



tourette syndrome association, inc.

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Medicaid Commission Public Meeting

Testimony

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My name is Sandra Hollis and for the last 8 years our family has been overwhelmed with the cost and symptoms of our son Zak's Tourette Syndrome. TS is a neurobiological disorder that is characterized by involuntary movements and sounds better known as tics. TS is a complex disorder that is treated by both a neurologist and a psychiatrist; therefore TS is classified as a mental health disorder. As a result, people with TS have been denied or greatly limited in receiving reimbursement for expenses of treatment relating to hospital stays, office visits and medications.

I am here to testify to the financial disparities that exist between the coverage for mental illness and physical illness and to that end request for mental health parity. One of Zak's medications was not covered at all by our insurance company at over \$300 a month for three years. This came to almost \$11,000 dollars. Also, the insurance company did not cover sufficient number of clinical visits that Zak required on a weekly basis; which was a decision made by a clerical person for the insurance company instead of Zak's physician. This decision resulted in Zak needing two different long term hospitalizations and these hospitalizations came well over \$150,000. During his hospitalizations we continually ran the risk of him being discharged every three days as they evaluated whether or not he was "severe" enough to warrant continued treatment.

These expenses would have been much cheaper if the insurance covered the services when we needed them and within our own community. For example, if Zak received the proper treatment every week, his treatment would total \$30,000 a year.

However, by not providing the appropriate treatment locally Zak required 5 months of out-of-state hospitalization which totaled \$172,500. At this point I am struggling to find a psychologist that will accept our insurance as they run a minimum of \$150 an hour and he needs twice a week visits as he stabilizes from his latest hospital stay. That comes to \$1200 a month. We are already paying \$150 a visit out of pocket for his psychiatrist. We simply can not do that.

While my family battled whether or not our son would receive the testing and services he required for his Tourette Syndrome a friend of ours was dealing with her own physical illness. She went in weekly for expensive transfusions and was hospitalized routinely and she never had to worry about being discharged and being medically unstable.

For these reasons, the Tourette Syndrome Association has requested in writing the inclusion of Mental Health Parity in the Commission's report regarding long-term recommendations for Medicaid. We would like the Department of Health and Human Services to eliminate the financial disparities that exist as well as the restrictions on the frequency of treatments to simply offer the same level of coverage for mental health care as is provided for medical and surgical care under Medicaid.

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