



## **LOST LIVES**

### **THE PAUCITY OF QUALITY IN HUMAN SERVICES**

**Tom Nerney**

*To date quality assurance systems have ignored almost every critical component of quality that all individuals would choose as necessary for a minimally adequate quality life. In addition the unspoken “bargain” made with many individuals who need support is to require all or most of their everyday freedoms to be surrendered in return for support. This raises a core public policy question: can we ever have quality in a system that does not support freedom?*

How we define and measure what we mean by quality in the arena of disability creates the foundation for how long term services and supports are organized and reimbursed. Most importantly, how we answer this question has profound implications for individuals with disabilities and for the costs associated with our definition of quality. The Medicaid community-based quality assurance systems must comply with minimal CMS standards with a lot of flexibility in their application. A majority of these guidelines are directed at system requirements, and not personal quality of life components.

#### **Background**

The entire Medicaid program spends in excess of 340 billion dollars annually. Approximately one third of that is spent on institutional and community services for individuals of all ages who have a disability. These dollars represent a critical component of each state budget and have been identified by organizations such as the National Governor’s Association as the single greatest fiscal threat facing state budgets. In some states the Medicaid line item represents the single greatest state expenditure. Medicaid currently serves almost 50 million Americans or approximately 20% of the entire population of the United States. Long term support services consume just fewer than 40% of total Medicaid expenditures for 14 million of the entire number served under Medicaid.



The Medicaid system is essentially a state program with federal oversight and matching dollars that is indexed to the relative poverty of the state. That said, each state makes its own commitment to serving individuals. State commitments vary widely from a per person low of \$2,722 in New Mexico to highs of over \$7,000 in states like New York, Connecticut, Maine and Rhode Island. The national average expenditure per person is \$4,202. It is a regulation driven program of incredible complexity and detailed organization characterized by a sense of liability and fear of transgressing one or more of countless regulations. An estimate of the number of pages of regulations necessary to maintain and continue this system easily exceeds 600,000. By way of contrast, another program that no one pretends to understand are the 75,000 pages that comprise the Internal Revenue Code rules and regulations.

The Medicaid program is in serious fiscal trouble. States are routinely denying eligibility or limiting it severely. The cost of current services is becoming prohibitive. Hundreds of thousands are on waiting lists - some for many years. More will become eligible under the health reform bill recently signed by the President. Nursing homes and public institutions capture the lion's share of Medicaid long term care expenditures. Per capita expenditures in these types of institutions frequently are two to three times more costly than community supports.

The current Medicaid program is on a collision course with demographics. As America ages, the sheer number of those needing support will overwhelm the current system. Within the developmental disability population more individuals live at home with an aging caregiver than are currently served. For historical and other reasons the mental health population has never achieved anything resembling equity in the way Medicaid dollars are allocated. Before our eyes, the current system is already collapsing.

An example illustrates the very best that this current system can provide. A young adult needs assistance in many activities of daily living. Eligible for Medicaid funding, this person soon finds out that the contracted homecare agency often provides different people to help, are often late and sometimes don't show up at all. However, a new program has just been adopted by the state and this individual is allowed to hire whomever he wishes including friends and relatives.



He successfully hires a former schoolmate who provides these services in a timely fashion. This new program is called (among other things) self direction or participant driven services.

This new and progressive approach is then evaluated. There is no question that the “program” is successful. When interviewed by independent evaluators the person served expresses satisfaction with the services he has planned and receives.

The present human service system, even under its most progressive interpretation, has chosen *services* as the norm for what constitutes quality. And so the ultimate qualitative goal is an expression of satisfaction with the services delivered, as it is in virtually all quality assurance systems. In this example there is a service outcome that makes getting up in the morning and carrying out basic activities of daily living possible. This is the very best that can be accomplished under the present system. Why is it inadequate?

What has developed very naturally based on this type of quality norming is the construction and sale of a product or commodity called a human service program. (This is true on both the community and institutional sides of the current system.) Key to this approach is the adoption of qualitative standards featured by most corporations and industries--primarily consumer satisfaction. This has even resulted in calling those served “consumers” and some of these individuals inadvertently adopting the language of consumerism to define themselves. The standard remains **the same - the J. D. Power commercial and industry norm for quality. The concentration on documenting services rather than outcomes has been carried to an absurd length.**

Attention to the desires and aspirations of those served are close to afterthoughts in a complex system that is so vast and so regulated that it is beyond the understanding of any one person.

There are no consequences if personal goals are not reached. In fact, in most states the unspoken purpose of a quality assurance system is reduced to health and safety concerns—a worthwhile goal but one that goes to the beating heart of where this complex system focuses on liability at the expense of real life goals. For liability issues there are consequences. For real quality of life issues there are no consequences if they are not met.



Central to the pretense of real quality and personal control, and central to the need to stay within program and service boundaries, is the embracing of what is called “person centered planning”, a phrase that supposedly places the person with a disability at the center of the planning process for the provision of services. This is the major way that the human service industry pretends at real quality. A “person centered plan” is vital to what is currently deemed quality for the person because it can now be “demonstrated” that the individual plan is now “owned and endorsed” by the person to be served within a system that features low or no expectations.

There is no universally acceptable definition for what “person centered” means. Each state gets to define its meaning and it may even differ from place to place within the same jurisdiction. This renders the very notion of person centered planning essentially meaningless. In fact, it constitutes a form of paternalism and is frequently rife with conflict of interest. Whatever authority is ceded to the individual with a disability during this planning process can be withdrawn or overridden at any time by managers of the current system. The “authority” of the person served then is neither authentic nor binding.

Worse still is the typical composition of the planning team often mandated by state regulation, professional traditions or provider rules: staff of the service provider, the case manager and often other professionals. This can be done with the person present or not and with family/allies present or not. In other words, conflict of interest is built into the very system. Those who are required, or typically assist in planning, frequently have a financial stake in ongoing and future support and service elements selected in the plan. CMS does not recognize this conflict of interest and it is not recognized as a problem at the state level. It also constitutes one of the strongest predictors of increases in cost. There is never an incentive to get better value for the dollars when the planning group’s self interest depends on how the budget is apportioned.

The present system of services then is founded on quality concerns devoted more to system operations, service programs and their operation than to the quality of life of the person to be served. Much more time and effort in many systems are devoted to billing, billing codes, service definitions and reimbursement issues than to quality.



*By norming quality on the person's ability to use both public and private funds to craft a meaningful life in the community, we would take a far different path with our Medicaid Waiver dollars, our service definitions and the type of planning done by individuals.*

We can see this by returning to the example of the young man cited at the beginning of this paper who eventually gets to hire his friend to provide services. What is wrong with this is not the authority to hire a friend and thereby improve his services. What is wrong is what is left out and ignored.

In all probability we would find out with a clearer analysis that this man is probably personally impoverished, may have no control over transportation, and has no close friends or even the support to make close friends by being an integral part of his community. The best of the old system ignores or only partially addresses what gives every other person quality in their lives: a place to call home with control over the front door; community membership; long term relationships; and, at least a plan to address poverty. **The best of the current system gives an individual the *services* to get up in the morning. Conversely, by norming quality on key universal human aspirations, this individual would now have a *reason* to get up in the morning. This is one essential difference between self direction and self-determination.**

### **The System of the Future**

Across the country, individuals with and without disabilities universally include the following four indices of what constitutes quality or would constitute quality in their lives:

- A safe place to call home with authority over anyone who enters and especially anyone who needs to touch his/her body
- Real membership in, and contribution to, the community with control over the means of transportation
- The support needed to continue relationships and forge new ones, including intimate ones
- Support to end near total impoverishment virtually required at the intersection of Medicaid and Social Security



Norming human service on the lives and the aspirations of individuals with disabilities is central to individuals leading self-determined lives. What has evolved in the Medicaid funded human service programs is a set of standards that focus on service delivery and largely ignore standards universally understood to be central to our very humanity. If our public policy supports equal citizenship for individuals with disabilities then it needs to offer the potential for achieving equal quality for these same individuals--equal to what every citizen takes for granted. This means that an elderly person with a disability will not only be supported to live in his own home but (as a result of person *controlled* planning) to name just one example, keep his family and social relations intact. A person in recovery will be able to freely choose those supports which meet clinical needs and also have a holistic plan for living a full life where any clinical goals are in support of a full and meaningful life. An individual with a developmental disability will be able to take monies available and leave non outcome-based day programs. Instead, this individual can pursue a meaningful job or begin self employment. From wandering in small groups around the community like congregate tourists, each individual will be able to construct and carry out activities that truly connect with the community or result in real work. From earning below minimum wage, (which gives the lie to "medical necessity") the individual plan can now include tools to reach each of the goals articulated in these examples. In these, and in all other examples of personal planning, human services are provided in support of a full life. They become tools in pursuit of a life rather than ends in themselves. The present system has it exactly backwards.

It is very bad public policy to offer individuals who need support, services that require them to surrender basic freedoms that all Americans take for granted. With costs rising and waiting lists growing, observe what would likely happen to an individual depending on which path is taken. On Monday this person enters a human service program. The public cost goes from zero on day one to \$100,000 annually on the next. This same person with exactly the same disability and level of disability goes from zero public cost on Monday to anywhere between \$25,000 and \$50,000 annually. (This is for illustrative purposes only) This is a simple way to illustrate the irrationality of the present system. By moving the resources to the person instead of placing a person in a predetermined program slot or bed, the possibilities of becoming more cost effective



while addressing real quality become more apparent. What would have to be in place for this to happen?

First, a conflict of interest-free plan, driven by the person to be served, would be developed with freely chosen assistance as desired. The plan would include how the person is going to address crafting a meaningful life in the community using the four universal human aspirations as bedrock for the plan: a place to call home, real membership in the community, continued or newly developed long term relationships, a plan to utilize some new resources (brokers/peer supports are two examples) to help with this plan and its implementation, and finally, strategies to address forced impoverishment. Depending on age, a plan to get a job or start a microenterprise will be routine, a plan to incorporate long term care insurance and ethically structured reverse mortgages will become a natural part of the human support system. In other words, the introduction of private resources to the publicly funded system will become commonplace because it is essential.

In this type of planning, with assistance as needed, clinical needs are obviously included as well as close attention to health and safety issues. It is becoming clearer that persons served without close committed relationships are most in jeopardy with regard to health and safety. Typical health and safety standards do not even address who is in the person's life.

Another effect arises immediately. The typical or traditional provider pyramid becomes upended and the most important workers in the lives of any person who needs supports take their rightful place at the top of the pyramid. Negotiations for living wages and benefits become central to the lives of those fully impoverished - those with disabilities--together with the second most impoverished group - direct support workers. What emerges here is the mutual interest of those with disabilities, and those who spend more time with them than anyone else in the entire human services industry.

### **Lost lives or Self-Determination**

With proper fiscal supports, that are also conflict of interest - free, this newly designed system can finally direct to individuals with disabilities, the resources to strive for a meaningful life just as every other citizen. New types of service definitions need to be written, meaningless

35425 Michigan Ave West, Wayne, MI 48184. 734-722-7092

[www.centerforself-determination.com](http://www.centerforself-determination.com)



paperwork substantially reduced, and attention to the basic life goals for all individuals to be served, are at the heart of self-determination. To continue the present system is not only fiscally unsound, it consigns those served to lives lost to loneliness, personal impoverishment, and full or partial exclusion from real community life; lives lost to regulations, program requirements, surrendering basic and ordinary freedoms; and lives lost to a sophisticated pretense at quality without equality based on shared universal human aspirations for a meaningful life.