



Testimony before the Senate and Assembly Human Services Committees

JOINT OVERSIGHT HEARING Oversight of California's Regional Centers: ensuring integrity, transparency, and best practices in a challenging fiscal environment November 4, 2010

Good Morning, members of the Senate and Assembly Human Services Committees and staff.

On behalf of people with developmental disabilities, their families, and advocates, I want to thank you for this opportunity to discuss the California developmental services system.

My name is Marcy Good. I am the Chairperson of the State Council on Developmental Disabilities and a member of Area Board X on Developmental Disabilities serving Los Angeles County. More importantly I am the mother and friend of Alex, a young adult who accesses services through the developmental services system in California. Of all my accomplishments, I am most proud to be Alex's mom, supporter and advocate, for he exemplifies how a person with disabilities can learn, grow and be successful in society despite his labels. I wish I could say it has been an easy journey, considering the entitlement to services California enacted and fought to maintain, the talent of many teachers and providers of services, and the fortitude of consumers and their families to overcome barriers, whether intended or not, in order to access services and supports to allow them to be included, productive and assets as opposed to liabilities to society.

Today, I was asked to focus on the recent California State Auditor report addressing the developmental services system and specifically regional centers from a family/advocate perspective.

"The Council advocates, promotes & implements policies and practices that achieve self-determination, independence, productivity & inclusion in all aspects of community life for Californians with developmental disabilities and their families."

I particularly appreciate this opportunity since consumers and families were not given an opportunity to provide input to the Auditor although the recommendations impact their lives. In the future we would hope that California adopts the credo of “nothing about us without us” as the Legislature has today.

Before I discuss some specific issues, I want to be clear that consumers and families appreciate California’s efforts to maintain a system of services and supports designed to meet our needs from birth to death and while critical of some of the operational approaches, still believe the original design of local control and accountability is a far more acceptable than a solely state operated delivery system. However, the growth of a system from serving a projected 25,000 people to nearly 250,000 over 40 years, has evolved into its own bureaucracy that now requires more transparency at the regional center level and oversight and accountability for regional center actions at the State level.

The sheer size of regional centers as corporate bodies many have outgrown the concept of local control, thus placing volunteers board members in a compromising position of attempting to make policy for a multimillion dollar corporation, while coming from a family level operational environment. The natural outcome is for the staff to assume more and more control over the policymaking of the corporation, thus reducing the intended citizen control. This coupled with lack of uniformity among the policies and operational procedures of regional centers has served to undermine consumers and families’ faith that the system is there to meet their needs as opposed to supporting corporations. And when the anticipated remedy to this situation is to seek oversight and accountability for regional centers policies and actions from the Department of Developmental Services (DDS), consumers and families perceive that DDS has little control over actions of the centers or ability to take timely and definitive corrective action. This feeling may be due in part to the lack of transparency in the system.

Consumers and families experience how the business practices of regional centers ultimately impact consumer choices and access to services and supports. Purchase of service review groups and multilayer approval processes, dilute the ability of consumers and families to control and even influence their choice of services and providers and thus undermines the core of the individual planning process. This coupled with the lack of information about choices and options available to consumers and families, further degrades the intent of the planning process and removes flexibility that might be expected as part of the system. Denial due to lack of service options or delay in processing requests are becoming the norm rather than the exception, thus increasing consumer and family concerns and the sense that they must be willing to fight every step to access services and supports.

Families' fears and trepidation are exemplified by the Audit's findings that staff do not believe there is a safe venue to raise suspected improprieties at regional centers. If staff is intimidated, imagine how a consumer or family feels when they need to stand up and fight with a center, knowing the center holds most of the cards unless the family has the fortitude and resources to take a center on through fair hearing and legal processes. Many simply give up.

Consumers and families are seriously concerned that the Auditor's report suggests that regional centers must purchase the "cheapest" services and supports under the July 2009 cost-effectiveness amendments to the Lanterman Act. While not disagreeing that regional centers need policies and consistency in the selection of vendors and in the rate setting process for those vendors, we do not believe that should be construed as only using the "cheapest" vendor without a cost benefit analysis of how that vendor can meet the needs of a consumer or family in an economical manner. This is particularly important when factoring in the long-term cost to the consumer and system should they receive inadequate services and supports because it was cheap but achieved none of the planned outcomes. We caution the Legislature to be cognizant of this concern if or when considering any potential action relative to the audit report.

Consumers and families can cite specific instances of these generalized concerns, but would rather spend energy on working collaboratively to increase consumer/family control and flexibility within the service system via self-determination and individual choice budgeting options; receive more information about their options and how to exercise those options; be allowed more flexibility to determine how to meet their needs and desired outcomes; like regional center staff, not be intimidated by the system and receive case coordination services from empowered staff who share the consumer/family values and will advocate for them; identify and examine methods to achieve cost efficiencies in regional center operations such as consolidation of some administrative functions; and potential amendments to the DDS/regional center contracts that give DDS more oversight and timely intervention into regional center policies and actions if found to be inconsistent with the intent of the Lanterman Act.

Again, thank you for the opportunity to participate in this hearing. The State Council and consumers and families stand ready to be part of the process toward enhancing the system while being mindful and protective of the public's assets.