

EMPLOYMENT PERSONAL ASSISTANCE SERVICES (EPAS)
EVALUATION REPORT

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Table of Contents

Executive Summary	3
Introduction	5
Purpose of Evaluation	7
A Description of EPAS Program Participants as of December 2004	8
Participant Demographics	8
Program-related Statistics	8
Employment-related Statistics	9
Participant Interview Data	9
Methodology	9
Sample Description	10
Interview Findings	11
Employment Support Plans	11
Health and Safety Issues	12
Satisfaction with Paid Supports	12
Preparation to Supervise Personal Assistants	13
Satisfaction with EPAS Service Broker	14
Employment-related Issues	14
Impacts on Other Life Domains	15
Awareness of Other Work Incentives	16
Other Issues and Concerns	16
EPAS Service Broker Interview Data	16
Methodology	16
Interview Findings	17
Enrollment and Recruitment	17
Implementation	17
Additional Comments	18
Summary of Findings	19
Recommendations	19
Limitations of this Study and Recommendations for Future Evaluations	21
References	22
Appendices	
Appendix A: EPAS Quality Assurance Interview Form	23
Appendix B: Supplemental Questions for EPAS Quality Assurance Interviews	24
Appendix C: EPAS Service Broker Questions	26

Executive Summary

Program Purpose and Overview of Services

The goal of the Medicaid Employment Personal Assistance Services (EPAS) program is to help individuals with disabilities to maintain employment, which is essential for them to be able to sustain or increase their self-sufficiency and quality of life. EPAS is a Medicaid State Plan service implemented in July 2002 that provides employed individuals with disabilities with personal assistance services. The service must support their employment and may include assistance or cueing with daily living activities such as bathing, dressing, transportation, help with shopping, housecleaning, and reminders to take medication.

The EPAS program was developed under the direction of the Utah Work Incentive Initiative (now called Work Ability), funded by a federal Medicaid Infrastructure Grant, and administered by the Utah Department of Health. Work Ability is a systems change project with a goal of improving health care coverage and employment supports for individuals with disabilities. EPAS services are funded by Medicaid through a state plan personal care option.

Purpose of This Evaluation

This evaluation of the EPAS program was conducted by a team of evaluators from Utah State University and the University of Utah. Its purpose was to provide a "snapshot" of the 35 individuals participating in the EPAS program (as of December 2004), and to provide more in-depth information regarding EPAS participants' personal experiences and how they view the effectiveness of the program in relation to their employment situations, health and well-being, and overall quality of life. This information was gathered from administrative data for the 35 EPAS participants, interviews with the two EPAS service brokers, and interviews conducted during October and November 2004, with a sample of 15 individuals who had been enrolled in EPAS for a minimum of 6 months.

Key Findings

Findings from this evaluation process indicated that, overall, program participants were satisfied with both EPAS staff and services. EPAS staff earned especially high marks from participants for their responsiveness to consumer needs and outreach efforts. Also worth noting is the fact that a majority of the 15 individuals interviewed were utilizing other Work Ability related programs in addition to EPAS. Ten (67%) of the individuals were using the Medicaid Work Incentive (MWI) to qualify for EPAS and nine (60%) had utilized the Utah State Office of Rehabilitation (USOR) Benefits Planning Assistance and Outreach (BPAO) program.

As of December 2004, there were 35 individuals with disabilities who were employed and participating in the EPAS program. For these 35 participants:

- The median wage was \$6.12 per hour.
- The median number of hours worked per week was 20.
- One-half of the participants worked in food service or janitorial/housekeeping jobs; the other half were in professional occupations or clerical, retail jobs.

Participants who were interviewed expressed high levels of satisfaction with the tangible supports EPAS provides. Participants also pointed out the program's less tangible benefits in

relation to their work situations, capacity to work, and work attitudes. Specifically, the following benefits were noted and by how many respondents:

- Have more energy to work/less fatigue (4)
- Financial situation improved (3)
- Hours at work were increased (2)
- Increased social skills at work (2)
- Without support, individual feels s/he would not be able to work (2)
- Attitude toward work has improved (2)
- Received promotion (1)
- Responsibilities at work were increased (1)
- Able to negotiate more favorable working conditions (1)
- Lowered absenteeism (1)
- Able to find a new job in desired field (1)

Follow-up studies could determine if the benefits identified by participants have positive impacts such as reducing employee tardiness and absenteeism, decreasing interpersonal conflicts at work, and increasing participants' capacity to improve the quality and/or circumstances of their work environments.

Summary

Findings from this study must be viewed as preliminary, but data indicate that the program is being well implemented as indicated by both administrative data and that collected from participant and service broker interviews. While EPAS undeniably provides tangible supports that help participants maintain and even improve employment opportunities, participants equally value important benefits such as reducing stress and anxiety, building self-esteem and self-confidence, and a heightened sense of well-being.

Introduction

The Ticket to Work and Work Incentives Improvement Act (TWWIIA) of 1999 was signed into law to help remove barriers to employment for individuals with disabilities and provide them with increased opportunities and supports to return to work, work more hours, or try working for the first time. The main purposes of TWWIIA are to:

1. Provide health care and employment preparation and placement services to individuals with disabilities that will enable those individuals to reduce their dependency on cash benefits;
2. Encourage states to adopt the option of allowing individuals with disabilities to purchase Medicaid coverage that is necessary to enable such individuals to maintain employment;
3. Provide individuals with disabilities the option of maintaining Medicare coverage while working; and
4. Establish a return to work ticket program that will allow individuals with disabilities to seek the services necessary to obtain and retain employment and reduce their dependency on cash benefit programs (U.S. Committee on Ways and Means, 1999).

In order to advance the purposes of TWWIIA, the Department of Health and Human Services (DHHS), under Section 203 of the Act, designated the Centers for Medicare and Medicaid Services (CMS) as the lead agency responsible for developing a grant program to support states in their efforts to improve access to health care coverage for individuals with disabilities who want to work. As a result, CMS created the Medicaid Infrastructure Grant program, also known as MIG grants, which is authorized for 11 years with \$150 million dollars appropriated for the first five years of the program. MIG states receive a minimum of \$500,000 per year of the grant period. The MIG grants provide money to states to develop or enhance one or both of two core Medicaid components, a Medicaid Buy-in program for people with disabilities who are working and a program to provide personal assistance services to support individuals with disabilities to maintain their employment.

The state of Utah was one of the first 25 states to receive a MIG grant. All 25 states receiving MIG grants during the initial funding cycle opted to use at least a portion of the funds to develop a Medicaid Buy-in program that allows individuals with disabilities who are working and making more than 100% of poverty to continue receiving Medicaid by paying a monthly premium based on their income and household size. In Utah the Medicaid Buy-in program is known as the Medicaid Work Incentive or MWI. In addition to developing Buy-in programs, 19 of the first 25 MIG States, including Utah, also opted to expand personal assistance services to support individuals with disabilities in maintaining their employment.

Work on the Utah MIG grant began in October 2000, under the direction of the Utah Work Incentive Initiative project (renamed Work Ability). Work Ability is administered by the Utah Department of Health, Division of Health Care Financing and is a system change project to improve health care coverage and employment supports for individuals with disabilities. The Work Ability project led the effort to establish both the Medicaid Work Incentive and the Medicaid Employment Personal Assistance Service (EPAS) program.

The Department of Health (DOH) EPAS program is a Medicaid State Plan service, implemented in July 2002 that provides individuals with disabilities, who are working, with personal

assistance services to support them in maintaining employment. Personal assistance services that may be provided under the EPAS program include assistance with Activities of Daily Living (ADLs) such as bathing, dressing, eating, and transferring; and with Instrumental Activities of Daily Living (IADLs) such as shopping, cooking, money management, cognitive cueing, medication management, symptom management, and transportation. The personal assistance services may be provided at home or at work. To be eligible for the EPAS program an individual must:

- Have a disability as determined by the Social Security Administration or the Utah Medicaid Office.
- Have a current Medicaid card.
- Work at least 40 hours per month in an integrated, competitive job setting. (Work in a sheltered workshop does not qualify.)
- Need personal assistance in order to work. (This is determined through a comprehensive assessment conducted by Medicaid.)

Individuals receiving services through one of Utah's Medicaid Home and Community Based Waiver programs that offer personal assistance services (MR/DD, Physical Disabilities and Aging Waivers), are not eligible for the EPAS program. Two other Waivers (Technology Dependent and Acquired Brain Injury Waivers) do not offer personal assistance services, thus recipients enrolled in one of these Waivers can access EPAS.

For an individual who does qualify for the EPAS program, personal assistance services may be provided at home and/or at work. Personal assistance services received in the workplace as part of the EPAS program are not to be confused with job coaching or reasonable accommodations provided for under the Americans with Disabilities Act (ADA) and requested by an employee with a disability.

The EPAS program also allows an eligible individual to hire his or her own qualified personal assistant or work with a home health agency. Under the "consumer-directed" option, an individual finds and hires his or her own personal assistant(s), and then works with a fiscal employer agent that handles the business aspects of employing an assistant (e.g., cut paychecks, withhold applicable taxes). Under the home health agency option, the agency takes care of hiring the assistant(s) and is responsible for all aspects of employing the assistant(s).

Individuals may receive assistance in decision making from a guardian or a proxy. A guardian is a representative that is designated by a court to make health care or other legal decisions on behalf of an adult who has been determined by a judge to be incapacitated. A proxy is designated by an individual with a disability to assist the individual in decision making, but is not legally appointed by a court. The EPAS program involves either guardians or proxies in the process of employment support planning, selecting a personal assistant or other decisions, when appropriate.

In Utah, as in much of the nation, just fewer than fifty percent of individuals receiving disability benefits from the Social Security Administration have a psychiatric impairment as their primary disability. This, along with the fact that personal assistance services have traditionally focused on meeting the needs of individuals who have physical disabilities, led the Work Ability project to contract with Valley Mental Health (VMH) to conduct an innovative pilot project to determine

how personal assistance services could be enhanced to better meet the needs of individuals with psychiatric impairments who work. The pilot study was conducted between July 1, 2003 and December 31, 2004 and was administered separately from the Department of Health EPAS (DOH EPAS) program during that time. At the conclusion of the pilot study, individuals receiving services through the pilot program were integrated into the DOH EPAS program.

The overall purpose of the VMH EPAS pilot project was to develop and coordinate a consumer-directed personal assistance service model to support individuals with psychiatric disabilities in competitive employment. The specific objectives of the pilot project were:

- To develop customized employment supports using a personal assistance model for 30 to 50 individuals with a mental illness who also meet the Utah State definition for serious and persistent mental illness, who have a promise of a job or are employed, and who are having difficulty keeping their job.
- To evaluate the effectiveness of a consumer-directed PAS intervention for maintaining competitive, community employment.
- To identify the components of personal assistance and how they differ from other job related services, such as job coaching, for the person with a psychiatric impairment.

The target population for the pilot were individuals with a serious and persistent mental illness, who wanted to work, were Medicaid eligible, and had a history of never working or difficulty working. Enrollment criteria included:

- Person has DSM-IV Diagnosis and meets the Utah State definition of serious and persistent mental illness
- Person has unsuccessful work history or no work history
- Person is Medicaid eligible
- Person is not an active substance abuser
- Person is not homeless
- Person has no current criminal charges
- Person is an open client with VMH
- Person is working or has a promise of a job (40 hours per month or more)
(Valley Mental Health [VMH], 2003)

A detailed report of the VMH pilot and subsequent outcomes are forthcoming and will be available through the Work Ability project.

Purpose of Evaluation

This evaluation describes outcomes for participants of both the DOH EPAS and the VMH pilot and was conducted under the auspices of the Center for Persons with Disabilities (CPD) Interdisciplinary Training Division at Utah State University. The purpose of this evaluation is:

1. To provide a description of the individuals currently participating in the EPAS program (as of December 2004).
2. To better understand EPAS participants' personal experiences and perceptions of the program in relation to their employment situations, health and well-being, and overall quality of life.
3. To identify strengths in program implementation and make recommendations for program improvement.

A Description of EPAS Program Participants as of December 2004

Since the program's inception July 1st 2002, 63 individuals have applied to participate. Forty-nine were determined eligible, 12 were ineligible, and two had applications pending as of December 31, 2004. As of this date, 35 individuals were considered "active" program participants and are described in more detail below.

Participant Demographics

More than two-thirds of current program participants are men (24); 11 are women. With the exception of one Native American woman, all current participants are White. (It should be noted that according to the most recent census, 89.2% of the population in Utah is listed as White [U.S. Census Bureau, 2000]). Twenty-two (63%) of participants have never been married, seven are divorced. Thirteen (37%) of active participants have a psychiatric impairment, ten (29%) have a physical disability, nine (26%) have a developmental disability, and three (9%) have a traumatic brain injury. Finally, 12 of the current participants (34%) have a proxy or guardian.

Program-related Statistics

Twenty-three individuals participated in the DOH EPAS program, and 12 participated in the Valley Mental Health (VMH) pilot. As appropriate, the findings for each of these groups will be reported separately. Following is a list of referral sources to the EPAS program:

- VMH pilot study (12)
- Outreach by Work Ability staff (6)
- Division of Services for People with Disabilities (5)
- School districts (4)
- Private service provider (2)
- One individual was referred through each of the following sources: USOR BPAO, Vocational Rehabilitation, Utah Parent Center, Multiple Sclerosis Society, friend, self through the Work Ability website

The majority of current participants (30) use a fiscal employer agent to pay their EPAS assistants, while five receive EPAS services through a home health agency. Eighteen of the current program participants require help with both ADLs and IADLs. Seventeen participants require help with IADLs only. A particularly important support is help with transportation, which is utilized by more than three-quarters of current participants (27). Additionally, approximately one-quarter of program participants (8) require assistance with ADLs and/or IADLs in the workplace.

Current program participants have been enrolled in EPAS between 1 and 30 months, with a mean of 9.5 and a median of 8 months. Due to the wide range in this statistic, the median is the more accurate measure of length of program participation. Most EPAS participants are using the Medicaid Work Incentive (18), or qualify for a free Medicaid card (15) based on income, to meet the Medicaid eligibility requirement for the program. Of the two remaining individuals, one was using the Social Security 1619(b) provision to receive Medicaid and the other received Medicaid through the Technology Dependent Waiver. In addition to utilizing the EPAS program, twenty-

three (64%) of EPAS participants have also utilized the USOR Benefits Planning Assistance and Outreach program.

Employment-related Statistics

The 35 EPAS participants are engaged in the following types of work (categories are based on self-report):

- Janitorial/Housekeeping (17)
- Professional (8) [e.g., social service worker, lawyer, database manager]
- Retail/Sales (6) [e.g., customer service, telemarketing, grocery stacker/bagger]
- Clerical (4) [e.g., receptionist, mail room worker, bookkeeper]

“Number of Months on Current Job” ranged from 3 months to a high of 30 years 7 months. “Number of Hours Worked per Week” ranged between 10 and 40. Twelve individuals work between 10 and 19 hours per week, 9 work 20 hours per week, and 13 individuals work more than 20 hours per week. Finally, salary ranges between \$5.15/hr and \$19.54/hr. Fourteen individuals earned \$5.15 -\$6.00/hr, eleven earned \$6.01-\$8.00/hr, six earned \$8.01-\$10.00/hr, and three individuals showed earnings of more than \$10 per hour (specific hours and wage data were not available for one individual). Table 1.1 below summarizes these three employment-related statistics for current program participants.

Table 1.1 Summary of Employment-related Statistics

Employment Category	Mean	Median
Number of Months on Current Job	36.00	17.50
Number of Hours Worked per Week	20.59	20.00
Hourly Wage	7.37	6.12

Median hours worked per week and hourly wages were comparable for DOH EPAS and VMH pilot participants. There was a difference in terms of the number of months at current job (11.5 for VMH pilot and 20.0 for DOH EPAS participants).

Women currently enrolled in EPAS are employed more hours per week than men (median = 23 hours as compared to 20 for men). They have also been on their current jobs for a longer period of time (median = 23 months as compared to 17.5 for men). Counter to the prevalent labor market trend, their earnings are also higher, with a median of \$8.25 per hour as compared to men’s median earnings of \$6.12.

In terms of other notable employment-related differences, participants receiving services through home health agencies (5) had worked more months at their current job, with a median of 60 versus 17 months for those using the consumer directed approach. It should be noted, however, that the number of participants in this category (5) is very small in comparison, and these results are heavily skewed by 2 individuals with a long employment history.

Participant Interview Data

Methodology

An evaluation plan to monitor the overall impact of the EPAS program on individual participants was developed by the Employment Supports workgroup, which included both consumers and

provider agency staff. The overall evaluation was designed to monitor how EPAS services are being provided to individuals and what impact these services are having vis-à-vis maintaining employment and enhancing participant's quality of life. This initial evaluation was designed as a quality assurance process for the Medicaid agency to use for the EPAS program.

A semi-structured interview format was developed (see Appendix A) that addressed seven key areas related to satisfaction with services provided by personal assistants, home health agencies, fiscal employer agents, and EPAS service brokers. A set of supplemental questions (see Appendix B) was added to the main quality assurance form just prior to the interviews being conducted. These supplemental questions were designed to gather more general information regarding the overall experience of individuals participating in the DOH and VMH EPAS programs and addressed attitudes toward work, finding and supervising personal assistants, referrals to other Work Ability programs, changes in work situations due to EPAS, impact of EPAS on overall well-being, etc.

At the time of the interviews, a total of 18 individuals met the criterion of EPAS program participation for a minimum time period of 6 months. Of these, one individual could not be contacted, and two declined to participate, for a total sample of 15 (participation rate of 83%). The interviews were carried out face-to-face during the months of October and November, 2004, by a team of independent evaluators (two from Utah State University and one from the University of Utah).

Completed interview forms were compiled and analyzed by a member of the CPD evaluation team. Questions that lent themselves to quantitative analysis were coded and entered into SPSS 13.0 for Windows. Qualitative analysis was carried out by means of line-by-line analysis of text and the identification of higher-order themes with the aid of a word-processing program. Qualitative data are utilized to both clarify and add depth to the quantitative findings and are presented in the consumer's own words where possible.

Sample Description

Similar to the gender ratio of current active program participants, nine of the 15 individuals interviewed were men and six were women. In terms of Race/Ethnicity, all were White. Nine of the individuals interviewed had a psychiatric impairment and six individuals had a physical disability. Only one participant had a designated proxy or guardian.

Nine individuals were enrolled in the VMH pilot program, and six in the DOH EPAS program. Four individuals received services through a home health agency and 11 through a fiscal employer agent. Only two individuals were receiving assistance in the workplace as well as in the home. Ten of the individuals were using the Medicaid Work Incentive to qualify for EPAS and nine had utilized the Work Ability BPAO program.

Interviewed participants indicated that they had been referred to EPAS in the following ways:

- Through outreach by the VMH Service Broker (6)

- Through outreach by other human service agency staff (e.g., Vocational Rehabilitation, DSPD, nonprofit organizations) (5)
- Through word of mouth or other source (e.g., one individual was at a conference for people with disabilities) (4)

Following is a description of the types of services participants said they had received:

Activities of Daily Living:

- General support with ADLs (6) [e.g., dressing, eating, personal hygiene etc.]

Instrumental Activities of Daily Living:

- Housework (9)
- Laundry (6)
- Meal Planning/Preparation (6)
- Shopping (6)
- Transportation (5)
- Socialization/Someone to confide in (4)
- Wake-up calls/Other reminders (3)
- Help with organizing/Time management (3)
- Job-related problem-solving (3)
- Budgeting (2)
- Assistance with schooling/training (2)
- Adaptive equipment (1)

In terms of employment status, 14 individuals were employed at the time of their interviews. One individual had recently been laid off and was actively seeking work.

Interview Findings

Very few differences among either the DOH EPAS or VMH EPAS groups or among the fiscal employer agent and home health groups could be detected from the quantitative measures gathered during the interview process. None of the differences were statistically significant.

These measures were the extent to which:

- 1) the Employment Support Plan is being implemented;
- 2) health issues are addressed;
- 3) safety issues are addressed;
- 4) participant is satisfied with paid support (e.g., attendants, fiscal agent, home health agency);
- 5) participant is satisfied with EPAS Service Broker;
- 6) participant feels that s/he is able to supervise paid support; and
- 7) personal attendants are integrated into the workplace.

The qualitative data that follow provide a richer description of participants' experiences in each of these areas.

Employment Support Plans

Eleven participants felt that their Employment Support Plans (ESPs) were being satisfactorily implemented and that both ADLs and IADLs were adequately addressed. Four individuals indicated there were areas where improvement was needed, but also noted that these were

relatively minor and that they were making satisfactory progress in resolving the issues in these areas them.

“All my needs are being met. But it still feels awkward for me to let someone in. For many years I did it on my own. I’m very, very grateful for limited support in grooming and meal preparation.”

Health and Safety Issues

Similar results were obtained in terms of participants’ perceptions that health and safety issues were satisfactorily addressed. Two individuals receiving home health agency services noted that initially they had been worried about having someone they didn’t know in their home, but that had only been a temporary concern. Both of these individuals have significant mobility impairments. Seven individuals mentioned they felt a greater sense of safety or security because of their involvement in the program.

“The nights I worked in the winter when it was dark and snowy and I had all those [bus] transfers—I used to dread that.”

Satisfaction with Paid Supports

Participants expressed more concerns in relation to their paid support. Nine individuals indicated that they were satisfied with their paid supports, five indicated a need for improvement, and one person was dissatisfied.

Personal Assistants

Most VMH participants had employed more than one personal assistant (PA). They expressed some trial-and-errors in learning to find what constituted a good match for them.

“Finding someone who was both qualified and who I was personally comfortable with was the biggest challenge. There were some people who were qualified and came well-recommended, but I was not comfortable with them.”

Two VMH pilot participants who employed family members as Personal Assistants indicated a need for improvement in the personal assistant, and one was dissatisfied with the personal assistant. The dissatisfied individual felt he was being exploited. Both of these participants were concerned with how to draw appropriate boundaries with family members who had also become employees.

“I can’t express myself to her [a relative]. She takes advantage of me. She doesn’t keep things confidential.”

Turnover

Turnover was an issue for nearly all participants and occurred for a variety of reasons, both positive (PA found better employment opportunity or returned to school) and negative (relationship did not work out). Two individuals utilizing home health agency services felt they were frequently “breaking in” new staff, and that this was basically an unavoidable problem. Another individual in this group felt awkward “ordering people around.”

“I’m the type of person that doesn’t like to say anything bad. I want to be friends. I don’t want to say, ‘Do this, do this, do this.’”

Transportation

Some VMH pilot participants (4) expressed concern with regard to what they perceived as a lack of flexibility related to transportation assistance (e.g., some need transportation for trips that are not strictly work-related). Indeed, it appeared that some PAs were more flexible in this regard than others. For instance, one PA stopped at a local mall when transporting a program participant from work to home so that the participant could pick up a birthday present for her husband.

“Present all the options so people don’t feel like there’s such a narrow pathway.”

Recruitment of Personal Assistants

Most (12) participants did not have any trouble recruiting PAs. Two felt the process could use some improvement (these concerns were related to turnover); one individual on the VMH pilot felt there could be better screening of prospective employees, and that new hires sometimes expected they were going to be paid for more hours or receive higher salaries. Recruitment sources/methods for finding PAs included the following:

- Utilizing assistance from the VMH Service Broker to place advertisements or assist with recruitment in other ways, including screening or assistance with interviewing (5).
- The PA was hired through a home health agency (5).
- The participant hired a friend, neighbor, or relative (4).

Home Health Agencies

An issue that may be unique to participants using home health agencies was a reluctance to complain, as expressed by two individuals. For example, one individual was having a problem with one attendant, but worried about saying anything as it was hard to find someone to come in as early as he needed.

Fiscal Employer Agent

Two participants reported that the fiscal agent* was late on at least two different occasions in processing time cards and issuing paychecks to their personal assistants. This created a number of problems for the affected personal assistants. One of the EPAS participants who employed an impacted assistant stated that these types of problems can make it difficult to retain good assistants over a long period of time.

**It should be noted that the Utah Medicaid agency has only one approved fiscal agency currently approved and available to provide these services.*

Preparation to Supervise Personal Assistants

Thirteen of the program participants interviewed felt they were good employers (two participants felt they could use some improvement in this area). All of the nine individuals on the VMH pilot program had received structured training on how to supervise PAs, and eight indicated they would be interested in follow-up training.

Interestingly, participants in the DOH EPAS program felt slightly more prepared to supervise PAs and attendants than did VMH pilot participants. However, they also rated their supervisory training as less adequate than did VMH pilot participants (range = 0 to 2, with 0 being not sufficient and 2 being very sufficient; DOH EPAS participants had a mean score of .33 compared to a mean of .89 for VMH pilot participants).

Satisfaction with EPAS Service Broker

Thirteen individuals felt very positive about their respective service broker. The role of the EPAS service broker is similar to a case manager by assisting individuals with applying for EPAS, developing an employment support plan, ensuring recipients receive an appropriate level of service from the EPAS program, and providing information and referrals to other appropriate services. Comments included the following:

“She respects that it’s my plan.”

“She responds to my calls immediately.”

“I know I need someone to advocate for me and she’s that person.”

“I give _____ an A+. She’s been awesome. She’s helped me a lot.

“She always goes the extra mile . . . She treats you like a person.”

Two persons interviewed indicated a need for improvement in this category. One felt that his service broker was “upset” because he had been thinking about quitting the program.

Employment-related Issues

Both DOH EPAS and VMH pilot participants gave comparable ratings to questions regarding improvements in work situations and work attitudes. Summarized below are positive and negative comments relating to the program’s impacts on individuals’ work situations, their capacity to work, and work attitudes.

Positive Comments

- Has more energy to work/less fatigue (4)
- Financial situation improved (3)
- Hours at work were increased (2)
- Increased social skills at work (2)
- Without support, individual feels s/he would not be able to work (2)
- Attitude toward work has improved (2)
- Received promotion (1)
- Responsibilities at work were increased (1)
- Able to negotiate more favorable working conditions (1)
- Lowered absenteeism (1)
- Able to find a new job in desired field (1)

“[My work situation] has changed in a good way. It has given me the help I’ve needed so I can go out and make the money.”

“I’m learning to be more assertive and I’ve worked my way up. I’m over 4 individuals now. Those social skills [from being an employer] definitely translated at work.”

“I’ve learned to be more conservative about what I say and how to be more appropriate in how I express myself at work.”

“My job’s important to me. It’s easy to make friends there and I’m never more than 5 minutes late now. I can stay focused better.”

“It relieves stress by improving my home environment so I can keep my mind where it should be when I’m at work. When things are cluttered around me, my moods swing more and it’s easy to feel overwhelmed.”

Negative Comments

- Difficulty with supervisors at their jobs (2)
- Work situation has worsened (had been living minutes from work, but was transferred by employer; commute now over an hour on bus and very tiring) (1)

Impacts on Other Life Domains

Nearly all consumers (in both the VMH pilot and DOH EPAS programs) articulated a number of benefits from working that carried over into other life domains. In addition, comments focused on the importance of EPAS in reducing fatigue and stress, improving social relationships, and contributing to overall improved functioning and enhanced quality of life. Responses are grouped under three categories below:

Impacts on Self-confidence and Self-esteem

- Working built self-confidence and self-esteem for some individuals (5)
“I like being productive and out in society. You feel good about yourself.”
“I’m excited about my new job. I was finally able to go out and get into something that I want as a career.”
- Being an employer was a confidence booster for some individuals (4)
“It made me feel important.”
“I feel more confident making decisions now. I don’t have to check with my supervisor every 2 seconds.”

“It’s about empowerment. Consumers [individuals with disabilities] need to know they can do things and even take leadership roles.”

Impacts on Family and Other Relationships

- More energy to help out grandmother and to tend nephew and niece when needed (1)
- Gained respect in community (1)
- More comfortable having people visit as home is cleaner (1)
- Feels better about cleanliness, appearance and how others relate to him now (1)
“I have a girlfriend I plan to marry. . . I’m clean, healthy, and eating good. Seems like there’s something to my life now. I have a reason for living now.”

Improved Levels of Functioning

- Reduces stress, improving overall ability to function; manage problems (7)
- Improvement in general well-being (4)
- Improved time management skills (3)
- Improved social skills (3)
- Nutrition (3)
- Better mood (2)
- Personal Appearance/Cleanliness (2)
- Improved problem-solving skills (1)
- Learned better budgeting skills (1)

“It is a great programBlife-changing because I don’t have to spend time worrying about how I am going to pay for the attendant care that I need to work and have a greater sense of well-being because I don’t have this stress.”

“My attitude [toward work] has improved. I feel much better about my appearance going to work . . . Look at my home. It helps me feel good to come home at night to a clean house.”

“EPAS has turned my whole life around. My previous situation was untenable.”

Awareness of Other Work Incentive Programs

When asked about other work incentive programs or information regarding benefits planning, many consumers were unaware of the official terms used, but with prompts and explanations, it became apparent that nearly all were aware of these services and most had participated in benefits planning. Individuals with specific questions were referred to their Service Broker if they required additional information.

Other Concerns and Issues

Several individuals mentioned concerns or problems with Social Security and Medicaid that, although not directly related to the EPAS program, had a negative impact on their overall work situation:

- Many individuals felt they could work more hours or even full-time, but were unsure of how working more would impact their Social Security, Medicaid, and other benefits and were afraid to be left without a safety net (5)
- Individuals had ended up in Social Security overpayment situations (2)
- Individuals said there had been numerous mistakes in calculating Medicaid spenddown (2)
“The rules are too complex. One-stop shopping is needed.”
- Some wished the EPAS program could make provisions to provide personal assistant services for recreation or leisure needs (2)
- Individual had difficulty re-qualifying for Medicaid (1)
“. . . a little more information up front about maintaining Medicaid eligibility would help.”

EPAS Service Broker Interviews

Methodology

The service broker for the DOH EPAS program and the VMH pilot program were contacted by EPAS evaluation staff, by telephone, and asked the same five open-ended questions (see Appendix C). The first question addressed what is working well in the recruitment and enrollment phase of the programs and the second question addressed what could be improved or done differently in these areas. The third and fourth questions asked what has been working well in the implementation phase of the programs and what could be improved or done differently in this area. The final question asked for any other comments or suggestions regarding how to improve the DOH EPAS program in the future. Although the VMH pilot has ended and the participants have been transferred into the DOH EPAS program, the VMH service broker was asked to reflect on her experiences in each program area during the pilot and answer accordingly.

Interview Findings

Both service brokers reported similar experiences with what has worked well in each of the program areas and in many cases offered complementary ideas for improving each area. General issues and themes are reported by program area. As appropriate, responses from a specific service broker are reported.

Enrollment and Recruitment

Each of the service brokers reported that the process for enrolling an individual in the EPAS program is working well. For an individual who is already receiving Medicaid, the enrollment process takes 2-3 weeks from the time of referral to starting in the program. The enrollment process for an individual who is not yet receiving Medicaid can take 4-6 weeks, largely due to time it takes to get on Medicaid. Neither service broker felt that there was a need to improve the current enrollment process.

Both service brokers stated that ongoing outreach efforts have been successful in increasing enrollment. The DOH service broker also stated that current recruitment methods have helped the program serve individuals with a wide range of disabilities (see *Participant Demographics*, p. 9). The VMH service broker reported that recruitment efforts were generally more successful when she was able to provide individualized training and information about the program versus recruiting in a large group setting. According to the DOH service broker, outreach to rural areas of the state is one area that is in need of improvement. Participants currently utilizing the EPAS program are predominately residing along the Wasatch front with a few individuals residing in more rural areas (i.e., Cache and Wasatch counties).

Implementation

There are several areas of the implementation phase that both service brokers report are working well. The Employment Support Plans that guide the amount and type of assistance that an EPAS participant receives have evolved into a very comprehensive and effective document. The process of developing the support plan is person-centered and each individual is able to choose whom they would like to be involved in developing the support plan in addition to the service broker. Other participants in the support planning process may include family members, guardians, advocates, or case managers from other agencies and service providers.

The VMH pilot program had particular success in working with the local community college, university, and private employment agencies to develop a pool of personal assistants from which participants using the fiscal employer agent model could hire. This provided opportunities for individuals to find a good match when hiring and did not leave them in a position where they had to hire whoever applied. Additionally, the VMH service broker stated that the training materials that were developed to train participants to be employers and also to train potential personal assistants were very helpful. Although, she did find that these materials were more effective when used individually compared to the trainings that were done with large and small groups. A nice addition to the training materials was the packet of information on using and signing up for fiscal agent services, which was provided by the fiscal employer agent

Concerns about Fiscal Employer Agent

A major area of concern for both service brokers, involves the unreliable, inconsistent, and inadequate service provided by the fiscal employer agent to EPAS participants who hire their own assistants. Over the course of the last program year, the fiscal employer agent has failed to pay several personal assistants on time on multiple occasions and in some cases did not pay them at all. Resolving these issues has been time consuming and frustrating for both service brokers. The DOH service broker has documented at least 62 separate contacts she has made to resolve such payment issues. Both service brokers have had extensive difficulty in reaching anyone at the fiscal employer agent office, either by telephone or email, who is able to resolve these issues. On the occasions when they have been able to reach the appropriate person the service brokers have been told that the necessary paperwork has been lost and needs to be sent again in order to process payment. Additionally, the VMH service broker reported that there have been at least eight separate instances when the rate of pay on a timecard submitted by an employer has been changed and reduced prior to paying the personal assistant. The most recent instances of such changes occurred after the VMH service broker had met in person with a representative of the fiscal employer agent, and during the meeting the representative agreed that this should not have happened and committed to resolve the issue immediately.

Concerns about Home Health Agencies

The current reimbursement rate from Medicaid to home health agencies that provide EPAS services is another area of concern voiced by the DOH service broker. As reported by the agency to the service broker, the reimbursement rate is too low for these agencies to cover their overhead expenses and pay the personal assistants an adequate wage. The DOH service broker has recently been contacted by three of the largest home health agencies in the state who have stated that they are not willing to provide EPAS services because of the low reimbursement rate. According to the service broker, this will significantly restrict the choice of providers for EPAS participants who choose to utilize the home health agency option.

Participant orientation and training

In order to improve the EPAS program in the future, both service brokers mentioned that the training needs of participants need to be more adequately met. With just one service broker now that the two programs are combined, the current case load and the number of responsibilities involving recruitment, enrollment, and implementation significantly limit the amount of time that the service broker can devote to individual training on being an employer or working with an agency.

Additional Comments

Other suggestions offered by the service brokers include: continue to strengthen the mental health component of EPAS services and enroll individuals with psychiatric disabilities; and consider how the program might offer or work with other service providers to offer pre-employment personal assistance services (e.g., provide an assistant to drive an individual to a job interview or help complete an application so the individual can become employed and qualify for EPAS).

Summary of Findings

Findings from this evaluation process indicated that overall program participants (from both the VMH pilot and DOH EPAS program) were satisfied with both DOH and VMH EPAS staff and services. In addition, EPAS services helped individuals to maintain employment, increase wages and work effort. EPAS staff earned especially high marks from participants for their responsiveness to consumer needs. They were viewed as supportive, approachable, and caring. Additionally, both the DOH and VMH service broker reported that overall the recruitment, enrollment, and implementation components of the program are working well with a few areas that can be improved particularly around the fiscal employer agent option.

While EPAS undeniably provides tangible supports (e.g., transportation and housework assistance) that help consumers maintain and even improve employment opportunities, some of its greatest benefits may be in reducing stress and anxiety, building self-esteem and self-confidence, and contributing to a heightened sense of well-being. These less tangible benefits may have such positive impacts as reducing employee tardiness and absenteeism, decreasing interpersonal conflicts at work, and increasing the capacity to improve the quality and/or circumstances of consumers' work environments. While this evaluation of the EPAS program is preliminary, the patterns demonstrated thus far indicate the potential for increased employee productivity and job retention.

Recommendations

1) Additional Training for EPAS Participants

There were several issues raised by interviewees that could best be addressed by providing all EPAS participants with enhanced one-on-one or small-group follow-up training/support sessions or additional mentoring. Because the service broker's time to provide such individualized ongoing training is extremely limited, based on the current case load and program staff level, alternate training options and trainers may need to be considered in order to address this recommendation. One such option would be to consider the development of a peer-training program that trains EPAS participants to become trainers on specific topics for newer participants. Another feasible option may be to contract with local Centers for Independent Living or other providers, who may have training programs that address the same or related topics that would benefit EPAS participants. Another possible long-term solution to address the training needs of participants would be to increase the number of staff positions within the EPAS program, with at least one staff member dedicating at least 50% of their time to developing and providing training.

Regardless of who ultimately provides training to EPAS participants, it is recommended that additional training be offered in at least the following areas:

- Developing communication skills that allow the individual as the employer to provide appropriate feedback--both positive and negative--to PAs. Role-playing and other experiential activities may be especially useful to help consumers anticipate and practice ways to handle difficult or awkward situations.
- Exploring ways for the employer to clarify with PAs their expected number of work hours. Misunderstandings related to the number of hours a PA would be needed by a participant were fairly common and may be a factor in PA turnover.
- Establishing appropriate boundaries with PAs, particularly when individuals choose to employ relatives or friends. Additional monitoring and support from the EPAS service broker may be necessary in these circumstances as respondents reported that personal boundary issues were difficult to negotiate and some remained problematic.
- Developing self-advocacy skills and how to communicate concerns about unsatisfactory service to home health agencies. Some respondents using the home health agency option expressed feelings of vulnerability and a reluctance to express these concerns directly to the agency for fear of jeopardizing future services that are critical to maintaining employment.
- What services and activities are covered by the EPAS program. Some PAs appeared to exercise more personal judgment with regard to whether or not a task was "work-related." Although consumers expressed greater satisfaction with PAs who were somewhat more flexible in this regard, such flexibility could conflict with the EPAS program's overall requirement to provide personal assistance services that are employment related.

2) Fiscal Employer Agents

- Based on the feedback from participants and service brokers, explore the options for promoting the development of additional fiscal employer agents to provide participants using the fiscal agent option with a choice of providers.

3) Home Health Agencies

- Bring the issue of home health agencies declining requests to provide EPAS services, due to the low Medicaid reimbursement rate, to the attention of the appropriate parties for consideration and further discussion.

4) Outreach and Recruitment to Individuals with Disabilities

- Review outreach and recruitment strategies to ensure they are adequate for enrolling women and ethnic minorities; adapt strategies as needed to increase program participation by underrepresented groups.
- Begin to develop outreach and recruitment strategies that address the need for EPAS services in rural areas. This may include developing the capacity to provide timely

assessments by Medicaid staff or qualified contractors in areas outside the Wasatch Front to both determine initial eligibility for the program and establish the amount and type of assistance needed for an individual.

5) Recruitment/Employment of Personal Assistants

- Based on the experience of the VMH pilot, explore ways that the EPAS program can work with other appropriate agencies and providers to develop a qualified pool of personal assistants that individuals utilizing the fiscal employer agent model can access. Such a pool would help address the need for "back-up" support for individuals when PAs are ill or encounter other problems that prevent them from being available for work; this in turn affects the ability of the individual relying on the PA to make it to work. Opportunities for PAs to call in sick without jeopardizing their job and the job of their employer may also help reduce the high turnover reported by some respondents.

6) Information and Referral

- Continue to be proactive in assisting EPAS participants to understand the importance of maintaining Medicaid eligibility and provide assistance as appropriate in working with Medicaid eligibility workers to determine the best Medicaid program for each individual (e.g., MWI vs. Spenddown)
- Continue to be proactive in referring EPAS participants to additional community resources as needed. In particular, continue to encourage individuals in the EPAS program to meet with a Benefits Specialist to gain information about additional SSA work incentives that would be beneficial or could help them avoid an overpayment situation with their Social Security disability benefits. If an individual is already in an overpayment situation refer them to a Benefits Specialist and also to the Utah Disability Law Center for further assistance in resolving the overpayment.

Limitations of this Study and Recommendations for Future Evaluations

Limitations

This formative evaluation is cross sectional, i.e., it is a descriptive "snapshot" of EPAS participants at a particular point in time. Thirty-five participants designated as "active" during the month of December 2004, are described demographically and in terms of program- and employment-related statistics. The 15 EPAS consumers who participated in the interview process during the months of November and December 2004 were not randomized, but purposively selected based on the criterion of length of participation (minimum of 6 months). Because study methods were neither randomized nor longitudinal, findings must be viewed as preliminary and may not be generalized to the larger population of EPAS recipients.

Future Evaluation Recommendations

- 1) Utilize a larger sample size (which will be a natural outcome of the program's maturation and growth).
- 2) Consider collecting baseline data relevant to outcomes of potential interest (e.g., reduced tardiness, absenteeism, improvements in employment situations).

- 3) Utilize a single interview form to improve interview flow and avoid redundancy.
- 2) Retain the practice of obtaining in-depth information through semi-structured interviews with individuals who have been on EPAS for at least 6 months.
- 5) If feasible, track participants and former participants over time to gather longitudinal data for a better understanding of longer-term program outcomes.

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Appendix A

EPAS Quality Assurance Interview Form

Consumer		Date and Time	
E-PAS Service Broker		Site/Home Address	
QE Reviewer			

Observations/Interviews are intended to verify implementation of services and supports that are documented in a person's files. Indicate whether each of the following is present (i.e., yes or no) or needs improvement (N/I) and include comments where necessary.

Quality Indicators:

	Yes	No	N/I
<p>1. Employment Related Support Plan is being implemented. (May be observed or method of implementation may be discussed; consider changes made to strategy or implementation as a result of progress, lack of progress, or regression)</p> <ul style="list-style-type: none"> • Are needs identified? • Are needs addressed? • Are IADLs/ADLs addressed? 			
<p>2. Health Issues are addressed. (Receiving routine medical care, follow-up treatment, and medications as needed; other health issues are adequately addressed)</p> <ul style="list-style-type: none"> • At home? • At work? 			
<p>3. Safety Issues are addressed. (Any concerns voiced by the person; awareness of safety issues)</p> <ul style="list-style-type: none"> • At home? • At work? 			
<p>4. Individual is satisfied with paid support (i.e., attendants, fiscal agent). (Interactions are positive; assistance is provided as needed and requested; comfortable relationship with assistants/fiscal agent staff; preferences are known and respected; paid supports demonstrate dignity and respect)</p>			
<p>5. Individual is satisfied with E-PAS service broker. (Assistance is provided as needed and requested; comfortable working relationship with service broker; needs, desires, and preferences are known and respected)</p>			
<p>6. Individual feels that they are a good employer (e.g., expectations for attendants are communicated clearly; any concerns with attendants performance are handled appropriately)</p>			
<p>7. Personal Attendants are integrated into the workplace (e.g., have there been any problems with colleagues or employer regarding personal attendants at work)</p>			

Appendix B

Supplemental Questions for EPAS Quality Assurance Interviews

1. Where did you find your personal assistant(s)?
2. Did you have any difficulties finding your personal assistant(s)
3. How is it working out with your current personal assistant(s)?
4. Did you feel prepared to supervise and manage your own personal assistant(s)?
5. Would you be interested in more training that would help you supervise and manage your own personal assistant(s)?
6. Since going on EPAS, has your work situation changed, either in a good way or a bad way? (e.g., more friends, work more hours, make more money, improved self-esteem)
7. Have your attitudes towards work changed in any way since you went on EPAS?
8. Has EPAS made a difference in other areas of your life besides work?
9. How did you hear about the EPAS program?

Have you heard about any of the other Work Ability programs like BPAO (Benefits Planning) or MWI (Medicaid Work Incentive)?

- # Benefits Planning, Assistance and Outreach: counsels SSI and SSDI recipients on how working may affect their benefits.
- # The Medicaid Work Incentive program: allows people with disabilities to work and still keep their health care benefits by paying a monthly premium for their Medicaid card.

Have you used either of these work incentives?

If “yes”: Did you find the work incentive(s) helpful?

If “no”: Would these work incentives be helpful for you?

10. How can the EPAS program serve you better?

11. Do you have any other comments you'd like to make about your experience with the EPAS program?

Appendix C

EPAS Service Broker Questions

- 1. What is working well in the recruitment and enrollment phase of the EPAS program (e.g., getting referrals to the program, establishing Medicaid eligibility, getting the initial assessment completed in a timely manner)?**
- 2. What would you do differently or improve in this area?**
- 3. What is working well in the implementation phase of the EPAS program (e.g., getting a plan written, training individuals to be employers, finding qualified PAs, working with the fiscal agent or home health agency)?**
- 4. What would you do differently or improve in this area?**
- 5. Are there any other comments or suggestions you have for how the EPAS program can be improved in the future?**