

Discovery Is...

A White Paper by

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Discovery is...

- ✓ a process that involves getting to know people before we help them plan;
- ✓ spending time with people, instead of testing or evaluating them, as a means of finding out who they are;
- ✓ the best way to find out the best that people have to offer;
- ✓ enhanced when we get to know people in settings *where they are most who they are*;
- ✓ a way to identify the unique contributions offered by persons who might not compete as well as others;
- ✓ not a plan, but the foundation of all person-centered planning that seeks to customize outcomes for people;
- ✓ compatible with self-determination and choice.

Discovery provides a substitute to comparison-based testing procedures in that already-existing information is utilized rather than information developed through formal assessment methods for purposes of answering the question, “Who is this person?” The information identified during discovery can be captured in a narrative format often referred to as a *profile*. Discovery and the resulting profile are used to guide individuals with meaningful life outcomes such as jobs, community activities, residences and relationships. The process is especially suited for matching an applicant to job possibilities that make sense. The person’s entire life experiences are taken into account, rather than single instances of performance. Discovery begins with a provider representative meeting with the applicant and family at the home of the applicant. These visits, along with other discovery activities, give the individual and family information about their powerful roles in the process and allow the provider to compile basic information that is necessary to begin person-centered planning.

To round out discovery, providers might schedule time to spend with individuals during activities representative of those that comprise the majority of a person’s typical day. Providers might also accompany the person during planned community activities in both familiar and novel settings. This interaction allows the providers to get to know the applicant and to assist in identifying personalized preferences and conditions for employment as well as individual contributions to be offer to employers. A comprehensive form that describes the person in a narrative manner – the *profile* – can then be developed. For adults, the profile is developed only in relation to specific planning needs for events like getting a job or selecting a home. In school, the profile becomes a work in progress during the transition years of the student’s school career passed on from teacher to teacher until graduation. The document, along with other discovery materials such as a *presentation portfolio*, is then passed on to adult employment service personnel to be used as a basis for job development and community supports, as appropriate.

Families and friends, along with staff and advocates, play a critical role in discovery. With permission from the individual, the provider talks with all the people who are important in that person's life. Providers seek to uncover *descriptive rather than evaluative* perspectives. Descriptiveness is also a characteristic of the written profile document. By embracing descriptiveness, providers allow each person's attributes to be recognized and appreciated without comparing people to others or to arbitrary standards of performance and behavior. The entire discovery process, including writing the narrative form, takes approximately 16-24 hours to complete.

Customized, Person-Centered Planning is...

- an activity that follows discovery and is based on the information and findings that result from getting to know each individual;
- owned by the individual, not the provider or the system;
- focused on facilitating discrete outcomes in employment, life activities, housing and educational goals that reflect the unique conditions, preferences and contributions of the individual;
- an opportunity for the individual, not the provider or system, to “hold trumps” in deciding the direction and outcomes of services and supports;
- a process that allows the individual, not the labor market, to direct job development efforts;
- compatible with choice and self-determination.

A customized, person-centered planning meeting is held with the applicant, family, friends, advocates, the provider, VR counselors and others chosen by the applicant. This planning meeting adheres to the values associated with the best of person-directed, person-centered values. The applicant, with support from family or others, as necessary, holds “trumps” during the meeting and decides the direction and outcomes of the plan. For employment, the meeting describes a job development plan in the form of a blueprint that includes:

- * What works and what doesn't work for the individual;
- * The person's preferences, contributions, and conditions for employment;
- * The types of job task the applicant feels should comprise the job,
- * Specific employment sites where a customize job might be developed for the applicant; and
- * Employment leads & relationships with possible employers.

This innovative yet common sense strategy differs from those approaches traditionally used in the disability field in a number of important ways:

- (1) The vocational profile consists of **already-existing information** rather than information developed solely for the purposes of evaluation. Choosing a particular job or other outcome for a person is based on **information obtained from the person's entire life** and not from an instance of performance.
- (2) The profile is used only as a **guide for matching** an individual to an appropriate job or other activity and *must not* be used to exclude a person from opportunities to work or participate in the community.
- (3) The profile seeks to have **ecological validity rather than predictive validity**. It is more important that a match makes sense in relation to a person's life than to attempt to predict success. Predicting measures almost invariably predict failure for persons with severe disabilities.
- (4) The use of the profile **frees the applicant from** the necessity of **taking standardized or norm-referenced tests** to prove their readiness. Readiness to begin work and participate in the community is assumed for all persons.
- (5) The use of a profile indicates a belief that **a person's skills, experiences, available supports, preferences, needs and living situation cannot be best captured on a standardized checklist**. A descriptive, narrative format composed of open-ended categories allows for each person to be described in a unique manner.
- (6) The profile strategy seeks to **welcome, empower and involve applicants, their families and friends** rather than to exclude them. Natural, common sense approaches to employment and live activities are given priority over strategies which rely solely on professional judgment and service.

*Examples of Discovery and Customized
Employment in the lives of persons with significant disabilities
Marci, Everywoman*

Marci is a woman from Ft. Worth, Texas, who experiences the most significant impact of disability in her life. Marci represents almost perfectly an entire group of people in our society for whom the idea of a meaningful life evokes feelings of confusion, complexity and doubt. Even if society were to embrace the notion that Marci should have a life of participation and passion, membership, relevance and the opportunity for contribution, figuring out how to assist her to accomplish all that would still be difficult.

As a child of the “94-142” generation, she had access to educational services in a manner that earlier members of her group never dreamed of. However, the role of schooling in the lives of persons with the most significant disabilities is often as unclear as role of adult services in assisting people with such labels to be active participants in our culture. The implied promise of an effective and inclusive education is that if one goes through it, there should be some clear benefit in relation to adult life as a result. When Marci reached twenty-one, the path ahead seemed to lead only to an adult day center or to her family’s living room. To her parents thinking, this kind of life seemed unfair, boring and unsatisfactory.

While Marci’s parents were confused as to what a meaningful life should look like, they felt she needed to make a contribution to her community and be appreciated for that contribution. Some would say that Marci and persons like her should simply be appreciated, honored and included in society “for whom they are”, without arbitrary or typical expectations. While Marci’s parents certainly agreed with the idea of acceptance for their daughter, they wanted far more. They wanted Marci to experience the daily routines, the variety, the ebb and flow of a typical life. Most particularly they wanted Marci to have a job.

But who was this young woman on the cusp of adulthood? In an effort to have that question answered for purposes of receiving adult services, her family had Marci “evaluated” by a well-known vocational evaluator. The results were devastating. Marci was described as functioning as a seven-month-old infant. If this assessment was accurate and meaningful, it was obviously a stretch to imagine that Marci might work for pay in the community. But her parents felt that this view of Marci -- this comparative, competitive view -- did not have any practical relevance. Instead, with assistance of a handful of supporters who were willing to take a risk, they embraced the idea of *discovery*.

Discovery allowed Marci’s complex life to be explored rather than to be compared to others. And it provided a new way of looking at her disability. Instead of seeing Marci’s life in relation to traditional indicators of success such as skill levels, productivity, independent performance and the like, she could be viewed from the perspective of what works in her life, what moves her to be present, and what kinds of supports might she need to make a contribution. We found that instead of capturing Marci in a two-page assessment report of comparative performance that her complex life could be described in a document the size of a book. Of course, no one wanted to write a book before Marci became employed, so a ten-page descriptive profile was used to capture all the information found in discovery.

Marci doesn't speak and the communication she uses is the most subtle imaginable. Since birth, her mother says that Marci has never shown emotion though facial expression. Her body is often in a state of movement and, occasionally, what appears to be agitation. Her mom says that when the external situation is pleasing and meaningful to Marci, she becomes still, attentive, and present. It provides the clearest way for Marci to express choice and preference. Marci rarely interacts in a physical manner with objects and people, but we learned that she does have some control over her right arm that is less rigid from spasticity than her left. She often moves that arm across the front of her body in a gentle rocking motion from right to left.

The process of discovery was essential to uncover the subtle manner in which Marci expresses her feelings and reacts to the world around her. We were able to determine the environmental conditions that seemed to fit best with Marci as well as those situations and people she seemed to prefer over others. What was missing from the equation was a way for Marci to contribute in a workplace.

In reviewing her school records, it was discovered that teachers had attempted to introduce a saucier- shaped electrical switch to Marci for purposes of turning on a tape recorder for playing music. Marci seems to enjoy the effect of music and this was thought to be a functional task that might lead to other ways for her to control her environment. Hand-over-had assistance was offered to Marci to first turn on, and then turn off, the tape player. However, that task was quickly discontinued due to what was perceived as resistance on Marci's part. After careful consideration and analysis of this activity by a dedicated support person a flaw was discovered. While turning on tape player is undoubtedly a functional task for those of us who love music, turning it off not as functionally motivating. The proposed solution involved using a 20 second telephone answering tape with music that Marci seemed to like. She would be assisted to turn the music on and after twenty seconds the tape would stop and rewind automatically. The next assist would be to turn the music back on.

This single idea, derived through discovery, was the basis for Marci's job using Customized Employment as a *specialty stapler* in the personnel office at the Fort Worth Star Telegram, the daily newspaper for that city. She has been working for over three years in a job in which the hours are set to meet Marci's needs. The switch that Marci turned on, initially, to hear the music she liked, operates the stapler. Within a couple of months, the music was no longer needed. She receives commensurate pay for her work and assistance from a job trainer funded by the Medicaid Waiver program in her state. Since starting work, Marci has routinely made more per hour than her support personnel. During the past year, shredding of personnel documents has been added to her responsibilities. This task utilizes a sheet feeder, which Marci operates with her switch, comprised of an old ink-jet printer Velcro taped to the top of the office's auto- feed shredder.

Marci has been employed for six year at the Star Telegraph. But this job only cracks open the door to the possibility of Marci having a life that approximates the rhythms of those led in her community. Beyond the workplace, she needs assistance to first identify and later participate in activities that connect her to her community. In the summer of 2001, Marci and her family agreed to participate in a self- determination pilot in her county. Through this project, Marci has begun to receive assistance to explore and participate in her community. as they work toward an inclusive lifestyle for Marci.

Michael Callahan

Putting the Puzzle Together for Efrain

Just a few years ago, Efrain, a Hispanic young man with autism and 20 years old, was spending most of his day in a classroom with other students with disabilities in Alice, Texas. Today he is working in a job of his choice. This is the story of how the pieces of a complex puzzle were assembled to offer a clear picture of Efrain to his parents, teachers and employers.

While Efrain had done some work exploration around the school, he was not perceived as someone who would be employable. It was thought that his need for structure could not be found anywhere outside of his classroom or his home. It was predicted that only his teacher or family could support him.

The diagnostician from his school began looking for another way to evaluate students like Efrain. She engaged in a group training that built teams around each student to learn a new way of planning for people with disabilities. The teams included people who would become each student's circle of support. The team that included Efrain and his parents began to gather information about him. They began initially by thinking differently about him by moving away from their traditional "can do" and "cannot do" lists. They focused their energy on discovering those things in Efrain's life that were important to him, like when he smiled and when he was calm. Team members, including his teacher, went to his home to get to know him in his most comfortable settings.

The time spent with him and exploring how he got things done told the team how to support Efrain and how to have others see him at his best. They noticed his careful attention to detail and his ability to recognize when things were out of place. The team discovered that Efrain's free time at home was spent in his room with a VCR, that he operated competently, and as well as with a Nintendo machine, that he played often. He kept each of his videos in a special order and checked these often during the time he was at home to assure they remained in order. When family guests came to his house, he stayed in his room unless certain people that he knew were there. Then he was willing to come out and visit.

When Efrain went into the community with his family or teacher, he was told where he was going. It was discovered that when he is ready to leave a setting, he would start rocking and motioning for the door. By recognizing his rocking as meaningful communication, the team discovered an effective communication tool to begin to help Efrain establish the amount of time he wanted to spend in certain environments.

Later, it was discovered that in places that were quiet, with few people, like bookstores or libraries, Efrain was willing to stay for longer periods of time than in noisy settings. On one of his community activities the teacher assisted Efrain to visit the local bookstore. He stayed in a section where people were calmly sitting and reading. Efrain smiled the entire time, at least an hour. He watched others and sat while others were reading. This indicated that being in small groups or with one or two people made him feel comfortable and calm. He was able to focus on his book.

Since his mother was a vital part of the group, she began to view her son from the viewpoint of Efrain's capacities and preferences. As discovery unfolded, information about Efrain became clearer and more useful. His mother used a picture sequence of several routine tasks to give him directions without telling him every step. The discovery of this effective support has opened many doors for him to gain the independence and the pace needed to do a variety of activities at school and the community.

Additional discovery occurred by being around this young man and observing his daily schedule. It was discovered that he always is dressed in neat khakis and cotton, button-down shirts, unless in the gym with his father. He always stands very erect and looks attentive with a large pleasant smile when he is calm.

People routinely approach him and speak to him and he smiles and remains quiet. Other insights by the team were that Efrain's family and people around him at school – students and teachers -- were very willing to do things with Efrain, as long as they knew what he wanted.

As the discovery process began to be understood, team members eagerly selected things to do with Efrain to learn about him. His mother and father coordinated the team's efforts and assembled a portfolio of pictures of him doing the things he enjoyed. They used this portfolio to introduce others to him, especially the staff who would be seeking employment for him. Later, the portfolio was redesigned so that potential employers could see Efrain as an applicant with something to contribute to businesses.

Discovery was used to direct the first efforts to seek employment for Efrain. His ideal conditions of employment were discovered to be in small working environments, in places where people communicate with gestures or not a lot of words. It was important that Efrain would work where the same people worked every day, non-public area with a small number of people. A good workplace for Efrain to work would be where a manager or coworker would take time to check on what he is doing and to give him information by showing him instead of using words. His work tasks would need to be performed in a consistent routine, changing infrequently.

It was discovered that a major area of interest of Efrain's involves machines. His particular ability to maintain a routine and perform with consistency would be valuable to an employer who wanted tasks done predictably. It was discovered that Efrain is a man with an eye for detail. He makes sure that everything gets done as it should and that nothing gets put in an improper place. Efrain's life painted a clear picture for the team, once they attuned themselves to see him as a person with potential skills and contributions to offer.

The group of people assisting Efrain to plan for employment developed a list of tasks that Efrain could perform and that an employer might need. They then identified a listing of local employers that represented a fit with Efrain's ideal working environment. The team considered the local library for sorting, collecting, and inventorying of books and video tapes. They also looked at a local law firm for tasks such as shredding, copying, or anything involved working with machines or videos. They also talked with the local hospital.

It turned out that Efrain was a perfect match for the neatly dressed, quiet people working in the hospital. They had a need for someone to shred documents. The confidential documents are shredded in a room without other employees, but a few coworkers are nearby and can provide assistance to Efrain during work and breaks. This was an ideal match! Efrain has been at the hospital for over a year. He uses his picture chart to assist him to get in and out of the hospital without someone accompanying him. He has one coworker that he goes to when he needs assistance and to just sit with sometimes.

The team then took what they discovered about Efrain and included him in regular classes throughout the day. They asked a couple of students who knew him to walk to the new classes with him. They identified students who were likely to stay in the local area after they graduated and then facilitated opportunities for them to spend time with Efrain. His parents began planning with those students to assist Efrain to participate in many of the things other young people do in Alice, Texas.

According to his parents, Robert and Elena, “The first phase of the Project, the *discovery phase*, made us see our son, Efrain, through a different set of eyes. What we saw as negative traits turned out to be positive attributes. He was allowed the opportunity to take risks with dignity by being matched to a job he could be successful at.”

Norciva Shumpert

“My son just watches those awful cop shows...” James’ Story

James started school in 1982 at the age of six. He attended a school for students with disabilities. At this time students with disabilities attended a separate school in our city. When I first met James, he was seventeen years old. He was enrolled in my transition class at the Vocational Center of our town’s high school. James was like most typical seventeen-year-old students in that the experience of high school was exciting and terrifying at the same time. He was always a quiet, well-mannered young man who was neatly dressed. James was diagnosed as educationally disabled in the area of autism. He was also eligible for language-speech as a related service. By all outward appearances, he does not appear to be disabled.

James was included in the printing class at the vocational center in addition to my classes. The instructor was very willing to make any type of accommodations that were needed for James. When we started getting ready for job placement in my vocational class, I suggested to James that we should look for a print shop job. James did not say much and was always agreeable with me. So, I talked to the local owner of a print shop, who was willing to have James work there. The department of vocational rehabilitation pays the students’ salaries as an incentive for the employer during their training period. The job at the print shop was not what James and I had expected for him. They would have him empty the trash, sweep, strip negatives and pick up trash.

I talked with a friend about hiring James at his local business. Tab Industries is an industrial equipment sales, service and rental company. The owner agreed to hire James so he left the job at the print shop. His new job was in an office where he put labels on brochures, attached pamphlets to the brochures. Also, he counted out in packs of twenty and banded the brochures together. His employer wrote on one of his evaluation forms that, “James has worked very well here. We appreciate the work that James is doing. He has been a great help.” The owner gave James a bonus check at Christmas along with the other employees. He was very much a part of the company. He worked at this site until the end of the school year. When school started the next school year, the employer was no longer mailing out the brochures. So, I looked for a new job site for James.

At that time in my career, I was merely placing students in job slots that were available in our community. I never asked them about their dreams and tried to match their interest or passion to a job. If I was able to place them in a slot that was available in the community, I felt at this time that I was doing a good job. Most of the agencies that evaluated my students perceived them as “unemployable”.

A job slot was available at our local Burger King Restaurant. James needed a job, and the slot was available, so I placed him at this job site. James interviewed with the employer, picked up his uniform and was asked to be at work the following Monday. Well, something I forgot to tell you, James is never late, and he does not miss school. He stated his job at Burger King. The duties included putting ice in the machine and washing trays in the kitchen. After about a week on the job he started showing up for school late. Then he started missing a day or two each week. I started calling his home and his mother said he did not want to come to school. This was not like James. I started thinking that all of this started around the time he went to work at

Burger King. Well, I decided it was the uniform he was wearing. The pants must be too long or something of this nature. I went over to his house and talked with him about the uniform. He would not tell me if he liked it or not. I was very concerned about James. I called a friend who worked at a center for adults with disabilities in our area. We brainstormed about why he may not want to come to school. At this point I was not sure it was the job. James did not show up for school again, so I called and asked his mother if I could come over and talk with her. My friend and I visited with James and his mother. In our visit, we discovered the job was the reason he no longer wanted to attend school. We also were able to discover more about James in his home setting. We looked at the things he had in his room and on his walls to tell about some of his interests and who he really was. I set up another meeting with James and his family to meet at his home the next week.

At this time my friends at Marc Gold & Associates introduced me to the strategy of *discovery*. For those of you not familiar with this strategy, it is an information gathering process used in place of traditional assessments to assist people with disabilities to identify employment and life needs. I decided to ask James and his family if we could go through this process with him in order to match his interests and skills in acquiring employment for him. We met several times at James's house and I also went out in the community with James. I was learning more about James by being around him in other settings. Attending the profile meeting was James, his parents, brothers and sisters, adult service providers, student teacher, Marc Gold and Associates and me.

At this meeting his parents told us he had always wanted to be a policeman, more to the point they said, "He's always watching those awful cop shows." To his family, this was his life-time dream. He had things in his room that also indicated this choice. At the meeting, we discovered that my student teacher's mother worked in an office next to the Sheriff's department. We then had a connection with the Sheriff of our county. I met with the sheriff and described James to him. We discussed job duties that James had done in the past. In this meeting, we covered James's conditions, preferences and contributions. The sheriff was ready to meet James and have him start work. James began his job in 1994 at the Jackson County Sheriff's Department. His beginning job duties were organizing folders of reports in numerical order.

Today, James is a full time clear in the Sheriff's office. He goes to elementary schools with an officer and the drug dog to speak with the children. At lunchtime, he usually goes down to a local restaurant with the officers and gets a burger and even has lunch with the Sheriff about once a week. James has been in the local newspaper several times during the past years. He is referred to as honorary detective under his picture in the newspaper. One of the officers told me he only wished his other law enforcement officers were as dependable as James. He said, "You can set your clock by James. He is always on time for his job, and ready to go when the day is completed."

James has long since graduated from our school district. I visited James last month at the Jackson County Sheriff's Department, where he has been employed for seven years. After telling my students and other teachers about this story I always tell them dreams do come true, so make sure you pursue your dreams even if they seem far-fetched.

Charlotte Guy

“We just want to work together”

Glen and Otto grew up in New Orleans as a part of a large African American family. As the oldest brother, Glen always had a protective attitude about his younger siblings, especially his next oldest brother, Otto. Glen graduated from special education classes in the New Orleans area and faced an uncertain adulthood. Glen is not able to walk and, as a result, uses a wheelchair for mobility assistance. He also born without use of his arms and he learned to use his mouth to control items such as his wheelchair and the computers that he strived to access in libraries and at school. When Glen graduated from school he was asked if he wanted to work by both VR and local service providers. He seemed reluctant and kept putting off people who urged him to move toward getting a job.

A year passed and Otto reached graduation age. He also had attended special education classes in his local school district and had disabilities similar to his brother. In fact, a number of siblings in the family had physical disabilities as a result of a genetic condition. When Otto had graduated, he and Glen applied for employment services in their community. But they had a clear pre-condition: the two brothers wanted to work together. They now reflect on that time with memories of admonitions from numerous representatives of the rehabilitation system – counselors, providers and advocates - urging them to “grow up and get on with life.” They were told that adults get their own jobs; separate from family members and that employers would not be interested in employing two brothers with disabilities.

So, they waited. Glen and Otto would not give in to the perspectives that would require them to separate in order to be served, and thus, stayed at home for years – six years for Glen and five years for Otto. They waited until the spring of 1994. Coincidentally, United Cerebral Palsy (UCP) had received a national grant that offered choice and control in the rehabilitation process. The local UCP affiliate participated in the project and contacted Glen and Otto. Glen was the first to apply for services. As a participant, he would receive access to funds in a personal budget that he would control for purposes of purchasing employment services of his choice. When Glen received notice that he was accepted, he then encouraged Otto to apply. Shortly thereafter, Otto was notified that he also was accepted.

At that point, things started to get interesting. The brothers, with assistance from an advisor that they hired, asked the project office for permission to blend their two budgets into one larger budget and to hire a job developer to find both brothers a common job. This request was unexpected and unique to the project. After much consideration and consultation among staff, managers and funders, the brothers were notified that they could, indeed, blend their budgets as requested. Discovery was the first service that they purchased.

The process of discovery was to be crucial for Glen and Otto. Up until that point, professionals had simply offered widely held perspectives about employment, without really getting to know these men, their lives and their family. The brothers changed that by hiring a new provider in town to get to know them. The provider’s job was to explore, to uncover the rationales and the realities of Glen and Otto’s desire to work together.

The importance of discovery is that it is a process that not only welcomes the stated preferences and conditions held by participants, but that it also uncovers the unspoken, often less apparent, considerations that will ultimately affect employment success and satisfaction. Glen and Otto were clear that they wanted a job working with computers, even though neither brother had practical experience in that area. They were convinced that if they could each have a computer system of their own, accommodated to their own unique way of accessing and imputing data, that they could learn how to make a contribution to an employer, possibly in the area of specialized data entry.

Their joint budget, therefore, contained requests to purchase each brother a computer, complete with basic office suite software. Glen felt that a mouse would be the best method to interact with the computer while Otto, with better voice control, wanted to use a voice-activated system, Dragon Dictate. The brothers made the case that by owning their own adapted desktop systems, they would be more marketable to potential employers. They also felt that they could use the time during job development to acquire the basic skills they would need on the job.

However, behind the scenes, there were other, powerful issues to be considered. Glen reluctantly admitted that he had developed a strong attraction to afternoon television, one that he did not really care to break off. Glen described himself as a “morning person”, who liked to get up and get things done early (so he would have his afternoons free). Otto on the other hand loved to sleep in until late morning. A job that would start at eight or even nine o’clock would require significant lifestyle changes that could present punctuality problems as the initial excitement of a job began to wear off. These differences seemed to present contradictions to their assertion that Glen and Otto wanted to work together.

Through careful discovery and respect for the brother’s unique lifestyles, their job developer began to conceptualize an image of a job that would meet both their desire to work together as well as their differing personal needs. Within two months of completing discovery, compiling a descriptive profile and facilitating a joint, person-centered employment plan their job developer was successful in negotiating a job in a firm in which Glen would start at 8:30 AM and work until 12:30 PM, doing straightforward data entry of customer information. Otto would come in at 12:00 noon, and work until 4:00 PM. The brothers had thirty minutes each day to coordinate work-related information. The accessible van that brought Otto stayed to pick up Glen for his ride home.

This job reflected almost perfectly the wishes of Glen and Otto and met their needs for nearly three years. During that time the brothers learned much about computer-based customer lists as well as arranging for the coordination and support of professional training events, an aspect of their firm’s business. However, while the project was still in operation, the project office received word of Glen and Otto’s resignation. The letter was met with sadness until, about two week later; a new request for a joint budget was received. The brothers had decided that the best way to truly spend work time together was to start their own business. Glen and Otto started a business that provides professional meeting audio and video taping services, especially to entities in the disability field in the New Orleans area.

Michael Callahan

Getting to know Jenni

When people talked about Jenni, often all they said was, “She’s a character!” It wasn’t until later, during discovery, that we came to understand what that meant. Yes, Jenni is a character. When Jenni’s Mom first began thinking about employment for Jenni, she was about to graduate from high school in 1999. She had done some volunteer work at the school in the library and in the cafeteria. But there did not seem to be a clear direction of employment for Jenni.

Through the initiative of Sherri, Jenni’s mother, a local volunteer team was empaneled to look at Jenni in a different manner than is typical for persons with significant disabilities. The core team member included Jenni’s teacher and her mom. They began by gathering information and spending time with Jenni in different places, places where Jenni already goes during her life in her hometown of Ocean Springs, Mississippi. Jenni and her mom were involved in numerous routines: school, church, household chores and running a “cab” for the rest of the children in the family. We discovered that Jenni had a large family as well as an extended “family” comprised of people in the community who knew her. Jenni is known as a person who speaks to everyone. Occasionally, team members would notice that Jenni would hug people that she saw out in the community. It was much later that we discovered that she knew all of these people.

When first asked what tasks, Jenni did for chores at home, her family could think of no tasks for which she was routinely responsible. But upon listening and watching, we discovered that she had a very important informal chore. Jenni was the family recycler. She cleaned all of the containers and prepared them for pick up by the recycle company. It was her job and she was proud of it, showing it to us. She also would get upset and move you out of the way, if you started to do one of her tasks. We discovered Jenni had other things that she offered to the family. She keeps up with everyone in her house -- 8 people -- not including visitors. She knows where folks are most of the time. She is observant of people, particularly her younger twins.

One of the reasons that Jenni followed her mom’s schedule was due to her seizures. She has four different types of seizures and she has seizures almost every day. With this information, we began to make some cautious assumptions. These were quickly proven to be unnecessary. In fact, we discovered that Jenni knows when she is going to seizure and will come tell you. Initially, we thought she needed to be constantly supervised. We discovered that she often arrives home unsupervised for up to 15 minutes before she checks in with her mom.

By watching her family interact with Jenni, we discovered a way to support her during her seizures and how to make her feel more at ease after she has a seizure. We discovered that Jenni occasionally has muscle spasms in her arm, which is constantly bent along with her wrist that is tightly turned toward her body. If given the time and opportunity to relate her feelings, she will tell you she is having a tingling in her arm. These signs are confusing to read, so it is difficult for her to tell whether her sensations are a seizure or simply a spasm.

Getting to know Jenni involves being willing to laugh. Jenni has a few phrases that she uses to get a laugh, to start a conversation, or to break tension when she feels it. We discovered that Jenni had never been in an environment that required her to stay within the conversation and not use a phrase to move the conversation towards humor. She uses teasing or touching to get you to listen to her. You can only discover these traits by spending time with her around others, like in her home or school.

In talking with her Dad, we learned that Jenni loves paper. She uses it for art, she cuts it into strips and shapes, and she makes things out of it. She also likes to be around people. Jenni would seek people out during the day and at home. She volunteered at church in the children's room.

While visiting her in school and observing her, we discovered that Jenni would come into the room and start putting together a wooden United States puzzle without being asked to do so. She paid very close attention to the different shapes and matched them to the map on the wall. She seemed to prefer to do tasks that required her to work with her hands, especially with her right hand that she uses more easily than her left. She has a way of getting most anything done with one hand, using her hand that is usually held against her body to offer additional support. She always seems to determine to finish what she started. By watching her we discovered that she does things at her pace. When she was encouraged to perform at a faster pace, she would stop working. When allowed to proceed at her preferred pace, Jenni completed almost every task she started.

The team focused on Jenni's interest to do tasks using her hands, to interact with objects rather than people. Reflections concerning her contributions grew with time as we continued to recognize who Jenni is. Though it was difficult to see, we learned that she is focused and wants to do her work.

Following discovery, Jenni's family and friends came together to plan her employment. The team realized that Jenni needed a place where people there would be willing to let her move at her own pace and that would accept and assist with her seizures. She needed a setting in which coworkers would call for medical assistance if her seizures continued and who were willing to assure that she did not leave with strangers. She needed tasks she could perform sitting down most of the time and a casual place that would tolerate Jenni's need to occasionally hug people who are close to her.

A local volunteer agrees to represent Jenni to employers for job development. A portfolio was developed that featured both pictures and narrative information about Jenni and her possible contributions to an employer. Jenni got her first job from the very first job calls at a local company in the "logistics" business about a half mile from her home. She worked for 2 hours a day 5 days a week preparing baseball caps for an embroidery machine. She worked there for eighteen month and was laid off along with a number of other employees when the owner had a stroke and management changed.

Jenni's mom once again pulled the team together and we looked at all the new things Jenni had experienced while working at her job. We used this information to direct her next employment plan.

This time, we felt that Jenni could work more hours with additional responsibilities. We also discovered she needed a job that did not change as often as the tasks in her original job. We looked to her family and friends help to identify additional tasks and potential sites that would match Jenni's conditions, preferences and contributions. Since part of discovery involves identifying connections between the applicant and the community of employers, we found several potential work sites in which the owner knew Jenni from family relationship, community or church.

Her second job was developed in the business of a fellow church member, a man who owns the local gas company. The company needed someone to stuff the envelopes for all of the new propane customers. Jenni gets to work with her hands putting information together and her tasks are performed in the break room, where coworkers come and visit throughout the day. She goes to work from 10am to 2pm daily and has an hour off for lunch. Since the site is downtown, her mom often assists Jenni have lunch with other friends and family.

At the base of it all, Jenni is like the rest of us. She will continue to learn, and we will continue to discover things about her that will direct her future employment. Since she is a young woman, she will be sorting through the difficult issues of life, no longer as a child, but as a young adult. After two jobs, she now dresses and acts differently. She knows the value of a paycheck and the power of spending her own money. She continues to be a "character" to those around her, but she now picks the places in which she wants to be playful.

Norciva Shumpert

Can Carley Work?

When the concept of Carley working for pay in her Montana community, without a job coach, was first introduced to her IEP team, several of the team members balked, thinking this was not possible. Although to her family, who had always set high expectations for her and supported her to be as independent as possible at home, employment seemed like the next logical step in her preparation for transition from school to adulthood.

The impact of Carley's disability can distract you from thinking in terms of what she could bring to an employer and a job. It is easy to focus on what she can't do physically and all the daily activities with which she needs support and will always need support. At school, she had always had a one to one support person with her, from the time she exited the school bus upon arriving at school to the time she got on the bus to go home at the end of the day. Her support person performed various therapy routines, supported her in the rest room, fixed her meals, assisted her to eat and basically directed her day, much of which was spent in a classroom with several other students with significant support needs. There wasn't an expectation for her to be as independent as possible or to participate in events and classes with non-disabled peers on her own, much less to become an employed adult and taxpayer upon graduation from high school.

In order to develop a job for Carley, we needed to discover what her interests, skills and actual support needs were so that we could confidently approach an employer and market Carley in an effective and respectful manner. At first, we didn't have a vision of what she could bring to an employer or what the ideal job tasks or environments looked like, which made job development impossible. At age 16 she hadn't had any work experience or preparation. The team began discovering information about Carley by spending time with her, observing, letting her show us what she could do before we "helped". We included people who knew her well, her mom, who guided us with her 18 years of experience implementing strategies to enable Carley to participate and do for herself. We encouraged school staff to back off and see what Carley could do without so much assistance.

The biggest eye opener for her teacher was the challenge of supporting her to come in from the bus and get to her classroom by herself in the morning. He had always assumed that she needed a 1:1 support person to get in the door and take the elevator to the second floor. As he began to analyze what he was providing for support and why, Carley basically demonstrated that she didn't need this level of assistance. Another student would let her in the door to the school. With minimal training, she learned how to operate the elevator and what to do if it got stuck, and she could maneuver the elevator door and her wheelchair if there wasn't another adult in her way. This learning experience set the tone for the school staff to begin supporting the students to be as independent and competent as possible. It became the staff's role to provide training and to assist the students to determine how they could do things in a different way or with an adaptation which enabled them to participate more fully and independently in various activities.

We discovered that Carley was great at showing people how to get places, she knew where things were, and she had a great memory. She was a very social young woman. When we went out in the community with her it appeared that she knew half of the town. At school, she wrote notes to friends using the computer or e-mails and when she got home from school, she was on the phone using her new Delta Talker. Through several work experiences we learned that Carley was highly motivated to do things independently, took her job seriously, had a strong work ethic and loved to please her supervisor.

As we gathered more information about Carley, the picture of the ideal employment situation emerged. She needed an accessible environment, roomy enough for her to get around in her chair and with job tasks and materials that she could physically maneuver. She did best with an established routine, and she needed support initially with new tasks to identify or create adaptations when she couldn't physically perform a portion of the task as anyone else would. She could deliver items, give directions or assist customers to find things, perform data entry on the computer, identify things that are out of place and return them to the appropriate location. The IEP team identified Wal-Mart as a work environment which matched Carley's ideal characteristics of a job environment and job tasks.

The job development team consisted of her teacher, her para-professional and her Mom. When they met with the manager of Wal-Mart, they had a clear vision of what Carley could contribute to his store. They had actually listed over 70 items, categorized by department, as examples of items they knew she could return for the store. They described her skills and abilities as: "She has eyes like a hawk. She will find things that are out of place and return them to their correct location. She is meticulous. She won't return an item to the shelf where it doesn't belong. And, if she doesn't know where something goes or needs help, she will seek someone out and ask them. She is also very capable of directing people at how to help her." This was a skill her mom had worked with her on to develop at home to direct her personal care attendants.

Carley was hired to stock the end cap displays, the check out candy and the clip strips located in various departments throughout the store. She continues to do returns for Customer Services as needed. She recently completed her 90-day probationary period and moved into permanent employee status. She works at the store 3 hours each day and then proceeds on to school. As of next week, her job coach will have faded from the job site. Carley plans to continue her employment at Wal-Mart after graduation this May, and she would like to increase her hours. This summer her sister and Mom served as Job Coaches, financed by Tribal Vocational Rehabilitation. She is on the waiting list for local DD employment services and will be eligible for a PASS plan upon high school exit which could also fund ongoing follow-along or personal care supports at work.

Ellen Condon