OVERSIGHT HEARING

FINAL REPORT ON THE CLOSURE OF AGNEWS DEVELOPMENTAL CENTER: KEEPING THE PROMISE OF THE LANTERMAN ACT

Assembly Committee on Human Services
Jim Beall, Jr., Chair
and
Assembly Select Committee on Disabilities
Wesley Chesbro, Chair

State Capitol, Room 437
April 27, 2010
2:30 – 5:00 p.m.

BACKGROUND BRIEFING PAPER

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Background Briefing Paper

Introduction

What was to become Agnews Developmental Center was established by an act of the California Legislature in 1885 as a facility for the care of people with mental disabilities. The first patients were received in 1888. Individuals with developmental disabilities were first admitted to a special habilitation program that was activated in 1965. In 1972 the programs for mental health patients were discontinued and the center served only people with developmental disabilities. The last resident left Agnews in late March 2009.

The introduction to the January 2005 Plan for the Closure of Agnews Developmental Center explained that:

> This plan differs significantly from the plans implemented for the two most recent closures of developmental centers in California—Stockton Developmental Center (Stockton) in 1996, and Camarillo State Hospital and Developmental Center (Camarillo) in 1997. Those closures resulted in the transfer of large numbers of individuals to other State-operated facilities. In contrast, this plan is not just about closing a developmental center; it is also about the development of an enhanced community service delivery system in the Bay Area that can meet the needs of the majority of Agnews' residents. The basic principle underlying this plan is to provide opportunities for the residents of Agnews to remain in their home communities. To achieve this objective, the

[1] "Keeping the Promise of the Lanterman Act" was the title of a 1984 report prepared by the Assembly Office of Research. *Keeping the Promise of the Lanterman Act: Report 1: Quality Services for People with Developmental Disabilities*, Assembly Office of Research (April 1984).

plan provides for the development of new resources and innovative programs throughout the Bay Area. This will be accomplished by the development of a substantial and sustainable increase in appropriate housing, establishment of new program models, and use of State resources (including some Agnews' staff) in the community during a transition period.

The issuance of the Final Report on the Agnews closure plan is an opportunity to evaluate the implementation of the plan—to assess the extent to which it was successful in achieving its stated objectives, and to identify lessons learned, both of which can inform future such endeavors so they will be even more successful.

This Briefing Paper provides a context and background for considering the Final Report on the closure of Agnews.[2]

State developmental centers

Four remaining State Developmental Centers (DCs)[3] are licensed and federally certified as Nursing Facility (NF), Intermediate Care Facility/Developmentally Disabled (ICF/DD) and acute care hospitals. One smaller state-operated facility[4] is licensed as an ICF/DD. These facilities provide an array of services and supports for individuals who have been determined to be in need of a secure environment, or who have special medical and/or behavioral program needs.

As facilities that provide 24-hour services, DCs deal with all aspects of the individuals' lives. This includes everything from residential services through skill training, specialized health-care and other therapies to leisure and recreational opportunities.

The DCs' 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. These services are supplemented, as needed, with medical, dental, nursing and a wide variety of other specialized services such as physical therapy, occupational therapy, speech therapy and language development.

Residents receive training on the skills and competency necessary to live successfully in the community. Individuals with medical conditions receive special supervision and medical and nursing care in NF units. A full-range of behavior intervention and behavior-skills training services are available for persons who need them.

If able to participate, residents under age 22 attend school either in community schools or in developmental center classes. Adult individuals participate in a wide variety of

[2] The Agnews Closure Plan and reports on the closure process, including the Final Report, are available at: http://www.dds.ca.gov/AgnewsClosure/Home.cfm.
[3] Fairview DC (Costa Mesa), Lanterman DC (Pomona), Porterville DC (Porterville), Sonoma DC (Eldridge).
[4] Canyon Springs (Cathedral City). A second smaller (up to 50 residents) state-operated ICF/DD facility, Sierra Vista (Yuba City), was closed in December 2009.

vocational and skill-development programs both on the grounds or in the community if appropriate. All individuals are given the opportunity to participate in a variety of recreational activities and leisure pursuits.

Declining developmental center population

When the first two of the state's 21 regional centers were established as a pilot in 1966 the population of the state's eight DCs (then called state hospitals) stood at more than 13,000. In 1969, the regional center system was expanded to cover the entire state by AB 225 (Lanterman), Chapter 1594, Statutes of 1969, the Lanterman Mental Retardation Services Act. In 1973, the mandate was further expanded to include additional developmental disabilities by AB 846 (Lanterman), Chapter 546, Statutes of 1973, the Lanterman Developmental Disabilities Services Act ("Lanterman Act"; Welfare & Institutions Code Section 4500 *et seq.*).

Since enactment of the Lanterman Act and its precursor, the Lanterman Mental Retardation Services Act, the population of the state's developmental centers has significantly declined. By 1975-76, the developmental center population was reduced to approximately 11,000. In 1979, a decade after enactment of the Lanterman Mental Retardation Services Act, the DC population was down to 9,000, and 10 years later, in 1989, the population stood at 6,700. The DC population for the last 15 years is shown in Table 1. Table 2 shows the DC population as of March 31, 2010.

The trend toward deinstitutionalization

The decline in California's DC population reflects a national trend in the provision of services to people with developmental disabilities—from institutional to home and community-based services and supports. Following are some of the primary factors responsible for this trend:

Court cases on the nature of institutionalization

Notwithstanding the range and quality of services offered in DCs, within the array of living options, large institutions are recognized to be the most restrictive and least integrated alternative. As the U.S. Supreme Court noted in its landmark opinion in *Olmstead v. L.C.* (1999) 527 U.S. 581, 601, "confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment." And, the Supreme Court said, "institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life." *Id.* at 600.

Table 1. Developmental Center Population[5]

Total Population on the Last Wednesday of December	
Date	**Population**
Wednesday, December 30, 2009	2,153
Wednesday, December 31, 2008	2,404
Wednesday, December 26, 2007	2,668
Wednesday, December 27, 2006	2,878
Wednesday, December 28, 2005	3,044
Wednesday, December 29, 2004	3,237
Wednesday, December 31, 2003	3,473
Wednesday, December 25, 2002	3,605
Thursday, December 27, 2001	3,738
Wednesday, December 27, 2000	3,795
Wednesday, December 29, 1999	3,876
Wednesday, December 30, 1998	3,932
Wednesday, December 31, 1997	4,046
Wednesday, December 25, 1996	4,327
Wednesday, December 27, 1995	4,870
Wednesday, December 28, 1994	5,517

Table 2. Current Developmental Center Population[5]

Population on March 31, 2010	
Agnews Developmental Center	0
Fairview Developmental Center	456
Lanterman Developmental Center	389
Porterville Developmental Center	578
Sonoma Developmental Center	632
Canyon Springs	54
Sierra Vista	0
Total:	2,109

[5] Source: DDS Website: http://www.dds.cahwnet.gov/DevCtrs/AllFacPop.cfm.

Constitutionally, courts have long held that involuntary state institutionalization involves a "massive curtailment of personal liberty." *E.g., Conservatorship of Roulet* (1979) 23 Cal.3d 219, 224. Therefore, in the absence of a knowing and voluntary request, admission to a state DC requires a court determination that the individual meets stringent admission criteria following a hearing meeting the highest due process standards. *In re Hop* (1981) 29 Cal.3d 82.

National trend

The population of large state institutions has been declining nationally for decades as the prevailing values and views of best practices for providing care and services to people with developmental disabilities have evolved from a medical/institutional model to a person-centered/community-based model. For example: In 1977, an estimated 83.7% of people with developmental disabilities receiving residential services lived in residences of 16 or more people. By 2007, an estimated 85.7% lived in community settings of 15 or fewer people, and 72.3% lived in residential settings with six or fewer people. *Residential Services for Persons with Developmental Disabilities and Trends Through 2007*, Research and Training Center on Community Living Institute on Community Integration/UCEDD, Univ. of Minn. (August 2008), p. vi. The population of large state facilities for people with developmental disabilities declined from 99.7 per 100,000 of the general population in 1967 to 12.2 per 100,000 in 2007. *Id.* at iii. Between 1990 and 2007, the average daily number of people with developmental disabilities living in large state institutions decreased by 55.9%. *Id.* As of June 30, 2007, eight states plus the District of Columbia were no longer operating any large (16 or more residents) state facilities for people with developmental disabilities. *Id.*

The Lanterman Act

Foremost among the factors leading to deinstitutionalization of people with developmental disabilities in California are the policies and values embodied in the Lanterman Act itself. The Lanterman Act was largely the result of the pioneering efforts of parents looking for community alternatives to institutionalization or remaining at home for their children, particularly as they became adults. Their cause was championed in the Legislature by, among others, Jerome Waldie, Leroy Greene, Alfred Alquist, Clair Burgener, Nicholas Petris, Charles Warren and, of course, Frank Lanterman—co-authors of AB 691, the 1965 bill that established the first regional centers.

In the Lanterman Act, the Legislature delineated the rights of people with developmental disabilities, the first of which is a "right to treatment and habilitation services and supports in the least restrictive environment. Treatment and habilitation services and supports should foster the developmental potential of the person and be directed toward the achievement of the most independent, productive, and normal lives possible. Such services shall protect the personal liberty of the individual and shall be provided with the least restrictive conditions necessary to achieve the purposes of the treatment, services, or supports." Welfare & Institutions Code § 4502(a).

In its landmark opinion in *Association for Retarded Citizens-California v. Department of Developmental Services* (1985) 38 Cal.3d 384, 388, the California Supreme Court noted that "[t]he purpose of the [Lanterman Act] is twofold: to prevent or minimize the institutionalization of developmentally disabled persons and their dislocation from family and community ... and to enable them to approximate the pattern of everyday living of nondisabled persons of the same age and to lead more independent and productive lives in the community." The Court further noted that "the Act defines a basic right and a corresponding basic obligation: the right which it grants to the developmentally disabled person is to be provided with services that enable him to live a more independent and productive life in the community; the obligation which it imposes on the state is to provide such services." *Id.* at 391. "It is through the IPP [individual program plan] procedure that the right the Act grants to each developmentally disabled person and the obligation it imposes on the state are implemented; through it, the developmentally disabled person on an individual basis receives, *as an entitlement*, services that enable him to live a more independent and productive life in the community." *Id.* at 392 (emphasis added).

The Department of Developmental Services (DDS), the state department responsible for overall administration of the Lanterman Act, has expressed its commitment to the Lanterman Act's preference for community-based living and service options, noting, for example, that: "For years DDS policy has been grounded in the conviction that large and necessarily segregated institutions should never be used where effective community-based service and support alternatives exist. Based on a general social consensus, this policy has guided efforts to reduce the developmental center population through development of additional resources for community-based living arrangements, services, and supports." *Admission and Community Re-entry Processes at State Residential Facilities: A Guide to Statutory Requirements, Judicial Findings (Case Law) and Administrative Procedures in California*, California Department of Developmental Services (2004), p. 2 (available at: http://www.dds.ca.gov/publications/docs/Admission_CommunityReEntry.pdf).

The *Coffelt* settlement

The *Coffelt v. DDS* lawsuit was filed in 1990 on behalf of a class of 2,000 DC residents whose individual program plan (IPP) teams had recommended them for community placement but who nonetheless remained institutionalized. As a result of the court-approved settlement, DDS agreed to reduce the statewide DC population by 2,000 over a five-year period (April 1993 to July 1998). In fact, the population was decreased by approximately 2,452 over the settlement period.

As significant as the population reduction itself, the *Coffelt* settlement also resulted in the development and expansion of community residential service models, adoption and implementation of quality assurance standards, development of crisis intervention services and supports, and increased federal financial participation for case management and to enhance community-based services. It also led to statutory changes to the IPP and assessment process to make it more person-centered. In addition, the settlement enabled

the closure of two DCs—Stockton DC (in 1996) and Camarillo State Hospital and DC (in 1997). The final report of a multi-year longitudinal study tracking quality of life outcomes for those moving to the community under the *Coffelt* settlement concluded that "the Movers are, indeed, better off ... than they were in [DCs]." *Final Outcomes of the 3 Year California Quality Tracking Project,* Center for Outcome Analysis (June 2002), p.2. Family members were, "on the whole extremely satisfied with the community situations of their relatives. ... The overwhelming majority of families would not want their relatives to return to a [DC]." *Id.*

HCBS Waiver

Under the Home and Community-Based Services Waiver for People with Developmental Disabilities (HCBS Waiver), the state is able to obtain federal funds for certain eligible consumers who are receiving regional center-purchased services. The HCBS Waiver enables the state to utilize federal Medicaid funds for long-term services in the community, rather than institutions, for consumers who are eligible for Medi-Cal and meet the ICF/DD level of care. Thus, most DC residents who move to the community continue to have their services funded with matching federal Medicaid dollars. California's initial HCBS Waiver was approved in 1982, with a cap of 3,360 individuals. The cap has progressively increased and will be 95,000 in fiscal year 2010-11.

Community Placement Plan

The Community Placement Plan (CPP) provides dedicated funding for comprehensive assessments of selected DC residents, for identified costs of moving from DCs to the community, and for deflection of selected individuals from DC admission. Welf. & Inst. Code § 4418.25. Regional centers submit annual lists of those persons it intends to move out of a DC in a given year, including the resources, services, and supports each person will need. It also identifies the persons who will be evaluated each year to move out of a DC the following year. The CPP is one of the strategies DDS has used to develop permanent affordable and accessible homes. The CPP played an important role in developing housing options and community resources for people who moved from Agnews DC.

The extent to which the CPP is adequately administered by DDS and utilized by all regional centers to enable individuals to move to the community at a reasonable pace has been a matter of some controversy. It was an issue in the recently settled class action lawsuit, *Capitol People First, v. DDS*, alleging that DDS and regional centers were not sufficiently meeting their obligations under state and federal law to provide or develop resources that would enable institutionalized consumers to live in less restrictive, community-based living arrangements. (See footnote 6, p.9.)

Regional Resource Development Projects (RRDPs)

The RRDPs were initially piloted in 1987 and authorized by the Lanterman Act in September 2002. At the time, each of the seven developmental centers had an RRDP assigned to assist in activities related to admissions, transition planning, deflection and

resource development. In the late 1990's, Stockton and Camarillo DCs were closed, leaving the Delta and Westlake RRDPs to continue to serve consumers in those geographic areas. In 2008 the Delta and Westlake Regional Projects were closed, and the remaining RRDP's that are attached to an existing developmental center, continue to serve consumers throughout California. With the closure of Agnews, the Regional Project of the Bay Area relocated to Sonoma DC.

The RRDPs are designed to:

- Assist consumers and their interdisciplinary planning teams with planning and transition from DCs to community living alternatives and provide post placement follow up.

- Assess consumers experiencing difficulty in their community environment and identify possible supports to preserve their community living arrangements.

- Assist in the transition to, or preservation of, community living arrangements by providing focused training on specific needs to consumers, families, service providers and regional center staff.

- Communicate with the regional centers regarding the development of the annual CPP.

The ADA and *Olmstead*

Enacted by Congress and signed by President George H.W. Bush in 1990, the federal Americans with Disabilities Act (ADA) prohibits discrimination on the basis of disability in employment (Title I), public services provided by governmental entities (Title II), and public accommodations provided by private entities (Title III). Among Congress' findings in enacting the ADA are the following:

- Historically, society has tended to isolate and segregate individuals with disabilities, and, despite some improvements, such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem;

- Discrimination against individuals with disabilities persists in such critical areas as ... institutionalization; and,

- Individuals with disabilities continually encounter various forms of discrimination, including outright intentional exclusion, ... failure to make modifications to existing facilities and practices, ... [and] segregation....

42 U.S.C. §§ 12101(a)(2), (3), (5).

In the *Olmstead* case, the United States Supreme Court considered the question of whether the ADA prohibition of discrimination may require placement of persons with

disabilities in community settings rather than in institutions. The answer, the Court held, is yes: Under the ADA's "integration mandate," unnecessary institutionalization is a form of discrimination based on disability in violation of Title II of the ADA. States are required to provide community-based treatment for persons with 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." 527 U.S. at 607. A state could demonstrate its compliance with the ADA integration mandate, the Court said, if it has "a comprehensive, effectively working plan for placing qualified persons with mental disabilities in less restrictive settings, and a waiting list that moved at a reasonable pace not controlled by the State's endeavors to keep its institutions fully populated." *Id.* at 605-6.

Increasing DC costs

Due to the level of fixed costs at the DCs and the need to maintain minimum staffing levels, the cost per resident continues to increase as the total resident population decreases. Lanterman DC, for example, which the Administration is proposing for closure, has an annual budget of approximately $116 million for about 396 residents—approximately $293,000 per resident.

As recently as five years ago, DDS data showed the average annual cost per person residing at a DC was about $228,000. The Governor's 2010-11 Budget includes total funding for the DCs of $640,889,000 for a projected average DC population of 2,008 residents—roughly $319,000 per resident. This contrasts with proposed total funding of $4.2 billion to provide services and supports for 249,975 persons with developmental disabilities in the community. Thus, approximately 13% of the total DDS budget would fund services and supports for the approximately 0.8% of the total consumer population who live in DCs.

The Agnews DC closure plan

The integration mandate of the ADA, together with the Lanterman Act entitlement to the services and supports needed by each person with a developmental disability to enable them to live in the least restrictive, most integrated setting consistent with their individual needs and preferences, compel DDS and regional centers to make concerted efforts to end unnecessary institutionalization in state developmental centers. Following the *Coffelt* settlement period, the pace of moving individuals from DCs to the community slowed significantly. This led to the filing, in January 2002, of another class action lawsuit, *Capitol People First v. DDS*, alleging that the state was not sufficiently meeting its obligation to institutionalized consumers under the Lanterman Act and federal law to ensure that they received services in the least restrictive, most integrated settings.[6] Not

[6] Court approval of the settlement of the case was granted on April 24, 2009. Information on the settlement is available at: http://www.dds.ca.gov/CapitolPeopleFirst/index.cfm.

long after the filing of that lawsuit, Governor Gray Davis' Budget for FY 2003-2004 proposed the closure of Agnews DC.

The planning process for the closure of Agnews began in Fiscal Year 2003-2004. DDS solicited broad participation from internal and external stakeholders including consumers, family members, area boards, advocates, and community providers to develop a plan that would result in an orderly transition of consumers into alternative services and supports. In October of 2003, the teams completed their recommendations and reports that served as the basis for the plan. After several public meetings in Fiscal Year 2003-2004, the Agnews Closure Plan was submitted to the Legislature in January 2005 and approved with the enactment of the Budget Act of 2005. The Governor's initial budget proposal called for the closure by July 2005; the Plan itself called for the closure by June 30, 2007. The last resident left Agnews in March 2009.

While the Plan was developed through the budget process, there were a number of bills vetted through policy committees that were critical to the closure process:

- AB 2100 (Steinberg) (Chapter 831, Statutes 2004), and SB 643 (Chapter 551, Statutes of 2005), supported the development of permanent housing through the Bay Area Housing Plan, and added family teaching homes as a new service delivery option.

- SB 962 (Chesbro) (Chapter 558, Statutes of 2005) established a pilot project for the creation of homes licensed by the Community Care Licensing division of the Department of Social Services to serve adults with special health care needs in the Bay Area.

- AB 1378 (Lieber) (Chapter 538, Statutes of 2005) authorized Agnews' employees to work in the community to support the transition of Agnews' residents into community living options.

Conclusion

With the recent submission to the Legislature of the proposed plan for the closure of Lanterman Developmental Center, it is a particularly appropriate time to examine the Agnews closure.

The 1984 report, *Keeping the Promise of the Lanterman Act* (see footnote 1, above), concluded that "[DCs] do not ... function to meet the needs of a unique population by providing a unique service model; rather, *[DCs] function to make up for the deficiencies of communities*. Without sufficient resources in California communities to provide stable, quality services for people who have extraordinary developmental needs, the [DCs] must provide backup services. If high-quality, stable, and effective community resources are developed, need for the [DCs] backup services will diminish." (P. 83, emphasis in original.)

It is significant that, through the IPP process, it was determined that almost all former Agnews residents could move to community living arrangements. Between July 1, 2004 and March 27, 2009, a total of 327 Agnews residents transitioned to living arrangements in the community (including five who returned to their family homes); and 20 residents transferred to other DCs. Thirty percent of those who transitioned to the community lived at Agnews for 31-40 years, 56% had significant health and extensive personal care needs, and 39% required significant behavioral support. This has clear implications for the residents of other DCs, all of which (with the possible exception of the secure treatment program at Porterville DC) serve populations similar to Agnews. While those remaining in DCs, generally, have more severe disabilities and more complex needs than most consumers living in the community, there are many individuals currently living safely and successfully in the community, including the former residents of Agnews, with equally severe disabilities and complex needs. This is strong support for the conclusion drawn 26 years ago in *Keeping the Promise of the Lanterman Act*—that the primary obstacle preventing most remaining DC residents from moving to the community is not their disabilities or needs, but the availability of resources to meet those needs and the commitment to ensuring that those resources are developed and provided.