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October 30, 2010

The Honorable Jim Beall, Jr.
State Capitol
P.O. Box 942849
Sacramento, California 94249-0024

Subject: Joint Oversight Hearing of California's Regional Centers

Dear Assemblyman Beall:

I write to you as a resident of California, a Navy wife, and the mother of five children – of whom three are current consumers of the San Diego Regional Center for the Developmentally Disabled while another is a former consumer of the same entity. Thank you for the opportunity to share some of my experiences and conclusions.

- **SDRC leadership is not transparent.** I have served for years on the local Area Board of the State Council for Developmental Disabilities. At our public meetings on more than one occasion, I have requested that SDRC publicize a complete list of the services that it provides to consumers, from cradle to grave. The Executive Director agreed to do so, but has never made such information available despite a website that makes such an endeavor possible at no cost to the RC.
- **SDRC "service coordination" is an oxymoron.** During the 15-years of my interactions with SDRC, I can recollect only a *single* instance where my child's service coordinators suggested a service. The culture, from my vantage point, seems to treat provision of services to persons with developmental disabilities as a strange amalgamation of imposition and covert operations. From a parent's perspective, seeking help from this Regional Center involves researching among the parent community, accusing the Regional Center of having a particular program, and then needing to request using some sort of "secret password" (i.e., using the correct lingo to qualify for and trigger the request to reach a decision-maker).
- **SDRC decision-makers seem to believe that they can operate as "judge" for appropriate parenting.** In the real world, there exists a wide range of acceptable parenting strategies and priorities. But once one's child is diagnosed with a developmental disability, one is subjected to continuous judgments from strangers who use their power to "award" publicly-funded social services as a way to shape parental behavior. I am not talking about illegal, immoral, or illicit actions – I am talking about lawful, rational, and safe activities of daily living that other residents of California take for granted. That is patently contrary to the sense of liberty and personal freedom that founded our nation and is available to non-disabled citizens. I am aghast at the types of comments that have been made to me and other parents. These comments range from the absurdly irrelevant "your carpet has a stain" to the wholly lacking in compassion "your child will never be normal" to those outside the scope of the commenter "she seems kind of 'Spectrummy'". What other segment of the California population must open their private homes to a pseudo-state agency and tolerate rude, inappropriate, and undignified remarks? The ultimate arbiter of services for youngsters with autism, because my son has a history of

chronic fevers, etiology unknown, had the audacity to recommend that my family not allow him to participate in community-based outings "for his own good". How will that 7-year-old gain skills for independence (as is the theoretical mission of the DDS system) if he lives in a familial bubble? In my experience, my family's ability to live as we wish in our own residence is limited by SDRC. That type of protectionism, from a person who surely knows better, is the opposite of self-determination and "people-first".

- **SDRC is single-handedly jeopardizing the provision of supportive programs for the families of active-duty armed forces.** The military implemented several programs to supplement services (e.g., respite care during deployment or for exceptional family members, ABA services for certain beneficiaries with autism spectrum disorders, etc.). The Regional Center's reaction, upon learning of these services, has been to immediately eliminate such services to military families. Please note that the services were never intended to supplant state-provided services; they were intended to put into place additional supports for a multiply-at-risk population. Families manage kids with disabling conditions absent the physical presence of one parent; in our case, my husband spent 18-months away from us within a period of 24-months. Cost-shifting on the backs of those who volunteer and sacrifice is a discouraging and unethical practice.
- **SDRC has not been successful at developing new programs to serve our burgeoning adolescent and adult population whose disability (autism) does not neatly fit into any existent adult service model.** SDRC has unmet demand for residential options. SDRC has not supported its current vendors, awarding its staff payment for furlough days or small raises while vendors have seen their rates cut time and again. SDRC is not even doing a reasonably decent job at serving the young population, by mandating a level of parental involvement that is nothing short of paternalistic. Does it not help our state to have parents of individuals with exceptional needs producing and contributing to our communities and economy? Does it stand to reason that because an individual birthed a person with a developmental disability that a pseudo-governmental entity can deny service to the person with the disability because of the lack of capacity or participation of his/her parent? The state's responsibility is to the person with the disability – whether they were blessed with a healthy, functional, and economically-comfortable family or not.
- **Where is self-directed service?** This RC clearly has no incentive to switch to a program that will result in a reduction in operating expenses, budget and staffing at the RC. The state could save millions of dollars by eliminating the gate-keeping, paper-pushing folks who spend the bulk of their time preventing services from reaching consumers. People will vote with their dollars for the services that are necessary, beneficial and appropriate. In the vast majority of cases, the only person on the planning team with a longitudinal, direct interest in the person with the developmental disability is the parent or guardian or conservator. Those folks having greater control will be the best course for funneling dollars into meaningful programs – and for bringing rationality back to the DDS budget.

I sincerely hope that these and other issues will receive attention of your committee members. Thank you allowing me to contribute to the dialogue from afar.

Very truly,

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