A Review of Current Trends in Quality Assurance of Services Provided to Persons with Developmental Disabilities

Prepared by
Gary L. Siegel, Ph.D.

**Institute of Applied Research
St. Louis, Missouri**

July 2000

Context for the Focus on Quality

There is a significant movement to improve the quality of services for persons with developmental disabilities that has reached into most corners of this country. The movement has been shaped by three primary factors.

The first originates in the transition in the service system that has become community-based through a process of steady deinstitutionalization. For a time, standards and methods that were developed to measure the quality of care in institutions were simply transferred to community settings. However, in the last few years, as the proportion of residential services recipients has dropped nationally to under 30 percent (Braddock et al., 1998), this practice has faded. The institution is no longer the point of comparison for evaluating services. Quality is no longer defined in terms of what was wrong with institutions. The operating assumptions today are that community living, freedom from abuse and neglect, education for self-development, privacy rights, personal safety, etc., are required characteristics of the service system, not indications of its quality.

The second factor that has sharpened the focus on quality arises from the increased emphasis that has been placed in recent years on consumer-centeredness. While this can be seen as having an internal derivation within the field of developmental disabilities—emphasis on the importance of individualized services and person-centered planning has been promoted by leading voices within the field for more than 10 years—it has been reinforced by features of the broader social environment in more recent years. Leaders within American business and government have increasingly come to recognize consumer-centeredness as a characteristic of effective organizations. Quality has come to be recognized within the economic and political institutions as resulting from efforts to be responsive to what consumers want. This can be clearly seen in The Malcolm Baldrige Award which honors American businesses that display excellence in quality management (see George, 1992). Customer focus and customer satisfaction is one of the core indicators of quality. Quality is to be judged by customers. All product and service characteristics that contribute value to customers and lead to customer satisfaction and preference are to be key foci of a company's management system. Customer-driven quality is thus a strategic concept. It is directed toward customer retention and market share gain. It demands constant sensitivity to emerging customer and market requirements, and measurement of the factors that drive customer satisfactions and retention.

The cultural shift represented in the Malcolm Baldrige Award has turned what had been an ideal within the developmental disabilities field into an operating assumption

about good practice (see, for example, Agosta & Kimmich, 1997; Smull, 1995; DiLeo and Morton, 1993; Racino, 1992; Mount, 1992; Lovett and O'Brien, 1992; and Smull and Harrison).

In 1993, at a conference addressing quality of services available to persons with developmental disabilities, Clarence Sundram, Chairman of the New York State Commission on Quality of Care for the Mentally Retarded, commenting on an approach that was quickly fading into the past, observed: "In fact, since the people being served had little choice about where they were going to receive services, what services they were going to receive or how good or bad they were, their concerns were largely irrelevant."[1] Today, there is a new consumerism that characterizes the field.

The third factor that is shaping the current focus on quality in the field of developmental disabilities is the increasing identification of quality services with the quality of life of the consumer. As is the case with consumer-centeredness, this is reflective of a more general trend in the broader culture. Throughout the developed world there has been a strong and growing interest in re-examining and determining personal values, to understand to a greater depth what is fulfilling to individuals in their lives, and to base both the activities of life and whole lifestyles on personal values and understandings. Correspondingly, quality of life issues have become an area of primary focus in the field of developmental disabilities (See, for example: Brown, 1997; Brown, Bayer, and Brown, 1992; Goode, 1994; and Schalock, 1990, 1996, 1997). The quality of life of participants has become an increasingly dominant theme in the planning and evaluation of services (Dennis et al., 1993; Lakin, 1993), and it has become an important independent variable in the examination of program outcomes (Halpern, 1993). Robert Schalock has been particularly instrumental in tying quality assurance and quality of life together in practice.[2] He sees a paradigm shift in progress that directly impacts quality assurance activities, a shift that involves not only consumer empowerment but equity.

The link between quality of life and quality assurance is evident in a new initiative to improve services for persons with developmental disabilities in the Canadian province of Ontario (see Brown, Raphael, & Renwick, 1999). The province's "Quality of Life Project" essentially represents an effort to establish a quality assessment system. The project has established four guiding principles in quality of life assessment:

1. Quality of life for people with developmental disabilities consists of the same aspects of life as for all other people.
2. Quality of life is based on common aspects of life for all humans, but it also reflects, from person to person, varying degrees of importance placed on those aspects of life.

3. Quality of life for all people reflects how satisfied they are with aspects of life that are important to them.
4. People live in environments. Thus, quality of life results from the interconnection between people and the environments in which they live.

Quality Assurance

Important resources on the development of current thinking about quality assurance in the field of developmental disabilities include: Bradley & Bersani (1990); Brodsky & Wilson (1992); Lakin, Larson & Prouty (1994); Polister, Blake, Prouty & Lakin (1998); and The President's Committee on Mental Retardation (PCMR, 1999). The PCMR has recently issued a publication that addresses quality assurance. In it, the committee discusses the changing definition of quality, with a de-emphasis on compliance and process issues and an increased focus on how programs affect the lives of the people they serve. The PCMR notes that:

- Quality is increasingly being measured by the achievement of personal outcomes which are important to the individual.
- Emerging quality assurance programs are beginning to emphasize providing the highest possible quality of life. This new way of looking at quality considers what the person wants and needs holistically and it recognizes that the measures of quality of life are the same for people with disabilities as they are for everyone else.
- Emphasis is being placed on providers "owning" their own internal quality improvement programs rather than having the definition and reinforcement of quality being imposed by the outside. Service providers are beginning to develop or adapt their own standards, monitor their own progress, and develop mechanisms for continuing quality improvement.

Part of the problem with moving from a compliance-based to a value-based system is that quality becomes more amorphous and more complex. The PCMR notes that quality is a continual evolution with no definite end and something to which service providers and service systems should have the endurance and ability to keep working toward perpetually.

Systems, Methods and Activities

Many states are in the process of formulating or reformulating quality assurance systems for the provision of services to persons with developmental disabilities. These systems tend to be characterized by an increased emphasis on quality of life and consumer-centeredness and a decreasing emphasis on process compliance and prescriptive rules and standards. The new systems are likely to involve more contact with individuals who receive services, and they tend to focus more on consumers, their satisfaction and choices, than on the provider agency. Other emerging trends include increased decentralization of quality assurance activities, tying quality assurance reforms to managed care and using cross-disability quality indicators.

New efforts to impact quality may involve the introduction of comprehensive, state systems or local initiatives with a set of service providers. The focus may be placed on monitoring or tracking systems, technical assistance, the use of volunteers, the increased involvement of families and other stakeholders, professional training and development, consumer monitoring, the sharing of best practices, better networking, or finding new ways to achieve a greater degree of self-determination for consumers. A key source of information on new quality assurance initiatives is the Reinventing Quality project of the University of Minnesota (see Polister, Blake, Prouty, and Lakin). The following is a summary of some of quality assurance systems, methods and activities that deserve attention.

Statewide Systems of Individualized Planning and/or Tracking. A number of states have introduced new statewide information and evaluation systems in an effort to impact quality of services. The Massachusetts Department of Mental Retardation, for example, restructured its certification process in the mid-1990's with the introduction of the Quality Enhancement Survey Tool (QUEST).[3] QUEST is used to measure the impact of services on the quality of life of consumers of both residential and day programs, including employment. Each year a sample of individuals served by each provider participates in a survey of six quality of life areas—rights and dignity, individual control, community membership, relationships, personal growth and accomplishments, and personal well-being. A seventh area defines outcome measures for organizations.

The Colorado Progress Assessment Review (COPAR)[4] is a system for the longitudinal evaluation of quality. Structured and unstructured questions are asked of a sample of service recipients or proxies and service providers to determine program and service outcomes. Questions are asked before and after participation in new service initiatives to determine whether they have improved the lives of the persons served. To

assist the development of COPAR, the state contracted with Allen Shea and Associates to examine state-of-the-art and best practices in quality assurance instruments utilized throughout the country. The review is available as part of the Measurement Tool survey's Final Report. (See: http://www.allenshea.com//colorado.html)

Oregon has developed what it calls a System of Continuous Quality Improvement[5] that has been utilized in a number of other locations across the county. The system consists of a set of information gathering tools including: survey forms to assess family satisfaction with residential and vocational programs; consumer interview protocols to assess satisfaction with residential and vocational programs; surveys to assess satisfaction of service staff; and observation protocols to be used by "Advocates Involved in Monitoring (AIM). A profile of Oregon's System of Continuous Quality Improvement can be found in Brodsky and Wilson (1992). This book also describes the application of total quality management approaches to small programs for persons with developmental disabilities. It presents a seven-step system for developing and implementing an improvement plan.

California has developed a process called the Life Quality Assessment (LQA)[6] meant to ensure that people with developmental disabilities have an active role in assessing their quality of life and satisfaction with services and supports. An individualized planning process is based on 25 life quality outcomes in the areas of choice, relationships, lifestyle, health and well-being, rights, and satisfaction. (The entire list of 25 outcomes is attached as an example of common outcomes that drive new quality assurance systems.) There is a considerable amount of information about California's Quality Assurance system available on the Internet, including at the Department of Developmental Services site (see for example: http://www.dds.cahwnet.gov/QA/main/qa001.cfm) and at the website of Allen Shea and Associates (see for example: http://www.allenshea.com//change.html).

In New York state, a quality improvement project called COMPASS[7] has been piloted. COMPASS is intended to promote improvement and an innovative approach to agency management, planning and service delivery. It comprises four elements: consumerism, outcomes, management plan, and agency self-survey.

Vermont[8] has begun using a database tracking system that focuses on individual health, safety, rights and quality of life and consumer choice. The system can track a single goal longitudinally for one consumer, a provider agency or the entire state system.

Top-Down Efforts. While planning and information systems address quality primarily from the perspective of individual consumers, some states have also tried to impact quality through administrative oversight and the establishment of standards. New York state, for example, has had an independent Commission on Quality of Care for the

Mentally Disabled[9] for some time. The commission's job is to be a proactive oversight body that investigates and initiates systems changes.

In an effort to assure quality in community services, Alaska has established nine service principles to guide service delivery.[10] The first principle is that individuals are to be actively involved in and determine the design and implementation of their service plan. Another is that services are to promote natural and community supports. Another feature of the Alaska system is that state payment for services is tied to consumer satisfaction: If the consumer is not satisfied, funding is not released and the state looks into what can be done to satisfy the consumer. Iowa and Maryland are two other states that have implemented outcomes-based performance standards that include areas of consumer empowerment and choice.[11]

A number of states are exploring adapting managed care strategies to reconfigure funding and service delivery. To do this requires reliable performance outcome measures for monitoring and evaluating performance.   A multi-state project was begun in 1997 conducted jointly by the National Association of State Directors of Developmental Disabilities Services and the Human Services Research Institute (Cambridge).[12] The goal is to identify and test a core set of indicators that can serve as the foundation for assessing how well a state's public developmental disabilities system is performing.

Another way states have impacted service quality is through programs of training and professional development for community-based staff and by providing technical assistance to community agencies. North Dakota, for example, has set up a program of professional development through Minot State University that involves certificate, undergraduate and graduate components. Ohio uses a training program called "Universal Enhancement" to improve the skills of community-based provider staffs and emphasizes quality of life areas. The Kansas UAP has developed a professional training program for community agencies that employs a train-the-trainer model. The Minnesota Governor's Planning Council and the University of Minnesota's Institute on Community Integration have develop a Statewide Direct Service Training Initiative for direct service and paraprofessionals in community agencies that is provided through more than 26 technical colleges across the state. The Illinois Planning Council has developed a training program to equip community-based workers with skills necessary to develop relationships with businesses and employers to promote supported employment programs. A project of long-standing is North Carolina's Developmental Disabilities Training Institute that is the source of staff training and technical assistance to provider agencies in local communities. Finally, Best Practices[13] is a project in southern Arizona that provides opportunities for an exchange of innovative and exemplary ideas among provider agencies as well as families.

Consumer and Family Monitoring. Monitoring systems have been put in place in some locations involving volunteers, often consumers and families. In Oklahoma, for example, there is a program called OK AIM[14] (that utilizes the model developed in Oregon). Teams of volunteers composed of consumers, family members, friends and advocates visit provider agencies to evaluate services and suggest improvements, and to assist consumers in choosing between services and providers. Nebraska has established Quality Review Teams[15] composed of a person with a developmental disability and at least one other person without a disability that visit persons living in group homes and other residential settings. In Philadelphia similar teams visit former residents of congregate living facilities who are in community placements and assess their satisfaction and life quality. In Maryland, a volunteer organization called Community Monitoring[16] operates four programs with the assistance of family members, provider staff, consumers, professionals, and advocates in service monitoring. The main focuses of Community Monitoring are 1) improving the quality of life of residential services recipients, 2) establishing inter-personal relations among persons with disabilities and other members of the community, 3) providing support to families, and 4) facilitating life planning.

Family and Consumer Focused Projects. There are a number of state and regional projects that have tried to impact quality of services by focusing directly on families. Voucher programs are one example. In Minnesota, Dakota County has implemented a program designed to test the feasibility of supporting the efforts of families to maintain children and adults with disabilities in their own homes by allowing them to make their own provider selections and arrangements.[17] A second Minnesota project is the Parent Case Management Program[18] that seeks to enable persons with disabilities and parents and guardians to participate more fully in the management of supports and services. A corollary to this is a program for people of color which tries to be a culturally sensitive instrument for empowering families from divergent cultures. A third Minnesota initiative is Partners in Policymaking[19] which is designed to educate participants about best practices over a broad set of issues, build leadership skills, and develop the ability to influence public policy at all levels of government.

Other family and consumer focused projects include: the Partnership Fund in Georgia that funds advocates and consumers to participate in educational and advocacy training events; The Neighborhood Living Project in Oregon that focuses on consumers in community-based residential settings; and the Family Support Network, an education and information service in Massachusetts.[20]

Self-Determination Projects. The Robert Wood Johnson Foundation has funded an initiative to facilitate the transformation of service delivery systems into self-determination support systems. The grants are made to states which in turn sub-contract

with community-based organizations. The goal is bottom-up change in which consumers and their "circles of support" transform service systems by the priorities they set and the self-directed options they choose.

Hawaii[21] is one of the states to receive a grant and the system it is trying to implement is typical in its attempt to incorporate the values underlying the initiative. Hawaii's system these six parts:

1. Person-centered planning—in which individuals identify where they would like to take their lives and how they will utilize available resources (community, state, family, friends, etc.) in the most efficient way.

2. Participant management—in which individuals are the decision makers for determining how their budgeted funds will be spent.

3. Support broker—a guide and advocate working on behalf of the participant, helping him or her to develop lifestyle plans and teaching and/or providing them with skills for allocating resources so that their goals are achieved.

4. Pooling of existing resources—in which federal and state resources are consolidated and managed by a community support organization.

5. Restructuring rules and procedures—the state and providers seek to facilitate service acquisition rather than defining what services ought to be provided

6. A quality assurance system tracks outcomes and satisfaction of consumers.

The projects being undertaken with Robert Wood Johnson Foundation grants, of which there are about 20 currently, each have certain unique aspects. Arizona is utilizing peer monitors, trained volunteer mentors who will act as "buddies" to individuals with developmental disabilities and their families. In Iowa, county teams have been formed to facilitate implementation and overcome barriers. Maryland hopes to utilize the project to balance more effectively the needs and desires of consumers already receiving services with those waiting for services . Massachusetts is helping providers convert from contract-based agencies to choice-based businesses. Massachusetts is also working with families in cultural minority groups that are considered to have been historically disenfranchised from the rest of the support system. Michigan is utilizing a performance indicator system that it developed as part of its move to a managed care approach to services. In a number of states—such as Connecticut, Oregon, and Minnesota—persons with disabilities and their support group of family and friends are being given training and technical assistance.

Washington[22] illustrated the changes it sees happening as it moves from a service provider driven system to one driven by individuals and their families in the following schema:

Service Provider Driven System	→	Individual & Family Driven System
- contracts for slots	→	- individual resource allocations to people
- quality focus on programs	→	- focus on customer satisfaction
- technical assistance to service providers	→	- support for individual/family decisions
- programs meet people's needs	→	- real lives in neighborhoods/communities
- decisions by providers/case managers	→	- decisions by individuals/families

System Design Issues

Designing and implementing a quality assurance system that meets emerging values is a complicated task. According to Bradley, writing in 1990, it involves:

- Designing a quality assurance system that protects the well-being of people with mental retardation but that is not intrusive into people's homes and job sites.
- Ensuring that people with disabilities are involved in the process of setting standards and monitoring programs.
- Developing a quality assurance system that is capable of assessing a constellation of specialized and generic services rather than discrete facilities and programs.
- Assessing whether or not people are receiving services that are truly meeting their needs.

More recently, the President's Committee on Mental Retardation (1999) has expanded this list of challenges to include:

- The need to protect people with disabilities while simultaneously allowing them to exercise a full range of choices and self-determination.
- Developing consensus on what makes good service practices while maintaining flexibility, individualization, and continued innovation.
- Developing a system that can encourage and support the improvement of services while convincing those who provide services that consumer well-being will be strictly defended.
- Creating a quality assurance system that changes to meet the needs of the time while granting providers some stability and predictability.
- Balancing the need for providers monitoring the quality of their own services with the need for an outside disinterested monitoring system.

At a more practical level, the PCMR suggests that some things that quality assurance systems can measure are the following:

- *Inputs.* Inputs may be such things as the number of staff provided, or the number of hours of staff training. Traditional quality assurance is heavily concerned with inputs.

- *Process.* Traditional quality assurance also monitors compliance with regulations that prescribe exactly how a service is to be delivered. Some examples are: required daily logging of consumer's activities and moods or cleaning the kitchen counters with bleach solution twice a day.

- *Impact.* Impact refers to the effect on the greater society. An example might be the effect on the community through supported employment in terms of contributing diversity to the work force, supplying hard-to-find labor, and providing stable, long-term employees.

- *Reactions of participants.* This might refer to their satisfaction with the program, staff, home, etc., or what they liked most or least about the services.

- *Organizational effectiveness.* Quality measurement can also relate to the activities of an organization in such areas as having a mission, appropriate policies, sufficient human resources, and fiscal responsibility.

- *Data profiles created by Management Information Systems.* These are computer-based systems intended to provide an ongoing data base to improve the quality of organizational or system-wide decision making.

- *Quality of life.* The concept of quality of life is rapidly becoming the assumed desired result of good services. Quality of life is difficult to define for others. Yet it is what most outcome models of quality assurance try to look at.

- *Outcomes.* Outcomes are the basis of most new quality assurance programs. "Outcomes" is a vague term with multiple meanings. It is currently trendy and often misused. An outcome is the "result, consequence, aftermath." In the context of services and supports for people with developmental disabilities, it has been defined as changes in adaptive behavior(s) and role status that are logical consequences of the (re)habitation service(s) (Schalock, 1995), or the way in which the program influenced the participants and the community.

Outcomes used in the quality assurance system adopted in California (Life Quality Assessment) that was discussed above are listed on the following page.

Valued Life Quality Outcomes
for Californians with Developmental Disabilities
Tracked in the Life Quality Assurance System

Choice
1. Individuals identify their needs, wants, likes and dislikes.
2. Individuals make major life decisions.
3. Individuals make decisions regarding everyday matters.
4. Individuals have a major role in choosing the providers of their services and supports.
5. Individuals' supports and services change as wants, needs, and preferences change.

Relationships
6. Individuals have friends and caring relationships.
7. Individuals build community supports which may include family, friends, service providers/professionals, and other community members.

Lifestyle
8. Individuals are part of the mainstream of community life and live, work, and play in integrated environments.
9. Individuals' lifestyles reflect their cultural preferences.
10. Individuals are independent and productive.
11. Individuals have stable living arrangements.
12. Individuals are comfortable where they live.
13. Children live in homes with families.

Health and Well-Being
14. Individuals are safe.
15. Individuals have the best possible health.
16. Individuals know what to do in the event of threats to health, safety and well-being.
17. Individuals have access to needed health care.

Rights
18. Individuals exercise rights and responsibilities.
19. Individuals are free from abuse, neglect and exploitation.
20. Individuals are treated with dignity and respect.
21. Individuals receive appropriate generic services and supports.
22. Individuals have advocates and/or access to advocacy services.

Satisfaction
23. Individuals achieve personal goals.
24. Individuals are satisfied with services and supports.
25. Individuals are satisfied with their lives.

References

Agosta, J., & Kimmich, M. (1997). Managing Our Own Supports: A Primer on Participant-Driven Managed Supports. Alexandria, VA: The Center for Managed Long Term Supports for People with Disabilities.

Bersani (Eds.), Quality assurance for individuals with developmental disabilities: It's everybody's business. (137-146). Baltimore, MD: Paul H. Brookes Publishing.

Bradley, V.J. (1990). "Conceptual issues in quality assurance". In V.J. Bradley & H.A. Bersani (Eds.), Quality assurance for individuals with developmental disabilities: It's everybody's business. (137-146). Baltimore, MD: Paul H. Brookes Publishing.

Bradley, V.J., & Bersani, H.. (Eds). (1990). *Quality Assurance For Individuals With Developmental Disabilities: It's Everybody's Business*. Baltimore, MD: Paul H. Brookes Publishing.

Braddock, D, Hemp, R., Parish, S., & Westrich, J. (1998). Fifth Edition. *The State of the States in Developmental Disabilities*. Washington, D.C.: American Association on Mental Retardation.

Brodsky, M., & Wilson, D. (1992). *Continuous Quality Improvement in Oregon's Programs for People with Developmental Disabilities*. Salem, OR: Paradigm Systems.

Brown, R. 1. (Ed.) (1997). *Quality of life for people with disabilities: Models, research and practice*. Cheltenham, United Kingdom: Stanley Thornes (Publishers) Ltd.

Brown, I, Raphael, D. & Renwick, R. (1999) *Quality of life and life changes for adults with developmental disabilities in Ontario.* Toronto, Canada: Centre for Health Promotion.

Brown, R. L, Bayer, M. B., & Brown, P. M. (Eds.) (1992). *Empowerment and developmental handicaps: Choices and quality of life.* Toronto, Canada: Captus University Publications.

Dennis, R. et al. 1993. "Quality of Life as Context for Planning and Evaluation of Services for People with Disabilities." Exceptional Children, 59,6:499-513.

DiLeo, D. and Morton, M. 1993. *Customer-Driven Services and Self Advocacy and Empowerment*. Infolines, TRN, St. Augustine.

Goode, D. (Ed.) (1994). *Quality of life for persons with disabilities: International perspectives and issues.* Cambridge, MA: Brookline Press.

George, Stephen (1992). *The Baldrige system: The do-it-yourself way to transform your business.* New York: Wiley & Sons.

Halpern, A. 1993. "Quality of Life as a Conceptual Framework for Evaluating Transition." Exceptional Children, 59,6:486-499.

Lakin, C. ed. 1993. Quality Assurance for Persons with Developmental Disabilities. Research and Training Center on Residential Services, Minneapolis.

Lakin, K. C., Larson, S. A., & Prouty, R. (1994). Assessment and enhancement of quality services for persons with mental retardation and other developmental disabilities. In M. F. Hayden & B. H. Abery (Eds.), *Challenges for a service system in transition: Ensuring quality community experiences for persons with developmental disabilities* (pp. 207-230). Baltimore: Paul H. Brookes Publishing.

Lovett, H. and O'Brien, J. 1992. *Finding a Way Toward Everyday Lives: the Contribution of Person Centered Planning*. Pennsylvania Office of Mental Retardation, Harrisburg.

Mount, B. 1992. *Person-Centered Planning: Finding Directions for Change Using Personal Futures Planning*, Graphic Futures, New York.

Polister, B. H., Blake, E. M., Prouty, R. W., & Lakin, K.C. (1998). *Reinventing quality – The 1998 sourcebook of innovative programs for quality assurance and service improvement in community settings*. Minneapolis: Research and Training Center on Residential Services and Community Living, Institute on Community Integration, University of Minnesota.

President's Committee on Mental Retardation (1999). *Changing Systems-Booklet #5.* Administration for Children and Families, Hubert H. Humphrey Building, Rm. 352-G, 200 Independence Avenue, S.W., Washington, D.C. 20201.

Racino, J. 1992. *"People Want the Same Things We All Do." The Story of the Area Agency in Dover, New Hampshire*. New York Center on Human Policy, Syracuse.

Schalock, R. L. (Ed.) (1990). *Quality of life: Perspectives and issues*. Washington, DC: American Association on Mental Retardation.

Schalock, R.L. (1995). *Outcome-Based Evaluation.* New York, NY: Plenum Press.

Schalock, R. L. (Ed.) (1996). *Quality of Life in Health Promotion and Rehabilitation.* Chapter 9. Quality of Life and Quality Assurance. Sage Publications.

Schalock, R. L. (Ed.) (1996). *Quality of life, volume I. Conceptualization and measurement*. Washington, DC: American Association on Mental Retardation.

Schalock, R. L. (Ed.) (1997). *Quality of life, volume II.Application to persons with disabilities*. Washington, DC: American Association on Mental Retardation.

Smith, G., & Ashbaugh, J. (1995). Managed Care and People With Developmental Disabilities: A Guidebook. Alexandria, VA: National Association of State Directors of Developmental Disabilities Services, Inc.

Smull, Michael W. (1995). Revisiting Choice (from AAMR's News and Notes). Support Development Associates. Kensington, MD. Available at www.allenshea.com/choice.html.

Smull, Michael W., and Harrison, Susan B. Person Centered Planning and Perversion Prevention. Support Development Associates. Kensington, MD. Avaliable at www.allenshea.com/choice.html.

Sundram, C. (1994). Quality assurance in an era of consumer empowerment and choice. *Mental Retardation,* 32 (5), 371-373.

End Notes

[1] Sundram's views can be found in a 1994 paper in the journal *Mental Retardaion* (32 (5), 371-373) entitled "Quality assurance in an era of consumer empowerment and choice." In it he discussed many of the challenges to assuring quality for people with developmental disabilities and described the key element as the ability to make choices.

[2] See Chapter 9 Quality of Life and Quality Assurance in his book *Quality of Life in Health Promotion and Rehabilitation.*

[3] Massachusetts Department of Mental Retardation, 160 North Washington Street, Boston, MA 02114. June Rowe is the Director of Survey and Certification.

[4] Colorado Developmental Disabilities Services, 3824 West Princeton Circle, Denver, C) 80236. Ruth Brown is Section Chief of Program Evaluation and Information Services.

[5] Cf. Paradigm Systems (the contractor that developed the materials), P.O. Box 967, Salem, OR 97308. Contact: Darla Wilson (503/363-8609).

[6] Training and Quality Assurance Section, Department of Developmental Services, 1600 Ninth Street, Room 320, Sacramento, CA 95814. Contact: Anne Smith.

[7] Quality Assurance, State of New York Office of Mental Retardation and Developmental Disabilities, 44 Holland Avenue, Albany, NY 12229. Jan Abelseth, Deputy Commissioner.

[8] Vermonth Department of Developmental and Mental Health Services, 103 South Main Street, Waterbury, VT 05671. Theresa Wood is Chief of Medicaid Services and Program Evaluation.

[9] New York State Commission on Quality of Care for the Mentally Disabled, 99 Washington Avenue, Suite 1002, Albany, NY 12210. Gary O'Brien is Chairman.

[10] Alaska Division of Mental Health and Developmental Disabilities, P.O. Box 110620, Juneau, AK 99811. Derrill Johnson, Program Administrator.

[11] Cf. The Council on Quality and Leadership in Supports for People with Disabilities, 100 West Road, Suite 406, Towson, MD 212204. James Gardner, Chief Executive Officer.

[12] Cf. Human Services Research Institute, 2336 Massachusetts Avenue, Cambridge, MA 02140. Valerie Bradley and John Ashbaugh are Co-Directors. And see Smith & Ashbaugh (1995).

[13] Contact: Cathy Sweeney, Division of Developmental Disabilities, Quality Advocacy Unit, P.O. Box 13178, Tucson, AZ 85732.

[14] Quality Assurance Unit, Developmental Disabilities Services Division, P.O. Box 25352, Oklahoma City, OK 73125. Dennis Bean, Programs Administrator.

[15] Contact: Cathy Anderson, Director, Nebraska Developmental Disabilities Division, P.). Box 94728, Lincoln, NE 68509.

[16] Bay Shore Services, Inc., 614C Eastern Shore Drive, Salisbury, MD 21804. Susan Atwood, Director.

[17] Contact: Susan Hanson, Dakota County Social Services Department, 161 N. Concord Exchange, Suite 400, South St. Paul, MN 55075.

[18] Parent Case Management Program, Institute on Community Integration, 103 Pattee Hall, 150 Pillsbury Drive S.E., Minneapolis, MN 55455. Marijo McBride, Project Director.

[19] Contact: Colleen Wieck, Executive Director, Minnesota Governor's Planning Council on Developmental Disabilities, St. Paul, MN 55155.

[20] Contact: Jeanne Vincent, Network Coordinator, Adsum, Inc. 105 Bank Street, Fall River, MN 02722.

[21] Contact: William Christoffel, Deputy Director, Hawaii Department of Health, 1250 Punchbowl Street, Honolulu, HI 96713.

[22] Center for Disability Policy and Research, 146 North Canal Street, Suite 313, Seattle, WA 98103. Lyle Romer, Project Director.