

**ARIZONA HEALTH FUTURES**  
*Policy Primers: a nonpartisan guide to a better understanding of key terms and issues in the Arizona health policy landscape.*

## You Call the Tune: The Promise and Challenge of Consumer-Directed Care

**ITEM:** Rebecca G lives in a modest central Phoenix home with her retired husband. These days, she gets a little forgetful and, because of her arthritis and heart trouble, needs assistance with bathing and dressing. The couple could also use some help with housekeeping and meal preparation. Their case manager thinks they should move into a long-term care facility. They think if they could just hire Mrs. Garcia's niece and a nice neighbor down the street to help out here and there, they would be able to stay in their home. If they were part of a consumer-directed care program, they could.

**ITEM:** Eleanor J, 86, soon will be discharged from the hospital but continues to need assistance with bathing and dressing, as well as episodic nursing care. Since her husband has been gone, she rarely gets out of the house and knows that if she goes home, she won't be able to get to her bridge game at the senior center. Eleanor has heard about consumer-directed care, but doesn't know whom she could get to help out, or how she would find, train and manage a caregiver on her own. The security and social opportunities offered by the assisted living center that her case manager recommends sound like a better fit for her.

**ITEM:** Steve M has been in and out of behavioral health institutions for the past 20 years. Choosing a consumer-directed care program was a big step in his recovery plan. His case manager suggested living in a group home, but he likes the idea of keeping his own apartment and using a trusted friend to help him remember to take his medications and attend to daily living tasks, as well as a fiscal agent to help him manage his monthly stipend. His friend and the case manager suggest ways that he may want to use his money, but Steve knows that he has the authority and the responsibility to make his own decisions.



## You Call the Tune

In the brave new world of health care, you, the American consumer, will conduct your own orchestra. You will exercise choice and control over personal services, and how those services are delivered. Information on options will be transparent and fully accessible, choices will be abundant and appropriate to your level of need and social and economic conditions. The money will follow *you*, and not the providers of services and their vast bureaucratic infrastructure.

You,  
not someone else,  
will call the tune.

And you,  
not someone else,  
will ultimately be responsible  
for how the tune plays out.

## A Revolution, or a Fad?

It sounds so *American*: the power and dignity of the individual, freedom of choice in a market-driven economy based on competition, the emphasis on self-determination and personal responsibility. Judging from the pronouncements of those who champion greater consumer involvement in the choice and execution of personal health care services, the country is on the verge of a major revolution in the way our health care system is designed and operated.

But what is a revolution for some is just the latest fad for others – or what is worse, a not-so-subtle movement to decrease public funding, shift costs to those individuals least able to pay for them, and increase the growing gulf between the haves and have nots, all in the name of so-called self-determination, personal choice and responsibility.

What about persons with physical and mental disabilities, those without families or strong social support systems, those who lack the capacity and resources to put real flesh on the bones of self-determination? Where do they fit in this glorious world of consumer-driven care?

That is the subject of this *Arizona Health Futures Policy Primer*. We focus specifically on what is referred to as *consumer-directed care (CDC)*, with a particular emphasis on its growing application among persons with physical and mental disabilities. We provide a definition, distinguish it from other aspects of consumer-focused care, trace its history, discuss its status in Arizona, and provide an overview of the benefits and challenges it poses based on a review of the critical literature, emerging practice, and interviews with Arizona stakeholders. We conclude with suggestions for future health policy and practice.

# An Introduction to *Consumer-Directed Care*

In 1996, the National Institute of Consumer-Directed Care Services developed the following definition of CDC:<sup>1</sup>

*Consumer direction is a philosophy and orientation to the delivery of home- and community-based services whereby informed consumers make choices about the services they receive. They can assess their own needs, determine how and by whom these needs should be met, and monitor the quality of services received. Consumer direction ranges from the individual independently making all decisions and managing services directly, to an individual using a representative to manage needed services. The unifying force in the range of consumer-directed and consumer choice models is that individuals have the primary authority to make choices that work best for them, regardless of the nature or extent of their disability or the source of payment for services.*

## Benefits

Regardless of age or type of disability, people want to lead a satisfying and productive life in a setting of their choosing. Given a choice, who wouldn't?

The genesis of CDC was a response to the institutional bias in Medicaid, and an effort to provide long-term support and services to individuals in home and other community settings. The concept of consumer direction has since been broadened to encompass not just a choice between institutional or home- and community-based services (HCBS), but to give consumers a choice between agency-based services or more direct control over who provides their care, when they receive it and how it is delivered.

## What Consumer-Directed Care is *Not*

CDC should not be confused with the higher-profile expansion of Consumer-Defined/High-Deductible Health Plans (CDHP/HDHP), although they share similarities. Both place the consumer at the locus of decision making on issues affecting access, quality and cost. Both require transparent, valid and relevant information upon which to base those decisions. And both assume that if the consumer has a personal stake in making those decisions based on the relevant information, they will be cost-conscious shoppers and smarter users of products and services.

But there is an important difference. While the primary goal of CDHPs is to control costs by making consumers more price conscious, such plans remain based on the traditional fee-for-service medical model of licensed, credentialed and regulated providers – exactly what CDC programs call into question. CDC programs may in fact realize cost savings, but their primary goal is to give choice and control over *what, when, how* and *who* provides services and support. In a CDC program, a client may choose to hire her niece to provide in-home care and set the fee. She wouldn't have that flexibility in today's standard CDHP/HDHP.

When compared to traditional models of agency-based care, consumer direction seeks to provide more flexibility, including options that allow for the direct purchase of equipment, transportation, nutrition and personal care services. Within a CDC model, the individual, or a designated representative, assumes authority for hiring, training, supervising and firing the attendant of their choosing – often a family member or friend.

Under the traditional model, client needs are assessed by a licensed professional to efficiently allocate service hours among specific categories, and funding is based on historical provider expenses for those services. Critics of this approach call it “the achievement of consistency over rationality” and challenge its underlying assumptions – “that professionals know better than the consumer what his needs are, that the present system represents the most efficient and equitable allocation of resources, that provider charges and costs are rational, and that individual characteristics somehow predict costs.”<sup>2</sup>

Proponents of self-direction point to research indicating increased consumer satisfaction with the quality of care, lower cost and greater flexibility in the types of providers and support services, and the scheduling of those services. They also argue that self-direction promotes autonomy and independence, which are the cornerstones of recovery for persons with cognitive disabilities.

## Challenges

The benefits of CDC are not without significant challenges, as proponents of more traditional agency-based services are quick to point out. Greater consumer control, authority and choice of providers and services do not absolve responsibility for quality of care, client safety, professional judgment and authority, and accountability for the expenditure of public funds.

As taxpayers, are we expected to pick up the tab for consumers who, despite their best intentions, make bad choices? When the care proves to be inferior and the allocated money runs out, what then? How about people with significant cognitive disabilities? Just who determines ‘competence’ and ‘self-sufficiency,’ and where do we draw the line for authority over how public funds are spent in individual cases?

And what about the potential to “game” the system? Surely we aren’t so naïve as to believe all consumers and family members who may get a check to provide home-based care are scrupulously honest and will keep an accurate account of hours worked and services provided. It stretches credulity to believe that such care is preferable and would consistently produce better results than care overseen by licensed professionals through credentialed programs and services based on evidence-based practice.

## What Do Consumers Say?

Despite what some see as the advantages of CDC, it’s not for everyone. Studies of consumer interest in self-directed services find a high degree of variability, ranging from 78% in a national study among individuals with disabilities over the age of 50, and 69% among family caregivers of individuals with cognitive disabilities in California, to just 30% in a Boston-based study of home care clients over the age of 64.<sup>3</sup> While individual studies have indicated that younger persons, those with existing informal care networks and those with less severe disabilities prefer CDC models, the research on consumer preferences for CDC remains inconclusive.

Based on studies of consumer preference, local communities considering or implementing a CDC model should assess the degree to which a host of factors – age, gender, race/ethnicity, education, the nature/severity of disability, family status, availability of informal caregivers, satisfaction with agency-directed care and prior experience as an employer – impact the local marketplace.

Others point out that the preference for consumer-directed care varies by age and severity of disability, with younger and more robust individuals opting for CDC, leaving individuals with the greatest challenges (i.e., the most complex, severely disabled and elderly) in traditional agency-based programs.<sup>4</sup> If money follows the individual, and if payment is not tied to case severity, the economic viability of traditional agency-based programs may be diminished, and along with it the care for our most vulnerable citizens.

### Proceed With Caution

Considering the pros and cons, the judgment of most people regarding CDC falls somewhere in the middle. While they generally agree that consumers should have choice, autonomy and control over the care they receive, many also raise concerns. Citing risks to the physical and financial well-being of consumers whose cognitive capacity may be limited, the need to assure accountability for public dollars and the time it will take to develop a system that includes necessary safeguards, consumers and providers alike voice a combination of caution and optimism for consumer-directed care.

## A Capsule History of Consumer-Directed Care

Consumer direction in the provision of home- and community-based long-term care and support services is part of a broader trend toward consumer-oriented care. Consumer orientation has taken hold throughout the health care delivery system, encompassing CDC delivery models as well as consumer involvement in research, program evaluation, quality improvement initiatives and broader system reform efforts.

Public programs have supported the growth in consumer orientation by providing both a source of funding for direct services and by fostering the creation of an environment that supports self-direction. A chronological review of key national legislative and judicial decisions outlines the legal and regulatory framework for home- and community-based services (HCBS) and consumer direction:<sup>5</sup>

- **REHABILITATION ACT OF 1973** Extended civil rights to persons with disabilities and established the Rehabilitation Services Administration to provide grants for vocational rehabilitation, home care assistance, supportive employment centers and independent living centers.
- **1981 – OMNIBUS BUDGET RECONCILIATION ACT** Established 1915(c) waivers that allowed states to provide HCBS as an alternative to institutional care under Medicaid. Subsequent waivers supporting consumer direction included 1915(b) waivers that changed provider choice requirements and allowed states to use cost savings to fund additional services, and Section 1115 waivers that allowed the development of demonstration projects by waiving service and eligibility requirements.
- **1990 – AMERICANS WITH DISABILITIES ACT** Extended the equal access requirement for physical facilities and replaced the Rehabilitation Act provision for “least restrictive environment” with “most integrated” services, shifting the emphasis from institutional settings to home- and community-based services and supports.

*“One of the challenges will be agency opposition. CDC may decrease their revenue from providing case management services. The clients most likely to move to the CDC program are the ‘easy’ clients, leaving the agency with those who are the hardest to serve.”*

Agency Director

“Self-sufficiency is a myth. No one is self-sufficient. It’s just a matter of trying to keep in balance – physically, socially, psychologically, spiritually – as much as possible.”

Agency Director

- **1997 – BALANCED BUDGET ACT** Included a provision for a Medicaid Buy-In that allowed states to provide health care coverage for persons with disabilities to work without loss of Medicaid benefits and to cover habilitation services in residential and day care settings. Both of these provisions are key to the concepts of self-determination and community engagement for persons with disabilities.
- **1999 – SUPREME COURT DECISION IN OLMSTEAD V. L.C AND E.W.** Required public entities to provide services for persons with disabilities in the most integrated and appropriate setting, regardless of the nature of the disability.
- **1999 – TICKET-TO-WORK AND WORK INCENTIVES IMPROVEMENT ACT** Provided benefits planning and assistance and allowed states to provide health care coverage for people with disabilities who work and might otherwise lose Medicaid/Medicare coverage, thereby facilitating integration and participation of persons with disabilities in the community.
- **2000 – NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM** Amended the Older Americans Act of 1965 to support care provided by informal family caregivers, including information and assistance to access existing resources, individual and group counseling and support, caregiver training, respite care and limited supplemental services.<sup>6</sup>
- **2001 – NEW FREEDOM INITIATIVE** Required coordination of existing initiatives and funding of new activities to receive services and support that enable persons with disabilities to remain and participate in their community, as distinct from an institutional setting. Several related programs under the New Freedom Initiative include:
  - **INDEPENDENCE PLUS** This program expedites the process for states to request 1115 and 1915 waivers that allow for more effective and efficient use of Medicaid funds for self-directed care. The waivers focus on four elements of self-direction – person-centered planning, individual budgeting, financial management systems and support brokerage.<sup>7</sup>
  - **REAL CHOICE SYSTEMS CHANGE/AGING AND DISABILITY RESOURCE CENTER GRANTS** This competitive grant program provides assistance to help states develop programs that support community-based care for persons with disabilities.<sup>8</sup> Some states have used these grants to assess infrastructure and policy changes that support consumer direction. Other states, including Arizona, are implementing coordinated systems of information, assistance and access for all persons seeking long-term care services.
- **2005 – DEFICIT REDUCTION ACT (DRA)** Further encouraged states’ efforts to overcome the historical bias toward institutional care and facilitate choices that enable transition to community-based systems through establishment of a competitive grant program under the rubric of *Money Follows the Person* as a “rebalancing” initiative within Medicaid. Targeted to elderly and disabled Medicaid recipients, this program provides funding to help states overcome Medicaid’s institutional bias and rebalance their long-term care systems. The program will provide a higher matching rate for some home- and community-based services, as well as increase the types of expenditures that will be covered.<sup>9</sup>

## Driven By Advocacy

These national legislative and judicial decisions, and the programs they have spawned, have been driven by groups that advocate for the rights of adults with physical disabilities through the independent living movement. More recently, advocacy groups representing older Americans, developmentally disabled children and adults with psychiatric disabilities have

joined the call for greater flexibility, choice and autonomy in the provision of community-based services. The populations most frequently included in nascent CDC programs have been those with the ability to self-direct. Other programs have limited the participation of those with cognitive impairments or required them to have a representative to assist with service-related decisions.<sup>10</sup>

Within this complex mélange of limitations, concerns and accommodations, consumer-directed care options continue to expand. Today, the majority of funding for home- and community-based services comes from Medicaid waiver programs that enable states to provide a broader range of services and allow beneficiaries to have somewhat higher income levels. The Older Americans Act also provides a source of funding for non-medical home- and community-based support services through the National Family Caregiving Support Program (NFCSP). In addition to federal funding, states may also fund programs that support CDC.

## The Money *Follows You*

To take advantage of the flexibility offered by federal waivers, the Centers for Medicare and Medicaid Services (CMS) has identified four basic models along a continuum of “money follows the person.”<sup>11</sup>

- **TRADITIONAL AGENCY MODEL** An agency assumes responsibility for recruiting, hiring, managing, training and dismissing employees who provide basic assistance to individuals living in a community setting. The agency determines the hours, wages and tasks that will be provided for the client based on a standardized needs assessment performed by a licensed professional, such as a case manager or registered nurse. The scope of services, allowable tasks and financial arrangements are defined in a contract between the Medicaid agency and the provider agency.
- **TRADITIONAL MODEL SUPPORTING CHOICE** The provider agency may utilize a person-centered planning process that incorporates consumer choice and control by allowing the consumer to identify and refer an attendant of their choosing to the agency. The agency may also maintain a list of potential attendants for consumers to consider, along with providing back-up coverage. The provider agency maintains its contract with the Medicaid agency and continues to receive funding directly, which it uses to pay the attendants. As the employer of record, the agency remains responsible for oversight of attendant services.
- **AGENCY WITH CHOICE** This model provides an increased level of responsibility for the consumer through his/her designation as the *managing employer*, although the agency remains the employer of record. The consumer recruits and selects the attendant and establishes wages and hours, but refers him/her to the agency for payroll functions. Attendant training may be provided by the consumer, the agency or a combination of both. The agency may provide additional services to the consumer such as assistance managing an individual budget or educating the consumer on how to hire and manage an attendant.
- **FISCAL/EMPLOYER AGENT MODELS** These provide Medicaid program participants with the highest level of flexibility and empowerment. In this arrangement the consumer, or his/her representative, is the employer of record and assumes all responsibilities of that role. In practice, most states that have adopted this model find that consumers/representatives generally delegate payroll and tax filing to a designated fiscal agent. This model significantly changes the role of the provider agency, which may offer a range of support and consultative services, including serving as the fiscal agent.

## The Consumer and the Client: What's the Difference?

In most CDC models, the individual receiving care is the 'consumer' or 'client.' What complicates this relatively straightforward identification of the consumer as-client are other models that encompass the family caregiver or the family unit itself as the client.<sup>12</sup>

Program administrators tend to think of the 'consumer' as a dyad consisting of both the individual and his or her family. The reality of many caregiving situations, particularly those that involve cognitive impairment or severe disability, is one in which the consumer and caregivers are inextricably intertwined. In this light, incorporating family caregivers into CDC programs is both effective and consistent with public policy and prevailing values that favor family support and caregiving capacity. What no one argues about is the economic value of unpaid caregiving by family and friends, which was estimated to be \$257 billion nationally in 2003. In Arizona, the estimated annual market value of informal caregiving was \$4.6 billion, representing the efforts of almost 500,000 caregivers and 523 million hours of care.<sup>13</sup>

Interestingly, consumer direction options are offered more readily in programs that identify someone other than the care recipient as the consumer. In a 2004 survey, of the 73 programs that identified the individual as the primary client, 44 (60%) reported offering a consumer-directed option. By comparison, of the 44 programs that identified the family caregiver as the client, 39 (89%) offered a consumer directed option. Of 31 programs that designated the dyad of individual with the disability and family caregiver, 22 (71%) provided a consumer-directed option.<sup>14</sup>

### A Challenge to the Principle of Self-Determination

Programs that define the family as the client may pose a fundamental challenge to individual self-determination and become a source of tension when it comes to decision making. Family and informal caregivers are key partners in consumer directed programs, but their role in actual decision-making about services and providers ranges from gathering information and coordinating care, to the actual provision of care as a paid caregiver, and finally, to acting as a representative or surrogate decision-maker. If the family/caregiver is defined as the client, and if decision-making authority is vested in someone other than the individual care recipient, a key philosophical tenet of the CDC model itself is potentially called into question – the principle of self-determination and the shift in the locus of decision making from agencies to consumers. For persons with cognitive impairments, this is a particularly challenging issue.

*In Arizona, the estimated annual market value of informal caregiving was \$4.6 billion, representing the efforts of almost 500,000 caregivers and 523 million hours of care.<sup>13</sup>*

## Support for Family Caregivers

Historically, the traditional medical model of long-term care required that frail elders sacrifice autonomy as a condition of receiving services – a trade-off that many who could have benefited from support services were not willing to make.<sup>11</sup> As Arizona’s population demographics change, including both the “coming of age” of the baby boom generation and an increase in the proportion of people under the age of 18, the dynamics of caregiving are bound to change as well.<sup>16</sup>

Today, most states offer consumer-directed options for family caregivers. A 2004 survey identified 106 options, representing 71% of programs, that offered some degree of consumer direction. Depending on the source of funding, the type of consumer direction available to family caregivers varied considerably, with programs funded through the National Family Caregiving Support Program including the most options. Overall, consumer direction programs across the states offer a range of choices:<sup>17</sup>

- 49% of programs across 43 states give the family a choice of respite providers.
- 33% of programs across 35 states provide caregivers with a menu of services from which to choose.
- 25% of programs across 29 states offer a voucher or budget for respite and supplemental services.
- 17% of programs across 20 states provide direct payments to family members to purchase goods or services.

Some things, however, never change. While traditional models of care have plan administrators and medical professionals making the decisions and providing oversight, families still provide most of the care.<sup>18</sup>

### Control and Choice Vary

A recent survey of 154 state and/or federally funded caregiver programs identified 106 programs that offer some type of consumer direction. However, the extent to which consumers exercise real control and choice varies by state and by program within states. Many programs limit consumer ‘choice’ to a choice between contracted home-care agencies, with little or no consumer input regarding the actual types of services or their delivery. Others provide consumers with full autonomy and authority for decisions, but retain control of financial transactions. Only a handful offer consumers full autonomy and authority for services and fiscal responsibility.

For example, while 73 (49%) of the programs give the consumer/family a choice of respite providers (including non-spouse family members) direct payments to consumer/family members to buy services or supplies are permitted by just 26 (17%) programs.<sup>19</sup>

### Cash and Counseling

In addition to federally-funded programs, private funders have also taken note of the self-direction movement and supported projects to foster the independence and autonomy of persons with disabilities. The largest of these is *Cash and Counseling*, a collaborative effort of a private foundation and two federal agencies. The *Cash and Counseling* program provides a monthly allowance to persons who receive personal care or HCBS through Medicaid. Participants have the option of how to spend funds allocated to them, including the purchase of adaptive/assistive equipment, home modification and personal care services. Counseling (rather than traditional case management) and fiscal assistance help consumers to manage their personal budget either directly or with the assistance of a person they designate as a representative.<sup>20</sup>

The Center for Self-Determination outlines five principles for reforming and restructuring systems of care:<sup>21</sup>

- Freedom to decide how to live one's life and develop recovery strategies and life goals based on universal human aspirations and personal ambitions.
- Authority to control the dollar resources in order to make purchases and expenditures that advance both recovery and life goals.
- Support for highly personal and unique plans of recovery that allow for purchases both within traditional services and from the wider community.
- Responsibility for using public dollars wisely, decision-making with freely chosen assistance when needed, and for becoming a contributing member of one's community.
- Confirmation of the important role that persons with disabilities (and families when appropriate) need to have in restructuring the system of supports and providing leadership.

# Factors Driving the Expansion of Consumer-Directed Care

## Self-Determination

The self-determination movement has been a motivating force behind consumer-directed care. The movement grew out of the physical and developmental disability communities, where the concepts of self-direction and independent living have paved the way for the broad philosophical approach of self-determination as well as its embodiment in CDC programs. A host of federal, state and local programs now support the expansion of self-determination and consumer direction to a growing array of persons with disabilities.

While barriers still exist for some populations, such as persons with cognitive or psychiatric disabilities,<sup>22</sup> there is growing recognition of the ability of individuals to make reasoned choices about the care they receive – that is, to *determine for themselves* the nature, implementation and intended effect of that care. Because CDC offers more independence and autonomy, improved satisfaction with the flexibility of services, greater convenience regarding service hours and tasks and fewer reported unmet needs, supporters argue that consumer direction enables persons with disabilities to craft a meaningful life, and not just “receive services.”<sup>23</sup>

The key distinction here is the shift in locus from *the system to the person*. Traditional models tend to focus on the system, and how a given individual can be provided services within it. CDC models see people in the context of their community and organize their efforts to empower the individual and provide support within a broader context. In this way, CDC takes a resilience-based approach, emphasizing individual capacity and ability, rather than deficits and needs.<sup>24</sup>

## Self-Determination and Self-Direction

The trend toward consumer-directed care is closely linked to the *self-direction* movement that began within the disability community and is quickly being adopted by persons with developmental disabilities, psychiatric disabilities and other cognitive impairments. Consumer advocacy, consumer choice and other consumer-driven efforts such as peer recovery programs are examples of this. Self-direction shifts the power for decision-making to the individual, which in turn facilitates the development of individualized recovery plans and control of the resources necessary to realize them.<sup>25</sup>

Self-determination is a broader concept, within which self-direction helps persons with disabilities “to achieve a meaningful life in their community, filled with important human connections and relationships and, among other important life issues, seek financial security and income.”<sup>26</sup> Within the self-determination paradigm, there is an expectation that persons with disabilities, cognitive impairments or other limitations will continue to contribute to the greater good of society.

## Increased Satisfaction

When given a choice between agency-based services and a consumer-directed model, both care recipients and family caregivers seem to prefer the CDC model.<sup>27</sup> Findings

from a comprehensive evaluation of the *Cash and Counseling* demonstration program indicate that relative to agency-directed services, *Cash and Counseling* participants reported greatly improved satisfaction with care without any adverse effect on participants' health or safety. In addition, participants reported decreased unmet need and increased flexibility, particularly the ability to receive assistance during 'non-business' hours.<sup>28</sup>

Families of consumers who have chosen CDC programs also report improved quality of life, less burn-out, better health status, less stress and frustration and better job performance for those who are employed outside of their caregiving role.<sup>29</sup> It should be noted that in many situations, the consumer designates a proxy, often a family member, to represent the consumer's interests. In early research studies, it was often the proxy who responded on behalf of the consumer to surveys about CDC satisfaction. Later studies addressed this potential bias by segmenting respondents into consumer and proxy groups, noting in particular when the proxy respondent was also the caregiver.

### **Choice and Control = Improved Satisfaction**

Consumers place enormous value on being able to hire family, friends or others of their own choosing, and being able to direct and supervise the tasks and care they provide. A survey conducted for AARP found that, among people over 50 with disabilities, 53% preferred to manage and pay the worker directly, 25% preferred to manage the worker and have the agency receive the money and pay the worker, and just 15% preferred agency-directed services.<sup>30</sup> Similarly, a survey conducted by the National Association of State Units on Aging (NASUA) found that 78% of state aging directors indicated that older consumers are highly satisfied with consumer-directed services.<sup>31</sup> Caregivers hired directly by the consumer are more likely to 'fit' the consumer, have longer tenure and be more likely to perform 'unauthorized' tasks and work extended/unpaid hours.<sup>32</sup>

The relationship between choice, control and satisfaction with services shouldn't be surprising. People who purchase in-home support services with private funds have always exercised choice and control. By the same token, older persons and persons without disabilities take choice and control over what they purchase, and from whom, as a matter of course. CDC advocates ask why decision-making authority should be any different for an older person, a person with a disability or a person receiving public support.

### **Workforce Shortages**

Another argument for CDC programs is the healthcare workforce shortage, which is approaching crisis proportions in the long-term care arena.<sup>33</sup> By expanding reimbursement for caregiving to informal caregivers – usually family members, friends or neighbors – CDC programs increase the pool of available workers. This is a particularly significant issue within ethnic and rural communities where cultural and geographic barriers often pose additional challenges for caregiving.<sup>34</sup>

One study that assessed Medicaid-eligible consumers' interest in a CDC model found higher levels of interest among African Americans and Hispanics when compared to Caucasians. When asked why this might be the case, minority focus group participants referred to strong family networks that emphasize caring for one another.<sup>35</sup> Conceivably, the experience gained by family and informal caregivers by virtue of caring for a friend or relative may represent the start of a career path in health care that would begin to address the traditional under-representation of ethnic minorities among healthcare professionals and paraprofessionals.

*A survey conducted for AARP found that among people over 50 with disabilities:*

**53%**

preferred to manage and pay the worker directly

**25%**

preferred to manage the worker and have the agency receive the money and pay the worker

**15%**

preferred agency-directed services.<sup>30</sup>

CDC programs also resolve the need to have multiple caregivers – each with their own regulatory and licensure restrictions – to provide a broad range of skills and services for many consumers. Under a CDC model, the consumer may be the direct employer and train and supervise the provider of care, who may provide both unskilled attendant care services as well as skilled clinical services that would otherwise be provided by a licensed professional. Skilled care provided by a family member or friend is generally exempt from professional licensure requirements, even when that care is compensated through a CDC arrangement.

### **Increasing Healthcare Costs**

As healthcare costs continue to spiral, cost-containment has emerged as one of the primary reasons for adopting CDC programs. In fact, consumer direction may be more the result of a “fortuitous alignment” of political, structural and fiscal concerns than of philosophical positions and advocacy efforts.<sup>36</sup> Economic analyses have repeatedly found that CDC programs lower long-term care costs by substituting personal care services for institutional care, negotiating rates tied to the unique service needs of an individual rather than adhering to agency fee-schedules, substituting assistive/adaptive equipment for services, and paying only for services that are actually needed and provided.<sup>37</sup> CDC proponents argue that it’s cost-effective not because it saves money, but because it obtains better value for the money.<sup>38</sup>

CDC programs may also generate savings for publicly-funded programs because they would no longer pay agency and administrative or management costs. In turn, this allows consumers to receive more hours of service, or to negotiate higher wages than those normally paid to agency attendants.<sup>39</sup> Where increased costs were found, they were generally due to improved access to services, where hiring a family member or friend alleviated agency staff shortages that precluded consumers from receiving their full allocation of service units. Even in cases where CDC program costs were found to be higher than regular agency services, they were still offset by lower nursing home costs.<sup>40</sup>

### **The Downside Risk**

The downside risk of considering the cost-containment benefits of CDC is the tendency of public officials to respond to (perennial) budget crises by cutting program budgets. Taking a lesson from the health insurance industry, where cost-shifting to consumers continues apace, advocates note that it will be imperative to maintain adequate funding for a range of support services that enable persons with disabilities to remain engaged as contributing members of society.<sup>41</sup> As one advocate put it, “this could be the first step in a market-based approach to cost-cutting in the guise of ‘consumer direction’ and ‘personal responsibility.’”

*CDC proponents argue that it’s cost-effective not because it saves money, but because it obtains better value for the money.<sup>38</sup>*

# Challenges Facing Consumer-Directed Care

## Culture

CDC presents a challenge for service providers at all levels. On one hand, as advocates for their clients, they support the right of consumers to be involved in decisions that impact their care. On the other hand, if those decisions shift control – and dollars – directly to the consumer, effectively bypassing the formal system, service provider agencies and healthcare professionals are not likely to embrace it with unbridled enthusiasm.

Promoting consumer direction will entail a significant transformation of both the culture and the infrastructure of the current system. Provider agencies' roles will evolve to technical support and consultation, case managers' roles will take on the characteristics of a consultant rather than a director of services, and consumers' roles will expand to include management and administrative functions. Most importantly, informal resources that provide a network of community-based support beyond the consumer-caregiver dyad will be critical to the success of consumer-directed models.<sup>42</sup> It remains to be seen whether these informal, community-based support networks will be able to reach the scale necessary to support increasing numbers of consumers who choose to receive services through a CDC model.

This challenge is compounded by a well-established culture in long-term care – indeed, in the entire healthcare industry – based on the medical model, where disability and frailty are viewed as deviations from the norm, and all manner of institutionalized care settings and standardized and categorized procedures are devised to reduce these deviations. Professionals who have spent their entire career utilizing care planning and management practices that tend to focus more on client disabilities than strengths may resist a shift in their role to that of a “guide on the side,” and view it as a threat to their sense of professional judgment and autonomy. One doesn't change a culture based on the traditional medical model overnight, and well established institutional practices are always resistant to change, no matter what the field. This culture shift is already underway in settings all across the country, including Arizona, but it may not move at either a rapid nor predictable pace.

## Client Resistance

Not all consumers will embrace CDC enthusiastically. Moving in tandem with a culture of institutionalized care is a tradition of client expectation that the case manager will make all the arrangements and handle the details – a “one-stop shopping” approach. As in the purchase of health services generally, consumers are used to having others purchase plans and services on their behalf (traditional employer-based health insurance) and deferring to professional authority on what's best for them. CDC doesn't work without consumer empowerment, and some clients, especially the frail elderly who have been used to “receiving” prescribed services for a long time and lack confidence, may prefer dependence.

In some cases, dependence may be a perfectly acceptable choice. Consumer empowerment is a two-way street of education and acceptance for both the client and the provider. It will be easier for some than for others – and it won't happen overnight.

*“Health care professionals – doctors, nurses – still don't get it. They don't acknowledge the capacity of consumers to make decisions, and it's hard for them to change the nature of their training and a practice culture in which their professional expertise is what matters the most.”*

Social Services  
Advocate

## Societal Attitudes

Societal attitudes toward the elderly, especially those with substantial impairments, present a roadblock for CDC. Despite evidence to the contrary, there is a sense that the frail elderly are neither capable of, nor especially interested in, assuming control over their own care. More than a few dinner table conversations among adults center on “what to do about Mom,” who “doesn’t know what’s best for her” anymore. This attitude is especially prevalent if the consumer has a cognitive impairment. If CDC programs are to become the norm, and

not the exception, of care for those with significant disabilities, social attitudes will have to be sufficiently broadened to allow for the same level of trust, risk – and yes, failure – that is accorded to fully functional adults and constitutes the full dimension of a complete life. Regrettably, many in our society still view those with disabilities as “the others,” and do not believe they still retain capabilities, strengths, and a sense of self-dignity and purpose as exercised through making choices.

## Fraud and Abuse

Another barrier to implementation of consumer direction is concern about greater risk of financial fraud and abuse. Arguably, the risk of fraud and abuse is lessened when consumers select family or friends as caregivers, but there is always potential to “game” the system in any fiduciary relationship. CDC programs are no exception.

In the case of publicly-funded programs, the risk of fraud applies not only to consumers who may not receive services they have negotiated and paid for, but also to the public source of funding for those services. Lack of financial oversight potentially may lead to all manner of mischief. To address this, virtually all CDC programs offer fiscal intermediaries to assist with accounting and reporting – and provide oversight for expenditures. Despite the ‘moral hazard’ concerns about financial gamesmanship, there is no *prima facie* evidence to suggest that consumer-directed decisions about

## Levels of Empowerment in CDC

Consumer-directed care exists along a continuum that is characterized by a broad orientation to consumerism, empowerment and choice with regard to the substantive decisions that affect the client’s day-to-day activities and overall well-being. Consumers often choose to designate a representative to make decisions on their behalf as the first line in a hierarchy of surrogate decision-makers and advisors. This hierarchy may include case managers, physicians, nurses and even advocates, all of whom act in the best interest of the consumer – and all of whom may ironically *disempower* the consumer in the process.

Empowerment is a matter of degree, reflecting the level of authoritative decision-making actually carried out by the consumer. One suggested scale distinguishes six levels of substantive empowerment:<sup>43</sup>

- **LEVEL ONE** – the person makes no substantive decisions about services.
- **LEVEL TWO** – the person makes no substantive decisions about services, but is informed of decisions made on their behalf.
- **LEVEL THREE** – the person is routinely asked to give advice and consultation to the actual decision-makers about services.
- **LEVEL FOUR** – the individual routinely makes a *significant minority* of substantive decisions about their services.
- **LEVEL FIVE** – the individual routinely makes a *significant majority* (55 to 90%) of key decisions.
- **LEVEL SIX** – the individual routinely makes the vast majority of key decisions such that empowerment is not an issue.

Empowerment is often in the eyes of the beholder. Many consumer-oriented programs seek the input of the consumer, but reserve actual decision-making for the client’s representative or service professionals. The larger issue is the degree to which individual consumers who are represented by advocates actually exercise authoritative choice.

services, rates or workers are any less efficient or cost-effective than agency-based decisions. Regardless of the locus of decision-making, accountability for public funds requires a system infrastructure to ensure their judicious use.

## Quality and Safety

A concern voiced by provider agencies, professionals and advocates alike is the risk to consumer health and safety from untrained/unskilled caregivers. For some, the underlying assumption is that quality of care is most likely to be assured by agency training, oversight and regulation. While experience with consumer direction has actually found fewer negative outcomes than care provided through agency-based programs,<sup>44</sup> effective quality management must be an integral component of a CDC program.

The need to balance consumer autonomy with quality of care is just one aspect of quality in a CDC program, addressing primarily the clinical aspects of care. The crux of the issue, noted by Joey Ridenour, Executive Director of the Arizona State Board of Nursing, is the ability of the consumer to self-assess and self-refer to a higher level of care. In traditional systems of care, the onus is on the professional to recognize and respond to signs of trouble in accordance with their training and scope of practice. Ridenour notes that while some consumers and caregivers are capable of self-assessment and referral, others may not recognize a problem until it becomes serious.<sup>45</sup>

Quality improvement in consumer-directed HCBS programs, however, is broader than just clinical care. Another aspect of quality is the need to balance consumer needs and abilities with oversight and accountability for public funds. This presents the dilemma of how the quality assurance process can honor the principles of self-direction *and* provide program oversight with regard to eligibility, allocation of funds and compliance with an individual purchasing plan.

Fortunately, demonstration programs such as *Cash and Counseling* have developed resource guides on ensuring and improving the quality of services in a way that balances system quality assurance activities with consumers' interests. For example, researchers at Miami University developed *A Guide to Quality in Consumer-Directed Services* that provides an in-depth review of quality issues in the context of consumer-directed care, along with model quality assurance program training guides, consumer surveys, reporting forms and other resources.<sup>46</sup>

## Authority and Liability Issues

In a traditional model of care, authority for decision-making rests largely with healthcare professionals, provider organizations and governmental agencies, where it is tied to responsibility for action, accountability for results and legal liability for outcomes. Assuring quality in such a system relies primarily on licensure, regulation, periodic inspection and quality review of treatment records.<sup>47</sup>

As authority to make choices shifts to the consumer, so does the responsibility, accountability and liability for those choices. Judging the quality of services falls within the oversight and purview of the consumer and/or a designated representative rather than an organization or regulatory agency. Personal autonomy and self-direction go hand-in-hand with the "dignity of risk," which recognizes that assuming authority – and taking responsibility for the outcome – is a key component in the development of new coping skills.<sup>48</sup>

*"In a CDC model, how does the consumer know what level of service to ask for and what's reasonable to expect? What comparative analysis do they have? None. Many are too timid and afraid to ask for what they need."*

Agency Director

This does not mean that provider organizations and governmental agencies are absolved of all responsibility. Governmental agencies that administer public programs are still held responsible for maintaining a comprehensive system and ensuring that people have access to it, as well as providing financial accounting and reporting of public funds.

Similarly, service provider organizations retain some level of responsibility for ensuring an appropriate balance between consumer choice and safety. For governmental agencies and providers, this raises the concern of being held responsible for the outcomes of consumers' choices without having the authority to intercede when they disagree with those choices. Although CDC demonstration programs have concluded that the liability risk of injury under CDC is no greater than agency-provided care – and in fact may be less with CDC provided by a family member<sup>49</sup> – liability risk remains a legitimate concern, prompting some states to modify their licensing and certification requirements to reflect the shift to person-centered and self-directed care models.<sup>50</sup>

## Who is *Li*able?

Liability issues fall into two general categories, *professional* and *vicarious*.

**PROFESSIONAL LIABILITY** arises from the need to balance individual rights with the state's responsibility to protect its citizens from harm, generally through professional licensure and regulation. While few states have explicitly addressed consumer direction, most have sufficient flexibility to accommodate the delegation of professional care activities to unlicensed caregivers.<sup>51</sup> Arizona falls somewhat in the middle on this issue, specifically exempting family caregivers from licensure standards and providing some flexibility with regard to incidental care provided by a person employed primarily as a domestic servant, while remaining silent on the role of other paid or unpaid informal caregivers, including those employed through a consumer-directed care arrangement.<sup>52</sup>

**VICARIOUS LIABILITY** stems from the doctrine of *respondeat superior*, which refers to the oversight responsibility of an employer for acts of the employee, or similar situations of delegated authority. In traditional models, the agency is responsible for oversight of the employee who provides direct care, including negligence, abuse or injury caused by that worker. Because CDC models shift authority for hiring, training and oversight of the worker directly to the consumer, overall risk of liability in CDC programs is generally lower than for traditional models, and agency responsibility for oversight and supervision is limited to a consulting role.

In some states, vicarious liability concerns have been addressed by structuring CDC programs in such a way that the consumer is supported in his decision-making, while the risk to other entities is mitigated through clear and explicit program guidelines that reinforce the decision-making role of the consumer and delineate the responsibilities of all parties, including the consumer, designated representative, worker, provider agency, fiscal agent and the governmental unit.<sup>53</sup> Despite such evidence and assurances to the contrary, concerns about vicarious liability remain high on the list for provider and government agencies.

## CDC and Managed Long-Term Care

Growth and interest in CDC have followed a parallel track with growth in the number of persons who receive services through a managed care organization (MCO), raising the question of compatibility between the two.

On one hand, managed care places greater emphasis on outcomes, and resources are tied more closely to clients' needs. On the other hand, managed care follows a medical model, which places the professional rather than the consumer in control of decision-making.

To answer the question of compatibility, managed care organizations were surveyed with regard to their attitudes and practices surrounding consumer direction. While their experience and knowledge about CDC were limited, 66% of the MCOs indicated that consumer direction was being discussed within the organization. Another 32% allowed consumers to hire and fire their own workers, 47% allowed clients a major say but did not allow hiring and firing of workers, and 21% did not allow either option.<sup>54</sup>

### The Cost-Benefit Equation

To no great surprise, when asked about potential reasons for implementing CDC, those MCOs that allowed consumers to hire/fire workers rated the benefits of CDC higher than the MCOs that retained total control of worker employment. The MCOs that retained control of worker employment indicated significantly higher levels of concern about potential problems with CDC.<sup>55</sup>

Balancing profitability and budget constraints against the perceived interests and benefits of clients – the cost-benefit equation – is the central issue of concern as MCOs consider adopting consumer-directed models of care. But while both the research and our own conversations with providers indicate that balancing organizational profitability with consumer interest and independence is a vexing issue, these are not necessarily incompatible goals.

Beyond financial feasibility, other studies have shown that, from the perspective of consumers, both traditional agency models and consumer-directed care are associated with positive outcomes. Although the differences between them are not large, the majority of outcomes show statistically significant positive differences with consumer-directed care.<sup>56</sup>

“Service providers are *well meaning*,  
but often they are too paternalistic.  
Many of *these consumers* are well into their 80s,  
so they must know something.”

Policy Advisor

## Other *Policy Issues*

In addition to previously discussed issues of public accountability, fraud and abuse, quality and safety, and authority and liability, there are other important issues of public policy and practice to consider in the expansion of consumer-directed care:

“Of course everyone wants daily housekeeping services. Who wouldn’t?”

Service Agency Director

### Commodification

The commodification of health care refers to treating medical and health services as “commodities” that, like other commodities, are purchased and supplied in a competitive marketplace. With regard to CDC, programs that allow for direct payment of health services to family caregivers can be said to be “commodified” to the extent that services that were once provided for free are now purchased. In effect, the patient becomes the *consumer*, and the family caregiver becomes the *provider*.

### For Love or Money

Beyond the logistical arrangements, direct payment to family caregivers raises some fundamental social questions about public and private responsibility for caregiving, and a host of philosophical and pragmatic policy issues.<sup>57</sup>

Those who oppose direct payments to a spouse or parent base their arguments on the ethical imperative of family members to care for each other – out of love, not for the money – followed by more prosaic economic constraints that lead them to question why scarce public dollars should pay for care that would – or ought to be – provided for free anyway.

Concerns about the fiscal impact of CDC also extend to the so-called “woodwork effect.” Many persons with disabilities and their families *refuse* institutional care and agency-based home care services, but *would* seek support from a consumer-directed care program that directs financial resources to a family caregiver.<sup>58</sup> These concerns may be exaggerated or misplaced, however, as experience with HCBS programs over the past 25 years has shown them to be cost-effective alternatives to institutional care. Often this has been the result of program criteria that limit eligibility for services to participants that would otherwise have been highly likely to be institutionalized.<sup>59</sup> As one of the first states to embrace HCBS through an 1115 waiver, Arizona has realized significant savings in its Medicaid long-term care program.<sup>60</sup>

Those who argue that direct payments to a spouse or parent caregiver should be allowed take a more pragmatic perspective. In their view, payment to family caregivers is one way to address health workforce shortages, improve outcomes for consumers and families, and enable family caregivers to continue to provide care.<sup>61</sup> Noting that 70% of unpaid caregivers are women, some people also see this as a gender justice issue and part of a broader ethical obligation to recognize and support informal caregivers.<sup>62</sup>

## The Effect of CDC on Family Caregivers

Research on the effect of CDC on family caregivers is somewhat equivocal and depends largely on the locus of decision-making. In practice, it's often difficult to distinguish the effects on consumers from the effects on their family caregivers. Both report increased satisfaction related to reductions in unmet needs under consumer direction, and in practice consumers often delegate decision-making authority to a family member representative. In this situation, significant benefits accrue to the family caregivers, who report reduced levels of stress and frustration, lower levels of physical, financial and emotional strain, better health and improved job performance for those employed outside the caregiving role.<sup>63</sup> Such positive responses are likely related to increased control and ability to coordinate resources to best meet the needs of the person they are caring for. However, with a greater push toward self-direction among persons with both physical and cognitive disabilities, family caregivers may also report increased levels of stress and frustration when the decisions of the care recipient are not in agreement with what the caregiver would choose.<sup>64</sup>

Given a choice, most consumers will select a family member as their caregiver.<sup>65</sup> The central question in determining if a family member should be paid for caregiving involves an assessment of how much 'free' care is available to the individual in need of assistance. If assistance is needed beyond what is available through family and friends, the overriding consideration for publicly funded care should be cost-efficiency.

## The Impact of Changing Family Demographics

That being said, changing family demographics may pose a challenge to CDC programs, as the promise of reimbursement is just one incentive in maintaining informal care networks. A more vexing question in the future will be the availability of informal/family caregivers. The impact on caregiving for seniors may be particularly acute, as today's seniors have fewer children, higher rates of divorce and longer life expectancy, all of which contribute to a higher likelihood of living alone.<sup>66</sup> Because most CDC participants hire a family member or friend to provide personal assistance, a network of family and friends from which to draw is a key prerequisite for a successful program.

Finally, the financial impact of informal caregiving is also felt by the employers of family caregivers. A 2006 study on the impact of informal caregiving on business estimated the average cost per employee for each of the 16 million full-time, employed caregivers to be \$2,110 – a total cost to employers of \$33.6 billion. Costs included \$6.6 billion in turnover, \$13.3 billion in absenteeism and workday interruptions, \$4.8 billion in full- to part-time work and \$7.2 billion due to eldercare crises and unpaid leave.<sup>67</sup>

Considering all these factors, there are good reasons to support a CDC policy of direct payment to family caregivers, but not if it eventually undercuts the emotional and ethical bonds that hold families together against the relentless forces of an impersonal and competitive marketplace. We know that blood is thicker than water. We hope that it's thicker than money.

*We know  
that blood is  
thicker than  
water. We  
hope that it's  
thicker than  
money.*

“If the exercise of choice triggers competence inquiries by those involved in administering the self-directed care program or approving the individual’s recovery budget, self-directed care will collapse in both concept and execution.”<sup>68</sup>

Susan Stefan,  
Center for Public  
Representation

## Competence

Not all choices are permissible in self-directed care – nor should they be if the goal is to balance autonomy and independence with the responsible and efficient expenditure of public dollars. The concern about consumer choices is really a concern about consumer competence.

Competence is both a clinical and a legal concept that is measured in terms of abilities and actual decisions, both of which can vary over time. Different decisions require different levels of competence, and there is no single accepted test to determine one’s level of competence at a given point in time. Judgments about competence are therefore “value-laden, discretionary and culturally bound.” Because most questions of competence arise from decisions to refuse recommended services or treatments, potential issues of competence must be addressed at the outset.<sup>69</sup>

## Fix the Environment, Not the Individual

In much the same way as independent living advocates focus on improving the environment, rather than fixing the individual, advocates for self-direction re-frame the issue of competence by focusing on programs and systems that address *a priori* criteria for participation, parameters of choice and contingencies during periods of crisis. Most often, these issues are addressed through the use of fiscal intermediaries, advance directives and the designation of health care proxies or powers of attorney. For self-directed care programs, advance planning, crisis plans and designation of a trusted surrogate decision-maker can be included in the recovery/service plan.

Framing the issue of competence this way avoids its pejorative connotations when framed in a direct discussion of self-determination. Questioning the client’s competence is the very antithesis of self-determination, and trained caregivers – family members included – know from experience that it can often impede, rather than enhance, compliance and recovery. On the other hand, neither a trained healthcare professional nor a lesser trained family caregiver can afford to allow the person receiving the care to do irreparable harm to herself or others; hence the need to spell out the conditions under which consumer choice can be restricted well in advance of the provision of care itself.

## Health Information

Advocates for persons with psychiatric and other disabilities note that concerns about competence and the ability to make “good” choices may be more aptly characterized as questions of information or skills. Either way, the first step in making a wise decision is to have accurate and adequate information. The next step is to develop the necessary skills, such as the ability to keep personnel and financial records and follow applicable employment laws and regulations.

The trend toward increased responsibility for consumers in making decisions about their health care goes hand-in-hand with the effort to make care both more accessible and affordable.<sup>70</sup> This effort has resulted in a growing number of internet-based information sites, such as *WebMD*, *Hospital Compare*, and *Quality Tools*. However, publicly available information on health care quality and price – still in its infancy – focuses almost exclusively on formal, acute-care services such as insurance plans, hospitals and physicians, and is of little use for a consumer seeking informal, and often unlicensed, personal care services.

## The Importance of Health Literacy

Even more basic are fundamental issues regarding literacy. In particular, consumers' health literacy has increasingly come into question. Defined as the "degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions," the Institute of Medicine estimates that approximately 50 percent of the adult population may lack the literacy skills needed to navigate the healthcare system.<sup>71</sup> As a function of culture, language, education, age and access to resources, limited health literacy represents an additional challenge to self-direction.

But having more information isn't the only ingredient for assisting consumers to make decisions about their care. Self-efficacy – the belief in one's ability – is also a factor. A core element of healthy psychological functioning is the belief in one's control over one's environment. Too often, so-called "bad" decisions are little more than decisions with which those in a position of authority disagree. The trick for self-directed care programs will be to distinguish a truly detrimental choice from what may simply be a different choice.

There's a word for the wrong choices that we all make from time to time. It's called *learning*.

**“The developmental disability community  
is already steeped in the self-determination mentality.  
The aging community will have more to learn  
and need more training to make the cultural shift  
to consumer direction,  
as will the behavioral health providers.”**

Social Services Advocate

### Consumer-Directed *Co-Ops*

The Federated Human Services Co-Op has developed an innovative model of consumer-directed care that places consumers, literally, in the owner's seat.

With membership ranging from 20 to 100 consumers, and operating budgets ranging from \$3 million to nearly \$15 million, co-ops enable consumers to build on each other's strengths and compensate for each other's limitations. In a world of agency-driven care, they also represent a unique business model. The co-ops contract with government funders as a qualified Medicare/Medicaid provider, then sub-contract for services, such as administrative management, attendant training and fiscal agent duties. But it's the consumers – who represent at least 80% of the ownership – who call the shots.

The key to success for the co-ops? Shared information. As one member put it, “as opposed to other provider agencies that guard their information as proprietary, we freely share information with each other, making the co-op network a more efficient, less costly and higher quality delivery system.”

# cdc in Arizona

The Centers for Medicare and Medicaid Services (CMS) touts the state's Long Term Care System (ALTCS) program as a model strategy for system support of community-based care.<sup>72</sup>

Arizona is ahead of the national curve when it comes to CDC.

In Arizona, it has been possible to realize the spirit and values of personal choice in programs that are not consumer-directed in the strict sense by incorporating components of consumer direction into programs that provide long-term care and community-based services to elderly and physically disabled individuals.

The Centers for Medicare and Medicaid Services (CMS) touts the state's Long Term Care System (ALTCS) program as a model strategy for system support of community-based care:<sup>72</sup>

*The Arizona Long Term Care System (ALTCS) uses a managed care model to provide long-term support for older people and people with physical and developmental disabilities at risk of institutionalization... The state's capitation methodology serves as a policy tool for rebalancing the system. The ALTCS pays a blended capitation rate to the health plans such that the plan is paid the same amount regardless of whether a person lives in a nursing home or in a home or community residential setting. In setting the capitation rate, the state assumes that a certain percentage of each plan's enrollees will be served in the community. Each year, the state adjusts the target rate of people to be served in community-based settings. With this system, plans are provided with a natural incentive to serve more people in the community.*

## Better Home- and Community-Based Services

A basic tenet of the ALTCS program is consumer involvement in deciding where they want to live, and the services needed for them to remain in a home- or community-based setting. Consumers are provided information about program contractors and the types of living arrangements and services that are available through them. Case managers are charged with facilitating service delivery and placement based primarily on the consumer's preferences. There is no limit on the number of consumers who can reside in home- or community-based settings; however, Medicaid does limit expenditures to no more than the institutional cost of care.<sup>73</sup>

Initiation of home- and community-based services (HCBS) is a strength of the ALTCS program. The 2004-2005 External Quality Review of ALTCS program contractors found that the average rate for HCBS was 89.2%, exceeding even the long-range benchmark.<sup>74</sup>

## The SAIL Program

The Senior Adult Independent Living (SAIL) program is a primary source of case management and personal care services for older and disabled adults and their families in Maricopa County.<sup>75</sup> For example, utilizing a traditional model of in-house case management and contracted service provider agencies, the Area Agency for Maricopa County (Region One) provides a range of services that include case management, adult day

health care, home-delivered meals, home nursing services, personal care assistance, home-making/repair/chore services, and the provision of durable medical equipment.<sup>76</sup>

Although the 2005 Strategic Plan for the Maricopa County Area Agency on Aging calls for efforts to “enhance the quality and availability of programs and services for the elderly,” including a pilot of consumer-directed home care services as one of its objectives,<sup>77</sup> consumer direction in aging services within Maricopa County is still on the drawing board.

## Community-Based ≠ Consumer-Directed

Although these programs follow the *concept* of consumer orientation, three key factors differentiate them from a true CDC model:

1. Most consumers’ choices are limited to those services/employees provided by contracted provider agencies.
2. Authority for service and placement decisions generally remains vested with the agency case manager.
3. In programs that do allow consumers to designate a care provider, the agency retains responsibility for training and oversight, as well as payroll and other fiscal responsibilities.

For example, ALTCS’ HCBS Attendant Care program allows consumers to choose a caregiver, including a family member or friend, who is then provided basic training and employed by a formal provider organization. Within the constraints of the provider agency, the caregiver provides services at the direction of the consumer, including the types of duties assigned and scheduling of services. However, the payer/provider agency maintains authority for services, allocation of funding and financial accounting.

## Plans to Expand CDC in Arizona

In recent years, both ADES and ALTCS have taken steps to more fully realize the transfer of authority for individual decision-making from government and provider agencies to consumers.

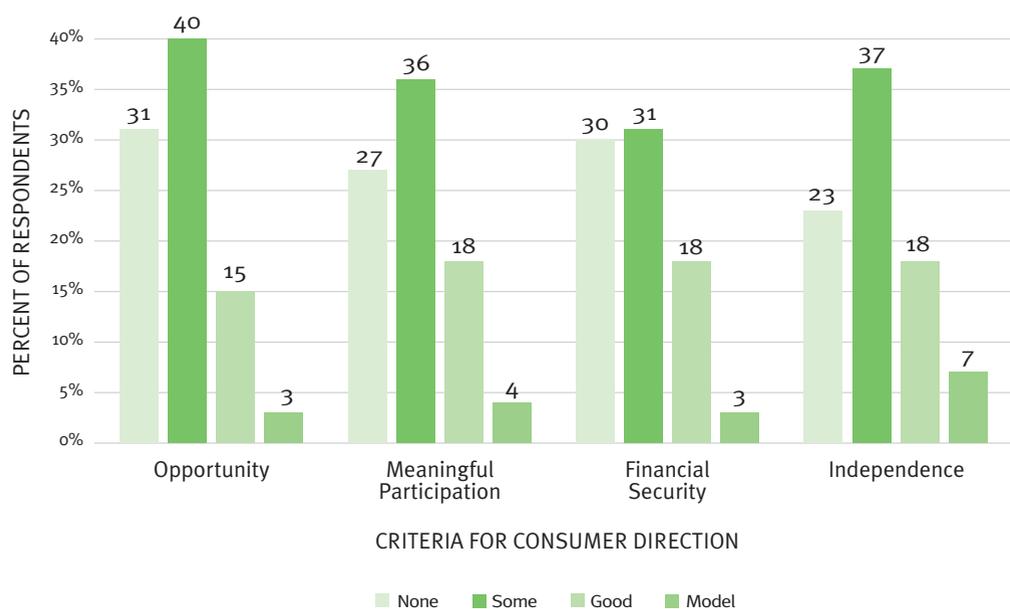
## ADES – Aging and Adult Administration

One goal of the Arizona State Plan on Aging for 2004-2006 is to “improve the quality, availability and accessibility of non-medical home- and community-based services...” To achieve this goal, the Plan notes ADES’ intent to “explore alternative methods of service delivery, including consumer-directed care...”<sup>78</sup>

As a first step toward greater consumer direction, ADES conducted a series of stakeholder meetings, information gathering sessions and public forums to assess interest and system readiness for development of a consumer-directed model of care. In the process, they discovered a general lack of consumer awareness, concern among stakeholders about difficult or complex processes, and a lack of communication, coordination, integration and continuity of care in programs and services throughout the state. On a positive note, they also found interest and support from the aging network for moving toward consumer direction in aging services.<sup>79</sup>

*As a first step toward greater consumer direction, ADES conducted a series of stakeholder meetings, information gathering sessions and public forums to assess interest and system readiness for development of a consumer-directed model of care.*

**Figure 1: Progress Toward Consumer Direction**



Source: SLHI analysis of participant responses to Consumer Direction Tool.

*Although there were slight variations between different groups, all of them followed similar patterns in their ratings of progress toward each of the four criteria for consumer direction.*

Utilizing a tool that asked whether currently available programs help consumers make decisions about their care, meeting participants rated progress on four criteria:

- Do individuals have opportunities to participate in the community in ways that are meaningful to them?
- Do individuals with disabilities participate in decisions affecting their lives, and are they consulted about changes in policies?
- Do programs assure that participants have enough money to support themselves and are able to feel secure in the community?
- Are individuals able to make decisions affecting their lives in the community?

Although there were slight variations between different groups, all of them followed similar patterns in their ratings of progress toward each of the four criteria for consumer direction (Figure 1). About 30% saw little or no progress toward CDC, 30%-40% saw some progress, 15%-18% saw good progress, and 3%-7% thought there were indications of some “model” programs.

## ALTCS

In its 2006 request for proposals (RFP), ALTCS took a further step toward comprehensive consumer direction by announcing their intention to implement a CDC model program beginning in October 2007. The proposed program will afford consumers the opportunity to assume full control of services. To comply with Title XIX requirements, a fiscal intermediary will be responsible for handling payroll, taxes and other defined requirements. Recently, the program contractor for Pinal and Gila counties was awarded additional funding to develop a CDC model that can be adopted by all ALTCS contractors for Elderly and Physically Disabled programs.

AHCCCS/ALTCS has been awarded a federal technical assistance grant to facilitate implementation of CDC. AHCCCS also has requested an amendment to its Section 1115 waiver that will enable spouses to be paid caregivers. If the waiver amendment is approved, the grant will be used to address cost neutrality issues. In addition to improved member and caregiver satisfaction and consumer authority for decision-making, two other expected outcomes of the project are an expansion of the available workforce through recruitment of caregivers from non-traditional sources and a reduction in caregiver turnover.<sup>80</sup>

*“I see five key implementation issues.*

*First, balancing the budget and providing enough  
funding for consumer services.*

*Second, addressing the delegation of skilled tasks.*

*Third, defining the role of the fiscal intermediary.*

*Fourth, training of members and caregivers  
for their responsibilities under the new CDC program.*

*Fifth, overcoming resistance and training provider agencies and  
case managers about the philosophy of consumer-directed care.”*

Alan Schafer, Manager, Arizona Long Term Care Services (ALTCS)

## Pinal/Gila CDC

Pinal/Gila Long Term Care was recently awarded a supplemental funding contract by ALTCS to implement a consumer-directed care model that will expand the scope of options for members who live at home and need assistance with activities of daily living (ADLs).

Key elements being developed include:

- Establishing functional eligibility criteria to ensure that members/member representatives are capable of understanding the risks, rights and responsibilities and can manage an employee.

- Defining service specifications for non-skilled services (housekeeping, personal care and attendant care) that will be covered initially.
- Reviewing legal issues such as compliance with federal and state statutes and regulations, and developing guidelines that address potential member and program liability.
- Developing a Quality Assurance mechanism that balances member autonomy and potential risks.
- Defining the role of case managers and other healthcare professionals under the CDC model with regard to assessments, benefit determination and coordination of administrative and service-related functions.
- Developing criteria and guidelines for employment-related issues such as the responsibilities of the fiscal agent, background checks, initial and ongoing training and back-up plans in the event of an attendant not being available.
- Establishing guidelines for training and education of consumers, family members, agency staff, fiscal agents and others involved with the new CDC model.

Julie Bubul, Case Management Administrator for Pinal/Gila LTC, noted that the CDC model

*grants the member the maximum amount of independence and empowers him or her in the most vital areas of his or her life. The underlying premise for consumer-directed care is that individuals have the right and the ability to make decisions about how best to get their own needs met and to evaluate the quality of the services received. This includes having primary control over what services they will receive, when they will receive them and who will provide them.<sup>81</sup>*

### **Arizona's Commitment to CDC**

Finally, in support of its CDC efforts, AHCCCS has applied for grant funding under the *Real Choice Systems Change* program to plan and implement a statewide electronic care assessment and planning tool that would incorporate person-centered planning and consumer direction.

All of these efforts attest to Arizona's commitment to CDC, which is also evident in the numbers. Between 2000 and 2006, enrollment in the ALTCS program for elderly and physically disabled (EPD) persons increased from 16,509 to 22,256. During this same period, the proportion of members residing in an institutional setting *fell* from 54% to just 37%, and for members between the ages of 21 and 64, the rate of institutionalization is just 23%.<sup>82</sup>

*All of these efforts attest to Arizona's commitment to CDC.*

# Suggestions for *Policy and Practice*

Consumer-directed care is one way to begin addressing the challenges of limited resources and changing population demographics in a way that increases satisfaction and autonomy of people of all ages with disabilities. It offers the opportunity for autonomy, independence and engagement within a supportive and inclusive community, as well as the potential for greater efficiency and effectiveness that translates to cost savings for the entire system.

Supporters argue that not only is it the right thing to do from a social perspective, it's the smart thing to do from an economic perspective. Changing population demographics, increasing rates of disability stemming from the increasing incidence of chronic disease, changes in family structure and workforce shortages all point to a future in which the demand for and cost of supportive services for persons with disabilities will continue to rise. To stem that tide, the availability and maintenance of informal care networks will be critical.

CDC is not a panacea, however, and it's not for everyone. Persons with severe disabilities will continue to need agency-based, professional services and round-the-clock care. Some will even prefer it to having to make all the arrangements for care themselves, or to rely on an appointed agent. Busy, dispersed families are accustomed to having others take care of family members and may be unable – or unwilling – to shoulder more responsibility themselves, even if they get paid for it. Officials with responsibility for dispersing public funds for health services will be concerned with issues of accountability, competence, liability and efficiency. And for CDC to work at all, consumers will need far better information on making decisions concerning access, quality and cost than exists today.

We conclude with summary suggestions for policy and practice:

- **PLAN NOW FOR IMPLEMENTATION OF CDC PROGRAMS.** Even if CDC isn't on the horizon of your agency or program today, chances are it will be in the future. What does it mean to be a consultant and fiscal intermediary instead of a case manager and contractor? What types of training, information, consumer information and communication strategies need to be in place?
- **PLAN NOW FOR GREATER CONSUMER SUPPORT.** This needs to occur at both the agency and state level. Given the larger movement to greater consumer involvement in all facets of health care, both public and private programs need to provide up-to-date, accurate and relevant information on sources of care (a registry of home care workers, for example), the quality of that care (tracking and disseminating consumer feedback, surveys, quality metric checks), fiscal intermediary guidelines, templates for consultant contracts, active peer support networks, and market studies on costs. Our guess is that once a CDC market is established, all manner of vendors will step in to broker the information gap between consumers and services.
- **DEVELOP A COMPREHENSIVE MONITORING STRATEGY.** It is especially important for both state and local agencies to have monitoring systems for CDC programs that facilitate a "quick and confidential means of reporting, tracking, reviewing and acting upon program issues," as well as conducting periodic audits of various CDC program-

*For CDC to work at all, consumers will need far better information on making decisions concerning access, quality and cost.*

matic components such as consulting and fiscal management contracts.<sup>83</sup> The principles of transparency and oversight that apply to consumer support apply to monitoring of the quality of services as well.

- **TRACK PUBLIC INVESTMENT.** The monitoring function is a two-way street. As payers and regulators anticipate cost savings and increased efficiency from CDC programs, consumer advocate groups and provider agencies need to track actual program outcomes to ensure that quality doesn't suffer if public budgets are in fact cut back. Ideally, the CDC model will result in better outcomes, improved consumer satisfaction and reduced costs, but not every scenario plays out so neatly. This needs close attention.
- **GEAR UP FOR TRAINING AND EDUCATION.** CDC programs will require retraining of current staff used to more traditional roles and training for new staff, as well as training for informal caregivers who may be asked to fill more formal roles. In addition to retooling health care training programs in colleges, universities and technical institutes, agency providers will no doubt have ongoing training programs for both staff and consumers based on a CDC philosophy and strategies. Some already do.
- **DEVELOP AND EXECUTE A COMPREHENSIVE STATE HEALTHCARE WORKFORCE STRATEGY.** In addition to monitoring the supply of both formal and informal caregivers, the state should design and implement a workforce strategy that incorporates CDC practices in addressing the imbalance between urban and rural caregivers, identifies emerging areas of need (e.g., chronic disease management) and fosters a culture that places professional expertise and experience at the service of greater consumer choice, and not as the sole arbiter of it. This will lead to changes in scope of practice, licensing and credentialing, and greater community involvement in developing local workforce strategies.
- **DO NO HARM.** CDC does not apply uniformly across the entire community of persons with disabilities. For example, its application in the behavioral health community, while promising, faces a different set of needs and challenges than the physically disabled community. At some level, we will continue to need traditional agency programs and service providers, and they should be supported as well. Whatever the setting, the first principle is to do no harm.

“Consumers want to *accept risk*.

The way they see it, they have the right  
to *make decisions*, and their reward  
is *independence*.”

Agency Director

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## ***Our Mission***

*To improve the health of people and their communities in Arizona, with an emphasis on helping people in need and building the capacity of communities to help themselves.*

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St. Luke's Health Initiatives is a public foundation formed through the sale of the St. Luke's Health System in 1995. Our resources are directed toward service, public education and advocacy that improve the health of all Arizonans, especially those in need.

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