Thought you would want a copy of this thoughtful article due to the following:

- It discusses a number of options that have the potential to protect the integrity of a "voucher-type" system.
- Although intended for the Robert Woods Johnson self-determination project, it is certainly applicable to CASA-type service-delivery.
- It includes Medicaid, Dept. of Labor and IRS issues.
- It has the potential to impact centers for independent living and create new roles as brokers or intermediaries.

Best regards,
IRENE M. WARD & ASSOCIATES

Irene Ward

IMW:sap

Beyond Managed Care: Self-Determination for People With Disabilities

By Thomas Nerney and Donald Shumway

INTRODUCTION

Persons with developmental disabilities often receive services or supports from a variety of human service agencies under contract to a public funding source. This "third party" payment method is the preferred way to operate under current Medicaid and most state regulations. Human service agency budgets usually get constructed or built from the average payments made by these funding sources multiplied by the number of people served by that agency. These annual payments are frequently based on rate setting and purport to represent what a person with a certain level of disability will cost in public care. Of course, the type of service offered has much to do with this cost, e.g., group home, sheltered workshop or supported employment. Other factors may also influence these costs. When a vacancy occurs, human service agencies move quickly to fill this "slot" because their overall budget is usually dependent on serving the same or more individuals referred to them by the funding source.

Although current Medicaid statutes allow individuals with developmental disabilities to "choose" or change providers if they are not satisfied, the reality in most states is that individuals are not always allowed these choices because of the closed market that the very method of state and county contracting procedures have created over the years in response to traditional program budgeting and other State and Medicaid regulations.

Contemporary political discussions of long-term care center mainly around issues relating to the cost of this system for persons with disabilities. Congressional and Administration attempts to slow the growth in Medicaid spending for acute health care costs impact directly on Medicaid funding for long-term care. Acute and long-term care share the same budget as well as the same federal oversight and bureaucracy. Indeed, it can be argued that one of the reasons for the current high per capita costs associated with the system of long-term care for persons with developmental disabilities emanates directly from the clinical and medical orientation and regulation associated with Medicaid and the Health Care Financing Administration.

The irony that should not be lost on anyone is the almost total impoverishment of the majority of people with developmental disabilities in the richest and most costly system of care in this country.

There is almost universal consensus that Medicaid spending will be slowed. Primary among these reasons is the inability of state budgets to keep up with these spiraling costs. The looming federal deficit shrouds any discussion of alternatives. Long waiting lists of eligible persons in many states contribute to the pressure to reduce costs. Given the

exigencies of the present system, however, most states have not been able to lower individual costs appreciably. Many states have leveraged the vast majority of their state funds in order to meet the match requirements of the Medicaid program. Demographics, however, may be the most salient reason to question the viability of our present, expensive system of long-term care. The burgeoning population of elderly people who will come to rely on a dwindling supply of federal and state dollars, as well as a decreasing supply of caregivers who will be available as a labor supply, may be the most important reasons to create significant changes in the system. The present crisis presents an opportunity to re-examine our present assumptions regarding long-term care with an eye toward making it more cost-effective, as well as bringing it into line with the aspirations of people with disabilities and families.

Aside from high per person costs, there are two important problems with the present system. First, individuals or consumers frequently have no choice over which agencies will provide their services or supports and, more importantly, have no control over the quality or nature of the services or supports rendered. Second, because of the way many states have organized their systems of services, individuals with a disability have no choice other than to utilize the services of "qualified" human service agencies—those agencies certified and organized to provide highly regulated programs. This has the effect of limiting choices to current service providers and barring more informal supports.

How, then, can the individual or the family truly control the nature and quality of supports that may be required? Put another way, how can the "consumer" become a real consumer and, within a competitive marketplace of options, become the actual employer (if desired) for personnel hired for various tasks? For states and localities, the question becomes "How can we put structures into place that will enable people with disabilities and families to truly control resources?" Of all the questions that arise in conjunction with self-determination or consumer controlled supports, this is the question that raises the most complex issues. The bottom line issue, however, is whether a professionally structured system of services is ready to relinquish control. Other issues range from interpreting current Medicaid regulations (which specifically prohibit giving cash to individuals or families in order to arrange their own supports) to issues surrounding the applicability of IRS and Department of Labor regulations. This paper, then, deals with options or choices that individuals with disabilities or families can make today under current regulations and laws in order to achieve self-determination. It explores both the requirements that must be met and the organizational mechanisms that might prove to be good choices. The purpose is to call for a recognition of the options that extend beyond current service delivery methods and to challenge the assumption that the sterile solution of managed care is the only or the preferred next step in this vital support system. We start with the basic principles of self-determination and then take a closer look at three organizational or reengineering issues:

- Fiscal Intermediaries or controlling dollars without dealing with cash;
- Independent brokering of supports that an individual or family may desire; and
- Organizing a coherent response in a managed care culture.

PRINCIPLES OF SELF-DETERMINATION

The following principles are meant to provide a philosophical foundation for substantive system change that incorporate the values deeply held by persons with disabilities, families and friends and advocates:

FREEDOM

The ability for individuals with freely chosen family and or friends to plan a life with necessary support rather than purchase a program;

AUTHORITY

The ability for a person with a disability (with a social support network or circle if needed) to control a certain sum of dollars in order to purchase these supports;

SUPPORT

The arranging of resources and personnel—both formal and informal—that will assist an individual with a disability to live a life in the community rich in community association and contribution; and

RESPONSIBILITY

The acceptance of a valued role in a person's community through competitive employment, organizational affiliations, spiritual development and general caring for others in the community as well as accountability for spending public dollars in ways that are life enhancing for persons with disabilities.

A new way of organizing and delivering supports must be found. These four principles simply describe the conceptual basis for this approach. Each principle has important operational dimensions which should be observed without unduly restricting the forms in which these new ways of delivering supports may grow. For example, each state is organized in different ways and needs to make its own assessment of how to operationalize these principles.

Freedom in this context means that people with disabilities will have the option of utilizing public dollars to build a life rather than purchase a pre-determined program. Freedom means that individuals with disabilities, within some rational and cost-efficient system, will be able to control resources via individual budgets in order to gain the necessary experience in living and to move the dollars when their life choices change.

Authority means that individuals with disabilities really do have meaningful control over some limited amount of dollars. While many persons with developmental disabilities will need assistance in controlling dollars and planning their lives, those chosen by the person with a disability should be ever mindful of the need to ascertain the real desires and aspirations of the person who chose them to assist.

Support is the opposite of "programming." Assisting a person with a disability to nurture informal family and friends as part of a support network is key for those who

have these natural resources in place. For those who do not, creating this informal network is important and hard work. Support includes the notion of participating in the rich associational life of the person's community. One of the underlying assumptions of this principle is simply that ordinary community members, under more natural circumstances and environments, will welcome and support people with disabilities. It is important for us to remember that we have allowed public dollars to become an instrument of isolation and an artificial barrier between the person with a disability and the wider community.

Responsibility, like freedom, is a new word in our vocabulary. Both words belong in the same sentence. People with disabilities should assume responsibility for giving back to their communities, for seeking employment whenever possible, for developing their unique gifts and talents. For too long, individuals with disabilities have been seen and treated as dependent and incapable of being contributing members of our communities. The intense over-regulation of programs and the setting of goals and objectives to meet the needs of the human service system more than the aspirations of people with disabilities, have conspired to prevent people with disabilities from truly contributing to the associational life of their communities, the spiritual life of our churches and synagogues, and the cultural and artistic life of our cities and towns.

These basic principles confirm the necessity for creating structures to support their implementation. They exclude the status quo fee for service payment and program model, as well as the managed care models that rely on networked service delivery with utilization controls. These structures must include the development of an individual budget based on a capped amount of dollars that can be used to build the supports a person needs by purchasing only what is needed and paying only for what is received. Caring social networks will become important for most individuals with disabilities as well as the presence of independent brokerage in order to assist in both identifying and arranging necessary supports. Dollars spent can then be both invested in building a future and invested close to where the person lives.

Self-determination is not person-centered planning, although person-centered planning is a clear prerequisite for implementing these principles. Self-determination is an attempt to fundamentally reform both financing mechanisms and basic structural aspects of the current service delivery system.

INDIVIDUAL BUDGETS AND FISCAL INTERMEDIARIES

Even if giving cash were an option under current regulations, it is a path fraught with danger: tax filings, unemployment insurance, complex forms to fill in and deadlines to meet—let alone the intricacies of these systems. This is not to say that cash is a bad idea for those who might desire to do this work if it ever becomes possible to use it under the federal Medicaid statute. In fact, even under a cash payment system, individuals might want to consider following the same course as those who opt for control of resources without physically receiving cash. So, under the present system, how can individuals or families gain control over dollars but not become saddled with these legal and regulatory requirements? The first answer is to allow individuals with the help of freely chosen friends and family (and professionals they trust) to construct a highly individualized budget plan usually based on some percentage of current service costs or other capitation method. Individual budgets separated from existing congregate budgets provide real freedom for individuals and families to both purchase what they truly need and pay only for what they get. Self-determination requires the human service system to transfer total individual resources—individually negotiated depending on current need—in order for real control over the long-term to rest with individuals with disabilities. Under this arrangement individuals with disabilities can then organize the supports they need to live and work effectively in their own communities. They can build on already present informal supports or with assistance if necessary create informal support networks—sometimes called circles. When these circles are free to plan to assist an individual to create a life, these individuals can purchase only what is desired and necessary. Certain economic efficiencies may then materialize—especially if informal supports are the backbone of the life plan. When individuals are free to develop a plan for a life rather than required to purchase a program from an agency, they can gain the experience and, hopefully, the relationships necessary for future decision-making that will be based on these experiences. The hallmarks of individually controlled budgets are freedom and responsibility. Each year or as often as necessary individual annual plans can be constructed based on a predetermined set of dollars and past experience of what works and doesn't work. (It is wise to create a "risk pool" of some of the dollars saved in order to provide a certain amount of insurance for these individuals.)

The second part of the answer (which also appears in an obscure part of the Internal Revenue Service code) is called "Fiscal Intermediaries." This organizational/intermediary function allows individuals with disabilities (or families) to serve as the employer of record (or this other intermediary) individual or organization can become the employer of record) for any staff hired to provide supports and allows this other organization or individual to manage all tax flings and payments to these staff. Fiscal intermediaries simply provide technical and fiscal supports without usurping the primacy of the individual with a disability, family and friends. It is important to maintain the integrity of self-determination when another individual or organization becomes the employer of record. However, there is no reason to assume a priori that the integrity of self-determination cannot be maintained under these circumstances. For example, when a local or regional funding source becomes the fiscal intermediary, it is important that steps are taken to insure that the authority for purchasing supports does not revert to the fiscal intermediary—although this arrangement can help insure that individual budgets are constructed in practical and life affirming ways.

Fiscal intermediaries may also assume functions associated with brokering that relate to assisting individuals in designing support plans and purchasing supports. These supportive functions can include various quality assurance measures (determined for the first time by individuals with

disabilities), recruitment and training issues and monitoring.

There are reasons why the Internal Revenue Service would welcome the use of fiscal intermediaries. One of the most pressing is the temptation for individuals acting as employers to pay support staff as private contractors rather than as employees and, in this process avoid paying taxes that are due. (In many cases staff should be considered employees rather than private contractors.) Conversely, there are many instances when payments for certain types of support can be paid under the rules of contracting rather than formal employer/employee relationships. Skilled fiscal intermediaries can assist in making these kinds of determinations. Utilizing a fiscal intermediary then allows for a form of dual employment: the individual hired is an employee of an organization that will provide all of the paperwork necessary to meet federal and state requirements, but the person with a disability (with assistance when necessary) will actually hire and manage these individuals. The very structure of the work to be performed by employees, consultants and companions emanates from the desires and plans of the individual with a disability.

What organizations can be a fiscal intermediary? State and local agencies may become fiscal intermediaries. Counties or even individuals may become fiscal intermediaries as well. This designation, however, should only be incorporated into a system that preserves all of the principles of self-determination.

What can fiscal intermediaries do? These organizations or individuals can assume a variety of tasks from simply filing the proper taxes and paying employees (like a payroll company or a bank) to assisting with some of the functions of independent brokering such as staff recruitment and training. Ideally, brokering responsibilities should be separate from service provision. However, it is not impossible to imagine a local or regional/county funding source incorporating both fiscal intermediary status and some brokering functions. Much will depend on the real independence and authority of the brokering agent. We need to gain far more experience in how these functions can best be carried out without compromising the independence of those served by these structural reforms.

In contemplating the functions of a fiscal intermediary it might be helpful to understand the requirements that must be met for all employees:

Employment Taxes Income taxes, Social Security taxes, federal and state unemployment insurance, worker's compensation All of the payments listed above must be paid for anyone considered an employee rather than an independent contractor. Minimum Wage and Overtime As a general rule all employees must be paid minimum wages or higher if an individual state has a minimum wage law that exceeds the federal minimum. While fiscal intermediaries have no say in these issues, they can be valuable in assisting individuals and circles in understanding the sometimes complex and subjective rules that apply to workers in one's own home, for example. The Fair Labor Standards Act which governs federal minimum wage and overtime provisions is easily as complex as the Internal Revenue Code. What makes these labor laws particularly complex is the interaction between the federal Fair Labor Standards Act and the labor laws of a particular state. One example may suffice. If an individual with a disability hires someone to provide personal assistance and that person lives in the home, then room and board may be or may be not considered income for purposes of remuneration. This all depends on whether the live-in situation is primarily for the convenience of the person with a disability or for the worker. This situation gets even more complex when a determination must be made concerning whether the worker is a "companion" under the Fair Labor Standards Act. In some cases companions do not have to be paid minimum wage. There are important fiscal savings if you are able to hire someone in a "companion" role rather than as a typical employee. The federal labor laws may exempt these individuals from the overtime provisions of the federal statutes. A good fiscal intermediary would be able to provide needed advice in these areas. These issues can best be sorted out by an individual or organization familiar with these regulations.

Personal Injury and General Liability Issues of personal liability need to be addressed in a manner that will put individuals with disabilities and families at ease. While Workmen's Compensation will provide coverage for injuries on the job, other legal matters may get raised ranging from disputes over employment practices and wages to differences that may get created over issues of negligence or acts that are deemed harmful to another. This area of personal liability is one that can in most cases be adequately covered by typical agency insurance and is one of the best reasons for considering the use of a properly insured fiscal intermediary.

Medicaid Regulations While typical arrangements for "services" or supports to individuals are usually done through contracts between human service agencies and state, county or local funding sources, there exists the possibility for these funding sources to move decision-making control of individually designed and approved budgets directly to individuals and families. Depending on how a state's Medicaid waiver is written, authority for doing this may be possible under current regulations. A local or regional funding source may also serve as the fiscal intermediary or some other arrangement may be created. While Medicaid regulations appear to prohibit any system that does not provide direct payment to qualified providers of service, this can be addressed by having the fiscal intermediaries become the billing agents for Medicaid dollars. Recent communications from the Secretary of the Department of Health and Human Services indicate a real willingness on the part of the federal government to support self-determination. Potential providers of services or supports can also voluntarily assign their reimbursement to these fiscal intermediaries under a more restrictive interpretation of the Medicaid regulations.

For example, a regional authority like a county or a not-for-profit organization that distributes funds to human service agencies could change their contracting authority and create individual budgets for those served by these agencies. Individuals and families would then be free to create life

plans of their own and purchase supports from existing agencies, new agencies or from ordinary community members—or some combination of these. Either the funding source or, perhaps, a consumer-directed organization, could then serve as the fiscal intermediary. It is wise to separate the functions of a fiscal intermediary from the direct provision of service or support. Requiring the dual signatures of both the person with a disability and the fiscal intermediary in order to approve fund dispersal would be one way of implementing self-determination under current Medicaid regulations.

INDEPENDENT BROKERING

It is important to note here that "brokering" functions, i.e., arranging for the series of supports a person may need, or management functions, i.e., day-to-day supervision of these supports, may also be contracted out by the individual with a disability or family. Both brokering and management functions can become functions that human service agencies willing to re-tool for the future might consider in lieu of providing more traditional services.

Brokering responsibilities become an important linchpin in a fundamentally reformed system. While we need to gain much more experience in how this function can best be provided—through "case management" systems, individuals or agencies, there is some agreement on the role that brokers should perform. Service or support brokers or brokerage agencies become the mediating arm between the person with a disability and the provision of necessary supports. Individuals who perform these functions arrange with others to carry out the plans developed by the person with a disability or family and arrange for all necessary supports. They do not provide these supports. They become "personal agents" for the person with a disability and that person's circle or social support network. Of all the roles a broker may assume there are several that seem to fit well with this function:

- Assisting in defining support needs and life dreams;
- Assisting in providing information and resources;
- Assisting in identifying potential formal and informal service providers and supports;
- Assisting in arranging/contracting for services and/or supports; and
- Assisting in ongoing evaluation and other consultations.

One of the primary skills necessary to perform this function is the ability to build on informal supports that may already be present in a person's life or assist the person to help create these informal supports over time. A primary goal could be understood as assisting the person to become connected or reconnected to their community. Skills in bartering or exchange would also be helpful in this role.

Experience needs to be gained in determining how best to provide these functions. Newly created consumer controlled organizations might be one method. Independent Living Organizations might also prove to be valuable. Existing case management systems could be re-tooled to provide these functions under some circumstances. No matter what method is chosen, it is imperative that everyone recognize the authority of these individuals and that these individual brokers represent the interests of the person with a disability.

For all of these reasons, utilizing a fiscal intermediary and incorporating the functions of an independent support broker has many advantages. Even when professional or clinical services are needed and a fee negotiated with a particular individual or organization, it is helpful to have an individual broker or agency broker—one without a conflict of interest—function on behalf of an individual with a disability. What is important to incorporate in any of these arrangements is the shift in real control of these monetary resources directly to individuals with disabilities, their families where appropriate, and social support networks or circles. All of this can be accomplished under current federal statutes and regulations. Exceptions might occur in particular states where regulations, laws or even Medicaid waivers might have to be modified. Because it is likely that fiscal intermediaries and independent brokerage will be the desired method in most instances, it is important that the integrity of the self-determination process be protected at every stage. It is wise to consider the brokering role as separate from any individual or agency that might provide services. However the restructuring takes place, two important elements should dominate. First, it will often be necessary to put into place independent brokers or personal agents, who, for a fee if necessary, assist in planning and contracting based on an individual plan and budget. Part of this responsibility might be to assist with ongoing quality assurance and advocacy. Second, it is important that new structures only be created when absolutely necessary. Otherwise, a growing percentage of available dollars will be siphoned off for expenses connected with these organizational structures. Converting existing organizations into new roles may be more cost-effective.

Certain training needs will become self-evident. While much attention has been spent on the re-design of personal plans based on consumer preferences, little attention has been paid to the need to train people on the imaginative use of resources, the utilization of ordinary community members and organizations and the creative use of traditional Medicaid monies previously used to purchase pre-arranged programs. In fact, the retraining of support personnel used to the program requirements and narrow focus of Medicaid regulations may be the largest training need that will develop.

What must be kept in mind, no matter how this new system is constructed, is the primary goal of individual and family decision-making (depending on the age of the individual) together with the social goal of maintaining or instituting real connections to the person's community and associational life. Some examples may illustrate these arrangements. Mary was on a waiting list for services for several years. Mary's family was very involved in providing support for her in their own home. Rather than have Mary and her family wait for years in order to take her into the human services system at a cost that might exceed $50,000, Mary and her family were given an individual budget of $15,000 that they were free to use to hire assistants at appropriate times to support Mary in pursuing her life ambitions. Mary and her family had complete authority to recruit and hire some part-time individuals to provide this assistance.

The regional funding authority maintained a relationship with the family and supported their choices for various staff functions by providing all payroll and tax filing requirements. If Mary and her family decided to replace a particular worker, their decision was always honored. Mary and/or her family or friend could provide the brokering function themselves if they felt comfortable. An independent individual or agency could also provide this brokering function. The broker could be paid as a result of a contract with the funding source or from the individual budget allocated to Mary.

John, who lived in a group home for many years, decided that he wanted to live a shared life with another person without a disability. In the past, John might have been "placed" in a family home. Today, with an individual budget, John can rent his own home, condo or apartment and interview friends and interested strangers who might want to share a home and give some support to John in return for free or reduced rent. Depending on John's needs, a fee for extra support might also be paid to this person and/or to another. The house is John's. With enough assistance, John and, hopefully, friends and family, can evaluate the effectiveness of these supports. When changes need to be made, John doesn't have to move. Others move. Again, John may need the assistance of a broker, perhaps an agency to help manage staff, and certainly a fiscal intermediary which will pay John's bills at his behest. In a typical case managed system a number of choices exist in order to make this possible. Case managers could assume the role of "personal agents" or brokers who not only assist John in setting up his home but also assist in monitoring the quality of what John is purchasing. John could have his individual budget physically reside with a county funding source and, upon John's and his personal agent's recommendation, a system for approving payments could be set up. John might also have a friend or relative who would fulfill some of these brokering or monitoring functions.

The ways and methods to reorganize the present system are many and varied. A lot will depend on the present structures that are in place and an evaluation of how these structures can be modified or replaced with others.

CHANGE IN A MANAGED CARE CULTURE

As the rush to managed care that we have seen in acute health care has become a harbinger for long-term care, self-determination strategies can be offered as a more appropriate alternative to meet the states' needs to control costs. As Ashbaugh and Smith have reminded us, person-centered managed care concepts can incorporate self-determination strategies. Offering these strategies may be a way for states to answer the managed care movement where it has already surfaced and as a way to surpass it where it does not presently loom. If the goal of managed care is to control costs, self-determination may be a way to demonstrate "how more can be done with less." Some examples may be helpful by comparing just three common managed care strategies to self-determination:

• CAPITATION replaces typical fee for services by identifying groups of individuals with similar average costs. Payment is then made based on the average cost of all care and supports for the individuals within the group, setting an overall cap on the number of dollars that can be spent. These capitation "costs" are usually derived from estimating that purports to represent what groups with certain levels of disability will cost—sometimes based on standardized assessment tools. Capitation amounts can be good or bad—depending on how they are shaped. They are fraught with danger and confusion for individuals and their families.

From one perspective, capitation will almost certainly keep individual costs arbitrarily high because it is difficult to capture the value of informal supports under managed care conditions that do not allow for maximum freedom (with increased resources during emergencies) and promote informal supports. On the other hand this payment methodology is susceptible to arbitrary budget cutting and profit taking. These forces in combination may mean that individuals will not get the support they need, efficiently and responsively delivered, when capitation exists independent of the principles and values of self-determination.

Self-determination begins with financial planning structured and allotted for assuring that natural supports are the foundation for an individual life plan. Additional formal services can be arranged but only as needed. Self-determination is then in a position to viably cap the individual cost somewhere below (sometimes between 10 and 25 percent below) current service costs. This creates an insurance pool for those who need more time to develop informal supports, provides "risk management" for those who may seek increased support from time to time, as well as assisting individuals who will contract only for those supports they actually need. Over time it has the potential to free some existing resources for those not now receiving any support. Self-determination strategies also match managed care strategies in melding funding sources into one coherent stream.

• UTILIZATION MANAGEMENT is a managed care concept that shifts the decision-making for needed assistance away from the service delivery level to a management level. Frequently, standardized "practice guidelines" are used to establish limits on volume and type of services. Self-determination moves control away from remote middle management and into the most decentralized levels of, ourselves, our families, and our local communities. This builds local capacity and self-reliance. It creates an opportunity for investment in lifelong relationships and opportunities.

• RESTRICTING CHOICE OF PROVIDERS is a managed care strategy that limits providers to those who agree to abide by program specific cost limits imposed by the managed care company. This restricts such needed access to special supports. Self-determination actually reverses this strategy by increasing the options available to individuals by allowing persons with disabilities to begin with the purchase of supports from generic community groups and ordinary community members, family and friends, and with provider agencies as necessary.

THE CHALLENGE OF THE FUTURE

Self-determination will involve profound changes in how the present system is organized and financed. It will require provider agencies to re-think their roles, substantial re-

training of many in the service system and a fundamental commitment to honoring the aspirations of those with disabilities and families and friends. Quality assurance will gain new meaning L in a system based on the principles of self-determination. We may wonder years from now how we thought we could measure quality assurance in a system devoid of freedom. Given the current climate of fiscal retrenchment the options are few. We can stand still or offer a new vision for the future— a vision that is both fiscally conservative and truly responsive, finally, to those we profess to serve. We need to both work together and learn together in order for the four principles of self-determination to have real meaning in the lives of those with developmental disabilities and their families and friends.

Freedom Authority Support Responsibility