Self-Directed Employment for People with Developmental Disabilities: Issues, Characteristics, and Illustrations

Jo-Ann Sowers, Debra McLean, and Cynthia Owens

Journal of Disability Policy Studies
VOLUME 13, NUMBER 2, Fall 2002
Copyright© **PRO-ED, Inc.**
Reprinted with permission

There is a growing belief that to affect the persistently high unemployment rate of individuals with developmental disabilities, a paradigm shift from professional- to customer-directed services must occur. Using this approach, individuals will (a) have the knowledge they need to make informed choices and to direct the employment process, (b) choose from the full array of job and career choices available to other individuals in their communities, (c) receive individual and ongoing advice and support, (d) begin the employment service process by defining their career goals and paths, (e) have individual budgets that reflect their unique career goals and paths, (f) determine the services and supports they will use their funding to purchase, and (g) contract directly with service providers. There are many unanswered questions about how a customer- directed employment service system can most effectively and efficiently be structured and how it affects customers, providers, and funding agencies.

The good news is that over the past three decades tremendous advances have been made in the employment arena for individuals with disabilities, including those with developmental disabilities (Mank, 1994; Wehman & Kregel, 1995). A number of laws, regulations, and federal initiatives have decreased many of the barriers and disincentives to employment for people with disabilities (Premo, Richards, & Kailes, in press). The federal government, along with state and local governments, has invested significant funding in initiatives aimed at enhancing the capacity of systems to assist individuals with developmental disabilities in becoming employed in community businesses. For example, between 1985 and 1993, the Office of Special Education and Rehabilitation Services (OSERS) awarded grants to states to enable them to shift from facility-based, sheltered workshop and day activity programs to community-based, supported employment services for individuals with developmental disabilities (Bellamy & Melia, 1991). Through these state systems change initiatives and many government funded demonstration projects, the capacity of individuals with developmental disabilities, including those with the most significant disabilities, to work in real jobs in their communities has been proven (Sowers, Milliken, Cotton, Sousa, Dwyer, & Kouwenhoven, 2000; West, Revell, & Wehman, 1992).

The bad news is that more than 80% of people with disabilities are still unemployed (Louis Harris & Associates, 2000). In addition, almost 80% of individuals who receive employment or day services funded by state Departments of Mental Retardation/Developmental Disabilities agencies, continue to do so in sheltered workshops and day activity programs (Dreilinger, Gilmore, & Butterworth, 2001). There are numerous and interrelated reasons for the persistently high unemployment rate of people with developmental disabilities (Mank, 1994; Wehman & Kregel, 1995), including that many of the initiatives to eliminate or reduce work disincentives have been in effect for only a brief period of time, some disincentives continue to exist, and Medicaid regulations continue to permit providers to offer facility-based services (Mank, 1994). In addition, many professionals and families still do not believe that a job in a community business is a feasible or important goal for individuals with significant

developmental disabilities (Sowers, Dean, & Holsapple, 1999).

Some analysts and advocates suggest that the original goal of supported employment has not been realized because insufficient training and technical assistance has been devoted to building the capacity of the stakeholders within the current service structure. However, some of these same people, as well as many others, also believe that real change will not occur until the service structure itself is changed from one that is professional directed to one that is customer directed (Callahan, 2000a; Cotton & Sowers, 1996; Mank, 1994; Mast, in press; Wehman & Kregel, 1995).

Customer-Directed Employment Service System

A number of demonstration projects have been and are continuing to be implemented around the country in order to identify the key elements of customer-directed service models that maximize customer control of service decisions and system efficiencies and to determine the impact of these approaches on individuals (e.g., services received and outcomes achieved) and systems (e.g., costs, provider agencies). Between 1994 and 1999, the seven Rehabilitation Services Administration's Choice Projects explored approaches for increasing employment and service choices among individuals served through state vocational rehabilitation programs (Stoddard, Hanson, & Temkin, 1999). These projects involved individuals with various disabilities, including those with developmental disabilities. In 1996, the Robert Wood Johnson Foundation's Self-Determination for Persons with Developmental Disabilities Project funded 19 states to begin to create systemic change that would enable people with developmental disabilities to directly control their services and the funding allocated for these services (Moseley, 1999). There are also a number of efforts that are being conducted by state and local developmental disabilities agencies to implement and field-test customer directed services. Mast (in press) described projects in the states of Michigan, Texas, and Washington. Participants in these projects are being supported to develop a whole-life plan that includes work, home, and recreation; to choose the services and supports they want and need to reach their goals in these areas; to develop an individual budget that will be used to purchase these services and supports; and to choose among agency and independent providers for their supports.

For a number of years, Oregon's Office of Developmental Disabilities Services (ODDS) has been exploring and field testing customer-directed services. Oregon was one of the states funded in 1996 by the Robert Wood Johnson Foundation. A key activity of the Oregon project was the establishment of Self-Determination Services offices throughout the state. Each of the local offices had a customer- and family controlled board of directors that developed policies and procedures that promoted customer-directed services. Each customer had an individual budget that was developed based on a person-centered plan, had the opportunity to hire or contract with a wide array of supports (e.g., friends, independent providers, agency providers), and paid for their services through a fiscal intermediary.

Between 1994 and 1999, Oregon's ODDS funded the Oregon Technical Assistance Corporation to conduct the Family Management Grants Project (McLean, Greenwood, & Herrin, 1998). The purpose of the project was to field-test a customer and family-directed approach that focused on employment services and outcomes for adults between 18 and 26 years of age who were on their county's wait list for day and employment services. Through the Family Management Grants Project, 67 individuals with developmental disabilities obtained employment in community jobs using a customer-directed

approach. The Family Management Grant Project served as the basis for the Careers, Community, and Families (CCF) project, which was also funded by Oregon's ODDS. The CCF project, which was conducted between 1999 and 2001 by the National Center on Self-Determination, focused on developing the capacity of stakeholders in three communities to support customers and families to direct the employment process (Sowers, McLean, & Holsapple, 200 1). Through the project, 14 individuals with significant developmental disabilities obtained employment in businesses in their communities and one person, with the assistance of her family, started a business family (Sowers, McLean, & Stevely, 200 1; Sowers, McLean, Stevely, et al., 2001).

Using the lessons learned through these initiatives, Oregon has made a commitment to transforming its state system of services into a customer-directed program. A new Medicaid waiver that reflects this shift has been approved, 10 brokerages are being developed across the state, and a substantial amount of training and technical assistance funding has been allocated by the Oregon Department of Human Services (DHS) to develop the capacity of the brokerages. Oregon's DHS is committed to employment services and outcomes within its emerging customer-directed system change effort. Thus, the agency has specifically allocated a significant portion of the training and technical assistance funding for developing the vision, knowledge, and skills of stakeholders (e.g., customers, families, personal agents) regarding employment.

Key Characteristics of a Customer-Directed Employment System

The purpose of the remainder of this article is to review key characteristics of a customer-directed employment process for individuals with developmental disabilities. The seven characteristics discussed here have been identified based on the experiences gained and lessons learned through the initiatives and demonstrations in Oregon and other states.

Characteristic 1:
Customers have the knowledge they need to make informed choices and to direct their employment process. Perhaps most important, customers and their families must believe that individuals with developmental disabilities, including those with significant disabilities, can work in a wide array of typical community jobs and that their quality of life will be enhanced by doing so. They must also gain at least a basic knowledge of the strategies and approaches that have been demonstrated to be effective in achieving this outcome for individuals with developmental disabilities (e.g., person-centered employment planning, person-specific job development and job creation, and co-worker supports). In addition, customers and their families need a basic understanding of the various funding resources and agencies, the written and unwritten rules for accessing this funding, how to creatively combine these resources, how to develop an individual budget, and the steps involved in directing how these funds will be allocated. Finally, customers and their families must have the opportunity to learn the specific strategies involved in choosing and directing service providers (e.g., developing a specific list of services they want, developing interview questions, interviewing potential providers, deciding which provider they will choose to work with, taking the lead in meetings, reviewing bills, dealing with provider performance problems).

During the first 4 months of the CCF project in each of the three communities, monthly group trainings were conducted for the participants and their families. Funding and provider agencies (e.g., school transition staff, VR counselors, case managers) were also invited to attend the monthly

meetings. These meetings lasted between 2 and 4 hours. A CCF career advisor (a staff person paid through grant funds) presented information on one or more topics (e.g., person centered planning, funding, hiring and directing providers) for about an hour, using numerous case examples of individuals with developmental disabilities to illustrate the concepts and strategies. These stories and case examples enabled the participants and families to gain a vision of the possibilities of community-based employment. The career advisor then illustrated the concepts and approaches with the participants and families. For example, the career advisor facilitated a person centered plan for a participant at one of the first training meetings. The remainder of the meeting time was devoted to discussing local systems issues and challenges (e.g., the vocational rehabilitation counselor office is short of money until July) and to the sharing of ideas among the participants and families (e.g., possible job connections).

Characteristic 2:
Customers should choose from the full array of job and career choices available to other individuals in their communities. The majority of individuals with developmental disabilities continue to be assisted in working in a limited number of occupations, such as food service and cleaning jobs, which typically offer low wages and few opportunities for advancement (Sowers, Cotton, & Malloy, 1994). In addition, they have been offered a narrow range of career path options (e.g., job placement and coaching); options such as self-employment, apprenticeships, technical training schools, or college have rarely been considered.

The CCF participants and their families were encouraged during the group meetings and at their individual person centered planning meetings to "think outside the box" of jobs they believed were possible to obtain and to translate their unique interests and talents into job ideas. Of the 15 participants, only 2 chose to work in a food service or cleaning job, and I of these individuals chose to start her own food service business. The CCF participants and their families were also provided with information about the different types of job path and support options they could choose from and were assisted in considering these options in light of their career goals through the person-centered planning process.

Characteristic 3:
Customers receive individual and ongoing advice and support. Customers and their families need ongoing advice and support to develop and refine their career goals and paths, to build and revise their individualized budgets; to meet and negotiate with various funding agencies; and to interview, hire, direct, and possibly fire providers. The CCF participant's and families required very different amounts of support depending on a number of factors, including the complexity of the participant's employment plan (e.g., the number of different funding resources that needed to be used), the availability of quality providers and the actual performance of the provider chosen, the willingness of the local funding agencies to be supportive, and the confidence of the customers and families in their own ability to negotiate with funders and providers. The career advisor met almost weekly with a few participants and their families during the first several months after their career plan was developed and accompanied them to meetings with funding agencies and providers. For others participants and families, the career advisors provided input and advice primarily via phone or e-mail once or twice a month.

The extent to which the system-wide implementation of customer-directed employment services will

result in an increase in the number of people with developmental disabilities who are employed in quality community jobs will in large part be a function of the commitment and knowledge of the individuals who will serve as personal agents. As suggested earlier, Oregon's Department of Human Services has recognized this and is committing substantial resources to provide training and technical assistance specifically focused on employment issues to the personal agents who are being hired by the new brokerage agencies.

Characteristic 4:
Customers' career goals and paths drive the employment service process. Using a customer-directed employment services approach, decisions about how much funding will be allocated, how the funds will be used, and which providers and services will be chosen are derived from the job goal and path that has been identified by the customers. As previously suggested, it is important that the person who facilitates the planning process has expertise in helping people with developmental disabilities become employed in community jobs. Traditionally, the staff of employment agencies take the lead in helping people with developmental disabilities develop a job goal and path (or decide that work will not be a goal). In addition, it is usually assumed that regardless of the identified goal, the agency will provide the services to reach that goal. A conflict exists because providers naturally prefer that individuals choose goals and paths that fit within their agencies' existing service menus, and that the goals can be achieved with their agencies' current resources (i.e., it will not cost more than is typically expended). Subtly or not so subtly, customers are encouraged to "choose" from among the provider's menu of programs and services, and to "choose" the amount of services that fits the resource configuration of the agency (e.g., one staff member for every eight consumers).

Because case managers and vocational rehabilitation counselors typically do not provide direct services, they have less of a conflict of interest when helping individuals identify career goals and paths and the services they want and need. However, the way case management and vocational rehabilitation agencies and their staffs' roles are designed permits potential conflicts of interest. For example, vocational rehabilitation counselors have a service budget that they must "spread across" as many clients as possible. Thus, counselors may encourage clients to aspire to modest career goals in order to limit the amount of funds that will need to be authorized for services.

A variety of different approaches are being field-tested via customer- directed demonstrations and initiatives to attempt to provide individuals with developmental disabilities the opportunity to develop their goal and service desires, as well as their budgets, prior to choosing services and without the conflicts of interest inherent in the current system. Through a number of self-directed model projects, personal agents have been hired directly by county or regional developmental disabilities case management agencies, provider agencies, or agencies that provide both case management and direct services (Mast, in press). All of these projects have attempted to create "fire walls" between the role of the personal agent as planner and facilitator and the agency's budgetary oversight and service provision functions. In large part, this is being done by creating job descriptions that clearly and explicitly delineate the expectation that the personal agents help the customers identify the goals and services they desire, help customers actively seek out resources that they need to reach their goals, and encourage customers to choose from among the full array of potential providers of service and support in their communities.

Many advocates for customer- directed services suggest a service planning model that incorporates

an organization whose only roles are to help individuals identify their goals and services and to "broker" available funding and service resources that they need to achieve their goals (Cotton & Sowers, 1996; Salisbury, Dickey, & Cameron, 1987). As previously described, Oregon is developing formal brokerages throughout the state. The brokerage organizations applied through a competitive contract process; those that were selected received a contract from the state. In order to help ensure that the personal agents who work for the brokerages provide self-directed services, each program must have bylaws and procedures that promote customer control and direction and a board of directors that is composed primarily of customers and families. Although most of the brokerages have been developed as separate private, nonprofit, or for-profit organizations whose only roles are to provide personal agent services, a few will be conducted through existing provider agencies, and one will be conducted through an existing case management agency. Many of the same strategies being used by other demonstrations to decrease the conflict of interest between the personal agents and the other roles of the operating agency are being required by the Oregon DHS of these brokerages.

Characteristic 5:
Customers have individual budgets that reflect their unique career goals and paths. Rate setting has long been a challenge in professional-directed systems, and it continues to be within the context of customer-directed system changes. Two key rate setting approaches have been advocated and debated. The first approach is to allocate a maximum or "capitated" funding level for each individual based on either that individual's funding level history or an average funding level across all individuals (or subsets based on level of support needs). The second approach is to set no cap or maximum amount prior to the person-centered planning. When this approach is used, funding agencies typically calculate an average target level of funding across individuals. If an individual's plan greatly exceeds the target and other funding sources cannot make up the difference, various procedures are used to determine how much of the funding the agency will offer to the individual. Each of these approaches has advantages and disadvantages. Establishing a maximum funding level can limit the amount of true choice a person has. On the other hand, providing a maximum may encourage individuals and families to develop their plans to ensure that they spend all of their allocated funding. The key concern about the second approach is that it requires making more complex decisions regarding people with high service needs or desires and permits less clarity in terms of budgetary spending projections. Of course, this is similar to the challenges faced by vocational rehabilitation agencies within the context of their individualized funding approach. With regard to the frequently expressed concern that people will request large amounts of funding, data from all of the demonstration's projects have consistently shown that people develop modest budgets (Callahan, 2000a, 2000b; Mast, in press).

A key to individualized budgeting within the framework of a customer-directed employment approach is resource leveraging. The CCF project utilized the maximum funding level approach by establishing a cap of $3,000 per participant. During the initial planning period, participants were encouraged to forget about the stipend and not to let it limit their thinking about what they wanted or needed. In addition, the importance of using as many different resources as possible was emphasized and participants and families were supported in doing so by their career advisors.

The importance of collaborative planning and resource utilization among disability funding entities (e. g., developmental disabilities, vocational rehabilitation, school) has long been advocated. However, most individuals with disabilities and their families will attest to the fact that relatively little of this

actually occurs. The different funding streams are rarely creatively comingled to enable individuals with developmental disabilities to access the resources they need to pursue a quality job or career. In addition, few providers or disability funding agencies actively pursue other resources (e.g., Social Security Work Incentive or Work Incentive Act One-Stop programs). In part, this is a result of the natural tendency of organizations to focus on their own service mandates, procedures, and funding rules and regulations. When providers of day and employment services for individuals with developmental disabilities are asked about the barriers they face in helping more people go to work, they frequently identify the low level of funding available through Medicaid or state mental retardation/ development disability programs (Sowers, Dean, & Holsapple, 1999). However, it is also the case that many of these agencies devote little effort to accessing other funding sources for individual consumer services. On the other hand, experience has shown that when individuals with developmental disabilities and their families are supported in taking the lead in their employment planning, they are committed to making the effort to access the various resources available to support going to work (Mast, in press; Sowers, McLean, & Stevely, 2001).

All of the CCF participants accessed at least two different funding sources for employment assistance. Most of the participants used more than two funding sources and a few used as many as five. For example, one participant used direct funding from his school district (e.g., to pay for job finding assistance), the CCF stipend, vocational rehabilitation, Work Incentive Act Individual Training Account funds, and a Social Security Administration Plan for Achieving Self-Sufficiency (PASS).

Characteristic 6:
Customers determine the services and supports they wish to purchase with their funding. Traditionally, the employment process begins with individuals' being referred to or, in more progressive systems, allowed to choose among, the available agencies to receive services. In a customer- directed system, individuals are first assisted in identifying the types of jobs they wish to pursue and the paths they would like to use to reach their goals, and then they are asked to choose the providers that are best able to help them reach their goals. Individuals are also encouraged to consider the full array of support options that are available in their communities.

Through the CCF project, customers and families were encouraged to consider obtaining the services of existing service provider agencies, individuals who operated as independent employment specialists, or other individuals who might be interested in, and suited to, providing employment assistance and support. Although there were a large number of providers in the urban community where the CCF project was implemented, few of these were able or willing to provide the type of services desired by the participants. There was only one provider agency in each of the two smaller communities. Only two participants contracted with a provider agency, one participant contracted with a family friend, and five participants contracted with individuals who had been operating as independent employment specialists. A number of these independents had prior employment assistance experience working for agencies. Others had minimal vocational training experience in their roles as classroom special education aides or teachers. One person chosen was a parent of a child with a disability who had no formal experience. Two individuals had no prior experience in the disability or employment field and were selected by the customers and families based on their community connections. All of the "novice" providers expressed interest in continuing to provide independent employment services to other people in the future, and some are considering becoming part- or full-time employment specialists.

Characteristic 7:
Customers contract directly with their providers. For a service provider to truly be accountable to a customer with disabilities, he or she must understand that they work for the individual, not for the agency that allocates the service funds. One method to ensure that this understanding is established and maintained is for the customer to negotiate and develop a service contract directly with his or her provider. The contract includes many of the same things that would be in a vocational rehabilitation authorization to a provider, including delineation of the specific services that will be provided, how these will be provided, rate of pay, and time limits of the contract. It also should include customers' other desires about how their services will be delivered (e.g., meet with me weekly to create a "to do" list of activities and to report on the previous week's activities). In addition to the contract, the customer must be directly involved in actually paying the provider. Due to tax, liability, and fraud concerns, service funds typically are not given directly to the customer. Most demonstration projects are using some type of fiscal intermediary or fiduciary agent approach, which means customers review and approve invoices before the provider is paid.

The CCF project contracted with a private, nonprofit agency to provide fiscal intermediary services, including paying the provider after the customer and his or her family had reviewed and approved the invoice. The fiscal intermediary agency was able to guarantee payment within 5 working days of the signed invoice submission. This was particularly important for the independent employment specialists who had low cash reserves. Some of the new brokerages in Oregon will offer fiscal intermediary services, but others will contract with agencies that only provide these services.

Andy and Cynthia Owens' Story

When some people learn about the characteristics of customer directed employment approaches; they do not believe that it is possible for individuals and their families to truly take the lead in directing their own services. Other people do not perceive the approach as being significantly different from the current service system. The stories of individuals and families who have had the opportunity to direct their own employment services helps "bring to life" how customer- directed services actually work, how this approach is different from (or similar to) traditional professional-directed structures of service planning and delivery, and how these services can affect the lives of people with developmental disabilities. The story presented here was written by the mother of one the participants in the CCF project. This is an abbreviated version of a much longer story that was published with the stories of a number of other project participants (Sowers, McLean, Stevely, et al., 2001; see Note).

The Beginning.- Doubts and Fears
A couple of years before Andy would turn 21 years old and no longer be eligible for school services, I suggested a couple of "special needs" camps that he might like to go to during the summer. I admit that I played them up, but he was having none of it. After 30 frustrating minutes, I asked, "What do you want to do, get a job?" I was surprised when he said, "Yes". At the time, he could only communicate "Yes" and "No" by turning his head to the left or right and his wheelchair had to be pushed around by someone else.

Andy's father, David, and I had met the previous month with the staff at his high school and talked over our plans for Andy's life after he turned 2 1. I didn't know it at the time, but this was Andy's first

"transition" meeting. I can remember explaining that we saw no future for Andy after high school, because of the long wait-list for services. No one disagreed with my vision of Andy's future nor did they offer any options. I left that meeting feeling depressed.

Becoming an Informed Customer

In June of 1999, we attended our first CCF meeting with the other young people and their families in the Tri-County area. We got an overview of the steps involved in helping a person with a developmental disability get a quality community job and how to direct the process. Andy, David, and I were excited because we now were going to get the training and guidance we needed to help Andy get a job.

We set-up a Person-Centered Planning meeting. We had it on a Saturday at our house and mailed out invitations that Andy and I had designed to create a feeling of celebration. We invited Andy's school and church friends, family friends, and school staff, and our CCF Career Advisor facilitated the meeting. Everyone contributed new ideas about the type of jobs that Andy might be able to do, but the best ideas came from Andy's friends. We also decided that we needed to revisit the issues of communication and mobility for Andy. We wanted him to be able to communicate with his coworkers, and if he could use a power wheelchair it would help him to be more independent.

Using the information we gathered at the Person-Centered Planning meeting, we developed a Career Resource Plan that described the assistance Andy would need to become employed, including someone to help him find and learn a job, transportation, an augmentative communication device and a power wheelchair. We even estimated the amount of money that this assistance would cost.

The first thing we did when the school year started was to set-up a meeting with the school staff to review the Resource Plan and to request that the school district contract with someone to look for a job for Andy, to provide training to him, and to consult with his coworkers about how to support him. We also asked the district to allow us to pick the person who would work with Andy. I believe they approved our request because we were informed parents and we had a very clear plan and proposal for what we needed.

I then began interviewing job developers. This was a real disappointment, because there are so few job developers or agencies who truly believe that people like Andy can work or who know how to make this happen. I did find a person who worked as an independent employment specialist who believed in Andy and our vision.

I, along with our Career Advisor, met weekly with the employment specialist, giving her input about the types of businesses to approach and the kinds of tasks to look for. I was very frustrated with the slow progress, because time was ticking away in Andy's last year of school. I knew we needed to get more going in order for him to have a job by the time June came around. Andy didn't like the idea of letting someone go, but he decided to and we started over.

Job Carving and Adaptations

We knew that Andy probably couldn't be hired into an existing job position at a company. We talked with businesses about tasks that Andy might be able to do and that they would be willing to "carve"

from existing positions. One of these companies was Powell's, a large bookstore in Portland. One task that had promise was in the Price Task Force (PTF) department, where all of the books are entered into their inventory by employees who scan bar codes with a laser gun. The PTF department staff were excited about the challenge of figuring out how Andy could work there. Because Andy could not pick up the books or the laser gun, they came up with the idea that if the books moved along a conveyor belt and the scanner was positioned over the conveyor in a holder, Andy could use his head switch to operate the conveyor belt and, thus, scan-in the bar codes. We found a local assistive technology team who agreed to design and build this device.

The Vision Becomes a Reality: Andy Goes to Work

Andy's first day of work was only a couple of days after he graduated from high school. Andy started out earning $7.68 an hour scanning books using the switch-operated conveyor belt. Another part of Andy's job is to input information into a computer. After a book is scanned, the book information comes up on a computer on a table in front of him. His new Dynavox interfaces with the computer through a head rest that has two switches in it-he hits the left side to move the conveyor belt and then the right side of the head-switch to activate the Enter key function to input the book information in the computer data base.

During the first couple of months on the job, Powell's was reimbursed for Andy's salary while the conveyor belt was being refined and he was learning his job. We used a portion of our CCF stipend funds to reimburse Powell's. After several months, Andy was able to scan as many books as other employees and Powell's agreed to discontinue the wage reimbursement.

As summer was coming to an end, the need to replace his school aide grew closer. We found Stephanie, a young woman who is the daughter of someone I know. Although Stephanie has a sister with a developmental disability, she has no formal experience working in the field. However, she believes that Andy can do anything that he wants and she is a perfect fit with Andy and his coworkers at Powell's.

The Rest of the Story

Vocational Rehabilitation (VR) has been a very enthusiastic supporter of Andy's employment at Powell's. Andy's VR counselor agreed to pay for the design of another piece of equipment that will further increase Andy's productivity and independence. Stephanie now loads books on the conveyor belt for Andy who then activates the belt through a head-switch to move the books under the scanner. The assistive device that the design team is building will load the books automatically when Andy hits his head-switch. Our goal is that with this piece of assistive technology, Andy will be independent enough that Stephanie will not have to be at the job site all of the time. We know someone will need to be there at least part of the time to help him with his personal care needs, but we hope that we can slowly reduce how much help he needs with his job tasks and that coworkers can provide those supports.

The team has also written a PASS Plan for Andy. Through the PASS Plan he can use some of his wages to help pay for Stephanie to work with him at Powell's, while keeping his SSI check at the amount that it was before he went to work. Andy is also taking a couple of classes at Portland Community College. In addition, we have finally gotten a power wheelchair for Andy, paid for by insurance and Medicaid.

The Journey Continues
Andy is happier than I ever thought possible. He loves his new life after high school. For me, I keep thinking that even a year ago the idea of Andy graduating and the unknown future scared me to death. I can honestly say that helping Andy's dream come true has been the hardest thing I have ever done. It has also been one of the most rewarding.

A Message From Andy
Andy wants to tell everyone, "Most people didn't think I could work in a real job in the community, but I was determined to prove that I could. I like that I proved a lot of people wrong. My mother helped me find and hire people ... and directed them to do the things that I wanted them to. I am proof that anyone can have a job that they like. My advice to other young people is that you can and should work and that you have to be determined and get other people to help you reach your goals.'

Conclusions

Over the past few decades, a great number of changes have been made for people with developmental disabilities with the goal of improving their lives. However, as is true for all people, substantial improvements in the quality of their lives can only be achieved when individuals with developmental disabilities have the freedom, control, and power that permits changes to be made by them. As previously suggested, the true measure of the success of customer-directed employment approaches will be the extent to which the persistently high level of unemployment of people with developmental disabilities is reduced. By being able to control how his or her funds are spent, each individual will be able to influence the quality of his or her employment services and outcomes. Over time, the choices made by each person will create the market forces needed to influence the nature and quality of the employment service system for other individuals with developmental disabilities. When enough people are able to access quality jobs in their communities, receive decent wages, and move out of poverty, they will be able to gain true economic freedom and the concomitant power to influence services, businesses, and political agendas in their communities, states, and nation. Of course, these outcomes will not be realized quickly or easily.

As is true for all individuals who have had little experience with freedom and self determination, people with developmental disabilities and their families will have to learn how to use their new opportunities and powers. In addition, provider, funding, and regulatory agencies and staff must also learn how to function in this new and very different environment. As Mast (in press) points out, there are many unanswered questions about how a customer-directed employment service system can most effectively and efficiently be structured, as well as how it affects customers, providers, and funding agencies. The only way to answer these questions is to move forward in implementing this important new paradigm. We already know the answer to the most important question: "Should individuals with developmental disabilities have the same employment opportunities and choices as other citizens?

ABOUT THE AUTHORS

JO-ANN SOWERS, PhD, is the co-director of the Center on Self Determination and adjunct associate

professor of public health at Oregon Health & Science University. Her work focuses on self determination, employment, and postsecondary education. DEBRA MCLEAN, MA, provides training and technical assistance to self- advocates, families, and organizations through the Oregon Technical Assistance Corporation. CYNTHIA OWENS is a training and technical assistance specialist at the ARC of Oregon. Address: Jo-Ann Sowers, Center on Self- Determination, Oregon Health & Science University, 3608 SE Powell Blvd., Portland, OR 97202.

NOTE

From Self-Directed Employment: Story Book of Oregonians with Developmental Disabilities (pp. 4-11), by J. Sowers, D. Mclean, J. Stevely, C. Owens, G. Avery-Grubbs, and K. Schumaker, 2001, Portland: Oregon Health & Science University. Copyright 2001 by Oregon Health & Science University. Reprinted with permission.

REFERENCES

Bellamy, T., & Melia, R. (1991). Investing in people: Launching supported employment on a crowded public agenda (Part 2). Journal of Disability Policy Studies, 2(l), 19-38.

Callahan, M. (2000a). The meaning of choice: Implications for systems and providers. Report for the Presidential Task Force on Employment of Adults with Disabilities.

Callahan, M. (2000b). Personal budgets: The future of funding. Journal of Vocational Rehabilitation, 16(l), 15-26.

Cotton, R, & Sowers, J. (1996). Choice through knowledge: Knowledge =power. Durham: Institute on Disability, University of New Hampshire.

Dreilinger, D., Gilmore, S., & Butterworth, J. (2001). National day and employment service trends in MR/DD agencies. Research to Practice, 7(3), 2-3.

Louis Harris & Associates. (2000). 2000 N.O.D.lHarris survey of Americans with disabilities. Washington, DC: Author.

Mank, D. (1994). The underachievement of supported employment: A call for reinvestment. Journal of Disability Policy Studies, 5(2), 1-24.

Mast, M. (in press). Client-driven systems: A customer-directed approach [Monograph]. In L. R. McConnell (Ed.), Systems change: Emerging service delivery models [A Report on the 23rd Mary E. Switzer Memorial Seminar]. Alexandria, VA: National Rehabilitation Association.

McLean, D., Greenwood, L., & Herrin, B. (1998). Self-determination in SE: Families as job developers. Supported Employment InfoLine, 9(5), 1-3.

Moseley, C. (1999). Making self-determination work. Durham: University of New Hampshire, Institute on Disability.

Premo, B., Richards, C., & Kailes, J. (in press). A framework for disability policy in the 21st century:

Informed choice and consumer empowerment: Redefining, redesigning and reforming services [Monograph]. In L. R. McConnell (Ed.), Systems change: Emerging service delivery models [AReport on the 23rd Mary E. Switzer Memorial Seminar]. Alexandria, VA: National Rehabilitation Association.

Salisbury, B., Dickey, J., & Cameron, C. (1987). Individual empowerment and social service accountability. Vancouver, BC, Canada: The G. Allan Roeher Institute.

Sowers, J., Cotton, P., & Malloy, J. (1994). Expanding the job and career options for people with significant disabilities. Developmental Disabilities Bulletin, 22(2), 10-18.

Sowers, J., Dean, J., & Holsapple, M. (1999). The alternative to employment (ATE) study: Toward full inclusion. Salem: Oregon Office of Developmental Disability Services, Department of Human Services.

Sowers, J., McLean, D., & Holsapple, M. (2001). Careers, community, & families project. The Rural Exchange: Addressing the Diversity of Rural Life, 14(l), 13-14.

Sowers, J., McLean, D., & Stevely, J. (200 1). Self-directed employment: A toolkit for Oregonians with developmental disabilities. Portland: Oregon Health & Science University, National Center on Self-Determination.

Sowers, J., McLean, D., Stevely, J., Owens, C., Avery-Grubbs, G., & Schumaker, K. (2001). Self-directed employment. Story book of Oregonians with developmental disabilities. Portland: Oregon Health & Science University, National Center on Self-Determination.

Sowers, J., Milliken, K., Cotton, P., Sousa, S., Dwyer, L., & Kouwenhoven, K. (2000). A multi-element approach to creating change in a state employment system. In J. Nisbet & D. Hagner (Eds.), Part of the community: Strategies for community membership. Baltimore: Brookes.

Stoddard, S., Hanson, S., & Temkin, T. (1999). An evaluation of the choice demonstration projects: Final report. Berkeley, CA: InfoUse.

Weliman, P., & Kregel, J. (1995). At the crossroads: Supported employment a decade later. Journal of the Association for Persons with Severe Handicaps, 20(4), 286-299.

West, M., Revell, G., & Weliman, P. (1992). Achievement and challenges (Part 1): A five-year report on consumer and systems outcomes from the supported employment initiative. Journal of the Association for Persons with Severe Handicaps, 17(4), 227-235.