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Chairwoman Sen. Carol Liu and Members
Senate Committee on Human Services
1020 N Street, Room 521
Sacramento, CA 95814

Dear Senator Liu and Committee Members:

I submit this written testimony in reference to your Committee hearing scheduled for March 22, 2011, entitled "The Lanterman Act in 2011 and Beyond," because I will be unable to attend the hearing and testify in person. I am an attorney practicing in the area of developmental disabilities for almost 15 years, as well as a family member of an individual with a developmental disability, and have experienced the DD system from many angles.

First of all, I thank the Committee for scheduling this hearing. For the reasons set forth below, I also urge the Committee to continue this important inquiry, and to hold additional hearings to receive broader input and review the status of the Lanterman Act once the "Best Practices" process contemplated by this year's DD trailer bill has been completed and the Legislature has seen the result. I urge the committee to protect the integrity of the entitlement of the Lanterman Act and the IPP process.

As the California Supreme Court ruled in 1985, the Lanterman Act creates an "entitlement" to services, where the State is obligated to purchase "services that enable him [or her] to live a more independent and productive life in the community." A vitally important part of this system is the Individual Program Plan (or "IPP"), where each individual's needs and desires are reviewed, and where people with developmental disabilities and their families are able to exercise their "right to make choices in their own lives." Welf. & Inst. Code § 4502(j).

The IPP is the mechanism under which "the rights of developmentally disabled persons and the corresponding obligations of the state toward them under the Lanterman Act are implemented." In recent years, however, the rights of those this system serves, as effectuated by the IPP, have been steadily eroding. Some individuals and families find that the IPP process is not working as intended, and that many of the requirements and specifications of the law regarding the IPP are not being followed.

I believe it is very important for the Committee to hear from those whom the Lanterman Act and the IPP process was designed to serve and protect: The individuals with developmental disabilities and their families. While the perspective of those administering the system is one part of the picture, it would be incomplete to rely only on the testimony of those running the current system. I urge the committee to solicit the

input and participation of consumers and family members, who have the greatest stake and interest in the future of the Lanterman Act.

The Bureau of State Audits report surveyed some regional center staff and service providers, and identified serious problems with vendor selection, contracting processes, lack of documentation in IPPs, and widespread fear of retaliation and favoritism. However, as the audit report acknowledges, it did not examine substantive results of IPP meetings, nor did the report survey consumers or family members about their experiences and views on the IPP process or the Lanterman Act system as a whole.

In order for your Committee to make informed and wise policy determinations and choices regarding the future of the Lanterman Act, the views, hopes, desires, and experiences of consumers and family members must be taken into account. If concerns about favoritism, retaliation, and failure to follow the law are prevalent among service providers and regional center staff, there is no reason to believe that those concerns are not also prevalent among consumers and families.

To date, the only real effort to begin to collect this data has been undertaken by Keeping the Lanterman Promise, an independent statewide organization of family members, friends, and advocates, which can be found online at KTLP.org. Our online survey has received over 800 responses from across California, and the results thus far have been provided to your committee staff. I believe that the results of this survey paint a much different picture of the system than you are likely to receive in testimony at your Committee hearing.

In its responses to the State Audit, DDS has claimed that it is cannot "interfere" with the operations of regional centers, because they are independent, community-based organizations. DDS also claims that its authority is limited by the 1985 Arc v. DDS Supreme Court decision, which noted in passing that "the responsibility of DDS ... does not extend to the control of the manner in which they provide services or in general operate their programs." But DDS' narrow view overlooks the Supreme Court's directive that DDS "has jurisdiction over the execution of the laws relating to the care, custody, and treatment of developmentally disabled persons."

DDS also ignores Sections 4433, 4434, and 4629, each of which impose affirmative oversight obligations and authority on DDS. The Department of Developmental Services has an explicit "obligation to ensure that laws, regulations, and policies on the rights of persons with developmental disabilities are observed and protected." Welf. & Inst. Code § 4433(a)(1). Furthermore, the Legislature has recognized the Department's "responsibility to monitor regional centers" (§ 4434(d); *see also* § 4629(e)), and has directed "that the department ensure that the regional centers operate in compliance with federal and state law and regulation and provide services and supports to consumers in compliance with the principles and specifics of this division." § 4434(a). DDS' contracts with each regional center must "include a provision requiring each regional center to render services in accordance with applicable provisions of state laws and regulations." § 4434(c); *see also* § 4629(b). "In the event that the department finds a

regional center has violated this requirement ... the department *shall* promptly take the appropriate steps necessary to ensure compliance with the law." §4434(c) (emphasis added). All of these sections were enacted in 1997, over a decade after the ARC v. DDS decision, and so the Supreme Court decision cannot be construed as limiting or interpreting subsequent legislative action. On the contrary, the statutes indicate legislative intent to give DDS *more* authority (and responsibility) than the Supreme Court outlined in 1985.

The reality is not that DDS cannot exercise oversight authority, but that it has chosen not to do so. In order to insure that the IPP process as set forth in the Lanterman Act is being followed, the Legislature should direct DDS to in fact monitor and oversee the IPP process, as the State Auditor recommended. The authority to do so already exists, and Senator Liu's pending SB 382 would be another important step in this direction.

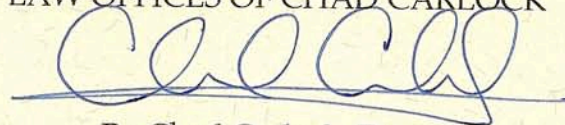
Finally, a few comments about "Best Practices" (formerly "Service Standards") and the Department's Work Group process. Many consumers and family members lack confidence in this ongoing process, and have not been permitted to participate or learn about what is happening in the process. The process has been opaque to the vast majority of consumers and family members. The process also assumes a certain result, as it asks "What should Best Practices look like?" instead of first considering "Should we implement Best Practices?" I do not believe that the Department's confusing online survey, coupled with the Work Groups, will provide adequate representation or input for the finished product to be anything but a proposal by and from DDS. In past years, the end result presented by DDS was claimed to have been a consensus product, when in fact that was not the case. I am hopeful that the same representation will not be made this year.

The IPP is an individualized process, focused on the needs and choices of the individual and their family. By definition, categorical caps or limits are fundamentally inconsistent with the IPP and the Lanterman Act entitlement as it currently exists. Placing limits on services, be they soft caps, hard caps, or elimination of entire service categories, is antithetical to the objectives and promise of the Lanterman Act. Limits on services cannot be considered a "best practice" under any reasonable definition of the word "best."

Again, I thank the committee for holding this hearing and for the opportunity to provide this input.

Sincerely Yours,

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By Chad Carlock, Esq.