retardation: Steps toward the ethics of community. In L. Rowitz (Ed.), *Mental retardation in the year 2000* (pp. 39–51). New York: Springer-Verlag.
- Devlieger, J. P., Rusch, F., & Pfeiffer, D. (2003). Rethinking disability as same and different: Towards a cultural model of disability. In J. P. Devlieger, F. Rusch, & D. Pfeiffer (Eds.), *Rethinking disability: The emergence of new definitions, concepts, and communities* (pp. 9–16). Antwerp, Belgium: Garant Publishers.
- DeWalle, 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.
- DeWalle, I., Van Loon, J., Van Hove, G., & Schalock, R. L. (2005). Quality of life vs. quality of care: Implications for people and programs. *Journal of Policy and Practice in Intellectual Disabilities, 2*, 229–239.
- Diener, E., & Suh, E. (1997). Measuring quality of life: Economic, social, and subjective indicators. *Social Indicators Research, 40*, 189–216.
- Donaldson, S. E., & Gooler, L. E. (2003). Theory-driven evaluation and action: Lessons from a \$20 million statewide work and health initiative. *Evaluation and Program Planning, 26*, 355–366.
- Emerson, E. (2005, May). *In defense of objective social indicators*. Paper presented at the Roundtable of the IASSID Quality of Life Special Interest Research Group, Vancouver, Canada.
- Etxeberria, X. (2004). Ética y discapacidad [Ethics and disability]. *Siglo Cero, 35*, 68–79.
- FEAPS. (2001). *Manuales de Buena Práctica* [Manuals of good practices]. Madrid, Spain: FEAPS. Retrieved October 1, 2006, from www.feaps.org/confederacion/calidad_bbpp.htm
- Fantova, F. (2005a). *Manual para la gestión de la intervención social* [Manual for social intervention management]. Madrid, Spain: CCS.
- Fantova, F. (2005b). *Tercer sector e intervención social* [Third sector and social intervention]. Madrid, Spain: PPC.
- Felce, D., & Perry, J. (1996). Assessment of quality of life. In R. L. Schalock (Ed.), *Quality of life, Vol. I: Conceptualization and measurement* (pp. 63–73). Washington, DC: American Association on Mental Retardation.
- Felce, D., & Perry, J. (2006, March). *Living with support in the community: Factors associated with quality of life outcomes*. Paper presented at the VI Internacional Conferencia sobre Discapacidad, “Investigación, Innovación y Cambio,” Salamanca, Spain: INICO, University of Salamanca.
- Friedman, T. L. (2005). *The world is flat*. New York: Farrar, Straus, & Giroux.
- Gambrill, E. (1999). Evidence-based practice: An alternative to authority-based practice. *Families in Society, 80*, 341–350.
- Gardner, H. (1985). *The mind's new science*. New York: Basic Books.
- Gardner, J. F., & Carran, D. (2005). Attainment of personal outcomes by people with developmental disabilities. *Mental Retardation, 43*, 157–174.
- Gine, C. (2004). Servicios y calidad de vida para personas con discapacidad intelectual [Services and quality of life for people with intellectual disabilities]. *Siglo Cero, 35*, 18–28.
- Hartley, S. L., & MacLean, W. E., Jr. (2006). A review of the reliability and validity of Likert-type scales for people with intellectual disability. *Journal of Intellectual Disability Research, 50* (Part 11), 813–827.
- Hayden, M. F., & Nelis, T. (2002). Self-advocacy. In R. L. Schalock, P. C. Baker, & M. D. Croser (Eds.), *Embarking on a new century: Mental retardation at the end of the 20th century* (pp. 221–234). Washington, DC: American Association on Mental Retardation.
- Human Services Research Institute (HSRI). (2006). *National Core Indicators Project*. Retrieved on April 6, 2006 from www.hsri.org/docs/786_p6_consumer_2004_final.pdf
- Hunter, D. (2006). Using a theory of change approach to build organizational strengths, capacity, and sustainability by not-for-profit organizations in the human service sector: Daniel and the rhinoceros. *Evaluation and Program Planning, 29*, 180–185.
- International Organization for Standardization (ISO). (2003). *ISO 9000 quality management: ISO standards compendium*. New York: American Standards Institute.
- Isaacs, W. (1999). *Dialogue and the art of thinking together*. New York: Currency.
- Jenaro, E., Verdugo, M. A., Caballo, C., Balboni, G., Lachapelle, Y., Otrebski, W., et al. (2005). Cross-cultural study of person-centered quality of life domains and indicators: A replication. *Journal of Intellectual Disabilities Research, 49*, 734–739.
- Kaplan, S. A., & Garrett, K. E. (2005). The use of logic models by community-based initiatives. *Evaluation and Program Planning, 28*, 167–172.
- Keith, K. D., & Bonham, G. S. (2005). The use of quality of life data at the organization and systems level. *Journal of Intellectual Disability Research, 49*, 799–805.
- Lick, D. W. (2006). A new perspective on organizational learning: Creating learning teams. *Evaluation and Program Planning, 29*, 88–96.
- Maryland Developmental Disabilities Administration. (2004). *Managing for results*. Annapolis, MD: Author.
- Matikka, L. M. (2000). Comparability of quality of life studies of the general population and people with intellectual disabilities. *Scandinavian Journal of Disability Research, 2*, 83–102.
- Mawhood, C. (1997). Performance measurement in the United Kingdom (1985–1995). In E. Chelmsky & W. R. Shaddish (Eds.), *Evaluation for the 21st century: A handbook* (pp. 134–144). Thousand Oaks, CA: Sage Publishers.
- McConkey, R., & O'Toole, B. (2000). Improving the quality of life of people with disabilities in least affluent countries: Insights from Guyana. In K. R. Keith & R. L. Schalock (Eds.), *Cross-cultural perspectives on quality of life* (pp. 281–289). Washington, DC: American Association on Mental Retardation.
- McLaughlin, J. A., & Jordan, G. B. (1999). Logic models: A tool for telling your program's performance story. *Evaluation and Program Planning, 22*, 65–72.
- MTAS (Ministerio de Trabajo y Asuntos Sociales). (2005). *Anteproyecto de ley de promoción de la autonomía personal y atención a las personas en situación de dependencia* [Preliminary plan of the law of promotion of personal autonomy and attention to people in dependency situations]. Madrid, Spain: Author.

- Murrell, S. A., & Norris, F. H. (1983). Quality of life as a criterion for need assessment and community psychology. *Journal of Community Psychology, 11*, 88–97.
- Nabaskues, I. (2003). *Globalización y nueva políticas local* [Globalization and new local politics]. Victoria-Gasteiz, Spain: IVAP.
- Nebraska Department of Health and Human Services. (2006). *2006 Nebraska developmental disabilities provider profiles*. Lincoln, NE: Author.
- Nolan, B. C. (2001). *Public sector reform: An international perspective*. New York: Palgrave Publishers.
- Orthner, D. K., & Bownen, G. L. (2004). Strengthening practice through results management. In A. R. Roberts & K. Yaeger (Eds.), *Handbook of practice based research* (pp. 897–904). New York: Oxford University Press.
- Orthner, D. K., Cook, P., Sabah, Y., & Rosenfeld, J. (2006). Organization learning: A cross-national pilot test of effectiveness in children's services. *Evaluation and Program Planning, 29*, 7–78.
- Patton, M. Q. (1996). *Utilization-focused evaluation*. Thousand Oaks, CA: Sage Publications.
- Putnam, R. D., & Feldstein, L. M. (2003). *Better together: Restoring the American community*. New York: Simon & Schuster.
- Reinders, H. (1999). The ethics of normalization. *Cambridge Quarterly of Health Care Ethics, 6*, 481–489.
- Renger, R., & Hurley, C. (2006). From theory to practice: Lessons learned in the application of the ATM approach to developing logic models. *Evaluation and Program Planning, 29*, 106–119.
- Renwick, R., Brown, I., & Raphael, D. (2000). Person-centered quality of life: Contribution from Canada to an international understanding. In K. D. Keith & R. L. Schalock (Eds.), *Cross-cultural perspectives on quality of life* (pp. 5–22). Washington, DC: American Association on Mental Retardation.
- Richardson, G. (1990). *Feedback in social science and systems theory*. Philadelphia: University of Pennsylvania Press.
- Schalock, R. L. (2001). *Outcomes-based evaluation* (2nd ed.). New York: Kluwer Academic/Plenum Publishers.
- Schalock, R. L. (2004). The emerging disability paradigm and its implications for policy and practice. *Journal of Disability Policy Studies, 14*, 204–215.
- Schalock, R. L. (2005). Introduction and overview to the special issue on quality of life. *Journal of Intellectual Disability Research, 49*, 695–698.
- 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. 261–279). West Essex, UK: John Wiley and Sons, Ltd.
- Schalock, R. L., Gardner, J. F., & Bradley, V. J. (2007). *Quality of life of persons with intellectual and other developmental disabilities: Applications across individuals, organizations, systems, and communities*. Washington, DC: American Association on Intellectual and Developmental Disabilities.
- Schalock, R. L., & Jensen, M. (1986). Assessing the goodness-of-fit between persons and their environments. *Journal of the Association for Persons with Severe Handicaps, 11*, 103–109.
- Schalock, R. L., & Luckasson, R. (2005). *Clinical judgment*. Washington, DC: American Association on Mental Retardation.
- Schalock, R. L., & Verdugo, M. A. (2002). *Handbook on quality of life for human service practitioners*. Washington, DC: American Association on Mental Retardation.
- Schalock, R. L., Verdugo, M. A., Jenaro, C., Wang, M., Wehmeyer, M., Xu, J., et al. (2005). Cross-cultural study of quality of life indicators. *American Journal on Mental Retardation, 110*, 298–311.
- Schneider, M. (1976). The “quality of life” and social indicators research. *Public Administration Review, 15*, 297–305.
- Schuh, R. G., & Leviton, L. C. (2006). A framework to assess the development and capacity of non-profit agencies. *Evaluation and Program Planning, 29*, 171–179.
- Schwartz, R., & Magne, J. (2005). Assuring the finality of evaluation information: Theory and practice. *Evaluation and Program Planning, 28*, 1–14.
- Senge, P. M. (1990). *The fifth discipline*. New York: Doubleday.
- Senge, P. M. (2006). *The fifth discipline: The art and practice of the learning organization* (Rev. ed.). New York: Doubleday.
- Spector, J. M., & Davidsen, P. I. (2006). How can organizational learning be modeled and measured? *Evaluation and Program Planning, 29*, 63–69.
- Tamarit, J. (2005). Hacia un sistema de evaluación de la calidad en FEAPS [Towards a quality evaluation system in FEAPS]. *Intervención Psicosocial, 14*, 295–308.
- Thompson, J. T., Bryant, B. R., Campbell, E. M., Craig, E. M., Hughes, C. M., Rotholz, D. A., et al. (2004). *Supports Intensity Scale Manual*. Washington, DC: American Association on Mental Retardation.
- Umb-Carlsson, O., & Sonnander, K. (2005). Comparison of the living conditions of adults with intellectual disabilities in a Swedish county and in the general population. *Journal of Policy and Practice in Intellectual Disabilities, 2*, 240–248.
- Van Loon, J. H. M. (2006). *Arduin: Emancipation and self-determination of people with intellectual disabilities: Dismantling institutional care*. Leuven-Apeldoorn, the Netherlands: Garant.
- Van Loon, J. H. M., & Van Hove, G. (2001). Emancipation and self-determination of people with intellectual disabilities and downsizing institutional care. *Disability and Society, 16*, 233–254.
- Verdugo, M. A., Schalock, R. L., Keith, K. D., & Stancliffe, R. J. (2005). Quality of life and its measurement: Important principles and guidelines. *Journal of Intellectual Disability Research, 49*, 707–717.
- Verdugo, M. A., Gomez, L., Arias, B., & Martin, J. C. (2006, May). *Validation of the eight domain model of quality of life*. Paper presented at the symposium on “Quality of life outcomes: Their empirical development, verification, and use,” at the International Summit on Social Inclusion. Montréal, Canada.
- Walsh, P. N., Emerson, E., Bradley, V. J., Schalock, R. L., Hatton C., & Moseley C. (2006). *The outcomes and costs of supported accommodation for people with intellectual disabilities*. Dublin, Ireland: National Disability Authority.
- Wolfensberger, W. (2002). Why Nebraska? In R. L. Schalock (Ed.), *Out of darkness and into the light: Nebraska's experience with mental retardation* (pp. 23–52). Washington, DC: American Association on Mental Retardation.