

Consumer Roles in Monitoring Community Services for People with Developmental Disabilities

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During the 1900s, the primary societal response to the needs of people with disabilities (if any at all) was for the state, acting as the good parent, to step in to meet the needs, protect the interests, and promote the well-being of persons viewed as dependent. Much of this attention to people's needs and well-being came at substantial cost to individual rights and desired ways of living. Today the "progressive" faith that government can define what will be good for people and then cause that good to occur is dying. It is not diminished because government failed to identify real social problems (for example, poor conditions in institutions or people being neglected or exploited.) The faith in government is diminished because the solutions to these real problems are themselves undesirable and inadequate. The legacy of this experience is an understanding that:

- 1) Whatever the cosmetic changes, real reforms produce perceptible improvements in the real lives of people;
- 2) There is no one perfect definition of what will meet the needs of all people even when they share identifiable distinctions (for example, being impoverished or homeless, having a developmental disability); and
- 3) The use of discretionary authority by the government on behalf of another person without that person's involvement will often be insensitive or abusive, or at least it will be perceived that way.

The first initiatives designed to address the inadequate quality of services for persons with disabilities focused on creating standards. These standards defined and required adequate quality in the physical, safety, and health conditions in which people lived or in the provision of habilitation or rehabilitation to assure people's optimal development. Today such standards are increasingly viewed as unnecessarily burdensome and even counterproductive, particularly as supportive services have moved from institutional to community settings. Among the by-products observed from traditional "compliance with standards" approaches have been:

- 1) A frustrating and counterproductive appetite for paperwork,
- 2) The development of adversarial relationships between service providers and government,
- 3) Inhibition of innovation and rational risk-taking in favor of rule following,
- 4) Loss of self-determination for the people being protected,
- 5) Lack of involvement by government agencies in promoting "well-being" by means other than rules, and

- 6) Promotion of an idea that supporting people well and protecting them well is the same thing.

The challenge of reducing harmful by-products of systems of quality assurance is not simply a matter of responding to "problems" in current systems. The realities in which such improvements must be envisioned are dynamic and moved by practical forces, including:

- ***There are a vast and rapidly growing number of settings in which community services are provided.*** Home and community care systems have become extremely dispersed and, as a result, they challenge government quality assurance monitoring efforts. As an example, in 1977, there were 11,025 separate households in which persons with developmental disabilities received out-of-family residential services. Twenty-two years later, in 1999, that number had grown 10-fold to more than 113,000 separate out-of-home settings (Prouty & Lakin, 2000.) In addition, there were hundreds of thousands of additional persons served in their family homes. This growth has continued without commensurate growth in the number of people available to monitor the quality of services received in these dispersed settings. Similar trends are seen among other "disability groups."
- ***There is doubtful reliability and validity in traditional quality assurance approaches.*** Current quality assurance approaches are not producing acceptable results. Most are inadequate in terms of efficacy, reliability, and validity. Virtually all of the federal court rulings and settlements related to the quality of institutional care in the past 20 years have involved facilities that had been certified as in compliance with standards for Intermediate Care Facilities for persons with Mental Retardation (ICFs-MR.) The highly publicized Washington Post series by Katherine Boo on the scandalous conditions of community ICFs-MR in Washington, DC raised doubts about validity of ICF/MR standards applied in the community. It is well known that different monitors who survey the same settings cite different deficiencies (Reid, Parsons, Green, & Schepis, 1991). A recent set of studies that focused on the backbone of service design and quality assurance, the Individual Program Plan (i.e., Plan of Care) showed no association between what is written in people's plans and their relative roles of engagement in or their accomplishment of outcomes in real life (Stancliffe, Hayden & Lakin, 1999, 2000).
- ***Most quality assurance has little ability to contribute to improvement of most service providing agencies.*** A 1990 report of the U.S. General Accounting Office, focusing on quality assurance in health care, contained an observation that is highly relevant to services for persons with disabilities:

Quality assurance systems typically concentrate on quality assessment and the identification of the relatively small number of providers whose care is obviously unacceptable. They do comparatively little in attempting to directly improve the overall levels of quality provided by the majority of health professionals (GAO, 1990, p. 8).

Effective quality assurance should contribute more than identifying the worst agencies, those unable to meet the minimum levels expected by current regulatory practices. Effective quality assurance systems focus on the variables and resources that can improve quality in all agencies. Standard-based quality assurance has limited capacity to be effective in such a role.

- ***The ability to define, measure, and improve service quality in terms of outcomes important to service recipients is a foundation of quality, but it is still seldom the primary basis of quality assurance.*** There is a growing commitment to developing a service system for persons with disabilities that focuses on the outcomes that people want in their lives. Efforts to integrate concepts and to practice person-centered planning, consumer-controlled housing, consumer-directed supports, individually managed budgets and so forth all reflect the goals of helping people achieve individually desired outcomes.

The standards of the major accreditation organizations have established expectations that measurement of individually valued outcomes should be integrated into the management practices of agencies seeking accreditation. Outcome systems are, however, very complex. It is relatively easy to assure that a person has a bedroom of specified square footage, that there is documentation that staff have sufficient hours of training in specific topical areas, or that service recipients have been assessed and individual programs plans have been developed and implemented. It is much harder to determine whether people have improved their functional skills, increased their social networks, or become more satisfied with their lives.

Despite the complexity, the growing consensus appears to be that there is much benefit in quality definitions, assessments, and monitoring practices related to individually-based outcomes. Therefore, we should invest in a future of quality assurance based on such outcomes. But outcome-based quality assurance, remains threatening and is still infrequently implemented as a substantial component of an "official" approach to quality assurance. However, there are, examples of efforts to try to build quality assurance around ideas of valued consumer outcomes (for example, Massachusetts' QUEST system.)

Consumer Involvement in Assessment of Consumer Outcomes

A society that provides and pays for services for persons with disabilities has a right and a responsibility to articulate purposes for those services and expect indications that those purposes are being realized. The single most commonly articulated purpose of social services today is to enhance people's quality of life. The concept of quality of life, is largely personal, but most definitions articulated by persons with disabilities include components like these:

- Physical presence in the community,
- Health, safety, and comfort,

- Personal growth and development,
- Social and familial relationships,
- Participation in valued roles of the society, and
- Independence, individuality, and choice.

Definitions and assessments of quality in services that seek to attend to such components of quality of life must do so in ways that attend to individual differences and appreciate the sensitivity of the information being gathered. They must also accommodate the differing capacities of service recipients to understand and respond to the topics of the assessment.

It has been suggested that people who know the challenges of disability, who have experience in receiving services and who are viewed as peers have advantages in gathering information from "peers" in individually oriented, "outcome-based" systems of quality definition and assessment. However, quality assurance systems remain a formal social function with substantial responsibility to service users and substantial implications for service providers and their funders. Such functions must be carried out in a manner that assures dependable monitoring of people's health, safety and well-being, appropriate detection of inadequate performance, and improvement in people's lives through positive influence on the services they receive. Therefore, we must put more attention on the actual performance of consumers in quality assessment, the difficulties noted in such efforts, and how they might be improved.

Consumer Monitoring Boards

In the fall of 1990 Congress enacted Section 1930 to the Social Security Act to allow 8 states to provide "Community Supported Living Arrangements" (CSLA) services to persons with developmental disabilities for a five-year period. CSLA permitted states to target specific subpopulations (like those not meeting ICF-MR level of care needed and therefore not being eligible for Medicaid Home and Community Based Services), specific geographic areas, specific packages of services and state-specific approaches to quality assurance.

There was, however, one specific quality assurance requirement placed on states. In addition to the formal state regulatory activities, Congress also established that "the state will provide a system that allows for monitoring boards consisting of providers, family members, consumers, and neighbors." States undertook the development of Community Monitoring Boards (CMBs) with good faith and high expectations, but the development and implementation of the CMBs were one of the greatest challenges for the states. Four of the 8 CSLA states substantially revised the original plans that were outlined in the original application to HCFA and recreated their monitoring board systems. In its last year of the CSLA "demonstration" one state was still in the process of developing a CMB system.

Although not required by statute, each CSLA state separated its quality assurance program (i.e., state licensing and certification reviews) from the CMB reviews. Most

analysis of the separation between the formal state survey process and the largely informal, volunteer staffed CMBs concluded that it created a CMB review system that was less seriously recognized, less well defined in purpose, and less useful in improving services than might have been the case.

Community Monitoring Teams in California.

California's "Community Monitoring Teams" (CMTs) within its CSLA program are of particular interest because they were developed regionally (therefore, there were more of them), with more independence, variety, and formality than CMBs in other states. California specifically excluded members of a person's immediate family, "circle of support" or service providers from CMT responsibility for the person, irrespective of individual preferences.

California CMTs were given a broad charge to monitor "key aspects of the consumers situation and quality of life [through] observation and interviews with the consumer and the consumer's family, personal advocate and/or roommate." Quality of life interviews were required at least quarterly in the first year, but could be less often after that. In many instances the frequency of visits was substantially less than required. The primary impediment to the implementation of CMT requirements was substantial underfunding. With insufficient funding most CMTs were dependent on volunteers. In almost all instances individuals working as part-time (usually quarter-time) contracted employees with no benefits coordinated the volunteers.

One exception to this typical pattern was a CMT that was wholly contracted with a citizen advocacy organization, which established a paid-staff CMT approach. This CMT was made up of persons with disabilities. It was reported to differ from the volunteer CMTs most in being more oriented toward more formal monitoring of regulatory compliance. Its staff were more structured in their observations and adversarial in interactions with providers than other CMTs. The citizen advocacy CMT's attitude was in sharp contrast with the attitude expressed by the CMT coordinator in a contiguous region. The Coordinator of CMT volunteers observed that there were no teeth in CMT monitoring. She viewed the CMT role as identifying "gaps" in peoples' lives and trying to get someone to attend to them. The level of passion in the citizen advocacy CMT was notably higher.

Concern about lack of clarity in the CMT role was often expressed in California. Recommendations were frequently made about clarifying general expectations regarding what CMT was to "monitor," what its reports were intended to accomplish, and even the extent to which individuals receiving CSLA were compelled to open their homes and share their problems with "strangers" on the CMTs. CMT staff noted that CSLA recipients sometimes felt reluctant to speak negatively to "strangers" due to fear of losing their services. They also noted that without a clear role for CMTs some agencies passively resisted CMT activities. The CMT, regular monitoring, case managers, circles of support and other "supports" added up to a remarkable number of people moving through people's otherwise relatively normal lives asking questions that were seldom asked of other people.

California's original plans for 14 CMT teams of several people each visiting the homes of more than 35-40 people each never materialized. The number of volunteers required to sustain the planned model, the demands that it would place on recruitment, training and retention activities and the logistics of schedule and travel were simply not sustainable under the modest funding available for CMTs. In the end most CMT visits were on a 1-to-1 basis with members of the "team" coming together periodically to share and integrate what they learned in the individual visits. Most CMT visits with service users did not include the person with disability in the actual face-to-face (or telephone) visit.

Despite the difficulties, volunteer monitoring was generally viewed as useful. Families and consumers noted their appreciation for the state's providing an opportunity to comment on their lives and their services. In the end agency administrators expressed more favorable impressions of the concept than staff of the regional and state agencies. They did comment, however, that there was no clear flow of information from the CMTs to the agency. They noted that if such feedback had been provided, CMTs could have been of considerable assistance to agency management in pointing out problems and limitations in their services and contributing to improving individuals' lives. One agency director summarized that, "We are very supportive, but it needs to be taken more seriously. [The CMT] needs a clear purpose and people doing it need training." Although CSLA recipients were integrated into California's Medicaid HCBS program at the end of the CSLA program, the CMTs did not survive.

Observations about consumer monitoring in all CSLA states.

Within the 8 states providing CSLA (including California), CMBs were managed either by state agencies, local governmental entities (for example, area or county boards) or non-governmental organizations under contractual agreement with the state. CMB members were almost always volunteers, although some compensation was often available to participants with disabilities. There were requirements for CMB members to be screened, trained, and pledged to confidentiality. However, the enforcement varied from state to state. There was also a great deal of variability in the make-up of CMBs. The variability within the state was as great as the variability among states. Only California required that the CMBs be independent from service providers, immediate family members, and members of the recipients' circles of friends. Most states included a wide range of CMB participants, including members of service agency boards of directors, provider agency staff, local government officials, friends and family members, as well as other service users.

There was general support of the CMB concept within all states. But interviews with CMB members and observers found a number of concerns and recommendations. These included:

- There was a need to clarify what CMBs were expected to observe and report and to identify the purpose and audience of their reports.

- There was consensus across states that under-funding could (and did) contribute to inadequate coordination, support and training of volunteers, and insufficient preparation and distribution of reports. Inadequate funding generally reflected a lack of purpose, lack of a clear role and lack of value attributed to consumer involvement in quality assessment.
- The number of volunteers to be recruited, trained and retained to sustain the volunteer CMB model with CSLA programs, and the logistics of scheduling and travel was not manageable under the budgetary, social and regulatory realities faced. The result was diminished quality and influence.
- Service providers noted that the lack of information flowing from the CMB visits back to their agencies prevented CMBs from contributing to the quality of services. CMB members noted frustration at submitting reports that were often never seen at the service site being visited or by the persons and programs for which they were most relevant.
- There were a number of technical difficulties in the CMB reviews, including problems of developing survey instruments for persons who varied in communication skills. Efforts to develop alternative interviews were undertaken by some CMBs, but there were few efforts to determine the validity and reliability of these approaches. This validation would have been expected if the efforts were given a valued role in quality assurance.
- CMB members noted that they needed clarification of their roles. They were not sure if they should simply gather information about potential problems that others would attend to, identify problems in people's lives and play a role themselves in having these problems attended to, or assure agency compliance to state standards.
- People working on independent CMB teams, who did not otherwise know the CSLA recipient, commented that interviewing the individual provided only a snapshot of someone's life. They expected that people who knew the person well would probably get a more complete and realistic picture.
- Some CMB members became more actively involved in recipients' lives than desired by recipients. Some CSLA recipients did not want or feel they needed the level of involvement that was being offered.
- A lack of clarity among CSLA recipients and family members about the role and responsibilities of CMB members sometimes caused problems. For example, CSLA recipients sometimes expected CMB members to be more effective in advocating on their behalf regarding matters brought out in the CMB review.
- Because CMB's were added on to the "official" quality assurance program, there was a perception of burden attached to CMB activities. This might have been diminished if they had been better integrated into a single quality assurance program.

- Concerns were raised in the different states about the necessity of the CMBs visiting the homes of the recipients. While all states specified conditions under which people could choose to not participate in CMB reviews. Still, there were questions about how to present the option to not participate within the context of informed choice, the states' responsibility to offer this component of CSLA quality assurance, the CMBs' potential contribution to the quality of a person's services and individual's opportunity to not participate in CSLA if he/she did not want to participate in the Community Monitoring Board program. Telephone surveys and mail questionnaires were developed in some states to fulfill assessment responsibilities with people who did not want to be visited.

Other Consumer Monitoring Initiatives

There have been a number of other consumer monitoring initiatives of interest that involve persons with disabilities. One model, built around inclusion of persons with developmental disabilities as members of a team is reflected in "Advocates Involved in Monitoring Programs (AIM), including Oklahoma AIM. The AIM model includes persons with developmental disabilities on a review team comprised of people with and without disabilities. Another model of consumer monitoring involves monitoring teams made up exclusively of people with developmental disabilities. Such efforts to recruit, training and support persons with disabilities as monitors of the quality of life and services are reflected in the Maryland "Ask Me" program.

Integrated Teams - Oklahoma AIM.

An Oklahoma court order to deinstitutionalize persons with developmental disabilities required a monitoring process that would increase the involvement of consumers and their families in assuring the quality of community services. After reviewing various systems for monitoring service quality, a statewide committee of consumers and staff members selected an Oregon model called Advocates Involved in Monitoring (AIM). The Oklahoma Department of Human Services contracted with the Tulsa Arc to establish and operate a monitoring program, Oklahoma Advocates Involved in Monitoring (OK AIM).

Under the leadership of Tulsa Arc and a statewide committee of consumers, teams of OK AIM volunteers included persons with developmental disabilities, family members, friends and advocates for persons with disabilities. The goal was to try to assure and enhance service quality. Among the premises guiding the implementation of the assessment and the associated information system were:

- a) Although choice is an essential component of quality, the integrity of choice is compromised when there is no information on the performance of agencies among which one must choose;
- b) Existing quality assurance and the associated minimum standards could neither adequately assess nor significantly improve the quality of services; and

- c) Survey processes could not adequately attend to the most important aspects of people's lives and environments such as respect, friendship and a sense of belonging.

The OK AIM assessment program is based on several principles, including

- a) People with developmental disabilities are people first,
- b) They are entitled to the same privileges and responsibilities as others,
- c) Their services should allow them to be full members of their communities,
- d) They should be able to choose their own service providers and evaluate the effectiveness of their own services,
- e) Their opinions should be respected as most important in evaluating services, and
- f) They should have the information to make service decisions based on agencies' performance.

These principles are integrated into a guidebook containing a total of twenty-seven items used by surveyors in reviewing services to persons with disabilities. The handbook is employed both in the six hours of training provided to all surveyors and as an ongoing resource in conducting reviews.

Teams visit provider agencies to evaluate services and suggest improvements based on information gathered on relationships within the home and with neighbors, community involvements, recognition of rights, protections of health and safety and other topics. At the end of each visit a written report is developed. Service providers are permitted to review and respond to a draft report and to respond to recommendations contained in it. In the end the primary audience of the report is service users and service providers.

Evaluations of OK AIM suggest that providers are responsive to surveyor team suggestions and that direct-care staff often display more positive attitudes toward persons with disabilities because of OK AIM initiatives. But it is important to recognize that the Oklahoma AIM has no sanctioning authority and that its influence is limited to persuasion of service providers and information for consumers to assist them in choosing services.

Teams of persons with disabilities - Maryland's "Ask Me."

The Arc of Maryland and People On the Go operate the "Ask Me!" Project with funding from the Maryland Developmental Disabilities Administration and the

Maryland Developmental Disabilities Council. This pilot project is now in its third year. In year 2 about 535 people served by 21 provider agencies were interviewed. The interviewers were 40 trained, professional, paid staff with developmental disabilities. The *Ask Me!* Survey instrument is based on a quality of life model that asks questions which fall into six areas:

- 1) Satisfaction,
- 2) Health, Safety and Dignity,
- 3) Community Integration,
- 4) Employment,
- 5) Transportation and
- 6) Independence.

The instrument was developed with participation of persons with developmental disabilities. All *Ask Me!* Interviews are conducted in face-to-face interviews. Respondents use a format of happy, neutral and sad faces for respondents to point to as a visual support for their responses.

Ask Me! interviewers work in pairs. Project support personnel are available to assist in setting up interviews, arranging transportation and answering questions. All reviewers are given basic training. Evaluation data show that the experience of interviewers appears to increase the quality and completeness of the survey. With good interview technique and a good instrument, *Ask Me!* provides information that can be used by a) service providers to evaluate their own services, b) service funders to evaluate the services of the different agencies they fund, and c) consumers to differentiate between service options.

Analysis of the reviews indicates that the most positive responses were in the following areas:

- Getting needed services,
- Having transportation,
- Knowing what to do in case of fire,
- Having people help you reach goals,
- Having people help you to learn to do things on your own, and
- Feeling important to your families.

The most negative responses included opportunities to date, having a pet if you desired and having friends come over to your home.

Ask Me! Has undergone evaluation showing that interviewees respond the same way on the 3-point satisfaction scale on 50% of the items repeated a year apart. A small sample of proxies (usually family members) responded the same way on only about 25% of items repeated a year apart. While proxy responses tended to indicate improved quality of life over a one-year period, self-respondents actually reported a slight decrease in most domains between year 1 and year 2 interviews.

These statistics were viewed as general support for the reliability of persons with developmental disabilities as self-respondents in the *Ask Me!* format and the validity of actual service recipients (rather than proxies) as respondents.

Because of the communication requirements of *Ask Me!*, the intellectual and receptive language skills of interviewees are important. Slightly less than 20% of the interviewees in Year 2 were persons with severe or profound intellectual disabilities. Including more severely intellectually impaired persons as respondents in all forms of outcome based performance assessment is a challenge, but it may be an even greater challenge in system in which the interviewers themselves have intellectual and communication difficulties.

Summary of Experiences with Consumer Monitoring

Despite the many difficulties, interest continues to grow in ways to include people with disabilities in the definition and implementation of quality assessment and improvement programs. On the other hand, evaluations and direct observation of these various experiments in consumer monitoring yield a number of observations, concerns and criteria for success. These include:

- Approaches to consumer monitoring have included models in which persons with disabilities have worked alone in monitoring teams (with support as needed) and in which they have been integrated into teams with other stakeholders.
- Consumer monitoring team programs rarely if ever hold an official status in which the findings of the teams have bearing on the official licensing or certification status of service providers, on their funding or on requirements for changes in their programs.
- The lack of official authority for consumer monitoring teams has affected their perceived status, ability to cause change and in some instances even to gain access to agencies and individuals.
- The "add-on" status of consumer monitoring programs (the fact that they are not part of the official licensing or certification activities) has often caused the teams to be viewed as adding new burden to service providers and sometimes to consumers.
- Service providers, family members and service users tend to consider the role of consumer monitoring involvements as valuable (or at least potentially so) and tend to see more value (or potential value) in them than do government officials.
- The Consumer monitoring programs' effectiveness is very greatly affected by their frequently limited budgets and dependence on volunteers.

- The Community monitoring programs' lack of official status has limited the study of the reliability of their performance in actual data gathering.
- Personal qualitative observations of actual teams in the field have suggested that team members with developmental disabilities are particularly susceptible to cuing respondents, failing to recognize repetitious patterns of response, failing to pick up cues that interviewees do not understand questions asked, and other threats to validity and reliability.
- The lack of "official" status of consumer monitoring teams has minimized concerns about reliability and validity. Expansion of consumer roles to a more official status (with consequences to funding, sanctions and reputation) would require careful study and development of training and performance programs to assure optimal reliability. (But monitoring teams with persons with disabilities should not be held to higher standards of performance than the current systems not including people with disabilities).
- Often there are no clear identifications of the purpose, products and audiences of consumer monitoring programs. Team members often struggle to find an identity and agencies and consumers visited by the teams often struggle to find the outcomes and benefits of their participation.
- Making consumer monitoring approaches work effectively requires that they have:
 - 1) Recognized, validated and empowered status;
 - 2) Protocols that are based on validated and agreed to outcomes of importance on which performance will be expected and publicly reported;
 - 3) Standards for information gathering and analysis that reflect minimum standards of demonstrated effectiveness (inter-rater reliability, team reliability in identifying areas of limitation, quality control for cuing, recognition of patterned responses, respondent acquiesce, etc.) so that monitoring approaches are defensible as being sufficient for "official purposes";
 - 4) Means of recruiting, training and rejecting team members based on established criteria for performance;
 - 5) Sufficient funding and organizational support to promote good performance by teams remembering that a key component of professional roles is pay for work performed with skill; and

- 6) Clarification of the purpose, products and audience of the teams and assurance that the rates, products and their uses are developed, understood and accepted by all stakeholders.

The engagement of persons with disabilities, including people with intellectual and developmental disabilities, as part of official government responsibility to assure the health, safety and general well-being of persons receiving services is still relatively rare. It is an area in which much more effort and commitment is justified. It is also an area in which tokenism is a major potential threat. It will be a major challenge to find real roles for people with disabilities explicitly define those roles, treat people as professionals in those roles, train them for and expect high performance in those roles, and secure acceptance of people with disabilities as valued and reliable implementers of service assessment and improvement models. But this seems worthy of the required struggles.

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