

FILTHY LUCRE

CREATING BETTER VALUE IN LONG TERM SUPPORTS

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The Present

In the early 1990's the first monograph on self-determination (Nerney, T. & Crowley, R., 1994) began with a recitation of "simple truths".

All communities have as members people with disabilities. They are people of worth and value. They belong to family and neighborhoods. They are citizens, fellow workers, customers, and parishioners. They are one of us. Members of our families, our churches, our neighborhoods, people with disabilities who are our friends, our co-workers, our customers, are unwittingly being harmed.

We went on to describe some of that harm. People with disabilities still lived in isolation from the wider community. Funding for services or supports was out of their control. People with disabilities were not truly respected for their capabilities. They were not "consumers" in any real sense. In fact, we said very

clearly that individuals with disabilities were treated like commodities. We spelled out the "harm" in simple, straightforward language. We ended what we called simple truths with this:

We have a choice. We could let the isolation continue, but now that we know the simple truths, the harm would continue with intent. Or, we can start a revolution. A revolution to design community mutual support and common cause. A revolution for self-determination.

Over the years the self-determination movement has gradually begun to grapple with the implications of the original intent. As we discuss the issue of money, public dollars, we need to reflect on the adequacy of those dollars, the distribution of those dollars and, finally, what those dollars can legitimately buy. However, before we address the manner in which rates are set and dollars are allocated for individuals with disabilities, we can and must address the *purpose* of public funding.

Two implications of our original analysis are especially important for any discussion of the purpose of public dollars: the impoverishment of individuals with disabilities in the present system and a fundamentally different understanding of quality:

Poverty

Impoverishment has two important dimensions: lack of any real control over the way dollars are spent—presumably in the person's name; and, lack of even small amounts of money to spend on personal purchases, relationship based activities and community membership. Both of these factors contribute heavily to the isolation and loneliness of individuals served by the present system. It renders them powerless in a society where personal power and decision-making are highly regarded.

Quality

Public policy leaders need to adopt a different definition of quality. This new definition must rest on expectations for individuals with disabilities that mirror the expectations all other members of this society have for themselves. Current quality assurance systems are normed on disability programs and services; rather, quality should be normed on aspirations that all human beings have—not on satisfaction with human service environments and interventions. A new approach to this issue will be described in a future publication from the Center for Self-Determination.

The promise of self-determination for both individuals and human service systems rests less on the *formula* for distributing public dollars and more on the increased *value* purchased by those dollars. Focusing on obtaining *better value* for public expenditures holds out real promise for more efficient human service systems and more meaningful lives for individuals with disabilities. A new concept of quality promoted through the principles of self-determination can become operationalized through the expenditure side of individual budgets.

This paper is concerned with initiating a new dialogue on the issue of setting the amount of dollars for an individual, and distributing those dollars through person-centered budgets. It briefly describes:

- A future of severely constrained resources;
- A discussion of current attempts to address the issue;
- A set of public policy questions that need to be addressed before we make premature funding determinations;

- A new tool: person-centered budgeting; and
- A set of recommendations for carefully proceeding to address the issues that go to the very heart of self-determination-creating a system that views public dollars as an investment in the lives and futures of individuals with disabilities.

The Question

The question of how many dollars to put at the disposal of a person with a disability under the rubric of self-determination has become a heated public policy issue. It is ironic but totally predictable that human service systems would for the first time insist on fairness or equity in the distribution of public dollars just when the promise of power and control may shift to individuals with disabilities and families and allies. That said, it is a fair question. Simply put, it should have been asked a long time ago.

Resource Allocation And The Purpose Of Public Funds

States engage in many forms of rate setting and resource allocation. Largely, this has served as a justification for contemporary services and provider arrangements and the costs associated with those arrangements. Some states, especially since the advent of self-determination, have taken a closer look at their reimbursement systems. These new approaches attempt to remove perceived biases, create more consistent and equitable ways to distribute public dollars, and some even rise to the challenge of "predicting" costs based on multiple factors analyzed through regression analysis.

These approaches are mostly limited to determinations of how much money to put at the disposal of individuals with disabilities. In this sense they fail two of the most important tests for designing reimbursement systems for long term care:

1. Determining first the purpose of public funds; and
2. Analyzing current public expenditures in light of these purposes.

The failure to incorporate these two points leaves us without the tools to create better value for these expenditures (more cost efficient and personally meaningful systems) as we face a very uncertain financial future.

The Future

The future interests of individuals with developmental disabilities as well as all other disabilities are inextricably linked with one of the greatest cultural, social and economic changes in American History: *the aging of America*. The issue of how resources are allocated in the future is directly related to the very adequacy of those resources.

As the demographics of this country inexorably change from 12.5% of the population over age 65 to 20% over the age of 65, we can accurately predict the following crises:

- The competition for scarce Medicaid resources will increase dramatically. The fastest growing population of those who are aging will be those most in need of assistance-those over the age of 85.

- While the vast majority of assistance to this aging population is given freely from family members today (over 80% and mostly by adult female children), within twenty years this cohort of adult children will diminish significantly. As the population of older Americans doubles the population of adult female children increases by only 7%. This will exacerbate the problem of increasing significantly the pool of potential direct support workers. This "double bind" is described by Mary Ann Wilner:

Since women in this age group provide the vast majority of both paid direct-care services and family care, this care gap in the United States will increasingly become a double bind: families who cannot care for their older members by themselves will find relatively fewer paid staff available when they turn to the formal system for assistance. (Wilner, M. A., 2001).

- The current pool of direct support workers is shrinking in dramatic fashion as a result of inadequate wages and lack of status across all human services. It already constitutes a national crisis.
- Even if the public support dollars were to increase significantly to keep pace with the growing population of those requiring some assistance, there is little hope under the present system that an adequate and trained or interested workforce could be developed.
- Within the field of developmental disabilities alone, demographic projections indicate that within twenty years the more than 500,000 individuals with a developmental disability currently living at home with an aging caregiver will more than double. Aging caregivers are caught between their own aged parents and their adult children with disabilities-an excruciating double bind.

As America ages the competition for scarce resources, especially under the Medicaid program, is going to increase dramatically. This dilemma has the potential for dwarfing the twin crises in Medicare and Social Security.

In the face of this crisis two problems remain intractable: the near total impoverishment of individuals with disabilities within this system of long term care and the low wages and attendant difficulty in attracting and keeping a workforce to support individuals with disabilities. The first problem results in increased isolation and loneliness of individuals with disabilities, rising costs associated with supporting these same individuals, and increased dependency on a system constructed with all the attributes of a massive welfare system. The second problem raises the specter of tens of thousands of Americans in need of support as they age or become disabled without the *workforce* or the *resources* to provide those supports.

Percolating this future is an oft-unacknowledged fact that illustrates the massive inequity within the emerging crisis in resources and personnel: the differences in average expenditures across the states vary so considerably that if every state spent on average what Connecticut spends, Medicaid Home and Community-Based Waiver expenditures would double overnight. If every state spent what Mississippi or even California spends, the "savings" to the Medicaid program would be significant: \$4,802 annual average Waiver expenditure in Mississippi versus \$65,611 average Waiver expenditure in Connecticut; \$15,198 average Waiver expenditure in California versus \$52,576 in Pennsylvania. Even *within* states this pattern can be seen from wealthy to poor counties or regional authorities. It profoundly questions the

unexamined organization and expenditures of current human services and the unexamined assumptions that undergird the present system.

Self-Determination is a reform movement committed to moving control of the resources for long term support directly to individuals with disabilities, their families and allies. The foundation for self-determination is the restoration of the ordinary freedoms that all Americans take for granted to individuals who have had to forego these freedoms simply because they need support. **Part of this foundation must include a new analysis of the worth of current expenditures and a commitment to realizing a better, more cost effective system for supporting individuals with disabilities.**

Current State Funding Allocation Strategies

The question of how to allocate dollars fairly or equitably for an individual budget has been determined so far primarily by the adoption or combination of one of two strategies. One approach creates a rate setting matrix based on assessing levels of disability, usually focused wholly or primarily on a person's "deficits". These methodologies typically incorporate various functional assessment tools. Most are, not surprisingly, based at their core on historical service provider costs which in turn are based on typical provider based service designs. The second approach uses one or more approaches to person-centered planning in order to determine how many dollars may be needed.

Two examples at diametrically opposite ends of this spectrum serve to illustrate the wide range of current solutions to the question of how to set the amount of money for a personal budget. Michigan and New York represent the ends of this continuum. In a March 2001 memo to the executive directors of Michigan's Community Mental Health Service Programs, the Deputy Director for Mental Health (including Developmental Disabilities) and Substance Abuse wrote:

It has come to our attention that some community mental health service programs and their provider networks have been using functional assessments (such as the ICAP) to determine, outside the person-centered planning process, the kinds and amounts of services and supports people with developmental disabilities will receive. While a functional assessment can legitimately be viewed as one tool to assist in gathering the information necessary to assist consumers achieve the goals they have identified in their person-centered plans, the Department does not support its use for the purpose of determining the cost and degree of services in lieu of genuine person-centered planning.

By contrast New York State self-determination documents record the following:

Budget amounts for the self-determination initiative were developed by linking people's level of ability (emphasis added) and needs for services to the actual Medicaid billings for calendar year 1998.

In fact, the New York instrument incorporates a series of 29 questions that mostly record deficits that characterize the person. As a result of this "score" a person with a disability will then achieve one of 32 levels of funding. These amounts range from \$47,195 to \$85,082.

Functional Assessment Strategies

Assessment-based methodology approaches the issue of equity in a way that is understandable. The underlying assumption of such traditional assessments is that costs are based primarily on a person's disability. The behavior scale in the New York assessment tool, e.g., records 13 different behaviors that range from onerous to awful.

Most deficit-based assessment methodologies rely on regression analysis as a major way to "explain" or account for how costs are generated. Many states rely on this method to both generate their "predictive" models and justify them. In fact, what states succeed in doing is to create a consistent method for allocating funds based on models of service that potentially ignore both the promise and the practice of self-determination.

Once the definition and the promise of self-determination are entered into this equation then these approaches can be viewed as more tautological than predictive. **They "predict" costs based on a history of providing typical services whose costs are already entered into the equation.** The tautology becomes more apparent if one considers using the New York assessment tool in Mississippi. All assessment-based and resource-based allocation systems are only "good" for the state in which they were developed. It becomes readily apparent that these strategies are simply a way to apportion dollars based on existing expenditures in a way that mimics fairness and/or equity. The adequacy or inadequacy of the existing expenditures is never raised.

Deficit-based "costing" is only valid if we restrict opportunities to traditional service arrangements and, even then, there is massive evidence that these traditional service arrangements hide actual per person costs. Assessment-based approaches rely heavily on traditional, congregate service configurations and expenditures, not actual per person costs. Additionally, assessment-based systems with weighted reimbursement pose the hazard, noted in the special education literature, of creating increased "disability" in order to increase reimbursement. Virtually all deficit-based assessment tools are predicated on costs in the existing system, not for a new environment specifically designed for an individual that includes a range of paid and unpaid supports.

For purposes of this analysis it must be pointed out that this method can be misleading and frequently non-predictive. A US News and World Report article on self-determination, April 16, 2001, (Shapiro, J., 2001) highlighted two examples of individuals who "scored" at or above the very expensive end of the New York instrument. Both ended up with a superior quality of life at costs well below what that score would have made available. One person is currently spending at the beginning continuum of the New York scale and the other person has systematically reduced public expenditures over the last six years—a phenomenon not even contemplated by assessment based systems.

Other anecdotal evidence has been growing about the shortcomings of deficit-based assessments. The first important data set to emerge from the self-determination movement was compiled by Michael Head, Michigan's self-determination coordinator. (Head, M., 2001) Head's analysis of the pre and post "costs" associated with 285 individuals who moved into a self-determination approach from typical human services is compelling:

1. \$694,663 was "saved" over pre self-determination expenditures.
2. Nine new individuals were served at a cost of \$485,708.
3. Net savings of \$208,855 still resulted even after a 3% increase in the number of those

served.

Head's analysis also noted that the higher the previous "cost" the more the savings. This was found in the original pilot on self-determination in New Hampshire as well.

What we witness in looking at functional assessment-based strategies is the achievement of consistency over rationality. This may very well result from our refusal to address the sheer poverty of some state and county expenditures compared to the relative richness of others. Rate setting or resource allocation systems then can be used as a justification for an inherently unfair distribution of public dollars, a justification of very generous allocations as well as a justification of provider costs that may bear no actual relationship to a personally desired future for the person with a disability.

To be truly rational, allocation systems must rest on a foundation of supports and/or services that meet explicit public policy requirements related to a new foundation of what constitutes "better value" for the dollars expended. This new understanding will also require a new and better analysis of expenditures at the provider level. For example, a review of a "supported employment" payment in a Mid-Atlantic state serves as an illustration of the necessity for increasing our analytical repertoire. A person placed in a below minimum wage seven person "work crew" generates \$9,100 a year to the provider agency in state payments. The direct costs of "supervision" for the person with a disability, including benefits, is about \$3,400. Transportation adds another \$1,000. The administrative costs of this contract amount are over \$2,000 and the middle management costs exceed \$2500-including \$1,000 for the services of a job placement coordinator!

These costs are not atypical and represent a set of expenditures on an individual level that we may not be able to justify in the future. Long-term we are going to have to determine what expenditure level can be used to justify the outcomes associated with that public investment. Is an expenditure of \$9,100 justified by an annual income of under \$2,000 for the person with a disability? Both rational and irrational expenditure patterns are built into our typical provider costs that form the basis for assessment methodologies.

James Conroy, Ph.D. in "The Correlates of Cost" (Conroy, J., 2001) reaches the following conclusion after examining both Michigan and other data using regression analysis:

One thing in the regression table is particularly clear and interesting: the importance of factors other than individual characteristics is strong in the self-determination paradigm. The fact that we can explain so much of the variance in individual budget amounts from variables that are not individual characteristics should stimulate serious discussion among states and agencies considering using a traditional rate-setting model.

Conroy's work and Head's Michigan data begin the process of moving from anecdotal evidence of the failure of deficit-based assessment and the inadequacy of resource allocation systems to a more data-based analysis of these shortcomings. **We have a growing body of evidence that shows deficit-based and resource-based assessments and allocations are faulty. They rely on the assumption that the present system is rational, that provider costs are rational and that individual characteristics somehow predict costs.** They are harmful long-term if they prevent us from gaining the evidence we need to appropriate dollars in a more rational way, address the inadequacy of resources in many jurisdictions, and gain some basic understanding of how to be more cost effective system-wide without harming individuals with disabilities in the future.

Person-Centered Planning

Person-centered planning was not originally designed to be a rate-setting methodology. As the prime determinant of an allocation, it lacks the precision needed by policy-makers and funders who have the fiscal obligation to manage finite appropriations for services within a state, region or county. There is no universally accepted definition of person-centered planning nor is there yet much understanding of how to convert person-centered planning into a person-centered budget. There is a marked tendency for strong families and advocates to utilize person-centered planning effectively, while those without this good fortune often fail to garner similar supports and resources. It is unrealistic to suppose that the attainment of personal goals, on a highly individual basis, can serve as the sole foundation for allocating scarce resources. However, with other qualifying mechanisms, person-centered planning may emerge as a least one element of a rational process allocation process.

Michigan, for example, has established a mediating or negotiating process that allows for some administrative control over total resources. While it still leaves in place the hazard of strong circles and support coordinators garnering more dollars than weak or ineffectual circles or support coordinators, it is markedly different from deficit-based methodologies. In fact, Michigan incorporates an approach to ascertaining the approximate amount of dollars for an individual by "targeting" the amount based on current service costs. That is, an amount or range is determined based on current or typical expenditures in various locations without creating an arbitrary ceiling on the final amount. This approach, while not meeting all of the recommendations in this paper, appears to address present and future fiscal crises in a more realistic fashion. Hence, the positive initial data from Michigan. There is no assumption in Michigan that once the amount is determined that individuals will "buy back" typical services as is the apparent or de facto expectation in New York.

Other Approaches

Wyoming has developed an assessment-based approach, DOORS, that falls somewhere between New York and Michigan but veers sharply toward a platform that may make self-determination more of a reality. While relying on assessment-based methodologies it incorporates other features that give it more credibility. Wyoming incorporates the following system principles:

- The resource amount is created independent of the services or supports selected;
- The rate-setting factors are not based solely on people's "deficits";
- This resource amount is determined independent of service provision and support coordination, and includes a process by which the team can recommend adjustments to it; and
- Individual teams become the primary decision-makers in resource management.

However, DOORS rests in part on the old assumption: that current distribution of resources among Home and Community-Based Services waiver participants reflects historic *rational* decisions that had taken into account the *needs* of each individual (emphasis added). There are several problems here. Current expenditures and expenditure histories and patterns are *simply not rational*. The Wyoming strategy implies that typical services are organized rationally (and cost effectively?) and that the "needs" of individuals are currently being met. Both assumptions seem unwarranted.

DOORS was not developed to implement self-determination. It was intended to be a fair and equitable means to enable local teams to purchase authorized services from certified providers. What is clear is that the Wyoming system seems headed in a positive direction to the extent that local planning teams have a great deal of flexibility and even control. The allocation system is consistent and probably superior to others. But, without addressing the impoverishment of the individuals being served and the setting of high expectations, it fails to be grounded in the very foundation of self-determination. It simply does not go far enough. It, too, ignores the expenditure side of the dollar equation.

What is striking about all three states' methodologies-New York, Wyoming and Michigan-is that they are ultimately forced to ground their methods in current provider generated costs. Wyoming and Michigan strategies, however, can serve as a good foundation for creating allocation amounts until we gain more experience and until we create the public policy needed to guide the second half of the dollar equation-expenditures.

States then are approaching this issue with these very different perspectives. Some are attempting a combination of more than one approach. Some states or localities compare individuals with others currently served with comparable disabilities or with costs associated with models of support within the existing service array in order to determine allocation amounts. Others offer a range of dollars based on typical service costs or even allow provider agencies to determine the budget amount based on their own typical costs. Still other states have initiated self-determination waivers or programs that place a ceiling, typically low, on the amount of dollars a person can receive.

Regardless of methodology, it is important to note that virtually every state strategy concentrates almost entirely on the first half of the dollar equation: setting the amount or determining the rate. Almost none concentrate on the critical issue of the purpose of these funds: what they can purchase and what they should promote.

The Nature of the Question

One of the important misconceptions about the question of determining an amount of funding for an individual is that this is simply a technical question. What formula or equation works best? How does one construct this formula? What elements need to be considered? When it is addressed solely as a technical question, and states spend millions of dollars on this, it fails.

Without understanding the meaning of self-determination and its implications, the promise of better value for the dollars will almost always suffer. Both equity/fairness and cost effectiveness (better value) must go hand in hand if we are to design an allocation methodology and a new system to support self-determination and rationally contemplate serving all those in the future who will need support. This does not mean that self-determination must carry the entire burden of fairness and equity. The present system left unchanged is still subject to future legal challenges based on the lack of equity and fairness in the system. The three states highlighted above at least are grappling with this issue.

Filthy Lucre

An open discussion about money, fairness and the need to be equitable as well as cost effective while still meeting essential needs and desires remains one of the most difficult conversations to mount. Many individuals with disabilities, family members and advocates simply do not trust the "system" and frequently will not move away from the proposition that this long term care benefit correlates exclusively with the amount of dollars available to the individual. Conversely, states and counties or regional authorities have demonstrated no particular skill at learning how to trust individuals with disabilities, family members and advocates. Instead, a highly regulated, overly prescriptive set of rules and regulations govern their approach to those who depend on public dollars.

This impasse must be resolved. This will not begin to happen until the powerless in this equation, those with disabilities and their families, attain equal status in the development of public policy. Likewise, state DD agencies are sometimes powerless over important provisions of their own Medicaid waivers simply because they do not control them adequately.

This means, among other things, that each side must begin to learn to trust the other; each side has to see real benefits for collaborating; and, each side has to have a real voice in systems change that adequately reflects the values of self-determination. This will undoubtedly mean that the current way Medicaid funds are distributed both across states and within states will have to be adjusted. From the beginning, self-determination has been built on the bedrock of improved quality through responsible freedom, and, fiscal conservatism in the sense that there is a better way to obtain increased value from current public expenditures. The issue cannot be avoided.

The Michigan data now reinforce the original findings of the New Hampshire pilot at least with respect to individuals at the high end of public expenditures. The question needs to be re-asked as "How do we achieve better value for the dollars?" (including cost effective strategies that do not decrease the adequacy of the resources) no matter how the amount is set.

The Question Is Premature

The evidence to date after eight years of demonstrations is clear: *The question itself is premature.* The posing of the allocation question first presupposes that current, typical approaches to providing human services are adequate and rational and it confuses the benefit of long term care with the amount of money available to a person. From its inception self-determination has proven to be cost effective not because it attempted to "save money" but because it was predicated on obtaining a better value for the money.

If the movement toward constructing a new foundation for long term care based on the principles of self-determination is going to be successful then the motivation cannot be to "save" money. This tension over dollars must be addressed up front. If the motivation is to obtain better value for the dollars then a series of questions must be answered *before* constructing a final methodology for allocating public funds. The answers to these questions will then lead us to a better understanding, if not an ultimate solution, to the essential question of how to determine the amount.

Under What Circumstances Is The Question Premature?

- *It is not possible to determine an amount of funding needed until it is determined what can be purchased.*

Too often the underlying assumption of typical assessment-based and allocation strategies for determining expenditures (not "costs") is that the "product" is already known. Deficit-based assessment invariably leads or nudges individuals back to the old pre-packaged products that have historically been sold. Only real person-centered planning begins to move away from this assumption. The problem with person-centered planning, however, is that, performed in a vacuum, it gives funders and policy-makers no way to manage costs in a fair or equitable way.

- *Systems that a priori restrict what can be purchased or from whom supports may be purchased to traditional services and service providers do not have the knowledge necessary to become fair and cost effective or construct a system that encourages cost efficiency.*

These typical systems never reduce costs (except through draconian cuts) and develop no ability to reallocate dollars in a fairer way even within states or particular regions or counties. Many human service systems still attempt to micro-manage individual line items and many set out provider qualifications that significantly limit the choices an individual or family may have. These strategies actually accomplish the opposite effect of their intent. They certainly control lives but have negligible effects on costs. In fact they tend to increase costs as choice, imagination and creativity are reduced.

- *Virtually all of the evidence to date demonstrates that both increased quality and cost effectiveness have been achieved through the efforts of individuals with disabilities and families together with a small cadre of professionals under a new set of "rules" that have been largely ignored.*

These pioneers were only effective when they were accorded a degree of freedom themselves-an event still waiting to happen in most systems. Individuals with disabilities will never be truly free until their families and close allies are also free. One of the implications of this insight is that a set of new tools needs to be developed and person-centered planning as we know it must move into person-centered

budgeting within a system that provides much more flexibility.

- *The question is premature when there is a lack of vision or understanding of self-determination.*

One erroneous underlying assumption is that self-determination is about choice within the present array of human services. Self-determination is about providing the assistance a person needs to craft a meaningful life deeply embedded in the community. It is not about choosing one provider over another. Allocation systems built on the wrong premise play directly into the arms of the old system. The same product gets re-packaged and sold under new rhetoric. Individual control of resources combined with freedom and flexibility in their use is central for people to achieve meaningful lives and move away from non-outcome based activities and dead-end "placements."

- *The question is premature unless person-centered planning and individual budgeting become melded and one holistic budget is developed that ends the bifurcation of individual lives.*

The evidence to date strongly indicates that bifurcating a person's life into "residential" and "day" or "vocational" domains leads to increased costs in areas like transportation and administration. In fact powerful evidence demonstrates that holistic planning and budgeting have a direct and positive affect on cost. A simple example is the situation of a person who wants to create a new living environment and obtain meaningful work. Locating the home where the person lives close to where the person wants to work has a real effect on that person's discretionary budget. This simple fact is often ignored, in part because funding agencies have historically taken for granted the continuing impoverishment of the individuals they serve.

- *The question is premature when there are no incentives in the present system to spend money in a cost-effective way.*

Many systems will not allow dollars to be carried over from year to year nor do they allow for cost effective one-time investments or financial incentives to individuals with disabilities and families to be cost effective. This is discouraged by both federal and state regulations. In addition, most systems do not allow for "insurance pools" to ease the anxiety of those who might be willing to try something different but have no expectation of a safety net. Many systems will not, e.g., allow a family to make a purchase only indirectly associated with the person's disability even though that purchase will strengthen the family in their resolve to continue serving that person at home often at lower cost than an out-of-home placement.

- *The question is premature when there is no expectation that most individuals with developmental disabilities will generate income privately or contribute even in small ways to their own support.*

The great majority of individuals with developmental disabilities do not work or work at below minimum wage or for insignificant hours. The entire rationale for entering the world of business and commerce needs to be challenged. Evidence has been generated that even those with significant physical and cognitive disabilities can engage in microenterprises by changing both budgeting rules and the job descriptions of direct support workers. The failure of states and the entire Medicaid program to encourage creativity here has resulted in annual expenditures of billions of dollars for "alternatives" to real employment, alternatives that have no personal, culturally appropriate outcomes for persons with disabilities.

- *The question is premature until the tools that are used for budgeting are changed to reflect the application of the principles of self-determination.*

One of the great failures of the system changes built upon self-determination is the loss of vision in translation from the individual planning document to the budget document. The very tool itself, the individual budget form, must change if a different outcome is expected. The biggest pitfall and the most important issue in the failure of self-determination, is the lack of a meaningful personal budget developed with imagination, creativity and moved under the control of individuals with disabilities, families and allies.

- *The question is premature until conflicts of interest are directly addressed and structural changes are adopted.*

The Tools of Self-Determination (Attachment A) outlines some elementary standards for independent support coordination, fiscal intermediaries and individual budgets. Traditional case management systems need to be fundamentally changed and/or independent brokering must be added as an additional "service." Fiscal intermediaries are necessary to free the dollars from existing service contracts.

- *The question is premature until human service systems decide whether self-determination will be available and encouraged for everyone or limited in a way that leaves intact the present array of services for the majority of individuals served.*

Redistributing public dollars more fairly will be nothing more than a glimmer of hope unless decisions are made to thoughtfully and planfully de-construct the present system to encourage more creative and value-based purchasing that holds some promise for creating better value for public expenditures.

- *Finally, the question is premature until public funding authorities decide to address the issues of loneliness, personal impoverishment and low or no expectations for individuals with disabilities.*

The very premises of self-determination have been largely ignored at the expense of technical changes to outmoded and unexamined reimbursement systems.

Personal Budgeting

When these issues are addressed *before* developing a funding allocation strategy, they may then lead to an individual amount of funding that can be used to create a new type of budget, a budget that focuses on universal human needs rather than human service responses to real or perceived disabilities.

One of the important training exercises offered through the Center for Self-Determination is designed to bring clarity and better value to the reality of actually planning and budgeting for an individual. **It is only through crafting individual line items that address the issues of universal human needs that real quality can be achieved for individuals with disabilities.** In this exercise small working groups of personnel and family are broken out into smaller sub-groups to develop a plan and a budget simultaneously for the same individual based on the principles and understanding of self-determination. Each group is given a different amount of money with most amounts significantly below existing provider costs.

The results are almost always startling. Groups with much fewer resources frequently arrive at higher

quality plans. The end result of this hands-on exercise is for everyone to understand that the "benefit" is not necessarily how much money is available but rather how free the planning participants are to use their imaginations, utilize their communities more fully, and listen more closely to individuals with a disability and those who know them best.

This exercise is preceded by a review of a new way of thinking of public dollars as an investment in a person's life and adopting a new set of assumptions. Although adequacy of resources must be assured, the exercise increases participants' understanding of fundamental problems with the present system of planning, budgeting and allocating funds. Today, services trump supports, hourly staff trump companionship and the amount of money is seen as the benefit-the more money the greater the benefit.

Participants in this exercise are asked to review a new set of assumptions and use a new budgeting tool. The new assumptions are simply: every person with a disability will "have his or her own place," and every person will "generate income." The entire planning and budgeting exercise, meant to be real for actual individuals, is predicated on meeting the needs of a person with a disability that are universal to all human beings.

If the goal of self-determination is to craft a life that is personally meaningful, culturally appropriate and with a plan and a budget that is cost effective, then almost every assumption regarding the present system must be raised and addressed. The following budget tool is not meant to be used as a form to obtain reimbursement. It is meant to assist in translating the plans and vision for the person to a budget document that can then be converted into appropriate reimbursement forms. It is an example only of a process that encourages conversation about money as an investment in the life of a person with a disability rather than as a mechanism to pay for services. For purposes of this training disability specific needs are subsumed within the supports generated in order to achieve a meaningful life.

This training also demonstrates that personal planning and budgeting is not a meeting. It is an ongoing conversation that demands and requires the participation of only those who are truly committed to the person, invited by the person, and able to objectively represent, when needed, the person's desires and dreams. For those without family or friends system representatives must insure the presence of strong allies who determine that mutual trust and personal commitment are present (conflict of interest-free) in those who provide assistance.

What follows below is a very partial illustration of both a tool and a process that addresses universal human needs and blends person-centered planning with personal budgeting.

Section One

Where & With Whom a Person Lives

Home

Rent/Mortgage

Utilities

Cable

Insurance

Other

Companionship

Personal Assistance

Wardrobe & Grooming

Barber/beauty shop

Mealtimes

Training

Transportation

Section Two

Community & Relationships

Contributions

Gifts/cards

Memberships/Organization Dues

Transportation

Church/Synagogue/Mosque

Romance

Culture

Theater/Music

Museums

Other

Recreation

Sporting events

Movies

Section Three

Business & Commerce/Generating Income

Jobs

Employment Agency/Broker

Co-worker support

Employer Training

Subsidize Wages

Wardrobe

Transportation

Other

Business Ownership

Business Plan

Materials/equip

Accounting

Legal

Insurance

Vehicle Costs

Section Four

TOTAL ANNUAL COSTS:

One Time Investments

Communication Technology

Mobility Technology

Other Technology

Security deposit

Other

Capital Costs

Down payment on a house

Vehicle Purchase

Education

Home modifications

Business Equipment

Other

TOTAL ONE TIME COSTS:

Section Five

Management/Administration

Independent Support Broker

TOTAL BUDGET

Each section of the personal budget form is designed to address critical human needs. Each section has many blank lines under the presumption that individuals are highly unique. Virtually every category and line item can be transferred to a budget reimbursement form. Some line items specifically address cost effective approaches that also reach to the foundation of the meaning of self-determination. The new definition of quality is subsumed within the line items included in this representative budget template.

Some examples of the significance of certain line items:

Section One

- Companionship e.g., is always introduced before paid staff but never to the exclusion of paid staff.
- Wardrobe and grooming replace "clothes" and hygiene to indicate the importance of self image and community participation.
- Mealtimes replace "food" as a line item to focus on the social implications of food in this society.
- Transportation overlaps in every section.

Section Two

- The importance of budgeting for community connections and for fostering and maintaining relationships is highlighted in this section.
- Romance, e.g., is addressed privately during planning but included as a possible category for everyone. Virtually all of the costs associated with romance translate to reimbursement forms under transportation, mealtimes and contributions and gifts.

Section Three

Generating income privately is a big part of the exercise and the training. There are no exceptions. Participants learn enough about microenterprises, e.g., to understand that changing the work of direct support workers (more meaningful work) can frequently make the difference in even a person with a significant disability running a small or tiny business with assistance. Everyone will have small or moderate expenditures that may not be appropriate for public funding.

Section Four

One time non-reoccurring expenses get explored here. Contemporary planning frequently leaves out very cost effective one-time purchases. This section also covers the need to budget administrative and management costs as well as the extra assistance (above and beyond case management and support coordination) that individuals may need to coordinate this fairly labor intensive approach.

The examples cited above are illustrations of a method to blend a new view of quality (higher expectations for everyone/universal human needs) with built-in cost effective strategies that are designed into the actual line items in the budget training template. What follows are a series of recommendations that need to be considered by all human service systems grappling with the enormity of this system change.

Recommendations

Human Service Administrators need to engage individuals with disabilities, families and allies in a new conversation based on their equal role in the development of public policy and the creation of a new system of long-term supports. Everyone must come to this table realizing that there are compelling reasons to create a system of supports that is more equitable and allows for the purchase of better value for current and future expenditures. Assurances must be given that quality will improve and flexibility and freedom will prevail.

A new understanding about the benefit of public dollars as the vehicle for crafting a meaningful life must replace the current obsession with the amount of money as the major benefit and the provider of services as the customer. Specifically, systems of support and services for people with disabilities should adopt the following strategies:

- Broad service definitions in both Medicaid and state/county programs that encourage flexibility and promote the use of other public funds generic to the wider community;
- Expansive definitions of "qualified Medicaid Providers" that encourage family, friends, neighbors and allies to provide support. Include the speedy policy adoption of microboards and other innovative strategies for families and allies to receive public dollars comparable to provider agencies;
- Full acceptance of informal care givers including any family member as a legitimate

provider;

- Expect that every individual with a disability will generate at least some income privately;
- Call a moratorium on non-outcome based "community experience" programs and a halt to work activity placements, with long term plans to phase these out and replace them with culturally acceptable notions of producing income. At some point public dollars are going to have to be associated with publicly supported outcomes that resonate with the entire society;
- Acceptance of one-time purchases that allow for communications and mobility technology, down payments for homes, and equipment and/or inventory for microenterprise development;
- Encourage direct contracting (through fiscal intermediaries if necessary) with employers for co-worker support, training, transportation and short term wage subsidies;
- Adopt new quality assurance systems that emphasize universal human needs and aspirations thereby holding human services accountable to outcome measures that are similar to the expectations that all Americans have;
- Define person-centered planning and meld it with person-centered budgeting that translates personal goals and aspirations to public reimbursement. This will entail changing the tools for planning and budgeting in order to accommodate highly personal budgets. It will require a more holistic approach to planning and budgeting that ends the bifurcation of people's lives into day and residential domains;
- Immediately publish all current reimbursement rates for all services and supports and graphically represent current public expenditure patterns by type of service;
- Institute fundamental training and re-training efforts aimed at all constituencies by persons skilled and experienced with the implementation of self-determination in all of its practical dimensions;
- Allow individual brokering as a non-duplicative support that is conflict of interest free as well as re-tool current case management and support coordination functions so that these individuals can truly represent persons with disabilities;
- Create fiscal intermediaries so that dollars for support will be freed from provider contracts;
- Create fiscal incentives for provider agencies to move away from owning buildings and homes that indenture individuals with disabilities to their long-term mortgages;
- Create fiscal incentives for individuals with disabilities and families so that those who realize cost efficiencies can share or benefit in the savings on a one-time basis;
- Create small insurance pools to encourage moderate risk taking for those who desire to pursue more creative options;
- Institute a more sophisticated but non-intrusive data collection and analysis system that documents new, value based purchasing and tracks outcomes based on a new quality assurance system-a system that is non-intrusive to the person and family and that encourages creativity without second guessing very local decisions; and

- Raise expectations for what human services should deliver by creating a quality assurance system that moves from satisfaction with typical human services or compliance with uniform standards to more universal standards for what constitutes a quality of life in the United States-one shared by all other citizens.

Underfinanced systems can use these strategies as well as adequately financed ones. Underfinanced state or substate systems will still need to advocate for reimbursement closer to the mean or the norm for the entire country. Underfinanced systems must also look to resource re-allocation where institutions both public and private are still funded. Long term, re-allocating dollars both within states and across states will have to happen.

The current truth about "setting the amount" of dollars under self-determination is that it is still inextricably tied to current allocations for typical service providers. It will remain so until we gain more experience and document new efficiencies as well as set a whole new cohort of expectations for human services, a set of expectations that mirrors what all humans want and need.

References

Conroy, J.W. (2001). The Correlates of Cost. Unpublished manuscript. Narberth, PA.

Head, M. (2001) Pre and Post Costs in Michigan's Self-Determination Initiative. Unpublished manuscript. Ann Arbor, MI

Nerney, T., Crowley, R., & Kappel, B. (1995). An Affirmation of Community: A Revolution of Vision and Goals. Creating a Community to Support All People Including Those With Disabilities. Durham, NH: University of New Hampshire Institute on Disability.

Shapiro, J.P. (2001, April 23). Why there's really no place like home. New ways of caring for the severely disabled. U.S. News and World Report.

Wilner, M. A. (2000). Toward a Stable and Experienced Workforce. Generations; The Journal of the American Society on Aging. 60-65.

ATTACHMENT A

COMMUNICATING SELF-DETERMINATION: FREEDOM, AUTHORITY, SUPPORT AND RESPONSIBILITY

Thomas Nerney

The Tools of Self-Determination

With the vast extension of self-determination projects across the country and the wide adoption of the

principles of self-determination, it may be helpful to step back for a moment and reflect on what we have learned thus far about some of the technical and structural issues associated with truly successful individual budgets, support brokering and fiscal intermediaries. Not every issue is yet crystal clear and it is anticipated that some ambiguity may remain especially in those projects that are still experimenting with systems change.

These three areas do not exhaust the range of system change issues but at this stage appear to be fundamentally necessary for the success of self-determination at the personal and family level. Typical human service systems find it difficult to make these fundamental changes. Other changes in personal planning and the restructuring of provider agencies also need to be addressed.

Addressing conflicts of interest in the present human service system has always presented itself as critical to the implementation of self-determination. If individuals with disabilities are ever going to attain a degree of freedom then those freely chosen to assist them will also need to be free. This simply means that no one gets to assist an individual/family unless that person is invited and remains totally committed to the individual with a disability and not to existing "services" or organizations. Those who assume these new roles will have to embrace the principle associated with rejecting overt or unconscious conflicts of interest. This is sometimes a long, arduous process.

One of the not so surprising results thus far reveals that creativity in planning appears to be very much related to avoiding conflicts of interest. Assisting individuals to achieve meaningful life goals (the goal of self-determination) appears to require both freedom and creativity. The same appears to hold true for cost effectiveness. Simply "buying back" existing services, with the option to move to another provider, doesn't meet the ultimate goal of self-determination nor is it cost effective. In fact, the federal Medicaid statute currently guarantees provider choice. That said, however, many individuals and families have little experience outside typical human services nor do they necessarily trust the current system to support them in meaningful ways outside typical human services. Developing trust between individuals with disabilities/families and human service system representatives, and gaining experience from those who pioneer self-determination, are important aspects of this change.

EMERGING BEST PRACTICE IN SELF-DETERMINATION

Two relatively innovative assumptions are beginning to under gird the self-determination movement for all individuals with disabilities. One is that all persons will "have their own place", and, two, that virtually all individuals can work in meaningful employment and/or produce income through the development of microenterprises. Folks with disabilities may indeed want to live with another person but that is always a freely chosen situation and one susceptible to re-negotiation when necessary. More and more projects across the country are gradually changing the goal from "getting a job" to one of "producing income". This enables everyone to understand that there are many ways to secure employment and to start a small business. Individuals within their budgets can (with assistance from a variety of sources) contract directly with employers for co-worker support, transportation and even training. Individual budgets can be used to help secure or pay down the cost of equipment necessary for a small business.

IDEAL STANDARDS FOR INDIVIDUAL BUDGETS, SUPPORT BROKERING AND FISCAL INTERMEDIARIES

INDIVIDUAL BUDGETS

Based on current best practice individual budgets meet ideal requirements for self-determination when the budget is actually controlled by the person and their freely chosen allies. Public dollars are now seen as an ongoing investment in the person's life and the obligation to be responsible as well as contribute to one's community becomes part of the budget development. In many demonstrations these ideal standards are only partially reached, but this represents an important step in the right direction. This means that the following is in place:

Individually created

The person with a disability and freely chosen family and friends create individual budgets. This includes the creation of unique line items that reflect the distinct dreams and ambitions of the person with a disability.

Authority over Personnel

Any person who works for the individual with a disability is hired and can be fired as well. In fact all employees and consultants work for the person and that person's social support network. Even if another organization assumes some legal responsibility to become the employer of record, all personnel and consultants work for the person with a disability.

Flexible

Within approved amounts, dollars can be reasonably moved from line item to line item as long as the essential supports are maintained. New line items may also be created as well as old ones erased.

INDEPENDENT SUPPORT COORDINATION

The linchpin to the success of creative, highly individual budgets and life plans is the function that is variously referred to as independent support coordination, personal agents, or independent brokering. What is important with regard to this function is the potential for conflict of interest. This is a person who may help with plan development, assist in organizing the unique resources that a person needs and even assist with ongoing evaluation of these supports. There are many ways that this function can be carried out from family members doing it to case managers assuming new roles. One creative project allows the person with a disability to select anyone they know and trust and pays them separately if necessary. Sometimes ongoing and regular support coordination is also required and some individuals are actually including this in their individual budget since it meets the test of a "service". The characteristics of an independent brokering function include:

Independence from Service Provision

It is important to keep this function separate from any form of service provision in order to avoid both the appearance and the reality of conflict of interest. Even those "brokers" who have great integrity should not be put in a position of divided loyalties. Current systems which feature service provision and support coordination may take years to accomplish the transition. Many individuals with disabilities and

families have relationships and loyalties in place that need to be respected while this transition proceeds.

Real Authority

Whether the person is an independent contractor, or an independent agency is used, this function has to carry some state, county or publicly sanctioned authority if this person is going to adequately represent the person with a disability. Again, it should be clear that the person who carries out this function works for the person with a disability. It is always their choice who provides this function.

FISCAL INTERMEDIARIES

Fiscal intermediaries are simply organizations, places really, where an individual budget gets parked or banked. The functions carried out by a fiscal intermediary include, but are not limited to, check writing for all bills and personnel costs, tax withholding, paying worker's compensation, health insurance and other taxes and benefits that might be appropriate depending on the individual's budget. The fiscal intermediary works for the individual and remains accountable for insuring compliance with all federal and state laws. Minimum standards include:

Individual Budget Isolation

This means that every person's individual budget is isolated from any other and certainly from traditional provider contracts. The money is available upon receipt of an approved budget and is accounted for by the fiscal intermediary to the public funding authority as well as to the person with a disability.

Conflict of Interest Free

Fiscal intermediaries have no other duties that conflict with their role. This means that they are independent of service provision. If the fiscal intermediary is a government or quasi government agency, it has specific rules that prohibit the use of this money for any other purpose.

Close to the Person and the Community

Fiscal intermediaries, to the extent possible, should be generic, neighborhood, community organizations that enable the person with a disability to create relationships with personnel who work there in regular community settings. The closer this function moves to a "neighborhood bank" the better for the person with a disability.

These are ideal standards. Some human service systems can move faster to implement them. Others may take much longer. They deserve more discussion, examination and further demonstration. There are numerous ways to meet these ideal standards long term. Further demonstration and even experimentation will bring new knowledge and insight into improved ways to implement these ideal tools of self-determination.