

THE IMPORTANCE OF INCOME

THE POVERTY OF HUMAN SERVICES: AN INTRODUCTION
BY THOMAS NERNEY

CHOICE AND CONTROL OF EMPLOYMENT FOR PEOPLE
WITH DISABILITIES
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Self-Determination for Persons with Developmental Disabilities

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AN INTRODUCTION

by

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THE POVERTY OF HUMAN SERVICES

INTRODUCTION

Self-determination addresses the stunning lack of freedom experienced by individuals with disabilities and their attendant poverty in the present human services system.

One of the great ironies of our human service approach to supports for people with developmental disabilities is the near absolute impoverishment of individuals *within the most costly system of "care" in the world*—a system that spends twenty-five billion dollars annually, averages almost \$90,000 a year for those in institutions, and often exceeds this per person amount in many public and private congregate care facilities. This situation persists in the face of tens of thousands of individuals with disabilities who receive no supports from this human service system.

For persons with developmental disabilities, their lack of disposable income is directly related to their continued isolation from our communities and their overwhelming lack of true friendships and relationships. Their shocking lack of control over the resources spent to support them contributes to their isolation and loneliness amid untold expenditures presumably made in their name. It supplies an added wrinkle to our notion of poverty in this country: wealth, without the means to spend it in ways that meet any personal desires or dreams. Enormous amounts of money are spent annually to bolster a system that individuals with disabilities did not design.

ENFORCED POVERTY

While the self-determination movement cannot solve the problem of poverty in any traditional way, it does address the pernicious effects of that poverty by speaking to some of the most intractable problems in the field of disability: *isolation from the community, lack of real friendships and relationships, and lack of disposable income; i.e., income that all Americans use to enhance the quality of their lives*. It places these problems within the service system's enforced poverty of individuals with disabilities. Self-determination requires that we confront the enormous disparities between the dreams of individuals with disabilities and the expenditures made on their behalf.

Self-determination also demands that we address questions of equity like we have never had to before, including the growing number of "have nots" waiting for supports. As more and more individuals and families begin to understand that similarly situated

persons with disabilities both within a state and across states are given very unequal amounts of resources, an accounting will have to take place.

As knowledge of current expenditures seeps closer and closer to folks with disabilities—family members and even direct support staff and service or support coordinators—there will emerge a preliminary evaluation of the worth of these expenditures—their cost-effectiveness, if you will. This may startle policy makers in the field of developmental disabilities. As the resources being utilized become clearer, more and more questions will emerge concerning one hundred thousand dollar to ten thousand dollar expenditures for similarly disabled individuals or expenditures between five thousand dollars and twenty thousand dollars so that an individual with a disability can "earn" ten dollars to thirty dollars a week. In resource rich systems, expenditures over one hundred thousand dollars per person are not uncommon.

We have created a situation where we know a lot about facility and program costs but very little about the costs associated with supporting individuals with disabilities based on their desires and wishes. As individuals and families gain experience in self-determination, and as those without these resources begin to understand, this tension will only heighten. It is important that this discussion and any resolution be carried out by those committed to individuals with disabilities. Others may not take the time to insure that better alternatives are created.

CURRENT MYTHOLOGY

The problem of the loneliness of individuals with disabilities is not simply a result of lack of friends, relationships and community memberships. It is, rather, a result of pervasive poverty, human service configurations and congregate settings that isolate individuals from the community, as well as misplaced priorities for spending public dollars. It is also a result of a wider cultural failure that places little value on the gifts that we can all contribute. We wrongly place the blame for this situation on the person's cognitive disability and, sometimes, charge direct support workers with solving it, failing to understand that their role in the system may be as much of a barrier to the wider community as a bridge to it.

POVERTY

Seldom do we see the link between the poverty of people with developmental disabilities and their lack of community and personal relationships. We forget just how much ordinary community members rely on money to cement their ties both to communities and to other individuals. Instead, we have ignored this central truth and rely, instead, on a shallow concept of "informal supports" and "unpaid friends"—noble goals, but, for some

unfathomable reason, often out of the reach of folks with cognitive disabilities. This is especially true of those who receive 24-hour supports.

But this kind of human service poverty has a secondary and equally toxic consequence. Others control the sometimes enormous resources that get distributed in typical human service environments. The person with a disability is bereft of basic human freedom in exchange for other-directed human supports/services. This stunning lack of freedom is a high price to pay for having all of one's "needs" met-with the exception of the satisfaction of those needs universal to us all that make life worth living: the contemplation and then the quest for a meaningful life suffused with relationships and membership in one's community.

HUMAN SERVICES VS COMMUNITY

This issue, the deep, personal, poverty of so many individuals with disabilities, gets ignored as a central problem, precisely because we do not recognize the role of money in our own relationships and community connections. As a field and to a person, we commit ourselves to the idea of community and relationships, but never acknowledge the reality that individuals with disabilities, just like everyone else, need cash or disposable income to navigate their communities in successful ways and need cash to carry out the simple rituals and rites associated with friendships and relationships. The entire idea of contribution on the part of people with disabilities gets lost irrevocably because they are so frequently placed in situations where they are perceived as *taking*, not *giving*.

This kind of powerlessness and poverty will do that to you. Reciprocity is the hallmark of both good relationships and meaningful community ties. Money is not the only path to reciprocity, but disposable income may be one of the fundamental social ways that reciprocity can best be expressed and implemented. Simple acts of buying coffee or dinner for a friend, purchasing a present for a relative, or preparing a home-cooked meal for a co-worker are frequently beyond the reach of many individuals with disabilities in this system.

RECIPROCITY

Central to any notion of friendship and community association is this concept of reciprocity. Both friendships and communities are two-way streets. Some individuals overcome the odds in this equation by the simple force of their personalities or their volunteering activities. However, even here the controlling environments of our human service structures place so many restrictions on the movement and choices of individuals, let alone the experiences necessary for reciprocity, that people with disabilities are not only seen as dependent but actually become so in many cases. If we are to be successful in addressing the twin problems of loneliness and poverty, then we are going to have to re-

examine the role money plays in the current system and re-think money as an investment in people's lives, not as a source of productive employment for us.

MISPLACED PRIORITIES

Simply put, when everything and everyone in the present system is paid for, there is no more money left for the individual with a disability. Poverty has become a residual entitlement as well as a precondition for receiving support. We have a distinct predilection in human supports/services for solving every other problem with money, more money preferably. When an individual presents a challenge to the present system, we hire someone, also, ironically, at close to poverty wages, to help control the problem. Until we learn to think differently about money and how it is used, we will neither alleviate the loneliness of so many nor adequately address the issue of poverty.

THE DESIGN OF THE HUMAN SERVICE SYSTEM

On a more complex level, there are structural reasons why individuals remain so poor: the income limitation related to program eligibility is just one of these. The paternalistic organization of services is another. We have concentrated on organizing "models" of service instead of allowing and encouraging supports for living. All of the money in the present system gets used by those of us who work in the system.

SELF-DETERMINATION AS A SOLUTION

Control of human service dollars for supports required in all dimensions of one's life, combined with real, remunerative employment and the production of income, provide what may be the two most important answers for both the poverty of individuals served by the present system and the lack of meaningful relationships and community associations.

THE PRINCIPLES

Self-determination rests on four basic principles:

1. Freedom to develop a personal life plan

The work of those committed to persons with disabilities is simply to assist in operationalizing freedom for those who may need assistance in exercising this basic American right.

2. Authority to control a targeted sum of resources

Systems committed to persons with disabilities have to first isolate the dollars available, no matter whether capitation strategies are utilized, and insist that the dollars be under the control of individuals and freely chosen family and friends. This means that the dollars are also free. They can be re-configured, priorities can be changed and the dollars can follow the individual.

3. Support to obtain personal goals

Those caring individuals who are committed to individuals with disabilities have to also be free to provide assistance both within and without existing systems to achieve the type and intensity of supports that an individual may desire.

4. Responsibility for contributing to one's community and using public dollars wisely

Individuals with disabilities and those close to them have the ordinary obligations associated with freedom in America. These are obligations of citizenship and include the obligation to spend public dollars in ways that are life-enhancing and cost-effective. This obligation includes engaging other social, business and religious organizations in ways that help re-define and build community for all of us.

This new way of doing business is vastly different from traditional provider agency contracts and moves the field of developmental disabilities solidly into consumer and/or family control of resources depending on the age of the person. Individuals only pay for supports they actually obtain and only use public dollars to the extent they are needed. Traditional provider agency contracts tend to remain in force over extended periods of time whether or not the individual obtains any or sufficient employment, and whether the individual is satisfied with the outcomes of the funder/provider agency contract. Under this new scenario, people with disabilities and/or families and friends seek only what they need and pay only for what they get.

STRATEGIES FOR CHANGE

Human Service Systems

MEDICAID

Eligible individuals with disabilities generate state and federal dollars based on their personal circumstances and disability. The dollars are generated in their names. This benefit or "entitlement" is originally an individual one. This individual benefit or entitlement is then lost amid the state's contracting and regulatory mechanisms. It becomes a provider or corporate entitlement and the individual must accept what the provider offers. Individuals with disabilities become commodities in this system. We need to revisit the nature of the original entitlement and insure that it remains an individual one, especially in the field of long-term care.

In return for attempting to lower the average cost of many in the present system, and in return for addressing the unequal distribution of resources in the present system, the system obligation, as part of this new agreement, becomes one of promoting responsible freedom and insuring maximum flexibility and control of resources by those who need

them. This new "bargain" with public funding authorities becomes a demonstration of how individuals and families can make the system more efficient and equitable in return for freedom and flexibility.

While there are many dimensions to the present human service system, there are several areas that need to be addressed simultaneously. State Medicaid waiver programs frequently need to be changed, not only to concretely support self-determination, but also to make it clear that the present human service system is moving inexorably toward personal control of resources. States like Minnesota and Michigan have set the pace for including these features in already approved waiver amendments or in anticipation of new waivers that will meld current dollars, remove incentives for congregating people with disabilities and give individuals control over their own budgets.

Medicaid eligibility provisions can also be addressed in state waiver plans. However, the combination of Medicaid eligibility standards and SSI and SSDI eligibility criteria have sown the seeds of enforced poverty, and this will require both state and federal action. The Medicaid waiver rejection of room and board costs, rational only under the presumption that individuals can never achieve meaningful or "substantial" income from work, needs to be re-examined as do present formulas that decrease SSI and SSDI payments even as relatively small amounts of personal income increase. Tens of thousands of individuals with developmental disabilities remain unemployed or under-employed at tremendous cost to the present human services system and at tremendous personal cost to the individuals simply because we have failed to develop rational and cost-effective solutions to these barriers.

INDIVIDUAL PLANNING AND BUDGETING

RETHINKING MONEY

Re-thinking money, the role that public dollars play in the present system, offers one way to begin a more powerful analysis of these issues.

Self-determination explicitly requires that individuals with a disability have some targeted sum of dollars that they are free to use in ways that help them obtain the supports that they need. Often with the help of family members, friends and/or selected staff, individuals with disabilities will be able to formulate life goals including where and with whom they would like to live, how they would like to be connected to their communities based on their interests, as well as obtaining remunerative employment and career development.

Two of the most powerful changes that occur at the individual level under self-determination are freedom for those invited to assist someone in planning a life (rather than purchasing a program or slot) and the electricity that individual budgets inject into the

planning and budgeting process. Person-centered planning takes on new meaning when individuals know how much they can spend, are free to prioritize budgets and can purchase wherever the dollars will bring the most value.

THE RECOGNITION OF CONFLICT OF INTEREST

The real failure of contemporary person-centered planning is rooted in the unwillingness of those who currently assist people plan to acknowledge clear conflicts of interest. They do not articulate their conflicts or address them in any adequate fashion. This conflict of interest concerns itself mostly with control of the dollars. In the existing system, the majority of those who come to the traditional planning table have imposed on them conflicts of interest over their present employment status or represent agencies with conflicts of interest over their current contracts. Sometimes agency-owned property is involved. Untold billions of dollars in property costs literally mortgage individuals with disabilities to the present system arrangements. The person with a disability remains a commodity and person-centered planning under this regimen leads inexorably to buying back what those at this planning table have been selling.

Within this context, person-centered planning becomes cruel and unusual punishment for the person with a disability. They are assisted to dream, form life goals and then are not free to pursue them in any meaningful way except under the strictures of the present system. It is for this reason that only those invited by the person with a disability should be able to assist in planning and budgeting. Those with current conflicts should be required to eschew them in a new relationship of trust with those who invited them. This is the major reason why independent brokering and fiscal intermediaries are so important to self-determination.

PLANNING PRINCIPLES

In many states personal planning and budgeting are assuming for the first time that every person with a disability can live in their own place and can earn money in productive ways. Just as the human service system must address certain issues, this personal planning and budgeting process enables individuals and those freely chosen to assist them to address (among other things) the following issues: Moving from human service planning and human service "needs" to planning around human needs and human desires. This means that the first priority for planning addresses those needs that are universal. This process explicitly eschews traditional human service "needs" and "responses." Under self-determination, planning moves from supervision and staffing, incompatible with freedom, to support and companionship, the community membership approach. Individual budgets get developed that include domains that all community members understand:

- Moving from 24-hour supervision to a home with support and companionship including resources for transportation.
- Moving from budgeting food, fuel, and clothing as a simple maintenance expense to creating food and clothing budgets that recognize the social role of mealtimes and the expression of personality in selecting wardrobes.
- Moving from low paying work or quasi work situations directly to real jobs and income-producing activities. Individual budgets give persons with disabilities the freedom to contract directly with employers, utilize friends and family, support their own wages, pay co-workers directly and create business opportunities for themselves. When assistance is needed in arranging these activities, fees can be budgeted for these supports.
- Moving from human service arrangements to community relationships. This means that individuals can now budget for the costs of community memberships, the reciprocity attendant on relationships, and the contribution expected of all community members.
- Moving to individual budgets which allow for the possibility of one-time investments. The cost of support is frequently related to the inability of individuals to purchase both mobility and communications technology, create the resources for a down payment on a home, and purchase business-related, income-producing equipment and property.
- Moving to individual budgets that now allow for fees to be included so that any and all of the resources needed can be arranged and managed. This means that provider agencies who share these values can re-tool and become expert at assisting individuals to obtain these supports, help them manage the supports and assist in other ways that would enable the person to live the life desired. They could assist the planning circle, independent broker and others for fees that would be negotiated on the person's behalf. The dollars for support, however, remain under the individual's control and are drawn down on a regular basis according to a negotiated plan.

FROM CASE MANAGEMENT TO INDIVIDUAL REPRESENTATION

Traditional case managers and case management agencies are beginning to convert to independent brokering or to support the creation of independent brokering agencies. These individuals will have the authority to assist individuals and families in planning and arranging the resources needed. Working in conjunction with fiscal intermediaries, these

new personal agents will finally represent the desires and dreams of individuals rather than support the limited range of current services and enforce human service regulations.

The self-determination movement has posited the necessity for both independent brokering and fiscal intermediaries. Independent brokering assures that individuals and families can have access to assistance with planning and implementing individual dreams, as well as in monitoring the configuring of resources independently of present service provision. Fiscal intermediaries are, among other things, repositories of the dollars that will be utilized by an individual with a disability or a family. The State of Oregon has created an independent brokerage house where individuals and families can go to obtain just enough assistance with planning and implementing a life with needed supports. Other states like Maryland are moving in the same direction with even bolder proposals that would eventually place all of the system's resources within consumer run, resource and brokering agencies.

STATE AND PROVIDER AGENCIES

Most current human service contracts limit creativity, keep the power away from individuals with disabilities and families, and allow a monopoly to determine just what folks with disabilities "need." States are complicit in this pre-determined assumption of human service "needs." They reinforce and nurture specific funding streams often tied to slots and programs in human service industries and environments. Too often provider agencies believe they have ownership of beds and slots, which they then believe government has an obligation to help them "fill."

Everyone pays a high price for this. The obligation of states ought to rest on a different assumption: the money does not belong to those who operate the present system but to those who are supposed to be served by it. Those responsible for the system at the policy level become guardians or trustees of the money together with individuals with disabilities and families. This means that state, county and local officials will have to move the contracting authority in such a way that individuals and families actually get to control the resources.

This change will require fundamental alteration in the structure of provider agencies. At the very least, provider agencies must compete, and, instead of offering slots and programs, offer support in implementing the individual's life dream. Provider agencies in a number of states are beginning to experiment with a variety of ways that they can change their culture; their congregate, slot-based service system; and their hierarchical structures. Those who value the principles of self-determination will, in exchange for fees, support the implementation of a desired life for a person with a disability without attempting to control the resources necessary to support that life.

A NEW QUALITY ASSURANCE

It is inconceivable that the human service system could pretend for so long that it had designed complex systems of "quality assurance" without guaranteeing basic American freedoms. *Where there is no freedom there is no quality.* Self-determination posits the necessity for basic freedom before we can even begin to determine quality. People with disabilities, families and friends will now be able to set qualitative goals that will determine the nature of quality assurance. The present system measures liability assurance. It focuses on safety and professional responsibility/liability at the expense of individual hopes, dreams and aspirations. The future system can now begin to re-think the nature of "quality" and listen to the voices of those it presumably serves to start this process. In re-defining quality, we must now look at measuring the degree of freedom a person with a disability possesses as well as the plenitude of an individual budget that ameliorates the insidious consequences of personal poverty.

THE IMPORTANCE OF INCOME

Almost 75% of people with disabilities remain unemployed today in an economy that has seen unemployment plummet for all other workers. The situation is so bad that these individuals do not even *get* counted in the unemployment statistics released by the US Labor Department. Of those who do work, their hours and employment opportunities are significantly constricted by various aspects of present program eligibility guidelines, income limitations, asset limitations and human service configurations. The situation is even more drastic for individuals with developmental disabilities.

The specter of unemployment and underemployment for individuals with disabilities has remained intractable for the last decade in spite of important successes with various approaches to supported employment. The evidence that virtually all individuals with disabilities could work if support and environmental changes were provided has not led to the increases in employment that should have been achieved.

SELF-DETERMINATION CAN OFFER A REVOLUTION IN EMPLOYMENT

Once personal career goals are established, the individual, with control over an individual budget and with independent assistance, is then free to contract directly with new provider agencies who share these values, with an employer for support which can vary from wage supplementation for training periods to co-worker support and even transportation. The individual may also desire to contract with an experienced job developer or someone to assist in identifying potential jobs and in negotiating a fruitful arrangement with an employer. Fees can be paid for these supports/services out of the individual budget.

These possibilities should bring us to re-examine the assumptions we have made about the systemic problems and, perhaps, force us to shine a brighter light on structural problems that we have not previously addressed. Are we prepared to finally remove the structural barriers that have created these enormous disincentives to work? Are we prepared to re-examine what passes for day and vocational programs?

Across the range of disability conditions, Medicaid medical insurance has posed a stark dilemma for many individuals who want to work. Because of income limitations set into the eligibility requirements for Medicaid, many individuals have been caught in a Catch-22 situation: if they earn even barely enough to survive, they remain in danger of losing their medical insurance. This problem is exacerbated for those individuals who also rely on Medicaid to supply their resources for long-term support. The penalties for working have been built into a complex multi-jurisdictional set of eligibility criteria. For persons with developmental disabilities supported in living arrangements, the loss of SSI income, even when Medicaid is not lost, means that almost 100% of their earnings have to go toward room and board—providing a further rationale for not earning any substantial wages.

The willingness of the present Medicaid program to pay for activities that do not result in meaningful income is a source of rising concern. A rational approach to removing the barriers to income production could go a long way in helping states achieve a better balance in their Medicaid program and reap a better investment from their state tax dollars.

Just as individual budgets can become better understood as vehicles for a tremendous increase in employment for individuals with disabilities, we must look to the current assumptions that under-gird the present attempt at obtaining meaningful employment for persons with disabilities. Foremost among these previous assumptions is the goal of "jobs, work or employment" within the present system of disincentives. What if we were to change the goal? How much further could self-determination revolutionize the world of work for all individuals with disabilities no matter how significant those disabilities?

A NEW GOAL: THE PRODUCTION OF INCOME

If we were to substitute the goal of income production for jobs and work we could make real earnings possible for any individual with a disability. While there is nothing wrong with fast food restaurants and cleaning jobs, what if the person with a disability were the owner or part owner of a business (e.g., hot dog stand or cleaning business) either alone or in partnership with community members? If public dollars are now to be thought of as an investment in the lives of people with disabilities, then we must take the next step and think seriously of some of these dollars as capital or investments in the

person's small business community. Even those without the ability to perform physical tasks associated with a certain kind of work could employ others. Some individuals could simply be the instruments of passive income from community business ventures where they gain socially as well as monetarily. Others might buy or rent equipment necessary for the performance of certain jobs. Still others might buy small franchises either alone or in conjunction with community members.

All of these activities could change the fundamental relationship that individuals with disabilities now have with their communities. The world of small business has great potential for assisting individuals with disabilities to become integral parts of their communities. The concept of supported entrepreneurial employment, via the development of individual budgets, could revolutionize the world of work provided that we make available the technical resources as well as the limited capital they would need.

We would have to develop this technical capacity utilizing community members with skills in small business development. We would have to learn to embrace local financial institutions both as fiscal intermediaries and as sources of capital. We would have to gradually shift the focus, legally especially, away from the welfare culture associated with Medicaid and income and asset limitations—at least for as long as it takes individuals to become successful. We would have to learn how not to put all of a person's money at risk. These are the new challenges of a new era when folks with disabilities and families finally have the opportunity to see public dollars spent more efficiently and as investments in the life of a person with a disability.

The development of individual budgets and the freedom that self-determination offers finally make possible the assumption of valued community roles and responsibility for citizenship. The income earned from regular jobs, those subsidized by individual budgets and those that result from entrepreneurial activities, return to the person with a disability with no strings attached. Of all sources of income in a person's budget, income from work, no matter how it is obtained, is free to address those dreams and aspirations in ways that other sources of public revenue never could. They allow for the budgeting of those items not usually reimbursed by traditional state and federal programs like Medicaid.

INTEGRITY

The notion of integrity is essential to self-determination. Understanding conflicts of interest and insuring that freedom becomes a reality for all individuals with disabilities requires that we address the issue of integrity with some passion. Writing about values in America, Stephen L. Carter (*Integrity*, 1996) articulates three components of integrity:

1. Discernment of what is right and what is wrong—serious moral reflection;
2. Acting, even at personal cost, on what one has discerned; and

3. Saying openly that one is acting on one's understanding.

Carter applies these principles to both political and personal life. They seem to have especially important meaning for self-determination. We have allowed the present human service system to force individuals with disabilities to trade their basic American freedoms for other-directed services and supports. We have minimized the conflicts of interest in the present system. We have kept individuals with disabilities poor and powerless. Only personal and group acts of integrity will lead us to reverse this course, examine all of our present assumptions and do the hard work associated with this movement.

Choice and Control of Employment for People with Disabilities
A White Paper

by

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CHOICE AND CONTROL OF EMPLOYMENT FOR PEOPLE WITH DISABILITIES

INTRODUCTION

Get a job. Get a career. Get a life. Adults at every rung of the socio-economic ladder in our society invest a working lifetime in their choice of jobs that lead to careers. Past generations imagined a series of job types across decades of employment - typically all with the same employer. The current and emerging economy, with the constant restructuring of market forces and businesses, requires a more flexible employee who must expect to change both jobs and employers with some frequency. Labor statistics now show that the typical American worker will change careers three to five times over a lifetime. As employment has become less secure, employees are learning that it is necessary to take control of their careers and to negotiate, to personalize and to carve out working conditions which meet the needs and preferences of both the employer and the individual.

This changing pattern of employment means that people in the work force must make choices about jobs and about how those jobs become careers. At the heart of getting a job and changing jobs are questions about choice. What employment choices can be made? How are possibilities pursued and understood? Who decides? How are such decisions made? Can employer requirements and expectations be negotiated?

People with disabilities and their supporters are asking these same questions about employment. They are asking these questions not only in the context of a new economic environment but, more importantly, in the context of a social service system that has typically limited choices in employment or imposed a structure of employment services on people with disabilities. That structure has, by and large, controlled the types of jobs and the types of work environments available for people with significant disabilities. The last fifteen years has brought a much broader range of employment possibilities for people with disabilities. The restricted opportunities of sheltered workshops or activity programs have given way to the broader possibilities of real choice in individualized jobs in the community.

However, it is also clear that people with disabilities have not, by and large, had free choice of employment and employment services, nor have they had control of the processes or the resources invested in their employment. While on the surface choice may seem to be a relatively simple matter, in reality it is complex and confusing. Are people

with disabilities encouraged to make choices in jobs? Is information about possibilities and opportunities available and understood? What resources are available to support someone's employment and will the available providers be willing to work for people with disabilities? Who controls the resources? Is choice in employment a free choice of many options, including those identified by the customer, or is it a forced choice among limited options? Who decides what is acceptable and meaningful and what is not? Who holds the trump cards and has the final word?

The answers to these questions challenge the traditional basis of employment services for persons with disabilities. In order to answer them in a manner most likely to favor the individual, it is necessary to embrace the value of person control and choice as one of the most defining aspects of employment. Choice in employment is as complex as it is important.

- True choice in employment depends on having preferences, information, options and control. It also requires willing supporters or providers to accept the challenge of meeting someone's choices.
- Having an employment preference depends on having considered at least several possibilities in order to develop a preference for one kind of work over another.
- Experiencing possibilities for various kinds of work depends on either knowing one's preference, having opportunity to experience different options or having the information necessary to consider a likely preference. It is also possible for others to look closely at a person's life for indicators of possible work preferences.
- The opportunity to experience possibilities depends upon a context in which exploration is valued and encouraged.
- Informed choice results from a complex interaction of information, advice, options and supports. Although these factors can be easily perverted to favor the system or other stakeholders other than the person of concern, they also can be utilized to assure that choices made by the customer reflect the individual's true preference.
- After the experiences, the options, the advice and the information have been considered by the person and a choice is made, the final litmus test for success

depends on the willingness and capacity of those who are called on to provide services, representation and support for employment. Choice is a hollow promise if the necessary supports for employment are not available.

For people with more significant disabilities, the possibility of choice in jobs and support services expanded with the emergence of supported employment. Because supported employment means jobs in the community, the range and variety of jobs available for people with significant disabilities expanded. *However, people with disabilities and advocates clearly point out that the options made available, and control of the resources for the services, have continued to rest in the hands of professionals and our bureaucracies and defined by arbitrary assumptions about the labor market.*

Questions about choice, control of resources and self-determination are now being asked by people with disabilities about where they live and with whom they live, about family support and access to neighborhood schools. Questions are now raised about informed choice in the decision-making process and who controls the process. Questions are now posed about the available financial resources for community services and who controls and makes the decisions about how those resources are spent.

Choice and control in many aspects and decisions about employment are also now clearly a part of the Vocational Rehabilitation Act and the Americans with Disabilities Act. Yet real choices in daily life and in employment have been more rhetoric than reality. However, the U.S. Congress was sufficiently concerned about the issue to direct the Rehabilitation Services Administration to fund pilot projects to demonstrate real choice in employment parallel to the existing Vocational Rehabilitation system, as a part of the 1992 re-authorization of the Rehabilitation Act. Seven projects were funded for a five-year effort to examine the feasibility of offering choice and personal budgets to persons with disabilities traditionally served by Vocational Rehabilitation, including persons with significant disabilities. Three of the projects were within state rehabilitation agencies and the remaining four were managed by private, non-profit organizations.

Conventional wisdom about employment services has assumed it was best to fund programs for services that are then offered to consumers in the role of service recipients. Selection of the options to offer, the process for making decisions and the control of resources has rested with the system, not the person to be employed. The only choice available was to accept the program or to not accept it. Real choice means that the options, the process of decision-making and the control of the resources move from the system's control to the person's control.

This shift in control has profound implications on employment services for people with disabilities. Those implications affect the heart of the relationship between support personnel and people with disabilities on a day-to-day basis, the configuration of services in the community and the broader system of funding and regulating government programs.

FEATURES OR INDICATORS OF INDIVIDUALIZED CHOICE IN EMPLOYMENT SERVICES

Any discussion of choice in employment must recognize that this is a concept which needs to be perceived from two different, but critically important, perspectives: factors relating to the individual's journey towards employment and factors relating to the system's implementation of a choice effort. There are a number of indicators which relate to the individual perspective of choice.

1. Acceptance of the individual as the starting point and driving force in all services and supports

Traditionally, employment for persons with disabilities has been more about the arbitrary services available from a provider or the perceived needs of the labor market than the needs, conditions, preferences and contributions of the applicant. A commitment to choice requires that funders and providers alike embrace the commitment to choice. The individual should be the focal point of the planning, job matching, job development and task restructuring activities which are used in the process of employment. Indeed, more than a focal point, the applicant must be the guiding force for all the decisions and strategies which affect the job. Indications of this commitment to choice involve:

- informing all applicants of the shift,
- starting all planning and interactions with a "blank slate" agenda that is free from system and program assumptions,
- implementing an information-gathering process which develops an optimistic and descriptive picture of the person,
- developing a personalized employment plan which describes the applicant's conditions, preferences, and potential contributions, as well as a prospective list of potential employers for job development,
- representing the person in job development in a manner which connects the planning process to employers' needs through the use of job restructuring techniques, and

- providing naturally-referenced job analysis and job site support strategies which allow the applicant to successfully meet the demands of the work place.

2. Control of Money

A sub-set of choice, as well as an indicator that it is available, occurs when the individual controls the money which has been set aside for employment services. While it is possible to offer significant choice to customers without placing them in control of their resources, whenever someone does have that control, they almost certainly have choice. Placing the control of resources in the hands of the ultimate consumer creates a number of challenges to individuals with disabilities. Often, this represents the first time they actually become monied customers, buying employment supports, rather than "consumers" in name only as service recipients. This status places the applicant in the same position as all of us in society who experience difficulty in dealing with the interaction between a seller and a buyer. We know this to be among the most frustrating and confusing of life's challenges.

3. Consumer Empowerment

Empowerment is one of the trickier words in human service jargon. On its face, many providers, advocates and bureaucrats embrace empowerment as an ideal outcome and indicator of quality services. However, when persons with disabilities are truly empowered, professionals seem to begin to lose sight of the higher aspects of this value and begin to cautiously urge system-friendly values such as fiscal responsibility, safety, quality service provision and the need to assure a source of support for those who will need it. Indeed, empowerment and these system values are not incompatible. In fact, consumers are best empowered when all of these factors are considered. The real issue in empowerment, choice, self-determination ~ whatever the name we give to prerogative and control - is determining who owns the solution to the problem.

Traditionally, human issues have been solved through the ownership and direction of the system designed to respond to those issues. People with disabilities are somewhat like residents of public housing in a local community. The people have the need for housing, but the system owns the structures, the land, and the prerogative. Empowerment is like the homeowners in a community. Sure, the bank may own the mortgage, but the homeowners own the structure, the land, and almost all the decisions concerning what goes on about the house.

Empowerment requires systems and professionals to embrace a fundamental power shift rather than simply adopting an attractive new value. Empowered consumers can say "no," "when," "how," "where," and "yes" when they choose. For this reason, a new

relationship between providers and consumers must be defined, new roles must be identified and new rules must be accepted. And since power is not easily shared or relinquished, providers must carefully consider the depth of responsibility that comes with embracing empowerment for persons with disabilities. It is critical that empowerment not become yet another hollow promise diluted by providers in their effort to maintain control and prerogative.

4. Role of Advice

The ownership of the process, the essence of choice, empowerment, and self-determination, rely on people with disabilities making informed decisions about their goals and service needs. Good advice is an individualized blend of **information**, **opinion** and workable **options** offered to a customer in a manner which can be understood and utilized. Information and advice have been fundamental aspects of the provider/consumer relationship. The provider has been responsible for virtually all aspects of employment for persons with disabilities, including the provision of advice. Provider's services have included gathering facts and offering opinions on the customer's efforts to become employed as well as defining the questions, issues and barriers which need to be addressed. The provision of provider-centered advice and information has been an area of concern voiced by many persons with disabilities. It is becoming clear that we must find unique ways to offer advice that shift the focus away from provider ownership of advice and information to a broader, more natural and customer-centered basis. This can be accomplished only through the acceptance of outside sources of advice.

It is important to distinguish between two aspects of informed choice - information and opinion. *Information* relates to the body of knowledge or facts associated with an issue or a decision. It would seem that by this definition, information would be free of opinion or personal bias. However, since most providers work for systems with rules and traditional responses to certain situations, it is often difficult to know whether an interaction concerning informed choice is factual or biased in some way.

Opinion refers to the feelings that someone has concerning a subject or problem. Since the opinion aspect of advice is almost inherently biased, good advice should contain alternate avenues for customer consideration, as well as the opinion of those offering the opinion. Indeed, good advice is an individualized blend of **information**, **opinion** and workable **options** offered to a customer in a manner which can be understood and utilized.

SYSTEM INNOVATIONS IN EMPLOYMENT SERVICES

Innovations in the process of planning and delivering individual employment services and systemic level innovations are now operating that hold bold promise for putting choice and control in the hands of people with disabilities.

At the heart of choice in employment for people with disabilities is change in the individual level planning and processes where personal decisions are made. Only when preferences are developed and choices are made at the personal level will meaningful employment and careers result in long-term control and satisfaction by people with disabilities. Personal employment decisions for people with disabilities must occur, however, in the context of the service system that has the resources for developing and supporting employment for individuals with disabilities. While changes are needed, and are emerging in the individual processes of employment planning and supports, change is also needed in the system that funds and regulates employment services. Systemic change that fosters greater choice is also beginning to emerge in some parts of the country.

STATE DEVELOPMENTAL DISABILITY AGENCY EFFORTS

In a small number of states, people with disabilities are becoming free to choose the provider of their employment services. For example, in some communities in Oregon, persons with developmental disabilities who are new to the service system and in need of supported employment are provided with a list of community providers of supported employment services. With assistance from the case management system, these individuals and their supporters are encouraged to interview a number of these providers of supported employment in order to decide which they choose for assistance to secure and maintain a job in the community. Once the person has chosen the program, then the funding system provides the resources for that person's employment supports directly to the chosen provider of service.

This approach provides a choice in one way - a choice of which agency provides supported employment services. However, in this circumstance, an individual must choose from a limited set of providers of service that already exists. In communities where there is but one provider of supported employment services, such a choice has no meaning. In addition, merely providing a choice among vendors does not guarantee that employment planning is conducted with an individual that honors the person's preferences and choices.

In other communities in Oregon and in Washington, not only are people new to the system encouraged to choose the provider of their services, but all of those with

developmental disabilities in employment services are allowed and encouraged to choose their provider of service and to leave one provider and be served by another if they wish. This means that funding is assigned to individuals and that the money moves from one provider to another based on the individual's decision about which program they prefer. In order for this to work, funds must be assigned to individuals, rather than having monies block-funded to service providers. Only with resources tied to individuals and with flexibility in seeking non-traditional sources of service can there be a choice of providers. This requires more of a free market approach to services. This commitment to choice at the systemic level, however, must be complimented with the individual level choices discussed earlier in this paper.

Pilot projects in Oregon and Washington are experimenting with another design of individual choice in employment services. For example, for the past several years, the Oregon Developmental Disabilities system has funded "Family Management Grants" for a number of youth leaving high school. In this project, individuals and their families are assigned a given amount of funds (e.g., \$5,000). These funds must be spent for employment support. However, these funds may be spent freely on any configuration of employment supports. Individuals might select an existing supported employment service provider. However, they are free to purchase job development or employment supports from anyone they choose. They may choose a neighbor, a friend, a temporary employment agency or a generic business. The only constraint is that the funds may not be spent on someone who lives in the same house as the individual. The individual process for decision-making is supported by a well-designed, person-centered planning process which involves the person and the family, as appropriate. This design invests in the individual level (person-centered planning), gives direct control of the resources to the person, and allows and encourages the use of non-traditional providers of service. There is no expectation that a person has to choose an existing provider of supported employment services. This design provides a greater degree of freedom in choosing providers of supports than a design that requires that the choice be made from only among existing providers of service.

THE CHOICE DEMONSTRATION PROJECTS

The examples above represent a small selection of the efforts to increase choice through state developmental disability agency funds. Since 1993, the Rehabilitation Services Administration has funded seven demonstration projects as a test of the feasibility of increasing choice and as a comparison to the current rehabilitation system. At the system level, the state vocational rehabilitation agencies in Vermont, Washington and Arkansas

were selected for the demonstration. As a result of the first four years of the pilot effort, the state agencies in both Vermont and Washington have modified many of their policies, procedures and staff training approaches to reflect the acceptance and importance of consumer choice for customers served through local rehabilitation offices.

The demonstration projects in these two states explored a new role for the traditional rehabilitation counselor. Since counselors have moved away from direct job development and employment assistance over the years, the counselor role has evolved to that of a broker and gatekeeper. However, changes in the 1992 re-authorization of the Rehabilitation Act have lessened the gatekeeping powers once held by the counselor. As a result of statutory and regulatory changes regarding presumption feasibility and expedited eligibility, a counselor's role has largely become that of an account manager and broker. The choice demonstration projects in Vermont and Washington have maintained the best of the information and advice components of the counselor relationship, but they shifted the control and choice to the customer. In this way, the rehabilitation counselor is ideally positioned to assist consumers with management of the resources needed for employment, information concerning the possibilities and limitations of the system, referrals to potential service providers, assistance in dealing with conflicts with providers and other innovative supports which are necessary to assure success under the overall value of consumer choice.

The United Cerebral Palsy Associations' (UCPA) Choice Access project differs from the Vermont and Washington vocational rehabilitation agency efforts in that it is managed by a community service organization. The scope of the UCPA project is targeted more at the issues of assuring successful choices by individuals with disabilities than by a system. However, during the second year of the project, Michigan Rehabilitation Services (MRS), the state rehabilitation agency, adopted the procedures used in the UCPA approach for use in a statewide pilot. The UCPA design provides for individualized budgets controlled by the consumer, independent employment advisors who are hired by the customer, flexibility in the choice of providers and an outcome-based payment strategy which offers boilerplate contracts and other financial forms for use by the participants.

ISSUES IN IMPLEMENTING CHOICE AT THE SYSTEM LEVEL:

PROVIDER ISSUES

The Choice Demonstration Authority included in the Rehabilitation Act of 1992 proceeds from an assumption that if persons with disabilities could control the money available for the purchase of services and equipment, that the process of becoming employed would be more efficient, more satisfying and possibly less expensive. At this

point, it is probably safe to say that consumers find the control of money more satisfying. It is also possible that such an approach may be less expensive, especially when the high administrative costs of traditional services are considered. However, there are major provider hurdles to be cleared if the approach is to be considered efficient, especially for persons with more significant disabilities.

The problem is provider contracts. Persons with significant disabilities are often not able to achieve employment simply through the purchase of business products, equipment, assistive devices or other similar transactions. They typically need a variety of services to assist them with planning, representation, analysis, job site support and numerous job-related activities such as transportation and personal assistance. The difference between purchasing a product and negotiating for a service is significant. It is somewhat like the difference between buying a vacuum cleaner and paying to have one's house cleaned.

PROVIDER RELUCTANCE

Providers of services for persons with disabilities have traditionally maintained a service relationship with funding sources at the local, state or federal level. Under this approach, providers basically please the funders and provide the service to persons with disabilities. *This disconnected relationship has been the focal point of advocacy by persons with disabilities and their advocates to remove providers from their position in the middle. In this way, the funding relationship would exist between the service recipient and the provider since the funding source would flow funds directly to the person with a disability.*

Given a choice between pleasing a general funding source or a specific person - typically with significant disabilities and strong preferences - providers naturally tend to gravitate toward the more traditional and comfortable relationships. This has significant implications in a demonstration which places control of the money in the hands of service recipients. Traditional providers have demonstrated that they are not excited about the prospect of becoming a part of a market economy within the human services field.

The recognition of this issue presents a challenge to state vocational rehabilitation agencies, developmental disabilities agencies or independent entities which may wish to implement a voucher demonstration within their state. It cannot be assumed that if persons with disabilities have money to spend, providers will come.

The following strategies are suggested to increase the willingness of providers to participate in a voucher demonstration:

- Link the receiving of traditional contract dollars to the willingness of providers to accept a reasonable number of persons with vouchers,
- Clarify to providers that personal budgets likely represent the direction of future funding and that the state funding source embraces the concept,
- Provide ample opportunities for providers to receive training on the demonstration's processes and offer them opportunities for input into the design,
- Encourage individuals and smaller providers to step up and fill the service needs of persons with vouchers - in other words, create competition,
- Make sure the suggested rates are reasonable and that payment processes and reimbursement times are as efficient as possible,
- Provide consumer training to persons with disabilities in the demonstration so that they can become informed customers, and
- Welcome generic providers such as employment agencies, community job resources and others into the local provider pool.

TRAINING NEEDS

In the shift towards a more market-like approach to meeting human service needs, the capacity of providers is a critical concern. In an area where providers have traditionally struggled to provide quality outcomes - employment for persons with significant disabilities - shifting the control of money, alone, will not be sufficient for success. It is somewhat like having a mortgage approved for the construction of one's dream home and not being able to find a contractor willing or able to build it. The solution to this issue rests in the availability of training and technical assistance for providers.

A state agency or other entity which wishes to implement a personal budget project for employment must build in the provision of training and ongoing technical assistance to traditional agencies; to new, independent persons who may decide to become providers; and to generic providers who have not had experience offering support to persons with disabilities.

RECRUITMENT AND DEVELOPMENT

Perhaps the best way to insure that persons with disabilities have access to willing providers is to increase the number of providers available for selection. This requires a

different approach to recruitment and development of providers than is called for under a traditional funding relationship. Traditionally, funding sources have carefully, even reluctantly, sought out new providers. This occurred due to the expectation on the part of the providers that continued funding would be made available for support of a group of targeted individuals. Under a voucher system, state agencies can encourage provider development without incurring the responsibility for continued funding. Providers will survive or fail based on their ability to attract and please customers who need employment supports.

It is of critical importance that state agencies realize that providers will not embrace a person-controlled budget strategy easily. Traditional providers will likely need strong and regular encouragement to participate and generic and independent providers will need to feel welcome and included in meetings and trainings.

DISTINCTIONS AMONG PROVIDERS

While there are no officially recognized categories of providers, the following headings offer a useful distinction in the types of providers encountered in a voucher project:

1. **Traditional Agency** - This type of provider is an organization or company which has a current funding relationship with the state vocational rehabilitation agency, developmental disabilities agency, Medicaid agency or other similar funding source for persons with disabilities.
2. **Independent Agency** - This is an organization or company which has emerged to respond specifically to the market created by the voucher project. Independent agencies often perform similar services such as medical rehabilitation or develop from an individual provider growing into an agency or company.
3. **Individual Provider** - This is an individual, often a former employee of a traditional agency, who offers employment services directly to individuals with disabilities as a sole proprietor.
4. **Vendor** - This is a company, agency or individual who sells products or indirect employment-related services to project participants.
5. **Generic Provider** ~ This is a company, individual or agency which traditionally provides employment services in the community, but not to persons with disabilities.

An effective demonstration or system on vouchersing needs all these types of providers in order to meet the needs of a diverse group of persons with significant disabilities.

Gatekeeper Issues

Public rehabilitation agencies are currently struggling with how to provide vocational rehabilitation services in a manner that promotes and requires participant self-determination and control of both the decision-making process and the use of service dollars. At the root of the struggle are the frequently held assumptions or a facsimile of the following: responsible stewardship of public funds demands that funds are controlled by the public agency. If participants are going to receive quality services, then those services need to be directed and controlled by individual(s) with professional expertise. The recipients of services require scrutiny prior to being trusted by professionals. This is manifested by how few states allow self-reporting to be the sole source required for eligibility determination. These assumptions create a dichotomy for many public rehabilitation agencies. When current policies and procedures reflect the above underlying assumptions, then implementing a service that facilitates participant self-determination and control becomes, at best, difficult and frequently impossible. Choice, self-determination and participant control require a different set of assumptions, policies and procedures.

THE ROLE OF THE STATE AGENCY'S POLICY AND PRACTICES

The challenge facing public rehabilitation is to examine what gatekeeper issues need to be kept, while removing the ones that impede participant choice. Certainly there is a need for policies and procedures that enhance and insure a quality service for participants, that reflect responsible use of public dollars and facilitate participants having self-determination and control in their rehabilitation services. The trick becomes how to establish the correct balance, a balance which clearly defines the parameters that the agency and participants must function within, but allows the participant to direct the process. The common fault is to err on the side of requiring extensive accountability and proof prior to allowing the participant any real control. *A choice policy or self-determination policy cannot just be overlaid or added to the current policies. Agencies need to rigorously examine their policies and change them accordingly.*

ACCOUNTABILITY

A critical component of removing counselor control and replacing it with participant choice and control is believing that the participant will use it effectively. In order for an agency to place control and choice with the participant, it must insure that it has the

structure to provide the participant with information, because without providing the participant with solid information choices will not be effective. The questions to consider around information are: what information is given to participants, how is that information conveyed, how large is the circle of people that provide the information, who owns the information, is information written about the participant or for the participant, what role do they have in providing input on the information.

The gatekeeper issue which raises the largest concern centers squarely on who controls the dollars. Public agencies need to examine the assumptions they hold around participants controlling their dollars. If control of vocational dollars is not given to participants then the promises of choice and self-determination are hollow.

RECOMMENDED FEATURES OF SYSTEMS WHICH SUPPORT INCREASED CHOICE

These examples provide insight into important features of a system that encourages support in order to give meaning to the individual level choices for individuals. Funding agencies and states are in a position to re-create structures that support the provision of meaningful choice in employment. Revising the processes for individualized employment planning is necessary but not sufficient. Revising the system that controls regulations and funding must also occur. The following are features of a system that embraces the value of choice in employment.

Assignment Of Funds To People Rather Than Programs

Conventional funding strategies have provided money for programs to operate certain kinds of services. Programs then open their doors to individuals offering either the services they think people with disabilities need or the services the funding source requires. Typically, the funding is controlled by the provider of service by contract with the funding agency. If a person with a disability leaves the program, there are no changes in the program's level of funding because the money is assigned to the program-not to the person.

To assure real choice, this practice must change and money should be assigned to individuals. If money is assigned to people, then the money can follow the person to the service provider of their choice. This also implies a "free market" approach in employment services wherein the customers ~ people with disabilities - are free to select those providers they wish based on their preferences and confidence in whom they choose.

Individualized Funding Rates

The "one rate fits all" approach to employment services may be convenient for funding structures and provide the surface appearance of fairness; however, everyone associated with employment services knows that "being treated equally does not mean treating everyone the same." The cost of employment planning and support varies greatly with the individual and the job match. As such, the rate of funding should be individualized for each person. Naturally, it will be important that some reasonable range be established. Also, funding agencies must be able to anticipate, compute, and afford some average cost of services over time. However, even when long-term funds have been attached to individuals, the tendency is to assign the same rate for each person. The concept of personal choice, as well as supported employment overall, will benefit from individualized rates in a critically important way. When set rates of funding follow individuals - whether with a personal budget or controlled by the system, the mathematical concept of average disappears. A fixed or set rate for services will almost certainly be based on some existing average costs of traditional block funding. Those rates include the entire range of costs, above and below the average, experienced by service providers in offering employment to persons with disabilities. However, when the average amount becomes the budget amount for a person, the figure becomes a capped amount. The way to avoid this potential for unfairness, as well as to save money from those who will require less funding than the average amount, is for systems to individualize the budgeted amount of funds to be received by each person with a disability.

Flexible Definition Of Service Providers

In addition to promoting selection of service providers, the system can foster choice and creativity by accepting a more flexible definition of service providers. Conventional wisdom, as well as many state and federal regulations, have supported the "qualification" of providers. While this practice ostensibly is designed to assure that quality services are offered to customers, it actually limits the number and variety of sources available for the provision of employment services. Additionally, the practice of qualifying providers is viewed by many advocates and persons with disabilities more as a way to assure the funding needs of a select group of providers rather than a means of assuring quality in employment services. In a free market where individuals choose providers, services can be selected based on individual preferences, satisfaction and outcomes. Credentials and certification of providers can be a quality factor for consideration by customers rather than a pre-condition for inclusion in the array of possible providers. With a looser definition of

service provider qualifications, individuals and their supporters can develop or recruit a variety of non-traditional individuals or organizations for employment supports. For example, a person with a disability might choose a neighbor who works in a certain industry to help them get a job because of the contacts that person has within that industry. Another person might select a former staff person from a residential program because of their long-standing relationship. Another person might select a temporary employment agency for assistance because someone they know works there. Others might select from more traditional service providers. With a more flexible definition of provider of service, choice can be much more creative and much more individualized. This is particularly important for persons with disabilities who live in small towns or rural areas which may have only one traditional provider (or none at all) to experience a true choice in providers.

Investment In The Process Of Helping People To Understand Options And To Make Decisions

The social service system also has a responsibility to make an investment in, and commitment to, the individualized processes that are necessary to support people with disabilities, including persons with significant disabilities, to understand options and make decisions. This implies a role in the system for a position which might be referred to as a "choice planner." This person would assist individuals to consider possibilities and to develop or select employment support providers. This role should be independent of existing service providers to avoid conflicts of interest. The social system has a responsibility to recruit, train and support people who will fill this role. Without this kind of role in the system, the free market cannot be totally successful in offering meaningful choice that results in employment that is meaningful and satisfying to the individual with a disability.

Support For Self-Employment And Entrepreneurial Activities

Choice provides the unique opportunity for persons with significant disabilities to join that most essentially American club ~ self-employed entrepreneurs. When decisions concerning service dollars are controlled by systems and programs, the chance to start a business of one's own is difficult and unlikely. Agencies funded by state developmental disabilities monies rarely support individuals to become self-employed and state vocational rehabilitation agencies have placed so many controls on this option that entrepreneurship is often the least utilized approach to employment within various states. However, when we consider that between 11% -13% of all Americans are self-employed, it should not surprise us that many persons with disabilities will opt for this type of employment when they have control of their resources.

To be fair, there have been understandable concerns regarding the promotion of self-employment by systems and agencies. There is a fear, based on the assumption that many small businesses will fail in their initial years of existence, that persons with disabilities who try the entrepreneurial route will be left unemployed and possibly in debt within a short time. Additionally, there have been concerns about the lack of interaction with other, non-disabled persons if home-based businesses are selected. It is feared that people who are already isolated and alone will become even more so as a result of their employment choices. There are further concerns about the ability of traditional human services to effectively support persons who need access to successful business strategies and practices, as business is not an area in which human service agencies have done well. State funding agencies have been concerned that paying for the cost of developing small businesses will be more expensive than payments to providers for employee-based employment. Finally, there is a concern that persons with more significant disabilities, particularly persons with intellectual disabilities, will not have the skills necessary to be successful in business.

When the value of choice and objective reality is considered in relation to these concerns, however, a shift towards an acceptance of self-employment by those responsible for policy and funding is warranted. There are several studies which carefully examined the assertion that a majority percentage of entrepreneurial businesses fail in the first year or two of business activity (Aley, 1993; Duncan, 1994). These studies found that when factors such as voluntary closure, retirement, changes in ownership and sales of businesses were factored out, that entrepreneurial efforts failed at the rate of 18%-20% over a period of eight years (Arnold & Seekins, 1994). This is obviously far better than the retention/failure rates for regular competitive employment.

The issue of isolation is more complex. It is true that some forms of self-employment such as home-based businesses might restrict interactions with persons who do not have disabilities, as required by supported employment. However, this is an issue of competing values. Which is more important-self-determination/choice or integration? While many would assert that both values are critically important, it is clear that some persons with disabilities may choose a more isolated form of self-employment over an integrated job with an employer. In this case, it seems most respectful to support the choice of the person with a disability.

While it is probably true that human service agencies currently have limited expertise to share with persons seeking self-employment, it is not necessary to limit support to these traditional sources. There are varied, generic resources in almost every

community which can provide the information and support necessary for persons with disabilities to make informed and effective choices about their business plans. Choice and self-determination allow people to look outside the traditional supports funded by systems and take advantage of naturally existing community resources.

The anticipated high costs for self-employment are a largely unfounded fear. The experience of the five-year, RSA-funded choice project demonstrations is that the costs for self-employment are only about 12% - 20% higher than the costs of regular employment. When the opportunity to build capital and other assets is factored into the equation, entrepreneurial businesses are justified.

Perhaps the thorniest issue of self-employment involves the impact of intellectual disability on decisions, success and cost. There is a possibility that decisions about persons with developmental disabilities owning their own businesses might be influenced more by supporters, family members and providers than by the persons themselves. A commitment to effective person-centered planning techniques can help assure that the preferences of persons with the most significant disabilities direct the pursuit of self-employment. The success of new businesses will probably depend upon supports offered to the individual, just as in regular employment. However, it is possible that an employee, supplier or business customer, rather than a job coach, might be able to offer some of the supports needed. Finally, there is almost no available data on the cost of self-employment for persons with cognitive disabilities. It is likely that the cost for these persons, as in regular employment, will be more than the 10% - 20% increase stated above. The trade-off, however, might be in the ability to more finely target an employment match when all the business opportunities in a community are made available to persons with significant disabilities.

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DR. MANK HOLDS A BACHELOR'S DEGREE IN PSYCHOLOGY AND ENGLISH FROM ROCKHURST COLLEGE IN KANSAS CITY (1975), A MASTER'S DEGREE FROM PORTLAND STATE UNIVERSITY IN SPECIAL EDUCATION (1977), AND A DOCTORATE IN SPECIAL EDUCATION AND REHABILITATION FROM THE UNIVERSITY OF OREGON, EUGENE (1985) A PROLIFIC WRITER AND RESEARCHER, DR. MANK HAS AN EXTENSIVE BACKGROUND IN EDUCATION AND EMPLOYMENT FOR PERSONS WITH DISABILITIES. HIS INTEREST ALSO INCLUDES A FOCUS ON THE TRANSITION OF PERSONS WITH DISABILITIES FROM SCHOOL TO WORK. OVER THE PAST FIVE YEARS, DR. MANK'S WORK HAS EXPANDED TO ENCOMPASS NOT ONLY PERSONS WITH DEVELOPMENTAL DISABILITIES, BUT THOSE WITH MENTAL ILLNESS, PHYSICAL DISABILITIES, AND PERSONS WITH TRAUMATIC BRAIN INJURIES.

SINCE 1985, DR. MANK HAS MAINTAINED RESPONSIBILITIES FOR GRANT WRITING AND MANAGEMENT OF 13 FEDERALLY FUNDED PROJECTS IN WHICH HE HAS BEEN THE PRINCIPAL INVESTIGATOR, DIRECTOR OR CO-DIRECTOR. HIS BACKGROUND IN THE CORE FUNCTION DOMAINS OF THE UAP AT THE UNIVERSITY OF OREGON IN THE AREAS OF RESEARCH, TRAINING AND TECHNICAL ASSISTANCE, DEMONSTRATION PROJECTS, AND GRADUATE PERSONNEL PREPARATION PROGRAMS CORRESPOND WITH THE PURPOSE AND SCOPE OF ACTIVITIES AT THE ISDD

DR. MANK IS A MEMBER OF THE EDITORIAL BOARDS OF THE JOURNAL OF THE ASSOCIATION FOR PEOPLE WITH SEVERE HANDICAPS (JASH), THE JOURNAL OF VOCATIONAL REHABILITATION, THE JOURNAL OF DISABILITY POLICY STUDIES AND A CONSULTING EDITOR FOR THE JOURNAL ON MENTAL RETARDATION. HIS WORK HAS BEEN RECOGNIZED AT THE NATIONAL LEVEL WITH AN APPOINTMENT TO THE EXECUTIVE BOARD OF THE FOUNDATION OF THE ASSOCIATION FOR PERSONS IN SUPPORTED EMPLOYMENT. HE HAS ALSO BEEN APPOINTED TO THE WORLD ASSOCIATION FOR SUPPORTED EMPLOYMENT WHERE HE IS INVOLVED IN DEVELOPING A SUPPORTED EMPLOYMENT NETWORK IN ITALY, SPAIN, BELGIUM, ENGLAND, AND IRELAND