With a little help from my friends…

A series on contemporary supports to people with mental retardation

Changing Systems

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Acknowledgments

The President's Committee on Mental Retardation (PCMR) is proud to present *With A Little Help From My Friends*…a series on contemporary supports to people with mental retardation.

This forward thinking series of booklets is intended to support people with mental retardation and related conditions to participate as full citizens in their communities in every aspect of their life.

The President's Committee has made a commitment to contribute information to the field that will promote the quality of life and inclusion of people with mental retardation and developmental disabilities. This series of five booklets provides timely, innovative and creative 'possibilities' for issues ranging from; how people can direct their own services to assure a full life in the community…to critical issues of addressing challenging behaviors to funding options for supports and services.

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It is our belief that this PCMR publication series will contribute to the future direction of services and supports for people with mental retardation into the next millennium. Our work is cut out for us but, *With A Little Help From My Friends*, we can achieve our ultimate goal of lifelong community inclusion for people with mental retardation.

Valerie J. Bradley
Chair

Gary H. Blumenthal
Executive Director

PREFACE

Services and supports to people with mental retardation have undergone significant change in the last 50 years. Today people with disabilities are living longer. They and their families are asking for and expecting meaningful support to live their lives as full citizens in their own communities.

This series of five booklets provides information in a comprehensive but basic manner designed for individuals who do not know much about how supports are currently provided, but who would like to know more about the history of services and supports as well as current issues and future trends.

The following is a brief overview of the information and issues covered by each booklet:

Speaking Up, Speaking Out (Booklet #1): This booklet covers definitions and prevalence of mental retardation, issues in the current legal system, along with self-advocacy and self-determination.

Growing Strong (Booklet #2): This booklet covers issues and topics in early intervention, family supports, and the educational system.

Real lives (Booklet #3): This booklet covers services and supports in the areas of supported living, vocational opportunities, and supported recreation.

I Am Who I Am (Booklet #4): This booklet covers a variety of specialized support needs including **challenging behaviors, supports to the aging, culturally competent supports, and person-centered planning as a tool for providing supports that are meaningful to the individual.**

Changing Systems (Booklet #5): This booklet covers issues in quality assurance and funding of supports and services.

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A Note About Language

Who we are is as much about how others see us as it is about our physical beings. We can eat right, exercise, and believe in ourselves all we want, but if no one ever notices it won't last for long. So what does it mean to be "a person with mental retardation?" Does it say something about a person that is meaningful and relevant? Does it tell people something about that person that is valuable, helpful, or essential?

When asked, most self-advocates with mental retardation will make it clear that the label "mentally retarded" is stigmatizing and limiting. If the label comes before the person then a large part of who that person is has already been defined.

Despite clear indications from self-advocacy groups that the words mental retardation should be "retired," support professionals and agencies that oversee support systems struggle with how to provide the necessary assistance to people who need it, without defining who is eligible (i.e., creating a label). By its very nature service provision hangs onto labels in order to know where to best put resources. The dilemma of dropping all labels and still accurately describing who can receive supports through State agencies is not solved. But there is a clear mandate from the people who receive these services and supports that people—not labels—always come first.

That part is simple. It's a commitment that when we talk, write, or otherwise communicate about people with mental retardation or any disability we never put the word "disability" before the word "person;" that when we have the chance to educate others about people-first language, we do; and that as we look at the global issues of how to support people, we remember that it's the person, not the service, that matters. It's a sign of respect. It's a sign that although not all the questions have been answered correctly, we are up to the challenge. Spread the word: "People First!"

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Overview

As people with developmental disabilities continue to have greater opportunities to receive individualized supports and as these supports are designed to provide opportunities for inclusion in communities of choice, the importance of and difficulty in ensuring quality and securing funding become more complex. Changing Systems is designed to provide information regarding various approaches to quality enhancement and information on how services and supports are and can be paid for given these new challenges. Quality and funding in light of potential managed care models are also explored.

What Gets Measured Gets Done: Quality Assurance and Enhancement

The importance of monitoring the quality of services received by people with developmental disabilities became very apparent in the 1970’s when various exposés uncovered scandalous conditions in State institutions. Many people living in these institutions were subjected to substandard living conditions: children were tied to cribs, adults wandered naked and ate off the same floor where they were "bathed" by being sprayed with a hose. Sexual and physical assault by staff were common, as was neglect of even the most minimal standards of health and safety. The Federal government responded to this intolerable situation with a long list of regulations designed to eliminate this abuse and neglect. These regulations required documentation on a huge number of health and safety issues, as well as documented proof that people were given certain types of opportunities (e.g. recreational, medical, etc.) and that environmental factors were in place (e.g. a certain amount of living space, availability of personal grooming supplies, etc.)

As time went on, a cry was heard to return people to their communities. Many felt that despite health and safety regulations, the isolation of these large facilities, and the people living and working in them, made abuse and neglect more likely. A service system was eventually developed that provided more options, and during the 1980’s and 1990’s many people moved from large, isolated institutions to smaller, homelike group homes located in community neighborhoods. With this move to the community, the values underlying the service delivery system changed, and ideas like choice, normalization, community integration and inclusion, having friends and intimate relationships, became the desired criteria for a quality program. But while the setting was different, the methods for assessing quality in these new smaller settings was not. The hundreds of Federal regulations developed for better living conditions in large congregate care facilities followed people into the community group homes.

These state-of-the-art community group home services began to tarnish with time. Increasingly, people began to realize that living in the community was not the same as being part of the community. People with mental retardation and other developmental disabilities lived in typical homes but they had few friends and community connections, and they generally lived, worked and played in segregated settings. Not only were the standards created during the era of institutions inadequate to monitor quality of life in areas of personal satisfaction with services, they also interfered with areas such as choice and self-determination. This shifting focus of services from basic health and safety to individualized

> **"For the first time in my life I am experiencing the quality of life that is standard for a person without disabilities. I have been given the opportunity to live my life as I choose. I have a good life, not just by the standards for a person with a disability, but by the standards of any person. I now realize what I have been deprived of and what I can expect in the future. The limits that were placed on me have been eliminated, although I still have my disability."**
>
> *Michael J. Kennedy - in Quality Assurance for Individuals with Developmental Disabilities: It's Everybody's Business*

consumer-centered supports has not been met with and equal shift in monitoring for quality in these services. Because formal quality assurance mechanisms have not kept pace with these structural and ideological changes there is a great deal of frustration about what is getting measured compared to what many people feel is most important.

Quality assurance in residential facilities for people with developmental disabilities has primarily meant compliance with the regulations developed for Intermediate Care Facilities for the Mentally Retarded (ICFs/MR) and other State and Federal regulations. These regulations specify minimum standards of care, focus on process (e.g. that meals are made by following strict nutritional guidelines and served at a certain time) and rely heavily on documentation. Reviewers periodically make site visits to regulated facilities and write up the deficiencies that are observed. In response to these citations, service agencies write plans to correct the identified deficiencies. Stories abound about site visits where the adherence to regulations appears to be more important than the actual people who are receiving services. For example, reviewers coming out and never seeing the person who is receiving the services, or issuing citations for trivial matters like crumbs in the toaster or the use of bar soap instead of liquid soap, are not uncommon. This regulation-based approach to quality assurance was developed for a system of large public institutions and assumed that services would continue to be provided in these settings.

Since the mid-1970's, and the birth of the partially Federally funded but State regulated Home and Community Based Services (HCBS) , a deinstitutionalization movement has resulted in services being provided in smaller, more geographically dispersed living arrangements. Yet, during this change, little consideration was given to the compatibility of institutional-based regulations with the new smaller, more homelike settings. Although, the principle of normalization (helping people who receive services to lead lives as much as possible like other people) had become the guiding principle of the reform movement, the practical implementation of this principle was not made part of many State policies and regulations. In fact, many States developed regulations very similar to Federal ICFs/MR standards. Ironically, although these regulations were put in place to improve services, studies have shown that in terms of choice, self-determination, and other areas of today's definition of quality of life, services are often superior in settings that are not subject to the intensive ICFs/MR regulatory structure.

The ICFs/MR regulatory structure is based on a medical model of providing services with an emphasis on providing "continuous active treatment" so that people's "deficits" can be fixed - making them more independent and more "appropriate." The medical model is slowly giving way to a supports model. In the supports model, the people who receive services are viewed not so much as patients or clients who need to be "fixed," but as people with the same needs and desires as other people, who have talents and abilities, but who need supports to live a full, rich life. The role of the service provider, therefore, becomes to help develop a variety of individualized supports to this end. In the medical model the emphasis is on preparing a person for normal adult living (i.e., the person must have a certain level of competency and skill before adult responsibilities and privileges are allowed) whereas in the supports model the emphasis is on supporting a person in normal adult living. The medical model is a professional/provider-driven system, the support model is driven by the choices and preferences of people with disabilities and their families. In this new approach, the traditional system of prescriptive rules and regulations, many of which are very intrusive and reinforce the "fixing" notion, seems meaningless and actually works against quality.

The following are some of the numerous problems that have been identified with both the process and the consequences of the regulatory-based approach to provision of care and quality assurance:

- *The process is ineffective and lacks reliability and validity.* Site visits are made infrequently (usually once per year or less) and reviews of paperwork, rather than meeting recipients of services or touring program sites, have been used for quality assurance. Perceived compliance with regulations often is dependent on the values and expertise of the reviewer. For instance, if the reviewer is a nurse there may be a stronger focus on medication administration procedures, whereas if the reviewer is a dietitian there may be stronger emphasis on written menus and adherence to dietary guidelines.

- *The process emphasizes paperwork and compliance becomes an end in itself, stifling innovation and creativity and perpetuating mediocrity.* For instance, much of the training effort and direct support hours in highly regulated facilities are devoted to making sure that staff understand and comply with the regulations rather than focusing on what the people receiving services want and need. There is little motivation for providers to improve services other than maintaining the minimal standards necessary to pass inspection.

Quality assurance means:

- **All people with disabilities will be treated like anybody else.**
- **Rules and regulations should correspond with the needs of the individual.**
- **The individual must be involved.**
- **People get the support they need.**
- **A person is allowed to choose where and with whom he or she wants to live.**
- **Services are available to people wherever they want to live.**

Michael J. Kennedy - In Quality Assurance for Individuals with Developmental Disabilities: It's Everybody's Business

- *The process places control and power in the hands of regulators and not people with developmental disabilities and their families.* It can be used to maintain and extend the power others have over people with developmental disabilities. Historically people with mental retardation and other developmental disabilities have not had very much power or voice in how they will live their lives. The regulatory system perpetuates this situation by making the regulations the focus of services. When people receiving services ask for something that conflicts with the regulations they are usually denied the request.

- *The process focuses on concrete and tangible things.* For example, the number of times a person leaves a facility to participate in a recreational activity, which can trivialize the more important quality of life factors, such as the caliber of relationships that a person experiences. It standardizes services and doesn't recognize differences in individual needs by assuming that quality means the same thing to everyone.

- *The process of monitoring has become an extremely expensive burden on already strained service system budgets.* Travel time and costs are higher and fewer people are seen. Modern services are located in many small places rather than in a few large places and there is a separation of vocational and residential services.

- *The current system is punitive and encourages even legitimate service providers to "cover-up."* Under the current system the threat of fines or closure is used as a way to keep service providers in compliance with the regulations. Providers who are honestly struggling with issues have learned to hide their problems from the reviewers in fear of citations and fines.

Looking back, the regulations implemented for many of the Federal and State funded programs have resulted in the basic health and safety needs of people with developmental disabilities being met. Arguably, quality of life could not have emerged as an important issue until the majority of people were safe and free from harm. Now it is time to look beyond—to get to the heart of quality and how it touches the lives of the people who receive services. It is time to look for approaches to identify and respond to the needs of people that substantially improve the quality of their lives, community membership, self-determination, and personal outcomes of community living.

New Definitions of Quality

Traditionally, if an organization was found to have all of its processes in order and to be in compliance with all of the relevant regulations, it was considered to be a quality program. Increasingly however, concepts of quality are extending to include how programs affect the lives of the people they serve. Some of the dimensions of quality currently being identified and discussed which relate to a person's satisfaction with services include the following:

- Quality is based on values, not regulations.
- Quality is different for different people and should be defined by them.
- Quality services are provided by people who genuinely care and know the person well (i.e. long-time direct support workers, family, friends).
- 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.
- Quality is very difficult, if not impossible, to assure or mandate through process compliance.

For the people who rely on the regular support of others in order to work, to take care of their homes, and to enjoy what life has to offer, there is no doubt that quality in services is very important. Quality assurance is the way that the system makes sure that services are the best they can be. With a change in the definition of what quality means there needs to be a corresponding change in quality assurance activities. Some elements of the new view of quality assurance are:

- 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.

The possibility of managed care models to oversee developmental disabilities services brings up new concerns which are just beginning to be addressed. Cost containment and accountability are two major components of managed care models which will influence future quality assurance. Under a managed care system it is likely that Management Information Systems will be used. These are large databases that let the managed care provider use data to estimate or compare characteristics of service providers as well as consumers. For example, how much supported employment costs at one service provider versus another. Cost/Benefit Analysis (i.e. a look at the possible outcome of services in comparison to the cost of the service), and consumer satisfaction surveys are likely to be common methods for assuring quality in a cost effective manner.

Developing and institutionalizing a quality assurance system that addresses the needs of this new service structure and these new values will not be easy. Quality assurance is performed at many levels of government by a range of agencies with different public health, safety, and programmatic responsibilities. This complex system has been described as a "web of interrelated regulations" or as an onion, where peeling off one layer only reveals another, and another, seemingly without end. In addition, there are a number of conflicts of interest inherent in changing the current system. For instance, each regulatory agency has a cadre of administrators and monitors, often unionized, whose jobs depend on the continuation of the current system. Advocates for people with developmental disabilities often defend the regulations which they have relied on to secure needed or desired services at the most basic level for those they represent. Additional challenges as identified by Bradley in 1990 include:

Service Provider's Needs in Quality Assurance.

- **Standards should be outcome-oriented.**
- **The quality of the survey experience is directly related to the quality of the surveyor.**
- **Technical assistance and education should be provided.**
- **Providers need to feel respected.**
- **Providers should welcome parent/citizen monitoring.**
- **Providers need assurance that the persons they serve are not overburdened by regulations.**

Derrick F. Dufresne - In V.J. Bradley and H.A. Bersani, 1990, Quality Assurance for Individuals with Developmental Disabilities: It's Everybody's Business.

- 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.

Navigating these hurdles and challenges must be done in the context of the following tensions:

- 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.

Redesigning Quality Assurance

There are a number of questions and issues related to designing quality assurance systems for this changing service system that need to be considered. Decisions about how the system will be designed and implemented must be made. Additionally, it is important to look at some newly developed alternative quality assurance models (i.e. accreditation and State-wide systems) to get ideas for recreating or modifying existing programs. Lastly, considerations for developing and using internal quality assurance systems should be considered.

Several general considerations should be explored before beginning to develop any quality assurance system including the following:

- Who will design the new system? Policy makers? Public administrators? Case managers/service coordinators? Program representatives? Consumer advocates? Families and guardians? Consumers?
- Most contemporary quality assurance projects are trying, to varying degrees, to secure input from all of these groups.
- Should basic health, safety, and rights information be treated differently from more individually prioritized factors?

- Should the quality assurance system apply just to direct service providers or to other parts of the system as well, e.g., case managers/service coordinators, protection and advocacy, funding agencies, guardians/conservators?
- Should a variety of methods be used (e.g., interview, satisfaction surveys, standardized instruments) because services are multi-dimensional?
- Should several people be involved in the evaluation activities? The more people that are involved, the more the information collected will be used. For example, if providers are involved, they can directly use the information to improve their services, and if community people are involved they will develop more understanding and support for the program.
- Does the process make sense for the consumer of services? Is the individual asked to sit through a 2-hour interview in which he describes his desires and frustrations only to have the information not used in any relevant way?

Once these global questions are explored, there are more specific questions to be answered: What is the purpose of the program? What is to be measured? How should it be measured? Who should be the evaluator? Who should be the respondent?

The following are some possible reasons for developing and implementing effective quality assurance programs:

One Family's Indicators of Quality

- **Location**
- **Community Participation**
- **Choices**
- **Safety**
- **Control of Finances**
- **Health**

Cathy Ficker Terrill - In Quality of Life Volume I: Conceptualization and Measurement.

- *To judge the program or to provide accountability.* In this case, individual consumer data would be aggregated and the total agency picture would be used for licensing or accreditation purposes.

- *To improve the individual consumer's services.* This would require separating information that applies to the individual out of the total agency evaluation and using it to plan the person's services.

- *To provide feedback for program improvement.* This may involve information about strengths and weaknesses or a composite rating which could be used by providers to publicize their programs.

- *To provide feedback for system improvement.* If information is combined for the entire system, it could give feedback about the system-wide strengths and weaknesses as well as trends.

- *To provide information about specific programs for consumers and other interested stakeholders.*

The following are some things that quality assurance programs could measure:

- *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 a 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.

Quality assurance could measure:

- **Input**
- **Process**
- **Impact**
- **Reactions of participants**
- **Organizational effectiveness**
- **Data profiles**
- **Quality of life**
- **Outcomes**

- *Data profiles created by Management Information Systems* (MIS). 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.

Some key points to keep in mind when considering outcome evaluation are:

- Measuring outcomes is rooted in values and who selects the outcomes to be measured is an important ethical issue. Some choices for who selects the relevant outcomes might be the consumer, the "experts", or law makers.

- Outcomes can occur at different levels, e.g., the individual, the family, the organization, or the community.

- Individual outcomes may refer to quality of life factors (e.g., living where one chooses) or to functional skills (e.g., cooking a meal) or valued social roles (e.g., being a member of the Jaycees).

- Although outcomes may be ultimately what counts, process should not be neglected. It is important for organizations to specify the process by which they intend to reach desired outcomes and to constantly evaluate its effectiveness.

- Focusing on outcomes should be balanced by systematically looking at unintended consequences as well.

- Measuring outcomes is difficult because outcomes take time to accomplish and they take time to measure. In addition, the definition of what constitutes a given outcome can vary and change over time.

- Outcomes are measured by selected indicators or proxies. They must be clear, specific, and measure factors that depict the outcome. Sometimes indicators are weighted in terms of their importance.

- Some strategies for outcome evaluation are (1) to compare the data to baseline data for an individual or group, (2) to compare the data to a control group, (3) to ask the participant or his or her representative to reflect back to determine whether the outcome is met, (4) to describe the outcomes in a narrative manner from the perspective of the customers and the providers, and (5) to have experts or community observers review indicators of outcomes.

Decisions need to be made on how quality should be measured. A major distinction is made between gathering information through quantitative and qualitative methods. Basically, quantitative methods use numbers, either to count things or to describe amounts of something. Quantitative methods work well for combining information and making comparisons which can be useful for obtaining information on the organization or the system as a whole. On the other hand, qualitative methods use words to describe things. Qualitative data gives more in depth understanding of what's happening and work well in understanding how services affect an individual's quality of life.

The following are some specific quantitative methods for gathering data:

- *Standardized instruments.* There are many standardized instruments in the developmental disabilities field, many of them measure functional skills. The Instrument for Client and Agency Planning is an example (ICAP).

- *Surveys with fixed responses.* Questions with fixed responses give specific answer choices for the respondent to choose, often by circling or marking an "X." An example would be, "Do you strongly agree, agree, disagree, or strongly disagree?" Each answer choice is given a number value so the average response can be calculated.

The following are some specific qualitative methods for gathering data:

- *Surveys with open-ended questions.* These questions allow the respondent to determine how to answer in their own words. Analysis is done by finding common themes. The analysis stage is more time consuming than that of surveys with fixed response questions.

- *Interviewing.* Interviews involve asking questions, either to the program participant or some other informant. Interviews can be structured by having a list of pre-determined questions or they can resemble an informal conversation, with the interviewer looking for certain information.

- *Focus groups.* Focus groups consist of a series of discussions with different, but similar, participants on a predetermined topic of concern using focused questions. The purpose is to gain understanding of various points of view.

- *Participant observation.* Participant observation involves social interaction between the evaluator and the program participant in the participant's own environment and involves collecting information systematically and unobtrusively.

- *Document review.* This refers to reviewing program or other written records to obtain the information that is desired.

The following are some possibilities for who should be asking the questions or monitoring quality:

- *External, professional evaluators/monitors.* This is the traditional approach. Some advantages are that paid staff are available and can perform reviews in a systematic, timely manner. They can be trained and gain experience which will contribute to consistency. Disadvantages are that this is an expensive system and funds are not available to have them spend sufficient time in programs to become familiar with them or to get to know the consumers. Also, strangers coming into the home and observing, reading program records, or asking questions is intrusive and can be very disturbing to the people who live there.

- *The consumer's support network and/or case manager.* An advantage of this approach is that the information obtained about the consumer's life and services can be used to improve them.

Family and Consumer Monitoring

Teams of family members, consumers, advocates, and agency representatives can become responsible for periodic evaluations of services, including on-site visits, interview with staff and program participants or their families, and review of relevant materials. We realize that this may be difficult for some consumers and/or family members in terms of time or otherwise, but a stipend or service (such as respite) could be offered. In fact, we suspect that many families would appreciate such an opportunity.

Susan Lehr and Robert Lehr - In Quality Assurance for Individuals with Developmental Disabilities: It's Everybody's Business.

- *Program staff.* Even in external quality assurance programs, there is often a provision for agency staff to do a preliminary self-assessment which is later verified by external evaluators.

- *Community monitoring teams.* These teams may consist of consumers, families, professionals, and interested community people.

The following are some of the possible people who should be telling us about quality:

- *The individual who uses the service.* Obviously, having the person respond to questions about his or her own services is the ideal choice. This brings up a number of challenges, however, when people have cognitive and/or communication disabilities. It may take more time to get the needed information which is more of a problem with external evaluators. It may involve having a support person interpret responses which may reduce the accuracy. Sometimes, there are some problems with response bias such as a tendency to repeat the last choice given (recency) or the tendency to agree with whatever is said (acquiescence).

- *The service providers*. Often the service providers, particularly with residential services, are the people who know the most about the individual's daily life. Direct service professionals get to know an individual's preferences and needs very well in the course of their daily interaction. The disadvantage of asking service providers about matters that reflect on the quality of service given is their obvious conflict of interest.

- *The individual's family.* Families have known the individual the longest and are usually the most committed to them. A disadvantage of using their perspective to evaluate quality is the tendency of all families to stress protection and security for their loved ones which may come at the expense of self-determination. In addition older people or people who were at one time separated from their families may not have close family members to fill this role.

- *The case manager/service coordinator.* The case manager is often officially charged with monitoring the quality of services and has the advantage of seeing the service system as a whole. The flip side of this may be a resignation that things can't be any better for a person given the constraints of the system. Case managers are responsible for high numbers of people (case loads) and therefore have difficulty in getting to know people well.

- *A combination of people.* It is desirable to get as many of the above perspectives as possible to be sure that an accurate and complete picture is obtained.

Examples of Alternative Quality Assurance/Enhancement Models

Some States and agencies have already begun using alternative forms of quality assurance and enhancement based on the new definitions of quality. External review processes are used to satisfy States expectations that quality services are being provided. Internally agencies are redefining their own ways of monitoring and improving on the services they provide.

One form of external quality assurance/enhancement is the use of accreditation where an outside agency reviews the service provider and accredits the provider for a certain length of time depending on how well it did. There are two major accreditation organizations that are active in the developmental disabilities field, The Council (formerly The Accreditation Council) and Carf. Both have revised their methodology extensively in the past few years to focus on individual outcomes.

The Council on Quality and Leadership in Supports for People with Disabilities (formerly The Accreditation Council). The Council developed the Outcome Based Performance Measures between 1991 and 1993 through a series of focus groups with people with disabilities across the country who identified what they wanted from their service providers. The original methodology has been met with a great deal of interest and is being used in many States for demonstration projects or as a basis for development of new State-wide quality assurance systems. The original 30 outcomes were identified in ten categories: personal goals, choice, social inclusion, relationships, rights, dignity and respect, health, environment, security, and satisfaction. Some examples of specific outcomes are: people have friends, people are afforded due process if rights are limited, and people are satisfied with services. In 1998 the Council released revised outcomes and methodologies. The 1998 outcomes include 24 personal outcomes clustered into seven categories: identity, autonomy, affiliation, attainment, rights, health and safeguards.

The organization seeking accreditation completes a written self-assessment which is submitted to the Council before the official review. The review is done by Council reviewers, usually in pairs, who interview and/or observe the focus person, and interview staff, and when appropriate, family members or friends. The Council's methodology suggests questions and criteria to determine whether the outcome is present—from the point of view of the focus person. Whether or not the outcome is met, the reviewers also make an assessment of whether there is an organizational process in place that supports the outcome. Additional Performance Measures for Organizations are assessed in the areas of assuring personal health, safety and welfare; fiscal management; human resources management; and planning and evaluation. Depending on the agency-wide results of the reviews, the organization may receive a one, two, or three year accreditation. Whether or not accreditation is granted, a written report which includes commendation (areas of strength) and recommendations (weak areas) is provided.

Carf...The Rehabilitation Accreditation Commission is an accreditation organization that has been in business since 1966. It accredits employment and community services including residential, vocational and supports to individuals and families. The 1996 standards and accreditation guidelines were developed following an extensive study to solicit thinking of a wide range of individuals and organizations concerned with persons with disabilities, a customer service needs analysis, input from the field (with an emphasis on listening to the persons served), and an international field review. Most recent revision of these standards was published in 1998. The accreditation standards are divided into three areas:

- *Organizational quality*. The existence and demonstration of organizational policies regarding:
    a. Input from persons served.
    b. Physical accessibility.
    c. Outcome measurement.
    d. Rights, health and safety.
    e. Human resource development.
    f. Leadership.
    g. Legal requirements.
    h. Financial planning and management.

- *Service quality.* Individual centered planning and service delivery and the organization's evaluation of consumer satisfaction.

- *Service specific standards.* The standards for community support services, for example, specify that services should be individually tailored, and that the organization should facilitate inclusion, relationships, self sufficiency, learning new skills, informed choice and decision making, and risk assessment among other things.

Carf reviewers ask organizational representatives to demonstrate their compliance with their own policies in the above specified areas. They also review agency documents, make observations, and interview the persons served, staff members and community members to confirm that consumers play a lead role in the planning, development, delivery and evaluation of the services they receive.

State models. Most States are in the process of redesigning their quality assurance systems and many, if not most, are substituting or including quality of life outcomes as a focus. There is a decreasing focus on document review and an increase in observation and interviews, particularly increased contact with the individuals who receive the service. Process measures continue to be assessed but with a greater emphasis on processes that are tied to specific outcomes. There is a general trend toward a reduction of prescriptive rules and standards and development of streamlined licensure and certification procedures. There is recognition of the importance of involving stakeholders in developing and building consensus on the new quality assurance systems. There is also an increased focus on individuals, their satisfaction and choices, as well as an emerging approach to focusing quality assurance on the individual rather than on the provider agency. Other emerging trends are increased decentralization of quality assurance activities, tying quality assurance reforms to managed care and using cross-disability quality indicators. Massachusetts, Oklahoma, and New York are among the States with re-designed quality assurance systems. Following is a brief summary of each of their programs.

Massachusetts. The QUEST (Quality Enhancement Survey Tool) program has been operating since 1994. It was developed by a group consisting of State officials, provider agencies, consumers and family members in order to align licensing and certification procedures with the Mission Statement of the Department of Mental Retardation (DMR). QUEST is a single tool that is applied to all individuals across all settings where services are provided. The survey consists of two parts. Part I measures quality of life outcomes in the areas of (a) rights and dignity, (b) individual control, (c) community membership, (d) relationships, (e) personal growth and accomplishments, and (f) personal well-being. Part II measures overall performance of the provider organization including (a) the organization's commitment to ongoing planning and evolutionary change, (b) how well staff are supported in providing high quality services, and (c) how well the organization safeguards the rights, dignity, and personal well-being of the individuals it supports. The survey is done by a team headed by a DMR staff person and includes either another DMR staff, other human service professionals or citizen volunteers. The team does interviews with consumers, support workers, and others who know the consumer well, and if necessary, they do observation and record review. The outcome of the survey is a single score which determines the length of certification (2 years, 1 year, or "with conditions"). The organization is also given feedback regarding both individual results and organizational performance. In addition to its use for certification, the data from the QUEST surveys is compiled for the entire service system and used to provide information about how the system is meeting its mission, to spotlight high-performing agencies, and to identify areas where technical assistance or training is needed.

Oklahoma. Oklahoma has a four tier quality assurance system. The first level provides for basic safeguards and consists of a State surveyor monitoring the standards that are specified in the State's contract with the provider. These standards consist of some funding requirements, health and safety standards, and include some personal outcomes such as opportunities for inclusion. The surveyor makes site visits at least once a year and interviews the individual receiving services, staff and families and reviews program documents.

Another level of the system monitors outcomes beyond the expectations of the contract. This program is called Oklahoma Advocates Involved in Monitoring (OK AIM) and is operated by the Tulsa Arc under contract with the Oklahoma Department of Human Services. Teams of volunteers composed of consumers, family members, friends and advocates visit provider agencies to evaluate services and suggest improvements as well as to gather information to assist consumers in choosing service models or providers. The reviews are done for every consumer every one to two years. The surveyors use a handbook containing 26 items in four categories to be assessed. The volunteer team reports back to the officials at the area office who follow up with providers. The recommended changes aren't always required.

Person-centered audits are another quality enhancement activity. In this program, State employees do a 4-6 week assessment of randomly-chosen consumers and his or her housemates. They look at the design of the service and assess whether it meets the person's desired outcomes as well as whether it is the most cost-effective appropriate alternative. This function is considered a technical assistance activity with reports being issued to the consumer's planning team as well as to the State regarding larger system issues.

A fourth level of quality assurance is provided under contract by Oklahoma State University. Researchers do an annual assessment of consumer quality of life outcomes for the majority of consumers in the State. The assessment consists of three parts: an interview with the primary care-giver, a consumer satisfaction interview (with a picture book format), and a qualitative site assessment. Survey results are given to provider agencies who use the results to improve service quality as well as to an Advisory Council for system planning.

Internal Quality Assurance

Increasingly service providers are implementing their own internal quality assurance programs. This is due in part to the popularity of such concepts as Total Quality Management, Continuous Quality Improvement, and The Learning Organization that have swept the business sector. Internal quality assurance also is propelled by the gap between what service providers feel their mission is and the indicators of quality that have been monitored by external sources. The following are some benefits to a provider in implementing internal quality assurance programs:

- An internal quality assurance program can help an agency prepare for external evaluation.

- It can help the organization determine if activities and results are in line with the organization's mission and help to increase the quality of life of consumers.

Considerations in Internal Quality Assurance

1. ***Provision of resources***
- **Time**
- **Training**
- **Internal reliability checks**
- **External reliability checks**
- **Oversight of the quality assurance program**
- **Use of information**

2. ***Alignment with the expectations implied in the quality assurance program***
- **Alignment with mission**
- **Alignment with staff training**
- **Ongoing staff involvement**
- **Training for board members, families/guardians, case managers, day program providers**

3. ***A continuous improvement cycle***
- **Periodic assessment of the review process**
- **Periodic assessment of the use of the review results**

- Quality assessment mechanisms can provide feedback for improvement and provide early warning signals of potential trouble. This is particularly important in the decentralized environments that are prevalent since deinstitutionalization. Program improvement can also be facilitated by sharing the quality practices that are discovered with the rest of the organization.

- Quality assurance activities can gather information to support structural changes and policy decisions.

- Another benefit of quality assurance for a provider emerges when direct service staff are directly involved in the process. Direct involvement increases the likelihood of buying into an agency's mission and values and consequently implementing the agency policies. Staff who are involved in the process are also exposed to contemporary trends.

- Quality assurance can be used to increase visibility of programs and to gain recognition and financial support for the agency.

- Providers using cutting edge quality assurance principles can have an impact on the larger service delivery system.

While there are significant benefits for a provider in implementing a quality assurance program, there are clearly challenges as well as including the following:

- The philosophy behind the quality assurance effort must be driven by the agency's mission and must be in alignment with all of the agencies policies and practices.

- The goal of quality assurance is not as clear as it was in the days when quality assurance was designed to assure safety and adequate treatment. An agency must decide on the standards to which it wishes to hold itself accountable.

- Paying attention to quality assurance ultimately means struggling with such issues as the tension between encouraging consumer choice and providing protection from harm and the question of who the customer is (i.e. the person receiving services or the people funding and regulating services).

- Quality assurance usually involves an element of intrusiveness and the harm/benefit ratio must be carefully assessed. As homes get smaller and more like real homes, finding the appropriate ratio gets more challenging.

- Quality assurance development may be seen as threatening to organization personnel, and there is likely to be organizational resistance to unwelcome news. It may provoke turf wars and it may instill fear of change as new roles emerge.

- It is especially important to have feedback and payback to direct service staff. In order to encourage ownership of the system and the philosophy behind it, they should be given information about use of the quality assurance program and reinforcement for their efforts to comply with its expectations.

- Providers need to have enhancement mechanisms ready to respond to the needs uncovered in the quality assessment. If such mechanisms are not in place, distrust and anger will ensue. The quality assurance system will be undermined by the idea that this system is not helpful either.

- Effective quality assurance demands strong leadership. One agency sums it up well: "The ultimate responsibility in any agency for ensuring the quality of service lies with the executive director. The degree to which he or she espouses and lives the principles is the degree in which the agency will implement them." (Dufresne, 1990)

It can probably be assumed that in this time of shifting expectations for the service delivery system, setting up a new quality assurance system would mean major organizational change. Managers should therefore approach it with a strong sense of commitment and a knowledge that letting it subside will be greatly disappointing to stakeholders and will greatly reduce their credibility in attempting future organizational changes. Some specific recommendations are:

- Begin by assessing the organization's readiness to change. Is there a perceived need for change? Is there a commitment to a vision? Do the key stakeholders really believe in the values behind the program?

- What is the organization's capacity for making changes at this time? Is there strong leadership that will guide the change? Ask: Are we able to commit the amount of time this takes right now? Are there lower priority things we can let go of? Can we allocate other necessary resources in addition to time—interest, expertise, a designated person to see it through, money for training and consultation?

- Ask if the necessary commitment can be made to carry the program through. Keep in mind that lack of follow through leads to a loss of credibility.

- Once begun, set up systems for follow through both on the individual and the organizational level. Make sure the individual recommendations are shared and periodically reviewed with the support team. Make sure staff and families and other stakeholders are informed about the status of the program and what is happening because of it.

- Set up feedback systems. Share stories throughout the organization about successes that have come from the program.

- Consider having external reviews periodically to get an objective assessment and to learn how external standards compare with the agency's.

- Use the results to set up improvement plans for the facilities and the agency as a whole. Keep data and have systems for follow-through and review.

- Strive for total system alignment. The mission statement, values and visions, training system, staff performance appraisals, consumer services, etc. should all work together.

Since "what gets measured, gets done," redesigning quality assurance systems provides an opportunity to change service delivery to more closely match many new definitions of quality. Quality assurance programs use extensive resources (e.g., money, expertise, time of both the evaluator and respondent), and the expectations implicit in the new programs raise hopes of higher quality and more relevant service delivery. For these reasons, there is an obligation to make maximum use of the results of these evaluations.

Designing a quality assurance system in line with the new definitions of quality and with attention to ensuring that the results are used should go a long way toward making quality assurance more relevant and the service system more effective. This new way of looking at quality is exciting for consumers and service providers alike. There are, however, additional challenges and issues which will need to be dealt with on the road to transformation. Some of them are: the difficulties of organizational and system change, the need to negotiate new roles for system participants, the tension between responsibility and overprotection, and, perhaps most of all, the need for great creativity on the part of all players in the midst of alternative and new funding mechanisms and constraints.

Money, Managed Care and Self-Determination

Quality enhancement? How can the quality of services to people with developmental disabilities be enhanced without additional money, and in the midst of a possible change in funding through managed care? Frankly, when it comes to money, it seems that the more there is, the more gets spent, and the more is needed. And, more doesn't always mean better. In considering services and supports for people with developmental disabilities this certainly rings true. As services have been developed and funded over the years, and as the demand for people needing services has grown, there is a constant struggle to make ends meet. Nationally there are still thousands of people on waiting lists who want services, and yet even existing services seem to be "underfunded." There never seems to be enough to pay decent staff wages, obtain needed assistive technology or services, or to help people participate in the activities they want to be a part of. Yet, services to people with developmental disabilities are some of the most expensive available today.

The remainder of this booklet is designed to provide information on how much money is spent on services to people with developmental disabilities, where that money comes from, and the types of services it buys. At a time of Federal Medicaid reform and the possibility of States using managed care models to fund and manage services, key information about managed care is reviewed. Additionally, the importance of integrating and ensuring participant definitions of needed services and supports is key to any managed care model discussed. Examples of processes and programs developed by States to ensure consumer-driven services are identified.

As stated, services to people with developmental disabilities are some of the most substantially funded public programs today. So, where does the money go? In Fiscal Year 1996 public spending for services to people with developmental disabilities totaled 22.8 billion dollars. *Table #1* shows, there has been a slow but steady growth in the amount of money spent on these services over the past 20 years. *Table #2* represents total spending for developmental disabilities services in 1996 by program category. [In 1996, over half ($13.9 billion) went toward community services; residential programs serving 16 or more people expended approximately one third ($7.34 billion); and less than 7 % ($1.6 billion) was spent on individual and family support services (supported living, personal assistance, supported employment and family supports).] *Table #3* reflects the amount of Federal Medicaid spending for 1996 in long term care for people with developmental disabilities. Other Medicaid represents Community Supported Living Arrangements, targeted case management, Model 50/200 waiver, clinic/rehabilitation services and personal assistance.

Table #1

Total Developmental Disabilities Spending

Fiscal Year	Billions of 1996 Dollars
1977	$8.5
1978	$9.0
1979	$9.6
1980	$10.1
1981	$10.6
1982	$11.0
1983	$11.4
1984	$12.0
1985	$12.6
1986	$13.3
1987	$14.2
1988	$15.1
1989	$16.6
1990	$17.4
1991	$18.3
1992	$19.1
1993	$19.7
1994	$20.8
1995	$22.3
1996	$22.8

Table #2

Total Spending by Program Category in 1996

Program	Spending
Community Services	60.9%
Congregate/Institutional Facilities	32.1%
Individual and Family Support	7.0%
Total Spending	**$22.8 Billion**

Table #3

Federal Medicaid Spending for Long Term Care in 1996

Program	Spending
State Institution ICFS/MR	34.9%
HCBS Waiver	29.3%
Private ICF/MR (<16)	15.2%
Other Medicaid	10.0%
Private ICF/MR (16+)	9.2%
Public ICF/MR (<16)	1.4%
Total Spending	**$9.4 Billion**

Source: Institute on Disability and Human Development, University of Illinois at Chicago, 1998.

People used a number of different types of services in Fiscal Year 1996. The following is the number of people who received various types of services:

- 90,745 received supported employment services;
- 45,172 received supported living;
- 12,582 received personal assistance;
- 280,535 received family supports (e.g. financial subsidy, respite care);
- 139,167 received residential service in large congregate settings;
- 55,227 received residential services in settings serving 7-15 people; and,
- 199,890 received residential services in settings serving 6 or fewer people.

These numbers show important trends regarding what types of services people are receiving with the 22.8 billion dollars that are expended each year, including:

- That a significant number of people who receive residential services live in settings with more than seven people.
- That supported employment options are used by only a small portion of the total number of people with developmental disabilities.
- That although relatively little money is spent on family supports & personal care attendant services this type of service impacts a large number of families and individuals.

Federal Medicaid spending accounted for approximately $9.4 billion in Fiscal Year 1996. As Table #3 shows, these Federal Medicaid dollars were used to pay for State institutions, public and private ICFS/MR services, Home and Community Based Services waiver programs (HCBS), Community Supported Living Arrangements (CSLA), targeted case management, model 50/200 Waiver, clinic/rehabilitation services, personal assistance and other related services.

> *Statistics used in this section provided by Braddock, D., Hemp, R., Parish, S., & Westrich, J. (1998) The State of the States in Developmental Disabilities, fifth edition.*

How Federal Medicaid Money is Used to Support People with Developmental Disabilities

The Home and Community Based waiver (HCBS) program is one of the most flexible pots of Federal money coming to the States to provide services to people with mental retardation and other developmental disabilities. This flexibility has lead to increased use of waiver money over the last ten years while the use of other programs, such as the ICFs/MR is on the decline.

Developmental disabilities service systems differ from State to State. Each has its own history and unique characteristics. Because of the flexibility of the HCBS program each State has been able to craft its program(s) to meet particular goals and objectives and there is considerable variability among them. Differences include the relative size of State programs, the services and supports offered and how they are administered.

Even though there are marked differences in developmental disabilities HCBS waiver programs among the States, there are many common threads. The vast majority of States employ their programs to underwrite the costs of community residential programs (group home and foster care) and training-oriented day programs under the "habilitation" service category. More and more States are offering supported living and in-home/family supports to serve as alternatives to "facility-based" programs. Nearly all States offer supported employment services, and most also offer housing modifications, assistive technology/adaptive aids and respite care through their programs. Some States offer health-related and therapeutic services through their HCBS waiver programs to supplement benefits that are available through the State's regular Medicaid program. About one-half of the States pay for case management services through their HCBS waiver programs; the remainder also furnish case management or support coordination services to waiver participants but use other Medicaid options to finance these services.

Nearly all HCBS waiver programs for people with mental retardation and developmental disabilities have undergone considerable change since they were first launched. Over the years, the number and range of services and supports that the "typical" State offers through its program has considerably grown. It is not uncommon today for a State to offer twenty or more distinct services through their HCBS. Generally, the increase in the number of services which the States are offering reflects the growing understanding of the need to offer supports to people in the community beyond the traditional residential and daytime settings. For example, the availability of Medicaid dollars through the HCBS waiver program served a major role in enabling States to develop, implement and expand supported living programs. States see considerable value in covering a wide range of services and supports so that plans of care can be more responsive to the particular needs of individual participants.

The HCBS dollars have some unique features in the way that they can be used that are not found in all of the Federal Medicaid funding that goes to States. HCBS funding has relatively few Federal requirements attached. While the flexibility that States have is by no means limitless, there is considerable latitude available to the States. In developmental disabilities, for example, there is room under the waiver authority to employ person-centered planning methods, assist people to participate in regular community activities, and to accommodate the needs of individuals with highly challenging conditions.

Why are HCBS Waiver services growing so rapidly?

- **Changes in HCFA policy**
- **Changes in program emphasis**
- **Number of states offering HCBS services**
- **Policy changes in large states**
- **Community placements and large ICFs/MR conversions**
- **State leveraging of federal funds**

Since 1990, there has been a rapid growth in the use of HCBS funds in services to people with developmental disabilities. Why has the HCBS program been growing at such a vigorous pace in recent years?

- *Changes in Health Care Financing Administration (HCFA) Policy.* There is little doubt that HCFA's removal of the limits that had been imposed on the size of HCBS waiver programs gave States the opportunity to dramatically increase the number of individuals participating in such programs. Obviously, most States have seized on this opportunity to expand their programs. Moreover, the types of services and hence, the potential eligible population also broadened as an outgrowth of changes in HCFA policies.

- *Changes in Program Emphasis.* Through the early 1990's, States—for a variety of reasons—concentrated their use of HCBS waiver dollars on individuals residing in more costly community group living arrangements or receiving family foster care services. In 1992, 70.5 percent of all HCBS waiver participants were served in agency-managed group homes or family care arrangements. Only 8.1 percent of all HCBS waiver participants lived in a home of their own; the remaining 21.1 percent resided in the home of a family member. By 1996, the proportion of HCBS waiver participants living in their own home had climbed by 130 percent and individuals living with their families represented 29.9 percent of all participants. Concurrently the proportion who resided in agency-managed residences or family care homes had dropped to 54.3 percent. The extension of HCBS waiver services to more and more individuals who live on their own or with their families reflects the shift in emphasis in State developmental disabilities systems away from facility-based programs to furnishing supports in the person's or the family's home. It also is an important contributing factor to the high nationwide rate of growth in program participants. Had States continued to concentrate program funding on traditional community residential service models, the program's overall rate of growth would not have been as great as it has been.

- *Number of States Offering HCBS Waiver Services.* The entry of additional States into the program during the early 1990's has had a significant effect on program growth; however, this factor has played itself out now that all States and the District of Columbia are offering HCBS waiver services to people with developmental disabilities.

- *Policy Changes in Large States.* The entry of New York State into the HCBS waiver program in 1991, and major expansions in the programs operated by California, Florida and Massachusetts has had a substantial effect on national statistics tracking HCBS utilization. These four States accounted for 59 percent of the nearly 84,000 individuals who were added to HCBS waiver programs during the period 1991-1994. Since 1994, growth in the HCBS waiver programs in these States has accounted for 30 percent of the approximately 99,000 increase in HCBS waiver participants nationwide. In 1990, these four States accounted for 17 percent of all HCBS waiver participants nationwide; by 1997, their share had grown to 37 percent. If these States had not aggressively employed HCBS waiver financing, overall program growth would have been far lower.

- *Community Placements and ICFs/MR Conversions.* Throughout this period, the States have continued to down-size and close large public facilities. Frequently they used the HCBS waiver program to pay for community services for former State facility residents. In some States, privately-operated ICFs/MR have been closed in favor of serving residents through the HCBS waiver program; in other cases, the facilities have remained and the financing has been shifted from ICFS/MR to the HCBS waiver program. As a consequence, some of the recent growth in the HCBS waiver program stems from reallocating Medicaid dollars out of ICFs/MR into other alternatives.

- *State Leveraging of Federal Funds.* In order to receive Federal waiver money, States must come up with some money of their own. In some cases, States have expanded their programs in order to leverage more State general revenue dollars with Federal Medicaid dollars. By qualifying more individuals and services for HCBS waiver funding (programs and services previously 100% funded by the State), States have been able to draw down increased Federal funds to serve more individuals and/or sustain existing services. It is difficult to tell how much of the increase in HCBS waiver participation represents genuine program expansion versus the leveraging of existing service dollars.

Federal dollars through the ICFs/MR program have a number of rules and regulations attached making them less flexible and less appealing in today's climate of individualized supports. That is a significant reason why most States are decreasing their use of the ICFs/MR program. The following is some basic information about the use of ICFs/MR programs to fund long term care for people with mental retardation and related conditions and how it compares to the use of dollars through the Home and Community Based Services waiver program.

Medicaid spending for developmental disabilities long-term services has grown in real terms since 1990, but at a significantly lower rate than overall Medicaid expenditures.

Because these are expensive, comprehensive services, spending on ICFs/MR services has continued to grow, climbing to $9.7 billion in 1996 even though ICFs/MR utilization has been declining. While roughly 50 percent more individuals participated in the HCBS waiver program than resided in ICFs/MR in 1996, spending on HCBS waiver services was slightly less than one-half the amount expended on ICFs/MR services. Even though HCBS waiver spending has grown very rapidly, it remains along way from catching up to the money spent on ICFs/MR services. However, the rate at which ICFs/MR spending has been growing has slowed considerably in recent years.

The annual costs of serving an individual in an ICFs/MR have increased steadily since 1990 from approximately $51,958 per resident per year to $73,572 in 1996. Annual 12-month costs of serving a person in the HCBS waiver program also grew during this same period; however, in constant dollar terms average per capita costs were virtually the same in 1996 as in 1990. Throughout the period, average HCBS waiver costs per participant was about 40 percent less than the costs of serving an individual in an ICFs/MR. HCBS waiver costs have proven to be more stable and considerably lower than ICFs/MR costs. When HCBS waiver and ICFs/MR spending are combined, since 1990, they increased in combination by 70.5 percent (from approximately $8.5 billion in 1990 to $14.5 billion in 1996).

Total Medicaid spending nationwide for all types of services (such as health care) more than doubled over the same period, increasing at an annual compound rate of growth of 14.1 percent. Hence, Medicaid spending for developmental disabilities long-term services has grown in real terms since 1990, but at a significantly lower rate than overall Medicaid expenditures. Based on the results of the 1997 HCBS waiver survey and assuming that recent ICFs/MR expenditure trends continue, we estimate 1997 Medicaid expenditures for specialized long-term service (ICFs/MR and HCBS waiver) for people with developmental disabilities will reach roughly $15.5 billion in 1997.

> *Information provided by Smith, G. & Gettings, R. (1997). Medicaid Home and Community Based Waiver Services and Supports for People with Developmental Disabilities: Trends Through 1997.*

Possible Future Directions of Long Term Care Spending

What directions are States likely to take in employing ICFs/MR and HCBS programs? There are several possibilities:

- *Continued Expansion of the HCBS program.* Most States will continue to expand the scope of their HCBS programs, although probably at a slower pace than has been the case over the past five years or so. In most States, the HCBS waiver program has become the preferred and in many cases, nearly the exclusive strategy for accessing Federal dollars to finance both current and expanded community DD services. With few exceptions, there is virtually no interest among the States in encouraging the development of new ICFs/MR facilities. Indeed as previously noted, several States are sponsoring or encouraging the conversion of existing ICFs/MR facilities. Simply stated, the future will see a continuation of HCBS waiver program expansion accompanied by declining ICFs/MR utilization.

- *Service Emphasis.* Program expansion will continue to be tied to the States' efforts to emphasize in-home/family support services and other integrated supports. In recent years, several States have taken steps to broaden their waiver service coverage beyond traditional 24-hour supervised residences and facility-based day programs. Based on discussions with State program managers, several States that used to limit their programs to more costly community services will be taking similar steps to broaden their programs in order to: (a) leverage as many Federal dollars as possible; (b) improve the overall cost-effectiveness of their programs; and, (c) provide greater flexibility in the services and supports that individuals can obtain through the HCBS waiver program. This, too, is a continuation of a program trend that began roughly in 1990 and has resulted in a steady increase in the service and support options that are available to waiver participants.

- *Payment Policy.* It is evident that there is mounting concern in many States regarding cost-effectiveness of existing MR/DD waiver programs. Even though nationwide the per participant costs of HCBS waiver services have remained remarkably stable since 1990 (and in most States have not increased in real dollar terms in recent years), officials in many States are concerned about such costs rocketing upward due to increased service utilization or increases in the prices paid for services and supports. At the same time, controlling spending by imposing tighter limits on utilization of certain services or tightly managing provider rates in order to contain costs also has real drawbacks, including the possible effects on quality, access to and availability of services as well as the ability to individualize support plans. Some States (AR, KS, MN) have taken steps to develop "tiered" payment limits that set maximums in terms of the total amount that may be expended on behalf of an

Future directions regarding ICFs/MR and HCBS:

- **Service emphasis**
- **Payment policy**
- **Managed care arrangements**

individual but permit flexibility in the make-up of the services and supports that a person might receive within the overall limitation. Other States are examining the utility of such stratified cost limits, either within a single HCBS waiver program or by creating multiple programs which correspond to various eligibility criteria. How widely and at what pace these approaches will be used is uncertain at this time.

- *Managed Care Arrangements.* The interest in reforming the financial management of HCBS waiver programs through tiered or stratified funding limits also has some States seriously considering shifting their programs to a more overt "managed care" model. In some respects, the HCBS waiver program has always had some features similar to managed care programs. In most respects, however, HCBS waiver programs for people with developmental disabilities were not designed and implemented as a managed care program employing all of the principles and strategies typically associated with managed care programs.

—adapted from Smith, G. & Gettings, R. (1997). Medicaid Home and Community-Based Waiver Services and Supports for People with Developmental Disabilities: Trends Through 1997. So, What is Managed Care?

So, What is Managed Care?

For most people, the phrase "managed care" is familiar and is associated with the way in which many of them receive their health care. People commonly associate the term, therefore, with a variety of "managed" care insurance companies that contain costs through limits placed on service utilization. However, while managed care strategies contain costs, they also have the potential to improve the efficiency and effectiveness of service systems.

Unfortunately, most people do not see the latter side of managed care. Consumers fear that managed health care will mean long waiting periods for appointments, lack of choice of primary provider, and reduced access to services. Providers fear it will mean delays in payment, less control over what services can be provided, and disruption of existing consumer-provider relationships. The image conjured by "managed care" is of an isolated "medical case manager" making decisions about what health services will be provided based more on their cost than on the individual needs. As a result, most people, recipients and providers alike, greet with mistrust the expansion of managed care beyond acute health care.

In reality, managed care is neither malevolent or compassionate. It is a collection of administrative methods aimed at rationalizing decisions regarding the allocation of scarce resources to a growing pool of potential consumers. Three key factors motivate the purchasers of managed care (employers and government): the cost, the quality and the demand (i.e. the number of potential recipients) for services. When a decision is made to use managed care strategies, one of these three elements has usually become more important than the other two. For instance, a State may be faced with exploding service costs and turn to managed care to rein them in; or it may look to managed care to help it define and improve quality; or it may be seeking to stretch limited State resources to serve a growing waiting list. Whatever the predominant goal—reducing costs, improving quality or expanding the number of people served—managed care techniques offer a rational and efficient approach to restructuring the system.

Under any given managed care arrangement, efforts are made to contain service costs in one or more of the following ways:

- by changing the price paid for services.
- by inserting economic incentives for providers to hold down their costs.

- by influencing how services are utilized by the number of available providers and the amount of services used.
- by better coordinating the services needed. (Smith & Ashbaugh, 1995)

"In reality, managed care is neither malevolent nor compassionate. It is a collection of administrative methods aimed at rationalizing decisions regarding the allocation of scarce resources to a group pool of potential customers."

G. Smith & R. Gettings, 1997.

Managed care strategies ultimately alter the flow of money and the balance of power in a service system, inevitably affecting all stakeholders in some fundamental way.

There are four major groups of players that interact in managed care arrangements— the payer, the managed care intermediaries, the service providers, and the service recipients—all of whom want to increase their power in the system and expand their access to the limited resources. It is important to understand who these players are and the stake that they have in the outcomes of managed care.

The *payer* in a managed care arrangement is the entity (private or governmental) that bears the ultimate financial responsibility for the services that individuals receive. In the public sector, the payer is the State agency charged with administering programs authorized under State law. When multiple funding streams are involved, there can be more than one payer. Because Medicaid is by far the largest funding source for developmental disabilities services, the State Medicaid agency would be a key payer in a managed care model for long term care services. With managed care, payers need to agree on a simple arrangement for managing resources—a managed care plan.

The *Managed Care Intermediary* is the link between the payer on the one hand and the service provider and/or the service recipient on the other. Typically, the managed care intermediary receives a fixed payment (called "capitation") from the payer, in exchange for the responsibility (the "risk") to provide all needed services to the specified service recipients in the entire pool. This entity arranges or provides the services, attempting to manage costs per recipient within the fixed payment. The intermediary's function may take a variety of forms including: a Managed Care Organization (MCO), a Managed Service Organization (MSO), or an Administrative Service Organization (ASO), all of which have different responsibilities and risks.

A *Managed Care Organization* (MCO) is responsible for seeing that services are provided as needed by service recipients, within the boundaries of the fixed amount of money the MCO received from the payer. The Managed Service Organization (MSO) has these same financial responsibilities but it also directly provides services and supports. The MSO may be an organized network of service providers, or it may be a single service provider that contracts for supplemental services that it can not provide itself. The Administrative Service Organization (ASO) is very different from both the MCO and the MSO. It is only responsible for administrative tasks (e.g. maintaining data bases, legal services), not service provision and it does not bear any of the financial risk associated with providing all needed services for a fixed amount of money.

Service providers. The service providers are the organizations and individuals who furnish the various services and supports. These may include formal organizations, both not-for-profit as well as profit-making entities. It may also include informal affiliations, such as volunteer church groups or community cooperatives, and individuals, paid and unpaid, who provide supports to one or more service recipients.

Service recipients. The service recipients are the people who receive services.

What are the major components or concepts of managed care? Managed care offers an array of technical mechanisms to improve or decrease costs in service systems, but these techniques can be confusing and increase complexity. There are ten basic components of managed care systems many of which are really not new to the field of developmental disabilities. What is perhaps new to the field of developmental disabilities is that managed care integrates all ten of these components into a coherent plan to contain costs while enhancing quality or expanding the number of service recipients. Here are ten basic components or elements of managed care systems.

Eligible population. This component basically determines who is in and who is out. Who will receive services and who will not?

Capitation. Capitation is the process whereby a fixed amount of money is paid in advance to cover costs of services needed by the eligible population.

Risk. Risk is the financial uncertainty associated with agreeing to provide all needed services to eligible service recipients in exchange for a single specified amount (the capitation).

Care criteria. Care criteria are the standards used to determine what services can be made available to any particular individual, based on the identified needs of the individual. This could be a list of allowable services, a "benefit package," or a set of criteria that must be met before services can be provided.

When Minnesota was considering a plan for managed care, this is what stakeholders had to say:
"Make sure that whatever happens, we don't go back to institutions or large 'group homes'. We have got to keep working to have everyone live in the community in regular houses and apartments."

"If we don't deal with personnel issues it won't matter who manages the system. This is not just a [developmental disabilities] issue; it will be the biggest issue for nursing homes, Personal Care Attendant and other human services, too."

The flow of money. Control over funds is a key to the power in any service system. In traditional managed care arrangements the payer contracts with the managed care entity, who in turn contracts with providers to deliver services. The intermediary and providers have a genuine interest in delivering quality services, yet as obligatory requirements are passed down, each entity must keep the one before it satisfied, with service recipients again occupying the lowest position in the structure. This dynamic is unaltered even when the provider network also takes on the intermediary role to function as a Managed Service Organization (MSO).

Network management. The formal arrangements for coordinating a group of providers under a managed care plan. This role is usually played by the managed care intermediary and the network consists of a group of affiliated service providers.

Care coordination or gatekeeping. Care coordination or case management is a system in which a single professional is responsible for ensuring that a recipient obtains the full range of services required.

Utilization review. Utilization review is a formal process for ensuring that the services and supports being furnished are necessary, appropriate, and the least costly available.

Service substitution. Service substitution is a process requiring the use of a lower cost but equally effective service in place of one of higher cost.

Quality assurance and improvement. Quality assurance consists of procedures to assure an acceptable level of performance, to protect participants, as well as to foster improvements in performance over time.

—adapted from Smith, G. & Gettings, R. (1997) Medicaid Home and Community-Based Waiver Services and Supports for People with Developmental Disabilities: Trends Through 1997.

Participant-Driven Managed Supports and Managed Care

What does managed care have to do with people with developmental disabilities? How can the value and philosophy base of consumer driven services and participant empowerment be maintained in light of changes brought about by managed care? Many people within the field of developmental disabilities have been working to understand the connections and possibilities in bridging managed care models with systems reform and participant-driven services and supports. The National Association of Directors of Developmental Disabilities Services, Inc. recently produced a publication entitled, "Managing Our Own Support", which provides information on using the "tools" of managed care to move toward more consumer-driven participant managed supports. They provide several reasons why the field of developmental disabilities should move toward participant driven managed supports.

Participant-Driven Managed Supports

Reduced to its essence, a participant-driven managed support system is an arrangement whereby the participant and/or family decides how limited service funds will be spent. This approach is consistent with emerging trends in the field, strengthens self-esteem, facilitates empowerment and can contribute to cost containment. The following are some reasons that participant-driven managed supports could be beneficial.

The Robert Wood Johnson Foundation has awarded self-determination grants to help eighteen States explore new approaches to empowering persons with developmental disabilities and their families. Grant amounts range from $100,000 to $400,000 and extend from one to three years. Nine of the eighteen States are receiving full three-year $400,000 commitments.

Reason #1: Participant-driven approaches are consistent with trends in the field. The opportunity to participate fully in community life is increasingly recognized as a right of all members of society regardless of ability. People with developmental disabilities have come to expect that their lives, like those of others without disabilities, will be lived in the community and will follow a self-selected rhythm which may involve work, home and play. They also have come to expect that they will be physically and socially integrated and that they will have opportunities to contribute to their communities. Finally, the extent to which an individual exercises control over life's many choices has become a critical measure of independence and well-being. Participant-driven approaches are consistent with these emerging ideals, because this allows consumers to choose which services and supports are most important in order to meet their particular needs.

Reason #2: Participant-driven approaches reflect sound practice. What is the best way to help another person? This is a difficult question, but it is clear that some ways of helping are more effective than others. Research across a variety of disciplines has repeatedly shown that to effectively help others the person receiving help needs to be encouraged to lead the way and to "take control" of his or her own life. Having such control has been positively correlated with an enhanced quality of life. This approach to helping others involves teaching the person receiving the help new skills, but it also requires that help be offered in ways that encourage the individual to recognize his or her own needs, dreams and aspirations, and to act on them by crafting and implementing personalized solutions (Brammer, 1993; Brickman et al., 1983; Dunst, Trivette & LaPointe, 1992; Skinner, 1995). Participant-driven managed supports embraces the idea of individuals and their families taking charge and leading the way in determining their needs for services.

The majority of past and present service practice surrounding assisting people with developmental disabilities emphasizes a more narrow focus, tied primarily to skill building (e.g., eating, dressing, fixing meals, crossing streets, cleaning house, performing a job) without providing many choices about what skills will be worked on. Many people with developmental disabilities spend much of their day learning a variety of life skills, using well regarded instructional formats, such as task analysis, chaining, and reinforcement. These practices are effective and should not be abandoned, however, building on research related to the broader view of assisting others, the field is coming to recognize that providing effective help or support to people with disabilities means more than skill building. Increasingly sound instructional practices that both enables and empowers the person receiving support to direct his or her own life are being developed and used. These new practices are already showing results.

In one recent study, adults with mental retardation who demonstrated self-determined behaviors were more effective problem-solvers, were more assertive and self aware, and had higher expectations regarding their own efficacy and the outcomes of their actions (Wehmeyer, Kilchner & Richards, in press). Similarly, Conroy (1997) found improved quality of life outcomes for individuals participating in New Hampshire's "Self Determination" demonstration project where participants exercised great freedom of choice regarding life goals and the arrangement of needed supports.

Reason #3: Participant-Driven Approaches Reflect A Valid Cost Containment Strategy. An underlying premise of traditional managed care strategies holds that: “Managed Care Organizations with network management responsibilities, free of political obligations, free of regulatory constraints and equipped with competent management can better run service networks." (Smith & Ashbaugh, 1995) Based on this belief, some argue that managed care companies can administer developmental disabilities systems in ways that both contain costs and maintain "quality". Yet this assumption is largely unproved in human services, and fully untested in developmental disabilities.

In contrast, an alternative assumption, which forms the basis of participant-driven approaches, holds that participant-driven managed supports are also a valid strategy for improving organizational performance. One of the central tenets of total quality management (Osborne & Gaebler, 1992) is "customer first" behavior, based on the premise that customers who do not find what they want, at a price they consider fair, go elsewhere to make their purchases (assuming there are other places to go). In this context, participant-driven models do support the goal of cost containment. Smith & Ashbaugh (1995) argue that:

> “Service recipients, working on limited budgets, will spend more prudently to get the most value for their money, and participant-driven arrangements will spawn a market economy in which those providers representing the most value will survive.”

In applying the ideal characteristics of participant-driven approaches to existing services and to proposed State reforms, the following questions are pertinent. They should be answered affirmatively by key stakeholders within States and local entities prior to embarking on reform toward participant-driven managed supports.

1. *Vision.* Are the values underlying the system reflective of participants' beliefs? Is the system seeking to improve the lives of people with developmental disabilities in terms of community inclusion, independence, and quality of life?

2. *Participant self-determination.* Do participants have a real say, at a systems level, in the design of disability policy? At an individual level, do participants have real authority over how funds are spent? Can they freely choose among services and among providers?

3. *Flexible array of services.* Are there real choices to be made? Are there different types of services, providers and administrative support arrangements available?

4. *Personal advocates/brokers and business agents.* Is there a voice for participants within the managed system (e.g. within the quality assurance mechanism)? Is the system-centered role of

gatekeeper balanced with a participant-centered control point? Are various types of intermediary organizations available to participants, to assist them with financial and administrative tasks?

Pertinent issues related to participant-driven approaches to existing services:
- **Vision**
- **Participant self-determination**
- **Flexible array of services**
- **Personal advocates/brokers and business agents**
- **Community partnerships**
- **Unified funding**
- **Outcome focused**
- **Cost containment**

5. *Community partnerships.* Does the system foster the creation of community and familial networks (e.g. supporting families to keep children at home vs. using out-of-home placements)? Are there incentives for organizations to collaborate in supporting participants (e.g. partnerships with acute care and long term care entities, or between day service and residential service providers)?

6. *Unified funding.* Are funds for services and supports unconstrained by categorical limitations? Is the participant or the participant's agency easily able to fund innovative responses to needs?

7. *Outcome focus.* Is the bottom line how well participants have achieved their desired goals? Does payment hinge on whether the participant is satisfied with the services and supports received?

8. *Cost containment.* Does the system manage within its budget? Is the system able to stretch the available funds to serve people who have been unnerved in the past?

Adapted from Agosta, J. & Kimmich, M. (1997) Managing Our Own Supports: A Primer on Participant-Driven Managed Supports.

Conclusion

As the new millennium approaches it is critical that the developmental disabilities field continues to analyze how current services are monitored, funded, how much money is being spent on these services and more importantly, whether or not the people receiving services (and those on waiting lists) are getting what they need and want. This must all happen at a time when the momentum within the Federal government is toward balanced budgets, cost-efficiency and Medicaid/Welfare reform. It's a time to be creative, expand possibilities, and create efficiencies while at the same time staying committed to consumer choice, participant-driven services and individualized supports. It's a time of change, it's a time of efficiency, it's an opportunity to seize!

Resources

Carf...The Rehabilitation Accreditation Commission. Carf has publications on its accreditation methodology and guides for consumer selection of service providers. Their list of publications can be obtained from them at 4891 East Grant Road, Tucson, AZ 85712, (520)325-1044 or fax (520) 318-1129.

Continuous Quality Improvement in Oregon's Programs for People with Developmental Disabilities. (1992). M. Brodsky and D. Wilson. This book describes the application of total quality management approaches to small programs for persons with developmental disabilities. It follows the quality philosophy of W. Edwards Deming, and uses a seven-step system for developing and implementing an improvement plan. The book also contains a profile of Oregon's System of Continuous Quality Improvement. Available from Paradigm Systems, P.O. Box 967, Salem, OR 97308-0967, (503) 363-8609.

Keeping the Promise: Managed Care and People with Disabilities. This publication provides information on a successful process that can be used by all key stakeholders in the field of developmental disabilities within a State or local system to develop a plan for how managed care will or will not effect services for people with developmental disabilities. The American Network of Community Options and Resources (ANCOR), 4200 Evergreen lane, #315, Annandale, VA 22003. (703) 642-6614.

Managed Care and People With Developmental Disabilities: A Guidebook. This guidebook was developed to assist States and organizations in understanding the complexities of managed care and how changes in funding methodologies could effect services to people with developmental disabilities. The National Association of State Directors of Developmental Disabilities Services, Inc. at 113 Oronco Street, Alexandria, VA 22314. (703) 683-4202; fax (703) 684-1395.

Managing Our Own Supports: A Primer on Participant-Driven Managed Supports. This primer is designed for all people within the developmental disabilities field. It provides concrete information on the principles of managed care, who the players are and on how participant-driven services and long term care can "fit." The National Association of State Directors of Developmental Disabilities Services, Inc. at 113 Oronco Street, Alexandria, VA 22314. (703) 683-4202; fax (703) 684-1395.

Quality Assurance For Individuals With Developmental Disabilities: It's Everybody's Business. (1990). V. Bradley, H. Bersani. (Eds). This comprehensive and still relevant volume contains 22 chapters of various perspectives and issues in the emerging ideas about quality assurance. Available from Paul H. Brookes Publishing Co., P.O. Box 10624, Baltimore, MD 21285-0624.

Quality Improvement In Employment And Other Human Services: Managing for Quality Through Change. (1992). J. M. Albin. This book contains basic information about the continuous quality improvement movement as well as tools for transforming an organization from facility-based to community-based employment services. Available from Paul H. Brookes Publishing Company, 800-638-3775.

Quality of Life, Volume I: Conceptualization and Measurement (1996) & *Volume II: Application to People with Disabilities.* (1997). R. Schalock (Ed). These books contain chapters on self-advocates' and family members' perspectives on quality of life, methodological considerations in measuring quality of life, application of quality of life concepts in service delivery, organizational change, public policy and cultural considerations, and whether the concept of quality of life can make a difference. Available from American Association on Mental Retardation. (800) 424-3688.

The Council on Quality and Leadership in Supports for People with Disabilities (formerly The Accreditation Council). The Council has a number of publications on their accreditation methodology, most basically Outcome Based Performance Measures. (1993). Other publications have a technical assistance orientation. A list of publications can be obtained from them at 100 West Road, Suite 406, Towson, MD 21204, (410) 583-0060 or fax (410) 583-0063.

The Fifth Discipline Fieldbook: Strategies and Tools for Building a Learning Organization..(1994). P. Senge, A. Kleiner, C. Roberts, R.Ross, and B. Smith. This more practical and readable adaptation of Peter Senge's original book gives brief explanations and practical exercises to facilitate learning and adopting systems thinking, personal mastery, mental models, shared vision and team learning. Available from Doubleday Publishing, 1540 Broadway, New York, NY 10036.

The State of The States in Developmental Disabilities. fifth edition. (1998). D. Braddock, R. Hemp, S. Parish & J. Westrich. This book provides information on trends and issues in developmental disabilities regarding: expenditures, institutional services, large private residential services, community services, State spending patterns, determinants of community spending, and models of State spending. The American Association on Mental Retardation, 444 N. Capitol Street, NW, Suite 846, Washington, DC 20001-1512.

Utilization Focused Evaluation: The New Century Text. (1997). M. Q. Patton. This new, greatly expanded third edition of Patton's popular book could serve well as a basic text on program evaluation. It has a strong focus on designing evaluations. Available from Sage Publications, (805) 499-0871.

What Legislators Need to Know About Managed Care. This brief publication provides practical information about managed care models, managed care organizations, how States have implemented managed care programs and the role of managed care in national health care reform. State profiles for Maine, Oregon, California, New Hampshire, Illinois and Missouri are provided. To obtain a copy contact the National Conference of State Legislators, 444 North Capitol Street, N.W., Suite 515, Washington, D.C. 20001.

Check out these WWW sites that contain information on managed care, funding and quality assurance:

http://www.nasddds.org - National Association of State Directors of Developmental Disabilities Services, Inc.
http://www.ancor.org - The American Network of Community Options and Resources.
http://theArc.org/welcome.html - Arc National
http://www.hsri.org - Human Services Research Institute

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.

Bradley, V.J. (1990a). "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 Co.

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.

Brammer, L. (1993) The Helping Relationship: Process and Skills (5th ed.). Boston: Allyn & Bacon.

Brickman, P., Kidder, L., Coates, D., Rabinowitz, V., Cohn, E. & Karuza, J. (1983). "The dilemmas of helping: Making aid fair and effective." In Fischer, J., Nadler, A., & DePaulo, B. (Eds.), New Directions in Helping, 1, 18-51. New York, NY: Academic Press.

Conroy, J. (1997). "Self-determination works, evaluation study finds." In Community Services Reporter, 4(1), 8.

Dufresne, D.F. (1990). "The role of service providers 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 Co.

Dunst, C., Trivette, C. & LaPointe, N. (1992). "Toward clarification of the meaning and key elements of empowerment." Family Science Review, 5, 111-130.

Osborne, D. & Gaebler, T. (1992). Reinventing Government: How the Entrepreneurial Spirit is transforming the Public Sector - From Schoolhouse to Statehouse, City Hall to the Pentagon. Reading, MA: Addison-Wesley Publishing Company, Inc.

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

Skinner, E. (1995). Perceived Control, Motivation, and Coping. Thousand Oaks, CA: Sage Publications.

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.

Smith, G., & Gettings, R. (1997). Medicaid Home and Community-Based Waiver Services and Supports for People with Developmental Disabilities: Trends Through 1997. Alexandria, VA: National Association of State Directors of Developmental Disabilities Services, Inc.

Wehmeyer, M., Kilchner, K., & Richards, S. (1996). "Essential characteristics of self-determined behavior of individuals with mental retardation. American Journal on Mental Retardation, 100(6), 632-642.

Glossary

Advocate: A person who speaks up and is active in working toward equal rights.

Arc National: A national advocacy group for people with mental retardation. There are also many State and local Arc chapters throughout the United States.

ASO: An Administrative Service Organization, a non-risk bearing entity that is hired to perform fiscal, legal, & administrative tasks.

Capitation: A method of service financing where the payer pays a fixed amount of money per person to a managing intermediary to deliver a set of services, whether or not the person uses the services.

Care criteria: List of allowable services, or standards used to determine what services can be provided.

Case management or care coordination: A system in which a single professional is responsible for ensuring that a recipient obtains the full range of services required.

Case rate: The dollar amount that the payer pays per "user" to the managing entity. Case rates are keyed to people who actually receive/use services. Capitation rates are keyed to an entire services group.

Cash and counseling: Describes recent innovative service arrangements for elderly Americans, where cash is paid directly to the individual needing assistance and the individual receives counseling from a paid professional to: set benefit levels, hire and fire, manage, assist the individual to find resources and monitor quality.

Consumer: A term often used to describe a person with a developmental disability who receives some type of services from a government or private agency. A consumer of services. This term is used in place of client to put the emphasis on the person as someone who uses services rather than someone who has a problem which needs professional help.

Decentralized: Spread out, not in one place. Residential services for people with developmental disabilities has become more decentralized since institutions have been replaced by many small group homes. This trend toward decentralization will continue as more people are supported in their own homes and with individual vocational supports.

Demographics: Percentages and real numbers that are useful in describing populations and understanding trends. For example, the percentage of people with disabilities between the ages of 25-40 who are employed full-time compared to the percentage of people without disabilities between the ages of 25-40 who are employed full-time.

Family support: Describes service programs for families who provide support at home for children, and sometimes adults, with developmental disabilities. Within a family "centered" or "driven" context, the programs make use of structured services, natural supports, and often cash assistance to: (a) make it possible for families to keep their family member at home, (b) assure that the person with disabilities receives needed services at home, (c) enhance the capacity of families to provide supports at home, and (d) realize some cost savings related to promoting care at home over out-of-home options.

Fee-For-Service: Reimbursement to a provider for the provision of services on a service-by-service basis.

Gatekeeping or primary care case management: A single practitioner is responsible for determining the quality and mix of services a recipient needs and receives.

Generic: As in generic community resources. Public resources available to all people regardless of ability such as parks, swimming classes at the local YMCA, or professionals like doctors/dentists.

Group home: A typical home in the community which has one or more people with disabilities living in it and receiving services. These homes can range in size from 2 people to 15 people and can be publicly or privately owned and operated.

Home and Community Based Services: A variety of services which are funded through the Federal Medicaid Home and Community Based Services Waiver program. HCBSS unlike ICFS/MR funding is a less regulated and more flexible pot of money which can help fund services provided in a number of settings including small agency run group homes, family homes, and a person's own home or apartment.

IEP/IPP/IHP/ISP: Individual Educational/Program/Habilitation/Service Plan. Individualized plans for a person receiving services which includes goals to be achieved in an upcoming time frame (usually 1 year). Traditionally these plans have been developed by teams of professionals with some input from family members and the individual receiving services. Goals focus on improving in areas where a person has a weakness.

In-Home services: Services provided in a person's home.

Institution: Large public or private residential program in which 16 or more people with mental retardation and other developmental disabilities live. Institutions are most often part of State-run hospitals and usually comply with the Intermediate Care Facility (ICFS/MR) standards set by the Federal government. Institutions were once the only place where people with mental retardation could receive residential supports, they are now the place of last resort for residential placement.

Integrated: A setting where people of all abilities and backgrounds work, live, or play together.

Intermediate Care Facilities for Persons with Mental Retardation (ICFS/MR): The first Federal program targeted to residential services for people with mental retardation. The size of ICFs/MR range from 6 people living in a community home to several hundred living in a large congregate setting (including units in State institutions). These programs require 24 hour supervision of the people who live in them.

Least Restrictive Environment: A clause in the Individual's with Disabilities Education Act which mandates that children receive education in the least restrictive settings possible.

Long term services and supports: Supervision or assistance given to a person with disabilities to help the individual complete daily living activities (e.g., eating, dressing, bathing, communicating, keeping a job, taking prescribed medications), learn new skills, maintain a general sense of safety and well-being, or otherwise pursue a normal daily life rhythm. Such assistance typically excludes medical interventions due to injury or illness.

Managed care: Various strategies that seek to maximize the value of services by controlling their cost and use, promoting their quality and measure performance to ensure cost effectiveness.

Managed care intermediary: The organization which links the payer and the service providers or recipients.

Managed Care Organization (MCO): The risk-bearing entity which receives a fixed payment to assure that a set of recipients get all the services they need as specified in the managed care plan; it does not directly provide any services.

Managed Service Organization (MSO): Like an MCO except that it is a network of service provider organizations, and does directly provide services.

Natural Supports: Supports which naturally occur in all people's lives. Some examples include, a friend who helps paint your house, a neighbor who picks up your mail when you are out of town, a coworker who picks up your paycheck when you are sick, the family member who introduces you to a potential new employer.

Network: A group of service providers assembled by an MCO or who come together independently to increase their competitiveness and to assure a clientele. The providers share responsibility for the network's smooth performance. Often service recipients are limited to using providers in the network, or have to pay additional costs to use an out-of-network provider.

Outcome: The benefit of services or supports.

Participant: People who are direct or indirect recipients of developmental disabilities services. In participant-driven service systems these individuals may play a strong role in directing policies and practices related to the delivery of services.

Participant-driven managed supports: A variety of strategies for administering systems to increase their effectiveness and efficiency, while maintaining a commitment to community integration and self-determination for people with developmental disabilities.

Performance indicators: Specifics, including service results, to be measured to determine service quality.

Person-centered planning: A planning process which looks at the person's strengths, needs and personal goals as a basis for service delivery. There are formalized forms of person-centered planning such as Essential Lifestyle Planning, MAPS, or Personal Futures planning, as well as informal ways of gathering information and listening to a person to see what they consider important in relationship to services and supports.

Personal assistance: One person assisting another with tasks individuals normally would perform for themselves if they did not have a disability.

Purchasing Alliance: A formal pact or union of service recipients where they act cooperatively to purchase or acquire needed services or supports from potential providers.

Qualified Mental Retardation Professional (QMRP): A person with a four year degree in a human services field and a minimum of 2 years experience working with people who have mental retardation or related conditions. The ICFS/MR regulations require that a QMRP review and approve any programs developed for people receiving services.

Quality Assurance: This term is generally used to refer to the complex web of regulations and standards, that have been determined to define quality, as well as the licensing and certification processes that enforce them. The focus of these programs is changing to include quality of life outcomes and quality assurance programs are starting to include expectations for quality improvement. Within managed care environments this means an organized set of activities intended systematically to ensure minimal safety of service recipients and to foster performance improvements.

Risk: Managed care entities assume responsibility for services and supports in exchange for receiving a fixed payment (capitation). If costs exceed this sum, the intermediary is "at risk" for the excess costs and covers the loss. If costs are less than the capitation, the intermediary earns a profit or retains revenue. In essence, it is the financial uncertainty associated with agreeing to provide all needed services for fixed payment.

Segregated: An environment where only people with a certain label or defining characteristic work, live, or play.

Self-advocate: A person with a developmental disability who is active in standing up and speaking out for the rights of all people with developmental disabilities.

Self-determination: To act as the principal causal instrument in one's life and to make choices and decisions regarding one's chosen lifestyle independent of undue influence or interference from others.

Semi-independent Living Services (SLS): A program for people with mental retardation who have low support needs and live for the most part independently with a few hours of services each week from paid staff.

Service substitution: A process requiring the use of a lower cost but equally effective service in place of a higher cost one.

Supported Living: A residential service model which is based on the provision of only those supports which the person needs- tailoring services to meet individual needs.

Utilization review: Evaluation by an outside party of the appropriateness, necessity, and/or efficiency of a given service for an eligible recipient.

Common Acronyms

The field of services to people with mental retardation and other related developmental disabilities uses literally hundreds of acronyms. While they can be useful for brevity, common courtesy requires that assumptions are not made while speaking, presenting, or writing. A term should always be defined the first time it is used and more frequently if the information is intended for people who are not professionals in the field. The following are just a few of some of the most common acronyms used:

AAMR - American Association on Mental Retardation (formerly Mental Deficiency)
AAUAP - The American Association of University Affiliated Programs for Persons with Developmental Disabilities
ADA - Americans with Disabilities Act
ADD - Administration on Developmental Disabilities (Washington, DC)
AFDC - Aid to Families with Dependent Children
ARC - Association for Retarded Citizens
ASO - Administrative Service Organization
BIA - Bureau of Indian Affairs
CAP - Community Action Program, or Client Assistance Program
CEC - Council for Exceptional Children
COBRA - Consolidated Omnibus Budget Reconciliation Act
COLA - Cost of Living Allowances
CP - Cerebral Palsy
CSLA – Community Supported Living Arrangement
DAC - Developmental Achievement Center
DD - Developmental Disabilities
DHHS - Department of Health and Human Services (Washington, DC)
DHS- Department of Human Services
DRS - Division for Rehabilitative Services (federal level); Division for Rehabilitation Services (state level)
DSP/W- Direct Support Professional or Direct Service (or Support) Worker
E/BD - Emotional/Behavior Disorders
ECFE - Early Childhood Family Education
ED - Emotionally Disturbed
EEOC - Equal Employment Opportunity Commission
ELP - Essential Lifestyle Plan
EMH/R - Educable Mentally Handicapped or Educable Mentally Retarded
EPS - Early and Periodic Screening
FAPE - Free Appropriate Public Education
FAS – Fetal Alcohol Syndrome
FERPA - Family Education Rights and Privacy Act
FY - Fiscal/Budget Year
GAO - General Accounting Office
HCBS - Home and Community Based Services
HCFA - (Federal) Health Care Financing Administration
HCPA - Handicapped Children's Protection Act
HMO - Health Maintenance Organization
ICAP-Instrument for Clients and Agency Planning
ICF/MR or ICFs/MR - Intermediate Care Facility or Facilities for Persons with Mental Retardation
IDEA- Individuals with Disabilities Education Act
IEP/IFSP/IHP/IJP/IPP/ISP/ITP - Individual Education Plan/Individualized Family Service Plan/ Individualized Habilitation Plan/ Individual Justice Plan/Individual Program Plan/Individual Service Plan/Individual Transition Plan
IQ- Intelligence Quotient
LEA - Local Education Agency

LRE - Least Restrictive Environment
LTC - Long Term Care
MA - Medical Assistance
MH - Mental Health or Mentally Handicapped
MI - Mental Illness
MR/RC- Mental Retardation and Related Conditions
NASDSE - National Association of State Directors of Special Education
NASDDD - National Association of State Directors of Developmental Disabilities
NIDRR - National Institute on Disability and Rehabilitation Research
OASDI - Old-Age, Survivors and Disability Insurance (also RSDI)
OSERS – Office of Special Education and Rehabilitation Services
OT - Occupational Therapist
P&A - Protection and Advocacy (System)
PASS - Plan for Achieving Self-Support, Social Security Administration, or Program Analysis of Service Systems
PCA - Personal Care Attendant
PCEPD - President's Committee on Employment of People with Disabilities (formerly PCEH)
PCMR - President's Committee on Mental Retardation
PCP- Person-Centered Planning
PFP - Personal Futures Planning
PKU - Phenylketonuria
PL - Public Law
PT - Physical Therapist
QA - Quality Assurance, or QE - Quality Enhancement
QMRP - Qualified Mental Retardation Professional
RFP - Request for Proposal
RRTC - Rehabilitation Research and Training Center
RSA - Rehabilitation Services Administration
SABE- Self-Advocates Being Empowered
SE - Special Education or, Supported Employment
SILS - Semi-Independent Living Services
SLA - Supported Living Arrangements
SLF/SLS - Supervised Living Facilities/ Supervised Living Services
SNF - Skilled Nursing Facility
SSA - Social Security Administration
SSDI - Social Security Disability Insurance
SSI - Supplemental Security Income
STWO- School-to-Work Opportunities Act
TASH - The Association for Persons with Severe Handicaps
TDD - Telecommunications Devices for the Deaf
VR - Vocational Rehabilitation
WAC - Work Activity Center

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