

# ***Quality – Standards, Values, Vision***

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## Quality – Standards, Values, Vision

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**Disclaimer:** The language used to describe people with developmental disabilities has changed over the past 50 years. In the earlier decades of this time period, terms and language that are now considered disrespectful and offensive, were acceptable.

As our field and society have come to recognize and urge the use of "people first" language and more respectful words to describe people with disabilities in spoken and written language, terms such as "retarded," "handicapped," "trainable," and "educable" have been replaced in many instances.

The remnants of what is now considered unacceptable language and terms may still be found in references to official governmental bodies (i.e. President's Panel on Mental Retardation), organizations that were founded during these earlier years, federal laws, reports (i.e. *Community Residences for Mentally Retarded Persons*), case law, and quotations. Please note the use of brackets around [mentally retarded] and [retarded].

## The 1960s – Emerging and Competing Perspectives

Prior to the 1960s there were few formal ways of thinking about quality in the lives of people with developmental disabilities. The 1960s saw the emergence of several approaches that would have a profound impact on how “quality” was defined and promoted.

### ***Minimal Standards***

At that point in history, a dominant view was that while institutions might have their problems, they could be improved by setting minimum standards for staffing and administering a public institution. In this view, “quality” has to do with setting standards for services offered, mainly in terms of staffing, and basically assumes that lives of quality will flow from services of quality.

Several efforts were under way in these early years including:

- In 1952 the American Association on Mental Deficiency (AAMD) published the report of a special committee on standards for institutions serving people with [mental retardation].
- The National Institute on Mental Health funded a major standards development project.
- In 1964 AAMD published Standards for State Institutions for the Mentally Retarded.
- In 1966, a number of national organizations formed the National Planning Committee on Accreditation of Residential Centers for the Retarded. The National Planning Committee included AAMD, the National Association for Retarded Citizens (now The Arc), the Council for Exceptional Children (CEC) and United Cerebral Palsy (UCP). In 1969 the Joint Commission on Accreditation of Hospitals invited the National Planning Committee to establish an accreditation council within its structure. This led to the Accreditation Council for Facilities for the Mentally Retarded (ACFMR). The ACFMR developed accreditation standards and conducted accreditation reviews of facilities serving people with mental retardation through the 1970s.

This mindset of minimal standards and institutional improvement led to The Technical Planning Committee of the American Association on Mental Deficiency (1964) recommending that a 500-bed institution for people with developmental disabilities should have "consultant physicians in pediatrics, psychiatry including child psychiatry, electroencephalography, neurology, neurosurgery, orthopedic surgery, physical medicine and rehabilitation, internal medicine, general surgery, anesthesiology, ophthalmology, otolaryngology, radiology, and pathology" who are to make regular visits to the institution and conduct clinics and ward rounds in it. Other personnel and services recommended by the AAMD Technical Planning Committee are on a similarly scale. (Tizard, 1969)

Gunnar Dybwad indicated in 1969 that actions resulting from the development of standards and reviews using them were missing the mark:

Unfortunately NARC has lost much of its original forcefulness, and particularly in the area of residential care it has not been aggressive enough in informing the general public, legislative bodies, and key professional organizations of the disgraceful situations in our state institutions, involving gross violation of state law and state standards, gross lack of the most essential pieces of clothing and bedding, gross violation of residents' civil rights, and instances of cruel and inhuman punishment, unjustified use of restraints, and prolonged detention. Of all these matters no one has a more penetrating knowledge than NARC's membership, but not enough has been done to use this knowledge strategically for the ultimate benefit of the institutionalized [mentally retarded] children and adults, who are so desperately in need of a forceful advocate. (Dybwad, 1969, pp. 400-401)

### ***Overview of the System of Services (Broken but Fixable)***

A second view emerged as various organizations looked at the pattern of services across the nation. "Quality" had to do with ensuring there were no waiting lists, that there were enough staff and facilities to respond to the demand. Early in his administration, President Kennedy established the President's Panel on Mental Retardation. In 1962, The Panel issued its report. The Panel was clear that the pattern of services were not meeting the demands on the system. The Panel made diagnostic statements about the nature of services and recommended courses of action for the future. It focused on many areas of service, but its statements about schools and institutions were typical.

While we have no definitive information on the quality of service available, we know that the school health program is minimal in many school systems.

Less than 25 percent of our [retarded] children have access to special education. Moreover, the classes need teachers specially trained to meet the specialized needs of the retarded. To meet minimum standards, at least 75,000 such teachers are required. Today there are less than 20,000, and many of these have not fully met professional standards.

The average waiting list [for residential institutions] continues to grow and the quality of service often suffers from limited budgets, low salary levels, and severe personnel shortages.

The quality of care furnished by State institutions varies widely, but from the standpoint of well-qualified and adequate personnel and the availability and use of professional services and modern, progressive programs, the general level must be regarded as low. In large State institutions the normal problems of administration and care are compounded by overcrowding, staff shortages, and

frequently by inadequate budgets. In face of these difficulties, it is to the credit of State authorities and superintendents that there are a number of good, and a few first rate, institutions. (President's Panel, 1962, and October 1962)

Like the "standards" approach, most of the emphasis was on staffing levels and qualifications, and physical facilities. The dominant pattern of service was congregation and segregation. Custodial care was the norm, though the President's Panel urged a therapeutic approach in all services.

In this same vein, in 1963 the National ARC Committee on Residential Care published a survey and study of state institutions for those with developmental disabilities in the United States. The survey focused on admission and preadmission procedures, food and clothing services, education, recreation and religion practices, volunteer services, and rehabilitation programs. (NARC, 1963, p. 9)

### ***Combating Dehumanization, Promoting Normalization***

A third set of perspectives began to look more directly at the humanity of services in the lives of people with disabilities. "Quality", it was argued, had to do with dignity, integration, and typical lives in the community, supported by services which humanized rather than dehumanized.

One set of perspectives was a much more aggressive view of how to improve institutions and add community services, while the second advanced the position that quality lives and services were to be found in the community, not the institution. Both of these perspectives were linked in some common values about the ways that people are dehumanized by controlling environments.

The work of Dr. David Vail in Minnesota was a leading example of a much more aggressive view of how to improve institutions, and a call for more community services. Vail had been greatly influenced by the work of Erving Goffman. In Asylums (1961) Goffman identified the typical features of life in a "total institution" and how those features dehumanize and depersonalize those who live in them. Vail adapted Goffman's criteria, and developed what he called the "Criteria of Hospital Dehumanization" (Vail, December, 1963) Vail used those criteria to stimulate discussion among the staff and patients of Minnesota's state hospitals. Vail elaborated on this perspective in his book, Dehumanization and the Institutional Career. In his book, Vail focused on the concept of dehumanization and rehumanization (or dignity). Gunnar Dybwad (1969) commented on the contribution of the perspective and its application in laying the ground work for the acceptance of the principle of normalization in North America,

It is therefore particularly fortunate that in 1966, David J. Vail, a well-known psychiatrist and administrator of the mental health and [mental retardation] facilities in the State of Minnesota, published a book entitled Dehumanization and the Institutional Career. In this brilliant work, Vail provides a detailed documentation of the many ways in which our institutions serving the mentally ill or the [mentally retarded] go about stripping from the residents their human

dignity, their identity, their motivations, their privacy, their basic human rights. In short, not only does Vail's book provide the most cogent reason for adoption of the general concept of normalization, but item by item it would be possible to put into juxtaposition for every example of dehumanization given by Vail a corresponding situation characteristic of the process of normalization. (Dybwad, 1969, p. 390)

In 1963, Vail claimed that "Minnesota's mental hospitals are already to a great extent 'social hospitals'. Yet the Legislature agreed that much remains to be done." (Vail, 1963) Vail did advocate for the development of dignified mental health treatment in the community. By early 1980, most Minnesota residents with mental illness had in fact been moved out of institutions. Unfortunately, they had virtually nowhere to turn in the community for alternative services or support. (Vail Place, History, 2009)

In Britain in 1962, Jack Tizard was making the case that the segregation from the community of children and adults with developmental disabilities reinforced prejudice and discrimination against them. The only way to prevent the stigma was integration. In the 1960s, Wolf Wolfenberger did a one year National Institute of Health research fellowship at Tizard's hospital.

When Tizard presented his views to a U.S. audience in 1969, he advocated for the development of quality services in the community. He emphasized the basic human needs of all people, and using those common needs as the basis for judging the adequacy and quality of services.

It appears to me that the AAMD model of comprehensive, up-to-date hospital-type care has been put forward without sufficient thought having been given either to the role which such an establishment should serve in the general community or to the needs of the residents who will live in it. Remarkably few of the residents in mental deficiency institutions today require hospital treatment; very few even require basic nursing. ... Few [retardates] need hospital treatment; all need education, employment, a satisfying social and cultural environment, and, in the case of [retardates] who cannot live with their own families, a home in which they can live as normal a life as possible. In the large institution, it is difficult to provide for these needs. (Tizard, 1969)

Also in the early 60s, Tizard, along with colleagues in Scandinavia, were developing models that would demonstrate another way of responding to people.

By 1967, the International League of Societies for the Mentally Handicapped, at its Symposium in Stockholm, had adopted a position in favor of integration as the measurement of quality. It stated as a general conclusion that "the services provided for persons with developmental disabilities should in no way segregate them from the rest of the community; for example, classes, workshops, recreational facilities and living accommodations should be integrated, as far as possible into those provided for other members of the community." (Legislative Aspects of Mental Retardation, June, 1967)

By 1969, the stage was set for the introduction of the concept of normalization to the United States. The most influential document in terms of introducing normalization to North America was the President's Committee publication *Changing patterns in residential services for the mentally retarded*. Edited by Paul Krugel and Wolf Wolfensberger.

*Changing Patterns* included articles by Burton Blatt, Wolfensberger, Bengt Nirje, Jack Tizard, and Gunnar Dybwad, each supporting a view of "quality" quite different than the institutional model and its minimum standards.

Nirje (1969), for the first time in North America presented normalization as a unifying principle to guide advocacy for better life conditions, law, policy, standards, the design of facilities, and the operation of programs:

As expressed by N.E. Bank-Mikkelsen of Denmark, this principle is given in the formula "to let the [mentally retarded] obtain an existence as close to the normal as possible." Thus, as I see it, the normalization principle means making available to the [mentally retarded] patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society.

1. Normalization means a normal rhythm of day for the [retarded].
2. The normalization principle also implies a normal routine of life.
3. Normalization means to experience the normal rhythm of the year, with holidays and family days of personal significance.
4. Normalization also means an opportunity to undergo normal developmental experiences of the life cycle.
5. The normalization principle also means that the choices, wishes, and desires of the [mentally retarded] themselves have to be taken into consideration as nearly as possible, and respected.
6. Normalization also means living in a bisexual world. [They should not be segregated by sex, and should be supported by both men and women.]
7. A prerequisite to letting the [retarded] obtain an existence as close to normal as possible is to apply normal economic standards.
8. An important part of the normalization principle implies that the standards of the physical facilities, e.g., hospitals, schools, group homes and hostels, and boarding homes, should be the same as those regularly applied in society to the same kind of facilities for ordinary citizens (size, location, and so on). (Nirje, 1969, pp. 183-185)

Gunnar Dybwad (1969, pp. 387-389) suggested that "our highly interrelated concepts of residential service can be derived directly from the normalization principle. These are integration, dispersal, specialization, and continuity."

- Integration refers to those measures and practices which maximize a ... person's community participation.
- Every effort should be made not to congregate deviants in numbers larger than the surrounding community can absorb and integrate.

- Dispersal is difficult, perhaps impossible, to achieve without specialization of residential functions. It is inconceivable that a small residence in a neighborhood could adequately and simultaneously serve all those functions that the traditional institution serves.
- Continuity of personal functioning is important in achieving normalization. This requires a continuity of available services, and continuity between those aspects of a person's life which are supported by special services and those which are not.

In the 1970s Wolfensberger would begin a number of modifications of the original idea of normalization and develop a number of training and evaluation tools to bolster the quality of human services.

These developments informed the design and delivery of alternative approaches to service, approaches that were alternatives to institutions and could demonstrate higher quality outcomes in people's lives. They formed the basis for improving the standards of quality in court decisions, legislation and administrative standards.

## **Outrage**

The fourth kind of "quality" measure was a basic gut reaction to actually seeing conditions inflicted upon people with disabilities. As John O'Brien, so clearly states:

There is a place for scientific inquiry and for expert knowledge, but what is essential to changing life for the better is obvious to human senses –eyes and nose, ears and touch -- and registered in human emotion –terror and sadness, anger and depression. Denial and rationalization deaden perception and excuse inaction. (O'Brien, 2005, p. 5)

Two reactions of shock and shame drew the public attention to the state of affairs in the nation's institutions – a visit by Senator Robert Kennedy to several institutions followed by Burton Blatt and Fred Kaplan's words and photos published as *Christmas in Purgatory*. Blatt later published an article in *Look* magazine that brought the issue to a wider audience.

As Blatt (1969, p. 38) described the events before he and Kaplan took their action:

In the early fall of 1965, Senator Robert Kennedy visited several of his state's institutions for the [mentally retarded]. His reactions were widely published in our various news media, shocking millions of Americans as well as infuriating scores of public officeholders and professional persons responsible for the care and treatment of the [mentally retarded]. Most of the laymen with whom I discussed his visits reacted to the Senator's disclosures with incredulity. For it is difficult for "un-involved" people to believe that, in our country, and at this time, human beings are being treated less humanly and under more deplorable conditions than are animals. A number of the "involved" citizenry, i.e., those who legislate



and budget for institutions for the [mentally retarded] and those who administer them, were infuriated because the Senator reported only the worst of what he had seen, not mentioning the worthwhile programs that he undoubtedly was shown.

Subsequently, on Thanksgiving Day, 1966, Burton Blatt, a professor, suggested to his friend Fred Kaplan, a photographer, that they visit the wards of a public institution with a hidden camera. They did so in December. As Blatt relates,

Through the efforts of courageous and humanitarian colleagues, including two superintendents who put their reputations and professional positions in jeopardy, we were able to visit the darkest corridors and vestibules that humanity provides for its "journey to purgatory," and, without being detected by ward personnel and professional staff, Fred Kaplan was able to take hundreds of photographs. (Blatt, 1969, p. 39)

His description of their time there begins,

Almost immediately after I passed the threshold, an overwhelming stench enveloped me. It was the sickening, suffocating smell of feces and urine, decay, dirt and filth, of such strength as to hang in the air and, I thought then and am still not dissuaded, solid enough to be cut or shoveled away. But, as things turned out, the odors were among the gentlest assaults on my sensibilities.

This type of guerilla quality assurance approach perhaps did more than any decades worth of professional standard reviews to alert the nation to the issue of "quality" and the fact of dehumanization in residential institutions. One thousand copies of *Christmas in Purgatory* were published and distributed during the summer of 1966, without cost, to prominent legislators, commissioners of mental health, university professors, and leaders of the parent movement.

Blatt described what he saw as "cruel and unusual punishment". This foreshadowed another perspective on "quality" in the 1970s – the dramatic rise in court cases asserting that institutions were denying the fundamental citizenship rights of people with disabilities. (Blatt, chapter 6)

### **The 1970s – Rights and Relationships**

Many of the developments of the 1960s continued and expanded into the 1970s – accreditation reviews continued, normalization developed as a powerful tool for training and evaluation, and researchers monitored the state of the system.

And three new approaches and perspective on quality – court challenges, federal legislation that is quality and protection based, and relationship based advocacy.

## ***An Explosion of Tools to Assess Environments and Programs***

In 1977, the Accreditation Council for Services for Mentally Retarded and Other Developmentally Disabled Persons (AC/MR-DD) consolidated its standards for institutional and community (ICF/DD) services. The standards were organized into seven major sections:

- Individual program planning and implementation
- Alternative living arrangements
- Achieving and protecting rights
- Individual program support
- Safety and sanitation
- Research and research utilization
- The agency in the service delivery system

By 1978, Terri Johnson was able to identify and describe over 15 sets of standards and scales to measure quality or at least describe program characteristics for programs serving people with developmental disabilities. Some tools were for use by professionals but many were accessible to community members, parents and in some cases, self advocates.

Wolf Wolfensberger and Linda Glenn originally developed Program Analysis of Service Systems (PASS) in 1969, but it became part of the human service landscape in the 1970s with the publication of The Principle of Normalization (1972) and the development of an infrastructure for supporting the use of PASS and PASS 3 for training and evaluation purposes.

Wolfensberger transformed the statement of the normalization principle from Nirje's earlier presentation. While Nirje emphasized the principles in terms of outcomes -- making available to the people with developmental disabilities patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society. Wolfensberger shifted the emphasis to –

The use of methods and settings which are valued and familiar, to offer each person life conditions and opportunities which are at least as good as those of the average citizen, and as much as possible to enhance and support each person's behavior, status and reputation. (Wolfensberger, 1972)

Jack Yates (1979) summed up the essence of normalization as “the opportunity for equality: every person should have the right to share equally in the benefits and difficulties of life in the human community . . . We need to plan, act and teach on that basis.”

PASS contained 50 rating statements on a number of dimensions in the areas of Ideology and Administration

## **Ideology**

- Normalization-related
  - Integration (social and physical)
  - Appropriate interpretations and structures (age appropriate and culture appropriate)
  - Model Coherency
  - Developmental Growth Orientation
  - Quality of Setting
- Ideology related administration
  - Comprehensiveness
  - Utilization of generic resources
  - Consumer and public participation
  - Education of the public
  - Innovativeness
- Human science orientation (ties to academia and research climate)
- Regional Priorities (deinstitutionalization and age groups)

## **Administration**

- Manpower considerations (staff and manpower development)
- Operational Effectiveness (internal administration and finance)

By 1979, Wolfensberger was reformulating his approach and PASS transformed to PASSING based on Social Role Valorization.

Social Role Valorization, or SRV, posits that people who fill positively valued roles will be likely to obtain and receive the good things of life, while people who fill negatively valued social roles will find it much harder – sometimes impossible – to get the good things of life... SRV further posits that the two major avenues towards positively valued social roles are enhancement of image, and enhancement of competencies; the more positive one's image, and the more competent one is, the more one will have access to valued social roles, and therefore the good things of life. (Training Institute for Human Service Planning, Leadership and Change Agency, 2007)

James F. Budde (1976) from the University of Kansas developed a tool for analyzing and measuring deinstitutionalization across residential environments. ALERT (Alternative Living Environments Rating and Tracking System), His tool could be used to systematically track system changes and the extent to which individuals were being supported in higher quality environments. Budde described deinstitutionalization as a "simple process" –

... placing clients in the least restrictive environment, an environment providing models that develop and maintain culturally normal behavior. The end of the process for an individual client is the realization of his full potential – ideally, the ability to live independently and work in his chosen community. (Budde, 1976, p. 1)

ALERT was designed to measure output – changes in an individual or his individual life style. He developed based on four “life styles” – institutionalized, physical integration, physical and social integration, and independence. From this he developed a matrix of living environments which could be used for different purposes:

- Analysis of the service system living alternatives
- Collection and display of baseline data
- Planning and projection of living alternatives
- Comparison of living alternatives over time (baseline compared to subsequent data).

### ***Court Established Criteria for Quality***

The 1970s saw a wave of court cases focusing on education and institutions, rooted in a rights definition of quality – the right to an education, protection against discrimination and cruel and unusual punishment, the right to treatment and protection from involuntary servitude.

Some were sparked by exposés in the Blatt and Kaplan tradition. Widespread newspaper and television coverage exposed the deplorable conditions at Willowbrook State School in New York. The court called for the phasing out of the institution and recognized the “right to treatment”.

In Alabama, *Wyatt v Stickney* established the right to treatment and the right to habilitation. New standards were developed based on four key principles:

1. Humane psychological and physical environments;
2. Qualified staff in numbers sufficient to administer adequate treatment;
3. Individualized treatment plans; and
4. Services in the least restrictive environment.

In Massachusetts *Stewart v Phillips* (1971) ruled that student placements had to be based on a resulting positive educational benefit for them. If a placement did not result in a benefit, then it was discriminatory. *PARC v Pennsylvania* (1972) ruled that all children deserve an education and that separate facilities are inherently unequal. It gave concrete meaning to the idea of “least restrictive environment”.

In 1973 *Souder v. Brennan* and the Pennsylvania "Institutional Peonage Abolishment Act" began to undercut the common and standard practice of involuntary servitude in residential facilities.

These court cases were “early days” approaches that did not move far beyond the minimal standards approach of early accreditation standards. From the perspective of 1990, Michael Lottman summarized the period and its impact into the 1980s.

Although federal courts have been closely involved with state mental retardation and mental health systems since the early 1970s, a cautious, almost hesitant,

approach has characterized judicial actions in the area of quality assurance. Even in early decisions that advanced a “right to treatment” for residents of state institutions, the standards actually imposed by the courts reflected no more than minimally adequate habilitation or treatment ... A decade later, this reserve seemed even more evident as the focus of judicial inquiry was limited to whether a challenged practice or decision “is such a substantial departure from accepted professional judgment, practice, or standards as to demonstrate that the person responsible actually did not base the decision on such a judgment”. ... In truth, however, whether the standard was minimal adequacy or deference to professional judgment, judges have always been reluctant to impose detailed programmatic requirements of their own. (Lottman 1990 pp. 149-150)

### ***Federal Legislation for Quality and Protection***

In 1970, the Developmental Disabilities Services and Facilities Construction Amendments (P.L. 91-517) were the first effort by the U.S. Congress effort to address the needs of a group of people with disabilities labeled “developmentally disabled”. The act amended the Mental Retardation Facilities and Community Health Centers Construction Act of 1963. As such it authorized state allotment for the construction of facilities, but also for planning and services.

This first effort set up state planning and advisory councils. It required a State plan which was to become a mechanism for describing the quality and extent of services.

It also expanded university affiliated facilities program -- interdisciplinary training in institutions of higher education to help meet shortages of personnel to provide services to people with developmental disabilities.

In 1975, the Developmental Disabilities Assistance and Bill of Rights Act (P.L. 94-103) established a firmer basis for ensuring quality.

- It identified the "rights of people with Developmental Disabilities," which included Congressional findings such as the right to appropriate treatment and services designed to maximize individual potential.
- It added a requirement that all people served under authorized programs have in effect a written habilitation plan which states long-term habilitation goals, intermediate plans, and a plan for service delivery.
- It required that protection and advocacy programs be established in each state as a condition to receive a state grant. The protection and advocacy systems are designed to protect and advocate for the rights of people with developmental disabilities and to pursue legal, administrative, and other remedies to ensure the protection of rights for such people.

Written habilitation plans could serve as a basis for defining quality and accountability in terms of outcomes for individuals in many areas of life. The delineation of rights laid the groundwork for arguing that those plans should meet higher standards of quality. The protection and advocacy programs could serve as the basis for protecting quality.

The amendments also four priority service areas were established: case management services, child developmental services, alternative community living arrangement services, and non-vocational social-developmental services. The designation of priority areas would stimulate the development of model programs.

The emphasis on case management, as with the requirement of individual habilitation plans, helped establish at least the potential for individual based quality assurance.

### ***Relationships at the Heart of Quality Assurance***

The dominant view of “quality” and “quality assurance” focuses on services and systems, their programs and processes, and the outcomes the achieve, either in program quality or for individuals directly.

At the same time, there was a growing appreciation for the fact that “quality” is also a personal reality and perception. “Quality” is intimate to the extent that it is experienced uniquely by the individual. At this level of intimacy, the individual is more likely to experience “quality” when surrounded by people with whom the individual is in relationship, a relationship based on mutual understanding and commitment.

In this spirit, it is understood that fundamentally it is people and relationships that keep people safe and assure quality, not standards, courts and systems.

In the early 1970s, the idea of Citizen Advocacy was developed by Wolfensberger and Zauha (1973). Citizen Advocacy is built on one-to-one, freely given personal relationships between two people. One is a person with a developmental disability who has often been excluded from typical community life, and the other is a person who is living a good, ordinary life here in our community. The task of the advocate is understood to be one of representing (or supporting) a person so as to ensure that their point of view is heard or their rights upheld.

Four principles guide the work of Citizen Advocacy organizations:

- Each citizen advocacy relationship is freely given.
- Each citizen advocate is independent of human services, the citizen advocacy office, and, if necessary, his/her advocacy partner’s family. Loyalty to the individual person allows the advocate to speak out and act with freedom and clarity.
- Most citizen advocacy matches are established with the hope of developing a long-lasting relationship, some of which may be life-long.
- Each citizen advocate looks for ways to bring his/her protégé’s interests, gifts and needs to the larger community in ways that are dignified and enhancing to the person.

For more information go to <http://www.mnddc.org/learning/documents2009/81-ECS-MSP.pdf>

Over the years, this basic approach would be elaborated into a broader approach to grounding individuals who are in relationship into the Quality of Life and future experienced by the individual.

This commitment based on relationship is at the heart of circle building, personal futures planning (and all of its variations).

### **The 1980s – Quality in the Community**

There were a host of development in the 1980s but most had to do with developing quality assurance systems that could cope with the blossoming of community services; the involvement of citizens and consumers (families and self advocates) in monitoring services, and the ongoing efforts to match standards with values.

#### ***From Monitoring to Quality Assurance***

Val Bradley in 1984 and 1990 summed up some of the challenges related to quality assurance in the 1980s. She outlined the importance of quality assurance, especially when there are scarce resources and a competition for resources (institutional vs. community services, out of home placements vs. family support, and so on).

- Quality assurance mechanisms are necessary to ensure that the most effective and efficient services survive funding cut-backs. Without adequate information regarding the quality of services, the process of allocating scarce resources will lack foundation and will be too easily swayed by political pressures.
- Quality mechanisms are also important to the protection of client well-being in times of limited funding. As financial support becomes constrained, service providers may be forced to cut corners in order to meet continuing demand. If this process is not carried out in a rational and conscientious fashion, the interests of particular clients may suffer.
- The community system is serving more individuals with severe disabilities. Responsive quality assurance mechanisms are necessary to ensure that the promises that have been made to these sometimes vulnerable individuals and their families are kept and that community placement does not leave them stranded in potentially exploitative and abusive situations.

She pointed to the preoccupation with system builders who showed with “a furious and intense effort to construct a network of community living and working environments for persons with disabilities that could serve as alternatives to large institutions.” And then in the 1980, their attention shifted to “the development of an ‘infrastructure’ to manage the service delivery system, including the creation of case management, contracting and auditing systems, rate- setting formulas, and management information systems.”

This also involved developing certification and competency-based training regulations and strategies. Throughout the decade she argued that quality assurance was the major issues that was overlooked. (Bradley, 1990, pp. 3-4)

It is not sufficient to simply set standards, or even to monitor actions based on those standards. Without the capacity to respond to what is discovered, the process is ineffective. Bradley echoed the concerns of many others in saying that

... “most [quality assurance systems] are only partially effective and in some instances counterproductive. The problem stems from an inadequate balance between the aims of quality regulation and quality enhancement.... The imbalance stems from an over-reliance on mechanisms that are static, that fail to reward superior performance, that entail burdensome documentation requirements, and that are oriented to fault-finding rather than capacity enhancement. (Bradley, 1984, p. 10)

Three kinds of responses illustrated at least some of the possibilities – monitoring activities related to court ordered actions, consumer involvement, and a greater focus on the values that inform standards.

### ***Court Ordered Actions***

Several of the court ordered institutional closure and downsizing processes in the 1980s included court appointed monitors and evaluation efforts. To some extent at least, these processes included standards from the court orders, or at least inferred from them, monitoring and evaluation capacities, and a framework of responding, including court intervention.

Perhaps the best known such effort was the Pennhurst Longitudinal Study (Conroy and Bradley, 1985). Over a five year period, the study examined various dimensions of life in the community for people relocated from Pennhurst. The study was able to look at changes over time and compare results on the following dimensions:

- Implementation issues
- Growth and development
- Consumer satisfaction
- Quality of environments
- Family impact
- Neighbor attitudes
- Comparative analysis of the costs of institutional and community settings

One of the distinguishing features of the Pennhurst study was that the researchers gave attention to an often neglected outcome indicator – consumer satisfaction. This theme of looking to the people themselves would achieve fuller expression in approaches that matured in the 1990s.



Leismer (1984) based on the experience with the Plymouth Consent Decree, developed a list of 21 factors for “a mature and responsible community-based system of care”:

- Normalized residential settings
- Aesthetically and programmatically appropriate sites
- Selective screening of good administrators and providers
- Adequate staff-to-client ratios
- Coordinated service delivery system
- Individual program plan
- Staff with adequate training, pay and benefits
- Adequate age-appropriate, need appropriate day programs
- Adequate funding
- Rigorous standards for licensure
- Natural home support
- Citizen advocacy
- Supports for former clients living in the community
- Smallness of program
- Adequate and ample supportive services
- Case management
- Adequate transportation
- Behavior plans
- Performance contracts
- Flexible funding
- Community education

### ***Citizen and Consumer Involvement***

During the 1980s, an array of frameworks and manuals was also developed to inform the efforts of community members to ensure that the services offered in their community achieved what they hoped they would. A second dimension of this involvement was personal futures planning which brings people together with an individual to look at and secure the future. A third dimension was the emergence of the self advocacy movement as a powerful voice of people with developmental disabilities themselves and their efforts to define quality from their perspective.

**Consumer Tools.** PASS was developed in part as a tool that could be used by citizens, not just service professionals. At the same time, parent groups and

organizations, as well as others, developed local projects and manuals throughout the 1980s. Examples include:

- Partnership for Quality Services – Keep the Quality of Life Growing (Volunteer Monitor's Handbook) from the Arc Minnesota developed with a grant from the Minnesota Governor's Council on Developmental Disabilities.
- Monitoring Community Residences – Guidelines developed by ARC-Ohio (1984).
- Consumer Review of Programs (consumer program evaluation instrument for employment and education services to be utilized by program participants and other interested consumers) develop with a grant from the Maryland State Council on Developmental Disabilities (1985).
- The California State Developmental Disabilities Council's "Monitoring the Quality of Life Experienced in Living Arrangements: A guide to citizen participation" (1981).
- It's My Choice, produced by the Minnesota Governor's Council on Developmental Disabilities (Allen, 1984).
- ANDI for Consumers: A workbook for helping people with disabilities evaluated the places they live and work (Allen and Gardner, 1985) (based on *A Normalization and Development Instrument* by Ann G. Flynn and Sandra K. Weiss)
- <http://www.mnddc.org/learning/document/GT108.PDF> Family support a checklist for Quality Arc, 1983.

In 1987, the Minnesota Governor's Council on Developmental Disabilities launched Partners in Policymaking®. The core curriculum covers current issues, state-of-the-art approaches and best practices in many areas including legislative processes and strategies; communication and team-building; using assistive technology; independent living; creating inclusive communities; and employment. More than 23,000 Partners graduates in 2012 are part of a growing national and international network of community leaders serving on policy making committees, commissions, and boards at all levels of government. The program also reaches people through the online courses and apps.

Partners in Policymaking was quite consistent with the 1987 amendments to the Developmental Disabilities Act. The amendments strengthened a change in focus of DD Councils from service provision or demonstration to policy change. The amendments supported Councils adopting the role of public policy advocacy, and educating policymakers.

**Personal Futures Planning.** An even more personal level of quality assurance, personal futures planning and related approaches, was developed in the 1980s and into the 1990s. Personal Futures Planning is a planning and engagement process that involves:

- Getting to know the person and what his or her life is like now
- Developing ideas about what he or she would like in the future

- Taking action to move towards this, which involves exploring possibilities within the community and looking at what needs to change within services.

The people who care about and are close to the focus person come together. This can include family, friends, advocates, service providers and others. This small group focuses on opportunities for the person so that he or she may successfully develop relationships, be involved with the community, have control over his or her life, and develop the skills and abilities necessary to reach his or her goals. A personal futures plan is a vision of what that person wants to be and do. The plan changes accordingly as new opportunities and obstacles arise.

Other person centered approaches include:

- Life-Style Planning (O'Brien, 1987; O'Brien & Lovett 1992),
- The McGill Action Planning System or MAPS (Vandercook, York, & Forest, 1989)
- Essential Lifestyle Planning (Smull & Harrison, 1992) and
- Planning Alternative Tomorrows with Hope or PATH (Pearpoint, O'Brien, & Forest, 1993).
- It's Never too Early, It's Never too Late (Mount & Zwernik, 1989) video and books.

All these systems are based on similar values and principles which are embodied in John O'Brien and Connie Lyle's "Five Accomplishments" (1987):

- Community Presence: How can we increase the presence of a person in local community life?
- Community Participation: How can we expand and deepen people's friendships?
- Encouraging Valued Social Roles: How can we enhance the reputation people have and increase the number of valued ways people can contribute?
- Promoting Choice: How can we help people have more control and choice in life?
- Supporting Contribution: How can we assist people to develop more competencies?

These experiences can lead to the kind of personal growth that allows people to live lives of contribution and be valued members of their communities.

**Self Advocacy Voice.** In North America, the People First movement began in the late 1970s in Oregon and various parts of Canada. In the 1980s it spread rapidly and provided a forum for people labeled developmentally disabled to speak up for themselves and advocate for their own definitions of quality, in services and in their lives.

**Self Advocates Becoming Empowered (SABE)** (2009) describes itself as the United States' national self-advocacy organization. It has a national board of regional representatives and members from every state in the US. SABE believes:

- People with disabilities should be treated as equals.
- People should be given the same decisions, choices, rights, responsibilities, and chances to speak up and empower themselves.
- People should be able to make new friendships and renew old friendships just like everyone else.
- People should be able to learn from their mistakes like everyone else.

The goals of self advocacy organizations vary considerable from community to community and over time. The current goals of SABE include:

- Make self-advocacy available in every state including institutions, high schools, rural areas and people living with families with local support and advisors to help.
- Work with the criminal justice system and people with disabilities about their rights within the criminal justice system.
- Close institutions for people with developmental disabilities labels nationwide, and build community supports.

In the late 1980s, the Administration on Developmental Disabilities provided a grant to the World Institute on Disability to coordinate the Quality of Life Project. The purpose of the California and other projects was to speak directly to persons with developmental disabilities (consumers of service) and ask them to define for themselves the issues that are significant in their daily lives. The projects built on the National Quality of Life Project. The framework for discussion was guided by four important principles:

1. QUALITY OF LIFE for persons with disabilities consists of the same factors and relationships that are important to persons without disabilities.
2. The QUALITY OF LIFE of an individual is intrinsically related to the quality of life of other persons in his or her environment.
3. QUALITY OF LIFE is experienced when a person's basic needs are met and when he or she has the opportunity to pursue and achieve goals in major life settings.
4. QUALITY OF LIFE should be defined by the consumer and not by professionals. It is how the individual views his or her situation that determines the quality of life he or she experiences.

At the Quality of Life Project conferences, participants identified issues and recommendations related to family life, residential life, community participation, education, and work.

In addition to independent and autonomous self advocacy organizations, many service organizations began to develop consumer advisory groups of one sort or another.

And at the individual level, personal futures planning approaches and relationships developed through citizen advocacy and similar approaches recognized the voice of self advocates as central to the definition of quality and the basis of actions for those near and dear to the individual.

### ***Explicit Links between Values and Standards***

Through the 1980s a few accreditation standards began to adopt similar statements of value. These paralleled amendments to the Developmental Disabilities Act in 1984 and 1987 with an emphasis on help assuring that people with developmental disabilities achieve their maximum potential through increased independence, productivity, and integration into the community.

Pearce's (1990) descriptions of changes in the Commission on Accreditation of Rehabilitation Facilities (CARF) are representative of the times.

CARF, given that its history coincides with the deinstitutionalization movement and its initial commitment to community services, has had to confront the issue of the metamorphosis and the naming of values head-on in its standards setting process. Through a process that has taken place since 1984, and that has involved consumers, advocates, and national organizations as well as providers and other professionals, CARF has named one primary value that forms the underpinnings of all of its standards. That value says that people with developmental disabilities have, first and foremost, the right to have maximum control possible over their own lives. A corollary of that value is that people with developmental disabilities also have the right to live their lives maximally integrated into the fabric of the community within which they reside. The values of personal empowerment and community integration are amplified in the CARF standards.

Accreditation standards, however, must go beyond statements of philosophy and values and must set forth requirements for service providers that translate values into day-to-day practice.

For CARF, the following values must be reflected in practice for a provider of programs and services to people with developmental disabilities to be eligible for accreditation. Persons served must be offered the opportunity to:

- Receive services in an environment that promotes integration, self-sufficiency, and productivity.
- Receive programs that maximize their functioning.
- Determine the direction of their own lives through involvement in planning, decision-making, and implementation of their programs.
- Maximize their developmental potential through individual program planning that is goal-oriented, coordinated, interdisciplinary, and subject to time based review.
- Move among various programs and levels so as to ensure that services are provided in the most integrated, least restrictive environment possible.

- Be supported in their struggle for independence in an environment that promotes social and economic opportunities in the community through the removal of attitudinal, architectural, and other barriers. (Pearce, 1990, p. 223)

Similarly the Accreditation Council on Services for People with Developmental Disabilities began to have a separate set of standards related to values. The values section of the 1990 standards state (cited in Gardner and Parsons, 1990, p. 213):

There are a number of values that shape contemporary service delivery and that are reflected in these standards:

- (1) the family is the primary social environment for children with developmental disabilities and the basis for lifelong personal relationships for adults;
- (2) the community is the natural environment in which individuals should live, work, and play;
- (3) the fabric of social relationships supports individuals in that environment;
- (4) individuals with developmental disabilities have the same rights as those who do not have a disability; and
- (5) the individual and, where appropriate, the family should have some control over the individual's participation in services received.

We also espouse:

- (1) the principles of normalization;
- (2) the principles of age-appropriateness; and
- (3) the principles of least restriction.

The values section of the 1990 standards was divided into the following categories:

- Consumer empowerment and decision-making (5 standards)
- Community integration and social relationships (28 standards)
- Affirming and protecting rights of individuals (51 standards)
- Normalization, age-appropriateness, and least restriction (24 standards)

Despite an apparent consensus on the values and principles informing standards, great divisions continued among and between different stakeholder groups. The same words used by different groups had quite different meanings. To the extent that service providers and professional groups held most of the power and control of the system on the ground, many felt that interpretations of integration, normalization, least restrictive environment, personal empowerment, and so on were from the perspective of the service provider not those who receive those services.

For instance, CARF standards definition for "residential services" was:

A residence is a place where a person lives. The goal of a residential program is to enable those served to have the best possible Quality of Life through a program which is integrated into the community. Toward that end, services are typically provided in houses or apartments which provide a personalized living environment. (cited in Pearce, 1990, p. 228)

Contrast that statement with the definition of home described in the Minnesota Governor's Council on Developmental Disabilities publication (1987, 4) *A New Way of Thinking*. Home is seen in much more human terms and embedded in connections with community and relationships.

A real home is a place to live the most personal moments of our lives. A home provides security and comfort, allows us to make choices and express ourselves. The people who share our homes are usually the people with whom we choose to spend time, be ourselves and feel close . . .

Having a home, learning and working—each involves us as members of a community who both receive the support of others and make contributions to the community. Each involves us in the continuing process of individual growth and expression. Each involves us in developing relationships.

Having a real friend means being involved with someone who chooses to spend time with you just because they want to and not because they are paid to do so. Real friends broaden our opportunities and enrich our lives. Real friends are hard to find, It takes most of us a long time through contact with many different people to find that small group of friends who really matter. Opportunities that lead to friendships are essential.

## **The 1990s - Personal Outcomes and Self Determination**

Increasingly, people from different perspectives in the field were suggesting that quality assurance should focus on actual outcomes for individuals and capture the individual's point of view in defining quality. Two different approaches emerged in the 1990s to give expression to this idea. A series of accreditation/evaluation instruments developed with a focus on personal outcome measures. Meanwhile, self-determination became an organizing concept for a number of strategies to honor the underlying principles of individuals having control over their lives – Freedom, Authority, Support, Responsibility and Confirmation.

### ***Personal Outcomes***

In the late 1980s and early 1990s a number of organizations and communities took a look at the viability of traditional approaches to certification and accreditation.

In 1989, a research group in Nebraska with funding from the Administration on Developmental Disabilities, asked the question –

whether living in a community-based facility for persons with developmental disabilities, which is accredited by a nationally recognized organization, enhances an individual's perception of his/her quality of life or life satisfaction. Subsidiary questions investigated the effect of the location of the facility (urban vs. rural) and the informant (client vs. staff person) on an individual's perception of their quality of life. (Leibowitz, et. al., 1989, p. 4)

A major finding of the study was "that all residential facilities met state certification standards and would, in all likelihood, continue to do so for the foreseeable future. According to existing state regulations, the consumers' level of satisfaction was being met; program effectiveness was achieved." On the other hand, when they compared the facilities that were accredited or not, the results were different. The conclusion was that

We have yet to achieve a meaningful measure for the determination of program effectiveness based upon consumer satisfaction that has been operationalized by state authorities. Presently, the most effective measures for gauging consumer satisfaction are, by implication, outside of state policy. They remain voluntary with neither vigorous nor consistent incentives for their incorporation by providers. (Leibowitz, et. al., 1989, p. 31)

The recommended that policy discussions should focus on "the design and implementation of a more sensitive certification/accreditation system utilizing consumer satisfaction as a major variable in determining programmatic effectiveness." (Leibowitz, et. al., 1989, p. 34)

The 1991 Accreditation and Quality Assurance Study in California compared the accreditation instruments of the Accreditation Council on Services for People with Developmental Disabilities (ACDD), the Commission on Accreditation of Rehabilitation Facilities (CARF), and California's ARM (Alternative Residential Model). Two findings are significant to this discussion:

- It is obvious from the study results that mere implementation of some type of formal QA system has significant, positive effects on the attitudes of facility administrators and staff - attitudes which may well lead to positive changes in the residential facilities. (Shueman, 1991, p. 112)
- We repeat the earlier question of whether the cost and effort required by systems such as ACDD and CARF (and to a lesser extent ARM) make a significant difference in terms of the ultimate criterion of client outcome. We have seen from this study that the effects of such comprehensive systems are, at least over the short term, difficult to determine. (Shueman, 1991, p. 113)

The study concluded with a critical question – "... one might ask why we even bother with attempts to associate change with accreditation. Why not, alternately, place the focus directly on client outcome, define, in consultation with the client, desired behaviors and activities, and develop services intended specifically to achieve these ends? (Shueman, 1991, 114) The focus of quality assurance efforts should be placed on



measuring outcomes, and on eliminating those structures and processes which do not appear to contribute to desired outcomes.

Other states and groups were answering that question in the affirmative and developing instruments that focused on quality of life from the individual's perspectives. The Certification Project in Missouri (1992) recommended that the Department of Mental Health adopt certification principles which "place major emphasis upon the outcomes to be experienced by individuals receiving services and supports," and place minimal emphasis on regulation, and instead promote partnerships among agencies. The recommended approach is based on 14 principles – achieving inclusion; maximizing individual choice and decision making; supporting and promoting relationships; supporting and promoting contribution; promoting self-esteem through positive self-expression; facilitating and enhancing communication; facilitating empowerment; participatory management of program planning; assuring human rights, dignity and respect; assuring legal rights; assuring and promoting good health; and assuring individual safety; promoting wellbeing, comfort and security; and promoting positive behavior. Each principle identified an outcome, the benefits that outcome would have for individuals, and implications for action.

California undertook a similar process and developed *A Lifestyle and Life Quality Survey for Californians with Developmental Disabilities*. The survey identified 26 individual life quality outcomes in six areas – choice, relationships, lifestyle, health and well-being, rights and satisfaction. A survey instrument would guide discussions and information gathering with individuals. The survey process was designed "to give Californians with developmental disabilities and those who support them: a way to look at life quality, to identify what is working and what is not working; and to offer suggestions about ways to improve services and supports." (California Department of Developmental Services, 1995, p. 3)

In Maryland, the *Ask Me! Survey* (Bonham, et. al., 2000) was developed to collect information from people receiving services funded by the Maryland Department of Developmental Disabilities Administration to determine their satisfaction with the quality of their lives. The survey was based on the *Quality of Life Questionnaire* (Schalock & Keith, 1993) and the *Signs of Quality* booklet (People on the Go, 1996).

Meanwhile, The Accreditation Council on Services for People with Disabilities (now The Council on Quality and Leadership) began to embrace personal outcome measures as the core of its standards. In 1991, it developed *Outcome Based Performance Measures for Illinois Citizens with Disabilities* that included 30 personal outcomes in 10 different areas. It also began a process of consultation with people with disabilities to refine that list. Beginning in 1991, the Council met with people with diverse disabilities and asked them to identify the priority outcomes in their lives. According to the Council, Personal Outcomes are what people expect from the services and supports they receive. Personal Outcomes refer to the major expectations that people have in their lives." (The Council, 1997, p. 3) A set of Personal Outcomes were included in the 1993 edition of *Outcome Based Performance Measures* and became the identifying theme of the Council's approach. The 1997 edition was titled simply *Personal Outcome Measures*.

By 1997, the Council could reflect that it “redefined quality as responsiveness to people rather than compliance with organizational processes” and claim that it “remains the only accrediting organization to adopt personal outcomes as the measure of quality in services.” (The Council 1997, p. 4)

As have many others, the Council described the traditional measures of quality in programs:

Input measures focus attention on resources such as physical environment, financial support, people, and technology that go into a program. Standards that focus on square footage of living space in a bedroom, the per diem rate, or the number of full-time staff are concerned with inputs.

Process measures focus on how the inputs are used and arranged and describe how the organization operates. Standards that specify team member interaction or describe how planning decisions are recorded, reported, and reviewed are process oriented.

Program outcome measures describe the results for the service or support provider. Program outputs target service goals such as number of work placements, hours of overtime, the rate of rehospitalization, the number of therapy sessions, or the number of medications administered. (The Council, 1997, p. 4)

Personal Outcome Measures go beyond this and ask what impact inputs, process and program have on actual outcomes for people. The Council (1997, p. 4) describes three kinds of outcomes:

- Clinical Outcomes focus on cure and symptom reduction.
- Functional Outcomes focus on increasing functional status in a designated area.
- Personal Outcomes focus on the items and issues that matter most to people in their lives.

Personal outcomes help staff and the organization learn about the person and how the person defines the outcomes in each of 25 areas; organize resources and coordinate services and supports to facilitate; and measure the extent to which the person has achieved the outcome as he or she defined it.

This obviously turns the traditional focus on evaluating organizational supports on its head. According to the Council, there are two important principles that apply to personal outcome quality evaluation:

- It is not possible to measure individualized organizational supports without first identifying the personal outcome toward which the process will be directed; and
- Measuring individualized organizational supports alone creates the possibility of measuring a process that is no longer relevant because the person’s definition of the original outcome has changed. Personal outcome and organizational support questions go together. (The Council, 1997, p. 6)

The Personal Outcomes Measure list is similar to others developed in this period.

### **IDENTITY**

- *People choose personal goals.*
- *People choose where and with whom they live.*
- *People choose where they work.*
- *People have intimate relationships.*
- *People are satisfied with services.*
- *People are satisfied with their personal life situations.*

### **AUTONOMY**

- *People choose their daily routine.*
- *People have time, space, and opportunity for privacy*
- *People decide when to share personal information.*
- *People use their environments.*

### **AFFILIATION**

- *People live in integrated environments.*
- *People participate in the life of the community*
- *People interact with other members of the community*
- *People perform different social roles.*
- *People have friends.*
- *People are respected.*

### **ATTAINMENT**

- *People choose services.*
- *People realize personal goals.*

### **SAFEGUARDS**

- *People are connected to natural support networks.*

## **Self Determination**

The 2000 amendments to the Developmental Disabilities Act included a number of definitions that signaled the formalized acceptance of many new definitions of quality and quality assurance. They included:

**INCLUSION.** The term "inclusion", used with respect to individuals with developmental disabilities, means the acceptance and encouragement of the presence and

participation of individuals with developmental disabilities, by individuals without disabilities, in social, educational, work, and community activities, that enables individuals with developmental disabilities to:

- (A) have friendships and relationships with individuals and families of their own choice;
- (B) live in homes close to community resources, with regular contact with individuals without disabilities in their communities;
- (C) enjoy full access to and active participation in the same community activities and types of employment as individuals without disabilities; and
- (D) take full advantage of their integration into the same community resources as individuals without disabilities, living, learning, working, and enjoying life in regular contact with individuals without disabilities.

**INDIVIDUALIZED SUPPORTS.** The term "individualized supports" means supports that:

- (A) enable an individual with a developmental disability to exercise self-determination, be independent, be productive, and be integrated and included in all facets of community life;
- (B) are designed to:
  - (i) enable such individual to control such individual's environment, permitting the most independent life possible;
  - (ii) prevent placement into a more restrictive living arrangement than is necessary; and
  - (iii) enable such individual to live, learn, work, and enjoy life in the community.

**QUALITY ASSURANCE ACTIVITIES.** The term "quality assurance activities" means advocacy, capacity building, and systemic change activities that result in improved consumer and family-centered quality assurance and that result in systems of quality assurance and consumer protection.

**SELF-DETERMINATION ACTIVITIES.** The term "self-determination activities" means activities that result in individuals with developmental disabilities, with appropriate assistance, having:

- (A) the ability and opportunity to communicate and make personal decisions;
- (B) the ability and opportunity to communicate choices and exercise control over the type and intensity of services, supports, and other assistance the individuals receive;
- (C) the authority to control resources to obtain needed services, supports, and other assistance;

(D) opportunities to participate in, and contribute to, their communities; and

(E) support, including financial support, to advocate for themselves and others, to develop leadership skills, through training in self-advocacy, to participate in coalitions, to educate policymakers, and to play a role in the development of public policies that affect individuals with developmental disabilities.

The Minnesota Governor's Council on Developmental Disabilities conducted surveys of people with developmental disabilities and their families/guardians in 2000, 2005, and 2010 as part of the 5 year planning process. This is a brief summary of results by federal outcome prepared by MarketResponse International (2012):

### **Independence:**

1. The level of satisfaction with independence has gone down during the past decade from 65 percent to 60 percent to 55 percent.
2. The younger the person with a developmental disability, the less satisfied with the level of independence.
3. The more significant the disability, the less satisfied with the level of independence.
4. The most important factors of independence were rated as the ability to go places on their own, privacy, and living near people who are important to the respondents.
5. People with developmental disabilities are most concerned about selecting their provider, where they live, and with whom they live.

### **Productivity:**

1. The percentage of people with developmental disabilities who worked or volunteered changed from 84 percent to 58 percent to 76 percent (2000, 2005, and 2010).
2. The level of satisfaction with productivity has gone down and up during the past decade from 62 percent to 53 percent to 71 percent.
3. The average number of hours of work or volunteer time has stayed about the same 18 hours in 2000, under 20 hours in 2005, and 17 hours in 2010.
4. People with developmental disabilities want to work more hours and this number has increased from 17 percent to 31 percent to 35 percent.
5. The most important factors of productivity include: improving skills, taking on more responsibility, and receiving recognition for work achieved.
6. The more significant the disability, the less satisfaction with productivity.

## Inclusion:

1. Inclusion received the lowest rating of satisfaction from 55 percent (2000) to 54 percent (2005) to 50 percent (2010).
2. Young people with developmental disabilities are the most dissatisfied with their level of inclusion.
3. Key drivers of inclusion are being treated as an equal in society, being treated with respect in society, and the opportunity to develop relationships with people without disabilities.
4. People do feel included in their families.
5. The more significant the disability, the less satisfaction with inclusion.

Consistent with this emphasis on people with disabilities being more in control of their lives and definitions of quality, The *Center for Self-Determination* has identified five governing principles for Self-Determination and some of the specific meanings of those principles in everyday life. They are:

<b>Principle #1: Freedom</b> People with developmental disabilities must be free to decide how to live their own lives.	That means: <ul style="list-style-type: none"><li><input type="checkbox"/> Choosing where and with whom you want to live.</li><li><input type="checkbox"/> Choosing what you want to do and where and when you want to work.</li><li><input type="checkbox"/> Being free to do things that interest you.</li><li><input type="checkbox"/> Creating the support system you want and choosing caregivers that fit your needs and your personality.</li><li><input type="checkbox"/> Taking risks and possibly failing.</li></ul>
<b>Principle #2: Authority</b> People with developmental disabilities must have the authority to determine where and how to spend the public funds allocated to their support.	That means: <ul style="list-style-type: none"><li><input type="checkbox"/> Knowing and controlling the public funds allocated to you.</li><li><input type="checkbox"/> Deciding what aspects of your life should receive the most attention.</li><li><input type="checkbox"/> Having the authority to hire and fire the people who serve you.</li><li><input type="checkbox"/> Having your preferences heard and your decisions followed.</li></ul>
<b>Principle #3: Support</b> People with developmental disabilities must be allowed to organize resources in formal and informal ways that enhance their lives and are meaningful to them	That means: <ul style="list-style-type: none"><li><input type="checkbox"/> Being free to choose your caregivers.</li><li><input type="checkbox"/> Gathering input from people who care about you.</li><li><input type="checkbox"/> Being allowed to find the support services that are best suited to your situation.</li><li><input type="checkbox"/> Being free to switch services and service providers</li></ul>

as individuals.	if you're situation changes or you're dissatisfied.
<b>Principle #4: Responsibility</b> People with developmental disabilities must be given responsibility for the wise use of public funds and must be recognized for the contributions they make to their communities.	That means: <input type="checkbox"/> Receiving competitive wages for competitive work. <input type="checkbox"/> Being held accountable for the decisions you make. <input type="checkbox"/> Making good financial choices that support clearly defined goals. <input type="checkbox"/> Being given the chance to volunteer in the community and participate in community events.
<b>Principle #5: Confirmation</b> People with developmental disabilities must be allowed to play important, meaningful roles in restructuring the system.	That means: <input type="checkbox"/> Sharing your opinions with people in decision-making roles. <input type="checkbox"/> Acting as a change agent by taking part in the legislative process. <input type="checkbox"/> Sharing your stories to bring problems with the current system to light. <input type="checkbox"/> Gathering and sharing information. <input type="checkbox"/> Offering constructive ideas for change.

For these concepts to be put into practice and enable the individual to achieve quality, the individual needs a person-centered plan that outlines an individual's hopes, dreams, strengths, capacities, preferences and support needs, as well a control of the public funds allocated to his or her support. Control requires a tool kit containing individual budgets, independent brokering or support coordination, and agents to help the individual manage the funds.

This significantly raises the stakes in terms of quality. It moves beyond an individual defining quality in response to a set number of personal outcome measures and then determining the extent to which a program or service facilitates the achievement of those outcomes. It puts control in the hands of the individual, often with the assistance of friends and allies, to obtain the supports required to achieve his or her own defined and evolving lifestyle.

The Center has developed a series of guides to assist people to understand and advocate for the core concept of self-determination and essential ingredients that make it work.

- Guaranteeing the Promise of Freedom: Creative Individual Budgeting (June 2005)
- Crafting the Instruments of Freedom: Tools of Self-Determination (June 2005)
- Supporting the Promise of Freedom: The New Broker (September 2005)
- Real Life Quality Standards (December 2005)

Center for Self Determination ([www.self-determination.com](http://www.self-determination.com))

The quality standards are organized in six domains – health and safety; having a place of one’s own; community membership; important long-term relationships; the generation of private income; and control over issues of transportation. The standards in many aspects are similar to those of other instruments, but include more dimensions of personal power and control. The assessment sheet for “a place of one’s own” illustrates the control dimension:

<b>A PLACE OF ONE’S OWN ASSESSMENT</b>						
1 – No or Never 2-4 – Represents a Small or Large Compromise 5 – Yes or Always N/A – Not Applicable						
<b>Rating scale</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>N/A</b>
1. The home is a typical home, apartment or condo						
2. The home is in a typical and safe neighborhood						
3. The home is freely chosen						
4. Anyone who provides paid support to the person works for that person, including companions						
5. Anyone who lives with the person is there by mutual agreement or at the request of the person						
<b>For those who live within family homes and are supported with public dollars</b>						
1. The family has its needs for supporting the family member taken into account	yes			no		
2. If a minor, the person with a disability experiences inclusive education	yes			no		
3. If transition age, clear work/ higher education goals are established	yes			no		
4. If transition age, real work experience is accomplished through the school	yes			no		

### ***The Ongoing Challenge***

Throughout the history of measuring “quality” and “quality assurance” systems in the last half of the 20<sup>th</sup> century, there is a consistent underlying question – do these surveys, reviews, questions, and so on actually result in positive changes in the lives and futures of people with developmental disabilities?



Jim Conroy has conducted 150,000 individual surveys and has concluded that there are 10 building blocks to quality lives. Among the more personally meaningful blocks are:

- **Relationships** – family, friends, intimates, nonhumans, people in the nearby environment (community)
- **Engagement** – something to do that's enjoyable, meaningful, useful, produces means for that (money)
- **Freedom** - of movement & access, of action, of life design – independence, self-determination, person-centered planning
- **Comfort** – no pain, no fear
- **Security** – place to live one can count on
- **Mortality** – means & tools to face mortality, a higher reality, faith
- **Growth** – striving, learning, achieving, becoming better
- **Helping** – highest level of self-actualization – compassion – bettering other lives

At a gross level, the fact that some programs and facilities lose their licenses from state authorities ensures that instances of gross negligence end. The educative function of various quality tools helps develop a better understanding among staff, administrators and boards of directors about the dimensions of quality and the how their service is performing. And in some cases, positive change results. The challenge is to ensure that the increasing definition of quality in terms of personal outcomes and results translates into affirmative action within organizations and systems to ensure individuals are able to define outcomes that are indeed powerful in their own lives, not merely those offered by services, and achieve those powerful outcomes.

At the individual level, when individuals with disabilities and their allies join in articulating the individual's desire for quality then working together to achieve it, their actions are focused and unified in a common direction. They are clear about what they need to demand from the service system, both in terms of existing services and needed changes.

## References

AAMD Project on Technical Planning in Mental Retardation (1964). Standards for state residential institutions for the mentally retarded. *Monograph supplement to American Journal of Mental Deficiency*, 68, p. 4.

Allen, William T. (1984). *It's My Choice*. St. Paul: Minnesota Governor's Council on Developmental Disabilities. <http://www.mnddc.org/learning/document/GT110.pdf>

Allen, William T. and Gardner, Nancy E.S. (1985). ANDI for Consumers: A workbook for helping people with disabilities evaluate the places they live and work. Lawrence KS: Kansas University Affiliated Facility. (Editions in 1982, 1983, and 1985.)

Blatt, B. and Kaplan, F. (1967). *Christmas in purgatory*. Boston: Allyn and Bacon. <http://www.mnddc.org/parallels2/pdf/undated/Xmas-Purgatory.pdf>

Blatt, B. (1969). Purgatory. In R. Kugel and W. Wolfensberger, Eds. *Changing patterns in residential services for the mentally retarded*. Washington, D.C.: The President's Committee on Mental Retardation. pp. 35-49. <http://www.mnddc.org/parallels2/one/sidebar/029a.htm-3>

Blatt, B. (1969). Recommendations for institution reform. In R. Kugel and W. Wolfensberger, Eds. *Changing patterns in residential services for the mentally retarded*. Washington, D.C.: President's Committee on Mental Retardation. pp. 173-178. [http://www.mnddc.org/parallels2/pdf/69-CPS-PCR\\_Chapter\\_6.pdf](http://www.mnddc.org/parallels2/pdf/69-CPS-PCR_Chapter_6.pdf)

Bonham, Gordon Scott; Basehart, Sarah; and Marchand, Cristine Boswell (2000). Ask Me! FY 2000: The quality of life of Marylanders with developmental disabilities receiving DDA funding supports. Final Report of Year 3 Survey of the Ask Me! Project. The Arc of Maryland.

Bradley, Valerie J. (1984). *Assessing & enhancing the quality of services: A guide for the human services field*. Boston MA: Human Services Research Institute.

Bradley, Valerie J. and Bersani, Hank A. editors (1990). *Quality assurance for individuals with developmental disabilities: It's everybody's business. Conceptual Issues in Quality Assurance*. Baltimore: Paul H Brookes Publishing.

Budde, James F. (1976). Analyzing and measuring deinstitutionalization across residential environments with alternative living environments rating and tracking system (ALERT). Lawrence, Kansas: Kansas University Affiliated Facility at the University of Kansas.

California Department of Developmental Services (1995). A lifestyle and life quality survey for Californians with developmental disabilities. Reference guide and survey summary. Sacramento: CA Dept. of Developmental Services, Quality Assurance Division.

Chatham-Savannah Citizen Advocacy Office (2009). What is citizen advocacy?  
<http://www.savannahcitizenadvocacy.org/what-is-citizen-advocacy/>

Conroy, J. (December 7, 2011). Quality: Enhanced insight over the years. Presentation to the Minnesota Governor's Council on Developmental Disabilities. St Paul, MN.

The Council on Quality and Leadership in Supports for People with Disabilities (1991). Outcome based performance measures for Illinois citizens with disabilities. Developed for the Illinois Planning Council on Developmental Disabilities and the IL Dept. of Mental Health and Developmental Disabilities. Landover MD: The Council. 1991.

The Council on Quality and Leadership in Supports for People with Disabilities (1997). Personal outcome measures. Towson MD: The Council. 1997.

Dybwad, G. (1969). Action implications, USA today. In R. Kugel and W. Wolfensberger, Eds. Changing patterns in residential services for the mentally retarded. Washington, D.C.: President's Committee on Mental Retardation. pp. 385-428.  
<http://www.mnddc.org/parallels2/pdf/index-comm.html> (1969, Changing Patterns in Residential Services for the Mentally Retarded, Chapter 17.)

Gilhool, T. PARC case Gilhool on Gunnar Dybwad.  
<http://www.mnddc.state.mn.us/parallels2/one/video08/gunnar/tomGilhool.html>

Goffman, Erving (1961). Asylums: Essays on the social situation of mental patients and other inmates. New York: Doubleday.

Jackson, Robin (1995). Care in the community: The contribution of Jack Tizard. *British Journal of Developmental Disabilities*, 41, pp. 151-158.

Johnson, Terri Z. (1978). Annotated directory of environmental assessment Instruments: A listing and description of instruments used for measuring characteristics of environments serving people with developmental disabilities. Pomona CA: University

of California, Los Angeles – Neuropsychiatry Institute Research Group at Pacific State Hospital. September 1978.

Leibowitz, J.M., McClain, J.W., Evans, E.A., Ruina, P. & Rauner, T. (1989). A social-ecological analysis of the quality of life of persons with developmental disabilities living in community-based facilities. Omaha: University of Nebraska Medical Center, Meyer Children's Rehabilitation Institute.

Leismer, J. (1984). The discriminating connoisseur's guide to quality in community-based services for persons with mental retardation. Also known as Prevention of institutional admissions and returns (Especially those due to client behavioral difficulties). (unpublished paper, 1981).

Lottman, Michael S. (1990). Quality assurance and the courts. Chapter 12 in Bradley and Bersani, (Editors) (1990).

MarketResponse International (April 27, 2011). Survey of individuals with developmental disabilities and family members in Minnesota, report addendum. Minneapolis: MarketResponse International.

Minnesota Governor's Council on Developmental Disabilities (1987). A New Way of Thinking. St. Paul MN: State of Minnesota. January, 1987. <http://www.mnddc.org/past/1980s/1980s-16.html>

Mount, Beth and Zwernik, Kay (1989). It's never too early, It's never too late: A booklet about personal futures planning for persons with developmental disabilities, their families and friends, case managers, service providers and advocates. <http://www.mnddc.org/learning/document/GT075.PDF>

NARC Committee on Residential Care (1963). <http://www.mnddc.org/parallels2/pdf/60s/62/62-MRN-DOH.pdf>

Nerney, Tom with Pat Carver and Kathleen Kovach (2005). Real life quality standards. Volume IV, 1<sup>st</sup> Edition, December 2005. Wayne MI: Center for Self-Determination.

Nirje, Bengt (1969). The normalization principle and its human management implications. *Changing Patterns in Residential Services for the Mentally Retarded*. The President's Committee on Mental Retardation. <http://www.mnddc.org/parallels2/pdf/index-comm.html> (1969, Changing Patterns in Residential Services for the Mentally Retarded, Chapter 7.)

O'Brien, John (2005). A disgrace to the nation: A turning point in the struggle to replace institutions. *Tizard Learning Disability Review* 10:1, 12-17 (2005).

O'Brien, J. & Lyle, C. (1987). *Framework for accomplishment*. Lithonia, GA: Responsive Systems Associates.

Partners in Policymaking Curriculum <http://www.mnddc.org/learning/document/GT106.PDF>

Pearce, C. Kaye (1990). Building Values into Accreditation in Bradley and Bersani (Editors) (1990).

People on the Go (1996). Signs of Quality. Annapolis MD: The Arc of Maryland.

The President's Panel On Mental Retardation (October 1962). A proposed program for national action to combat mental retardation. October 1962.

<http://www.mnddc.org/parallels2/pdf/60s/62/62-NAC-PPM.pdf>

The President's Panel On Mental Retardation (1962). Mental Retardation: A national plan for a national problem. U.S. Department of Health, Education, and Welfare, 1962.

<http://www.mnddc.org/parallels2/pdf/60s/62/62-MRN-DOH.pdf>

S.A.B.E. Self Advocates Becoming Empowered (2009). *Who We Are*. <http://www.sabeusa.org/>

Schalock, Robert L. (1996). Reconsidering the conceptualization and measurement of quality of life. In Robert L Schalock (Ed.) *Quality of Life: Volume 1, Conceptualization and Measurement*. Washington DC: American Association on Mental Retardation, (pp. 123-139).

Shueman, Sharon A. et. al. (1991). The Accreditation And Quality Assurance Study: A Comparison of Three Types of Quality Assurance Programs in Small Community Residential Facilities: Impact, Appropriateness, and Cost. Sacramento: California Department of Developmental Services. May 1991.

Tizard, J. (1969). Residential services within the service continuum. In R. Kugel and W. Wolfensberger, Eds. *Changing patterns in residential services for the mentally retarded*. Washington, D.C.: President's Committee on Mental Retardation, (pp. 197-210).

[http://www.mnddc.org/parallels2/pdf/60s/69/69-CPS-PCR\\_Chapter\\_8.pdf](http://www.mnddc.org/parallels2/pdf/60s/69/69-CPS-PCR_Chapter_8.pdf)

Training Institute for Human Service Planning, Leadership and Change Agency (2007). *Overview of PASSING: A tool for analyzing service quality according to social role valorization criteria*. Syracuse University: February 2007.

Vail, David J. (1966). *Dehumanization and the Institutional Career*. C.C. Thomas (1966)

Vail, David J. (1963). *The Criteria of Hospital Dehumanization*. Mental Health Newsletter. Minnesota Department of Public Welfare. Vol. 3, No 10. December 1963.

Vail Place (2009). Website. <http://www.vailplace.org/> Minneapolis, MN.

Willowbrook Expose <http://www.mnddc.org/parallels2/one/video/willowbrook.html>

Wolfensberger, Wolf (1972). *The Principle of Normalization in Human Services*. Toronto ON: National Institute on Mental Retardation.

Wolfensberger, Wolf (1969). *The Origin and Nature of Our Institutional Models, Changing Patterns in Residential Services for the Mentally Retarded*. The President's Committee on Mental Retardation.

<http://www.mnddc.org/parallels2/pdf/index-comm.html> (1969, *Changing Patterns in Residential Services for the Mentally Retarded*, Chapter 5.)

Wolfensberger, Wolf and Glenn, Linda (1975). *PASS 3. Program Analysis of Service Systems – a method for the quantitative evaluation of human services*. (Field Manual and Handbook) Toronto ON: National Institute on Mental Retardation. (PASS originally published 1969, PASS 2

Wolfensberger, W. & Zauha, H. (1973). *Citizen Advocacy and protective services for the impaired and handicapped*. Toronto, ON: National Institute on Mental Retardation.

Yates, Jack (1979). *The principle of normalization*, In *normalization training through PASS 3: Coordinators' Handbook* by Connie Lyle and John O'Brien. Responsive Systems Associates, June 1983.

Hokanson, Wieck, C., Nichols, M.J. (1994, 2001). *Making your case*, Minnesota Governor's Council on Developmental Disabilities.

- <http://www.mnddc.org/learning/document/GT108.PDF> Family support, a checklist for quality, the Arc USA, 1983.

Resources Used from MN Governor's Council on DD website:

**Parallels in Time 1**

**Parallels in Time 2**, including video, documents, slide shows and posters

**A History of Human Services, Universal Lessons, and Future Implications**, Wolfensberger, Thomas. 2009.

**With an Eye to the Past**, including documents

**The Evolution of the Quality of Care**, Jim Conroy video interviews and transcripts

**The Learning Center: A Virtual Library**

**Partners in Policymaking**, resources section