

**Pennsylvania Council on Independent Living (PCIL)**

**Priority Backup Personal Assistance Services (PAS) System Study**

**for the**

**Pennsylvania Department of Public Welfare's Ticket to Work  
Medicaid Infrastructure Grant**

**and the**

**Pennsylvania Advisory Committee on Employment (ACE)**

# **“Backup PAS and Employment Findings Report”**

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## **Executive Summary**

### **Overview**

The “Backup Personal Assistance Services (PAS) and Employment findings” contained in this document are the Phase I outcomes of a two (2) phase project, undertaken by the Pennsylvania Council on Independent Living (PCIL), pursuant to an initiative of the Pennsylvania Department of Public Welfare’s (DPW) Ticket to Work Medicaid Infrastructure Grant and Statewide Advisory Committee on Employment (ACE). The overall goal of the project is to research and to incorporate best practices from around the Commonwealth of Pennsylvania and nationally addressing the issue of backup PAS for persons working or who wish to work and develop a priority system for backup PAS for individuals who use this service and are employed or seeking employment in two locations in Pennsylvania. Phase II of the project includes using this Backup PAS and Employment Finding Report as a foundation for the development of a piloted administrative structure of priority backup PAS for the targeted consumers identified above in collaboration with PAS providers, Local Advisory Committees on Employment (LACEs) and consumers in Pittsburgh and Schuylkill County. After the pilots end, recommendations will be developed that delineates how a reliable backup PAS system can be implemented in other parts of the state.

The research involved with the development of this report included: (1) two Consumer Forums; (2) Develop and administer PAS Provider Surveys statewide to PAS providers of the ACT 150 Attendant Care Program (ACP) and Attendant Care Waiver Program (ACWP); (3) Develop and administer Consumer Surveys statewide to all ACT 150 ACP and ACWP PAS consumers; and (4) Conduct Informal National Research/Networking with other states and national organizations for promising practices on backup PAS.

### **Conclusions**

A description of the methodology utilized in conducting Phase I and the specific findings summarized there from are contained in the body of this report. The survey and forum participants highlighted numerous issues that require serious consideration in formulating a more comprehensive

and empowerment-based backup PAS system in Pennsylvania. The conclusions drawn from the findings are summarized as follows:

- ◆ The backup PAS model(s) utilized to provide services are systemically, organizationally, philosophically, and programmatically dissimilar. Moreover, the models should empower the recipient/consumer of services to the maximum extent possible. The barriers to uniform and functioning backup PAS for consumers arise from existing bureaucratic structures and program requirements.
  - DPW should begin transforming a medically-based priority PAS structure to an empowerment-based priority and backup PAS structure, with shared responsibility between the PAS provider and consumer, to support individuals with disabilities to remain in their homes, determine own goals, support employment and participate in all our communities have to offer.
  - DPW should investigate ways and determine feasibility of replicating the PDA waiver backup PAS component into other home and community-based services.
- ◆ Barriers exist to information regarding the availability of backup PAS and all of the wide range of recruitment methods.
  - DPW should clarify responsibilities with PAS providers regarding paying for personal assistant (PA) advertising and ensuring consumers know that backup PAS is available 24/7.
- ◆ A large number of consumers indicate that a lack of backup PAS prevents them from working. The backup PA workforce is largely unpaid; unpaid family members are used due to current requirements; backup PAs experience low wages; and have lack of incentives.
  - DPW should address workforce development issues to allow family members and spouses to be paid as backup PAs for consumers.
  - DPW should increase PA wages and provide for financial incentives such as a higher wage for backup PAS provision.

- ◆ Barriers exist to knowledge and understanding of advantages or disadvantages of different service models with regard to backup PAS.
  - DPW should ensure that consumers are being informed and trained on the Pennsylvania Model of PAS.
- ◆ A significant number of consumers want to work more hours or want to work at some level, and are working towards employment.
  - To promote employment, DPW should continue to work with PCIL on the development of a piloted administrative backup PAS structure in Pittsburgh and Schuylkill County.

## Introduction

In late July 2003, the Pennsylvania Council on Independent Living (PCIL) undertook the examination of Priority Backup Personal Assistance Service (PAS) in Pennsylvania as a result of the Commonwealth of Pennsylvania's dedication to eliminating employment barriers faced by its citizens with disabilities (**See Appendix A, Project Fact Sheet**). Specifically, workers with disabilities must have access to supports and accommodations they need to be successful just as people without disabilities. The Commonwealth has PAS programs that can provide the necessary supports for individuals to be employed. However, these services are not always available or constructed in a manner that supports employment. The result is that many individuals willing to work do not have the opportunity to do so.

To succeed in reducing the PAS related barriers and increasing employment, an examination was needed to uncover best practices and procedures for the establishment of a priority backup system for PAS. The rationale behind this examination is necessary given that the reliability of PAS is critically important for those who utilize this service to get to work, to be employed, and to remain employed. When a personal assistant is not timely or does not arrive at all, the ability of a person using PAS, to be employed or maintain a job, is impacted. Moreover, PAS is an essential way of supporting individuals with disabilities in their independent living.

This *"Backup PAS and Employment Findings Report"* is presented to the Department of Public Welfare (DPW) and the Statewide Advisory Committee on Employment (ACE) to provide identified problems discovered related to employment and back-up PAS and indicate what some of the promising practices may be for implementing a priority backup process in Pennsylvania. Also, the report will be the basis towards or foundation for the development of an administrative structure of priority backup PAS for employed individuals or individuals who want to be employed.

This report includes three major areas of research:

- 1) Backup PAS Best Practices Summary
- 2) Backup PAS Reliability and Effectiveness Summary
- 3) Backup PAS National Promising Practices Summary

The Backup PAS Best Practices Summary will provide information from current PAS providers in Pennsylvania on their methods of assuring reliable backup PAS, especially as it relates to employed persons to whom it provides PAS.

The Backup PAS Reliability and Effectiveness Summary will provide information from current consumers of PAS participating in the ACT 150 Attendant Care and the Attendant Care Waiver Programs to include consumers who use PAS and who work. This data will portray the consumers' perspective on the reliability and effectiveness of their backup PAS; what does and does not work in achieving reliable backup in a quantifiable and clear manner by service area; and a clear definition of *"wishes to be employed"*.

The Backup PAS National Promising Practices Summary will provide information from other states and national organizations on the issue of backup PAS to determine promising practices occurring across the nation; and, how those practices may be applicable to Pennsylvania.

## Method

Several measures and steps occurred to operationalize the goals and objectives of the *Priority Backup Personal Assistance Services (PAS) System Study*. PCIL's Executive Director, Michael Auer, serves as project director for the study. To capture backup PAS information from Pennsylvania PAS Providers, PAS Consumers, and from other state/national organizations the following activities occurred:

- ◆ Held two Consumer Forums
- ◆ Developed and Administered PAS Provider Surveys
- ◆ Developed and Administered Consumer Surveys
- ◆ Conducted Informal National Research/Networking

The Pennsylvania Council on Independent Living (PCIL) identified Holleran Consulting to provide guidance on survey administration and analysis, as well as, to design and construct survey instruments to be administered to PAS consumers and providers. This firm specializes in research of the long-term care spectrum and community needs assessments. Additionally, they have worked with the Pennsylvania disability community with other statewide advisory groups, such as the Pennsylvania Rehabilitation Council. The DPW Office of Social Programs (OSP) Attendant Care Program (ACP) Manager was also identified to partner with to plan distribution and administering of the consumer and provider surveys. The OSP implements the statewide ACT 150 ACP and the Attendant Care Waiver (ACWP) programs. These programs are consumer controlled and an important goal of the programs is for it's consumers to maintain or work towards employment.

Holleran Consulting participated in two conference calls, coordinated and facilitated by PCIL, to gain anecdotal and informative data in an open forum type setting: one with Pennsylvania Center for Independent Living (CIL) staff on July 29, 2003; and one with Pennsylvania United Cerebral Palsy (UCP) staff on August 6, 2003. The participants assisted in shaping the development of the project by providing their critical input as Medicaid enrolled and/or state contracted PAS providers, as well as, advocates on issues that consumers and providers face regarding backup PAS. This input was used in developing consumer forum topic agenda (**See Appendix B, Consumer Forum Agendas**), the consumer survey and provider survey.

PCIL strongly believes in the merit of qualitative data/consumer input in addition to quantitative data. In collaboration with Three Rivers Center for Independent Living (TRCIL) and the Pittsburgh Local Advisory Committee on Employment (LACE), a consumer forum was held in Pittsburgh at TRCIL on September 5, 2003 wherein 25 persons attended **(See Appendix C, Consumer Forum Brochures)**. Also, in partnership with Anthracite Region Center for Independent Living (ARCIL) and the Schuylkill County LACE, a consumer forum was held in Frackville, Schuylkill County at More Mobility Showroom on September 11, 2003 wherein 19 persons attended. At both forums, participants included local PAS providers, Office of Vocational Rehabilitation (OVR) District Offices, other disability related organizations, LACE members and CIL consumers. The participants assisted in shaping the development of the project by providing their vital input as consumers, advocates, and the interested community regarding backup PAS. The information was used in developing the consumer survey, provider survey and the definition of *“wishes to be employed”*. In addition to the forums, the project director consulted with the Pennsylvania OVR Executive Director regarding methods OVR uses to determine if consumers wish to work.

Both the provider and consumer surveys were developed via a three draft and four draft process, respectively, with enormous input and suggestions from ACE; LACEs; DPW; Center for Workers with Disabilities; Mr. Jerry Finn, Professor, Temple University, School of Social Administration and CILs.

The provider survey was mailed on December 5, 2003 to 22 PAS providers of the ACT 150 ACP and ACWP, identified by OSP, who serve Pennsylvania statewide **(See Appendix D, PAS Provider Listing)**. The first class mailing included a cover letter; a coded survey by provider; a Self Addressed Stamped Envelope; and project fact sheet **(See Appendix D, Provider Survey)**. The survey was uploaded on the PCIL website ([www.pcil.net](http://www.pcil.net)) to enable respondents, if desired, to utilize a web based process to expedite submission, promote accessibility both in facilitation and for persons with disabilities; and to log entered data into a text database for storage and retrieval.

The overall return rate was 77% or 17 of 22 providers responding. Of those respondents, 65% (14) of their responses were received via U.S. Mail First Class and 15% (3) were received via online submission.

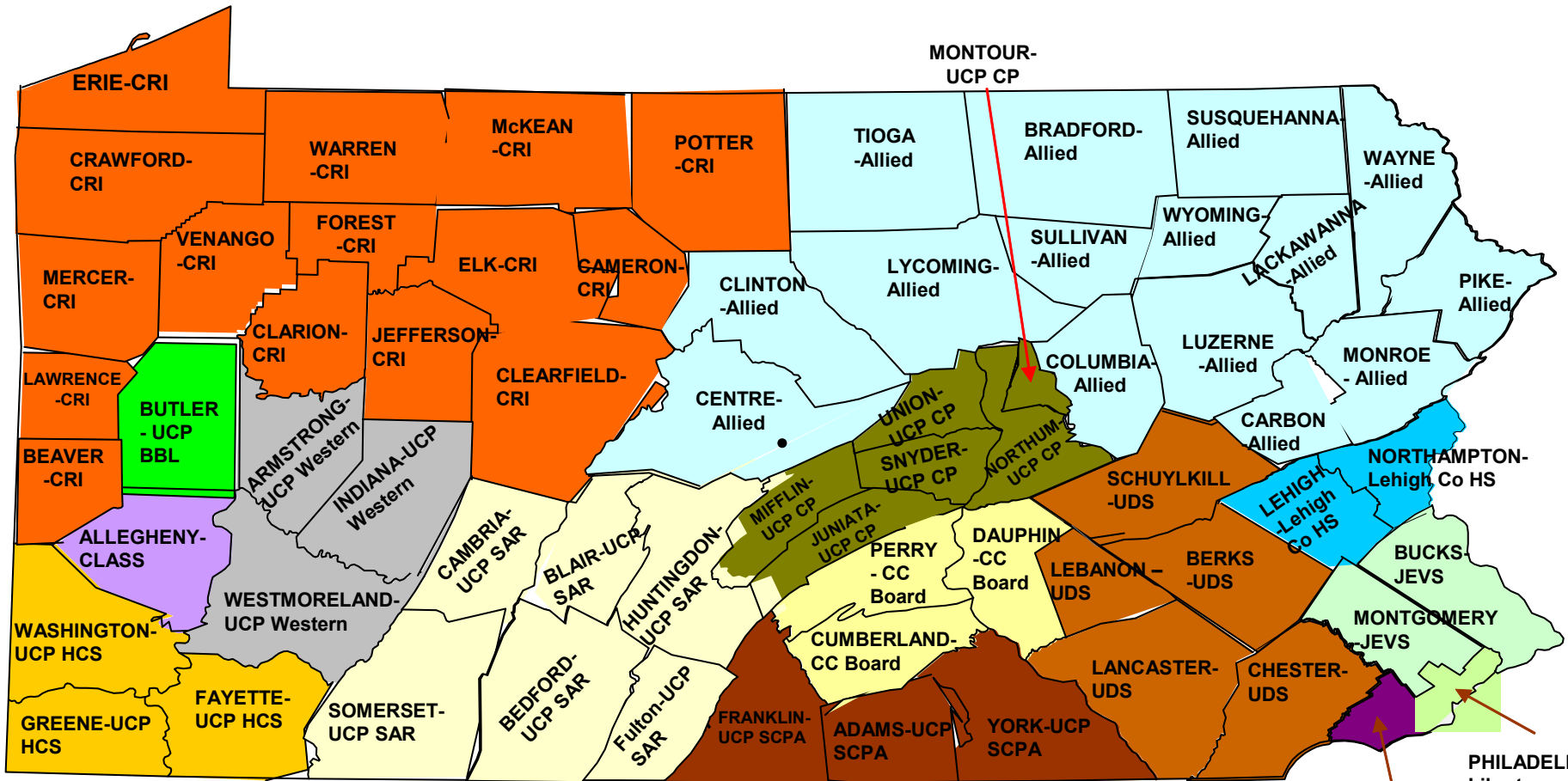
The consumer survey was mailed by OSP on December 18, 2003 to 4,148 ACT 150 ACP and ACWP PAS consumers, identified by OSP, statewide. This population is equal to the entire number of consumers served in both the ACT 150 ACP and ACWP. The first class mailing included a cover letter, a coded survey by each of the 15 ACT 150 ACP service areas (**See Table 1**), a Self Addressed Stamped Envelope; and a Medical Assistance for Workers with Disabilities (MAWD) brochure for outreach (**See Appendix E, Consumer Survey**). Again, the survey was uploaded on the PCIL website ([www.pcil.net](http://www.pcil.net)) for the same purposes noted above.

Prior to the mailing of the surveys, a “*Pre-Test*” was conducted per recommendations from Professor Finn and the Centers for Workers with Disabilities. With assistance from the Center for Independent Living of Central PA (CILCP), 5 local consumers formed a test group and agreed to participate in the “*Pre-Test*”. The test group found no problems with following and completing the survey.

The overall return rate was 19% or 764 of 4,148 consumers responding. Of those respondents, 97% (746) of their responses were received via U.S. Mail First Class; 2% (13) was received via online submission and 1% (5) was received via call-in on PCIL’s toll free phone number. A total of 121 surveys were undeliverable to the addressee. An analysis of returns by service area was performed as well. The number of returns by service area ranged from 7% to 41% (**See Table 2**). The survey data was analyzed using SPSS software.

While the overall return rate is common in survey research, the results must be interpreted with care since we do not know how representative the returns are of the entire population.

15 Act 150 Attendance Care Program Service Areas  
Table 1

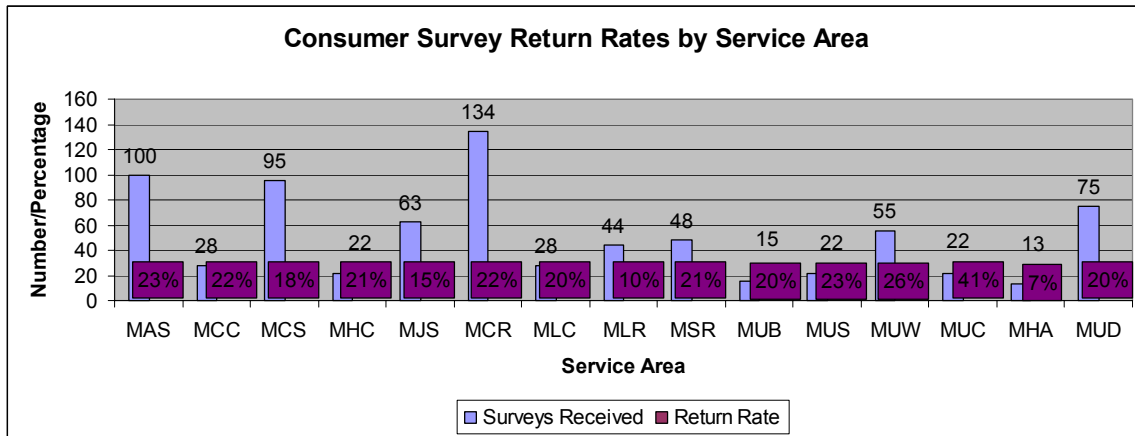


	Allied Services	Region MAS		Liberty Resources	Region MLR
	Cumberland Co. Board of Comm. (CC Board)	Region MCC		Jewish Employ Voc Services (JEVS)	Region MJS
	UCP of Beaver, Butler, and Lawrence (UCPBBL)	Region MUB		Homemaker Service Metropolitan (HSMA)	Region MHA
	Community Living and Support Services (CLASS)	Region MCS		UCP of Central PA (UC.P CP)	Region MUC
	Community Resources For Independence (CRI)	Region MCR		UCP Home & Comm Serv. (UCP HCS)	Region MHC
	Lehigh Co. Office of Aging/Adult Services (Lehigh Co HS)	Region MLC		UCP South Central PA (UCP SCPA)	Region MUS
	United Disabilities Services (UDS)	Region MUD		UCP Southern Alleghenies (UCP SAR)	Region MSR
	UCP Western	Region MUW			

PHILADELPHIA-  
Liberty  
Resources,  
HSMA, and JEVS  
for certain zip  
codes

Source: DPW OSP

**Table 2**



Concurrently with information gathering methods noted above, PCIL identified Andrea Williams as a volunteer to research other states and national organizations for promising practices on backup PAS. Ms. Williams is a lifetime disability advocate; HCBS Resource Network Board Member and Chair of its Technical Assistance Exchange Committee. PCIL identified and informally surveyed the following organizations due to their recognized research and knowledge of PAS and the Ticket to Work Medicaid Infrastructure Grant authorized under the Ticket to Work and Work Incentives Improvement Act of 1999 (TWWIIA):

- ◆ Mark Newsome, Project Director  
American Public Human Services Association  
Center for Workers with Disabilities
- ◆ Steve Lutsky, Director, Division Community Systems Improvement  
Centers for Medicare and Medicaid Services (CMS)  
Disabled and Elderly Health Programs Group
- ◆ Pam Doty, Program Analyst  
Department of Health and Human Services  
Office of Assistant Secretary for Planning and Evaluation (ASPE)

- ◆ Lee Beezanson, National Project Director  
Dee O'Connor, Past National Project Director  
Kevin Mahoney, Deputy Director; Associate Professor Boston College; National Cash and Counseling Grants  
Andrea Williams, Chair TA Exchange Committee  
Bob Kafka, ADAPT Organizer and Member TA Exchange Committee  
HCBS Resource Network
- ◆ Brian Burwell, Vice President Research and Policy Division  
The MedStat Group
- ◆ Maureen Michaels, Robert Wood Johnson Foundation
- ◆ Kate Seelman, Ph.D.  
Past NIDRR Director  
University of Pittsburgh  
Associate Dean, Disability Programs  
Professor of Rehabilitation Sciences and Technology
- ◆ Lex Frieden, Senior Vice President, The Institute for Rehabilitation and Research (TIRR); ILRU Director  
Richard Petty, Director for the Community Living Exchange Collaborative  
Independent Living Research Utilization Program (ILRU)
- ◆ World Institute on Disability (WID)

In addition to contacting the above persons and entities, Ms. Williams and the project director participated and joined the Centers for Workers with Disabilities PAS Task Force committee wherein they have begun looking at backup PAS.

The information obtained from these informal surveys will be discussed in detail later in this report. However, despite accessing these national leaders in home and community based services, only one promising practice was discovered.

# Results

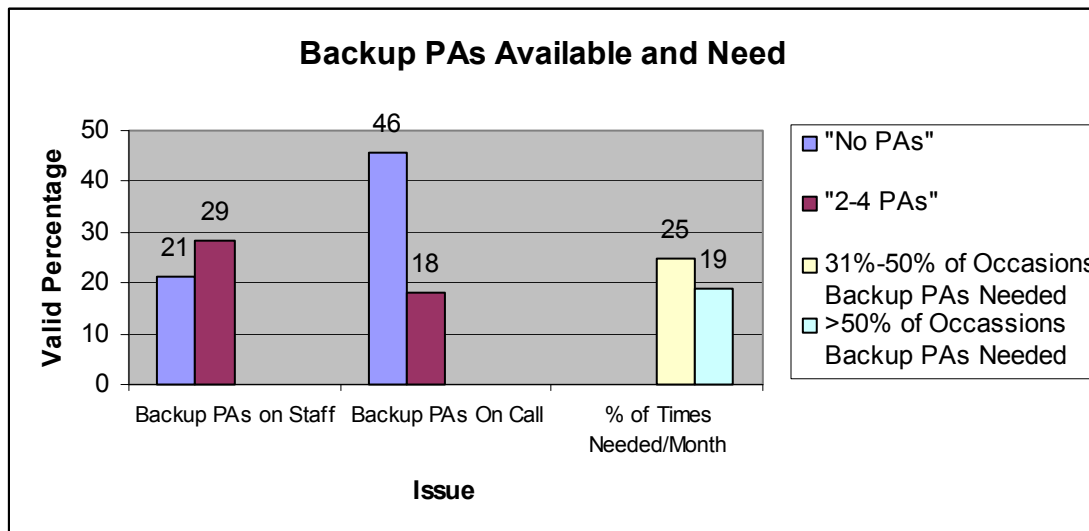
## Backup PAS Best Practices Summary

Pennsylvania PAS providers are a critical partner in identifying issues and best practices regarding the provision of backup PAS. Therefore, this summary provides data collected from current PAS providers of the ACT 150 ACP and ACWP in Pennsylvania on their methods of assuring reliable backup PAS, especially as it relates to employed persons to whom it provides PAS, and other related information.

Of the 17 PAS provider respondents, a range of 23 consumers to 600 consumers are served. In that range, 62% of the providers' consumer base is employed at a rate of 0% - 5%; 19% of the providers' consumer base is employed at rate of 6% - 10%; and 19% of the providers' consumer based is employed at a rate 11%- 14%. Of the respondents, 25% have been delivering the program for 1 -5 years. A majority of the providers, 56% (9) have been administering PAS for 15 – 20 years; 13% for 20 – 25 years and 6% for 50 years.

### **Availability of Backup PAS**

Over 21% of the respondents have no backup PAs on staff and 46% have no backup PAs on call. In addition, 25% stated in a typical month, backup PAs are needed in 31% -50% of PAS provision occasions and 19% stated backup PAs are needed for more than 50% of the PAS provision occasions for the consumers they serve respectively.

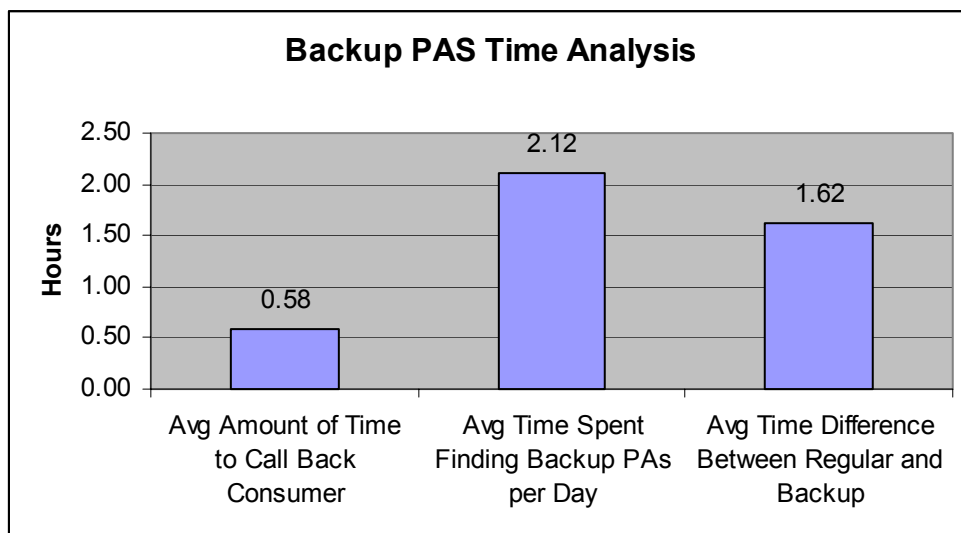


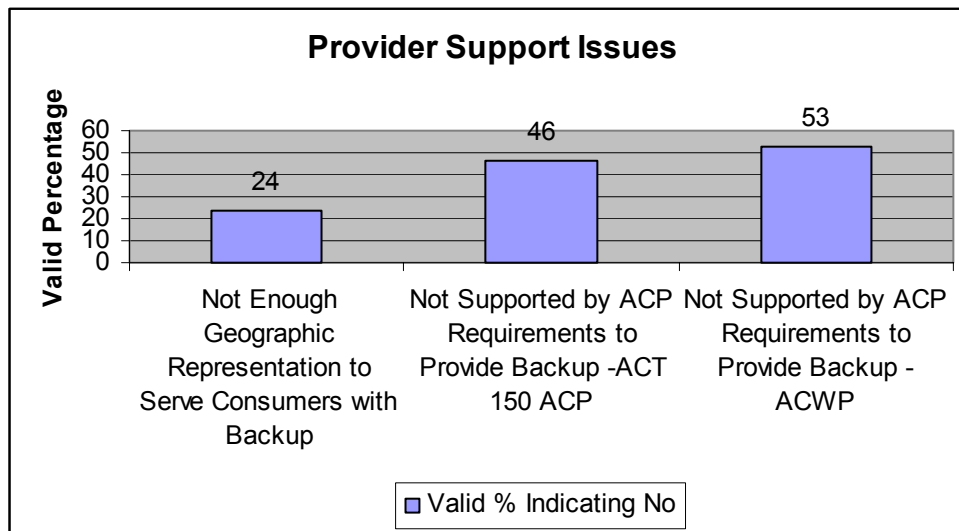
A total of 88% of the PAS providers state they have the capability of responding to backup PAS 24 hours a day, 7 days per week. Moreover, 82% have a call off policy for PAs not able to arrive as scheduled to assist a consumer. Examples of some components of call off policies are as follows (*note: this is for providers with backup staff or on call staff*):

- ◆ PA must call off, preferably in 24 hours advance, but between 1 – 6 hours in advance of scheduled consumer visit or as soon as possible and speak directly to their supervisor or on-call staff person as well as the consumer.
- ◆ Providers utilize beepers, pagers and established “call off” lines.

A few of the respondents indicated that they offer the consumer employer model only and therefore do not offer backup PAS to their consumers.

On average, it takes PAS providers .58 hours to respond to a request from a consumer in need of backup PAS and an additional 1.62 hours for a backup PA to arrive at the consumer’s home for a total of 2.2 hours response time. Actual times range from 15 minutes to 1 hour to respond to a consumer’s call for backup PAS and 40 minutes to 2.5 hours for a backup PA to arrive. The respondents indicate that on average they spend 2.12 hours per day finding backup PAS for consumers.





Many providers (24%) indicated that they do not have the geographic representation to service consumers with backup PAS. In addition, 46% do not feel supported by the ACP requirements in the ACT 150 ACP and 53% in the ACWP. Explanations for these responses include:

### **ACT 150 ACP**

- ◆ The state does not explain the difference in priority backup and general backup to the consumer when they call the state.
- ◆ Funding is not adequate – would be helpful if family could be paid backup!
- ◆ Finding backup is a problem.

### **ACWP**

- ◆ The state does not explain the difference in priority backup and general backup to the consumer when they call the state.
- ◆ OSP wants the capability of 24/7. Rate not high enough to cover incentive pay for on call backup anytime, especially for evenings and weekends.
- ◆ Backup is paid at a higher pay rate; reimbursement rates are not higher. Cost of an outside agency is more than reimbursement
- ◆ It would be easier to ensure coverage if family members could be paid.

## **Other Disincentives – Backup PAS 24/7 Responsibility**

- ◆ Continues to lessen the responsibility of the consumer model person in having secure backup in place and some consumers don't feel compelled to even try. The responsibility should be shared. Provider can assist consumer's finding backup as staffing shortages in some areas become worse. Allowing a family member to be compensated would help many consumers.
- ◆ Staffing and amount of time are the disincentives.
- ◆ No incentives, no funding to support new initiatives to recruit or retain backup.
- ◆ For consumer hire models, all workers comp/UI/IRS/other paperwork must be completed, sent to fiscal agent, and processed before a new attendant can provide care for pay. Takes quite a bit of time.

A sum of 93% of the respondents felt that it is somewhat difficult to extremely difficult to retain skilled and reliable backup PAs. Over 53% of the respondents felt that backup PAs should receive a higher wage than regular PAs. Further, 43% of the respondents pay for backup PAs only when they provide the backup PAS and 29% pay backup PAs whether or not they deliver backup PAS.

Incentives are provided to both backup PAs and on call backup PAs by 43% and 47% of the providers respectively. More specifically, incentives include:

- ◆ Time and one half pay or 10% differential for evenings and weekends.
- ◆ Higher wage to start plus more vacation and sick leave.
- ◆ Pay to be on call of \$25 per weekend day, yearly raises based on performance and spot bonuses for going over and above expectations.
- ◆ Premium pay rate, paid to be on call, paid travel time and mileage reimbursement.
- ◆ Floaters are scheduled to be available during their time slots. They cannot refuse to serve any consumer.

The PAS providers (31%) fund those incentives out of their agency general fund or unrestricted funds.

The respondents identified several avenues of recruiting backup PAs as listed below:

- ◆ Recruit from applicant and PA pool, students from local universities, job fairs, in-services, Career Links, job banks and newspapers.
- ◆ Understand they may be asked to work over their regular schedule. It is in the agency personnel policies that they must be available.
- ◆ Job fairs, in-services, newspapers, bulletin boards at colleges, universities, word of mouth (2) (attendants and consumers.)
- ◆ Informally, the floater coordinator maintains a list of PAs that are on down hours.
- ◆ Use a casual pool list to determine actual availability and commitment.

However, as reported previously, numerous disincentives exist that prohibit many PAS providers from operationalizing backup PAS with best practices or at all. In fact, 70% of the respondents indicated that overall, backup PAS is somewhat to extremely difficult to provide effectively. A total of 40% of the PAS providers have no system of prioritizing backup PAS needs and 64% do not prioritize consumers regardless of their employment status. However, consumers with basic assistance needs; with health and safety risks; that live alone without personal backup PAS support are identified as a top priority for backup PAS. Generally, PAS providers indicated that a standardized priority backup PAS system may not address all of the possible changes associated with consumers' unique support systems and situations routinely changing. Additional dynamics occur for PAS providers who do not employ PAs and contract out for agency model services as well as assist consumers to hire their own employees.

Additional comments from PAS providers included:

- ◆ Do not recruit employees to serve only as backup PAs.
- ◆ There are no recruitment methods known for backup PAs.
- ◆ When hiring PAs we identify those who are willing and have the desire and flexibility to be used as backup. In the past, we offered higher hourly rate as an incentive, but found inconsistent need for them as backup so they often take regular jobs as they need steady income.
- ◆ PDA waiver allows consumers to choose and setup their backup systems with one or more agencies.

All of the respondents or 100% would support a policy that would allow consumers to pay family members to provide backup PAS.

## **Backup PAS Reliability and Effectiveness Summary**

Consumers are the primary voice in shaping and developing future policy regarding backup PAS. As such, this summary will provide the consumer survey results from current consumers of PAS participating in the ACT 150 Attendant Care and the Attendant Care Waiver Programs to include consumers who use PAS and who work. This data will portray the consumers' perspective based on personal experience with the reliability and effectiveness of their backup PAS; what does and does not work in achieving reliable backup in a quantifiable and clear manner by service area; and a clear definition of "*wishes to be employed*".

Of the respondents, 60% or 460 were female; and 40% or 301 were male. Almost 75% of the respondents were either between the ages of 40-50 or 51-59. When comparing the age demographic with the number of years the consumers have received PAS, 63% or 475 have been consumers for 1 to 6 years.

Pennsylvania is very unique with its geographical area. Primarily it is rural, however, where the respondents live statewide were proportionate regardless to their type of area. In contrast, where the respondents live by each of the 15 service areas indicates a significant difference. A majority or 9 of 15 service areas are rural as reported by the respondents (**See Table 3**).

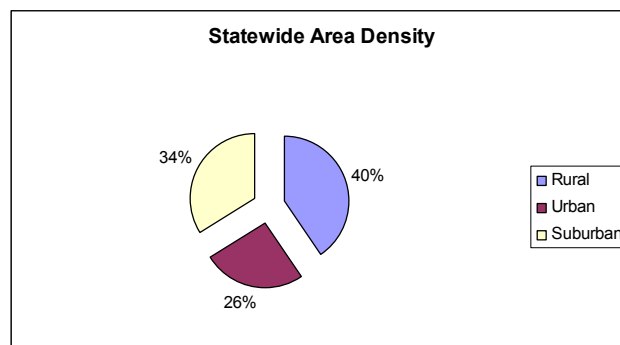
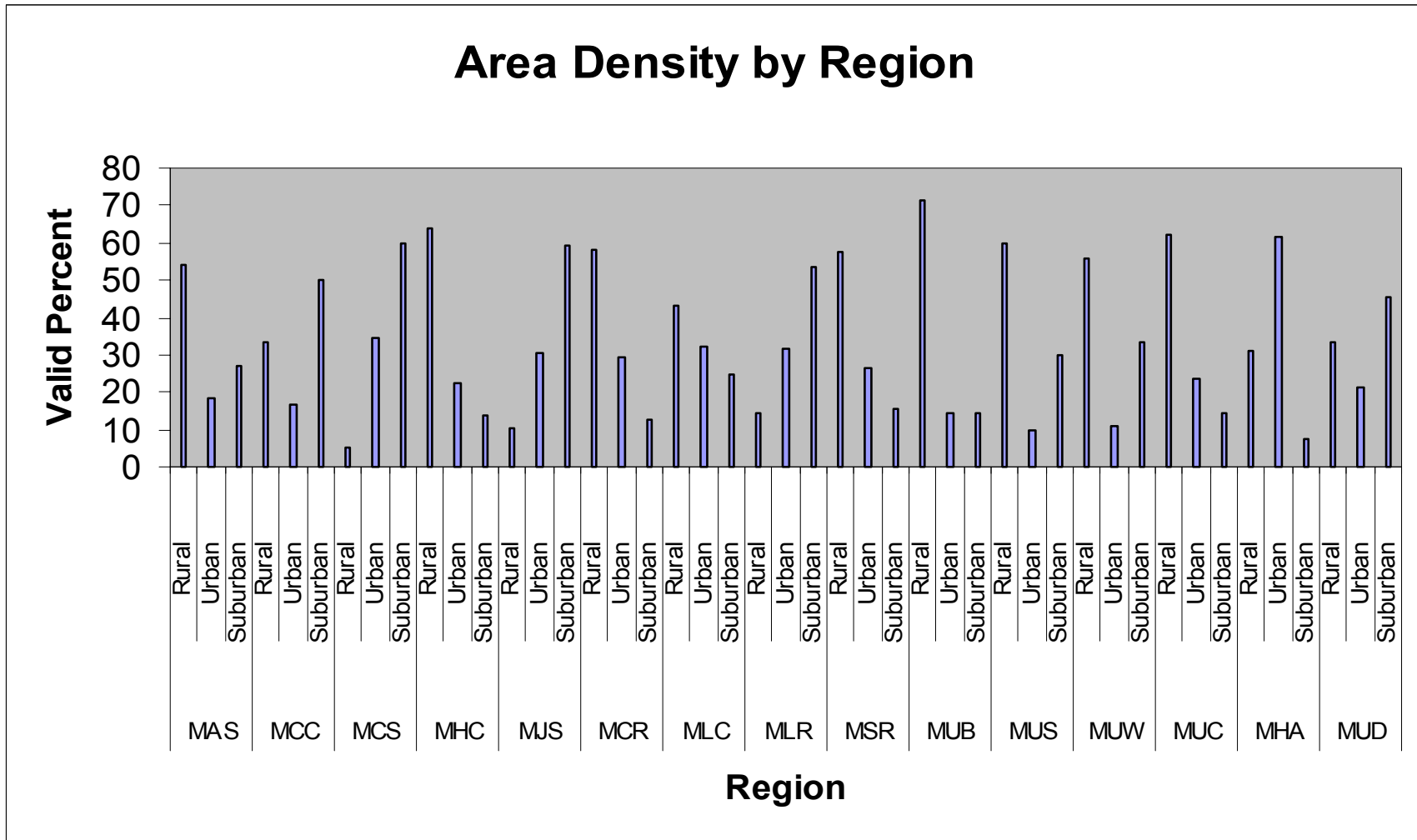


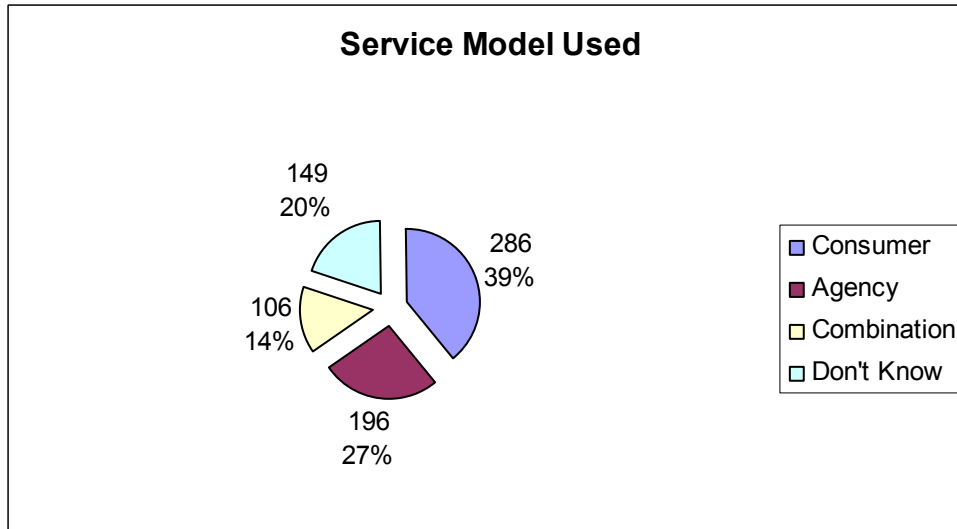
Table 3



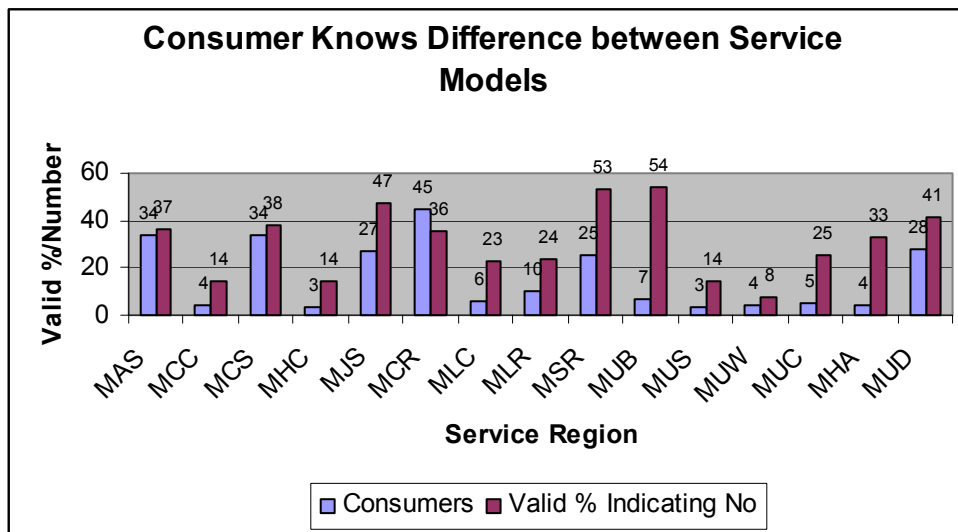
## Transportation

The respondents reported that a majority, 64% or 481, rely on others for their mode of transportation. Conversely, only 11% or 79 drive themselves and the remaining 25% utilize public transportation.

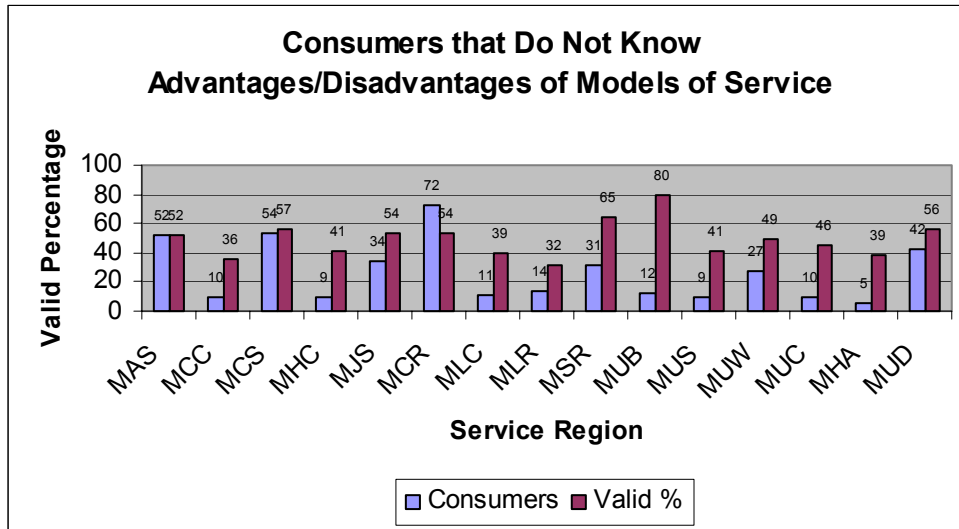
## Service Model



The graph above depicts which service model the respondents use. It indicates that most use the consumer model, 27% use the agency model, 14% use a combination thereof, and a staggering 20% or 149 did not know which service model they use. Further, 33% do not know the difference between the service models. The range by service area depicts that 8% - 54% of the consumers were unaware of their service model.

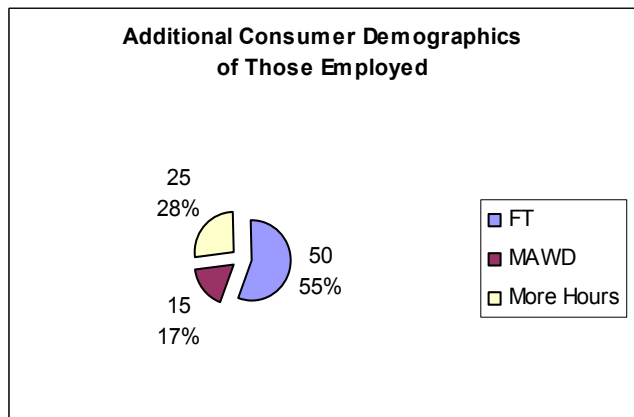
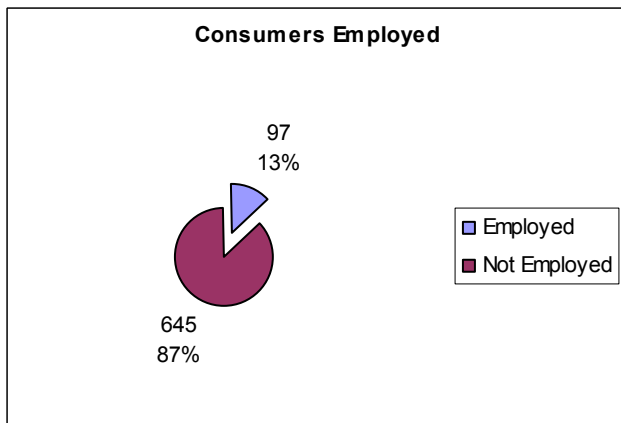


In addition, 51% of the consumers responding were not sure of the related advantages or disadvantages of the service models. The range by service area is from 32% - 80%.



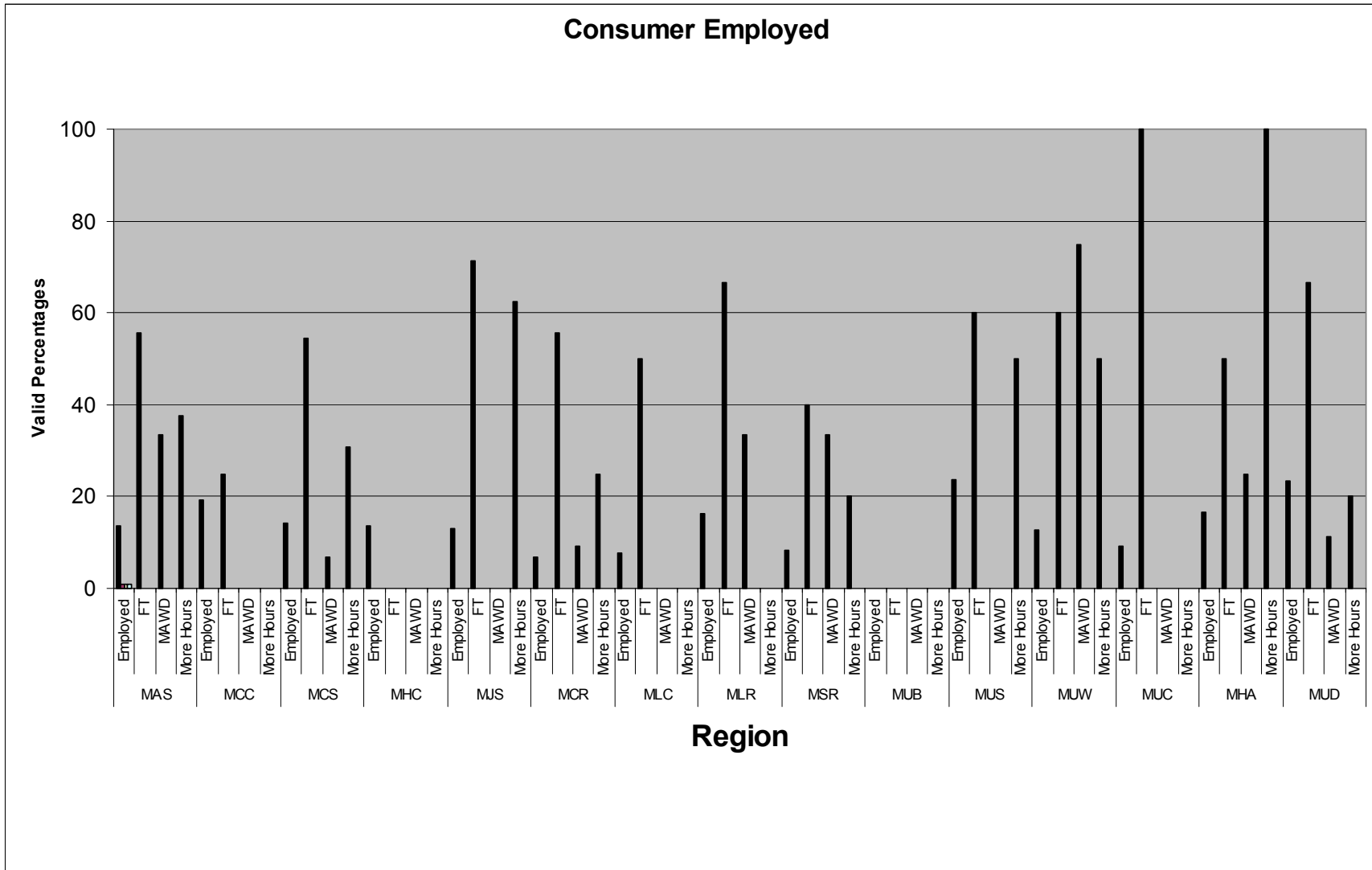
## Employment

Employed respondents are 13% and 87% are unemployed. Of those 97 employed: 55% are employed full time; 17% are using the MAWD benefit; 28% want to work more hours.



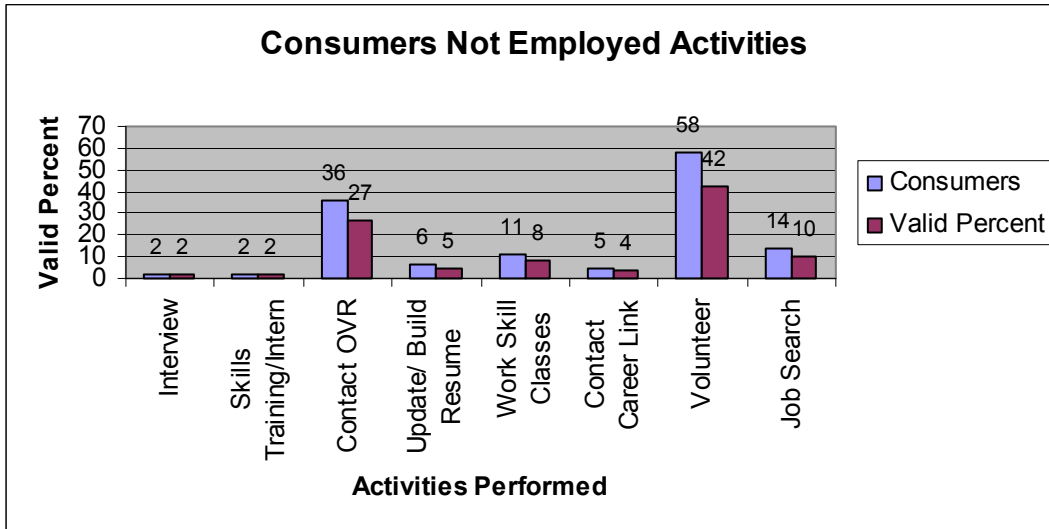
These same categories by service region present a different picture (**See Table 4**). The range of those employed is 0% -24%; employed full time is 0% - 100%; using MAWD benefit 0% - 75% and wanting to work more hours 0% - 100%. Moreover, 1 service area has none employed; 2 service areas have none employed full time; 7 regions have none using the MAWD benefit and 6 having none wanting to work more hours.

**Table 4**



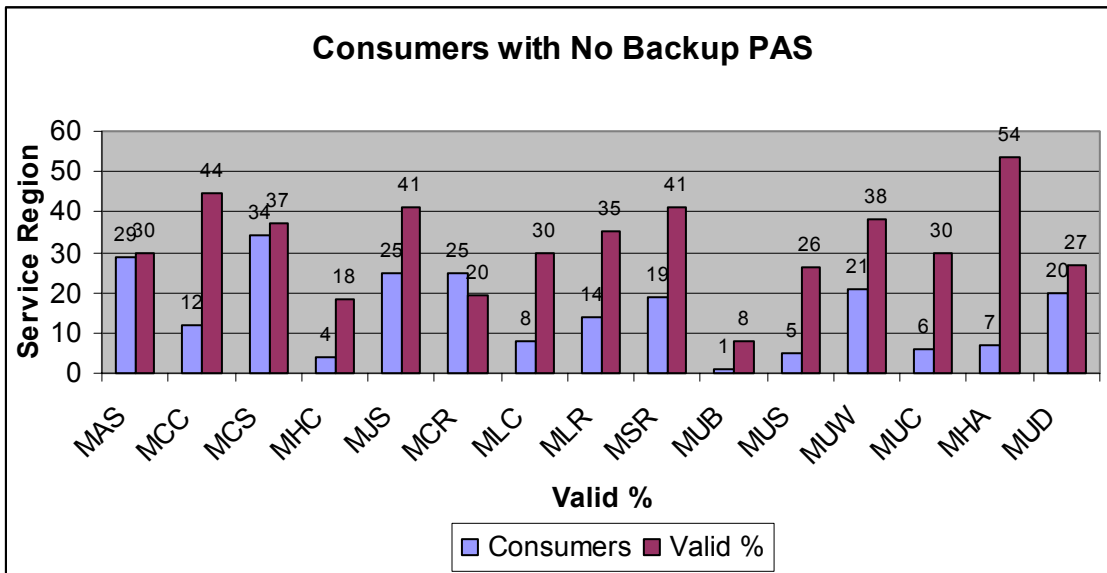
Of the unemployed respondents (87%), 10% want to work within different ranges of hours per week. In fact, 40% want fewer than 20 hours per week; 32% want 20-29 hours per week and 28% want 30-40+ hours per week.

Some respondents are working towards employment with several employment-related activities primarily with being OVR consumers and volunteering their time.

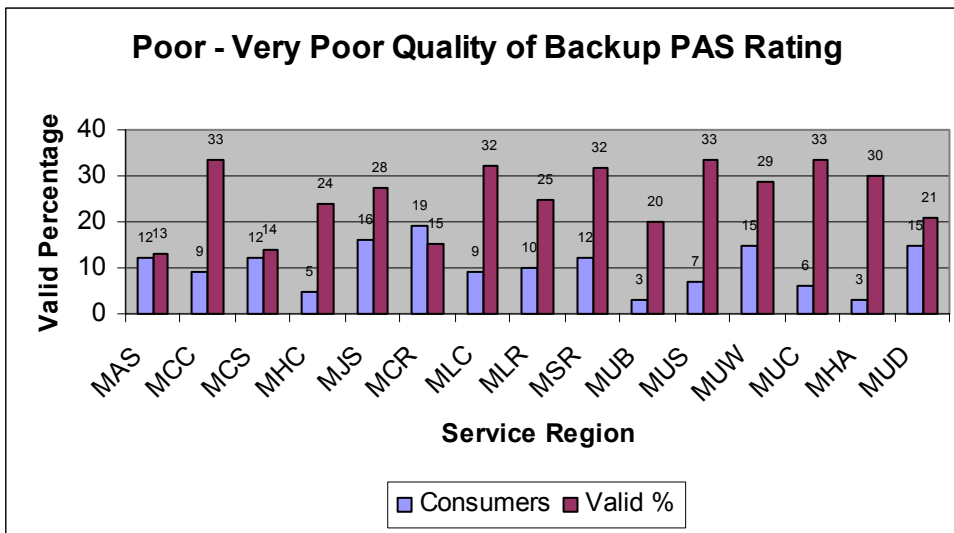


### Backup PAS

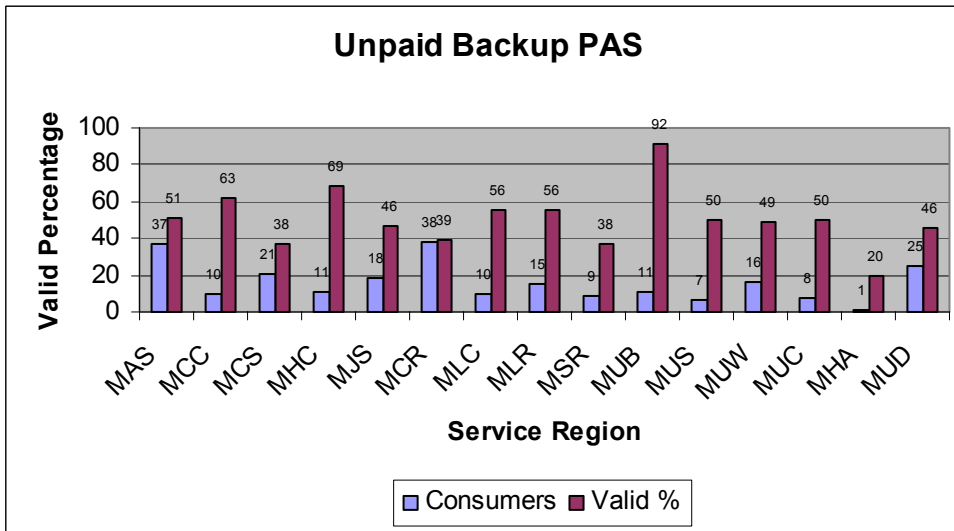
A sum of 32% or 230 of the respondents indicated that do not have backup PAS. A range of 8% - 54% of consumers reported have no backup PAS by service region.



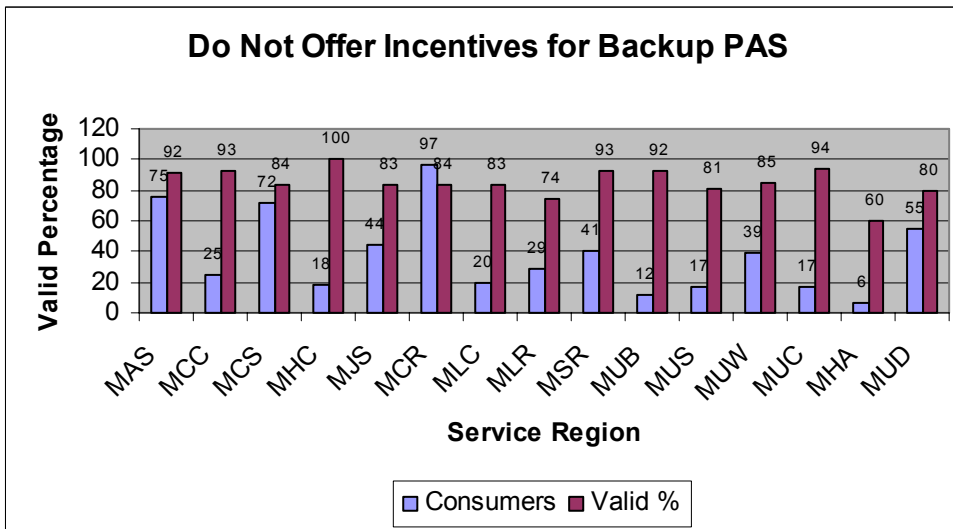
Over 26% (153) of the people survey rated the quality of their backup PAS either very poor or poor. A range of 13% - 33% likewise reported the same by service region.



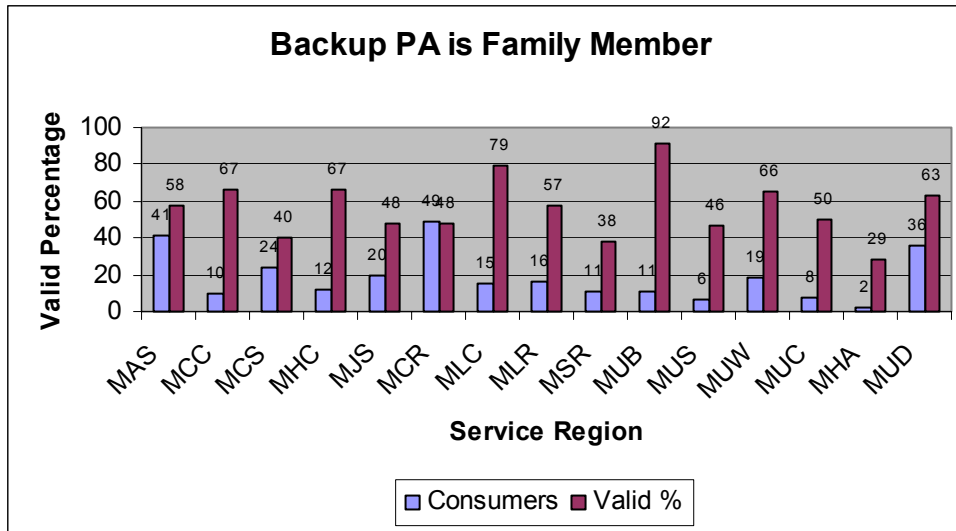
A total of 51% (237) of the consumers indicated that their backup PAS is unpaid. A range of 38% - 92% of the respondents reported their backup PAS was unpaid by service area.



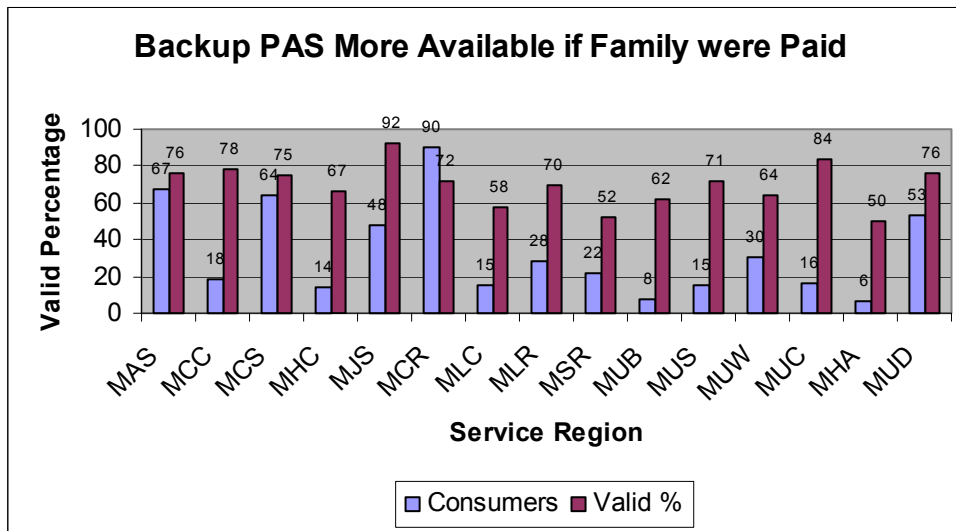
Just over 85% (567) of the respondents do not offer incentives for backup PAS. A range of 60% - 100% report the same by service region.



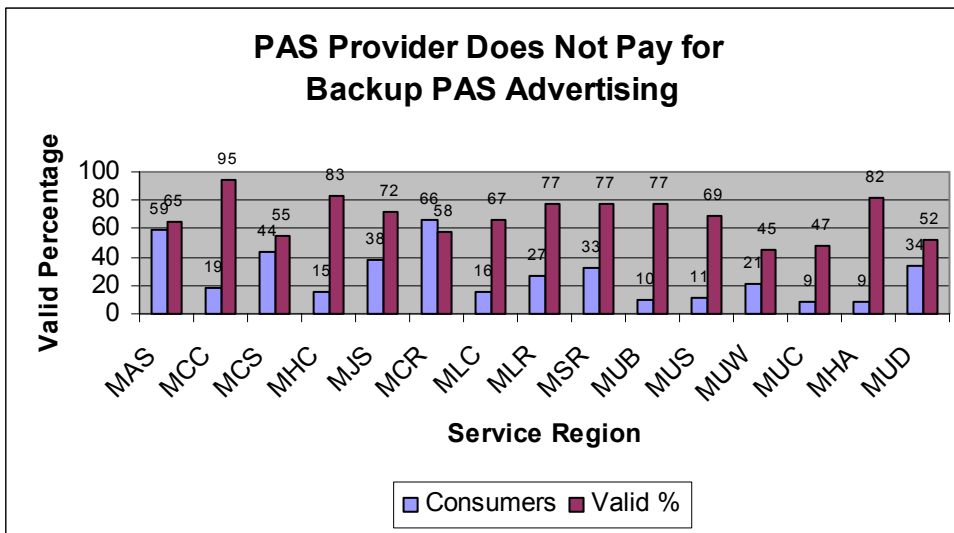
Over 56% or 280 consumers indicated that their backup PAS is family members. A range of 29% - 92% by service region indicate that their family is the source of the backup PAS as well.



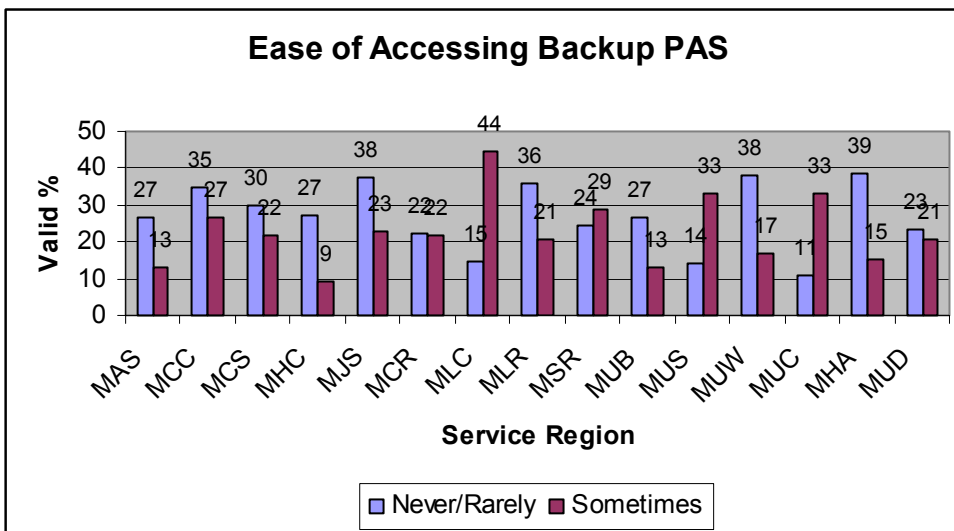
A total of 70% (494) of consumers feel that backup PAS would be more available if family could be paid. By service region, respondents felt that same ranging from 50% - 92%.



A sum of 63% (411) of consumers stated their PAS provider does not pay for advertising for backup PAS or was unsure. A range of 45% - 95% by service region indicated the same.



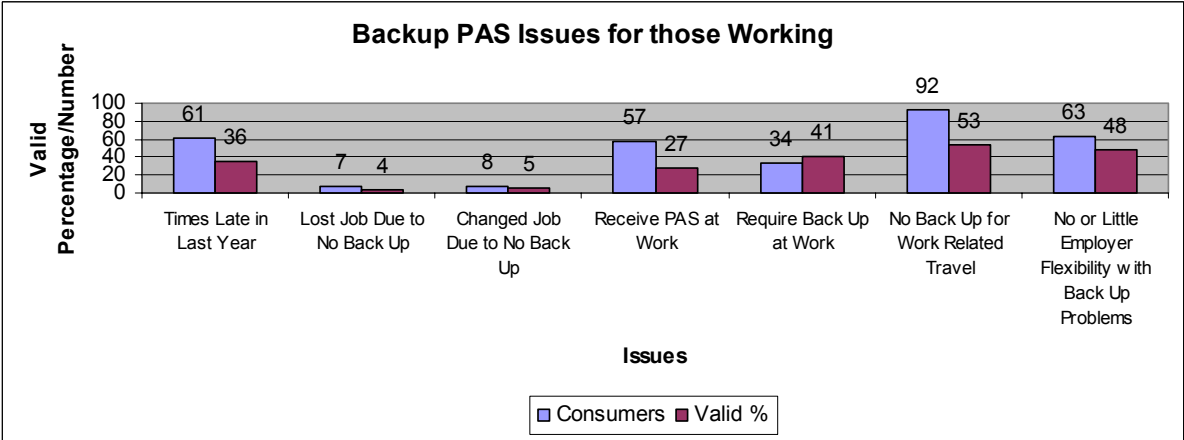
Over 27% (195) consumers indicated they never or rarely access backup PAS when needed. A range of 11% - 39%, by service region, rarely or never access backup PAS when needed. Furthermore, 23% (154) access backup PAS sometimes; by service region a range of 9% - 44% access backup PAS sometimes.



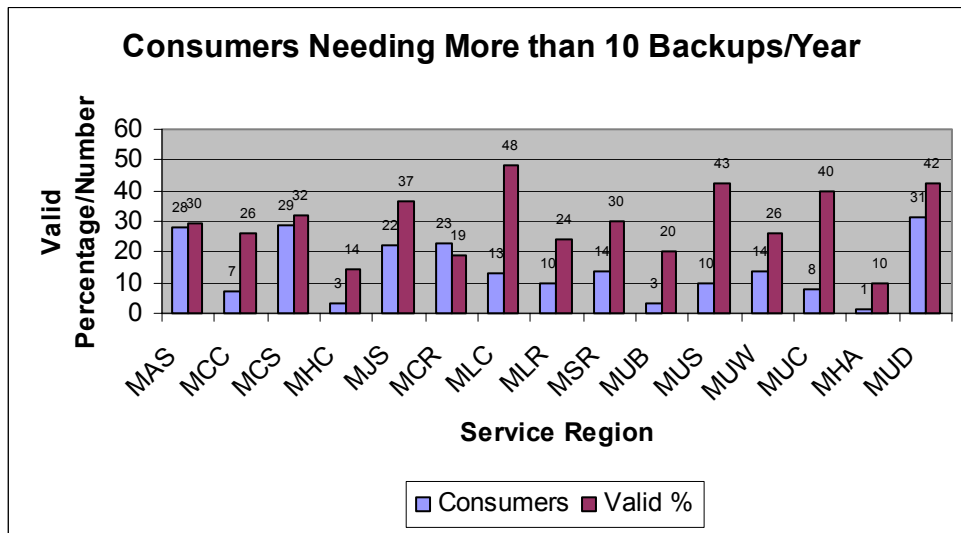
A sum of 57% (417) indicated backup PAS was not available to them 24 hours/day 7 days/week or were unsure. By service region, a range of 41% - 72% indicated the same.



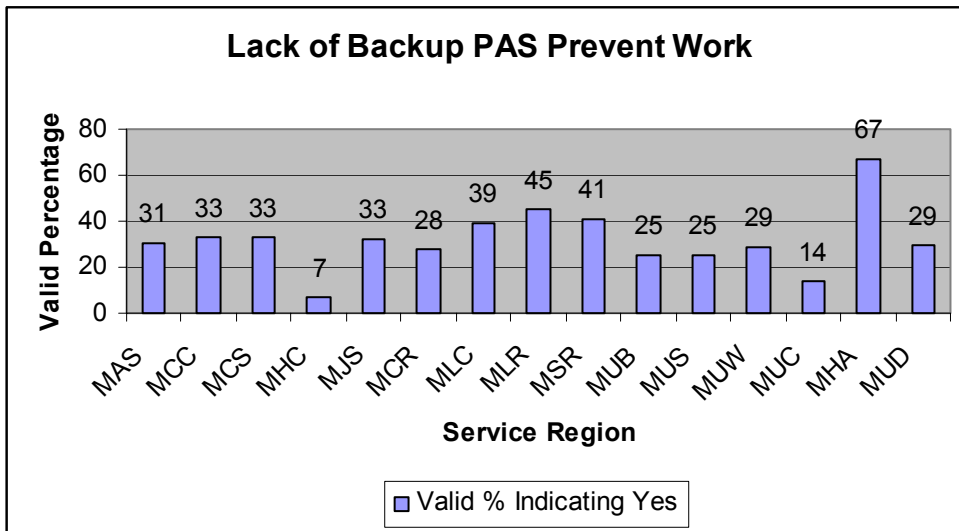
The following data is for PAS users employed now or ever: 36% (61) consumers were late to work due to no backup PAS; 4% (7) consumers lost their job due to no backup PAS; 5% (8) changed jobs due to no backup PAS; 27% (57) receive PAS at work; 41% (34) require backup PAS at work; 53% (92) have no backup PAS for work related travel and 48% (63) have no or little employer flexibility with backup PAS problems.



A total of 30% needed backup PAS more than 10 times per year. When reviewing the result by service region, a range of 10% - 48% at the same level exists for backup PAS.



Just over 32% of the respondents indicated that a lack of backup PAS prevents them from working. A range of 7% to 67% of consumers reported the same by service region.



Seven consumers reported that they lost their employment due to no backup PAS. Eight consumers changed their job to due lack of backup PAS.

Pearson Chi Square Tests reveal several factors and issues related to the core purpose of this study to include:

- ◆ There were no differences in responses about the following based on area density:
  1. Rating the quality of backup PAS ( $x^2$  2.38, df4,  $p < .665$ ).
  2. Lack of backup PAS prevents work ( $x^2$  4.23, df4,  $p < .375$ ).
  3. Employment rate of consumers ( $x^2$  .607, df2,  $p < .738$ ).

- ◆ Consumers with backup are more likely to receive wages. 15% of consumers with backup PAS receive wages compared with 91% of consumers without backup PAS and receive no wages ( $\chi^2$  3.87, df1,  $p < .049$ )
- ◆ Those with wages are more likely to need a greater number or more times of backup PAS. 32% of consumers with wages need backup PAS more than 12 times per year ( $\chi^2$  19.03, df6,  $p < .004$ ).
- ◆ Those with a wage are more likely to use consumer model ( $X^2$  12.664, df3,  $p < .005$ ).
- ◆ Those with a wage are more likely to require backup PAS at work. The majority (60%) of consumers with a wage require backup PAS at work ( $\chi^2$  8.54, df1,  $p < .003$ ).
- ◆ Those with a wage are more likely to know the service model they use. 93% of employed consumers know their service model compared to 78% of unemployed consumers ( $\chi^2$  12.664, df3,  $p < .005$ ).
- ◆ Those with backup PAS and wages are more likely to know the differences in models. 82% of consumers with a wage know their service model compared with 18% without a wage ( $\chi^2$  11.80, df1,  $p < .001$ ).
- ◆ More consumers have backup PAS in the consumer and combination models compared to the agency model. 58% of consumers have backup PAS in the consumer and combination models ( $X^2$  15.376, df3,  $p < .002$ ).
- ◆ PAS providers who pay for advertising are more likely to have consumers with backup ( $X^2$  12.831, df2,  $p < .002$ ).
- ◆ Consumers who have been in the program for more than 10 years are more likely to have backup compared to consumers with 1-3 years in the program ( $X^2$  17.041, df4,  $p < .002$ ).
- ◆ Those who believe that paying family members would increase the availability of backup PAS are more likely to say that lack of backup PAS prevents work ( $X^2$  7.726, df2,  $p < .021$ ).

- ◆ Family members who are backup PAs are much more likely not to get paid. 20% of family members get paid compared to 90% of non family member backups ( $X^2$  233.257, df1,  $p < .000$ ).
- ◆ Those with a wage are more likely to have a family member as backup. 65% of consumers with a wage have family provide backup PAS ( $X^2$  3.82, df1,  $p < .05$ ).
- ◆ Those without 24/7 backup PAS are more likely to have lack of backup PAS prevent work. 52% of consumers without 24/7 backup PAS responded that a lack of backup PAS prevents work moderately or a great deal ( $X^2$  9.600, df4,  $p < .048$ ).
- ◆ Those with good quality backup are not prevented from working. Those with poor quality backup are more likely to have it prevent work. 60% of consumers with good quality backup are not prevented from working compared with 46% poor quality backup and are prevented from working ( $X^2$  19.021, df4,  $p < .001$ ).
- ◆ Consumer rate quality of backup PAS higher when backup PAs are paid ( $X^2$  7.89, df2,  $p < .019$ ).
- ◆ Consumer rate quality of backup PAS higher when they have 24/7 backup PAS available ( $X^2$  98.78, df4,  $p < .000$ ).
- ◆ Consumers rate quality of backup PAS higher when they have backup PAs available to travel for work ( $X^2$  12.59, df4,  $p < .013$ ).

The survey respondents indicated practices that work and do not work used to retain or recruit backup PAS and Personal Assistants (PA) as follows:

### What Works

Backup Live In	Praise
Meals/Dining Out	Friendship
Gifts	Recommendations
Clothes	Transportation Money
Write out backup system	Receiving Advance Notice
Out of Pocket Money	Hire Multiple Personal Assistants
Time Off	Use family, neighbors and friends
Flexibility	Cash/Pay for travel time
Parties	Personal Referrals
Use a Home Health Agency	Have regular PA train backup
Personal Advertising	Use PAS Provider Floater PA
Give backup PA part time hours	Shorten routine in backup situation
Adequate call-off notice	Differential pay

## What Does Not Work

Lack of familiarity with needs and training	Schedule can't be changed – Consumer and PA
Limited or infrequent work hours	Availability – short notice, early am, not 8am to 3pm only
Spouse/Family late for work	Spouse/Family has to leave work
Spouse/Family call off work	Lack of pay for family members
Lack of good wage/benefits	Dependability and reliability
Timing/Arrival of backup PA	Agency/Provider cooperation
Disrupting Spouse/Family Lives	Constant Re-Training
Understanding diverse disabilities	Lack of consumer education
Personal/Emergency call offs	Lack of PAs

### **Definition of “Wishes to Work”**

Several avenues were explored to gain input on the development of a definition of someone wishing to be employed. Those primarily involved in this definition development are consumers via the forums and survey.

However, Mr. Stephen Nasuti, OVR Executive Director was interviewed to ascertain what factors OVR views in determining someone who wishes to be employed, as well as, the PAS Providers, LACEs and ACE. Someone wishing to be employed is self determined goal. However, the following activities and factors indicate characteristics of such a person:

- ◆ People with disabilities are generally presumed to be capable of engaging in gainful employment.
- ◆ Shows interest and has desire to work. Making progress towards employment while taking into consideration of unforeseen issues such as a relapse of a medical condition.
- ◆ During the initial ACP assessment (intake) this is a question which is asked of the consumer and then again during reassessments.
- ◆ Interviewing, submitting resumes/applications.
- ◆ Working on transportation to and from job.
- ◆ Working with OVR, training, college, networking, volunteer.
- ◆ Reviewing employment classifieds/job search.
- ◆ Improving health, appearance, grooming.
- ◆ Logistic and goal planning.
- ◆ Receiving and participating in independent living skills training.

The following definition of someone wishing to be employed is offered:

“Individuals with disabilities who demonstrate they are working towards employment and/or actively looking for work, including individuals with the most significant disabilities.”

## **Backup PAS National Promising Practices Summary**

The following summary will provide information on the issue of backup PAS to determine promising practices occurring across the nation; and, how those practices may be applicable to Pennsylvania. Those informally surveyed included major disability related organizations, national leaders in disability field/community and the nationally recognized leaders in provision of Home and Community Based Services (HCBS) across the United States were contacted.

Mr. Mark Newsome, Project Director, from the American Public Human Services Association, Center for Workers with Disabilities provided referrals to organizations/persons already identified by PCIL. Ms. Williams and the PCIL project director participated and joined the Centers for Workers with Disabilities PAS Task Force committee wherein they have begun looking at backup PAS. This committee provided no additional data regarding backup PAS.

All other inquiries made to the contacts noted in the “*Methods*” section bared no new information on promising practices for backup PAS except for one. All contacts indicated that our contact base was extensive and far-reaching. Brian Burwell, Vice President Research and Policy Division for The MedStat Group provided Backup PAS information on promising practices in California. **(See Appendix F, Promising Practices in Home and Community Based Services).**

These two promising practices are being implemented, one each, in Alameda and San Francisco Counties, California. The PCIL project director interviewed Mr. Charles Calavan, current executive director of the Alameda County Public Authority and former executive director of the San Francisco Public Authority. The two public authorities implemented a system to provide backup PAS to consumers when their personal backup PAS system fails.

The San Francisco Public Authority’s On-Call Workers program created a pool of personal assistants (PAs) willing and able to meet most emergency needs. The PAs are not on-call. The Public Authority, which employs the PAs directly, only pays for hours in which the PAs provide back-up support. Currently 15 to 20 PAs are available for back-up support. They receive \$14 to \$15 per hour, including reimbursement for travel costs. San Francisco’s program does not limit the length or frequency of visits under this back-up program. Participants access

back-up support by calling the Public Authority. Public Authority staff then calls the PA pool until they reach someone willing to serve the participant. Participants calling after business hours leave a message. Public Authority staff checks messages each night during the week and on weekend and holiday mornings. Two Public Authority staff receive \$150 per month each to check the messages and to call the worker pool. The San Francisco County back-up assistance program currently averages 260 hours of support per month. The average cost of back-up assistance for this program is \$20 per hour. Mr. Calavan reported that although this program filled a gap in the continuum of service to consumers; it was not a system that filled immediate backup PAS needs. This is attributable to the frequency of checking backup PAS requests.

The Alameda County Public Authority's Rapid Response system provides consumers living in Oakland with a free round-the-clock PA replacement service on a short notice for emergency situations. For example, a backup PA may be needed when a regular PA quits untimely, PA has scheduled time off or is unable to arrive as scheduled. The Public Authority reduced the hours of back-up assistance a consumer used from that person's regular monthly allotment of service hours. In addition, its goals are to increase consumers' safety and sense of security, and provide a replicable model.

The Public Authority contracted with a community service agency with 5 or more years experience to offer non-medical assistance with essential activities of bathing, dressing, eating, toileting, in and out of bed or wheelchair. The contract had a cost ceiling to implement cost controls. The agency employed eight PAs, a supervisor, and a dispatcher. In order to ensure that PAs would be available at any time, the PAs received \$3.50 per hour for the hours they were on-call, in addition to payment for the hours in which they provided support. The Public Authority expected a replacement PA to arrive at a consumer's home within one hour of a telephone request. Visits were limited to three hours, and participants could not use back-up assistance more than four times per month. Interestingly, chronic or frequent use of the service was monitored in an effort to provide assistance to consumers to develop or improve personal backup PAS plans.

After the pilot, the Alameda County Public Authority revised the model to establish a regular program for back-up support due to high costs with the on call system. Utilization was lower than expected, possibly due to

lack of knowledge of the program, and a common belief among people aware of it that it was for emergencies only. About three-fourths of the paid hours were for on-call hours, an average of 705 hours per month at actual support cost of \$110 per hour. The Public Authority pays an agency on a fee for service basis, with no payment for on-call hours. Instead, the Public Authority will pay \$24/hour for routine service calls and up to an additional \$12/hour when a worker arrives within 2 hours of an urgent call, with the worker receiving most of the additional money. Mr. Calavan indicated the financial incentives system was implemented for speedy dispatch of PAs since no contractor would guarantee a one hour arrival time.

In both the on call and fee for service practices noted above, the contracted agency provider responded to a Request for Proposal (RFP) issued by the Public Authority. The provider had to demonstrate several performance measures and quality service provision necessary to provide a screened and capable replacement for consumers requesting the service. The PAs are part and full time employees of the provider. Several crucial components of a quality backup PAS program included:

- ◆ Ensure consumer access to timely and reliable backup PAS.
- ◆ Capability to respond to non traditional office hours of operation requests with a qualified dispatcher and dispatching system.
- ◆ Measures to monitor and measure quality and how it improves the program services to include staff plans.
- ◆ A documented grievance/appeals procedure for consumers and PAs.
- ◆ Provider mission and vision to support the service. Prior experience and history.
- ◆ Support and implement the principles of the independent living philosophy: consumer control; choice; and community participation.
- ◆ Responsiveness to fluctuating and/or increased service levels.

The evaluation of the Alameda County Rapid Response pilot indicated participants that used the program found it valuable. Ninety-one percent of pilot participants considered the type of support offered very important. Sixty percent said they would highly recommend the program to other participants.

## Discussion

During the writing of the research results, overarching themes began to emerge from both PAS providers and consumers.

Our research found:

- ◆ 70% of the PAS providers felt that backup PAS is somewhat to extremely difficult to provide effectively. A significant number of consumers (32%) do not have backup PAS.
- ◆ 88% of the PAS providers indicate they have the capability to respond to backup PAS needs 24 hours per day, 7 days per week. A sum of 50% of the consumers never or sometimes access backup PAS.

A different view of backup PAS exists between consumers and PAS providers. Consumers view a needed backup PAS occasion to be one where a personal assistant is not timely or does not arrive at all, the ability of a person using PAS to maintain a self determined independent lifestyle of their choosing and to be employed or maintain a job, is impacted. On the other hand, according to the qualitative responses from PAS providers regarding issues or needs that drive their priority backup system, consumer health and safety was ranked first. Moreover, priority care and backup coverage are two different types of assistance.

According to the Attendant Care Program Requirements (April 1, 2002) , priority care is care needed by consumers to ensure their health and safety wherein PAS providers are required to have the capability to respond to such needs 24 hours per day, 7 days per week. Backup coverage is a substitute service source that can be available to provide PAS when the normally scheduled PA is unavailable. PAS providers encourage the use of family, friends, and neighbors for this need. If a consumer has no backup system in place or their backup system fails, PAS providers shall notify the consumer of what to do if they need assistance. Consumers shall take the primary responsibility for arranging backup coverage and priority care.

Contractors are ultimately responsible to ensure that priority care is provided to all consumers. Backup coverage is not necessarily defined as a responsibility lying solely on the PAS provider.

**Recommendation:** *DPW should begin transforming a medically-based priority PAS structure to an empowerment-based priority and backup PAS structure, with shared responsibility between the PAS provider and consumer, to support individuals with disabilities to remain in their homes, determine own goals, support employment and participate in all our communities have to offer.*

The PAS providers who do not have backup PAs on staff or on call provided several practices/approaches as a result of the survey. Most practices are informal in nature and do not support a truly reliable and timely backup system. For PAS providers with backup PAs on staff or on call offer more efficacies due to performance standards in personnel policies. A provider did reference the Pennsylvania Department of Aging (PDA) waiver allowing consumers to choose and setup their backup systems with one or more agencies.

**Recommendation:** *The DPW should investigate ways and determine feasibility of replicating this PDA waiver component into other home and community based services.*

Analyses	Chi Square Analyses
<ul style="list-style-type: none"> <li>• 32% consumers - have no backup</li> <li>• 26% consumers - rate the quality either very poor or poor</li> <li>• 63% consumers - unsure or did not know if the PAS provider pays for backup advertising</li> <li>• 57% consumers - unsure or did not know if backup PAS is available 24/7</li> </ul>	<ul style="list-style-type: none"> <li>• Those with good quality backup are not prevented from working</li> <li>• Those with poor quality backup are not prevented from working</li> <li>• Those with backup are more likely to have PAS provider pay for backup</li> <li>• Rate quality good when backup is available for work related travel</li> <li>• Geographic location had no impact on backup in general.</li> </ul>
<p><b>Discussion:</b> Consumers are not aware of available backup PAS and all of the wide range of recruitment methods. Inconsistency exists regarding whether or not a PAS provider pays for advertising for PAs. A strong relationship exists between consumer having information and having a functioning backup system.</p>	
<p><b>Recommendation:</b> <i>DPW should clarify responsibilities with providers regarding paying for PA advertising and ensuring consumers know that backup is available 24/7.</i></p>	

Analyses	Chi Square Analyses
<ul style="list-style-type: none"> <li>• 20% consumers - did not know what service model used</li> <li>• 33% consumers - did not know difference in service models</li> <li>• 51% consumers - do not know difference in advantages or disadvantages of service models</li> <li>• 63% consumers - have been in ACP for 1-6 years</li> </ul>	<ul style="list-style-type: none"> <li>• Those with a wage are more likely to use the consumer model</li> <li>• Those with backup and a wage are more likely to know difference in service models</li> <li>• More consumers have backup in the consumer and combination models</li> <li>• Those with 10+ years experience in ACP are more likely to have backup</li> </ul>
<p><b>Discussion:</b> A large number of consumers do not know what inherent benefits with regard to backup PAS exist in different service model due to a lack of information and/or experience in the program. With reliable backup, consumers become more confident in their personal support system which is a necessity prior to becoming employed.</p>	
<p><b>Recommendation:</b> <i>DPW should ensure that consumers are being informed and trained on the different service models in the Pennsylvania Model of PAS.</i></p>	

Analyses	Chi Square Analyses
<ul style="list-style-type: none"> <li>• 51% consumers - backup is unpaid</li> <li>• 56% consumers - backup is a family member</li> <li>• 70% consumers - backup would be more available if family members were paid</li> <li>• 100% providers – backup would be more available if family members were paid</li> <li>• 32% consumers - lack of backup prevents them from working</li> <li>• 85% consumers - do not offer incentives to backups</li> <li>• 57% providers – do not offer incentives to backups</li> <li>• 93% providers – somewhat to extremely difficult to recruit/retain skilled and reliable backup</li> </ul>	<ul style="list-style-type: none"> <li>• Quality rating of backup is good when backup is paid</li> <li>• Family members who are backup are more likely to be unpaid</li> <li>• Those who believe that paying family members would increase the availability of backup PAS are more likely to say that lack of backup PAS prevents work</li> </ul>
<p><b>Discussion:</b> A significant amount of backup PAs are unpaid and unpaid family members. A low wage, family member exclusions and/or lack of incentives for the PA exist. In addition, a large amount of consumers feel that backup prevents them working and do not have personal resources to provide incentives for backups other than family members. According to OSP, 6% of all ACP and ACWP consumers are employed. Further significance on the need for better backup is portrayed with a 13% employment rate in this study. Also, 8 consumers changed jobs due to lack of backup which inhibits career choice.</p>	
<p><b>Recommendation:</b> <i>DPW should change policy to allow family members and spouses to be paid as backup PAs for consumers; increase PA wages and provide for a financial incentive such as a higher wage for backup PAS provision.</i></p>	

Analyses	Chi Square Analyses
<ul style="list-style-type: none"> <li>• 28% of employed consumers want to work more hours</li> <li>• 10% of unemployed consumers want to work with full or part time</li> <li>• 42% consumers - volunteering</li> <li>• 27% consumers - OVR consumers</li> </ul>	<ul style="list-style-type: none"> <li>• Consumers with backup are more likely to receive wages</li> <li>• Those with wages are more likely to need a greater amount or number of occasion of backup</li> <li>• Those with wages are more likely to require backup at work</li> </ul>
<p><b>Discussion:</b> A significant number of consumers want more hours or want to work at some level. In addition, some consumers are working towards employment by volunteering and participating in OVR programs. Backup is a critical component to those working or wanting/wishing to work.</p>	
<p><b>Recommendation:</b> <i>Continue to work with PCIL on the development of a piloted administrative backup structure in Pittsburgh and Schuylkill County.</i></p>	