PRINCIPLES and RECOMMENDATIONS
from the
QUALITY OF LIFE PROJECT

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In its short life there were many people who contributed substantially to the Quality of Life (QOL) Project. With over a hundred persons involved in significant roles, it will not be possible to name everyone who enriched the work. This lack of citation in no way lessens extent of so many peoples’ commitment and contribution. Many have been moved by the QOL work and identify strongly with it. An apology to all those who read this acknowledgement and feel that their name should appear here; the absence is strictly due to lack of space, not appreciation.

The QOL Project evolved out of discussions with the Administration on Developmental Disabilities (ADD). Ray Sanchez and Judy Moore of ADD were extremely helpful in the planning and implementation of the Project. They also were courageous in allowing the Project to take shape in process—a requirement of an initial attempt to deal with a very complex issue.

While important ideas were contributed by many, John Powers, Mariellen Kuehn, Adolph Ulenak and Robert Smith participated in critical discussions during the concept development phase. The basic approach employed is due largely to their work, and students of QOL owe these persons’ efforts some recognition. Kuehn conducted the initial review of the literature. Others who helped clarify issues related to QOL in particularly noteworthy ways were: Bob Rosenberg (Capital People First); Ed Roberts (the World Institute on Disabilities); Ethan Ellis; Mary Cerreto; Bob Schalock; Michael Reif; Alfred Healy; and Bill Kiernan.

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PREFACE

In response to increased social interest in quality of life (QOL) and QOL related activity in the field of developmental disabilities, the Administration On Developmental Disabilities (ADD) supported the Mental Retardation Institute/University Affiliated Program (MRI) to conduct the Quality of Life for Persons with Developmental Disabilities Project. Project goals reflected the current concern for QOL in human services, the growing consensus that direct consumers of services should be involved in decisions that affect their own lives, and particularly the need to develop agreement on what QOL means in major life spheres. The activities of this project were to:

* create a research-based agenda about QOL issues for persons with disabilities and their families;
* enhance direct consumer involvement in setting agendas in training, research, evaluation, social policy and program development;
* achieve consensus about a framework to discuss QOL and set QOL guidelines in major life settings.

Toward these ends, MRI first planned a review and synthesis of the QOL research literature. A work group consisting of consumers with disabilities, advocates, professionals and other citizens was conducted to explore and validate a research-based framework in which to discuss QOL. A national conference was then organized to enhance consumer awareness of QOL issues, elicit consumer input in defining critical QOL issues and formulating recommendations on QOL matters. Finally, a small work group reviewed project findings and made recommendations to ADD based on QOL Project materials.

The following series of technical reports documenting these activities are available:

Quality of Life: A Review and Synthesis of the Literature - describes the literature and suggests a QOL model that is useful for policy, research, program planning and evaluation.

Discussing Quality of Life: Framework and Findings of the Work Group on Quality of Life - presents a research based framework for discussing QOL and its application by a group of consumers, professionals and advocates.

The Proceedings of the National Conference on Quality of Life - explain the approach and findings of the national conference.

Principles and Recommendations of the Quality of Life Project - presents a synthesis of the findings and recommendations as viewed by the final work group.

The purpose of the final work group was to formulate a comprehensive set of recommendations about QOL for persons with disabilities based upon what was learned through the Project’s activities. Work group participants were given a summary of project findings and tentative recommendations, and were asked to review these in preparation for a day long meeting. Each came prepared with a short paper commenting on the finding/recommendations. Present at the meeting were William Jones of American Association of University Affiliated Programs, Robert Shalock of the Mid-Nebraska Region Mental Retardation Services, Al Healy of the Iowa University Affiliated Facility, Mariellen Kuehn of the
Waisman Center, Ed Roberts of the World Institute on Disability, Raymond Sanchez of ADD, Judy Moore of ADD, Ansley Bacon of MRI, Daniel Crimmins of MRI (meeting chair), and David Goode of MRI. Mary Cerreto of the Accreditation Council for Developmental Disabilities and Betty Pendler of the New York Developmental Disabilities Planning Council did not attend but submitted written comments.

This report provides principles of QOL and related recommendations, that were derived from the project. These principles and recommendations, which represent a consensus of the final work group, are presented under the following three general headings: Definition and Conceptualization; Measurement and Assessment; and, System Impact/Enhancing QOL. QOL principles under each general heading are also relevant to the other two general headings; for example, principles applying to the Definition and Conceptualization of QOL are also relevant to recommendations made regarding Measurement and Assessment, and System Impact/Enhancing QOL. Recommendations are numbered cumulatively and further categorized under three general headings as: Consumer-Related; Professional/Provider; and, System-Wide.
PREAMBLE

Because QOL, as used in this project, was only partially based upon the findings of empirical research, it is important to include a preamble explicitly stating some of the value assumptions associated with this approach. QOL is something that all persons understand and relate to in a similar way and is basically a simple thing. This makes it a powerful social policy concept and orientation to delivery of supports and services. A QOL orientation to supporting persons with disabilities organizes the provision of supports and services to make the following values realities in the lives of persons with disabilities.

An approach to the term Quality of Life (QOL) for persons with disabilities consistent with usage in the Quality of Life Project is one that emphasizes the whole individual, not just his or her disability. Looking at individuals from a QOL perspective focuses on the strengths and abilities of persons with disabilities. It also acknowledges that people with disabilities are essentially similar to other people in society, but with certain functional limitations. Most persons with disabilities have expectations and dreams, and like others want to control decisions concerning their lives as much as possible. Most persons with disabilities want to have friends, to be able to choose to be involved in the social relationships that make up their community, to feel valued and to be economically and/or socially productive, to be able to choose to participate as citizens in government, to have the choice to take risks that are necessary to achieve goals meaningful to them, to have the choice to be a romantic or sexual person, and so on. In short, most persons with disabilities want for themselves the same choices others in the society want. QOL is a concept that gives primacy to the individual's point of view. It can and should account for the experiences of persons with severe cognitive, emotional or physical disabilities and reflect the very different ways such persons may see the world and set goals within it. QOL is a concept based primarily upon a recognition of and respect for the viewpoints and perspectives of persons with all types and degrees of disabilities.

DEFINING AND CONCEPTUALIZING QOL

Principles

QOL for persons with disabilities is made up of the same factors and relationships that have been shown to be important to persons without disabilities.

QOL is experienced when a person’s basic needs are met and when he or she has the opportunity to pursue and achieve goals in major life settings.

The meaning of QOL in major life settings can be consensually validated by a wide array of persons representing the viewpoints of persons with disabilities, their families, professionals, service providers, advocates, and others.

The QOL of an individual is intrinsically related to the QOL of other persons in his or her environment.
QOL of a person reflects the cultural heritage of the person and of those who surround him or her.

Consumer-Related Recommendations

1. In order to assure that the definition of QOL employed in social policy is consistent with the way persons with disabilities and their families think about QOL, additional input from consumers is required.

Several individuals in the work group recommended that additional input from consumers about QOL definition and issues was an important next step. The group suggested open discussions, delphi method, focus groups, and in-depth interviews as methods to get such input. Currently projects in New York and California are collecting additional data from consumers and their families utilizing these approaches. Additional states should consider implementing similar projects.

2. Because of the social nature of QOL, it is critical to develop supports and services that are based on an understanding of the relationship between QOL and family supports, independent living, personal attendant care, and staff quality of work life (for example quality of work life in community residences).

For a person with a disability to experience a good QOL he must be in settings where others also experience a good QOL. The most important dimension in determining QOL is the relationship between the individual with disabilities and those who regularly and directly interact with him/her in the setting. There is a direct link between quality of family life and quality of work life and the QOL of individuals with disabilities. Family supports, quality of work life programs and staff development, and approaches to integration that are sensitive to these relationships and consistent with QOL principles should be supported.

3. Ethical studies evaluating the use of QOL in decisions regarding persons with disabilities across the life cycle need to be undertaken.

The term QOL is used differently in different parts of the human service system. For example, for neonates in intensive care units, decisions about the use or withholding of medical care are made based on the presumed QOL that the child will experience. This use of QOL is substantively different from the way it was used in this project. The various ethical contexts in which QOL is used should be studied critically and from a values-based perspective.

Provider/Professional Recommendations

4. The entire concept of service provision has to be redefined around individual needs and with QOL as a service outcome.

Despite our description of plans as being individualized it has been recognized for some time now, there is a tendency to define services in terms of what is available rather than based on the needs of
individuals. Supports and services should be based upon the individual’s needs to the maximum degree possible. Programs and service models that successfully do this need to be identified and information about them disseminated.

5. In addition to considering QOL in the direct supports and services given to consumers, providers need to develop a quality of work life orientation towards service delivery staff.

A direct implication of recommendation #2 is that providers of services need to develop an explicit orientation to staff development that would include enhancement of quality of work life (QOWL) for their staff. This would importantly include advocating for higher salary levels, provision of resources and supports that would enhance awareness, knowledge and skills, development of employee-administration committees, providing staff with control of work-related decisions, developing options for career growth and development, etc. There is activity of this type occurring all over the nation but it needs to be examined carefully and consolidated. Exemplary programs should be identified and information about them disseminated.

6. The concept of provider should be expanded to include unpaid persons such as community members, volunteers and relatives.

The organization of supports should be expanded to include not only the professional providers but also peers and other volunteers, community members and organizations, families and friends. There are many models of supports currently being developed that include these elements (peer counseling, Joshua Tree and circle groups, direct stipend family support services, community-based planning, etc).

7. Providers need training in a QOL, value-based orientation to service delivery.

Providers of services do not always design practices on an explicit value-base. There are training models for management by values that should be evaluated and the best of these should be widely replicated throughout the service system. See Recommendation #22.

System Wide Recommendations

8. QOL policy, assessments, and programs need to reflect cultural differences and promote cultural identity.

Being able to participate in activities that promote cultural identity is an important way for many persons with and without disabilities to enhance their QOL. Supporting organizations and opportunities that allow for persons with disabilities to do this is crucial to QOL for these persons. Model programs need identification, dissemination and replication.

9. ADD needs to guide the impact of QOL development on consumers, providers and professionals, and the system.

See Recommendations #29 and 37 (below).
MEASURING AND ASSESSING QOL

Principles

The development of measurement and assessment procedures that are based upon the concept of QOL is important in the development of resources and supports for persons with disabilities and their families.

QOL is a construct best assessed through primary consideration of subjective factors as determined by individuals with disabilities and their families, as well as through a consideration of social factors as determined through social validation.

Consumer-Related Recommendations

10. A methodical approach should be taken to developing client-centered instruments and procedures to determine individual QOL needs.

While there is a tremendous amount of activity in this area, it is thus far fragmented. The various models for QOL planning (though not always called that) need to be reviewed. A relatively small group of researchers, clinicians, self-advocates and others should be supported to develop a process and instrumentation for a client-centered and driven model of individual program planning. This group should have sufficient support to achieve this goal (perhaps three years continuous funding) as well as others related to QOL assessment and evaluation (see Recommendation # 13). A system that can accommodate persons with profound mental retardation or significant communication disorders needs to be a central consideration for this group.

11. Planning of supports and services for individuals needs to be linked to QOL outcomes for these persons (Individual QOL Enhancement Planning).

An important aspect of designing the QOL assessment system described under recommendation # 10 is the development of an evaluation process and instrumentation that links QOL planning with outcomes for individuals. Such an evaluation process should involve the person with the disability to the maximum degree possible. The group working on assessing QOL should also have as a goal the development of an evaluation process that is outcome oriented.

12. Flexible quality of family life self-assessments need to be designed and linked to family supports.

A similar process is needed that parallels recommendations #10 and 11, which allows families to assess their quality of family life, links these assessments to supports, and evaluates impact of supports on quality of family life. Process and instrumentation could be developed through the same mechanism described in #10 & 11.

Professional/Provider Recommendations

13. Program evaluations that are QOL-oriented, have high consumer participation, and that are
Another set of QOL evaluation processes need to be designed to determine a program’s effectiveness in enhancing QOL for its clients. The evaluation of a program in terms of its ability to enhance QOL for its overall client population should be based upon the assessment of QOL for individual clients in that program. Because of the relatedness of recommendations #10, 11, 12, 13, & 15 and the desirability of methodological consistency in these instruments and procedures, it is suggested that one set of persons be responsible for working on these assessment/evaluation procedures. Some institutional structures to support such activities are described in Recommendation #29.

14. **Professionals and providers need training in how to employ client and family assessments of QOL and support individuals and families in these activities.**

It should be understood that the production of QOL assessments and evaluations needs to be accompanied by training for management, staff and professionals in a values-based, QOL-oriented way of thinking about services and support (see Recommendation #7). This should include training in how to support individuals and families in QOL assessment and evaluation of service impact. Such training should be part of the development of the protocols described in recommendations #10, 11, 12, 13, & 15.

15. **A system to measure quality of work life in organizations serving persons with disabilities needs to be designed and linked to staff development.**

See Recommendation #2. Quality of work life assessment and enhancement is a critical component of any system designed to enhance the QOL of persons with disabilities who live in residential service settings. Staff should have a program of staff development, career opportunities, rewards for good performance, and autonomy in job-related decisions. They should also be held accountable in terms of their contribution to programmatic and individual QOL enhancement efforts. Quality of work life assessment will only make sense in an organization with a strong management and staff development orientation.

16. **Managers in service agencies need to be trained in a management by values orientation.**

Related to Recommendation #7. There is a general need for management training in our field, and for attracting more competent administrators and managers. Especially important in human services is the sensitivity of management to values underpinning service philosophies and policies. Training in values that enhance QOL in human service management needs to be supported. There are some good beginnings in this area and these should be disseminated more widely.

**System Wide Recommendations**

17. **ADD should develop a structured agenda to support QOL assessment, evaluation, research and policy activities for persons with disabilities.**

There are several related agendas that need to be coordinated in order to guide the impact of QOL policy on the field. This suggests that some mechanism exist through which a structured agenda could be produced in these areas. This could be achieved through an Institute mechanism, as sug-
gested in recommendation #29, or through a program project grant from the government, or through other structures. This kind of coordination is, however, strongly suggested in the future development of this concept.

**IMPACTING THE SYSTEM/ ENHANCING QOL**

**Principles**

QOL enhancement is made up of activities that emphasize the strengths and capabilities of persons with disabilities and their families.

The concept of QOL is important to examine as the basis for social policy in our country generally, as well as for its specific application to social policy for persons with disabilities.

**Consumer-Related Recommendations**

18. **Building upon the strengths and abilities of persons with disabilities and their families in order to allow them to control their own lives to the maximum degree possible is a primary way to enhance their QOL.**

It was generally felt by many Project participants that one of the primary issues in QOL was the control of persons with disabilities and their families over their own lives. Support of training, programs, planning, policy and other efforts that build upon this value and recognize these capabilities and strengths is a general recommendation of the QOL Project.

19. **In order to build upon strengths and abilities it is necessary to train families and individuals in the rights and responsibilities of decision-making, and to support them in the decision-making process.**

A critical avenue to allow persons with disabilities to assume control of their lives in a meaningful way is to provide them with the information and supports necessary for informed decision-making. Family decision-making should be supported in medical, developmental, and educational settings. This means actively engaging the family in decision-making and supporting them during the process. Similarly individuals with disabilities must be provided information and supports that allow them to participate in a decision-making process to the degree that they are capable. Decision-making curricula exist and there are service settings that employ procedures such as those described. These should be examined, evaluated and disseminated. If no satisfactory curricula exist, they should be developed.

20. **The training activities of self-advocacy groups that have as their mission empowering consumers and their families should be supported.**

Consumer and self-advocacy groups conduct two types of training: training consumers in advocacy skills and dissemination activities that have a values, policy or public education orientation. Part of QOL for persons with disabilities is the other in society taking the time and interest to listen to what they have to say. Opportunities for persons with disabilities to sensitize others to those aspects of
the physical and social environment that enhance their QOL should be supported. Occasions when persons with disabilities can come together and network around key policy and service issues are also necessary.

21. **Persons with developmental disabilities should be recruited into the system in positions of authority.**

Because the experience of disability is best understood by people with disabilities, they should ‘run their own show’ to the degree that this is possible. This includes helping to manage the service and regulatory system in significant ways. Persons with disabilities who have the appropriate skills and abilities should be recruited into the system. This will allow them to take control of their own lives to an even greater degree, as well as influence the development of policy, programs and training in ways that are consistent with the disability experience.

**Professional/Provider Recommendations**

22. **Professionals and providers need to be trained in a values-based orientation to services that emphasizes client and family strengths and capacities.**

Paralleling Recommendation #7 all levels of persons involved in helping those with disabilities and their families need to be trained in a values orientation in providing services and supports. Training should not be done one time only but must be on-going. One needs a constant awareness of value issues in decision making related to provision of services; those involved face such decisions every day and need a community of support to help make correct decisions. It is important to identify training programs that are value-based and that can be used with direct-care and professional staff. These training programs should be evaluated and those that are successful should be disseminated and replicated. It is also important to incorporate regular meetings around value issues in the management plan for organizations. It may be worth considering the creation of a Task Force or Special Committee on Values in Human Services for Persons with Developmental Disabilities whose mandate would be to guide the development of management by value training and training in a value orientation to direct care and professional staff.

23. **Direct care staff require training that will allow them to support persons with disabilities and their families to enhance their QOL.**

This is a very important recommendation. Currently most training for direct care staff does not include providing information and skills that are specifically related to enhancing QOL for consumers. Persons with severe physical disabilities or mental retardation often have problems in meeting people and having friendships. They have trouble getting and keeping jobs, or finding community groups to join, in getting out of the house, and so on. These are the things that they find most important and should occupy an important place in training direct care staff. The general idea is that training curricula need to be developed that are consistent with enhancing QOL as it is perceived by persons with disabilities.

24. **Funding and regulatory strategies need to be found that allow providers to be innovative and rewarded for success. Current policies do not facilitate innovation.**
Many involved in the QOL Project felt that the current systems of regulation, evaluation and funding do not allow service providers to be innovative in their attempts. Providers are generally not rewarded for success at habilitation or integration. (Conversely, it was also noted that many poor quality providers are not held accountable for doing a poor job--see Recommendation # 36). The problem of lack of incentives for good performance and innovation is recognized in many states. Known strategies that deal with this problem that have been successful should be identified and disseminated. A document such as Strategies for Innovation and Success that describes and integrates these attempts would be appropriate.

25. **The provider community can enhance QOL of persons with disabilities by developing peer counseling programs that match persons with disabilities who are productive, independent and integrated with individuals who are less so.**

Of particular merit in enhancing the lives of persons with disabilities are programs that utilize the experience and capabilities of other disabled persons as peer counselors and/or friends. Peers who are disabled and who have successfully dealt with some of the problems that persons with disabilities face can be strong role models to those who may not yet have dealt with issues. Peers with disabilities have a better understanding of the position of other persons with disabilities and of the dynamics involved in many of the problems that persons with disabilities face. There are many examples of peer counseling programs that are claimed to be highly effective. Effective peer counseling/friends programs should be replicated nationally.

26. **Rather than adopting the notion of an ever more normal continuum of vocational and residential services, providers should aim at achieving a relatively stable, self-selected life style for consumers.**

The notion of a continuum of services, graded from restrictive to unrestrictive or less normal to more normal, and through which all persons need to progress, should be reconceptualized. As continuums function in some systems they constitute an endless series of hurdles for clients. As soon as persons with disabilities are successful in mastering one environment, they are told that they now have to move on to a more normal environment. Instead, it should be the goal of the residential services to have the person with disabilities decide how he or she wants to live. There should be residential options from which a person may choose rather than a system through which he or she must progress.

**System-Wide Recommendations**

27. **QOL is sufficiently generic to serve as the basis for a national social policy for persons with disabilities. There is a need for such a policy.**

The conclusion that QOL should be used as a social policy concept for all citizens was reached by many individuals involved in the QOL Project. Its strength as a social policy concept derives from its broad applicability. At the same time it has a clear pertinence to persons with disabilities and should be developed with their concerns at its center. Thus, there is a need to focus policy activities on an interagency level to consider how quality of life might serve as the basis for social policy generally in our society, and to develop specific quality of life policy in the field of developmental
disabilities.

28. All future activities related to QOL for persons with disabilities need to be strongly coordinated with major disability groups.

A general feeling of those active in the QOL Project was that even stronger coordination of QOL development activities needs to exist with consumer organizations. While QOL is a generic concept to which everyone relates, QOL for persons with disabilities and their families is of primary importance to the disability community. For QOL to reach its potential as a social policy concept it must be developed so that it reflects the input of persons with disabilities, and this must be known by the disability community. One way to ensure that this would be the case is by creating a National Task Force on the Enhancement of Quality of Life for Persons with Disabilities and Their Families. Such a group could be composed primarily of representatives from self-advocacy and consumer groups and would both monitor and suggest activities related to QOL enhancement for this population.

29. Because of the complexity and scope of activities required to advance the investigation of QOL and utilization of QOL in the disabilities field, a coordinating entity such as a National Institute on QOL for Persons with Disabilities (or a Research and Training Center) should be established.

An important result of the QOL Project is the conclusion that QOL is sufficiently dynamic and generic to act as a fundamental concept in the field of disabilities. A long term strategy to the development of QOL needs to be formulated and an umbrella structure needs to be constructed as a way to focus and coordinate activities. There are several ways to think about how this might be done: a Research & Training Center on Quality of Life; an Institute on QOL funded by ADD; and Institute funded by multiple federal agencies; or Institute funded from different funding streams (federal, private, state).

The purpose of creating such a structure would be to carry out activities in QOL program development, research, training, and dissemination, and to coordinate activities of professionals, consumers and others active in this area. Because there is no individual QOL assessment instrument, (or individual QOL program development procedures), or QOL program evaluation methods, the development of instruments that are consistent with what we know about QOL must be a primary focus of a QOL Institute or R&TC. Other initial activities could be to: develop a clear values-base and QOL orientation; identify clinics and programs using QOL and examine their methodologies; provide technical assistance to programs and local/state planning groups; field test QOL instruments in model clinics/programs; provide regional and national QOL training activities; support training by consumers and self-advocacy development; and begin targeted dissemination of QOL research to consumers and on the community level.

The Institute or R&TC would have to coordinate with other key public agencies (NICHD, NIMH, MCH, NIDDR, MCH, UAPs, DDPCs, P&As) and be supported by key consumer groups (EFA, UCPA, ARC, NICL), provider groups, foundations, and related institutes. Strong representation of persons with disabilities on the Board of any Institute or R&TC is essential.

The development of such an Institute should be put on a "slow track." Through a competitive planning grant, the first year should be spent in planning the development of QOL in policy, program development, assessment and evaluation, and training, and determining how the Institute could
best support this development. In the next year implementation of this plan should begin through a coordinated central structure. This would be done through the Institute governing competition among proposals meeting criteria for longevity, replicability, dissemination, etc.

30. **QOL must be marketed to all parts of the disability system including: P&As, DDPCs, UAPs, ILCs, R&TCs, consumer groups, self-advocacy organizations and professional groups.**

While QOL is clearly an issue of growing interest to many in the disability field both nationally and internationally, its importance and value is not known to most persons in the field. The concept needs to be explained to all segments of the system. These groups need to know what role they can play in helping to promote QOL as a social policy in the disabilities field. Targeted publications aimed at achieving this for these audiences need to be produced and disseminated.

31. **Public education combating old stereotypes about disabilities and emphasizing integration and QOL need to be undertaken.**

Part of the promotion of QOL should include public education activities aimed at debunking stereotypes of persons with disabilities and their families. One way to do this is by promoting public education facilitated by persons who have disabilities. Public service announcements and other public media presentations should be produced conveying information about the strengths of persons with disabilities and their viewpoints about achieving a good QOL for themselves.

32. **Activities that facilitate participation of persons with disabilities and their families in policy formation, community and other forms of planning, and in networking around QOL issues should be supported.**

Related to recommendation #18 this recommendation highlights the importance of creating a community of interest around QOL by supporting community-based, and other levels of, planning and networking around QOL issues. The inclusion of persons with disabilities and their families into these kinds of efforts is a primary way to enhance their QOL. The projects currently being run in New York and California will begin networking in each state around QOL issues. Other states should consider running similar work groups about QOL issues.

33. **One important way to strengthen community participation and integration of persons with disabilities is by enhancing their participation in community secondary associations such as Boy Scouts, Girl Scouts, Boys Clubs, Ys, etc.**

Activity with community groups and associations is a primary avenue for some persons to enhance their QOL and should be available equally to persons with disabilities and their families. Secondary associations that currently operate successful mainstreaming programs for children and adults with disabilities should be identified and described. Training and technical assistance that allow for successful inclusion of persons with disabilities needs to be made available more widely to the generic community organizations.

34. **The building of informal, unpaid networks of supporters and/or person-centered teams of paid and unpaid supporters is another important way to enhance community participation of persons with disabilities.**
Related to Recommendation #6. There are a number of interesting new approaches to support systems that involve volunteers and other paid and unpaid providers. These are named Joshua Tree groups, circles and person-centered teams. These approaches should be evaluated carefully and those that are successful in enhancing QOL for those involved should be disseminated and replicated.

35. An immediate way to impact on the evaluation of programs is to incorporate QOL in national accreditation processes such as ACDD, JCAHO, and CARF.

The development of QOL evaluation and program planning protocols and instruments will take some time. In the meanwhile, one immediate way to impact service delivery with a QOL orientation would be to consider including QOL standards in national accreditation processes. This could be done by providing each of these accreditation groups with training in a QOL orientation. Each of the organizations could then institute activities that would establish such an orientation in their accreditation process.

36. The system needs to have 'guts'—reward good programs and eliminate bad ones. Presently too many programs of poor quality are tolerated and supported.

Related to Recommendation #24. For a variety of reasons, the current system both allows poor programs to continue providing services even though unsuccessful, and fails to reward programs that are successful. The issues involved with the closing of poor programs are sometimes complex but must be faced. Likewise, figuring out how to reward programs for good performance may also be difficult but must be done. Information from states that have instituted quality assurance and enhancement mechanisms that accomplish these goals needs to be reviewed and disseminated. New programs and solutions that will allow for the system to have 'guts' need to be formulated.

37. An important way for ADD to assure that program development, training and research is consistent with QOL enhancement is to utilize QOL principles as the basis for their RFP process.

One important way to systematically ensure that programs and training supported by ADD enhance QOL is to utilize the QOL principles in this document as the value-base for decisions about competitive applications in the RFP process. This suggests that in addition to the criteria suggested in the specific announcement for competition, applications will be judged in terms of their consistency with QOL principles. There should be a special announcement of these principles in the Federal Register and they should appear thereafter with regularity as part of the announcement for RFPs.