

November 2006 CMS MIG Conference (Chicago, IL)
Workgroup #1: Personal Assistance Services (PAS) Research

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Session Objectives

- To identify potential sources of administrative information about workplace PAS availability and use
- To identify strategies for collecting additional information about workplace PAS availability and use
- To describe strategies for assessing need for additional PAS services
- To identify strategies for evaluating new workplace PAS initiatives
- To connect with other states conducting research and assessment on workplace PAS

This was an interactive session, designed to function as a workgroup, for information sharing among states interested in the research topic of PAS in the workplace. The states participating had varying levels of experience in conducting research on PAS availability and use, and in developing analysis plans for new initiatives.

States generally know how to identify the extent to which PAS services should be available through the Medicaid state plan and waivers. This session was intended to think of new sources of information and strategies for collecting new information.

Discussion Notes

Potential (non-Medicaid) sources of information on Workplace PAS availability

Workplace PAS services may be available through several sources in your state. These sources may have administrative data about PAS availability and use, or may be a location for collecting new data.

- Agencies that work with consumers who have developmental disabilities or mental retardation
- Vocational rehabilitation programs
- Agencies that provide direct services
- Agencies or organizations that coordinate direct services workers or provide training or certification
- Independent living centers
- Faith-based agencies (although these are typically more geared toward the senior population)
- Agencies that provide services to people with mental illness
- Agencies that work with people with alcohol or drug addictions
- Employers, particularly state agencies

In addition, look for places where agencies and information intersect. They may have done some of the work already to compile data. For example,

- a database that combines information about waiver services and other state services

- a database created under a grant, such as the MIG, to store information collected from different sources

Definitional issues around Workplace PAS administrative data

Using administrative data always creates challenges when different sources use different terminology or definitions. Chances are, there won't be an exact match across sources. Decisions will need to be made about what is similar enough to include, as well as what is different enough that it should be excluded.

With regard to Workplace PAS, definitions may be driven to some extent by

- funding streams – what will or will not be paid for
- living situation of the consumer – the same type of service may be viewed differently, depending on whether someone lives independently or in an assisted environment

Potential sources of information on Workplace PAS Use

Actual use of Workplace PAS might not be in line with the level of availability as allowed through state plans, waivers, and external sources. For example, WI found high underutilization in an initiative to offer Workplace PAS in part due to the limited numbers of providers who were offering needed services. Use of Workplace PAS might be limited or constrained by such things as

- consumer choice about using services
- practical availability due to insufficiencies in the numbers or quality of personal care workers
- employer attitudes about use PAS services in the workplace

Administrative sources, as mentioned above, might keep information about use as well as availability. Another strategy for learning about Workplace PAS use would be to conduct a survey. Surveys of provider agencies or independent contractors who deliver services are a possibility. Surveys of employers may not be practical for obtaining information on PAS (unless embedded within a broader survey), but an employer case study may be helpful to learn about what conditions make a work environment friendly to workplace PAS and other accommodations.

As a sidebar, questions were raised about guidelines as to what employers should cover as opposed to what should come from PAS. Will there be differences across states. The ADA defines what employers should provide. (Your TA Provider may be able to offer more information on this.) Your state's employment leadership network may also have information.

Sources of new information on Workplace PAS availability and use

Surveys

One strategy for collecting new information is to conduct a survey. While developing and administering a complete survey on Workplace PAS may be prohibitive, there may be an existing survey conducted in your state where questions could be added. (Or the information may already be collected on a survey.) Some potential sources are surveys administered

- by state agencies that offer services to consumers with disabilities or provide employment services

- for quality assurance purposes
- by service providers or advocacy groups
- by university-based researchers studying disability or employment-related topics
- through other grant-funded projects or research

When conducting a new survey, consideration should be given to how you define the sample of people you contact so that responses are representative. Consideration should also be given to what kind of information, or how much information, you should include about the program so that you strike a balance between making sure the respondents are responding about the same thing and leading the responses based on the information you've provided.

If you obtain information from an existing survey, consider how the sample population will affect the generalizability of the data. Also keep in mind that the context of the survey and the other information may affect the responses.

Other sources

NIDRR has funded projects and research on personal assistance services; there is currently one operating in the San Francisco Bay area. This may be a source of information. However, one workshop participant advised that the NIDRR website is not particularly user-friendly for obtaining comprehensive or comparative information. Coordinating with NIDRR initiatives may also offer an opportunity for information gathering.

While it might not meet immediate needs, adding questions to administrative systems can be helpful for long term data gathering. It may take a few years to come to fruition, but for a service that is expected to be ongoing or increasing in availability and use, laying the groundwork to collect information in two or three years can be worthwhile.

Questions were also raised as to whether the census could provide any information about Workplace PAS or whether there would be a way to look indirectly through longitudinal employment data.

Evaluating new Workplace PAS initiatives

New initiatives provide an opportunity to build a research component into the project. Strategies for collecting research information can be developed along with program implementation strategies, consumers can be contacted at enrollment about participating in research, and evaluation can track the entire course of the initiative.

Kansas will be conducting research on their new Workplace PAS initiative. They anticipate seeing a high degree of movement from health and community based services (HCBS) to the new initiative. The evaluation plan includes:

- a comparison of people who remain on HCBS v. those who move to the new initiative
- collecting survey data to identify any attitudinal differences between the groups
- tracking utilization and earnings between the groups

In new initiatives, there is a possibility that the treatment and comparison groups will differ in one or more ways. This can be particularly problematic if participants self select into the initiative, but differences can also occur under controlled circumstances. One way to handle this problem is to statistically adjust for differences between groups. If a large number of differences

exist, correction can be handled by computing a propensity score that simultaneously adjusts for multiple differences using one variable.

Specific topics in Workplace PAS research

Self direction

One workshop participant inquired as to whether any states had looked specifically at self-direction in workplace PAS. Kansas, Alaska, and Minnesota had.

- Alaska found that the self-direction component greatly affected the use of the program
- Minnesota found similar results, but felt that more data collection was needed to better determine how the program is being used.
- In general, it was suggested that flexibility is needed for services to be effective
- There were also findings/concerns that conflicts exist between the advance pay model for self-direction and asset limits for some buy-in programs. (See your TA provider for more discussion of this.)

Potential areas of support in Workplace PAS research from the MIG-RATS

1. Continuation of this session's discussion through formation of a Workplace PAS research workgroup
2. Input on research designs or tools developed to assess Workplace PAS
3. Coordination of research instrument testing with other states so that the in-state response population does not need to be tapped for testing
4. Help states identify the demands associated with implementing certain research plans
5. Coordination of a multi-state research project is probably not practical at this point, given the wide variation in project status across states