

**Independent Living Research Utilization**

# **Hallmarks and Features of High-Quality Community-Based Services**

**Second of Three Papers on  
Unlocking the Code of Effective Systems Change**

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<sup>1</sup> A list of participants can be found at <http://www.ilru.org/html/projects/CMS/colloquiumindex.htm>

## I. Introduction

Over the past several years, staff members and partners of the Independent Living Research Utilization (ILRU) team have provided technical assistance, training, publications, and other support to the Real Choice Systems Change initiative of the Centers for Medicare & Medicaid Services. As we conducted this important work, we began to observe there were clear distinctions between those programs that achieved (or showed real promise for) enduring change and those programs that failed to realize their full potential. In 2004, after almost four years of working with Real Choice grantees, we took the step of looking much more closely at how to foster meaningful, sustainable changes in the social services systems that support people with disabilities. We identified six outstanding projects that had received Real Choice Systems Change grants; each of these projects initiated significant and beneficial change in their respective states (Arkansas, Connecticut, New Hampshire, New York, Oklahoma, and West Virginia). The chosen projects were diverse in many respects, including --

- the scale, scope, and character of the service systems in place,
- the people and needs that were the focus of the changes,
- the types of participants involved in the change process,
- the changes being pursued, and
- the history and duration of the change process.

We asked representatives of these projects to reflect on their experiences and share lessons they learned about systems change. We interviewed project staff and consumer leaders. We wanted to know whether there were common factors that are central to achieving people-friendly systems change.

In January 2005, ILRU continued its investigation by inviting representatives from the six projects and other key Real Choice Systems Change leaders to a colloquium to discuss key elements of meaningful and sustainable systems change.<sup>2</sup> The group spent 2 1/2 days in Houston in active dialogue focused on three topics:

- Key components of systems change
- Features of a high-quality community service system
- Promotion of self-direction and consumer control in service programs and systems

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<sup>2</sup> Readers interested in the original three papers used as catalysts to stimulate dialogue at the colloquium may access them at <http://www.ilru.org/html/projects/CMS/colloquiumindex.htm>

From our study of successful programs and the recommendations and guidance of the colloquium participants, we have developed three papers that address these central aspects of the creation of enduring change.

The first paper in the series, *Key Components of Systems Change*, creates an overall framework for the discussion of systems change and serves as a summary of the concepts discussed in all three papers. In addition, it includes several specific recommendations that can be applied now by any grantee, state, or program to enhance prospects of achieving enduring change in home and community based services.

This paper, *Hallmarks and Features of High Quality Community Based Services*, the second in the series, identifies the features of high-quality integrated community services and the systems that support them. The paper is a first step toward the creation of a catalog of what key leaders, the practitioners, users, and advocates who supported development of this paper, consider to be some of the most important features of integrated home- and community-based services; features that distinguish them from services considered more traditional and less supportive of choice and full integration. In its present form, it serves as foundation work for additional exploration and discussion of what constitutes truly effective community-based services. The paper will undergo continuing development in discussions with representatives of projects and consumer leaders in states. The author's believe the paper, in its current form, will augment assessment of existing systems and planning of new or improved systems and, after refinement, it will become an even more useful tool for those involved in systems transformation.

The third paper in the series, *Promoting Self-Direction and Consumer Control in Home- and Community-Based Service Systems*, examines what contemporary social service systems can do to promote consumer-directed services. We identify different features that make a service "self-directed," and we identify characteristics of successful consumer direction and self-determination. As with the second paper, in its present form, it serves as foundation work for additional dialogue and will also undergo continuing development in discussions with representatives of projects and consumer leaders in states.

## II. Hallmarks and Features of High-Quality Community-Based Services

Home- and community-based services are a relatively new feature on the disability services landscape. Historically, people who experienced a disability or chronic illness relied on informal service from family, formalized supports delivered in institutional settings, or restrictive, medically-oriented community services that often constrained options and limited integration into community life.

There are many definitions of home- and community-based services, most of which are related to funding streams and programs associated with a particular set of services. In simplest terms, home- and community-based services are services that are needed by people with disabilities to live in their own homes in the community. Examples include assistance in making a transition from an institution or nursing home to the community; personal assistance with such activities as bathing, dressing, and grooming; and independent living skills training. Closely related to the definition of home- and community-based services is the concept of independent living, first defined as

*Control over one's life based on the choice of acceptable options that minimize reliance on others in making decisions and in performing everyday activities. This includes managing one's affairs, participating in day-to-day life in the community, fulfilling a range of social roles, and making decisions that lead to self-determination and the minimization of physical or psychological dependence upon others. (Frieden, et al. 1979)*

When home-based and community-based services first began to appear, they were highly experimental; little was known about what factors made them more or less successful. Over time, however, states and community organizations have gained experience in providing home- and community-based services through formalized structures. We are now in a good position to ask, "What are the features of high-quality community services (and the systems that support them) which foster integration and full inclusion?"

We recognize from the outset that the term "quality" is subjective and multidimensional. From one perspective, the most important definition should come from those using the services. Yet in evaluating formalized services, the authors propose that the term must embrace the concepts of integration and inclusion, as well as more traditional views of quality that include factors such as overall effectiveness, accountability, efficacy, and cost-benefit analysis.

With this complexity in mind, ILRU and those who participated in the colloquium identified features of high-quality services that support integration and inclusion. We started by acknowledging agreement on three fundamental overarching hallmarks. These global hallmarks are:

- High-quality services meet the service needs of those served.

- High-quality services are based on sound theories and practices.
- High-quality services are competently and efficiently administered.

Most would agree these three fundamental themes are consistent with mainstream thinking on quality management in human service systems. In addition, the authors, with the assistance of colloquium participants, identified two additional hallmarks:

- High-quality services support integration and inclusion of the individual so he or she can be as much a part of the community as possible.
- High-quality services foster diversity.

In this paper, we describe specific features of home- and community-based services that exemplify the five hallmarks listed above. Our purpose is to identify and present, in one paper, the most important hallmarks of high-quality community services. Of course, several of the highlighted features have been written about by other authors. Further, this paper does not attempt to provide a comprehensive listing of features. Instead, we address those features considered to be of the greatest importance by one group of key leaders, service users, advocates, and experienced practitioners.

Colloquium participants helped us by both testing the initial catalog and amplifying and adding depth to the initial presentation. Their feedback took place in reaction to the initial papers we presented for review. Their comments were made both prior to and during the colloquium.

### **Hallmark One: High-Quality Services Meet the Service Needs of the Persons Served**

What is it that makes services and the systems supporting them truly responsive to user needs? Those we interviewed and who participated in the colloquium identified the following features.

#### **1. Personalized Services**

Services can be adapted to meet the unique needs of the individuals served. There is a growing belief among those receiving services and their advocates that building service supports around the needs of the individual is a fundamental requirement of any service system. Much of the work in person-centered approaches draws on this principle. One colloquium participant stated, “Systems traditionally do not begin with the voice of the consumer, they only end with it.” Although few disagree with the concept of adaptability, how well services are individualized is often a matter of degree. When systems, policies, and practices are not properly adapted, individual service users may have to adjust to ill-suited services that intrude on their autonomy or are otherwise harmful.

If systems were to start with the voice of the consumer and allow the consumer to define what the services for them were to be, as well as end with the consumer determining whether the system achieved its goals, it is more likely that the services will actually meet the unique needs of the individual.

Meeting needs means more than simply making available what is needed. It also means meeting needs in a useful and sensitive way. Services must offer a workable fit between individual needs and preferences and program content; service programs must be flexible enough to change if this fit doesn't materialize.

## 2. Flexible Service Definitions and Policies

Broadened service definitions and service policies can further custom design of services, including what occurs when a service is provided, who provides it, who is responsible for decisions, etc. Service definitions and policies are often restrictive and prescriptive and flexibility can be promoted by not "ratcheting down" such definitions and policies. Involving those who receive services in the creation of definitions is also crucial. Consumer direction is also addressed in Hallmark Three: below.

## 3. Responsive, Flexible, and Changeable Services

Another feature of high-quality community services is that the systems supporting those services have mechanisms for staying in communication with users to keep abreast of changes in their lives and to respond in flexible and creative ways.

The lives of service users are dynamic, just as are the lives of most people. As service users experience new dreams, goals, and circumstances, they may need a new array of services and supports to meet those needs.

It is worthwhile to ask "what is needed in the service system to meet individual needs?" A colloquium participant stated: "We ask 'what does a person need,' but it may be more important to ask, 'what does this community, group, workplace, and system need' in order to support that person?" A high-quality community service system responds in flexible and creative ways as life changes for the people it serves. Services that rely too heavily on across-the-board standardized, and non-negotiable service options will clearly be unable to respond in the ways that meet people's ever-changing needs.

## 4. Blended Formal and Informal Supports

As the growing numbers of consumer-directed programs in the nation are demonstrating, services do not necessarily need to be provided through paid, formal supports offered by agencies and professionals. Informal supports often provide rich possibilities for meeting the needs of service users. Informal

supports include support from family, friends, neighbors, and others in the community. Examples include having a neighbor shop for groceries, having a family member assist with cooking or grooming, or asking a church member to run errands. The evidence is mounting (such as demonstrated in the Cash & Counseling program) that the quality of informal supports can be quite high and integral to a comprehensive package of supports.

Formal supports may still be crucial to a person's well being. When a community service creatively blends informal and formal supports that the person desires and needs, the service adds benefits to that person's life that formal supports alone cannot achieve. Formal systems can meet the needs of service recipients and they can also help them leverage the resources of their communities to enrich supports.

#### 5. Personalized Safeguards that are not Invasive

High-quality community services provide intentional and *personalized* safeguards. It has become popular in business to create "cultures of safety" to focus the attention of managers and workers on safety. The same can be done in service systems. However, those involved in administering and delivering services are also called to avoid invasive practices. Most people manage their lives to minimize the risks that they can control. Individuals who use services also need to manage risks. Service systems have a role in supporting them as they do so, but controlling risk can become invasive. It may be harmful if the social service system imposes across-the-board safeguards. It is important that those providing services engage in thorough and thoughtful discussions of risks with those receiving services and that they together establish means for addressing those risks. Colloquium participants recommended identifying a transparent and objective process--perhaps a consumer review process--to prevent risk assurances from being burdensome or invasive. Care must be taken to ensure those receiving services have the same level of autonomy that others have and that service systems do not become overly prescriptive.

#### 6. Minimized Bureaucracy for Service Users

It is important that service users experience as little bureaucracy as possible, that they be spared from dealing with the forms of bureaucracy they find onerous. Service system designers and managers should consider thoughtfully what information must be gathered to determine eligibility and to provide service system accountability, and then gather only that which is absolutely essential. Administrators should establish mechanisms that streamline assessments and reviews and ensure that these can be accomplished with an absolute minimum of disruption to the daily routine of the person receiving services. They should consider carefully where the boundary is between risk management and restrictive, unnecessary control, then eliminate or reduce provider control in

those situations in which control on the part of service users (or families) is more appropriate.

## 7. Information and Education Supporting Service User Choice

The popularity of consumer-directed options continues to grow because service users and their families perceive these services as highly beneficial. In our culture, it is a part of people's nature to want to "captain their own ship."

One key aspect of successfully personalizing services is to recognize that people may need education and training in order to participate fully. If people don't know what options are available, they are unlikely to make an informed choice. People who lack experience in making autonomous decisions (for example, adults who grew up in the Special Education system) may well need skills training to maximize their potential. As more individuals and families develop the tools to make their own choices, more of them will embrace the concept.

Regardless of background or circumstance, all service users can benefit from comprehensive, user-friendly information about services and options. Also, one colloquium discussion group suggested that informational resources should not necessarily be created solely from "within the system." Consumers and advocates can play an important role in creating materials, information, and training about services and options.

### **Hallmark Two: High-Quality Services Are Based on Sound Theories and Practices**

#### 1. Use of Best Practice Models

The defining assumptions at the core of service models must be consistent not only with what people actually need, but also with "best practice" service models that have been shown to be effective. Sometimes service models are adopted with little appreciation for their theoretical foundation or the evidence for and against these theories. Service models are based on some theory or assumption. The advantage of understanding the underlying theory is that it can be appraised consciously rather than followed uncritically. Leaders in service systems are called to -

- Review best (evidence based) practices literature often.
- Examine best practices in other states through facilitated technical assistance activities (when available) or through other informal means.
- Incorporate ongoing quality evaluation and accountability standards into the system design.

- Incorporate improvements based on best practice evidence and evaluation findings.

More and more, best practice models are demonstrating creativity and innovation and have been the basis for many of the most-appreciated recent improvements in community-based services.

## 2. Consumer Involvement in Research and Model Development

Colloquium participants noted there is a dearth of consumer involvement in research. They suggested that consumers (service users and advocates) be the impetus, the “drivers,” of policy research and evaluation. Consumer dominated research into best practices is essential, participants said. “Instead of having ‘experts’ develop the research and consumers ‘bless’ it, have it start with the consumer.”

### **Hallmark Three: High-Quality Services Are Administered Competently and Efficiently**

#### 1. Consumer Direction of Services

Colloquium participants underscored a widely held advocacy perspective: consumer involvement at all levels of service systems is essential to ensure that services are truly responsive to user needs. Many projects use an advisory body or consumer task force that may be required by funding sources. Colloquium participants stressed that consumer leadership must be authentic, meaning that users and advocates must be involved in true decision-making bodies. Some Real Choice Systems Change projects have successfully created and maintained advisory bodies that have authentic policy setting authority. However, by the definition of advisory, this is usually not the case. To create authentic opportunities for consumers to have a substantive say in policy setting, colloquium participants recommended that decision-making bodies should include at least 51 percent consumer membership and that program administrators should make every effort to support users and advocates in their leadership roles. Support includes providing travel allowances and personal assistance services related to consumer participation, ensuring meetings are conducted in accessible locations, and providing all materials in alternate formats. Employing service users in decision-making roles and as consumer consultants can ensure service programs are responsive to consumer voices. Participants also stated that consumer leadership should be at all levels of program administration, community, state, and federal. The third paper in this series addresses consumer direction in service systems.

## 2. People-Centered and Vision-Driven Services

A service can be very well administered and yet be misguided in its models and practices so that its outcomes are actually harmful to people. “Management” is not the same as leadership, and a well-managed service is not necessarily a people-centered service. Values-based leadership mobilizes people not only to be effective, but more important, to be effective at the right things, in the right way, and for the right reasons. At the outset of any systems change effort, it is useful for all stakeholders to engage in a process of values identification and clarification so that a common set of values and objectives can be established. Values that are supported by all will thus drive program implementation. This kind of consensus building can lessen the possibility that a program will get off track. When there is a clear vision, service leaders can bring the organization and service practices back to a people-centered and vision-driven mission.

## 3. Effective Administration of Service Programs

High-quality community services must be well administered to ensure not only program integrity and quality, but also to ensure the functionality, dependability, and consistency of the services being provided to users. Systems of administration should incorporate mechanisms to ensure accountability to service users and other stakeholders. Administration is a support function that helps to achieve the key purposes of services. Thus, a well-administered service not only pleases administrators, but also achieves the people-centered purpose for which the service was designed.

## 4. Feedback Loops and Quality Management for Continuous Service Improvement

The same mechanisms that promote service flexibility, through staying in communication with users, can also support continuous improvement. Those who deliver and administer services can go beyond traditional evaluation approaches to incorporate a variety of continuous-improvement, learning-organization techniques to ascertain how well (or if) services meet user needs. This involves not only evaluating effectiveness, but incorporating mechanisms that effect rapid changes in services and systems when feedback points to such needs. Among the aspects of services and systems that should be assessed continuously are effectiveness, responsiveness, quality, timeliness, and overall user satisfaction. Colloquium participants described this as “developing a culture of customer satisfaction.”

## 5. Leader and Staff Competencies Supporting Effective Services

Administrators and service providers must have the skills and abilities to offer services that are responsive to user needs and that support integration. Selection criteria for leaders should take into account not only program and administrative

experience, but also understanding of consumer direction and the philosophies and perspectives expressed in the key themes of this paper, as well as the competencies to implement them. This is also true for staff development activities. Ongoing support and skills training is a critical ingredient for ensuring that leaders and staff possess the competencies that will help them ensure services will be judged to be of “high-quality” by those who use them. The first paper in this series offers several specific recommendations for training of service system leaders.

## 6. Cost Benefits of Services

The term “cost benefit” refers to the balance between a program’s costs and benefits: the better the balance, the more economic the service. In other words, the value for money is either impressive, or it is not.

The only way this balance can be evaluated, however, is to be clear about what “benefit” refers to; cost alone is meaningless until it is linked to what benefits the money has produced. The key question is, do the services genuinely meet people’s needs at a reasonable cost? An expensive service may fail to yield much consumer benefit, while a very inexpensive service might be powerfully effective.

Expenditure levels must not be equated with quality outcomes. In fact, spending too much can interfere with quality if money is spent on the wrong things or if money is spent on meeting desires rather than needs. A service is most cost-beneficial if it effectively uses resources to provide the services its users really need. Determining the cost benefit of services, colloquium participants said, is one way of being accountable to users, stakeholders, and the larger community.

### **Hallmark Four: High-Quality Services Support Integration and Inclusion**

#### 1. Services Embedded in the Community

Although the concept is difficult to define, perhaps because the word community has so many connotations, the colloquium participants generally agreed that because high-quality community-based services are built around and meet the needs of individual users, the administration of those services should include local users and (to a lesser degree) providers. If parties who are remote from a community control the services, and if those parties are not accountable to service users or to the community, then services are *not* considered to be community-based. Colloquium participants emphasized the importance of bringing decision-making to the community level, as close to the service user as possible.

## 2. Support of Social Inclusion

Institutional social services have traditionally removed people from their natural communities to relatively segregated locations. This can result in lives of permanent exclusion. A high-quality community service does not separate people from their natural communities. Separation deprives people of civic participation in the name of service, treatment, or protection. If service providers do not value keeping users connected to their communities, or if providers do nothing to enable those connections, service users will become isolated, either coercively or from the simple lack of options for connection.

## 3. Support in Acquiring Valued Social Roles and Positive Social Images

The ability to take full advantage of community life is contingent on whether an individual has access to social roles that he or she values. A service can markedly assist individuals by helping them to be seen in a positive way and to acquire the social roles they value within community life. If a service leaves its users stigmatized, socially devalued, and bereft of life roles they desire, that service fails to meet the human needs for respect and status commonly available to other citizens. High-quality community-based services enable an individual to develop positive roles and interactions based on the person's preferences.

Colloquium participants were careful to distinguish this concept from "empowerment," stating that empowerment is highly personal and that others cannot give or take away personal power. Nevertheless, they readily acknowledged that services and service systems could either support or hinder inclusion and that these systems should, at all cost, support inclusion.

### **Hallmark Five: High-Quality Services Acknowledge and Support Diversity**

Participants in the colloquium expressed not only their own support of diversity, but also their strongly held belief that services and service systems can either foster or hinder diversity, and that systems should aggressively further diversity.

#### 1. Nondiscrimination in Service Delivery and all Operations

Most service programs are prohibited from discrimination by various state and federal laws. This is certainly the case when programs receive federal funding. Nondiscrimination requirements include race, ethnicity, gender, age, disability, and in some states, other protected classes. All aspects of program operation can be covered, including nondiscrimination in service delivery and employment. Those addressing the issue in the colloquium acknowledged that nondiscrimination is not only a primary obligation, it is also a widely held expectation of service users and advocates and that programs should be exemplary in their compliance with such requirements. Further, colloquium participants were emphatic that programs avoid discrimination and promote

inclusion not only within the organizations that administer services, but also in all stakeholder activities such as task forces and advisory bodies.

## 2. Antiracism and Cultural Competence in Service Programs

There is a growing expectation that programs must go beyond compliance to address diversity by engaging in antiracism efforts and fostering cultural competence. Those administering programs must make it a priority that leaders, staff, and others involved in service programs (including advisors and boards) acquire culturally-related competencies in service delivery, employment, and all other aspects of service systems.

### **III. Conclusion**

In this paper we have described hallmarks and features of high-quality services identified by users, practitioners, and advocates. We present these elements as a framework that can be helpful in designing improvements in existing systems and in developing entirely new systems. This paper is in no way the final word on what high-quality services are and what they are not. Our understanding of the key features of a high-quality community-based service continues to grow and expand as we collectively gain experience in designing and improving consumer-directed, quality-driven service options. We hope this paper will serve an immediate purpose of providing a catalog that lists and describes the features of services that support consumer choice, integration, and inclusion, the features that service users and advocates believe distinguish progressive service systems from more traditional ones. We believe such a catalog will be of value to program developers, evaluators, and managers and that it will facilitate further discussion and discovery among all stakeholders working to transform the social services systems that serve people with disabilities.

## IV. Reading List

This list, which is common to all three systems change papers produced by ILRU, contains the two publications which were referenced in the second and third papers, but primarily is offered as a reading list for those wishing to read more about improving service systems to make them more responsive to people with disabilities, the users of those systems. The list draws from many fields, not just human services. Not all materials are still in print, but the reader should be able to locate all these references in most large libraries.

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