<u>Senate Human Services Committee Members</u> November 2, 2010

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Dear Assembly Members:

My son Kyle is a client of the San Diego Regional Center. He is now 27 years old and receives services from the SDRC. The services we've received have been poorly administered and fiscally irresponsible.

I'd like to start out by telling you a little bit about our relationship with Regional Center. First, Kyle has Autism, Epilepsy, Tourettes Syndrome and Life Threatening GERD. He doesn't have a normal sleeping pattern do to his seizure disorder. He can (and does) go through periods of aggression. He's 24 hour supervision too. Throughout his school experience, he was in the most restrictive environment which is non public schools. He did very well in that placement.

Working with the SDRC has been a major stress for my husband and me. Kyle was kicked out of public school. We had to wait for 6 long months before we found a placement that would take him. Meanwhile, I had to quit working since Kyle had no placement. We need help so bad. My husband works full time. I worked part time in Special Education. I wrote a letter to SDRC and request extra respite hours that I so badly needed since I was home with him 7/24. I got a call from my caseworker and was simply told NO!

We never got a letter to deny our request. Kyle was home with me 7/24 over the span of 7 long months. At that time we only got 30 hours of respite per month. I was Kyle's Community Base Instructor, Speech Therapist, OT plus his mother.

When I went to research how to file a complaint in order try again to receive more respite. I found out the complaint went right to the SDRC Chair. What a conflict of interest!! Needless to say, I never got back <u>anything</u> in writing. I quickly learned there is no accountability with SDRC to uphold the law.

Three weeks ago, I got a call from my new caseworker. She told me that my 40 hours of respite was going to be cut down to 30 hours. Once again, no letter. SDRC is mandated to write a letter of any changes to our services. I told her I needed my respite so bad because I've had 5 back surgeries. 3 Neck Infusions (with a plate) and 2 lower back surgeries and a Disc Ectomy. The last surgery almost killed me. My husband has a bad back and is in PT too.

The last time I asked to have the extra respite they started to put pressure on me to have my next surgery. Especially from Bill Stein. He said he had the same problems as me. He stated he lives with it just fine! I asked him if he's had surgery? He said no. Yet, he tried to minimize my medical problems. I've even loss feeling in my legs and couldn't drive which was the last reason for having surgery. He doesn't have a son who is big and aggressive that he has to bathe, shave, and wipe him down after showers every day. I cook for Kyle, keep everything locked so he doesn't eat everything out of our refrigerator. Wash his clothes, take him everywhere, give him medications, watch him closely and the list goes on.

We ended up going through Due Process for the extra respite my doctor felt we needed as a family. Bill Stein wanted it to go to Committee. That's illegal so we went to Due Process with an Attorney. I was able to get the extra respite for one year despite my doctor's recommendations of 80 per month. Kyle is a Medical Waiver Client with the SDRC so you know that he needs extra services etc.

We have been trying to get my son set up in Supportive Living. The SDRC has set up road block after road block. We had an agency finally agree to take Kyle as a client. Then the SDRC said a woman named Peggy Web of Mosaic would have to come in and assess Kyle. She is a former SDRC Employee.

I wrote a very detailed synopsis on my son Kyle and turned it in to the SDRC prior to Peggy turning in her report. Peggy continued to go around and interviewed Kyle's Program. Some of the employees of his program called me in confidence to tell me she is saying we were trying to make Kyle sound like a monster!! She never looked at his history!!

Finally, she spoke with the program's behavior specialist. He's done respite for us. On occasions when he had Kyle, he would call us and ask us to pick him up because Kyle was being too aggressive and loud. Needless, he set her straight.

Once we got the report back from Peggy Web, she wasn't present. When Bill Stein handed it to me so both my husband Steve and I could look at it. I instantly got mad. I ask Bill how much did this report cost?? He looked at me puzzled. He said why? I said I want to know!! He said around $1600 plus. Over half that report was my report copied and included with hers. She never asked to use my report along with hers. This is the SDRC to try to get us to give up on Supportive Living for our son. We still are perusing it since it would be the appropriate way for Kyle to live. He wants to live at the Townhome we currently rent out.

I could go on with many other problems and illegal interactions we've had with the SDRC over the years. I feel I can offer you a solution to the problem of lack of accountability with the Laterman by SDRC so parents/consumers get a fairer opportunity to receive (or get denied) services & therapies.

If you all could work towards removing a specific clause in the contract that DDS has with all the Regional Centers in California. That clause is the one that states parents can't bring attorneys to Due Process and have them collect Attorney Fees against the Regional Center.

If you lifted that clause and ***allowed*** parents to collect Attorney Fees, you would see the climate change with the way Regional Center works with family. In fact, you might even see them hold themselves accountable to their own mission statement (and the Lanternman Act) that they've been unaccountable for years!!

Thank you for your time with my concerns and recommendations. Please feel free to contact me with any questions.

Respectfully Submitted,

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