

To Whom it May Concern,

My daughter Katelin is 24 and suffers from Rett syndrome; a neurological disorder that has stolen verbal communication among other symptoms as well as the inability to follow commands and severe anxiety.

2.5 years ago I moved to California and almost immediately started looking for a dentist. Given that she cannot be examined without being under general anesthesia I needed a dentist with hospital privileges. Working with Harbor Regional Center and the dental coordinator there it took MONTHS to get into see the dental coordinator, more weeks to get a name of a dentist and months after to try and get an appt. only to have both that dentist and the dental coordinator cut off all communication with myself and my daughter's case worker (who valiantly tried to help me) Next began a futile search with the aid of Denti-cal to find a provider. I was sent all over LA county to dentist after dentist who were incredulous that I was sent to them with my child, saying they did not have hospital privileges and that they would never sedate her in the office. I was VERY clear with denti-cal of the need for HOSPITAL privileges. All this time, my daughter had a small cavity on the front of her front tooth.

After nearly TWO YEARS, I was finally given a office that did have hospital privileges, in Fresno, which is 4 HOURS away from me, for every visit there I had to get a hotel room because my daughter cannot travel 8 hours in one day. What ensued at that office is the stuff of nightmares.

They told me that since they could not get xrays without putting her under they couldn't prove that the cavity was a cavity by Denti-cal standards and that because she needed to be put under to GET xrays was not a good enough reason by Denti-cal to put her under. Mind you the cavity was clearly visible and they turned me away. I called them down the road and said the cavity is getting bigger, I was told to bring her in, again they could not get xrays and said the same thing. At this point I told the lead dentist that I was not leaving until he took his pointy metal instrument and stuck it in her tooth and told me it WASN'T a cavity. Which he did and said, "you're right, it's a cavity". I filled out the paper work and she was put on the wait list. I called after a couple of months and was told the schedule's made out 'til June and she's not on it. Soon after my daughter exhibited extreme pain, loss of appetite and loss of weight. I ended up having to take her into the emergency room, they prescribed an antibiotic and Tylenol with Codeine. I called the Fresno office and they would not bump her up; her physician called, no luck. By this time she had an increase in self injurious behavior, damaging my apartment, herself and myself. She is now on daily doses of Tylenol with Codeine. In desperation, I called the Senate and was put in touch with a new program called "Case Management"; I'm told my daughter is their first client. While they are attempting to resolve this issue to my satisfaction, I have been told that since the tooth now needs a root canal and there are currently no endodontists with hospital privileges that in all likelihood the tooth will need to be pulled and a bridge inserted.

A cavity that for the lack of communication, caring and availability of providers was not taken care of and now needs a root canal, and for lack of providers and what Denti-cal will allow needs to be pulled. My child is NOT a second rate citizen. I have struggled for nearly two years to work within this system to have her needs met and she is now to be punished unnecessarily for the failure of that system. In particular, the lack of communication of the Dental Coordinator at the Regional Center level is the single most defining factor of this entire experience. My understanding is that said person works for Denti-cal and not the Regional Center and so the fault lies completely with them. Had that person done their job properly and coordinated with the original dentist instead of cutting off all communication my daughter would have had her cavity taken care of over a year ago. This is substandard care of a person in a population that cannot speak for themselves and regardless

of how desperately I tried, has resulted in me failing my child. If my daughter was your child, I have no doubt that you would find this system grievously at fault, as do I.

Sincerely and with respect,
Melinda Lancaster