FINAL REPORT
UCPA’s CHOICE ACCESS PROJECT

A FIVE YEAR DEMONSTRATION FUNDED BY
THE REHABILITATION SERVICES ADMINISTRATION
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PROJECT SUMMARY

United Cerebral Palsy Associations (UCPA) was one of the seven organizations awarded a grant by the Rehabilitation Services Administration as a part of the re-authorization of the Rehabilitation Act of 1973, as amended in 1992. The amendments authorized a demonstration to examine ways to increase choice in employment for persons with disabilities. As a result of years of strong advocacy in securing state and federal funding legislation for supported employment and in implementing innovative employment services, UCPA felt that offering access to employment services through personal budgets controlled by individuals represented the next step to increase choice and in assuring access to meaningful jobs for persons with severe disabilities.

The UCPA project was based in three sites across the eastern U.S.: Detroit, New Orleans and Pittsburgh. Local UCP affiliates were chosen to provide site management of the project activities -- UCP of Detroit, UCP of Greater New Orleans and UCP of Pittsburgh. Each project site was to identify 15 persons per year for services for a targeted total of 225 participants over the five year demonstration. The actual number of persons served during the entire demonstration was 221. During the course of the project, the Pittsburgh site management shifted to a local service organization, Sharp Visions, and 30 “remote individuals” were added in the final year from locations throughout the country. One hundred and thirty four (134 or 60.6%) participants became employed and of that number twenty nine (29 or 21%) became self-employed.

This project began in 1993 and ran its five year course, officially ending in September, 1998. However, it was granted an extension year in which participants could spend down their resources and the actual, final date for cessation of services was September 30, 1999.

The project used Choice Coordinators in each of the three sites to assist persons with disabilities to receive advice and purchase needed employment services. These coordinators were housed in local UCP affiliates in each area. Participants were encouraged to hire (or recruit volunteer) employment advisors to facilitate the delivery of services offered by providers and to offer information, options and opinions concerning informed choices. A Local Referral Committee comprised of volunteer local stakeholders selected participants and resolved disputes. Employment services were provided on a contract basis by local agencies and individuals selected by participants. Providers were required to attend free training offered by project technical assistance staff, to agree to a
fee-for-service relationship with participants and to use project contract forms available to participants.

PART I - PROJECT FOUNDATIONS, FOCUS AND OBJECTIVES

The genesis of the idea for the UCPA project came from a blending of several influences that were coming together in the early 1990’s:

a) UCPA had responded to the traditional poor representation of persons with significant physical disabilities in employment services with the development and implementation of powerful, individualized employment strategies resulting in significant gains in employment in a series of federal employment demonstrations -- the 1987 - 1990 Demonstration Project; the 1992 - 1997 UCPA/PWI Project and the 1992 - 1995 Research and Demonstration Project.

b) Persons with disabilities, including persons with significant physical disabilities were demanding more control and “say-so” both in the manner that employment services were offered and in the controlling of public funds set aside for the purchase of those services.

c) A clear set of organizational values had been articulated by UCPA that included a mandate to pursue strategies and programs that assured the maximum ownership by persons with disabilities and their families.

But perhaps the most clarifying influence for this project involved a young man with significant, multiple disabilities and his family in New York. During a long term support relationship with this man that spanned his school transition into adult employment, UCPA staff members, including the project director for the UCPA Choice Access initiative, were able to see firsthand the fit between powerful, individualized employment strategies and personal control of financial resources. Andrew’s family fought to direct and control the funds that would have traditionally gone to a service agency. This man’s experiences provided the blueprint for the processes that were adopted in the Choice Access Project.

Since persons with physical disabilities have traditionally been the primary focus of UCP service affiliates, this project elected to target these individuals for service. But we also wanted to assure that the benefits of choice and control were available to all persons with physical disabilities, not just those felt to be the most likely to benefit from scarce resources. For that reason, the Choice Access project targeted individuals with disabilities who experienced a life impact in the areas of mobility, communication and manipulation. Typically, persons might be felt to have a significant disability with the presence of any one of these indicators. However, we felt that in order to assure eventual access to
all persons, regardless of the significance of their disability, that it was necessary to target people who experienced all of the factors that indicate physical disability. This decision was to be a defining factor of our demonstration and will be discussed at greater length in following sections. In order to demonstrate that choice in employment and control of resources were feasible concepts, the following objectives were submitted in the original proposal were outcome based and referenced actual project activities.

Objective 1

To facilitate individualized Choice Plans for a minimum of 45 individuals with the most significant physical disabilities each year who choose to develop such plans. This effort resulted in a customer driven strategy for realizing goals in areas of significant importance to these individuals (totaling up to 225 persons over the five year project).

Objective 2

To identify desired employment outcomes and employment-related services and supports through customer-driven, individualized employment-focused planning, guided by the project-validated Vocational Profile Process for all participants choosing to use this process.

Objective 3

To ensure customer selection, purchase of and access to desired employment-related services and supports, resulting in meaningful, integrated employment for all participants.

Objective 4

To evaluate the outcomes, cost-effectiveness, feasibility and replicability of the customer choice process for achieving desired employment goals.

Objective 5

To produce the project’s findings and practices in user friendly products and otherwise disseminate and provide technical assistance to potential adopters of project practices.
PART II - UNIQUE FEATURES OF THE PROJECT

A. The project’s design was developed from a lineage of previous national employment demonstrations.

UCPA has recognized that in order for persons with severe physical disabilities to become successfully employed, effective and individualized strategies must be available to service providers. We made a long-term commitment to develop such approaches and we embedded them in the design of the Choice Access project. This project individualized employment services by suggesting that participants purchase services which result in:

1. The development of a descriptive and optimistic narrative profile of an applicant to be used as the basis of planning,
2. Implementation of an individualized employment planning process which creates a personalized blueprint for job development,
3. Tailored job development representation which negotiates, carves or creates individualized jobs and entrepreneurial businesses,
4. An analysis of the job sites developed for applicants, and
5. Facilitation and assistance of successful job performance using natural supports and quality instruction

B. The project targeted persons with severe physical disabilities, for whom traditional rehabilitation services had not typically been successful.

The project focused on the employment needs of persons who experience a life impact of their disability in the areas of communication, manipulation and mobility. This group is traditionally the most under-represented in achieving successful employment outcomes from both vocational rehabilitation and developmental disabilities services. Approximately 40% of the participants in the project also experienced an intellectual disability, although it was neither a factor which was considered for acceptance or one which excluded persons from participation.

C. The “qualified provider” requirement required by VR regulations was resolved by offering a qualified process to participants and providers based on a “building code” concept developed from the UCPA Self-Directed Staff Training Curriculum

Federal regulations required that all choice projects assure that participants selected “qualified” providers for service delivery. Rather than requiring certification or licensure to assure qualified providers,
UCPA used a “building code” strategy, which described the quality components of effective employment assistance. This approach utilized the UCPA Self-Directed Staff Training Curriculum for Supported Employment, which was developed through a project funded by RSA. General components and indicators of quality employment services were identified in this document which are much the same as the components for house construction used by communities to assure that quality housing results for home buyers. By using a qualified process rather than qualified individuals or agencies, participants had a much broader range of choices for service providers.

D. Choice Coordinators fulfilled a redefined role of traditional rehabilitation counselors and Employment Advisors provided independent, third party advice to participants on either a paid retainer or volunteer basis.

Each project site was managed by a part-time Choice Coordinator (.75 FTE) whose job was to provide outreach and recruitment, to develop a pool of providers and advisors, to liaise with the Local Referral Committee (see below), to assist participants develop a Futures Plan for Employment and to handle all local project data and financial forms. A UCPA employment staff person was assigned to each site to provide part time technical assistance and training of providers and advisors.

In order to assure informed choice, the project recommended that participants hire (or recruit on a volunteer basis) an Employment Advisor on either an outcome or retainer basis to provide perspective in navigating the treacherous human service system. The advisors then assisted participants in negotiating with service providers to obtain their employment outcomes. Participants could then select from a variety of service providers -- traditional agencies, individual providers, friends, generic services, anyone except a family member who currently lives in the same residence.

A pool of advisors was maintained by each Choice Coordinator to assist participants to identify individuals. Advisors chosen by participants fell into three categories: a) persons with disabilities who knew how the system works (about 65%); b) local advocates who wished to assist participants part-time (about 25%); and, c) parents or family members (about 10%).

E. Acceptance into the project was made by a volunteer citizen committee, comprised of stakeholders, who offer participation based on the severity of life impact of disability rather than on performance. Employability is assumed for all applicants and persons with more significant disabilities are considered first for selection.
Applicants to the project applied through the Choice Coordinator and all names were forwarded to a Local Referral Committee. This committee was comprised of local volunteers who were stakeholders in the employment of persons with severe physical disabilities. Minimally, each committee had a person with a disability, a family member of a person with a disability, a UCP agency representative, a local VR counselor and a local school representative. Additional members were locally added to achieve a maximum size of nine members. The LRC was charged with the difficult task of selecting the fifteen participants each year for each site. No tests or evaluations were allowed to be used and the committee members were directed to assume “employability” for all applicants. Additionally, the committee had an affirmative action mandate to include person with the most severe disabilities as well as persons who are minorities.

F. Each participant received a targeted amount of funds, which were held in individual accounts, with UCPA acting as a fiscal agent.

Upon selection by the Local Referral Committee, each participant received $9,466 which was drawn down from the federal government by UCPA and held in individual accounts. These funds were under the sole control of the participant. Payments were made through the use of Request for Payment forms initiated by the service provider and approved by the participant. As the “Remote Participants” were added in the final year of the project the set amount for budgets was shifted to an individually determined rate. The reasons for this shift are discussed in the “ASSUMPTIONS” section of this report as it represents an important departure from our original intent.

G. Each project site was assigned a technical assistance consultant who provided the Choice Coordinator and Local Referral Committee members with support and who provided training to employment advisors and service providers.

Training consultants provided a minimum of three, multi day training and technical assistance visits each year as well as on-going telephone assistance to Choice Coordinators. Training was provided to providers, advisors and local referral committee members as well as to participants and family members on the indicators of quality, individualized employment, on contracting and invoicing for services and payments, on consumer empowerment and responsibilities and on overall project design and outcomes.
PART III - THE DESIGN OF THE PROJECT

The basic concept of the project was to offer improved choice in employment services by offering vouchers or personal budgets for participants to hire their own service providers. UCPA acted as a fiscal agent for the project in that we maintained an individual account for each participant. The following section describes the various roles and procedures used to implement project services.

A. STAFF

Project Director(s)

A part-time (.75 FTE) project director directed all project activities from a UCPA Employment Field Office on the Gulf Coast of Mississippi. Michael Callahan was project director for Years I - IV of the project and he shared project director duties with Norciva Shumpert for Year V. Both co-directors provided oversight of the project’s extension year in a contributed manner from UCPA. Nancy Batson was retained on a half-time basis by Remote Participants during the project’s extension year to provide support and feedback through the Mississippi Field Office. The reason that all project management was conducted out of Mississippi was due to the residences of the project directors and the location of UCPA’s Employment Field Office.

Voucher Accountant

Since UCPA was the fiduciary for all participants, we needed a staff person to manage all personal accounts, to review and approve contracts and payment requests and to prepare documentation for the checks that were written out of the UCPA national office in Washington, DC. Sonia Hester was the project’s Voucher Accountant on a part-time (.75 FTE) for the entire five years of the project, not including the extension year. She worked in the Mississippi Project Field Office.

Technical Assistance Providers

Each of the three project sites was assigned a contract technical assistance and staff training person using funds from the 5.5% indirect rate in the grant. These nationally-based TA providers visited their assigned project sites an average of four times per year to offer training courses to new and existing providers, to employment advisors and to participants. They also assisted Site Coordinators in dealing with local problems, data collection and overall project direction. Norciva Shumpert was assigned to the Pittsburgh site, Melinda Mast assisted the Detroit site and Brenda Carson worked with New Orleans. All TA providers were available to the project for the entire five years.
Site Coordinators

Each project location had a Site Coordinator who provided project oversight, conducted project activities and generally managed the project in the local areas. The Site Coordinator’s job was to insure that participants obtained the kind of employment outcomes that they wanted. The Coordinator was also responsible for recruiting new applicants, coordinating the Local Referral Committee, assisting participants to develop a Choice Plan for Employment, approving contracts and requests for payment and collecting data on the project.

Site coordinators provided participants with a number of direct services in addition to their general project duties:

1. Taking applications for project services;
2. Describing the project in general terms during the application process;
3. Developing a Choice Plan that described the relationship and importance of work in each participant’s life;
4. Informing participants of the local list of approved employment facilitators;
5. Assuring satisfaction with the outcomes provided by employment advisors and service providers;
6. Approving all voucher contracts and requests for payment regarding service providers;
7. Collecting data and coordinating project training for providers and facilitators; and,
8. Maintaining contact with the project office regarding all project activities.

Each of the three Site Coordinators was part-time (.75 FTE) and each was housed in different locales: in Detroit, the local UCP affiliate was used, in New Orleans, the Parish Office for Citizens with Disabilities offered free space and in Pittsburgh, a local service agency -- Sharp Visions -- contributed space. The Site Coordinators were as follows:

New Orleans Adrian Couvillion
Pittsburgh Susan Linders
Detroit Leslyn Angel (Years 1 - 3); Paul Landry (Years 4, 5 Ext. Yr.)
Local Referral Committee

The Local Referral Committee was responsible for deciding who received project services. After participants submitted an application form, the Site Coordinator presented it to the Local Referral Committee for consideration. This committee, composed of a person with a physical disability, a family member of a person with a disability, a representative of the local UCP affiliate, a vocational rehabilitation representative and two or three other persons, had the difficult task of deciding who we should serve. Our target group was persons whose disabilities impacted their lives in the areas of communication, mobility and manipulation.

Each year the Local Referral Committee identified approximately 15 people in each of the three sites. Applicants were officially project participants only after the committee has selected them for services. Committees were projected to meet approximately four times per year, but most committees met a minimum of every other month and some even met monthly to assure an even flow of participants for the project.

The Local Referral Committee also acted as an arbitrator on disagreements between participants and service providers or advisors. If any party felt that there was a problem with a payment or the quality of a service, the Site Coordinator initiated a Conflict Resolution Process, described in each Voucher Contract.

Employment Advisors

We were required by the projects’ RFP to assure that participants used “informed choice” in their selection of providers and the types of services that they felt they needed to become employed. To help assure that each participant was as fully informed as possible in making their choices, we instituted the role of the Employment Advisor to advise participants through the maze of employment services. We strongly recommended that participants hire an advisor for assistance. In fact, we required every participant to identify someone to act as a facilitator, even if that person was a family member. It was not necessary to pay advisors who were willing to volunteer their services.

We provided a recommended list of advisors, however, participants were free to hire others, as long as that person was willing to attend a training provided free of charge by the project, to fill out the necessary forms that we required and to abide by the processes that the project used and the participant stipulated.

Any individual could act as an employment advisor, but participants could pay only those persons who did not share a household with them, except for paid personal care attendants. This meant that participants could hire a parent,
sibling or other relative as long as they did not live with them. If participants wished to receive employment advice from someone who lived with them, that person had to be willing to volunteer their services.

Employment advisors could not provide employment services, though they did work directly for participants. Activities provided by advisors included:

1. Helping participants interview potential service providers;
2. Setting up meetings and calling contact people;
3. Offering information, options and opinions to help participants decide which providers might best meet their needs;
4. Helping participants understand the terms of their contracts, services and payments;
5. Verifying that a provider had done a good job;
6. Assisting to solve any problems which participants might have had with a provider; and,
7. Assuring that customer satisfaction with all services.

We made a clear distinction that an employment advisor was not a service provider. We clarified that, even though advisors might offer to, it was not an advisor’s job to provide transportation, personal assistance services and other similar duties. Their primary duty was to assist participants to find necessary services and assist with issues of negotiation, contracting and payments.

Service Providers

Service providers were the individuals, agencies or companies that participants hired to provide them with the services that they needed to become employed. A provider could be anyone, except one’s employment advisor or Site Coordinator. Participant’s could pay all service providers, except for family members who shared their home. As with employment advisors, our project maintained a list of individuals and agencies that had applied to become service providers and had attended training offered through the project. Participants could choose from among any of those providers as well as other individuals, agencies or companies as long that they were willing to apply for project provider status, to attend a project training (offered free of charge) in the area of service they would be providing and to follow the employment process adopted by the UCPA Choice Access Project.

The most challenging thing for participants and provider alike to remember was that service providers worked for them, not for the project. This was very different from traditional relationships between persons with disabilities and their service agencies. Often, service providers either forgot that this new relationship was in use or they simply did not know how to treat participants as true customers with money to spend. The employment advisor and Site
Coordinator had to consistently remind service providers of this unique situation. Participants were also encouraged to take the initiative to advocate for respect and customer focus from their providers.

**B. FINANCIAL MATTERS**

**Voucher Contracts and Requests for Payment**

Once participants selected a service provider, a Voucher Contract was completed. This contract, described fully in the attached Participant Handbook, was the legal document which UCPA used as a basis to pay for all services in this project. Participants could have more than one Voucher Contract if they chose or needed to have multiple providers. The employment advisor and Site Coordinator assisted participants to understand and complete their Voucher Contract(s).

Service providers were only paid after they provided the service that was requested, to the participant’s complete satisfaction. If participants were not satisfied with the performance of a service provider, UCPA would not pay the provider, unless they successfully completed the Conflict Resolution Process described in the Voucher Contract. In this case, the provider might receive payment if it was felt by the Local Referral Committee that payment was warranted. In all cases, the participant’s satisfaction was our highest consideration in resolving payments to providers.

Request for Payment forms were submitted upon successful completion of the terms of a Voucher Contract. Participants were cautioned not to sign any Request for Payment form from a service provider unless they were fully satisfied with the completed service. Participants and providers alike could cancel a contract at any time, within five days, by sending a letter to the other party and the Site Coordinator. For conflicts between providers and participants, it was typical that the Local Referral Committee would authorize at least partial payment for the amount of work performed by the Provider during the time that the contract was valid, unless it was clear that the work performed was not up to the standards set by the project.

**Participant Resources**

The money that was set aside for participants in this project was, perhaps, the most innovative aspect of this new way of assisting people with disabilities to become employed. In developing the federal proposal, we had to estimate the amount of money it would likely take for an average person with significant physical disabilities to become employed. We also had to include the cost of certain equipment and other services such as transportation and personal assistance services, that might be necessary for employment. We came up with
an average of $10,666 per person, including the advice component. This amount was based on our experiences over the past eight years in UCPA's national employment projects. The following section describes how we anticipated that the $10,666 would be spent:

- $1,200 Allocated to the Site Coordinator's salary for direct services
- 1,000 For payment of the Employment Advisor for all phases of service
- 750 For development of a Vocational Profile
- 250 For the Profile Planning Meeting
- 2,000 For Job Development -- finding the participant the job they want
- 250 For a Job/Technology Analysis of the job, before work starts
- 5,216 For Employer directed job site supports (job coaching), equipment, personal assistance services and any other legitimate, job related expenses

$10,666 Total funds allocated to each participant

1,200 Less direct service amount allocated to site coordinator’s salary

$9,466 Actual amount controlled by participant

Since the federal grant required all grantees to conform to a strict 20% administrative formula, its was necessary to assign the direct service components of the Site Coordinators salary to each participant’s budget. This meant that participant’s had direct control of $9,466. This was federal money which would typically go to vocational rehabilitation state agencies, but, under this project, went to individual budgets.

It is important to recognize that these figures represented anticipated costs, only.

Participants were not required to conform to these projections and were free to negotiate with providers or to reconfigure the line items. Participants who chose self-employment had to submit a business plan and specially designed forms. Their budgets looked considerably different than the one above. These figures did represent the suggested rates that participants might wish to pay providers and they quickly became “standard rates” (see Assumption #2, below).

Additionally, we now suggest that each participant’s budget be individualized. For a discussion, see Assumption # 1.

**Restrictions on Choice**

There were some strings attached, even to a project dedicated to offering as much participant choice as possible. The following areas, in addition to those discussed in Assumption # 18, below, were either restricted in some way or not allowable:
1. In order to purchase equipment or pay for tuition for schooling, participants had to clearly demonstrate the need for that equipment or training in relation to a specific job.

2. For purchases over $5,000, participants had to indicate how they had used every other means possible, such as Medicaid, to purchase those items.

2. Participants had to use a bidding process, mandated by the UCPA purchasing policies, for purchases over $2,000. Three bids were necessary to buy these items.

3. Participants could not choose to pay for sheltered, volunteer or non-competitive employment (required by the federal regulations governing these projects).

4. Participants could not pay family members or anyone with whom they shared a residence.

5. If participants negotiated with providers for a rate of 50% more than the “suggested” rates, approval had to be obtained from the Local Referral Committee.

What happened if a participant’s money ran out?

Occasionally, participants expended all the funds in their account. There were a number of possible reasons that money might become depleted:

1. A participant might still require supports -- job site supports, personal assistance, etc. -- although all their money has been spent;
2. A "big ticket" purchase had depleted funds before all services were provided;
3. The participant lost a job and needed more money in order to become re-employed.

Each case was handled differently. In the case in which a participant required additional services and the money had run out, a request was made to the Site Coordinator for the Local Referral Committee not close the case. An estimate of the additional of funds necessary for the participant to become "stabilized" on the job was provided to the Local Referral Committee and the committee decided whether to provide the funding and how much would be provided.

In the case in which the purchase of a "big ticket" item might deplete an account, a participant would request the purchase from the Local Referral Committee. If approved, the project disregarded the purchase of the item in relation to that
account. In other words, the amount of the purchase was, in effect, added to the $9,466 so that there was no negative impact for the purchase.

In the event that a participant lost a job and needed additional funds to become employed, there were two possible scenarios that were used: a) If there was still money in the participant’s account, the remaining money was used to purchase new employment services. A new Vocational Profile or Profile Meeting was not recommended if the participant felt that the original products were still relevant. At the point that the money ran out, the participant would then implement situation #1, described above. b) If the participant’s status had been officially “closed” (see Closed Status, below) and they had no more money in their account, the participant could ask the Site Coordinator to re-submit their name to the Local Referral Committee for reconsideration as a new participant. Former participants received consideration for acceptance above other applicants. If selected for service, a new estimated funding amount was assigned by the committee for an amount typically less than $9,466.

Participants who resigned their active status for personal reasons could re-apply at any time. However, if they had previously expended project funds, the Local Referral Committee would deduct that amount from the previous amount of $9,466.

Closed Status

Federal regulations required that our project must determine a point of “closure” for each participant. Closure meant that the participant’s account was no longer open and the funds could not be used to pay for additional services. A participant was “closed” under the following conditions:

1. When an employed participant voluntarily requested closure.
2. When all of the money allotted to an employed participant was spent, including any additional funds approved by the Local Referral Committee;
3. When a participant dropped out of the project before becoming employed; or,
4. When an unemployed participant ran out of funds and was denied new participant status or additional funds by the Local Referral Committee.

The Local Referral Committee directed Site Coordinators to send participants a letter informing them of their closed status. If they felt that they had been closed inappropriately, they could appeal using a conflict resolution procedure to:

   a. The Local Referral Committee;
b. The Project Director; or,
c. Their state's Client Assistance Program (CAP), a part of every state's vocational rehabilitation agency

C. EMPLOYMENT FACILITATION COMPONENTS AND STRATEGIES

UCPA has developed an excellent track record in employing persons with severe physical disabilities since 1987. We have learned that virtually everyone is "employable", given clear expectations, sufficient resources and quality supports. It became was clear to us however, that money alone was not enough to assist people who have truly significant disabilities to become employed. It also takes effective support strategies and a firm expectation of success. One of the "strings" to the money associated with this project was that participants and their service providers would follow a time-proven process to achieve employment. This process involved five "Core Employment Services":

a. A person-centered planning process called the **Vocational Profile**;
b. A meeting that linked planning with job development called the **Profile Planning Meeting**;
c. **Individualized Job Development** that targeted the type of job(s) that the participant wanted;
d. **A Job/Technology Analysis** of the employment site and the specific job duties; and,
e. **An Employer-Directed Support Plan** which provided all the support needed to assist the participant to successfully perform the job.

These essential components of the plan were felt to be necessary for all participants, unless they could clearly make a case with the Site Coordinator or the Project Director as to why they felt that a component(s) was not necessary. We realized that this process meant that participants would have less choice and flexibility than if we did not impose it. However, we felt strongly that if a process like this was not followed, that it was extremely unlikely that participants with significant physical disabilities would get a good job of their choice. The following section provides a description of the components of the employment approach utilized by the Choice Access Project.

**The Vocational Profile**

The Profile, a discovery strategy, is designed to allow a job developer to get an accurate picture of the participant’s life -- skills, preferences and needs. Typically, the human service field has tried to accomplish this by relying on standardized tests, work samples or by other means to prove "readiness to work". UCPA felt that everyone who wished to work, could work. But we felt that it was critically important to get to know the applicant well enough so that a job
developer could relate to an employer the unique contributions that the participant brings to a job.

We told participants to expect service providers to spend between 15 - 25 hours of time getting to know them by asking questions, observing at home and in the community, talking to family and friends, reading records of programs they had attended and by interviewing human service staff who knew them. Providers were also expected to conduct a thorough inventory of participant’s neighborhood, their section of town, and areas they frequently visit. The provider should note transportation availability, potential job sites, accessibility and safety factors and numerous other issues which help to frame the participant's life within the community.

We suggested that participants pay approximately $750 for a completed Vocational Profile. We offered a sample format and provided a completed Profile to be used as a guide for both participants and providers (See Participant Handbook, attached). The finished profile is a typed document that contains the following considerations:

a. The Profile should be written in positive language, stating what participants can do, not focusing on things that they cannot do.  
b. The Profile should be written in language which the participant, their parents (if appropriate), and the Employment Advisor could understand.  
c. The Profile should be neatly typed and each item on the form should be addressed fully, unless it is clear that an item is not relevant.  
d. If the participant disagreed with a certain item(s) on the profile, they told the provider (with assistance from their advisor) and requested that their perspective be added to the profile. The provider should be willing to re-type the profile with the requested changes.  
e. The bottom line is that participants should feel good about both the process of developing the profile and the way in which the profile form describes them. If they did not, they were encouraged not approve payment for the profile.

The Profile Planning Meeting

The Profile Meeting follows the development of the Vocational Profile. This critically important meeting is designed to link the participant with the job search efforts of the job developer. UCPA required that the provider who completed the Vocational Profile be hired to manage one’s Profile Planning Meeting. This meeting takes approximately 2-2 ½ hours to complete. We suggested that participants pay $250 for the Profile Meeting. Ideally, the Profile Planning
Meeting was be held in home or nearby, in a library, community center or other public facility. By the end of the project we found that the provider’s office could be an acceptable place to hold a Profile Meeting, due to the inconvenience of having a large group in a participant’s home.

The provider initiated the Profile Meeting after the participant approved payment for the Vocational Profile. Sufficient notice, at least a week, was given to persons who were asked to attend. It was critically important to have the right people at a Profile Meeting. The participant and, if appropriate, family members decided who should attend. We recommended that participants consider the following guidelines when deciding who to ask to a Profile Planning Meeting:

a. Family members or relatives who were felt to be able to contribute positively to a meeting concerning the participant’s employment;
b. Close friends, neighbors, mentors or advocates who could offer helpful information and ideas;
c. The service provider, job developer (if separate from the profile provider), and the Employment advisor; and,
d. Any human service staff, former teachers or other persons who were paid to provide services.

The number of persons at a profile meeting ranged from just a few individuals to as many as 10 - 12 people. Participants invited the number of people with which they were most comfortable. We did find that it was possible to invite too many people. When the number of persons attending went beyond 12 - 15 people, there was actually a negative effect of too much input and too much time required.

The purpose of a Profile Planning Meeting is to direct job development efforts. Job developers need specific information to take to employers. Additionally, the job developer needs to know where a participant might want to work and where to avoid. The Profile Meeting results in a three part form. The form includes a) characteristics of an Ideal job, b) the types of tasks the applicant wishes to performs and c) specific employers who may have these types of jobs.

The job developer actually develops a "blueprint" of the kind of work the participant wants to do and a prospecting list of employers who will be contacted. Additionally, the Profile Meeting provider developed a checklist of the participant’s conditions, preferences and contributions so as to evaluate any job possibility offered by the job developer.
Job Development

Job Development was the linchpin of the project’s success. It involves using a representative to strike an employment deal with an employer on behalf of the participant. The service provider contacted community employers targeted in the Profile Planning Meeting in the sequence decided by the participant. In the past there were a number of approaches which had not proven to be successful in developing jobs for persons with severe physical disabilities. The Choice Access Project was committed to change these ineffective practices and we implemented an alternative approach in this project. Rather than simply calling on random employers to see if openings existed, this project required that job developers target employers identified during the Profile Meeting and relate to them the specific contributions of the participant represented.

If an employer need existed for the skills the participant could offer, an individualized job description was developed with the employer. A job description was negotiated specifically for the participants that took into consideration their conditions and preferences, as well as their unique contributions.

Suggested payment for Job Development in this project rewarded timely performance. Quality job development is often a time-consuming activity. In an attempt to assure that that participants received priority status from their providers, UCPA suggested a payment based on the speed with which participants were offered an acceptable job. The rates of pay which we suggested were:

a. $2,000 for a job found within 60 days of the Profile Meeting;
b. $1,500 for a job found from 61-90 days of the Profile Meeting; and
c. $1,000 for a job found from 91-120 days of the Profile Meeting.

If a provider had not found an acceptable job within 120 days of the Profile Meeting, we suggested that participants either find new provider or negotiate a fixed rate for less than $1,000 in most cases. This system was designed to encourage providers to get on with the process of job development. We felt that, typically, a good job could be found within a 60 day period, if a focused effort was made by a provider. However, it was also possible that a good faith and timely effort might not result in a job, even within the 120 day period. If the participant felt that the provider had made a sincere effort to find a job, they could enter into another Voucher Contract for the $2,000 amount (or more, with approval) with the same provider. We recommended that the job developer provide participants with documentation that described the employer contacts made and the problems encountered during the initial contract period.
The reality, over the course of the project, was different than we anticipated. While the suggested fees described above were well above local rates, the monetary incentive did not seem to be a significant factor in speeding up the job development process. The average length of time participants were in job development was just over three months. Additionally, if providers had not found jobs within the time which higher pay was available, their enthusiasm waned. We recognized reluctantly that as long as they had access to other, traditional funding sources, that providers did not really suffer for their lax performance. Even worse, participants often waited eighteen months or longer just to find a job developer willing to represent them. A discussion of the problems associated with a dual funding system is found in Assumption #3, above.

**Job/Technology Analysis**

A Job/Technology Analysis is performed after a job has been developed, but before the participant begins work. The Job/Technology Analysis provided the employer the participant and the support provider with a clear picture of the company in which the participant would be working and the duties to be performed. Additionally, the provider identified any accessibility, equipment and job station changes which may have been needed to for the participant to successfully perform the job. We required that the provider selected to assist with Job Facilitation and Support should complete the Job/Technology Analysis. We suggested that this process should require about 10 hours of the provider’s time and we recommended that participants pay $250 for a completed analysis.

We stressed the importance of completing the job analysis before the participant began work. Commonly, providers tended to combine the job analysis activity with a supported employee’s initial days of work. We felt this approach missed important opportunities for support providers to learn about the culture of a work setting and to establish relationships that could then be transferred to the participant.

**Employer-Directed Support Plan**

Since the 1980’s, job trainers or coaches have provided employers the additional supports necessary to assist employees with severe disabilities to perform their jobs. During the early ‘90’s, job coaching had been criticized based on the observation that job coaches often had gotten in the way of the relationship between employers and supported employees. UCPA felt strongly that outside assistance is often needed by employers and by persons with significant disabilities. However, we recognized that some changes were necessary to help insure that participants would be as fully included in their jobs as possible. For this reason, we implemented an Employer-Directed Support Plan to assist both participants and their employer with the ideas, supports and training necessary
for success on the job, and at the same time, identify a clear role for service providers.

The issue of job site supports presented us with a challenge not found in the previous components of the process described here. Each of the other components could be completed as discrete products, allowing participants to pay or not pay based on their satisfaction. Job site support, on the other hand, is on-going by its nature. It seemed necessary for us to shift from a product outcome payment to an hourly rate in this component of service.

Another issue in job supports involved the use of “natural supports” within a participant’s job. The concept of natural supports had become so important in the early ‘90’s that Congress had allowed that such supports could be used as a source of extended services within supported employment and, as appropriate, within typical VR services. In our proposal we indicated that, as a project, we would promote the use of natural supports for all participants. The problem we had not anticipated was that we began to understand that the idea of natural supports was really much more a value of the system on behalf of a participant than a concept compatible with a contract between a participant and a provider. When the system controlled resources, providers could be directed to implement natural supports and could be rewarded for their efforts. When participants control resources, the provider has a natural and understandable motivation to maximize the amount of support (and associated resources) possible.

For this reason, we suggested that participants implement a plan that was Employer-Directed, indicating that the participant works for the employer, not the service provider. Since we felt that participants would probably need an outside provider to assist in ways that employer’s were not able to do, we wanted to assure that the employer felt "ownership" of the participant’s needs. By asking the employer to direct support plans, we felt it was more likely that supervisors and co-workers would be interested in planning with the participant to meet job support needs. We suggested that it was the provider’s role to make this happen.

The concept was implemented in the following manner. Before beginning the first day of work for the participant, the provider would introduce the Employer Directed Support Plan (available in the Participant Manual) to the employer. During the first month of work, we recommended that the service provider be available to provide the new employee and the employer with assistance as much as every hour worked. For instance, if a participant worked four hours per day for five days a week during the first month, we would approve that the employer could direct the service provider to provide the participant with approximately 80 hours of support for that month (4 hrs./day x 5 days/week x 4 weeks/month = 80 hrs.). We recommended that participants pay approximately $25/hr for this support.
In return, the participant should expect to receive all the training and support needed to begin their job in a successful manner and the employer should receive assistance to effectively work with the participant in the way that all new employees are oriented and trained. Participants should also expect to receive data sheets describing their performance and learning and a written description of any interactions between the provider and employer.

Towards the end of the first month at work, providers were expected to meet employers to develop the following month's support plan. Based on the experiences of the first month, we felt that employers could better estimate participant's actual support needs. We expected the number of hours offered by providers to go down as employers became better able to meet participants needs.

This approach did not work as smoothly as we had hoped. The amount of time required for project staff to monitor these plans made the strategy problematic. Additionally, there was a built in conflict of interest; the same providers who were hired to provide supports were also counted on to clearly describe the employer-directed support strategy. We felt certain that this did not routinely occur. To attempt to remedy this, we urged participants to do the following:

1. To have their employment advisor or parent (or anyone else they trusted) to assist them to explain to the employer that funds need to last as long as possible, and ask for help conserving them.
2. To negotiate for a cheaper rate from the provider after the first month.
3. To hire providers that participants felt would work with to conserve funds.
4. To look for co-workers in the participant's work area, or even on another shift, who might provide assistance on certain tasks at a significantly reduced rate.
5. To ask the Site Coordinator and advisor for ideas and suggestions.

Related Services

There were a number of related services, related to employment, that could be purchased through project funds. The following sections briefly describe these services and the conditions we had for purchasing them. The key idea to keep in mind is that it was necessary that all Related Services must have been shown to relate directly to the completion of one of the Core Services described above or to the participant’s job.
Transportation  The project assisted participants to cover transportation costs which you incur during the development of any of the Core Services. It did not pay for transportation for employment advisors or service providers. Once a job was developed, we allowed funds for transportation assistance for up to one month. If after one month, participants felt that additional time was needed to develop a transportation solution, an appeal to the Local Referral Committee for a one month extension was possible.

Personal Assistance Services  Project funds could be used to pay for the cost of job-related personal assistance services under some conditions. The use of these funds operated much in the same manner as Transportation funds. That is participants could use their budget to get personal assistance services started, but not to provide a long-term solution. It was permissible to use project funds to pay for personal assistance beyond the first month of employment, as long as the conditions for support to were based on an "as-needed" basis and could be paid in discrete units of service, identified in advance, rather than on an open-ended, hourly basis.

Therapies  Participants could pay for speech therapy, occupational therapy and physical therapy services as long as the therapy related directly to their job or to the completion of one of the Core Services. This project would not pay for on-going therapy generally related to a participant’s disability. The reason for this is once again related to the amount of money which was available through this project. Those services often cost $75 per hour or more and a regular therapy regimen could deplete an account in a few months. Examples of job-related costs which could be covered include:

a. A seating evaluation by a therapist to determine the best type of office chair to use;
b. A range of motion evaluation by an O.T. to determine if a participant could safely perform a repetitive movement required by the employer; or,
c. Speech therapy to help incorporate job site jargon into a communication device.

Rehabilitation Technology  Rehab Technology included any assistance that was needed to adapt or modify a job, or make a work area accessible. These costs were fundable under this project. It was necessary for the participant to get a letter from the employer stating the need for the service and why it was felt that the employer should not make these changes under reasonable accommodation, at no cost. If the employer felt that it would place an undue hardship on the company to
make the accommodation, the project paid for any reasonable support. The project did not typically pay for the cost of construction, re-
construction and labor. We suggested that the participant, provider, or advisor negotiate a reasonable compromise such as having the participant pay for the services of a Rehab Technologist and for the employer to pay for the cost of the changes.

We realized that this was a sensitive area which got into the concerns which many businesses had surrounding the American's with Disabilities Act (ADA). If a participant felt they needed assistance, they were encouraged to call their Site Coordinator or their state’s Client Assistance Program (CAP). We had few, if any, complaints or concerns raised by employers in this area.

Equipment As discussed previously in this report, participants could purchase equipment which related directly to their job. For this reason, most equipment purchases were not approved until a job had been developed. However, as the project unfolded in Years III - V, we began to consider requests during the job development stage so certain equipment would be available when a job began. Equipment fell into two basic categories: a) Lower cost purchases for items costing less than $2,000; and, b) Big-ticket purchase for items costing more than $2,000. As in the case of Rehabilitation Technology, it was be necessary to get a letter from the employer, or from the participant, stating why the equipment was needed and why the employer felt that the participant should purchase it. All equipment purchases required advance approval from the Site Coordinator and Big-ticket items fell under UCPA bidding guidelines.

PART IV - ASSUMPTIONS

In order to embark on a project of such fundamental significance, UCPA had to proceed from a set of assumptions that would direct the course of an uncharted journey -- how to offer increased choice and financial control to assist persons with significant disabilities to become “customers” or purchasers of employment services, as opposed to “consumers” or recipients of services. Some of these assumptions were outlined in component form in the Request for Proposal (RFP) from the Department of Education and others were developed as a part of our unique response to the RFP regarding project design. The RFP directed each submitting party to include a project design that addressed the following components:

A. Consumer direction This component of the RFP required that persons with disabilities should direct their information gathering process, employment planning, selection of targeted outcomes and the selection of providers.
We built participant direction and control into the design of the project by having consumers direct their employment plans, choose advisors and providers, approve payment for services, acknowledge satisfaction of every service rendered, negotiate rates and withdraw from contracts in cases of non-performance.

B. Informed choice The informed choice component of the federal requirements addressed the concern that participant “choice” not simply be a matter of individual preference but that information on consequences, costs and options be made available to participants before choices were made.

The UCPA project suggested that participants use funds from their budgets to retain the services of an employment advisor to assist with selection of providers, negotiation of rates and services, provision of information, options and opinions related to employment decisions and assistance and support throughout the employment process. Participants could also recruit volunteer advisors, if available, in order to save resources in their budgets.

C. Qualified providers In keeping with the regulations of the Rehabilitation Act, each grantee had to assure that the providers selected by participants for employment services were in some manner “qualified” to provide those services.

The Choice Access approach was unique in that we utilized a “building code” approach to qualifying providers in addition to providing service providers with free training and technical assistance. The building code concept was based on a Self-Directed Staff Training Curriculum on Supported Employment developed by UCPA in the early ‘90’s for a NIDRR funded innovative research project. Providers were required to attend free trainings offered by technical assistance personnel assigned to each site and they were required to follow the processes outlined in the curriculum. In this way, participants could select anyone other than persons with whom they shared a residence to provide services, as long as those persons or agencies agreed to attend free training and follow the strategies described.

D. Consumer satisfaction Each project had to show how the satisfaction of participants drove the major outcomes of employment -- planning and goal setting, payments to providers, the relevance of outcomes obtained, treatment received during services and the process as a whole.
UCPA developed a satisfaction component that was part of every payment approval submitted by the participant. The concept is similar to the customer response form that are common today after one purchases a new vehicle from a car dealer. Additionally, the profile planning meeting addressed the ideal characteristics of employment for each participant and those characteristics became a blueprint for the job developer to use for customer satisfaction purposes after a job was developed.

E. **Complete separation from vocational rehabilitation services -- no current IWRP** A final component required that the funds from the choice demonstration not be mixed with other funds associated with VR services. This separation was necessary to allow a comparison with traditional VR services.

This requirement was easily met since UCPA is a non-profit service agency, not connected to any government entity. Our site coordinators assured that each applicant either had a closed status with VR, or if active, assisted applicants to resign their active status with VR before project services were initiated.

F. **80% of all funds had to be in control of participants** This requirement responded to criticism from advocates that too much of the taxpayer dollar was siphoned off for administrative costs before the participant received access to funds. This percentage was an absolute target for each project.

We found that, while we were successful in conforming to this absolute requirement, that the 80% target for funds to be controlled by the participants was onerous and limiting. UCPA took a 5.5% indirect rate for this project, which was far below our federal negotiated indirect rate. The indirect rate was considered a part of the 20% administrative allowance for these projects. Additionally, we re-invested all of the indirect back into project services, especially in the area of training and technical assistance and staff raises. A much more reasonable rate for administering a personal budget/choice effort, excluding a reasonable indirect rate, would be 25% of the total funds.

These required components were each based on a set of assumptions that drove the implementation of the overall choice demonstration initiative. In response to the required components, UCPA developed a design that was based on assumptions in keeping with what we perceived to be the best practice values and strategies available at the time. As the implementation of the project proceeded, some of the assumptions were sustained and others had to be adjusted as we learned from our experiences. The following section presents
those critical assumptions and whether they were sustained or had to be revised based on our experiences.

It is our feeling that this information represents the real “data” of the project. While the information presented in the DATA section, below, is factual and even interesting, our experiences and the resulting reflections comprise the true meaning of the choice experience. These assumptions are far more generalizable to other situations, systems and groups of people.

1. We thought the only way to fairly provide a “voucher” was to use a set standard rate for all participants.

For the UCPA project the rate that emerged from our proposed calculations was $9,466 per participant. This rate was based on an historical average of costs from 1987 - 1992 in employment projects managed by UCPA. We had found that the average cost of employment services from intake to the point of initial stability on the job was approximately $7,500. We had also traced the average costs of worksite accommodations for persons with significant physical disabilities and had found an average of $2,500. When we finalized our proposal, considering the money available and the projected number of persons to be served, the compromise figure of $9,466 emerged. We anticipated that some persons might need more funds and they could apply for a budget increase and we figured that some might need less or might drop out before expending their total budget and, hence, would spend less. The actual amount expended by project participants for regular employment was $8,360, with a range from $1,750 to $15,821. For self-employment the average was slightly higher, $8,660, with a range of $2,525 to $21,227.

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

We now feel that a better approach is to individualize the budget process by having the employment plan drive the development of a personalized budget for each applicant. Of course, its possible to have guidelines that set reasonable parameters for proposed budgets to fall within, but each budget can reflect the unique needs of each participant. In the final year of the project, UCPA was given permission to expand its project services to include approximately 30 individuals who lived remote from the three project sites. We implemented an individually determined budget process for these remote participants and their
average budget was $4,335 with a range from $3,365 to $6,200. In order to implement this type of budget process it is necessary to have costs associated with discovery and planning available to participants before budgets are developed and a committee (or designated individual) must be impaneled to approve proposed budgets. In a new grant effort, subsequent to the Choice Access Project, UCPA has implemented an individualized budget process for persons with significant physical disabilities using DOL One-Stop Career Centers for employment services.

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

We provided a list of costs that were developed in consultation with local providers, VR counselors and state DD personnel in each of our three project areas. A suggested reasonable price list was included in all standard contracts for each service outcome purchased by participants. Providers had access to these costs though the participant manuals that were provided to each person in the project. The structure relating to these suggested rates allowed participants to either negotiate for the suggested rate or less without any prior approval from project staff. Participants could also contract to pay up to 50% more than the suggested rate for a discreet service, but they would receive a call from the Site Coordinator with information on less expensive services. Costs beyond the “suggested rate plus 50%” level had to be approved by the Local Referral Committee or project director.

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

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

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

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

First, nearly all initial providers were traditional service agencies in the DD field
with on-going contracts with state funders to provide supported employment to
persons served in-house. The relationships and incentives of tradition services
are markedly different than those in choice and as long as service agencies had
their traditional contracts there was little motivation to change perspectives to
work with a few choice participants. Similarly, agencies that did contract with
choice participants did little to shift staff roles. A job developer, for instance, is
traditionally funded by VR or DD funds within a typical agency. When a choice
participant signed a contract with such an agency, the job load associated with
the participant was simply added to the existing duties of the job developer.
When these competing outcomes were present, the choice participant was
almost always considered as an after-thought and was forced to wait.
Finally, providers have been charged by funders with the responsibility of
assuring outcomes that are consistent with the needs of the funding source.
This relationship is almost reversed in choice. Rather than pleasing funding
sources, providers must please participants. The shift is very challenging for
providers and one that is not consistent with other services.

We cannot say that we successfully resolved the issues associated with
traditional providers. We were, however, successful in finding an alternative --
non-traditional providers. Throughout the course of the project, we recruited and
trained a host of small, independent providers who became the primary source
of services from project participants. Overall participants contracted with 64
independent providers as opposed to 19 traditional, agency providers.
4. We anticipated that the clarity necessary to deal with the tough questions raised by choice would best be gained by comparing our participants to regular customers doing business with generic services in the community such as contractors, lawyers or retail outlets.

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

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

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

The regulations guiding the RSA demonstration authority were explicit in directing projects to take individual choice to a higher standard -- informed choice. There must have been concern that when the public dollar is used for purchasing goods and services that personal choice should be influenced by useful facts and professional perspective. In the early ‘90’s it certainly remained an open question whether persons with disabilities would make good choices with proper information and whether persons with significant intellectual disabilities could be counted on to make choices at all.

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

6. **We considered that the role performed by our site coordinators could define a new role for VR counselors in a choice-based system.**

The traditional role of a VR counselor is a multi-faceted one with responsibilities that include counseling, advice, gatekeeping and approval associated with finances and outcomes, determination of appropriateness for services, responsibility for closures, contracting with service providers and meeting the needs of the system. We assumed that there would need to be a facilitating staff person assigned to each participant, but that the role would need to be very different than a typical VR counselor’s. Components that were similar included a) the management of a caseload of participants (from 60 to 90 participants by the end of the project), b) recruitment and intake of participants, c) providing information on how the system works, and, d) responsibility for collecting data on participants.

However, there were also major differences between the roles we felt were necessary for choice. We felt that the Site Coordinator should not be the primary source of information and advice. Instead, they assisted participants to recruit and hire advisors and, as appropriate, volunteer supporters. Coordinators never made choices concerning the selection of providers, the outcomes identified by the participant or the degree of satisfaction felt by the participant. They had to encourage providers to be interviewed by participants rather than approving them for a qualified list. Perhaps the most challenging difference was that coordinators could not approve payments for providers without first getting approval from the participant. We feel strongly that these and other similar role changes are consistent with a valued, evolving role for VR counselors as they work to bring real choice to the rehabilitation process.

7. **We felt that service providers would willingly learn and embrace an individualized, choice-directed employment approach if they received sufficient training and support.**

Based on the dismal numbers of persons with significant physical and multiple disabilities included in the national employment data, we felt that service providers would eagerly anticipate and subsequently use a tested, effective process such as the one offered by our project’s technical assistance personnel. The approach was based on a sequential set of outcomes that allowed for provider pay along the journey towards employment. These approaches had been used effectively for six years by previous UCPA employment projects to individualize the discovery, planning and job development process and to avoid
the barriers in arbitrary job descriptions for persons with a significant impact of disabilities.

In reality, we found that providers struggled with the degree of individualization required by this approach and they often fell back to labor market, general strategies in the areas of job development and job site facilitation. A high degree of staff oversight of providers, continual training on the strategies and clear and even tough-minded advocacy by participants, advisors and volunteer supporters was necessary to keep providers focused on quality individualized services.

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

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

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

9. We suggested that a discovery process would offer an alternative to traditional comparison based evaluation procedures to drive employment planning.

Persons with disabilities have traditionally had to prove their fitness to work by passing a battery of evaluation and assessment procedures in a manner that indicated their feasibility. The choice demonstration began less than year from the passage of the 1992 Amendments to the 1973 Rehab Act by Congress. In
the '92 Amendments, Congress directed VR to remove the feasibility determination and to generally presume applicants feasible for employment outcomes. However, the regulations had not yet been written in 1993 to spell out how this shift should occur. The UCPA project embraced an expectation of feasibility and responded to the need for information on participants through a discovery approach using the Vocational Profile Strategy instead of a more traditional evaluation and testing approach.

We found the Profile Strategy to be fully sufficient to provide service providers all the information necessary for individualized employment planning and personalized job development. The time required to complete a profile ranged from 11.5 hours to 18 hours. This process was compatible with the payment for outcomes approach described in Assumption # 8.

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

One of our fundamental assumptions at the beginning of the choice project was that offering participants control of resources would speed up the attainment of desired employment outcomes. We felt that by shifting control to participants that we placed them in the driver’s seat and would bring a degree of personal advocacy and responsibility to the process.

However, it didn’t happen in that manner. Instead of speeding up the process, control of resources by participants seemed to have a complacency effect on many participants. Once they knew the money could not be touched, except through the delivery of outcomes that they approved, many participants seemed to relax their advocacy efforts and accept a lack of movement by providers. This was completely unanticipated, although, in retrospect, it follows a certain logic. Sometimes we’re at our most vulnerable when we are closest to our goal or when a major hurdle has been reached.

Beyond this, we must recognize that choice and true individualization are simply messy concepts. When we welcome people to bring into their quest for employment all their hopes, needs, dreams, negatives, and perspectives and then add to the mix the powerful ingredient of prerogative, things are going to become complex very quickly. This complexity, and the associated time delays, must be accepted as a natural part of offering choice service.

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

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

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

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

As the availability and use of home office technology increased during the ‘90’s, we also encountered a wholly unanticipated challenge in this area -- participants did not typically have personal access to the computers, fax machines and e-mail accounts that might have increased the speed with payments could be processed. As payment and form systems advance with the use of technology, it is critical that customers have access to that technology in order to effectively participate in the benefits.
12. We assumed that the third party advice component was sufficient for personal empowerment in the area of consumerism.

This issue is similar to the payment approval issue addressed in Assumption #11 but it is much broader in scope, encompassing the areas of empowerment, consumer responsibilities, satisfaction and conflict resolution. From the outset we anticipated that persons with significant physical disabilities and their families would find it challenging to shift from a “client” role to that of a customer with money to spend. We assumed that providers would likely return to a traditional service provider relationship and that participants would need support from a third-party source to deal with these challenges. In addition to the information, options and opinion we expected from Employment Advisors, we also felt that they could run interference for participants when conflicts arose. Along with support from project staff, we were confident that the advisor role would be fully sufficient to address any “customer” problems that might arise.

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

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

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

13. We made the assumption that persons remote from project sites could get
the supports they needed from a volunteer support circle and from paid
advisors.

During the last year of the project, RSA gave us permission to extend the scope
of our project from geographic areas surrounding our three project cities to a
nationwide scope. We proposed to include thirty participants in areas remote
from our project site. This status meant that there would not be a Site
Coordinator to assist those individuals with the supports that were available to
other participants. We did assign a project level staff person to assist remote
participants by phone, fax and e-mail, but this was not a local support. To
remedy this, we required that each application we received from persons wishing
to become a remote participant contain a local, volunteer support circle that
would ideally provide the supports not available from a site coordinator.
All remote applicants were able to identify a support circle as a part of their
application. However, the composition of the groups varied widely. Some
participants chose family, close friends and volunteer professionals while others
primarily selected service providers. Overall, we found that the support circles
did not function as anticipated, as an effective advocacy and support function.
Rather, strong individuals within the support groups -- typically one person from
each circle -- emerged as the key to success. These roles were filled by
participants themselves, parents, close friends, local professionals not
connected with the individual and staff persons from a service agency
associated with the applicant. The most common and effective leaders were
parents who took the responsibility to make things happen. Also effective were
local professionals not connected to the applicant. These were persons who
had some degree of control of their time and had a relationship and vested
interest, though not a responsibility, to help the applicant become employed.
The least effective leader was a staff person connected to an agency that
currently or formerly provided services to the participant. These persons found it
difficult to advocate for participants over the needs of the agency and they also
had problems in following through with commitments.

In retrospect, we would still encourage the development of a support group, but
we would stress the importance of identifying and recruiting a strong lead person
to direct the process.

14. We felt that self-employment was of minor importance and would likely
lead to isolation of participants.

Prior to the early '90's self-employment was rarely an outcome of supported
employment services for persons with significant disabilities. Prior to that time,
self-employment was largely characterized by either retail businesses developed as a result of governmentally mandated set-asides for persons with milder impact of disability in their lives or in telemarketing of household goods by persons with more significant disabilities. UCPA had avoided encouraging self-employment due to a variety of reasons:

a) We feared that most self-employment business would be at home, isolating participants from integrated interactions with regular co-workers.

b) We were concerned that traditional providers knew little about the strategies and skills needed to start a new business.

c) We felt that the choice and direction of self-employment would likely come from some service provider’s desire to own a business rather than the participant’s passion to become an entrepreneur.

d) We had heard that the vast majority of new small businesses failed within a year or so of their inception.

For these reasons, the UCPA Choice Access project did not anticipate that self-employment needed to be included as a possible outcome for participants. However, as the project unfolded and as other projects, particularly the one managed by Vermont’s state VR agency, began to share their outcomes, we came to realize that we needed to reconsider our assumptions. Input, experiences, and research by other choice projects indicated that a number of our fears were unfounded. For instance, we found that it was a myth that most new businesses failed in their initial year. In fact, adjusting for business being sold, voluntary closures, retirements and other similar factors, the failure rate of new business over a five year period is no worse than that associated with supported employment retention rates. We also acknowledged that all self-owned businesses would not be isolated. In fact, business employees and customers can offer the same opportunities for integration as co-workers and supervisors.

But perhaps the most compelling reason to embrace self-employment as an option for participants was that, as participants repeatedly said, “It's my choice, it’s what I want to do.” If we were to truly offer choices to participants, we simply had to extend not only the opportunity but the encouragement for anyone who desired that outcome to be able to pursue it. Overall, 21% of participants (29 of 134) who became employed chose self-employment in our project.

15. We thought that existing service agencies would be a key factor in the success of project participants.

As we designed the proposal for Choice Access, we surveyed the existing local providers in close geographic proximity to each site. Our assumption was that those traditional providers would comprise the most utilized resource from which
participants would purchase services. In a survey of local service providers that offered supported employment to persons with significant physical disabilities we found a total of 28 agencies among the three sites -- 11 in New Orleans, 9 in Detroit and 8 in Pittsburgh.

However, by the end of the first project year only 19 of those agencies had applied to be providers -- 7 in New Orleans and 6 each in Detroit and Pittsburgh -- and few were being chosen by participants. Our initial response was to re-double our efforts in recruiting agency providers and in assisting them to make themselves available to prospective participants. However, agency providers seemed reluctant to enter into contracts with participants, especially in the critical area of job development.

This unanticipated circumstance created a need for us to recruit, encourage and incubate new, smaller and non-traditional providers. We began this effort early in Year II of the project and continued our recruitment throughout the course of the project. By the fifth year of project services, the number of active agency providers had decreased to 15 while the number of non-traditional providers had grown to 64 -- 24 in New Orleans, 19 in Pittsburgh and 21 in Detroit. Without these new providers, the outcomes of our project would have been considerably reduced. By the project’s end, 14% (9 of 64) of the non-traditional providers had started employment agencies and were offering services beyond the scope of the Choice Access Project.

16. We assumed that a volunteer, citizen committee could make effective decisions about enrollment, budget revisions and conflicts for participants.

As we looked at the procedures that had been traditionally used to offer persons with disabilities access to scarce, public services, we noticed that people were selected either by proving their competence through evaluations, by being the “next in line”, by becoming a squeaky wheel or by knowing someone in power. Since we knew that the opportunity to get access to a personal budget worth nearly $10,000 was likely to attract more persons than our small demonstration project could accept, we needed a process for selection that had integrity and that was as fair as possible. Our solution was to recruit and impanel a volunteer citizen committee comprised of local stakeholders described earlier in this report (see page 6).

We not only discovered that the three Local Referral Committees representing each of our three project sites performed their responsibilities in an effective and efficient manner, they also willingly expanded their duties to include resolving local conflicts between provider, advisors and participants as well as considering, revising and/or approving budget revisions and participant re-applications. Each committee consisted of an average of seven members and,
remarkably, stayed together with less than 10% turnover across the entire 6 years of project services.

17. **We hoped that families would work to support participants in their quest to become employed.**

We began Choice Access with an assumption that, if people controlled their resources, families and informal supporters would feel empowered to assist participants to become employed rather than depending on agencies to do the job for them. The entire process used by UCPA was one that welcomed families and friends into the process. The discovery component of the Vocational Profile started at the participant’s home and values the perspectives of family, neighbors and friends rather than arbitrary performance on tests and evaluations. The Profile Planning Meetings were held only if more people not paid to attend could come than those paid to attend. The blueprint for job development was developed through input from family and supporters and provided a clear indication as to whether the job developer found an appropriate job for the applicant.

As the project unfolded, we found that family and non-paid support was perhaps the most critical variable for success. Families routinely took the lead in making calls for persons who found communication difficult, they provided transportation assistance to meetings, interviews and, in some cases, to work, and, in about 10% of the total cases, family members became advisors to participants.

18. **We felt that the purchase of technology and academic training was best considered in relation to a specific job as opposed to a generally perceived need.**

The relationship between assistive technology, academic training and employment opportunities for persons with significant physical disabilities has been discussed for years. For years there has also been a “chicken and the egg” argument concerning which comes first -- is it necessary to have technology or education prior to the onset of employment, to make employment possible, or is it necessary to have a job in order to identify the technology or schooling needed to perform the specific job they have obtained? In the area of technology, it depends on what the technology is to be used for. Some technology such as power wheelchairs, scooters, and augmentative communication devices relate to general needs for participants and can be purchased prior to employment. Other purchases such as specially designed desks, reachers, computers, and speciality software are probably best purchased after a specific job has been developed. A similar case can be made for academic preparation.

Complicating factors to this issue are that technology and schooling are expensive, often costing $10,000 to $20,000, and funds for employment, such as
those available from VR, are to be used in conjunction with employment, not in a
general life manner. In a number of years of discussions with persons with
significant physical disabilities, we found a troubling syndrome relating to the
relationship of participants, VR counselors and access to technology and
secondary academic opportunities. VR counselors have recognized for decades
that assisting persons with the most significant physical disabilities is a
challenge. This challenge often resulted in a lengthy, sometimes open-ended,
period of time for persons to become employed. However, over time, those
participants continued their advocacy to become employed and typically wanted
something tangible from counselors. It was not unusual for counselors,
confronted by lack of an employment outcome and by continual advocacy by the
participant, to offer to purchase either the technology desired by the participant
or secondary education services or both. Service agencies such as UCPA
would often encounter angry young adults with significant physical disabilities
who had first rate mobility and communication technology or a college degree
(sometimes an advanced degree) or a combination of both, and yet remained
unemployed.

Our decision in Choice Access was to limit technology equipment purchases and
academic preparation to the specific needs of an actual job. If a job required a
non-speaking applicant to communicate with customers, an augmentative
communication device would be approved. If a manual wheelchair user needed
a power chair or scooter to deliver products within a large company, that device
could be purchased. If an employer required that an applicant be proficient in a
data base software program, the tuition for the course could be approved. If a
participant needed mobility or
communication technology for general life purposes, assistance was provided to
seek funding from Medicaid, local charities or other sources.

This decision was sustained for most the project’s life. However, in the last year
of the project and in the extension year, we began to consider some flexibility in
each area. We still feel that both technology and academics are best
considered in relation to a specific job, choice based services require a careful
consideration of the gatekeeping decisions that might restrict access to
participants.

V - LESSONS LEARNED, STORIES FROM CHOICE

This section features vignettes describing choice participants and staff of the
Choice Access Project. UCPA asked project staff, advisors and participants to
submit stories about their experiences in the project.
A Site Coordinator’s Experience
(This vignette was written by Paul Landry, the Site Coordinator for the Detroit site for Years IV, V and the extension year. As a professional with cerebral palsy, Mr. Landry offers a critique of three critical roles within the project, participants, advisors and the site coordinator.)

Participants

For the participants, the employment process used in the project was successful in that it actively involved them in letting them participate in a very individualized process. By doing this, the participant was able to shine, to show their abilities and to affirm what they did in everyday life. During the process with the Person Centered Planning, Vocational Profile and Vocational Profile Meeting, participants were actively involved and felt very empowered. The hardest time in the process was the job development stage that kept participants waiting far too long. The job development stage was difficult because participants did not feel that they were as much in control. Providers seemed to feel that they need not meet with the participant until a job was developed. Provider’s acted as if meeting and reporting to the participant on what they had been doing was a waste of time and that time would better be spent going out looking for jobs.

Participants within the project were given a voucher or budget and could apply for additional funds if they had further needs in order to maintain employment. The use of the funds had to be for an employment outcome and the participant had to be actively involved with the process. At times I felt at times that participants did not take the ownership of the having the funds and just saw that their budget as money available to them. One strategy that I wished I had tried earlier was to send participants a monthly or quarterly report of their funds spent and fund's that were still available. A strategy that seem to begin to work was providing participants with a timeline to indicate the process is moving. This could of been more productive if a “funds report” were attached. One thing that we needed to accomplish for participants was for them to have more ownership with how their funds were spent and to feel that the services they approved must worth the funds that were expended.

Even though funds were made available through the grant, participants still had problems. Due to governmental supports available to individuals who were in the project, they did not see a loss when things did not go well. They did not take problems as a personal loss. People saw their traditional programs as something that they could always go back to, or maybe to a different program, but they felt the system would always support them. I felt that participants needed to know that they should take the support as a foundation. Then they could build upon that support with a commitment to succeed. Simply stated, for participants to take on the responsibility of being successful themselves, instead of relying upon the system when things did not go well for them. Too often,
people wanted to blame the system instead of taking charge and ownership of their own situations. We all need support but we also need to take ownership in making our own decisions from the support that is provided.

Advisors

Some of the best advisors that provided service within project came from the disability community. They were people who understood the system and who were willing to help change to the system to an outcome-based choice model. Good employment advisors seemed to be able to assist the individual throughout the project and yet maintain a neutral position during the individual’s choices and decision-making. Through the process, we saw that it was typically better to hire the employment advisor before the participant’s Person Centered Planning meeting. In that way the advisor could be acquainted with the individual’s support needs. At the end of the project, we began to have the participant and the employment advisor develop a timeline to assist in moving the process along and to see the progress that had been made. The timeline also helped the participants to put parameters on how they wanted their services delivered. Additionally, the timelines helped the coordinator to better facilitate the process with the participant’s input and support needs.

Site Coordinator

In this project, the site coordinator’s role could be looked upon much like that of a local VR counselor, except that the coordinator played more of a role as a facilitator who maintained the participant’s budgets and their contracts. The difficult part of the position, was to negotiate contracts when participants had never been in the position of buying services or knowing the going rates for employment services. One problem that we still struggle with is allowing individuals to only buy items such as a computer or taking computer classes in relation to a specific job. The project did not want to become merely a way for participants to get equipment, but to have the equipment tie into a related employment outcome.

As a coordinator, I often had to work on daily basics with advisors to facilitate the process and to insure that the participant directed the process. At times, I would have to be involved with providers in negotiating contracts with the participant.

Employment Dream Comes True for Choice Participant

(This vignette was written by Adrian Couvillion, the Site Coordinator for the New Orleans site for the entire five years of the choice demonstration project and he was retained by a number of participants to assist them in their extension year. Mr. Couvillion brought to the project the unique perspective of having a significant life impact of cerebral palsy, in addition to his professional skills.)
Wallace Norcross came to our program in Year three. His family and friends thought, that because of his severe disability, Wallace could never become employed. Wallace’s mother came with him to our initial meeting and said that she just couldn't see how could ever get a job. After talking with her, she reluctantly agreed to let us look for a job for Wallace. After his profile meeting and many weeks of waiting during job development, Mr. Norcross accepted a job at a local K-Mart Store. He was hired as a security guard to discretely watch the shoppers. His job began during the Christmas season. Wallace was so intent on doing a good job that he would sometimes stay too close to the shoppers and they would report him to the manager. Because of the customers reporting Wallace, at the end of the holiday season he was laid off. We then went to work on identifying a new job for Mr. Norcross, this time one that made more sense and in an occupation more suited to his preferences.

During a Profile update, we discovered that Wallace was an avid baseball fan. His job development provider was able to get an interview for Wallace with our local baseball team, the New Orleans Zephyrs. After several meetings with the Zephyr’s personnel staff, we were able to secure a job for Mr. Norcross. He was hired as an usher and promotions clerk, giving out gifts as the fans enter the stadium. He was fortunate enough to be working for the team they year they won the minor league's World Series! We consider this placement to be one of the best we made in the entire project. Wallace truly enjoys going to work and his co-workers enjoy working with him. He talks with the players, knows all the staff and has made many friends with the fans going to the games. Finally, the choice project was been able to help Mr. Norcross secure a new motorized wheel chair lift to help him get in and out of his home and to guarantee access to the community. Wallace’s mother always thanks me for getting him the job. She called me the first day that they had put in the wheel chair lift at his home.

**Stephen's Hager's Business**

(This vignette was written by Ellen Condon, from the Rural Institute in Missoula, MT, who was also Stephen’s advisor)

When Stephen Hager first applied for United Cerebral Palsy Choice Access project funds he was 18 years old, still attending high school and living at home. Through the special education program at his high school he had been on several visits to employers, and he had done some in-school jobs such as collecting attendance, shelving books in the library and helping with lunch preparation in the cafeterias. He participated in different ways depending on the activity. He had no formal community job training or work experience nor had his team entertained the idea of community employment as an outcome for transition from high school.

Stephen’s parents arranged volunteer work for him at the local Humane Society walking dogs with support and spending time with the cats. They insured that he
was very involved as a member of his community, volunteering at the local art festival, attending summer camp, and participating in his churches youth group. Stephen's family always believed that he had lots to offer his local community and could be a contributing member. They thought that Supported Employment was a great idea but they weren't sure how to turn Stephen's gifts into marketable skills for an employer.

After Stephen and his family had begun the application process to United Cerebral Palsy's Choice Access Project, they were also informed that Stephen had received a funding slot with the local Developmental Disabilities Agency, REACH Inc., for residential and day program service. Stephen moved into a group home with five other people and began receiving day program services at the sheltered workshop. When they family learned that they had access to the choice project funds they chose to use them to augment what the local developmental disability provider was offering. They contracted with a staff person from the agency to complete Stephen's Vocational Profile.

Through the Vocational Profile process, Stephen's team discovered that he loves noisy, active environments with lots of opportunity for interaction. He is personable, loves to laugh, he attracts people and he loves to have fun. We found that Stephen needs support with all activities of daily living. He uses a wheelchair, standing table, and a walk-about for support in mobility. The team did express the desire to get more information about assistive technology to enable Stephen to communicate with customers in his job and to increase his opportunities to participate in job activities. The team traveled to Montech, the University of Montana’s Rural Institute’s assistive technology lab, where they received information and ideas about several switches and augmentative communication devices which Stephen could use on the job. They also had the opportunity to gather lots of information about how best to position Stephen to maximize his control of switches and other technology.

During the Profile meeting Stephen's team decided that self-employment would best meet Stephen's "characteristics of an ideal job". The first idea they broached was selling Peace Frogs Products from a cart. After some research the family decided to continue exploring alternative ideas. The second idea on the prospecting list was creating a business partnership with a local artist with whom Stephen and his family already had a relationship. This turned out to be the ideal partnership and job match.

Stephen has now formed Stephen Hager Enterprises, a collaborative venture with a local water colorist, Jerolyn Dirks. Together they create watercolor images that are printed onto note cards. Stephen creates the background layout by pressing and pounding pigments on paper which leaves softly mottled patterns. "These fluid, spontaneous shapes spark more discoveries and creative detours
than any of the planned paintings I do," says Dirks. Jerolyn had the idea that Stephen's energy and active, animated movement could be used to create art. She has him listen to upbeat jazz music which is his favorite as he creates patterns on water color paper. He uses a special table which enables him to stand while he works. Several of Stephen's creations went into Dirk's Rock climber picture which was this year's Special Olympics Logo. Currently the team has a series of four floral print cards and are planning ahead for the next series.

Stephen and Jerolyn's work was displayed at the Empire Federal Savings and Loan in Bozeman, MT, and Dirks displayed the works at the International Licensing show in New York where she was pursuing having their images made into mugs, magnets, and tee-shirts. During the summer months of 1999, Stephen sold his cards at the Farmers market in Belgrade, MT. It was a great opportunity for him to meet people and market his cards. He uses his Voicepal communication device to greet people. The cards are available for purchase at several businesses around Belgrade and Bozeman.

Stephen participates in all facets of his business. He participates as much as possible in most meetings with business managers. Stephen has his own business account where he uses a hand stamp to endorse his checks. REACH Incorporated staff assist him to check his voice mail, Web site and e-mail daily to gather new orders for cards. Stephen folds some of his cards with assistance of an adapted jig and his younger sisters assist him with the packaging when he gets backlogged with orders. His parents oversee the business and financial management issues and REACH staff assist him with the overall day to day management duties and marketing.

Stephen's parents Terri and Vic feel that things are going very well. Terri stated that "I helped Stephen take control of the year from the development of the Vocational Profile through the job development phase and then to the business start up phase. Again Stephen has raised the eyebrows of many of those who learn of his business and who have watched it develop over the months. The response has been positive. I see the note cards as a beautiful, artistic product. This process has allowed us to really look at Stephen's strengths, abilities, and contributions. We couldn't be more proud as his parents!" This is particularly poignant since nineteen years ago Stephen's family was advised to institutionalize him.

Packages of 8 cards are priced at $15.00 and are available through Hager Enterprises, P. O. Box 4430, Bozeman, MT 59772.

Choice and Natural Supports -- Karen Appleaum's Story
(This vignette was written by Susan Linders, Choice Coordinator for the Pittsburgh site for Years 2 - 5 and the extension year. Ms. Linders is an
Karen joined the Choice Access project in 1994, during the initial year of project services. She had sustained a traumatic head injury as a result of an accident and she lives in a supported living arrangement in Pittsburgh. As a young adult with a significant disability, Karen had gained a reputation of being either unreasonable or unrealistic in relation to her employment goals. Many in the system felt that she was simply unemployable. When the project began, Karen hired a local service agency to assist her to become employed, then she later fired the agency because she felt that they did not produce results in a reasonable time. This did not help enhance her reputation among local service providers.

After a period of waiting and interviewing various potential providers, Karen settled on a small, independent provider who had gone into business in response to the choice project. The new provider looked at the efforts that had been made by the traditional agency and a unique arrangement was made for job development. Since Karen had previously turned down numerous jobs that had been offered, there was fear on the part of the new job developer that there might never be a realistic chance for being paid. With our assistance at the project, Karen and her provider negotiated an individualized job development in which the provider charged her $10 for each employer contact identified in the Profile Planning Meeting and $5 for each follow-up contact. If a job was accepted, the balance of the traditional fee of $2,000 would then be paid.

The job developer contacted numerous employers and presented Karen with a number of job possibilities felt to be consistent with her ideal job characteristics. Karen declined every opportunity presented to her. Instead of becoming discouraged, her provider called a second Profile Planning Meeting to address Karen’s concerns and her reasons for rejecting the job possibilities that had been presented. During that meeting, it was suggested that Karen’s resistance was due to fear of the unknown and to negative experiences with prior service providers. Karen agreed that fear might be the reason and stated that, all along, she really wanted to work with her father who owns a small supply business. Since her father was present, the Profile Planning Meeting turned into a job development negotiation. Karen’s father stated that he had been unsure whether there would be a conflict of interest using support funds in a family business, whether it was really best for Karen to work there and whether they could work together as supervisor and employee.

After a lengthy discussion, Karen’s father agreed to carve out an administrative assistant position for her. They first set clear workplace rules and expectations which Karen agreed to follow. Her work responsibilities include entering
accounts receivable and payable information into a database, updating
transactions, filing invoices, creating mailing lists and tax reporting.
Karen and her job developer determined that she would accept job site supports
more readily from an existing employee in the business than from a service
agency. With permission from Karen’s father, the job developer approached an
employee with whom Karen had a previous relationship and a $2.00 per hour
incentive raise was offered using choice funds. The employee readily accepted
and a support contract was written between Karen and her co-worker for a
discrete period of time in the first several months of employment.

Karen purchased a computer from her choice account and she wanted to start
slowly, one day at a time for five hours per day. When the project ended she
was working three days per week and planning to increase her hours soon. In
the time since Karen joined the family business, there have been noticeable
changes. Her father says that he and his daughter have a different, better
relationship -- from dependent adult child with a disability to a contributing
member of the family business. Karen is now a voting member of the business,
along with other family members.

Linda Miller’s bumpy road to employment
(This vignette was written by Barbara Cardinal, Associate Executive Director of
UCP of Detroit. Ms. Cardinal provided local site management of the Choice
Access site in Detroit throughout the entire life of the project.)

Lynda became a participant in the Detroit site of the Choice Access project
during the second year. At the time her of selection in the project, she attended
a POHI (Physical and Other Health Impaired) program in the local school district.
It is important to realize that, in Michigan, students in special education
programs stay in school until they are 26 years old. Linda exited the school in
1997. She had never had any community employment or vocational
programming during her school years. Lynda has a significant impact of
physically disability. Upon entry into the project, Lynda had just received a new
power wheelchair and a computer that assisted her in communicating with
others. With her new adaptive equipment Lynda could now focus on improving
her mobility and communication.

Lynda’s main supports are provided by her parents. They are very proud of her
and what she has accomplished. Her sisters and brother, as well as friends and
teachers also support Lynda. Everyone understood that getting a job was very
important to Lynda. Lynda supervises and monitors her younger nieces and
nephews. She is always willing to help others in any way she can. She creates
formats and designs projects for her family, friends and her teacher. The
discovery process indicated that she wanted to work in the computer field and
maybe expand to other interests such as fashions, art and design. Lynda has
always shown a flair with the clothes she wears.. Her parents had visioned
Lynda running her own computer company. However, they were willing to support her in whatever employment or career she chooses.

During her first year with the Choice Access Project, Lynda gave a presentation to the Statewide Community Mental Health Board Members, with assistance from the Choice Access Coordinator. Clearly Lynda was the star of the presentation. Using her new computer she spoke to the whole group regarding her dreams for employment. Her parents were very proud of her and the Board Members saw a living example of choice.

Lynda hired a Service Provider to do the Vocational Profile and facilitate the Vocational Profile meeting. A critically important thing that we learned over the past six years was the importance of the discovery process. Profiles that were done incorrectly or done in haste would not yield necessary information. One of the problems that plagued some of the customers was finding willing and responsive service providers. Lynda, like several others, chose to fire her first provider and hire one who would be consistent and who would produce a finished product that satisfied Lynda.

Lynda finally was able to hire a Job Developer who began looking for a job that met Lynda’s preferences, contributions and conditions. A job was carved out at the Traveling Book Worm, a local book store. The core routines consisted of entering data into the computer and designing flyers and brochures. Lynda could work at her own pace. The quality of her work was important as well as accuracy. The employer oversaw her training as with the training of all new employees. Her co-workers were willing to help Lynda learn her job. This was the very job that Lynda wanted. It was in a quiet, supportive environment. She would be working with computers and designing flyer and brochures.

Lynda began working at the bookstore in August of 1997. With assistance of the Job Facilitation and her employer Lynda was successful in learning the job. However, the job was not without problems and barriers. Transportation was a big problem. She often had difficulty getting to the job site. She tired easily and it was difficult for her to get projects done in a timely manner. This did not keep her from doing the job. It only made things difficult and frustrating. I believe this is one of many reasons why so few people with disabilities are employed.

Lynda worked at the Traveling Book Worm until the bookstore went out of business during the last months of the project. With the closing of the store, Lynda was once again unemployed. By quickly accessing Choice funds, Lynda began to investigate other options. She hired a new service provider who was proficient in writing business plans for people who want to start their own business. Lynda and her family met with the service provider and they began to explore the options of Lynda working at home. Working from her home would

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228-205-4586; fax 228-205-4597; www.marcgold.com
allow for breaks when she became fatigued. This was also consistent with the original dreams of her parents.

Her service provider began researching a new business in the arena of designing brochures, cards, flyer, etc. She ascertained that there was a need for personalized name tags and stickers for taverns, the purpose was to choose a designed driver. An assessment was done on the computer equipment that Lynda was using at that time. The result of the assessment was the Lynda would need to update her equipment in order for her business to be successful.

As the project ended, her new business was just emerging. Therefore her business plans had to be put on a fast track. A Business Development Plan was completed for a home based computer graphics and database service. The target audience for the business is to other neighborhood businesses as well as neighbors, friends and family.

Lynda solicits businesses by using her computer and she provides the following products and services:

- Personal mailing lists
- Labels for cards and invitations
- Flyers and sales announcements
- Greeting cards and invitations
- Personalized party favors such as: labels for candy, buttons, etc.

Lynda’s mother assists with pick-up and delivery. The family provides space for her business. They also assist with utilities, budgeting, invoices and taxes. Both of Lynda’s sisters use their business contacts for marketing and business ideas. She is currently contacting the Michigan Department of Career Development Small Business Development Centers, as they specialize in business owners with disabilities. They can assist her in learning techniques such as: marketing and pricing.

Lynda bought the needed computer equipment and had it installed. Initial training was purchased to increase her knowledge of the computer. The training also helped her with accuracy. Further training will be necessary. The service provider was willing to continue to work with Lynda on honing her computer skills.

In the very beginning of the process the parents had talked about Lynda having a home based business. We learned from Lynda that the discovery process offers many avenues to explore. Starting a business never entered the picture until the last year of the project. We do not discount the job that Lynda had prior to her home based business, it provided valuable information for Lynda. It assisted her in making a decision and commitment to owning her own business.
It is not easy to start one’s own business and Lynda is certainly taking a risk. However, she is undaunted and is going forward with her business plans.

Through all the entire process Lynda had the same Employment Advisor. This allowed Lynda to have consistent contact with one person who knew the services she wanted and who would assist her in following through with her dreams.
VI - PROJECT DATA

This section deals with the outcome data collected on choice participants throughout the course of the project. UCPA contracted with Virginia Commonwealth University’s RRTC to collect employment data on participants and our project’s voucher accountant also maintained financial data.

A. **Demographic data of project participants**

Our proposal to RSA indicated a target for our project of 225 participants. Over the course of the project we actually provided services -- persons who at least had a profile and plan developed -- to 220 persons. Additionally, we had another 40 persons who were accepted for the project but dropped out prior to receiving any services. For purposes of this report, only those participants who actually received services and used budgets are considered -- 221 participants.

**Age at intake:** \( N = 221 \)

\[ \text{Mean}=34.1 \text{ years}, \ SD=11.2 \]

The age of those in self-employment was higher \( 37.0 \text{ years} \) (\( N = 29 \))

The age of those employed in regular employment \( 33.42 \text{ years} \) (\( N = 105 \))

The age of those who did not become employed \( 33.37 \text{ years} \) (\( N = 87 \))

**Sex of Participants:**

- Employed:(\( N=137 \)) Female 40.74% Male 59.26%
- Not Employed:(\( N=84 \)) Female 60.94% Male 39.06%

**Race of Participants:**

- Employed:(\( N=137 \)) Afr.-American 34.81% White 59.26%
  Other 5.93%
- Non-Employed:(\( N=84 \)) Afr.-American 27.42% White 70.97%
  Other 1.61%

**Marital status:** \( N = 221 \)

- 97.2% Single
- 2.8% Married

**Primary disability:** \( N = 221 \)

- 73.7% Cerebral palsy
- 2.1% Spina bifida
- 1.1% Spinal curvatures
- 1.1% Post-polio
- 3.2% Muscular dystrophy
- 5.3% Head injury
6.3% Health impairment
7.4% Other physical impairment

Secondary disability:
9.1% Additional physical impairment
30.2% Mental retardation
3.7% Mental illness
5.5% Sensory impairment
5.5% Health impairment
12.8% Other

Percent of participants with significant/severe disability:
98% Significant/severe disability
2% Milder disabilities

B. Employment characteristics of participants who were employed

Employment status of project participants: N = 221
60.6% Employed during project N = 134
21.0% Self-employed of those who gained employment (29 of 134)
39.4% Did not achieve employment (87 of 221)

Average/range of funds spent by participants:
$8,360 (Range $1,750 - $15,821) Participants in regular jobs
(N = 105)
$8,660 (Range $2,525 - $21,277) Participants in self-employment
(N = 29)
$1,146 (Range $500 - $6,000) Participants not employed
(N = 87)

Average length of time in project before job was developed
12.8 months (range 1 month to 57 months) from application to the
time the job began

Average length of time in job development
2.41 months (range 2 days to 24 months) from the time the job
development contract was signed. (N = 134)

Average wages of participants who were employed (on first day of work)
$5.09 (range: $4.25 hr. -- 12.00 hr.)

Average number of hours of participants who were employed (during first
week of work)
19.69 hours (range: 4 hours/week -- 40 hours/week)
Average length of time to closure
Participants who became employed in regular jobs (N=134)  31.33 months
Participants who did not become employed (N=87)  22.14 months
Overall participants (N=221)     28.06 months

C. Descriptions of participants from completed profiles (taken from a sample of 103 profiles)

Current residential situation:  
46.8% Lives in home of parent(s) or other family member(s)  
4.6% Home/condo owner  
25.7% Rents house, apartment, condo  
0.0% Transitional living center  
21.1% Group home, boarding home  
0.0% Nursing home  
1.0% Public housing unit  
0.0% Homeless  
1.0% Other

Family support available:  
13.8% Did not appear to be available  
20.2% Available but limited  
66.1% Appeared available and adequate

Friends and social groups:  
6.4% No close friends or social contacts  
49.5% Few close friends  
44.0% Many friends and social contacts

Neighborhood of residence:  
12.5% Poor  
41.3% Urban  
79.8% Middle class  
52.9% Suburban  
7.7% Upper class  
5.8% Rural

Transportation availability:  
67.6% Public transportation  
29.4% Transportation by parents or other family members  
68.6% Transportation by other sources

Education history:  
33.3% Did not complete high school  
20.4% Completed non-degreed special education program  
31.5% Completed high school or equivalency
8.3% Completed vocational/technical program or associate degree
6.5% Completed bachelor's degree
0.0% Completed master's degree or beyond

School Integration opportunities:
58.5% Regular school
41.5% Special school

Classroom integration opportunities:
30.9% Regular education classes only
19.1% Resource and regular education
50.0% Self-contained special education

Vocational program in school:
46.5% Yes
53.5% No

Community training in school:
39.2% Yes
60.8% No

Recreation/leisure training in school:
52.6% Yes
47.4% No

Percent with work experience:
90.8% Informal work performed at home
67.9% Formal chores performed at home
62.4% Informal jobs performed for others
42.6% Sheltered workshop
44.0% Previous paid competitive work

Potential employers in family:
79.8% None
16.5% Some, willingness not confirmed
3.7% Some, willingness confirmed

Potential employers among friends:
82.6% None
12.8% Some, willingness not confirmed
4.6% Some, willingness confirmed
Potential need for accessibility assistance, technology, etc.:
- 42.2% Few or none
- 47.7% Some
- 10.1% Many

Physical, health restrictions:
- 6.5% Strict limitations
- 56.5% Some limitations
- 3.0% Negligible

Behavioral challenges:
- 7.4% Serious
- 56.5% Some
- 37.0% Few

Negotiations required with employers:
- 13.0% Significant
- 48.1% Moderate
- 38.9% Minimal

D: Choice and Satisfaction

The following questions were asked each time a participant chose a provider or advisor: Participants were assisted by family members, advisors, staff or friends, as appropriate, to respond to the questions.

1. “I feel that I made an informed choice to select the provider identified in the attached contract.”

<table>
<thead>
<tr>
<th>Response</th>
<th>Un-employed</th>
<th>Reg. Employed</th>
<th>Self-Employed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes, definitely</td>
<td>95%</td>
<td>91%</td>
<td>83%</td>
</tr>
<tr>
<td>Yes, somewhat</td>
<td>5%</td>
<td>9%</td>
<td>16%</td>
</tr>
<tr>
<td>Not much</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Not at all</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
</tr>
</tbody>
</table>
2. “What influenced your decision to select this provider?”
   (Participants checked more than one category)

<table>
<thead>
<tr>
<th>Reason for decision</th>
<th>Un-employed</th>
<th>Reg. Employed</th>
<th>Self-Employed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reputation in community</td>
<td>33%</td>
<td>39%</td>
<td>36%</td>
</tr>
<tr>
<td>Personal knowledge/experience</td>
<td>44%</td>
<td>61%</td>
<td>45%</td>
</tr>
<tr>
<td>Responsiveness/timeliness</td>
<td>55%</td>
<td>39%</td>
<td>18%</td>
</tr>
<tr>
<td>Cost/price quoted for services</td>
<td>22%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Recommendations by others</td>
<td>44%</td>
<td>27%</td>
<td>73%</td>
</tr>
<tr>
<td>Provider lived close to participant</td>
<td>22%</td>
<td>6%</td>
<td>18%</td>
</tr>
<tr>
<td>Provider had experience working with persons with phy. disabilities</td>
<td>33%</td>
<td>52%</td>
<td>45%</td>
</tr>
</tbody>
</table>

3. “Why didn’t you choose other providers?” (Participants checked more than one)

<table>
<thead>
<tr>
<th>Reason</th>
<th>Un-employed</th>
<th>Reg. Employed</th>
<th>Self-Employed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reputation in Community</td>
<td>0%</td>
<td>0%</td>
<td>25%</td>
</tr>
<tr>
<td>Poor responsiveness</td>
<td>57%</td>
<td>64%</td>
<td>50%</td>
</tr>
<tr>
<td>Poor attitude/lack of respect</td>
<td>29%</td>
<td>14%</td>
<td>0%</td>
</tr>
<tr>
<td>High cost of services</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Lack of employment experience</td>
<td>43%</td>
<td>21%</td>
<td>50%</td>
</tr>
</tbody>
</table>

4. “How satisfied were you with the services that you received?” (From both advisors and providers)

<table>
<thead>
<tr>
<th>Response</th>
<th>Un-Employed</th>
<th>Reg. Employed</th>
<th>Self-Employed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Better than expected</td>
<td>71%</td>
<td>69%</td>
<td>56%</td>
</tr>
<tr>
<td>Fully satisfied</td>
<td>15%</td>
<td>25%</td>
<td>44%</td>
</tr>
<tr>
<td>Minimally satisfied</td>
<td>14%</td>
<td>6%</td>
<td>0%</td>
</tr>
<tr>
<td>Un-Satisfied*</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
</tr>
</tbody>
</table>

* The reason that our data did not indicate any “Unsatisfied” responses is that payments would not be made to providers if the satisfaction data attached to the Request for Payment form indicated that response.
Before submitting such a request, the Site Coordinator would assist the participant and provider through the Conflict Resolution process outlined in the Participant Manual. During the course of the project, we had four (4) conflict resolution procedures.

VII -- PROJECT IMPACT AND CONCLUSIONS

The ultimate impact of this project and the entire demonstration, beyond the importance to the individuals who became employed, will unfold during the coming years. As changes are made to future versions of the Rehab Act, the ADA, SSA initiatives and the Workforce Improvement Act, the knowledge and perspectives gained during this demonstration will undoubtedly be considered. At this point, it seems that the ideas of choice and control of resources by participants will grow rather than wane in the new century. In fact the changes are already occurring. This project has had significant impact on a number of initiatives across the country -- in VR, DD services and in WIA/One Stop career centers. Three examples include:

The Rehabilitation Renaissance Project

This project, begun in 1996 and continuing currently, represents a replication of the Choice Access project by Michigan Rehabilitation Services, the state VR agency in Michigan. Initiated by the state VR director at that time, Joe Skiba, this project has been conducted through a contract with UCP of Detroit. Our local UCP affiliate and VR joined forces to pilot a system implementation of the Choice Access design initially in six VR regions in 1996 and twelve regions currently. This project replaces the Choice Access site coordinator position with a VR counselor and uses almost all the design components of the original project, with minor modifications to suit a state-wide VR system.

The One-Stop to Success Project

This Department of Labor funded initiative (July 1, 1998 - September 30 2001) represents the next step in UCPA’s effort to extend the lessons of Choice Access. We have taken the Choice Access approach, with necessary modifications, into WIA mandated One-Stop Centers in Denver and Detroit. We are recruiting approximately 45 persons with physical disabilities each year to apply to their local One-Stop center to receive assistance and services similar to Choice Access. A critically important difference is that this project allows for participants to individualize their budgets, which are funded through a blended funding strategy that combines VR, DD, DOL, SSA and other funding sources held by the local UCP affiliate as a broker or fiduciary. UCP of Colorado and UCP of Metro Detroit are cooperating with UCPA in this effort.
Clark County Washington’s Developmental Disabilities Services

This is a local effort initiated by a county DD funder to utilize the design of the Choice Access project to address the needs of students with disabilities transitioning from local school districts. Clark County’s plans call for, eventually, the personal budget/choice design will be available to all persons served by the county. At this point the county is negotiating with the regional VR office in hopes of developing a design that will allow both DD and VR services to be used in a personal budget, directed by participants. The county has contracted with a third party entity -- the Washington Initiative on Supported Employment (WISE) - - to provide third party advice, planning assistance and brokerage services. The participant manual and project design strategies used in the Choice Access and One-Stop to Success projects will be modified to meet the needs of this local project.

The final challenge

At this point, we feel that the report on UCPA’s Choice Access Project speaks for itself. However, as the disability field heads into a new era of employment and rehabilitation relationship with persons with disabilities, we wish to assert the following reasons why choice and control of resources is such a critically important issue for all persons with disabilities, especially for persons with the most significant disabilities.

1. **Because it’s what the people want.** Or many of them it seems. There is increasing advocacy by persons with disabilities, families on waiting lists, advocates and even legislators to offer individuals increased choice and control of the resources that society sets aside for service. This trend is indicative of a shift from agency-controlled services to individually-determined services.

2. **Because it’s the law, at least in the Rehab Act.** Since the 1992 and 1998 amendments, the Rehabilitation Act of 1973 requires counselors to develop individual plans for employment that affords “the opportunity to exercise informed choice in selecting an employment outcome (what you want), the specific vocational rehabilitation services (what you need to accomplish what you want) to be provided under the plan, the entity (service provider) that will provide the vocation rehabilitation services and the methods (the way you want it done) used to procure the services...”(emphasis and parentheses added). The Rehab Act represents a clear trend in federal legislation that favors choice and control.

3. **Because it’s the best way out of the “whose choice is it?” conundrum.** As increasing numbers of people have the chance to
become employed in the community, the idea of “choice” is being used by those who wish to stay in institutions, workshops, group homes and other congregate settings as a rationale to continue such programs. Choice and control of resources offer all customers the opportunity to tailor services to meet their needs. Of course if you choose segregation, you would have to find others willing to spend their own share of public resources to pay the price and you couldn’t rely on public funds to underwrite or additionally support such programs.

4. **Because it's the only way to assure that “one size fits all” managed care rates do not predominate access to needed employment services.** The base value of managed care is to save money while ostensibly offering a minimum standard of service. Most managed care systems depend on a capitated rate for payments that is based on the lowest possible amount of money that will, on average, meet the service demands for typical individuals in the system. The human service field is rapidly moving towards such managed care approaches in the area of employment. Since the rates will be set on historical costs for persons traditionally served -- persons with less significant disabilities -- people with the most significant disabilities will be severely under-funded. Choice allows for individually determined budgets that reflect the needs of each person.

5. **Because people make better choices than agencies and employers.** Labor-market and agency-focused perspectives concerning work often do not meet the needs, preferences and “why work” rationales of individuals with disabilities, especially persons with the most significant disabilities. When the employment negotiation is between service agencies and employers, with the outcomes focused solely on labor market and funding considerations, the needs of the individual are often overlooked. In fact when the needs of individuals are left out of the equation, many persons are simply left out of employment because they are not considered able to meet the arbitrary conditions negotiated between agencies and employers.

6. **Because work is becoming a personalized concept for all of us in our society.** As our society and economy change, we are beginning to understand that our life’s work must be more about who we are and what we need and less about the arbitrary shape of job openings. In order for anyone, and especially for persons with disabilities, to personalize a job for themselves, it is first necessary to be able to exercise a degree of choice and control over the resources, the outcomes, the supports and the methods necessary to achieve that tailored job.
7. **Because what we're doing now is not working well enough.** Our traditional agency/system approaches simply are not responding to persons with complex needs. Despite efforts that have been made for the past decade and a half to include persons with significant disabilities, there has been very little success. People with greater skills or less significant disabilities always seem to get available employment opportunities. This is due to a litany of rationales that range from high employer demands, to insufficient preparation, to lack of sufficient funding. It seems likely that if the traditional approach continues in the future, employment opportunities for persons with significant disabilities will remain scarce. However, if these individuals and their families have choice of outcomes, providers and methods and control of resources, they stand a real chance to break through into meaningful employment.

8. **Because choice and control will re-define the relationship between service organizations and persons with disabilities.** For decades, persons with disabilities have been at the distant end of a “trickle down” service system that drained precious resources to pay for arbitrary administrative costs, cast people into a “client” or service recipient role and placed them in any open slot in the labor market. We’ve even adopted “consumer” and “customer” language in an attempt to remedy this problem. True choice and control allows participants to direct their services, to choose providers and to decide whether or not to pay for work performed. This shift is much more representative of the way apartment hunters, car buyers, grocery shoppers -- everyday “monied” customers -- do business. Service agencies will have to embrace the kind of true customer respect, service and satisfaction behaviors of their generic counterparts or they will go out of business.

9. **Because it’s likely to be best way to access and utilize generic services.** As the issues surrounding the impact of disability on life become more accepted as a “natural part of the human experience” (from the preamble to the ADA and the Rehab Act), the role of the generic service and vendor community has increased. Its inevitable. When individuals become a part of a generic culture, setting or organization, they typically want to utilize the same services as everyone else. However, in the disability field, people have found it difficult to gain access generic resources due to the funding relationships held by disability-specific agencies. Choice and control can allow individuals to shop around and select service providers and vendors from the generic community.
10. **Because most Americans believe in choice and control as fundamental ideals -- they represent the ultimate extension of self-determination and independence.** At the heart of our culture is a belief that we should be able to choose and have say-so in the fundamental aspects of our lives -- housing, health care, child care, higher education. Since work is perhaps the most defining characteristic of citizenship, it is necessary to include employment in the list of life activities over which we have choice and control.

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

**Why choice and control?**

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

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

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

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

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

*Because it redefines in a customer-focused manner the rationales for staff and organizations to become certified or qualified.*
The Choice Access project wishes to express its appreciation to the participants and staff of the project office, national office and sites who helped make this effort possible:

Project sites:

**Detroit**

Elmer Cerano, Executive Director, UCP of Metro Detroit  
Barbara Cardinal, Associate Exec. Dir., UCP of Metro Detroit  
Leslynn Angel, Site Coordinator  
Paul Landry, Site Coordinator  
Melinda Mast, Technical Assistance Provider

**Pittsburgh**

Ruth Siegfried, Executive Director, Sharp Visions, Inc.  
Susan Linders, Site Coordinator  
Norciva Shumpert, Technical Assistance Provider

**New Orleans**

Paul Bussell, Executive Director, UCP of Greater New Orleans  
Adrian Couvillion, Site Coordinator  
Brenda Carson, Technical Assistance Provider  
(Thanks to the Jefferson Parish Office for Citizens with Disabilities)

**Remote Sites**

Nancy Batson, Coordinator

**Project Office**

Norciva Shumpert, Project Co-Director  
Sonia Hester, Voucher Accountant  
Leslie Mallette, Administrative Assistant

**National Office**

Michael Morris, Former Executive Director of UCPA (Yrs. 1-5)  
Chris Button, Former Associate Executive Director of UCPA (Yrs. 1-5)  
Jeanette Harvey, Former Executive Director of UCPA (Yrs. 5 - Ext.)  
Karen Flippo, Former Associate Executive Director of UCPA (Yrs 5 - Ext.)  
Kirsten Nyrop, Executive Director of UCPA