

medicaid
and the uninsured

**CONSUMER DIRECTION
OF PERSONAL ASSISTANCE SERVICES
PROGRAMS IN MEDICAID**

Insights from Enrollees in Four States

Prepared by

Adrienne Dulio and Michael Perry, Lake Research Partners,

Henry Claypool, Paraprofessional Healthcare Institute

And

Molly O'Malley, Kaiser Commission on Medicaid and the Uninsured

March 2008

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The Kaiser Commission on Medicaid and the Uninsured provides information and analysis on health care coverage and access for the low-income population, with a special focus on Medicaid's role and coverage of the uninsured. Begun in 1991 and based in the Kaiser Family Foundation's Washington, DC office, the Commission is the largest operating program of the Foundation. The Commission's work is conducted by Foundation staff under the guidance of a bipartisan group of national leaders and experts in health care and public policy.

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EXECUTIVE SUMMARY

Medicaid provides health coverage to 58 million low-income Americans including nearly 8 million individuals with disabilities. Medicaid covers a broad range of services designed to meet the unique needs of the population it serves including inpatient and outpatient hospital services, prescription drugs, as well as long-term services and supports, such as personal care and home health services, needed by people with disabilities to live independently in the community. Over the past two decades states have increased efforts to direct their Medicaid long-term care delivery systems away from institutional services towards more community-based services in response to consumer demand and the Supreme Court ruling in the *Olmstead* case, which confirms the discriminatory nature of policies that lead to the unnecessary institutionalization of participants on public programs such as Medicaid.

A significant policy development in Medicaid home and community-based services over the past ten years has been the growth in state programs that allow Medicaid beneficiaries to direct their own personal assistance services, known as Consumer Directed Personal Assistance Services (CD-PAS) programs. Many people with significant disabilities living in the community require personal assistance services to assist them with performing the most essential activities of everyday life and self care such as using the bathroom, bathing and dressing. Consumer directed programs give Medicaid beneficiaries, rather than traditional agencies, varying degrees of responsibility for hiring, scheduling, training and paying direct care workers. CD-PAS is available in an increasing number of state Medicaid programs, although a relatively small number of Medicaid beneficiaries are currently enrolled in this type of program model.

The *Kaiser Commission on Medicaid and the Uninsured* supported this focus group project of adults with disabilities in 4 states – California, Colorado, New York and Virginia – who are enrolled in Medicaid Consumer Directed Personal Assistance Services programs. This research was undertaken to learn about Medicaid enrollees' experiences in the program and their opinions about key features of the program including recruitment issues and degree of responsibility over services. The focus groups also sought to identify ways in which to improve upon the programs that administer these services.

Findings:

Value of Consumer Directed Services to Adults with Disabilities

- **Medicaid beneficiaries enrolled in CD-PAS value the independence and control associated with consumer direction.** Focus group participants are strong supporters of CD-PAS. In every focus group and with the majority of participants, having control over their services and supports is the most

important aspect of CD-PAS. They highly value the ability to choose their own direct care workers and set their own schedules. Many participants have experienced more traditional home support services and feel this system did not work well for them.

- **Continuity in direct care workers leads to greater overall satisfaction with CD-PAS.** Most CD-PAS enrollees have forged close relationships with their direct care workers in contrast with traditional agency models where Medicaid beneficiaries often have to deal with new direct care workers on an ongoing basis. The stronger the bond, the higher level of support they receive, CD-PAS participants say. Many feel the power to hire and train their direct care workers under CD-PAS is a main factor in why they have formed such close bonds with them. They are able to choose direct care workers with qualities they are seeking and this leads to a better match between Medicaid enrollee and attendant.
- **Most acknowledge that a Medicaid consumer directed model is not for everyone.** Participants say CD-PAS programs demand a great deal of responsibility and organization on the part of the Medicaid enrollee. In this regard, CD-PAS appeals to a particular population, one that is often younger, more active, and more inclined to take on a lot of responsibility. This is particularly true when it comes to finding workers and submitting payroll sheets. Participants suggest that some individuals may need or want more support and oversight than the consumer-direction model has to offer. For example, the traditional agency model is appealing to those that require a minimal amount of help each day. Individuals enrolled in an agency model say that very few direct care workers want to work for only a few hours but an agency will have longer lists of those interested in part-time work.

Experience with Workforce Issues in CD-PAS Programs

- **CD-PAS participants report problems recruiting good, reliable direct care workers and dealing with poorly performing attendants.** Findings, hiring, and firing direct care workers can be challenging which is why some individuals choose not to participate in this type of program. Most speak of the difficulty in finding qualified, trustworthy direct care workers. The low pay and, in most cases, no health coverage make recruitment and retention of direct care workers harder. Those requiring odd or minimal hours and presenting geographic hurdles report greater difficulty finding interested direct care workers. Registries of potential workers are maintained by some state programs but consumers report dissatisfaction when these are not kept current. Additionally, some CD-PAS Medicaid beneficiaries report keeping poorly performing direct care workers because of the difficulty involved in finding and training new attendants.

- **A few CD-PAS enrollees have had serious problems with their direct care workers.** Although many are positive now about their direct care workers and have close relationships with them, some have had mixed experiences in the past. In most cases, the complaints are about tardiness and unreliability. However, more serious problems, such as stealing and abuse, emerged in the focus group discussions.
- **Most CD-PAS enrollees lack a sufficient back-up system to deal with unanticipated events.** Unlike with traditional home care, participants do not have sufficient back-up systems if their direct care workers do not show up. Many rely on their direct care workers for most of their daily functions and so it is not an option to just “do without.” Participants exert a great deal of time and energy looking for direct care workers to ensure they have coverage and adequate shift backup. According to individuals who choose not to enroll in CD-PAS programs, having emergency back-up is the most important factor that compels them to continue using an agency system.

Experience with Quality and Coordination of Services in CD-PAS Programs

- **Many participants desire additional support with certain responsibilities in consumer directed programs.** CD-PAS enrollees are on their own to hire, manage, and fire direct care workers. Some value this independence yet believe that limited support would be beneficial in situations when problems arise, such as a poorly performing worker or a stealing direct care worker. A few participants also acknowledge that they refrain from seeking help because they do not want to seem incapable of all the responsibility that the consumer directed system requires.
- **All participants in CD-PAS want to stay in the program and shared ideas for improvement.** Despite having concerns, participants still prefer CD-PAS to the traditional agency home support system. All participants say they want to remain in the program, but many worry about future cuts to Medicaid, and CD-PAS programs in particular. Participants share many ideas for improvement of their CD-PAS programs, including better training of both direct care workers and enrollees, better customer service, higher pay and health insurance for direct care workers, and more help with recruitment and screening of direct care workers.

Conclusion

Consumer direction of personal assistance services is an increasingly prominent method for Medicaid programs to provide community living services to individuals with disabilities, yet most acknowledge that the responsibilities involved with CD-PAS are not for everyone. These programs offer varying degrees of control to the Medicaid beneficiary with corresponding levels of responsibility (hiring, supervision, recruiting and paying of the direct care worker) and risk.

The insights gained from this project show participants are strong supporters of the CD-PAS model of services and supports. Independence, freedom and control are the aspects of CD-PAS they value most, yet participants believe the system can be improved. A clear message from the focus groups is that to improve Medicaid CD-PAS programs more attention in developing innovative ways to monitor quality and finding appropriate mechanisms to address safety concerns for the beneficiary is warranted. Ultimately this involves striking the appropriate balance between the risk that these voluntary participants assume and the need on the part of the state and federal government to ensure that program participants are not unduly exposed to dangerous and unhealthy situations. Developing additional supports for consumers to manage their responsibilities and increasing attention to workforce issues are also important areas of focus as states continue to expand and improve access to Medicaid home and community-based services.

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INTRODUCTION

Among leaders and advocates for community living, Medicaid Consumer-Directed Personal Assistance Services (CD-PAS) programs are viewed as an increasingly important component of state Medicaid programs. CD-PAS programs give beneficiaries, rather than or with the assistance of agencies, the power to hire, train, supervise, and fire direct care workers. Personal assistance services (PAS) are services that assist individuals with performing the most essential activities of everyday life and self care such as using the bathroom, bathing and dressing and can also include supports such as housekeeping, meal preparation, grocery shopping, and paying bills.

The *Kaiser Commission on Medicaid and the Uninsured* sponsored this focus group project of non-elderly adults with physical disabilities enrolled in Medicaid CD-PAS programs in four states: California, Colorado, New York and Virginia. The purpose of the focus groups was to learn about enrollees experiences in the program and their opinions about key features of the program including recruitment issues and degree of responsibility over services. The focus groups also sought to identify ways that programs that administer these services could work more efficiently and improve services they deliver. A related report based on interviews with state program administrators provides insight into the history of CD-PAS in Medicaid and the specific programmatic features of each state's consumer direction program.¹

Research Methodology

To learn about the experiences of adults (18-65)² enrolled in CD-PAS, Lake Research Partners conducted four focus groups with enrollees between October and December 2006 and four telephone interviews with individuals who chose not to enroll in a CD-PAS program in April 2007. The focus groups were conducted in four locations – Denver, CO; Berkeley, CA; Alexandria, VA; and New York City, NY. Participants represented a mix of gender, age, racial and ethnic background, and urban/rural differences, where possible, in order to gain insight into how these factors affected their experiences with CD-PAS.

Participants were identified by the various organizations with responsibilities for administering the state CD-PAS program. Individuals had to be enrolled in a CD-PAS program for at least six months in order to participate. They were paid \$75 for their involvement in the project and participation was voluntary. A breakout of focus groups and telephone interviews follows:

¹ H. Claypool and M. O'Malley, *Consumer Direction of Personal Assistance Services in Medicaid: A Review of Four State Programs*, Kaiser Commission on Medicaid and the Uninsured, March 2008.

²Two focus group participants were over age 65: one in Denver (66) and one in California (67).

Breakout of Group and Individual Interviews

Focus Group #	Date	Site	# of Participants
1	11/17/06	Denver, CO	5
2	12/05/06	Alexandria, VA	7
3	12/06/06	Berkeley, CA	5
4	12/11/06	New York City, NY	2
One-on-One Interviews #			
1	April 2007	Denver, CO	1
2	April 2007	Denver, CO	1
3	April 2007	Berkeley, CA	1
4	April 2007	Berkeley, CA	1

Profile of Participants

For this project we interviewed a total of twenty-three individuals. Nineteen of the participants were adults with disabilities enrolled in Medicaid CD-PAS programs and four participants were enrolled in traditional agency models. These four participants were selected in order to gain a better understanding of the rationale behind their decision not to enroll in their state's CD-PAS program. Participants had an array of disabilities including multiple sclerosis, muscular dystrophy, chronic obstructive pulmonary disease, reflex sympathetic dystrophy syndrome, Grebe syndrome, and arthrogyrosis. Conversation also revealed numerous secondary, often chronic health concerns, such as fatigue, pain, infections, and nausea. Mental health concerns, namely depression, also affect many in this study.

The extent to which each participant relies on the program varies greatly. Most require more hands-on assistance, intimate services and support, such as bathing and using the toilet, usually round-the-clock, seven days a week. At the other end of the spectrum are a few who need help mainly with cooking and cleaning, for a few hours daily, a few days each week. Some participants – mainly those who require round-the-clock support – may employ up to 12 workers at a time who rotate shifts. Others require only two or three. The average time spent in a CD-PAS program was roughly five years, with a few participants in California reporting 12-year tenure. Most participants came to the program early in its inception.

Many participants were highly informed about their Medicaid CD-PAS programs and are advocates for themselves and others. This was especially true of most participants in Denver, and Berkeley and New York City. These participants appear to have access to program administrators and know how to get their problems solved. In some cases, such as Colorado and California, participants were involved in the creation of their state's program and currently work on its behalf. One Berkeley participant is an attorney who works on behalf of people with disabilities, while others lobby their state legislature on behalf of their program. Many in Denver are "peer trainers" to newcomers to their program.

These are important contextual points. In fact, participants say they may not represent the average Medicaid CD-PAS enrollee. They are clearly more informed than typical consumer-directed care enrollees and also more able to take on the responsibilities of the consumer-directed model. They acknowledge that others who have disabilities and are covered by Medicaid may not be able to thrive in this model of personal care assistance without making additional supports available to prospective participants.

FINDINGS

I. Value of Consumer-Directed Services to Adults with Disabilities

Most participants praise CD-PAS and say the program gives them independence.

Most of the comments participants make about CD-PAS programs are positive. Across the sites, participants talk about the *flexibility* this system provides. They can create their own schedules, choose direct care workers they want, and arrange services more easily as their needs change. There was much more red tape and limitations placed on them in traditional agency model personal care assistance, they said. Under the previous system, they were assigned a set number of service hours per month by an agency, and they were unable to hire family members as their direct care workers.

“If it has to do with me or my body, I want control of that.”

CD-PAS Enrollee in Alexandria, VA

Because these are capable, “take charge” kinds of people, the independence the program provides is highly valued. In every focus group and with the majority of participants, having control over their services is the most important aspect of CD-PAS. “It’s wonderful. It’s liberating. It’s like opening a whole new world,” said a participant in Berkeley. As a Denver participant put it, “You get to decide what your health needs are and you can direct your care.” A New York participant said, “Just what the title is, consumer directed; the consumer is directing their own care.” Finally, an Alexandria participant called the CD-PAS model “ideal” and described it as “living on your own successfully.”

The importance of independence and control cannot be underestimated with these participants. These are core values that emerge again and again in the discussion. “I’m living alone, but I have constant care in the mornings and the evenings and the program has helped me regain my independence again,” explained a participant from Denver. Another participant from Denver said, “I don’t know about anybody else here but I was very suicidal right after my accident. I mean, that was where I was going... and without the CD-PAS program that’s probably where I’d be.”

Most participants feel CD-PAS compares favorably to traditional home care.

Many participants have experienced more traditional home care services and feel this system did not work well for them. A few New York participants are very negative in their comments and spoke about direct care workers who stole from them, were unreliable, or neglected them. Others talked about bureaucratic hoops they had to jump through in the old system to arrange the support they needed. They talked about rigid rules and a system in which they felt powerless and vulnerable. Many

explained that under that system, they did not feel cared for. A participant in New York explained the differences:

“[There is] more flexibility as far as the way you want your schedules to be and if there’s certain medical things that you may need... like I use a breathing machine when I have to sleep so using certain things that I have to use... under regular home care they have to have someone else come in to do those things for you and it’s very rigid.”

Since CD-PAS, many feel they have improved physically and mentally and enjoy a better quality of life. They feel they are cared for by individuals who give better support, are on time, and are trustworthy. More specifically, they can sleep, eat, and use the bathroom when they want to – which wasn’t the case before. They no longer have to “watch the clock” either. As a participant in Denver said, “The biggest change is I can get up when I want. I can go to the bathroom when I want. I’m not on their regimen. I can live my life the way I want to live my life and I get much better care. If I want to take an hour grooming me from top to bottom I could do it or if I want to do it in 10 minutes, I can do it.”

“The biggest change is... I’m not on their regimen. I can live my life the way I want to live my life and I get much better care.”

*CD-PAS Enrollee in
Denver, CO*

In contrast, the traditional agency model is appealing to those that require a minimal amount of help each day. One individual enrolled in a traditional agency model says that very few workers want to come in for only a few hours but an agency will have longer lists of those part-timers than he could generate on his own. Another individual, in California, agrees. He found it easy to find excellent workers via his agency who were looking for part-time work while attending graduate school.

Continuity in direct care workers leads to greater overall satisfaction with CD-PAS.

Another striking similarity across sites and participants is the close bond that most have formed with their direct care workers. Many directly link this close relationship with their satisfaction with CD-PAS. Many feel their care is better because of these bonds. Stemming from this is the critical importance participants place on longevity – the ability to maintain the same direct care worker for an extended period of time. Participants explained that the tasks performed are often very intimate; establishing a certain comfort level is critical to a successful and lengthy relationship. Prior to CD-PAS, many participants said that turnover in direct care workers was a big problem but this is less of an issue now. A few participants also say care is better because they feel more comfortable giving feedback to their attendant when they have known them for a while.

“That’s the main thing that happens... we become friends in the process.”

*CD-PAS Enrollee in
Alexandria, VA*

Many are thankful that they found an attendant that works well with them. Many say their direct care workers have gone above and beyond their duties to support them. A New York participant explained, “She is always there for me. When I tell you with all the financial problems that are going on right now, she brings food for me. She will buy things that I need and you know she’s just a very lovely woman; she is very good to me.” Others feel uncomfortable with professional labels such as “direct care workers,” “personal care assistants” and “caregivers” but think of them more as close friends and family caregivers. A Berkeley participant said that her attendant “jumps through hurdles” to get her the medications and equipment she needs.

Ultimately, many feel the power to hire and train their direct care workers under CD-PAS is a main factor in why they have formed such close bonds with them. They are able to choose direct care workers with qualities they are seeking and this leads to a better match between enrollee and attendant, they believe.

While most participants appreciate the control CD-PAS has brought to their lives, they also acknowledge it is not appropriate for everyone.

Participants say CD-PAS programs demand a great deal of responsibility and organization on the part of the enrollee. This is particularly true when it comes to finding workers and submitting payroll sheets. “It is enormous, it is overwhelming for a Medicaid beneficiary to try to go through that process when you’re dealing with all kinds of personal issues and debilitations,” says a Berkeley participant. Some participants say they are aware of individuals who do not want all the hassle and responsibility of this system, while others prefer a combination of both personal assistance and traditional home care. A participant on New York explains,

“For some people this Consumer Direction is not right. They’re better off staying with agency care.”

*CD-PAS Enrollee in
Denver, CO*

“We’re all individuals and everybody’s needs are different. So one method of home care that may be suitable for one person, may not be suitable for the next. So they have to seriously sit down and evaluate the two and then make the decision of what’s best for them; and that if they’re not good at speaking and directing, I don’t see how self-direction is going to work.”

In the end, some individuals suggest that an “ideal” home health services model is one that combines the best of both agency and consumer-directed care, where the agency is the “go-between” or intermediary between the individual and government. “That would be just great,” says one individual.

II. Experience with Workforce Issues in CD-PAS Programs

CD-PAS participants value the control that the program offers yet recruitment of workforce is a reoccurring theme.

While most seem settled and satisfied with their direct care workers, many participants across sites say it is a constant juggle of hiring and firing. Because some participants have multiple direct care workers, they are often in the process of replacing one. There are many factors involved in this issue. The first has to do with finding qualified individuals. This is particularly important because of the intimate services and supports needed and also because of their level of dependence on these individuals. In the past, some have been robbed or abused and are more wary now about using classified ads in newspapers or other anonymous sources for direct care workers. They have safety and other concerns about letting strangers in their homes even to conduct the interviews. However, some use these sources and report no problems.

“That’s part of the game. Recruiting is an ongoing thing in CD-PAS.”

*CD-PAS Enrollee
in, Denver, CO*

One individual enrolled in a traditional agency model says that he is uncomfortable with the screening or training processes required by consumer-direction programs. He finds it unnecessarily stressful and prefers that an agency handle those aspects. “It’s always at the back of my mind,” he says, “that someone might steal or take advantage of me.”

Many rely on word-of-mouth referrals from existing direct care workers or friends to find new direct care workers. Many also use a registry of direct care workers to identify workers. Both California and Virginia have established registries of direct care workers.³ However, some beneficiaries are not satisfied with the worker registries. They find them out of date or too limited (i.e., does not include anyone in their area). Some also feel there is no quality control over who is on the registry lists, while others would like to see a rating system included with comments from former employees of the worker. An enrollee from said, “They have a list, a list that you can get with all those different names [from] and you don’t know who’s who... and how many hours they worked and all this stuff. But you don’t know why they’re not working anymore or what the story is with them.”

A few California participants also feel that registries tend to have more “medical professionals” such as trained nurses who often do not want to work the longer shifts that some individuals need or to perform certain tasks. An enrollee from Berkeley commented, “I found the registry workers tend to be more from a medical model. They want a 6 to 8 hour shift, which I don’t have. They refuse

³ H. Claypool and M. O’Malley, *Consumer Direction of Personal Assistance Services in Medicaid: A Review of Four State Programs*, Kaiser Commission on Medicaid and the Uninsured, March 2008.

to do certain tasks. I mean they are a lot more restrictive; they only want to work certain times.”

Dealing with poorly performing direct care workers is difficult.

Some program participants comment that they keep their poorly performing direct care workers because they do not want to go through the hassle of replacing them and possibly finding someone worse. Some find it hard to critique their direct care workers and give feedback that could improve the support they give. The reason is that they are very dependent on these individuals and worry that if they comment on their performance, the direct care worker may not show up for their shift next time or will be purposely late. An enrollee from New York said:

“It’s hard when you have to depend on everyone to do everything for you. It’s a scary feeling when you have to worry about, “Well, if I voice my opinion and I tell this person I don’t like what they did and they get angry and they leave, what am I going to do. Or tonight they don’t show up because they want to get back at me for whatever they didn’t like that I said and it’s hard. And sometimes you bite your tongue. Sometimes you don’t say certain things because the fear takes over and then you have to figure out another way to do it. So it can be stressful in its own way.”

This is an area where some participants said they would like help. They would like someone to talk to who can offer advice. “I don’t know what to do about it,” said an Alexandria CD-PAS enrollee. She said that one of her direct care workers is very sloppy and that she must keep after her constantly to help keep her home neat. She describes another of her direct care workers as “stubborn” and the two have fought recently. The enrollee feels torn about whether to fire either or both – considering how difficult it can be for her to find someone new and then train them – or just deal with them and their problems.

A few CD-PAS enrollees have had serious problems with direct care workers.

Although many are positive now about their direct care workers and have close relationships with them, some have had mixed experiences. Or, in cases where the participant has five or more direct care workers, they inevitably have one or two who are causing problems. In most cases the complaints are about tardiness and unreliability. This is no small issue for those participants who rely on their direct care workers for all of their personal care and who have limited back up systems.

“They didn’t come and I kept calling them and I kept waiting and nobody ever showed up so I had to sit in my chair all night long.”

*CD-PAS Enrollee in
New York City, NY*

However, more serious problems with direct care workers emerged in the discussion. As the New York participant mentioned, some have been robbed by their direct care worker. An Alexandria participant told how her direct care worker was helping her take cash out of an ATM but did not return the ATM card to her purse. The direct care worker then used the ATM card to steal money from her. She described this experience as devastating and still feels very vulnerable and wary because of this experience.

Others talk about physical and sexual abuse. In many cases, they are repeating experiences from friends. However, some participants are victims themselves and have directly experienced this kind of abuse.

Most CD-PAS enrollees lack a sufficient back-up system to deal with unanticipated events.

An appropriate back-up system or plan to deal with unanticipated events is an essential part of consumer direction.⁴ Many participants in this study have had to rely on back-up direct care workers, family and friends, and an “emergency backup system” where available when their regular direct care workers are delayed or cancel. Some have had to go to the ER to get services simply because their direct care worker did not show-up. Many rely on their direct care workers for most of their daily functions and so it is not an option just to “do without.” Those with family and friends nearby to help out are the lucky ones, but rare in this study. Rather, most live independent lives away from family and a number say most of their friends have disabilities too – making them inappropriate even as temporary caregivers.

“They put you in the emergency room on the gurney, you sleep there until they put you back in your chair, go home in the morning for your morning worker. That’s what happens.”

CD-PAS Enrollee in Berkeley, CA

One Berkeley CD-PAS enrollee lives in a county that has an emergency backup system that enrolled individuals can call when they are stuck without a direct care worker. But in most other locations – even within California, participants say such systems do not exist and they are “on their own” if their direct care worker does not show up.

According to individuals who choose not to enroll in CD-PAS programs, having emergency back-up is probably the most important factor that compels them to continue using an agency services model. One of these individuals says that he feels more secure relying on the agency model, largely due to its backup capabilities. “You’re given a long list of people to call,” he says, speaking of his agency in Colorado. He prefers not to shoulder the “burden,” as he calls it, of maintaining his own list of backup workers.

⁴ H. Claypool and M. O’Malley, *Consumer Direction of Personal Assistance Services in Medicaid: A Review of Four State Programs*, Kaiser Commission on Medicaid and the Uninsured, March 2008.

Low pay and, in most cases, no health coverage make recruitment and retention of direct care workers harder.

Although this varies by site, many say a low salary and no benefits make stabilizing the workforce that much harder. California and New York offer an affordable health care plan and dental benefits to direct care workers. New York’s plan also makes provisions for workers to accrue paid leave benefits.⁵ In addition to California making health coverage available to direct care workers, they also increased rates, so some participants have seen improvement there. One participant said that before those changes, “You were lucky if you could keep one for a month.”

Most still feel the pay is too low and in sites without health insurance coverage for direct care workers, many consider the lack of benefits to be a major barrier. Participants in Alexandria, for example, explain that the rate for direct care workers in that metropolitan region of Virginia are set by the state’s CD-PAS program and it is currently at \$10.82 an hour. One participant commented that this low rate reflects how little the government values that kind of work and of how little respect the government has for this particular job. These feelings were less intense in Denver, where some participants felt direct care workers were paid “pretty good” and “better than the [home health] agencies]. Some participants say their direct care workers need other jobs in order to make a living. A participant from Alexandria commented, “All my direct care workers have main jobs, like I’m just their part time because they don’t make enough you know.” Others make accommodations for their direct care workers to make the job more enticing. For example, one participant in Alexandria allows her direct care worker to bring her child to work, therefore saving on child care dollars. She said, “I don’t mind that she brings her children to work and it’s kind of like an exchange for the pay being so low that, you know, I let her bring her kids.”

“A few people that I tried to interview or offer the job to, when they see the amount of pay, that’s it, they don’t want it.”

CD-PAS Enrollee in Alexandria, VA

Some say they often lose their direct care worker to better paying jobs in nursing homes. They feel that the direct care worker position is seen as a stepping stone to better paying work in nursing homes and elsewhere. Others feel the low pay attracts untrustworthy people to the profession, and that worries them. A participant from Alexandria said, “I have had one attendant that stole from me and you know I had to get rid of her, but I mean that just goes with the people that are coming to this low pay job.”

⁵ H. Claypool and M. O’Malley, *Consumer Direction of Personal Assistance Services in Medicaid: A Review of Four State Programs*, Kaiser Commission on Medicaid and the Uninsured, March 2008.

CD-PAS payroll problems can make it hard to retain workers.

Many participants, mainly in Berkeley but also a few in Alexandria, said there are problems with the payment system in CD-PAS that can make it hard to retain their workers. Many in these cities report delays in payments to their direct care workers. For example, one participant said her direct care worker received late payment three times in the last year. Many participants also said that they encounter hassles trying to fix or adjust hours and payments because of changes in their workers' schedules. A participant from Berkeley commented:

“I had to tell my worker in advance that Theresa was going to work 42 hours, but in reality Theresa ended up working 50 hours because Sam got sick. And so I either have to personally have Sam give Theresa money or I have to call the social worker, tell them about the change, which may or may not make it into your computer. And if I submitted a timesheet that was different than what the computer expected, it would bounce back. And then they wouldn't get their check.”

In California, unlike Denver and Alexandria, there is no electronic or fax system available to them. They must send the timesheets by mail. This is ripe for problems, they say. A Berkeley participant said, “There is no direct deposit, and because they have to be sent [mailed] to the County, timesheets get lost. Or if the paycheck gets lost, that's even worse.” Also, when participants are hospitalized, they say their direct care workers must go without pay, and that is problematic too. There is also a delay in getting that first paycheck. A participant in Berkeley explained:

“I hire a new person for today, they're going to be working for me at least a month, if not six weeks before they see a first paycheck. If this person has never worked for IHSS before, they need to trust me, that they're going to get paid six weeks down the line for all the work they been doing.”

III. Experience with Quality and Coordination of Services in CD-PAS Programs

Many participants say there is little to no help with their care situation and desire some additional support with certain responsibilities.

They are on their own to hire, manage, and fire direct care workers. Some value this independence and do not want someone looking over their shoulder. “For all of us who have the ability to hire our own [direct care worker], then we should have the ability to monitor our own status,” said an Alexandria participant. Some relish that they alone are in charge. “I run mine like a small business and I'm the boss,” said a Denver participant.

“[Yes,] you can direct your own care. It doesn't mean I don't need assistance in some type of way.”

*CD-PAS Enrollee in
New York City,
NY*

But some feel there is a middle ground of at least some limited support. A few, in New York, also feel there is no one to turn to when problems arise, such as a stealing direct care worker. They also would like more pointers on how to speak with their direct care workers so that they are more effective in their jobs. Others are concerned that if their capacities decrease, there will be no one checking up on them and re-evaluating their needs.

A few participants also acknowledge that they refrain from seeking help. One New York participant explained that he was reluctant to tell his CD-PAS program about his stealing direct care worker because he was afraid they would think he was not capable of all the responsibility that the system requires.

Participants express other challenges with CD-PAS such as transportation issues, language barriers and too few hours.

A number of participants who live outside of cities say that they have problems finding and keeping direct care workers because of where they live. For example, some Alexandria participants live in suburbs and say the program's registry does not include any individuals in her area. Others there say that they sometimes lose good direct care workers because they tire of the commute. And still others say direct care workers often lack cars and so the limited public transportation in their area is expensive and unreliable. A participant in Alexandria explained, "If you earned the low wage [you] couldn't drive. [Direct care workers] don't have a driver's license or something and they would need a bus route and there was no bus route to my house."

A few Alexandria participants mention language barriers with their direct care workers. One participant there said that more and more of the direct care worker workforce is made up of individuals with limited English proficiency and this can cause problems. In fact, one participant said she recently had to fire a direct care worker because of language barrier issues.

Finally, one participant said she was not given enough hours of personal care assistance. She explained that she had recently moved to Alexandria but used to get more hours back in her home state. She said, "Back in Wisconsin where I used to live I used to get more hours and I would be able to have more time with my direct care workers."

Most feel awareness of CD-PAS is low and outreach could be improved.

Most participants heard about the program through word-of-mouth – from others in the disability community – and not from CD-PAS programs, which do little to promote this option to Medicaid consumers. As a result, they say, many people who could possibly benefit from CD-PAS are unaware of its existence. Denver participants say that their CD-PAS program could use "better marketing," like newspaper or TV ads. "What is supposed to happen is you go to your doctor or

your therapists and they are supposed to have the knowledge,” says a Denver participant. A Berkeley participant believes that less than 10% of Californians eligible for that state’s CD-PAS program are enrolled. If “they don’t know about it, how can they take advantage of it?” she says.

Those who have chosen to participate in CD-PAS want to stay in the program and worry about losing it.

Despite some of the challenges mentioned above, participants have adapted to a more independent lifestyle and to controlling their services and supports and they do not want to give this up. Participants feel fortunate to have found a system that works well for them and worry that it will be taken away. One participant in Denver became teary-eyed every time she spoke of losing CD-PAS. These participants fear cuts to Medicaid and what that might mean for their consumer-directed program.

A few also acknowledge that if their condition worsens and they no longer had the capability to control their services, then change would be inevitable. But for now, all CD-PAS participants say they want to continue with CD-PAS and cannot imagine going back to receiving traditional home health care services.

CONCLUSION

Consumer direction of personal assistance services is an increasingly prominent method for Medicaid programs to provide community living services to individuals with disabilities, yet most acknowledged that the responsibilities involved with CD-PAS are not for everyone. These programs offer varying degrees of control to the Medicaid beneficiary with corresponding levels of responsibility (hiring, supervision, recruiting and paying of the direct care worker) and risk.

The insights gained from this project show participants are strong supporters of the CD-PAS model of services and supports. Independence, freedom and control are the aspects of CD-PAS they value most. Despite their very positive feelings about CD-PAS, participants believe the system can be improved. Improvement ideas center on improving consumer service and increasing outreach for CD-PAS programs. Specific ideas include: develop a backup system; better training, including more training hours for direct care workers; provide greater pay and/or health benefits for direct care workers; help with screening and recruiting of direct care workers; provide a liaison for enrollee to turn to for support, information, and advice; and increase education about CD-PAS.

A clear message from the focus groups is that to improve Medicaid CD-PAS programs, more attention to developing appropriate methods of monitoring quality and safety is warranted. Ultimately this involves striking the appropriate balance between the risk that these voluntary participants assume and the need on the part of the state and federal government to ensure that program participants are not unduly exposed to dangerous and unhealthy situations. Developing additional supports for consumers to manage their responsibilities and increasing attention to workforce issues are also important areas of focus as states continue to expand and improve access to Medicaid home and community-based services.

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