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# Beneficiary Centered Care in Services to Persons With Developmental Disabilities

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*This article provides an overview of the findings from the Evaluation of Medicaid's Community Supported Living Arrangements (CSLA) Program. Results suggest that CSLA provided a useful model of beneficiary centered care for persons with developmental disabilities. The implications of the findings of this evaluation for current management of Medicaid programs are discussed.*

## INTRODUCTION

The past quarter century has brought dramatic changes in the kinds of places where people with mental retardation and related developmental disabilities (MRDD) live. In 1967, there were 228,500 people with MRDD living in State institutions (194,650 in MRDD institutions and 33,850 in psychiatric facilities). By June 1996, those populations had been reduced to 63,400 people. In the 19 years between June 1977-June 1996, the number of people living in community housing with 15 or fewer residents increased from 40,400 to 228,900 people, whereas those living in settings of 6 or fewer residents increased from 19,700 people to 172,500 people. By June 1996, 31 of 51 States, including the District of Columbia, were serving a majority of their MRDD long-term care beneficiaries in settings with no more than 6 residents (Prouty and Lakin, 1997).

Such changes in care are also evident in the Federal Medicaid program. On June 30, 1982, there were 140,752 residents of congregate-care facilities certified to participate in the Medicaid Intermediate Care Facility for the Mentally Retarded (ICF/MR) program, with 131,038 living in ICFs/MR of 16 or more residents, 7,142 living in facilities of 7-15 residents, and only 2,572 living in facilities of 6 or fewer residents. There were only 1,381 persons enrolled in the new Medicaid Home and Community Based Services (HCBS) waiver program for financing cost-effective community alternatives to ICF/MR. By June 1996, there were 129,449 residents of ICFs/MR, with 85,109 living in facilities of 16 or more residents, 24,412 living in facilities of 7-15 residents, and 19,928 living in settings of 6 or fewer residents. Most remarkably, the Medicaid HCBS program provided services to 190,230 people with MRDD, an estimated 134,900 (70.9 percent) of whom were living in residential arrangements other than the home of parents or other relatives (Prouty and Lakin, 1997).

Such dramatic shifts to community settings as the focus of Medicaid long-term care have given pause to reflection about how much these changes affected opportunities of people with developmental disabilities to control their own lives, services, and outcomes in ways implied in the notion of beneficiary centered care. Articulation of the ideals of beneficiary centered care, with its encouragement of choice, self-determination, support of personal goals, and promotion of independence, has most

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frequently for individuals with developmental disabilities been subsumed under the term supported living. Within MRDD long-term care systems, the ideals of supported living have required revolutionary changes in basic practices and expectations of both providers and recipients of care. Supported living as an ideal and as a service approach has been built around several general propositions (Bradley, Ashbaugh and Blaney, 1994; Smith, 1990; Taylor, Bogdan, and Racino, 1991):

- People must have homes of their own, in which they control their own front door, select themselves, and live with people they choose.
- The selection and financing of people's housing should, as much as possible, be treated as distinct from the selection and financing of the services and supports they receive.
- People must exercise choice and control in what services and supports they receive and from whom.
- People must define the lifestyles they want and be supported in achieving them, and where their experiences have been limited they must be afforded experiences and assistance in developing and expressing preferences for their lifestyles.
- Everyone in people's lives must learn and practice new ways of listening to what they want and dream about, and must redefine themselves as allies in helping them achieve as much of what they want in life as can be achieved.
- Service providers must learn how to be less intrusive in the ways that they bring services and supports into people's homes, and must be sensitive to and respectful of their homes and the rights and courtesies associated with them.
- Service providers must learn new ways of operating to deliver services

in different ways to different people in different places and adjust to a market in which persons served and revenues generated are determined by demand from individuals, not contracts to care for groups.

- Quality assurance systems must assess and contribute quality in ways that are defined by what the individual and other key individuals in the person's life want and expect from the services and supports they receive.

As with beneficiary centered care, proponents of supported living note that ultimately supported living is not achieved simply through new service rules or approaches to funding, but involves fundamentally new attitudes and new commitments to the dignity and desires of beneficiaries with developmental disabilities to control their own lives.

## **MEDICAID COMMUNITY SUPPORTED LIVING ARRANGEMENTS**

Beginning in 1981, Medicaid Home and Community Based Services (HCBS) waiver programs became available to States to provide services to persons with MRDD who would otherwise be at risk of placement in ICF/MRs or Nursing Facilities (NFs). State programs developed under this authority were granted substantial latitude to pursue the goals of beneficiary-centered (or person-centered) care, but until recently substantial constraints were placed on States' use of the HCBS waiver (Government Accounting Office, 1996). Specifically, States' HCBS program growth was limited to their ability to demonstrate that the State would otherwise have had sufficient ICF/MR bed capacity to serve those persons in the HCBS waiver program as well as those who remained institutionalized (i.e., the "cold bed" policy). As a result, many States during the late 1980s

desired opportunities to expand Medicaid-financed community services beyond what States felt they could under the cold bed policy. States and disability advocates were also eager to test an officially sanctioned Medicaid service delivery program that was primarily established on the principles of supported living (or beneficiary-centered care).

After several years of not reaching agreement on more substantive Medicaid reform, in the fall of 1990 Congress enacted Section 1930 to the Social Security Act to allow up to eight States to provide Community Supported Living Arrangements (CSLA) to Medicaid-eligible persons with MRDD for a 5-year period. CSLA permitted targeting of services to specific groups and geographic areas, removed demonstration of ICF/MR or nursing home level-of-care need as a condition of eligibility, allowed each State to develop its own quality assurance plan within defined Federal guidelines, and provided flexibility in the services provided. Among the broad categories of CSLA service States were authorized to provide were: personal assistance; training and habilitation to increase integration, independence, and productivity; 24-hour emergency assistance; assistive technology and adaptive equipment; support services for community participation; and other services consistent with CSLA goals if approved by the Secretary of Health and Human Services. Total Federal expenditures for the CSLA program were capped on an annual basis in each of the program's 5 years at a 5-year total of 100 million dollars. The authorized funding was evenly divided among the eight States that were selected to add CSLA to their State Medicaid program.

Twenty-seven States applied for authorization to add CSLA services to their State Medicaid plans. The programs of the eight States whose applications were chosen in a

competitive review process (California, Colorado, Florida, Illinois, Maryland, Michigan, Rhode Island, and Wisconsin) varied with respect to target populations, numbers of participants, services provided, cost per participant, and in other ways. However, they did share common goal statements related to general principles of supported living presented earlier including consumer choice and control over their homes, services, and providers; person-centered planning; focus on individually desired outcomes; and other programmatic elements consistent with beneficiary-centered care.

Although the CSLA legislation authorized enrollments of CSLA beneficiaries in Fiscal Year (FY) 1991, the legislation's enactment at the beginning of FY1991, the time needed by HCFA to establish procedures for inviting, preparing, and reviewing State applications, the internal HCFA activities to establish regulations, and the internal activities among States eventually selected to create rules and administration procedures and to implement the selection and enrollment of individual participants, caused a substantial practical shortening of the 5-year authorization of Congress. In fact, although technically beginning in October 1990, CSLA services were not initiated in any State until February 1992, beginning with Rhode Island, with Colorado's initial enrollment not coming until August 1992 (i.e., almost at the end of Year 2 of the 5-year program).

## **Evaluation Methodology**

Planning meetings with a National Advisory Committee, State CSLA coordinators and HCFA staff served to identify the primary purpose of HCFA's CSLA evaluation identifying, describing, and examining the outcomes and implications of different State approaches to implementing

CSLA. A case-study approach was used to permit consistency in the areas and issues attended to in each State and to permit flexibility to describe the variability among States. The focus of the site visits was to examine the service-system redesign, as well as the approaches that appeared to be more or less successful. As a result, respondents were consistently questioned about what was working well in CSLA, what could be improved, and what aspects and roles of the State implementation efforts were valuable, benign, and impeding in achieving the State's objectives.

Working with the National Advisory Committee and HCFA staff, four major topics were identified for each State case study. The first topic included philosophy, the goals and objectives of the CSLA program, and the nature and effectiveness of efforts to achieve them. Second was the State and local organization for CSLA, which included service definition and design, access, and use of resources; cross-agency administrative and program relationships; financing; and specific approaches taken in key areas such as person-centered planning and provider recruitment. The third major topic was the nature and effectiveness of quality assurance and quality enhancement approaches which included approaches to licensing, quality assurance, and use of consumer monitoring boards. The final topic was ongoing and resolved policy issues.

A structured interview protocol was developed; within each topical area the interview protocol contained sections specifically targeted to informants with different CSLA roles and perspectives, including State officials, provider agencies, and program participants.

Week-long site visits were conducted by two-person teams in each CSLA State. Interviews conducted during the site visit were structured to balance a representa-

tive sample of CSLA agencies, geographic location, people served, and the maturity of the agency's CSLA program. Although the number of interviews with agency personnel, people with disabilities, families, and other local community members varied by State, in each State from 65 percent to 80 percent of scheduled interview time was committed to service-level interviews. Service recipients and family members were provided options of being interviewed on an individual basis or as part of a group forum. Most families and people with disabilities chose to be interviewed in their homes.

In addition to the interviews, the evaluation involved extensive document review. Documents obtained and reviewed included State CSLA applications, CSLA manuals, and descriptions of CSLA developed to inform potential people with disabilities, family members, and others about CSLA and its application procedures. These documents were augmented with a wide variety of policy, planning, administrative, and other documents of State and local government agencies and of private service-providing organizations.

States participated in two program-related surveys. These surveys gathered information on the number and characteristics of program enrollees and on CSLA services and expenditures for enrollees. Respondents were the State CSLA coordinators. The surveys included common data elements that could be reported in at least five of the eight CSLA States.

### **Program-Status CSLA Eligibility**

The legislation creating the CSLA program contained certain requirements for program eligibility, but also provided States with latitude to target sub-populations of eligible individuals. Each State implemented procedures that screened for

Medicaid eligibility, determined the presence of a developmental disability, and assured that CSLA services were provided only to people living in their own homes or homes of relatives (as stipulated by the legislation). The only exception was California's CSLA service to assist people in finding a home of their own prior to initiating CSLA supports.

States targeted a range of sub-populations for CSLA services. Although there were subtle differences in the specifications of each State's targeted sub-populations, three groups were targeted in all eight CSLA States. They were (1) adults not receiving, but needing community supports (including those who did not meet ICF/MR or NF level of care criteria), (2) adults who were currently receiving traditional residential services, but who wanted to have more control over their homes and services, and (3) young adults in transition from special education, family support, and other children's services so as to avoid entry into traditional long-term care. Three States also targeted adults who were unable to remain in their current living arrangements because of abuse, neglect, or an illness and disability involving the individual's primary caregivers.

By September 1995, enrollment across the eight States reached 3,441 individuals, an average of 73 percent of projected enrollment. Although some States such as Wisconsin and Colorado substantially exceeded projected enrollment, other States such as Maryland served far fewer than originally projected. Variations were affected by State and local decisions regarding the use of authorized spending, the average expenditure per enrolled beneficiary, and the degree of State commitment to enrolling as many eligible who could benefit from services as possible, within each State's budget cap.

## **Demographic and Diagnostic Characteristics**

Within the CSLA program, the distribution of male and female participants was generally similar across States. African Americans made up 12 percent of all CSLA beneficiaries, but varied substantially State to State (from 25.5 percent in Maryland to 1.1 percent in Wisconsin). Most CSLA beneficiaries were in the 22-39 year age range, ranging from 54.7 percent in Illinois to 76.3 percent in California.

One of the advantages of CSLA for States was that, unlike the HCBS program, participation was not limited to persons who would otherwise be eligible for ICF/MR services. CSLA provided access to Medicaid long-term care services for Medicaid-eligible persons who did not need, did not want, or would not benefit from full-time care, supervision, and habilitation. As a result of States' being able to use CSLA to provide community services to people who were not ICF/MR-eligible and their related ability to use HCBS to provide community services to those who were, where CSLA was implemented the 3,441 persons served did exhibit diagnostic characteristics that were generally different from those living in community-based ICFs/MR. In a comparison of the characteristics of CSLA recipients as reported in State data sets (Lakin, Hayden, and Burwell, 1996) with the characteristics of community ICF/MR residents from HCFA's Online Survey Certification and Reporting System (OSCAR), Larson and Lakin (1995) showed CSLA participants to be much more likely to have mild or no mental retardation than community ICF/MR residents. Overall, 18.8 percent of CSLA recipients did not experience mental retardation, with the individual States ranging from 38.7 percent in Maryland to 1.6

**Table 1**  
**Living Arrangements of CSLAs, by Participating State**

Type of Living Arrangement	Participating State							
	California <sup>1</sup>	Colorado <sup>2</sup>	Florida <sup>3</sup>	Illinois <sup>4</sup>	Maryland	Michigan <sup>5</sup>	Rhode Island <sup>6</sup>	Wisconsin <sup>7</sup>
<b>Independent</b>								
	Percent							
Alone in Own Apartment, Room, or House	38.0	30.2	(3)	25.5	22.6	24.6	13.6	27.6
With Friends/Other CSLA	19.0	11.5	(3)	47.2	33.3	28.5	27.1	29.0
Total Independent Living	57.0	41.7	(3)	72.7	55.9	53.1	40.7	56.6
<b>With Family</b>								
With Natural Parents	10.0	51.2	0.0	22.6	18.5	42.3	(6)	(7)
With Other Relatives	6.0	4.4	0.0	4.9	8.9	4.6	(6)	(7)
With Foster Parents	1.0	0.0	0.0	0.0	0.0	0.0	(6)	(7)
Total Family Living	17.0	55.6	0.0	27.4	27.4	47.4	55.1	25.6
<b>Staffed Housing</b>								
Paid Roommates/CSLA Staff	14.0	2.7	0.0	0.0	16.6	0.0	0.0	6.9
Group Living Arrangements of Four or More	12.0	0.0	0.0	0.0	0.0	0.0	4.1	0.0
Total Staffed Living	26.0	2.7	0.0	0.0	16.6	0.0	4.1	6.9

<sup>1</sup>California statistics are estimates.

<sup>2</sup>Colorado's statistics on living arrangements of CSLA participants are based on January 1995 statistics (where total number of recipients=295).

<sup>3</sup>Florida data did not distinguish whether CSLA recipients lived alone or with friends; none lived with family or in staffed housing.

<sup>4</sup>Illinois' statistics were based on reports including 63.8 percent of CSLA participants.

<sup>5</sup>Michigan's statistics were based on reports including 89.7 percent of CSLA participants.

<sup>6</sup>Rhode Island's statistics were based on reports including 98.0 percent of CSLA participants, and did not distinguish among the "types" of family members with whom participants lived.

<sup>7</sup>Wisconsin's statistics were based on reports including 98.6 percent of CSLA participants. Wisconsin's data did not distinguish the specific status (living alone, living with friends) for 16.2 percent of persons living on their own. Data did distinguish among the "types" of family members with whom CSLA participants lived.

NOTE: CSLAs are community supported living arrangements.

SOURCE: University of Minnesota, Institute on Community Integration, Center on Residential Services and Community Living.

percent in Colorado. In comparison, the OSCAR database showed 1.3 percent of community ICF/MR residents not to have mental retardation. Although 27.7 percent of CSLA participants experienced moderate to profound mental retardation, 81.4 percent of community ICF/MR residents experienced moderate to profound mental retardation. A majority of all CSLA participants (53.5 percent) were reported to have mild mental retardation. This compares with 17.3 percent of community ICF/MR residents. Although States tended to serve relatively fewer people with severe and profound mental retardation in CSLA, more than 400 were served. Following mental retardation, cerebral palsy and epilepsy were the most frequent reported

primary disabling conditions of CSLA participants.

This substantially lower degree of cognitive impairment and greater functional independence among CSLA participants was interrelated with many of the changes, challenges, and ambiguities experienced within the Medicaid or developmental disabilities program agencies implementing the CSLA programs. Issues of autonomy, freedom, safety, and control were substantially magnified in State programs in which participants were less cognitively impaired, more knowledgeable about community life, younger, and more assertive than was typical for Medicaid long-term care programs.

## Living Arrangements

Table 1 summarizes the living arrangements of CSLA participants in August 1994. As shown, only about 1.3 percent of CSLA recipients lived in group settings of 4 or more persons. California reported the largest number of persons living in group settings, but this in part reflected California's assistance to persons in locating and preparing to move to a home of their own under CSLA, including people still residing in group homes. In all, about two-thirds of all CSLA participants lived on their own, either alone or with non-paid roommates. Another 29 percent lived with family members, a proportion that varied a great deal among the States (from about half in Colorado, Michigan, and Rhode Island to none in Florida).

These living arrangements are in sharp contrast to those of HCBS participants in the participating CSLA States. In 1996, only 11 percent of HCBS participants lived in their own home, whereas 45 percent lived in a residence owned, rented, or managed by an agency (data were available for five of the eight CSLA States—Colorado, Florida, Illinois, Rhode Island, and Wisconsin) (Prouty and Lakin, 1997).

## CSLA Participant Independence

CSLA's authorizing legislation identified six broad services as well as an "other" category in which States could receive service authorization. Table 2 summarizes the variety of services offered to CSLA participants in each of the States. A number of services were provided in each of the States, including support to help people explore and become involved in community activities, support for activities of daily living, and instrumental activities of daily living, teaching or coaching of independent living skills, and case management or ser-

vice coordination. Seven States provided 24-hour emergency services and transportation. A majority of States provided assistive technology, adaptive equipment, and home modifications, behavior management, and counseling. Services that were unique to one or two State programs included vouchers, individually controlled budgets and subsidies, home-starting assistance in finding or furnishing a home, best practices information to help raise people's knowledge, and expectations about community living options. CSLA participants were also eligible for a range of services not directly funded through CSLA, including Medicaid State plan health, equipment and personal care services, or vocational rehabilitation services. In California and Michigan, such non-CSLA services were viewed as generic entitlements to be used prior to any specialized CSLA services.

Services that supported independent living and community integration (e.g., personal assistance services [PAS], transportation, and assistive technology) appeared to be more widely available in CSLA. For example, although all CSLA States provided PAS, fewer than 50 percent of HCBS waiver programs offered PAS in 1992. Transportation, offered in seven of eight CSLA programs, was provided in approximately 40 percent of HCBS programs (Harrington and DuNah, 1994).

The vast majority of CSLA participants, on whom work-activity data were reported, were employed. An estimated 35.5 percent were involved in supported employment, 12.1 percent in competitive employment, and 39.6 percent in sheltered work programs. CSLA States were authorized to spend Federal funds up to a capped amount in each year, while maintaining the required State Medicaid cost-share. In FY 1992 each CSLA State was authorized to spend \$1,250,000 in Federal funds, increas-

**Table 2**  
**Types of CSLA Services and Supports Offered, by Total Number**  
**of States Providing the Service and Support**

Type of Service and Support	States								Number Providing
	CA	CO	FL	IL	MD	MI	RI	WI	
<b>Community Participation Supports</b>									
Supported Living Consultation: Explores community services and natural supports available, and develops methods to access additional services and supports	X	X	X	X	X	X	X	X	8
Community Participation Services: Provides support to participate in community activities and functions that are desired and chosen by the individual, including services for retirees	X	X	X	X	X	X	X	X	8
Transportation Services	X	X	—	X	X	X	X	X	7
<b>Personal Assistance Services</b>									
Paid Roommates	X	X	—	—	X	—	X	—	4
Personal Care Supports: Assistance with e.g., dressing, eating	X	X	X	X	X	X	X	X	8
Supervision Services	X	X	—	—	—	—	—	—	2
Household Chore Services	X	X	—	—	X	—	—	—	3
Child and Infant Care Assistance for Parents with a Developmental Disability	—	X	—	—	—	—	—	—	1
<b>Instrumental Activity Support Services:</b> Assistance with e.g., money management, shopping, communication, and decision making									
Behavioral Management Services	X	X	X	X	X	X	X	X	8
Communication Services or Devices	—	X	—	—	—	—	—	X	2
Counseling and Therapeutic Services	X	X	—	—	X	—	X	X	5
Professional Care Services (RN, LPN, Certified Nurse Aide, or Home Health Aide)	X	X	—	—	X	—	X	—	4
Physical or Speech Therapy	X	X	—	—	—	—	X	—	3
<b>Training and Habilitation Services</b>									
Independent Living Teaching: Teaching skills in ADL and IADL	X	X	X	X	X	X	X	X	8
Self-Advocacy Training	X	X	—	—	—	—	X	—	3

See notes at end of table.

ing to \$4,375,000 in FY 1995. Table 3 provides summary statistics on State expenditures. As shown, actual Federal expenditures were substantially less than available Federal resources. In the final year of the program (FY 1995), expenditures were only 58.5 percent of original projected expenditures. In 1995, three States used 70 percent of their budget allocation (California, Illinois, and Michigan), whereas three States—Florida, Maryland, and Wisconsin—used less than one-half of their CSLA allocation. Per capita expenditures also varied substantially among the States. California and Maryland had the

highest per capita costs, but shared the highest proportion of individuals with disabilities other than mental retardation (34 percent and 39 percent, respectively). Florida and Wisconsin had the lowest per capita expenditures and served the highest proportions of persons with mild mental retardation (68 percent and 58 percent, respectively). Direct comparison of State CSLA expenditures can be misleading because of the different populations served, but also because of the different services available and the extent to which other Medicaid State plan services were used before CSLA financed services.

**Table 2—Continued**  
**Types of CSLA Services and Supports Offered, by Total Number**  
**of States Providing the Service and Support**

Type of Service and Support	States								Number Providing
	CA	CO	FL	IL	MD	MI	RI	WI	
<b>24 Hour Emergency Assistance/Response System</b>									
24-Hour Emergency Assistance: Ensures someone will respond in an emergency	X	X	X	X	X	—	X	X	7
<b>Assistive Technology</b>									
Evaluation of need for assistive technology; Purchasing, repairing, or replacing devices; and training	X	X	—	—	X	X	X	X	6
<b>Minor Home or Environmental Modification Services or Adaptive Equipment</b>									
Assessment of need for and provision of modification to home to enable community living, security, and accessibility	X	X	—	—	—	X	X	X	5
<b>Best Practices Training Services</b>									
Addresses training needs of professionals, family members, and others about critical issues in supported living	—	X	—	—	—	—	—	—	1
<b>Respite Care Services</b>									
Provides support for a family member beyond scheduled personal care	—	X	—	—	—	X	—	X	3
<b>Other Services &amp; Supports</b>									
Special Financing Arrangements									
Case Management	X	X	X	X	X	X	X	X	8
Cash Vouchers or controlled budgets with intermediate payer	—	—	—	—	—	X	X	—	2
In-Home Subsidy Program	—	—	X	—	—	—	—	—	1
<b>Home Starting Services</b>									
Assistance in locating a home to rent or buy	X	—	—	—	—	—	—	—	1
Assistance in acquiring household goods	—	—	X	—	—	—	—	—	1

NOTES: CSLA is community staffed living arrangement. ADL is activities of daily living. IADL is instrumental activities of daily living.

SOURCE: University of Minnesota, Institute on Community Integration, Center on Residential Services and Community Living.

One major factor affecting the lower use of authorized (and originally projected) expenditures for CSLA services was the increased flexibility and permitted expansion of Medicaid HCBS waiver use after 1991. As noted earlier, one of the motivations of States to seek the CSLA benefit was the ability to expand Medicaid-financed community services beyond what they had been able to accomplish under the cold-bed policy. But concurrent to the authorization of the CSLA benefit was a substantial reduction in Federal application of cold-bed standard in authorization of State HCBS program growth. As a result,

between mid-1991 and mid-1995 the eight CSLA States enrolled about 3,500 people in CSLA; during this same period these States increased Medicaid HCBS enrollments by 30,630 to a total of 45,592 HCBS participants. According to State officials, during this period HCBS and CSLA operated largely independently, and the slower development of CSLA participation and services reflected the normally slower development of new programs as opposed to the already developed HCBS programs, as well as the special challenges of developing services around the ideals of supported living. Required elements of CSLA,

**Table 3**  
**CSLA Expenditures, by Participating State: Fiscal Years 1994 and 1995**

Expenditures	Participating States								Total
	California	Colorado	Florida	Illinois	Maryland	Michigan	Rhode Island	Wisconsin	
<b>1994</b>									
Total	\$6,200,000	\$1,344,066	\$2,787,929	\$4,977,000	\$3,245,336	\$4,415,491	\$2,972,846	\$3,008,000	\$28,950,668
State	\$3,100,000	\$609,401	\$1,254,568	\$2,488,500	\$1,622,668	\$1,926,479	\$1,371,374	\$1,203,200	\$13,576,190
Federal	\$3,100,000	\$724,665	\$1,533,361	\$2,488,500	\$1,622,668	\$2,489,012	\$1,601,472	\$1,804,800	\$15,364,478
<b>1995</b>									
Total	\$6,265,380	\$4,324,226	\$3,164,000	\$6,922,410	\$3,367,450	\$5,894,144	\$5,092,028	\$3,342,000	\$38,371,638
State	\$3,132,690	\$1,975,305	\$1,423,800	\$3,461,205	\$1,683,725	\$2,534,484	\$2,348,953	\$1,336,800	\$17,896,962
Federal	\$3,132,690	\$2,348,921	\$1,740,200	\$3,461,205	\$1,683,725	\$3,359,660	\$2,743,075	\$2,005,200	\$20,474,676
1995 Federal as a Percent of Available	0.72	0.54	0.40	0.79	0.39	0.77	0.63	0.46	0.59
Per Capita CSLA in Dollars	\$24,683	\$13,949	\$4,305	\$10,699	\$19,693	\$13,127	\$12,511	\$7,110	\$11,151

NOTE: CSLA is community supported living arrangement.

SOURCE: University of Minnesota, Institute on Community Integration, Center on Residential Services and Community Living.

such as the Community Monitoring Teams, also slowed program growth.

## **IMPLEMENTATION CHALLENGES**

In at least six of the eight States involved in the CSLA program, State officials acknowledged that CSLA played a major role in redefining State goals for services to persons with developmental disabilities that would endure the September 1995 program termination. As they looked toward the future, they noted that the question was not whether supported living would be expanded under Medicaid HCBS and State funding, but how. Even in two States in which State officials remained relatively non-committed toward CSLA and supported living generally, families, service providers, and others saw in the initial steps taken under CSLA a foundation for higher expectations based on the ideals of supported living. As an evaluation of Maryland's CSLA program noted, "Supported living is viewed as the wave of the future. It is being demanded by increasing numbers of individuals with disabilities and family members." (Kimmich 1995).

All CSLA States began in 1991 with proposals indicating that supported living was viewed as a strong commitment within the State. To different degrees, CSLA helped each State move closer to fulfilling that commitment. In some States that movement and CSLA's contribution to it was large, highly visible, and widely acknowledged. In Rhode Island the CSLA experience made major contributions to the commitment and expertise to move forward with the Medicaid Section 1115 CHOICES proposal to create a State managed long-term care program based on the ideals of supported living. In Michigan the existing Medicaid HCBS program was reshaped

around the principles and practices of supported living. CSLA contributed substantially to moving supported living from a few pockets of experience and recognition to a Statewide network in Wisconsin, California, Florida, and Colorado. Even in Illinois and Maryland, where respondents expressed somewhat less enthusiasm for the extent to which their States made CSLA a priority and developed it as a clear departure from traditional service approaches, CSLA provided beginnings to supported living that continue to expand. In each of these States it is difficult to define the outcomes of CSLA, in part because there are many pressures and opportunities to pursue supported living beyond CSLA per se, in part because the impact of CSLA continues to grow. It is possible, however, to examine some of the challenges faced in CSLA States in implementing their CSLA programs, as well as the responses to and lessons learned from these challenges.

### **Balancing Choice and Risk Under CSLA**

Each of the eight CSLA States made commitments to honor and support the personal preferences of participating individuals, while at the same time attending carefully to protecting their basic health and well-being. It is common for adults to experience some degree of tension between their personal preferences and their health and well-being. People choose to do things that compromise their health and well-being through at-risk practices such as drinking alcohol, eating fatty foods, engaging in unprotected sexual activities, frequenting places and consorting with people that increase the probability of unfavorable occurrences, and so forth. For most adults these are viewed as normal life

choices and, as ill-advised as an individual's choices may seem, considered his or her risk to take.

For people receiving CSLA services, these tensions are magnified by the fact that an individual's judgment is often impaired (about 80 percent of CSLA recipients were formally diagnosed as having substantial cognitive limitations, i.e., mental retardation). Local and State government officials, private service providers, CSLA recipients, and their families wrestled with establishing the balance between their responsibility to protect and monitor each participant's health and well-being and the participants' freedom to make choices about their own lives. The balances established varied substantially from State to State, and this section reviews those efforts to establish quality assurance programs for CSLA. Four interrelated topics were examined: (1) the formal State regulatory systems for CSLA, (2) Community Monitoring Boards, (3) efforts to operationalize State commitments to individual choice and empowerment, and (4) the implications of CSLA reforms to quality assurance in general.

### **State CSLA Regulatory Systems**

There are four basic minimum consumer protections contained in the authorization of the CSLA benefit. Each participating State was required to guarantee that: (1) each CSLA participant was protected from neglect, physical and sexual abuses, and financial exploitation; (2) CSLA providers were to take all reasonable steps to assure that employees, contractors, or volunteers are not individuals who have been convicted of child or client abuse, neglect, or mistreatment, or have a criminal record involving physical harm to a service recipient; (3) individuals or agencies are not unjustly financially enriched

through financial abuse; and (4) individuals and agencies are not named beneficiaries of insurance policies. Each CSLA State provided HCFA with assurances and related procedures to guarantee these minimal protections.

When HCFA established application procedures to select States to provide CSLA services, it included requirements that substantially augmented the minimum protections required by Congress. These additional protections included that each State "assures that it will provide ongoing monitoring of the health and well-being of each recipient," specifying the procedures to be implemented, the qualifications of persons responsible for monitoring, the frequency and type of monitoring, and the manner of documenting the monitoring. In developing these procedures States struggled not only with the tension between protecting health and well-being and affording people the level of control over their homes and personal lives, but also with issues related to utilizing elements of existing community regulatory systems or developing essentially new systems for CSLA. The following observations may be made about these struggles and their outcomes:

- States that have attempted to integrate CSLA monitoring with aspects of existing community regulatory systems for CSLA encountered difficulties where existing regulations for community residential services were viewed in conflict with key principles of supported living.
- States that originally attempted to develop detailed and uniform standards for CSLA generally found the need to move toward approaches with more flexibility and sensitivity to individual circumstances and preferences.
- States have had to redefine and renegotiate or otherwise struggle with rules and expectations of administra-

tive structures related to Medicaid certification of community support agencies, licensing of homes in which CSLA recipients live, and reimbursement or payment systems.

- State quality assurance systems that have maintained traditional relationships between regulatory and provider agencies based on inspections and violation and correction requirements were viewed as being antithetical to continuous quality improvement and the ideals of shared responsibility of CSLA, and in the process brought to surface issues of trust and adversarial relationships that were evident in other programs.

In many ways CSLA programs recreated many of the issues evident in existing regulatory systems. Traditionally, regulations were developed to remove or substantially restrict the possibilities of danger, neglect, and abuse. When significant possibilities of risk were identified through undesirable, actual, or hypothetical situations, rules were created to reduce those possibilities. Regulations that accommodate supported living require some degree of acceptance of the risks of daily living. It is hard to overstate how fundamentally challenging it was for traditional regulatory agencies and systems to adjust to acceptance of risk and the detriments of protection. The extent to which States did so was affected by the following:

- The strength of leadership and commitment within the State for supported living that communicated the intention and expectation that regulatory agencies would participate positively in achieving the goals of CSLA.
- The extent to which it was recognized that CSLA required a substantially reconceptualized, more flexible, and individual outcomes-based approach to monitoring.

- The extent to which those doing the monitoring were taught and appreciated the values of CSLA and viewed their role to be in service to these values (i.e., they were helping people to be in control of their own homes or in charge of selecting support providers).
- The extent to which monitoring agents recognized the challenges and ambiguities of CSLA and were viewed as being co-involved in solving problems, not just finding fault or writing correction orders.
- The extent to which monitoring was used as a mechanism for identifying needs and actually securing support to help respond to needs and problems.

## **COMMUNITY MONITORING BOARDS**

In addition to the formal State regulatory apparatus involved in monitoring CSLA services, Congress also established that “the State will provide a system that allows for monitoring boards consisting of providers, family members, people with disabilities, and neighbors.” Although States undertook the development of Community Monitoring Boards (CMBs) with good faith and high expectations, the development and implementation of CMBs were one of their greatest challenges. As an indication of these difficulties, four States substantially revised the plans contained in their original CSLA applications and redesigned their monitoring-board systems. In the final year of CSLA one State had still not fully implemented its monitoring board system. Although not addressed in statute, each State separated its State licensing and certification review program from the largely informal, volunteer-staffed CMBs, causing the CMB reviews to be less consequential, less well-defined in purpose, and less useful in

improving services than might have been the case.

The CMBs were managed either by State agencies, local governmental entities (e.g., area or county boards), or non-governmental organizations under contractual agreement with the State. CMB members were almost always volunteers, although limited compensation was often available to consumer participants. Requirements that CMB members be screened, trained, or pledged to confidentiality varied State to State. There was also a great deal of variability in the make-up of CMBs, with the intra-State variability often as great as the variability among States. One State required that the CMBs be independent from CSLA service providers, immediate family members, and members of the participants' circles of friends. But in other States, service improvement, including provider agency staff and directors, local government officials, friends, family members, and people with disabilities who were directly involved in CSLA, was viewed as an important part of the understanding, communication, and learning that the CMBs were designed to achieve. CMBs typically conducted their service evaluation and satisfaction reviews through face-to-face interviews with consumers.

Although the vast majority of respondents were supportive of the concept of CMBs, some had concerns about the implementation of the concept in their State. These concerns included the following:

- There was a need to clarify the purpose of the CMS, what they were expected to observe and report, and who was to be the intended audience of their reports.
- Underfunding contributed to inadequate coordination, support of volunteers, and preparation of reports, and was indicative of the lack of purpose and clear role.

- The number of volunteers required to sustain the volunteer CMB model and the logistics of scheduling and travel was more difficult than anticipated.
- In most States and locales, service providers noted a lack of information flow from CMB visits back to their agencies that precluded contributions of CMBs to their efforts to improve quality of services. Many CMB members likewise noted their frustration at submitting reports through channels, later to learn that they were often never seen at the service sites that were visited.
- In about half of the States, people with disabilities and service providers noted high levels of redundancy in the roles of the CMB and State licensing and surveying agencies. There was a sense that this placed an unnecessary burden on people with disabilities and their support staff, but also that if integrated a combined State and CMB review might better define and attend to the important features of quality in supported living services.
- There were a number of technical difficulties in the CMB reviews. The most commonly noted were problems of (1) developing survey protocols that were applicable for persons who varied in communication skills, and (2) developing an alternative to face-to-face interviews for persons who declined visits.
- A number of people, working on independent CMB teams who did not otherwise know the CSLA participant, commented that interviewing the individual provided only a snapshot of his or her life, and those who knew the person well would probably elicit a more complete and realistic picture if they could be made an integral, ongoing part of the quality review process.

In summary there was substantial support outside the traditional monitoring agencies for the basic premise behind the CMBs, that CSLA participants should have access to persons who are independent of the traditional licensing and surveying, service coordination, and service provision roles, who are available to them to register and elicit responses to their dissatisfactions and needs for services. But operationalizing this premise, providing a well-defined role for CMBs, integrating the role with other licensing and quality assurance activities, and sustaining a largely volunteer effort proved to be a significant challenge in most States.

## RIGHT TO INFORMED CHOICE

One of the important protections promised CSLA recipients was the right to make the choices that determined their lifestyles. The majority of participants picked where and with whom they wanted to live, and how they spent their free time. Although the level of day-to-day choices for people in other State services was unclear, the CSLA recipients interviewed were pleased with the freedom and choices that they enjoyed. Still, there was a large variation across States in providing CSLA recipients with opportunities for informed choice. Among the areas in which interstate comparisons showed relative limitations in the support for people to make informed choices were:

- Information about the CSLA program not being provided at a reading level that people with developmental disabilities could understand, making people dependent on others for interpretation.
- Information not being provided in alternative formats for recipients (e.g., audiotapes, videotapes).

- Informational and advocacy support not being financed outside the government or provider network, making potential CSLA recipients dependent upon traditional system professionals to convey information to them.
- Training and technical assistance about philosophy, choice, safety, reasonable expectations, assertiveness, and conflict resolution being limited.
- Limited efforts being undertaken to develop systems of value-based training for service providers and direct care staff.
- Recipients being provided fewer choices than expected or promised in State proposals (e.g., being told services could be received only from a particular agency in an area, or that the process to change agencies was too difficult to attempt to make the change).

Concerns about people actually achieving control over their lives were expressed most often about situations in which CSLA recipients received services from the same agency (and sometimes in the same setting) as prior to their CSLA enrollment. Agencies that prior to CSLA had been congregate-care providers often faced particular difficulties in fully supporting consumer control. Although many State officials noted the difficulty in using policy and rules to promote the ideals of individualization and choice, efforts to do so were made. As an example, Florida's effort included:

- Guaranteeing multiple providers in each location and assuring choice of providers.
- Providing independent professionals to assist people in making and expressing informed choices.
- Monitoring service provision to assure that people were receiving

what they chose and were promised, and that requests for change were acted upon.

CSLA and broader issues of quality-assurance CSLA served as an important demonstration of the viability and utility of new approaches to quality assurance. Unlike traditional quality assurance that is built on a foundation of expert opinion about the nature and indicators (i.e., standards) in quality of care, the CSLA program made a significant effort to place each individual's view of quality of life for himself or herself at the foundation of the quality assurance approach. Although each State undertook this reform with varying levels of conviction and success, in each State the effect created significant challenges in redefining the purposes and redesigning the practices of quality assurance.

One of the major challenges to States was to institute quality assurance systems that viewed quality not as the absence of that which may harm one, but the presence of that which could support people in defining and pursuing the lives they want to live. This requires a quality assurance approach that was better able to accept multiple definitions of quality, cognizant that CSLA recipients may view quality in ways that vary from traditional definitions, even these of more recent traditions like normalization or maximum inclusion. It also required that a quality assurance approach define itself as co-involved in achieving the qualities of life desired by CSLA beneficiaries.

In no State did CSLA guarantee people the lifestyle they desired. In fact, in every State the basic poverty of CSLA recipients and the limits of CSLA services often precluded it. But in at least six of the eight CSLA States, the quality assurance system was generally viewed as directly allied with the individual in the pursuit of his or her

desired lifestyles. It was this sense of quality assurance as attending to a person, not to an agency or facility; as being involved in improving all CSLA recipients' lives, not just those receiving substandard services; as viewing quality as an ongoing quest, not a status; as viewing quality as being contributed to by many sources (meaningful consumer choices, independent case managers, community monitoring teams, government licensing certifying teams, etc.), not solely by government monitoring; and the related differences noted above that made the CSLA approaches to quality assurance most notably different from traditional approaches.

Although CSLA has served to effect new ideals of quality, there were significant challenges in realizing these ideals within systems that were primarily designed for protective roles. Among these challenges noted were:

- Developing infrastructures of quality assessment, information sharing, training, and technical assistance that are capable of improving all programs of support, not just those of notable inadequacy.
- Fostering the development of a multi-agency coalition on quality to identify and respond to common difficulties realizing the goals of supported living.
- Cutting across the boundaries of the multiple financing and service programs that need to be incorporated to support people in all essential aspects of their daily lives (e.g., Medicaid State-plan services, vocational rehabilitation services, transportation services, housing programs).
- Recruiting, training, compensating, and retaining sufficient numbers of caregivers who have the attitudes and abilities to support people without controlling them at available levels of compensation.

- Providing service coordinators with the commitments, system-knowledge, individual authority, independence, and sufficiently small caseloads to be able to support people as they wish to be supported.
- Defining individual and shared agency responsibilities, risks, and sanctions in balancing consumer choice and appropriate safeguards to honor the principle of consumer control, while fulfilling societal expectations of reasonable protections appropriately accommodating the limitations that make the individual eligible for CSLA.

### **Overcoming Social Isolation**

Assisting people to make connections with others and with activities in the community was the most frequently cited challenge in making CSLA live up to its ideals. Direct support providers consistently noted that a primary obstacle to community participation was the attitudes held by the community. They frequently noted that the community needed “to be educated.” Some staff described specific efforts to this end (e.g., a staff member and CSLA participant going to lunch at the same place once a week in order to develop acquaintanceships and interaction). But staff also observed that characteristics and personality traits of CSLA participants were important factors in the vast differences in the successes of CSLA participants in acquiring and maintaining friendships.

Social isolation or limited social relationships were reportable, particularly challenging for people who had been living in group settings. Typically these individuals came to CSLA with relationships that were often limited to other people with disabilities with whom they had lived or worked, family members, or paid staff. Among factors reported to contribute to CSLA partic-

ipants being able to achieve a satisfying level of social integration were inclusion in the social network of their support staff, friendships formed at places of employment, relationships that were nurtured with neighbors, regular participation in community activities and organizations, and residing in the neighborhoods and social networks of one’s childhood or previous place of residence.

States varied in the extent to which attention to inclusion was viewed as a primary responsibility of agencies, but in all States the CSLA quality assurance monitoring greatly expanded attention to people’s satisfaction with their social inclusion. This was done without dictating the nature or amount of social inclusion that any individual should achieve, but that attending and responding to each individual’s desired level of social inclusion was a basic responsibility in supported living. States were particularly varied in the extent to which they provided specific support, information, or training to increase the capacity of service providers, case managers, direct support staff, and consumers to increase social inclusion of CSLA participants.

### **Recruiting, Training, and Retaining Qualified Support Providers**

The quality of the direct support is obviously a critical factor in the success of supported living. Although all CSLA States stipulated in their applications that people with disabilities would have a choice of providers, no State could provide unlimited choice because of requirements related to agency certification, cost-containment requirements, prevention of victimization, and conflict of interest. Defining and sometimes limiting relationships between CSLA recipients and direct support providers was an issue faced by all States. Because

many CSLA services and supports lent themselves to flexible, part-time, non-technical, and non-traditional employment and compensation, there was a range of options for identifying and hiring direct support providers. Still, the vast majority of direct support providers were recruited, supplied, trained, supervised, and paid through formal service agencies. The ability for the CSLA participants to change direct support providers at their preference appeared to be a well-honored principle. But it did cause problems for agencies because most found it increasingly difficult to recruit support staff at available wages, and when they found and trained dependable support staff they wanted to retain them in the agency, even if an individual CSLA recipient preferred someone else. This challenged agencies in being able to develop long-term budgets and make commitments to the people they hired as employees. Although these problems were not viewed as insurmountable, they were very significant, particularly for small, newly formed CSLA agencies. As agencies developed flexible alternatives to traditional staffing, new problems often arose. For example, when family members were allowed to be paid service providers, benefits included cost effectiveness, simplicity of service delivery, and maintenance of important relationships, but problems included difficulty in monitoring, the meaning of consumer control, conflicts about CSLA recipients' choices, and identification of whose wants and needs were really being met.

## **CRITICAL FEATURES TO SUCCESS IN CSLA**

### **Providing Leadership**

The success of State CSLA programs was clearly linked to the quality of and

commitment to leadership in the sponsoring State agencies, the local administrative agencies and support providing agencies. Key and consistent aspects of effective leadership are summarized below.

### **Clear Authoritative Leaders**

The substantial changes and high expectations of CSLA created many uncertainties among those responsible for implementation. In every State consumers, service providers, and others who were faced with new services, new regulations, and new expectations acknowledged the importance of experienced, committed, and empowered leaders who could and would speak with authority. When States identified and empowered leaders of their CSLA programs, and those leaders were visible and active in promoting CSLA and were allowed to respond directly to questions and requests for assistance, creative and personalized alternatives developed. The lack of a clearly visible leader who could speak with authority or provide timely response to questions of policy and practice was a substantial frustration in some States. Such absence was associated with CSLA programs that differed least from the community services available prior to CSLA. This occurred because service providers, licensers, case managers, and others who were unclear about the opportunities and expectations for a new beneficiary-centered approaches to service tended to replicate traditional services, record keeping, and other practices of existing Medicaid programs.

### **System Designers Involved in Implementation**

CSLA programs were more effective and energetically administered in States in which persons in CSLA administrative

roles had played key roles in developing the State CSLA application. Conversely in States in which applications were developed by individuals who did not subsequently play key CSLA roles, programs tended to be more bureaucratically defined and controlled and there was less risk-sharing by State officials. In these States variation between CSLA services and typically available community services was notably less, and those who had hoped that CSLA would be a catalyst for change were often disappointed. States in which the driving force behind the CSLA proposal was people outside the developmental disabilities program agency experienced the greatest difficulty in creating substantial change through CSLA. Clearly when radically new roles for beneficiaries and administrators were design features built in by key administrators who played key roles in designing the program, CSLA tended to have considerably more active, involved, empowered, flexible, and ultimately successful leadership.

### **Leadership by Example: Models of Effective Practice**

Because of the substantial changes required in moving from traditional agency-controlled staffed housing to beneficiary-controlled supported living, the presence within a State of one or more existing service entities that could model the principles and achieve the goals of supported living was extremely useful. This leadership by example was important both to demonstrating organizational approaches to providing supported living services, but also for establishing and maintaining high standards and expectations for those services. For example, Michigan's CSLA providers frequently noted that they benefited from having an excellent, established

and widely recognized supported living program in the Midland-Gladwin area to serve as a model. In California, Colorado, and Wisconsin, informants also mentioned the importance of opportunities to visit and talk to administrators, support providers, and people served by established, effective, supported living agencies. Sharing information among CSLA service providers also served as a positive vehicle in identifying effective practices.

### **Providing Adequate Flexibility**

The States that were most successful in developing their CSLA programs on supported living principles were those most able to be flexible and accommodative of variety in options for delivery and paying for services. Flexibility allowed the most specific and creative accommodations to people's differences in the kinds and amounts of support they needed, where and how they wanted to receive support, and how the support was used to contribute to the individual's lifestyle.

## **PROVIDING EDUCATION AND DEVELOPMENT**

All CSLA States had at least elements of supported living programs at the time CSLA began, but each was challenged to greatly expand the levels of knowledge, expectations and resource development. Following is a summary of some of the key aspects of the education and development programs.

### **Teaching New Perspectives and Attitudes**

In seeking to establish new visions and renegotiated roles in service provision substantial education was required. Of particu-

lar importance were efforts to assist case managers, administrators, and direct service staff to differentiate principles of individual control in supported living from the choice making in traditional community living programs, in which staff still control outcomes by controlling the options. Most CSLA States made substantial early investment in communicating differences between a support approach and a staffed housing model. Florida and California developed and disseminated high-quality manuals on supported living to help communicate such differences. Videotapes developed in two of the Michigan CSLA sites were also noted to be helpful in communicating the expectations of the supported living approach. As the CSLA coordinator in Colorado noted, "Communication in its multiple and varied forms seemed to be the linchpin and often times the nemesis."

But State CSLA coordinators also noted that it "takes more than talk and education materials." Time was viewed as critical to gain and benefit from experience, to establish examples of success and failure, and to build personnel skills and confidence to risk the comprehensive changes required. Opportunities for families and people with disabilities to learn about supported living from sources other than service providers were also considered important, as were opportunities to learn, discuss, and problem-solve side-by-side with direct support staff, agency managers, and case managers. For persons who had formerly been residents of congregate-care settings and their families such efforts were viewed as some of the most effective ways of communicating that they had new roles and power.

## **Developing an Infrastructure of Support**

The individual State site visits demonstrated the importance of building an infrastructure of education, training, and technical assistance among States that are developing or expanding beneficiary-centered service approaches. CSLA provider agencies frequently noted the benefits they experienced, or more often felt they would have experienced, from an infrastructure of support for workshops, training, technical assistance, and other assistance on supported living and for sharing information among government agencies, service coordinators, provider organizations, support staff, people with disabilities, and others on key topics such as person-centered lifestyle planning, building and sustaining circles of support, sources of access and financing for desired supports, connecting people within their community, and so forth. It was noted that such an infrastructure should include opportunities to share successful experiences across peer groups (e.g., managers of provider agencies, service coordinators, families and people with disabilities). The value of such experiences were directly noted, as well as inferred, by the comments of those who felt they were "trying to figure this out on our own," and suffered a sense of inefficiency, insecurity, and isolation in the process. Many respondents identified specific areas of needed technical assistance or training related to those noted above. Other respondents identified the importance of bringing committed agencies and individuals together to solve their own problems, to create their own needed assistance (e.g., in one community a local Arc was funded to facilitate

person-centered planning for a number of agencies), and to enhance shared vision and expectations among persons in potentially conflicting roles.

## **STATE TRANSITIONS AT THE END OF CSLA**

The Medicaid CSLA program was terminated at the end of its 5-year authorization period in September 1995. Prior to termination the participating States had operated with varying degrees of confidence that some mechanism would be developed to provide continuation for the CSLA program. Therefore, States began at different times and with differing intensities to develop alternatives for CSLA program participants. However, each State recognized the need to develop transition policies and plans prior to the termination of the program. Table 3 briefly summarizes the transition plans developed and implemented for CSLA recipients following the termination of the CSLA program.

Many State officials expressed substantial frustration with the termination of CSLA and the prolonged period of ambiguity about the program's future. With the end of CSLA there was among State officials a clear sense of loss regarding primary emphasis on people deserving greater control over their lives and service, on community connections, and on a more informal, less systematized approach to meeting people's long-term care needs. But these same officials nearly universally noted the impacts of value-driven, flexible, and creative aspects of CSLA, and credited the program as having made important, lasting contributions to the quality and consumer-focus of services available to State residents with developmental disabilities. CSLA was viewed in each of the participating States as having been an important catalyst for change that will eventually affect

the lives of many times the 3,500 persons who actually participated in the program.

## **BENEFICIARY CENTERED CARE IN THE CSLA EXPERIENCE**

Although virtually every State in the United States has been increasing individualized community services in recent years (e.g., Medicaid Home and Community Based Services recipients grew from 51,000 in June 1991 to more than 190,000 in June 1996), CSLA brought a clearer focus and higher expectations for a beneficiary centered approach to services. In the process it heightened attention to the distances between the ideals of the emerging systems of support and the common practices in the traditions of congregate care. These discrepancies were found in CSLA efforts to move from models of supervision to needed support, from rules to protect safety to negotiations of a balance between safety and personal freedom, and from being accountable for clear and fixed expectations of government entities to being responsive to the changing preferences of service recipients. In every CSLA State, countless stories were told of the difficulties in making these transitions, the financial hardships faced by agencies, the government risk-avoidance on difficult decisions, and frustrations of consumers whose SSI payments allowed them few of the housing options of which they had dreamed. Yet it was extremely rare that any service user, family member, or service provider involved in CSLA felt there was any other acceptable future in service delivery for persons with developmental disabilities. That future seemed so clear to those involved in CSLA because the principles of supported living seemed so right to them. People with developmental disabilities should have control over the basic decisions of their daily lives, be able to live

in places that are their own homes, have lifestyles that they choose, be listened to, be able to choose the people who provide the most basic and intimate supports to them, and be the ones who define the quality in quality assurance. The struggle to honor such principles was a different challenge in each State, in each community, and for each individual, but there was a remarkably consistent sense that it was the right struggle.

One legacy of CSLA will be its contribution as a catalyst of person-centered services under the principles of supported living. CSLA provided a direct and important expansion of supported living in at least six of the eight States, and stimulation to the development and expansion of supported living in all CSLA States, with particularly notable and lasting effects. To illustrate, Michigan redesigned and rewrote its Medicaid HCBS program following its CSLA experience. The new design makes Michigan's HCBS program operate more like CSLA, with greater flexibility and less regulatory specificity. Wisconsin's most recently renewed CSLA/HCBS waiver, effective in 1996, continues to promote the ideals of consumer choice, consumer-directed services, and person-centered planning that were key in CSLA. Another legacy of CSLA was its demonstration of methods of enhanced consumer control of services and support providers, and even financial resources allocated for those services with the framework of existing Federal Medicaid rules. These experiments contributed substantially to the expansion of individual support methodologies in many State waiver programs. For example, Minnesota, a non-CSLA State, recently added a "consumer-directed community support" service to its HCBS service menu. CSLA also contributed to the high levels of interest and participation in the Robert Wood Johnson Foundation

funded Self-Determination projects operating in 28 States and to many other State initiatives in consumer-controlled housing, individually managed budgets, and other methods enabling people to control more of their lives and their services.

Another legacy of CSLA may well be to show the potential of Federal influences and incentives to plant the seeds of substantial system change within long-term care. Historically the Federal government has been notably neutral on how States utilize Medicaid funding. As long as programs met the minimum of Federal standards, the Federal government has shown no particular interest in whether States' disabled populations live in institutions, in community group homes, or in homes and with lifestyles that reflect their preferences. As more of the control of Medicaid shifts from Federal to State levels, even fewer of the Federal interests in the well-being of persons with disabilities are likely to be evident. It is not necessarily negative that traditional Federal quality assurance and oversight roles will be reduced, provided, of course, that there is some Federal mechanism remaining to insure that these roles are reasonably replaced, and possibly improved upon, at the State level. Indeed, such shifts from Federal to State control of standards, which have substantially been accomplished already in the shift from ICF/MR to HCBS financing, may allow HCFA to identify new and perhaps more effective roles to improve the quality of long-term care for persons with disabilities. Such roles might well extend beyond the relatively passive and time-limited roles HCFA plays in granting section 1115 (a) waivers for States to develop demonstrations "likely to assist in promoting objectives in Medicaid."

The CSLA experience would suggest that providing more active, directed, and long-term incentives for experimental, sys-

tems change or seeding efforts that reflect and promote HCFA's commitment could yield important and lasting effects. Clearly, in the case of CSLA the outcome is one that will last long beyond the termination of the program and ultimately will affect many times the numbers of people who were actually served. In the process of demonstrating CSLA, much was learned to guide the kinds of Federal support to States that would make such efforts more effective, including: (1) the Federal government taking a lead in recruiting and supporting a small number of States to serve as laboratories for testing the viability of ideas and ideals that might improve service delivery; (2) the benefits of bringing representatives of this small number of States working on the same kinds of systems change coming together periodically to learn from and problem-solve with each other; (3) the need for early-on training and technical

assistance for persons in leadership roles; (4) the importance of assistance in building in-State electronic and direct-contact networks of those involved in the effort, including those who model the desired performance; and (5) the benefits of integrated evaluation procedures as a way of examining outcomes across all participating States as well as variations among them.

Attending to the specific lessons of CSLA can assist Federal, State, and local agencies, advocates, service users, and families build more beneficiary centered approaches of long-term care for persons with disabilities. Attending to the general lessons of CSLA may help define new and valuable roles for the Federal government or more and more of long-term care shifts from Federal to State control, whether through State-initiated waiver programs or eventual changes in the Federal Medicaid program.

## TECHNICAL NOTE

### CSLA Transition Programs

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#### California

All but a few (fewer than 10) of California's CSLA recipients were determined to be HCBS eligible. Most CSLA participants were moved into California's expended HCBS waiver, but because of State funding mechanisms, some of the less costly CSLA recipients were not included in the HCBS program. California saw no significant downside to the termination of CSLA and the need to move people from CSLA to HCBS. In fact, California officials always operated on the assumption that CSLA would end in September 1995 and plans were under way to move people into HCBS even before it became evident that the CSLA program option would remain available.

#### Colorado

Almost all CSLA recipients were included in a special waiver application for Supported Living Services (SLS) specifically written to continue services for CSLA recipients and to keep focus on the goals and approaches of CSLA. A very small number of individuals who were determined not to be HCBS eligible received continued support provided through state-only funding. Under CSLA there was a maximum allowable expenditure of \$20,000 per year, but the SLS alternative provided for an average of \$10,659. Therefore, several individuals with high cost support plans were transferred to the comprehensive model of services in order to maintain their current

level of services, which reduced both their control over how and where services were provided and their choice of providers.

#### Florida

All 735 CSLA recipients were transitioned into Medicaid HCBS. Although about 50 recipients did not meet ICFMR criteria, Florida requested a model waiver to continue services to these persons. Florida officials never viewed CSLA as a permanent program. It had always been planned that the spirit of CSLA would have to be transitioned to the HCBS program. CSLA seems to have had a significant impact on changing the HCBS program approach to service delivery.

#### Illinois

More than 500 CSLA recipients were moved into the Medicaid waiver program. The ICFMR eligibility criteria was amended and the new criteria were used to assess former CSLA participants for HCBS eligibility. This permitted some CSLA recipients who otherwise would not have qualified for the HCBS waiver to do so. Ample capacity existed in the waiver to transition all CSLA recipients. Only 10-15 individuals who were receiving intermittent CSLA supports did not qualify for HCBS waiver program and these persons continue to receive support with 100 percent State funding.

## TECHNICAL NOTE—Continued

### CSLA Transition Programs

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#### Maryland

Maryland amended its HCBS waiver to add capacity for 150 CSLA recipients. About 20-30 CSLA recipients were not moved into the waiver. Some are being served under State-financed programs. Maryland's HCBS amendment also added two new services to accommodate CSLA transition: Community integration and training.

#### Michigan

Michigan redesigned and rewrote its entire Medicaid HCBS program following the CSLA experience. The new design makes the whole HCBS program operate much more like CSLA, with greater flexibility and less regulatory specificity. Almost all former CSLA participants were enrolled in the HCBS program and encountered no disruption of support or changes in providers.

#### Rhode Island

CSLA participants were moved into the Medicaid HCBS waiver, but the administrative requirements for doing so were considered particularly burdensome. The HCBS waiver program did not permit the use of vouchers, thereby requiring 140 CSLA recipients and key elements of the Rhode Island CSLA program to be transitioned to agency-provided services. Rhode Island considered this outcome of the termination of CSLA to be a significant step backward. Rhode Island's future hopes really lie in HCFA approval toward implementing supported living models under a State managed care arrangement with the Federal government.

#### Wisconsin

In Wisconsin, most people participating in the CSLA program moved to the HCBS program in September 1995. Wisconsin submitted a CSLA/HCBS waiver application to HCFA which was approved with an effective date of January 1, 1996. The new CSLA/HCBS waiver will continue to promote the ideals of consumer choice, consumer directed services, and person-centered planning that were key in the CSLA program approach.

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