

Personal Budgets: The future of funding?

by

Michael Callahan

Marc Gold & Associates, LLC

1147 Robinson Street
Ocean Springs, MS 39564
228-205-4586 | fax 228-205-4597
www.marcgold.com
Micallahan@aol.com

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Traditionally, persons with disabilities have received their services through a “trickle down” system that starts at the federal government or state house and filters down through a series of bureaucracies, departments, agencies, counselors, staff and finally to the service recipient. Along the way, a significant percentage of the original service dollar is siphoned off by each entity that touches the funds. Additionally, since the money is coming from the top down to the ultimate user, those higher in the funding chain have prerogative in the manner in which funds are spent. Facilities are built, offices are rented, equipment is purchased, staff salaries are paid, vacations and leave time negotiated, all in the name of providing services to persons with disabilities.

In recent years, persons with disabilities and their advocates have begun to question this system. During the congressional debate that surrounded the re-authorization of the 1992 Rehab Act, advocates criticized the amount of money diverted in the name of administrative costs in vocational rehabilitation services. They also decried the lack of choice and control by consumers of the rehab system. Congress () responded by directing VR to assure choice in the “type and source” of services needed by the individual with a disability. Simply stated, this means that people have the right to select the type of employment services they individually need and that they should be able to choose the provider(s) of that service.

However, Congress was not yet specifically directed state VR agencies to give over control of resources to the participant who needed service. Instead, a five year demonstration to enhance choice using “vouchering” or personal budgets was authorized. United Cerebral Palsy Associations (UCPA) was successful in competing for one of seven national projects, funded for five years plus a one year extension, that ended in 1999. During the six year project, we learned a great deal about the issues surrounding individual control of resources for persons with significant physical disabilities..

When the Rehab Act was most recently reauthorized in 1998, as part of the Workforce Investment Act of 1998, Congress further strengthened the Act to include enabling individuals to exercise choice in a) selecting employment outcomes, b) identifying the specific services needed, c) choosing the provider of the service, d) identifying the setting(s) to be used, and e) selecting the methods necessary to procure the services. (Rehab Act 34 CFR part 361).

The debate within the service and rehabilitation sectors of the disability field initially focused on the concept of a *voucher* -- an authorization by a funding entity that

allows a person with a disability to spend a certain amount of money to purchase a service or product. However this idea generated much negative debate and the use of the term *voucher* is not politically popular at this time. The phrase *personal budget* has since emerged to accurately and appropriately convey the idea of an individual controlling the resources that society sets aside for various services. With a personal budget, individuals are given control over either a pre-determined average amount of money or an individually-determined amount approved by a function of the funding system. In most instances, these funds are not transferred to people but are held by a fiscal intermediary such as VR, local DD services, school districts, one-stop employment centers or private organizations. Participants then enter into contract relationships with providers, vendors and other disability-specific or generic entities to purchase the services and products they need to become successfully employed.

In this way, the funding stream is literally turned on its end. The components of the traditional stream that once were assured their “cut” along the way, now must show a reason to receive funding and be *chosen* by the participant before getting paid. Additionally, since performance contracts are typically used, payments are contingent on the participant’s satisfaction of the services identified in the contract as well on the receipt of bona fide outcomes.

More questions than answers

The ramifications of this shift are only beginning to become clear. At the core of the issue lies a power struggle of who gets to control resources. Our well-intentioned “customer” and “consumer” language adopted by the human service field will be put to a test. The question, “Are we really prepared to be directed by the needs, preferences and perspectives of persons with disabilities and their families?” lies at the core of this issue. Another critical, and, as yet, unanswered question is, “Will persons with disabilities be able to get the services they need to become employed if individuals rather than systems control the resources?” It is fair to say that it remains unclear at this time as to whether the current service agencies that have depended on a top-down funding relationship with a funding source can maintain their current viability in a customer-driven, market economy. And there are an array of troubling questions such as: “Can we continue to be advocates as well as service providers under this approach to funding?”; “Who will maintain the long-term commitment to people when all services are bought on a contract basis?” and, “Will the manager of the brokering service simply become another level of the bureaucracy that siphons away limited resources?” We simply do not know all the answers at this time.

We do know however, that once people are free to choose and control their lives and their resources, things are not likely to go backwards. We have an obligation to work with persons

with disabilities and their families to seek a workable balance that results in people with service needs and those who provide them to both successfully achieve their goals.

Assumptions and Realities

The UCPA project on personal budgets and choice provided a wealth of information, experience and opportunities for reflection on this topic. Every major service demonstration effort begins with a set of assumptions concerning both the systems involved and the people to be served. The following section presents a selection of the assumptions with which UCPA entered into the project as well as a discussion of the realities regarding those assumptions based on our experience (Callahan, 2000).

1. *We thought the only way to fairly provide a personal budget was to use a set standard rate for all participants.*

This approach did not prove feasible. While the establishment of a set budget rate for each participant seems equitable and certainly assists in planning, it is not individualized, as required by the Rehab Act and it results in standardization of costs. In our experience, we found that once we established a set budget amount, we lost the statistical effect associated with “average”. The widely varying costs that made up the average rate must then be contained within a capitated amount once a budget rate is set. Additionally, participants tended to spend up to the amount of money available, if the rate was known in advance.

We now feel that a better approach is to individualize the budget process by having an employment plan drive the development of a personalized budget for each applicant. Its still possible to have guidelines that set reasonable parameters for proposed budgets to fall within, but each budget can reflect the unique needs of each participant. In a new grant effort, subsequent to the Choice Access Project, UCPA has implemented an individualized budget process for persons with significant physical disabilities using DOL One-Stop Career Centers for employment services.

2. *We projected that it was useful, perhaps even necessary, to provide participants with an idea of reasonable costs associated with services.*

We provided a list of costs that were developed in consultation with local providers, VR counselors and state DD personnel in each of our three project areas. A suggested reasonable price list was included in all standard contracts for each service outcome purchased by participants. Providers had access to these costs though the participant manuals that were provided to each person in the project. The structure

relating to these suggested rates allowed participants to either negotiate for the suggested rate or less without any prior approval from project staff.

This assumption remains one of the most complex issues that were raised during the project. We found that while participants found the suggested rate lists very helpful, suggested rates quickly became standard rates, with providers expecting to get at least the suggested rate. Only rarely were participants able to negotiate for lower rates than those suggested in the contracts and only a handful of providers saw the value in offering services at rates lower than those suggested. However, it remained unclear to us how to resolve the dilemma. Participants need to have information concerning reasonable costs and service providers have not had much experience or motivation to move to a more market-oriented, individualized, customer approach. At this point, we still recommend that suggested rates be offered to participants and that providers be given assistance and encouragement to shift to a customer focus.

3 *We felt that if persons with significant disabilities had control of financial resources that they could easily buy the services they needed in a market-like service economy.*

Traditionally, persons with significant physical disabilities have been the most under-served group in vocational rehabilitation, even within supported employment. These individuals are often overlooked in favor of other persons with disabilities who experience a less significant impact of their disability relating to employment. We felt that if this group had access to funding, that providers would respond. It seemed reasonable to assume that the funds would be a magnet to attract the needed services as long as the rates to be paid were reasonable. In our case, they were better than average, especially for job development services.

We have referred to this issue as the “Field of Dreams” assumption -- “If you fund them, they will come.” In this case “them” are the participants and “they” are the providers. Unfortunately, our experience did not turn out this way. From our perspective, providers remained as reluctant to engage participants with significant disabilities with money to spend as they had in a more traditional service relationship. At first we simply blamed providers for their lack of response. As we listened and observed more closely, however, we began to notice factors that might be contributing to this reluctance.

We cannot say that we successfully resolved the issues associated with traditional providers. We were, however, successful in finding an alternative -- non-traditional providers. Throughout the course of the project, we recruited and trained a host of small, independent providers who became the primary source of services from project

participants. Overall participants contracted with 64 independent providers as opposed to 19 traditional, agency providers.

4. *We anticipated that the clarity necessary to deal with the tough questions raised by choice would best be gained by comparing our participants to regular customers doing business with generic services in the community such as contractors, lawyers or retail outlets.*

The relationship between persons with significant disabilities and service agencies in the rehabilitation field has been hierarchical and has rarely been truly balanced. This type of relationship often results in a parental or “professional knows best” attitude with service recipients. The changes that are implicit in choice, however, call for a shift towards more of a balanced, horizontal relationship. Since our traditional practices have not included such relationships, we decided to base our perspectives on the generic relationships that exist between businesses and customers with money to spend.

We found that this generic focus was extremely effective in resolving the numerous unanticipated issues and questions that arose throughout the choice demonstration. These analogies gave us insight into negotiating contracts, including providers in the planning process, negating contracts, resolving conflicts and clarifying expectations.

5. *We assumed that persons with significant disabilities, even those with intellectual disabilities, could make effective choices if given assistance from volunteers and third party advisors and that “informed” choices would be “good” choices.*

The regulations guiding the RSA demonstration authority were explicit in directing projects to take individual choice to a higher standard -- informed choice -- and we assumed that the best advice would be independent, outside the system.. Our experiences indicated that both of these assumptions were valid. As long as participants had access to supports from friends and family, paid third-party advisers and optimistic staff, the choices they made were responsible, even frugal, and in keeping with a professional perspective. In fact, the role of family and other personal support seemed to be a key ingredient for success. While almost all participants utilized a paid advisor, the benefit of the advisor varied in relation to the non-paid supports the participant received. The greater the personal support, the better the advisor was able to offer individualized assistance. Persons who had less personal supports seemed to have somewhat standardized experience. Additionally, approximately 40% of the persons in Choice Access reported that they had some degree of intellectual disability. We could determine no difference in the choices made by that group and those without intellectual disability.

6. *We assumed that payment for outcomes was a surer route for participants to achieve their employment goals than open-ended, hourly payments for service categories.*

Traditionally, funding sources contract with providers for employment outcomes that are based on either hourly rates or “slot” payments that are monthly or yearly. In these instances, providers receive payment whether outcomes are provided or not, as long as associated activity was performed by providers. This arrangement has come under scrutiny in the ‘90’s with many funders shifting to “fee for service” arrangements in which providers receive payment upon completion of employment outcomes. A similar concept has been referred to as “Milestones”, whereby funders pay providers based on the completion of concrete steps towards employment.

Since countless persons with significant disabilities have worked to gain access to employment services only to find that the time ran out due to lack of funding, we decided that the best way to assure outcomes was to link provider pay to discrete outcomes related to employment. In a process somewhat similar to Milestones, the UCPA project identified a set of sequential Core Employment Services including the Vocational Profile, Profile Planning Meeting, Job Development, Job Analysis and Job Site Facilitation as well as Related Employment Services such as Personal Assistance, Equipment, Transportation, and Therapies. These services were only be paid upon completion of the service and delivery of the product. We also included the Employment Advisor to be paid on a retainer basis, similar to a lawyer or financial advisor.

7. *We anticipated that choice-based services would result in quicker outcomes for participants than traditional services.*

One of our fundamental assumptions at the beginning of the choice project was that offering participants control of resources would speed up the attainment of desired employment outcomes. We felt that by shifting control to participants that we placed them in the driver’s seat and would bring a degree of personal advocacy and responsibility to the process. However, it didn’t happen in that manner. Instead of speeding up the process, control of resources by participants seemed to have a complacency effect on many participants. Once they knew the money could not be touched, except through the delivery of outcomes that they approved, many participants seemed to relax their advocacy efforts and accept a lack of movement by providers. This was completely unanticipated, although, in retrospect, it follows a certain logic. Sometimes we’re at our most vulnerable when we are closest to our goal or when a major hurdle has been reached.

Beyond this, we must recognize that choice and true individualization are simply messy concepts. When we welcome people to bring into their quest for employment all

their hopes, needs, dreams, negatives, and perspectives and then add to the mix the powerful ingredient of prerogative, things are going to become complex very quickly. This complexity, and the associated time delays, must be accepted as a natural part of offering choice service.

8. *We thought that participants and project staff could effectively and easily deal with the payment approval process, if a “boiler-plate” design was offered.*

On the surface it seemed so simple and straight-forward, participants should only pay for services that met the terms of the contract and satisfied the customer. This perspective is consistent with all generic customer/contractor relationships. We felt with assistance from the site coordinator and advisors, participants could easily approve payments for services rendered to them and that site coordinators could effectively monitor such approvals and process the requests in an efficient manner. We provided participants with a detailed handbook of sample, boiler-plate contracts and approval forms as well as samples of quality service products. We felt that the handbook, along with the advisor supports, would be sufficient to assist participants to handle the process of getting providers paid for services.

The reality was that this area was one of the most challenging in the provision of choice-based services. It became clear to us that no one in the system -- providers, project staff, advisors or participants -- had much experience handling specific contracts that contained details such as signatures, monetary rates, statements of work and approval components. This inexperience led to a certain amount of laxity in processing payment forms which, in turn, led to numerous delays in getting checks out to providers. The delays were also caused by a lack of understanding of the role of documentation on the part of providers. Participants often received payment requests without receipts, required products or data forms. Providers would routinely submit payment requests for services not described in the Service Contract with the participant. In addition to their lack of experience with contracts, participants and staff alike found it difficult to negotiate for quality when a provider was pushing for payment approval.

While we were able to address these concerns with constant project-level oversight, increasingly clear contracts and support, future efforts to provide choice must recognize the underlying complexity associated with placing payment approval responsibility on the shoulders of participants. Participants and their supporters need training in the generic strategies that all customers need to assure satisfaction and quality and they need support from paid advisors and project staff to deal with the difficult situations that often arise when a provider wants to be paid.

9. *We assumed that the third party advice component was sufficient for personal empowerment in the area of consumerism.*

This issue is similar to the payment approval issue addressed in Assumption # , but it is much broader in scope, encompassing the areas of empowerment, consumer responsibilities, satisfaction and conflict resolution. From the outset we anticipated that persons with significant physical disabilities and their families would find it challenging to shift from a “client” role to that of a customer with money to spend. We assumed that providers would likely return to a traditional service provider relationship and that participants would need support from a third-party source to deal with these challenges. In addition to the information, options and opinion we expected from Employment Advisors, we also felt that they could run interference for participants when conflicts arose. Along with support from project staff, we were confident that the advisor role would be fully sufficient to address any “customer” problems that might arise.

As with many other assumptions, this issue proved much more complex than we anticipated. We found that advisors were often as inexperienced as everyone else in handling the new challenges created by choice. Advisors needed as much training and support as providers and yet it was not always a good fit to provide training for both parties at the same time. This meant considerably more training was required than originally anticipated.

We also found that the relationship between the advisor and the participant was complex in a subtle way. When participants were applying for the project, we noticed strong self-advocacy efforts on their part to gain access to project services and to get started. However, once participants hired their advisors, we began to see a pulling back in the area of self-advocacy in favor of support by advisors. Some of this is natural and to be anticipated, but its very easy to experience the downside -- a return to “client” status by participants in which they wait for others to make things happen. This awareness created a dilemma for us in that we were strongly opposed to participants having to possess the skills and motivation necessary for strong personal advocacy as a pre-requisite for services. We were equally determined that they should not have to attend pre-service empowerment training as a condition for selection.

However, we discovered that choice-based outcomes are affected by the degree of personal responsibility and sweat equity invested by the participant and their closest supporters. We also had to admit that the body of generic information that defines an effective customer was both critical and missing from many participants. Our resolution was to offer a series of free, optional trainings on generic consumerism strategies for

participants, family members, advisors and other supporters. In a future efforts to increase choice, we suggest far more attention to this critical area.

The Structure of a Personal Budget System

One of the initial determinations necessary to implement a personal budget system is a clear set of values that will guide the answers to the vast array of questions that arise subsequent to the initiation of this approach. It is necessary for those currently in power, as well as those who wish to benefit from the power shifts implicit in personal budgets, to negotiate a set of perspectives that will provide a base for decision-making and implementation efforts. The set of guiding values that were implicit in the UCPA project are provided in the appendix as an example of a set of values compatible with personal budgets (Callahan, Mast, Skiba & Shumpert, 1998).

It should be noted that consensus on this topic is likely to be difficult to achieve. The more effective route for developing a set of clear values is for the current funding entity to commit to a personal budget approach and to seek input from all stakeholders -- persons with disabilities, providers, family members, advocates and bureaucrats. Based on that feedback, a set of values can then be generated that will serve as the initial basis for direction and decision making. As more is learned during implementation, the guiding principles can be amended, as necessary to address critical issues.

Determining the funding driver

At the core of a personal budget approach is the issue of how much money gets allocated to each participant. Of course, rates and rate setting have been system issues for years as funding authorities have struggled to determine a fair, yet economical, rate to pay to agencies that provide services. But rate setting for individuals creates a whole new ball game. Broadly speaking, there are two ways to get at rates for individuals: a) use of a pre-determined, average rate for all persons, perhaps with categories for varying levels of need; and b) individually determined budgets, perhaps with suggested rates for various types of services..

The simplest approach, but less-preferred based on our experiences, is to offer a **set rate** to each participant. When a pre-determined rate is used, the budget drives the subsequent plan in that expenditures need to fit within the resources available. In fact, by pre-determining the budget, it is also likely that more arbitrary structure than individualization will occur throughout the employment process. Another artifact of pre-determined rates is that the statistical concept of “average” is lost. Even though original rates were set by average costs, once that average becomes a rate it changes to a “cap” or maximum amount. Individuals, and indeed funding systems, no longer have access to the range of lesser or greater resources that went into determining the set rate, resulting in

decreased individualization . Perhaps the most disturbing result of pre-determining rates is that this strategy seems to distance participants and their families from ownership of their budgets. Since the amount is arbitrary and structured, set rate budgets can seem like “monopoly money”, fun to play with but not quite real.

There are, however, benefits to using a predetermined rate. Fiscal planning for systems is much easier. By estimating the likely number of persons to use personal budgets and multiplying by the rate, a yearly budget can efficiently be estimated. It is also possible to add an individualized factor into the rate to account for persons who might request more than the set rate. Another benefit of pre-determined rates is that the system can guarantee that a threshold amount of resources is available to people by committing to provide the rate at the outset. When individualized rates are uncertain, systems might more easily back off a commitment to provide funds at a higher level than is typical. It has also been our experience that some participants and their families want the simplicity of a pre-determined cost structure when confronted with the increased responsibilities of managing a personal budget.

The more difficult route is to *individualize budget rates*-- to have each participant’s plan drive their budget amount. Under this strategy, individualized discovery, employment planning and budget development needs to be a “core service” of the system to insure that each participant gets access to a personalized process that identifies their unique needs, preferences and estimated service costs. It is therefore critical for this initial component of service be controlled by the participant as much as possible. But on the face of the issue there is a possible contradiction. If planning is a core or universal service of a system, can it be controlled by the individuals? With what budget would they pay for such a service? Since the personal budget would not be developed until *after* the planning process, control of resources for the purpose of planning creates a values dilemma or possibly a contradiction.

Issues such as this make personal budgets so challenging and controversial. At times there are no simple solutions to resolve competing values conflicts. An approach used by United Cerebral Palsy Associations in a current personal budget demonstration within One-Stop Career Centers (UCPA, 1998) is that planning costs are estimated on a pre-determined basis -- yet still controlled by the participant -- and the remainder of the budget is individually determined.

Individualized budget rates are preferred over set rates in that this approach addresses almost all the negatives of set rates. The true variety that is characteristic of individualization begins to appear. The statistic of average begins to operate as different people request varied amounts of resources. Ownership of one’s budget is enhanced since

participants and families have to invest “sweat equity” to make difficult decisions. An additional value of this strategy is that most of the disability field’s systems are governed by strict guidelines or statutes that require individualization. Personal budgets act to focus attention on this issue in a way that traditional funding approaches do not. It has been easy for systems to tout individualization and yet provide funding on a slot or set rate basis. Personal budgets will not allow that as easily.

There are, however, challenges to an individually determined rate strategy. Fiscal planning for systems will be much more difficult, at least initially. Until a critical mass of individual experiences becomes available, fiscal planning will need to include a “fudge factor” for unanticipated costs. This argues for a pilot demonstration strategy to be implemented with funding systems at the state, county and local levels. And without a firm commitment to set amount of money, funders can more easily back away from obligating funds to a budget, especially one that is significantly higher than typical. Additionally, the blank-slate starting point of personalized rates may overwhelm some individuals and their families. These factors require a firm commitment to bring to this effort greater than average oversight and thought as well as a supports structure that can be accessed when needed by participants and families.

Compartmentalizing the gatekeeping role from planning

Another aspect of individualized budget rates involves the approval of proposed budgets. The closest system approximation that our field utilizes exists between the rehabilitation counselor and a person with a disability. While the funding relationship between counselors and consumers has rarely utilized personal budgets, the “case dollars” assigned to counselors and used by consumers share characteristics with personal budgets (and could easily evolve to a personal budget approach). In the traditional situation the counselor is charged with both developing a plan *and* approving spending targets and limits. It has become obvious, at least to many consumers and advocates, that this dual role can stifle creativity and individualization within the planning process. While realistic monetary goals need to be considered, it makes sense to separate the roles of planning and gatekeeping.

A personal budget approach that maximizes individualization, variety and personal responsibility should offer access to discovery, planning and budget development from a source different from the one that approves the budget and obligates the funds. The UCPA One-Stop project, referenced above, uses contract planners chosen by participants to assist the participant to develop and submit plans and representatives of funding sources to approve or amend budgets and obligate funds. Within a VR office one approach might be to empanel a small committee of two or three counselors to consider and approve the

budgets submitted by other counselors on behalf of consumers. Committee membership could rotate so as to assure separation of the planning and gatekeeping roles. A developmental disabilities authority such as a county or region could assign a committee of staff to approve the budgets of participants who received planning assistance from in-house planners or from contract providers in the community.

An even more comprehensive approach is to have personal budget resources approved as a joint process by *blending funding* from a variety of sources such as VR, DD, SSA/Medicaid, Mental Health and other funders. In this strategy, a funding committee comprised of representatives who are authorized to commit resources on behalf of their agency consider each budget proposal along with the individual's employment plan and discovery information. In UCPA's current One-Stop to Success project we are finding that personal budgets are acting as magnets to attract funds from sources that traditionally insisted that their services be delivered separately from others. The benefits to persons with disabilities are obvious.

The role of structure within a personal budget approach

From the surface, it might seem that the most individualized budget strategy would be one almost entirely without a system-imposed structure. One in which participants could freely allow their unique styles, directions, needs and preferences to define the scope and amount of their budgets. But with public dollars it is always wise to consider the art of the possible as we attempt to break free of conventional restraints. And fiscal caution is not the only consideration. Personal budgets cause participants to confront some of the most confusing and hidden aspects of human services such as, "What are my options?"; "What is a reasonable rate to pay for a service?"; "What services do I need to become employed?" and "How do I know if a provider is qualified?" The answers to these and countless other questions, that arise as individuals control their budgets, are not always intuitive. In fact, providers and systems may not have clear answers to such questions. For these reasons, it makes sense to offer a degree of structure to participants within a personal budget approach so that guidance is available for those who might need it or want it.

It is possible for participants to reduce the need for structure by utilizing the supports available through friends and family, though the traditional supports of a counselor or case manager, or through the paid services of an advisor. Regardless, input from outside the funding system is a form of structure in and of itself. The flexibility of a personal budget approach should include access to independent, paid advice if desired by the participant.

The personal control structure within a personal budget approach can take several forms. It can address the process of employment, costs, contracts, provider qualifications and conflict resolution procedures. Additionally, the issue of structure arises around the guidelines for self-employment initiatives, spending limits, thresholds for bids from vendors and allowable related services such as transportation, education, therapy and personal assistance. UCPA has developed project participant manuals, available from the UCPA Employment Field Office, that address these issues.

It is important to recognize the level of personal/family responsibility that this concept requires. Many participants and their families may embrace arbitrary structures as a way to deal with the pressures of making decisions and negotiating. Therefore, there is a delicate balance that needs to be maintained when a system implements a personal budget approach between the relationship of any structure -- imposed or voluntary -- and individualization. Structure tends to be a coagulant, a magnet for the array of possible ideas, directions, and aspirations of participants. Even prudent, necessary and voluntary structures have the tendency to draw creativity back to a point of standard practice. But structure is also a calm area, a point of refuge for many persons who are exhausted from their efforts to get what they need. While implementers of a personal budget system must constantly encourage and assist participants to think beyond the bounds of the structure and needs of the system -- to keep pushing limits -- they must also recognize that fatigue can cause people to need some structure. This can be a delicate balance to strike for anyone planning to implement personal budgets. Therefore, it is probably better for the system to encourage variability within a gentle structure than to assume that it will naturally occur in a non-structured system as a responsibility of participants.

The Confusing Role for Providers

Personal budgets raise a number of troubling questions concerning the roles of a variety traditional entities of the disability field -- VR counselors, case managers, and especially service providers. While there are functional similarities for the roles of VR counselors and case managers within a personal budget approach, the traditional role of the service agency must be fundamentally reconsidered. Since service agencies have traditionally been funded by systems to provide employment outcomes for a large number of individuals, significant changes are required for them to respond effectively to the unique needs and funding resources of individual customers.

This certainly implies a shift towards a “market economy” relationship with customers. Just as businesses have to attract and meet the needs of customers, so also will service providers under a personal budget approach. Service recipients will no longer be assigned by the county or region, they will individually choose providers to receive

discrete outcomes. Providers will no longer be able to predict with certainty the funds that they will receive during a fiscal year, since they will have to compete for business from participants. These and countless other changes will confront providers as the disability field embraces the shift towards choice and personal control of budgets. These changes raise valid questions for which, at this time, there are few clear answers:

“Will service agencies simply become contract businesses like house builders or accountants?”;

“Can non-profit organizations really operate as businesses?”;

“Will the relationship between providers and persons with disabilities be based solely on performance contracts, and if so, what does that mean?”;

“Can providers determine a certain type of employment activity (such as a work crews, NISH contract or sheltered workshop) and market that activity to individuals with disabilities?”;

“Will smaller, independent providers undercut the cost of large agencies at the expense of quality, dependability and safety?”; and,

“Is there a middle-ground position in which individuals can control budgets and providers can predict revenues and maintain services?”

The most prudent approach to answer these elusive questions seems to be, to quote John O’Brien (1997), is to “live into the answers”. Systems and providers need to start small, manageable demonstrations while they are still in the calm period before widespread system implementation hits. The experience of the RSA choice demonstration, across most projects, was that providers were extremely reluctant to enter into contract relationships with individuals. If providers remain reluctant, the answers to the questions raised above will be discovered by systems, advocates and legislators, without input from providers. It is important now for providers to work with funders, advocates, families and persons with disabilities to craft the shape of local personal budget efforts. This is not to say that provider can or should try to head off the movement towards individual control of resources. This would create a tragic confrontation between traditional allies. Rather, providers need to know and influence the forces and rationales that will drive the need for them to re-structure current practices.

Just as with the gatekeeping role and planning discussed above, providers have to accept a separation from functions that have comprised basic services. The clearest separation exists between advice and service. A personal budget approach requires that advice be available from a source outside service provision. This is much like a new car buyer going to a consumer report source or friends for information rather than accepting the advice of the car dealer. A more subtle and possibly conflicting separation needs to

exist between the development of a proposed budget and providers. The case for the separation at this stage exists so as to offer participants maximum flexibility and choice and so that market influences rather than “inside deals” drive the budget rates. However, this separation is not without a downside. In the case of a family who wishes to build a home, a builder may be consulted to determine costs. In fact, some families might not even shop around for a better deal and stick with the builder who quotes the first price. While the family may have saved money by seeking other bids, they undoubtedly saved time and hassle by sticking with one builder. Can this practice be allowed with personal budgets for employment? Possibly, but it is unclear at this time. This is an example of the kind of decisions that will be made in the system implementation of a personal budget approach and why providers need to participate in the development of its structure.

Who manages the overall effort?

If state and local funders proceed with the perspectives offered in this chapter, initial implementation efforts for personal budgets will be small and undoubtedly located within the local system. That is to say that if a local or regional VR office initiates a demonstration, it would be managed within that office. If a county DD authority starts a small pilot, it might be housed within the DD office. At this point, it's hard to justify a rationale for a service provider agency to initiate or manage a personal budget effort. The conflicts of interest are simply too great.

However, as the size of the implementation begins to grow and as funders look to the future of a larger scale system response, the issue of management becomes more complex. A number of communities and states are looking into the concept of a central “brokerage” to manage personal budgets. Under this strategy, a third party entity would receive funds from one or more sources -- VR, DD, etc. -- and provide overall management of all personal budgets. While on the surface, this seems to be an attractive option, there are numerous unintended results that might occur. For instance, “How much additional administrative money might the brokerage siphon off from the sparse resources available for budgets?” And, “Will a central brokerage compete with a series of smaller, “niche” efforts that are either localized, targeted to certain groups or agency-specific?”

Perhaps the thorniest issue that a third party, central brokerage raises is whether the services of the funding agencies become redundant, obsolete in light of this new approach. Many advocates might, at first glance, applaud the possible demise of traditional systems such as VR or DD in favor of a new, individually-friendly structure. But we recommend thoughtful consideration, as well as measured pilot efforts, before deciding on a direction of management. In fact, we suggest that systems such as VR, DD

and Mental Health Services (as well as other entities such a Medicaid, United Way, etc) have discussion that consider forming a cooperative brokerage (that could involve the use of a third party manager) that not only utilizes the best services available from each entity but blends funding from a variety of sources. We make this suggestion based on the belief that if these powerful systems are not owners of the personal budget idea, they will work to marginalize the implementation of the approach for survival and control.

Conclusion

The issue of personal budgets is somewhat like a hurricane lurking out in the ocean. We all know that big storms exist and that when they hit the aftermath is often significant in impact. We even know that they serve a function in the bigger scheme of things. Its just that we don't want them to affect us. And let's be clear, if personal budgets become the way we do business in the disability field, we will all be significantly affected. It will not be a minor blow, it will be a full scale storm. But it will be a storm that many feel needs to occur -- one that clears away the traditional structures and allows for new ones to be built. At this point the steering currents remain uncertain. It is not at all clear whether personal budgets will become the future of funding. But this authors feel that the concept represents a likely future. Based on the experiences of the national Choice Demonstration (Callahan, 2000), the following observations represent the steering currents for personal budgets, control and choice:

1. ***Because it's what the people want.*** Or many of them it seems. There is increasing advocacy by persons with disabilities, families on waiting lists, advocates and even legislators to offer individuals increased choice and control of the resources that society sets aside for service. This trend is indicative of a shift from agency-controlled services to individually-determined services.
2. ***Because it's the law, at least in the Rehab Act.*** Since the 1992 and 1998 amendments, the Rehabilitation Act of 1973 requires counselors to develop individual plans for employment that affords "the opportunity to *exercise* informed choice in *selecting an employment outcome* (what you want), the specific vocational rehabilitation *services* (what you need to accomplish what you want) to be provided under the plan, the *entity* (service provider) that will provide the vocation rehabilitation services and the *methods* (the way you want it done) used to procure the services..."(emphasis and parentheses added). The Rehab Act represents a clear trend in federal legislation that favors choice and control.
3. ***Because it's the best way out of the "whose choice is it?" conundrum.*** As increasing numbers of people have the chance to become employed in the community, the idea of "choice" is being used by those who wish to stay in

- institutions, workshops, group homes and other congregate settings as a rationale to continue such programs. Choice and control of resources offer all customers the opportunity to tailor services to meet their needs. Of course if you choose segregation, you would have to find others willing to spend their own share of public resources to pay the price and you couldn't rely on public funds to underwrite or additionally support such programs.
4. ***Because it's the only way to assure that "one size fits all" managed care rates do not predominate access to needed employment services.*** The base value of managed care is to save money while ostensibly offering a minimum standard of service. Most managed care systems depend on a capitated rate for payments that is based on the lowest possible amount of money that will, on average, meet the service demands for typical individuals in the system. The human service field is rapidly moving towards such managed care approaches in the area employment. Since the rates will be set on historical costs for persons traditionally served -- persons with less significant disabilities -- people with the most significant disabilities will be severely under-funded. Choice allows for individually determined budgets that reflect the needs of each person.
 5. ***Because people make better choices than agencies and employers.*** Labor-market and agency-focused perspectives concerning work often do not meet the needs, preferences and "why work" rationales of individuals with disabilities, especially persons with the most significant disabilities. When the employment negotiation is between service agencies and employers, with the outcomes focused solely on labor market and funding considerations, the needs of the individual are often overlooked. In fact when the needs of individuals are left out of the equation, many persons are simply left out of employment because they are not considered able to meet the arbitrary conditions negotiated between agencies and employers.
 6. ***Because work is becoming a personalized concept for all of us in our society.*** As our society and economy change, we are beginning to understand that our life's work must be more about who we are and what we need and less about the arbitrary shape of job openings. In order for anyone, and especially for persons with disabilities, to personalize a job for themselves, it is first necessary to be able to exercise a degree of choice and control over the resources, the outcomes, the supports and the methods necessary to achieve that tailored job.
 7. ***Because what we're doing now is not working well enough.*** Our traditional agency/system approaches simply are not responding to persons with complex

needs. Despite efforts that have been made for the past decade and a half to include persons with significant disabilities, there has been very little success. People with greater skills or less significant disabilities always seem to get available employment opportunities. This is due to a litany of rationales that range from high employer demands, to insufficient preparation, to lack of sufficient funding. It seems likely that if the traditional approach continues in the future, employment opportunities for persons with significant disabilities will remain scarce. However, if these individuals and their families have choice of outcomes, providers and methods and control of resources, they stand a real chance to break through into meaningful employment.

8. ***Because choice and control will re-define the relationship between service organizations and persons with disabilities.*** For decades, persons with disabilities have been at the distant end of a “trickle down” service system that drained precious resources to pay for arbitrary administrative costs, cast people into a “client” or service recipient role and placed them in any open slot in the labor market. We’ve even adopted “consumer” and “customer” language in an attempt to remedy this problem. True choice and control allows participants to direct their services, to choose providers and to decide whether or not to pay for work performed. This shift is much more representative of the way apartment hunters, car buyers, grocery shoppers -- everyday “monied” customers -- do business. Service agencies will have to embrace the kind of true customer respect, service and satisfaction behaviors of their generic counterparts or they will go out of business
9. ***Because it’s likely to be best way to access and utilize generic services.*** As the issues surrounding the impact of disability on life become more accepted as a “natural part of the human experience” (from the preamble to the ADA and the Rehab Act), the role of the generic service and vendor community has increased. Its inevitable. When individuals become a part of a generic culture, setting or organization, they typically want to utilize the same services as everyone else. However, in the disability field, people have found it difficult to gain access generic resources due to the funding relationships held by disability-specific agencies. Choice and control can allow individuals to shop around and select service providers and vendors from the generic community.
10. ***Because most Americans believe in choice and control as fundamental ideals -- they represent the ultimate extension of self-determination and independence.***
At the heart of our culture is a belief that we should be able to choose and have

say-so in the fundamental aspects of our lives -- housing, health care, child care, higher education. Since work is perhaps the most defining characteristic of citizenship, it is necessary to include employment in the list of life activities over which we have choice and control.

And if the reasons on this list aren't enough, here's more:

Why choice and control?

Because it exposes the "shell game" that the current service system uses that allows large waiting lists to exist and grow, largely without citizen response.

Because it opens the door to employment opportunities such as self-employment and entrepreneurship.

Because it's consistent with and encourages emerging "sweat-equity" and personal responsibility strategies such as peer lending, micro-loans and personal/family investment.

Because it allows funds from a variety of resources to be blended in a manner not feasible in the traditional system.

Because it requires new, more responsive and respectful, staff roles and provider/customer, counselor/customer relationships to be developed.

Because it redefines in a customer-focused manner the rationales for staff and organizations to become certified or qualified.