

Thank you for the opportunity to speak to you today about this about individuals with Intellectual/Developmental Disabilities and their medical needs in the community. I am here today as before, representing my granddaughter, Cayla Moore. Cayla is a 22 year old young woman impaired with severe IDD. Who by the way, with the assistance of her very dedicated teacher, walked across the stage with the 2014 graduating class of Alvarado High School.

After monitoring yesterday's testimony about pending changes in the agencies that are put in place to help Cayla I am more hopeful than ever. The system has so many layers and doors to go through to get to services that many families give up. Cayla's mother gave up very early on. She has been completely out of the picture for nine years now. My son, Cayla's daddy, gave up on the system and has done everything he could do to provide for her without outside resources. He and I are her primary caregivers.

We got no help at all until Cayla was 18 which was very helpful....until she had her 21st birthday. Although there was no change in Cayla, her benefits were cut in half. Attendant care is essential and it was cut in half. The nightmare began. We continue to struggle to get her needs met. Senator Birdwell's staff has been very helpful. Without their assistance I hate to think where we would be. Also, I am very grateful to Representative Raymond and the House Committee. They have allowed me to testify on two different occasions and were very supportive both times. I am very encouraged about the potential to make changes to the broken system. I know that I have been very fortunate to make the contacts in DADS, HHSC and the legislature. We have been able to make some real progress. I do realize that most families are not in a position to advocate for their loved one. The greatest concern that I have is what will happen with Cayla after I am no longer here. I have to make every effort to ensure her a quality of life that will provide her the dignity and respect that she deserves. By helping to make these changes for Cayla, the lives of hundreds with similar situations will be helped as well.

Most recently I spoke with the House Committee about the need for dental services for adults with IDD. Cayla was born with a condition called Rubenstein-Tabi Syndrome. One of the struggles that she deals with is sensory issues. Cayla cannot bring herself to open her mouth for doctors, dentist or caregivers to exam or treat any issues in her mouth or throat. Because of this we are unable to brush her teeth, and she cannot she brush them herself. She has to be under anesthetic for the dentist to even look inside her mouth. The last time a dentist tried to brush her teeth without anesthesia there were three dental assistants, her dad and myself physically holding her in the chair while the dentist brushed; an experience none of wants to repeat. This was the last trip to that particular dentist. That visit was a follow up to a procedure done in the hospital under general anesthetic which resulted in her losing 13 teeth in October 2009.

Since that time we have searched for a dentist that accepts Medicaid and is willing to treat special needs patients. We have finally found just such a dentist and he is wonderful. He has introduced us to a new procedure that will be a life changing solution for Cayla and others like here. The process involves making a prosthetic for the upper and lower and attaching them using posts similar to implants but using only 4 posts for each full plate. These prosthetics will not decay, will not require daily care and cannot be taken out of her mouth. Cost for this work is estimated at \$50,000.

Having these adaptive aids would solve many health and safety issues for Cayla. She has a very unusual bite; which along with 13 missing teeth make chewing very difficult. Cayla frequently chokes and because of her limited cognitive abilities struggles without understanding what is going on. Last year her school had to call 911 and paramedics were sent to assist. Tooth decay and gum disease are more than problematic. Cayla is non-verbal and unable to tell us when she is in pain and again will not allow us to look into her mouth. Our first clue that she is in pain is if she doesn't eat her ice cream.

As you already know Adult Medicaid has no dental benefit. The HCS Waiver provides \$1,000 per year. The HSC Waiver for Level of Need 6 (pervasive) has an annual budget of \$168,615, of which we will use approximately \$52,000 to cover attendant care. We are told that none of the remaining \$116,615 can be used

to meet Cayla's need for dental care. There are instances when money can be moved from one category to another to provided needed services.....but not dental?

If we are about the business of serving these individuals, should we not look at their individual needs? Person Centered Planning can only happen if legislative action creates change in existing policy. I have attended several meetings in the last few months with various groups involved in the redesigning of Medicaid and implementing Managed Care. I appreciate all the effort and activity that is happening to improve services. I sincerely hope for real change to occur.

Respectfully submitted,

Ellen Bauman