

February 10, 2011

The Honorable Mark DeSaulnier
Chair, Senate Budget Sub-committee #3 on Health and Human Services
State Capitol, Room 4203
Sacramento, CA 94249

Dear Senator DeSaulnier,

My daughter was diagnosed in 2000 with autism spectrum disorder (ASD). Since that time, our world has been turned upside down. The focus of my life has shifted from any sense of normalcy and been thrown into complete and full-time care for my autistic child. Our family has worked tirelessly to provide her with the ABA therapy in our home, an appropriate school placement, invaluable medical intervention, and loving emotional support.

I am writing to strongly urge the budget subcommittee #3 on Health and Human Services to reject Governor Brown's recommendation to cut an additional \$750 million in funds for the Department of Developmental Services. I am asking the amount of the cuts be more in line with the reality that the population served by DDS can likely handle a "reduction" rather than a complete "elimination" of supports which are needed to have any meaningful quality of life now or in the future. Our children are not numbers simply to be slashed. There are lives and futures at stake!

You see, I have been blessed with people in my life who were touched with autism prior to the Lanterman Act. A close family friend took their daughter, "Diana", to Sonoma State Hospital in the early 60's for an evaluation. Their daughter was diagnosed with autism, is now in her late 40's, and is still a resident of Sonoma State Hospital. Her mother, a close friend of my mother's and someone I see often when I visit my childhood home, has a heavy heart every day of her life. When she sees my daughter, I see the complete sadness and regret for her own daughter: if she only had been born in a different time.

One of the first therapists to work with my daughter spent 6 months working at Sonoma State Hospital with adults with autism.

Having two individuals in my life that have first hand experience, emotional first hand experience, with the result of NO INTERVENTIONS for a child with autism has given me a sense of what I do NOT want for my, or anyone else's, family member.

The need for me to assure my daughter does not end up in a facility, where she will surely not receive the one-on-one care and medical attention she needs to ensure her condition does not completely debilitate her goes to the core of my being. To say I am extremely fearful for her future is a gross underestimation. I am terrified!

My daughter receives ABA from a Non Public Agency (NPA). I have worked countless hours coordinating her program with Alta California Regional Center and her local school district. Every goal, every skill, must be taught through repetition, with reinforcement. It must be mastered, generalized and maintained. She must be taught functional, self help, social, speech, conversational, theory of mind, educational and safety skills, etc. As a three year old, the only skill she had that scored in the normal range was "imitation". An appropriate placement for her did not exist. We had to design our own.

When placed in an autism class, she regressed terribly. She does not belong in a special day class. She cannot attend regular education on her own. She needs bell-to-bell support: a one-on-one aide with her at all times, coordinated between home and school with her full family support. The skills needed for school must be taught at home first. They are then introduced in the school setting and she is able to generalize them to the classroom and be successful. This takes a team: her home "family" team, her NPA team, the school staff portion of her "team". It takes every piece to give her the education she is entitled to as a US Citizen.

That includes the piece provided by Alta California Regional Center. How can she be successful at school without the underlying skills? The answer is she cannot. If she cannot be successful in the general education setting (with aide support, with reinforcement, with accommodations and modifications as per IDEA), there is no placement that is "appropriate" (as per IDEA). She will be forced to be educated at home. Isolation is not what a child with ASD needs. In my daughter's case (and many others), the need to be with "typical" peers is a cornerstone to her education. Where else is she going to learn (once again with one-on-one support, prompting when needed, always with reinforcement, accoms and mods) how the world around her works? People with ASD do not ponder their environment like typical people do. They do not watch their parents and peers, follow their every move, listen to words and figure what they mean. No, ASD children must be taught in broken down steps. The point is: they CAN BE TAUGHT. They are being taught. The Regional Center system is

contributing to the futures of many, many children with ASD, and it will pay off in cost savings in the years to come.

The Regional-Center-provided ABA therapy my daughter has received has taught her functional skills that are invaluable. Think of every self help step you take each day. My daughter could do NONE of them (with the exception of putting finger food or a cup to her mouth.) when she started her ABA therapy. Potty training, teeth brushing, safety skills, the meaning of simple words like "STOP" helped tremendously with safety, words like "WAIT" helped us to be able to go out into public without a totally out of control child, hair brushing, washing, labeling of everyday items most kids know by the time they are two years old, tolerating doctor and dentist visits, desensitizing to blood draws and shots, swallowing pills, trying new foods, understanding dangers, recognizing the foods she can and cannot eat (severe allergies, GFCF diet implemented), allowing someone to cut her hair, dealing with menstruation (as she hit puberty), tolerating loud places such as movie theatres, she had to even be taught (with picture id) the name of her family members. The list could go on for pages.

She has come a long way, but she has much more to go. And so do many more children. Will the State of California cancel their promise to my child? Will the next generation of ASD children go by the way of the past? Will we need to open more Sonoma State Hospitals? Where will the explosion of ASD children go? What will their families do when they grow up and their "little" behaviors become as big as they are? What will happen when their aging parents can no longer take care of them? What if a parent was to die prematurely? Will their siblings or other family members be able to take over? I shudder to think.

Without continued teaching, and maintaining of skills, REGRESSION is what lies ahead. When a parent is aging, when a child is regressing, when a family has no support, can they stay intact?

I have given up any chance for a career of my own. I have given up almost every social relationship I had prior to autism. I have long since mourned what most would call a "normal" life. But this letter is not about me. It is about society as a whole and the relatives of, and the professionals who have chosen to work with a population of people who in previous generations were allowed to flounder, to waste away, to not live a meaningful or fulfilling life. There are many support people more than willing to do more than their part to keep their loved ones with them, even if it means that IS THEIR DAY IN AND DAY OUT JOB FOR THE REST OF THEIR LIVES. But they CANNOT do it if they have no respite care, no Individual Program Plans, no SUPPORT. Individuals with autism (and other developmental disabilities) cannot be left at home with families that

are not prepared for what the disability brings. They cannot be thrown into “group” situations in school or social settings and be expected to learn from their surroundings. It doesn’t work that way. If they are not given the opportunities to reach their individual potential, they will need much more costly services as adults.

You see, we parents of kids with autism feel we have a gun to our heads. We are in a race with the clock. Our children’s brains are forming every minute of every day. They will be filled with fuzziness, buried in repetitive behaviors, stuck in time, or even worse, REGRESSING, if they are not given the chance to be taught how to live. This cannot be done by the family alone. IT IS PHYSICALLY IMPOSSIBLE!

I strongly urge the budget subcommittee #3 on Health and Human Services to reject Governor Brown’s recommendation to cut an additional \$750 million in funds for the Department of Developmental Services.

Please work toward a more realistic solution to the budget challenges we face here in California. This proposed solution may appear to save in the short term, but WILL cost much, much MORE for the next generations.

I ask you to not only think of my daughter, but think of the ASD kids that are not yet born. The epidemic is not going to stop. Please, please, think of Diana. If she could, she would tell you, “I wish I could live with my family.” And If I were to bring her mother to testify she would plead, “Please do not force any more to live as my daughter has been for the last forty plus years.”

That is what these cuts will bring.....

Respectfully submitted,

Parent of 13 year old with autism