

Chapter 9: Self-Direction and Health Care

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Chapter 9

Self-Direction and Health Care¹

This chapter discusses ways in which self-direction programs, especially those that provide individual budgets, can facilitate participants' access to health care and maintain and improve their health and functioning. The chapter also discusses how Nurse Practice Acts can hinder or facilitate self-direction, how states can address safety risks when participants have extensive health care needs, and how a few states have incorporated self-direction options into managed care plans.

A. Health Care Needs of People with Disabilities

Because chronic diseases and medical conditions can limit functioning—and functional limitations (particularly those due to mobility impairments) can increase the risk for medical complications and secondary disabilities—many people with functional limitations need and receive considerably more medical care than the average person in their age cohort.² Medicaid beneficiaries with functional limitations, in particular, are heavy users of medical care as well as long-term term services and supports.³

Additionally, although personal assistance services (PAS) are generally non-medical in nature, PAS can include the provision of assistance with routine health or health-related tasks, some of which may be under the purview of state Nurse Practice Acts (NPAs). If so, by law, they can only be performed by licensed nurses, with some exceptions (discussed below). PAS can also include tasks generally performed by physical and occupational therapists, such as range of motion exercises to prevent contractures and to improve or maintain functioning.

Some health-related PAS includes routine activities that do not require special skills, such as reminders to take prescription medications and physical assistance in taking medications (e.g., opening a container). Other activities include procedures that require special training and skill (e.g., urinary catheterization and tube feeding). The need for assistance with at least one health or health-related task is very common among Medicaid program participants (hereafter, participants) who need long-term services and supports.⁴ The Cash & Counseling Demonstration and Evaluation (CCDE) found that between 86 and 92 percent of primary informal caregivers of working-age adult and elderly participants reported providing some health-related PAS.⁵

B. Ways in Which Self-Direction Can Facilitate Access to Health Care

Participant-directed PAS and the ability to direct an individual budget, in particular, have been found to reduce unmet needs, reduce the likelihood of

adverse health events, and reduce the use of nursing homes and other medical services.⁶ However, to maximize the likelihood of these positive outcomes, states need to ensure that participants have flexible budgets and the authority to purchase a wide range of goods and services that meet their health and rehabilitative needs and improve or maintain their functioning.

In states that provide flexible budgets, the goods and services that may be purchased include assistive technologies and related repair services; environmental modifications; medical and personal care supplies, including prescription and over-the-counter drugs not covered by Medicaid or Medicare; rehabilitation services; and transportation services. Not only do such goods and services often reduce dependence on family caregivers or paid workers and promote independence, they often meet medical needs or have a health promotion role.

Participants in New Jersey’s Personal Preferences Program used their budgets to purchase air conditioners (for individuals with respiratory conditions); special mattresses and chair pads to help prevent pressure sores; and equipment and home modifications to prevent falls, scalding, and other injuries.⁷ While some of these items are coverable as Medicaid benefits, they may not be covered in a particular state or waiver program, or the particular brand or model that best meets a participant’s needs may not be covered. Sometimes an item is coverable under the traditional waiver program but only after a lengthy prior-authorization process.

Improved Access to Long-Term Rehabilitative Therapies

A sizable subgroup of CCDE participants used their budgets to purchase physical, speech, occupational, and respiratory therapies. While these services are provided in the traditional health care system, their amount, scope, and duration are typically limited and choice of therapists may also be limited. A striking feature of participant-directed approaches to rehabilitation is that families and professionals—freed from the usual coverage restrictions—often work together to devise therapeutic regimens that not just maintain and improve function, prevent secondary disabilities, and prevent medical complications, but have recreational and social features that make them enjoyable for participants, their families, and workers. Enjoyment improves perseverance with therapy and also satisfies the desire of people with disabilities and their families to “have a life, not just a care plan.”⁸ The CCDE qualitative case studies include many additional examples.⁹

Improved Access to Medical Transportation

Lack of transportation is a barrier to obtaining medical care in the community. The burden of providing transportation and escorting Medicaid beneficiaries to and from medical appointments falls disproportionately on family members because agencies typically will not permit employees to drive participants in their own or the participant’s car.¹⁰

The CCDE found that complaints about the standard Medicaid-authorized providers of medical transportation services were common. Procedures for obtaining medical transportation services were often described as cumbersome and the services themselves as unreliable, causing participants to miss medical appointments. Lack of transportation that interferes with timely medical care can lead to nursing home admissions, particularly for persons with serious and/or multiple chronic illnesses.¹¹

When individuals have control over their individual budget, they can use it to obtain medical care when they need it by paying friends, neighbors, or workers to drive them to medical appointments. They can also use taxis or more reliable paratransit services than those authorized by Medicaid. In one of the CCDE states, a participant purchased a used collapsible wheelchair that could be put in a car trunk so that he could be transported in an ordinary car instead of requiring a specialized van to accommodate his regular wheelchair.

Reduced Costs of Dependence on Medical Technology

Self-direction can also reduce the costs associated with dependence on medical technology such as respirators, which requires caregivers—paid and/or unpaid—to be capable of operating and keeping the equipment functioning at all times. Some medically fragile individuals (many of whom are children) need to have awake and alert caregivers 24-hours a day. In the traditional service system, Medicaid will typically pay for a registered nurse to provide care at night—and at other times to provide respite for unpaid caregivers.

In self-direction programs, participants and their families can choose who will provide this skilled care and in the CCDE parents often preferred to hire someone other than a nurse—often a family member—to provide respite care. Thus, self-direction programs can reduce the cost of providing care to technology dependent individuals. Children in Florida’s CCDE program had 30 percent lower costs for private duty nursing than children not in the program.¹²

Some concerns may be raised about unlicensed workers assuming responsibility for skilled nursing care; however, informal caregivers who provide care to technology-dependent family members are rarely licensed nurses and research has shown that parents of medically-fragile children do not perceive licensing to be either necessary or sufficient. Rather, they want workers to meet *their* standards, that is, before leaving their child in the care of another person, they want to be sure the person understands their child’s condition, what care the child needs, and can calmly and competently deal with an emergency.¹³

Because knowing what to do in an emergency can have life or death consequences, parents often want to train respite caregivers themselves and observe them providing care repeatedly before entrusting their children’s care to them. Home health agencies operate with a staffing model similar to that of

hospitals and nursing homes, which assumes that licensure guarantees that nurses can substitute for another. Although they may assign the same nurse(s) to a case, whenever they can, the agency's standards for quality care do not accord the same value that families do to the development of long-term relationships and rapport between individual nurses and patients and their families.

Employing unlicensed personnel to perform skilled nursing tasks is only possible if a state's Nurse Practice Act has provisions permitting them to do so under certain conditions (e.g., when provided in self-direction programs). Nurse Practice Acts and their importance for self-direction programs are discussed in the next section.

C. Nurse Practice Acts: How They Can Hinder or Facilitate Health-Related Personal Assistance Services

The nursing profession is regulated at the state level through state Nurse Practice Acts (NPAs), which differ by state. NPAs determine which nursing services must be provided by or under the direct supervision of licensed nurses, generally referred to as “skilled” nursing services. Because NPA provisions may present barriers to community living for individuals with skilled nursing needs—including those who direct their own services—states need to determine whether their own NPAs present such barriers and, if so, take steps to remove them.

Individuals with skilled nursing needs who are dually eligible for Medicare and Medicaid can receive skilled services through the Medicare Home Health Agency (HHA) benefit or the Medicaid State Plan HHA benefit. States may also use the private duty nursing optional State Plan benefit, and skilled nursing services not otherwise available under the Medicaid State Plan may also be made available through §1915(c) waiver programs.

Despite the availability of these services, participants with skilled nursing needs are often admitted to nursing homes because it is impractical and prohibitively expensive to send licensed nurses to their homes to administer medications and perform other tasks that must be done daily or multiple times daily.

As described above, health-related personal assistance services can include procedures that NPAs consider to be skilled services, such as urinary catheterization and tube feeding. To enable unlicensed workers to perform such procedures, states can amend their NPAs to permit nurse delegation or to exempt certain individuals from the NPA's provisions under certain circumstances.

Nurse Delegation

Nurse delegation refers to the legal authority that permits and defines requirements for a licensed nurse to train and supervise unlicensed assistive personnel (UAP) (e.g., nurse aides, personal assistants) to perform certain tasks that otherwise only a licensed nurse may perform.

Requirements for nurse delegation differ across states. Some NPAs list specific skilled procedures that may or may not be delegated and others give broad discretion to the licensed nurse with respect to decisions about appropriate delegation of procedures. However, there is a clear consensus across states that activities requiring the exercise of professional judgment as distinct from procedural skills may not be delegated.

Delegation is case-by-case; that is, tasks are delegated to a particular UAP with respect to specific individuals only. Generally speaking, a skilled task that can be delegated needs to be highly routinized and its outcome must be highly predictable, especially insofar as the task can be safely performed without life-threatening consequences. NPAs typically require the nurse to document the teaching provided, to observe the satisfactory performance by the UAP of the tasks taught, and to provide written instructions for the UAP.

However, requirements for subsequent nurse supervision vary. Often NPAs require periodic, onsite supervision but may permit telephonic monitoring or (more rarely) only require that the nurse be available for follow-up if needed. Supervisory requirements may also vary by task. Because the nurse retains overall accountability for nursing care, the nurse must transfer delegation responsibility to another licensed nurse if he or she will no longer be available for oversight.

Delegation is more widely practiced in nursing homes and residential care facilities than in home care because the opportunities for frequent, ongoing supervision of UAPs performing delegated tasks are greater in these settings, especially those that have licensed nurses on site. Experimentation with nurse delegation in home care agencies is only just beginning. However, some states, most notably Washington and Oregon, have successfully used nurse delegation in home care in combination with participant-directed services for many years. Oregon, for example, makes extensive use of contract nurses who are independent providers of nursing consultation. They specialize in teaching Medicaid participants, their family caregivers, and paid workers the specific skills required to meet participants' needs. Although they are required to make periodic monitoring visits, the emphasis is on teaching and being available for consultation.¹⁴

The major reason nurses are unwilling to delegate more responsibility for health-related tasks to UAP—even when the state's NPA permits them broad discretion to do so—has been uncertainty about the nurse's professional or civil liabilities for any adverse consequences of poor performance of delegated tasks.

Thus, NPAs with vague nurse delegation requirements may appear permissive, but these statutes leave too much uncertainty for nurses to feel able to delegate with confidence. Oregon and Washington State have dealt with such concerns very effectively by including clear language in their NPAs that exempts nurses from professional liability—that could result in the loss of their licenses—as long as they follow clearly defined NPA requirements for delegation. Oregon’s statute also exempts both nurses and UAP from potential civil liability if they comply with NPA requirements.

Exemption

Exemption means that NPA restrictions on who may perform or teach nursing tasks are not considered applicable. NPAs traditionally have exempted family members and often have exempted “domestic employees” of clients and their families as well. In recent years, a number of states have amended their NPAs to exempt participant-directed personal assistants specifically, or more generally, individuals whose services are financed under Medicaid or another public program.

For example, Colorado’s Consumer-Directed Attendant Support program operates under an NPA exemption.¹⁵ New York’s NPA includes both a general exemption that would apply to private payers as well as public program participants; and an explicit, more specific, exemption for the participant-directed services option under its Medicaid State Plan personal care service program, called the home attendant program.¹⁶

Under an exemption, participants or their family members who routinely perform certain tasks may train paid and unpaid caregivers to perform these tasks. The individuals who provide the training also provide ongoing supervision. Because family members are almost always exempt from NPA restrictions, nurses may train them to perform what are otherwise classified as skilled nursing tasks only to be performed by licensed nurses within their legal scope of practice.¹⁷ Moreover, licensed personnel who train family members are not legally required to provide ongoing supervision of their performance, nor held legally liable for any adverse consequences that result from any errors they make. Family members and others who have been trained can determine when they need to consult with a nurse or have the nurse provide training for others.

Oregon and Washington were among the first states to include participant-directed services in their “Age and Disabled” waiver programs, and to pioneer Nurse Practice Act reforms to allow widespread nurse delegation to UAPs—including participant-employed home care workers—to perform what would otherwise be defined as skilled nursing tasks that only a licensed nurse would be authorized to perform.¹⁸

In both states, Medicaid officials and other advocates for NPA reform had to convince their State Boards of Nursing to support the reforms. They encountered

initial resistance which had to be overcome via negotiation, and reforms occurred in phases. The process was more overtly contentious in Washington than in Oregon, but one positive result of having to convince skeptics and opponents in Washington was that research was carried out to ensure the safety and efficacy of allowing participant-directed aides to perform skilled nursing tasks.¹⁹

States that need to amend their NPA to facilitate the provision of health-related PAS can use other states' experience to support their efforts. A number of state boards of nursing have held "summits" to which they invited outside experts, including representatives of other states' boards and the National Council of State Boards of Nursing, as well as prominent nurse experts from academia to consider reform options.²⁰

D. Concerns about Health and Safety Risks and Liability for Poor Health Outcomes

State officials, health and social services professionals, and some advocates often express concerns about health and safety risks associated with participant-directed services. They worry that self-direction programs will cover-up self-neglect and allow poor judgment free reign. They envision worst case scenarios in which poor quality participant-directed attendant care and/or self-neglect and "bad choices" result in adverse health outcomes, perhaps even death.

State officials' concerns about self-direction programs are often based on their statutory duty to ensure the health and welfare of HCBS waiver participants and some fear that their states may be sued over adverse health outcomes allegedly caused by the negligence of participant-directed aides.²¹ However, research from the CCDE found that on four out of five measures of adverse health events (contractures, bedsores, respiratory problems, urinary infections, and falls), the differences in reports of such incidents for participants were lower than for non-participants.²² Although concerns have been raised that self-direction is risky for elderly persons, especially those with dementia or for individuals with mental and behavioral health diagnoses in addition to physical disabilities, the research evidence does not corroborate such concerns. Indeed, several studies indicate that outcomes can be even more positive for individuals in these subgroups, who can designate a representative to handle some or all participant responsibilities.²³

The low incidence of adverse health events among CCDE participants does not mean that state program administrators or participants themselves can afford to ignore the potential for their occurrence. Participants with certain kinds of conditions may be particularly vulnerable to adverse health events generally, and more at risk for adverse health events due to poor quality attendant care and/or failure to access timely medical care. Such vulnerabilities must be addressed. However, persons at greater risk for adverse health events often make excellent candidates for self-direction programs because they themselves can facilitate

access to both health and rehabilitative care. Additionally, having greater control over their services will help them ensure that all their needs are met.

Risk Management Strategies in Self-Direction Programs

Both the traditional service delivery system and self-direction programs need policies and procedures to manage risk for all participants, not just those with health care needs. However, risk management is a particularly salient issue when participants need skilled nursing services on a daily basis. So, although backup and critical incident management is discussed in this chapter, the discussion is applicable to all participants in all self-direction programs. Chapter 8 also discusses backup plans and critical incident management as key components of a quality management system.

The appropriate strategies for ensuring that necessary backup services are available, and for minimizing and managing other risks, are somewhat different for self-directing participants than for those receiving traditional services, but there is no reason to impose stricter requirements on participant-directed services. CMS initially urged states to adopt “systemic” approaches, such as having one or more contracts with home care agencies to provide backup attendant care to self-directing participants. However, based on state and participant feedback, the emphasis now is on more individualized approaches; in particular, having participants identify risks and develop risk management and backup care plans to prevent and address risks as part of a person-centered planning process.

With the revision of the HCBS waiver application, CMS now requires that an individualized “contingency” or backup plan be established as part of a service plan developed using a person-centered planning process. The focus on individualized planning and risk management means that states are not required to establish a systems response (except for natural and man-made disasters). Such plans must address all risks identified during the planning process and provide alternative arrangements for the delivery of critical services, taking the participant’s preferences into account.

The essence of the plan for self-directing participants typically involves identification of individuals who can be called on to provide backup assistance on an emergency basis or during a period when the participant has lost a regular worker and needs assistance while recruiting a replacement. If and when backup workers must be paid (often family, friends, and neighbors will agree to fill in temporarily without pay), the key task is to complete the employment paperwork (including Medicaid provider agreements) for backup workers in advance.

In some cases, participants may be able to obtain emergency backup by calling a worker registry that is already a qualified Medicaid provider or whose individually listed workers are already qualified Medicaid providers, but this option is usually only available in large metropolitan areas.²⁴ Another essential

element of the contingency plan is to ensure the ability to summon help in an emergency. This is where a flexible budget can be of considerable help. For example, a participant with paralysis might decide to purchase a voice-activated telephone to summon assistance from bed, whereas someone with a different kind of disability might prefer a device that does not require speech but operates by pushing a button.

It is also important to bear in mind that traditional and participant-directed services are not in separate, water-tight compartments, requiring beneficiaries to choose to be wholly in one or the other system at any given time. States may permit waiver participants to direct some but not all of their services. The backup plan for a participant in Kentucky who receives “blended” services—that is, some agency and some self-directed PAS—designates a participant-directed attendant who will work when agency services are unavailable.²⁵

There is a growing body of self-help literature and other resources designed to empower individuals with disabilities (and providers) by teaching them how to manage risks associated with personal assistance services. For example, the Institute for Social Research (ISR) at California State University/Sacramento developed both participant and provider handbooks for the State’s In-Home Supportive Services Program (IHSS).²⁶

The IHSS participant handbook addresses such topics as (1) how to locate, interview, and screen personal care attendants for hire; (2) how to establish and maintain appropriate boundaries between themselves and their IHSS workers; (3) safety precautions; (4) and how to recognize and report abuse, neglect, and mistreatment. The provider handbook covers similar topics. The ISR also developed shorter brochures on the same topics. These materials have all been published and made available online in multiple languages. The participant and provider handbooks are available in English and four other languages and the participant brochures are available in nine languages.

CMS’ position on how to address emergency backup care, risk management, and critical incident reporting has evolved considerably over the past six years since CMS first sought to promote expansion of self-direction through the Independence Plus initiative. CMS and many state officials initially perceived participant-directed services as riskier than traditional services and sought accordingly to impose special requirements on programs that offered them.

However, they came to realize that issues such as inadequate backup; poor quality care; and abuse, neglect, and mistreatment also affect traditional case-managed services provided by licensed agency providers. In fact, many participants who want to self-direct do so because of negative experiences with traditional services. They feel that they are better able to obtain backup services and manage the risks associated with community living when they have the choice and control that comes with self-direction.

Both CMS and the states have learned a great deal from work done under the Real Choice Systems Change grants. Colorado used a Systems Change grant to conduct participant focus groups and stakeholder interviews to obtain input on the development of a planned statewide emergency backup system. However, a consensus emerged that an individualized plan of participant safeguards is most appropriate for self-direction programs. (See box below for more information.)

Colorado’s Study of Risk Management Approaches

The purpose of Colorado’s Systems Change Independence Plus grant was to develop a state strategy for attendant backup and critical incident reporting that would both satisfy CMS Independence Plus requirements and meet the approval of self-directing participants. Colorado had earlier received a §1115 Research and Demonstration waiver to implement a small pilot program—Consumer-Directed Attendant Services (CDAS)—that allowed participants to hire their own attendants. Budget authority for goods and services was only available at the end of the year to pilot participants who did not use all of their allotted funds for attendant care. Participants were allowed to use half of their savings to purchase other goods and services; the other half was returned to the state and credited as Medicaid program savings.

The program was particularly well suited for studying risk management strategies because pilot participants would otherwise have received attendant care from Medicare/Medicaid certified home health agencies under the Medicaid Home Health Services benefit. Those eligible for the CDAS option were heavy users of home health services (averaging about \$2,500 per month when Colorado first applied for the §1115 waiver). Most had conditions such as paraplegia or quadriplegia, some used respirators, and all required skilled nursing care. Colorado amended its Nurse Practice Act to allow participants to train and supervise their individually hired attendants to perform certain nursing tasks such as cleaning and replacing urinary catheters.

Because of their extremely high level of physical disability and their need for skilled nursing tasks, the participants in the Colorado CDAS program appeared to be particularly vulnerable to adverse health consequences if abandoned or otherwise abused, mistreated, neglected, or given poor quality care by their hired attendants. The State conducted a series of focus groups with 42 attendant care users (including both CDAS program participants and home health agency clients) to elicit their views on how to secure backup attendant care as well as requirements for critical incident management reporting systems.²⁷ The findings are summarized below.

Backup

- Participants did not want to be required to use home health agencies as backup for attendant services because, in their experience, these agencies failed to provide backup workers even when they had signed Medicaid provider contracts in which they guaranteed the State that backup services would be provided.

(continued)

- Most individuals attracted to self-directed services prefer a “customized” backup approach and are willing to arrange their own backup services.²⁸
- For individuals with mobility impairments, assistive technologies can enable them to call for backup assistance when needed (e.g., cell phones carried at all times, wearable personal emergency response call systems, and voice-activated telephones). Such systems are particularly important for participants with severe mobility impairments, such as persons with quadriplegia.

Critical Incidents

- Participants defined critical incidents as including—but not limited to—instances of abuse, neglect, or mistreatment by attendants.²⁹
- Participants expressed frustration with past attempts to report critical incidents to home care agencies, case managers, and state program officials. They felt that adult protective services (APS) officials might be more likely to take incidents seriously, but were wary of reporting to APS because they feared that they would no longer be allowed to direct their care or would be pressured to enter a nursing home or residential care setting.
- Participants would not hesitate to report criminal incidents to the police and felt that the police would take such complaints seriously, but recognized that criminal behavior could be difficult to prove in a “he-said-she-said” situation with no other witnesses.³⁰
- Most participants felt that they could solve their own attendant problems by simply firing problem workers, but they wanted to be able to protect other participants from hiring the aides they fired through a system that would enable them to file a complaint or file a negative employment reference without those having to be officially substantiated and sanctioned.³¹
- Most participants strongly favored preventive strategies that would make critical incidents much less likely to occur. They neither favored or opposed criminal background check requirements—primarily because most of the critical incidents they had personally experienced did not involve criminal behavior. Even when it did (e.g., theft) it was so difficult to prove that they felt similar past behavior would have been unlikely to have been prosecuted and show up in a criminal background check.
- Participants favored strategies that emphasized networking among self-directing participants, enabling them to make referrals to each other and to share aides. They wanted the CDAS program to develop a registry (a job bank) where they could advertise and which would facilitate their ability to screen potential hires. This approach could be compatible with encouraging participants to write references (positive or less favorable) for former employees that could be made available in connection with web-based worker registries such as *www.RewardingWork.org*.

In general, consumers preferred risk management strategies that they considered to be effective and, especially among the CDAS participants, that they perceived as giving them more control and, therefore, more ability to take actions to ensure their own health and welfare.

Most people, whether disabled or non-disabled, want to be independent, healthy, and safe and the evidence suggests that self-direction can promote all of these goals simultaneously. Thus, many people with disabilities are attracted to self-directed services options because, in their experience, having minimal choice or control also means they have little ability to protect themselves from harm. A young woman in Iowa who had been living in an institution transitioned to the community with a roommate and paid workers using the State's new self-direction option. In the institution, she had been repeatedly frightened and injured by the aggressive behavior of other residents, which had exacerbated her own behavioral issues. When asked about the biggest change the program had made in her life, she said simply: "I feel safe."³²

Legal Liability: A Review of Court Cases

With regard to concerns about liability, the empirical evidence does not support the notion that directing one's services is inherently riskier than receiving agency-provided services, or that it requires an acceptance of trade-offs between enhanced independence and protecting health and safety. A law review article addressing liability issues in self-directed services found a dearth of reported court cases involving allegations of adverse health outcomes resulting from poor quality home care services.³³

With only two exceptions, all recorded court cases involving home care involve either agency providers or, less frequently, individual providers hired by private payers. All of the aides or nurses whose incompetent or negligent care was alleged to have caused harm were unrelated to the plaintiffs. The authors theorize that most lawsuits are directed at agencies because individual aides or nurses have few assets and the likelihood of recovery is too low to make legal action worthwhile.

They also theorize that suits involving publicly funded participant-directed services—directed either at the workers themselves or at the state—may be rarer than suits against agencies (or privately paid home care workers) because a significant percentage of participant-directed workers in public programs are family members. Family members who provide unpaid assistance are not legally liable for accidental harm, but could be held liable for accidents that occur while they are "on-the-clock" as paid aides.³⁴ Both paid and unpaid family members (as well as unrelated individuals and agency workers) could be criminally liable under adult protective services statutes if abuse or neglect is determined to have been intentional.

In the only two cases involving public program participants with non-agency providers, the suit was directed exclusively or primarily at the state and/or a state-employed case manager rather than the worker. Only one of the cases reviewed involved a participant-directed worker—a licensed practical nurse (LPN) who had been hired by a public program participant. The participant filed suit against the

state, not the LPN. Another case involved an “individual provider” (i.e., someone who was not employed by an agency). However, this paid worker was selected by the public program participant’s case manager, not by the program participant. The suit was directed at the case manager, the government agency, and the aide. See the box below for a description of these two cases and the legal reasoning that produced opposite outcomes.

State officials may find it useful to study the other cases in the law review article, even though they all involved agency workers or private pay situations.³⁵ So often, negative views about self-direction are based on concerns about “risk” and “liability”—terms which are rarely, if ever, explicitly defined. The cases discussed in the article are instructive because they make clear that quite simple actions could have prevented the adverse outcomes. According to the authors, the “most common negligent caregiving scenarios involve some variation on leaving the consumer unattended...[which] may involve anything from failing to show up at the scheduled time or leaving early, to momentary lapses of monitoring that resulted in injury to the consumer.”

In one such case, a home care worker failed to show up as scheduled and the client who was recovering from a hip fracture tried to transfer without assistance from his wheelchair to his walker, fell, and re-fractured his hip. (This was apparently a miscommunication; the agency worker thought he was supposed to provide services five days a week instead of seven and failed to show up the first weekend). The agency was held liable.

In another case, a woman with Multiple Sclerosis did not receive timely emergency medical care because she had been left unattended by her home care worker. The worker’s defense was that her only duties and obligations to the client involved cooking, cleaning, and other household tasks. The court ruled for the plaintiff, noting that the home care worker had been instructed regarding the patient’s medical condition and the circumstances under which she might need emergency care. While the court’s judgment was that the homecare worker owed a “duty of care” beyond contractual obligations to cook and clean, they noted that the worker’s failure to honor that duty was “ordinary negligence” not a more specific type of professional or health care-related negligence (also known as “malpractice”). The authors of the law review article note that this was true of all of the cases where the court ruled against a provider of home care aide services. They also note, however, that some cases could well qualify as “criminal negligence” under adult protective services statutes if the negligence is willful and the resulting harm is significant.

Even though the authors found no evidence of lawsuits having been brought as a result of participant-directed aides abandoning their employers, such incidents are known to have occurred. In one egregious case, a Medicaid participant with quadriplegia in Utah had his own apartment and received personal assistance

Reeder v. State of Nebraska. Reeder, paralyzed in an auto accident, enrolled in a self-direction program under Nebraska's Aged and Disabled waiver. An LPN hired by Reeder was approved as a paid Medicaid provider in the capacities of personal care aide (PCA) and LPN. After this LPN had been providing care for Reeder for about two months, he developed decubitus ulcers on his feet. Although he consulted a podiatrist and the LPN followed the podiatrist's treatment orders, the ulcers did not heal and became infected. After a lengthy hospitalization and facing possible amputation, Reeder filed suit against the State based on two theories of liability: that the LPN was an "employee" of the State, which was vicariously liable for her negligent care or, alternatively, that the State had breached an independent duty to select and train a nurse who was competent to provide the care required.³⁶

The case was ultimately decided by the Nebraska Supreme Court, which ruled against Reeder. The court found that the State's statutory duty was to provide compensation for health services, not a duty to provide the actual services. The court also determined that by maintaining periodic contact with clients receiving health care benefits and maintaining a general interest in their welfare, the State's case managers were nevertheless neither trained or authorized to make medical judgments as to the quality of care provided to clients or to intervene in the provision of care, and therefore had no legal duty to do so.

The law review authors noted that the well-established "public duty doctrine" protects states from lawsuits alleging a breach of a general duty to the public. This obstacle is difficult for plaintiffs to surmount absent a "special relationship exception," which refers to a situation in which the state has, in fact, assumed a responsibility and, thus, a duty with respect to the welfare of a particular individual. The one successful lawsuit against the state discussed in the law review—*Caulfield v. Kitsap County, Washington State*—illustrates the

requirements that must be met to establish such a special relationship exception.

Caulfield v. Kitsap County, Washington State.

Caulfield had Multiple Sclerosis, needed 24-hour care, and lived in a nursing facility until his state Department of Social and Health Services-employed case manager arranged for his transfer to in-home care and an aide to care for him—considered an "independent provider," not a home care agency employee. The case manager failed to visit him for more than a month after his transfer to home care, despite having given him assurances that she would continue to be his case manager. When she did finally visit him, she observed major changes in his condition and heard his complaints about his aide. Pursuant to an inter-agency agreement between the state agency and Kitsap County, the State's case manager transferred the case the following day to a county social worker who noted problems requiring "immediate attention." Nonetheless, the county social worker did not promptly contact or visit the plaintiff.

Eight days later, the aide called the county social worker because he was concerned about the plaintiff's deteriorating condition, and the social worker told him to call 911. Upon admission to the hospital, the plaintiff (according to the appellate court's written opinion) had "urosepsis, pneumonia, saline depletion, contractures, was malnourished, suffered severe weight loss, and had severe bed sores that cut through his flesh to his bone." Also according to the ruling, "Even though Caulfield had Multiple Sclerosis, he had previously had some ability to function at levels that allowed an appreciable amount of independence and freedom. But because of negligent caregiving, he lost most of his previous ability to function independently."

At trial, the jury in *Caulfield* returned a verdict finding that the county, the State agency, and the worker were negligent and proximately caused the plaintiff's injuries and apportioned damages totaling \$2,626,707. The county appealed but the appellate court sustained

the verdict on the grounds that Caulfield's relationship with his case manager involved an element of "entrustment" by virtue of the dependent and protective nature of the relationship. This judgment was based on various facts of this particular case, including Caulfield's inability to get out of bed or reach a telephone to call for assistance; the case manager's knowledge concerning Caulfield's illness, disabilities, recent nursing home discharge, and vulnerable circumstances; and, perhaps most importantly, that a case manager, not Caulfield, had selected and hired the paid worker and had been unresponsive to Caulfield's complaints about the worker. Further, the case manager did not make good on her assurances to Caulfield with regard to the level of involvement, monitoring, and supervision she would provide.

These two contrasting cases are especially interesting because they illustrate the point that service provision by "independent providers" is not always synonymous with "participant-directed services" and that courts are capable of perceiving the distinction. *Caulfield* can also be read as a cautionary tale about how much responsibility for selecting and supervising "independent providers" case managers could or should attempt to assume. The facts presented at trial indicate that Caulfield was not prepared to assume the responsibilities of self-direction and had no family member or friend who could serve as his representative. The case manager knew this, which is why she chose the independent provider and promised Caulfield that she would monitor his care. Instead, she did not even visit as frequently as state rules required for any case, let alone one involving an individual recently discharged from a nursing home, with no informal supports, who did not feel up to assuming the responsibilities inherent in self-directed services.³⁷

The *Reeder* case illustrates another key point: adverse health events cannot always be attributed to poor quality, negligent, or abusive care. Courts want to see evidence

that poor care was at fault. Nor is an adverse health event (e.g. a bedsore with serious complications) indicative, in and of itself, that a participant was incapable of self-direction and should not have been permitted to self-direct.³⁸ Many of the lawsuits reviewed that resulted in judgments against home care agencies or even individual caregivers did, in fact, involve bedsores, and evidence was presented that the type of care necessary to prevent bedsores was not delivered.

The facts presented at trial in *Reeder* were, however, ambiguous; they did not clearly indicate that the LPN provided poor care or that Reeder was self-negligent. Reeder sought medical help when the bedsores appeared and his caregiver followed the advice provided.³⁹ The judge's decision in *Reeder* also indicates that courts are likely to be reasonable with respect to interpreting the state's statutory obligation to "ensure the health and welfare" of an HCBS waiver program participant. Courts are unlikely to hold states strictly liable for any and all adverse health events that befall self-directing program participants.

In sum, the principle take-away lessons from *Reeder* and *Caulfield* are: In a self-direction service delivery model, participants must truly be in charge; they must know that the responsibility as well as the authority is theirs, and they must be willing—or have representative decision makers willing—to accept this responsibility. Representative decision makers could be a family caregiver or, as is more common in self-determination programs for persons with profound mental retardation, may take the form of a "circle of support" that may even be formally constituted as a "microboard."⁴⁰ States need to have some kind of support and quality assurance mechanisms; courts are unlikely to specify what those should be, but will expect the state to have them and to follow and enforce their policies and procedures.

services from an attendant whom he directed. When the participant and his attendant had an argument, the attendant left and did not return. Left immobile in bed, the participant had no way to call for assistance and several days elapsed before he was found and taken to the hospital. During the period he spent alone in bed, he had no food or water and received no bowel and bladder care. Although he experienced serious medical complications and nearly died, he did recover and expressed a desire to continue living alone with a new self-directed attendant. He had to appeal the state's original determination that he not be allowed to do so, but eventually prevailed.⁴¹

Note that in this particular case, the problem was not lack of backup workers, but the lack of a communication device to signal the participant's need for help. If the participant had been able to purchase a voice-activated telephone with funds from an individual budget, he would have been able to call for help. In fact, it would be prudent for states to cover the cost of such phones as an "assistive device" for any waiver participant who cannot move without assistance. In other words, this anecdote would be misinterpreted if it is used to illustrate the "riskiness" of participant-directed attendant care rather than the need to identify creative ways of enabling people with very severe disabilities to communicate their needs for assistance.

The second most common type of negligent caregiving scenario involves inadequacies in the provision of care. Again, only a handful of litigated cases were found. One involved hot water scalding, which happened while the aide was giving the care recipient a bath. Another case involved a fire that killed both the participant and the aide—caused by household clutter in too close proximity to a space heater, which, it was alleged, the aide should not have permitted.

Several cases involved falls; for example, an aide who was assisting an elderly man who used a walker to go outside for a walk, allegedly failed to notice water on the floor of his apartment building's elevator; the man fell, broke a hip, was hospitalized, and died. The authors note that, whereas people with chronic illnesses and disabilities may be more susceptible than others to such accidents, the risk potential is scarcely unique to situations involving the provision of paid personal assistance services to this population. These are among the most common household accidents and, as such, are classic causes of action in tort liability. This is also why even when paid care providers are the defendants, such cases are litigated as "ordinary negligence" not health care-specific negligence ("malpractice").

It is noteworthy, that the types of accidents that give rise to such litigation are highly preventable. For example, hot water scalding can be prevented by installing inexpensive technologies to prevent water temperatures in showers and baths from becoming high enough to cause scalding. Similarly, falls can be prevented by fixing water leaks, repairing broken stairs, etc., and fire and fall

hazards caused by excessive clutter (e.g., piles of newspapers) can be eliminated by hiring aides who will do heavy cleaning.

Typically, home care agencies do not permit their aides to do heavy cleaning or trash removal, and no one expects home care agency aides to know how to perform “handyman” chores such as installing scald guards, fixing minor plumbing problems, or repairing broken steps. Use of specialized heavy cleaning, chore, handyman/home repair, or trash removal services are advisable if an individual aide could be injured performing such tasks. These are all goods and services that self-directing participants with flexible individual budgets would be able to purchase.

Arguably, state policymakers and program officials may be more afraid of and, rationally, have more to fear from, bad press involving allegations of negligent care-giving than from lawsuits. At the beginning of the CCDE, it was anticipated that the demonstration programs might well experience an incident that could become a public relations nightmare. The participating states were encouraged to rehearse “damage control” strategies for dealing with bad press. As it turned out, none of the CCDE states or the 12 replication states experienced such an incident.

In closing this discussion of legal liability, it is important to realize that even with the best precautions, negligent caregiving will never be 100 percent preventable. CMS’ position is that risks associated with the possibility of negligent caregiving do not preclude self-direction.⁴²

E. Incorporating Self-Direction Options in Managed Care Plans

When the CCDE was in the planning stages, in the mid 1990s, the conventional wisdom was that self-direction and managed care represented conflicting philosophical approaches to service delivery and were, therefore, incompatible. It was thought that managed care organizations (MCOs) epitomized the ultimate in professional management, whereas self-direction exemplified individuals’ empowerment. When approached in the mid-1990s about participating in the CCDE, officials from several states explained their lack of interest as a consequence of their state’s intent to develop managed care plans that integrated health care and long-term services and supports.

Since that time, however, surveys have found that many MCOs are now open to incorporating self-direction options.⁴³ Moreover, as will be described below, some managed care plans have already incorporated significant opportunities for self-direction, proving that managed care and self-direction can be compatible. Experience to date with self-directed services in managed care plans suggests that it may be more difficult to combine self-direction and managed care in states and localities where there is no prior history of offering self-direction and where MCO leaders do not perceive it might benefit both the MCO and plan members.⁴⁴

Managed Care in Medicaid and Medicare

Managed care organizations (MCOs) are funded through capitation payments to provide a category of services (e.g., primary and acute health care, long-term services and supports, or mental health services) or a combination of services (e.g., primary, acute, and long-term care). MCOs are financially at risk to provide services to plan members within the total amount of capitated funding.

Medicare beneficiaries (both elderly and younger adults receiving Social Security Disability Insurance who qualify for Medicare coverage) cannot be required to enroll in Medicare managed care plans (called Medicare Advantage and Medicare Advantage Plus). However, Medicare Advantage and Advantage Plus plans cover certain services that are not otherwise covered by Medicare.⁴⁵

Dual Medicare/Medicaid eligible individuals (called dual eligibles) and people with disabilities who qualify only for Medicaid may, at state option, be required to enroll in managed care plans to receive Medicaid covered services. Voluntary enrollment into Medicaid managed care plans takes place under §1915(a) authority. Mandatory enrollment of Medicaid beneficiaries into Medicaid managed care plans requires federal approval of a §1915(b) “freedom of choice” waiver and, if HCBS waiver services are included, states must seek federal approval for a “(b)(c) combination” waiver.⁴⁶

To date, only a small number of managed care plans have been federally authorized to integrate Medicare as well as Medicaid-funded coverage, including long-term

services and supports coverage. These include several Minnesota Senior Health Options available statewide; Wisconsin Partnership county-based plans; the Mass Health Senior Care Options, which is mostly statewide; and local PACE (Program for All-Inclusive Care for the Elderly) sites located in a number of states.⁴⁷

Thus, dual eligibles enrolled in Medicaid plans who elect to receive Medicare services under a managed care plan will generally have to enroll in two separate plans. Medicaid managed care plans may be offered by Medicare Advantage MCOs (called “companion” plans), but Medicaid beneficiaries may choose to enroll in a Medicaid plan run by a different organization, and they might have to be in Medicare and Medicaid managed care plans under different auspices if the beneficiary’s Medicare Advantage MCO does not sponsor a Medicaid companion plan. These separate Medicare and Medicaid managed care plans may “coordinate” coverage but they cannot fully integrate Medicare and Medicaid funds by treating them as fungible. Medicare part D drug coverage, in many cases, must be provided under yet another plan.

Thus, dual eligibles could find themselves enrolled in three separate managed care plans: one for Medicare-covered primary and acute health care services other than prescription drugs, one for drug coverage, and another for Medicaid “wrap-around” coverage. Moreover, even the most comprehensive plans tend not to assume full risk for nursing home care, coverage for which is typically limited to 90 or 180 days.

Self-Direction Options in Fully Integrated Health/Long-Term Care Managed Care Plans

Minnesota requires all Medicaid-eligible persons over age 65 to enroll in a Medicaid managed care plan. Dually eligible seniors may choose to enroll in a plan that covers all of their Medicare and Medicaid benefits or they may elect to receive their Medicare covered services on a “fee-for-service” basis. For younger disabled persons, enrollment in both Medicaid managed care and Medicare managed care (if they are Medicare eligible) is voluntary.

Dual eligibles under age 65 may elect to enroll in a single plan that covers both Medicaid and Medicare services. Managed care plans include State Plan personal care services and §1915(c) waiver services. Coverage for nursing homes under Minnesota’s Medicaid managed care plans ranges from 90 to 180 days.

In 2005, when Minnesota first began to offer the Consumer-Directed Community Supports (CDCS) option to Medicaid beneficiaries eligible for §1915(c) waiver programs, the programs were still in the fee-for-service system. As of 2006, however, §1915(c) waiver coverage was folded into managed care and MCOs were told that they had to make CDCS available to their members. The timing of the introduction of CDCS in Minnesota was not ideal because the program had scarcely begun when it had to be integrated into Medicaid managed care as a result of the mandatory Medicaid managed care enrollment policy. This also happened at the same time that Medicare Part D was being launched.

As a result, dual eligibles in Minnesota had to make several decisions at once: which Medicaid managed care plan to join, which Medicare drug plan to join, and whether or not to opt for CDCS. Possibly because of decision overload, enrollment in CDCS has grown slowly. Some MCO care managers are more comfortable than others in recommending CDCS to their clients or supporting clients’ decisions to join CDCS. In this respect, the attitudes of MCO care managers toward self-direction are not much different than those previously observed among case managers in traditional fee-for-service §1915(c) waiver programs, when they have been asked to offer self-direction options to their clients.⁴⁸

Minnesota CDCS program officials contracted with an evaluator to conduct “key informant” interviews (in 2006) and focus groups (in 2007) to gauge the attitudes prevalent among health/social services professionals from MCOs, counties, provider organizations, and financial management services entities. Both the key informants and focus group participants voiced overall support for the self-direction philosophy. Support increased between 2006 and 2007, apparently as care managers began to have personal, positive experiences with CDCS. Nevertheless, the 2007 focus group participants revealed some hesitations and concerns about the CDCS option.

The focus group responses suggest that, whatever hesitations they may have about the CDCS option specifically, most participants perceive self-direction as something that should and will grow over time. Most focus group participants thought that CDCS would be especially helpful in overcoming labor shortages and—for this reason—would be especially useful in serving older persons in rural areas, which often have shortages of traditional providers. However, most focus group participants wanted CDCS enrollment to grow slowly so as not to overwhelm the capacity of care managers and MCOs to learn how to work well with CDCS participants.

Apart from Minnesota, only a few managed care programs cover a comprehensive range of primary, acute, and long-term care services and incorporate self-directed services options. These are: the Arizona Long-Term Care System, Texas Star Plus, and the Wisconsin Partnership Plan, which are Medicaid-only plans; dual eligibles either continue to receive Medicare-covered services through the fee-for-service system or they must enroll in a separate Medicare MCO. In these plans, self-direction appears to be largely limited to allowing plan members to select, manage, and dismiss independent providers of personal care, homemaker/chore, and/or respite services.

Self-Direction Options in Long-Term Care Managed Care Plans

Wisconsin Family Care—a managed care plan covering only Medicaid-funded long-term services and supports—also offers self-direction options. About one third of Family Care participants direct at least one covered service by employing personal care, homemaker, chore and/or respite aides directly. Participant-directed workers may be family members.

Independence Care Systems (ICS) is one of several New York managed long-term services and supports plans and the only one that offers its members the option to hire their own aides or use agency-based personal care or home health services.⁴⁹ Cooperative Home Care Associates—a 20 year old worker-owned home care agency—is the preferred provider for agency-delivered PAS, although members may use other Medicaid-participating agencies. Self-directed services are provided through Concepts for Independence, an agency that serves as the employer-of-record (using the agency with choice self-direction model) for home care workers recruited by self-directing ICS members.

ICS provides training on a voluntary basis for self-directing plan members on how to recruit and manage personal assistants. ICS also has plans to launch its own agency with choice as well as a registry to assist members in locating personal assistants who want to work directly for plan members. Approximately 20 percent of ICS members (i.e., 200 of 1,000 members) direct their personal assistance services at any point in time. Workers are exempt from the New York State Nurse Practice Act and are able to perform nursing tasks such as medication administration, catheterization, and tracheotomy suctioning.

Unlike traditional managed care providers, ICS maintains an open network. If members have providers from whom they want to obtain disability-related services, but who are not network members, ICS is often willing to add those providers to its network. Except for its relationship with Cooperative Home Care Associates, ICS rarely provides services directly or through close affiliates. However, ICS will develop new services if no good providers are available. One such example is its member-responsive wheelchair service and wheelchair repair service.⁵⁰

Some of the specialized support services that ICS provides highlight the resources that a managed care plan (perhaps only a managed care plan, which has flexibility to cover services not normally available in fee-for-service Medicaid) can mobilize to empower participants and promote their involvement in peer networking and support, day-to-day plan operations, and policy-making. For example, ICS provides a “clubhouse” for plan members to attend classes and support groups, and to engage in many other social activities. It has also developed alternative activities to substitute for traditional adult day care, including seminars on health issues and disability culture, support groups for women, Weight Watchers groups, classes in English as a Second Language, and classes to obtain a General Equivalency Degree (in lieu of a regular high school diploma), as well as social events.

These activities often address health issues and social needs simultaneously; even when they have little or no health focus and are either educational or almost purely social, they promote mental health among ICS members, particularly those at risk for depression and substance abuse. They have enabled members to form mutually supportive relationships, learn new or improve existing skills, and gain critical health-related information. Several participants have significantly reduced their weight. ICS also employs some plan members who participate in developing the plan’s coverage policies.

Resources

Publications

Hughes, S.L., & Sabatino, C.P. (2004). *Addressing Liability Issues in Consumer-Directed Personal Assistance Services: The National Cash and Counseling Demonstration and Selected Other Models.* Washington, DC: Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation.

This report addresses the liability issues that may arise in government-sponsored, consumer-directed personal assistance programs (CDPAS). In analyzing these issues, the report focuses on the programs implemented in Arkansas, Florida, and New Jersey as part of the Cash & Counseling Demonstration, but also briefly describes an analysis of potential liability for two well-established CDPAS programs, California's In-Home Supportive Services Program and New York's Consumer-Directed Personal Assistance Program.

Available at: <http://aspe.hhs.gov/daltcp/reports/cdliab.htm>

A shorter article based on this report is available at: <http://www.cashandcounseling.org/resources/20060303-104025>

Mahoney, K.J., Meiners, M.R., Shoop, D., and Squillace, M.R. (2003). *Cash and Counseling and managed long-term care? Case Management Journals, 4(1), Spring: 18-22.*

This article presents the results of a survey on the interest of managed care organizations in developing a Cash & Counseling option for delivering long-term personal assistance services.

Available at: <http://www.cashandcounseling.org/resources/20060126-112344>

Reinhard, S. C., & Farnham, J. (2007). *Nurse Delegation and Consumer Direction in Home/Community Settings.* Presentation to the North Dakota Board of Nursing in Bismarck, ND: May 17, 2007.

This is one of several presentations that staff from Rutgers Center for State Health Policy make when invited to meet with a State Board of Nursing to discuss nurse delegation and self-direction. Typically, the invitation for such a meeting and presentation is initiated by state program administrators. Available at: <http://www.cshp.rutgers.edu/Downloads/7360.pdf>

Reinhard, S. C., & Farnham, J. (2006). *Invitational Forum: Advancing Consumer Choice Through Better Understanding Of Nurse Delegation.* New Brunswick, NJ: Rutgers Center for State Health Policy & National Academy for State Health Policy: Community Living Exchange.

This summary report (with background material) is an example of one of several nurse delegation summits that staff from Rutgers Center for State Health Policy

have convened to bring together nursing leadership from around the country to discuss nurse delegation in relation to self-directed services.

Available at: <http://www.cshp.rutgers.edu/Downloads/6700.pdf>

Appendix available at: <http://www.cshp.rutgers.edu/Downloads/6710.pdf>

Reinhard, S.C. & Young, H. (2006). *Guiding Principles for the Nurse-Consumer Relationship: Improved Collaboration and Support of Consumers' Community Living*. New Brunswick, NJ: Rutgers Center for State Health Policy.

In April 2004, Rutgers Center for State Health Policy convened national and state leaders in nursing practice and regulation to develop consensus principles to guide the profession's collaboration with people who want to live in their homes and communities. This discussion paper summarizes the work of multiple participants over the course of two years. The 2004 draft principles were revised and endorsed by the American Academy of Nursing's Expert Panel on Aging in November 2005. They are offered as a foundation for further dialogue within and across states.

Available at: <http://www.cshp.rutgers.edu/Downloads/6590.pdf>

Reinhard, S.C. & Quinn, W.V. (2004). *Consumer-Directed Care and States' Nurse Practice Policies*. New Brunswick, NJ: Rutgers Center for State Health Policy & National Academy for State Health Policy: Community Living Exchange.

State policy with respect to nurse delegation varies considerably. A review of state nurse practice acts and regulations was first conducted in 2001 and, as of 2004, few states had, as yet, made substantial progress in developing nurse practice policies that specifically address self-direction, although most states do have more flexibility for nurse delegation than nurses and consumers realize. This issue brief summarizes a follow-up study conducted with the executive staff of state boards of nursing.

Available at: <http://www.cshp.rutgers.edu/Downloads/6870.pdf>

Web-Accessible Resources

National Council of State Boards of Nursing

Web address: www.ncsbn.org

Historically, the National Council of State Boards of Nursing has supported the concept of nurse delegation. State officials who want to enable self-direction for individuals with health care needs by modifying Nurse Practice Acts, can find information about nurse delegation at this website. Use the search term "nurse delegation." The site also includes reports on a wide range of nursing practice issues, some of which are relevant to the delivery of home and community services, such as information on State Nurse Aide registries.

Citations, Additional Information, and Web Addresses

- 1 Pamela Doty is the lead author of this chapter. Janet O’Keeffe is the co-author.
- 2 For example, see Fried, T.R., Bradley, E.H., et al. (2001) Functional disability and health care expenditures for older persons. *Archives of Internal Medicine*, 161(21), 2602–2607. A longitudinal cohort study of a representative sample of community dwelling persons aged 72 or older linked clinical data with data on two years of expenditures for Medicare-reimbursed hospital, outpatient, and home care services and Medicaid-reimbursed nursing home services. The 19.6 percent of older persons who had stable functional dependence or who declined to dependence accounted for almost half (46.3 percent) of total expenditures.
- 3 Among “aged/disabled” participants in the original Cash & Counseling Demonstration and Evaluation, over 80 percent were dually eligible for Medicare and Medicaid, and the average share of their combined Medicare/Medicaid expenditures that went toward medical care greatly exceeded the costs associated with their use of personal care services, home and community-based services, or other long-term services and supports.
- 4 In Florida and Arkansas, 70 and 76 percent, respectively, of directly hired workers provided assistance with medications, as compared to 26 and 20 percent of agency workers. In New Jersey, the percentage of agency workers who said they helped with medications was higher (54 percent) but still significantly less than the percentage of directly hired workers who said they did (81 percent). Dale, S., Brown, R. Phillips, B., & Carlson, B.L. (2005). *Experiences of Workers Hired Under Cash and Counseling in Arkansas, Florida, and New Jersey*. Available at <http://aspe.hhs.gov/daltcp/reports/workereexp.htm>

In the Florida CCDE, parents of minor children with MR/DD in the treatment group reported fewer missed doses of medication than parents of children in the control group and the difference was statistically significant. Among other related findings (not all cited here), a statistically significant increase in access to medication assistance for minor children with MR/DD was found among the subgroup of treatment/control group participants who, though receiving other traditional waiver services, had not been receiving paid aide care at baseline. Foster, L., Dale, S., Brown, R., Phillips, B., Schore, J., & Carlson, B.L. (2004). *Do Consumer-Directed Medicaid Supportive Services Work for Children with Developmental Disabilities*. Available at <http://aspe.hhs.gov/daltcp/reports/ddkidsMss.htm>

In all three states, significantly higher percentages of participant/family-directed workers reported providing wound care (for pressure sores). Almost a quarter of such workers in Arkansas and New Jersey said they provided assistance with pressure sores, whereas only 9 to 10 percent of agency

workers said they did so. Participant-directed workers also were significantly more likely than agency workers to report providing help with physical therapy exercises (Arkansas and Florida) and with ventilators, feeding tubes, and special care of the feet (Arkansas). Dale, S., Brown, R., Phillips, B., & Carlson, B. L. (2005). Op. cit.

- 5 This finding was at baseline, prior to random assignment to treatment/control groups. Ibid.
- 6 Carlson, B.L., Dale, S., Foster, L., Brown, R., Phillips, B., & Schore, J. (2005). *Effects of Consumer Direction on Adults' Personal Care and Well-Being in Arkansas, New Jersey and Florida*. Available at <http://aspe.hhs.gov/daltcp/reports/adultpcw.htm>
- 7 Kitchen equipment and modifications can make it easier for individuals to follow special diets, eat healthier meals, lose weight, and manage medical conditions such as diabetes. Although not designed specifically for use by people with disabilities, some kitchen equipment may not be affordable to Medicaid beneficiaries, especially those eligible for SSI, (e.g., microwave ovens and grills). Meiners, M., Loughlin, D., Sadler, D., & Mahoney, K. *Clarifying the Definition of Personal Care*. Available at <http://www.cashandcounseling.org/resources/20060126-102403>
- 8 Quote from Jackie Golden, mother of a son with Angelman's Syndrome, enrolled in Maryland's self-determination program, funded under a Medicaid Independence Plus §1915(c) waiver. Jackie Golden spoke at a national conference on self-direction in 2001; see <http://aspe.hhs.gov/daltcp/reports/01cfsum.htm>
- 9 P., Simon-Rusinowitz, L, Loughlin, D., Eckert, J. K., & Mahoney, K.J. (2007, February). Case histories of six consumers and their families in Cash and Counseling. *Health Services Research*, 42(1), 533–549.
- 10 In the CCDE, transportation was the most commonly reported unmet need among demonstration participants at baseline (prior to random assignment to treatment/control groups) and the reductions in unmet need for transportation were statistically significant for treatment group members compared to controls, especially in Arkansas. Carlson, B.L., Dale, S., Foster, L., Brown, R., Phillips, B. & Schore, J. (2005). Op. cit.
- 11 Ibid.
- 12 Ibid. In the CCDE, children “not in the program” refers only to children in the control group.
- 13 Lee Zacharias. (1997). Unpublished findings of focus group in Tampa, Florida with parents of children with MR/DD prior to CCDE implementation.

- 14 Oregon's statute explicitly distinguishes between teaching and delegation. The former, unlike the later, does not involve ongoing, periodic supervision.
- 15 The Colorado legislature granted the exemption when it authorized the State to seek a §1115 waiver for the program. Dulio, A. & Perry, M., Claypool, H., O'Malley, M. (2008). *Consumer Direction of Personal Assistance Services Programs in Medicaid*. (Kaiser Commission on Medicaid and the Uninsured). Washington, DC: Kaiser Family Foundation.
- 16 Reinhard, S. C., & Farnham, J. (2007). *Nurse Delegation and Consumer Direction in Home/Community Settings*. Presentation to North Dakota Board of Nursing in Bismarck, ND: May 17, 2007. Available at: <http://www.cshp.rutgers.edu/Downloads/7360.pdf>; Reinhard, S. C., & Farnham, J. (2006). *Invitational Forum: Advancing Consumer Choice Through Better Understanding Of Nurse Delegation*. New Brunswick, NJ: Rutgers Center for State Health Policy & National Academy for State Health Policy: Community Living Exchange. Available at: <http://www.cshp.rutgers.edu/Downloads/6700.pdf> Appendix: <http://www.cshp.rutgers.edu/Downloads/6710.pdf>
- 17 Physicians can also train family members to perform nursing tasks, but generally, it is nurses who train family members in home settings. Many younger adults with disabilities report having been trained to perform paramedical tasks and instructed also in how to train others to perform these tasks while in rehabilitation hospitals. See ADAPT website: <http://www.adapt.org/>
- 18 Reinhard, S.C. & Young, H. (2006). *Washington's Nurse Practice Policies for Home and Community Living*. New Brunswick, NJ: Rutgers Center for State Health Policy & National Academy for State Health Policy: Community Living Exchange. Available at: <http://www.cshp.rutgers.edu/downloads/6480.pdf>. Reinhard, S.C. & Quinn, W.V. (2004). *Oregon's Nurse Practice Policies for Home and Community Living*. New Brunswick, NJ: Rutgers Center for State Health Policy & National Academy for State Health Policy: Community Living Exchange. Available at: <http://www.cshp.rutgers.edu/Downloads/6870.pdf>
- 19 Sikma, S.K. and Young, H.M. (2003). Nurse delegation in Washington state: a case study of concurrent policy implementation and evaluation. *Policy, Politics, and Nursing Practice*, 4 (1): 53–61. Young, H.M. and Sikma, S.K. (2003). Self-directed care: an evaluation. *Policy, Politics, and Nursing Practice*, 4 (3): 185–195. Young, H.M., Sikma S.K. (2002). *Evaluation of the Implementation of Self-Directed Care in Washington State: Final Report*. Seattle, WA: University of Washington, School of Nursing. Available at: <http://www.dshs.wa.gov/pdf/EA/GovRel/Leg1102/SDC.pdf>

Young H.M., Sikma S.K., Eyres S.J., et al. (1998). *Nurse Delegation Study Final Report*. Seattle, WA: University of Washington. Available at: <http://www.doh.wa.gov/hsqa/uwstudy.doc>

- 20 Susan Reinhard, R.N., Ph.D., Director of AARP's Public Policy Institute in Washington, D.C., has organized numerous state nurse delegation summits both national and state specific since the late 1990s. These meetings have brought together nurses on state Boards of Nursing, staff of the Chicago-based National Association of State Boards of Nursing, university-based nurse researchers and educators, state Medicaid disability and aging program officials, and prominent disability activists, such as Bob Kafka of ADAPT, who was highly influential in bringing about NPA reform in Texas, his home state. Two of the states in the CCDE—New Jersey and Arkansas—obtained regulatory flexibility from their Boards of Nursing as a result of nurse delegation summit meetings.
- 21 These concerns can pose barriers to developing programs and to enrollment, if, for example, health and social services professionals discourage eligible individuals from enrolling. In 2000, Arkansas held a series of focus groups with social workers, nurses, pharmacists, and physicians to determine if they would be willing to refer Medicaid beneficiaries to IndependentChoices—the new Cash & Counseling program participating in the CCDE.

Although many comments were positive, some participants (especially nurses) expressed concerns about the competence of participant-directed aides and the potential for abuse and participants' reluctance to report it. The inclusion of older persons in self-direction programs in particular raised these concerns. Interestingly, physicians and pharmacists were more open than nurses to the idea of referring patients to the program and distributing brochures. However, they wanted to have all of their questions and concerns addressed by program staff before making referrals.

- 22 Non-participants refers only to individuals in the control group.
- 23 Tilly, J. (2007). *Consumer-directed Home and Community Services for Adults with Dementia*. Washington, DC: Alzheimer's Association. Available at http://www.alz.org/national/documents/Consumer_Direction_issue_brief_2007.pdf
- Wiener, J. & Khatutsky, G. (2007). Are consumer-directed home care beneficiaries satisfied? Evidence from Washington State. *The Gerontologist*, 47: 763–774.
- Kunkel, S. R. & Nelson, I.M. (2005). *Profiles of choices consumers*. Scripps Gerontology Center. Miami University of Ohio. This paper is available at: http://www.scripps.muohio.edu/research/publications/documents/Final_Choices_Report.pdf

Shen, C., Smyer, M., Mahoney, K.J, Loughlin, D.M., Simon-Rusinowitz, L.S., & Mahoney, E.K. (2008). Does mental illness affect consumer direction of community-based care? Lessons from the Arkansas Cash and Counseling Program. *The Gerontologist*, 48: 93–104.

- 24 Many of the California In-Home Supportive Services county public authorities operate worker registries as do some Centers for Independent Living. For a list of and links to direct care worker registries servicing 22 states, see <http://dswresourcecenter.org>.
- 25 See Kentucky’s Consumer-Direction Option Video at <http://www.cashandcounseling.org/resources/20070622-141705>
- 26 Available at: <http://www.csus.edu/isr/reports.stm>. Select: Educational Materials for IHHS Consumers and Providers. Prepared for the California Department of Social Services (September 2006)
- 27 Colorado’s program made an excellent “laboratory” for exploring risk management issues and strategies because it had only a few hundred participants. As a result, participants who attended focus groups to discuss risk management strategies represented a more sizable percentage of all participants than is usually the case when focus group methods are employed to obtain open-ended participant feedback. The State also interviewed key stakeholders to obtain their input on the same topics. A report that weighs the pros and cons of alternative approaches to risk management is available at <http://www.colorado.gov/cs/Satellite/HCPF/HCPF/1210324172195>
- 28 One CDAS participant described an approach that was prevalent among CDAS participants: “I have several aides who work for me, and I have different people who are available at different times of the day. I have two people who are almost always available early in the morning. Those are the times when we have the shortest time to be able to find somebody. But I’ve also had times when my chair has broken down, so I’ve just gone through my list of aides and called until I’ve found somebody to come and take me to the repair shop, or take me to the ER, or whatever is necessary. It’s just a matter of having enough staff. I don’t just have one or two people working for me. I actually have about 14 people on my list. I don’t have a hard time finding someone to cover at the last minute.”

Another CDAS participant talked about her strategy for ensuring coverage if her morning attendant must cancel. “I’ve set up a system where she has a backup person if she’s sick. It’s her responsibility to call the backup person, to make sure I can get out of bed.” This same participant emphasized the importance of hiring and retaining reliable attendants—“I pay everyone pretty decently and treat them well”—and firing unreliable attendants—“If somebody does a no-call-no-show, they don’t ever come back again.”

In a true emergency, when no other help is available, consumers reported relying on “911” police and fire/rescue services. Savvy consumers planned ahead for this contingency. One CDAS participant said that when he first moved into his neighborhood, he wheeled over to the local fire station and introduced himself. “I told them I might call if I needed help,” he said. “They encouraged me to call if I needed to.” He has done so, about half a dozen times, without a problem.

- 29 Most acknowledged having experienced such incidents, though none reported having suffered adverse health consequences. The reported incidence of theft and disrespectful behaviors (mockery, verbal abuse) was much greater than for physical abuse or neglect that could cause physical harm. Thus, harm was primarily psychological; program participants felt anxiety and fear.
- 30 Focus group members also said that the incidents they had experienced rarely involved criminal behaviors. Focus group members recommended that the state establish some kind of registry where consumers could report abusive, neglectful, poor quality attendants.
- 31 A formal abuse reporting system and registry (such as those that already exist for nursing home abuse or elder abuse in general) typically require authorities to investigate and make a positive “finding” before someone can be labeled an abuser, which may require a standard of proof that cannot be met.
- 32 Recounted by an Iowa state official at the Cash & Counseling Annual Meeting in Albuquerque New Mexico (October 4, 2007).
- 33 In most of the small number of cases reported, the defendants were either home health/home care agency providers or individual aides, hired and supervised on a private pay basis, typically by the families of disabled adults or children. Hughes, S.L., & Sabatino, C.P. (2005). Addressing liability issues in consumer-directed personal assistance services: The National Cash and Counseling Demonstration. *Stetson Law Review*, 35(1), 251–382.

This article is based on the report prepared for the U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, Office of Disability, Aging, and Long-Term Care Policy and for Boston College. The report is available at <http://aspe.hhs.gov/daltcp/reports/cdliab.htm>

Hughes and Sabatino note that “reported” cases are those in which a judge, usually of an appellate court, has written an opinion with factual findings and legal holdings, and the opinion has been published in an official or unofficial law reporter system or has otherwise been made generally available (most often by inclusion in one of the two main commercial legal data bases, Westlaw and LexisNexis).

- 34 However, suing a family member clearly has additional consequences with respect to family relationships that are not present when a worker is unrelated to the plaintiff. Moreover, suing a family member could cause economic harm to the plaintiff (especially if the plaintiff lives in the family member’s home) even if the plaintiff is awarded a judgment. However, the broader literature on tort claims, including medical malpractice suits, strongly suggests that the nature of the relationship between the service provider and service recipient—both before and immediately following the behavior that is perceived by the service recipient (or service recipient’s family) to have caused harm—greatly affects whether or not a suit will be filed and whether or not the suit will be dropped or settled prior to going to court.

That is, a longstanding relationship, previously perceived to be a good one is less likely to result in litigation; similarly, if service providers do not prepare to defend themselves legally by cutting off contact, withholding information, and otherwise behaving very defensively and, instead, express concern and “sorrow” in regard to adverse outcomes (without, however, accepting responsibility for having negligently caused those outcomes), the likelihood of litigation decreases.

- 35 Reeder had also sued the state on the theory that the LPN, because she was paid by Medicaid, was a “state employee.” However the legal ruling was that she was an “independent contractor.” Note that as a licensed (i.e. professionally trained) nurse, this individual could be considered an independent contractor rather than the participant’s domestic employee, even though she was providing more aide care than skilled nursing.
- 36 Why did Caulfield’s case manager hire an independent provider rather than refer him to an agency which would presumably have provided more supervision than the case manager did? The most likely explanation seems that Caulfield, who was paralyzed and had no family, required paid home care almost around-the-clock and that would have cost more than nursing home care. This is the dilemma: for some high-need individuals, only self-directed services can be a cost-effective alternative to nursing home care, but the participant must either be capable of self-direction or have a representative who is available and willing to assume the responsibility.
- 37 Reeder’s lawsuit rested on arguments that claimed he was not really “self-directing” his care because the LPN was a state employee and the State was responsible for ensuring that he received high quality care that should have prevented bedsores from developing.
- 38 Information about bedsores provided by the Mayo Clinic notes: “Bedsores can develop quickly, progress rapidly, and are often difficult to heal. Yet health experts say many of these wounds don’t have to occur. Key preventive measures can maintain the skin’s integrity and encourage healing of bedsores,

(yet) ... Even the most conscientious care can't always prevent serious or life-threatening infections ...” The Mayo Clinic website also points out that individuals with paralysis are at high risk of developing bedsores and that the actor and disability advocate Christopher Reeve died from complications of a bedsore. See information at: <http://www.mayoclinic.com/health/bedsores/DS00570>

- 39 A Microboard—which comes out of the person-centered planning philosophy and is therefore created for the sole support of one individual—is formed when a small group (micro) of committed family and friends join together with a person with challenges to create a non-profit society (board). Together this small group of people address the person’s planning and support needs in an empowering and customized fashion.
- 40 Hughes, S.L., & Sabatino, C.P. (2005). Op.cit.
- 41 Helen Roth, personal communication to Pamela Doty, September 2, 2008.
- 42 The §1915(c) HCBS waiver template instructions are available at https://www.hcbswaivers.net/CMS/help/version_35_1915c_Waiver_Application_and_Accompanying_Materials.zip
- 43 A few years after the original CCDE pilot programs began, MCO surveys were conducted to explore how they viewed the compatibility of self-direction and managed care. In one survey of 64 MCOs, 69 percent reported that self-direction was under discussion within the organization and about 45 percent indicated that they were open to the idea at least for some plan members. Organizational factors associated with greater openness to self-direction include: larger size, covering populations broader than just elderly persons, and not being PACE programs. Mahoney, K.J., Meiners, M.R., Shoop, D., and Squillace, M.R. (2003). Cash and Counseling and managed long-term care? *Case Management Journals*, 4(1), Spring: 18–22. Available at: <http://www.cashandcounseling.org/resources/20060126-112344>

In a more in-depth profile of 38 MCOs, 12 reported allowing plan members to employ their own workers, including nine that permitted employment of friends and relatives. Most of the MCOs that did not allow plan members to exercise employer authority or even to have much input into the professional care plan perceived little or no interest among plan members in self-direction. Overall, the 38 managed care organizations were evenly split as to whether they perceived self-direction to be a threat to plan profitability. Few of the plans that allowed members to employ workers perceived self-direction as threatening their profitability, but the plans that reported giving members a “major say” in care planning but not employer authority (87 percent), were quite worried about self-direction as a potential threat to profitability. Meiners, M.R., Mahoney, K.J., Shoop, D.M., and Squillace, M.R. (2002). Consumer

direction in managed long-term care: An exploratory survey of practices and perceptions. *Gerontologist*, 42 (1): 32–8.

- 44 Wisconsin offered self-direction options in its HCBS waivers prior to instituting its managed care program—Family Care—which also allows participants to direct their services. In contrast, Texas had no tradition of self-direction, but Americaid—one of the managed care plans under Texas Star Plus—offered participant-directed aide services because one of its executives believed that the option could be more cost-efficient and increase participant satisfaction. Texas officials then decided that Americaid should not have a competitive advantage by virtue of offering self-directed aide services and made this a requirement for all Texas Star Plus plans. The employer authority has since become available in the fee-for service sector in Texas as well. Beginning in 2001, the State gradually added self-direction options in its State Plan personal care services program and in all of its HCBS waiver programs.
- 45 The Medicare Modernization Act of 2003 created a new type of Medicare Advantage coordinated care plan focused on individuals with special needs, who are identified as (1) institutionalized, (2) dually eligible, and/or (3) individuals with severe or disabling chronic conditions. Milligan & Woodcock (Op. cit.) outline three different approaches and their pros and cons for coordinating acute and long-term care for dual eligibles by linking state Medicaid programs with Medicare Advantage Special Needs Plans (SNPs): (1) a voluntary integrated program, (2) a mandatory Medicaid managed care program with potential side agreements with Medicare Advantage SNPs, and (3) a model involving an administrative services organization (ASO) arrangement. In an ASO arrangement, Medicaid pays a case management fee to Medicare Advantage SNPs or to another entity to coordinate the delivery of Medicaid services with the Medicare Advantage SNPs operating in the state (this third model is a “non-risk” contract for performance of Medicaid administrative functions).

Some observers hoped that this legislation would result in proliferation of integrated acute/long-term care managed care plans to serve the nation’s approximately 7 million dual eligibles who, on average, are in poorer health and more likely to have chronic diseases and disabilities than other Medicare beneficiaries. Provost Peters, C. (November, 2005). *Medicare Advantage SNPs: A New Opportunity for Integrated Care?* National Health Policy Forum, Issue Brief, No. 808. Washington DC: George Washington University.

As of September 2007, there were a total of 478 SNPs, including 320 for dual eligibles. Of 1,021,800 enrollees, 722,286 were dual eligibles. Milligan Jr., C.J. & Woodcock, C.H. (February 2008). *Medicare Advantage Special Needs Plans for Dual Eligibles: A Primer*. Commonwealth Fund Issue Brief, Commonwealth Fund Publication 1108, Volume 31. Available online at

http://www.commonwealthfund.org/publications/publications_show.htm?doc_id=670364

Unless reauthorized by Congress, however, the SNP program will sunset December 31, 2010. <http://www.cms.hhs.gov/SpecialNeedsPlans/>. Thus, the future of SNPs remains uncertain. In addition, even though SNPs were authorized, in part, to encourage coordination of Medicare and Medicaid benefits for dual eligibles, only seven states currently have operational programs to coordinate Medicare and Medicaid benefits and of these seven states, only three have dual eligible enrollment in Medicaid managed care programs of at least 10,000 enrollees (Minnesota: 35,000; Arizona: 24,000; and Texas: 20,000). Milligan Jr., C.J. & Woodcock, C.H., Op. cit.

- 46 Federal Medicaid officials have been reluctant to approve (b)(c) combination waivers unless states provide assurances that one plan would not be given a monopoly in perpetuity with respect to Medicaid managed care enrollment. This emerged as an issue in Wisconsin and Michigan with respect to county-based managed care plans for HCBS waiver services.
- 47 For more information about PACE, see <http://www.medicare.gov/Nursing/Alternatives/Pace.asp> and the National Pace Association website <http://www.npaonline.org/>.
- 48 This is expected because when §1915(c) waiver coverage was required to be integrated into managed care in Minnesota, MCOs often hired or contracted with the same waiver care managers who had worked in the fee-for-service system. Although this enabled MCOs to staff up quickly to assume responsibility for the waiver program, the drawback is that it may also take some time for care managers who are used to working in a fee-for-service environment to become aware of the opportunities that managed care has to offer for synergy between self-directed HCBS and improved access to health care. (For example, many managed care plans have been quicker than physicians in private practice to see the value and cost-effectiveness of delegating some medical tasks to nurse practitioners and other physician extenders. They may similarly be more open to and better able to implement nurse delegation in combination with self-direction of unlicensed assistive personnel than traditional HCBS providers.)
- 49 ICS serves only adults with disabilities who became disabled in adulthood prior to age 65. ICS medical care managers coordinate services with fee-for-service medical providers (i.e. physicians and hospitals). ICS currently manages only long-term services and supports, but its goal is to become a “disability competent integrated system of care” that can manage acute medical care as well as long-term services and supports for its members. Surpin, R. (2007). Independence care system: A disability care coordination organization in New York City. *Journal of Ambulatory Care Management*

30(1):52–63. Information about ICS is available at http://www.icsny.org/about_us_mission.html.

50 http://www.icsny.org/building_a_community_wheelchair.html