

First of all, we'd like to thank you for this opportunity to speak to you. We understand how valuable your time is and appreciate your concern about overextensions draining the Medicaid system.

Our son Samuel was born 3 ½ years ago and was rushed into emergency surgery immediately after delivery to repair an opening in his back, and afterwards, Doctor Riesner, a neurosurgeon explained Samuel's diagnosis of Spina Bifida Hydrocephalus. Five days later, he was once again rushed into emergency surgery to have a shunt installed to drain fluid from his brain. Since then, he has undergone several different surgeries, most of which are on an emergency basis. Samuel can feel no pain in his lower body, is incontinent and needs to be catheterized every 3-4 hours, nor can he make any bowel movement on his own. There is no main stream base line for this diagnosis so we live one day at a time. There are cases where children can thrive independently, but unfortunately our son can not. He can not get out of bed, dress, feed or bath himself. Scans and MRIs have determined that because of a small cerebellum, Sam has lack of control over motor skills. He needs help and support to be able to sit and/or play with toys. Even in his wheelchair, he needs to be watched. When he crawls, as he has no control over his trunk, he slams his head into the floor and we must watch his mouth and teeth, not to mention his head bruises and possible shunt damage. His communication is extremely limited and he has a severe speech delay.

We were told in the beginning to seek out funding through the Katie Beckett Deeming Waiver. He qualified immediately. We experienced no problems until we moved in May of 2004 from Cobb County to Forsyth County.

Even though Medicaid and both the Cobb and Forsyth County offices were informed previous to the move, we were told to file his 2004 paperwork for review to Cobb County the paperwork would be transferred subsequently. When his review came due again in May of 2005, a full year later, we once again received the paperwork from Cobb County. Alarmed, I called the office and we were once again instructed to turn in the papers to the Cobb County office, not Forsyth where we were living and where he was receiving treatment. We complied and heard nothing further and were shocked to receive seven months a "Final Denial Letter" dated December 22, 2005 from the Georgia Department of Community Health. We never received any initial notice or correspondence to indicate there was a problem. Even though it was the holidays, we contacted Georgia Department of Community Health and was told to submit a request for an appeal at that time, even though the letter indicated that we should now ask for a hearing. Following instructions, we submitted the various reports and paperwork on January 31. We then received a letter dated February 21, 2006 informing us that he had been denied again based on his re-evaluation. His case had been reviewed and denied a second time by the same review nurse. Per that letter we requested a hearing in writing within 30 days, which we did on March 8. To our surprise, on March 13th, we received a letter dated February 23rd (prior to them having received our request) indicating that the request for a hearing was denied. Obviously, there is no logical paper trail and we are in limbo as to his care.

Samuel is continually reviewed by therapists and doctors and those reports are sent to Medicaid for billing purposes at least every three months. It seems redundant that the parents must also spend an incredible amount of time submitting the same paperwork when there has been no change to a child's diagnosis. It forces us to deal with excessive paperwork from many departments which causes a lot of anxiety, time away from our other children and family, besides interrupting the necessary on-going care of Samuel. There should be a more streamlined way of handling the evaluation process. If an appeal is made, then it should be reviewed by another entity. Medicaid is vital to children like Samuel. It unfairly puts a further burden on us to have to deal with this each year. Understandably, if a diagnosis is changed, then certainly a formal review should be made. But in cases such as this, it should be more transparent and there should be one central case worker that is available to us, the parents, the school and other care-takers such as therapists to centralize the paperwork. We shouldn't have to make dozens of phone calls each time a piece of paper arrives in order to find the right contact person or department. We follow the instructions and then find out we were informed incorrectly and his care is back in jeopardy. Having a child with special needs is emotionally draining from day one and on a continual basis. Having this further anxiety each year is truly horrible.

I appreciate you allowing us to tell you about how the system impacts us. We are appreciative of the assistance that Medicaid has afforded us and hope that you can use our testimony in your evaluation process.

Daniel and Leslie Esteban
March 14, 2006