

The Purpose of Public Funding for Individuals with Disabilities

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Self-Determination or Lost Lives

The failure of public policy to adequately address the issue of the common humanity of individuals with disabilities has resulted in the substitution of human services and human service environments and programs for real life and high purpose. Individuals with disabilities have become human service subjects within a system of long-term supports that has no expectations that common life goals based on universal human aspirations can add great depth to the notion of addressing the health and welfare of individuals with disabilities.

Present public policy inadvertently supports *lives lost* to programs and rules that deny or ignore our common humanity, our common aspirations and dreams, and our common sense of responsibility to become contributing members of our society. Our present public policy forces individuals with disabilities into lives of personal impoverishment and frequent loneliness.

The purpose of public funding must move to a nobler goal of assisting individuals and families achieve lives of high purpose deeply embedded in their communities, engaged in meaningful relationships and pursuing both economic and spiritual goals.

The History and Meaning of Self-Determination

The promise of self-determination from its inception was rooted in increased quality, increased power for individuals with disabilities, increased status within the community for these same individuals and, at the policy and organizational level, a fairer, more equitable distribution of public funds. It was just over a decade ago that the first

demonstration on self-determination in New Hampshire began with a grant from the Robert Wood Johnson Foundation. The two populations included in this initial pilot were individuals with intellectual disabilities and individuals with acquired brain injury as well as with a small number with concomitant psychiatric disability.

The original purpose outlined the “harm” that resulted from typical human services for these populations. Self-determination was not some form of rugged individualism but rather recognition of our inter-connectedness and shared vulnerability. This included loneliness, isolation and the powerlessness experienced when public dollars are out of the control of individuals with disabilities and families.

This fundamental shift in power was predicated on the human service system adopting structural changes that would facilitate and hasten the shift in power necessary for self-determination to become a reality for tens of thousands of individuals presently served and for those tens of thousands currently awaiting public dollars for support. At its heart the self-determination movement was committed to obtaining better value for the dollars currently expended. Self-Determination then, under this rubric, became organized around a set of principles rather than a set of human service interventions or environments. These principles were not human service categories and tried to capture both the political significance of this change and the implications for individuals at a very personal and transformational level:

Freedom, the opportunity to choose where and with whom one lives as well as how one organizes all important aspects of one’s life with freely chosen assistance as needed; **Authority**, the ability to control some targeted amount of public dollars; **Support**, the ability to organize that support in ways that are unique to the individual; **Responsibility**, the obligation to use public dollars wisely and to contribute to one’s community. In 2000 at the request of individuals with disabilities, The Center for Self-Determination, headquartered in Wayne, Michigan, added **Confirmation**, the recognition that individuals with disabilities themselves must be a major part of the redesign of the human service system of long term care.

Since 1993 when a small cadre of 45 individuals with truly significant disabilities began this revolution, self-determination has spread in many forms including self directed services that capture one important part of self-determination but not its fullness.

Night and Day

In 2003 Ricky W. a man with intellectual disabilities who lived for many years in a state institution, moved into an apartment in Hartford CT that was in a poor and unsafe neighborhood. That was all he could afford with his meager Social Security benefit. Medicaid funds would not help supplement his room and board costs. Returning to his apartment from the store he was confronted by four teenagers who beat him to death with soda bottles. In that same state that year Richard M. who lived at the same institution for thirty years without even having a visitor made plans to buy his own condo. Richard was labeled profoundly disabled and autistic. He does not use speech. But the principles of self-determination were used 13 years ago to surround Richard with a circle of support and long term allies. Control of a very modest budget was obtained. Friendships and commitments were fostered and developed. Richard has a life and a future. His total costs are much less than similarly disabled persons.

The System of the Future

The design of the new system requires three essential elements:

Individual budgets represent the translation of the person's hopes and dreams into a budget document controlled by the person/family with assistance when needed.

Independent assistance, peer supports or brokering which is the provision of unbiased and competent advice and support for the person with a disability in designing and carrying out the life plan and budget provisions.

Fiscal Intermediaries which are organizations or individuals who provide financial assistance with bill paying, accountability for public funds, taxes and benefits as well as other types of financial assistance that may be needed.

These system re-design features make it possible for any person with a disability, no matter how significant, to benefit. There can be no exceptions to the restoration of full citizenship to individuals with disabilities.

The system of the future for long term care must now move to increased flexibility with public Medicaid funds for long term support that promotes more creativity, creates outcomes of better value and addresses the unsustainable costs of the present system. The system of the future would encourage working and self employment as well as the creation of targeted savings accounts (Individual Development Accounts), the infusion of private money through new trusts, long term care insurance and ethical reverse mortgages seamlessly blended with public dollars.

The Perfect Storm

Each of these three storms—increasingly scarce Medicaid resources, the demographics of the young disability and elderly populations, and the shrinking workforce—will very soon converge to create the perfect storm and rock the entire long term care disability system. At the end of the recent stimulus infusion states will face even more intractable deficits.

This is not to suggest that self-determination can ever hope to carry this burden alone. Self-determination is not a magic bullet and it requires careful and thoughtful re-design of the present system. However, it remains one of the few advances in the field of disability to demonstrate cost efficiency as well as increased quality. States and projects report current costs at or below that of typical human services. With the advent of “The System of the Future” it is possible to hope that with more individuals entering the work force, remaining out of expensive institutional settings, getting better connected to their communities and entering more long term committed relationships, together with the infusion of private dollars, costs will decline while quality soars. The original demonstration over 15 years ago with 45 individuals saved \$300,000 annually.

Re-Thinking Quality

Self-determination requires a fundamentally new foundation for establishing quality and quality assurance systems in the field of long term care and behavioral health. The goal of the self-determination movement has always been to assist individuals with disabilities to craft a meaningful life in their communities, rich in relationships and deeply connected to their communities and the world of business and commerce where age appropriate.

Some contemporary quality assurance systems, depending on what public policy choices are made, may be adequate for the first step in this revolution—supporting control of human services by individuals with disabilities and their freely chosen allies. This is so because control of and satisfaction with the services or supports are seen as the goals of this first step. Therefore it still makes sense for many in the quality assurance world to continue to rely on levels of satisfaction with services or supports as the primary foundation for quality assurance. There are major points of agreement on the need to shift control of a targeted amount of resources directly to the person with a disability/family. There is a new awareness of the role responsibility plays with this freedom to choose providers and services as well.

Both approaches raise the issue of the very purpose of public funding. Self-Determination takes the position that this purpose must be related to a person with a disability having a purposeful life, having the ability to seek the same goals that all others have related to personal relationships, membership in the community, and establishing an economic and spiritual future. The problem with contemporary public policy in this view is that there are no high expectations for individuals with disabilities. In truth, there are *no* expectations beyond satisfaction and “choice” even in systems adopting “control” of resources by individuals with disabilities. Human services have remained the goal and control of those services has become the foundation of self-directed services and supports. As a result self-direction measures the adequacy of the services, the person’s control of these services and the person’s satisfaction with them. Admirable steps in a

new direction. Self-Determination sees supports and public dollars as means to an end not an end in itself. Lives of high purpose require a deeper foundation.

Once we move from evaluating the adequacy of and control over services and supports to the goal of crafting a meaningful life (self-determination), we will have to move from simply evaluating services to evaluating outcomes in the lives of real people. We will move from simply addressing the adequacy and satisfaction as well as control of the services to the quality of personal lives. And this means that we have to fundamentally change our quality assurance systems from ones that posit and evaluate only increased *satisfaction* with services and supports to ones that reach a much higher standard: the realization, through the use of public dollars and supports, of meaningful lives predicated on universal human aspirations and supported by public policy that sets high expectations for the receipt of public dollars. This self-determination rethinking of quality then translates concretely into personal budgets that reflect spending plans to achieve at least the following: a safe place to call home with control over who enters the front door, the continuation or the fostering of relationships and community membership, and the production or protection of at least modest resources to escape the penurious existence of so many Medicaid and Social Security beneficiaries.

This new view of quality starts with re-examining health and safety issues and moves inexorably to universal human needs for friendships and relationships, freedoms common to all citizens, secure economic futures and contribution and community belonging.

A person with a physical disability may need assistance in getting up, dressed and having breakfast each morning. A person receiving behavioral supports may need assistance provided through counseling or peer support. Being satisfied with who provides this assistance and how they provide it are worthy questions and satisfaction-type evaluations adequately get to the answers. But they miss the point and the goal of the self-determination movement, which holds that this is simply not sufficient. Self-Determination is moving to a deeper personal and public policy issue: *why get up in the morning at all?* In other words why are individuals with disabilities not accorded nor

expected to have purposes in life similar to those without disabilities. Virtually everyone else arises to carry out daily responsibilities, work, earn income, plan for life goals, take care of family members, contribute to the common good, exercise citizenship. Until people with disabilities are accorded the same expectations our view of quality will remain severely constrained. It will focus solely on the services. Until the foundation of our benefit and program structures are changed people with disabilities will remain forever impoverished, frequently consigned to unsafe housing, unable to work because of Social Security disincentives and live lives of minimal quality.

Only by positing high expectations and positive outcomes related to certain universal human needs can we ever set a higher standard that also meets the public policy test of quality and cost effectiveness.

The Meaning of the Dignity of Risk

Free men and women take risks. The very notion of freedom implies the possibility of risk. Human service discussions of risk center on issues of health and safety. As if with newfound freedom individuals with disabilities are somehow predisposed to create situations that will jeopardize their well being. Self-determination is not about doing whatever one pleases with public dollars. It is not about creating additional risks to health and safety. In fact it can be argued persuasively that self-determination properly implemented better addresses issues of health and safety. Self-Determination at its core promotes long term committed relationships. Without these relationships individuals with disabilities remain forever in jeopardy with health and safety issues. Vulnerable people especially, but not unlike most everyone else, need someone to rely on and in whom they can place their trust.

But self-determination properly implemented does increase risk for individuals with disabilities. It seems important to recognize these risks and even to encourage them. What are they? By addressing universal human needs and desires and aspirations, self-determination poses several risks not usually contemplated by traditional or typical

human service systems. By addressing forced impoverishment people with disabilities face the possibility of failure—failure at work or at self-employment or loss of assets. By addressing our connections to our communities people with disabilities face possible rejection. By focusing on the universal human need for friendships and even intimate relationships, self-determination poses the risk of heartbreak.

These are the risks that define us as human beings, make us strong and reflective and carry the promise of true community and family membership. With every one of these risks there is now hope. With assistance individuals with disabilities including those with intellectual and cognitive disabilities, psychiatric and physical disabilities, older Americans with disabilities and those with brain injury, need to face the risks associated with membership in the human race. They need to accept responsibility for the exercise of freedom. They need to understand that the dignity of risk is what makes us human. The possibility of hope prevailing outweighs the fear of failure in a system of supports that truly values every person and finally aims to re-capture lives lost.

The dignity of risk then is central to our new understanding of what the support system of the future needs to be-- characterized by high expectations and the risks that all people must take to create lives of high purpose and great meaning.