

medicaid
and the uninsured

**Consumer Direction of Personal Assistance Services in Medicaid:
A Review of Four State Programs**

Prepared by

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

One of the most significant developments over the last ten years in Medicaid long-term services is the growth in programs that allow Medicaid beneficiaries to direct their own personal assistance services. Consumer direction of personal assistance services (CD-PAS) is one model of service delivery that gives Medicaid beneficiaries, rather than traditional home health agencies, varying degrees of control over hiring, scheduling, training, and paying personal care attendants. This background paper draws on interviews with program administrators from four states – California, Colorado, New York, and Virginia – who were experienced with the programmatic features of CD-PAS in their state. In each state profile, we identify and discuss eligibility criteria used in each state, participant support services, and the method of financial management used by Medicaid beneficiaries to pay their direct care workers.

FINDINGS

The number of Medicaid beneficiaries directing their own personal assistance services is small, compared to those that receive traditional agency directed services in the community, but participation is growing. Consumer direction is available in an increasing number of states across the country – 42 in 2006. While CD-PAS is a highly desirable arrangement for certain Medicaid beneficiaries, it is not for everyone. Participation rates in three of the four programs were around 10 percent of those eligible. Participation rates could be attributed to a lack of knowledge about the opportunity to self-direct, or a lack of ability to assume the required responsibilities of hiring, scheduling, and paying direct care workers.

Consumer training and support with recruiting workers for Medicaid beneficiaries participating in consumer direction varies considerably across the states. Colorado was the only state that required a training course and completion of a proficiency exam before a beneficiary can enroll in CD-PAS. The other states offer a range of peer support on a voluntary basis. CD-PAS participants face challenges recruiting direct care workers because they lack the infrastructure and economy of scale that agencies use to recruit workers. Finding workers to assist Medicaid beneficiaries with intimate daily tasks requires a significant investment of programmatic and personal resources. A registry of direct care workers is the primary method used by beneficiaries to identify workers. Both California and Virginia have established registries of direct care workers, although registries have been criticized by some beneficiaries as unreliable in their efforts to identify quality direct care workers. Registries can play a key role in helping to develop a backup plan or system to deal with unanticipated events, such as arranging for assistance when an unscheduled need arises. The San Francisco Public Authority offers an on-call service to Medicaid beneficiaries who need backup support. An appropriate backup system is an essential part of consumer direction, but not all states view it as a state responsibility.

Wages, benefits and training are key issues that influence a worker's decision to accept a position as a community-based direct care worker. The programs interviewed in California and New York offer an affordable health care plan and dental benefits to direct care workers. The program in New York also makes provisions for workers to accrue paid leave benefits. Only California had a formal voluntary training program that was available to prospective employees in consumer directed programs. The Public Authority in San Francisco developed its own training program for direct care workers to learn the basic skills necessary to provide personal assistance to people with significant disabilities.

Consumer satisfaction is the exclusive measure for the quality of service in consumer direction programs. Standards for measuring the quality of service, other than consumer satisfaction, do not exist. New York and Virginia had mechanisms in place to monitor quality through beneficiary satisfaction – derived from the ability of the individual to make certain personnel and scheduling decisions about the personal assistance services allocated to them. Promoting choice and control in CD-PAS should not come at the expense of beneficiaries being placed in a situation where they must choose between having the autonomy that these programs allow but receiving substandard support with personal assistance needs. While creating rigid systems that monitor health and safety may not be warranted it appears - at a minimum - that making more resources available to consumers and workers would raise the quality of CD-PAS.

CONCLUSION

People with disabilities have been vocal advocates for securing greater control over Medicaid community-based long-term services and supports. Consumer direction offers Medicaid beneficiaries the flexibility and independence to individualize their services. Having greater control over these services is a high priority for some, but not all Medicaid beneficiaries with disabilities. The reasons appear to vary, but it is important that these individuals continue to have a choice regarding their assumption of the responsibilities that come with consumer direction and that it not be forced on those that do not desire this type of arrangement.

This analysis of consumer direction in four states found substantial variation in key programmatic features and unevenness in resources devoted to Medicaid beneficiary supports. As states and advocates continue to develop programs that give beneficiaries greater control and responsibility over their personal assistance services careful consideration should be given to how best to support the Medicaid beneficiary. In addition, consumer direction is possible without using an individual budget model, as evidenced by the three states in this study that rely on other models of consumer direction including the public authority and fiscal/employer agent models.

As states move forward with consumer directed options in Medicaid, there are several issues that need further examination and analysis. They include building additional support for people that desire these arrangements so when they enter into these programs they are able to have a sense of security that should part of their support system fail them on a particular day, they have resources to turn to for assistance. Secondly, the need to better understand the issues that affect direct care workers such as wages and benefits is important. In the field of home and community-based services, the evolution of consumer direction warrants close monitoring and further examination to identify ways to optimize the delivery of the services and supports and to maximize the positive outcomes for Medicaid beneficiaries.

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MEDICAID’S ROLE IN PROVIDING CONSUMER DIRECTION OF PERSONAL ASSISTANCE SERVICES

One of the most significant developments over the last ten years is the growth in programs or initiatives that allow Medicaid beneficiaries to direct their own personal assistance services. Many people with significant disabilities living in the community require personal assistance. Personal assistance services (PAS) are services that assist individuals with performing the most essential activities of everyday life and self care. They include a variety of basic and essential supports that often involve the most intimate human functions such as using the bathroom, bathing and dressing. PAS also includes supports necessary to live in the community such as housekeeping, meal preparation, grocery shopping, and paying bills. Some policymakers refer to these services as providing assistance with activities of daily living (ADLs) and instrumental activities of daily living (IADLs).

Within the Medicaid program, there are a number of options for making personal assistance services available to Medicaid beneficiaries including: the mandatory home health benefit, that is oriented to providing skilled nursing services in community settings and is used by some states to provide access to personal assistance services for some beneficiaries; the personal care option used by 33 states to provide access to some personal assistance services; and home and community-based services (HCBS) waivers which all states operate at least one.¹

This background paper includes a history of consumer direction of personal assistance services in the Medicaid program and describes the different types of program models states employ to allow Medicaid beneficiaries to direct their own personal assistance services. The paper profiles four state consumer direction programs drawing on interviews with program administrators who were experienced with the programmatic features Consumer Direction of Personal Assistance Services (CD-PAS) in their state. In each state profile, we examine the similarities and differences across programs areas including eligibility criteria, participant support services and the method of financial management used by Medicaid beneficiaries to pay their direct care workers. A related report by the Kaiser Commission on Medicaid and the Uninsured, based on focus group interviews with beneficiaries enrolled in CD-PAS, provides insight into enrollees’ experiences and opinions about key features of consumer directed programs.²

Background

➤ *What is Consumer Direction of Personal Assistance Services?*

Consumer direction is the process by which Medicaid beneficiaries are allowed varying degrees of responsibility for hiring, scheduling, and paying personal care attendants to provide assistance with activities of daily living. The concept of consumer direction began with the Independent Living (IL) movement in the 1970s when individuals with disabilities demanded greater control over the services they receive in the community and in an attempt to achieve greater integration of individuals with disabilities into the community. 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. In 2006, 42 states allowed some form of consumer direction.³ This model of service delivery represents a significant

change in how many people with disabilities receive the personal assistance they require. Program participants are enthusiastic about the independence, freedom and control that they experience. Statements like “I got my life back” suggest that it is a significant improvement in how these services have been provided to them previously.⁴

CD-PAS programs are designed to enhance the independence, choice and control of personal assistance services for Medicaid beneficiaries with disabilities. Consumer direction programs allow Medicaid beneficiaries to exercise personal choice and participate in the development of their own care plan. Prior to the first CD-PAS programs, individuals, no matter how capable and interested in managing aspects of their community based supports, had to work with a Medicaid home health agency who was responsible for overseeing the delivery of these intimate and personal services. Typically individuals receiving community-based personal assistance services are evaluated and then receive a certain set of services or certain number of hours of services from a home health provider. While home health agencies can be responsive to the needs of their clients, many people with disabilities have raised concerns over how home health agencies provide these services. Commonly reported problems have included: being unable to decide **who** provides the assistance services; being unable to decide **when** during the day the services are delivered; and, feeling that certain **personal preferences**, especially with respect to very intimate services are not honored.⁵

➤ *What are the Models of Consumer Direction of Personal Assistance Services?*

Central elements of consumer direction differ from more traditional home health services in that the Medicaid beneficiary has control over how – and by whom – their personal assistance services will be provided. This includes instructing the direct care worker to provide these services in a fashion that is consistent with their personal preferences, and having control over when these services will be delivered. Beyond these core principles there is variation in how other aspects of personal assistance services are delivered. There are three general models of consumer direction of personal assistance services:⁶

- **Agency with choice:** These are programs that provide services to the Medicaid beneficiary. They range from a traditional home health agency which assumes most of the responsibilities for arranging services to agencies that involve Medicaid beneficiaries in arranging multiple aspects of their personal assistance services.
- **Public authority:** These are programs that rely on the Medicaid beneficiary to structure and arrange who, when and how their personal assistance services will be provided. The public authority makes information regarding screened individual providers available to the Medicaid beneficiary.
- **Fiscal/Employer agent:** These are programs that typically rely on the Medicaid beneficiary to assume the role of the employer and the responsibility for arranging most aspects of their personal assistance and submitting information to a fiscal agent that performs payroll functions for the Medicaid beneficiary under contract with the state. Individual budgets are typically associated with Fiscal/Employer agent models of consumer direction. As a program design feature, individual budgets allow a portion of the Medicaid benefits package to be “cashed out” and individuals are required to make

decisions about how their personal assistance needs will be met. They often develop a care plan approved by an agent of the state that outlines how much of a particular type of service they need and then the individual must determine how much they want to pay for these services.

States first major experience with consumer direction within Medicaid comes from the individual budget model. In the 1990s, the Department of Health and Human Services, in partnership with the Robert Wood Johnson Foundation, established the “Cash and Counseling” demonstration program under Section 1115 waiver authority. The demonstration was designed to test the policy merits of an individual budget that would give Medicaid beneficiaries with disabilities the opportunity to direct their own long-term services and control of their budget. Arkansas, Florida and New Jersey were the three original Cash and Counseling states. Cash and Counseling programs are now being implemented in 12 additional states. With the passage of the Deficit Reduction Act of 2005 states have new flexibility to provide self-direction of personal assistance services (using the Cash and Counseling individual budget model) without needing to request a waiver from CMS.

While Cash and Counseling holds the potential to expand the ability of individuals to control their own services, there are drawbacks to this approach. In particular, questions have arisen with respect to whether adequate protections are in place to guarantee the sufficiency of the individual budget.⁷ Additionally, some individuals may wish to control certain aspects of how their services are provided without assuming the responsibility for all of the administrative and supervisory responsibilities that come with managing an individual budget.

STUDY APPROACH

For this study, we conducted telephone interviews with program administrators in four states (California, Colorado, New York and Virginia) who were familiar with the operational details of consumer direction of personal assistance services in their state. We examined these four state programs in order to gain insight into the different models of consumer direction and how Medicaid state plan services and/or waivers are used to provide personal assistance services.

Interviews were conducted between January and April of 2007 with the following individuals:

- California’s Public Authority Model: The Executive Director of the San Francisco In-Home Supportive Services public authority;
- Colorado’s Fiscal/Employer Agent and Individual Budget Model: The Director of Accent Intermediary Services, the fiscal agent that holds a contract with Medicaid;
- New York’s Managed Long-Term Care: The President of Independence Care System, a managed long term care plan; and,
- Virginia’s Fiscal/Employer Agent Model: The Director of Advocacy and Services, Endependence Now, a center for independent living that acts as a service facilitator.

Consumer direction is available to many individuals with “different categories” of disabilities. For this project, we selected programs that serve people with physical disabilities under age 65. This group has the most extensive experience in consumer direction of personal assistance services and is credited with the creation of consumer direction as an outgrowth of the Independent Living movement. Geographic diversity was also a consideration in site selection.

We profile each state program and identify variations around three core elements of consumer directed programs:

- **Process for assessing eligibility for consumer direction.** The determination of eligibility includes a functional or needs-based assessment by agents of state government and verification that the individual is financially eligible, as is the case for all those who seek Medicaid services. While the credentials of the individual hired by the state to conduct the needs assessment vary from state-to-state, it is typically someone performing tasks traditionally associated with social work or nursing.
- **Who performs the financial management functions.** Financial management services typically entail legal responsibilities that any employer must fulfill along with the payment of workers for services performed.
- **Manner in which direct care workers are identified.** A final critical element of these consumer directed programs is the ability of the individual to identify workers willing to provide the personal assistance authorized by the state.

I. STATE PROGRAM PROFILES

California: Public Authority Model

Since 1993, California has operated the In-Home Supportive Services Program (IHSS) to make Medicaid personal care services available to qualified individuals. There are approximately 400,000 people in the IHSS program statewide. In San Francisco City and County, 17,000 individuals are receiving services with a corresponding number of 16,000 workers. While most people direct their services, some of those served in San Francisco receive services from an agency. Individuals in 5 of the 57 other counties also have this type of choice of self-directed services or agency provided services. With the exception of those that take advantage of these programs, beneficiaries are responsible for directing their own personal care services in California. The primary role of the IHSS public authority system in California is to facilitate the identification of direct care workers by IHSS consumers and serve as the employer for purposes of collective bargaining. The San Francisco public authority is governed by a board for which consumers are a majority of the board.

Eligibility Assessment

In California, each county’s social services office performs an assessment of the individual’s need, works with the Medicaid agency to make a determination of eligibility, allocates services, and refers Medicaid beneficiaries interested in consumer direction to the IHSS public authority.

California's Medicaid (Medi-Cal) state plan includes the optional personal care benefit which is the primary source of personal assistance services for the majority of people with Medi-Cal that direct their personal assistance services. The services that Medicaid beneficiaries may direct for themselves include homemaking and personal care services. The maximum number of personal care hours that can be allocated to an individual is 283 a month. While consumer satisfaction is the primary means of monitoring the quality of service, the county performs, at a minimum, an annual reassessment during a home visit, which provides the county social services agency an opportunity to verify continued need for personal care services and an opportunity to interact with the beneficiary on matters of quality related to IHSS sponsored services. The Medicaid beneficiary can request that county social services conduct a reassessment should they feel that their personal care needs have changed.

Financial Management

The IHSS system has a unique division of labor of the financial management services. IHSS public authorities serve as a co-employer with the Medicaid beneficiary but have a limited role in facilitating payment to workers. The public authority provides support to Medicaid beneficiaries on matters related to the filling out and filing of timesheets and serves as the employer of record for the direct care workers. Signed timesheets for each worker are sent to the county social services office where the payroll data is entered into the state's IHSS payroll system. Then, twice a month, based on the information provided by the county, checks are issued, through the mail, directly to the direct care worker. As a result, employer responsibilities are shared by three parties: the Medicaid beneficiary as employer for purposes of selection and supervision of direct care workers, the public authority as the employer for purposes of collective bargaining, and the state which performs all formal payroll functions.

Counties are required to make financial contributions to the IHSS program and the financial support differs from county to county which translates into significant variations in the hourly rate that a direct service worker is paid. In San Francisco, for example, the hourly wage is \$10.41; in some rural counties the state minimum wage is the prevailing wage. On January 1, 2007 the state minimum wage was increased to \$7.50 per hour. In San Francisco, the direct care worker is eligible for healthcare coverage when they provide a minimum of 25 hours of service per month. A description of the health care coverage for employees of the San Francisco Public Authority is summarized below (Figure 1).

“When we started offering health benefits I saw a dramatic change in who was coming through our door interested in being a home care worker.”

– Executive Director, San Francisco
In-Home Supportive Services
Public Authority

Figure 1. Healthcare Coverage for Employees of the San Francisco Public Authority

In March of 1999, the IHSS Public Authority began offering a new job benefit for individual providers. Eligible IHSS workers can sign up for a plan called HealthyWorkers, health coverage provided by the San Francisco Health Plan.

For a premium payment of just \$3 per month, Healthy Workers members get these benefits and more from primary care physicians and specialists affiliated with the clinics of the San Francisco Department of Public Health. Services include:

- Wellness check-ups and routine care from your primary care provider (PCP)
- 24-hour access to a PCP
- Emergency care at San Francisco General Hospital
- Specialty care
- Family planning services
- Eye exams and eyeglasses
- Prescription drugs
- X-rays and tests
- Maternity care
- Mental health services
- Health education classes and materials

Additional services such as MRI, dialysis, durable medical equipment, orthotics/prosthetics, home care supplies, and family planning are available to San Francisco Health Plan members through a network of contracted ancillary providers. San Francisco Health Plan contracts with six medical groups and their affiliated hospital for clinical services. Individual physicians, other health care providers, and clinics participate in a closed network.

Participant Support

Along with its collective bargaining responsibilities, the IHSS public authority supports the consumer to develop a cadre of workers that can provide the personal assistance services authorized by the state. The public authority does this by creating a computerized registry of qualified direct care workers. Once the worker provides documentation to the public authority that they can legally work in the United States and passes a reference check, they can be placed on the list of qualified workers on the registry. The public authority can create customized lists of qualified direct care workers based on a consumer's preferences and need. While these worker registries vary from program to program, they typically include; contact information, parts of the service area that the individual can serve, information about their credentials and skills, their

willingness to perform certain types of services. While certain family members may be paid by Medicaid to provide personal assistance services, it was only in 2004 when California received an Independence Plus waiver that restrictions against paying spouses and parents of dependent children were lifted.

Various training options are available to direct care workers in San Francisco who want to enhance their workplace skills. The training courses are voluntary and Medicaid beneficiaries are not required to hire a worker with any formal or informal training. Medicaid beneficiaries are not required to hire a direct care worker from the registry compiled by the public authority but any potential worker must be eligible to legally work in the United States and pass a criminal background check. Medicaid beneficiaries are not allowed to hire a parent or spouse as their direct care worker under this program.

Voluntary training programs are available to Medicaid beneficiaries interested in building supervisory skills related to the management of their IHSS. The public authority in San Francisco has staff that provides peer support to individuals that are grappling with the management of direct care workers and other responsibilities that come with consumer direction. As an additional support, the San Francisco IHSS public authority operates an on-call service, which is available to Medicaid beneficiaries as a “back-up” system should their regularly scheduled worker be unable to perform a previously scheduled visit. These individuals working for this on-call service are employees of the public authority and are required to participate in a mandatory 20 hour training course on providing direct care services.

Colorado: Fiscal/Employer Agent and Individual Budget Model

The Consumer Directed Attendant Support (CDAS) program was established in 2002 when CMS granted the state a Section 1115 research and demonstration waiver, creating an individualized budget for participants to self-direct their services, which allows them to determine how much each worker will be paid. At the time of the interview there were approximately 270 people enrolled in the program. This is a pilot program that permits a maximum of 500 individuals to participate. In this consumer direction model, Medicaid beneficiaries are responsible for arranging most aspects of their care plan, while a fiscal agent takes responsibility for all payroll functions under contract with the state. Unlike the three other programs profiled in this report, Colorado allows Medicaid beneficiaries to direct certain skilled home health along with other home and community-based services. This Colorado waiver program was up for renewal in 2007.

Eligibility Assessment

Colorado has a single point of entry for residents interested in receiving Medicaid long term services and supports. The state contracts with a variety of governmental and non-governmental organizations in different regions of the state to perform a functional assessment to determine eligibility for these services. While the original design of the CDAS program required that the individual have a utilization history on which the individual budget would be based, the state has since dropped that requirement and allows the initial assessment of need to be used as the basis for developing an individual budget, which is based on a care plan. If the individual is eligible

for long term services, they may choose to participate in the program. The number of hours allocated each month depends on the individual assessment and varies by individual. The only additional requirement for participation in the program is that a physician must provide a letter to the program stating that the individual is capable of directing their personal assistance services or has a representative to act on their behalf. Colorado does not devote specific resources to monitor quality within CDAS.

In this consumer directed program, personal assistance services include certain skilled care services (i.e., suctioning, catheter care and tracheotomy care) and an array of home and community-based services. To permit the self direction of the skilled care services the Colorado legislature granted an exemption to the nurse practice act when it authorized the state to seek a waiver from CMS.

Financial Management

Colorado Medicaid contracts with a fiscal agent to perform all payroll functions and to serve as the employer of record. Once a Medicaid beneficiary identifies a potential direct care worker and the required information is provided to the fiscal agent, a determination of employability can be made. As in other consumer directed programs, this process includes a review of documentation provided by the prospective direct care worker to determine if they can legally work in the United States along with a criminal background check to screen out individuals found guilty of certain criminal offenses. Once an individual has been screened by the fiscal agent and entered into the payroll system, the Medicaid beneficiary determines the rate of pay for the direct care worker, which must be at least the minimum wage. No health care benefits are offered to direct care workers as part of the CDAS program.

The fiscal agent processes timesheets that are properly completed and withholds all relevant tax, FICA and other payroll deductions, issues checks to each provider, issues reports to the state, and is ultimately responsible for terminating a direct care worker by removing them from the payroll system. The state relies on the records of the fiscal agent to conduct a quarterly review of each individual's budget to ensure that it has not been overspent. If the budget is overspent the Medicaid beneficiary is notified that if they continue to spend more than their budget allows their participation in the program will end. On the other hand, twice a year during the budget reconciliation process conducted by the state, the balance in the budget is divided. Half of the balance is returned to the state and the Medicaid beneficiary is allowed to spend the other half on any medical service Medicaid does not cover or related support deemed to enhance the individual's independence.

Participant Support

There is no registry of direct care workers available to program participants. Direct care workers are not required to have any formal training or enroll in a training course to work with Medicaid beneficiaries in the CDAS program. The Medicaid beneficiaries involved in shaping CDAS assert that the best form of training for direct care workers comes from learning about the individual preferences of the Medicaid beneficiary.⁸

Different from the other programs we examined for this paper, the CDAS program requires that prospective Medicaid program participants take a 20 hour training course and pass a test. If an individual does not believe they need the training course, they are given the option to

demonstrate their ability to assume the responsibilities of coordinating services and managing their personal assistance workers by taking the same proficiency test given to those individuals that have completed the training course. Other than the initial training program, Medicaid beneficiaries receive no formal assistance from the state or other organizations to support the identification of potential direct care workers, access to an on-call or back-up support system, or the supervision of direct care workers. CDAS does allow the beneficiaries to hire a parent or spouse to provide personal assistance services. The state now offers beneficiaries over the age of 55 the option of directing their personal assistance services but they may not hire a spouse to provide these services.⁹

New York: Managed Long-Term Care

Independence Care System (ICS) is a nonprofit Medicaid managed long-term care organization in New York City, which offers its members both agency model personal care services and consumer-directed personal assistance services. It also provides a wide range of home and community-based services making it a variant of the “agency with choice” model. ICS serves Medicaid beneficiaries with physical disabilities, who live in New York City, who are over 18 years of age, and require a nursing home level of care. It has promoted consumer direction, since its inception in April of 2000. Approximately 140 consumers of the 1,000 person membership are currently directing their personal assistance services—a participation rate of 14%.

New York State’s Consumer Directed Personal Assistance Program (CDPAP) is conducted through fiscal intermediaries, which operate under contract with the counties. The CDPAP was initiated in 1996. In 2006, there were 8,615 individuals directing their personal assistance services statewide.^{10, 11}

Eligibility Assessment

Typically, a representative of the county social services conducts a needs assessment and gathers the information provided by the individual necessary to determine financial eligibility for Medicaid services. In the case of ICS, a standardized assessment of functional needs is used by all Medicaid managed long-term care plans and submitted to the City for review. In addition, an ICS nurse assesses the hours and home care that will be required. The financial eligibility of the beneficiary is established prior to enrollment with ICS.

When a Medicaid beneficiary enrolls with ICS, a care manager works with the Medicaid beneficiary to develop an individualized services plan. If the consumer chooses to direct their personal assistance services, they review their personal care home health and required nursing tasks with the care manager prior to hiring their personal assistant. If the consumer’s needs change at any time, they may request that their care manager reassess their needs at any time. The primary mechanism for monitoring quality in this system is through the care coordinator. Consumers also have the right to discuss or file grievances with the organization’s advocacy staff.

Financial Management

When the ICS plan member chooses to hire, train and supervise their personal assistant services, ICS contracts with Concepts of Independence, an organization under contract to NYC

government to serve as a fiscal intermediary. ICS must contract with an organization already under contract to the City to act as a fiscal intermediary. Concepts for Independence, is responsible for processing the direct care worker’s payroll. Concepts for Independence is responsible for fulfilling the legal requirements established by the city and state as the employer of record for the direct care workers. As a vendor agency under contract to New York City for the provision of CDPAP fiscal intermediary services, Concepts for Independence bills Medicaid for the personal assistance services provided to ICS members that self-direct. After this process is complete, Concepts of Independence can issue payment to the direct care worker based on the number of hours worked, evidence of which is provided by the ICS member in the form of a signed timesheet. The hourly wage paid to a new employee is \$9.60 with a differential wage paid for weekend work and benefits include paid leave, group health insurance, disability and unemployment insurance.

Participant Support

Medicaid beneficiaries in this program primarily identify direct care workers through informal networks but Concepts of Independence does operate a telephonic system where direct care workers may leave a recorded message about their preferred working arrangements or availability. ICS is planning to develop a registry of direct care workers that have been recommended as competent and reliable by other ICS members to serve as a complement to

“To the extent that you can provide training and support.... back ups that help people find additional workers and emergency services you will increase the number in consumer directed services.”

– Rick Surpin, President ICS

the registry compiled by Concepts of Independence. Medicaid beneficiaries directing their own personal assistance services in NY may not hire their spouse, parent, son, daughter (or in-law), but may hire another relative if that relative is not living in the home or resides in the home only because the amount of care needed makes their presence necessary. There are no special training requirements for direct care workers in the New York consumer directed program. While most direct care workers in New York City are represented by a local health care union, the workers paid through the consumer directed agency have not been organized by the union.

Medicaid beneficiaries who choose to direct their personal assistance services are not required to have any special training to participate in the consumer directed program; however, ICS plans to conduct training for its members interested in consumer direction. ICS has dedicated staff positions to promote and work with those interested in directing their personal assistance services.

Virginia: Fiscal/Employer Agent Model

The Commonwealth of Virginia permits consumer direction of personal assistance services for individuals enrolled in the state’s elderly and disabled HCBS waiver program, which is called the Elderly and Disabled Waiver with Consumer Direction (EDCD). The Virginia Medicaid program has allowed consumer direction of personal assistance services offered through this HCBS waiver since 1997. Today, there are approximately 12,000 people eligible for consumer direction through the EDCD waiver. At the time of the interview there were approximately 800

people, or almost 7 percent of the eligible population directing their personal assistance services. Virginia operates a fiscal agent model designed to perform certain payroll functions while the Medicaid beneficiary manages their own care plan and schedule of direct care workers.

Assessing Eligibility

The Commonwealth of Virginia uses a universal assessment instrument to determine eligibility for nursing facility and waiver services. The assessment is conducted by a team from the state department of health and the county social services agency. If the individual is eligible and decides to receive services in the community, they are provided the option of directing their personal assistance services. If they decide to direct their services they must work with a service facilitator (a community support entity), which provides limited support to the consumer and functions as an informal quality monitoring service by contacting the Medicaid beneficiary on a regular basis. Like the other consumer directed programs, the Medicaid beneficiary must be able to manage their own personal assistance or have a representative to coordinate a schedule of direct care workers, and assume the other managerial responsibilities that come with consumer direction. The Medicaid beneficiary receiving services is responsible for finding direct care workers to provide the personal assistance services, making schedule arrangements with worker(s), and making arrangement for unanticipated or emergency situations where personal assistance is required. Personal care is the only Medicaid benefit that may be self-directed and no beneficiary can receive 24 hour care in a community setting, however there are some beneficiaries that receive upwards of 20 hours a day of personal care.

Financial Management

The Department of Medical Assistance Services contracts with a private company to serve as the fiscal agent to perform certain legal and administrative functions, which makes it possible for the state to pay the direct care worker selected by the beneficiary. For each potential direct care worker, the fiscal agent receives an “employment packet” consisting of information provided by the potential direct care worker. The fiscal agent uses the information provided in the packet to verify the potential direct care worker’s legal status regarding employment. They also conduct a background check to screen workers for criminal activity that would disqualify them from providing direct care services. The fiscal agent also requires that the potential direct care worker be tested for exposure to Tuberculosis.

The state sets the payment rate for the direct care workers in consumer directed arrangements. The fiscal intermediary processes timesheets, when properly completed, withholds all relevant tax, FICA and other payroll deductions, issues checks to each provider, issues reports to the state, and is ultimately responsible for terminating an employee by removing them from the payroll system operated under contract with the state. Workers are not offered health care benefits though the program.

Participant Support

The service facilitator is also responsible for compiling a registry of potential direct care workers, although there is no requirement that the list be current or that the organization conduct

[When a Medicaid beneficiary] no longer needs or wants to hire the person there are some significant issues that the person with a disability who may have never had to fire someone or something of that nature and they feel very uncomfortable or even unsafe...

- Director Advocacy and Services,
Endeppence Now

ongoing outreach to potential direct care workers. The service facilitator must be available during regular business hours but is not required to be available to the Medicaid beneficiary outside of these hours or for help with emergency or back-up support when the Medicaid beneficiary is unable to find a direct care worker. There is no requirement for direct care workers to receive training before they begin working with beneficiaries. Certain family members may be paid by Medicaid to provide personal assistance services, however restrictions against paying spouses and parents of dependent children remain.

The Medicaid beneficiary receives limited support from a service facilitator, which the state pays to perform peer support. Those directing their own personal assistance services in Virginia must agree to work with a service facilitator, which visits the Medicaid beneficiary in their home on a regular basis. The facilitator periodically calls the individual to assess their need for additional support with their responsibilities for arranging their personal assistance services. The service facilitator provides various forms of support (i.e., training of Medicaid beneficiary to participate in the program, assistance with employee packet, creating a schedule for getting needs met, recruiting direct care workers, using the registry, developing a back-up system, planning for emergency situations, the responsibilities of supervising a worker, interactions with the fiscal intermediary).

II. FINDINGS ON PARTICIPATION AND PROGRAMMATIC FEATURES ACROSS STATES

The following section discusses some of the similarities and differences we found across the four states' CD-PAS programs. While the programmatic features of each program varied, our interviews revealed several common themes relating to program participation, availability of consumer supports, workforce, and quality. Key programmatic features are summarized below and in Table 1.

Program Participation

The Issue: The number of states offering some form of CD-PAS in the Medicaid program has grown significantly in the last decade. Virtually every state offers some form of consumer direction. The need for greater control over how the most intimate aspects of beneficiaries' daily lives are carried out is a consistent theme among those promoting CD-PAS options in the Medicaid program. Medicaid beneficiaries enrolled in CD-PAS highly value the ability to choose their own direct care workers and set their own schedules.¹² The traditional home health agency model of service delivery is often heavily influenced by the medical orientation of the staff, which makes arrangement for their "patients." Consumer direction was, in some ways, a reaction to the medical orientation taken in providing routine, largely non-medical services in an individual's home.

Finding: **The number of Medicaid beneficiaries directing their own personal assistance services is small, compared to those that receive traditional agency directed services in the community, but participation is growing.** While CD-PAS is a highly desirable arrangement for certain Medicaid beneficiaries, it is not for everyone. Participation rates in three of the four programs were around 10 percent of those eligible. Whether current participation rates are due to a lack of knowledge about the opportunity to self-direct or a lack of ability to assume the

required responsibilities, many Medicaid beneficiaries with personal assistance needs that live in the community currently rely on traditional provider networks to deliver their personal assistance services.

Table 1. Programmatic Features of States’ Consumer Direction Programs in Medicaid

		<u>California</u>	<u>Colorado</u>	<u>New York</u>	<u>Virginia</u>
		Public Authority	Fiscal/Employer Agent and Individual Budget	Managed Long-Term Care	Fiscal/Employer Agent
Availability of Consumer Supports	Training for CD-PAS Participants		✓		
	Peer Support for CD-PAS Participants	✓			✓
	Can Hire Certain Family Members	✓ Including a spouse or parent	✓ Including a spouse or parent	✓	✓
	Registry of Direct Care Workers	✓			✓
	Back-up System for CD-PAS Participants	✓			
	Individual Budget		✓		
Workforce	Training for Direct Care Worker	✓			
	Access to Health Insurance for Direct Care Worker	✓		✓	
Quality	Quality Monitoring Mechanism			✓	✓

Source: Data were collected from interviews with program administrators familiar with the programmatic features of CD-PAS in each state.

Availability of Consumer Supports

➤ *Consumer Training and Supports*

The Issue: Medicaid beneficiaries who receive HCBS from traditional home health agencies do not have the responsibility of supervising, training or scheduling of the direct care workforce. As individuals chose to participate in consumer direction these responsibilities, to varying degrees, shift to the Medicaid beneficiary. When traditional agencies hire staff to assume the responsibilities of training, scheduling and supervising the direct care workforce, staff members receive some form of training on these job-related responsibilities. While the philosophical tenants of consumer direction hold that the individual with personal assistance needs inherently knows how and when PAS should be provided, training on management of employees and recordkeeping for payroll purposes requires skills that some Medicaid beneficiaries do not possess. Balancing the responsibilities that Medicaid beneficiaries enrolled in consumer direction programs must assume with the beneficiary's capacity to perform these skills appears to be a process that is underway in some CD-PAS programs.

Finding: Consumer training and support with recruiting workers for Medicaid beneficiaries participating in consumer direction varies considerably across the states.

Some form of training or peer support for Medicaid beneficiaries on the responsibilities of CD-PAS is an important programmatic feature; however, there is considerable range in the requirements made on Medicaid beneficiaries choosing to direct their own services. In Colorado, Medicaid beneficiaries must attend a 20 hour training course and successfully complete a proficiency exam, or if the individual believes that they are capable of fulfilling the responsibilities associated with self-direction of PAS they may take the exam without participating in the training course. In Virginia, the service facilitator works with the Medicaid beneficiary on a regular basis to help them with the range of responsibilities in that state's program. California offers peer support through the public authority to those participating in the program to help them learn how to complete timesheets in addition to the basics of arranging a schedule. New York's managed long term care program has two staff positions that work with Medicaid beneficiaries to ensure that they are able to supply the information needed by the organization designed by the City of New York to process consumer directed payroll.

➤ *Locating Direct Care Workers*

The Issue: Finding workers that are willing and able to assist Medicaid beneficiaries with intimate daily tasks is at the very core of CD-PAS. If a Medicaid beneficiary is unable to develop and maintain a group of direct care workers to provide personal assistance services, the beneficiary is unlikely to find consumer direction a viable option for addressing their personal assistance needs. In consumer direction it is very difficult for Medicaid beneficiaries to offer a full-time position like traditional employers can. In many cases for a direct care worker to secure a 40 hour work week with one beneficiary, they would need to work almost every day of the week, often coming to the Medicaid beneficiary's home more than once a day. When these factors are added to the current direct care workforce shortage, it can make recruiting workers for consumer direction difficult.

Finding: Locating workers willing to provide personal assistance services requires a significant investment of programmatic or personal resources, with the exception of consumers that exclusively hire family members or acquaintances. In the four programs examined, all Medicaid beneficiaries enrolled in CD-PAS assumed responsibility for selecting direct care workers, but support with locating direct care workers varied among the programs. California and Virginia made a registry of direct care workers available to all Medicaid beneficiaries enrolled in CD-PAS. The Colorado program has no formal support available to beneficiaries, which often resulted in these individuals competing with employers of facility-based operations as well as home health agencies serving people in home and community-based settings. In Colorado, Medicaid beneficiaries reported greater success in finding workers when they were able to offer a wage that was greater than what traditional employers were paying direct care workers.¹³

➤ *Paying Family Members for Personal Assistance Services*

The Issue: In Medicaid, allowing parents and spouses to be paid for providing personal assistance services has raised concerns. The Cash and Counseling demonstrations tested the extent to which paying these family members would result in fraud and/or abuse and revealed the following:

In all three Cash and Counseling programs, counselors were alert to the possibility that people occasionally might attempt to enroll their relatives in Cash and Counseling to obtain the allowance for their own use. A few questionable situations were identified through the initial home visit. Counselors referred such cases of potential exploitation to state program staff for investigation. Before the first allowance was paid, some of these cases were referred to adult protective services (or a similar program) or to the traditional program.¹⁴

Another reason the restrictions against paying a spouse or parent remain in place is due to the sizable population of spouses and parents that family members with disabilities rely on for support and assistance with activities of daily living. It is thought that lifting these requirements would result in significant numbers of Medicaid eligible people wanting help caring for their family members that live at home. A number of states, however, have lifted these restrictions.

Finding: States appear to embrace the flexibility to permit some family members to deliver services, but waiving the Medicaid prohibition against parents and spouses being paid to deliver services is not available in all CD-PAS programs. All four programs examined permit certain family members to provide personal assistance services to the eligible family member. California and Colorado have waivers from CMS which permit a spouse or parent of a dependant child to receive payment for providing personal assistance services in their programs.

➤ *Identifying Direct Care Workers*

The Issue: Medicaid beneficiaries that choose to direct their own services lack the infrastructure and economy of scale that agencies use to recruit direct care workers. Furthering the challenge of locating potential workers is that the need for assistance can occur any day of the year and during specific times of the day that often fall outside of established business hours. For

example, an individual may require a limited amount of support (one to two hours) in the early morning and a similar amount in the late evening during a weekend or holiday. Compounding the difficulty that Medicaid beneficiaries may experience is the limited amount of work hours available to potential workers. This makes it difficult to offer a direct care worker an attractive work schedule unless they seek part-time employment. Finding individuals to fill these “shifts” and perform intimate tasks at odd hours of the day often requires a great deal of persistence on the part of the consumer. When beneficiaries are unable to identify workers through familial and other social networks they often look to more established methods of finding workers such as running an ad in the newspaper or posting a position online where healthcare workers often look for employment opportunities. One way that consumer directed programs have addressed the challenge of finding direct care workers to cover shifts is by creating a registry of workers that understand the unique nature of the work.

Finding: A registry of direct care workers is the primary method used by beneficiaries to identify workers with whom they are not already acquainted. The public authority in San Francisco compiles and maintains a registry as the primary means of assisting Medicaid beneficiaries to identify workers willing to work in consumer directed arrangements. The public authority devotes significant resources to this service. While the primary purpose of the public authority is to give direct care workers access to a collective bargaining process with the state, assisting Medicaid beneficiaries to identify members of the in-home support services’ workforce is an essential function of the San Francisco public authority. In Virginia, each service facilitator is responsible for providing a registry to the Medicaid beneficiary. Colorado mentioned that a registry was under development and the initial registrants would be direct care workers recommended by Medicaid beneficiaries currently directing their own services. This formalization of peer support is common practice in the other programs which already offer a registry to beneficiaries.

➤ ***Planning for Unanticipated Events***

The Issue: One essential responsibility of individuals participating in consumer direction is to develop contingency plans for unanticipated events. The type of events that Medicaid beneficiaries must plan for include: arranging for assistance when an unscheduled need arises, finding someone to fill a shift when the regular direct care worker is sick, or finding a last minute replacement when an unanticipated event on the worker’s part prevents them from being available (i.e. car trouble, child care problems) to fill their assigned shift. 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 model.¹⁵

Finding: An appropriate back-up system or plan to deal with unanticipated events is an essential part of consumer direction, but not all states view it as a state responsibility. In all four interviews, officials were mindful of the fact that Medicaid beneficiaries need to develop back-up systems to participate in CD-PAS programs. The San Francisco public authority offers an on-call service to Medicaid beneficiaries. While the New York program is planning to develop a system to complement the telephonic service available to ICS members that use the services of the fiscal agent. In Colorado and Virginia the responsibility to make back-up or contingency arrangements resides exclusively with the consumer.

➤ *Individual Budgets*

The Issue: Cash and Counseling programs have been successful in raising awareness of one method of providing Medicaid beneficiaries greater control over their personal assistance services through the use of an individualized budget. As states and advocates continue to develop programs that give beneficiaries greater control and responsibility over their personal assistance services careful consideration should be given to how best to support consumers in this regard. Requiring beneficiaries to manage a budget when their primary desire is to have a greater say over whom and how their services are delivered may be beyond the premise of consumer direction. While many advocates are interested in increasing the flexibility of the Medicaid benefit through the use of individual budgets, some concerns exist, especially around the practice of converting any part of the Medicaid benefit into cash. For example, advocates argue that other services or benefits of the Medicaid program should be included in an individual's budget such as certain items of durable medical equipment. Another concern about this model is whether the adequacy of the individual budget is equal to the individual's personal assistance needs and responsive to changes in need over time.

Finding: Consumer direction is possible without using an individual budget, as evidenced by the three states in this study that rely on other models of consumer direction. In this study, only Colorado relied on an individual budget to allow beneficiaries to self-direct their personal assistance services. The other three states rely on different methods of financial management to pay direct care workers. In San Francisco's public authority model, government employees verified hours and processed payroll fulfilling the role of fiscal intermediary. In New York, the role of the agency that processes payroll takes on a number of responsibilities that are traditionally associated with the formal role of the employer, such as extending paid leave to employees and offering health care benefits. Similar to Colorado, Virginia relies on a fiscal intermediary that is under contract to the state to perform payroll functions but the program does not require participants to manage their budget.

Workforce Issues

The Issue: Many Americans receive healthcare benefits from employer-sponsored policies yet many direct care workers are believed to lack access to a group policy because their employer does not offer one. In consumer direction, the responsibilities of the employer are shared among different entities. This fragmentation of responsibility creates an environment where assuming a leadership role in addressing the needs of the direct care workforce is likely to fall through the cracks. The atomization that occurs when one worker is connected to just one consumer raises a number of questions about other employment related benefits such as sick and paid leave.

Finding: Wages, benefits and training are key issues that influence a worker's decision to accept a position as a community-based direct care worker. The California and New York programs offered an affordable healthcare and dental benefit to direct care workers. In Colorado and Virginia CD-PAS direct care workers were unable to purchase a group health care policy as a benefit of their employment. In Virginia, the service facilitators do not provide information to direct care workers about how one can access health insurance or coverage. Only in the New York program were workers able to accumulate paid-leave benefits (sick and vacation leave).

In contrast to facility-based long-term care settings such as nursing homes that have training requirements for direct care workers, the home health care industry often has different training requirements for different types or levels of service. Only California had a formal voluntary training program that was available to prospective employees in consumer directed programs. The public authority in San Francisco developed its own training program for direct care workers. The training provides an opportunity to learn about the basic skills that most direct care workers should have when providing personal assistance to people with significant disabilities. The training program also serves as a stepping stone for direct care workers interested in career opportunities beyond providing personal care through the in-home support services program.

Quality

The Issue: Medicaid beneficiaries enrolled in CD-PAS are on their own to hire, manage and fire direct care workers. Some value this independence but others welcome some additional support with certain responsibilities, such as dealing with a poorly performing direct care worker.¹⁶ The quality of home and community based services, including consumer direction of personal assistance services, has been the subject of increased scrutiny. CMS requires states to have a Quality Management Strategy in place for all Medicaid services, which includes HCBS whether provided as part of the state plan or through a waiver. CMS also supplies states with a number of resources to aid them in monitoring the quality of service provided in the community. In addition, the Deficit Reduction Act of 2005 (DRA) mandates that the Agency for Healthcare Research and Quality (AHRQ) develop a set of metrics that measure the quality of HCBS. These efforts arise out of a concern that the system for monitoring the health, safety and welfare of Medicaid beneficiaries living in community settings is underdeveloped.

Some Medicaid beneficiaries and their advocates have been critical of using measures developed for institutional settings to assess and monitor the quality of service delivered in home and community based locations. The monitoring of personal assistance services delivered in one's home is often criticized as intrusive coupled with the concern that current standards used to assess the quality of HCBS have an unnecessary medical orientation. The development of quality standards that respect the needs and preferences of individuals with disabilities living in the community and address health and safety concerns of these beneficiaries is important.

Finding: **Consumer satisfaction is the exclusive measure for the quality of service in consumer direction programs.** Standards for measuring the quality of service, other than consumer satisfaction, do not exist. In the four consumer direction programs we examined, New York and Virginia had mechanisms in place to monitor quality through beneficiary satisfaction which is often derived from the ability of the individual to make certain personnel and scheduling decisions about the personal assistance services allocated to them. The Virginia program pays a community based organization to visit the Medicaid beneficiary in their home on a regular basis and check in by phone on a more frequent basis to help the beneficiary with the tasks of consumer direction. These organizations are also available by phone during the work week. These organizations do not perform a comprehensive case management service instead they provide information and training to the Medicaid beneficiary. While these responsibilities are not structured as a quality monitoring system, the organization does have the opportunity to

monitor the relative success of the individual in managing the responsibilities of consumer direction. In New York, the program offers a consumer directed option to those enrolled in their managed long term care plan. The organization provides care coordination for all of its members including those that self-direct their personal assistance services. The care coordination operation includes staff members, nurses and social workers that monitor the quality of services and the ability of the beneficiary to successfully direct their personal assistance services.

CONCLUSION

People with disabilities have been vocal advocates for securing greater control over Medicaid community-based long-term services and supports. They have worked effectively in nearly every state to make consumer directed options available to certain groups that require Medicaid services to live in their community. But while having greater control over these services is a high priority for some, it is not true for all of those that are eligible to participate in these programs. The reasons appear to vary, but it is important that these individuals continue to have a choice regarding their assumption of the responsibilities that come with consumer direction and that it not be forced on those that do not desire this type of arrangement.

This analysis of consumer direction in four states found substantial variation in key programmatic features and unevenness in resources devoted to Medicaid beneficiary supports. As states and advocates continue to develop programs that give beneficiaries greater control and responsibility over their personal assistance services careful consideration should be given to how best to support the Medicaid beneficiary. In addition, consumer direction is possible without using an individual budget, as evidenced by the three states in this study that rely on models of consumer direction that do not require Medicaid beneficiaries to manage a budget.

As states move forward with consumer directed options in Medicaid, there are several issues that need further examination and analysis. They include building additional support for people that desire these arrangements so when they enter into these programs they are able to have a sense of security that should part of their support system fail them on a particular day, they have resources to turn to for assistance. Secondly, the need to better understand the issues that affect direct care workers such as wages and benefits is important. In the field of home and community-based services, the evolution of consumer direction warrants close monitoring and further examination to identify ways to optimize the delivery of the services and supports and maximize the positive outcomes for Medicaid beneficiaries.

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- ⁵ Interview with Julie Reiskin on the creation of the CDAS program in Colorado, May 2007.
- ⁶ From Scherzer, T., Wong, A., & Newcomer, R., (2007) *Financial Management Services in Consumer-Directed Programs*
- ⁷ Crowley, J. *An Overview of the Independence Plus Initiative to Promote Consumer-Direction of Services in Medicaid*, Kaiser Commission on Medicaid and the Uninsured. November 2003. <http://www.kff.org/medicaid/4151.cfm>
- ⁸ Dulio A., M. Perry, H. Claypool and M. O’Malley. *Consumer Direction of Personal Assistance Services Programs in Medicaid: Insights from Enrollees in Four States*, Kaiser Commission on Medicaid and the Uninsured, March 2008.
- ⁹ http://www.chcpf.state.co.us/HCPF/Syschange/App_CompChart.asp
- ¹⁰ Email conversation with officials from New York state on May 1, 2008.
- ¹¹ In other states, participation rates were reported in the interviews. We do not have comparable numbers from New York. For a rough extrapolation, we assume that the number of people receiving personal assistance services (including both agency-directed and self-directed) has increased from year-to-year. By using the numbers of consumer directed participants in 2006 with the total number of people receiving personal care services in 2003, we estimate that 10% participate in self-direction. Since we believe the number of people receiving personal assistance has grown, the true participation rate is likely to be slightly lower.
- ¹² Dulio A., M. Perry, H. Claypool and M. O’Malley. *Consumer Direction of Personal Assistance Services Programs in Medicaid: Insights from Enrollees in Four States*, Kaiser Commission on Medicaid and the Uninsured, March 2008.
- ¹³ Ibid.
- ¹⁴ Phillips, B.et.al (2003), *Lessons Learned from the Implementation of Cash and Counseling in Arkansas, Florida, and New Jersey*.
- ¹⁵ Dulio A., M. Perry, H. Claypool and M. O’Malley. *Consumer Direction of Personal Assistance Services Programs in Medicaid: Insights from Enrollees in Four States*, Kaiser Commission on Medicaid and the Uninsured, March 2008.
- ¹⁶ Ibid.

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