

December 18, 2013

Diana Dooley, Director
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1600 Ninth Street, #460
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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,

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