



April 2006

CPAC Author's Report

**Quality Services and Quality Jobs for Supporting
Californians with Developmental Disabilities**

Carol Zabin, PhD

UC Berkeley Center for Labor Research and Education

CALIFORNIA POLICY RESEARCH CENTER, UNIVERSITY OF CALIFORNIA
1950 ADDISON ST., STE. 203, BERKELEY, CA 94720-7410
PHONE / FAX: (510) 642-5514 / 8793; WWW.UCOP.EDU/CPRC

TABLE OF CONTENTS

INTRODUCTION	3
CALIFORNIA'S SERVICES FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES	4
The development of community-based services	4
California in national comparison	5
<i>Features of the delivery system</i>	5
Overall funding commitment	5
Development of person-centered services.....	6
Growth Projections for Person-Centered Services	8
THE DIRECT-SUPPORT WORKER STAFFING CRISIS	8
The Workforce.....	10
Compensation and Its Impact on Stakeholders.....	11
<i>Wages and benefits</i>	11
<i>Impact of poor compensation on turnover</i>	11
<i>Impact of turnover on quality of services</i>	12
Training and the changing job description of direct-support workers	12
The proliferation of small agencies	14
Consumers as employers.....	17
Family vouchered services.....	17
Self-directed waiver	17
Workforce challenges in consumer-directed services.....	18
RECOMMENDATIONS AND STRATEGIES FOR CHANGE	19
Rate reform	20
Training infrastructure	20
Funding and compensation	21
The social enterprise PEO model.....	22
CONCLUSION	22
REFERENCES	23
APPENDIX	28

INTRODUCTION

With the 1999 Olmstead ... decision, there could not be a more pressing urgency for federal and state agencies to find solutions to the direct-support workforce crisis. There is no foreseeable way that continued efforts to provide equal access to community services can occur without finding resolutions to the problems of DSP recruitment, retention, and training (Hewitt and Lakin, 2001).

California's developmental disabilities services system assists approximately 200,000 consumers, employs 90,000 workers, and costs over \$3 billion per year (California DDS, 2005). Since 1993, the number of people served by the California Department of Developmental Services (DDS) increased by 70%. This dramatic growth is attributed to the increasing lifespan of people with developmental disabilities and the aging of family caregivers, as well as an increase in rates of autism (California DDS, 2005; Braddock and Hemp, 2004, 9). To meet the needs arising from the rapid increase in the numbers of people with developmental disabilities, ongoing growth and development of community services is required. This is a substantial challenge for California.

The service system in California for people with developmental disabilities has been a system in transition since the passing of the Lanterman Developmental Disabilities Services Act in 1969. A consistent stream of advocacy initiatives in California and nationally have culminated in landmark legislation and court decisions, such as the Americans with Disabilities Act (1990) and the Supreme Court's *Olmstead* decision (1999). All have mandated deinstitutionalization and the creation of new services in community settings, recognizing the civil right of people with developmental disabilities to determine their own life plans, residences, and service providers. The system that once consisted of large, segregated, public facilities has been decentralized and operates through private community-based entities: nonprofit regional centers and nonprofit or for-profit provider agencies.

Decentralization and community control have made innovation in service provision possible, but there have also been unintended consequences. While new service models in the community have proliferated, little attention has been directed toward developing a workforce infrastructure adequate to attract and retain qualified and well-trained workers. The erosion of wages and benefits for workers in community settings has resulted in high vacancy and turnover rates, low levels of training, and few career opportunities for direct-support workers. The responsibilities of direct-support workers have changed and expanded but systemwide infrastructure for training and professional standards has not been created to respond to this transformation. The proliferation of small agencies, while allowing innovation and responsiveness to local needs, has also made it more difficult to develop training programs and internal job ladders within agencies. And though the new self-directed service voucher program offers great promise for expanding consumer direction and choice, it further atomizes the workforce, with workers employed by individual consumers.

Direct-support workers provide consumers with a wide range of supportive services to assist them in leading self-directed, community and social lives, including habilitation, health, employment, transportation, recreation, and home management supports. Some forms of

assistance are personal and intimate—for instance, direct-support workers may assist consumers with bathing, dressing, or toileting or help lift or transport consumers. In addition, direct-support workers assist consumers in navigating relationships with family, neighbors, co-workers, and others, advocating for their rights and interacting in a broad array of work and social environments. Support work in this environment is both a service and a quality of relationship. The overall quality of service for the consumer with developmental disabilities depends upon the cultivation of trust and mutual respect between the support worker and the support recipient. In a work environment characterized by high turnover and vacancy rates and inadequate supports such as training and mentorship, these essential features of the caregiving relationship, trust and respect, erode, directly affecting the consumer’s experience not only of quality of care, but of quality of life.

The neglect of the direct-support workforce is no longer sustainable. The staffing crisis is now widely cited as the most significant barrier to growth in community services (Larson, Hewitt, and Anderson 1999; Braddock and Mitchell, 1992; Hewitt and Lakin, 2001). As the state seeks to expand the availability of high-quality services for people with developmental disabilities, it must overcome the problem of recruiting and retaining sufficient numbers of qualified and well-trained direct-support workers.

This report documents the dimensions of the direct-support staffing crisis in California and its effects on services for people with developmental disabilities. It recommends the creation of a set of workforce supports that are customized for this decentralized service system. The recommendations for state action include initiating incentive-based rate reform that encourages improvements in key areas associated with the direct-support workforce and in the quality of services provided, investing in a workforce development infrastructure, and improving compensation of direct-support workers. In addition, the report recommends support for the development of a financially self-sustaining professional employer organization (PEO) that provides services to small- and medium-sized employers and reduces the costs of workforce supports and agency administration. This strategy resolves the contradiction that has arisen in the community system by combining decentralized services with economies of scale to resolve workforce issues and administrative inefficiencies.

CALIFORNIA’S SERVICES FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES

THE DEVELOPMENT OF COMMUNITY-BASED SERVICES

Across the nation, in all states, including California, the provision of services for people with developmental disabilities has undergone tremendous transformation since the 1970s. The dominant mode of service delivery has shifted from large public state institutions to smaller, decentralized, community-based settings. The process of deinstitutionalization has entailed both moving people from large institutions to community services and building community services that have all but eliminated new institutional placements (Coucovanis et al., 2005:14).

These changes occurred within a dynamic political environment of advocacy, litigation, legislation, court rulings, and the development of new federal long-term care programs. The Americans with Disabilities Act of 1990 codified the civil right of people with disabilities to choice, independence, and community inclusion; the U.S. Supreme Court’s *Olmstead* decision ruled that states are required to provide services in the most integrated setting possible. The

federal government has supported the shift to community settings through the Medicaid Home and Community Based Services (HCBS) waiver, which creates the incentive for states to develop noninstitutional services (Hemp et al., 2001).

As placements in large institutions have declined, the number of residential settings nationally has grown enormously. Nationally, in 2004 there were almost 150,000 residential settings of 15 or fewer people. This figure reflects a growth of 1485% since 1977, with 97.5% of that growth due to the increase in the number of residential settings for 6 or fewer people (Prouty et al., 2005b:77–78). These changes have resulted in a dramatic shift in the relationship between service provision and the state. In the 1970s and earlier, the states were major providers of services through large institutions supported by state budgets. Currently, however, states are major purchasers of services from private, nonstate vendors (Stancliffe and Lakin, 2005:4). In 2004, only 2% of residential settings were operated or served by state agencies nationally (Prouty et al., 2005a:v). In other words, in most states, the process of deinstitutionalization has also been a process of privatization of publicly funded services.

CALIFORNIA IN NATIONAL COMPARISON

Features of the delivery system

California is unique in the nation for its entitlement legislation for people with developmental disabilities, codified in the 1969 Lanterman Developmental Disabilities Services Act (the Lanterman Act). Everyone with a documented developmental disability is, under state law, entitled to the individualized services determined by their regional center assessment, regardless of economic status or other criteria. However, the entitlement law does not always guarantee service provision (Fishman et al., 2003:32). Though no formal waiting lists exist (Braddock et al., 2002:126), consumer access to the services of their choice is limited by agency reimbursement rate and start-up funds freezes, the staffing crisis, and variation across regions in types of service development.

The Lanterman Act also initiated the statewide system of 21 regional centers that carry out the dual functions of service coordination and contracting with service providers. Regional Center service coordinators create an individualized service plan for each consumer and refer consumers to appropriate provider agencies or reimburse their families if they directly hire support workers. The Regional Center system, which has its own state funding stream, insulates developmental disabilities services from competing county-level social service demands. Regional Centers are private nonprofit entities supervised by community boards with heavy consumer and family representation and are designed to respond to local needs (Fishman et al., 2003). As a result, California has one of the most decentralized service delivery systems in the nation.

OVERALL FUNDING COMMITMENT

Funding is a key measure of the commitment California has made to developmental disabilities services compared to other states.

State funding commitment

- California devotes 78% of its total spending for this population to community services, giving it a rank of 24th in the nation.
- California's fiscal effort, which is a measure of spending on developmental disabilities services as a percentage of state per capita income, has been consistently below the U.S. average since 1977. In 2004, California spent \$3.57 per \$1,000 of aggregate statewide income compared to the national average of \$4.11 (Braddock and Hemp, 2004:3).

Federal funding level

California is underutilizing the potential of the HCBS waiver and needs to develop methods of accessing these important federal funds to meet future needs (Braddock and Hemp, 2004:7–8).

- In 2004, only 27% of total spending on services for people with developmental disabilities in California accessed federal HCBS waiver funds, which ranked the state 42rd among all states in utilizing this funding stream (Braddock et al., 2005:30). This is a large improvement over 2001, when only 18% of total spending on services for people with developmental disabilities in California accessed federal HCBS waiver funds, and this change reflects substantial recent work by the state in this area (Braddock et al., 2002:102).

DEVELOPMENT OF PERSON-CENTERED SERVICES

The Lanterman Act and federal mandates have not only called for deinstitutionalization, but have also set forth the ideals of self-determination and community inclusion. California, like other states, seeks to develop services that enhance these goals by supporting consumers' ability to live and participate in their local communities and achieve control over their own everyday lives. Its evolving delivery system includes residential and day services that range from mini-institutions that offer little choice for consumers to services that more closely embody the ideals of self-determination and person-centered services. Among the many services provided through the state regional center system in California, the service categories that are generally recognized as person-centered services are independent-living and supported-living services, supported-employment and integrated work and day programs, family supports, and the new self-directed service program.

Quantitative measures that compare states with regard to their relative success in creating person-centered services are imperfect, but they do provide a basis for measuring California's ranking. The following indicators show that California has ample room for improvement.

Reduction in the size of residence

The proportion of people with developmental disabilities in residential placements of six or fewer people is commonly used as a first-cut indicator of a state's commitment to high-quality community services. Some of these residential placements are "six-pack" group homes, which offer little choice for consumers, while others more closely embody the ideals of person-centered services, such as supported living, discussed below.

- California ranks 17th out of 50 states in terms of the percentage of people residing in settings of 1 to 6 people (Braddock et al., 2005:19). In California in 2004, 83% of those served in out-of-home residential placements resided in settings for 6 or fewer persons, with 3% living in settings of 7 to 15 residents, and 14% residing in settings of greater than 16 residents (Braddock, 2005:19).

Supported- and independent-living services

Supported-living services (SLS) and independent-living services (ILS) enable people with all levels of disability to live in homes that they control. This includes people's ability to choose their residence and their roommates, the services they receive and the providers of these services, and what they do during the day. ILS and SLS provide person-centered alternatives to group homes, where consumers usually share their home with at least five other consumers, share a bedroom, and have little control over their daily lives.

- In 2004, California reported that 17,528 participants used supported-living services. Per capita spending (the spending per citizen in the general state population) on these programs was low in California, at only \$7.53, much lower than the national average of \$11.15. The utilization rate, calculated here as the number of participants per 100,000 citizens of the general state population, was 49 in California. California is slightly below the national average of 53 (Braddock et al., 2005:38). Although this is not an exact measure, because it does not include independent-living services, it does suggest that California's supported-living programs are subaverage when compared nationally.

Supported employment

People with developmental disabilities now have some access to supported-employment services that provide job developers to help people with developmental disabilities find jobs in the competitive labor market. They provide a person-centered alternative to sheltered workshops, where people with developmental disabilities perform piecework in a segregated shop setting and typically earn subminimum wages. Integrated work and community inclusion (IWCI) programs is an emerging service model that offers longer-term and more flexible work supports than supported-employment services. IWCI holds promise for increasing the small number of people with developmental disabilities who currently work in competitive work environments (Mautz, 2003).

- In 2004, there were 9,297 participants in California's supported-employment programs, and spending per capita among the general state population for these services was \$2.12, below the national average of \$2.34 (Braddock et al., 2005:42). In California, 18% of all day-work participants are working in supported employment, compared to the national average of 24%. Once again, these statistics show that California is providing services at lower rates than the national average. These figures include some noncompetitive work settings, and so they are not as precise as possible, but are the current best figures available.

Family supports

Family supports are those services that provide respite, daycare, and transportation for families caring for children or adults with developmental disabilities at home. Respite services, which allow family caregivers much needed breaks from intensive care giving, are often the first services that families ask for from regional centers. In California, about 30,000 families use respite services. This utilization rate far exceeds that of any other family support available through the regional center system. Family support vouchers give individual clients and their families more latitude in determining how, when, and by whom services are provided. Families hire respite workers for only a few hours each month, often hiring relatives, friends, and neighbors. Since most people with developmental disabilities live with their families, family supports are an essential part of person-centered services.

- In 2004, 81,074 families were served by family support services, with an average of \$4,615 spent per family. The average spending per family nationally was \$5,005. This ranked California 20th of all states reporting on total family support spending per family (Braddock et al., 2005:46).

Self-determination

The most recent service innovation is California's version of national self-determination programs, here called self-directed services program. Of all the services available, the self-directed services waiver gives consumers the greatest degree of flexibility and control over the services they need. Self-determination programs let the client manage his or her own service budget, selecting the services and the personnel who provide them. These service programs have expanded rapidly throughout the nation since the first pilot project in New Hampshire in 1993, as they have been shown to shift control over services to consumers and their close allies and increase quality of life, while on average reducing costs (Conroy, 2002). The new self-directed services program was developed based on the experience gained in pilot projects in five regional centers. Starting in 2006, upon approval of a federal waiver, self-direction will be available across the state for as many as 9,000 consumers over the next three years.

- The Center for Outcome Analysis estimates that up to 42 states are in various phases of experimentation and planning for service programs that allow the person with developmental disabilities and their allies control over their individual monetary allocation and budget (Conroy et al., 2002). Programs such as these began in New Hampshire in 1994 with funding from the Robert Wood Johnson Foundation. In California, demonstration projects were initiated in 1998 and will soon be available statewide (Conroy et al., 2002; California DDS, 2006).

GROWTH PROJECTIONS FOR PERSON-CENTERED SERVICES

Expanding person-centered services to meet future demand is an essential component of service quality and accessibility improvement. Since DDS does not maintain waiting lists for services, it is not possible to quantify the current unmet demand. There is anecdotal evidence from supported-living providers who have long waiting lists that demand for this type of service

exceeds supply, but no overall numbers exist. In addition, DDS does not produce long-term projections of specific service categories.

Table 1 shows projected growth for ILS and SLS services in California through 2014.¹ For the detailed methodology for the growth projections for ILS/SLS services, see Appendix 1. The growth projections for ILS and SLS services over the next 10 years are based on projections of the two components of growth: 1) the growth in the overall adult DDS caseload² and 2) the change in the ILS/SLS share of that caseload. Two scenarios illustrating different assumptions about the shift to ILS/SLS services from other services are used to project growth. The lower, or most conservative, scenario assumes that the ILS/SLS share of the pie for each age group will remain stable (i.e., the same percentage as in 2004), except for small changes due to the continued downsizing of state developmental centers. The second scenario assumes a continuation of 1993–2004 trends in the residential settings of adult DDS clients, which have shown a steady transition of people from group homes and family caregivers to ILS/SLS.

Table 1 Projected ILS Caseload in 2014: Two Scenarios

	<u>Adult Caseload</u>	<u>% ILS/SLS</u>	<u>ILS/SLS Caseload</u>	<u>% ILS/SLS Growth</u>
2004	102,823	17%	17,480	
2014 lower	156,724	17%	24,637	41%
2014 higher	156,724	26%	40,369	131%

Source (2004 caseload): Client Master File (CMF status 2, 8), DDS Quarterly Client Characteristics Report for the end of Dec. 2004.

As Table 1 shows, ILS and SLS caseloads will grow from 17,480 in 2004 to 24,637 with very conservative assumptions. If recent trends in the transition from group homes to ILS and SLS continue, the number of clients choosing ILS and SLS will grow to 40,369. As the projections suggest, a substantial expansion of ILS and SLS will be needed to meet the demand for services. Correspondingly, initiatives to help expand these services are essential to their future availability. These projections highlight the need for planning for future growth in demand.

¹ These projections were calculated by graduate student researcher Jonathan Hoffman while working at the UC Berkeley Labor Center. We are indebted to his diligent work in developing these growth projections.

² Adult status and age cohort are important variables in this analysis because current distribution of residence types varies across age groups. Virtually all ILS/SLS recipients served by the Department of Developmental Services (DDS) are adults due to the design of these services that enables individuals to live separately from their family of origin.

THE DIRECT-SUPPORT WORKER STAFFING CRISIS

The process of deinstitutionalization has dramatically affected the conditions of employment for direct-support workers serving people with developmental disabilities. This section documents four fundamental changes and their effects on workers, consumers, and employers in the community-based developmental disabilities system. First, the dismantling of the state system of institutional care turned public sector, unionized jobs with health insurance, pensions, training, and career ladders into poorly paid jobs with fewer benefits, little training, and very few opportunities for career advancement. Second, the growth and evolution of the community system has dramatically changed the job description of direct-support workers without constructing a new infrastructure or adapting the previous infrastructure for worker training and education. Third, the creation of a decentralized community-based system resulted in the dramatic proliferation of agencies and employment settings, resulting in challenges for agency-based recruitment, retention, and training strategies. Fourth, the expected growth in the number of workers directly hired by consumers through the new self-directed service program will further atomize the workforce, also creating challenges for upgrading direct-support jobs. These specific conditions must be considered in proposals to solve the staffing crisis, which will be addressed in the last section.

THE WORKFORCE

Recent estimates suggest that there are approximately 750,000 direct-support workers (full-time equivalents, or FTEs) serving people with developmental disabilities in both institutions and community settings in the United States (Lakin, Larson, and Hewitt, 2005). By 2020, the report estimates that demand for direct-support workers will grow by 37%, translating to almost 1,200,000 (FTE) direct-support workers. There is a paucity of demographic data specific to direct-support workers in California because the state does not collect data on workers in the subcontracted community services sector. However, Shea et al., using DDS expenditure data, estimated the number of workers in community services to be approximately 91,000 (Shea et al., 2003). Many of these employees are part-time, and this figure translates to approximately 59,000 FTE jobs. Projections of direct-support worker need in the future suggest that this work force needs to be supported, developed, and expanded to adequately meet future needs.

Industry Segment	Individuals			Full-time Equivalent (FTE)
	Total	Full-time (or more)	Part-time	
Community-care residential	30,000	20,000	10,000	26,000
Day programs, look-alikes, and habilitation	16,250	13,250	3,000	14,750
Independent-living/supported-living services	15,000	9,000	6,000	12,000
Nonagency vendored services (e.g., in-home respite, transportation)	30,000	1,000	29,000	6,000
Total	91,250	43,250	48,000	58,750

Shea et al., 2003, p. 11.

Data on the demographic makeup of California's direct-support workers is scarce. Wheeler's survey of workers in community-care facilities across the state shows that 70% of direct-support workers are female and 59% are African American, Latino, or Asian. This survey estimates that 10% of workers had less than a high school education, 66% had a high school diploma, 5% had an associate degree, and 19% had a bachelor's degree or above (Wheeler, 2002:17). However, little is known about the direct-support workforce employed outside of community-care facilities in California.

COMPENSATION AND ITS IMPACT ON STAKEHOLDERS

Wages and benefits

Across the United States, direct-support workers in institutional settings are generally paid much higher wages than workers in community settings. In 2004, starting wages for direct-support professionals in large state facilities were \$17.01 per hour, with a mean hourly wage of \$20.05 for all direct-support professionals employed in these settings (Larson et al., 2005:52). The 1999 California State Auditor's Report documented that workers in state developmental centers earned almost twice (197%) as much as those in community settings (Sjoberg, 1999).

The most recent survey data on wages available in California is Wheeler's 2002 survey of community-care facilities, commissioned by DDS after the state instituted wage pass-throughs of 9.3% in 1999 and 9.5% in 2000 (Wheeler, 2002). The study showed that after the wage pass-throughs, wages in community-care facilities averaged \$10.24 per hour (Wheeler, 2002).

Data on benefits for direct-support workers is inconsistent or unavailable. Wheeler's provider survey estimated that approximately 65% of community-care facilities provided health insurance benefits in 2001, up from about 30% before the wage pass-throughs; however, the data does not indicate take-up or coverage rates (Wheeler, 2002:27). Zabin's small sample of 20 ILS and SLS agencies showed that 75% provided health insurance, and though take-up was high, only approximately 50% of workers were covered because of the prevalence of part-time workers who did not meet the minimum hour eligibility requirements (Zabin et al., 2004).

The wages that direct-support workers earn are clearly not sufficient to support a family in California. The California Budget Project (CBP) calculates a "self-sufficiency" family budget for one- and two-earner families of a variety of sizes and ages (CBP, 2001; 2005). This modest budget includes rent, food, health insurance, and child-care services. The CBP reports that in 2005, a two-parent family with both parents working full time required an hourly wage for each parent of at least \$15.37. The self-sufficiency wage for a two-parent family with one wage earner was \$21.22, and \$25.96 for a single-parent family. Even a single adult with no dependants required an hourly wage of at least \$12.44 to meet the self-sufficiency standard. Providing essential support for some of California's most vulnerable people is not a family-sustaining job.

Impact of poor compensation on turnover

Low wages for direct-support workers result in high rates of turnover and vacancies. Hewitt and Lakin's review has documented extremely high rates of turnover, ranging from 41% per year to over 71% per year in community settings, compared to a range of 14 to 34% in institutional settings (Hewitt and Lakin, 2001). According to the California State Auditor's Report (1999),

turnover rates in the late 1990s (the most recent year for which data is available) averaged 50%, and vacancies remained unfilled for an average of three months. Wheeler's 2002 study documented turnover rates of 24% in community-care facilities after the two wage pass-throughs in 1999 and 2000 (Wheeler, 2002).

There are many studies that show that low wages are the primary driver of high turnover in developmental disabilities services workers. Lakin's and Braddock's seminal national studies (Lakin and Bruinink, 1981; Braddock and Mitchell, 1992; Larsen and Lakin, 1999) use cross-sectional analysis to show the strong relationship between higher wages and lower turnover in developmental disabilities services workers. More recently, due to wage increases for direct-support workers in several states and sectors, studies have been able to directly measure the difference in turnover before and after wage increases. A study of in-home supportive services (IHSS) home-care workers in San Francisco (Howes, 2004) analyzed the impact of large wage increases in this newly unionized sector. The study showed that between 1997 and 2001, as wages rose from the minimum wage to \$10.00 plus health and dental benefits, turnover dropped by 30%. A study of direct-support workers in developmental disabilities in Wyoming showed that when total compensation rose from \$9.08 in 2001 to 13.19 by 2004, turnover dropped from 52% per year to 32% (Lynch et al., 2005).

Impact of turnover on quality of services

The relationship between turnover and the quality of services for consumers has long been recognized by leading scholars concerned with the direct-support workforce in a variety of care sectors (Hewitt and Lakin, 2001; Braddock and Mitchell, 1992; Zabin, 2003). In some sectors, such as personal-assistance services for the elderly and physically disabled, the length of match between direct-care giver and consumer—directly related to worker turnover—is used as a direct measure of quality, because this indicator appears consistently in consumer-satisfaction surveys (Reif, 2002). In the child-care field, research has shown that children in child-care centers with lower turnover rates consistently have better outcomes on a variety of measures (Whitebook, 1998). In services for people with developmental disabilities, Braddock and Lakin have noted the particular need for continuity of care both to achieve basic health and safety objectives and to nurture the developmental progress called for in the Lanterman Act. As Hewitt and Lakin note, “lack of continuity makes it extremely difficult to develop and sustain the trusting and familiar relationships that foster personal growth, independence and self-direction” (Hewitt and Lakin, 2001).

Low wages for workers directly affect consumers and their ability to direct their own lives. Consumers and advocates have argued for increasing consumers' decision-making power over hiring, supervising, and dismissing the workers who assist them in their daily lives. Indeed, this philosophy of autonomy is at the heart of the self-determination movement. However, the consumers' right to choose their support workers cannot alter the systemic problems associated with turnover, vacancy rates, and training supports.

TRAINING AND THE CHANGING JOB DESCRIPTION OF DIRECT-SUPPORT WORKERS

The shift from institutions to community settings is not merely a shift in venue. It is a change in job description for direct-support workers that entails more responsibility and independence from supervisory staff (Lakin, Larson, and Hewitt, 2005). This change is greatest for workers in the services most closely defined as person centered—ILS and SLS, family supports, supported

employment, and self-directed services—and smallest for direct-support workers in traditional day programs, sheltered workshops, and community-care facilities work who still work under the direction of on-site supervisors, conducting structured and routinized programs (Hewitt and Lakin, 2001).

Direct-support workers in ILS, SLS, supported employment, integrated day programs, some family supports, and self-directed services are required to perform a broad array of tasks, autonomously and independently, as they assist consumers in leading self-directed lives. They provide medication supports, implement behavioral plans, teach new self-care skills, design and implement augmentative communication systems, and provide sophisticated supports to consumers with a very wide array of disabilities (Lakin et al., 2005). In addition, direct-support workers assist consumers in navigating relationships with family, neighbors, co-workers, and others, advocating for their rights and interacting in many different work and social environments. In person-centered services, they are accountable not only to their employers, but to consumers and families, who have a greater role in hiring, supervision, and possible termination (ibid). These support services often are offered in consumers' homes and in dispersed settings in the community and include interfacing with the public, working with informal caregivers, and teaching self-advocacy to consumers.

These kinds of responsibilities and skill needs require investment in training and ongoing learning for direct-support workers. In California, there is relatively little investment in training for direct-support workers. Legislation³ to require training of direct-support workers was passed after a 1998 federal compliance review of California's home- and community-based services waiver program found that the state was not in compliance in a number of areas, including the preparation of support workers (Health Care Financing Administration, 1998). The state now requires direct-support workers in community-care facilities to complete 70 hours of training over a two-year period or pass a competency test. The legislation does not tie a pay increase or other incentive to completion of the training. DDS contracts with the California Department of Education, which in turn contracts with local Regional Occupational Centers and Programs (ROCPs) to administer training and testing. As of 2003, almost 40,000 workers had passed the training requirement, although 65% passed via testing rather than by participation in the training (DDS, 2003).

Apart from minimal first-aid and CPR training, there are no training requirements for direct-support workers in other community services such as ILS and SLS, supported employment, or respite care (ibid). The Regional Centers provide occasional optional training on a variety of topics, which vary by Regional Center, but essentially, employers are on their own in the development and procurement of training for their employees.

California's lack of training infrastructure for developmental disabilities services in community settings stands in sharp contrast to the training infrastructure for direct-support workers in institutional settings. Psychiatric technicians in institutions have a clear job ladder, with

³ Section 40. Section 4681.5 in the Welfare and Institutions Code.

corresponding educational requirements and state licensure, along with a professional association, the California Association of Psychiatric Technicians. The psychiatric technician license is parallel to Licensed Vocational Nurse (LVN) and requires 1,530 hours of instruction at accredited schools plus supervised clinical experience.

This infrastructure has not been used in community settings, largely because of the philosophical rejection of the institutional model of services by advocates and actors in the community system. However, California, like most other states, has not created an alternative infrastructure for training that is based on the values and philosophy of the community system. Agencies are left on their own to train their workers after hire, and a deprofessionalization of direct-support work has occurred.

A number of organizations across the nation have developed resources that states can use to train and educate direct-support workers in person-centered services and develop skills standards, certifications, and degree programs. These include the College of Direct Support curriculum developed at the University of Minnesota, which provides a competency-based online training program for direct-support workers and supervisors in person-centered services. This training is much more comprehensive than that mandated in California for community-care facilities. The Department of Labor funded the development of the Community Support Skill Standards in 1996. This has become a nationally recognized set of professional standards that has been used as a tool to create curriculum and career paths (Lakin, Larson, and Hewitt, 2005:47).

These resources have helped a number of states build their training infrastructure to a greater degree than California. In New York, for example, the City University of New York (CUNY) JFK Institute for Worker Education has developed associate, bachelor's, and master's degree programs in Disability Studies that train incumbent service workers in community settings. The JFK Institute has created multiple partnerships with agency providers and unions to ensure that training and education programs meet the needs of employers, advance workers' careers and compensation levels, and provide workers with transferable college credits. On a much smaller scale, Wyoming has instituted a career pathway program based on a U.S. Department of Labor-approved Direct Support Specialist National Apprenticeship program. Wyoming was also the first state to provide its agencies with access to the College of Direct Support and has built a career ladder program, with wage increases, based on completion of these training programs (Lynch et al., 2005). Ohio, Kansas, West Virginia, and Illinois are building similar programs to help attract, retain, and train direct-support workers in community settings (Lakin, Larson, and Hewitt, 2005: 50–52).

In sum, while California took a step forward when it instituted a two-year wage pass-through and new training requirements in 1998–2000, these investments are less than those made by other states. The curriculum is minimal compared to the nationally recognized standards and is tied to neither wage increases nor certification.

THE PROLIFERATION OF SMALL AGENCIES

The process of deinstitutionalization has shifted services from a small number of large, centralized public developmental centers to approximately 8,000 for-profit and nonprofit service agencies. The proliferation of many small agencies creates additional challenges to solving the direct-support staffing problem beyond those described above. Since the service delivery system

places the responsibility for workforce training on employers while also encouraging the proliferation of agencies, the training issue becomes a collective action problem that small- and even medium-sized agencies are ill-equipped to solve on their own.

DDS does not collect data on agencies, so it is not possible to document the size distribution of agencies providing services for people with developmental disabilities. Estimates by Shea et al (2003) suggest that approximately 8,000 provider agencies employ the 61,250 workers in community-care facilities, day programs, and independent- and supported-living services, as shown in Table 2. This averages to less than 8 workers per agency. Consumers and families employ an additional 30,000 workers, who hire workers to provide respite, transportation, daycare, or other services.

Large agencies do exist, and they usually offer congregate residential services as well as sheltered workshops or segregated day activities, but they are also moving into the service areas of supported-employment and person-centered services. Community-care facilities are often small mom-and-pop operations run by facility owners and their families (Wheeler, 2002; Shea, et al., 2003). While there are several large agencies that provide independent- and supported-living services, many person-centered services are provided by small- or medium-sized agencies. Since the early 1990s, when supported living became a service category, small, specialized supported-living agencies have proliferated. Other person-centered services, such as supported employment and integrated work and community inclusion programs, also tend to be provided by small, newer agencies (Mautz, 2003; Zabin et al., 2004).

Though a hallmark of flexibility, innovation, and community responsiveness, the proliferation of literally thousands of agencies also poses challenges for creating workforce supports. Zabin's research, summarized here, suggests that small- and medium-sized agencies face considerably different challenges than larger agencies.⁴ The research is based on in-depth interviews conducted with executive directors of 20 ILS and SLS agencies contracted by the San Andreas Regional Center (SARC) and other key informants.⁵ While the research is a case study limited to ILS and SLS agencies in one region of California, the main observations can be generalized to small- and medium-sized person-centered providers throughout California.

In the SARC area, 61% of ILS and SLS services are provided by small- and medium-sized providers that on average employ 30 employees. Most of these are agencies specializing in independent- and supported-living services. The large employers that provide 39% of ILS and SLS are multi-service agencies providing a mix of congregate residential services and sheltered workshops as well as more person-centered services.

⁴ The research defines small employers as those employing fewer than 20 direct-support workers, and medium as those employing between 20 and 100 direct-support workers.

⁵ See Zabin, Aroner, and Jacobs (2004) for a summary of this research. This research was funded in part by the California Health Care Foundation. The interviews were one- to two-hour semi-structured interviews conducted by Carol Zabin and Ken Jacobs of the UC Berkeley Center for Labor Research and Education. The research also relied on discussions with Bay Area Regional Center directors, consumer advocates, and other experts, including on-going discussions with the project's advisory committee. The quantitative data presented here is based on the 17 interviews for which we had reliable numbers; the qualitative data incorporates information from all 20 interviews.

Zabin et al. found that, although all of the agency directors were very concerned about low wages and faced recruitment and retention challenges, small- and medium-sized agencies faced other problems as well. Half of the small agencies did not offer health insurance benefits to their employees, and while all of the medium-sized agencies did offer health insurance, they offered less choice in plans than did the larger agencies interviewed for the study. Health insurance is a key retention strategy for employers in this sector. Since health insurance costs go down the larger the pool of workers, large employers have a clear advantage in this regard. Small- and medium-sized agencies also faced high administrative costs in other areas of their businesses.

Workforce training is another area in which small- and medium-sized agencies were at a disadvantage. Training requires time and resources and is something all agencies state that they would like to cultivate. However, the size of the agency contributes greatly to the ease with which training programs can be developed. The largest agency in the sample had a training specialist on staff, had developed a broad range of in-house training modules, and provided aid to employees seeking to gain colleges credits or degrees in related fields. In contrast, small- and medium-sized agencies provided employee orientations, a few days of job shadowing, and at best occasional ad hoc training for their staff. Small- and medium-sized agencies also had greater difficulty providing a career ladder for direct-support staff as there is little room for advancement or promotion within their structures.

Moreover, many small agency directors lack the business experience and expertise to operate their agencies efficiently. They choose their careers because of their commitment to mission and service, rather than their interest in running a small business. Zabin et al. found that agencies often operate from a crisis stance, mediating high staff turnover, constrained rates for their services, and lack of business savvy. Poor record-keeping is also not uncommon, and creates a risk for California in the context of federal audits.

Arguably, some problems could be resolved by increasing agency size. Yet there are compelling reasons to stay small. Many smaller agencies choose to stay small because they associate smallness with a higher quality of personalized care. This ethos has served to limit growth of individual agencies. In one example in the Zabin et al. research, a small SLS provider committed to helping expand this type of service chose to work with the Regional Center to spin off a new agency rather than expand her own agency.

Given the prevalence of small- and medium-sized agencies and the value that actors in the system attach to decentralization, models that help small agencies overcome the diseconomies of scale associated with their size are worth exploring. In the private sector, many small businesses outsource administrative tasks to professional employer associations (PEOs). By becoming the co-employer of the small businesses' workers, PEOs can provide payroll, tax compliance, benefit administration, workers' compensation insurance, and unemployment insurance management services at a lower cost than businesses' in-house costs for these tasks. Private-sector PEOs have not penetrated the health and human service fields because of the low profit margins in these public-funded services.

The Wisconsin Regional Training Partnership (WRTP) first suggested the development of a socially oriented PEO to serve small healthcare and child-care agencies in Wisconsin. One of the

nation's premier labor-management workforce development organizations, the WRTP proposed the PEO as a means of reducing healthcare insurance costs by pooling workers from multiple agencies. The WRTP is currently working with the Service Employees International Union (SEIU) to develop a PEO that can access the union's Taft-Hartley healthcare trusts. The PEO this group is developing will become the co-employer of the direct-service workers for administrative purposes, leaving control over hiring, supervision, and termination of workers with each individual agency. In the recommendations section of this report, we describe how such a model could serve the developmental disabilities sector in California.

CONSUMERS AS EMPLOYERS

More than 30,000 families with minor or adult children with developmental disabilities now directly hire workers to provide respite, daycare, and other services. Over the next three years, another 9,000 clients eligible for self-directed service vouchers will be able to directly hire their support workers. Greater consumer control over the hiring, supervision, and potential termination of paid support staff has emerged as an important element of the self-determination movement for both the physically and developmentally disabled (Center for Self-Determination website, accessed 2005; Heinritz-Canterbury, 2002). California has been a pioneer of such "consumer-directed services" which now are the main service model in the state's in-home supportive services (IHSS) program (*ibid*). As of 2002, there were at least 119 consumer-directed personal assistance service programs operating in 40 states (Scherzer et al., 2005). In this model of service delivery, consumers directly hire and supervise their paid assistants and can terminate them at will, without the involvement of service provider agencies.

FAMILY VOUCHERED SERVICES

Family assistance programs such as respite, daycare, and transportation services help families whose minor or adult children live with them. Currently, the hourly rate for respite services is \$8.67 per hour, out of which parents are required to pay employer taxes and mandated benefits. At the present time, the Regional Centers do not monitor whether those payments are made, though the recent approval of the federal Medicaid waiver for respite services means that parents are legally required to do so under penalty of perjury (http://www.dds.ca.gov/vouchers/Vouchers_Home.cfm). The rates for these services are so low that many families are unable to find workers. This is corroborated in a Minnesota study of HCBS recipients (Lakin, Larson, and Hewitt, 2005:42), which reports that among families receiving respite services, only 46% of the surveyed families reported that they received the hours of service they were authorized to receive and that services were available when they need them most of the time.

SELF-DIRECTED WAIVER

The new statewide self-directed services waiver is the most recent innovation in the service delivery system in California. This program is a supported voucher program, in which consumers are given authority over a budgeted amount of funds that they can spend at their discretion on the goods and services that they consider most useful. The voucher is supported in two ways. Consumers can hire a service broker to help them find appropriate services and navigate the developmental disabilities services system. They can also employ a fiscal intermediary to provide accounting services, comply with reporting requirements, and pay appropriate employer taxes and mandated benefits for employees. As with family voucher services, the new waiver allows consumers, rather than agencies, to directly hire their own workers.

WORKFORCE CHALLENGES IN CONSUMER-DIRECTED SERVICES

The direct employment of paid support workers by consumers presents a set of challenges for workers and for the development of a stable and qualified workforce. Currently, it is not clear that mandatory tax compliance and payment of social security, workers' compensation, and other mandated benefits occurs for workers hired by families to provide respite and other supports. The self-directed waiver program resolves this potential problem by including a fiscal intermediary who will carry out these tasks for the consumer.

However, the atomized employment relationship typical of consumer-directed services makes the provision of other workforce supports difficult and unlikely, adding stress to direct-support workers. In particular, provision of health insurance for individually employed workers is very expensive and unlikely to occur. In addition, for workers who wish to make their direct-support work a career, working for one consumer also poses problems. Workers with traditional employers are more likely to obtain new work when they are no longer needed by a consumer or to increase work hours by serving multiple consumers. Wage levels and promotions are negotiated at an individual level, and workers have even fewer opportunities for advancement than in agency work. Workers have little opportunity to voice concerns or join with other workers in collective action.

Although many of the people who provide these services are family and friends who may not need this level of workforce supports, others are trying to make a living doing this work and want to stay in the field. Unfortunately, we have no data in California about the proportion in either category.

A number of institutional innovations have been developed to address the employment issues associated with consumer-directed services. In many cases, they have been developed to ease the administrative burden placed on consumers who directly employ workers. A number of states with consumer-directed personal assistance programs now contract with a fiscal intermediary who becomes the employer of record for these workers. This intermediary processes timesheets, issues paychecks, files payroll taxes and mandated benefits, and maintains legally required employment records (Scherzer et al., 2005).

In California, Oregon, and Washington, public authorities have been created to serve as the employer of record for consumer-directed in-home personal assistance services with a much broader mandate than carrying out payroll administration. These authorities were developed specifically to address the workforce problems associated with consumer-directed services. The public authorities provide health insurance benefits for the pool of workers, offer worker training, and maintain worker registries to help consumers find workers and help workers find employment. In California, home-care workers have elected to join the Service Employees International Union (SEIU) or the American Federation of State, County, and Municipal Employees (AFSCME). The combined political voice of consumer and worker organizations has consistently led to significant wage increases and staved off budget cutbacks in recent years. And as stated earlier, these wage increases have had positive effects on worker recruitment and retention (Howes, 2004).

The model we present in the recommendations section of this report draws on the experience of different types of employers of record and argues for the importance of including workforce supports in the implementation of the self-directed services program.

RECOMMENDATIONS AND STRATEGIES FOR CHANGE

As services have shifted to community settings and have evolved to promote self-determination and consumer direction, direct-support work and employment have been fundamentally restructured. These changes require a set of workforce supports customized to this innovative and evolving service delivery system. They should be built on the common interests of consumers, employers, and workers. Successful solutions include responses to the following needs:

- Consumers need continuity of services in the setting of their choice, carried out by direct-support workers who have the training and education to provide person-centered services.
- Workers need high-quality positions as direct-support professionals that include self-sufficiency wages, health benefits, adequate and effective training, and career opportunities.
- Agency providers need public policies and funding that enables them to attract and retain qualified, well-trained direct-support workers. Agencies cannot carry the full responsibility of training workers, and smaller agencies in particular need assistance in reducing administrative costs and accessing health insurance for their workers.
- Policy makers need to fulfill the mandates of the Lanterman Act and the *Olmstead* decision in the most cost-effective manner possible.

The state would need to make **four fundamental policy changes** to solve the staffing crisis in California's community services system for people with developmental disabilities, improve system efficiency and quality, and prepare for the increased number of people who are likely to need person-centered services in coming decades.

- 1. Restructure reimbursement rates to create incentives for developing a stable and well-qualified workforce and for expanding person-centered services.**
- 2. Build a training, education, and career-advancement infrastructure for the community-based person-centered delivery system.**
- 3. Increase state and federal funding for developmental services to improve compensation for direct support workers**
- 4. Support the development of voluntary professional employer organizations that can serve small- and medium-sized agencies as well as clients and their families who directly hire staff**

RESTRUCTURE REIMBURSEMENT RATES

Incorporating incentives into reimbursement rates will result in expansion of California's person-centered services and develop a stable, well-qualified workforce. Continuing budget deficits make large, across-the-board rate increases unlikely in the near future. In this context, rate increases should be targeted at programs that improve quality, stabilize the direct-support workforce, and expand person-centered services. Initial rate augmentation would provide funding to promising efforts whose outcomes can be documented. If specific performance standards are achieved, the state could invest further in these successful models.

Across the nation, a recent trend in state policy is provision of higher reimbursement rates to agencies that demonstrate improvements in specific measures of quality or changes that are thought to lead to quality improvements. In Iowa, for example, nursing facilities can qualify for up to a 3% reimbursement increase for meeting up to 10 specific quality measures (Harmuth and Dyson, 2004). In other service sectors, higher reimbursement rates are tied to changes in agency practices that are linked to quality, such as participation in training programs. For example, in Wisconsin, child-care agencies whose workers participate in training are rewarded with wage pass-throughs (COWS, 2002). When the rate freeze on services for people with developmental disabilities is lifted, the state of California will have an opportunity to introduce differential reimbursement rates based on improvements in outcome or process quality.

BUILD A TRAINING, EDUCATION, AND CAREER-ADVANCEMENT INFRASTRUCTURE

The state of California must ensure that direct-support workers have the necessary preparation and skills to do a good job and to stay and build careers in the field.

Long-run goals

In the long run, the state needs to create an infrastructure for the training and education of direct-support workers that professionalizes the field in a way that reflects the values of the Lanterman Act, the ADA, and the Olmstead decision. Instead of leaving training to individual agencies, which tends to serve the status quo rather than improve practice, the state should support training to meet professional standards as it does for teachers, social workers, nurses, and other professions. This approach requires creating competency-based professional credentials and making them a job requirement. It also requires developing the community or state college infrastructure to make available courses and credentialed programs. Furthermore, the state can encourage career development by creating levels of certification for direct-support work and developing specialties based on service needs, such as supported living or supported employment, or particular types of disabilities, such as autism. Expanding person-centered services also requires training for supervisors and program directors, not only on topics related to developmental disabilities services, but also related to human resource and agency management.

The California Social Work Education Consortium (CALSWEC) is a model that holds lessons for the developmental disabilities sector. This consortium of public higher education institutions administers professional training for the child welfare system in California. It provides customized on-the-job training for county child welfare personnel as well as funding for social workers pursuing professional degrees who "pay back the public" through their continued employment in the system upon completion of their degrees. CALSWEC is currently creating a master plan for social work education, to design and implement training and education for future needs. CALSWEC has expanded to address the workforce needs in the mental health field, in

response to program development associated with the passage of Proposition 63. This kind of effort could yield tremendous results in the developmental disabilities sector as well.

Short-run goals

In the short run, the state should encourage pilot training projects in this sector, which can help build the expertise, partnerships, and constituency for a more comprehensive effort to professionalize the field. Federal WIA, state ETP, and other workforce development funds can be used to help finance training and education for direct-support workers serving people with developmental disabilities. To date, provider agencies have not tapped into the state's substantial training funding streams, though they have been used for training in related fields, such as personal assistance services, nursing assistants, and other long-term care services (Matthias et al., 2003).

These training funds should be used to encourage model training programs. The key components of a good training program include creation of strong partnerships with employers to ensure that the investment in training is customized to industry needs, establishment of credentials or other transferable credits for workers, and increased compensation for trained workers (Fitzgerald, 2004; COWS, 1999). Training and education is best designed and implemented on a multi-employer level (Tam, Johnson, and Molina, 1998). Multi-employer collaborations enable significant economies of scale, including development of partnerships with community colleges, curriculum adaptation, and financing for training.

INCREASE STATE AND FEDERAL FUNDING FOR DEVELOPMENTAL SERVICES TO IMPROVE COMPENSATION FOR DIRECT-SUPPORT WORKERS

Although public investment is needed to improve compensation for direct-support jobs, California general-fund resources can be contained by coupling solutions to the workforce crisis with more efficient business models as well as support from federal matching funds.

Deinstitutionalization was supported by federal and state governments not only because consumers fought for it, but also because it was perceived as a way to reduce service costs (Stancliffe and Lakin, 2005). A portion of the reduction in per consumer cost in community vs. institutional services does not compromise service quality and thus should be considered a legitimate cost savings. This includes the cost savings from lower institutional overhead and maintenance, access to greater levels of family and other unpaid supports, and reduction in unnecessary levels of service for people who can learn to be more independent (ibid). However, other types of cost savings in community settings derive from the erosion of wages, benefits, career ladders, and other labor standards, and these do jeopardize the quality, sustainability, and expansion of community services. Policy makers need to distinguish between these kinds of costs savings and avoid cost savings that negatively affect quality and continuity of care.

Improvement of direct-support jobs implies a substantial public investment over time. However, some portion of the cost of higher wages is offset by decreased turnover expenses, less use of public assistance by low-wage direct-support workers, and higher-quality services that help

people with developmental disabilities gain greater independence over time⁶. Moreover, California still lags many other states in capturing federal matching funds. These should be maximized.

In addition, the state is currently paying for inefficiencies created by the proliferation of employers in the community system. Small agencies experience higher rates for healthcare insurance, liability insurance, and workers' compensation insurance. Since they are funded almost exclusively by public monies, the government is in essence paying for these inefficiencies.

SUPPORT THE DEVELOPMENT OF PROFESSIONAL EMPLOYER ORGANIZATIONS TO SERVE SMALL- AND MEDIUM-SIZED AGENCIES

A financially self-sustaining professional employer organization (PEO) could serve small- and medium-sized agencies providing person-centered services by lowering administrative costs while preserving the autonomy of agencies and clients over personnel decisions. The PEO is designed to solve a number of problems that the community system faces by:

- ▶ Improving administrative efficiencies so that a higher percentage of funds can go toward providing services;
- ▶ Providing a mechanism for pooling workers to provide health insurance;
- ▶ Providing key start-up business services to facilitate the development and operation of new agencies;
- ▶ Improving worker recruitment through a sector-wide recruitment program that would match workers and clients and give part-time workers access to a greater pool of potential clients;
- ▶ Developing a multi-employer training initiative;
- ▶ Expanding opportunities for career advancement to retain dedicated workers;
- ▶ Improving record keeping to ensure compliance with federal requirements and better documentation of key measures of quality and workforce stability.

As stated earlier, the PEO is a business model that many small private-sector businesses use to reduce administrative costs.⁷ It is a co-employment strategy that allows the purchase of human resources and human resource management services on a multi-employer basis, reducing the costs for individual agencies. Direct-support workers employed by participating agencies have

⁶ The cost of turnover includes the cost of termination, recruitment of replacement workers, on-the-job training, and overtime or supervisory time to cover for unfilled vacancies. These costs have been estimated at from \$1,500 to \$7,500 per worker (PHI, 2005; Shea et al., 2003:21).

⁷ The National Association of Professional Employer Organizations estimates that 2 to 3 million workers are now "co-employed" by PEOs in the United States. See <http://www.napeo.org/peoindustry/faq.cfm#10>.

two employers: the PEO for purposes of payroll, benefits, and other human resource administrative services, and the agency or family for purposes of hiring, daily supervision, and decisions about staff termination. Provider agencies still manage all aspects of the day-to-day operations of their agencies, but the PEO provides economies of scale in administration. The PEO services include payroll, tax compliance, worker recruitment and screening, negotiation and administration of workers' compensation, unemployment insurance, and healthcare benefits.

The socially oriented PEO differs from a private-sector PEO in several ways. First, its mission is not to maximize profits but to improve services. As a consequence, costs to service providers are kept to a minimum, and the PEO's finances are transparent to agency customers. Second, the PEO focuses on services that improve the jobs of direct-support workers. A key benefit of the PEO approach is the provision of affordable health insurance and other employee benefits, important for employee retention. By drawing staff from multiple settings into a single pool, the PEO is able to access better insurance at lower prices (Stoney, 2005). The PEO also develops a sectoral training partnership among participating employers and seeks private and public funding supports for its implementation.

The PEO is also potentially a mechanism for giving consumers and workers greater voice in developmental disabilities services. As in California's IHSS public authorities, consumers can be represented on the advisory board of the PEO and help shape its priorities and direction. In addition, the PEO can be a means for a new form of labor-management partnership. As co-employer of provider agency workers, the PEO creates a second entity with which workers could sign a collective bargaining contract if they choose to unionize. This is a new form of unionism that focuses on partnering with the agencies to advance common interests, but eliminates the union's involvement in the daily supervision of direct-support workers. Unionization of the PEO could help agencies and workers obtain lower-cost health insurance because of potential access to union-sponsored Taft-Hartley health plans. In addition, unions bring to the table experience and infrastructure for designing, funding, and implementing full-scale training delivery systems (Takahashi and Melendez, 2002; Fitzgerald, 2006; Dresser and Rogers, 1997).

There are a number of different ways to create a PEO for developmental services. An existing organization, such as a large, anchor service provider agency or an IHSS public authority could become a PEO for small agencies and families who directly hire workers. A PEO could also be created as a stand-alone operation by interested stakeholders. The Regional Centers could play a leadership role in convening stakeholders to determine the best strategy for a particular region.

The PEO is a clear example of the kind of innovation that the state should support to improve the recruitment and retention of direct-support workers, reduce administrative inefficiencies, and expand person-centered services. Such a project needs initial funding for start-up and provider transition costs, but future rate augmentation should be based on meeting specific performance requirements concerning workforce stability, service quality, and expansion of person-centered services.

CONCLUSION

California's network of person-centered services for people with developmental disabilities is experiencing a staffing crisis that affects the quality and availability of person-centered services. Low wages, inadequate access to health insurance, and lack of training and career opportunities all lead to high rates of turnover and longstanding vacancies. Consumers, providers, and workers are all negatively affected by these conditions and have a common interest in improving them.

As the service delivery system has shifted from one characterized by large public institutions to a community-based system committed to person-centered services, little attention has been paid to the consequences for direct-support workers. The decline in wages and benefits, the changing job responsibilities, and the proliferation of many small agencies all pose challenges that require state action.

In order to expand the availability of services that promote self-determination and community integration, the state must target rate increases to programs that improve quality, stabilize the workforce, and expand person-centered services. It must create an appropriately customized training and education infrastructure for workers in these services. Finally, the state also must support innovations that overcome the inherent inefficiencies of a decentralized system while honoring its core values of decentralization. The PEO is a potent strategy that can help expand person-centered services, improve the recruitment, retention and training of direct support workers, and reduce the administrative inefficiencies of small- and medium-sized agencies.

The Lanterman Act and state and federal mandates that call for services that promote self-determination, community inclusion, choice, and independence are ideals that require continuing commitment and innovation. State support for improved compensation and training and incentive-based rate reform, combined with innovative projects like the PEO, provide a compelling model for system change in the 21st century.

REFERENCES

Braddock, D., and R. Hemp. 2004 (January). *Analysis of California's Commitment to Developmental Disabilities Services*. A report funded by the California Alliance for Inclusive Communities, Inc. (CAIC), and the Center for Disability Studies and Community Inclusion, USC, University Center of Excellence. www.caic.org/braddock.htm.

Braddock, D., R. Hemp, M. C. Rizzolo, D. Coulter, L. Haffer, and M. Thompson. 2005. *The State of the States in Developmental Disabilities 2005*. Department of Psychiatry and Coleman Institute for Cognitive Disabilities: University of Colorado.

Braddock, D., R. Hemp, M. C. Rizzolo, S. Parish, and A. Pomeranz. 2002. "The State of the States in Developmental Disabilities: Study Summary." In D. Braddock, ed., *Disability at the Dawn of the 21st Century and the State of the States*. Washington, D.C.: American Association on Mental Retardation. pp. 85–140.

Braddock, D., and D. Mitchell. 1992. *Residential Services for Persons with Developmental Disabilities in the United States: A National Study of Staff Compensation, Turnover, and Related Issues*. Washington, D.C.: American Association on Mental Retardation.

California Budget Project. 2001 (September). *Making Ends Meet: How Much Does it Cost to Raise a Family in California?* Sacramento: California Budget Project.

California Budget Project. 2005 (November). *Making Ends Meet: How Much Does it Cost to Raise a Family in California?* Sacramento: California Budget Project.

California Department of Developmental Services. Website accessed March 2006. www.dds.ca.gov.

California Department of Developmental Services. 2005 (December). *Fact Book, Eighth Edition*. Sacramento: Department of Developmental Services. www.dds.ca.gov/factsstats/pdf/factbook_8th.pdf.

California Department of Developmental Services. 2003 (December). *Fact Book, Eighth Edition*. Sacramento: Department of Developmental Services. www.dds.ca.gov/factsstats/pdf/factbook_8th.pdf.

California State Auditor. 1999. "Department of Developmental Services: Without Sufficient State Funding, It Cannot Furnish Optimal Services to Developmentally Disabled Adults." Sacramento: California State Auditor. Available online at: www.bsa.ca.gov.

Center for Self-Determination. Website: <http://www.self-determination.com>.

Center on Wisconsin Strategies (COWS). 1999. *High Performance Partnerships: Winning Solutions for Employers and Workers*. cows.org/about_publications_detail.asp?id=7.

Center on Wisconsin Strategies (COWS). 2002. *A Public Investment in Quality Care for Kids: An Evaluation of the Local Child Care Wage Initiative*.

Conroy, J., A. Fullerton, M. Brown, and J. Garrow. 2002 (December). *Outcomes of the Robert Wood Johnson Foundation's National Initiative on Self-Determination for Persons with Developmental Disabilities: Final Report on 3 Years of Research and Analysis*. Narberth, PA: Center for Outcome Analysis. www.outcomeanalysis.com/DL/pubs/RWJ-SD-Final-Report.pdf.

Conroy, J., A. Yuskas, J. Seiders, and M. Brown. (1999, September). *Community Based Supports in Rhode Island: 1999 Findings of the Quality Tracking Project*. Submitted to Rhode Island Department of Mental Health, Retardation, and Hospitals. Rosemont, PA: Center for Outcome Analysis. www.outcomeanalysis.com/DL/pubs/RI-QTP-r1.pdf.

Coucovanis, K., R. W. Prouty, R. H. Bruininks, and K. C. Lakin. 2005. "Current Populations and Longitudinal Trends of State Residential Settings." In R. W. Prouty, Gary Smith, and K. C. Lakin, eds., *Residential Services for Persons with Disabilities: Status and Trends through 2004*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration. pp. 3–18.

Dresser, Laura, and Joel Rogers. 1997 (December). *Center on Wisconsin Strategy Briefing Paper: Rebuilding Job Access and Career Advancement Systems in the New Economy*. Center on Wisconsin Strategy. Madison: University of Wisconsin.

Fishman, Eliot Z., Bruce C. Vladeck, Ann-Gel S. Palermo, and Margaret H. Davis. 2003. *The Olmstead Decision and Long-Term Care in California: Lessons on Services, Access, and Costs from Colorado, Washington and Wisconsin*. Oakland, CA. California Health Care Foundation.

Fitzgerald, J. 2006. *Moving Up in the New Economy: Career Ladders for U.S. Workers*. Ithaca: Cornell University Press.

Fitzgerald, J. 2004. "Moving the Workforce Intermediary Agenda Forward." *Economic Development Quarterly* 18(1):3–9.

Harmuth, Susan, and Susan Dyson. 2004 (March). *Results of the 2003 National Survey of State Initiatives on the Long-term Care Direct-Care Workforce*. Paraprofessional Healthcare Institute and the North Carolina Department of Health and Human Services' Office of Long Term Care (NCDHHS).

Health Care Financing Administration (control no. 0129.91). 1998 (January). *Compliance Review of California's Home and Community-Based Services Waiver Program for the Developmentally Disabled*. Washington D.C.: CMS.

Heinritz-Canterbury. 2002. *Collaborating to Improve In-Home Supportive Services: Stakeholder Perspectives on Implementing California's Public Authorities*. Paraprofessional Healthcare Institute.

Hemp, R., D. Braddock, S. Parish, and G. A. Smith. 2001. "Leveraging Federal Funding in the States to Address *Olmstead* and Growing Waiting Lists." *Mental Retardation* 39:241–243.

Hewitt, Amy, and K. Charlie Lakin. 2001. *Issues in the Direct Support Workforce and Their Connections to the Growth, Sustainability and Quality of Community Supports*. Research and Training Center on Community Living. Minneapolis: University of Minnesota.

Howes, Candace. 2004. *Upgrading California's Home Care Workforce: The Impact of Political Action and Unionization*. University of California Institute for Labor and Employment. Available online at <http://repositories.edlib.org/file/scl2004/03>.

Kahn, K. 2003 (October). Better Jobs Better Care Issue Brief, vol. 1, no. 1. Institute for the Future of Aging Services.

Lakin, K. C. and R. H. Bruinninks. 1981. "Personnel Management and Quality of Residential Services for Developmentally Disabled People." In: T. C. Muzzio, J. J. Koshel, and V. Bradley, eds., *Alternative Community Living Arrangement and Non-Vocational Social Services for Developmentally Disabled People*. Washington, D.C.: The Urban Institute.

Lakin, K. C., S. Larson, and A. Hewitt. 2005. *The Supply of Direct Support Professionals Serving Individuals with Intellectual Disabilities and Other Developmental Disabilities*. Minneapolis: University of Minnesota, Research and Training Center on Community Living.

Larson, S., S-Y Byun, K. Coucouvanis, and R. W. Prouty. 2005. "Staffing Patterns, Characteristics, and Outcomes in Large State Residential Facilities in 2004." In R. W. Prouty, Gary Smith, and K. C. Lakin, eds., *Residential Services for Persons with Disabilities: Status and Trends through 2004*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration. pp. 47–59.

Larson, S., A. Hewitt, and L. L. Anderson. 1999. "Staff Recruitment Challenges and Interventions in Agencies Supporting People with Developmental Disabilities." *Mental Retardation* 37:36–46.

Larson, S., and C. Lakin. 1999. "Longitudinal Study of Recruitment and Retention in Small Community Homes Supporting Persons with Developmental Disabilities." *Mental Retardation* 37(4):267–280.

Lynch, R., J. Fortune, C. Mikesell, and T. Walling. 2005. "Wyoming Demonstrates Major Improvements in Retention by Enhancing Wages and Training." Links: 35(9). www.ancor.org.

Matthias, Ruth, S. Chapman, J. Rickles, E. Morrison, P. Ong, A. E. Benjamin, and R. Newcomer. 2003 (December). *Final Process and Outcome Evaluation Report*. Los Angeles: University of California at Los Angeles School of Public Policy and Social Research, California Employment Development Department.

Mautz, Denise Michelle. 2003. *Developing an Organization that Provides Access to Integrated Work and Community Inclusion for Adults with the Most Significant Support Needs: Does*

Information Help? Doctoral Dissertation, University of California at Berkeley. 2004: Proquest Information and Learning Company. UMI Microfilm 3105128.

Prouty, R. W., K. C. Lakin, and R. Bruininks. 2005b. "Changing Patterns in Residential Services Systems: 1977–2004." In R. W. Prouty, Gary Smith, and K. C. Lakin, eds., *Residential Services for Persons with Disabilities: Status and Trends through 2004*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration. pp. 77–80.

Prouty, R. W., G. Smith, and K. C. Lakin, eds, 2005a. *Residential Services for Persons with Disabilities: Status and Trends through 2004*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

Reif, Laura. 2002 (July). *Paying for Quality: Preliminary Analysis of San Francisco In-Home Supportive Services: Consumer Evaluation of Quality of Care Findings*. Paper presented at the IAFFE 2002 Conference on Feminist Economics, Los Angeles. pp. 12–14.

Scherzer, T., and R. Newcomer. 2005. *Financial Management in Consumer Directed Programs*. UCSF Center for Personal Assistance Services. Unpublished manuscript.

Shea, Allen & Associates. 2003. *Assembly Bill 649: Selected Human Resource and Financial Implications*. Napa, CA: Don Forrest, Forest Consulting.

Sjoberg, K. 1999. *Department of Developmental Services: Without Sufficient State Funding, It Cannot Furnish Optimal Services to Developmentally Disabled Adults*. California State Auditor. Sacramento: Bureau of State Audits.

Stancliffe, R. J. and K. C. Lakin. 2005. "Context and Issues in Research on Expenditures and Outcomes of Community Supports." In R. J. Stancliffe and K. C. Lakin, eds, *Costs and Outcomes of Community Services for People with Intellectual Disabilities*. Baltimore: Paul H. Brookes Publishing Co. pp. 1–22.

Stoney, Louise. 2005. A Consultative Session on Establishing an Early Care and Education Private Employer Organization (PEO). www.earlychildhoodfinance.org/mitchell.htm.

Takahashi, Beverly, and Edwin Meléndez. 2002. *Union-sponsored Workforce Development Initiatives*. New York: Community Development Research Center, Milano Graduate School of Development and Urban Policy. Available online at www.newschool.edu/milano/cdrc/pubs/r.2002.3.pdf.

Tam, Tse Ming, Barbara Johnson, and Frieda Molina. 1998. *Sectoral Employment Intervention: A Handbook*. A handbook for practitioners and advocates of workforce development and community economic development to aid in the research, design, and implementation of a sectoral intervention project.

Wheeler, Barbara, Dawn Kurtz, and Tom Smith. 2002. *Evaluation of the Impact of WIC Section 4681.4 (Rate Increase) on Staff Turnover for Direct Support Workers in Licensed Community*

Care Facilities for People with Developmental Disabilities 1998–2000. Los Angeles: USC, University Affiliated Programs.

Whitebook, Marcie. 1998. *National Child Care Staffing Study*. Washington, D.C.: Center for the Child Care Workforce.

Zabin, Carol. 2003 (February). *Labor Standards and Quality of Care in California's Services for People with Developmental Disabilities*. Written expert testimony of plaintiff's expert witness, *Sanchez v. Johnson*, no. 04-15228, 2005 WL 1804195.

Zabin, Carol, K. Jacobs, and D. Aroner. 2004. *Research Findings on Improving Access to Health Care Insurance for Direct Service Workers in SLS and ILS Services*. Research Report for California Health Care Foundation. Berkeley: University of California at Berkeley Center for Labor Research and Education. Unpublished report.

APPENDIX

Projected Growth in Independent- and Supported-Living Services in California

Jonathan Hoffman

UC Berkeley Center for Labor Research and Education

INTRODUCTION

This analysis projects ILS/SLS caseload growth through 2014, based primarily on DDS caseload trends from 1993 to 2004. No such projections have been made by the DDS, other government agencies, or academic researchers. Braddock and Hemp (2004) examine supported-living caseload and spending trends in California and other states since 1996, but do not make any projections with respect to future growth in demand.

Between December 1993 and December 2004, the total number of individuals served by the California Department of Developmental Services (DDS) increased by 70 percent, from under 119,000 to approximately 201,000 clients. During this period, the number of DDS clients in independent-living services (ILS) or supported-living services (SLS) settings increased by 106 percent, from roughly 8,000 to over 17,000 (CDDS, *Fact Book*, 2nd–7th editions, 1999–2004; CDDS, *Quarterly Client Characteristics Report Index*, January 2005). As Table 2 and Figure 1 show, 17 percent of all adult clients were in ILS/SLS settings at the end of December 2004 (CDDS, *Quarterly Client Characteristics Report Index*, January 2005).

Continued growth is expected in the ILS/SLS caseload over the next 10 years, driven by two factors: (1) growth in the overall adult DDS caseload, and (2) an increase in the ILS/SLS share of that caseload. The *adult* caseload is the relevant figure because virtually all ILS/SLS clients are expected to come from the adult DDS population. At the end of December 2004, no DDS clients under the age of 14 were in ILS/SLS settings, and only two clients between the ages of 14 and 17 were in ILS/SLS settings (CDDS, *Quarterly Client Characteristics Report Index*, January 2005).⁸

Age is an important variable in this analysis because the distribution of residence types varies substantially across age groups. As Figure 2 illustrates, roughly one-quarter of DDS clients between the ages of 32 and 51 were in ILS/SLS settings in 2004, compared to only 3 percent of clients 18 to 21 years of age (California DDS, CDER Master File, *Quarterly Client Characteristics Report Index* for the end of December 2004).

TOTAL CASELOAD GROWTH

There are at least four reasons to expect growth in the overall population of adult DDS clients. First, the aging of current clients who are under 18 years of age will result in an increase in the number of young adults in the system. At present, the DDS caseload is disproportionately

⁸ Ninety-five percent of clients under the age of 18 lived at the home of a parent or guardian, and another 5 percent were in group homes (California DDS, CDER Master File, *Quarterly Client Characteristics Report Index* for the end of December 2004).

young, with individuals 0 to 13 years of age making up 33 percent of all active clients at the end of December 2004 (Table 1; DDS, *Quarterly Client Characteristics Report Index* for the end of December 2004).

Second, the aging of family caregivers is expected to lead to an influx of new adults in the system as people with developmental disabilities who are not currently served by the DDS find themselves in need of assistance when their family caregivers either die or lose the ability to provide adequate support. There are an estimated 219,000 Californians with DD who live with family caregivers and are not in the DDS system (California DDS, CDER Master File, *Quarterly Client Characteristics Report Index* for the end of December 2004; Braddock and Hemp, 2004, 9).⁹ Based on the age distribution in the general population, Braddock and Hemp (2004) estimate that of all Californians with DD who are supported by family caregivers, 22 percent live with caregivers who are over 60 years of age (9).

A third factor expected to drive growth in the adult DDS caseload is increased client longevity. As clients stay alive longer, the population of seniors in the system will expand (assuming that clients remain in the system as they age). The number of DDS clients 62 years of age or older increased by 61 percent, from 2,800 to 4,500, between 1993 and 2003 (DDS, *Fact Book*, 1999, 2004).

A fourth factor expected to drive growth is the increasing incidence of autism. From December 1998 to December 2002, the population with autism in California's developmental services system nearly doubled, from 10,360 to 20,377 (DDS, 2003).

ILS/SLS SHARE OF THE TOTAL CASELOAD

In terms of the distribution of residential settings, there is reason to expect movement of adult clients from other living arrangements—particularly group homes and family caregiver situations—to ILS/SLS, resulting in a larger ILS/SLS share of the pie. People have been leaving group homes for ILS/SLS in recent years: the ILS/SLS proportion of adult clients increased from 12 percent in 1993 to 17 percent in 2003, while the share in group homes decreased from 27 to 21 percent (Table 2 and Figure 3). This trend should continue, especially if the availability of ILS/SLS options increases. The aging of family caregivers is expected to result in an increasing number of DDS clients who turn to ILS/SLS (among other options) because they are no longer able to get support from family caregivers. The potential growth in ILS/SLS caseload from the closure of state developmental centers (SDCs) is limited, as the SDC population is only about 3 percent of the total adult DDS caseload; SDCs and state-operated community facilities had 3,185 residents as of March 30, 2005 (http://www.dd.ca.gov/FactStats/Population_info.cfm).

⁹ Braddock and Hemp (2004) estimate that in California there are a total of 340,000 people with developmental disabilities living with family caregivers (9). This figure is based on a DDS prevalence estimate of 1.58 percent (Larson et al., 2001) and data on out-of-home residential placements. The California DDS system currently serves roughly 121,000 people who live with family caregivers. This leaves 219,000 Californians who live with family caregivers and are not in the system.

DATA SOURCES

For information on caseload trends, we relied on DDS analyses of Client Master File (CMF) data, reported in the Department of Developmental Services *Fact Book* (2nd–7th editions) and the Department of Developmental Services *Quarterly Client Characteristics Report Index* for the end of December 2004. In addition, a 2005 analysis of CMF data conducted for the DDS by Amy Mickel and Stan Taylor (*Active Status Population: Growth Analysis*) provided information on the number of new clients who entered the system each year from 1999 through 2004, as well as caseload attrition rates from 1999 through 2004. We also obtained aggregate data from the DDS on the age distribution of individuals engaged in the intake and assessment process from 1994 through 2003.

The CMF contains demographic, case status, and service coordinator information on DDS clients. This information is entered into the CMF at the time of application for regional center (RC) services. The demographic variables in the CMF include age, residence type, gender, and ethnicity. DDS clients are coded as living in one of five residence types:

- **Own Home—Parent:** Home of a family member or guardian.
- **Community Care:** Setting such as a community care facility (CCF), psychiatric treatment center, rehabilitation center, or acute-care or general hospital.
- **ILS/SLS:** Independent- or supported-living services setting.
- **SNF/ICF:** Skilled-nursing facility or intermediate-care facility. ICF settings include developmentally disabled (ICF/DD), DD-habilitation (ICF/DD-H), and DD-nursing (ICF/DD-N) facilities.
- **Developmental Center:** State developmental center operated by DDS.

In terms of case status, the DDS codes active clients as falling into one of three categories: status code 1, 2, or 8. Children birth to age three who are at risk of having a developmental disability, or who have a developmental delay but have not been diagnosed as having a developmental disability, are categorized as status code 1; these clients qualify for early intervention and prevention services. Status code 2 refers to people who have been diagnosed as having a developmental disability and are being served in the community—that is, not in a state developmental center (SDC). Status code 8 includes people diagnosed as having a developmental disability and being served in an SDC.

METHODS

We project ILS/SLS caseload in 2014 based on (1) the predicted size of the total adult DDS population, by age group, and (2) the expected ILS/SLS share of the pie for each age group.

Overall Adult DDS Caseload, by Age

To project the overall adult DDS caseload in 2014, by age group, we considered (1) the size of each cohort in 2004 (Table 1), (2) the expected attrition in each cohort from 2004 through 2014, and (3) the likely number of new entrants who will be in each age group in 2014. The 2014 caseload for clients 32 to 41 years of age, for example, is predicted using the following formula:

[# of clients 22–31 years of age in 2004 (Expected % of those clients still in the system in 2014)] + Expected # of new entrants who will be 32–41 years of age in 2014

Percent of Cohort Still in the System in 2014

We extrapolated from 1999–2004 caseload attrition rates—the only data that we have on the proportion of clients who exit the system over time—to predict the number of current clients who will still be in the system in 2014. Of active clients who were between the ages of 18 and 21 in 1999, 18 percent were no longer in the system in 2004; the corresponding five-year exit rate for all other adult clients (that is, those who were 22 to 99 years of age in 1999) was 15 percent.¹⁰ Due to data limitations, we have no additional information on how attrition rates varied by age. Extrapolating from the 1999–2004 attrition rate of 15 percent, we assumed for purposes of this analysis that 28 percent of adults who were active clients in 2004 will no longer be in the system in 2014.

New Entrants, 2004–2014

We used the average number of people who entered the system (as status code 2) per year from 1999 to 2004 as an estimate of the number of new clients who will enter the system each year through 2014. This information comes from the *Active Status Population Growth Analysis* (2005). On average, about 13,100 new clients entered the system each year.¹¹ (On average, 6,050 active clients left the system each year; the average net caseload growth was 7,072.) To predict the age distribution of new entrants, we extrapolated from the age distribution of clients who went through the intake and assessment process from 1994 to 2003. Table 3 shows the projected age distribution of new entrants in any given year.

The method of estimating the total number of new entrants who will fall into a given age group in 2004 is best illustrated with an example. Table 4 (Total column) shows the estimated number of new entrants who will be 32 to 41 years of age in 2014, by year of entry. We assume an equal distribution of ages within an aggregated age group (for example, of all new entrants 22 to 31 years of age, equal proportions of 22 year olds, 23 year olds, 24 year olds, and so on). The second column indicates the expected annual number of new entrants who are 22 to 31 years of age, which we predict is 700 people per year. The third column shows the percentage of the group of new entrants that are in the 22 to 31 years of age group in 2005 but are in the 32 to 41 years of age group in 2014. In other words, ninety percent of new entrants who are 22 to 31 years of age in 2005 will be 32 to 41 years of age in 2014 (that is, everyone except the 22-year-olds); this figure declines by 10 percentage points each year, so that 10 percent of new entrants 22 to 31 years of age in 2013 will be 32 to 41 in 2014 (that is, only the 31-year-olds).

¹⁰ Of the clients 18 to 21 years of age in 1999 who were no longer in the system at the end of 2004 (N=2,000), roughly half became inactive, 15 percent died, 5 percent were categorized as not DD, 8 percent moved out of California, and 18 percent exited for some other reason. Among clients 22 to 99 years of age in 1999 who were not in the system in 2004 (N=11,000), nearly half died, one-third became inactive, 1 percent were categorized as not DD, 8 percent moved out of state, and 9 percent exited for another reason.

¹¹ The reason for taking the average from this five-year period and assuming a constant number of new entrants through 2014, as opposed to a steady increase each year (which would be expected based on projected growth in the overall state population), is that the number of new entrants fluctuated nonmonotonically from 1999 through 2004. Although five years is too short a time period to reach conclusions about long-term trends, in the absence of evidence of a steady increase in recent years, we adopt the conservative assumption that the number of new entrants will remain stable at roughly 13,500 people per year.

To predict the number of new entrants who will remain in the system through 2014, we extrapolate from the 1999–2004 attrition rate of 15 percent, or 3 percent per year. Table 5 shows the projected attrition rates for new entrants. Table 6 uses the results of Tables 4 and 5 to make a sample calculation of the number of new entrants from 2005 to 2014 who remain in the DDS caseload in 2014, who are in the 32 to 41 years of age group in 2014. This calculation is performed for each age cohort and aggregated to estimate the total increase in caseload for 2014.

Table 7 illustrates the projected overall adult DDS caseload in 2014, by age group. Figure 4 depicts projected caseload growth from 2004 to 2014 in each age category. The greatest growth is expected among young adults (18 to 31 years of age) and seniors (over 62 years of age).

PROJECTED ILS/SLS CASELOAD IN 2014

We consider two possible scenarios with respect to the distribution of residential settings in 2014 (Table 8). First, in the lower, or most conservative, scenario, we assume that the ILS/SLS share of the pie for each age group will remain stable (that is, the same percentage as in 2004), except for small changes due to the closure of developmental centers. In the second scenario, we assume a continuation of 1993–2004 trends in the residential settings of adult DDS clients, so that there is a steady transition of people from group homes and family caregivers to ILS/SLS.

Projected growth in ILS/SLS caseload for 2014 ranges from 41 percent in the lower scenario to 131 percent in the upper scenario (Table 8). The lower scenario shows that if there is no shift in the percentage of adults using ILS/SLS, the ILS/SLS caseload will grow from 17,480 in 2004 to an estimated 24,637 in 2014. In the higher scenario—which assumes an extension of 1993–2004 trends in the distribution of residential settings—the number of clients in ILS/SLS is projected to grow to 48,919 clients.

REFERENCES

Braddock, D., and R. Hemp. 2004 (January). *Analysis of California's Commitment to Developmental Disabilities Services*. A report funded by the California Alliance for Inclusive Communities, Inc. (CAIC), and the Center for Disability Studies and Community Inclusion, USC, University Center of Excellence.

California Department of Developmental Services. 2004 (December). *Fact Book*, 7th ed. Sacramento: Department of Developmental Services.

California Department of Developmental Services. 2003 (April). *Autism—Spectrum Disorders: Changes in the California Caseload, An Update: 1999 Through 2002*.

Mickel, A., and S. Taylor. 2005 (May). *Active Status Population: Growth Analysis*. Sacramento: California State University.

Table 1 Age Distribution of Clients in the System at the End of December 2004

Age	Caseload
0-13	33% (57,845)*
14-17	10% (17,834)
18-21	9% (15,863)
22-31	16% (28,365)
32-41	13% (22,812)
42-51	11% (20,298)
52-61	6% (10,635)
62+	3% (4,850)
Total	178,502

* 21,309 children from birth through age 2 were in the system as CMF status code 1: infants who are at risk of having a developmental disability or who have a developmental delay but have not been diagnosed as having a developmental disability.

Clients are defined as CMF status code 2 (active consumers) or status code 8 (residents of state developmental centers).

Source: Client Master File of January 4, 2005. Table 2, DDS, *Quarterly Client Characteristics Report Index* for the end of December 2004.

Table 2 Residential Settings by Year, Adult DDS Clients

Year	Residence Type				
	Parent/Guardian	Community Care	ILS/SLS	SNF/ICF	Developmental Center
1993	44%	27%	12%	8%	8%
1994	45%	27%	13%	8%	7%
1995	46%	26%	14%	9%	6%
1996	46%	26%	14%	9%	6%
1997	46%	25%	15%	9%	5%
1998	46%	24%	16%	9%	5%
1999	47%	24%	16%	8%	4%
2000	48%	23%	16%	9%	4%
2001	48%	23%	17%	9%	4%
2002	49%	22%	17%	8%	4%
2003	50%	21%	17%	8%	3%
2004	50%	21%	17%	8%	3%

* Consumers with status codes 2 and 8

Source: DDS, *Fact Book*, 2nd-7th editions.

Table 3 Projected Age Distribution of New Entrants

Age	% of New Entrants
0-13	59% (8,045)
14-21	23% (3,128)
22-31	5% (720)
32-41	10% (1,296)
42-51	1% (192)
52+	1% (192)
	<hr/>
Total	13,574

Table 4 Sample Calculation of New Entrants: Clients Who Will Be 32 to 41 Years of Age in 2014

Year of Entry	22–31 Years at Time of Entry			32–41 Years at Time of Entry			Total*
	# of entrants	% 32–41 in 2014	# of entrants 32–41 in 2014	# of entrants	% 32–41 in 2014	# of entrants 32–41 in 2014	
2005	700	90%	630	1,300	10%	130	760
2006	700	80	560	1,300	20	260	820
2007	700	70	490	1,300	30	390	880
2008	700	60	420	1,300	40	520	940
2009	700	50	350	1,300	50	650	1,000
2010	700	40	280	1,300	60	780	1,060
2011	700	30	210	1,300	70	910	1,120
2012	700	20	140	1,300	80	1,040	1,180
2013	700	10	70	1,300	90	1,170	1,240
2014	700	--	--	1,300	100	1,300	1,300
Total	(7,000)		3,150	(13,000)		7,150	10,300

* Total in Column 8 = Column 4 + Column 7.

Table 5 Projected Attrition Rates of New Entrants, 2004–2014

New Clients’ Year of Entry	% of New Clients in System in 2014
2004	72
2005	74
2006	76
2007	79
2008	82
2009	85
2010	88
2011	91
2012	94
2013	97
2014	100%

Table 6 Sample Calculation: New Entrants Who Will Be 32–41 Years of Age in 2014, After Attrition

Year of Entry	Projected # of Entrants Who Will Be 32–41 in 2014*	Projected Attrition: % in the System in 2014	Projected # of Entrants in the System in 2014**
2005	760	74%	562
2006	820	76	623
2007	880	79	695
2008	940	82	771
2009	1,000	85	850
2010	1,060	88	932
2011	1,120	91	1,019
2012	1,180	94	1,109
2013	1,240	97	1,203
2014	1,300	100	1,300
Total	10,300		9,064

* See Table 4.

** Column 4 = (Column 2) * (Column 3).

Table 7 Projected Overall Caseload in 2014, by Age Group

Age	2004–2014			
	Projected Caseload 2014	Caseload in 2004	% Growth	Calculations for Caseload 2014*
18–21	30,110	15,863	90%	$(20,919)(.72) + 15,048$
22–31	46,522	28,365	64%	$(38,785)(.72) + 18,597$
32–41	29,487	22,812	29%	$(28,365)(.72) + 9,064$
42–51	22,122	20,298	9%	$(22,812)(.72) + 5,697$
52–61	16,278	10,635	53%	$(20,298)(.72) + 1,663$
62+	12,205	4,850	152%	$(10,635)(.72) + (4,850)(.72)** + 1,056$
Total	156,724	102,823	52%	

* Projected caseload in 2014 = [Size of cohort in 2004 * (Expected % of cohort still in system in 2014)] + Expected number of new entrants who will be in the age group in 2014.

Example: Projected caseload of 18- to 21-year-olds in 2014 = [(# of 8–11 year old clients in 2004) * (% of those clients still in system in 2014)] + Expected number of new entrants (2005–2014) who will be 18–21 in 2014.

Projected caseload of 18–21 year olds in 2014 = $[20,195 * 0.72] + 15,048 = \mathbf{30,110}$.

** 4,850 = 62+ caseload in 2004.

Table 8 Projected ILS Caseload in 2014: Two Scenarios

	2004–2014			
	Adult Caseload	% ILS/SLS	ILS/SLS Caseload	% ILS/SLS Growth
2004	102,823	17%	17,480	
2014 lower*	156,724	17%	24,637	41%
2014 upper**	156,724	26%	40,369	131%

*** Assumptions for lower scenario**

A) Developmental centers: 50% of DC residents move to other residential settings: 10% of these people shift to ILS/SLS; 45% to community care facilities (CCFs), and 45% to ICF.

B) Other settings: no changes (i.e., ILS/SLS share of the pie remains the same as in 2004: 17% of adult caseload).

**** Assumptions for upper scenario**

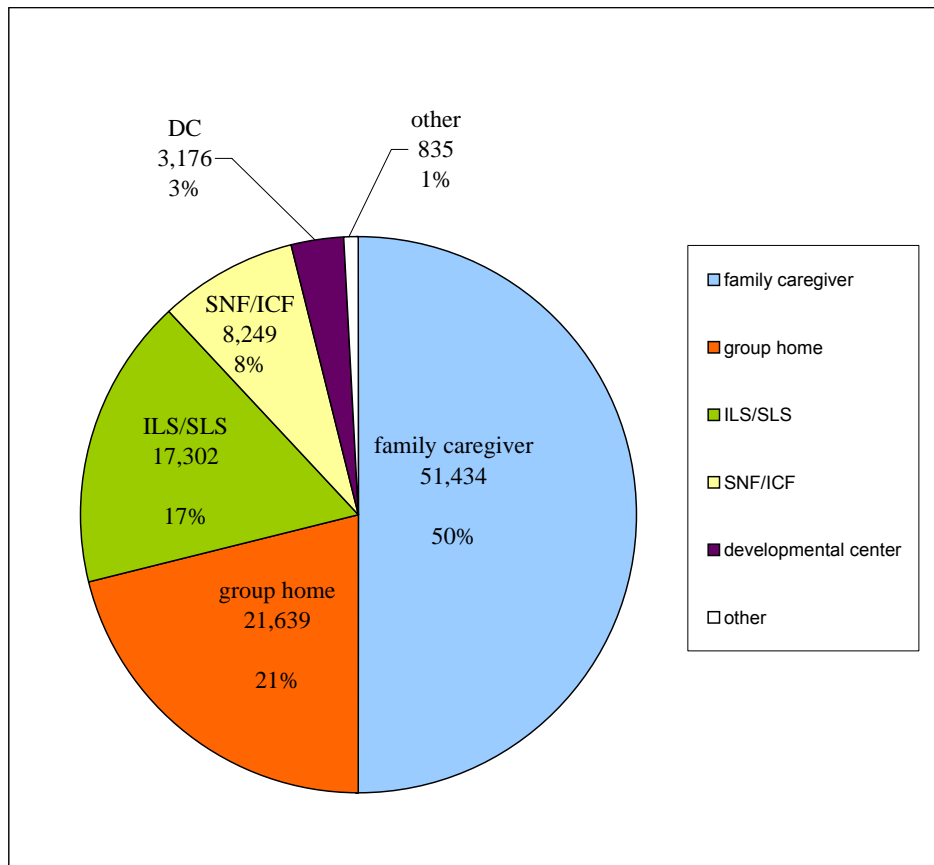
A) Developmental centers: 50% of DC residents move to other residential settings: 15% of these residents are served by ILS/SLS; 45% go to group homes, and 40% move to ICF.

B) Group homes: The share of clients in group homes declines by 22% due to movement to ILS/SLS.

C) Family caregivers: The share of clients living at home with family caregivers decreases by 10% due to movement to ILS/SLS.

Source (2004 caseload): Client Master File (CMF status codes 2, 8), DDS, *Quarterly Client Characteristics Report* for the end of December 2004.

Figure 1 2004 Adult Caseload by Type of Residential Service

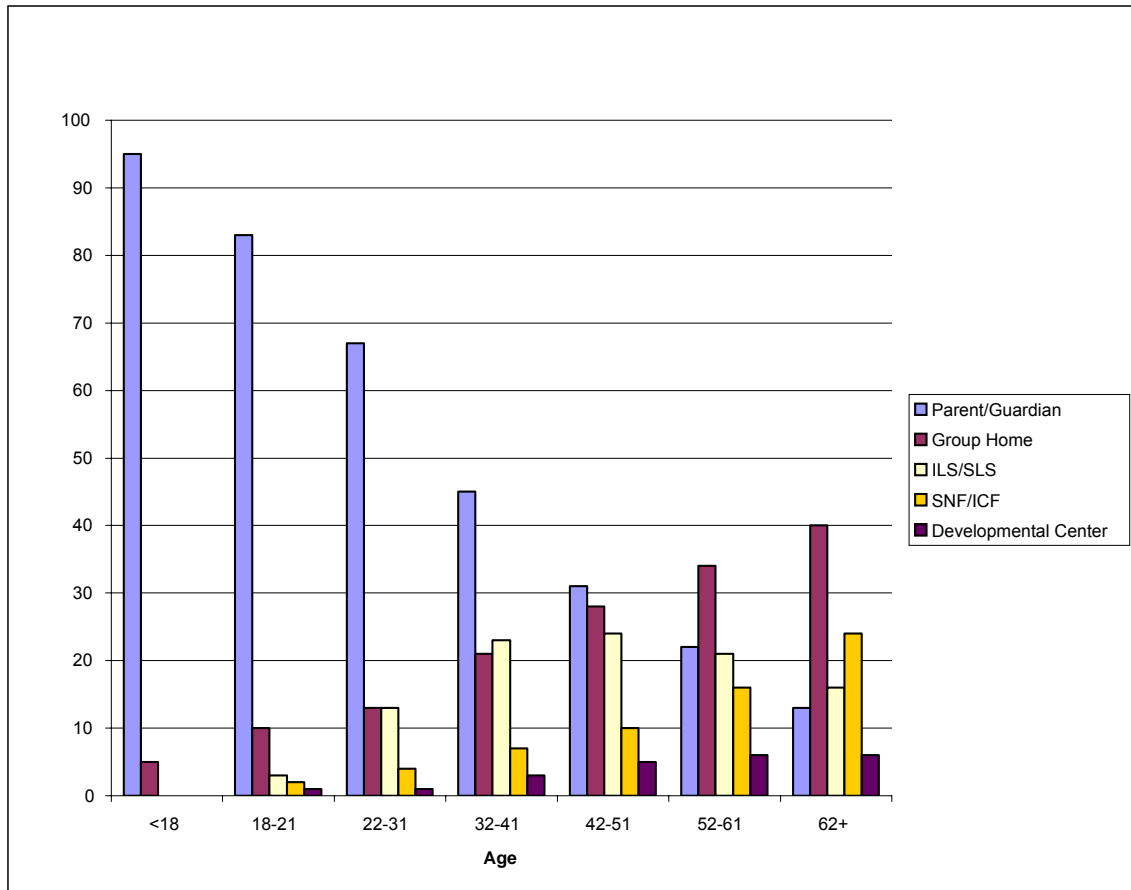


Total served clients, adults (status 0, 2, 3, and 8): 102,635

Source: CDER Master File of January 4, 2005 (DDS Quarterly Client Characteristics Report for the end of Dec. 2004)

Note: CDER information is not available for all clients

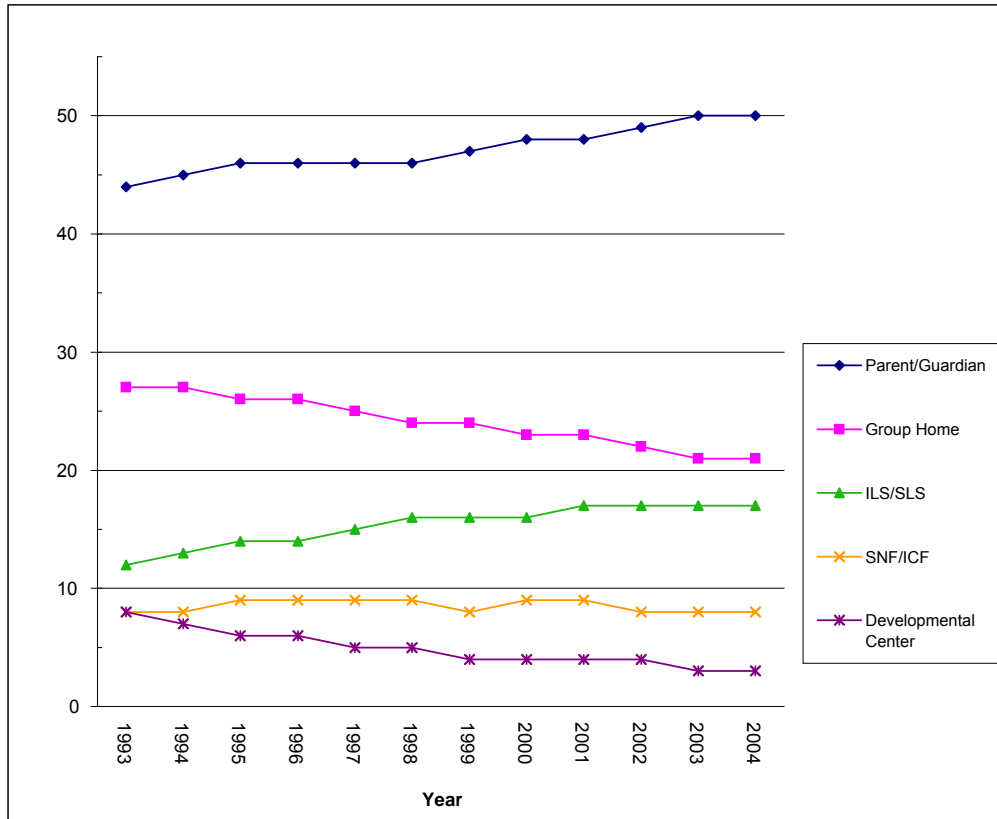
Figure 2 Residential Settings by Age, 2004



Source:

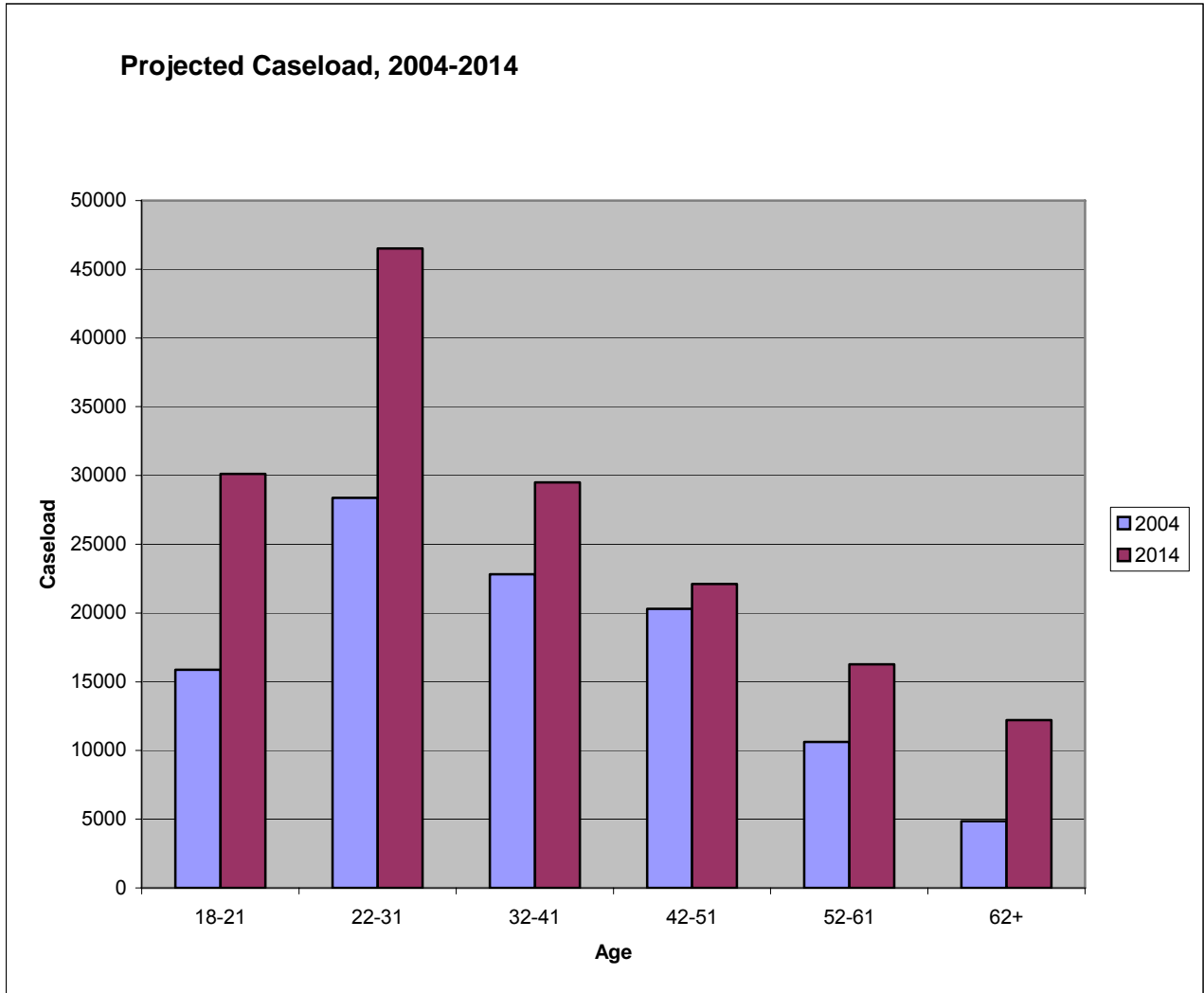
California DDS, CDER Master File, *Quarterly Client Characteristics Report Index* for the end of December 2004.

Figure 3 Residential Settings of Adult Clients, 1993-2004



Source: Client Master File (DDS Fact Books, 2nd-7th Editions). Clients include individuals with CMF status codes 2 and 8.

Figure 4 Projected Caseload, 2004–2014



Source (2004 figures): Client Master File, DDS, *Quarterly Client Characteristics Report* for the end of December 2004.