Department of Health and Human Services

OFFICE OF INSPECTOR GENERAL

Employment Programs for Persons with Developmental Disabilities



JUNE GIBBS BROWN Inspector General

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EXECUTIVE SUMMARY

PURPOSE

To describe promising approaches and barriers to employment programs for persons with developmental disabilities.

BACKGROUND

Developmental disabilities affect a person's ability to work, live, socialize, and maintain self-sufficiency. Nationally, the number of persons with developmental disabilities is estimated at approximately three to four million. To enhance the environment in which a person with developmental disabilities lives and to lessen the many barriers that they encounter, Congress enacted the Developmental Disabilities Assistance and Bill of Rights Act (42 USC 6000) to establish Developmental Disabilities Councils in each State.

The main goals of State Developmental Disabilities Councils include: promoting integration into work and community settings so that individuals with developmental disabilities are not separated or isolated from others; protecting individual rights; ensuring they will have accommodations they need; and ensuring they will have control over their own resources. Nationally, funding for State Councils was approximately \$65 million per year for 1996, 1997, and 1998.

We conducted this study in response to a request from the Commissioner of the Administration on Developmental Disabilities (ADD), Administration for Children and Families (ACF). Our purpose was to identify, describe and assess promising approaches to promote employment of persons with developmental disabilities. We based our study on information gathered from State Developmental Disability Councils, Vocational Rehabilitation agencies, Mental Health agencies, Mental Retardation/Developmental Disabilities agencies, job service agencies, and employers.

FINDINGS

Promising Employment Programs

While State Councils do not obtain direct employment for persons with developmental disabilities, they are instrumental in facilitating job opportunities for them. State Councils initiate demonstration projects by providing seed monies for promising employment approaches. These programs include public awareness, supported employment, and high school-to-work transition programs. Also, innovative employment approaches which Council directors indicate yield successful results are consumer

directed vouchers, entrepreneurial grants, and State hiring programs. In addition, nearly all respondents report that these promising and innovative programs could be replicated in other States.

Factors and Relationships Important in Obtaining Jobs

Many factors are important in creating jobs and in ensuring success in employment programs, including the involvement of the employer community, collaborative arrangements among State entities, and planning for long term support systems.

State entities also report that basing jobs on the personal interests of persons with developmental disabilities, effectively marketing them for appropriate jobs, and a unified State disability policy are critical to the success of employment programs.

Less than Effective Approaches to Employment

Ineffective approaches listed most frequently among respondents are: poor job matching; high speed production jobs which are too stressful; traditional sheltered employment agencies; mobile work crews and groups; offering too many financial initiatives to employers; and outdated pre-vocational training models. In many cases, these approaches also entail inherent barriers to employment of persons with developmental disabilities.

Barriers and Ways to Address Them

State entities report that some of the barriers which impede the development of employment programs are: a lack of transportation; fear of losing Medicaid or a monthly Supplemental Security Income check; negative perceptions held by employers; and lack of flexible financing arrangements among State entities. Respondents cite many methods to reduce or eliminate barriers, including individual transportation plans, cooperative financing, and business advisory councils.

Limited Employment Outcome Data

Very little management information exists on performance and outcomes of monitoring employed individuals with developmental disabilities. Data we reviewed is limited and inconsistent from State to State.

RECOMMENDATIONS

A number of positive initiatives are being undertaken by State Councils directly or through collaborative programs with other State agencies. However, identifying performance data is difficult. While it may be challenging for State Councils to capture

and measure extensive information on general effectiveness of employment programs, steps need to be taken to report the progress on individuals with developmental disabilities in obtaining and keeping jobs. To accomplish this, the ACF should consider the following:

Promising Practices Should be Shared Among States

State Councils identify a number of promising and innovative practices and generally feel these could be replicated in other States. In fact, some State Councils already require grantees to develop a replication manual for their demonstration projects. We believe that communicating these practices is in the best interest of employment programs and their effective operation. Three specific actions that ACF/ADD should consider include:

- 1) working with State Councils to develop an ongoing inventory of successful employment initiatives;
- 2) working toward developing a formal mechanism to allow State Councils to share promising employment approaches on a national level; and
- 3) communicating practices known to enhance the quality and efficiency of data documentation and reporting.

Core Data Requirements Should be Established to Evaluate Job Initiatives

State entities confirm the benefits of having outcome data to relate performance/ achievement, and to measure effectiveness. Despite activities underway to develop and implement such outcome data, we believe it would be beneficial for ACF to develop mandatory performance measures with which all State Councils must comply. We note that a beneficial tool in this effort may be the "Core Indicators" being developed by a workgroup of State Mental Retardation/Developmental Disabilities directors. While these performance measures are largely focused on State mental retardation issues, some of the measures may be valuable to apply to all persons with developmental disabilities.

AGENCY COMMENTS

The ACF concurred with recommendations in this report. We have made changes to the final report to reflect agency wording suggestions.

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INTRODUCTION

PURPOSE

To describe promising approaches and barriers to employment programs for persons with developmental disabilities.

BACKGROUND

Developmental disability is defined in the Developmental Disabilities Assistance and Bill of Rights Act, as amended by Public Law 103-230, as a "severe, chronic disability of an individual five years of age or older that is: attributable to a mental or physical impairment or combination of mental and physical impairments; manifested before the individual attains age 22; likely to continue indefinitely; and results in substantial functional limitations in three or more areas of major life activity." Nationally, the number of persons with developmental disabilities is estimated at approximately three to four million.

Major life activities which may be affected by a developmental disability include: self-care; receptive and expressive language; learning; mobility; self-direction; capacity for independent living; or economic self-sufficiency. Developmental disabilities affect a person's ability to work, live, socialize, and maintain self-sufficiency in a community setting. Individuals with developmental disabilities need a combination of special interdisciplinary services, supports, or other assistance of lifelong or extended duration. Such services or assistance are typically planned and coordinated individually. Without appropriate services, people with developmental disabilities are isolated rather than fully integrated into mainstream society.

State Developmental Disabilities Councils

The Developmental Disabilities Assistance and Bill of Rights Act established Developmental Disabilities Councils in each State. Their mission is "to assure that individuals with developmental disabilities and their families participate in the design of and have access to culturally competent services, supports, and other assistance and opportunities that promote independence, productivity, employment, integration, and inclusion into the community." The goals of the Developmental Disabilities Assistance and Bill of Rights Act include: promoting integration into work and community settings so that individuals with developmental disabilities are not separated or isolated from others; protecting individual rights; ensuring they will have accommodations they need; and ensuring they will have control over their own resources.

Specifically, State Councils are defined in the Statute as organizations designed to "promote (through systemic change) capacity building, advocacy activities, the development of a consumer and family-centered comprehensive system, and a coordinated array of culturally competent services, supports, and other assistance designed to achieve independence, productivity, and integration and inclusion into the community for individuals with developmental disabilities."

State Councils build on community and family resources to infuse new creativity and vision into policy and leadership of State, local, and private programs. While there are general priority areas for State Councils (i.e., employment, community living, child development, system coordination, and community education activities), the only Federally mandated area for all Councils is employment activities.

The Act specifies that State Councils will have administrative and program staff and must complete 3-Year State Plans. The State Councils must submit annual reports of performance to the Administration on Developmental Disabilities (ADD) within the Administration for Children and Families (ACF) covering goals as identified in State Plans and the select areas of emphasis in which their States will specialize. As of 1997, State Councils are required to select performance measures related to outcomes in the annual program performance reports to the ADD. The Councils submit outcome information on at least one measure out of a group of 22 employment-related performance measures. Each year, State Councils must demonstrate that they have assisted persons with developmental disabilities in their State in obtaining and keeping employment consistent with their interests, abilities, and needs.

State Council members are appointed by State Governors. One-half of the membership must include a combination of (a) persons with developmental disabilities; (b) parents/guardians of such persons; and (c) immediate relatives of individuals with developmental disabilities who are not employees of State agencies which receive funds or provide services.

State Councils are funded by Federal and State matching funds based upon a formula that involves the number of individuals in the States who are developmentally disabled. Nationally, funding for State Councils was approximately \$65 million per year for 1996, 1997, and 1998.

Administration on Developmental Disabilities

The Federal agency responsible for oversight of the State Councils is the Administration on Developmental Disabilities within ACF. It provides guidance to State Councils, sponsors and funds training sessions, and conducts monitoring functions for oversight and compliance with program guidelines. The ADD, along with ACF regional offices, provides technical assistance on policy and other issues to numerous Councils each year.

In addition, its staff conducts random, programmatic reviews of a small number of State Councils on management and technical issues. State Councils submit annual program performance reports to ADD covering program goals and accomplishments, and priorities and functions related to the various State initiatives and activities.

National Disability Associations

There are two national associations which provide support and advocate programs for persons with developmental disabilities -- the National Association of Developmental Disabilities Councils and the Consortium of Developmental Disabilities Councils. They encourage and promote activities of State Councils, and are active in legislative matters concerning developmental disability issues. The National Association of Developmental Disabilities Councils recently was awarded a contract by ACF to provide technical assistance to State Councils. This assistance is expected to strengthen State Councils' capabilities to construct an effective data management system and also assist the States to meet the data requirements mandated by the Government Performance and Results Act of 1994.

Vocational Rehabilitation and Mental Health Agencies

The Rehabilitation Act of 1973, as amended, authorizes the Department of Education's Vocational Rehabilitation program to provide comprehensive vocational rehabilitation services designed to help those with the most severe physical and mental disabilities return to the work force. This is primarily done through Federal funding to State Vocational Rehabilitation Agencies that directly provide services. These services include counseling, work evaluation, work adjustment training, job skills training, job-seeking skills training, and medical rehabilitation management.

The Federal/State vocational rehabilitation program is operated and administered through a combination of State general and blind-only vocational rehabilitation agencies and various other State and private facilities. These agencies provide individualized vocational rehabilitation services to accepted individuals according to a written rehabilitation plan that is jointly developed by a counselor and the individual. Counselors evaluate whether there is a reasonable expectation that the individual will benefit from vocational rehabilitation services in terms of their employability. This judgment is based on the individual's impairment and the availability of services and resources.

State Mental Health agencies are advocates for individuals who have a mental illness, which may or may not include persons with developmental disabilities. Their personnel interact with various institutions and organizations to assist individuals in their socialization and adaptive skills. State Mental Health agencies assess appropriate job opportunities for individuals with developmental disabilities and are influential in setting

Statewide goals and policies for persons with mental illness and developmental disabilities.

The Health Care Financing Administration (HCFA) has Home and Community Based Services (HCBS) programs available to assist persons with developmental disabilities in their jobs. These serve as waivers to the basic requirements that States have in operating their medical programs. The HCBS waivers approved by HCFA allow for limited reimbursement of prevocational services and supported employment services. Prevocational services are aimed at preparing an individual for paid or unpaid employment, but are not job-task oriented. Supported employment services are conducted in a variety of settings, particularly in work sites where persons without disabilities are employed. Supported employment services consist of paid employment for which competitive employment at or above the minimum wage is unlikely. In this manner, supported employment helps persons with developmental disabilities who, because of their disabilities, need intensive ongoing support to perform in a work setting.

SCOPE AND METHODOLOGY

The Commissioner of the Administration on Developmental Disabilities requested the Office of Inspector General to conduct this study.

Our purpose was to identify, describe and assess promising approaches to promote employment of persons with developmental disabilities. We based our study on information gathered from State Developmental Disability Councils, Vocational Rehabilitation agencies, Mental Health agencies, Mental Retardation/Developmental Disabilities agencies, job service agencies, and employers. We asked our respondents what approaches they believed were effective and what barriers they were confronting. We compared answers from different respondent groups to identify commonalities. We analyzed program performance reports and outcome data where available.

Our method does not yield proof of program effectiveness, but it does provide the best assessment of promising approaches based on the insights and experience of responsible professionals and evidence available in administrative records and allied documents. It provides leads and suggestions for approaches that appear worthwhile for further experimentation and development, and identifies some approaches which, based on experience to date, should probably be avoided.

We selected a judgmental sample of nine State Developmental Disabilities Councils. Six of the Councils are affiliated with the National Association of Developmental Disabilities Councils, while the remaining three Councils are affiliated with the Consortium of Developmental Disabilities Councils. In addition, seven of the nine sampled States have numerical employment goals outlined in their three-year State plans. We obtained a mixture of States with large populations and small populations. We also conferred with

ADD on State Council selection as to States which appear to have some promising employment approaches. The nine States are Florida, Massachusetts, Michigan, Nebraska, New Mexico, Ohio, Oregon, South Dakota, and West Virginia.

In addition to the 9 State Councils, we also obtained information from 9 Vocational Rehabilitation agencies, 8 Mental Retardation/Developmental Disabilities agencies, 4 Mental Health agencies, 10 employers, and 13 job agencies. We conducted telephone surveys of Executive Directors for the nine Councils to determine specific employment activities supported by those Councils during 1996, 1997, and 1998. We obtained and examined performance information submitted to ACF on program performance reports, reviewing the types, extent, and outcomes of employment programs supported by the State Councils which specifically assist individuals with developmental disabilities.

We conducted on-site visits at four of the nine sampled States. On-site visits were selected in part based on promising approaches identified in the telephone surveys. During these visits, we interviewed the Executive Director of the State Council and Council staff, the State Vocational Rehabilitation Director, the State Mental Health Director, the State Mental Retardation/Developmental Disabilities Director, a job agency, and at least one employer that participates in programs to hire persons with developmental disabilities. We gathered additional insights and perceptions on promising employment programs which expanded upon and substantiated our prior telephone discussions.

For the remaining five States, we gathered information from directors of Mental Health, Vocational Rehabilitation, and Mental Retardation/Developmental Disabilities agencies, as well as job agency directors and employers. In all, we gathered information from 53 State entities, employers, and job agencies. We gathered information on systematic processes, roles of various State entities, key factors and relationships among State entities, documentation of employment activities, and barriers and how to minimize them.

We conducted our review in accordance with the *Quality Standards for Inspections* issued by the President's Council on Integrity and Efficiency.

FINDINGS

Promising Employment Programs

While State Councils in most cases do not obtain direct employment for persons with developmental disabilities, they are instrumental in facilitating job opportunities for persons with developmental disabilities. The Councils initiate demonstration projects by providing seed monies for promising employment approaches. These demonstration projects are often in conjunction with State Vocational Rehabilitation, State Mental Retardation/Developmental Disabilities agencies, and local community providers and job agencies.

We found a number of promising program strategies to assist individuals with developmental disabilities to obtain jobs. Some employment programs have wide application, and are generally considered quite successful by all State Councils. These employment activities which are actively endorsed by all nine State Councils are public awareness initiatives, supported employment programs, and high school-to-work transition programs. A second category comprising innovative employment programs are consumer directed vouchers, entrepreneurial grants, and State hiring programs which Council directors indicate yield successful results. In addition, nearly all respondents report that these promising programs could be replicated in other States.

Public Awareness

All nine State Councils work to increase public awareness of the employability of persons with developmental disabilities through poster campaigns, periodic newsletters, legislative proposals, resource guides, videos, and conferences. They are also heavily involved in advocacy efforts to change perceptions and attitudes about persons with developmental disabilities. They work to place them in visible settings, thus raising the level of awareness of the competencies and abilities of persons with developmental disabilities. Some State Councils reduce and remove attitudinal barriers by highlighting current employment programs on an Internet website and by providing public recognition of exemplary employers.

Supported Employment

Supported employment includes paid work in a variety of integrated settings. It is directed to individuals for whom competitive employment at or above minimum wage has not traditionally occurred, and who, because of their disability, may need intensive ongoing support to perform in a work setting. Supported employment work sites range

from regular work sites without any physical accommodations to work sites especially designed for severely physically or cognitively challenged individuals. Examples of work sites we visited include a woodworking facility, a graphics arts company, and a factory with light assembly work. Supported employment programs traditionally have job coaches who provide initial training and adaptation to the job setting for a period of a few weeks to several months, usually until the person with a developmental disability can function virtually independently. As an example, the Developmental Disabilities Services agency in Florida reported that the number of individuals with developmental disabilities in supported employment programs in that State has increased approximately 38 percent from 1996 (2,840 persons) to 1998 (3,931 persons).

High School-to-Work Transition

High school-to-work transition programs create career opportunities for persons with developmental disabilities. These transition programs were developed because traditionally many persons with developmental disabilities had limited career options upon high school graduation. Transition programs promote the concept that if individuals with developmental disabilities acquire jobs right before or immediately after high school graduation, they are more likely to work and are prone to continue working during their adult years. The programs we examined appear to be very promising because students are allowed input in the decision-making processes of their individualized career plans. Michigan reports that transition programs for youth with developmental disabilities served in special education settings up to age 26 increased approximately 31 percent from 1996 (7,169 persons) to 1998 (9,398 persons).

Consumer Directed Vouchers

In five of nine States, we found examples of successful consumer directed voucher programs. Following the concept of person-centered planning found in transition programs, consumer directed voucher programs allow families and individuals with developmental disabilities to control a selection process of purchasing services and supports which will result in employment. Through the consumer directed vouchers, persons with developmental disabilities design individual employment plans to facilitate their goals. Families, friends, and the person with developmental disabilities work together to choose their own employment advisors, community-based providers of services, job coaches, and job agencies. Through this activity the Oregon family grants voucher program serves 25 families per year. In 1997-1998, the voucher program in Oregon helped to place 50 persons with developmental disabilities in employment.

Entrepreneurial Grants

Entrepreneurial grants provide financing for creative, individual business plans submitted by persons with developmental disabilities. Entrepreneurial grants support specifically tailored business plans which are often nontraditional ideas launched by forward-thinking persons with developmental disabilities wishing to pursue a unique job opportunity on their own. We note that three of the nine States sampled (Massachusetts, South Dakota, and West Virginia) are actively seeking requests for entrepreneurial grant proposals. Entrepreneurial grants provided the start-up costs for a lawn care service, an antique business, a typing service, and a shredding service for developmentally disabled individuals in West Virginia.

State Hiring Initiatives

We found State government hiring programs in Florida and Massachusetts, in which State government vacancies are specifically marketed for individuals with developmental disabilities. In Massachusetts, vacancy announcements are amended to emphasize the search for applicants with developmental disabilities across all levels of State government. In Florida, a program coordinator with developmental disabilities was hired through a grant from Vocational Rehabilitation. Through this program, over 20 individuals with developmental disabilities obtained (and many retained) their positions through this government hiring initiative from fiscal year 1996 - 1998.

Related to employment programs and their potential for promising outcomes, respondents identify a number of trends which have influenced employment programs over the past three years. Some of these trends are: a prevalence toward service industry jobs; increased public and employer awareness of hiring persons with developmental disabilities; and more focus on hiring persons with severe disabilities. Also, while a growing economy increases the availability of jobs for individuals with developmental disabilities, modern jobs requiring the ability to perform multiple tasks simultaneously render some persons with developmental disabilities incapable of conducting certain work. See Appendix A for a listing of trends reported by respondents.

Factors and Relationships Important in Obtaining Jobs

We identified a number of activities that are important in creating jobs and obtaining success in employment programs. These activities are based on comments from State Councils, State Mental Health agencies, State Vocational Rehabilitation divisions, State Mental Retardation/Developmental Disabilities agencies, employers, and job agencies.

Out of a total of 53 respondents, numerous factors are identified as important in creating jobs, including involvement of the employer community, building long term support systems for persons with developmental disabilities, and effectively marketing the skills of persons with developmental disabilities to businesses. Table 1 on the next page lists the major factors respondents believe are important to create jobs.

Table 1

Factors in Creating Jobs for Persons w/ Dev. Disabilities ¹		
Involvement of employer community	23 respondents	
Planning for long term support; building "natural supports" ²	19 respondents	
Effective marketing (filling an employer's human resource need)	10 respondents	
Basing job choices on personal interest	9 respondents	
Including family members and agencies in the job search effort	5 respondents	
Changing public and employer perceptions of abilities	4 respondents	
Opportunities for job try-outs	3 respondents	
A positive attitude towards persons with developmental disabilities	2 respondents	
¹ Study participants may have indicated more than one response.		

²"Natural supports" are coworkers, friends, neighbors, and family upon which the person with developmental disabilities relies.

Source: Office of Evaluation and Inspections (OEI) Survey, 1999

State entities, employers, and job agencies also indicate that there are many methods to foster and enhance important relationships. Out of 53 total respondents, the following relationships are cited in Table 2 as critical to the success of employment programs for persons with developmental disabilities.

Table 2

Relationships Important for Success in Employment Programs ¹		
Collaborating with other State agencies and entities to establish effective approaches	23 respondents	
Educating employers on hiring persons w/developmental disabilities	9 respondents	
Developing a unified State disability policy across agencies	6 respondents	
Working with agencies to implement coordinated, flexible funding	4 respondents	
Creating public awareness for supported employment	3 respondents	
¹ Study participants may have indicated more than one response.		
Source: OEI Survey, 1999		

When asked how employment programs can be enhanced, a job agency director said that common definitions and terms could be an asset to implementing better employment programs, and a State Vocational Rehabilitation director noted that a common database could enhance relationships in the employment programs. Also, a director of a State Mental Retardation/Developmental Disability agency said, "No one's work is ever finished," that after placement of a person with a developmental disability into a job, many entities, including job coaches, the State Council, Vocational Rehabilitation, and community providers must remain integrally involved in the continued oversight of achievements and problems of the newly hired employee.

Less than Effective Approaches to Employment

State Councils and entities that work with persons with developmental disabilities indicate there are a number of approaches which are less than effective in obtaining employment. Ineffective approaches listed most frequently among respondents were:

- Poor job matching
 - Merely filling "slots," as opposed to assessing the vocational interests of the person with developmental disabilities. Respondents say the more individualized the "match," especially if a job has been specifically carved out, the more likely the job will last;
- Jobs demanding high production These types of jobs are often very stressful, placing the person with developmental disabilities in an uncomfortable, high-speed, high pressure situation;
- Employees in these settings generally earn less than minimum wage with no benefits, and do not have opportunities for promotion. We were also told that some supervisors at sheltered agencies may retain their best workers to keep up with production demands, rather than allowing persons with developmental disabilities to compete in the private sector or move into a supported employment setting;
- Mobile work crews/enclaves
 We were told that placing individuals in roving work crews which perform cleaning and other custodial tasks in office buildings (perhaps spending 10 minutes in 20-25 different offices) does not allow for full integration of persons with developmental disabilities;

- It is important not to overemphasize tax incentives or "oversell" potential employees with developmental disabilities. Rather, job agencies and placement specialists should work to fill actual human resource needs which companies have. We were cautioned by one State that businesses might terminate an employee should financial incentives expire; and
- Prescribing outdated pre-vocational training models
 We were told that too much emphasis on skills building and job preparedness is a less than effective approach. While training of the employee with developmental disabilities is important, many employers are now conducting training themselves, reducing the need for extensive, pre-placement training.

Highlights of comments regarding ineffective approaches to employment are contained in Appendix B, which includes various responses from State Councils, State agencies, job agencies, and employers.

Barriers and Ways to Address Them

State entities informed us of many barriers which impede the development and administration of employment programs, with the greatest barrier that persons with developmental disabilities encounter being a lack of transportation. All State Council directors list transportation as one of the top five barriers to employment for persons with developmental disabilities. (Appendix C reflects the barriers rated by State Council directors).

The general consensus of Councils to remedy transportation problems is to assemble a task force of the friends, parents, siblings, relatives, neighbors, job coaches, and prospective coworkers of the person with developmental disabilities to devise an individualized transportation plan so that he/she has the ability to go to work on a dependable basis with a reliable mode of transportation.

Respondents also said that fear of losing a monthly Supplemental Security Income (SSI) check is a disincentive to work. People with developmental disabilities may also have chronic medical conditions, yet may not have health insurance to pay for the care. These two barriers may be addressed by the proposed Work Incentives Improvement Act of 1999, which will expand Medicaid options for States and encourage SSI beneficiaries to return to work by providing an assurance that cash benefits will remain available if employment proves unsuccessful.

Negative perceptions held by employers about the employability of a person with developmental disabilities are a common obstacle. Raising public awareness and support for obtaining jobs for persons with developmental disabilities can be accomplished through presentations to civic groups such as Chambers of Commerce, Lions and Rotary clubs, and employer groups, and by developing business advisory councils. Such advisory councils are groups of employers which periodically assemble to discuss employment needs in the community and how to effectively hire individuals with developmental disabilities. They can assist employers in understanding their responsibilities in regards to the Americans with Disabilities Act, specifically any physical accommodations which must be made to adapt their workplace for a prospective employee with developmental disabilities. Also, of the employers surveyed, 7 of 10 indicate that assistive technology is not needed for their newly hired individuals with developmental disabilities.

Communicative skills in a professional business setting are traditionally a weakness of persons with developmental disabilities. Work and social skills may be enhanced on the job with the assistance of a job coach and a supervisor. Also, a practical way to address concerns of employers is to demonstrate the various skills and abilities that the person with developmental disabilities can contribute to the job. Job agencies can work specifically with individual employers to make successful one-on-one matches.

Lack of flexible financing arrangements among State entities is a commonly expressed barrier by State Councils, Vocational Rehabilitation, State Mental Health, and State Mental Retardation/Developmental Disabilities agencies. Several State entities in Massachusetts recently developed a mixed funding stream through years of collaborative meetings where the various agencies used creativity to devise a manageable, cooperative arrangement of financing where community based providers charge the same amount for certain pre-approved services. This mixed funding stream is an outcome based payment system which allows funding to be assigned to developmentally disabled individuals who can choose their service components as well as providers of service.

Limited Employment Outcome Data

We talked to 53 respondents and reviewed 1998 program performance reports from the nine State Councils. We found data is limited and inconsistent from State to State. We could not find where outcome data is generally available for use in determining success, effectiveness, and performance aspects of employment programs. Respondents indicated in many cases that such data is not available or is questionable in terms of its usefulness and reliability. They believe that greater detail and more extensive data would be beneficial in their evaluation of employment programs and their effectiveness.

We found that very little management information exists on performance and outcomes of monitoring employed individuals with developmental disabilities. While State Councils obtain some data on a grant-by-grant basis, few State entities perform extended follow-up. Therefore, information on the length or range of time persons with developmental disabilities and employers participate in employment programs is generally not available. Also, in 34 CFR §361.56(d), Vocational Rehabilitation is permitted to "close out" successful job placements after 90 days. This makes it difficult to perform extended evaluations or comprehensive, longitudinal studies of the successes of employment for persons with developmental disabilities.

While State Vocational Rehabilitation agencies keep demographic information by certain disability categories, their data does not specifically discern which individuals served have developmental disabilities. Also, State Mental Health and State Mental Retardation/Developmental Disabilities agencies may follow different definitions for developmental disabilities.

The Nebraska and Oregon State Mental Retardation/Developmental Disabilities agencies advise us that two promising performance management initiatives are being conducted which assess the need for baseline performance information. A partnership between the National Association of State Directors of Developmental Disabilities Services and the Human Services Research Institute was formed in January 1997 to conduct the "Core Indicators Project." The purpose of this project is to develop nationally-recognized performance and outcome indicators that will enable individual State Developmental Disabilities Services agencies to benchmark performance in comparison with other agencies, as well as to provide longitudinal data to determine performance level from one period to the next. Employment data such as average hourly wages, number of hours worked, and length of time on the job is being considered for the indicator set.

The Oregon Office of Developmental Disabilities Services has a contract with the University of Oregon to collect employment data from local job agencies on a semi-annual basis. Information is monitored for all employment consumers. Performance measures include type of work, duration of employment, hours worked, and hourly earnings for each recipient.

In response to employment performance measures established by ACF in 1997, seven of the nine State Councils have established one or more numerical employment goals. Because employment performance measures are included in the current State Council Three-Year Plans (1998-2000), we asked each of the nine State Councils whether numerical employment goals influence the implementation and success of employment programs. Four of seven States with numerical employment goals respond affirmatively, noting the need to be outcome oriented for success. State Council directors' perspectives are shown in Table 3 on the next page.

Table 3

Importance and Impact of Numerical Employment Goals		
"Do numerical goals have a positive effect on the outcome of employment programs"?	Comments	
Yes.	We look at outcomes, not just the process.	
Yes.	We have become more outcome oriented.	
No.	Didn't change our strategy/methodology; it forced us to look at outcomes and ask, "So what?"	
Don't Know.	Puts pressure on a job agency/employment service provider to put a person in a job.	
Not applicable.	This State chose not to have numerical employment goals.	
Not applicable.	This State chose not to have numerical employment goals.	
No.	Not enough experience with goals yet to tell.	
Yes.	We are trying to be more in compliance with the Govt. Performance and Results Act. We look at end result, not just the process.	
Yes.	We don't have a lot of experience with goals; accountability is a good factor.	
Source: OEI Survey, 1999		

RECOMMENDATIONS

A number of positive initiatives are being undertaken by State Councils directly or through collaborative programs with other State agencies. However, identifying Statewide performance data is difficult. While it may be challenging for State Councils to capture and measure extensive information on general effectiveness of employment programs, steps need to be taken to report the progress of persons with developmental disabilities in obtaining and keeping jobs. To accomplish this, ACF should consider the following:

Promising Practices Should be Shared Among States

State Councils identify a number of promising and innovative practices and generally feel these could be replicated in other States. In fact, some State Councils already require grantees to develop a replication manual for their demonstration projects. We believe that communicating these practices is in the best interest of employment programs and their effective operation. Three specific actions that ACF/ADD should consider include:

- 1) working with State Councils to develop an ongoing inventory of successful employment initiatives;
- 2) working toward developing a formal mechanism to allow State Councils to share promising employment approaches on a national level. One method for accomplishing this is by ACF publishing and updating reports of State Council innovative practices on the ACF/ADD website at http://www.acf.dhhs.gov/programs/add, and by disseminating materials through mailings and conferences; and
- 3) communicating practices known to enhance the quality and efficiency of data documentation and reporting.

Core Data Requirements Should be Established to Evaluate Job Initiatives

State entities confirm the benefits of having outcome data to relate performance/ achievement, and to measure effectiveness. Despite activities underway to develop and implement such outcome data, we believe it would be beneficial for ACF to develop mandatory performance measures with which all State Councils must comply.

The current system of selectively choosing a small portion of the overall set of performance measures severely limits the ability of ACF to adequately assess operational effectiveness and outcomes of Council-sponsored employment initiatives. The ACF/ADD should consider working with State Councils to identify those specific mission-critical performance measures which must be addressed annually by each Council.

We note that a beneficial tool in this effort may be the "Core Indicators" being developed by a workgroup of State Mental Retardation/Developmental Disabilities directors. While these performance measures are largely focused on State mental retardation issues, some of the measures may be valuable to apply to all persons with developmental disabilities.

AGENCY COMMENTS

The ACF concurred with recommendations in this report. We have made changes to the final report to reflect agency wording suggestions. The full text of ACF's comments are included in Appendix D.

Recent Trends As Reported By Respondents¹

Low unemployment rates in the general population	19 respondents	
Substantial increase in service industry employment for the general population	13 respondents	
Increase in employer/public awareness	7 respondents	
Low wages and benefits; part-time work	7 respondents	
Increase in supported employment activities	6 respondents	
More opportunities for persons w/ severe disabilities	5 respondents	
Multi-tasking required of modern jobs	4 respondents	
Increasing number of home-based, self employed and entrepreneurial businesses	4 respondents	
Emphasis/move to "natural supports" ²	3 respondents	
Increased use of temporary job agencies which do not accept or employ persons w/ developmental disabilities	3 respondents	
Difficulty of finding jobs in rural areas	3 respondents	
Decrease in sheltered agencies/workshops	3 respondents	
Welfare-to-work population competing with persons with developmental disabilities for jobs 2 respondents		
¹ Study participants may have indicated more than one response		
² "Natural supports" are coworkers, friends, neighbors, and family upon which the person with developmental disabilities relies.		
Source: OEI Survey, 1999		

Ineffective Approaches, As Specifically Reported By Respondents

State Councils	Vocational Rehabilitation	Mental Health; MR/DD ¹ agencies	Employers	Job Agencies
Sheltered workshops. Large conferences.	Grants: when payments are made before services are rendered.	Program-based approach, rather than person centered planning concept.	Too much paperwork; bureaucracy got in the way.	Unwillingness of the employer to "carve out" an appropriate job for the person with a developmental disability.
Local coalitions cease when funding stops.	Work crews (these should only be used as a last resort).	Offering too many financial incentives.	Tax credit paperwork is difficult.	High pressure jobs with stress and heavy production schedules.
Treat the person as "charity."	Persons with severe disabilities require more than "natural supports."	Lack of transition services.	Overanxious expectations.	Inadequate screening. Poor fit between person and job.
Don't oversolicit businesses.	Training without job development.	Use of vocational assessment tools and tests.	Employer not taking the time to train.	Poorly organized small businesses with unsafe working conditions.
Meaningless jobs.	Begging for jobs.	Non-supportive parents.	Poor job matching.	Placing a person before they are ready.
Segregated worksites.	Granting money to groups.	Pre-vocational training models.	Harsh treatment, reprimands.	Lack of individual attention. "One size fits all" thinking.
Persons with severe disabilities need more than just "natural supports."		Local advisory groups tend to fall apart. Slotting.	Inventing/ making up work to keep the person busy.	Jobs which involve a lot of change or which demand mastery of many tasks. Jobs at less than
1.1				minimum wage.

¹Mental Retardation/Developmental Disabilities agencies

Source: OEI Survey, 1999

Barriers As Reported By State Councils¹

Florida	 Transportation People who need job coaches Loss of SSI/Medicaid Limited support of school systems/curriculums Performance-based funding leading to "creaming"
Massachusetts	 Attitudinal and systemic hiring barriers Transportation Cost-sharing agreements between service delivery systems Maintaining competent and qualified staff
West Virginia	 Transportation Loss of SSI/Medicaid Loss of health insurance Availability of employers Attitude
Michigan	 Transportation Job readiness skills of persons with developmental disabilities Loss of SSI/Medicaid People who need attendant care at work People with little or no communication skills
Ohio	 Loss of health insurance Transportation Loss of SSI/Medicaid People who need attendant care at work Employer ignorance, perceptions, and fears
Oregon	 Use of "alternatives to employment" for persons with severe disabilities State offset of disposable income for residential services Transportation Federal work disincentives (SSI/Medicaid) Minimum wage increase to \$6.50 in Oregon

¹ Barriers are listed in descending order of importance.

Nebraska	 Attitudes of employers Loss of health insurance Transportation Lack of social skills of employees Availability of employers
New Mexico	 People believe persons w/developmental disabilities cannot work Limited support of residential service providers Limited support of school systems/curriculums Loss of SSI/Medicaid Transportation
South Dakota	 Transportation Availability of employers People who need job coaches Limited mentoring/training opportunities Loss of SSI/Medicaid
Source: OEI Survey, 1999)

Agency Comments



DEPARTMENT OF HEALTH & HUMAN SERVICES

ADMINISTRATION FOR CHILDREN AND FAMILIES 370 L'Enfant Promenade, S.W. Washington, D.C. 20447

AUG 1 1 1999

MEMORANDUM

TO:

June Gibbs Brown

Inspector General

FROM:

Olivia A. Golden

Assistant Secretary for Children and Families

SUBJECT: OIG Draft Report: "Employment Programs for

Developmentally Disabled Persons,"

(OEI-07-98-00260)

Thank you for the opportunity to review "Employment Programs for Developmentally Disabled Persons". We appreciate the opportunity your office afforded us by examining employment programs for people with developmental disabilities and the interest and professionalism of the staff in the Kansas City Regional Office of Evaluation and Investigations.

The report findings are exciting and helpful. It is especially gratifying to know that, in addition the nine Councils in the study, other Councils are involved in similar employment programs. In addition, the report corroborates Federal DDC mandates in that the promising employment programs noted in the report were achieved through Council activities mandated by Congress, e.g., demonstration projects, public education, and advocacy.

We support your recommendation about sharing promising employment practices among Councils and believe this can be readily achieved by the Administration on Developmental Disabilities (ADD) and the programs it administers. Although we are breaking new ground in the area of data collection, State DDCs are using a fairly extensive menu of performance measures to report employment outcome data. I am confident that ADD and the Councils will develop a process to identify a small set of mandatory measures for all DDCs.

Page 2 - June Gibbs Brown

We recommend revising the report to reflect the Administration's sensitivity to people with developmental disabilities and their families. Information and recommendations about preferred language are attached. We also ask that the reference to lobbying under Public Awareness on Page 10 of the report be deleted. Although Council advocacy, information, and public education activities are sometimes misinterpreted as lobbying, DDCs may not use Federal funds for the purposes of lobbying.

Our collaboration with your office has been a positive experience. My thanks to everyone involved.

Attachment

Introduction

 Purpose, Background, State Developmental Disabilities Council, National Disability Associations (opening sentence), Vocational Rehabilitation and Mental Health Agencies, Scope and Methodology.

Findings

 Promising Employment Programs, Public Awareness, Supported Employment, High School-to-Work Transition Consumer Directed Vouchers, Entrepreneurial Grants, State Hiring Initiatives, Factors and Relationships Important in Obtaining Jobs, Less than Effective Approaches to Employment, Barriers and Ways to Address Thom, Limited Employment Outcome Data.

Recommendations

 Introductory paragraph, Core Data Requirements should be established to Evaluate Job Initiatives, Appendix A, Appendix B, Appendix C.

For additional information, please contact:

Lynne Lau Program Specialist, ADD (202) 690-6589

Attachment

USE OF LANGUAGE PREFERRED BY AND SENSITIVE TO PEOPLE WITH DISABILITIES

"People first" language recognizes the individuality of a person by placing the person before the disability. By focusing on "abilities" it is generally accepted in the field of disabilities. Letters, reports, and other documents used by the Administration on Developmental Disabilities (ADD) contain "people first" language.

Examples:

Use "people with developmental disabilities," "individuals with developmental disabilities," "a family member with developmental disabilities," "persons with developmental disabilities: (individual with epilepsy), etc.

Avoid using "the developmentally disabled," "developmentally disabled persons," "developmentally disabled individuals," and terms like the retarded, mentally retarded, epileptics, handicapped, etc.

Recommend using "people first" terminology throughout the report. Following are sections of the report where terms to avoid were found:

Report Title

 Revise the report title to read: "Employment Programs for People with Developmental Disabilities". Applles to the title page, inside cover page and all footer titles.

Incorporate "people first" language in:

Executive Summary

- Purpose, Background, Findings, Factors and Relationships Important in Obtaining Jobs, Less than Effective Approaches to Employment, and
- Recommendations, Promising Practices Should be Shared Among States, and Core Data Requirements Should be Established