

SURVEY OF PERSONAL CARE ATTENDANTS AND EMPLOYERS/SURROGATES REGARDING ESTABLISHMENT OF A VERMONT PAS REGISTRY

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# **SURVEY OF PERSONAL CARE ATTENDANTS AND EMPLOYERS/SURROGATES REGARDING ESTABLISHMENT OF A VERMONT PAS REGISTRY**

## **BACKGROUND**

Early in 2001, the Division of Vocational Rehabilitation (DVR), within the Department of Aging and Disabilities (DAD), was awarded a Medicaid Infrastructure Grant (MIG) from the Centers for Medicare and Medicaid Services for the purpose of developing infrastructures to support the competitive employment of people with disabilities and to remove barriers that keep individuals with disabilities from returning to or maintaining employment.

As part of the Vermont MIG, DVR is studying how Vermont's Participant-Directed Attendant Care (PDAC) Program, administered by the Department of Aging and Disabilities (DAD), can better support this population. Currently, each participant must recruit her/his own personal care attendants. This task would be faster and easier for some participants if a 'registry' of attendants existed. This report is the second phase of a comprehensive study of what it would take to establish an attendant registry in Vermont, and provides results of a survey of Personal Assistance Services (PAS) providers and their employers or surrogate-employers, as well as input from advocacy, social services and health care agencies that work with persons with disabilities in Vermont.

## **SURVEY METHOD**

In September of 2003, surveys were sent to PAS<sup>1</sup> providers and eligible participants (PAS employers or their surrogates) from several state programs. Surveys included a postpaid return mailer.

- **Providers:** ARIS<sup>2</sup> mailed the survey with payroll for consumer-directed PAS programs, and mailings were prepared using labels from DAD-administered payroll files.
- **Participants:** Surveys were mailed to participants in the DAD-administered ASP program, and in both participant-directed and surrogate Medicaid Waiver programs. Maximus<sup>3</sup> provided mailing labels for participants in the Department of Prevention, Assistance, Transition and Health Access (PATH) programs that cover PAS.

A total of 164 provider surveys and 206 participant surveys were tabulated using Access 2000. Frequency distributions, selection queries and cross tabulations were used to analyze responses, and to determine whether responses varied by demographic or other distinguishing features.

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<sup>1</sup> PAS is a generic term used in the MIG programs describing a variety of services that assist persons with activities of daily living. In Vermont different agencies and programs may use different terms for these services and for the job of providing these services. The programs that cover these services are the Participant Directed Attendant Care Programs and the Attendant Services Programs (ASP) in DAD, and the programs for children with special needs under Medicaid, administered by PATH, as well as Medicaid Waiver programs administered by the Department of Developmental and Mental Health Services (DDMHS). The providers of PAS are usually referred to as Personal Care Attendants (PCAs).

<sup>2</sup> ARIS is the Intermediary Service Organization (ISO) providing bookkeeping, payroll and tax and waiver billing functions for the consumer who is the employer of record of the provider of PAS services.

<sup>3</sup> Maximus is the state's contractor for enrollment and benefits counseling for the Medicaid and other support programs administered by PATH.

## RESPONSE FROM PAS PROVIDERS

### CHARACTERISTICS OF RESPONDENTS

**Demographic features** of the survey respondents are:

| GENDER | n   | %  |
|--------|-----|----|
| Female | 142 | 86 |
| Male   | 21  | 13 |

| AGE   | n  | %   |
|-------|----|-----|
| <19   | 6  | 1%  |
| 19-34 | 26 | 16% |
| 35-54 | 77 | 47% |
| 55-64 | 31 | 19% |
| 65-74 | 19 | 11% |
| 75+   | 3  | 1%  |

| ZIP of Residence | n  | %   |
|------------------|----|-----|
| 050**            | 14 | 8%  |
| 051**            | 9  | 5%  |
| 052**            | 6  | 4%  |
| 053**            | 12 | 7%  |
| 054**            | 31 | 19% |
| 055**            | 1  | 1%  |
| 056**            | 14 | 8%  |
| 057**            | 54 | 33% |
| 058**            | 21 | 13% |
| 059**            | 1  | 1%  |
| NH               | 2  | 1%  |

**Work status characteristics** of respondents are:

| P/R  | n   | %   |
|------|-----|-----|
| DAD  | 41  | 25% |
| ARIS | 124 | 75% |

| Pd PAS hrs Worked / 2wks | n  | %   |
|--------------------------|----|-----|
| NA                       | 6  | 1%  |
| <10hrs                   | 16 | 10% |
| 10-20                    | 35 | 21% |
| 21-31                    | 29 | 17% |
| 32-40                    | 20 | 12% |
| 40+                      | 59 | 36% |

| Other paid employment | n   | %   |
|-----------------------|-----|-----|
| No                    | 101 | 61% |
| Yes                   | 63  | 38% |
| NA                    | 1   | <1% |

| # of PAS employers | n   | %   |
|--------------------|-----|-----|
| 1                  | 140 | 85% |
| 2                  | 21  | 13% |
| 3                  | 4   | 2%  |

| Who is main PAS employer | n  | %   |
|--------------------------|----|-----|
| Not family member        | 95 | 58% |
| Family member            | 67 | 41% |
| NA                       | 3  | 01% |

### SURVEY FINDINGS<sup>4</sup>

1. **Nearly half of respondents would be interested in working more hours as a PCA than they currently do (43%).**

- Response varied by age group, with half of those between 19-54 wanting more hours, but only one-quarter of those over 54 desiring more work.

<sup>4</sup> In the current programs, the care provider is known as a Personal Care Attendant, or PCA. Therefore, this term is used throughout this report to describe the individual who provides Personal Assistance Services (PAS), the generic term used in the Medicaid Infrastructure Grant program.

- Those who care for a non-family member are much more likely to want more work than those who care for a family member. (Of those who want more work, 64% care for non-family member)
  - Regardless of the number of hours currently worked, the 40-50% who want more work holds true. Even 43% of PCAs working more than 40 paid hours/2 weeks said they would be interested in more hours.
2. **Spreading the word among family and friends is considered the most worthwhile method for finding new or additional work**, cited by 50% of respondents. Notifying social services agencies and churches was second, recommended by 32%. Advertising in local papers was listed by only 21% as an option. (Multiple answers were allowed.)
3. **A registry that performs some form of matching is significantly preferred over a “classified ad” style listing of available PCAs.** Sixty-two percent (62%) supported matching, and only 30% preferred classified ads. When asked to explain their answer, respondents overwhelmingly cited the time wasted and stress generated when the PCA and employer don’t match well. Typical of explanations given are:
- “Being more compatible from a list of matches would prevent turnover”
  - “This would eliminate wasted time on all aspects of looking for employment or employees”
  - “If employers knew about skills of PCA they could choose more wisely”
  - “Everybody needs are different as well as each PCA's ability may be different”
4. **There was strong agreement from respondents about information that should be included in a registry.**
- Over 80% of respondents said the registry should include information about prior arrests and convictions (90%), screening for abuse/neglect/exploitation (93%), names of prior employers and other references (88%), descriptions of previous PAS experience (87%) and job history (80%).
  - Between 50 and 80% said the registry should include motor vehicle violations (72%), specialized training (CPR, first aid, LPN) (76%), gender (65%) and languages other than English spoken (64%).
  - Only one item in the survey, social security number, was supported by less than 50% of respondents (42%)

Many respondents provided suggestions for additional items to include, such as age of PCA, special limitations, conditions or requirements (e.g. allergies, limits on lifting, dyslexia, vegetarian, HIV), smoking, own/drive a car, geographic availability, hours/days available, expected hourly rate of pay expected.

5. **Over half of respondents (56%) prefer to update their information by mail.** (Copy of profile is sent out every three months, they correct and return it within 30 days to stay on registry.) Less than 1/4 (23%) preferred using the telephone to call in updates, and only 17% preferred updating by Internet.
6. **Responding PCAs strongly support the inclusion of employer satisfaction reports (81%).** Reasons given were:

- Satisfaction reports will encourage or provide incentives for quality providers. (“If employers post reports, PCAs will try to do their best.” “It would let other PCAs know how they can improve, too.” “It’s nice to be recognized when you do a good job.”)
- Satisfaction reports will protect employers when they choose PCAs (“If they aren’t good workers they should be doing something else.” “People should know they can count on you and there is no abuse.” “If someone does not give adequate care they might not give it to others either and employers have right to know.” “Weed out the lazy deadbeats who abuse the program.”)

**Those who did not support including employer reports were most concerned that a personality conflict or simple incompatibility could mar a good PCAs record.** (“It may have been a home that you could not work well in or feel comfortable in, and that report could not be your best.” “Maybe just personality conflict.” “One bad experience could taint employee.”)

Suggested alternatives to posting employer reports were:

- Posting only positive reports, and DAD following up on negative reports to see if they are only personality conflicts, or are cases of poor quality, and if so the person should not be on the registry.
- Having PCAs post references, but not have employer postings
- Letting PCA respond to negative reference, and post both. (Note: this is the system used in California registries.)

**7. PCAs overwhelmingly support making the registry available to both state-funded and private pay employers (84% to 12%).** Consistently, the reasons given were:

- Source of funding is irrelevant when people need help. (“Both can use the information.” “It’s only fair.” “It’s harder for private paid; they don’t know where to get help most of the time.” “PCAs are hard to come by, especially good ones.” “Why not make it available to everyone?”)
- PCAs looking for more work can tap into both pools of employers. (“Because of shortage of nurses, some PCAs might be interested in other programs.” “If available to both would provide more work for PCAs.”)

Those who supported access to registry only for state-funded employers offered these reasons:

- Opening the registry to private pay employers will drive up the cost and complexity of operating a state-funded registry. (“Do you want to take on private pay?” )
- People eligible for state support need the service more. (“People who can’t afford should come first.” “Private pay seem to have more options.”)
- State funds should be used for state eligible. (“If the state is paying for it and monitoring it only the state funds should benefit.” “Or make those ineligible for state funding pay for the service.”)

**8. PCAs recommend placing stories and ads in newspapers (71%) and using social services agencies (68%) to find additional people who would be interested in being on the registry to find employment as a PCA.** Notifying people who are on unemployment, welfare and food stamps was named by 42%. The methods receiving the least support were: posters and flyers around the community (33%), stories on television news (31%) and radio announcements (24%).

Other suggested methods offered by respondents include:

- Notices for health care providers such as hospitals, nursing homes, home health agencies and doctors' offices.
- A website / the internet
- Churches, colleges and schools

9. **Opinion is divided on the preferred form the registry should take, but a printed booklet received the most support (51% named it as their first choice). A toll-free call-in registry was named #1 by 30%, and internet/website was the first choice of only 15% of respondents.**

In seeking opinions on this question, we first asked whether each format should be used, and then asked for a ranking of the three formats. This chart displays both answers:

| REGISTRY<br>FORMAT | Should this form<br>be used? Y = | First<br>Choice | Second<br>Choice | Third<br>Choice |
|--------------------|----------------------------------|-----------------|------------------|-----------------|
| Internet/website   | 48%                              | 15%             | 23%              | 47%             |
| Booklet            | 77%                              | 51%             | 33%              | 11%             |
| Toll-Free Call-In  | 74%                              | 30%             | 37%              | 25%             |

- **Internet:** Those who said this form should be used gave reasons of ease of use and stated that many people have Internet access now. Those who said it should not be used cited lack of Internet access, especially by the elderly, and many expressed privacy concerns.
- **Booklet:** Those who said this form should be used noted that a booklet is available any time, is user friendly and ensures privacy. Those who said it should not be used cited cost and that people might not save it if it is mailed to them.
- **Toll-Free Call-In:** Those who supported this model cited privacy, personal touch and easy access. Those who opposed it cited cost and concerns that the process would be time-consuming and possibly confusing.

The chart below displays the first choice of format reported by those who are seeking more hours of employment:

| FORMAT            | Those Looking for More Work Who<br>Prefer this Format |
|-------------------|-------------------------------------------------------|
| Internet/website  | 18%                                                   |
| Booklet           | 47%                                                   |
| Toll-Free Call-In | 33%                                                   |

The charts below display the first choice of format by age groupings. The first chart shows how the #1 votes are distributed through age groups, the second show the preference for each age group. The second chart shows that preference for the booklet is strongest is the 19-64 age groups (who dominated the survey response pool). Interestingly, the Internet format received the strongest support in the 65+ age group. (Caution: in this type of cross tabulation, many cells contain small numbers, so

generalization may not be possible from this data, unless the distribution of age in the PCA population is reflected in the survey response age distribution as well.)

|                          | <b>Percentage of #1 Votes By Age Grouping</b> |              |              |              |            |             |
|--------------------------|-----------------------------------------------|--------------|--------------|--------------|------------|-------------|
| <b>FORMAT/Age Group</b>  | <b>&lt;19</b>                                 | <b>19-34</b> | <b>35-54</b> | <b>55-64</b> | <b>65+</b> |             |
| <b>Internet/website</b>  | 8                                             | 16           | 44           | 20           | 12         | <b>100%</b> |
| <b>Booklet</b>           | 6                                             | 13           | 52           | 20           | 8          | <b>100%</b> |
| <b>Toll-Free Call-In</b> | 10                                            | 18           | 42           | 16           | 14         | <b>100%</b> |

|                          | <b>% (n) of Each Age Grouping that Voted the Format #1</b> |                 |                 |                 |                 |
|--------------------------|------------------------------------------------------------|-----------------|-----------------|-----------------|-----------------|
| <b>FORMAT/Age Group</b>  | <b>&lt;19</b>                                              | <b>19-34</b>    | <b>35-54</b>    | <b>55-64</b>    | <b>65+</b>      |
| <b>Internet/website</b>  | <b>16% (1)</b>                                             | <b>8% (2)</b>   | <b>8% (7)</b>   | <b>7% (2)</b>   | <b>35% (12)</b> |
| <b>Booklet</b>           | <b>33% (2)</b>                                             | <b>54% (13)</b> | <b>65% (54)</b> | <b>63% (17)</b> | <b>23% (8)</b>  |
| <b>Toll-Free Call-In</b> | <b>50% (3)</b>                                             | <b>37% (9)</b>  | <b>25% (21)</b> | <b>29% (8)</b>  | <b>41% (14)</b> |
|                          | <b>100%</b>                                                | <b>100%</b>     | <b>100%</b>     | <b>100%</b>     | <b>100%</b>     |

10. PCAs recognize the value of the registry to their employment status, and a significant majority is willing to pay a small annual fee for listing.

| <b>Annual Fee</b> | <b>n</b> | <b>%</b> |
|-------------------|----------|----------|
| \$0               | 33       | 20 %     |
| \$5               | 35       | 21 %     |
| \$10              | 36       | 22 %     |
| \$15              | 14       | 8 %      |
| \$20              | 9        | 5 %      |
| \$25              | 26       | 16 %     |
| NA                | 9        | 5 %      |

11. A strong majority of PCAs say that consumers should not be required to pay for using the registry. Among those who did support a fee, most were in the \$5 to \$15 per year range.

| <b>How much should consumers pay?</b> | <b>n</b> | <b>%</b> |
|---------------------------------------|----------|----------|
| \$ 0                                  | 97       | 60 %     |
| \$ 5                                  | 13       | 8 %      |
| \$ 10                                 | 15       | 9 %      |
| \$ 12                                 | 1        | <1 %     |
| \$ 15                                 | 12       | 7 %      |
| \$ 20                                 | 5        | 3 %      |
| \$ 25                                 | 8        | 5 %      |
| \$ 100                                | 1        | <1 %     |
| NA                                    | 11       | 7%       |

## CONCLUSIONS

1. Current PCAs support the establishment of a registry. Half of PCAs report a desire to work more hours, and responding PCAs report that the registry would be useful to them in finding additional work and to employers who may have trouble finding quality PAS providers. They believe it should be accessible for both state-funded and private pay PAS.
2. PCAs support a registry that attempts to match employers with PCAs who best meet their need criteria. A computerized selection process that provides employers with names of PCAs meeting key employer needs would be satisfactory.
3. PCAs uniformly agree on the information that should be included in the registry database to best facilitate the matching process. PCAs were willing to provide this information under oath, and prefer to update information quarterly through the mail.
4. PCAs strongly support including employer satisfaction reports in the registry database. The concerns of those who opposed this may be dealt with by having a fair process for resolving negative feedback report that result from personality conflicts, and not quality of care issues.
5. PCAs are willing to pay a modest annual fee to be listed (\$5-\$15 a year), but a majority does not support charging consumers.
6. A printed booklet is the preferred method, but a toll-free call-in registry also has support. A website as the only source for registry information is not supported, though it was supported if other options are also available. (If privacy concerns can be addressed – i.e. not posting personal information directly on the Internet, but using the Internet to send a query to the registry with mail or phone call-back – support for use of this option may increase.)
7. The availability of the registry for potential PCAs should be publicized among social services agencies, health care providers and through other community resources, including churches and stories placed in free weekly newspapers. The use of television and radio were not seen as effective methods of communication.

## RESPONSE FROM PAS PROGRAM PARTICIPANTS

### CHARACTERISTICS OF RESPONDENTS

**Demographic and participation features** of the survey respondents are:

| Program                                           | n  | Pct of Records |
|---------------------------------------------------|----|----------------|
| Participant-Directed Medicaid Waiver              | 23 | 11 %           |
| Surrogate-Directed Medicaid Waiver                | 49 | 24 %           |
| Attendant Services Program                        | 33 | 16 %           |
| PATH ASP Program                                  | 34 | 17 %           |
| Unidentified DAD-Administered Program (MW or ASP) | 67 | 33 %           |

| Gender | n   | %   |
|--------|-----|-----|
| Female | 137 | 66% |
| Male   | 64  | 31% |
| NA     | 5   | 2%  |

| Age Group | n  | %    |
|-----------|----|------|
| NA        | 2  | 1 %  |
| <25       | 30 | 15 % |
| 25-34     | 5  | 2 %  |
| 35-54     | 49 | 24 % |
| 55-64     | 31 | 15 % |
| 65+       | 89 | 43 % |

| ZIP of Residence | n  | %   |
|------------------|----|-----|
| 050**            | 27 | 13% |
| 051**            | 16 | 8%  |
| 052**            | 5  | 2%  |
| 053**            | 12 | 6%  |
| 054**            | 48 | 23% |
| 055**            | 0  | 0%  |
| 056**            | 25 | 12% |
| 057**            | 43 | 21% |
| 058**            | 25 | 12% |
| 059**            | 1  | 0%  |
| Unkn             | 4  | 2%  |

| Pd hr of PAS received in past two weeks | n   | %    |
|-----------------------------------------|-----|------|
| NA                                      | 4   | 2 %  |
| < 10                                    | 4   | 2 %  |
| 10-20                                   | 21  | 10%  |
| 21-31                                   | 38  | 18 % |
| 32-40                                   | 37  | 18 % |
| 40+                                     | 102 | 50 % |

### SURVEY FINDINGS<sup>5</sup>

- Most participants (62%) find their PCA from among their personal acquaintances.** Only 17% find a PCA by referral from friends and family, and 14% through referral by a social services agency or health care provider, usually the local AAA or home health agency. Among the 6 % who used other sources, most advertised in the newspaper.

<sup>5</sup> In the current VT programs, the care provider is generally known as a Personal Care Attendant, or PCA. Therefore, this term is used throughout this report to describe the individual who provides Personal Assistance Services (PAS), the generic term used in the Medicaid Infrastructure Grant program. The person receiving the PAS may be the PCA's employer, or care may be directed by a surrogate, or under the direction of an agency. To allay confusion, the person receiving PAS is referred to as Participant in this report.

The source of referrals used by participants varies by program. As the chart below shows, those in the surrogate directed care program rely less on personal contacts and more on family contacts. Those in PATH programs for children with special needs rely slightly more on agency referrals, most likely (and as noted in their written comments) in order to find specific skills and experience. In all programs, advertising or going outside of the support network of family, friends and trusted service agencies is minimal.

## 2. How Do PAS Program Participants Find Their PCAs?

| Program    |  | Personally Knew | Referred by fam/friends | Referred by agency | Other |
|------------|--|-----------------|-------------------------|--------------------|-------|
| 1 MW-PD    |  | 70%             | 9%                      | 17%                | 4%    |
| 2 MW-S     |  | 49%             | 29%                     | 16%                | 6%    |
| 3 ASP      |  | 72%             | 9%                      | 16%                | 3%    |
| 4 PATH     |  | 53%             | 18%                     | 21%                | 9%    |
| 5 Misc DAD |  | 71%             | 14%                     | 9%                 | 6%    |

## 3. When the PCA is ill or can't work, most participants have no way of finding another PCA to fill in.

- Forty-five respondents (22%) wrote comments indicating that they either go without care, or may be able to use the temporary assistance of others. ("Maybe someone will stop in to help." "I'm screwed, can't find backup." "I do without and it is very difficult." "There isn't anyone else.")
- 35% specifically stated that family or friends have to act as temporary caregivers. ("My husband has to fill in.")
- In around 18% of cases, the PCA helps find another caregiver, or the participant has multiple PCAs who cover for each other.
- Only 10% have a list of people they call when they need temporary help. ("I try but often can't find anyone." "Difficult to find people to take hourly work.")

## 4. By a significant majority (73%), participants prefer a registry that assists in matching them with suitable PCAs. Only 15% preferred a classified ad model, and 11% had no opinion.

- Participant comments noted that matching would reduce time spent interviewing, and would increase likelihood of compatibility. ("Better to match my personal needs." "I have certain needs and don't want to waste time." "I would not do well if I had to interview a lot of people." "Would be easier to know who is better match.")
- The problem of finding a PCA with particular skills and experience was frequently mentioned. ("Helpful to find someone with specific skills." "I prefer to base decision on my needs and PCA skills." "My son is autistic and needs knowledgeable aide.")

## 5. There was general agreement from participants about information that should be included in a registry.

- Over 80% of respondents said the registry should include information about the specific types of services the PCA is willing to perform (91%), the minimum/maximum hours per day or week they will work (86%) and information on prior arrests and convictions (82%).
- Between 50% and 80% would like the registry to include specific services the PCA will NOT provide (63%), whether they have a car (69%) and are willing to drive the participant (60%), whether the PCA smokes (62%) names of prior employers and other references (68%), references other than previous employers (60%) and specialized training (67%)
- Gender, willingness to work in a home with pets or a smoker, and languages spoken were of interest to a minority of participants.

Many respondents provided suggestions for additional items to include, such as age of PCA, special limitations, conditions or requirements (e.g. allergies, limits on lifting, dyslexia, vegetarian, HIV), geographic availability, hobbies and interests (mentioned by many participants from all programs), salary expectations, and willingness to work on short notice. Several participants noted that many intangibles are also desirable, such as kindness, flexibility, honesty, respect and patience.

**6. PCA background checks and criminal history are important to participants, and would influence their willingness to use names from the registry.**

- A significant majority (70%) said that they would be less likely to use the registry if background checks are NOT done on people before including them on the registry. 25% said it would not affect their use and 5% had no response.
- An even greater number (89%) said PCAs should disclose on their registry application whether they have a criminal history.

**7. Participants strongly support (83%) allowing them to post satisfaction reports on PCAs who have worked for them.**

- Participants are interested both in passing on information about poor care as well as giving praise to good PCAs. (“Good PCA deserve good comments.” “Bad PCAs should be off the registry.” “It keeps people honest.”)
- Participants also hope to learn more about the character and dependability of the PCAs they are considering. (“Because I would know the kind of person they are.” “Are they late a lot? Do they swear? Can they cook?” “Others who want to use them should feel more at ease.”)
- Only a few participants were concerned that satisfaction reports could wrongly assign a negative rating to a PCA. (“Could be a personality clash.” “Attendants should be able to post reports, too; could be misleading.”)

**8. Participants strongly support (83%) allowing both state-supported and private pay employers/consumers to use the registry.**

- PCAs are difficult to find, regardless of funding source, and the registry is seen as making the search easier. (“All in need of help could benefit from the registry.” “Everyone has trouble finding help.” “Everyone should have access to the names.”)
- With a larger pool of employers, more PCAs may sign up for the registry. (“Both would benefit.” “The bigger the pool of PCAs and people who need them, better for all.”)
- Those who prefer limiting the registry to state-funded participants only generally cited the potential for private pay to drain personnel from state programs. (“I don’t want someone taking my PCA away from me!” “Better choices for people with fewer resources.” “If there were enough PCAs for state programs, fine. Until then, state only.” “Private paid will outbid state.”)

9. **Participants advise using newspapers (72%), social services agencies and churches (72%) and posters in the community (41%) to advertise the registry to people needing a PCA.** Television and radio were recommended by only 1/4 to 1/3 of participants.<sup>6</sup> Participants offered these additional suggestions:

- Autism society and other support groups
- UVM, VSC, other colleges, especially education, health care and social work schools
- Elementary and secondary school guidance counselors
- Health care providers, such as hospitals (social services and discharge planners), home health, physicians

12. **Opinion is divided on the preferred form the registry should take, but a printed booklet received the most support (54% named it as their first choice). A toll-free call-in registry was named #1 by 23%, and internet/website was the first choice of 20% of respondents.**

In seeking opinions on this question, we first asked whether each format should be used, and then asked for a ranking of the three formats. This chart displays both answers:

| REGISTRY<br>FORMAT | Should this form<br>be used? Y = | First<br>Choice | Second<br>Choice | Third<br>Choice |
|--------------------|----------------------------------|-----------------|------------------|-----------------|
| Internet/website   | 55%                              | 19%             | 23%              | 41%             |
| Booklet            | 78%                              | 54%             | 29%              | 11%             |
| Toll-Free Call-In  | 68%                              | 23%             | 41%              | 27%             |

- **Internet:** Those who said this form should be used gave reasons of ease of use and stated that many people have Internet access now. Those who said it should not be used cited lack of Internet access, especially by the elderly, and many expressed privacy concerns.
- **Booklet:** Those who said this form should be used noted that a booklet is available any time, is user friendly and ensures privacy. Those who said it should not be used cited cost, difficulty of keeping information up-to-date and waste, because people might not save it if

<sup>6</sup> The survey asked people to select the three best methods for publicizing the registry, from a list of 5 possible – newspaper, television, posters, radio, agencies and churches. Not all respondents named three; no more than three per survey were recorded.

it is mailed to them.

- **Toll-Free Call-In:** Those who supported this model cited privacy, personal touch and easy access. Those who opposed it cited cost and concerns that the process would be time-consuming and possibly confusing to receive information orally. Many said they prefer to have something written in front of them.

The chart below displays the first choice of format reported by program. This shows that booklet (printed registry) is the preferred format in all programs, families covered by PATH programs are much more interested in using the Internet, and very few in the Waiver-Surrogate program want an Internet registry.

| <b>Percentage of Participants from Each Program Who Prefer.....</b> |              |             |            |             |                 |
|---------------------------------------------------------------------|--------------|-------------|------------|-------------|-----------------|
| <b>FORMAT</b>                                                       | <b>MW-PD</b> | <b>MW-S</b> | <b>ASP</b> | <b>PATH</b> | <b>Misc DAD</b> |
| <b>Internet/website</b>                                             | 14%          | 14%         | 24%        | 38%         | 19%             |
| <b>Booklet</b>                                                      | 68%          | 60%         | 47%        | 41%         | 59%             |
| <b>Toll-Free Call-In</b>                                            | 18%          | 26%         | 29%        | 22%         | 22%             |
|                                                                     | 100%         | 100%        | 100%       | 100%        | 100%            |

13. **Nearly two-thirds of participants are willing to pay at least a modest amount for an annual subscription to a registry.** Thirty percent state a willingness to pay between \$5 and \$15, and 20% are willing to pay between \$15 and \$25 per year.

| <b>Annual Fee</b> | <b>n</b> | <b>%</b> |
|-------------------|----------|----------|
| \$0               | 60       | 29%      |
| \$1-4             | 3        | 1%       |
| \$5               | 27       | 13%      |
| \$10              | 41       | 20%      |
| \$15              | 16       | 8%       |
| \$20              | 23       | 11%      |
| \$25              | 18       | 9%       |
| \$30+             | 3        | 1%       |
| NA                | 15       | 7 %      |

14. When asked if PCAs should pay an annual fee to be listed on the registry, participants supported higher fees than for themselves. Only 17% said PCAs should not pay a fee.

| <b>How much should PCAs pay?</b> | <b>n</b> | <b>%</b> |
|----------------------------------|----------|----------|
| \$ 0                             | 36       | 17%      |
| \$ 5                             | 28       | 14%      |
| \$ 10                            | 50       | 24%      |
| \$ 15                            | 25       | 12%      |

| How much should PCAs pay? | n  | %   |
|---------------------------|----|-----|
| \$ 20                     | 22 | 11% |
| \$ 25                     | 20 | 10% |
| NA                        | 25 | 12% |

## CONCLUSIONS

1. Current participants in programs providing PAS support the establishment of a registry. They report that it would be useful to them in finding a suitable PCA, and to PCAs seeking additional employment. They believe it should be accessible for both ate-funded and private pay PAS.
2. Participants support a registry that attempts to match them with PCAs who best meet their need criteria. A computerized selection process that provides employers with names of PCAs meeting key employer needs would be satisfactory.
3. There is general agreement on the information that should be included in the registry database to best facilitate the matching process. Participants expressed very strong support for background checks and the inclusion of criminal record information in the registry; use of the registry is predicated on background checks for a significant majority of participants.
4. Participants strongly support including employer satisfaction reports in the registry database. Only a few expressed any concerns or doubts about the value and importance of this information.
5. Participants willing to pay a modest annual fee to subscribe to the registry (\$5-\$15 a year), and also believe that PCAs should pay to be listed. They supporter higher fees for PCAs than for themselves.
6. A printed booklet is the preferred method, but a toll-free call-in registry also has support. A website as the only source for registry information is not preferred, though it was supported by most participants if other options are also available. (If privacy concerns can be addressed – i.e. not posting personal information directly on the Internet, support for use of this option may increase.)

Objections to a call-in registry noted the difficulty of getting contact information over the telephone, expressing preference for written material. Objections to a printed booklet noted the high cost, possible waste (booklets sent to people who don't need them) and the difficulty of keeping information up-to-date.

8. Participants report that newspapers, social services agencies and churches are the best way to communicate about the registry to people like themselves. A significant number also suggested health care providers and schools/colleges as venues for notifying participants and potential PCAs. Television and radio were not seen as effective methods of communication.

## **RECOMMENDATION: A REGISTRY MEETING THE NEEDS OF BOTH PCAS AND THOSE SEEKING PAS PROVIDERS**

Based on the findings of the survey, a registry is desired by PCAs and current participants in programs providing PAS. A registry serving the needs of both PCAs and those needing their services would have the following characteristics:

1. **The registry should gather a uniform set of information from PCAs, allowing those searching for a PCA to find candidates most closely matching their needs.** Several forms of registry could allow this:
  - The model used by California's Home Care Authorities gathers key information from PCAs via an application form. Individuals who need a PCA answer a series of questions (by telephone call or via Internet) on their personal needs, and a list of PCAs most closely matching their needs is generated and mailed to them. The individual then reviews the list, decides whom to interview and makes his/her own hiring decision.
  - Some registries operated by advocacy and social services groups collect a few key items from PCAs, such as geographic area served, gender, services offered, and provide a pamphlet or booklet containing this information to anyone who requests it.
  - Some registries are essentially a binder containing the PCA application forms, and individuals either visit the agency office or call and a staff person reviews the applications with them.
2. **The registry database should contain comprehensive, up-to-date information about each PCA.** The information, collected on an application form, could be updated by any PCA through the mail periodically. Some PCAs may make use of the Internet to update their information. PCAs should attest to information on the application by signing an oath. In addition to standard contact information, the application form should include:
  - specific types of services the PCA is willing to perform
  - special training and experience (e.g. conditions such as autism)
  - descriptions of prior PCA job experiences
  - geographic area served
  - age
  - minimum/maximum hours per day or week PCA will work
  - availability on short notice for temporary assistance (i.e. substitute for regular PCA)
  - availability on holidays
  - salary expectation
  - conditions or requirements (e.g. allergies, limits on lifting, dyslexia, vegetarian, HIV),
  - hobbies and interests
  - whether can provide transportation
  - smoker/non-smoker
  - names and contact information for prior employers
  - personal or character references (other than prior employers)
  - information on prior arrests and convictions

3. **Employers should be encouraged to provide satisfaction reports for inclusion in the registry.** Registries in other states provide useful examples for promoting fairness:
  - When an employer provides a negative report, the PCA is allowed to submit a response that is also included in the registry database. This allows PCAs to explain if the conflict was personality based, etc.
  - These reports are not publicly available. They are provided only to potential employers, and only when the PCA is on the list of “matches” provided to that potential employer.
4. **The standard background checks now performed on PCAs on behalf of the state should be conducted before including the person in the PCA Registry.** This should be in addition to the PCA being required to disclose any criminal background on the application, under oath. Anyone using the registry should be required to sign a statement attesting to their understanding of the extent and limitations of any background check provided.
5. **Names of potential PCAs should be provided to persons in writing – either by mailed hard copy or a printable list via an Internet website.** The strong support for a booklet format for the registry versus Internet related to lack of widespread accessibility to the Internet, as well as privacy concerns. The support for booklet over telephone related to a preference for having the information in writing for easier perusal. Still, many recognized the high cost of printing and distributing booklets that could be quickly out of date, as well as the simplicity and personal touch of using a toll-free hotline.

Consider the California registry model:

- Via toll-free telephone or an Internet website, individuals respond to a series of questions regarding their particular preferences and needs for a PCA.
- A list of “matches” is generated and mailed to the individual.

The model would appear to address the many otherwise conflicting needs and concerns:

- **Privacy:** Privacy of PCA information is maintained because nothing is directly published or available on the Internet. PCA contact information is mailed providing a record of who has requested/received the information.
- **Ease of Access:** Individuals can choose to access the registry by telephone or the Internet.
- **Matching:** The individual who needs a PCA receives a written list of potential matches, not all PCAs on the registry
- **Economical:** The individual who needs a PCA receives a written list of potential matches through the mail, resulting in far less cost than publishing a directory of PCAs who may or may not match the individual’s needs. The database from which the lists are drawn can be updated via the mail or over the Internet.

6. **A modest annual fee would be charged to PCAs and registry users to help underwrite the cost of establishment and maintenance of the registry.**
  - PCAs can be charged at the time of application for the registry, and allowed to remain on the registry for a year provided they update their information as periodically requested.
  - Registry users can be charged at the time of first use, and given unlimited access for a year.

## INPUT FROM ADVOCACY LEADERS

The recommended registry design was presented to leaders of advocacy groups working with individuals who use PAS. Their reactions and suggestions are described below.

### **Peter Youngbaer, Executive Director, Coalition for Disability Rights**

- It's valuable to have surveyed providers and consumers working in all of the PAS programs in the state because the types of services they need or can provide, the service definitions, the skills of PAS providers are all very different.
- The recommended design makes sense, providing easy access to a "short list" of possible matches.
- Give some thought to how a consumer will make use of this list: will there be help with contacting, interviewing, hiring? This now varies by PAS program --- some provide case management, service brokering, etc, others don't. Some program allow participant direction, others limit consumer to selecting from an agency-approved list. Make sure registry appropriately interfaces with each program's requirements.
- Keep the registry as "generic" as possible so as not to inadvertently reduce usefulness to any groups or individuals. For example, PCA is a term for a provider in particular programs. By calling it a PCA registry, you may be eliminating providers of respite care, homemaker services. Use generic terms and make it clear that the registry is not connected to any particular state program or type of disability or need.
- Make sure the registry operation reflects and reinforces the AHS reorganization effort. (Again, keeping it "generic").
- Registry probably should be operated from central office of AHS, rather than by any specific agency of AHS, or private, non-profit, in order to keep it generic, accessible and useful to as many programs, as many consumers as possible.

### **Scott Goyette, VT Center for Independent Living**

- As someone who has used PAS for 18 years, Scott believes that the registry described will be a valuable resource. Winnowing down candidates to a "short list" of those with suitable skills and experience is a great challenge for people with disabilities; registry can do this.
- Continuing current practice of background checks is important. Only those with background checks should be on the registry. It's important to disclose to consumers the limits of background checks (only VT), etc. If there is any way to expand or enhance the check, it should be incorporated into qualifications for registry.
- Scott noted difference among PAS programs in services provided to help people select, hire and manage their PCA. He asked if case managers would have access to database, or just consumers? Also, can consumer ask to have list sent to case manager? Or only to consumer? Or both? He believes that consumers should control hiring decisions and participate as much as they want in the entire process, but some will want help at different points along the way. Registry should allow this flexibility.
- Scott feels combination of Internet and telephone access to registry is important. VCIL survey found only 30% of their constituency has Internet access.
- Regarding fees for listing or using the registry, Scott referred to his own experience trying to find a PCA and the cost he incurred advertising, and the time wasted contacting people who weren't suitable. He said he was not surprised that the surveys showed a willingness to pay a subscription fee to be on or use the registry.

- Underscored privacy and confidentiality issues, how to protect and safeguard PCA and consumer information collected by the registry.
- Believes that state agency or advocacy organization could be the home, preferred advocacy organization because of ongoing and regular contact with individuals. Understands need to keep registry generic.
- Suggested contact with COVE group working on PCA association --- could that be a “home” for the registry? Strengthen workforce development aspects.

**Michelle Corrow, formerly Executive Director We Can, now co-director of PRIDE**

We Can was a parent advocacy and support program funded by PATH to link families in need of PAS to care providers. We Can recruited and screened personal assistants and developed a registry/database. Families in need of help would call and We Can would provide a list of three potential care providers who matched the family’s needs. Michelle said the need is very great for this service and while it was operating theirs was very successful matching families and PAs. She offered these observations on their program:

- Recruitment: We Can contacted every DET office in the state. They received around 100 referrals every couple of months this way.
- A committee of We Can volunteers would do an initial interview with PA candidates to “weed out” those individuals who clearly weren’t suitable for PAS. The candidate completed an intake form that included questions such as:
  - What would be your dream personal assistant job
  - What hours/days are you willing to work
  - What are your salary expectations
  - What experiences do you have
  - What kind of person would you like most to work with
- Parents who were in need of PAS for their children would call and staff would take the parents through an intake form:
  - age of child
  - abilities of child
  - expectations of caregiver: ADL services only, social, companion, etc
  - hours needed and approved hours
  - days
  - location
- PA candidate information was kept in a spreadsheet, and the staff would “eyeball” the database with the parent’s requests in mind. The three best “matches” were selected, and their information sent to parents. If the family hired someone, the person was taken off the registry. If none worked, staff would provide three more names.
- After 30 days We Can staff would call to see if PA was working out. Goal was to check in every six months, but grant from PATH ran out and program disbanded. At its peak, We Can was helping approximately 50 families
- Michelle was paid for 15 hrs week to carry out this function but found that it wasn’t enough. In retrospect she recognizes that she was providing a tremendous amount of other referral services and informal “case management” services, such as helping with special ed and health care needs, arranging transportation, program eligibility information other than PAS, etc. She noted that it is very easy to become engaged in all of the many needs the person has in addition to PAS, and that those staffing the registry have to “stay focused.”