

BALANCING SAFETY AND FREEDOM IN CONSUMER-DIRECTED SYSTEMS OF SUPPORT

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Freedom is not an ideal, it is not even a protection if it means nothing more than freedom to stagnate, to live without dreams,....

Adlai Stevenson

I. INTRODUCTION

Long term care is as intensely personal as the day to day events of each of our lives. Long term care is also a matter of public policy. People enter the long term care system to receive assistance that is not readily available to them in their own communities. The practice of long term care is, or should be, the practice of life. The support provided should increase the ability of the individual to experience personal freedom while improving his or her ability to live a safe and secure life in the community. The concept of freedom has two implications when applied to long term support: freedom from abuse, neglect and maltreatment and freedom to determine the course of one's life. Quality assurance for people receiving long-term assistance must protect against the provision of too little support, with the possibility of one being neglected, and the provision of too much support with the probability of the system taking over the life of the individual (Lakin, Larson, & Prouty, 1994).

Currently, people needing extended treatment or long term assistance rely upon family members to provide assistance or they purchase services directly, sometimes with the aid of private insurance. When personal resources become exhausted or if the cost of care is prohibitive, the only alternative is to enter the public long term care system. People move from a position of high personal authority, control and power when they are the purchasers of services, to one of significantly less authority and control when they become a "client" of the public or private human service system. Interdependence with family and friends is replaced by dependence on paid caregivers. Responsibility for protection from harm shifts to the service provider and freedom of action, personal autonomy, and choice become defined by the level of "risk" the provider is willing to tolerate. The individual becomes an observer to the events of his or her own life.

The structure of the service system for people with disabilities relies heavily on the concept that people who need long term care share certain basic characteristics. By providing services that meet common needs, a system can

achieve uniformity of care. This approach is believed to ensure that all those receiving support will be treated in a fair and equitable manner, without favoritism and without undue deference to the needs or particular circumstances of any single individual. Standardizing the design of services is expected to standardize the outcome. Although the concept of an one-size-fits-all model appears valid on its face, the reality is that the needs for support, treatment and training differ for each individual and change over time in response to varying personal and environmental factors. The emphasis on achieving uniformity of care actively inhibits the ability of a system to address each individual's unique life situation and personal goals (Kane, Kane & Ladd, 1998). Standardization of approach makes it virtually impossible to take advantage of opportunities for natural support that are available in the community as a result of normal relationships with family friends, neighbors, and others.

Over the past several years, growing dissatisfaction with the limited options provided by traditional long term support has led to demands for consumer control and program flexibility. Self-determination or consumer¹-directed care, in contrast to traditional models, is based on the belief that an individual's ability to experience both freedom and safety is significantly improved when he or she has control over the nature, extent and scope of the support received. This approach recognizes that quality of life, health and welfare is only achieved over the long term when controlled by the individual. The traditional system seeks to ensure necessary safeguards are taken through a professionally directed, provider led plan of treatment and support. Self-directed approaches, by contrast, assure freedom and safety by providing individuals with the tools and the authority necessary to manage the services they receive themselves. States that change systems to respond to demands for self-determination encounter a range of issues that challenge the best efforts to empower consumers to take charge over their lives. This paper identifies and reviews key issues involved in states' efforts to balance the need to ensure health and safety with the competing necessity to respect the right of the individual to freely determine the events of his or her life.

Freedom and Safety: The system of services for people with disabilities seeks to assure safety, health and welfare through methods that rely primarily upon regulation, periodic inspection, and the review of written treatment records. Designed to fit centralized institutional systems, this approach has not even been a particularly effective means for assessing intermediate care facilities for persons with mental retardation (ICF/MR) (Lakin, Larson & Prouty, 1994, Shea, 1992). It should not be expected to offer any better results when applied to the much more fluid and dynamic context of decentralized, consumer-directed, community services.

When individuals have responsibility for determining for themselves the supports they receive, for selecting providers and for directing their plans of care, the

¹ The term consumer is used in this paper to refer to individuals who acquire services for their own direct use, under their own direction.

service environment must be able to expand to include an array of nontraditional support providers offering varying amounts of assistance, as requested by the individual. This requires a level of flexibility that presents significant challenges to traditional methods of balancing freedom and safety by staff supervision, inspection, and review. People usually prefer, for example, to live in typical homes that meet community, but not facility, standards for structural integrity, fire and safety, and to seek employment in regular companies whose operations are accountable to industrial and occupational health and safety regulations, rather than those set by the disability service delivery system. Consumers who direct their own services in the community may not come into day to day contact with the “staff” of provider agencies (Tilly & Wiener, 2001), and may need to rely upon social contacts and natural supports for assistance when necessary. When individuals, rather than service providers, direct the program planning process, the service architecture takes on the appearance of a handcrafted patchwork quilt, with supports of differing types used flexibly to fill in the gaps that occur during the daily routines of life.

The protection of the freedom and safety of people receiving support in the community, is primarily dependent on two factors. First, the nature of the relationship between the person helping and the person being helped and second, the presence of a network of paid and unpaid support providers, family and friends who offer assistance, advice and social contact. Freedom and safety are assured when those who provide care value people with disabilities as individuals. Abuse, neglect or maltreatment does not, and perhaps cannot, occur in the presence of positive, respectful, and caring relationships where individuals care for each other as friends, coworkers, or neighbors, worthy of respect and equal treatment. On a daily basis, the quality of an individual’s experience is dependent on the character of the moment to moment interactions that take place between the person and those who provide support.

Etmanski (1997) noted that personal security is assured for most of the population by the interdependent relationships that exist among friends, families and communities. Unfortunately, current service systems require activities and attitudes on the part of support providers that actively inhibit the formation of lasting personal relationships that people typically rely upon to guarantee the health, safety, and welfare of their family and friends. Requirements designed to achieve uniformity of treatment force interactions between individuals and staff to be structured around the need to justify behavior and limit liability for mishap. The actions of staff become controlled more by the necessity to document their activities than by the need to establish the personal connections that people in society identify with a quality lifestyle.

Identifying Roles and Responsibilities: States, in concert with the federal government, have responsibility for assuring that the services furnished to people with disabilities under the Medicaid program protect their health and welfare. When the recipients of services control the nature, extent, and scope of support provided, this responsibility must be shared. Methods of quality assurance must

integrate the responsibility to respect individual choice and control with the need to protect a person's health and safety and remain accountable for the appropriate use of public dollars. The ability to successfully blend these objectives requires a delineation of the authority, roles, and responsibilities of all parties. A comprehensive quality management program must:

- Set the *authority* for decision making and the *methodology* for ensuring the person is free from harm and free to control the decisions of his or her life.
- Identify the *standards* to be met and the *outcomes* to be achieved by the individual and the system.
- Assign *responsibility* for performance and *accountability* for accomplishing set outcomes.
- Set the *content* and *methodology* of the process used to evaluate the quality of the person's life and the extent to which the supports provided enable the individual to access a quality lifestyle.
- Set the process by which deficiencies are turned to *strengths* and supports are *improved* to meet the standards and outcomes that have been set.

II. SETTING THE AUTHORITY

For the purpose of this discussion, "authority," refers to the power to enforce laws, determine outcomes to be achieved and to judge the results of actions. "Responsibility," refers to the capacity to act and to be held accountable for outcome performance, and, "a right is not what someone gives you; its what no one can take from you (Ramsey Clark, 1977)."

Authority to control is tied to responsibility for action, accountability for results and an obligation to assume legal liability for outcomes that accrue. Under the Medicaid program, states and the federal government share the ultimate authority for (a) defining expectations regarding quality, safety, and freedom, (b) determining the overall scope of activities and the types of supports furnished under the state's plan and, (c) setting the latitude of acceptable behavior with respect to the maintenance of an appropriate and responsive service environment.

Historically, the capacity to improve service quality and assure the freedom, safety, health and welfare of individuals receiving support has been based on a strong relationship between the state and the service provider. The individual receiving support was relegated to the role of *participant*, rather than *partner*, and placed in an advisory capacity in the design and implementation of his or her plan of care. Self-directed service models, by contrast, shift to the individuals receiving support the authority to determine the character of the plan of care, as well as the role providers will play in their lives. This means that the "default" position for the system is one in which significant, if not primary authority, rests with the consumer. The individual is assumed to be able to control financial and programmatic decisions, and is responsible for determining whether the support received impinges on his or her ability to exercise free choice. Individuals, of

course, vary in their ability and interest in taking on direct responsibility for their plan of support. Assignment of authority must be consistent with consumers' interests and their capacity to be accountable for the decisions they make. Some need considerable assistance to assume responsibility and participate in the decision making process. It is reckless, for example, to declare that an individual has the authority to be an employer of record for the purposes of supervising and directing support staff without making certain he or she can hold the responsibility for the decisions that are made and the accountability for actions taken.

Authority of the Individual: For the majority of United States citizens, the authority for balancing personal safety and free will rests with the individual. Each person has the primary authority to determine the adequacy, quality and acceptability of services he or she receives. Within the context of consumer directed support systems, the individual should have responsibility for identifying and assessing the key aspects of his or her life that are beyond the experience of the state or the provider to evaluate. The authority for determining the quality of the experience of living in a particular home, for example, rests most appropriately with the resident(s) of that home. The assessment process must take advantage of subjective experience of the individual and collect data that leads to an understanding of what it means to the person to work in a specific job or live in a particular home.

People who are unaccustomed to having the power to make decisions on their own typically need support and training in order to gain independence, confidence and an understanding of the alternatives available. Indeed, the concept of "dignity of risk" recognizes that people develop new coping skills only by taking on increasing levels of personal authority and responsibility through direct experience in real life situations. For many people who require assistance in decision making, choice becomes a negotiation process in which the individual bargains with the provider to be *allowed* to assume increasing levels of risk and independence. The structure of the current system mitigates individual control by placing significant accountability on the provider. In response to the concern this generates, providers may limit a consumer's opportunities for choice and decision making to protect themselves. A tool that offers the potential of facilitating the process of transferring control to the consumer is the *individual-risk contract*. This document is an agreement between the consumer and others that outlines the concerns and benefits associated with particular courses of action, the conditions under which the individual is assuming responsibility and the trail of accountability for the choices that are made. Although it has been used as a method of protecting the provider from liability, it can also be used by the consumer as a mechanism to assuage the concerns of others about the choices he or she intends to make.

Authority of the State: The state is the legal entity that holds the power to develop and operate an effectively working service delivery system. The state may decide to designate a separate organization or department to carry out its

duties in this area, but it retains the final decision making authority. In this role, the state has a broad responsibility to ensure people have access to the services they are eligible to receive, and to maintain a comprehensive system to address the needs of the full range of individuals who may require support. The state, by virtue of its role, has a unique view of the service system, one that is not shared by the consumer, the provider or the federal government. The state is able to assess aspects of support delivery that are not experienced by other entities, yet are critical to the maintenance of an effective system. For example, an important measure of the ability of a system to meet the needs of the population is the financial health of the provider agencies. As the funding agent, a state department typically has access to account records, audit histories, fund allocation decisions and statistical data that provide a picture of the financial health and viability of the organization.

Authority of the Provider: The provider has a view of the structure and functioning of the system that is not totally shared by the either state or the consumer. Like the consumer, the provider must manage the trade-off between choice and safety in decisions that are made each day. As provider organizations begin to offer a range of individualized consumer-directed services, their authority over the decision making process changes, as does their accountability for decisions that are made by individuals receiving support. Many providers have expressed the concern that consumer-directed approaches may place them in the position of being held responsible for decisions that were made by consumers without their review or involvement.

Shared Authority: Responsibility for protecting the consumer's health and well being is shared by the individual, family, guardians, the state, the provider, the members of the Circle of Support and others who participate in an individual's life. ²Because interests and responsibilities may legitimately overlap, authority for some decisions that balance an individual's freedom with his or her safety cannot be made without input from all concerned. Parents, family members, friends and support staff, play key decision making roles in the lives of people with cognitive disabilities. Whether assigned specific responsibilities as a court appointed guardian, as the representative payee for social security payments or as the fiscal agent, these individuals are responsible for acting in the best interest of the consumer. Their decisions are critical to the quality of life of the person receiving support, particularly at the point where freedom from harm meets the freedom of expression.

The decision making process used by individuals who act on behalf of consumers needs to be identified and discussed among members of a person's team. Do those appointed to act on behalf of individuals *substitute* their own personal decisions for those of the people they support, or is it their role to *represent* the

² The Circle of Support is a group of individuals chosen by the consumer to assist in the development of a person-centered plan, and to provide advice, support, and assistance in decision making.

wishes and desires of the individual, as they understand them to be? Studies suggest that guardian's opinions regarding satisfaction with services and adequacy of support received are not the same as those held by the people themselves (Culbert et al., 1996). Yet, the opinions of guardians frequently substitute for the perspectives of individuals with disabilities in specified legal matters. Although guardians have an important perspective on the quality of supports provided, Medicaid regulations are largely silent on their role with respect to the assurance of quality, health and welfare, and in the planning process in general. A discussion of the strengths and weaknesses of guardianship is beyond the scope of this paper. However, it is clear that the role of guardians must be carefully considered in the process of assessing the balance of freedom and safety because of their power to control opportunities for making decisions that are within the capacity of the individual.

Freedom and Responsibility: Freedom is inextricably linked to responsibility. When individuals receiving support are involved as full partners in the operation and direction of services, they take on responsibility for the decisions they make. People can be held accountable to the extent they have the capacity to respond, to act, and to understand the implications of their actions. The state or provider may assign the responsibility for assuring health and welfare to the individual in a self-directed approach, as long as he or she has the support necessary to become informed about the implications of decisions and truly answerable for the outcomes of those decisions. Assignment of authority for specific decisions to the person receiving support does not, however, totally displace the broader requirement of government to carry out its statutorily defined duties and responsibilities. The state remains obliged to ensure the presence of a comprehensive, effectively working system that is able to respond to the needs of individuals requiring support.

III. DEVELOPING STANDARDS AND OUTCOMES

In an individually-directed model, the standards and outcomes should reflect the authority of the individual to make the final determination regarding the purpose and direction of support. This approach represents a break from the traditional emphasis on safety and the management of professional liability that overshadows the need to focus on an individual's hopes and dreams (Nerney & Shumway, 1998). The standards and outcomes should reflect the person's need to receive: (a) direct support to access work, home-life and community activities, through assistance that functions to compensate for the particular condition that limits activity on the job, (b) training and skill development in order to access the activities, perform the work or complete the tasks without assistance, (c) ongoing ancillary services including, transportation, access to assistive technology, equipment repair, administrative assistance, etc. and, (d) necessary medical and health related treatment, dental, physical, speech and occupational therapies (Kane, Kane & Ladd, 1998).

As is described above, certain indicators of safety, health and individual freedom fall solely within the experience of the individual receiving services, while others may be best set and assessed by the state, provider or a combination of interests. Standards and outcomes can be developed by:

- An external group or organization that brings an outsider's perspective reflecting the general standards of individuals in society, families and the community at large.
- An external group that brings an insider's perspective reflecting principles of support provision developed by state or national governments, accreditation bodies, consumer or provider organizations.
- A subjective, consumer-centered process in which people receiving support and their chosen allies set criteria that reflect their perspectives on quality, control, management and the assurance of health and welfare.
- A combination of perspectives coordinated to produce standards, outcomes and expectations that incorporate both subjective and objective measures and meet the goals of each of the parties, consumer, state, federal government, providers.

The standards and expected outcomes that are set regarding the provision of a safe environment, the protection of health and welfare and the support of a person's right to exercise free choice are validated when consumers play a controlling role in the process and there exists a clear delineation of the responsibilities of the state, the service provider and involved professional staff.

The Individual Sets Support Outcomes and Criteria: The criteria against which the effectiveness of supports are measured is developed by the individual and his or her circle of support as a part of the person-centered planning process. The provider is held accountable for providing the support necessary to accomplish the outcomes of the plan to the criteria specified. In this sense, the plan becomes an official agreement Or contract between the service provider and the individual, identifying the scope of work for the provider and the conditions under which the consumer's satisfaction will be assured.

The State and the Individual Set the Standards for Providers: People with disabilities and their families repeatedly assert their desire to receive support in a manner that encroaches upon their lives as little as possible. Consumers expect services to be reliable, to respect their knowledge of the situation and to support their own authority to control the events of their lives. Standards should address the intrusiveness of the supports offered, their impact on the ability of the individual to express his or her free will, the quality of life the individual is able to access as a result of the supports provided, and the relationship between the three. The nature, responsiveness, quality, and effectiveness of the support received, whether from a large agency or the neighbor down the road, must meet the personal standards and expectations set by the individual. The state, in conjunction with those receiving support, should set the overall purpose, standards, and expected outcomes for the service delivery

system at large. These standards should be included in contracts with organizations and individuals that provide services. Support providers should participate in the process of policy development, bringing their expertise, knowledge of the “market” and understanding of the factors involved in the provision of supports, but should not have a controlling interest in the setting of standards and outcomes.

The State Sets the Standards to Measure System Effectiveness: In Medicaid waiver programs, the state, subject to the approval of the Federal authority, is ultimately responsible for identifying the standards and anticipated outcomes of services provided, and for controlling the assessment process. In most cases, it is the state that sets or validates the criteria used to determine the need for commendation or corrective action and the process by which support quality and responsiveness will be improved. A service system that reflects the principles of self-determination completes these responsibilities by working in close partnership with consumers to set the policies governing the provision of funding and the methodology used for determining the adequacy of support provided. The state does not act in the role of guardian to determine and provide supports it believes are in the best interest of the individual. Rather, the state works as the agent of the individual to ensure the system is financially healthy, cost efficient, comprehensive and able to effectively accomplish the outcomes that have been targeted for accomplishment.

IV. ASSIGNING RESPONSIBILITY FOR BALANCING FREEDOM AND SAFETY

Self-determination is best supported in an environment that specifies the roles and obligations of the person receiving support, the state, and the provider. Clearly defined responsibilities set the path of accountability for the achievement of set outcomes, the improvement of services and the correction of program or policy deficiencies. The traditional system allocates responsibilities among a defined group of state and provider bureaucracies. Providers are held accountable for the supports they offer by licensing or certification processes that are intended to enforce adherence to relevant policy, regulation and law. It is becoming recognized, however, that conventional methods of inspection, citation and correction ensure little more than “paper compliance,” and do not build the capacity of a system to assure, assess or maintain quality on an ongoing basis (Lakin, Larson, & Prouty, 1994; Bradley, 1990; Chaflee, 1990).

The design of a delivery system that supports self-determination, by contrast, is more flexible, open to creative solutions and shares authority and responsibility for decision making among consumers and independent providers without losing accountability for action. People directing their own services do not necessarily choose to receive supports from the existing network of providers. Consumers may desire to hire their own staff, control their own budget and personally decide whether or not a potential employee has the qualifications

necessary to provide the support in a manner preferred. Responsibility for assessing the safety, health and welfare of people in the service system is held by the state or delegated to county government, provider organizations or quasi-governmental bodies.

It is not uncommon for consumers living independently to have infrequent contact with professionals of the established service system. As such, traditional methods of survey and sporadic visitation do not provide an adequate basis to judge the quality of an individual's experience. In this context, significant attention needs to be placed on the design, set up and day to day operation of each person's network of support. If, for example, the individual is the employer of record and supervises staff who provide assistance, he or she has explicit responsibilities to comply with all relevant taxation, employment and worker's compensation laws. Additional responsibilities to follow state requirements for conducting staff background checks and identifying inappropriate or illegal behaviors on the part of those hired to provide support may have an impact not only on the individual's freedom, but his/her safety as well. The methods that are chosen to assess the quality of life a person enjoys need to be designed around his or her lifestyle, work habits and daily routines. Interestingly, people who control the supports they receive report that they feel more independent, successful and in charge of their lives (Tilley & Wiener, 2001), even though it may involve more work.

To be effective, the process for assuring free choice and safety needs to spread responsibility among the groups and individuals involved in the person's life by building it into the activities of the circle of support, the person-centered planning process, the work of the provider and of the state. Increasingly, states are involving people with disabilities, families, provider organizations and other citizens in the assessment process. The review process is changing to focus on the quality of life the individual is able to enjoy as a result of services provided. In the monograph, *Reinventing Quality* (1998), Polister, Blake, Prouty and Lakin describe activities in several states to improve service quality, and identify several practices that appear to be associated with high quality outcomes. The authors note that quality does not just happen but rather, results from a concerted effort on the part of all members of an organization to see the world from the perspective of the individual who is using the supports offered. The search for quality is never finished, but involves constant attention to the positive values that form the foundation of the effort; recognizing all people as individuals, fostering the development of personal relationships, and providing continuous opportunities for learning, cooperation, communication and positive self-assessment.

The Individual: In a consumer-directed system, the approach used to balance choice and safety must verify the validity of the consumer's perspective as the central component of the quality assessment process, and should be specified in the person-centered plan. The determination of the consumer's personal accountability should reflect a careful consideration by his or her Circle of

Support (see below) of the risks, benefits and opportunities of desired activities. Roles and responsibilities of all parties should be clearly identified. The authority of the individual, for example, needs to be recognized by the support broker, the members of the person's circle of support, the staff who work for or on behalf of the consumer, and the state itself through policies, practices, rules and regulations. Responsibility for ensuring that existing rules and practices do not prevent consumers from crafting their own plans of care as they see fit should be shared among all people involved in an individual's life as well as other participants in the service delivery system.

The Person-Centered Plan: Freedom and safety, health and welfare are best assured by the design and implementation of an individualized person-centered planning process that clearly identifies the measures that are being taken to assure that decision making processes is driven by the consumer. The planning process should evaluate the impact of the objectives that are set on the individual's freedom. The planning process should identify the mechanisms by which individuals are assured they are receiving the support described in their plan. The process should also describe the steps the person can take to address concerns by changing to another provider, hiring their own staff, changing the support plan, bringing administrative or legal action, or other means. Finally, the person-centered plan should set the terms and conditions that form the basis of the relationship between the individual and the support provider, and the criteria by which outcomes will be measured.

The Circle of Support: The responsibilities of the members of the person's Circle of Support, the support broker and other key individuals should be identified during the person-centered planning process. The accountability of Circle members, as well as any requirements placed on them to report risky behaviors or to intervene on behalf of the individual are also identified in the person's plan. Members of the Circle are typically involved with the consumer in an ongoing process of review, personal goal setting and risk analysis. The assignment of an official role for the Circle in the state quality assurance process, however, may compromise the ability of the members to be seen by the consumer as trusted friends who work on his or her behalf.

The State: The State has responsibility for ensuring the most vulnerable populations receive appropriate support and are free from abuse, neglect and maltreatment. In a Medicaid funded, individually-directed model, the State's role is to work in concert with the federal government, providers and consumers to evaluate the structural and functional components of the service system that are typically outside of the experience of the individual. Specific responsibilities should complement those of the individual, the circle of support and the provider and include, monitoring the financial practices of provider organizations, reviewing data management procedures, monitoring Medicaid and state fund related billing and payment practices, reviewing personnel and employment practices, and assessing allocation practices to ensure the funding provided is appropriately used to address identified priorities.

V. ASSESSMENT CONTENT AND METHODOLOGY

The approach used to evaluate a service system's ability to protect an individual's freedom and safety needs to respond to the change in the person's role from participant to consumer. Methods of assessment that view the individual as a passive recipient without the power to make substantive changes in the service mix or in the relationship with the provider undermine the authority of the individual and damage his or her ability to enforce real changes in support delivery. The content of the assessment should facilitate the process of shifting the nature of the relationship between the consumer and the provider from one based on "coercive" power, where consumers follow the leadership of an authority because they are concerned about what might happen to them if they do not follow, to one of "equilateral" power, where the two parties interact as equals, each deriving benefits from their mutual relationship (Covey, 1992).

Public and Private Standards of Care: In private-pay healthcare, standards are written and enforced on the assumption that the individual is capable of acting in his or her own behalf to seek redress of grievances. Consumers who are dissatisfied with a provider may choose an alternative organization or take administrative, legal, or civil action against the responsible party. When the state assumes responsibility for controlling the nature, scope, and extent of support offered, it assumes the role of the consumer by proxy and takes on an obligation for assuring the adequacy and appropriateness of care provided. Acting on behalf of an identified group of individuals in need, the state imposes rules and regulations to achieve a quality of care that, presumably, independent consumers would want for themselves. Shifting power to the individual poses a difficult challenge for most states because they have not been released from their overarching responsibility to assure the health and welfare of the individuals in the service system. The state remains accountable for the expenditure and oversight of public dollars. It must carefully scrutinize the delegation of responsibility for the management of even a relatively small amount of public funds.

The methods selected to assess freedom and safety in self-directed services must reflect the changing roles of the individual and the state. In the context of consumer-directed systems of support, the consumer must negotiate authority for decision making, choice, and control with the state and/or provider agency. Accepting the authority of the individual may mean accepting the level of oversight provided by the private-pay service delivery system, a less intensive process of review with weaker standards for the resolution of complaints. The process of assessment should build the capacity of individuals receiving support to take full advantage of existing avenues of complaint resolution, professional review, abuse and neglect notification, and legal assistance that are available to people who purchase care directly or through their employers. Individuals who

direct their supports may have minimal contact with the formal system. In the absence of direct oversight, the process for assessing the quality of consumer-directed services must take advantage of as many sources of information as possible.

360 Degree Assessment - Multiple Sources of Input: Methods of assessing support quality, health, and welfare in a self-directed system must be able to integrate data from multiple sources to produce a comprehensive, *360 degree* view of the quality of life individuals are able to access as a result of the supports received. The assessment process should be tailored to suit the various environments the individual passes through at work, at home and in the community to develop an understanding of what it means to the individual to be supported in each environment. The process should additionally capture the perspectives of those who interact with the consumer on a regular basis. People with disabilities should be included as active partners in the evaluation process, as well as members of the Circle of Support and others chosen by the individual. The results of these assessments should be brought together with self-evaluations completed by the provider agency and other reviews by accreditation bodies. This data, representing different perspectives, should be combined through the process of “triangulation” to develop an overall understanding of the ability of the individual to access a quality lifestyle in the community. Review results should be released to the public in the form of a “report card” documenting the effectiveness of the provider agencies at offering quality supports.

Focus on the Individual: The assessment process should document the perspective of the consumer and recognize the authority of individuals to determine the direction of their care, even if they choose to delegate responsibility for making some decisions to others. The evaluation should reveal what it means to the individual to reside in a particular home, neighborhood and living situation, to work in a particular job, to be unemployed or to engaged in unpaid community activities. The assessment should document the consumer’s perspective on support provided by an agency, what it means to work with individual staff members and whether a consumer believes his or her living situation inappropriately restricts freedom, or presents risk. The review should seek to determine the amount and nature of risk individuals can accept on their own and the conditions under which the individual can accept liability for his or her actions.

The evaluation should include the Circle of Support as a group of key informants and sources of information, rather than as an official agent of the review process. Some states implementing self-determination projects have experimented with the idea of assigning the Circle of Support responsibility for evaluating the quality and the health and welfare of the individual. The Circle frequently acts as the first line of defense to protect the individual from decisions that might place him or her at risk. Assigning the Circle formal duties in the quality assurance process, however, professionalizes a source of support that derives its strength from its unique role in the person’s life. Such action would place members of the Circle in

a conflict of interest if they had responsibility for passing judgment on situations or decisions that included their prior involvement. The assessment process should reveal how the group (a) actually functions to assist the individual to achieve the outcomes identified in the person-centered plan, (b) assists the individual to make informed decisions regarding alternatives for support and, (c) balances individual choice and control with the need to ensure personal health and safety.

Provider Capability: The evaluation should review the capacity of provider organizations to effectively implement consumer directed services, identifying operational procedures, rules, fund allocation practices, administrative requirements, and organizational structures that inhibit individuals from freely participating in decision making.

The concept of self-determination and its underlying principles of freedom, authority, support, and responsibility receive widespread support from people with disabilities and their families, state departments, and individuals who work for people with disabilities. While most agree that changes need to be made at the provider level, few organizations are currently structured or managed in a way that actively supports the capacity of consumers to take charge of their lives. The experience of states that received grants from the Robert Wood Johnson Foundation to incorporate principles of self-determination into their developmental disabilities programs underscores the challenge of restructuring the existing service delivery system (Moseley, 2000). Not only do states and provider agencies need to change their approach to supporting individuals, but they must also retrain the staff who provide the day to day support to have a clear understanding of the principles of self-determination and their own role in the process of empowering the individual to take charge of his or her life.

Regulatory Compliance: The assessment should examine the impact of state and federal regulations, as well as provider policies and procedures on the ability of consumers to direct the development and implementation of their own plans of care. The evaluation should start with the assumption that regulations, policies, and procedures should add value to the overall quality of life of the individual, and foster independence and community involvement. State regulations should reflect the primacy of the relationship between the state and the consumer. State policy should provide administrative backing for individuals who want to initiate, change, or terminate their contracts with support providers without concern that funding for the services they receive will be changed or withdrawn. Regulations should be assessed to determine the extent to which they allow consumers to configure support in the manner that best meets their needs. Consumers who hire people to work for them, for example, should be able to use alternative credentialing requirements that provide the latitude to adopt a more “consumer friendly” approach focusing on the ability of staff to produce the tangible outcomes identified by the consumer.

Complaints and Grievances: The assessment process should review mechanisms that are present to receive and quickly act upon complaints and concerns. The dispute resolution process should be open and fair, and include options that include independent mediation and arbitration to resolve differences and the use of neutral parties, such as ombudsmen, to intercede on behalf of the consumer. The process should include the focused involvement of people receiving services to both emphasize and validate the central role of people receiving support in a self-determined system.

VI. IMPROVING QUALITY BY REPLACING DEFICIENCIES WITH STRENGTHS

The process of evaluation leads to improvement when technical assistance, training, and direct support are provided to enable the individual and/or the organization to change practice to respond to the findings and recommendations of the assessment.

Determining the Need for Corrective Action and Technical Assistance: In a consumer-directed system, both the state and the individual share responsibility for determining the need for corrective action. Consumers have the ability to respond when they have the authority to control their service budget, to hire and fire staff, and to direct their plan of support. Deficiencies identified by the assessment process typically represent the outcome of a series of decisions that have been made, rather than the result of unique or isolated events. In this environment, the consumer should be involved in the determination of the specific corrective actions that should be taken and the individuals or organizations who will be held accountable for change. The process of assessment should link requirements for corrective action with the provision of technical assistance, training and direct support. The evaluation and improvement of the supports provided are two components of a process that is designed to strengthen the ability of the consumer to effectively achieve the outcomes that have been set. Where possible people with disabilities should provide training and technical assistance to providers to help them modify existing patterns of services.

Determining Responsibility for Action and Accountability for Results: The consumer must have the opportunity to take the lead in the process of determining the corrective actions to be taken and the individuals or organizations who will be held accountable for making the changes necessary to improve the supports received. The state brings a broader perspective and is in the position to determine whether the actions taken and expenditures incurred are consistent with the statewide system of care plan. This approach relies on the ability of consumers, with the help of their Circle of Support, to respond to concerns by taking direct action to change providers, to appeal decisions, rewrite job descriptions, or make adjustments to the person-centered plan.

Identification and Imposition of Sanctions and Rewards: Consumer-directed approaches rely on the ability of individuals receiving support to respond to concerns by taking direct action to change providers, appeal decisions, rewrite job descriptions or make adjustments in the plan of care to better address personal needs. The state should work with consumers to decide whether the actions that are proposed to address deficiencies are sufficient and appropriate to (a) meet the needs of the consumer, (b) build the capacity of the system to support people with challenging needs (c) strengthen the potential to accommodate new referrals and (d) meet the requirements of the statewide system of care plan.

In practice, people with disabilities, people who are older, and those with cognitive impairments frequently need assistance to effectively negotiate with providers regarding the identification and correction of problems. Some individuals with cognitive disabilities are not able to be held legally accountable for the decisions they make and it is unfair to place them in the position of ensuring that providers take the actions identified during the review process. Although the consumer must be involved in the process of assessment and ongoing review, the responsibility for imposing sanctions or rewards on providers most appropriately rests with the state as the legal authority.

VII. CONCLUSION

In many businesses, the outcome of the effort is a material object that can be seen, touched, and used. The effectiveness of the manufacturing process is determined by judging the quality of the outcome, the utility of the product itself. The product of human services, by contrast, is an experience, an event, or the demonstration of a learned behavior. The outcome is the result of an interaction or a series of interactions between individuals. What is present to evaluate is not an article that can be directly examined but a description of an activity that has been completed by one of the participants, a description that generally reflects only the perspective of the individual who documents the event in the record. Rarely, if ever, is it the consumer who provides the documentation.

Systems of long-term care rely upon rules and regulations to guide practice so as to achieve equity of treatment and access, uniformity of approach, and a level of care comparable to that which most people would want in their own lives. Because people with disabilities have been thought to be at risk and in need of protection, systems of support have emphasized safety and care to the exclusion of personal rights, liberty, and basic freedom. In many states supports can only be accessed in a manner that requires the individual to relinquish the fundamental freedoms that are guaranteed to all citizens by the Constitution.

In the real world, the perspective of the consumer is relied upon to set the standard of acceptability and quality. Yet, in human services, the commitment to professional judgment has allowed the perspective of people hired to perform the service to supplant that of the individuals who receive the service. In most

instances, neither state nor federal regulations require the perspective of the individual receiving support to be recorded, or considered as a controlling factor, outside of the initial program planning process. Staff's documentation of the progress of services, incidents of crisis or disagreement, or the effectiveness and utility of supports provided is typically the only point of view that is recorded. The potential for the perspective of the consumer to be overshadowed by the perspective of the provider threatens the success of efforts to expand opportunities for choice and self-determination. The following observation by Thomas Szasz (1973) provides an interpretation how the psychiatrist, in this case, frames the motives and actions of an individual within a "professional" perspective:

When the psychiatrist approves of a person's actions, he judges that person to have acted with "free choice"; when he disapproves, he judges him to have acted without "free choice." It is small wonder that people find "free choice" a confusing idea: "free choice" appears to refer to what the person being judged (often called the "patient") does, whereas it is actually what the person making the judgment (often a psychiatrist or other mental health worker) thinks.

In a system that supports self-determination and consumer direction, professional standards are neither sufficient nor acceptable by themselves to be used as criteria to judge whether a person's freedom to choose, to determine, to control what goes on in his or her life is inappropriately restricted by the supports that are provided, regardless of the reason those supports are provided.

States have a responsibility stand behind the people receiving support and to require that providers are engaged in an active process of listening to what people say they want from the service delivery system. States also have a responsibility to set minimum standards of support quality and responsiveness that providers must meet. The necessity of maintaining a comprehensive capacity to respond to the changing needs of individuals requires states to go beyond a free market approach of allowing providers to succeed or fail based solely on the decisions of consumers to use or avoid particular service providers. States must encourage the development of new alternatives for individual support that offer levels of responsiveness and flexibility that are beyond the scope of the current system.

In an individually directed system, the design of the process used to improve the quality of the of supports offered is pulled in several directions in response to the different perspectives of the individuals involved in support provision. The approaches employed balance issues of freedom and safety and include (adapted from Kane, Kane & Ladd, 1994):

- *Individual or Consumer-Driven Approaches* reflect the primacy of the role of the individual, and place responsibility for determining the boundaries of freedom and safety in the hands of the people receiving support. The consumer decides whether limitations imposed on his or her freedom by the

support provided is acceptable and responds by controlling the resources allocated on his or her behalf. Regulations are minimized, designed to facilitate access to a range of service options, and support the capacity of providers to change quickly to meet the evolving needs and preferences of consumers in a “free market” structure.

- *Regulatory Approaches* utilize rules, regulations, and established operational procedures to set the criteria, outcomes, and expectations for decision making. This approach relies upon the perspectives of others to make determinations on behalf of the individuals receiving support regarding the acceptability of the restrictions to personal freedom that are imposed by services. The state or other designated entity acts as the primary agent for all consumers, seeking to ensure quality, health, and welfare through standardized procedures of operation, regulatory compliance, and program review.
- *Provider Controlled and/or Professionally Driven Approaches* are based on the assumption that provider organizations and professionals are in the best position to effectively improve the quality of services. Provider controlled approaches rely upon external accreditation bodies, professional review boards, and self-assessment processes to guide decisions regarding appropriate service provision and treatment, and to maintain compliance with regulations.
- *Contractual Approaches* govern the decision making process by the use of contracts or agreements between the state and provider organizations or between individuals and service providers that detail expectations for service, the terms under which payment will be made, rewards for positive actions, and punishments for deficiencies. Decisions that balance an individual’s freedom with the need to ensure safety are governed by clinical guidelines, care criteria or treatment protocols set out in the contract.

In practice, states use a combination of approaches to assure service quality and the health and welfare of people receiving support. A system that fosters self-determination must consistently reinforce the central role of the individual receiving support. The system must be designed and operate in a manner that reflects the perspective that funds allocated to provide long-term support represent an investment in a person’s life, and a commitment to the proposition that an entitlement to receive services includes an entitlement to control those services.

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