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GOVERNOR

State of California
HEALTH AND HUMAN SERVICES AGENCY

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Statewide Health Planning and Development

January 13, 2014

The Honorable Darrell Steinberg
President Pro Tempore
California State Senate
State Capitol Building, Room 205
Sacramento, CA 95814

The Honorable John A. Pérez
Speaker of the Assembly
California State Assembly
State Capitol Building, Room 219
Sacramento, CA 95814

Dear Senator Steinberg and Assembly Member Pérez:

Pursuant to the commitment I made last spring to address the declining population in the developmental centers, the resulting fiscal pressures, the challenges of maintaining federal certification in aging facilities and the repeated calls to close these facilities immediately, and to fulfill the requirements of Section 14(a) of Assembly Bill (AB) 89 (Chapter 25, Statutes of 2013), I respectfully submit the enclosed Plan for the Future of Developmental Centers in California.

To begin this effort, I invited a broad cross-section of seasoned leaders committed to meeting the needs of people with developmental disabilities to serve on a Task Force to identify challenges, gather facts, share opinions and seek opportunities for improvement. The Task Force included consumers, family members, regional center directors, consumer rights advocates, labor union members, community service providers, and staff from the Department of Developmental Services. At the outset, there was great division and very little expectation that any consensus could be reached but throughout the six months of intense inquiry and effort, there was a unifying commitment that the well-being of each and every developmental center resident was at the center of our work.

By keeping our focus on the residents and through the open, honest and candid sharing of information and opinions, the full Task Force agreed to present this report and its six recommendations on behalf of us all. Some of the parents and some of the unions have qualified their support to be clear that they do not support any implication that the centers should be closed but the commitment to the need for fundamental transformation of the developmental centers system is shared by all.

I have been humbled and inspired by the understanding I have gained through the work of this Task Force. The Administration is committed to the goals set forth in this report and will continue the active stakeholder engagement that contributed so significantly to this work as we move forward with its implementation.

Respectfully,

Diana S. Dooley

Diana S. Dooley
Secretary

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Senator Tom Berryhill, Vice Chair, Senate Human Services Committee
Senator Mark Leno, Chair, Senate Budget & Fiscal Review Committee
Senator Jim Nielsen, Vice Chair, Senate Budget & Fiscal Review Committee
Senator Kevin De Leόn, Chair, Senate Appropriations Committee
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PLAN FOR THE FUTURE OF DEVELOPMENTAL CENTERS IN CALIFORNIA

Report to the Legislature
Submitted pursuant to Assembly Bill 89, Section 14(a)
(Chapter 25, Statutes of 2013)

Submitted by the
California Health and Human Services Agency
On behalf of the Task Force on the Future of Developmental Centers
1600 9th Street, Room 460
Sacramento, California 95814

January 13, 2014

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EXECUTIVE SUMMARY

Since the 1960s, with the passage of the Lanterman Developmental Disabilities Services Act (Lanterman Act), the role of the State-operated Developmental Centers (DC) has been changing. The resident population has dropped from a high in 1968 of 13,400, with thousands on a waiting list for admission, to 1,335 residents as of January 1, 2014. The population at each of the four facilities, originally designed to serve between 2,500 and 3,500 individuals, is now below 500, with Fairview DC at 318 residents and Lanterman DC at 101. Additionally, the trailer bill to the 2012-13 budget imposed a moratorium on admissions to DCs except for individuals involved in the criminal justice system and consumers in an acute crisis needing short-term stabilization.

Each year Community Placement Plan (CPP) funding ($67 million in Fiscal Year {FY} 2013-14) is provided to regional centers to expand and improve services to meet the needs of DC residents transitioning to the community. As new CPP-funded resources become available, on average 175 to 200 consumers move out of a DC into community-based services each year. With the CPP funding provided in FY 2011-12 through 2013-14, over 500 new residential beds will be available for DC movers during the next 18 months.

The moratorium, coupled with CPP placements and prior changes in the service delivery system, has reduced the reliance on State-operated DCs and expedited the decline in resident population in these facilities.

Without intervention, the role of the State in delivering direct services is rapidly diminishing. With the input and assistance of the Task Force, the State now has an opportunity to define and manage the transition from historically large congregate living facilities to more integrated and specialized services using the expertise and resources of the DCs to benefit the consumers.

The DCs will need to transition from large congregate 24-hour nursing and Intermediate Care Facility services to a new model. The recommendations of this Task Force are that the future role of the State is to operate a limited number of smaller, safety-net crisis and residential services coupled with specialized health care resource centers and public/private partnerships, as well as the Porterville DC - Secure Treatment Program (STP) and the Canyon Springs Community Facility.

Following are the six consensus recommendations endorsed by the Task Force with the qualifications and exceptions set forth in the attached letter from the Sonoma DC Parent Hospital Association (PHA), the California Association of Psychiatric Technicians (CAPT), and the California Statewide Law Enforcement Association (CSLEA).

- Recommendation 1: More community style homes/facilities should be developed to serve individuals with enduring and complex medical needs using existing models of care.

- Recommendation 2: For individuals with challenging behaviors and support needs, the State should operate at least two acute crisis facilities (like the program at Fairview DC), and small transitional facilities. The State should develop a new “Senate Bill (SB) 962 like” model that would provide a higher level of behavioral services. Funding should be made available so that regional centers can expand mobile crisis response teams, crisis hotlines, day programs, short-term crisis homes, new-model behavioral homes, and supported living services for those transitioning to their own homes.

- Recommendation 3: For individuals who have been involved in the criminal justice system, the State should continue to operate the Porterville DC-STP and the transitional program at Canyon Springs Community Facility. Alternatives to the Porterville DC-STP should also be explored.

- Recommendation 4: The development of a workable health resource center model should be explored, to address the complex health needs of DC residents who transition to community homes.

- Recommendation 5: The State should enter into public/private partnerships to provide integrated community services on existing State lands, where appropriate. Also, consideration should be given to repurposing existing buildings on DC property for developing service models identified in Recommendations 1 through 4.

- Recommendation 6: Another task force should be convened to address how to make the community system stronger.

The Administration is committed to these goals and will continue the active stakeholder engagement that contributed so significantly to this work through an approach modeled on the Agnews DC closure. The design and implementation of a fundamental transformation of the remaining DCs is essential and must proceed as quickly as possible.

I.
INTRODUCTION

The California Health and Human Services Agency (CHHS) submits this plan on behalf of the Task Force on the Future of the Developmental Centers (Task Force) and to fulfill the requirements of Section 14(a) of Assembly Bill (AB) 89 (Chapter 25, Statutes of 2013) which states:

> *SEC.14. (a) The California Health and Human Services Agency shall, on or before November 15, 2013, submit to the appropriate policy and fiscal committees of the Legislature a master plan for the future of developmental centers. In the preparation of this plan, the agency shall consult with a cross-section of consumers, family members, regional centers, consumer advocates, community service providers, organized labor, the State Department of Developmental Services, and representatives of the Legislature.*

This chapter provides pertinent background information and history leading to the creation of the Task Force. Chapter II describes the Task Force approach, the data and information considered by the Task Force, and the Task Force's observations covering: who is currently being served in a DC and their service and support needs; the resources that are or could be available in the community and in the DCs to meet those needs; other service models and their viability for improving services to this population; and funding considerations. Chapter III presents the recommendations of the Task Force for serving DC residents in the future.

HISTORICAL PERSPECTIVE

A need has always existed to provide care and services to individuals with intellectual and developmental disabilities. In 1853, a California system of large, public hospitals for the "mentally disadvantaged" began with the establishment of the Insane Asylum of California at Stockton (which later became Stockton DC) to provide in-patient care and treatment. In 1968 at its highest point, the system of state hospitals for the developmentally disabled served approximately 13,400 individuals in eight facilities, with another 3,000 individuals on waiting lists. For many years the state hospitals, now referred to as DCs, were the only alternative available to families of children with intellectual and developmental disabilities who were unable to be cared for at home.

Changes began in the mid-1960s, both in California and nationally, that would lead to the creation of community alternatives. California initiated a community program in 1965 by establishing two regional centers (now Golden Gate Regional Center and Frank D. Lanterman Regional Center) to test the concept of providing local, community-based services for persons who otherwise would require services in state hospitals. This experience formed the basis of the Lanterman Mental Retardation Services Act (now the Lanterman Developmental Disabilities Services Act [Lanterman Act], Welfare and Institutions Code Section 4500 et seq.) that extended the regional center system statewide in 1969, and established the foundation of the community program today.

With the development of the regional center system, dependence on institutional services declined over time. By 1979, the DC population was 9,000 with virtually no waiting lists for admission. Since then, the trend away from institutional care to community services has been accelerated through various laws and court cases, as briefly summarized below:

1. *Association for Retarded Citizens v. Department of Developmental Services* (1985), 38 Cal.3d 384 (ARC). In the ARC decision, among other holdings, the Court interpreted the Lanterman Act as creating an "entitlement" to services that enables each person with intellectual and developmental disabilities to live a more independent and productive life in the community.

2. Americans with Disabilities Act, 42 U.S.C. sec. 12100, et seq. (ADA). In 1990, the ADA was enacted to prohibit discrimination on the basis of disability in the provision of government programs and services.

3. *Coffelt v. Department of Developmental Services* (1990) (Coffelt). The Coffelt class action lawsuit alleged unnecessary placements of persons in DCs who could live in the community. The case was settled in 1994 resulting in more than 2,000 DC residents moving into the community over five years, and other system reforms. As a result of this lawsuit, the Department of Developmental Services (Department or DDS) budget was augmented for annual CPP funding, currently $67 million, which includes dedicated funding for the development of community-based resources that assist individuals transitioning from a DC to the community, and those being deflected from placement into a DC.

4. *Olmstead v. L.C.* (1999), 527 U.S. 581 (Olmstead). In Olmstead, the United States Supreme Court held that discrimination under the ADA includes unnecessary institutionalization of people with disabilities who can live in the community. The decision stated that "states are required to place persons with mental disabilities in community settings rather than institutions when the State's treatment professionals have determined that community placement is appropriate, the transfer from institutional care to a less restrictive setting is not opposed by the affected individual, and the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities."

The federal Centers for Medicare and Medicaid Services subsequently noted in a communiqué to states that Olmstead challenges states to prevent and correct inappropriate institutionalization, and to review intake and admissions processes to assure that persons with disabilities are served in the most integrated setting appropriate.

5. *Capitol People First v. Department of Developmental Services* (2001) (CPF). The CPF class action lawsuit alleged unnecessary segregation of Californians with developmental disabilities in large congregate public and private institutions. The lawsuit was settled in 2009, resulting in a greater focus on development of community resources, DC residents and families being provided information on community living options, and regional center resources to work with the DC residents and families.

6. AB 1472 (Chapter 25, Statutes of 2012). With ongoing budget constraints and many challenges facing the DCs, significant new policy limiting DC admissions and the use of institutional care in the community was enacted in the trailer bill to the 2012-13 Budget. Among other provisions, a moratorium was placed on DC admissions, with only limited exceptions for individuals involved with the criminal justice system or in acute crisis; comprehensive assessments were required for all DC residents to determine if community services are available to meet their needs; a new model of care was authorized that would allow for secured perimeters with delayed egress in a community home; and resources were prioritized to reduce state and local institutionalization.

Today, state and federal laws and court decisions clearly favor community integration over institutional care, defined nationally as congregate facilities with a capacity of 16 residents or more. Throughout the United States the population of persons with developmental disabilities receiving services in large settings of 16 or more has dramatically decreased. In 1977, this population represented 83.7 percent of the total number served. In 2007, 30 years later, it represented 14.3 percent. Thirteen states and the District of Columbia have no large state-operated institutions, while many other states have active plans for closure of some, if not all, of their large facilities. In California, the Lanterman Act entitlement to services ensures that an individual will receive appropriate services with any transition out of a large state-operated facility.

In early 2003, the Department, in collaboration with three Bay Area regional centers, consumers, families, and other stakeholders, initiated a planning process for the closure of Agnews DC. In January 2005, the Department submitted the resulting “Plan for the Closure of Agnews Developmental Center” to the Legislature. Unlike prior DC closures that relied in large part on consolidation of populations, Agnews DC was the first closure to incorporate the concept of community integration as the primary objective by developing community living options and supports. The foundation of the closure plan was the establishment of a stable source of housing with new residential service options; a community health care system that provides access to needed services; and state staff who continue to support DC residents once they move into the community. The final closure process was not driven by a specific date for closure, but by the availability of housing and support services. The health and safety of each consumer was the highest priority; transition to the community only occurred when all necessary services and supports were in place. In order to protect the civil rights of this vulnerable population in all environments, it is essential to prioritize policies and procedures surrounding the prevention, reporting, and management of abuse and neglect. Most of the approximately 400 Agnews residents moved to the community, only 20 individuals transferred to another DC.

DEVELOPMENTAL CENTERS TODAY

Currently, the Department operates four large DCs and one smaller community facility which, with some exceptions, are licensed and certified as Skilled Nursing Facilities (SNF), Intermediate Care Facilities/Developmentally Disabled (ICF/DD), and General Acute Care hospitals. The facilities provide 24-hour habilitation and treatment services designed to increase the residents' levels of independence, functional skills, and opportunities for making choices that affect a person's life. Before a person can be admitted to a DC, a court must determine that there is no other appropriate placement in the community and the individual is eligible for DC services pursuant to current law, and then issue an order for DC admission. As of January 1, 2014, these facilities were serving 1,335 residents with the number steadily decreasing. Services are provided by licensed medical staff including doctors, nurses, dentists, psychologists, and psychiatric technicians, along with many other professional and administrative staff.

In the community, the Department provides services and supports through contracts with 21 private, nonprofit regional centers to approximately 270,000 individuals with developmental disabilities. The DC population represents less than 1 percent of the total DDS consumer population in California. All DC residents are also served by a regional center.

As the population in the DCs has declined, the average acuity level of the remaining residents has increased considerably. Today the individuals residing in a DC typically have significant behavioral support needs or are very medically involved. Also, a substantial number of individuals have been dually diagnosed with mental health issues and/or have been involved in the criminal justice system. Many of these residents require one-to-one staffing at all times to prevent harm to themselves or others. Such significant changes in the DC population require ongoing adjustments in service delivery and staff support.

Although there are larger concentrations of people with severe disabilities and complex needs in the DCs, people with similar characteristics are being served successfully in the community. While some residents could successfully be served in the community today, additional specialized resources are required to meet the intense needs of the more difficult to serve DC population.

With significant budget reductions over recent years, various hiring freezes and staff furloughs, the DCs have struggled to meet the intense staffing needs and provide the level of service required in the facilities. Tragically, some incidents of abuse have occurred. Incidents of abuse compounded with staffing problems have resulted in licensing deficiencies at Sonoma DC, including partial federal decertification and loss of federal funding. Other DCs are also facing intense scrutiny from state and federal regulators.

The DCs are large institutions which were each designed to serve from 2,500 to 3,500 residents. As the population decreases, the average cost per resident increases due primarily to the high cost of maintenance and repair of the aging infrastructure designed to support a large facility with a higher resident population. The average cost of DC services is estimated to be over $400,000 per resident in FY 2013-14, an increase of almost $60,000 per resident from FY 2012-13. In addition, infrastructure needs are often not addressed due to the significant costs to repair or replace antiquated systems and a hesitancy to invest in these aging facilities with declining populations.

The reduction in population over the years and the associated costs of operation have led to the closure of three large DCs and one state-operated community facility since 1996. Currently, Lanterman DC is in the process of closing. New trailer bill language in AB 89, Section 13 (Chapter 25, Statutes of 2013), requires that the closure of Lanterman DC be completed no later than December 31, 2014. Today, each DC serves fewer than 500 residents, making these large institutions increasingly cost inefficient.

The current DC resident population and aging infrastructure, coupled with recent legislative action that significantly limits admissions to these institutions (most notably AB 1472 [Chapter 25, Statutes of 2012]), generates significant debate surrounding the DCs. Many stakeholders from within the disabilities community speak out against DCs, calling for their immediate closure; while many parents and families of DC residents strongly support the services and benefits provided by these facilities and believe that safety and stability of their loved ones' are dependent on the continued operation of the DCs.

CREATION OF THE TASK FORCE

Responding to the legal, fiscal, and legislative environment, and recognizing the need to define a path for the future of the DCs, the Secretary of CHHS, Diana S. Dooley, announced through a press release (Attachment 1) on May 22, 2013, that she was establishing a “Task Force on the Future of Developmental Centers.” She appointed representatives of consumers, family members, regional centers, consumer advocates, community service providers, organized labor, and the Department. The charge of the Task Force was to advise the Administration on the development of a master plan for the future of the DCs that, after careful consideration of specified factors, addresses the service needs of all DC residents and ensures the delivery of cost-effective, integrated, quality services for this special population. This initiative was later incorporated into the trailer bill to the 2013-14 Budget (AB 89, Section 14 [Chapter 25, Statutes of 2013]) and was supported by a grant from the SCAN Foundation.

Secretary Dooley sought diverse and important perspectives by selecting individuals who have proven themselves to be knowledgeable, caring and committed to the integrity of the system, and who would provide valuable thinking and insight to the process. Additionally, she invited the Assembly Speaker and the Senate President Pro Tem to designate a member from each House to represent the Legislature. Secretary Dooley announced the 21 members of the Task Force in a press release dated June 5, 2013 (Attachment 2). The members then embarked on a journey together to pursue questions and sources of information that would create a common understanding of the facts and prompt their constructive thinking on how to best serve DC residents in the future.

The deliberations and work of the Task Force culminated in six recommendations to improve the service delivery system. This plan lays out the data and materials that informed the process, and presents the general agreements reached for the future of the DCs. Although some members of the Task Force do not agree in all respects with the recommendations as stated, care has been taken to present a balanced perspective on the issues throughout this plan. Letters submitted by the Sonoma DC PHA, CAPT and CSLEA in response to the draft report are included as attachments 6, 7, and 8 respectively.

II.
TASK FORCE PROCESS AND DELIBERATIONS

PLAN DEVELOPMENT PROCESS

In the June 5, 2013, press release (Attachment 2) Secretary Dooley announced the 21 members of the Task Force on the Future of the Developmental Centers and laid out an ambitious agenda. The basic charge of the Task Force was to "gather facts, share opinions and seek agreement, where possible, on options for the future of developmental centers." The result was to be "a plan to assure quality, effective and efficient delivery of integrated services to meet the special needs of current residents living in the developmental centers." The last meeting of the Task Force was December 13, 2013, with the report and recommendations finalized for publication in January 2014.

Secretary Dooley convened and chaired a total of four Task Force meetings, with the first occurring on June 17, 2013. The meetings were open to the public, and public comments were received and recorded. To make best use of the members' time, a Work Group of Task Force members met between Task Force meetings and, based on identified topics, developed information, materials, and agenda items for Task Force consideration. Almost all of the Task Force members made themselves available for the Work Group meetings and additionally performed preparatory work outside of the meetings. Throughout the plan development process, data and historical documents were provided by the Department, and Work Group participants contributed important information from other sources. All materials were provided to the Task Force members electronically and made available on the CHHS website at www.chhs.ca.gov. Additionally, materials were submitted by the public participants. Task Force members were invited to tour DC programs which were coordinated by DDS staff according to individual schedules and preferences.

Packets of materials were prepared and provided before each Task Force meeting. These packets are included as attachments to this plan. They are described generally below, along with observations made by Task Force members.

WORK OF THE TASK FORCE

The work of the Task Force began with presentations and discussions regarding background information, pertinent data, and the important elements of the system of care. The overarching theme for the Task Force was to ensure the health and safety of the individuals being served, regardless of where they live. The Task Force members, although diverse in opinions and perspectives, shared significant common ground because, by virtue of receiving services, providing services, and/or having a friend or family member who is a consumer, they were all a part of the service system and able to contribute experiences and examples of best practices. The following observations were shared and became regular topics throughout the discussions:

1. A carefully crafted, comprehensive person-centered Individual Program Plan (IPP) is essential to the planning process and service delivery; one which utilizes assessments but is not solely driven by them, and one that incorporates input from a robust Interdisciplinary Team process.

2. It is critical that safe and secure services are delivered in the least restrictive environment possible, while still addressing personal quality of life. Given California’s entitlement to services for persons with intellectual and developmental disabilities, it is imperative that comprehensive services and supports are in place before a person moves from a DC.

3. Access to quality health and mental health services is essential regardless of where someone lives. DC families highly value the immediate access they have to a wide range of specialists with expertise in serving individuals with intellectual and developmental disabilities. Necessary health and mental health services include care coordination, appropriate and continuous medication management, and access to centralized medical records.

4. Stable, qualified staff is key to any successful model of care whether it is state operated or privately operated. The Task Force expressed interest in ways to facilitate the utilization of expert staff from the DC in the transition of residents into the community, such as the Community State Staff Program first implemented during the closure of Agnews DC.

5. Any model of care must receive sufficient and stable funding to be successful in accomplishing its goal.

6. Any solution must be fiscally responsible, including the ability to maximize federal funding. To meet the service needs of DC residents, alternatives must align with available resources. Task Force members sought significant information related to resource development options using CPP funding and the parameters for qualifying for federal funding.

7. The Task Force remained sensitive to the fact that, for the residents of the DC, the DC is their home and community, where their relationships are, and where they have lived for a long time. Any changes in their living arrangements must be done very carefully, with thorough planning, and by taking the time that is needed.

The initial data that was considered by the Task Force (Attachment 3) included: current consumer characteristics taken from the Client Development and Evaluation Report (CDER) for DC residents with comparisons to community consumers; DC population trends from 1969-70 to 2011-12; a breakdown of DC residents by level of care and regional center; community population data by regional center; a map showing DC locations and the areas served by each regional center; and, a June 2002 report titled, "Options to Meet the Future Needs of Consumers in Developmental Centers."

The Task Force carefully considered what additional information it needed throughout its deliberations. The first order of business was to fully understand the DC residents and to identify their needs. Information was requested for those individuals considered "difficult to serve." Task Force members generally shared strong interest in addressing the needs of persons with challenging behaviors and those involved in the criminal justice system. They looked at unmet needs, such as crisis intervention services, and service models from other programs and in other states. The Task Force also focused on the differences between community services versus the DC programs and services, to fully understand what could be replicated in the community. Information was requested both on successful programs as well as challenges from prior DC closure experiences so that both could be examined.

Following are the key subject areas discussed by the Task Force which lead to the recommendations presented in Chapter III.

SERVICE AND SUPPORT NEEDS OF DEVELOPMENTAL CENTER RESIDENTS

Attachments 3 and 4 contain considerable data from the CDER on the characteristics and diagnoses of the DC residents, which were reviewed by the Task Force. While the needs of the individuals are not unique to DCs and individuals with similar needs are already being served in the community, noteworthy is the concentration of individuals in the DCs with complex needs requiring higher levels of care. Following is a list of diagnoses and the percent of individuals in the DC system (1,484 total population as of July 1, 2013, including Canyon Springs Community Facility) with each diagnosis (Attachment 4, Packet 1, Item 1), as an indicator of service needs:

Diagnosis	Percent
Autism	16
Cerebral Palsy	39
Dual Diagnosis	48
Epilepsy	49
Hearing Deficit	9
Pervasive Developmental Disorder	2
Severe or Profound Intellectual Disability	67
Unable to Walk	50
Vision Difficulty	32

Additionally, 22 percent of the population has prevailing psychiatric/mental health issues, and 51 percent is prescribed at least one behavioral medication.

The primary service needs of the population as categorized by the DC programs are as follows:

Primary Service Need	Percent
Significant Health Needs	18
Extensive Personal Care	20
Significant Behavior Issues	16
Protection and Safety	31
Low Structured Setting	2
Specialized Secure Setting	13

Other significant observations are that 7 percent of the DC population has sex offense charges and may be Penal Code 290 registrants; 4 percent has assault-related felony charges; 1 percent has gang and/or drug-related issues; and another 1 percent has other felony charges.

Also of significance is the fact that the population is generally older with 18 percent over 61 years of age, and another 53 percent between the ages of 42 and 61 years. Forty-three (43) percent has lived in a DC for more than 30 years. The needs of an aging population become increasingly complex with time and present greater challenges for providing health care and appropriate services.

After reviewing the data, the information was organized into three primary service categories, although there are common issues and overlap: individuals with enduring and complex medical needs; individuals with challenging behaviors; and individuals involved in the criminal justice system. Within each category, there is a range of service needs, with some individuals being more difficult to serve.

The Task Force focused primarily on the more difficult to serve individuals who would require specialized services to be supported in the community.

For each of the three identified categories, the Task Force used a structured approach to discuss and analyze three areas of interest. First, the Task Force considered the most challenging aspects of providing services and supports to the particular population. Second, the Task Force identified the services and supports that are available in the system to meet those needs. Finally, the Task Force discussed what additional services and supports may be needed.

Following is a high-level synthesis of the Task Force discussion. A particular point or observation may reflect the comment of a single Task Force member.

Individuals with Enduring and Complex Medical Needs. As of October 30, 2013, 445 of the total DC population of 1,385, or approximately 32 percent, were receiving care in a SNF residence, indicating the population of individuals with significant medical needs. When individuals have complex, challenging or multiple medical conditions, certain conditions identified by the Task Force create a generally greater challenge associated with their care, as follows:

- Pica
- Prader-Willi Syndrome
- Seizure Disorders
- Feeding-related
- Respiratory care-related
- Diabetes
- Mobility issues
- Alzheimer’s or dementia
- Osteoporosis
- Dual Diagnosis

Various options already exist to serve and support individuals with complex medical needs, ranging from the family home with add-on or wrap-around nursing services; to the residential model authorized under SB 962 and SB 853 (962 homes); to an array of licensed health facilities, including state-operated alternatives. When considering the system needs associated with serving these individuals, the following areas were identified:

- Greater capacity is needed in the community for some services, such as 962 homes, ICF/DD-Nursing and ICF/DD-Continuous Nursing, with consideration for statewide locations.

- SNFs in the community should only be used for addressing short-term, acute needs. They are not an appropriate long-term environment for this population of individuals with enduring medical needs.
- Better coordination and continuity of health and dental care are needed in the community, such as a central “medical home” to facilitate communication, access to health records, and access to providers.
- All consumers would benefit from better medication management, which is essential for quality of life.
- Gaps exist in the community for psychiatric services.
- Greater access is needed in the community to Durable Medical Equipment (DME), adaptive technology, and other DC specialty services which utilize the expertise of DC staff.
- Specialized care is needed in the community for ventilator dependent individuals.
- Licensing challenges exist for providing day services to individuals with medical needs, including the use of medically related restraints and medication administration.

Of the 445 individuals residing in a DC SNF, it is estimated that roughly 315, or 70.9 percent, would need the services of 962 homes. This approximation is based on the percentage of individuals who moved from Agnews DC out of the SNF into a 962 home, and those who have moved or who are planning to move out of the SNF into a 962 home from Lanterman DC. The other 130 individuals may need the level of health care provided in an ICF/DD-Nursing or an ICF/DD-Continuous Nursing.

Individuals with Challenging Behaviors. It is estimated that approximately 227 DC residents have significantly complex and challenging behaviors. The Task Force considered the following behaviors or conditions as presenting the greatest difficulty in identifying service options when more than one are present:

- Elopement risk
- Aggressive social behavior
- Self-injurious behavior
- Pica
- Maladaptive sexual behavior
- Dual diagnosis
- Drug or alcohol abuse
- Vandalism or property destruction, including fire setting

Depending on the severity of the behaviors and the needs of the individual, particularly whether mental illness is involved, a wide array of service options exist, but with varying levels of desirability and availability, as follows:

- Individuals may reside in the family home with identified supports, such as respite services, or reside in their own home using Supported Living Services.
- A limited number of licensed residential facilities serve this population, some with delayed egress and some with psychiatric services.
- Individuals with behavior challenges need various support services, including specialized day programs.
- State-operated facilities serve this population, including crisis services at Fairview DC and transitional services at Canyon Springs Community Facility.
- Individuals may need acute psychiatric facilities.
- There are a limited number of crisis homes and a limited use of crisis teams available to serve this population in the community.
- The individuals with challenging behaviors are also served by emergency rooms and local hospitals, usually as a gateway to other mental health services in the community.
- On occasion, these individuals come in contact with local law enforcement and spend time in jail.

The Task Force considered several areas as common needs for all consumers. These areas were mentioned above for individuals with enduring medical needs and include: coordination and continuity of health and dental care; access to health records; as well as medication management. In addition, the following service needs were identified for individuals with challenging behaviors:

- This population needs greater access to appropriate, qualified and available professionals. Greater psychiatric services are needed generally throughout the system.
- More wrap-around supports for families would help to maintain individuals in the home.
- An increased capacity of crisis homes, crisis response services and step-down or re-entry programs are needed.
- An array of services are needed with the ability of individuals to move between levels as needs change, particularly for crisis services. There was a strong preference expressed for an individual to remain in his or her home with necessary services accessible and available to the provider to address the level of care changes.
- Better coordination is needed with law enforcement, to address vulnerability and risk of victimization issues, and prevent unnecessary involvement with the criminal justice system.
- Resources are needed that provide statewide access and not just access for a particular regional center's catchment area.

A general observation of some of the Task Force members is that the community system of behavioral and psychiatric services is the one area in most need of further development. Managing acute crises and effective coordination of mental health services were viewed as overarching system issues.

Individuals Involved in the Criminal Justice System. Roughly 200 individuals in the current DC population have had some involvement with the criminal justice system. Although the population is relatively small, the needs of the population are great. The Task Force considered the following factors as significant issues associated with their care:

- Whether the individual is charged with a felony, particularly a sex offense;
- Whether the individual is competent to stand trial; and
- For individuals who are incompetent to stand trial, whether they have a dual diagnosis of mental illness.

Options that exist today for this population include residing in their own or their family's home with monitoring and supports. Often these individuals reside in a locked facility that may include prison, a juvenile justice facility, Porterville DC-STP, or a psychiatric facility, but very few locked psychiatric facilities exist and their use is limited by recent trailer bill language. As an extension of these locked options, an individual may live in a half-way house, or receive parole or probation services. If an individual is determined by a court to be incompetent to stand trial, he or she will receive competency restoration training.

In addition to the common issues identified previously for all consumers (health and dental care coordination and continuity, medication management and access to health records), the following needs are associated with individuals involved in the criminal justice system:

- There are not enough locked community facilities to accommodate this population. It was noted, however, that these facilities face significant obstacles and NIMBY-ism (Not in My Back Yard) during development.
- More psychiatric and rehabilitation services are needed in the community.
- More treatment services are needed in the community for drug and alcohol abuse.
- It is difficult to find an appropriate placement for sex offenders released back to the community.
- There are safety issues associated with this population, such as addressing the risks of victimization and protecting non-offenders in the system.
- Increased coordination with the criminal justice system is needed to ensure appropriate community placements, protections, and monitoring.

The Task Force generally agreed that the services available at Porterville DC-STP are preferable for this population over prison or jail. The STP focuses on restoring competency as a primary function, but also provides rehabilitation programs, vocational education and other services in a secure environment. Secure treatment was viewed as primarily a responsibility of the State. It was recognized that some facilities serving the forensic population are funded using 100 percent General Fund.

Consideration was also given to the statutory cap on the STP population of 170 residents and whether the cap should be lifted; the possibility of expanding the services for other populations of individuals with challenging behaviors; and the need to address individuals with intellectual and developmental disabilities who are in jail (Attachment 5, Packet 5, Item 1).

Other Information Considered. To understand the service needs of the DC residents, the Task Force looked at other related information for additional insights and perspectives. The Task Force analyzed information concerning individuals who had previously transitioned to the community from a DC, and the subsequent moves by those individuals to other residential services (Attachment 4, Packet 1, Items 5 and 6, and Attachment 4, Packet 4, Item 3). The information identified the moves, but did not provide qualitative information about the reasons for the moves. Also considered was the client characteristics of DC residents and persons who had moved to the community from a DC (Attachment 4, Packet 4, Items 6 and 7).

The Task Force considered the assessment data being developed by the regional centers (Attachment 5, Packet 5, Item 2) as a product of the AB 1472 (Chapter 25, Statutes of 2012) requirements. This information is preliminary and was collected through a survey of regional centers based on comprehensive assessments completed in FY 2012-13. The data provided information about the potential service needs of the DC residents.

The work of the Task Force included data from the Statewide Specialized Resource Service (SSRS, Attachment 4, Packet 3, Item 1). The SSRS was developed in response to AB 1472 (Chapter 25, Statutes of 2012) to track the availability of specialty residential beds and services, specialty clinical services, and requests for DC services and supports when community services have not been identified, so that resources can be coordinated and accessed on a statewide basis. Only services developed using CPP funds are included in the SSRS tracking. The Task Force recommends expanding the SSRS to include non-CPP funded resources. The Task Force also considered the DDS report on “Crisis Intervention for Persons with Developmental Disabilities” dated May 2013 (Attachment 4, Packet 4, Item 8) while assessing the availability of services in the community.

DEVELOPMENTAL CENTER SERVICES AND RESOURCES

To ensure the service needs of DC residents will continue to be met, considerable efforts were made by the Task Force to fully understand the services available in a DC and the associated benefits. Listings of the specialty services at the DCs as well as general information about the various services and supports were part of the Task Force materials (Attachment 5, Packet 2, Items 1 and 2). Through discussions, the following benefits were associated with DC services:

- DCs have the flexibility to adjust services to meet the changing needs of the residents, creating a stable environment for each individual.
- DCs serve as a placement of last resort and a safety net for the system.
- Residents have access to an array of professional staff to address their health, treatment and habilitation needs, including specialty services.
- The DC employees are qualified, familiar with the special needs of the individuals they serve, and are compensated for the level of service they provide. If staff leaves their DC employment or has time off, the DC has flexibility to adjust staffing for proper coverage.
- The DCs' funding structure contributes to their stability and sustainability as a service provider.
- Given the property associated with DCs, residents are able to enjoy the freedom of the grounds and benefit from the calming environment while still safe and protected, which is particularly important for individuals with no safety awareness.

Another area of exploration was looking at the DCs for what they may offer in the way of potential resources. Two specific resources were regularly discussed by the Task Force. First, there was interest in preserving the expertise of the DC staff within the service delivery system. The Task Force expressed support for the Community State Staff Program that was part of the Agnews DC closure, and subsequently part of the Lanterman DC closure, whereby the DC contracted with providers and regional centers for DC staff to fill jobs in the community. DDS was reimbursed for those services, and the community benefited from the expertise of the staff and the continuity of services. There was general agreement among Task Force members that the system would benefit from preserving this resource. Also of interest was using the DC staff to bridge services with the community using a “health resource center” model.

The second resource of particular interest to the Task Force was the DC property. Materials were provided to the Task Force that described the current land use with maps of the facilities (Attachment 5, Packet 3, Items 1 and 2). Also, the surplus property process was shared, including the requirement that the net proceeds from the disposition of the surplus property be used for the retirement of State bonds pursuant to

Government Code Section 11011(g). Many of the members felt that this valuable resource should not be given up as surplus, but instead should be used for the benefit of the service system. The challenge is to define clearly what the future use should be.

In considering the future use of DC land, the Task Force became familiar with the Harbor Village Project at Fairview DC (Attachment 5, Packet 3, Item 3). The State of California entered into a public-private partnership using a 55-year lease of 60 acres at Fairview DC for the purpose of developing the land for employee and consumer housing. By leveraging state land resources, community integrated housing was successfully developed. This approach to using DC land generated significant interest from the Task Force members as they discussed new models of service delivery.

Additional DC resources identified by the Task Force as gaps in community services are the provision of DME, assistive technology, and specialty services such as the Sonoma DC shoe program, with emphasis on keeping equipment updated and repaired. These supports are available in the DCs and will be a continuing need for the DC residents, wherever they may reside in the future.

COMMUNITY SERVICE MODELS AND OTHER RESOURCES

The Task Force was interested in new service models for addressing the needs of DC residents who may be served in the community in the future. In particular, the members reviewed and discussed the Programs of All-Inclusive Care for the Elderly (PACE, Attachment 5, Packet 4, Item 1). PACE is a federal program that provides community-based health care and services to people age 55 or older who otherwise would need a nursing home level of care. A team of health professionals provide “one-stop” comprehensive health care within a complex of services and functions like a Health Maintenance Organization (HMO). Under the existing PACE model, the care is exclusive, and individuals electing this care give up their other medical coverage. Although serving individuals with intellectual and developmental disabilities would be very different from serving the elderly, the concept of an organized array of needed health services in one “health resource center” was very appealing. Significant interest was demonstrated by the Task Force members in designing a workable model that would address the unmet needs of the DC residents and potentially others at risk in the community.

Examples were provided from other states of Community Resource Centers (Attachment 4, Packet 4, Item 2). These Community Resource Centers are typically developed as medical or dental outpatient clinics serving large-facility residents and/or the community, but may include comprehensive services more like PACE. The service delivery model is flexible and may incorporate other services such as case management and evaluation, behavioral, and respite, with opportunities for research, training, and building expertise with community professionals. The Task Force discussed the safety-net concept from other states, to support individuals as they transition to the community.

The Task Force received material on the Multipurpose Senior Services Program (MSSP, Attachment 4, Packet 3, Item 4) for frail elderly adults who are certified for placement in a nursing facility but who wish to remain in the community. Through the MSSP, they receive social and health care management services, including adult day care, social services, personal care assistance, protective supervision, case management, meal services, and transportation, among others. Additionally, information was provided for the Community-Based Adult Services (CBAS) model that replaced the Adult Day Health Center (same attachment).

The services and supports developed and provided during the closure processes for Agnews DC and Lanterman DC were another area of consideration. Summaries were made available from both closures (Attachment 4, Packet 2, Items 7 and 8) and excerpts were provided from Lanterman DC newsletters and the DDS website (Attachment 4, Packet 3, Item 3). In addition to the residential service models, the Task Force was interested in the care coordination provided by the regional centers, especially for health and dental care. Also considered were the transition of health services to managed care, and the services provided by the DC outpatient clinics to ensure continuity of and accessibility to care.

The Task Force was interested in the least restrictive living options, such as providing necessary services and supports, either in the family home or in the individual's own home, using Supported Living Services, In-Home Supportive Services and other similar supports. The members considered ways of developing additional supports for making these viable options for the future of some DC residents. While they also considered the use of Assisted Living as an alternative, it was felt that Assisted Living is not designed today to address the needs of individuals with intellectual and developmental disabilities.

FUNDING CONSIDERATIONS

Information was provided to the Task Force related to the DDS budget and funding (Attachment 5, Packet 1). Members were sensitive to the past funding limitations affecting government programs generally over recent years, as well as the community rate freezes and other budget reductions affecting the disabilities service system. They remained vigilant during their discussions of funding considerations and the need to prioritize services carefully for development. Sources of federal funding that were discussed included the Home and Community Based Services Waiver, the

1915(i) State Plan Amendment, and Money Follows the Person. The Task Force received information on federal requirements for funding (Attachment 5, Packet 1, Item 7, and Packet 4, Item 5), including how facilities maintain “home and community character” in order to qualify for federal funding.

Also considered was the CPP funding that is included in the DDS budget (Attachment 5, Packet 4, Items 2, 3 and 4) for developing community housing, day programs, and other services. The CPP was originally established as part of the Coffelt settlement to facilitate the movement of DC residents who could be served in the community. The funding is provided to regional centers for assessments, resource development, start-up and placement costs, for the purposes of developing community resources to meet the needs of their consumers residing in DCs based on individualized planning efforts, and supporting the transition process. The CPP is also used to deflect consumers from DC admission. In 2012, with passage of the moratorium on DC admissions, the regional centers’ use of CPP funding was expanded to enhance the capacity of the community service delivery system and address the unique needs of individuals with challenging service needs. Additionally, 10 percent of the fiscal year 2013-14 CPP (excluding funding for assessments) is being used to fund regional projects, where two or more regional centers partner and develop resources for statewide use. The Task Force discussed barriers involved in the CPP process and in the development of community resources as it considered the need for additional homes and services.

With all of the information and data generated by DDS and the Task Force, the public comments and materials, and the in-depth discussions, the Task Force crafted recommendations for addressing the future service needs of the DC residents. The recommendations are presented in Chapter III.

III.

TASK FORCE RECOMMENDATIONS FOR FUTURE SERVICES FOR DEVELOPMENTAL CENTER RESIDENTS

When the Task Force on the Future of Developmental Centers began, there was broad recognition of the importance of defining the future for the DC residents. Their future was changing by virtue of the long historical trend toward community integration, now critically influenced by the moratorium on DC admissions (AB 1472 [Chapter 25, Statutes of 2012]). With the DC population declining, the per-resident costs of the DCs are dramatically increasing, and the DCs are no longer sustainable in their current design. Concurrently, the acuity level of the remaining population is increasing, thereby requiring an overall higher level of specialized care. The Task Force was charged to identify viable long-term service options for the health and safety of the DC residents and to ensure that appropriate quality services are available, accessible, and cost efficient for the benefit of the individuals as well as the system generally.

Extensive data was provided to the Task Force regarding the individuals served in the DCs and those with similar needs living in the community; the services provided to these individuals; the resources available in a DC and in the community; and budget and fiscal information (See Attachments 4 and 5). The Task Force grouped DC residents into three primary categories: those with enduring and complex medical needs; individuals involved in the criminal justice system; and residents with significant behavioral support needs. For each group, the Task Force considered existing community services as well as gaps in specialized services in the community. Additionally, the Task Force considered the overarching issue of access to specialty health care services and issues regarding the land and resources at a DC.

The Task Force agreed that there are some fundamental principles that are integral to any transition of a DC resident. These principles include: 1) individual service needs must be based on a comprehensive person-centered planning process; 2) services must be provided in the least restrictive environment appropriate for the individual; 3) the health and safety of the individual is paramount; and 4) Each transition must be accomplished carefully, and with thorough planning and coordination.

The Task Force developed six recommendations. The first three directly relate to services for the three primary groups of DC residents, especially those needing specialty services in each group. The fourth recommendation relates to access to specialty health care services in the community; the fifth recommendation is associated with the use of DC land and resources; and the last recommendation addresses the community system.

TASK FORCE RECOMMENDATIONS

Recommendation 1: Individuals with Enduring and Complex Medical Needs

Approximately 445 of the total DC population, or 32.1 percent, are individuals with complex medical needs receiving SNF care, many of whom have multiple medical conditions requiring specialty services.

Various community-based models of care exist to serve and support individuals with complex medical needs, ranging from the family home with add-on or wrap-around nursing services; to the residential model authorized under SB 962 and SB 853 (962 homes); to an array of licensed health facilities, including an ICF/DD-Nursing and an ICF/DD-Continuous Nursing. Based on the closure experiences with Agnews DC and Lanterman DC, 70.9 percent of the SNF residents are expected to require the 962 home level of care, or 315 individuals.

To serve DC residents with enduring and complex medical needs, the Task Force recommended regional centers assess and adjust their community capacity. One of five existing licensing categories should be considered for individuals with complex medical needs moving to the community: a 962 home, a small ICF/DD-Nursing, an ICF/DD-Continuous Nursing, a Residential Care Facility for the Elderly (RCFE), or a Community Care Facility with appropriate medical wrap around services. Each regional center should first explore existing resources (vacant beds), both within its catchment area and any available for statewide use, where appropriate and suitable for the consumer based on his or her comprehensive assessment. The regional center should utilize those existing resources to the extent appropriate and propose new community development through the CPP process to address the unmet residential and support needs of the population.

The Task Force further recommended the development of more homes/facilities using the existing models of care. However, they generally agreed that SNFs in the community should only be used for addressing short-term acute needs, and are not an appropriate long-term environment for consumers with enduring medical needs.

With regard to the role of the State, the Task Force recommended:

- The State use CPP funds for regional center development of more 962 homes and other needed residential and support services and day programs to serve DC residents in the community. The development of the additional 962 homes could be supported by annually targeting approximately $8.5 million in CPP funds over the next three years, or $25 million over the three-year period.

- DDS, working with the regional centers, determine the number of existing vacancies in homes/facilities and make this information available.

Recommendation 2: Individuals with Challenging Behaviors and Support Needs

Approximately 227 DC residents, or 16.4 percent, have significantly complex and challenging behaviors. The Task Force considered behaviors or conditions involving elopement, aggression, self-injury, Pica, maladaptive sexual activity, mental illness, substance abuse, and/or significant property destruction to present the greatest service delivery challenges requiring a wide array of options. Existing community services are insufficient to meet the needs of this population.

Greater access to specialty services is needed, especially mental health and medication management services, increased psychiatric care, and enhanced wrap-around supports to maintain individuals in their current community residence. With the increased capacity of short-term crisis homes, acute crisis facilities will be needed. In addition, the group recommended a new “SB 962 like” model with specialty wrap around services to provide a higher level of behavioral supports, crisis response services, and step-down or re-entry programs.

The Task Force also agreed that there must be a “placement of last resort” for individuals with significantly challenging behaviors. Consumers in crisis must always have a place to go when in need.

With regard to the role of the State, the Task Force recommended the State:

- Operate acute crisis facilities (like the program at Fairview DC) at least in the Northern and Southern parts of the State. These two 15-bed (or smaller) facilities may require development funds and would have an estimated annual combined operating cost of $8.8 million.

- Operate some transitional facilities (like the program at Canyon Springs Community Facility, only smaller). For example, a 15-bed (or smaller) facility would have an estimated annual operating cost of $4.4 million.

- Develop new “SB 962 like” model homes with specialty wrap around services to provide a higher level of behavioral supports. These 3-bed facilities could be developed using CPP funding at an estimated cost of $500,000 each, plus ongoing operating costs. Based on the current DC population, approximately 36 such homes would be needed if it were determined that this level of care was appropriate for those remaining in the DCs with challenging behaviors.

- Identify community capacity in existing models of care.

- Support regional center efforts to enhance supports to maintain individuals in their own homes.

- Provide or earmark CPP funding for regional centers to:
  - Expand mobile crisis response teams;
  - Expand crisis hotlines;
  - Expand day programs;
  - Create short-term crisis homes; and
  - Develop new "SB 962 like" behavioral homes (see above).

- Provide DC staff to assist with the transition of individuals with challenging behaviors.

<u>Recommendation 3: Individuals Involved in the Criminal Justice System</u>

Roughly 14.4 percent of the DC population has had some involvement with the criminal justice system. Although the number of residents is relatively small, the needs of the population are great. The Task Force considered dual diagnosis of mental illness; individuals charged with a felony, particularly a sex offense; and individuals incompetent to stand trial as significant issues associated with their care.

With regard to the role of the State, the Task Force recommended the State:

- Continue to operate Porterville DC-STP since it is preferable for this population over prison, jail, a locked psychiatric facility, or placement out of state. The Porterville DC-STP focuses on restoring competency as a primary function, but also provides rehabilitation programs, vocational education and other services in a secure environment. Secure treatment was viewed as primarily a responsibility of the State. It was recognized that some facilities serving the forensic population are funded using 100 percent General Fund. Continuing to operate the Porterville DC-STP has an annual cost of $76 million General Fund.

- Continue to operate Canyon Springs Community Facility as a re-entry program for criminal justice system-involved consumers leaving Porterville DC-STP. Continuing to operate Canyon Springs Community Facility has an annual cost of $16.1 million, which is eligible for federal financial participation.

- Consider changing the law to allow a continuum of services for competency restoration training rather than all forensic clients being committed to the Porterville DC-STP.

- Explore the development of alternatives to the Porterville DC-STP. Community options would allow individuals to remain closer to their family and regional center. These forensic facilities would likely be ineligible for federal financial participation.

Recommendation 4: Health Resource Center

The Task Force supported the need for coordinated health care services, including mental health, psychiatry, medication management, and centralized medical records. The group recognized the importance of the DC specialty services, such as the Sonoma DC shoe and wheelchair molding and the availability of medical professionals with vast experiences and expertise serving individuals with complex developmental and medical needs.

In particular, the Task Force reviewed and discussed PACE (Program of All-inclusive Care for the Elderly), a federal program that provides community-based health care and services to people age 55 or older who otherwise would need a nursing home level of care. PACE is designed for a team of health professionals to provide “one-stop” comprehensive health care within a complex of services and functions like a HMO. Under the existing PACE model, the care is exclusive, and individuals electing this care give up their other medical coverage. Although serving individuals with intellectual and developmental disabilities would be very different from serving the elderly, the concept of an organized array of needed health services in one “health resource center” was appealing.

The health care services and supports developed and provided during the closure processes for Agnews DC and Lanterman DC were another area of consideration. The Task Force was interested in the care coordination provided by the regional centers, especially for health and dental care. Also considered were the transition of health services to managed care, and the services provided by the DC outpatient clinics to ensure continuity of and accessibility to care.

The Task Force recommended exploring a workable model for a health resource center that would address the health needs of the DC residents after they transition to community homes. Where possible, the State should incorporate appropriate existing DC resources. The health resource center should address any gaps in service that may exist including, but not limited to, care coordination, dental, mental health, durable medical equipment, assistive technology, and DC specialty (such as shoes) services. Care coordination was considered a critical component for the successful transition and continued support of any resident, regardless of their other support needs. It was recognized, however, that as community services develop, the need for the health resource center services may change.

Since most DC residents are receiving Medi-Cal and the use of a service model focused on developmental disabilities will likely require prior federal CMS approval (a waiver or a State Plan Amendment), further work needs to be done to determine the most advantageous approach to providing the specialized, coordinated care.

Recommendation 5: Use of DC Land and Resources

The Task Force generally agreed unused (current and prospective) state DC land should be leveraged to benefit consumers rather than being declared surplus. Members understood surplus land disposition is controlled by the State Constitution and sales revenue cannot be diverted to the developmental disabilities system. However, the property should be considered for future State-operated facilities and to develop community services, including the Health Resource Center and mixed use communities similar to Harbor Village in Costa Mesa.

With regard to the role of the State, the Task Force recommended:

- State land should be retained and the State should enter into public/private partnerships to provide community integrated services, where appropriate. (Note: The four large DCs comprise a total of 2,181 acres of land, of which the core campuses use 878 acres, or about 40 percent of the acreage. Canyon Springs Community Facility has a lease agreement through September 2015, including additional acreage that could be developed. The lease agreement has an option to purchase or exercise a 15 year extension.)

- Existing State buildings on DC property should be used, as appropriate, for developing service models identified in the previous recommendations. Repurposing existing buildings requires meeting current building and seismic safety codes.

Recommendation 6: Future of the Community System

Although outside the scope of this Task Force's charge, the Task Force expressed a desire for DDS to form another task force to address ways to make the community system stronger. Among the many issues to be considered are: 1) the sufficiency of community rates and the impact new State and federal laws and regulations may have; 2) whether current regulations can be streamlined, particularly affecting the licensing of facilities; and, 3) whether certain benefits received by DC residents as part of a DC closure process should be broadened to others in the community. These areas have a significant and long term impact on services for individuals with intellectual and developmental disabilities.

The make-up of the next task force should be similar to the Task Force on the Future of Developmental Centers, including representatives from the DCs. However, the priority given to the work should be after significant progress has been made on Recommendations 1 through 5.

NEXT STEPS

The recommendations made by the Task Force include some recommendations that can be acted on quickly, while others need further work and development. Implementation of the recommendations with the greatest clarity should begin right away. Concurrently, to move in the direction recommended by the Task Force on the more involved recommendations and to continue the active stakeholder engagement that contributed so significantly to this work, the State will use an approach modeled on the Agnews DC closure stakeholder process to design and implement the fundamental transformation of the remaining DCs.

ATTACHMENT 1

State of California

HEALTH AND HUMAN SERVICES AGENCY

FOR IMMEDIATE RELEASE Contact: (916) 654-3304
May 22, 2013

California Health and Human Services Secretary Diana S. Dooley to Establish Task Force for State Developmental Centers

Sacramento – California Health and Human Services Agency Secretary Diana S. Dooley today announced she will establish a Task Force on the Future of the Developmental Centers. The Task Force will include a cross-section of consumers, family members, regional centers, consumer advocates, community service providers, organized labor, and the Department of Developmental Services.

The Task Force will be charged to develop a Master Plan that addresses the service needs of all developmental center residents, the fiscal and budget implications of the declining population, the aging infrastructure, staffing, and resource constraints, the availability of community resources to meet the specialized needs of residents now living in the developmental centers, a timeline for future closures and the statutory and regulatory changes that may be needed to ensure the delivery of cost-effective, integrated, quality services for this special population.

The challenges facing the residents of the state developmental centers are not new and not easily solved. Until the landmark Lanterman Developmental Disabilities Services Act was adopted in 1969 to establish community-based alternatives, the only care option available to families of children with developmental and intellectual disabilities was state-operated hospitals. Since then, federal and state legal mandates have contributed to the deinstitutionalization of more than 10,000 former developmental center residents and made significant investments in community-based resources. Today, California operates four large, old developmental centers and one small community facility serving a total of 1,510 residents with a budget of $545 million.

Last year, this Administration sponsored legislation, which placed a moratorium on new admissions to the developmental centers, required all residents to be assessed to determine if community services are available to meet their needs, and prioritized resources to reduce state and local institutionalization. As the combination of this admission moratorium, legal mandates, and investments in community-based services are decreasing the developmental center population by approximately 200 residents per year, continued operation of four large institutions is increasingly inefficient and cost prohibitive.

Secretary Dooley said in announcing the establishment of the Task Force, “The health and safety of citizens served by the developmental disabilities service system is a high priority for California therefore we must provide services to people with developmental and intellectual disabilities in the most integrated setting available to meet their needs and to avoid unnecessary institutionalization.”

The Secretary will make appointments to the task force by June 1, 2013 and will convene the first meeting by June 15. The Task Force will complete its work by November 15 and produce a written Master Plan that addresses:

1. The effective and efficient delivery of integrated services to meet the specialty needs of developmental center residents; and

2. The fiscal implications of developmental center operations, including the cost of resident care and services, maintenance of aging infrastructure, and utilization of existing resources.

State of California
HEALTH AND HUMAN SERVICES AGENCY

FOR IMMEDIATE RELEASE Contact: (916) 654-3304
June 5, 2013

California Health and Human Services Secretary Diana S. Dooley Appoints Members to the Future of the Developmental Centers Task Force

Sacramento – California Health and Human Services (CHHS) Secretary Diana S. Dooley today announced the members appointed to the Future of the State Developmental Centers Task Force which includes consumers, consumer advocates, regional centers, community service providers, organized labor, families of developmental center residents, members of the Legislature and the Department of Developmental Services staff. California operates four large developmental centers and one small community facility serving a total of 1,510 residents statewide with an annual budget of $545 million.

“It is essential to listen honestly and fairly to all the different points of view about how best to provide quality care for the people we serve at the developmental centers,” said CHHS Secretary Diana S. Dooley. “The Task Force will gather facts, share opinions and seek agreement on options for the future of developmental centers."

The Task Force will develop a plan to assure quality, effective and efficient delivery of integrated services to meet the special needs of current residents living in the developmental centers. It will consider the fiscal implications of developmental center operations, including the maintenance of the aging infrastructure, staffing, and resource constraints; the availability of alternative and community resources; a timeline for future closures; and any statutory and regulatory changes that may be needed to ensure the best care possible for this special population.

The Secretary will convene the first meeting of the Task Force on Monday, June 17 from 9:00 a.m. to 4:30 p.m. in Sacramento at the California Department of Rehabilitation, 721 Capitol Mall, Room 242. The Task Force will complete its work by mid-November and the meetings will be open to the public.

Task Force Members

Mark Barr, MS, has been a special education teacher for the Department of Developmental Services for over 23 years and is an elected labor representative for Service Employees International Union (SEIU) Local 1000. He and his wife are parents of a child with special needs whom they recently lost.

Catherine Blakemore, JD, is the Executive Director of Disability Rights California (DRC). DRC provides a broad range of advocacy services state-wide to Californians with disabilities. She has worked in the disability advocacy field for more than 30 years.

Ronald Cohen, PhD, is the Chief Executive Officer of United Cerebral Palsy of Los Angeles, Ventura, and Santa Barbara Counties since 1987. Cohen is an expert on developing housing for special needs populations and has testified before the California State Legislature and the United States Congress on alternatives to institutional living.

Theresa “Terry” DeBell, RN, is the President of CASHPCR (formerly called California Association of State Hospital Parent Councils for the Retarded), representing families from Fairview and Porterville

Developmental Centers. She is the Chair of the Governor`s Advisory Board at Lanterman Developmental Center where her brother Patrick lived for many years.

Terri Delgadillo, MSW, is the Director of the California Department of Developmental Services, the lead agency through which the State of California provides services and support to children and adults with developmental disabilities.

David De La Riva, JD, is the Senior Legal Counsel, California Statewide Law Enforcement Association (CSLEA). David joined CSLEA in 2005 as Legal Counsel where he oversees the day to day operations of the CSLEA satellite office in Huntington Beach and represents the Department of Developmental Services' peace officers.

Carlos Flores is the Executive Director (ED) of the San Diego Regional Center. He has 38 years of experience in the field of developmental disabilities. Carlos was the Branch Manager for the Prevention and Children's Services Branch of the Department of Developmental Services. He also has been the ED of the Redwood Coast Regional Center and ED of the Developmental Disabilities Area Board 10 in Los Angeles County.

Dana Hooper, MBA, is the Executive Director of Life Services Alternatives, Inc. (LSA). Dana is a technology industry veteran with extensive sales and marketing experience. He was previously a vice president of U.S. operations for a German software developer and on the leadership team at Speech Machines, Lernout and Hauspie and Centigram.

Connie Lapin is a co-chair of the Government Relations Committee for the Autism Society of Los Angeles. She is a speech pathologist, lecturer and consumer advocate for children and adults with Autism Spectrum Disorders and other developmental disabilities. Her son, Shawn, has autism.

Kevin MacDonald, MBA, has been the CEO of The Arc of Los Angeles and Orange Counties for the past 20 years. The Arc provides work and day services. Kevin established The Arc's Center for Human Rights. He did his Masters Internship at Fairview Developmental Center in Orange County.

Christine Maul, PhD, CCC-SLP, is a speech language pathologist and assistant professor in the Department of Communicative Disorders and Deaf Studies at California State University, Fresno. She is a parent of a resident at Porterville Developmental Center.

Kathleen Miller, LCSW, is President of the Parents Hospital Association for Sonoma Developmental Center (SDC), an organization that represents the families and friends of the SDC residents. Kathleen previously worked as a clinical social worker at SDC. Her son Dan is a resident at SDC.

Marty Omoto is an Advocate and Founder of the California Disability Community Action Network (CDCAN). He publishes a newsletter about the state budget and legislation with a following of over 65,000 people across the state. Marty had an older sister with developmental disabilities.

Ray Rocha is the President of the board of People First of California. He was previously vice president of People First of California and president of People First of Bakersfield. Ray works for Kern Regional Center where he helps other individuals with disabilities to access services.

Robert Riddick, LCSW, is Executive Director of the Fresno-based Central Valley Regional Center covering Tulare, Kings, Fresno, Madera, Mariposa and Merced counties, including the Porterville Developmental Center in Tulare County.

Will Sanford is the Executive Director of Futures Explored, Inc., a community-based organization that provides support to over 500 individuals with developmental and other disabilities each year.

Savaing Sok is a member of People First of California- Region 4 for Sonoma, Solano and Napa Counties. He is a 21-year-old resident of Sonoma Developmental Center and a member of the center's Human Rights Committee.

Kecia Weller is a member of the California State Council on Developmental Disabilities. Weller was formerly a teacher's assistant at the University of California, Los Angeles Extension Pathway Program, and has been a county supervisor appointee on the Los Angeles County Commission on Disabilities since 2002.

Brad Whitehead is a California-licensed Psychiatric Technician at Lanterman Developmental Center in Pomona where he has provided a broad range of medical and therapeutic services to center residents. Brad also serves as Lanterman Chapter president for the California Association of Psychiatric Technicians.

Note: The Assembly Speaker and the Senate President Pro Tem will each designate one member to represent the Legislature.

ATTACHMENT 3

PACKET OF MATERIALS FOR JUNE 17, 2013

Document

1. Consumer Characteristics at the end of March 2013
2. Developmental Center Population Chart
3. Developmental Center In-Center Population by Level-of-Care and Regional Center
4. Regional Center Population Residence Types as of June 1, 2013
5. Options to Meet the Future Needs of Consumers in Developmental Centers (June 2002) *
6. Level of Care and Regional Center Acronym Key
7. Map of Developmental Centers, State-operated Community Facility, and Regional Centers
8. Services Provided At Each Developmental Center

The above listed attachments can be found at the following address:

http://www.chhs.ca.gov/Pages/DCsTaskForce.aspx

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* This is a 98-page report that is available on the CHHS website at www.chhs.ca.gov/pages/DCsTaskForce. It is not included here because of its size.

ATTACHMENT 4

PACKETS OF MATERIALS FOR AUGUST 19, 2013

PACKET 1: CLIENTS

Document

1. Summary of Resident Characteristics by Developmental Center (DC)
2. Client Development and Evaluation Report (CDER) Data on DC Resident Characteristics
   (Distributed at first Task Force Meeting)
3. CDER Data on Consumer Characteristics Statewide
   (Distributed at first Task Force Meeting)
4. CDER Data Comparing Major Characteristics of Consumers in the DCs and the Community
   (Distributed at first Task Force Meeting)
5. Summary of the Number & Types of Moves Made By Individuals After Leaving a DC
6. Sample of Supporting Data Used To Create the Summary of Moves
7. Chart Summarizing DC Consumers by Legal Status
8. Data Requests—Client Characteristics
9. Chart Summarizing Use of Behavior Modifying Drugs with the Difficult to Serve Population

The above listed attachments can be found at the following address:

http://www.chhs.ca.gov/DCTFDocs/Clients%20Packet%20for%20Workgroup.pdf

ATTACHMENT 4

(Continued)

PACKETS OF MATERIALS FOR AUGUST 19, 2013

PACKET 2: INFORMATION COLLECTED ON OTHER STATES

Document

1. 2011 Ranking of States by Number of Residents at Large State Facilities

2. List of Completed and In-Progress Closures of State-Operated 16+ Institutions

3. List of 14 States that Have Closed All of their State-Operated Institutions

4. Summaries of Closure Efforts in 5 of the 14 State that Have Closed All Large State Institutions
    - Michigan
    - New Hampshire
    - Maine
    - Vermont
    - Indiana

5. List of 10 States with the Smallest Number of Residents Left in State-Run Institutions

6. List of Links to 18 Different Closure Plans for Various Institutions and States

7. Summary of Agnews Closure Process

8. Summary of Lanterman Closure Process

8. Policy Research Brief: Status of Institutional Closure Efforts in 2005

The above listed attachments can be found at the following address:
http://www.chhs.ca.gov/DCTFDocs/Other%20States%20Packet%20for%20Workgroup.pdf

ATTACHMENT 4

(Continued)

PACKETS OF MATERIALS FOR AUGUST 19, 2013

PACKET 3: RESOURCES

Document

1. Summary of Statewide Specialized Resource Service (SSRS) Usage and Content

2. Chart Summarizing Out-of-Home Living Arrangements

3. Excerpts Describing Service Options from Various Lanterman Newsletters and the Department of Developmental Services (DDS) Website

4. Summaries of Community-Based Adult Services (CBAS) and Multipurpose Senior Services Program (MSSP) Programs

5. Data Request—Number of People Who Moved into Non-Lanterman Developmental Center Resources

The above listed attachments can be found at the following address:

http://www.chhs.ca.gov/DCTFDocs/Resources%20Packet%20for%20Workgroup.pdf

PACKETS OF MATERIALS FOR AUGUST 19, 2013

PACKET 4: FOLLOW-UP DATA REQUESTS

Document

1. Articles Regarding Deinstitutionalization from Christine Maul
2. Examples of Community Resource Center Model from Kathleen Miller
3. Expanded Summary of Moves Made by Individual after Leaving a DC
4. Summary of Monthly Admissions, Transfers and Placements by DC
5. Residence Data on Individuals Who Moved from Stockton and Camarillo
6. Client Characteristics Information—DC Residents
7. Client Characteristics Information—DC Movers
8. DDS Crisis Intervention Report—May 2013
9. Psychiatric Supports for Agnews DC Movers
10. Developmental Center Services and Supports (meeting handout)

The above listed attachments can be found at the following address:

http://www.chhs.ca.gov/DCTFDocs/August%2019,%202013%20Task%20Force%20Data%20and%20Information.pdf

ATTACHMENT 5

PACKETS OF MATERIALS FOR OCTOBER 22, 2013

PACKET 1: BUDGET AND FUNDING

Document

1. Description of Budgeting Process for Developmental Centers and Community Services
2. Developmental Center Funding FY 2013-14
3. Summary of FY 2013-14 Operational Budget for Developmental Centers
4. Regional Center Funding FY 2013-14
5. Movers from Developmental Centers FY 2011-12 Regional Center Costs
6. Rate Setting Methodologies
7. Federal Funding Information

The above listed attachments can be found at the following address:

http://www.chhs.ca.gov/DCTFDocs/DC%20Task%20Force%20-%20Budget%20and%20Funding.pdf

PACKETS OF MATERIALS FOR OCTOBER 22, 2013

PACKET 2: DEVELOPMENTAL CENTER STAFF AND RESOURCES

Document

1. Specialty Services at the Developmental Centers
2. California Developmental Centers Services and Supports (Submitted by Terry DeBell)
3. Developmental Centers and Community Facility FY 2013-14 Positions
4. Contracts for Paid Employment at the Developmental Centers and Community Facility

The above listed attachments can be found at the following address:

http://www.chhs.ca.gov/DCTFDocs/DC%20Task%20Force%20-%20Staff%20and%20Resources.pdf

PACKETS OF MATERIALS FOR OCTOBER 22, 2013

PACKET 3: DEVELOPMENTAL CENTER LAND AND INFRASTRUCTURE

Document

1. Developmental Centers Land Use Summary
2. Maps of Developmental Centers
3. Harbor Village Project – Fairview Developmental Center

The above listed attachments can be found at the following address:

http://www.chhs.ca.gov/DCTFDocs/DC%20Task%20Force%20-%20Land%20and%20Infrastructure.pdf

PACKETS OF MATERIALS FOR OCTOBER 22, 2013

PACKET 4: COMMUNITY PLACEMENT PLAN AND COMMUNITY RESOURCES

Document

1. Programs of All-Inclusive Care for the Elderly (PACE) Summary
2. Community Placement Plan (CPP) Funding FY 2012-13 and 2013-14
3. Expanded Use of CPP Funding
4. Approved CPP Projects for Development FY 2012-13 and 2013-14
5. Facilities Ineligible for FFP and Out of State Placements
6. Estimate of Potential Need for ARFPSHN Homes
7. Regional Center Community Out-of-Home Living Arrangements
8. Residential Vacancies
9. Statewide Specialized Resource Service Data (Previously Provided)

The above listed attachments can be found at the following address:

http://www.chhs.ca.gov/DCTFDocs/DC%20Task%20Force%20-%20Community%20Placement%20Plan%20and%20Community%20Resources.pdf

PACKETS OF MATERIALS FOR OCTOBER 22, 2013

PACKET 5: OTHER INFORMATION

Document

1. Individuals in Jail Waiting for Admission to PDC Secure Treatment Program
2. Comprehensive Assessments Information

The above listed attachments can be found at the following address:

http://www.chhs.ca.gov/DCTFDocs/DC%20Task%20Force%20-%20Other.pdf

Parent Hospital Association (PHA)
Sonoma Developmental Center
Post Office Box 11264
Santa Rosa, California 95406

Date: December 15, 2013

TO: Diana Dooley, Secretary, Department of Health and Human Services

FROM: Kathleen Miller, LCSW, President PHA, Sonoma Developmental Center

RE: Clarification of the views of Kathleen Miller, task force member, supported by PHA members, family and friends of Sonoma Developmental Center residents, and members of the Sonoma Coalition to preserve services for SDC residents

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Idea 1: Establish a comprehensive medical resource center for the community

We heartily support this idea and the concept that a clinic be located on Sonoma Developmental Center land to serve center residents who move to alternative placements. We are also pleased that it can include supports for consumers living in other alternative community residential options, who have complex medical and behavioral needs as well as those individuals who are moving from developmental centers. We continue to support the idea that community services must: 1) include a range of options; 2) have access to stable funding; and 3) have available the necessary supports for individuals to live successfully outside developmental centers.

We also support the concept that a medical clinic be developed and maintained on Sonoma Developmental Center land that provides needed services to maintain the medically fragile individuals and behavior residents who are forced to move to alternative placements prior to them being moved. Those who are early movers must not be excluded from access to medical services simply because they were the first to move. Sonoma Developmental Center physicians should be given the option to work in medical clinics that serve these populations.

Idea 2: Use State Developmental Center land to develop community services, including a medical resource center and mixed use communities similar to Harbor Village

While we support the existing "Mixed-Use" Communities, such as Harbor Village, we do not support the expansion of such communities for current developmental center residents. We oppose the development of a large "Mixed-Use" Community on the Sonoma Developmental Center campus. Our reasons are as follow:

1- The residents with behavioral issues who currently reside in Sonoma Developmental Center require residences that do not have common walls and many require residences with structural supports. Residents with behavioral issues also benefit from having ample space to take walks and de-escalate when it is necessary. They require an accepting environment that is safe and allows them to be in charge of their behavior when they need to do so. They benefit from the calm, beautiful grounds and a few residents spend the large part of their day outside paying occasional visits to the farm, or store , or simply wandering the natural setting that is SDC. Also, some residents with these issues may require a residence that is locked for a time. However, if this is the case then provisions should be made to be able to transition to unlocked residences as they are able to handle them safely. It would be best if these moves can be accommodated while maintaining most of the elements of their environment. Some residents have changing needs in this regard and provisions will need to be developed that enable those individuals to be able to transition in place within their community from locked to unlocked residences as needed. Such requirements place serious economic constraints on the type of housing that would meet their needs and calls into question whether they can benefit from the advantages of living in a "Mixed-Use" Community.

2- We do not support the idea that community living is only possible in the company of non-disabled individuals. There are many examples of intentional communities, such as retirement communities, university campuses, housing arrangements for people with autism or other disabilities and developmental centers." Community" is more than "Mixed-Use "housing which under current regulations means three nondisabled residences per disabled residence. "Community" includes shared open space where people go to play, work, shop, eat, and celebrate life events together. Intentional communities for those with varied disabilities are often the first choice of consumers. Two such intentional community housing options currently exist in the Sonoma/Napa Counties in addition to SDC and both have wait lists.

3- Local communities may want to decide how much and what types of development occurs in their neighborhood. Restrictions may currently exist on DC land. Economic realities must be included in the decision of whether a "Mixed-Use" community may be the best use for DC land. There may well be other locations that would better fit such a "Mixed-Use" living project other than developmental center campuses. Much of those considerations lie beyond the scope of this task force.

4- We also feel it is important to point out that whatever else is on the DC land it will need to contain a crises program, a transition facility, a state facility for those whose needs are best met in state housing, and a medical clinic. We fully support the use of DC land for these uses first and foremost and these uses may not blend necessarily with a high density "Mixed-Use" Community.

5- We support a public/private partnership to create half-way ICF homes for behavioral residents who may reside for a time in the state zero reject facility. These homes can create a bridge to help residents transition into community housing or may need to provide a more long term residence for those who present a higher risk to both themselves or to the community. These homes can coexist with a state zero reject facility on Sonoma Developmental Center land.

Idea 3: Serving Individuals with Enduring and Complex Medical Needs

We support the examination and use of mortality studies and mortality data and their recommendations before the forced relocation of medically fragile developmental center residents.

While we understand that there are models of care in the community that provide services to consumers with significant medical needs, we do not agree that they negate the need for state operated facilities. Until death data confirming that these services, and the transitions to them, do not cause the decline and unintended deaths of medically fragile DC clients, they should not be forced into other living options. Currently we do not have access to this data.

Following the closure of Agnews Developmental Center, there were studies to look at the success of the closure and subsequent moves. While there were studies commissioned by DDS at considerable expense, they neglected to provide data on the one issue of concern to our families of medically fragile DC residents- the rate of deaths during the closure years in comparison to death rates prior to the closure process. When we attempted to obtain these data, we were given data that appeared to be inconsistent and incomplete. Attempts to get information on the rate of deaths during the current closure of Lanterman Developmental Center have yielded more inaccurate data or have been ignored.

Before we eliminate the safety net of the Developmental Centers for those with enduring and complex medical needs, we request that there be data collected on death rates. In the event that there is an increase in the rate of deaths during closures; we feel that needs to be addressed prior to any plan to move the remaining medically fragile individuals out. It is only reasonable that the DDS and anyone concerned about the safety and well being of these individuals would do this.

We also feel strongly that the clinic concept needs to be in place and ready to provide necessary medical support services before any medically fragile individuals transition to alternative homes. It is vital that they have access to enhanced medical services to maintain them in alternative settings.

Idea 4: Serving Individuals with Criminal Justice System Involvement

We support the state continuing to operate a secure treatment facility for those involved with the criminal justice system. We also support the continuation of Canyon Springs as a "step down" program for those leaving Porterville Developmental Center.

Idea 5-Individuals with Challenging Behaviors

We support state services for individuals with challenging behaviors including crises, stabilization and assessment, and residential services. Our reasons are as follows:

1 - Members of the Task Force understand and have stated that no model exists outside of the state facilities that can safely provide for some consumers with challenging behaviors. Closer examination of alternative housing reveals that what is best about an alternative housing model are the provision of enhanced staffing and access to behavior services. These models already exist in specialized housing arrangements with enhanced funding. These provisions have worked for some individuals, but have not worked for others who need even more services and supports. Adding increased restrictions on individual freedoms such as behavioral restraints and locking the homes, is not the answer. Without the intense oversight provided by layers of staffing and the many licensing requirements at the developmental centers there are too many opportunities for these restrictions to be misused. Locking the perimeter and/ or the building and mixing residents with different behavioral challenges, is very likely to lead to a dangerous situation. There is risk that such alternatives will not be safe much less therapeutic. The use of restrictive interventions should be used only with a high level of oversight.

2 - Developmental centers already have a process in place to ensure that consumers who are stable and ready to re-enter the community by selecting an appropriate living option, are able to do so. In fact, recent trailer bill language mandates that every single resident have a complete assessment to determine if they are able to make a move to the community. Any resident who expresses a desire to leave has immediate access to assistance from a Client Rights Advocate to assist them in realizing that wish. Without a mass forced relocation of the last remaining developmental centers of the challenging behavior residents, the DCs will continue to become smaller and leaner. What is needed now is not closure but restructuring to develop a state system to more cost-effectively serve this limited population

3 - Forcing those with intense behavioral challenges out of the developmental centers places them at unnecessary risk. We know from experience that this is a group of people that often suffer from all types of abuse, over or under medication, untoward police involvement, frequent evictions, a limited range of activities and other personal risks. For some people, the developmental centers have provided the only stable home they have ever known. We celebrate the stories of those who have gone to alternative homes and have been successful. Unfortunately, all too often, we families and friends are the only ones available when the community placement falls apart and the individual and the public are at risk. Too many families of behavior consumers have seen loved ones bounced from place to place due to the lack of necessary supports. Today, it is necessary to continue to have state residences to rely on so this will not happen.

What services should be included at Sonoma Developmental Center

1- Crises services are lacking in for many regional center clients. They can end up in emergency rooms, acute psychiatric centers created for the general population, and even jails. We believe a crises center that can be accessed quickly for those who need it could be a service that should be located on Sonoma Developmental Center grounds and staffed by experienced and qualified state staff.

2- A zero reject state facility, recommended by the task force, should be included in the services provided on the Sonoma Developmental Center site. There are current SDC residents who need to remain there for their safety and well being and this service needs to also be made available to behavior consumers who have been ejected from alternative residences.

3- Sonoma Developmental Center land is an ideal location for a medical clinic recommended by the task force to provide much needed medical services to medically fragile and behavioral former SDC residents who have been required to move to alternative placements. Medical services need to also include dental, durable equipment maintenance, and mental health services for these vulnerable former SDC residents.

4- Sonoma Developmental Center land is an ideal location for public/private partnership ICF homes. Some of these homes can serve as half way homes for behavior residents who are transitioning from the state facility to alternative homes outside Sonoma grounds. Additionally there could be ICF medical homes developed that serve the most medically fragile who would be at risk in other alternative placements. These ICF medical homes would be located near to the clinic to further insure that medical services are available as needed.

CAPT California Association of Psychiatric Technicians

December 18, 2013

Diana Dooley, Secretary
California Health and Human Services Agency
1600 Ninth Street, #460
Sacramento, CA 95814

RE: TASK FORCE ON THE FUTURE OF DEVELOPMENTAL CENTERS DRAFT REPORT

When I and concerned family members, professional staff, and friends and neighbors turned out in droves for a February 2010 hearing on the at-the-time proposed closure of Lanterman Developmental Center, conservator Terrence King asked attendees, "Is this a formality? Is this a hearing or are you hearing us?" Despite the words of King and more than 400 others, that hearing was just a formality – merely something to check off on a chart to say "stakeholders were involved in the process." Now, despite the words said and the tears shed at that hearing and elsewhere, Lanterman Developmental Center is set to close at the end of 2014.

Is the Task Force on the Future of Developmental Centers just another formality like the 2010 hearing, as well as other closure "processes" in recent years? With all due respect, when I was selected to serve on the Task Force for the Future of Developmental Centers, that is what I asked myself -- it seemed to be just another formality as I'd seen too many times in the past, this time on a statewide scale. Given the vastly unequal representation of those who value developmental-center services on the task force, the developmental-center voice already was at a disadvantage at the start and -- despite your personal, insightful and earnest efforts -- our discussions and draft report unfortunately reflect this imbalance toward "community" care.

But the clients and families I have served for more than 35 years at Lanterman and elsewhere in Los Angeles County are not formalities, and I was determined to be heard on behalf of those living and working in our California developmental centers. So as a vocal participant in the task force, I am taking one more opportunity to speak out. As pledged advocates for Californians with developmental disabilities and mental illnesses, that is was Psychiatric Technicians like me are charged – and honored -- to do.

As the task force's draft report says, "The recommendations of this Task Force are that the future role of the state is to operate mostly smaller, safety-net crisis and residential services coupled with specialized health care resource centers and public/private partnerships, as well as the Porterville DC Secure Treatment Facility and the Canyon Springs Community Facility."

This draft report is not a closure mandate and the included broad summary recommendation actually offers some hope for the continuance and reimagining of federally accredited, cost-effective, state-administered, professionally staffed and truly nonprofit services sought by many

Californians and their families. But many more details on what Californians with developmental disabilities need, want and choose – wherever they live – are sorely needed. Because of this reason, I respectfully cannot support the draft report and its recommendations as currently written.

MUCH MORE DATA IS NEEDED PRIOR TO TAKING ANY ACTION OF ANY KIND

Even with our discussions and the frankly superficial data provided to task-force members by the California Department of Developmental Services, we continue to know very little about those who have moved from developmental centers, even here in California. Where are they living? What "equal or better" services are they receiving immediately upon their moves, as required? What are their illness, injury, hospitalization and mortality rates – all of which are tracked in a developmental-center setting per federal regulations? These are life-and-death questions that remain unanswered – and remain unanswered even in the face of ongoing moves from California developmental centers as we speak.

While the draft report notes as a fact that "thirteen states and the District of Columbia have no large state-operated institutions," there is no data provided in our meetings on these other states' individual movers to shed any light – for better or for worse -- on this freestanding statement. However, as Samuel Bagenstos, former principal deputy assistant attorney general in the U.S. Department of Justice and an expert on deinstitutionalization, recently said, "It should not be surprising that the coalition of deinstitutionalization advocates and fiscal conservatives largely achieved their goal of closing and downsizing institutions and that deinstitutionalization advocates were less successful in achieving their goal of developing community services."

If we cannot answer the most basic questions on services for people with developmental services in our state and our nation before taking any action of any kind, the work of this task force is moot.

CALIFORNIANS ARE NOW DENIED THE FEDERAL CHOICE TO LIVE IN DEVELOPMENTAL-CENTER SETTINGS

The right of people with developmental disabilities to choose care in a developmental-center setting was barely touched upon in our task-force work. The draft report mentions the U.S. Supreme Court's *Olmstead* requirements: "[S]tates are required to place persons with mental disabilities in community settings rather than institutions when the State's treatment professionals have determined that community placement is appropriate, the transfer from institutional care to a less restrictive setting is not opposed by the affected individual, and the placement can be reasonably accommodated, taking into account the resources of the State and the needs of others with mental disabilities."

But in addition, a majority of justices noted in *Olmstead* that "[w]e emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings...Nor is there any federal requirement that community-based treatment be imposed on patients who do not desire it." And a plurality wrote, "No placement outside the institution may ever be appropriate . . . 'Some individuals, whether mentally retarded or mentally ill, are not prepared at particular times-perhaps in the short run, perhaps in the long run-for the risks and exposure of the less protective environment of community settings' for these persons, 'institutional settings are needed and must remain available.'" And, "as already observed by the majority, the ADA is not reasonably read to impel States to phase out institutions, placing patients in need of close care at risk... 'Each disabled person is entitled to treatment in the most integrated setting possible for that person — recognizing on a case-by-case basis, that setting may be an institution.'"

Also, federal Medicaid law and regulation require that beneficiaries be given the choice between ICFs/IID (which include federally accredited developmental centers) and HCBS waiver care. Therefore, states are required by federal law to offer individuals who are eligible for Medicaid home and community-based waiver services the choice between community-based care under the waiver program or institutional services, such as developmental centers.

As I and many others discussed at our meetings, and as emphasized in these federal decisions and regulations, a person's Individual Program Plan must rule all decisions in order to empower that person to live the life he or she wishes. I myself uphold that mandate every day in my work, respecting the wishes of individuals to receive services in whatever settings they desire.

However, the current California moratorium on developmental-center admissions goes against these federal findings and requirements. According to the moratorium, now only Californians in acute crisis can be admitted to developmental centers for a matter of weeks or in cases of criminal-justice involvement. When the possibility of lifting the moratorium was brought up in our discussions to again allow other admissions as individuals wished, it would flatly not be considered, effectively and entirely removing current federally regulated and professionally staffed developmental centers and services off the table, despite federal law.

If we as a task force are seeking to reimagine developmental centers and their services – along with other choices and services for people with developmental disabilities – now and into the future, then this major state denial of a federally recognized choice must be addressed.

DEVELOPMENTAL CENTERS AND STAFF ARE VALUABLE RESOURCES FOR TASK-FORCE PRIORITIES

Task-force members discussed the urgent need for three overarching priority services in the larger community for Californians with developmental disabilities: services for individuals with enduring and complex medical needs, services for individuals with challenging behaviors and services for individuals involved in the criminal-justice system. As I and others testified, these services and many more are all currently available at state developmental centers, but as I previously noted, these services are now denied to Californians under the state's admissions moratorium.

The broad recommendation issued in the draft task-force report does offer some hope of continuing and/or expanding state developmental-center-style services even into different venues and settings, which holds promise for Californians in need of these lacking services. Key among these ideas are:

- MEDICAL – Central medical homes, PACE-modeled one-stop centers, psychiatric services, specialty services, care for ventilator-dependent individuals and "962" nursing-services homes.
- BEHAVIORAL – Specialized homes and facilities offering "zero-eviction" wraparound services to Californians with challenging and potentially dangerous behaviors, as well as services to Californians with dual diagnoses and multiple diagnoses of co-occurring developmental, psychiatric and medical disabilities (individuals Psychiatric Technicians also are specifically licensed to assist, regardless of setting).
- FORENSIC – Continued utilization, expansion or replication of Porterville and Canyon Springs' state-operated rehabilitative services for people with developmental disabilities involved in the criminal-justice system, as well as group locked facilities.

Also of positive nature is the draft report's inclusion of seasoned developmental-center professionals as a key resource: "The general agreement that the system would benefit by preserving this [staffing] resource."

However, of note is the report's assumption that all who are currently in developmental centers wish to move, as shown in the example regarding 962 homes: "Of the 445 individuals residing in a DC SNF [Skilled Nursing Facility], it is estimated that roughly 315, or 70.9 percent, would need the services of 962 homes." While that statement notes their potential need, it does not note their wishes as outlined in their IPPs which, again, should take priority in any decisionmaking. Any developmental-center resident already has the right to move to another location as he or she wishes, although, as previously stated, that right does not now include the ability for others to move to developmental centers.

In addition, while there is task-force agreement that developmental-center staff are an important resource for Californians with developmental disabilities, nowhere is their use guaranteed in any of the possible proposed settings. For instance, in the locked private settings currently being implemented and included in our discussions and the draft report, rather than having these facilities state-implemented and state-staffed with licensed and certified professionals trained in these behaviors, these facilities are instead hiring direct-care staff with a mere 16 hours of training, setting these facilities – and residents – up for failure.

While we consider the future of developmental centers, we must also fully consider and utilize the resources they have available – whether in their current form or other proposed forms and venues -- for all who need or desire them.

WE ARE HERE TO SERVE

As I mentioned at the outset, Psychiatric Technicians are pledged, licensed nursing advocates for Californians with developmental disabilities and mental illnesses wherever they reside or receive services, including developmental centers, state hospitals, prisons and jails, skilled nursing facilities, county mental-health departments, acute hospitals, day programs, rehabilitation facilities, crisis teams, schools and school districts and many other settings. It takes a certain person to do our difficult, challenging but ultimately rewarding work, whose true hallmark is to always find hope in what oftentimes so many others have found hopeless -- so we, as a profession as a whole, are professional optimists.

Even with the concerns I've expressed here, I maintain the heartfelt hope that our task force has not been an exercise in futility or -- as voiced at our Lanterman hearing -- a mere formality, but that it actually marks the start of what must be a much more involved statewide and national conversation on the need for quality, professional services for all Americans with developmental disabilities. For 19 people to have done what we all have in just a few months is noteworthy, and an honest, in-depth, data- and choice-driven process must continue. I have enjoyed working with you and others as part of the task force, and I do hope I can continue to serve as a resource to help in whatever way possible, as my coworkers serve thousands of Californians 24/7.

Sincerely,

Brad Whitehead

Brad Whitehead, PT
California Psychiatric Technician License #20379

ATTACHMENT 8

THE VOICE OF LAW ENFORCEMENT, PUBLIC SAFETY & CONSUMER PROTECTION

CALIFORNIA STATEWIDE
LAW ENFORCEMENT ASSOCIATION

5762 BOLSA AVE. #104, HUNTINGTON BEACH, CA 92649 WWW.CSLEA.COM
PH. 714.894.4411
800.522.2873
FAX 714.893.3030

December 26, 2013

Via US Mail
Diana Dooley, Director
California Health and Human Services Agency
1600 Ninth Street
Sacramento, CA 95814

CSLEA has had an opportunity to review the Task Force Draft of the "Plan for the Future of Developmental Centers in California" which the California Health and Human Services Agency intends to submit to the California State Legislature. As the representative of the Peace Officers, Investigators and Firefighters who dedicate their lives to the well being of staff and clients at each of the Department of Developmental Centers' facilities, CSLEA is not in a position to endorse the overall conclusions drawn from this Draft which would likely result in the elimination of several Bargaining Unit 7 positions. CSLEA also lends its support to the position taken by the California Psychiatric Technicians in its letter to you, dated December 18, 2013.

The Developmental Centers, even if in a reduced form, remain the best hope for the continuing development of the clients who are served by them. The staff in place has the training to maintain the high standard which has satisfied the DC clientele for years. This sentiment was echoed by the parents of children who reside in the DCs, such as Fairview and Sonoma, during the public comment portions of the Task Force meetings. While it was satisfying to see and hear from those former clients who shared their stories of being able to live on their own, it must be remembered that they have been able to "graduate" to their current status due in part to the services provided at the DCs.

The Draft provides no assurances as to the number of Bargaining Unit 7 members which will remain on staff, where they will work, and how their roles may be altered in the future if the Draft's recommendations are carried out. Many questions exist which need to be answered, including what is the process for moving individuals out of the secure treatment areas and into the communities at large? Also, who will look for the clients when they eventually elope into the communities where they are housed? CSLEA feels the next step to be taken in this process is to analyze who would be responsible for ensuring the safety of the clients and of the staff who serve them. This should require the creation of a panel to examine these concerns. However, in contrast to the Task Force body, the panel should consist of a more balanced group, including a larger presence of individuals or organizations whose main intentions are not to seek the eradication of the current DC system.

ATTACHMENT 8
(Continued)

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CSLEA looks forward to continuing to work with HHSA and DDS in developing strategies to address these issues in the coming months and years. Regrettably, in its current state, we are unable to give approval to the recommendations included in the Draft.

Sincerely,

David De La Riva
CSLEA
Senior Legal Counsel