



**Planning for a Unified
Developmental Disabilities
Services System:**

A report to Californians with
developmental disabilities
and their families

Association of Regional Center Agencies

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Introduction

Introduction

California regional centers and the community-based developmental services system were born in the late 1960's as a result of the State's inability to provide needed services in its institutions. Research, now overwhelming, was then beginning to mount in favor of serving people in the least-restrictive, most-integrated settings. The realities and the research inspired parents of people with developmental disabilities to pressure the State to act.

The Lanterman Act created a system charged initially with addressing the needs of people on California's considerable waiting list for institutional care. Regional centers were successful in serving these people, and soon expanded their role to serving those coming out of institutions and creating alternatives for others who did not consider institutions a viable service option.

By the mid-1970's, regional centers had been so successful that the State began to place particular emphasis on deflecting and deinstitutionalizing children. Indeed, regional centers and staff at institutions have worked to such good effect that today few children are ever referred to state institutions.

By the early 1980's, the regional centers had been so effective and efficient that the disparity and disunity between the "community system" operated by the regional centers and the institutions operated by the State became a major topic of discussion. At this time, the legislature began to question why the system remained bifurcated. They charged the Health and Welfare agency to submit a report to the Legislature regarding the feasibility of creating a Unitary Budget for the system, with state institutions funded through regional centers. Ultimately, no action was taken to implement such a system because the state institutions were primarily funded with federal dollars, while the community system was 100% state funded. Policy-makers felt that creating such a system would jeopardize the federal funding stream.

During the same period, the State Council on Developmental Disabilities worked collaboratively with system stakeholders to find ways to preserve and shift resources from the institutions to the community without threatening federal funding. This included sponsoring widely supported legislation to allow the state to provide services as a part of the community system in small, home-like settings. Despite support by regional centers, area boards, organized labor, most state hospital parents, and the legislature, the bill was vetoed by the Governor at the

urging of some parents of Fairview Developmental Center residents. The Council also sponsored legislation to set aside the Developmental Centers' land and put it in trust for the developmental services system. This effort was unsuccessful, due to objections that it would remove legislative control of the resource.

In the decade following the early 1980's, development of community services for people with developmental disabilities stalled for lack of resources. Then the Coffelt lawsuit, filed by Protection and Advocacy, Inc. in 1992, resulted in the allocation of new money into the system and the successful de-institutionalization of over 2000 people. For people whose interests were linked to preserving the institutions, this created an incentive to find and exploit weaknesses in the community system. The attendant publicity stalled the efforts to bring people back to their home communities.

Currently, major developmental services public policy direction are under review in light of environmental changes, including:

- ◆ statutory and regulatory revisions;
- ◆ regulatory reviews and third-party audits critical of the state of the system;
- ◆ case law and settlements;
- ◆ current litigation;
- ◆ federal and state administrative reviews and actions;
- ◆ decaying infrastructure of and rising admissions to State developmental centers;
- ◆ funding crisis for the community service providers and system deficit projected for the regional center budgets;
- ◆ high and rising housing, space, and labor costs; and
- ◆ rising expectations of consumers and their families in light of self-determination and disability-specific services.

As the system moves into the 21st century, the legal, financial, and humanistic factors are aligned for California to finally unify its system of services for people with developmental disabilities. The system's resources should now be used effectively and efficiently to fulfill the Lanterman Act vision of people included as a part of their communities.

Executive Summary

Executive Summary

The time to create a unified system is NOW. The integration of the developmental services system is essential for the inclusion of the people served by the system.

Foundation

The purposes of the regional centers and the developmental services system as set forth in the Lanterman Act underscore the obligation of regional centers to assure that institutional care is an option only for those people who cannot be served by the community.

ARCA's mission and commitment must focus on fulfilling the Lanterman Act purposes within the context of the new federal requirements under *Olmstead v. L.C.* and the current realities confronting regional centers. The State has overwhelmed regional centers with un-funded mandates, while promoting unrealistic expectations for consumers and their families. At the same time, *Olmstead* places new pressures on the State to build community capacity as an alternative to institutionalization.

Every audit of the developmental services system has concluded that regional centers are under-funded in their own operations and therefore are unable to develop and maintain quality services required to fulfill their purposes and implement the *Olmstead* decision. Settled case law and current litigation (i.e., *Sanchez*) all point to the necessity for more funding in the community services system in order to assure quality services for people with developmental disabilities in their home communities. Moreover, data regarding the costs of institutional settings makes it clear that the cost of capital outlay and fixed operating costs will soon drive the costs of institutions to an absurd level.

The State Department of Developmental Services has taken the first step in leadership toward a unified system by proposing five principles for a new era in the system.

1. No capital outlays to rebuild developmental centers.

2. Homes limited to four persons or less.
3. Capture and extend developmental center resources into the community.
4. Leverage the developmental center land to create new resources.
5. Conduct highly individualized personal assessments and resource development before the move to the community.

To create an interlocking network of consumer and family information, support, and service solutions, the disparate pieces of the California developmental disabilities service system must together develop a Unified System of Developmental Services.

The Plan

ARCA provides this Plan and its accompanying report to catapult the system forward into a Unified System of Developmental Services that will both meet the *Olmstead* requirements in each of the unique California communities and fulfill the system's mandates under the Lanterman Act.

ARCA and its central or regional centers are proud to present the following Strategic Plan for a Unified system to the California and Federal developmental disabilities service systems.

- Goal 1: Develop comprehensive, effective, local plans to support people to live full and included lives in the community.
- Goal 2: Remove undusted barriers to plan implementation and to increasing community capacity.
- Goal 3: Build a unified, coordinated community service system.

We look forward to working together to develop a responsive service system, centered on Californians with developmental disabilities and their families.

Planning Environment

Planning Environment

FOUNDATIONS FOR PLANNING

The Association of Regional Center Agencies (ARCA), representing the twenty-one regional centers that serve over 160,000 Californians with developmental disabilities and their families, is proud to present its Strategic Plan for a Unified Developmental Service System. This Plan, founded on the Vision, Values, and Purposes of the community service system, will drive ARCA's 5-year mission.

Vision

All Californians with developmental disabilities live as full and active members of their communities.

Purposes

The Lanterman Act mandates that community-owned, non-profit agencies supply supports and services to people with developmental disabilities to:

- ◆ enable them to approximate the pattern of everyday living available to people without disabilities of the same age (W&I Code, 4501), and
- ▲ provide, to the maximum extent possible, treatment services and supports in natural community settings (4502.5); and in their home communities (4503, 4504).

The California Supreme Court (*Association for Degraded Citizens - California v. Department of Developmental Services* (1981) 30 Cal. 3d 344, 358, 211 Cal. Reporter 738, 739) interpreted the overall purpose of the Lanterman Act as:

- to prevent or minimize the institutionalization of developmentally disabled persons;
- to prevent or minimize their isolation from family and the community;
- to enable them to approximate the pattern of everyday living of non-disabled persons of the same age; and
- to enable them to lead more independent and productive lives in the community.

Operating Principles

The unified California system of care should be guided by three principles:

- Person Centered: life quality outcomes for people and families drive the system;
- Community Based: the system is owned by and reaches out to local community;
- Well Managed: information on efficient, effective services for development and improvement of each system piece as well as the coordinated whole.

Mission

The Association of Regional Center Agencies will promote the integration of separate services into a unified, equitable, accountable, and accessible service system by

- ◆ advocating,
- ◆ promoting and coordinating action,
- ◆ composing public policy, and
- ◆ sponsoring legislation

to realize the purposes and individual/family outcomes defined by the Lanterman Act and case law.

California's developmental services system is in a state of crisis. Converging system issues include litigation, statutory changes, de-certification of State developmental centers, disqualification of many regional centers for federal reimbursement, decaying developmental center physical plants, a large disparity between the services and funding of the community and the State services system, an inability of community care providers to hire and develop direct care workers, and changing labor and space markets in California.

ARCA believes the convergence of environmental motivations indicates the need for coordinated, comprehensive, and effective system-wide action in the next decade.

The attached document discusses the context of the California developmental services system. A short current state analysis of service system characteristics, demographics, and initiatives paints a compelling picture of one system, inefficiently broken in two. Finally, after describing this complex environment, ARCA presents an action plan with recommendations to optimize the effectiveness and efficiency of California's developmental disabilities system.

BACKGROUND FOR PLANNING

Current Context

The State of California has established two systems aimed at discharging its responsibility, as defined in the Lanterman Act, to persons with developmental disabilities. The regional centers and the State developmental centers share a common purpose: to increase opportunities and the potential of persons with developmental disabilities to live and participate in their community. The conclusion is inescapable: these two systems were designed to function as a unified and coordinated system while focused on meeting consumer/family needs, supporting their choices, and integrating them into their home communities. To the great misfortune of Californians with developmental disabilities and their families, this design has not been realized.

Audits by the Bureau of State Audits¹ and Citygate Associates² agree the community care system can serve the needs of all Californians with developmental disabilities - as per the intent of the Lanterman Act - if appropriately funded. Both the community and State tiers of the system serve individuals with the same kinds of characteristics and levels of functioning with the exception of those individuals designated as forensic (committed to developmental centers by the courts for real or alleged criminal activity).

Current system facts and statistics show that the community service system can - and does - serve the same population as is served by the developmental centers, but at a significant cost savings to California taxpayers. Further, the Bureau of State Audits and Citygate Associates agree that, with appropriate funding levels, the community care system can provide all services with a high level of security for families and consumers.

ARCA Commitment

ARCA recommendations focus on planning and coordination to implement a community services system that integrates State services and addresses the requirements of the recent U.S. Supreme Court decision in *Olmstead v. L. C.* The State of California is now at a critical decision point in terms of meeting its responsibility and obligation to people with developmental disabilities and their families. The ultimate goal should and must be that each consumer's civil rights are protected, and that each consumer will benefit equally from the State's commitment to provide services and supports in one's own community, as defined in the Lanterman Act.

The disparate pieces of the California developmental disabilities service system must work together to create a unified, interlocking network of consumer and family information, support,

¹Bureau of State Audits, 1999. *Department of Developmental Services: Without Sufficient State Funding, It Cannot Furnish Optimal Services to Developmentally Disabled Adults*

²Citygate Associates, 1999. *Department of Developmental Services: Regional Center Core Staffing Study Final Report.*

and service solutions that address the above issues to fulfill the purposes of the Lanterman Act (Welfare and Institutions Code §4500 et seq.) and the *ARC vs. DDS* decision (38 Cal. 3d 384, 388, 211 Cal. Reporter 758, 759).

To meet these challenges successfully, regional centers must proactively plan to individually and collectively leverage their resources into effective, coordinated solutions for a unified, equitable, accountable, and accessible system for Californians with developmental disabilities and their families.

An array of supports and services should be established that is sufficiently complete to meet the needs and choices of each person with developmental disabilities, regardless of age or degree of disability, at each state of their life, and to support their integration into community mainstream life. To the maximum extent feasible, supports and services should be available throughout the State to prevent the dislocation of persons with developmental disabilities from their home communities.

We have before us an opportunity to make meaningful systemic changes in California's systems that serve people with developmental disabilities. Embraced in the Lanterman Act are the principles supporting full inclusion for people with developmental disabilities into the mainstream of life in their communities. Over the past several years, progress has been made to ensure these people are guaranteed the same rights and privileges as people without developmental disabilities. To fully realize this goal, our plans must address the following environmental factors.

Statute and Regulation Revisions

Increasing complexity and policy-making by anecdote have characterized the intense policy-making period of the last six years. These new laws and regulations, though well intentioned, have not sufficiently improved the outcomes for the people we serve and have in some cases made the system unduly complex. Starting with SB 1383, which became law in 1992, many progressive ideas have become part of the service system. Recent statutes, promulgated at an unprecedented rate and at times developed in response to isolated incidents, have substantially increased the burden on regional centers in case management, quality assurance, and administration functions.

For example, SB 1038, SB 1039, and the Trailer Bills passed in the late 1990's specified among other requirements: transition from the State developmental center to the community; additional steps and documentation requirements to IPP preparation, including a documentation of a consumer's health status; additional work to maintain communication and effective working relationships between regional centers and their local county mental health agencies and local departments of health services; increased (unannounced) monitoring visits to various living arrangements; a complaint process for consumers; lists of areas of expertise that regional centers are required to have available such as special education, housing and criminal justice; and caseload ratios of 62:1 regardless of a center's operational priorities. As noted by many system auditors,

regional centers were not reimbursed for the additional workload these and other statutes required.

Regulatory Reviews and Third-Party Audits

Bureau of State Audits

In October 1999, the Bureau of State Audits (BSA) released a report entitled *Department of Developmental Services: Without Sufficient State Funding, It Cannot Furnish Optimal Services to Developmentally Disabled Adults*. The report focused on State funding of community-based services, and concluded that the State's system was designed to provide optimal service to consumers, but its success has been undermined by insufficient State funding and more than \$106 million in budget cuts over a four-year period. According to the BSA, until the State commits to ensuring that sufficient funding is available for this program, it will never be able to realize the spirit of the Lanterman Act.

The BSA recommended four main courses of action:

- ◆ The Legislature must take interim measures to align State funding with program costs.
- ◆ Additional funding should be earmarked specifically for increasing compensation for qualified direct care staff and reducing the caseloads for regional center case managers.
- ◆ The Department should expedite the completion of its service delivery reform efforts.
- ◆ The Department should carefully consider and implement its consultants' recommendations for the regional center budget process as quickly as possible.

Purchase of Service Variations Study and Follow-Up

In response to the 1998 Budget Act, DDS conducted an analysis³ of regional centers' Purchase of Service expenditures and the factors that contribute to the variances across the statewide regional center services system.

The study found that variances are a product of the process, not a determination of differences. If greater equity is assured in access, assessment, and services, what variances remain will be functions of diversity largely outside the control of regional centers. (Ibid, page iii)

A follow-up study is currently under development to determine what environment or process variables are causally related to the observed differences in expenditures, then goes forward in identifying variables that can be modified to effect desired changes in purchase of services budgets. This study proposes to create a valid and reliable measure of consumer outcomes, and which environmental and process variables correlate to outcomes.

³Department of Developmental Services, 1999. *Purchase of Services Per Capita Expenditure Variances in Regional Centers*.

Studies by Citygate Associates - 1998 and 1999

Citygate Associates, Inc. was retained by the Health and Human Services Agency after the Legislature mandated an independent review of regional center's placement practices, transition planning and monitoring of consumers' health and safety after their placement from developmental centers into community based residential programs.

The 1998 review⁴ by Citygate Associates underscores the regional center budgeting and operations difficulties, as well as the stressful work environment that case managers must endure. (In January 1998, the Federal Health Care Financing Administration (HCFA) corroborated this study, noting that high turnover and heavy caseloads limit case managers' duties to crisis management.)

The main findings of the Citygate study, however, paint a picture of a system without the funding to accomplish its mandates. Three issues were highlighted:

- ◆ Publicly funded agencies working for the same group of Californians (state departments, local licensing agencies, as well as developmental disabilities service system agencies and advocates) need to collaborate on shared outcomes, standards, measurement, etc., in order to use resources efficiently and plan comprehensively.
- ◆ Specialized services are non-existent or difficult to access under set rates and Medi-Cal fees.
- ◆ Consistent outcome and performance measures need to be developed for and used to monitor the entire system.

Coordination, information sharing, and a higher level of funding were recommended.

In 1999 Citygate Associates conducted another legislatively mandated study⁵ of the budgeting methodology for the regional center core staffing formula. The core staffing formula is used to provide an allocation for regional center personnel. No objective study of functional requirements or task analysis of workload demands created by state and federal requirements had ever been conducted since the inception of the regional center system.

Based upon their evaluation, Citygate made recommendations for a budgeting methodology which recognized some previously unaddressed functions performed by regional centers. The consultants attempted to differentiate between more difficult and complex cases versus less difficult consumers using CDER data. They assigned different caseload ratios for difficult versus less difficult consumers. Although the CDER was never designed to be used for this purpose, ARCA felt that their concept deserves further investigation.

⁴ Citygate Associates, 1998. *Department of Developmental Services: Independent Report on Developmental Services.*

⁵ Citygate Associates, 1999. *Department of Developmental Services, Regional Center Core Staffing Study, Final Report.*

However, Citygate's analysis and recommendations generally assumed current levels of funding would provide the parameters for the budgeting of their model. ARCA evaluated their report and recommendations thoroughly, agreeing some concepts were intriguing and should have further testing for their validity.

State Developmental Centers

The physical plant and programs of California's five State developmental centers are outdated, as their repeated failure to maintain federal accreditation makes apparent. For example,

- ◆ Sonoma Developmental Center in Eldridge, the largest such institution in the nation, failed six out of eight certification categories that measure how well it protects the health and safety of its residents in December, 1998. Sonoma regained and then recently lost its certification, at a loss of \$3.1 million per month in federal funding.
- ◆ Agnews Developmental Center in San Jose failed five out of eight certification categories in March 1999. Agnews was unable to regain certification for over a year, at a cost to the General Fund of \$2.1 million per month.

The Federal Health Care Financing Authority (HCFA) requires these obsolete facilities meet health and safety code requirements.

In accordance with these federal requirements, DDS commissioned an audit of the developmental centers. In late 1998, Vanir Construction Management released an audit of the infrastructure of the five developmental center campuses. The study found that the developmental centers:

- ◆ do not comply with major applicable medical facility codes;
- ◆ are operating under two types of waivers exempting them from critical life, safety, and health requirements;
- ◆ need many seismic improvements to comply with the Division of State Architect risk evaluation under the State Building Seismic Program; and
- ◆ have significant deficiencies meeting ADA accessibility requirements.

Further, Vanir found no major capital outlay projects had been accomplished since 1982, concluding that deferred maintenance had left the facilities with major infrastructure and physical plant inadequacies. The estimated cost to address these issues, according to Vanir in 1998, was between \$847 million and \$1.4 billion. Even if brought up to code, significant ongoing funding will be needed to maintain the physical plants of these old facilities. According to current estimates, State Developmental Centers require \$1.6 billion in repairs to meet federal Health Care Financing Authority physical plant requirements.

The Department continues to budget and expend significant amounts of dollars on infrastructure repair of developmental centers. In the current fiscal year \$27.1 million was appropriated by the Legislature for developmental center infrastructure needs.

According to a recent DDS report⁶, the need for specialized services exceeds both current and projected supply (even assuming the two new State institutions, Sierra Vista and Canyon View, operating at full capacity). Growth in the population of people with severe behaviors (estimated at 10.2% per year) and with more complex medical needs and disabilities (estimated at 3% per year) strain both current and projected service system resources. Employees of state institutions, with special training and assistance, could conceivably assist in meeting this need in community settings.

The Federal Health Care Financing Administration (HCFA)

As discussed above, California's developmental centers have been audited by HCFA and decertified for receipt of Medi-Cal funding because of their failure to demonstrate basic health, programmatic and safety standards.

In 1997 HCFA conducted a comprehensive audit of California's administration of the federal Home and Community Based Waiver program. It was critical of the statewide administration of the program by the State Department of Health Services (DHS) and dissatisfied with a number of other administrative and programmatic elements.

As a consequence, a number of changes were implemented that impacted both the State's administration and regional centers' implementation of program requirements without commensurate reimbursement for increased operations expenditures

Case Law and Settlements

In re Mar (California)

In the 1981 *In re Mar* decision (25 Cal. 3d 98) the California Supreme Court determined that the State's statutory scheme, which permitted the placement of "non-protesting" adults with developmental disabilities into developmental centers and did not provide for judicial review involving minimum due process and equal protection of the laws standards, was "immediately inhumane."

The Mar court stated, "We will have consistently recognized several related and controlling principles. '[Personal] Liberty is a fundamental interest, second only to life itself' (People v. Wilson (1976) 17 Cal.3d 235.) The court concluded "The word's dilemma is akin to that faced by the defendant described in a recent article, 'If you try to leave, they go to court to make you stay. If you do not try to leave, you demonstrate that you want to stay.' (DeLozier et al., *Anti-Institutionalization: The Promise of the Parrish Case* (1979) 31 Social L.Rev. 217, 232.)"

⁶ Department of Developmental Services, 2002, *Plan for Institutional and Community-Based Services*

Since the 1981 decision, absent a constitutional statutory commitment scheme, courts have been providing judicial reviews for admission of persons with developmental disabilities to developmental centers in a variety of ways. Five attempts to enact legislation to remedy these defects and establish standardized judicial review procedures for developmental center admissions have resulted in a Governor's veto or failed passage by the Legislature.

Last year, the California Judges Association introduced Assembly Bill 1257 to establish a uniform statutory procedure and process for admitting persons with developmental disabilities to State developmental centers. Some parents of developmental center residents opposed the bill because such procedures are intimidating to family members, and impose a heavy financial burden upon them and also the county with jurisdiction, and suggested reviews only on change of circumstances. (ARCA opposed the bill for other reasons.) The Governor found this argument compelling, and vetoed the bill for his feeling that more time is needed to develop a more measured approach that places less of a burden on the families of persons in developmental centers.

Coffelt Settlement (California)⁷

The *Coffelt* settlement led to the de-institutionalization of over 2,000 people with developmental disabilities, and resulted in enhanced community capacity for more than just the people moving from state institutions to the community. Undertaken during a period of severe economic distress, the funding following people from the institutions in the community was squeezed to 54% of historic state expenditure per person while they were living in the institution (not including use of generic resources). The nationwide average, according to the Center for Outcome Analysis, was 75%. In spite of this minimal level of funding, regional centers were able to place and maintain consumers and consumers continue to experience an enhanced quality of life, according to observation and surveys generated by the Center for Outcome Analysis monitoring project.

This funding shortfall, however, decreased the ability of regional centers to develop community capacity to continue to bring people out of institutions, and certainly the spillover effect of community capacity building was unable to support the needs of a growing population.

As a result, the community service system is quickly eroding to crisis and rising numbers of people are returning to over-populated, crumbling institutions. This means the least restrictive setting for many people is determined not by individual needs, but by artificially determined funding levels. This constitutes a failure of Lanterman Act vision.

Richard S. (California)

In April 2000, a federal court found in the *Richard S.* (SA CV 97-219-GLT) case that third parties—parents, guardians, or conservators—could not waive a developmental center resident's

⁷Coffelt v. Department of Developmental Services. No. 91-6401 (Cal Sup. Ct., January 19, 1994). MPDLR185.

right to community placement. A permanent injunction was issued against DDS's policy allowing family members or conservators to "veto" community placement from a developmental center, when such a placement was otherwise appropriate.

Derrick Clark Settlement (California)

In addition, the *Derrick Clark, et al vs. The State of California* settlement requires California to develop a reliable plan to identify and provide support services to people with developmental disabilities within the prison system. This plan could use State forensic services to develop appropriate program plans for consumers in the state prisons or who are diverted to developmental centers as a result of a crime.

Olmstead (Federal)

The U.S. Supreme Court ruled in *Olmstead v. L.C. (119 S.Ct 2176 (1999))* that unjustified isolation is properly regarded as discrimination based on disability. Further, the Court held that states violate the Americans with Disabilities Act (ADA) if they fail to provide community-based services for individuals with disabilities.

We conclude that, under Title II of the ADA, States are required to provide community-based treatment for persons with mental disabilities when the State's treatment professionals determine that such placement is appropriate, the affected persons do not oppose such treatment, and the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities.

Both the *Olmstead* decision and the following Clinton Administration federal policy letter (sent from Donna Shalala, Secretary of Health and Human Services, to U.S. Governors on January 14, 2000) provide guidelines under which a state can successfully defend itself against the charge of such an ADA violation.

Current Litigation

Sanchez v. Johnson (California)

In May 2000, a civil rights class action lawsuit entitled *Sanchez v. Johnson* was filed in federal court under the Americans with Disabilities Act against the California Health and Human Services Agency, and the Departments of Health Services, Developmental Services, and Finance. The suit alleges that these agencies fail to provide services in the most integrated, least isolated settings, discriminate against a class of people with severe disabilities, and fail to assure adequate reimbursement to providers of service.

Community Service System Funding Crisis

After a two-year review of the regional center system, the State Council on Developmental Disabilities concluded that the funding mechanism for regional centers bears little relationship for their mission.⁸ Because of this discontinuity, there is a high level of discontent in the community system at regional centers. The root cause of the discontent and dissatisfaction is the way in which regional centers are funded.

Operations Budget

A statewide survey of the regional centers conducted in November, 2000, indicates that virtually all centers cite their lack of ability to hire and retain an adequate number of service coordinators and other key positions as their chief problem in terms of operational issues.

Service coordinators are a regional center's key contact with consumers and their families. Currently some centers are unable to meet their statutory mandates to recruit and retain service coordinators sufficient to maintain a 62:1 consumer to service coordinator ratio as required by Welfare and Institutions Code §4640.6. Regional centers are unable to attract and retain service coordinators due primarily to the comparatively low salaries the core staffing formula requires the centers to offer. Some families have had two to three service coordinators in a one year period. Centers find themselves in a constant recruiting mode with 4-6 months given as the average time it takes to recruit a professional with bilingual skills. As new service coordinators are inexperienced and untrained, they are not prepared for the job, and as turnover of service coordinators is relatively high, continuity of service coordination becomes problematic. These factors combine to negatively affect consumer and family life quality and satisfaction outcomes.

In addition, centers are not adequately reimbursed to fund sufficient clerical and clinical support positions, case management supervision, or actual office rent. Nor are centers allowed geographic differentials to help them address strained labor markets by offering competitive salaries and cost-of-living adjustment. Without enough trained help to support consumers and families to navigate the system, the constant frustration of re-teaching new center staff and the need to share and re-share the same information makes the community system ineffective and inefficient for both service providers and service users. All centers have a deficit in the amount of funding for rent they receive. This fiscal year the deficit is projected to be \$11 million statewide. Operations funding, which could otherwise be used to fund salaries or positions, is used to defray the cost of the portion of unfunded lease payments.

⁸State Council on Developmental Disabilities, 2000. *2001 State Plan*. Sacramento, California.

Purchase of Service Budget

The regional center system's budget is a closed-ended allocation but an open-ended entitlement. Welfare and Institutions Code §4791 provided the Department of Developmental Services with the authority to take specified actions to ensure regional centers had balanced budgets. This provision of the Welfare and Institutions Code was scheduled to sunset on July 1, 2000. The Legislature extended it for another year with instructions for DDS to meet with stakeholders to gain consensus regarding this issue.

From year to year, centers attempt to manage their allocations in both Purchase of Service (POS) and Operations. Their boards have adopted POS funding policies, which are then edited by the Department as it attempts to ensure compliance with its interpretation of the ARC decision. Thus, these community-developed and -adopted policies are unable to serve their stated purpose, and give the centers virtually no ability to manage their budgets. As a result, the Department has found it necessary to juggle and move money around from center to center to make the statewide system whole.

In the current fiscal year the initial estimate for statewide sufficiency of allocation in POS funds is projected from a surplus of \$2.5 million to a deficit of \$19.8 million. While DDS believes it is too early to tell whether the system will end the year in a deficit, most DDS and regional center stakeholders agree that adequate funding for POS will become increasingly problematic in coming years. The Department's allocation methodology must be restructured to more adequately reflect the actual costs of the new services and processes such as self determination.

Regional Centers

As the economy has made its tremendous gains in the last three years, the costs of labor and space have both risen in response. Although the State's budget surplus has shown a corresponding rise, the State has not supplied regional centers with the means to meet labor and space costs. Regional centers' basic responsibilities such as service coordination, responsiveness to consumers and their families, and quality assurance are also compromised by the economy-driven turnover rates. Turnover and inaccessibility of service coordinators and community services specialists compromise centers' ability to maintain consumers in the community by compromising quality assurance activities.

Regional centers are unable to develop crisis, medical, dental, psychiatric, day program, and residential options, because providers cannot afford to operate with such high labor and space costs. Further, the services that are available are becoming too expensive to use, as the antiquated rate structure falls further behind realistic costs of providing services.

Community Service Providers

As noted above, the good economy has also hurt providers' ability to make ends meet. Low provider rates have eroded community service infrastructure as service providers are unable to hire and retain qualified professional service staff, and have no means to buy space in which to house staff to provide services. Like regional centers, the high turnover and low experience level of service provider staff is undermining effective services and quality assurance.

The combination of 1992-level rates and high space and labor costs is forcing many providers out of business, especially in higher-cost areas. Further, fewer providers are willing to open homes and programs, so that the supply of services is severely constrained.

Changing Expectations

Increased Federal Presence

Federal funds constitute a large percentage of the DDS budget. Federal monitoring agencies, primarily the Health Care Financing Authority (HCFA), have assumed a correspondingly increasing role in determining and monitoring the California developmental disabilities services system.

California's system is both large and complex, and must develop creative means to meet federal standards, ensure service quality, and support the locally determined character of our system while maintaining federal reimbursement levels.

Self-Determination

The national system has shifted significant control of resources toward the person with a developmental disability and his/her family. An extension of the person-centered planning idea, this change in philosophy and doing business will have significant ramifications for the coordination and provision of supports and services in California. For example, Supported Living forms the base for such services for adults, and will grow dramatically in the next few years.

In addition, the mass customization in supports and services requires that DDS, regional centers, and service providers design and provide services based on individual needs and preferences. This entails an entirely different way of thinking about the service system, and provides strong impetus to develop means to work together with other agencies for seamless wrap-around services for people and families.

Accountability for Performance and Outcomes

Another nationwide trend is the focus on accountability and the demand for outcomes. Such groups as *Reinventing Government* and *Innovations in American Government* honor exemplars of

ingenious, cost-effective problem solving in the public sector. The goals of these groups center on identifying broad patterns of innovation and capturing lessons with potential value in a wide range of circumstances.

Clear measures of results help citizens hold government and non-profit agencies accountable, and can also help agencies gain public support for extraordinary efforts. Faced with shrinking budgets and more intense demand, human services agencies have been encouraged to find creative ways to pool agencies and funds - often overcoming cumbersome regulations and entrenched bureaucracies - to help solve problems that are more complex than any single agency could handle alone.⁹ Locally, this focus finds support from service agencies tired of "policy making by anecdote", from people and families who need information to choose services, and from people who want to realize the vision of the Lanterman Act.

Current System Facts and Statistics

Residents

According to the Department's figures, as of October 1999, there were no meaningful differences between the challenges faced by people living in the developmental centers and those living in the community. For example:

- ◆ 2,504 individuals in the developmental centers with "major medical problems", 11,006 with the same conditions in the community.
- ◆ 2,403 individuals in the developmental centers with "profound mental retardation, 8,931 with the same diagnosis were served in the community.
- ◆ 530 in the developmental centers with one special condition, but 7,763 in the community.
- ◆ 364 with two special conditions in the developmental centers, but 3,329 in the community.
- ◆ 492 with three or more special conditions in the developmental centers, but 2,031 in the community.

Parallel Systems, Same Purpose

The State of California has established two systems aimed at discharging its responsibility, as defined in the Lanterman Act, to persons with developmental disabilities. Both systems share a common purpose: to increase opportunities and the potential of persons with developmental disabilities to live and participate in their community. One can view the purpose of developmental centers through their mission, which states, "The developmental centers' primary mission is to provide habilitation and training services that are designed to increase residents' levels of independence and functioning skills, ability to control their environment, and ability to live in community settings." (From the DDS web page - www.cahwnet.dds.ca.gov)

⁹ Altshuler, Alan. 1999. Ten Lessons from Innovations. Innovations in American Government Program, <http://www.innovations.harvard.edu/>.

The State also established a community system of supports and services for persons with developmental disabilities based on and coordinated by regional centers. The State defines the mission of regional centers as follows: "In order for the State to carry out many of its responsibilities, as established in this division, the State shall contract with appropriate agencies to provide fixed points of contact in the community for persons with developmental disabilities and their families, to the end that these persons may have access to the services and supports best suited to them throughout their lifetime. It is the intent of the Legislature in enacting this division that the network of regional centers for persons with developmental disabilities and their families be accessible to every [person and] family in need of regional center services." (Welfare and Institutions Code, §4500)

Funding

The populations are similar; the spending wildly divergent. The average expenditure for a person living in a developmental center is now over \$183,000. The average expenditure for a person living in the community is less than one-sixth of this amount. In total budget numbers, the 2.4% of California's population with developmental disabilities that live in the developmental centers account for nearly 30% of the total State developmental disabilities service budget (not including use of generic resources).

Service Provision

This inequitable system treats similarly-situated consumers in entirely different ways in terms of economic support, depending upon whether they live on one tier (the developmental centers) or the other tier (the community) of the system. Further, within the community service system, those who live at home are treated differently than those who reside in an out-of-home community placement.

Wages, benefits, and capital investment explain most of the discrepancy. Given the eroding ability of community care providers to attract and retain qualified staff, this two-tiered system results in distorted patterns of service, as well as reinstitutionalization for people who could be adequately served in the community. The inavailability of any on-call, specialized medical and psychiatric care seriously compounds this problem, as does the serious underfunding of California's Mental Health system.

In the past 35 years, the regional center system has demonstrated its cost-effectiveness in meeting the increasing challenges of consumers who reside in the community. The community model works for the consumers in the community, and will work for most of the consumers now cared for in developmental centers. This is demonstrated by the number of consumers who move successfully from them into small community settings and DDS's own statistics on movers versus stayers.¹⁰

¹⁰Center for Outcome Analysis Studies, 1994-2000. Berkeley Planning Associates study, 1997.

CURRENT INITIATIVES

DDS Restructuring

The Health Care Financing Administration (HCFA), the Bureau of State Audits, Citygate Associates, and other observers of our system have identified numerous deficiencies in both the regional center and developmental center systems. These deficiencies were created by years of under-funding each system, which current State funding patches have not adequately rectified. The cost of correcting outdated physical plants, seismic instability, and Americans with Disabilities Act (ADA) compliance issues make developmental center deficiencies a burning issue, and have motivated the legislature to require the Department to submit a restructuring plan for the developmental centers this year.

Developmental Center Options

In March 2001, as mandated by the California FY2001 Budget Act Trailer Bill, DDS will present a Developmental Center Options Study to the Legislature.

The Advisory Committee developed five principles to guide the study, which is currently in the interviewing and focus group stage:

- ◆ No capital outlays to rebuild developmental centers.
- ◆ Homes limited to four persons or less.
- ◆ Capture and extend developmental center resources into the community.
- ◆ Leverage the developmental center land to create new resources.
- ◆ Highly individualized assessments and resource development precede any person's move into the community.

In the meantime, in seeming contradiction to the principles above, DDS has leased two facilities, mini-institutions, to house people with developmental disabilities. Sierra Vista, in the North, and Canyon Springs, in the South, are both 50+ bed facilities designed to handle the growing population of people with behavioral and forensic needs in State institutions. Both facilities are facing major labor shortages, as well as other issues, which have delayed DDS's ability to fully open and license the facilities.

DDS Strategic Plan

DDS's draft strategic plan is based on five goals that speak to developing a system that is both more accountable as well as more efficient at meeting peoples' needs. In particular, strategies to address Goal 3 ("Expand the availability and types of services to meet current and future needs of individuals and their families") must include evaluating and implementing a range of alternative

community based models to serve individuals currently residing in developmental centers. The desired result of this admirable goal is to ensure a comprehensive array of services to meet the needs of individuals and their families. Integrating developmental center services into the community services into the community service delivery system would be a most effective means of reaching this result.

System Change Initiatives

Initiatives are now being developed and implemented on State-wide, regional, and local levels to address system deficiencies. Many regional centers are developing local initiatives which seek to develop community capacity to serve people currently residing in State developmental centers by eliminating the barriers that prevent regional center consumers from receiving needed services to support community life. These projects must be coordinated, replicated, and expanded to give the same opportunities to all Californians with developmental disabilities.

The Department of Developmental Services is reevaluating all the children who reside in developmental centers and all the residents of skilled nursing facilities.

Recent local projects address issues in this document, and should be reviewed for applicability to this Strategic Plan. Centers across the state are focusing on the development of small (2-3 bed) demonstration residential programs for persons with challenging behaviors. "Crisis" beds for short term treatment are often part of the effort. A few centers are focusing their energy on the development of residential programs for persons who are medically fragile. In addition, other regional center and multi-agency initiatives such as TeleHealth, TeleMedicine, and the Community Initiative have implications in both planning and implementation of a unified system.

Strategic Plan for a Unified System

Strategic Plan for a Unified System

Current Design

Shortly after becoming a State, California took responsibility for people with mental retardation and similar disabilities by building the first institutions (now called developmental centers) west of the Mississippi for their use and benefit. When the philosophy of care changed 100 years later, the State government encouraged families to keep disabled children at home or living nearby, and promised to continue the same levels of support historically provided in the developmental centers (DCs). This great promise was embodied in the Lanterman Act: a vision of a community system gradually taking over for an impractical and eroding State system.

The State system of care, established in the developmental centers, continued and its workers became government union members. Thus, California evolved a two-tiered service system, the developmental centers and the community care system, with vast funding differences between the union-staffed developmental centers and the community-staffed private, non-profit system. These funding inequities are defended on the basis of level of care differences between people served by each tier, and that the developmental centers serve a different, more profoundly needy population. As we have shown above, this defense does not hold.

Services

Because of depressed funding, the community system finds itself unable to maintain the level of secured services provided by the State solely in developmental centers. Unification of the two systems will better serve a growing population, and assure consumers and families a guaranteed level of care.

An array of supports and services should be established that is sufficiently complete to meet the needs and choices of each person with developmental disabilities, regardless of age or degree of disability, at each stage of their life, and to support their integration into community mainstream life. To the maximum extent feasible, supports and services should be available throughout the State to prevent dislocation of persons with developmental disabilities from their home communities.

Current Opportunity

We have before us an opportunity to make meaningful systemic changes in California's systems that serve people with developmental disabilities. Funded in the Lanterman Act are the principles supporting full inclusion for people with developmental disabilities into the mainstream of life in their communities. Over the past several years, progress has been made to ensure those people are guaranteed the same rights and privileges as people without developmental disabilities.

To fully realize this goal, and create a system that fulfills the Lanterman Act vision and mandate, we must work collaboratively to implement this plan.

The State of California is now at a critical decision point in terms of meeting its responsibility and obligation to people with developmental disabilities and their families. Effective implementation of the Olmstead decision in California is only possible through the community-based, person-centered, and well-managed community services system that already exists. Moreover, to be effective, this system must be allocated resources currently held hostage in the State system.

The ultimate goal should and must be that each consumer's civil rights are protected, and that each consumer benefits equally from the State's commitment to provide services and supports in ones own community, as defined in the Lanterman Act.

A Unified Service System

The disparate pieces of the California developmental disabilities service system must work together to create a unified, interlocking network of consumer and family information, support, and service solutions that address the above issues to fulfill the purposes of the Lanterman Act (Welfare and Institutions Code §4500 et seq.) and the Arc vs. DDS decision. (*38 Cal. 3d 384, 388, 211 Cal. Reporter 758, 759*)

Urgency must attend the opportunity that currently exists to unify the service delivery system in California, and to fully fund it. Unification would correct long-standing inequities that have been created and perpetuated by a two-tiered system that is separate and unequal - the community system administered by the regional centers and its network of community service providers, and the State administered developmental centers (DCs).

ARCA and its member regional centers are proud to present the following **Strategic Plan for a Unified System** to the California and federal developmental disabilities services systems. We look forward to working together to develop a responsive system, centered on Californians with developmental disabilities and their families.

GOALS, OUTCOMES, AND STANDARDS

The values and principles that direct the community system must also direct State services purchased as components of a unified system, and should guide this Plan, both in development and in implementation.

Goal 1: Develop comprehensive, effective, local plans to support people to live full and included lives in the community

Desired Outcomes:

- ◆ Local plans are developed through community-based process.
- ◆ Local plans contain all components required by *Olmstead*.
- ◆ Local plans contain guidelines for local service system functioning.

Standards:

Foundational to this goal is the planning process itself and who should be involved, as well as the types of plans developed in the process.

Process Standards:

1. Planning and implementation must be community-based and actively involve consumers, their families, regional centers, and community service provider networks if restructuring is to be successful.
2. Planning may include regional planning by one or more regional centers and their respective geographic areas.

Plan Standards:

1. All plans will be based upon individual, person centered planning, and will use State-adopted outcome measures as a major measurement of the plan's effectiveness.
2. Plans must address service issues so consumers and their families can know and feel secure that there is a service safety net so that they cannot be ultimately rejected, un-served, and/or under-served.
3. Plans will place the primary focus on developing and maintaining adequate capacity to serve all Californians with developmental disabilities in the community. Two parallel strategies - deflecting people from placement in the state institutions, and placing individuals out of State developmental centers into the community - will be used.
4. Plans will provide that regional centers have the discretion to vendor community-based programs that meet established standards whether they be private non-profit,

- private for-profit, or State-owned and operated, and will develop mechanisms that allow regional centers to vendor all these services.
5. Plans will adhere to the principles adopted by the State-wide advisory committee or by ARCA (*ARCA Position Statement on DDS Developmental Center Options Study*):
 - ◆ No capital outlays to rebuild developmental centers; leverage developmental center land to created new resources.
 - ◆ Homes are limited to four beds or less.
 - ◆ At their discretion, each consumer has a choice of his or her private bedroom.
 - ◆ Only those consumers for whom an appropriate private sector, community-based setting can not be found, as determined by the planning team, should be served in State-operated homes.
 6. Plans will develop and implement highly specialized clinical teams (i.e., psychiatrist, developmental physician, and behavioral specialist) who provide on-site diagnostic services.
 7. As a component of all plans, a quality assurance system based upon monitoring, coordinated outcome measurement, data collection, targeted timelines, and information feedback loops.
 8. Plans will include standards for initial and on-going vendorization of community-based programs that are based upon documented achievement of specified outcome measures.

Plans satisfying the *Olmstead* requirements should include needs assessments of both the individual and current service array; an assessment-based plan for community capacity development; transition services; and a quality assurance system based on monitoring, coordinated outcome measurement, data collection, targeted timelines, and information feedback loops. (For a complete description of necessary elements of any plan that proposes to satisfy *Olmstead* requirements, please see the *Template of Key Elements*, provided by the National Association of Protection and Advocacy Systems on their web page <http://www.mcare.net/tempkey.html>.)

Goal 2: Remove anticipated barriers to plan implementation and to increasing community capacity.

Desired Outcomes:

- ◆ Rates are adequate to stabilize system.
- ◆ Regional center funding is adequate to develop appropriate, integrated services (including clinical).
- ◆ Flexibility to provide appropriate, need- and choice-based services.

- ◆ Mechanisms exist to provide appropriate housing for consumers.
- ◆ Mechanisms exist so regional centers can buy services from the State as the provider of last resort.

Standards:

Regional centers of excellence: while this is precisely the role envisioned for the regional centers from the beginning of the system, adequate funds have never been provided to make the vision real. Regional centers have the knowledge and expertise to do highly individualized assessments, planning, and resource development, with State assistance for people who are threats to their communities. Most, if not all, individuals presently residing in developmental centers as well as many individuals currently at risk of placement could be living successfully in the community if these issues were addressed.

We must work as a system to remove the barriers that prevent centers from fulfilling this mandate, including

- ◆ the great difference in compensation paid to developmental center staff compared to community-based staff, and
- ◆ the outmoded and badly under-funded rate structures for the vast number of community service providers.

Recommendations:

1. Establish local markets for labor, space, and housing.
2. Tie standards to minimum person-centered and process-oriented measures, adjusting rates accordingly, for all programs.
3. Establish a mechanism to fund the actual cost of providing a developmental center program that follows the individual into his or her community placement.
4. Establish mechanisms so regional centers can purchase State services from developmental centers and from community-based State owned, operated and leased programs.
5. Establish rate parity.
6. Develop and implement common community-based funding packages for all service providers.

The best way to insure that an integrated system is finally brought to fruition is through a unitary budget. Regional centers would receive funding for purchasing State-operated services to meet the needs of a particular individual and the center would contract with the State for such services.

Goal 3: Build a unified, coordinated community service system focused on outcomes.

Desired Outcomes:

- ◆ State-provided services are included as elective service provider options through the community service system.
- ◆ State resources may be deployed through regional centers as a part of a unified service system to serve people in the community where no private provider is available or when the person poses a threat to their community.
- ◆ Consistent, coordinated information and education systems encourage continuing improvement in regional center provided and purchased supports and services.

Standards:

From the beginning, the service system was established to be community-based with regional centers and their networks of community service providers at the hub, rather than the State.

Unified System Operational Standards:

1. Services are available to any individual with demonstrated need regardless of whether they are presently residing or used to reside in a developmental center, have been deflected from placement in a developmental center, or will require a high level of restriction in the future.
2. The state budget appropriation methodology ensures regional center Purchase of Service allocations are adequate to fund the services required for consumers and their families as established by federal and State law.
3. Regional center Operations Budgets are funded according to the requirements set forth in the Lanterman Act, federal and State regulatory and statutory mandates, include cost of living factors, and require best business practices.
4. Statewide recruitment and retention programs for professionals who work for regional centers (including mental health and developmental medicine, behavioral specialists, pharmacists and service coordinators) prepare them to work effectively with consumers who have developmental disabilities.
5. Competency based training programs provide selected regional center staff and other professionals who serve regional center consumers in specific areas including adaptive technology, forensic case management, negotiation skills, measurement of quality assurance for outcome based standards and federal program requirements.