

SELF-DETERMINATION FOR PERSONS WITH DEVELOPMENTAL DISABILITIES

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DOING MORE WITH LESS: RETHINKING LONG TERM CARE

My name is Tom Nerney and I am Co-Director of The National Program Office on Self-Determination funded by the Robert Wood Johnson Foundation and located at the Institute on Disability at the University of New Hampshire. I am pleased to be able to testify at this forum on "The Anxiety of Elderly Parents Caring for Baby Boomers with Disabilities" and thank Senator Grassley and members of this committee for the invitation.

Our efforts to redefine and reshape the system of long term care for individuals with developmental disabilities impacts directly on this topic, and, furthermore, may have enormous implications for all individuals with disabilities. Elderly family caregivers are an important constituency who are part of a growing body of family caregivers including middle age families caring for elderly parents. Their anxiety about lack of services or supports is exacerbated by the limited choices available in the present human service system, Medicaid eligibility problems and lack of direction over these services or supports.

Within the field of developmental disabilities we have witnessed growing waiting lists in state after state for supports and long term care. The present system has become enormously expensive, frequently does not furnish the types of support that individuals and families desire and severely limits the freedom to design supports in keeping with the express wishes of those with disabilities and their family and close friends. One of the reasons for this is the complex, clinically oriented, regulation dominated, Medicaid program whose original design was meant to treat individuals with disabilities like patients. While much has been accomplished to address this issue in new and improved state waivers under Medicaid, there remains much more that needs to be done.

The challenge for all of us is simply this: *can we design a system of long term care that values the freedoms that all Americans take for granted and be cost effective? Can we design a system of supports that addresses the issue of quality while honoring the desires of individuals in need of support to live where they want and with whom they choose?*

This morning I would simply like to tell you what self determination means, give you some examples of the potential for both enhanced quality and reduced average costs, mention the new structural requirements for implementing this approach and discuss the implications of self-determination for all individuals with disabilities or chronic health conditions who warrant our support. Some recommendations then follow.

WHAT IS SELF-DETERMINATION

Self-determination is a national movement to redesign long term care for individuals with developmental disabilities that eschews traditional program model and facility placement approaches. Rather, self-determination is based on a set of fundamental American principles developed to guide our efforts in re-thinking our system of long term care and re-thinking how public dollars are apportioned and utilized. These principles are Freedom, Authority over Resources, Support and Responsibility.

Freedom in this context simply means that individuals with disabilities have the freedom to choose where they live, with whom they live and how they spend their time. This is done with the assistance of freely chosen family, friends and professionals.

Authority over Resources means that these social networks of individuals with disabilities and their allies control the budgeting of some targeted amount of resources and choose who provides any particular support as well as direct changes to the budget based on changing circumstances.

Support means that these individuals and family and friends can organize the unique supports that an individual may need and desire rather than have to fill a bed or a program slot in a typical provider arrangement.

Responsibility means that individuals with disabilities will carefully purchase only what they need, husband scarce public resources and contribute to their communities.

In early 1993 we designed a pilot to test this approach with 45 individuals in Southwestern New Hampshire with assistance from the Robert Wood Johnson Foundation. We took the then radical path of asking individuals and families what supports they valued, how they would like to see them developed and implemented and gave them the freedom to prioritize these supports as well as change them when they felt they were not working. These were all individuals served on a 24 hour basis within the current Medicaid waiver.

An independently funded evaluation by Conroy Outcome Analysis found greatly enhanced quality of life among the participants at the end of this demonstration. Not to be undervalued was the secondary finding: these individuals had enjoyed an increased quality of life while saving \$300,000--a reduction in average cost of from 12 to 15 percent.

As a result of this effort the Robert Wood Johnson Foundation moved to set in motion a series of demonstrations around the country. Today, there are small and large efforts in 29 states that are geared to pioneer self-determination and provide us with the information we need on the myriad ways that these principles can be implemented. In well over 100 communities thousands of individuals are working on transferring resources directly to individuals with disabilities and their family and close friends.

WHAT WE ARE LEARNING: THE POTENTIAL

Throughout the field of long term care state officials, advocates and individuals with disabilities as well as close family and friends are coming to some rather common sense conclusions. States are faced with a growing population of elderly individuals many of whom will need support. Demographics alone are cause for a fundamental re-evaluation of current expenditures as policy makers weigh the influx of an increasingly aging population on their Medicaid budgets. Just as nursing home placements represent the least desirable choice for elderly people nursing homes also represent the least desirable choice for cost conscious state officials. Even if enough "beds" could be built it is fantasy to believe that state Medicaid budgets could absorb these increased costs.

So too in the field of developmental disabilities. Many states have been moving away from the traditional institutional settings of yesteryear and exploring new ways to reinvest public dollars in order to serve more individuals in cost effective ways in our communities. Reallocating existing resources is the first step in this process. Moving from large congregate facility approaches to highly unique individual budgets designed by individuals with disabilities and their family and friends appears to be a logical next step in the re-design of our current system.

The self-determination movement has given state officials a new set of tools to both increase the efficiency of the present system and meet the aspirations of people with disabilities. Two states have recently generated data that gives a glimmer of how costs could be contained without denying needed

benefits to individuals and families. Both New Hampshire and Connecticut developed strategies that brought a targeted amount of resources directly to family caregivers and individuals with disabilities instead of taking individuals into the system in the old way.

In Connecticut, an average amount of \$20,000 was made available to a small number of families through a special appropriation from the State Legislature that emphasized self-determination. This was welcomed by these families on the waiting list and utilized in novel and ordinary ways. The twenty four hour cost of bringing any one of those individuals into the old system would have topped \$60,000 per person annually. In New Hampshire the average expenditure for those served under the Medicaid waiver is \$44,425 in the traditional system. Utilizing the principles of self-determination state officials gave priority to any waiting list plan that reflected the principles of self-determination. This strategy emphasized non-traditional and lower cost alternatives. The average expenditure under this approach was \$22,314.

We know quite a bit about the costs associated with congregate settings. We know very little about costs associated with supporting individuals in ways that meet their unique desires. Not every person is going to cost less than the present system. However, all of the preliminary evidence points to average reductions in public outlays under a self-determined system--a new way to think about serving more individuals with the same resources. This appears to be true for those currently served as well as those on existing waiting lists.

THE NEW STRUCTURAL AND SYSTEM REQUIREMENTS

Self-determination appears to require that we rethink almost all of our current assumptions about long term care and carefully develop the appropriate structural conditions to assure that real freedom is the hallmark of the new system and that quality and the wise, efficient use of resources undergirds the new system.

Individual budgets are developed by persons with disabilities and their allies based on a targeted amount of dollars usually set somewhere below current traditional costs. This is the first step in this structural reform. Two resources appear to be necessary in order for this to work properly.

First, the dollars themselves have to be physically located so that they can be drawn down in conformance with an approved budget. We refer to this as a fiscal intermediary and see it as essential to success. Currently state and county contracts are with provider agencies who budget their dollars on a set amount per person times the number of individuals in their contracts. In this way the dollars are subsumed in the agency contract and the individual never has control of them. Fiscal intermediaries are independent of service providers and also responsible for insuring the proper payment of taxes, withholding and understanding when individuals providing support are employees, independent contractors, homemakers or companions.

Second, the resources available to individuals must be understood and the information and planning necessary to utilize both traditional and community supports must be available to individuals with disabilities and families. This we call independent brokering--the presence of individuals or agencies whose sole loyalty is to the person with a disability.

In many of our project sites around the country state and county authorities are testing new approaches to both of these structural requirements. In one county in Minnesota a local bank has agreed to act as a fiscal intermediary and has issued checkbooks to individuals with disabilities who draw down the county money upon completion of an approved budget. The county provides the necessary information

and planning expertise that an individual or family may desire. In other places the county or regional authority may act as the fiscal intermediary. Some states are planning or already implementing independent brokering agencies where individuals with disabilities and families can go for partial or total assistance in developing and implementing individual budgets. Oregon has already created one such agency which incidentally is run by an independent board with a majority of consumers. Maryland is planning an even more ambitious effort. The Governor of Hawaii just signed ground-breaking legislation that places the person with a disability and social network in charge of both the plan and the resources. Minnesota and Wisconsin have added "self-determination" to their state waiver plans and state long term care strategies.

In many project sites traditional case managers are being trained and retrained to take on the role of independent broker. In many instances family members or close friends are allowed to carry out this function. The planning process itself is changing as only those in close and trusted relationships with the person with a disability assist that person in planning. Provider agencies roles change considerably under self-determination. They are now required to enter a new marketplace where individuals and families can choose them, reject them or simply contract for a type of assistance that the agency has a proven track record in providing. The new contracting authority is between the funding source--state, county or local-- and the individual with a disability.

Individuals with disabilities and families ask only for what they want and, now, will pay only for what they get. We are learning daily about the cost efficiencies inherent in this arrangement. We are also learning constantly about new and more effective ways to organize long term care that meets both individual and public policy expectations. We envision these projects as laboratories that will constantly bring us more information and improved ways of assisting individuals to live full and meaningful lives in their communities.

THE IMPLICATIONS

The implications of self-determination which apply in particular to the population of folks with developmental disabilities seem congruous for any person with a disability of any age.

The present system of long term care is based on a facility or congregate care mentality. Huge sunken costs in property and buildings consign individuals to these places in order to pay off mortgages or reduce capital debt. Self-determination is challenging this mentality and raising questions about holding persons with disabilities hostage to these investments.

Current expenditures are provider driven and reflect increasing costs associated with organizational needs. Self-determination challenges this method of contracting that almost always results in loss of freedom for the individual and cost increases annually. It simply does not allow for determining what a person wants and allow public dollars to be used in innovative ways to achieve these highly personal goals.

Public dollars are now seen as an investment in organizations and buildings. Self-determination insists that public dollars be seen as an investment in the lives of people with disabilities. Public dollars need to be used strategically to support existing family and community relationships as well as help create them where they do not now exist.

There are not current fiscal incentives for many stakeholders to change and help make this system more cost effective as well as honor the basic rights that all Americans take for granted. Self-determination can, over time, assist us in restructuring the fiscal incentives so that everyone has a reason to be more

cost effective.

Along with basic lack of freedoms, personal impoverishment characterizes the situation of most people with disabilities in the current system.

RECOMMENDATIONS

The Federal Medicaid statute should be amended to give permissive, a priori, authority to states that opt for including self-determination in their state plans. By encouraging this approach and making it easy for states to implement these principles, The Health Care Financing Administration can become a partner with the states in insuring quality while demonstrating cost effectiveness.

The Federal Medicaid statute should be amended to allow individuals with disabilities to utilize individual development accounts that would enable them (without losing Medicaid eligibility) to save and invest in home ownership, education and training, small business development, necessary communications and mobility technology and other items that hold out the promise of increasing disposable income, paying taxes like ordinary citizens and potentially lessening the costs associated with SSI/SSDI and even Medicaid itself.

This approach should be encouraged for all populations of individuals with disabilities, especially those with various physical and psychiatric disabilities.

In the field of aging it might make particular sense to examine the capacity of the Area Agencies on Aging to determine if they could play a significant role in implementing these principles for older Americans in need of long term support.