

To the OAH Judge:

We are writing in response to your Fair Hearing decision regarding our 10-year-old son who has autism. There are many items we are compelled to comment on now that the case has been heard and decided: your unprofessional conduct during the Fair Hearing; your poor decision, and the errors contained within it; the ramifications of your poor decision; and the inherent unfairness of the "Fair" Hearing process.

With regards to your conduct during the hearing, you acted unprofessionally on numerous occasions. On day one of our 3-day hearing, during the introductions of the issues by each attorney, you said within the first half-hour that you didn't think you would need to hear our witnesses (i.e. the claimant's witnesses), and that you anticipated being finished by 3pm that day. Surely there is no legal precedent for hearing the testimony of only one of the two parties, and surely this would not be condoned by a panel of your peers. Stating an end time at the start of day one suggests that you knew in advance how much testimony you were willing to hear, and certainly suggests a precalculated bias in favor of the service agency (in this case, Alta California Regional Center, ACRC). You also stated at the beginning of the hearing, with a chuckle, that you were not familiar with the Lanterman Act, that typically you handled dental licensure cases. We did not find this amusing or reassuring.

Also on day one of our three-day fair hearing, you allowed the service agency to introduce numerous issues which were not referenced whatsoever in its Notice of Action (NOA). This continued throughout the entire fair hearing. Not only is this not legally correct, it extended the fair hearing well-beyond the time it should have taken, costing us and the state many extra thousands of dollars. It also showed a clear bias in favor of the service agency as you allowed issue after issue that was not part of its NOA to be introduced, discussed at length, and then had to be rebutted by our attorney.

Additional wastes of time and money included your improper conversations with the service agency's director of children's services, and with its attorney. During every break, you engaged in conversation with them which included improper topics such as service agency responsibilities, other cases involving service agencies, Lovaas programs for children with autism (which is what we were fighting to continue for our severely impaired son), the list goes on. This conversation would continue even after all parties had returned from the break, further extending the length of the fair hearing, and the costs accrued by both sides.

On day two, you delayed the fair hearing by first getting lost, and then by not knowing how to operate your equipment. These two events delayed the start on day two by almost two hours. Furthermore, on day three at the end of the fair hearing, you allowed the service agency's attorney to belabor a point for well over a half-hour regarding whether or not to allow a 1997 fair hearing decision to be included in the evidence. The 1997 decision had nothing to do with the present fair hearing decision, which you yourself stated immediately, yet you allowed opposing counsel to continue arguing regarding its inclusion in the record. It was an issue for which you should have taken no judicial notice. Instead, almost an hour was spent at the end discussing this issue, and you further worsened the situation by allowing opposing counsel to submit a closing brief regarding it, which our attorney then had to spend time rebutting. This is yet another unacceptable and unethical waste of everybody's time and money. I should mention at this point that my husband had to take three days off from work to attend this fair hearing, and I am a busy mother of three who had to make many accommodations to prepare for and attend this lengthy fair hearing.

Next, we would like to comment on your poor fair hearing decision, and the errors in it. You yourself recount testimony that states the service agency had agreed to fund claimant's

behavioral program through February, 2005. You also state that the Director of Special Education for our School District would not be inclined to fund a program outside normal school hours for claimant. Later, you recount testimony that reflects the facts that claimant would regress without his in-home behavioral program, and that he would not be able to maintain his least restrictive environment placement in his regular-education third-grade class. Despite all of the above, your decision affirmed the service agency's termination of claimant's program. This makes no sense.

Your lack of understanding of the Lanterman Act is evident throughout your decision. The Lanterman Act exists to prevent an eligible consumer from ever going without necessary services. The Lanterman Act states that the Regional Center is to identify and pursue generic sources of funding. The current executive director has not done this. He has not met with SELPA directors and school district superintendents to devise a collaborative plan with which to serve consumers with autism. Instead, the two agencies (ACRC and school districts) point to one another as the fiscally responsible party. It is getting to the point that for every state dollar spent serving a child with autism, a greater amount is spent deciding who should fund that dollar, in spite of the fact that it is all state taxpayer money. For more than eight years, we have asked our school district to fund some of our son's in-home program...for more than eight years, they have said no. They have, however, funded eight hours per month of consultation services, and provided partial payment for his trained behavioral aide during school hours. This is where the Lanterman Act comes into effect, to protect the consumer and the family. If the generic source refuses to pay for needed services, then the Regional Center must pay as payer of last resort (also part of the Lanterman Act), and it is the Regional Center's obligation to require the generic source to fund, not the consumer's or the family's obligation. You have allowed the Regional Center to completely terminate our son's much-needed home program, before it secured a generic source to take over the funding of it. You have left our son without essential services, that will ultimately lead to his demise. When "education" won't pay, then the Regional Center must, as it is clearly defined as the payer of last resort in the law. Your decision completely disregards the Regional Center's responsibilities, as clearly stated in the Lanterman Act.

Another part of the Lanterman Act that you chose to disregard is the section which states that a consumer's goals and objectives should maximize opportunities for the consumer to develop relationships, be part of community life in the areas of community participation, housing, work, school, leisure, increase control over his or her life, acquire increasingly positive roles in community life, and develop competencies to help accomplish these goals. All of our son's goals are specifically directed at accomplishing the above. A school district is not required to maximize a person's potential, however, the Regional Center is required to do so. Without our son's in-home program, he will not continue to improve and better his current and future situation. As a matter of fact, he will terribly regress.

The ramifications of your poor decision are frightening. Let us explain the ripple effect of consequences that take place when a child with autism, and his family, are left without needed services. First, the child will no longer make progress, but instead, will quickly begin to regress. This has been documented many times over. As the child regresses, he will no longer be able to continue in his least restrictive environment. For starters, he will lose his ability to stay in his regular-education setting, and will then be moved to a special day class. That placement, also, will not last long without an in-home program supporting it. Next, will come the downgrade to a "Steps" program, which is basically warehouse babysitting, with high turnover of personnel, and low-functioning disabled children. As all this is occurring, the child's behavior and ability to function at home and within his family unit will begin to rapidly diminish. Without continued learning and after school structured programming, the child will begin to engage in more and more inappropriate and stereotypical behaviors. He will rapidly

begin to lose all the skills it has taken him thousands of trials and years of intensive intervention to learn, which will increase his frustration; subsequently, inappropriate and possibly aggressive behaviors will begin to abound. His ability to access his community will decrease day by day, as he will no longer have the appropriate social skills to take part in the community, especially as he gets bigger and stronger.

The impact on the family will be tragic. The mother will be at her wit's end, and will become isolated and depressed, as she is struggling to manage her large and unruly child. She will be less and less able to go out, as she will be confined to the home with her inappropriately behaving aging son. The siblings will receive less and less attention from their mother, as she is on duty 24/7 taking care of the child with autism. The siblings will be less and less able to access the community and partake in normal childhood activities, as their mother has become less and less available, and depressed to boot. The siblings will no longer be able to have friends over to the house, as their autistic sibling has become too embarrassing, and possibly threatening. Company at the house will also be a thing of the past, as will invitations to other people's homes. The father will find coming home to be more and more of a challenge. He may begin working longer and longer hours to escape the situation at home, or to earn more to try to reinstate some of the terminated services. In many cases, the father leaves the family, adding further stress to the mother and children. Eventually, the situation will become so bleak, that the parent/s will begin seeking a placement for their child. To their dismay, they will find a multi-year wait for a very marginal placement. (Should a placement be found, the state will then be paying much more than if it had provided the necessary and appropriate services in the first place.) Then, guilt will overtake their lives as they try to think of what they could have done differently to avoid having to place their child. Sometimes, the situation may become very tragic. Recently, Alta denied a single mother services for her child with autism. She was already in an emotionally fragile condition. She committed suicide.

The short-term consequences, long-term consequences, and ripple effects of terminating a child's needed services when there isn't another willing source of funding is tragic, both in terms of human consequences, and fiscal consequences. By a swipe of your pen, you have just devastated a child, a family, a community, and a state. Decisions like yours are lacking in their legal conclusions, in their morality, and in their humanity.

In conclusion, I would like to comment on the unfairness of the "Fair" Hearing system. There are inherent conflicts of interest in the system as it currently stands. The Department of Developmental Services (DDS) contracts with the Office of Administrative Hearings (OAH) to provide judges for fair hearings involving the 21 Regional Centers. The judges are paid by the Regional Centers, and the hearings are held at the regional centers. There is pressure to rule in favor of the regional centers, so the contract with OAH will continue to be renewed by DDS, which oversees the RCs. As if this weren't bad enough, in the rare event that a consumer/family actually wins a case, they are not reimbursed for their legal expenses. Knowing these things, in addition to the fact that most families can not afford an attorney, nor the time off work to prepare for and attend a fair hearing, the vast majority of families denied services never go to fair hearing. They know the odds are overwhelmingly against them. Attorneys also know this, and there are very few attorneys in town who handle these types of cases (most would have to be done on a pro bono basis). Regional Centers, on the other hand, almost always bring legal counsel to their fair hearings, even when the consumer/family is unable to do so. This is extremely unfair, and puts the consumer/family at an even greater disadvantage.

We hope that this letter makes whoever reads it more aware, knowledgeable, disturbed, and sympathetic to the plight of consumers with autism and their families. Systemic changes are

needed to remedy the many deterrents to providing timely and appropriate services to people with autism. We, as California taxpayers, and as human beings, will all suffer the consequences of not doing what is morally and legally right.

Sincerely,
The Parents of a Precious Child with Autism