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MARYLAND DISABILITY LAW CENTER

TESTIMONY BEFORE THE MEDICAID COMMISSION BY MARYLAND DISABILITY LAW CENTER

January 25, 2006

My name is Cathy Surace and I have been an attorney with the Maryland Disability Law Center in Baltimore, Maryland, representing children and adults with disabilities since 1985. MDLC is the federally funded and state designated Protection and Advocacy System (P&A) for the rights of persons with disabilities in Maryland. Over the past 20 years, my work has focused on helping families of children with disabilities, either with mental illness or developmental disabilities, access the healthcare services their child needs in order to continue to live safely with their family at home. I represent families in trying to obtain the necessary mental health or physical healthcare services that children have a right to receive under Maryland's Medicaid and MCHP programs.

The Medicaid Program under the Early and Periodic, Screening, Diagnosis and Treatment (EPSDT) law should continue to provide the critical community-based services that children with disabilities require to live at home. Without the continuation of these preventive and cost effective services, the institutionalization and custody relinquishment rates for children with disabilities will rise. Any anticipated cost savings from EPSDT cutbacks will be offset by increased federal and state government payments both within the Medicaid Program and across multiple agencies. The impact would include rising payments for inpatient hospitalization, emergency room visits, psychiatric residential treatment center care, intermediate care facilities for the mentally retarded (ICF-MR), and nursing home stays within the Medicaid Program. Even

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outside the Medicaid Program, government spending will rise. For example, according to data from one Maryland county, nonpublic school placements for children in special education rose dramatically when Maryland cut children from Medicaid funded psychiatric rehabilitation services. When community services are not available, some parents eventually relinquish custody to county child welfare agencies and the state juvenile justice agency, both of which receive substantial Title IV-E and other funding from the federal government.

Even now with the EPSDT mandate in federal law, families with children on Medicaid frequently do not know about the services that should be available to their children under the Program or cannot access the services when they apply. One of the problems is lack of provider availability due to low reimbursement rates for community-based services in Maryland's Medicaid program when there are higher rates set for hospitals and other institutional providers. The families of children with private insurance or no insurance who are not eligible for community Medicaid services seek out-of-home placements so their children can become eligible for Medicaid as a family of one.

A cost comparison from Maryland illustrates the wisdom of retaining and strengthening community-based services mandated by EPSDT because these services undoubtedly prevent many individuals with mental illness and developmental disabilities from being hospitalized. Maryland's reimbursement rate to providers for targeted case management is $368 per month per individual. Of this amount, the federal government will pay $184 per month per individual. Similarly, Maryland's reimbursement for one month of children psychiatric rehabilitation services is $389 per month with the federal government contributing $194.50 per

month per individual. According to the Maryland Health Services Cost Review Commission, the agency setting the rates for hospital stays in Maryland, the base cost of one day for one individual in a psychiatric hospital ranges from $660 to $1100 (median is $850). On top of this base cost, hospitals also bill for ancillary services (psychiatrists, pharmacy, therapy etc.) which add 50% to 100% to the per diem bringing the estimated cost for one day in a hospital for psychiatric care to approximately $1000 to $2200 per day. The federal government pays 50% or $550 to $1100 per day.

Should even a small percentage of people who lose EPSDT services be hospitalized as a result, or end up in other expensive Medicaid funded institutional settings such as residential treatment centers, nursing homes, and Intermediate Care Facilities for the Mentally Retarded, the state and federal government Medicaid programs will end up spending more rather than saving money. State governments and the federal government also will pay more for children with disabilities eliminated from Medicaid as some of the families relinquish custody or seek institutional placements where children are again eligible for Medicaid as a family of one, but this time requiring much more expensive services.

I speak based on my daily contact with hardworking and desperate families who call MDLC and whose children we represent. They tell us that if we cannot help them get the services their child needs under the community Medicaid program, such as case management, community behavioral aides, or in-home nursing, they cannot pick their children up from the hospital or take their children home from other placements when they are ready for discharge. They speak of being forced to “abandon” children or file criminal charges against their own children for

dangerous behavior in the home or community. My office also receives regular phone calls from facility social workers after parents take this drastic step. They report that in these situations children languish unnecessarily in hospitals, residential treatment centers and other facilities long after they are ready for discharge while government agencies scramble to find last minute placements or fight over which agency should take responsibility. Over and over again, when we ask families about their decision not to take a child home, we find that it was dictated by their inability to get supportive community-based services such as in-home supports.

Through my years working collaboratively with Maryland's state agencies to address systemic issues, MDLC also has witnessed that state and local government agencies -- outside of the Medicaid Program but operating with federal funding -- take responsibility and bear the cost when families of disabled children cannot obtain community-based services. In 2003, Governor Ehrlich established a Governor's Commission on Parental Custody Relinquishment and appointed me to serve on this Commission. Maryland's Commission found that a root cause of custody relinquishment is lack of access to services for the care and treatment of children with disabilities and that one part of the solution is to ensure that children with disabilities receive the Medicaid services their families rely upon for them to live safely at home.

Many parents in Maryland, as in other states, are forced tragically to give up legal custody to local departments of social services and the state juvenile services agency when they no longer can meet the needs of a child with severe behavioral problems or intensive physical and healthcare needs such as bipolar disorder, autism, and traumatic brain injury. Many families reach this decision after losing employment or housing, and incurring considerable debt. These

parents also pay the terrible price of losing the right to make parental decisions for their child and frequently are treated by overburdened child welfare case workers no differently from parents who have abused or neglected their children. But the largest fiscal costs are borne by the states and the federal government who then become fiscally responsible for bills covering extended periods of time for children in out-of-home care. Many of these children never return home.

Thank you for the opportunity to address the Commission. I recognize that your mandate is to make long-term recommendations on the future of the Medicaid Program to ensure its sustainability and reduce expenditures. Based on my 20 years of experience looking at how this Program actually operates and impacts families of children with disabilities in the state of Maryland, I urge you to realize that cutbacks in community-based EPSDT services will have many consequences that result in higher rather than lower spending for the federal government and the states. A reduction in EPSDT services will cause more children with disabilities to enter institutional facilities or other out-of-home placements that are not what is wanted by families or in the best interest of children. MDLC is willing to provide any technical assistance or gather any information that the Commission may need related to my testimony or within other areas of our expertise after today's hearing.

Addendum

I am providing the three examples from my recent work that I used in my oral testimony today to illustrate the basis for my testimony.

First, I reported about my receipt of a letter this week from the service coordinator of a child with developmental disabilities and mental illness in Harford County, Maryland who was rehospitalized at Kennedy Krieger Institute (KKI) in January 2006. This is taken verbatim from his letter with the names redacted:

> "[The child] was receiving inpatient services at KKI, he was released in July 2005. TBS [in-home behavioral aide] services were pursued prior to and after his discharge but without success. [The provider] stated that she could not find staff. . . . [The child] was readmitted to KKI in January 2006 due at least in part to a lack of services."

KKI's per diem cost is likely within or may exceed the higher end of approximate per diem costs ($1000 to $2200) explained above for psychiatric inpatient services in Maryland while the Medicaid rate for in-home aides is $20 per hour with children generally receiving between 20 and 40 hours per week of these services for a limited period of time.

Second, below is the redacted partial text of an e-mail I received last week from a family from Salisbury, Maryland whose 7-year old son is on the Maryland Model Waiver because of his traumatic brain injury. He is not receiving the Medicaid approved in-home nursing hours he needs to live safely at home and they are trying to avoid custody relinquishment of their son:

> "When there are no nurses, I have missed 8 to 10 hours of work because I must care for my son. When my son's school calls me at work I have to leave and pick him up for medical reasons. My nights are usually sleepless, and I have to struggle at work during the day. I am not complaining because, I want to be there for my son. It is very hard to work outside the household and care for a special needs child at the same time. I thank God for blessing my family with this special gift. We know our situation calls for love,

understanding and patience. I just feel that I should not have to struggle just to keep my child out of an institution or a group home. Please help [my] family to make a better life for [my son]. We live paycheck to paycheck just for survival, and we are afraid of losing our son home because we cannot afford to pay the mortgage in order to keep my son at home. Life is the most important thing to me and my husband, and we go out of our way to make sure that our family's life is as comfortable as possible.

-If [my son] were in a group home or institution [he] would have ample nurse care."

Finally, I provided one small example of the impact of cutting Medicaid services outside of the Medicaid Program on other federally funded state programs. Richard Bayer, the director of Upper Bay Counseling, testified before the Maryland General Assembly in November 2005 that the Cecil County Public Schools reported that after the Maryland Medicaid Program cut school-based psychiatric rehabilitation services in 2003, the number of children in special education placed by the County in nonpublic schools jumped from 34 children in 2003 to 92 children in 2004. They stated that 45 of the new placements were for children who had been receiving Medicaid psychiatric rehabilitation services and lost them due to the cutback. The County could no longer maintain them in the public schools. The reported average cost of a nonpublic school for Cecil County was $45,000 per year. The cost of one year of psychiatric rehabilitation services at the current rate is only $4,668.