



Quality Services and Quality Jobs for Supporting Californians with Developmental Disabilities

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California's developmental services system assists more than 200,000 people with developmental disabilities and their families, employs 90,000 workers, and costs over \$3 billion per year. Since 1993, the number of people served has increased by 70%, and this rapid growth is projected to continue.

The state's system of delivering services to this population has undergone a dramatic transformation since the 1969 Lanterman Developmental Disabilities Services Act recognized the civil right of people with developmental disabilities to determine their own life plans, residences, and service providers. The Lanterman Act also created an entitlement to services and established a system of 21 regional centers operating under the principles of decentralization and local community control.

A steady progression of federal and state legislation and court decisions has led to deinstitutionalization and the development of community-based services. The federal Medicaid Home and Community Based Services (HCBS) waiver has provided funding for flexible and innovative services in community settings. As a result, the system that once consisted of large, segregated public institutions now operates through private nonprofit and for-profit community-based agencies.

However, the community service system faces a staffing crisis, now widely cited as the most significant barrier to growth in services. The poor conditions of employment for workers who provide direct support to clients has led to very high vacancy and turnover rates, undermining the quality and availability of services. Deinstitutionalization has resulted in the erosion of wages and benefits for direct-support workers, and increased job responsibilities with no concomitant investment in training. It has also caused a proliferation of small agencies and allowed clients and families to directly hire workers, creating challenges for the provision of health insurance, training and other supports within atomized employment settings.

As the state seeks to expand the availability of services that promote self-determination and community integration, it must develop appropriately customized workforce supports to successfully recruit and retain sufficient numbers of well-trained direct-support workers. It also must develop innovations that overcome the inherent inefficiencies of a decentralized system while honoring its core values, including local control.

California's Progress in Developing Community Services

Two broad sets of quantitative indicators are commonly used to compare states' progress in developing community services: 1) their financial commitment to community services, and 2) the proportion of clients in "person-centered"

services. These services support clients' ability to live in settings they choose and control, participate in their own communities, and promote control over their everyday lives. They contrast with more traditional segregated services and mini-institutions within the community system that offer clients little choice or community inclusion. As these indicators show, California has ample room for improving its community services.

Financial Commitment

- ▶ California devotes 78% of its total spending for this population on community services, giving it a rank of 24th in the nation.
- ▶ Its fiscal effort, which measures spending on developmental 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 an average national level of \$4.11.
- ▶ California lags far behind most other states in accessing matching funds from the HCBS waiver program, the main source of federal funds for community services—particularly newer services that offer clients greater choice, independence, and community inclusion. In 2004, only 27% of California's spending on community services was based on HCBS waiver funds, ranking it 42rd in use of this funding stream.

Use of Person-Centered Services

A “first-cut” indicator of a state's commitment to person-centered services is the proportion of people with developmental disabilities in residential placements of six people. California is ranked 17th out of 50 states in the percentage of people living in one-to-six-person settings. However, some of these residential placements are “six-pack” group homes that offer clients little choice or control.

Supported- and Independent-Living Services. These services (SLS and ILS) enable people with all levels of disability to live in homes that they control, and provide a person-centered alternative to group homes. In 2004, 17,528 California clients used supported-living services—a usage rate of 49 participants per 100,000 of the general population, slightly below the national average of 53. No comparative data is available for independent-living services.

Supported Employment. These services provide job developers and coaches to help people with developmental disabilities find and work at jobs in the competitive labor market. They provide a person-centered alternative to sheltered workshops, where clients perform piecework in a segregated shop setting and typically earn subminimum wages. In 2004, California had 9,297 participants in supported employment programs, spending \$2.12 for these services per capita of the general state population. The national average was \$2.34. Eighteen percent of California's developmentally disabled day-work participants are in supported employment, compared to the national average of 24%. These figures include some noncompetitive work settings, but are the current best figures available.

Family Supports. These services provide respite, daycare, and transportation for families caring for children or adults with developmental disabilities at home. Because most people with developmental disabilities live with their families, family supports are an essential part of person-centered services. In 2004, 81,074 California families received these services, for 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 supported.

Self-Determination. The state's most recent service innovation is its interpretation of national self-determination programs, known in California as the Self-Directed Services program. Of all the services available, this program gives clients the greatest degree of flexibility and control over the services they need by allowing them to manage their own service budgets and select the services and the personnel who provide them. Starting in 2006, upon approval of a federal waiver, self-direction will be available across the state for as many as 9,000 current clients over the next three years. No national comparative data is available on these new programs, but the first programs commenced in 1993 in New Hampshire, while California initiated its pilots in 1998.

Growth Projections for Independent and Supportive Living Services

Meeting future demand for person-centered services is an essential component of improving service quality and accessibility. In 2004, approximately 17,500 clients in California chose independent- or supported-living services. Our analysis indicates that a continuation of recent growth trends in the transition from group homes and other settings will lead to the need for approximately 40,400 ILS/SLS services in 2014, or nearly 23,000 additional placements in the next eight years. These projections suggest the need for a substantial expansion of these services and highlight the need to plan for this growth in demand.

The Crisis in Staffing

Approximately 90,000 workers are employed in California's community services system for people with developmental disabilities, 70% of whom are female and 59% of whom are African American, Latino, or Asian.

Fundamental Changes in the Direct-Support System

Deinstitutionalization has dramatically affected the conditions of employment for workers providing direct support to people with developmental disabilities. Four fundamental changes have affected workers, clients and their families, and employers in the community-based developmental system.

1. Poor wages and benefits

Dismantling 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 and even fewer opportunities for career advancement. Although little data is available on direct-support workers, the last available survey of community-care facilities documented average wages of \$10.24 per hour in 2001 after wage pass-through legislation—a rate augmentation earmarked to increase compensation by almost 20% in order to retain direct-support workers. In the five years since then, reimbursement rates have been frozen. This wage is lower than a single worker with no dependents would have needed for basic self-sufficiency in California in 2005. Data on access to health insurance is even more limited.

Low wages are the main cause of very high turnover rates in community settings. In Wyoming, for example, when total compensation rose from \$9.08 in 2001 to \$13.19 by 2004, turnover dropped from 52% per year to 32%. California does not collect data on turnover, but small surveys reported turnover rates ranging from 24% to over 50%. High turnover forces providers to struggle to find qualified workers, undermines training, continually disturbs relationships between workers and clients, and ultimately undermines quality of care.

2. Changing job descriptions and lack of training support

Workers providing direct, person-centered services have very different job responsibilities than workers in institutions and traditional services. While the latter work under the direction of on-site supervisors in structured and routinized programs, workers providing person-centered services perform a broad array of tasks autonomously and independently as they help clients lead self-directed lives. For example, they provide medication supports, implement behavioral plans, teach new self-care skills, assist clients in navigating relationships with family, neighbors, co-workers and others, advocate for their rights, teach self-advocacy, and interact in many different work, home, and social environments. Workers in person-centered services are accountable not only to their employers but to clients and families, who have a greater role in hiring, supervision, and possible termination.

California community agencies are responsible for providing training that they have limited capacity to design or deliver. Recently the state instituted a 70-hour training requirement for workers in community-care facilities, which is less rigorous than nationally recognized standards and curricula, such as the federal Department of Labor's community-support skill standards and the University of Minnesota's College of Direct Support curriculum.

In contrast, California has invested significant resources in psychiatric technicians who provide direct support in institutional settings, in the form of well-developed training, career ladders, and a credentialing system. This infrastructure has not been used in community settings largely because advocates of and actors in community care philosophically reject the institutional model of services. A number of other states, including New York and Wyoming, provide models for professionalizing direct-support workers in person-centered settings through degree programs, strong partnerships with employers and unions, and career-ladder programs.

3. Proliferation of employers

The shift to a decentralized community-based system resulted in the creation of 8,000 community-provider agencies, with an estimated average employment of fewer than eight full-time-equivalent workers. Research in the San Andreas Regional Center area shows that 61% of independent- and supportive-living services are provided by small- and medium-sized agencies with an average of 30 employees. Agency directors value this size because they associate it with a higher quality of personalized service and responsiveness to local needs. In fact, decentralization and community control are core values of California's service system.

The proliferation of small agencies also has some drawbacks. Small agencies often lack business expertise and face high administrative costs, including payroll and other business services and insurance products. Healthcare insurance, which is one of the keys to retaining workers in this industry, is cheaper with a greater number of workers in the health insurance pool. In addition, the smaller agencies provide only minimal on-the-job training for their workers and are unable to provide career-advancement opportunities. These inefficiencies absorb resources that could otherwise be used for service provision.

A number of efforts are under way to overcome the diseconomies of scale and administrative fragility of small agencies in a variety of human-service sectors. For example, the Wisconsin Regional Training Partnership (WRTP), one of the nation's premier joint labor-management training collaboratives, is creating a professional employer organization (PEO) to serve small long-term care agencies and childcare centers. PEOs are now common in the private sector, lowering costs for small businesses by outsourcing human-resource administration to specialized firms that can provide payroll, tax compliance, workers'

compensation insurance, health insurance, worker recruitment and screening, and other administrative tasks at lower cost. The WRTP is creating a socially oriented nonprofit PEO that will pool workers from multiple agencies to provide healthcare insurance using a Taft-Hartley healthcare trust fund. This effort and others have informed the PEO proposal recommended below.

4. Families as employers

More than 30,000 families now directly hire workers to provide respite, daycare, and other services, and another 9,000 clients will be eligible for self-directed service vouchers over the next three years. Evaluations have shown that clients who are able to choose and arrange their own services and personnel have shown an overall increase in measures of satisfaction and quality of life because of their increased flexibility and choice.

Although this increased choice has had positive results for the families involved, it can create difficulties for workers—who experience greater difficulty finding work, often receive no workers’ compensation insurance coverage, and rarely have access to health insurance, training, or career advancement. 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 states have created private or public “employers of record” to help clients and families process timesheets, issue paychecks, file payroll taxes, provide mandated benefits, and maintain records. This eases the administrative burden for families while honoring their desire to hire and supervise their own workers. In some cases, employers of record also provide workforce supports that have improved the recruitment and retention of workers. California, Washington, and Oregon have created public authorities that provide home-care workers access to health insurance and training, and also maintain a registry to help match workers and clients. This model has not been applied in California’s developmental disabilities services, but could be used for the new self-directed services and other family-voucher programs. The PEO recommended here can serve a similar function as the public authorities, but using a private and voluntary mechanism instead of a public, sector-wide employer of record to pool workers.

Recommendations and Strategies for Change

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 and prepare for the increased number of people who are likely to need services in coming decades.

1. Restructure reimbursement rates to create incentives for developing a stable and well-qualified workforce and contribute to the growth of person-centered services. 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.

2. Build a training, education, and career advancement infrastructure for the community-based person-centered delivery system. Over time, the state needs to develop an infrastructure to professionalize direct-support work in developmental services by establishing professional credentials, linking training to degree programs, and providing career-ladder programs. In the short run, the state could use previ-

ously untapped state and federal workforce development funds to encourage pilot multiemployer training and education programs that can germinate statewide professionalization.

3. Over time, increase funding for developmental disability services. 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. Although public investment is needed to improve compensation for direct-support jobs, a significant portion of the cost will be offset by lower turnover costs, decreased use of public assistance by low-wage workers, and higher-quality services that will help people with developmental disabilities gain greater independence over time.

4. Support a professional employer organization that can serve small- and medium-sized agencies as well as clients and their families who directly hire staff. A financially self-sustaining professional employer organization could serve small- and medium-sized agencies providing person-centered services by providing administrative services while preserving the autonomy of agencies and clients over personnel decisions. The PEO would lower administrative costs by providing HR services and information for groups of agencies, making it in effect a co-employer. Services would include payroll, tax compliance, recruitment, HR information, staff training, and a registry, as well as provision of insurance (workers' compensation, unemployment, and healthcare).

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 recordkeeping to ensure compliance with federal requirements and better documentation of key measures of quality and workforce stability.

NOTES

Carol Zabin, PhD, a labor economist, is research director and associate chair of the UC Berkeley Center for Labor Research and Education. This briefing paper summarizes research she is conducting at the request of Senator Wesley Chesbro, chair of the California Senate Select Committee on Developmental Disabilities and Mental Health. The research is supported by the California Policy Research Center and the California Program on Access to Care of the University of California Office of the President. The author acknowledges the valuable help of research assistants Elisabeth Pohlman and Jonathan Hoffman. The full report may be found at the California Program on Access to Care's website at <http://www.ucop.edu/cprc/cpac.html>.