Policy Research Brief

RESEARCH AND TRAINING CENTER ON COMMUNITY LIVING
UNIVERSITY OF MINNESOTA

Implementation of Consumer-Directed Services for Persons With Intellectual or Developmental Disabilities: A National Study

This Policy Research Brief *summarizes the results of a national study on the status of consumer-directed services for persons with intellectual or developmental disabilities. The study was conducted at the University of Minnesota's Research and Training Center on Community Living and Syracuse University's Center on Human Policy, and its purpose was to investigate how consumer control is being implemented across states. Additional themes included the exploration of strategies, challenges, and best practices of consumer-directed services and supports. Information was gathered through interviews with administrators of developmental disabilities services in 42 states. This brief was authored by Pam Walker, Center on Human Policy; and Amy Hewitt, Matthew Bogenschutz, and Jennifer Hall-Lande, Research and Training Center on Community Living. The content is based on the comprehensive study entitled:* Implementation of Consumer-Directed Services: A National Study. *The study was supported through Cooperative Agreement No. H133B080005 from the U. S. Department of Education, Office of Special Education and Rehabilitative Services, National Institute on Disability and Rehabilitation Research (NIDRR). The authors wish to acknowledge Bonnie Shoultz, Perri Harris, Steve Taylor, Chas Moseley, Sheryl A. Larson, and Charlie Lakin for their contributions in the preparation of this brief. For further information, please contact Pam Walker, PhD, Research Associate at pmwalker@syr.edu or (315) 443-4290.*

■ Introduction

Consumer-directed support (CDS) options for individuals with intellectual or developmental disabilities (IDD) have become an increasingly prevalent service and funding option in the United States. A recent study indicated that the trend towards consumer direction in Medicaid is growing nationwide (Greene, 2007). However, there is great variability in the extent to which consumer direction has been initiated among the states. Most states that have implemented large-scale consumer-directed initiatives have not yet systematically evaluated their initial efforts.

Over the past two decades, states have been moving toward more individualized services, with increased choice and control for individuals with IDD and their families (Breihan, 2007; Moseley, Lakin, & Hewitt, 2004; Parish, Pomeranz-Essley, & Braddock, 2003; Tritz, 2005). Built on the premise of normalization (Wolfensberger, 1972), this movement was initiated, in large part, by the advocacy of individuals with disabilities and their families. It was supported by the incorporation of principles of self-determination (Stancliffe & Abery, 2003; Wehmeyer & Stancliffe, 2003), and person-centered supports (McBride & Sauer, 2006; Mount, 1992; O'Brien & Lyle O'Brien, 1998; Smull & Lakin, 2002) into the service system. Initial demonstration projects funded by the Robert Wood Johnson Foundation resulted in models of consumer direction and initial understanding of the effects of consumer control on services and personal satisfaction with those services.

The Centers for Medicare and Medicaid Services (CMS) defined consumer-directed programs as, "a state Medicaid program that presents individuals with the option to control and direct Medicaid funds identified in an individual budget, and in which the participants live in their own homes" (Department of Health & Human Services, 2003). Essential elements of self-direction include: (a) person-centered planning, (b) individual budgeting,

A summary of research on policy issues affecting persons with developmental disabilities. Published by the Research and Training Center on Community Living, Institute on Community Integration (UCEDD), University of Minnesota.

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(c) self-directed support, and (d) quality assurance and improvement (Department of Health & Human Services, 2003).

In the process of incorporating consumer control, states are taking unique approaches and using widely differing strategies (Bradley et al., 2001; Yuskauskas, 2005). The objective of this study was to investigate the various ways consumer control is being implemented across the states, and to learn about strategies and challenges in doing so.

■ Method

This study examined the extent to which states have implemented both individual budgets and consumer control over services for Medicaid Home and Community Based Services (HCBS) recipients with IDD. Consumer control was defined as encompassing services that involve both individual budgets and decision-making authority over the budget. An interview guide was developed and telephone interviews were conducted with 42 state directors of developmental disabilities services or their designated representatives during 2006 and 2007. The questions asked were descriptive and yielded information about the type of consumer-directed services offered, statewide access, utilization, expenditures, and funding source. Questions were also asked about evaluation and outcome data, program monitoring, and the successes and challenges of implementing this service option. Each interview lasted approximately 60 minutes. Eight states declined interviews.

The interviews focused on consumer control within HCBS for individuals with IDD. Some information was also obtained about state- and grant-funded pilot projects. Many states have additional consumer-directed services available to some people with IDD through other waivers (e.g., Aging and Disability) or through other types of programs (e.g., state funded community living programs). However, obtaining information regarding these initiatives was beyond the scope of this study.

This *Policy Research Brief* provides an overview of the states, and discusses information related to consumer-directed services as well as some of the events and circumstances that resulted in their establishment. It also offers a discussion of the key differences in implementation of consumer-directed initiatives across states, and discusses lessons learned by the states in the early stages of implementation of consumer-controlled support options.

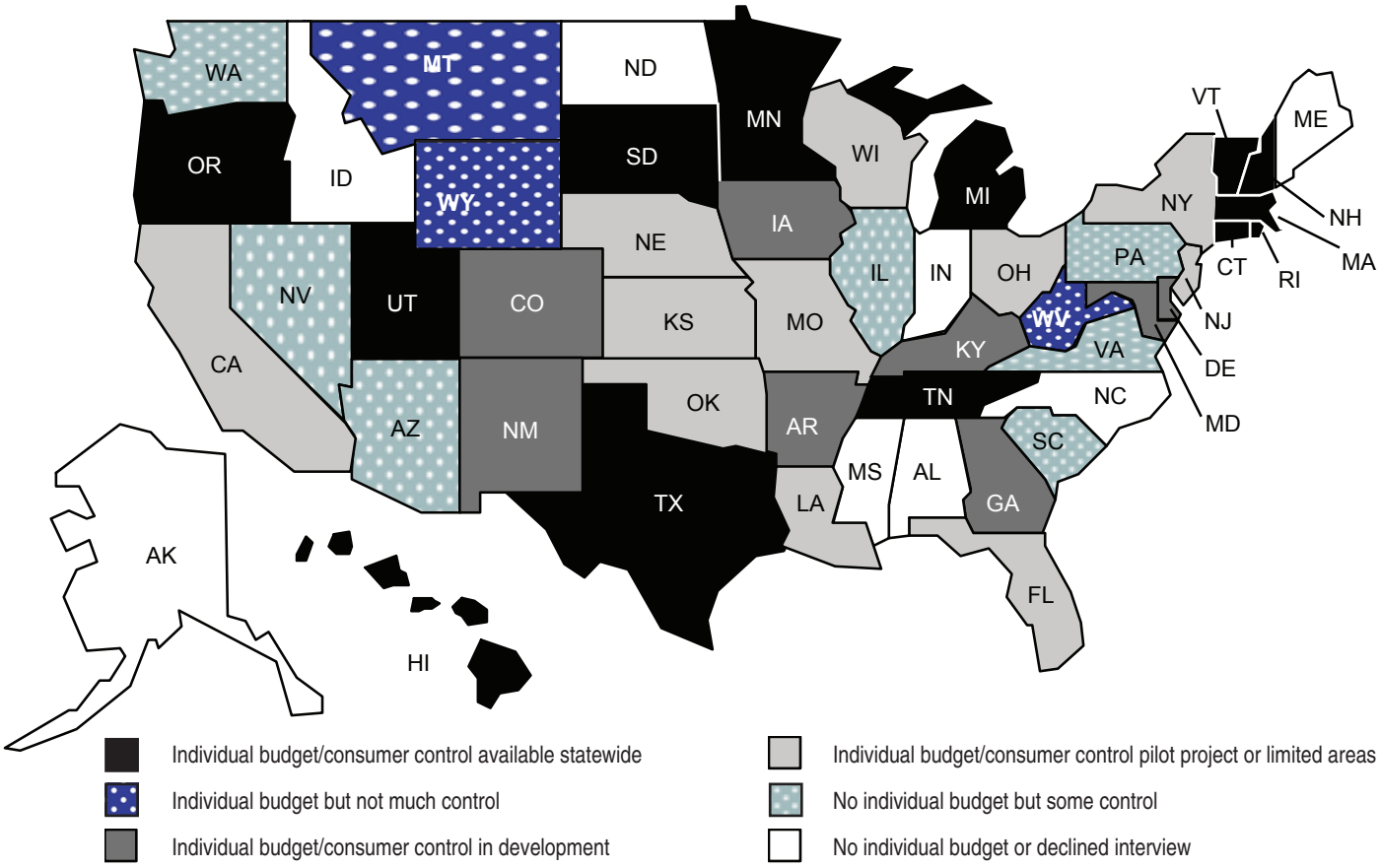
■ Findings

Status of CDS Among States

At the time of the interviews, 13 states had statewide availability of individual budgets and consumer control for at least some HCBS recipients with IDD. Eleven additional states had a consumer-directed option available as a pilot project to a limited number of people or available within a limited geographic area. At least four states anticipated expanding to statewide availability in the near future. Eight states reported that they were in final stages of development of a consumer-directed option, and anticipated that it would be available in 2006/2007. Eighteen states had not established individual budgets and consumer control and did not anticipate doing so. Three of these states reported having individual budgets, but without consumer control; seven states reported that they did not have individual budgets, but that they had some aspects of consumer control (e.g., people could hire their own staff); and eight states declined an interview either because they had not yet developed this option or because they had not implemented it. Figure 1 illustrates the status of individual budgets/consumer control across the states, as reported at the time of the interviews in 2006 and 2007. It is important to note, however, that the status of these states may be different now due to the rapidly changing nature of program implementation nationwide.

Some states provided specific data regarding the numbers of individuals who receive individual budgets and consumer control; other states provided what they called "rough estimates." The number of CDS participants ranged from 15 individuals in a small pilot project in Oklahoma to 4,000 individuals enrolled in the consumer-directed option in Oregon. Table 1 gives the number for each of the 24 states that had individual budgets and consumer control statewide, within a specific geographic region or as a pilot project, as reported at the time of interviews in 2006 and 2007. Based on these data, over 18,000 individuals around the nation are participating in a consumer-directed funding option. The states can be grouped into three general categories based on the number of people using individual budgets and consumer control. States with a large number of people who use individual budgets and consumer control (i.e., over 1,000) include Connecticut, Texas, Minnesota, Oregon, Florida, Wisconsin, Vermont, and Michigan. States with a mid-range number of people who direct their own services (i.e., 200-1,000) include South Dakota, New Jersey, New Hampshire, Massachusetts, Ohio, and Hawaii. States with a small number of people (i.e., less than 200) include Rhode Island, California, Oklahoma, New York, Kansas, Missouri, and Louisiana. States with the smallest numbers of participants were conducting CDS pilot projects, with the exception of Rhode Island.

Figure 1. Status of Individual Budgets/Consumer Directed Supports by State in 2006/2007



Map created in National Center on Educational Outcomes Data Viewer (http://data.nceo.info/)

The proportion of HCBS participants with IDD who were enrolled in consumer-controlled initiatives ranged from 0% to 50.4%. Five states enrolled more than 30% of HCBS participants in consumer-controlled initiatives, 5 enrolled between 5% and 29%, 13 enrolled some people but less than 5%, and the remaining states enrolled none. In 2006/2007, an estimated 3.8% of all HCBS recipients with IDD were enrolled in consumer-controlled initiatives nationally.

Factors Promoting CDS Initiatives

Several factors have promoted the initiation of consumer-directed Medicaid options in states. The two most significant factors are the Robert Wood Johnson Foundation's (RWJ) self-determination projects, and political and legal factors.

RWJ Self-Determination Grants

In 1991, RWJ funded a self-determination project in New Hampshire (Monadnock Developmental Services, 1996). In 1997, based in part on the success of this project, 18 additional states were awarded grants to promote self-determination. Not surprisingly, the RWJ state grants appear to have had a significant influence on the development of consumer-directed services across the country (Bradley et al., 2001). Of the 19 states that had grants, 10 (Vermont, Connecticut, Utah, Texas, Minnesota, Oregon, New Hampshire, Massachusetts, Hawaii, and Michigan) had statewide individual budgets/consumer control when interviewed for this study. Two other states (Maryland and Iowa) planned to add statewide individual budgets/consumer control in 2006. Four others (Kansas, Wisconsin, Florida, and Ohio) have individual budget/consumer control available as a pilot project or in part of the state. Lessons from implementing the RWJ grants influenced states as they developed strategies to institute consumer-directed models of support (Bradley et al., 2001; Sunderland, 2007).

Interviewees from states that had received RWJ grants acknowledged their influence. For example, one administrator commented, "The RWJ grant helped us move in this direction. It really showed us the kinds of things we needed to pay attention to, what would work, and what wouldn't work." Another administrator observed, "I think that it was incredibly influential in creating support service brokerages where you have staff who are not tied to traditional case management roles… Also, it gave us confidence that it was a do-able model."

Table 1. Number of Individuals or Families with Individual Budgets/CDS by State in 2006/2007

State	Individuals/ Families With CDS*	HCBS Participants With IDD**	HCBS Participants With IDD Receiving CDS
Available Statewide			
Vermont	1,060	2,102	50.4%
Oregon	4,000	9,416	42.5%
Michigan	3,000	8,283	36.2%
Utah	1,300	3,986	32.6%
South Dakota	815	2,522	32.3%
Connecticut	1,272	7,232	17.6%
New Hampshire	400	3,205	12.5%
Hawaii	245	2,363	10.4%
Texas	1,303	13,999	9.3%
Minnesota	1,300	14,291	9.1%
Rhode Island	114	3,073	3.7%
Massachusetts	200	11,460	1.7%
Tennessee	85	6,962	1.2%
Limited Area Or Pilot Project			
Wisconsin	1,035	13,938	7.4%
New Jersey	450	9,611	4.7%
Florida	1,000	31,324	3.2%
Ohio	200	14,370	1.4%
Kansas	80	6,869	1.2%
Nebraska	22	3,238	0.7%
Missouri	30	8,183	0.4%
Oklahoma	15	5,043	0.3%
California	150	69,782	0.2%
New York	90	54,251	0.2%
Louisiana	13	5,484	0.2%
Total in States Offering CDS	**18,179**	**310,987**	**5.8%**

*Some of the numbers were exact, while others were estimates.
**Data effective June 30, 2006.
Source: Prouty, Smith, and Lakin, (2007)

At the same time, 11 states (Rhode Island, Tennessee, South Dakota, Kentucky, Minnesota, Colorado, Idaho, Arkansas, Delaware, Nebraska, and Georgia) have developed or are developing statewide individual budget/consumer control without the benefit of the RWJ self-determination grants, using experience and lessons learned from other initiatives, such as Cash and Counseling, Community-Integrated Personal Assistance Services and Supports (CPASS), and flexible family support and community living programs.

Political and Legal Factors

Interviewees discussed the move to individual budget/consumer control in the context of political forces within the state. In some cases, political factors prompted a move toward consumer control. For example, an administrator in a Northeastern state described how a new political environment in the state led to an examination of funding and supports, which supported the implementation of consumer control:

> When there's a new political environment, they usually come in and want to start with a clean slate and want to look at what you're doing. So, we were asked to do that. We found we had a lot of people on the waiting list who didn't want group homes. We had over a billion-dollar budget for DD; less than 7% of that money was actually being spent on people at home. A third of the people who were receiving all of the services pretty much were living in group homes or institutions. The imbalance there was pretty dramatic.

In other cases, political factors have been an impediment. One administrator reflected that following a three-year pilot project, there has not been statewide implementation "because of some politics going on in the state." Other administrators commented on the importance of building a strong base of political support for consumer-directed services, particularly within a "fiscally conservative climate."

A handful of states have enacted legislation that promotes more individualized supports in general or, more specifically, consumer-directed supports. For example, California's 1993 legislation establishing a person-centered planning process was a step in the direction of more consumer control. In Kentucky, legislation required examination of self-directed supports as a possible option. In Oklahoma, the Olmstead Committee tried, unsuccessfully, to establish consumer-directed supports, but after pressure from advocates, a Senate bill was issued in 2005 appointing an advisory committee composed of families and consumers to work with the state to develop consumer-directed services.

Finally, in some states, such as Massachusetts, Tennessee, and Oregon, the evolution toward consumer-controlled supports was prompted, in part, by lawsuits. For example, one administrator noted, "Primarily, this came out of a lawsuit regarding the waiting list. The state was looking for options that would be more cost effective." An administrator in another state explained, "This waiver was developed as a settlement against a wait-list lawsuit. The state and plaintiffs agreed to come up with entitlement services with capped finances." A group of stakeholders was formed, and this group has met monthly to plan the implementation and to review outcomes of implementation.

Variation in CDS Among States

Analysis of semi-structured interviews with state developmental disabilities services directors (or their representatives) yielded several findings related to differences in how states are implementing consumer-directed funding initiatives. These differences highlight variability in the extent to which states have embraced consumer direction, as well as the difficulties inherent in introducing a new model of support provision. Key areas of variability are discussed in this section.

Eligibility

States varied widely in eligibility for individual budgets and consumer control. Key differences emerged in eligibility for adults versus children, geographic availability within each state, and whether consumer-directed options are available to all individuals who qualify for waiver services or only those who are on the state's waiver waiting list:

- *Children and adults*. Of the 24 states offering at least some degree of individual budget/consumer control, most offered this option to both children and adults. South Dakota was the only state providing the option only to children, except for a small number of adults through an agency with choice option. A few states (Oregon, New Jersey, Massachusetts, and Ohio) offered individual budget/consumer control only to adults.
- *Geographic scope*. Eleven states offered individual budget/consumer control either in limited geographic regions of the state or as a pilot project to a limited number of people, typically also in a limited area of the state. In states with county-based service systems, individual budget/consumer control may be county specific. For example, in Wisconsin, it is only fully available in Dane County, with some aspects of consumer control existing in other counties. An administrator in another Midwestern state commented that it is "theoretically offered statewide but the degree to which it is embraced varies across the counties." Other states have offered individual budget/consumer control as a pilot project to a limited number of people, most often within a limited geographic region. For example, California has had a pilot project in five of its 21 Regional Centers, involving 150 people. Oklahoma, Louisiana, and Kansas have had pilot projects with a limited number of people (15 in Oklahoma, 13 in Louisiana, 90 in Kansas) within a few areas of each state. Florida has had a larger statewide pilot project, with approximately 1,000 people, but limited to those who were part of the Cash and Counseling demonstration project. One state is working toward statewide implementation by "rolling out" eligibility across the state over a three-year period. An administrator discussed the reasons for this:

  One reason was obviously money. But, maybe even more important than the money was, we didn't want this to be a little pilot over here. We did really want it to be a system-wide opportunity for people, so we wanted to build it, and we wanted to do that slowly in order to make sure that we were making the adjustments and changes that we needed.
- *General availability versus waiting list availability*. Some states extend eligibility for individual budget/consumer control to all those who are eligible for developmental disabilities waiver services. A few states limit eligibility either to people who are on the waiting list for services (e.g., Tennessee, New Jersey) or to people who already receive services. Budgetary issues provided one rationale for the gradual roll out of services. Additionally, some administrators described the gradual roll out as a way to allow for adjustments that would need to be made in the program.

Assistance With Management of Services

A key component of self-determination is the availability of assistance with managing supports (Bradley et al., 2001; Olmstead, 1999; Smith, 2003). In implementation of consumer-directed supports, states recognized a need for different types and levels of assistance than provided by traditional case management. There are many ways that states are addressing this need. The two most common models of assistance are providing a combined service coordinator/broker role or providing a separate support broker role:

- *Combined service coordinator/broker role*. In some states, people who elect to direct their own services have access to a specialized case manager/service coordinator who has received training beyond that which is offered to traditional case managers and who may have a smaller caseload. In some states, such as Utah, all service coordinators have received additional training in order to be prepared to assist people who choose the "self-administered services" option. In other states, a separate set of service coordinators with new titles and somewhat different training has been created. Florida has trained some support coordinators to play the role of "consultants." An administrator described, "We train that person to perform a 'consultant service,' so they do it a little differently when people are managing their own care, so it's more of a consultant and less of a case manager." Connecticut created a "broker case manager" role for people who self-manage. They have a lower case load than traditional case managers (e.g., 20-30 versus about 40-100). Minnesota added an optional service called "flexible case management" designed so that 50% of case management costs are embedded in the individual budget. Beyond this, people can purchase additional "flexible case management." Participation in flexible case management is optional for most; however, some counties require particular individuals, who they

feel require more support, to purchase additional "flexible case management."

With the combined service coordinator/broker role, there is a risk that it is merely a change in title with somewhat different training instead of a real and significant change in roles. Evaluation of the Consumer-Directed Care (CDC) program in Florida found some problems associated with the use of case managers and support coordinators as consultants (Foster, Phillips, & Shore, 2005, p. 31):

> Florida's decision to recruit CDC consultants from the ranks of case managers and support coordinators was fiscally practical, and it was thought that consumers would benefit from the continuity of the arrangement. However, the decision also had a serious downside. Some consultants were the very case mangers who had been reluctant to enroll beneficiaries in CDC in the first place. Now they were expected to help beneficiaries on their way to consumer direction… Moreover, most consultants thought they were not adequately trained for their CDC roles.

- *Separate support broker role*. Other states have established a support broker role (e.g., Oregon, Tennessee, New York, Vermont, Wisconsin, and New Jersey) in addition to and distinct from case management. In some of these states, there is particular emphasis placed on the notion that these be "independent" support brokers. For example, over the past several years, Vermont has invested significant effort in developing support brokerage within the state. As described in an article by Smith (2003, pp. 296-297):

> Several formal trainings have been held to create a cohort of brokers in Vermont. Developed and led by people with disabilities, families, and professionals, these training sessions offer opportunities to explore values as well as provide specific information about topics that include person- and family-centered planning, taxes, liability, and insurance.

Wisconsin has invested significant time defining the role of support brokers and has compiled a manual entitled *Quality Standards for Support Brokers* (Dane County Department of Human Services and the Dane County Support Broker Coalition, 2006). They also invested significant time training these brokers. An administrator commented, "It became a much more valuable role as a result of these trainings."

Tennessee and New York have both case managers and support brokers. Tennessee has outlined distinctive roles for support brokers and case managers (Division of Mental Retardation Services, 2005). In the Tennessee model, case managers develop and monitor care plans, inform participants about support options, review budgets, and authorize emergency services. In contrast, Tennessee support brokers provide self-determination training, assist in management of personal care staff, help manage budgets, and evaluate the performance of support providers.

In New York, the support broker is referred to as a "start-up broker" and is available to people, in addition to a case manager, to assist in the first six months with the application process and start-up of consumer-directed services. Administrators in New York have been conscious about clarifying different roles for the case manager and start-up broker. An administrator in New York stated that it has sometimes presented a challenge to maintain separate roles for service coordinators and support brokers, and that the development of specialized checklists for each role has helped in delineating the roles.

New York has established specialized initial and ongoing training for the brokers. Likewise, when consumer control is implemented statewide, California will have separate service coordinator and support broker roles. Based on experience from the pilot project, California is considering using the support broker for start-up assistance and the service coordinator for ongoing assistance.

Finally, based on experiences in their state, an administrator in a Northeastern state commented on the need for attention to the types of people hired for these support broker roles:

> We started with hiring all the wrong people. We hired social workers. Nothing wrong with them, but we hired social workers who needed to be in control... One of the things we found is that the people who had the natural affinity for it were parents, and so we now give preference to people who have somebody with a developmental disability in their family as a support coordinator. That's brought tremendous advantages including a passion for this that has really helped a lot.

Limited Versus Unlimited Maximum Budget

In most states that offer an option for consumer-directed supports, the maximum individual budget is limited only by the Intermediate Care Facility for the Mentally Retarded (ICF/MR) rate. A few states, however, have significantly lower maximum budgets. For example, Tennessee has a budget cap of $30,000, Oregon has a cap of $20,000, New Hampshire has a cap of $30,000 on its Independence Plus waiver, and Delaware has a cap of $3,800. In its pilot project, Oklahoma has had a cap of $18,800 for adults and $12,200 for children. In one Northeastern state that currently has no cap, an administrator stated that they were, "sort of moving in that direction."

In states with lower capped budgets, the implementation of consumer control is occurring within the context of family support and/or addressing the waiting list. In Oregon and Tennessee, for example, the waiver was created to address the waiting list. For instance, one administrator remarked:

> We have a waiting list that's over 4,700 people; the state was looking for options that would be more cost-effective. The attorneys that filed the suit suggested we allow self-direction; they had much contact with families in the lawsuit, and they felt that was a strong need.

Types of Waivers

There is also variability among states in how consumer-directed options are integrated into the state's waiver system. Some states (e.g., Florida, Connecticut, Tennessee, Oregon, New Hampshire, South Dakota, Maryland, Kentucky, Idaho, and Delaware) have separate waivers for consumer-directed services, such as Independence Plus or family support/in-home support waivers. In 2006/2007, only a few states (e.g., New Hampshire, Connecticut, and Louisiana) offered Independence Plus waivers targeting individuals with intellectual and developmental disabilities and a few more were anticipating start-up of such waivers (e.g., Maryland and Kentucky).

Other states have amended existing waivers (e.g., Utah, South Dakota, New Hampshire, Hawaii, Arkansas, Nebraska, and Georgia) to add a component of consumer direction. A few states have amended existing waivers in addition to having a separate consumer-directed waiver. For example, in New Hampshire, families can direct services for children through the Independence Plus waiver, while adults can direct their own supports through an amendment to the existing waiver. Additionally, a few states have implemented (or plan to implement) individual budget/consumer control across all of their waivers (e.g., Vermont, New Hampshire, Rhode Island, Texas, Minnesota, Iowa, and Kentucky).

Hiring and Payment of Direct Support Staff

Most states had guidelines about who can and cannot be hired to provide support services. In general, the restrictions included age (must be 18 years old, or 16 in a few states), not a spouse or legal guardian, and no criminal background. Administrators in a few states mentioned exceptions. In Florida, for example, which offers consumer control through an 1115 Demonstration Waiver, people can hire anyone, including family members. An evaluation conducted by Mathematica Policy Research, Inc., attributed much of the program's success to this in that nearly 60% of consumers who hired workers hired family members (Foster, Phillips, & Schore, 2005). In Minnesota, parents of minors can be paid, but the rate cannot exceed the Personal Care Attendant (PCA) rate, which is about $15.08 per hour, and the hours cannot exceed 40 per week.

Some states offer little or no flexibility about what support workers are paid. In Hawaii, for example, pay is non-negotiable, based on set rates. In other states, there are predetermined rate ranges. Connecticut has established rate ranges for different types of services; for example, the range for "personal support" is $9.50-$16.50 per hour, while the range for "individual supports/habilitation" is $16.50-$22.50. Utah also has established minimums and maximums, with some latitude in between.

Other states give individuals and families a high degree of flexibility. As an administrator in the Northeast remarked, "The family is in control of how much they pay people. The beauty of the individual budget is that it allows the family to be able to negotiate their own wages and payments with each provider." Administrators in several other states (e.g., Oregon, Minnesota, Georgia, Florida, and New York) said that payment was flexible but that it must generally be within the "normal and customary cost" (Oregon), based on "community standards" (Minnesota), reflect "good and reasonable decisions" (Florida), or that people must be "prudent buyers" (New York). Generally, in these states, administrators went on to say that going beyond what is considered "normal and customary" is possible but requires justification (e.g., Oregon and New York). Texas specifies that pay must be at least 90% of program service rate; the other 10% may be used for employer support services with a cap of $600 per year on employer- and employment-related purchases.

■ Recommendations: Lessons Learned

The themes emerging from this research spotlight many of the best practices and lessons learned in the early period of consumer-directed funding programs. Many of these themes parallel previous findings, particularly from the RWJ pilot projects (Bradley et al., 2001). This section will build upon those previous findings to present a set of specific lessons for states in implementing consumer-directed initiatives.

Establish a Separate Support Broker Role

Based on pilot projects and initial statewide implementation, administrators in a number of states stressed the need for a support broker, distinct from a case manager or service coordinator. As previously noted, several states have devoted significant attention to the development of this role, based on lessons learned in the initial pilot projects. In Oregon, based on lessons from their RWJ project, they recognized the importance of having support brokers who are "not tied to traditional case management roles." California has operated different types of pilot projects in various Regional Centers. In some of these, the service coordinator role was combined with the support broker role while in others the two roles were distinct. Based on these preliminary attempts at implementation, California will establish the support broker as a separate role when consumer control is initiated statewide.

Build in Different Levels of Assistance

Related to the need for a separate support broker was the recognition by states of the need to build in a variety of levels of support for managing services and finances. For example, with its RWJ grant, Vermont developed the fiscal intermediary service (ISO) in the state. However, there were some individuals and families who wanted to manage their own supports, but needed additional assistance to do so. With a Real Choices grant, Vermont developed a Supportive ISO, which offers more assistance. In addition, the state developed a variety of management options, from self-managed to shared management/home provider managed. Many more people have chosen the shared management/home provider management than self-management (1,040 compared to 60).

Some other states are also choosing to build in a variety of levels of assistance. For example, after Texas officials began implementation, they recognized the need to provide more assistance to some individuals on employer responsibilities. In response, they created a service option called Support Consultation Services in addition to the supports already available through their consumer-directed support agencies. Connecticut has "broker case managers" instead of traditional case managers. However, if people would like more assistance, they can purchase a service called Family and Individual Consultation and Support. Arkansas is planning to build in three levels of assistance within financial management. Colorado is building in two levels of assistance: a "personal agent" and a "support broker." Other states are building in different types of support, such as peer mentors in Maryland or family circles in Hawaii.

Expect a Loss of Flexibility with System-Wide Implementation

Most states that have statewide consumer control options began with pilot projects (e.g., Utah, Tennessee, Minnesota, Oregon, New Jersey, New Hampshire, Massachusetts, Hawaii, and Wisconsin). In many of these states, the pilot projects were more flexible, particularly those that operated with state or grant funding. With the move to statewide consumer control through Medicaid HCBS, there was a loss of flexibility and the need to create more infrastructure and bureaucracy to support it. For example, an administrator in the Northeast reflected, "Doing it for a small pilot, it was really flexible, but as we've expanded, we've had to put in more bureaucratic kinds of checks and balances." In an attempt to retain as much flexibility as possible, state funds cover some things that are not covered through Medicaid. On the other hand, an administrator in a Midwestern state noted that the flexibility of the pilot project had some drawbacks, at least on the administrative side: "With the loose definitions, it came to feel like a runaway train; it was a nightmare for counties, the state, and families to understand the rules of the road, because there weren't too many."

Change Information Technology (IT) Systems

It is a vast, time-consuming undertaking for many states to adapt their information technology (IT) infrastructure to individual budget/consumer control. For example, an administrator in the Northeast reflected on some of the changes in their system:

> This is different than when our financial systems were built on major contracts, where you pay the same amount every month, and you make one payment for 100 people. This is much more labor-intensive because we didn't have the most up-to-date technology. We have put a huge emphasis on our IT stuff, hired some software programmers, changed our servers, and so on.

Some states have begun offering an individual budget/consumer control option while still making the required changes in IT. An administrator in a Midwestern state commented on the difficulties this posed for people who were part of their pilot project: "It is hard for people to direct their services, obviously, if they don't have the information to do it." Once an IT infrastructure is in place, it can help coordinate management and budget monitoring. For example, a Northeastern administrator talked about the importance of having established a live Internet record that allows individuals or family members, support coordinators, and fiscal intermediaries to have access to the same information.

Provide Adequate Information, Education, and Support

While planning for and implementing individual budget/consumer control, administrators in several states noted the importance of adequately informing and training individuals and families. A first step is developing the staffing and resources necessary to provide assistance. A lesson from the CPASS pilot project in Arkansas was that some staff members who assisted people with self-direction were not adequately trained. The reviewers noted, "Ongoing technical assistance in the mechanisms of self-direction such as individual budgets, rights, responsibilities, and risks, and the function of FIO [Fiscal Intermediary Organizations] among other topic areas would have been beneficial for those implementing the project and individuals receiving services" (Wagle, Agosta, & Melda, 2004, p. 14).

The types of information and training needed vary widely, and include the need to "communicate with people and educate them regarding the parameters of the program," the need to "help people have understanding and clarity about what their individual budget is and the value of it," and the need to "help people understand the responsibilities." A Connecticut administrator discussed the need to create an infrastructure to assist people with consumer-controlled services and individual budgets, while administrators in Florida and Utah emphasized clearly communicating with consumers about the parameters of the program and their

personal responsibilities within it. An administrator from the West stressed the importance of, "making sure [consumers] understand up front that this is a business and that money isn't just granted to you; it's not yours until it's spent on a legitimate service."

Assess Costs Within the Context of the Whole System

States that offer a consumer-directed option have usually collected some data on these services (e.g., who is participating, what services they are self-directing, costs for those services). However, most states have done little if any analysis of the data, making accurate cost comparison data scarce at this stage of implementation.

Cost savings are typically built into this option, such as 90% of provider rates or lower administrative costs. For example, several administrators noted that, "it would be safe to say they cost less, as the cost cannot exceed an agency budget," and "there is a discount in the formula on the consumer-directed side." Likewise, a Western administrator noted that the administrative cost for self-administered services is about 14% lower than for contract providers.

In a few other states, administrators offered some estimates or guesses as to cost savings. For example, an administrator in the Midwest stated, "More people are electing $4,500 a year as opposed to the $38,000 because they like the self-directed model; I would estimate it saved a million dollars last year."

Only a few states have systematically analyzed costs. In Texas, a study was conducted by the state Health and Human Services Commission (Texas Health and Human Services Commission, 2004). The services in Texas are cost-neutral by design. A cost-effect analysis of the CLASS program in 2004 found that the consumer-directed option costs $161.39 more per recipient per month than the non-CDS option. At the suggestion of the workgroup, analysis was expanded to examine the influence of authorized service utilization. Follow up study revealed that increased utilization of authorized services accounted for 60% of the cost difference. Adjusting for utilization differences, the cost discrepancy was reduced to $65.96 per recipient per month.

In a Florida analysis, Dale, Brown, and Phillips (2004) found that HCBS expenditures were higher for the "treatment group" (those using CDS) than for the "control group" (those not in CDS). This difference was due to two factors: the "treatment group" members had higher-than-expected resources allocated to them, and "control group" members had lower-than-expected HCBS expenditures. While Florida is trying to control CDS program costs (e.g., cost guidelines, further training of consultants/support brokers), the study also points to the need to examine why traditional service users had lower-than-expected expenditures. More broadly, the studies in Texas and Florida point to the need to assess the costs of consumer-directed services within the context of costs across all services and the system as a whole.

Adapt Monitoring and Quality Assurance Systems

In some states, quality assurance (QA) and monitoring for CDS are described as being the same as for more traditional services. In other states, there is less intense monitoring than in traditional services, with more reliance on the individual and family. For example, service coordinators in Utah are required to have a monthly face-to-face visit for people in traditional services but only quarterly for people in self-directed services. A few states also mentioned increased reliance on a circle of support for people who direct their own services. New York, for example, relies heavily on the circle of support, and everyone who has consumer-directed services is required to have a circle of support.

Data collected for QA/monitoring purposes, such as the National Core Indicators data, is not always separated out for individuals who direct their own services. However, some states are heading in that direction. Some states are also building in requirements for fiscal intermediaries or support brokers to do consumer satisfaction surveys (e.g., Minnesota, Oregon).

Several states that are implementing consumer control are revising their entire quality review system. For example, Massachusetts was designing quality outcomes for self-directed supports. They initially relied more on case managers but are now developing a more formal system. Oregon has contracted with the Human Services Research Institute to identify quality indicators for people who self-direct. But making these revisions to state systems has its challenges.

Emphasize Accountability and Equity

Although the issue has been covered more thoroughly elsewhere (Moseley, Gettings, & Cooper, 2003), this research revealed a few issues that were raised in relation to budgets and statewide implementation of consumer control. First, in relation to individualized funding, administrators talked about accountability. In particular, as an administrator from the West put it, having to "figure out the balance between private control of money and public responsibility and accountability for those dollars" is a key element to the long-term success of consumer direction. As consumer direction expands from pilot projects to system-wide implementation, administrators are being pressured to more clearly define the parameters and add more tracking and monitoring. An administrator in a Western state said that, "when it first began it was perceived as not having as many internal controls as with providers, so we have been trying to improve those."

A second significant issue that was raised is equity of individual budgets. States were struggling with how to create individual budgets that are "equitable and not idiosyncratic" (e.g., Massachusetts, New York, New Jersey). Based on existing research, New Jersey established four levels of need to guide budget development. Connecticut has found that cost standard guidelines are helpful. Minnesota has tried

to improve equity by moving from county-set to state-set budgets. Several states are engaged in efforts related to rate setting, restructuring, and the broader issues of equity and accountability.

Collaborate With Stakeholders

A number of state administrators noted the importance of collaboration between stakeholders in developing and promoting consumer-directed services. This can be challenging because different stakeholders have different interests. For instance, several state administrators reported that some constituencies, especially provider organizations, were still opposed to people with disabilities having control over money. One administrator commented: "People don't like to give up their control over people with intellectual impairments; the providers don't change easily." The Arkansas pilot project showed that an effective plan needs key stakeholders to share a clear vision of the plan and then agree to implement it together (Wagle et al., 2004). Additionally, lessons from the failed implementation of a Cash and Counseling demonstration project in New York illustrate the importance of establishing a clear vision of why the consumer-directed program is necessary and gaining buy-in from stakeholders in government, provider agencies, and self-advocacy groups (Sciegaj, Mahoney, & Simone, 2008).

Several states had effective stakeholders groups and administrators mentioned the key role that these groups played. For instance, a statewide planning retreat in Colorado that included self-advocates, professionals, and others, articulated the need for change in the direction of self-determination. Similarly, a Midwestern administrator observed that the move to consumer control "… started through advocacy. A stakeholder group went out and did some focus groups. It was a grassroots effort that started this." Stakeholders groups can help promote broader acceptance of the idea of consumer control. In another state, an administrator remarked, "Lots of people still don't believe in this but the stakeholders groups and the pilot have helped build buy-in."

Anticipate Increased Consumer Satisfaction

While there has been little systematic study or national evaluation, consumer-directed options are reported to be highly successful and satisfactory to those who use them. In a Florida study, parents reported greater satisfaction and fewer unmet needs (Foster et al., 2004). Another study in Florida found that 88% of consumers said they would "recommend the program to others who wanted more control over their personal care services." An administrator in a Southern state commented:

> Virtually everyone who has participated has loved it. They have found great freedom in it. It has limited government intrusion into people's lives and allowed them to be more creative in how they design services to meet their needs.

From the perspective of the state administrators, themes related to success include:

- Not having to fit people into program-specific slots.
- Seeing people succeed after experiencing frustration with traditional services.
- Real change has occurred in people's lives.
- Hiring people of one's choice, with less staff turnover.
- Reaching more diverse service users.
- More efficient use of resources.
- Collaboration between stakeholders, with increased participation by self-advocates.

■ Conclusion

This study provides an overview of the status of CDS options in the United States, from the perspective of administrators of state developmental disabilities services. The study revealed much progress towards implementation of consumer-directed initiatives, but significant variability among states remains. However, consumer direction is still very new, and for its long-term success the administration of consumer-directed programs will likely need revision. This brief has highlighted several key areas that warrant attention as states continue towards consumer direction.

As consumer direction expands, more comprehensive and systemic evaluation will be needed. National reoccurring data sources, such as the Residential Information Systems Project funded by the Administration on Developmental Disabilities, will need to gather annual data from states on consumer direction to monitor its growth and use across states. Further CDS outcome studies will be needed to understand the outcomes experienced by service recipients and the differences in these outcomes as compared to non-consumer-directed service users. And more study is needed on costs. This study was also limited in scope in relation to direct support staff issues. Future research will be needed to explore differences in pay and benefits, as well as various state initiatives related to expanding and improving the direct care workforce, especially in relation to consumer-directed services.

States are in the formative stage of offering consumer direction. While most understand the need to provide supports and training to individuals and families, little is known about the effects of these supports. Further opportunities to share and learn what states are doing is essential and will benefit states that already offer an individual budget/CDS option as well as states that are now exploring this option.

At the time of the interviews, several states were developing new separate waivers or amending their existing waivers. Future studies may provide a clearer picture of how states are embedding consumer direction within their waivers and the impact of different approaches on states' ability to implement consumer-directed services.

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Policy Research Brief
January 2009 • Vol. 20, No. 1

Policy Research Brief is published by the Research and Training Center on Community Living and Employment, Institute on Community Integration (UCEDD), College of Education and Human Development, University of Minnesota. This publication is supported, in part, by Cooperative Agreement #H133B080005 from the National Institute on Disability and Rehabilitation Research (NIDRR), U.S. Department of Education.

Managing Editor is Sheryl A. Larson. The opinions expressed are those of the authors and do not necessarily reflect the position of the Center or its funding sources.

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