

# **THE MEANING OF SELF-DETERMINED LIVES IN PUBLICLY FUNDED SYSTEMS OF LONG TERM CARE**

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This first written description of “Self-Determination” was based on a set of *principles* and in a demonstration of their efficacy, funded by a grant from the Robert Wood Johnson Foundation, targeted a group of individuals with significant brain injury and a group with developmental disabilities beginning in 1993. The principles have remained as a foundation for this effort ever since:

## ***Freedom***

The ability to make life decisions about where and with whom one lives and what important things one undertakes that parallels in every important way the decisions that those without disabilities make everyday.

## ***Authority***

The ability to control a targeted amount of public dollars together with private money in order to craft a life plan that results in the everyday freedoms that all Americans desire and the expectations that the lives of those with disabilities will mirror, with appropriate assistance when necessary, the lives of others in this society.

## ***Support***

The organization of these resources in ways that are unique for the individual and address the support needed because of a disability with a more holistic way of planning and budgeting that address perennial issues often lost in the system of traditional long term care: a place to call home, sustained relationships, community membership and for adults the production of private income through the world of business and commerce.

## ***Responsibility***

The commitment for the wise use of public dollars and with added flexibility in public funding seeking a more cost effective way to support individuals with disabilities. From its very inception Self-Determination challenged the high cost of “serving” individuals with significant disabilities with very few discernable outcomes that would be acceptable to a person without a disability.

The movement toward self-determined lives for individuals with disabilities has its roots in the civil rights movement as well as the patient autonomy movement and has been expressly articulated by people with disabilities ranging from those with psychiatric labels to those with intellectual disability labels. Organizations have developed that carry the ideals of accessibility—both physical and social, freedom from coercion and freedom to pursue everyday lives infused with high expectations. The first written expression of an organized approach to rethinking the federal Medicaid program began with a publication funded through the Robert Wood Johnson Foundation National Program Office on Self-Determination at the Institute on Disability, University of New Hampshire. (Nerney and Shumway, 1996).

Over the last twelve years this approach has evolved into specific recommendations for changes in public policy, Medicaid funding mechanisms, individual allocations and

personal budgets, eliminating forced impoverishment and a deeper view of what constitutes quality assurance.

## **Public Policy**

Self-Determination challenges the view that public funding is only about providing assistance based on a person's deficits. Taking into account the particular assistance an individual may require, Self-Determination posits a set of expectations that veer fundamentally away from a constricted view of medical necessity and toward creating policy that promotes meaningful lives. In its bare essence it promotes the view that public assistance is a vehicle to enable individuals who experience disability to live a life of everyday freedoms together with an acceptance of the responsibility to contribute to this society and to one's own welfare.

## **Medicaid Funding Mechanisms**

Many states and the federal government now recognize two of the structural reforms necessary for system change of this magnitude: independent and conflict of interest-free assistance to individuals and fiscal management agencies to disburse the public dollars on behalf of an individual with a mandate to both account for the dollars spent and address both benefit and federal/state tax and labor issues. Various self direction initiatives have reinforced these changes. Self-Determination goes further by questioning many contemporary service definitions and rate setting that limit creativity in planning and budgeting while failing to address issues of relationships, community and poverty.

## **Personal Budgets**

Individual allocations, ideally set below current traditional expenditures (for those in high cost settings) are then translated into unique budgets with the following set of expectations:

- *Individuals would have a safe place to live where they control who enters their home.*
- *Individuals establish real community membership.*
- *Individuals sustain current and facilitate new long term committed relationships.*
- *Individuals engage in the production of income through work and/or self employment as well as participate in other income and asset development initiatives including individual development accounts.*

## **New Quality Assurance**

The quality assurance paradigm would then move from *satisfaction* with services (the commercial consumer standard for product satisfaction) to quality outcomes associated with the four domains listed under personal budgets. This approach has the added benefit of better addressing health and safety issues by insuring that long term relationships are instrumental in advocating for the individual with regard to that person's health and safety.