

Community Supported Living Arrangements (CSLA) Evaluation

EXECUTIVE SUMMARY



**Developed for:
California Department of Developmental Services
1600 9th Street
Sacramento, CA 95814**

**by:
Allen, Shea & Associates
and
Claudia Bolton
Mark Rice**

**50 Chapel Hill Drive
Napa, CA 94559
(707) 738-0342**

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Introduction.

In October 1990, Congress amended the Social Security Act, and added Section 1930 to Title XIX, thereby establishing the Community Supported Living Arrangements (CSLA) program, as an initiative to provide supported living services to Medicaid-eligible individuals with developmental disabilities. CSLA is one funding stream for supported living, which is a set of ideas and practices regarding a chance to live safely and well in a home of one's own (alone or with others); respect for preferences and choice; a lifestyle that makes sense to the person; as much self-reliance as possible; and receiving personalized services and supports to make it happen.

Since the early 1980s, several states have used the Medicaid Home- and Community-Based (HCB) Services Waiver to provide supported living services. CSLA, however, represents the first official, federal recognition within the Medicaid program of supported living as a funded service. Yet, unlike most Medicaid-funded services, CSLA (1) was time-limited (sunsetting September 30, 1995); (2) funding was capped; and (3) statewideness was not required. Because of the cap, states were invited to submit applications. Twenty-seven did so, and eight states, including California, were selected.

In turn, California selected seven of its twenty-one regional centers to participate in the pilot. (For readers who are not familiar with the developmental services system in California, the Department of Developmental Services sets policy and provides funding for regional centers and state developmental centers. Twenty-one, nonprofit regional centers have contracts with the state to offer service coordination to eligible individuals and to fund community services not provided in any other way through vendored providers. Area Boards, now known as State Council Regional Offices, are mandated by state law to monitor the legal, civil and services rights of citizens who have developmental disabilities.)

No CSLA funds were expended in the first year (October 1, 1990 - September 30, 1991). States began using such funds to serve small number of people during the second half of

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the following federal fiscal year (FFY). We mention this time line to help in understanding the content of this report. Senate Bill (S.B.) 1383 amended the Lanterman Act in several important respects, taking effect January 1, 1993. (The Lanterman Act is California's basic, authorizing legislation that defines developmental disabilities; establishes regional centers; and, sets standards for intake, assessment, case management, service planning, and the purchase of services.) During FFY 94, the Department of Developmental Services issued its request for proposals for this evaluation of the California CSLA Program.

If service planning were to be person-centered, as newly required under S.B. 1383, one might wonder, for example, why the Department wanted to know to what extent "services and supports are designed to fit individual needs and desires, rather than the reverse." The answer is two-fold. First, legislative initiatives do not immediately change everyone's behavior. It takes time to disseminate information, to try new ways, and to incorporate new values within the work of agencies and individuals. Second, supported living, with its inherent flexibility and individualization, might teach us some things about ways of serving people better and in line with the new values expressed in the S.B. 1383 amendments to the Lanterman Act.

Purpose.

The purpose of the evaluation was to provide information about CSLA of value to the Department and to others. Supported living is here to stay, even though CSLA has come and gone. Other funds are (and will be) used for such purposes. Policies and practices can be improved. Toward that end, the Department asked us to study the effects of various factors (e.g., individual differences; family involvement; organizational policies and practices; costs) on service delivery and use of CSLA. Specific areas of inquiry and questions are presented on the following page.



The Basic Questions.

We were asked by the Department to consider the following questions in completing the evaluation:

What difference does CSLA make?

for persons receiving services?

for families?

for agencies providing services?

for regional centers?

- What are the public costs of providing CSLA services, and how do they compare with likely alternatives?
- What accounts for variation in CSLA-related costs (and service use per person)? geography? nature of the person's disability? service need? other factors?
- How do costs change over time? What accounts for variations in costs over time?
- How do the policies, procedures and practices of the players (DDS, regional center, CSLA agency, individual) influence: consumer outcomes; family outcomes; organizational outcomes; service use; and costs?
- How do other factors, such as length of participation in CSLA service delivery, consumer developmental characteristics, and service needs influence outcomes, service use, and costs?

Other questions that the evaluation sought to answer, include:

- How do California's CSLA costs compare with those in other States, and what accounts for differences?
- What's the impact of CSLA on regional center budgets, and on use of related services (e.g., ILS, licensed residential)?
- How do practices in California stack up with those specified in the CSLA Manual?
- What's happening with CSLA in other states? in supported living more generally? That is, what trends and new developments?

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Regarding Organizational Outcomes, we were asked to look at:

- Are services and supports designed to fit individual needs and desires, rather than the reverse?
- Is there appropriate use of generic services?
- Is there appropriate fading of paid services?
- Are intake and evaluation processes non-biased?
- Are there fewer disruptions in service delivery?
- Are there adequate safeguards for ensuring freedom from exploitation, abuse, neglect, and harm?

Framework.

The framework for this evaluation rests on the assumption that: (1) information about costs and demographics could be secured from existing data sets within the Department of Developmental Services, regional centers and CSLA agencies; (2) people closest to the action (e.g., individuals, families, service providers) would be our primary source of information about outcomes; and, (3) we would inquire as to how policies, practices and stakeholders affect each other and services provided.

Early in the process of designing evaluation protocols, two matters were clarified. First, the evaluation was to be largely formative rather than summative in nature, pointing to ways of improving services and personal lives by increasing living arrangement options. Second, we would provide anonymity to individuals interviewed and to agencies in order to enhance cooperation and candor.

Some of the Department's evaluation questions imply a conceptual framework (or theory) about individual and organizational behavior. One part of our task, for example, was "[To evaluate] . . . the relationships among consumer outcomes, family outcomes, organizational outcomes, service utilization, and cost, including identifying the factors which mediate these relationships." We approached this task by assuming that, through the course of time, one thing can influence another, and that the temporal sequence of

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"actions and reactions" can be important in interpreting the record. We look at the basic question of interrelationships at various places throughout the report, but especially in Chapter 8, entitled System Effects.

Methods.

While you will find a more detailed description of the methods we used to answer the evaluation questions in Appendix A, we went about our work in the following manner:

1. Convened representative community advisory groups to get ideas (e.g., other questions; issues), and to critique preliminary plans.
2. Convened a Design Team of experts from California and around the country for the same purpose.
3. Designed Survey Instruments and a plan for gathering information, storing it, and analyzing it.
4. Project team members completed the fieldwork. That fieldwork, most of which was carried out between February and September 1994, included:
 - Interviewing 151 of the 283 individuals who were participating in the CSLA pilot at the time and who consented to talk to us.
 - Collecting 278 Support Services Checklists completed and returned to us by CSLA agencies.
 - Sending out 71 mail questionnaires to family members (or close friends) of individuals.
 - Interviewing CSLA liaisons (and selected service coordinators) in the 7 regional centers chosen to participate in the programs.
 - Interviewing program directors and selected support staff in all but two existing CSLA agencies.
 - Interviewing most of the 7 regional center directors, and all of the 6 area board executive directors to get the 'big picture.'
 - Interviewing about 20 Community Monitoring Team coordinators and volunteers, and collecting 85 questionnaires regarding the people for whom

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they perform the friend/monitoring function.

5. DDS, CSLA agencies and regional centers assisted in compiling service lists, and other data, including cost information.
6. A follow-up, phone survey of four-fifths of the CSLA agencies on selected topics (e.g., costs, transition to non-CSLA funded supported living) was completed in July 1995.
7. We completed a cost survey of two comparable states in the CSLA pilot.
8. Routine and topical reports were submitted as requested.
9. A quarterly newsletter, *Imagine That!* (see Appendix C), was developed as a way to get information back to the field, and to maintain effective working relationships with those kind enough to assist with the evaluation.
10. The final report was written.
11. Two end-of-project presentations on our findings were made in October, 1995, at annual conferences held in Northern and Southern California.



Findings

Who did CSLA Serve?

On June 30, 1992, approximately a dozen adults were being served with CSLA funds. That fall, the number accelerated. By the time the evaluation began (August 1993), there were approximately 250 individuals on lists of CSLA service recipients. Where they lived is reflected by dots on the map of California, which can be found on the cover page. By October 1994, the number had risen to nearly 300, the approximate peak of participation. With movement in (and out of) CSLA-funded services, and subsequent decisions at two regional centers to use other services (or funds), the number continued to change (typically in a downward direction) from that point in time to the end of the project.

In terms of diagnostic indicators, in comparison with all individuals using regional center services and known to the Department of Developmental Services (DDS), CSLA service users were much more likely to have no mental retardation (or to be mildly retarded) and to be non-ambulatory (often associated with cerebral palsy). In terms of developmental level (DEV%), as reported on the Client Developmental Evaluation Report (CDER), the average score was 76% for CSLA participants. Individual scores ranged from a low of 4% to a high of 99%. (Developmental level is a measure derived from 23 CDER items related to what the person can or cannot do. Raw scores range from 23 to 98. Expressed as a percentage, each person's score= Raw score minus 23/75) X 100.) These averages varied little across regional centers, with the exception of one, which had an average score well below those of the other six centers. It's of note that the center was also one of two that used a lottery system to select applicants for CSLA.

Our Support Services Checklist tends to confirm that one regional center served a disproportionately large number of individuals with high support needs. Two other regional centers also reported high levels of support. Both serve major urban areas, where service expectations and costs may be relatively high. Across the fifteen items that comprise the Checklist, relatively high levels of support were said to be needed in the



areas of money, health, cooking, and getting around the community. At the other end of the spectrum, getting around the house, eating, communicating, and daily routines typically required less support.

Individual Outcomes

We inquired about valued outcomes through interviews with 131 CSLA service recipients. Twenty others were interviewed prior to moving to where they wanted to live and those interviews dealt only with plans and the like. Here are the highlights:

Choice. - Freedom and independence dominated responses to questions about what people liked best about their living arrangements. Approximately nine out of ten said they chose where to live and, if living with someone, their housemate(s) and how to spend their money. Not infrequently, some help was acknowledged. The percentage [of the 61% employed] who say they chose their jobs was somewhat less (73%). Fewer than half said they had a choice of two or more CSLA agencies. Agencies seemed to be making a conscientious attempt to honor choice in who helps, doing this more successfully with roommates, attendants and companions than in who fulfills the Community Support Facilitator (CSF) role. CSFs typically spend a few hours a week coordinating the work of others.

Health and Security. - Ninety-five percent of the people we interviewed said that they felt healthy most of the time. One in six, however, expressed a need for help with their health that they were not getting. Typically, such health problems (e.g., gastric intestinal difficulties) were chronic. No one said they needed a health service they could not get. Nearly nine in ten said they had a doctor. Most people felt safe in their homes or apartments; somewhat fewer felt safe in their neighborhoods. Their expressed concerns were typical of most folks living in low- to middle-income neighborhoods and apartments: street crime, lighting, and lack of police presence. Reasons for liking one's neighborhood typically focused on good neighbors; pleasant/quiet atmosphere; proximity to stores and services; and being close to friends. As to whether anything is

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scary about the living arrangement, thirty mentioned one or more perils. Typical ones included poor judgment (e.g., bringing the wrong person home); environmental hazards (e.g., getting burned on the stove); and being alone.

Satisfaction. - All but 5% of respondents said they "liked the way they were living now;" and four-fifths were definite. More than two-fifths of those we interviewed, however, said there were things they would like changed. Most frequently mentioned were (1) a change in who one lives with (e.g., alone; different roommate; intimate friend); (2) more or better support; (3) living somewhere else; and (4) changes in the physical environment (e.g., phones, TV sets, environmental controls, etc.). Other, miscellaneous desired changes dealt with attitude/communication issues with staff; having more money; jobs; schedules; friends; and getting out more. Asked "Are you happy with your life right now?," 69% expressed a definite "yes;" another 25% were less positive ("sort of"); only 6% said "No." The factors to which respondents attributed happiness (or unhappiness) typically related to freedom or independence, and relationships. Asked what would make life better, relationships were most frequently mentioned. Examples include: being closer to family and friends, living with an intimate friend, or a better roommate relationship. Asked ". . . [are you] better off now than you were a year ago, about the same, or not as well off?," 82% said better off; only 6% said not as well off. By and large, individuals expressed considerable satisfaction with services provided by their CSLA agency. Rated the highest were people and the help they provided. Slightly lower levels of satisfaction were expressed in regard to whether the agency is on my side; agency people being here when I need them; and being asked (and supported) in my goals or plans. Asked what they liked best about the agency, responsive assistance and nice, helpful people were most frequently mentioned. One in ten mentioned getting away from where they lived before. Asked "What could be better?," one in three said "nothing could be better." More or better help dominated the responses (40%), followed by less staff or improved staff attitudes (e.g., less control; less criticism) (11%), and an array of other things (16%).

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Other Valued Outcomes. - Nine out of ten individuals said they had one or more personal goals, which tended to focus on work, relationships, and living elsewhere. Of those employed, 13% told us the job was at a workshop or activity center, and this may understate use of segregated work settings. While generally satisfied with use of free time, given the opportunity (and support) more people would go places (e.g., out to dinner; see friends, etc.) than, as at present. The dominant leisure activity at present is something at home (e.g., watch TV; use my computer). Sports/physical activities; having jobs (or doing volunteer work); seeing family and friends more; and learning/going to school were things people wanted to do more of. Transportation, distance, and schedules were said to sometimes stand in the way. Nearly half said they belonged to clubs, groups, or organizations, and this probably understates things, because several volunteered information about church activities elsewhere in the conversations. In the course of our fieldwork, we saw no abuse or neglect. We did see a handful of instances, involving intrusiveness, where interactions could have been better. The vast majority of respondents said they had enough money for the basics (food, clothing, shelter, medicine). Nearly half said that, at some time, they had run out of money. All said they made do by borrowing from family or friends, eating leftovers, taking advantage of free meals, or going without. Asked what they would do differently if they had more money, travel/vacations was most frequently mentioned, followed by purchases (e.g., van, hot tub, wheelchair), increase in savings, and live elsewhere. Two individuals said they would drop their CSLA agency.

Support Needs. - By and large, individuals were pleased with their services and supports. Especially appreciated were personal qualities (listening; helpfulness; kindness). Least highly rated was whether staff asked about goals and plans and were supportive in attaining them. In many areas of life (e.g., doing more things; getting to know more people; getting a job; changing living arrangement; etc.), individuals said they needed support, typically from the CSLA agency. Over three out of four people who wanted changes said they had talked to someone from their CSLA agency, but over half of this number felt that staff were not helping with the change or where not doing enough, quickly enough.



Family Outcomes

Although we heard from a small group of individuals (in terms of reporting on statistical relationships), we learned the following from our family and friend survey respondents:

- ❑ They typically reported that their relatives or friends receiving services were happy, safe in their homes and neighborhoods, healthy and that they were happy with the people who work with them.
- ❑ More than half reported that their friends or relatives in CSLA had enough to do. Those who indicated that they did not, pointed to the need for more support or training, an unsafe neighborhood, isolation, or lack of money and/or transportation as barriers.
- ❑ Individuals who responded are typically in contact with service-recipient family members or friends through talking, visiting or having fun together.
- ❑ Family members and friends were most often involved with planning for or developing services and supports.
- ❑ On average, they spent about six hours per week in some way with friends and relatives who receive services.
- ❑ Most respondents felt that they were spending the right amount of time.
- ❑ Some would have liked to spend more time talking, visiting, having fun together or making sure that support services were provided.
- ❑ Most respondents stated that their friends and relatives in CSLA were better off, or as well off as they were one year ago.

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- ❑ The concerns expressed by relatives or friends typically had to do with unmet service needs or support staff.
- ❑ When comparing responses from friends and relatives, individuals with developmental disabilities, and community monitoring team members, we found that:
 - ❑ CSLA participants, relatives, friends, and community monitoring team members typically perceive key lifestyle questions (e.g., happiness, health, safety) in the same way.
 - ❑ CSLA participants, relatives, friends, and community monitoring team members typically agreed that individuals were happy, healthy and safe.
 - ❑ Area Boards reported that the most effective activities in facilitating an understanding of CSLA funded supported living service for families were (1) informal discussions during monitoring activities; (2) ongoing conversations with families of current or potential service users; (3) participation of family members in CMT activities; and (4) face-to-face meetings as a part of a circle of support.

Organizational Outcomes:

Services and Supports

What impact has CSLA had on agencies providing services?

On selected aspects of service and supports, our major findings are: Across the seven participating regional centers, 27 agencies (or branches of agencies in other regional center areas) took part. In October 1994, when about 300 people were being served, 12 agencies had 1-8 participants; 9 were serving 9-16; and 6 had 17 or more. Four agencies had been involved in supported living pilot efforts prior to CSLA. Another 12 had experience with independent or supported living services (ILS/SL) in other ways. Eleven were new to these approaches.



Are services designed to fit the person, or is the person selected to fit the service?

In planning services, getting to know the person is crucial. Spending time with the person, talking, listening, and observing is perhaps the best way to do an assessment. In approaching individuals new to their agencies, several used person-centered planning techniques, such as Personal Futures Planning, PATH, MAPS, or Essential Lifestyle Planning. Only one assessment tool, the CAP (Consumer Assessment Package) questionnaire, was prescribed by the CSLA Manual. All used it. Some agencies, especially those with an ILS background, used skill assessment tools, such as TRACS. Liberal funding of assessment encouraged completeness. Sticking to basics and adherence to a particular 'model' tended to constrain the breadth of assessment. Cost containment meant restrictions on hours or duration of assessment activities.

Several factors appeared to influence whether (and how) agencies got to know new people: (1) funding of (or lack of funding for) assessment; (2) the tradition or expectation of an agency's services (e.g., skill acquisition; sticking to basics); (3) costs and attitudes toward cost-containment and economic efficiency; and, associated with this third point, (4) whether the agency leaned toward a particular 'model' (e.g., paid roommate; supported cluster of apartments; three-to-an-apartment; etc.).

Beyond assessment and service planning, are services responsive to the needs and wishes of the individual?

Agencies varied in the kinds of relationships they promoted: for example, collaborative teamwork vs. professionally-driven approaches; or friendship between worker and participant, or maintenance of greater boundaries, with some professional distancing. These differences are considered important in terms of service needs and commitments to standing by people. "Models" along the lines noted above, also played a role. Their use typically meant that responsiveness was constrained by the particular approach used. Staffing

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arrangements tended to be more horizontal, but some agencies maintained hierarchical traditions. Several agencies tried hard to 'match' workers with participants, in terms of skills, attitudes, demeanor, interests, etc. Evidence from Individual Interviews suggests that smaller agencies were more likely than larger ones to offer participants choice in who worked with them. We think this stems from larger agencies having workers with seniority, and smaller programs growing quickly from a very small base. Regional center policies and practices also played a role. Some regional centers were more inclined to suggest agencies, than encourage the person to explore options and choose. Regional centers varied in whether liaisons knew most participants well, and in how often they sat down with CSLA agency program managers to problem solve. Some regional centers pursued fading of paid services more vigorously than others, or encouraged 'models' that were more costly (or less costly) than services might otherwise be.

In terms of generic services, by which we mean those not exclusively for people with developmental disabilities, most agencies vigorously pursued such services on behalf of those they served. Certainly this was true of housing (e.g., Section 8 Rental Assistance). Most agencies, but not all, worked hard to connect people to the IHSS program. Those that did not tended to be leery of participants having \$4.25 per hour workers, or were not as sophisticated as others in blending IHSS and CSLA-funding. Transportation continues to be a big problem in many areas of the State. When it comes to adaptive equipment and assistive devices, the process is reportedly too slow (getting Medi-Cal denials) and resources often inadequate within certain geographic areas. Access to physicians, and especially dentists, continues to be problematic for some. And, several informants said that mental health services were inadequate.

Regarding natural supports, 85 percent of the individuals we interviewed spent time with family and/or friends. Many CSLA recipients expressed interest in more friendships, greater intimacy, and more things to do. Agencies typically said that 'building natural supports' was among the hardest things to do. If it occurred,

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it tended to do so naturally. Most agencies were struggling with how to encourage natural supports. Based on interviews with service providers and CSLA participants, we conclude that agencies can help by emphasizing (1) that friendships can happen; (2) that both parties will benefit; (3) that discretion helps in facilitating connections (when to introduce, when not; coaching and encouraging; etc.); (4) that opportunities should be pursued; and (5) that friendship formation and community-building is serious and important work.

As to the fading of paid services, our initial fieldwork revealed uncertainty and some pessimism. "It's too early to tell" was not an uncommon reaction. From a more recent (July/August 1995) telephone survey, we know that fading does occur with some frequency. Reasons are typically greater confidence on the part of the person to do things without assistance; greater skill in some cases; establishment of routines, with associated fading of more expensive services (CSF, for example) for less expensive services; and natural supports (e.g., getting a job; or a boy friend taking the place of paid staff at night). Fading is not as likely, we were told, when the person has intense physical, medical, or behavioral needs. Indeed, in a few instances paid service and support needs rose over time because of physical or mental health issues. In one town, over a period of three-to-four years, associated with a supported living pilot (pre-CSLA), costs - in comparison with those at a large ICF - tended to be higher, but then came down well below the ICF average.



Organizational Outcomes:

Safety, Risk and Choice

The CSLA legislation emphasized safeguards (called Minimum Protections) to minimize abuse, and broke new ground in the area of Quality Assurance by calling for Community Monitoring Teams. Regarding Minimum Protections, major steps were:

- A requirement that CSLA agencies (1) check on the backgrounds of employees and agency volunteers; and (2) avoid practices that could lead to financial abuse (e.g., owner-lease-backs; being named beneficiaries in life insurance policies; controlling a consumer's money).
- Agencies were to: (1) provide employee training, covering specified topics; (2) establish a grievance procedure; (3) provide consumers with information and training on rights; and (4) carry liability and fidelity insurance.
- In addition, agencies were to have policies, procedures, and practices to include: (1) a 24-hour response system for each person, with training as appropriate; (2) a system and methods to ensure consumers received adequate health care; (3) a personal advocate when needed and desired; and (4) help in making connections and developing a circle-of-support (if desired).
- Regional center case managers and CSLA liaisons were to review services periodically, and DDS would conduct a formal [certification] survey at least annually.
- DDS certification reviews, which covered many of these matters as well as others, revealed substantial compliance with expectations. In initial reviews, a few deficiencies were noted, mostly in the area of personnel (job descriptions; employee screening; procedures to prevent exploitation). All were remedied before certification was completed.

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- California used its Area Board system for Community Monitoring Teams. CMT coordinators found recruitment and selection of team members one of their most challenging tasks. One CMT had a volunteer for each person; at the other extreme, one had a volunteer for every 12 participants. One CMT contracted out the service. One regional center contracted for on-going monitoring because the CMT had difficulty getting up and running. Of over 100 CMT members, two-fifths were service providers; a quarter were parents or siblings; and one-fifth were people with developmental disabilities. Attention was paid to good matches. Many CMT members initially used the 112-item Quality of Life Survey provided in the CSLA Manual, but subsequently went to a shorter set of questions with a more conversational style. A partial review of completed surveys revealed concern with (1) acquisition (and maintenance) of adaptive equipment and assistive devices; (2) choice (e.g., housemates; places to live; agencies); (3) lack of opportunities (and support) in developing social relationships; and (4) transportation. Problem resolution was initially problematic in a few instances, but Regional Center personnel, CSLA agency people, and Area Boards seem to have worked out effective ways of resolving issues. CMT coordinators emphasized that individuals were typically delighted with their supported living arrangements.
- The most frequently mentioned best things about supported living services, according to CMT members, were: (1) empowerment, choice, and control; (2) better and more integrated living arrangements; and (3) individualized, quality services. As to what's the best thing about being a CMT member, being a friend, playing a helpful role, or just being involved in an effort to make a positive difference in someone's life were mentioned most frequently.
- Compared with more traditional independent living services, CSLA heightened concern for the occasional conflicts between choice and risks to health and safety. Reasons included: (1) the emphasis on self-determination and choice within

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CSLA; (2) the very considerable interest in minimum protections and safeguards for health and safety; (3) the more varied backgrounds, needs, and desires of people, many of whom needed far more support than traditional for individuals attracted to ILS services; (4) the expectation that services and supports would respond to what a person needed or wanted, rather than be restricted to an agreed-upon set of services embodied in a standard curriculum; (5) the fact that several agencies were new to supported (or independent) living services; and (6) the new value of standing by individuals, through good times and bad, rather than terminating service relationships if people were irresponsible or had a tendency to get into trouble. In general, agencies (and regional centers) learned to balance choice with health and safety, typically going beyond training and counseling, where necessary, and bringing to bear ideas and influences from several angles. Risk assessment tended to be more informed, and teamwork (or collaboration) often played an important role.

Service Use and Cost

In March 1995, the average cost of CSLA services (per person per month) was \$2,240. This does not include SSI or other sources of personal income for basic needs such as food, clothes, and shelter. The average cost of CSLA services varied by regional center. The highest was \$3,040; the lowest, \$1,777. There is some evidence of "economies of scale" up to at least 15 to 20 consumers per agency - that is, per person per month costs, on average, were lower for programs of this size than for smaller ones, especially for the very small agencies with five or fewer service recipients.

About half of all CSLA service recipients accessed In-Home Supportive Services (IHSS). Thirteen percent were granted 280 or more hours per month. IHSS hours were positively correlated with CSLA outlays, and the regression coefficient for IHSS hours was statistically significant. We suspect that CSLA outlays would have been even higher in the absence of IHSS. Over a third (36%) of CSLA recipients lived with one or more other service recipients. About the same percent lived in close proximity to other

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consumers. Living with another consumer is associated with an average reduction in monthly CSLA outlays of about \$400; living with two consumers, about \$800.

On balance, fading of paid support is confirmed by our cost data. Excluding 843 (Equipment), 845 (Overhead) and extraordinary 842 (24-Emergency) outlays, remaining CSLA costs per person-month averaged \$1,994 during the initial full support month (actually 3-month average) for each person. By March 1995, this number had declined to \$1,829, or by \$166 per person. The average length of this period was 15 months. Over the same average time span, CSLA Agency (i.e., overhead) costs declined from 27% of the total, across agencies, to 18 to 20%. This suggests a further decline of \$180 per person-month. If a reduction in the use of regional-center-funded day program services were factored in, regional center outlays declined by another \$35 per person per month, across 300 CSLA participants. (The percentage using such day program services declined from 33% to 27% by March 1995.) The extent of decline in CSLA costs was greatest for (1) those who had received services for the longest period of time; (2) those with developmental level (DEV%) scores of 70 or above, who had no mobility limitations; and (3) among individuals living with other consumers receiving services, perhaps because they shared some resources.

Only at one regional center (B) did average CSLA direct-service costs increase over time. Regional Center G experienced the largest average reduction: -\$506 (or -25%), from initial full month of support to March 1995.

Of approximately 300 individuals receiving CSLA (or, in some instances, ILS or other SL) services in March 1995, 40% had been receiving ILS services just prior to CSLA. (A quarter of this number had been participating in SL pilots.) Another 21% had lived with family or friends; 23% in community-care facilities; and 16% in long-term health-care facilities. The monthly cost of CSLA services in March 1995 was about \$672,000 (\$2,240 x 300 consumers). Based on estimates (and reasonable assumptions) of the average public cost of various alternatives, we estimate that, in the short-run, CSLA added about 100% to what would have been spent had CSLA not existed (estimated

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public outlays of \$320,289 to \$387,525).

"About 100%" may overstate the change to the extent that many participants from parental homes would have gone into relatively expensive residential arrangements. It should also be noted that 50% of the cost of CSLA was new federal money. In the absence of CSLA, quite a number of participants would have received services funded wholly with state dollars.

In terms of personal and regional center correlates of unit (per person per month) costs, details have been relegated to Appendix D. In general, as highlights, we can report that:

- CSLA costs were higher for women than for men, perhaps due to greater protectiveness and the greater frequency of having dependent children in the household.
- Developmental level (DEV%) was inversely related to unit cost. Having mobility limitations or a Behavior Factor Score of 30 or higher (meaning a high level of maladaptive behavior) was associated, with considerably higher cost, on average. On the other hand, there is no statistical evidence that our measures of medical needs or sensory impairments were correlated with cost per person-month.
- Regional centers varied somewhat in costs, as already indicated. There is some statistical evidence that, controlling for service need, some regional centers had higher (or lower) costs than others.

System Effects

In terms of systemic matters, two organizational outcomes were of particular interest: (1) whether intake and evaluation processes were non-biased; and (2) whether there were fewer disruptions in service delivery. Regarding the first, . . .

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Regional centers used a variety of means in outreach efforts, often in collaboration with area boards, including dissemination of brochures and flyers; placing announcements and articles in newsletters; presentations to consumer, agency, and parent groups; and public forums and fairs where interested parties could meet and talk with service providers.

Regional center case managers played a key role. Just over half of the service recipients we interviewed said they had first heard about CSLA from their regional center Client Program Coordinators (CPCs). One in five learned about CSLA from a provider agency; one in ten from a family member or friend.

The nature, location, and pre-existing service offerings of agencies also played a role. Some agencies had been involved in supported living pilots or were providing ILS or supported employment services, and in cooperation with regional centers, encouraged CSLA services for some of those they were already serving.

At root, having access to information about supported living, and some source of personal advocacy (e.g., a CPC, an existing service provider, a parent or close friend), were important factors in who received CSLA services. Compared with all clients of the Department of Developmental Services, those who used CSLA services were more likely to be female (48 vs. 44%); to be non-ambulatory (38 vs. 26%); and to be non-Hispanic whites (80 vs. 53%).

Only two of the seven regional centers adhered to the CSLA Manual in terms of using intake and selection processes and panels of appropriate composition, with prioritization as a means of selection.

As to disruptions in service delivery, we cannot say whether they were less (or more) common. We had no comparison group. With unknowns associated with any new service, one might anticipate more discontinuities. On the other hand, agencies told us that they were standing by people rather than, in effect, saying to consumer: "take what

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we have, if you want it, or do something else." When a service termination was likely, agencies said that they worked hard to connect people to other services responsive to the individual's wants and needs. Early in the pilot, with time delays associated with start-up, quite a large number of applicants found other services while waiting. Once served, some returned to family homes (or licensed places) where they had lived before. A few people (e.g., parents; those used to a single ILS counselor) found the service too intrusive, or didn't want so many people in their lives. Some changed CSLA agencies for one reason or another - typically over problems with the service or the way in which an agency did business.

The CSLA pilot came at a time when supported living was in the air for a variety of reasons, and people were eager to expand living arrangement options. In terms of major events (e.g., S.B. 1383; the Coffelt Settlement Agreement; expansion of California's Home and Community-Based Services, Medicaid Waiver), the effects continue to work themselves out, with the Coffelt Agreement providing impetus for more Adult Family Homes (AFHs) and CSLA jump starting supported living arrangements. AFHs are like foster care homes for children. Adult Family Home agencies recruit and support homes, certified by the Department of Developmental Services, that serve no more than two adults.

When things are going right, the various players in the supported living drama are expressing themselves, making responsible decisions, being smart about the delivery of services (e.g., responsive; cost-effective), evaluating services as well as individual well-being, advocating for improvements, working diligently and effectively together, taking advantage of generic services and natural supports, pushing for 'regular lives,' in integrated, safe neighborhoods that make sense for each person, and working to fix some systemic problems, involving such matters as affordable housing, transportation, and adaptive equipment and assistive devices.

As a counterpoint, we highlight one situation where several positive influences were missing, and the cumulative effect would disturb nearly every outside observer. Despite

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general unhappiness about their situation and services, however, eight out of the nine service recipients in this one case said they felt "better off" compared with a year earlier. All had transitioned from an institutional setting.

In terms of basic influences on outcomes of interest, DDS, regional centers, CSLA agencies, individuals and families played important roles. All can take credit for the significantly improved lives of nearly all who were served. The Department's influence was rather global: (1) increased interest in alternative living arrangements; (2) greater use of person-centered planning techniques; (3) clarification of important issues, such as balancing risk and choice; (4) capacity-building in general; and (5) expansion of California's HCB Medicaid Waiver, with attention to supported living. Regional center effects were felt largely through (1) recruitment of CSLA agencies; (2) choice of agency; (3) the critically important role of case managers; and (4) how CSLA liaisons did their work.

Influenced by DDS, regional centers, and others, (1) many CSLA agencies adopted (or refined) practices in keeping with supported living values and principles; (2) some learned more about person-centered planning and personalized services; (3) many organized their work differently (e.g., more teamwork; more part-time helpers; etc.); and (4) some deliberately stayed small, while others grew quite rapidly. The influence of service recipients was felt in many areas. Two are especially noteworthy. First, some agencies chose not to provide incidental transportation. Independence, cost and other factors doubtless played a role, but liability concerns were also expressed. Second, some agencies sought to become providers of IHSS services, which can lessen choice. While appropriately meshing IHSS with regional center funded services can be complex, poor choices by service recipients were among the factors given by agency representatives in arguing for their greater control over helpers.

As to influences on service use and costs, many factors can be mentioned. Targeting people with significant mobility needs, parents, and others resulted in a wide array of service needs. Offering choice of agency within a huge state in both geography and

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population, along with higher-than-expected average costs, had an effect. The absence of certain approaches made a difference: (1) no caps on service use; (2) no RFP process to test interest and commitment; (3) no vouchers; and (4) no requirement as to the minimum number of people to be served with a given dollar outlay. Traditions in California (e.g., basic entitlement to services; complexity of the service system), along with the way CSLA was implemented in California, tended to inhibit much use of "independent service brokering." CSFs were brokers, but operated exclusively from within agencies providing other services.

Regional centers influenced service use and costs in several ways, including but not limited to: (1) which vendors were recruited and how they did their work; (2) targeting (or the lack thereof) of who would be served; (3) contractual arrangements, with one center using a capitated monthly rate system; and (4) policies and practices regarding adaptive equipment and home modifications. The influence of CSLA agencies on service use and costs was expressed through (1) the adherence of some to particular 'models' (e.g., paid roommate; 3-to-an-apartment; on-site support to people living in close proximity); (2) what type of service the agency had been providing earlier; and (3) the aspirations of various agencies (e.g., to stay small and excellent; to be large and cost-effective; etc.). The influence of individuals and families on service use and costs was felt largely through (1) any stimulus toward overprotectiveness; and, (2) high aspirations for a particular lifestyle.

Finally, with the end of the CSLA pilot, and the transition to other funding sources (most notably, the HCB Medicaid Waiver for those eligible), one can see the pervasive influence of resource limitations. Several regional centers and agencies have been considering managed care approaches. Agencies and centers are paying more attention to the prioritization of needs and wants. Centers are being more careful in authorizing extra funds for back-up and crises, leading one agency to require that new service recipients have a day program. More than one agency has moved to a paid roommate to cover night-time hours, reducing reliance on hourly staff for this purpose. Agencies varied in their outlook on who will be able to access supported living in the future. Some



felt that people with intense needs will be increasingly ruled out. Others felt that this is unlikely, in part because comparative costs may suggest supported living as an economically viable option for many. Less attractive rates may reduce interest of new service providers, but an expected reduction in paperwork and related restrictions may result in more providers, including independent assessors and independent service brokers, unaffiliated with agencies providing other services.

Trends and Comparisons Across States

Looking at both the HCB Medicaid Waiver and CSLA programs, both of which have been vehicles for advancing supported living as an alternative to facility-based residential services, one sees several trends:

- a broadening menu of services, to include several which undergird supported living, including personal care, personal assistance/attendants, supported living (by its own name), homemaker/chore services, respite, adaptive technology/assistive devices, and home modifications;
- support coordination (personal agent, or broker model), typically as a service to assist the individual in accessing a broader, more flexible, tailored set of services and supports, and to supplement the more traditional gatekeeper/service director role of case management within the MR/DD service system;
- increased use of person-centered approaches to planning;
- giving the individual more choice and control as to which agencies, and which people, will provide needed services (e.g., being able to "fire" the support services agency, without losing supported living services);
- establishment of policies to guide payment of family members for personal assistance and other services (although this option is not heavily used); and,
- a movement toward judging quality based largely on valued outcomes as viewed by the service recipient and involved family.
- States would like to see further changes in the HCB waiver program, so that they can make better use of it. Among the major suggestions:

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- making eligibility for HCB not dependent on eligibility for institutional services (and, in the case of supported employment, past institutional care as well);
- permitting the 'bundling of services,' and using a managed care approach;
- use of cash subsidies or vouchers; and,
- aligning the HCB program with certain tenets of CSLA.

The eight states chosen to participate in the CSLA pilot approached service delivery in similar, yet diverse, ways. Florida decided to use CSLA funds exclusively for Supported Independent Living Coaches, who (on paper, anyway) were expected to perform a series of tasks not unlike many counselors in personalized ILS programs in California.

Colorado's flexible approach emphasized the role of a Supported Living Consultant, who can work for an agency, be a family member, or work out of their homes, to broker and help access services. Michigan placed great emphasis on the role of the Individual Support Planning Committee, with the person receiving services being the employer (with assistance, as needed). Other states have used CSLA to advance certain reforms (e.g., independent case management; developing a unified system; etc.).

Sparked by CSLA, Rhode Island has proposed to the federal Health Care Financing Administration (HCFA) a research and demonstration project, called CHOICES, that would represent the first major restructuring of long-term care. All federal Medicaid funds, along with state dollars, would be put into a single resource pool. Individuals would exercise control over their share of resources. Support brokering would substitute for traditional case management. A unitary, cross cutting set of standards would replace program-by-program standards. And, a managed care health plan would be installed to ensure access to a reliable system of medical services.

Service costs in California, which were originally projected to be quite low, have been toward the high end of per capita costs across the eight states. Several factors may account for this: (1) the scope of services offered by each state CSLA program; (2) the absence of much experience in California with supported living for individuals with

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significant needs, and associated high start-up costs; (3) relatively high wage rates and housing costs; (4) the significant service needs of many California CSLA participants (e.g., nearly 40% non-ambulatory); (5) the difficulty (and expense) of assuring choice in a very large State, in terms of both population and geography; (6) the configuration of living arrangements (e.g., percent supported in family homes; living alone; living with one or two other service recipients); (7) the relatively low average annual cost of services in California under the rapidly expanding HCB waiver program; (8) the limited options in California between supported living, as an ideal, and conventional group homes (licensed; typically serving six people each); and (9) some aspects of the way in which CSLA programs were implemented. In this regard, in California, we suspect that the following influences were felt: a well-established tradition of regulatory control permeating the service system; limiting the Community Support Facilitator role to agency employees; fear of liability; and rigid practices around vendorization and the use of contractors.

We were able to compare billing rates per hour of service in California with those in Michigan. The average (or median) rates for personal assistance, training and habilitation, and support for community participation are much the same. The spread (or dispersion) in rates is much greater in Michigan than in California. Hourly rates near the lower levels of distributions tended to be higher in California than in Michigan, with just the reverse true toward the high ends of the distributions. The influence of two factors are difficult to weigh. On the one hand, the California hourly rates are doubtless lower than they would be in the absence of separate funding of the indirect service category called CSLA agency. This may be offset by lower average wages and other prices in Michigan compared with California.

Where Do We Go From Here?

Now, it's time to reflect on the findings in this report, and to offer recommendations for service users, providers and policy makers. For supported living not to be restricted to the "lucky few," we will have to get smarter (and better) in the use of generic services,



natural supports, and working together within an atmosphere of principled, consensus decision-making, trust, and hard work. The result, we feel, will be better lives and better use of available public resources. The struggle to balance such resources with wants and needs, in the near-term future, will not be easy - in part, because of the State's fiscal woes and the fact that most everyone is learning new ways of thinking and doing. While seeking additional resources, it makes sense for everyone to work for increased efficiency and more affordable services.

Recommendations

Here's an overview of the 48 recommendations spelled out in Chapter 10:

- Adults with developmental disabilities and their allies need to work with others (elderly; people with other disabilities) at all levels to get the resources (and respect) needed to support a wider array of living arrangement opportunities.
- Interested individuals (and family members) should work with regional centers and others to put to good use the option of Parent-, Family-, Consumer-Coordinated supported living.
- To the service provider and quality assurance community (supported living agencies; regional centers, DDS, and Area Boards), we recommend the following:

An array of cost-effective approaches. - Development of a wider array of approaches to supported living, including service brokering, placing greater authority for resource allocation decisions in the hands of consumers (with the help, if needed and desired, of a Circle-of-Friends), and avoiding over-reliance on a particular model (e.g., paid roommate; on-site apartment support; 3-to-a-dwelling; etc.). Greater cost-effectiveness should flow from these and other initiatives; changes in vendorization practices; and managed-care-type contracts. We need to assess (and reassess) when Independent Living Services (ILS) or

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Supported Living (SL) makes sense. We must speed access to adaptive equipment and assistive devices (and repairs), without loss of federal matching funds.

Devising patterns of support. - Flexibility in assessment, with use of person-centered techniques and attention to technology, adaptive equipment, and home modifications, allowing sufficient time (with resources) to get-acquainted and to figure out supports and services that make sense. Prioritizing needs and wants, and being responsive (directly and indirectly) to areas of unmet need: e.g., getting out and about; friendships; roommates; moving; getting a job; etc. Taking time to talk about hopes, dreams, and plans for the future, and finding ways to assist, directly or indirectly.

Community membership and quality relationships. - Being clear on desired relationships between helpers and service recipients. Welcoming and working with families and close friends, if this is what the service recipient wants. Collaboration and teamwork, from the start, will encourage the involvement of family and friends, if this is what is desired (and possible). Honoring preferences regarding informal support networks. Supporting efforts to facilitate the development of natural supports and community membership. Helping people form and maintain quality relationships with family, friends, and others, including people with disabilities. Considering additional ways to do this (e.g., friendship matching).

Paid helpers. - Devising ways to work with people, so that they have as much choice as possible regarding those who provides services and supports. Improving recruitment, selection, training, and supervision of support personnel, with emphasis on teamwork at the level closest to the service recipient. Finding ways to substitute lower-paid for higher-paid workers without adversely affecting Quality of Life and services.

Life quality and service satisfaction. - Using individual interviews to learn



about service needs and service satisfaction. Supporting continued involvement of family and friends in service evaluation, and in the service planning process (e.g., How would you like to be involved?). Defining quality in terms of valued outcomes as viewed by service recipients and (where appropriate) family and friends. Including health and safety if overlooked by others. Finally, greater clarification of responsibilities for various outcomes.

Balancing risk and choice. - Continuation of technical assistance and information dissemination regarding risk assessment and ways to balance choice and risk. Developing clear guidelines and exemplars regarding liability of service providers.

Teaching, learning, and technical assistance. - Teaching/learning, with an emphasis on (1) various approaches to person-centered planning; (2) building community connections; (3) team-building; (4) conflict resolution; and (5) how to use In-Home Supportive Services (IHSS) wisely. Developing and making available, information on adaptive equipment and assistive devices. Creating ways (e.g., job outposting) for regional center staff to do direct service, and for agency people to learn more about regional centers.

Dealing with some broad, systemic matters. - Considering ways to merge DDS and DR funds, so that a service provider can respond to integrated employment opportunities. Considering further amendments to California's HCB Medicaid Waiver - if such continues - for supported employment. Working with others (1) to extend and improve IHSS and its effective use; (2) to develop decent, well-managed, integrated, accessible, low-cost housing; (3) to expand and improve use of the Section 8 Rental Assistance Program, with emphasis on shared housing and full portability; and (4) to extend and improve use of generic transportation.

Best practices, and continuous quality improvement. - Learning from one another, and from "best practices" everywhere they can be found, by looking at

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the experience of providers, intermediate units, and State MR/DD agencies throughout the country.

In Closing, . . .

A great deal has been accomplished through the CSLA pilot. Most noteworthy, in our minds, are the following:

1. The lives of 300 or so Californians have been significantly improved! There have been major spin-off effects (e.g., HCB Medicaid Waiver) as well.
2. Choice and regular lives, with accommodations and support, have been given greater emphasis.
3. Service providers have learned a lot about supporting people who, in an earlier era, had no opportunity to live in their own homes.
4. We need to figure out, and put into place, a wider array of cost-effective living arrangement possibilities attractive to adults with developmental disabilities, and responsive to how they see their lives unfolding.
5. The preconditions for supporting more people in their own homes have been established (knowledge, experience, will) in California - thanks, in large measure, to CSLA.