BEFORE THE OFFICE OF
THE HEALTH CARE ADVOCATE

Testimony of Sheldon Toubman Concerning Denials of Applied Behavioral Analysis Services for Children with Autism in Violation of Federal Medicaid Law

October 17, 2012

Good afternoon. My name is Sheldon Toubman and I am a staff attorney with New Haven Legal Assistance Association. I am here to testify concerning the policy of the Department of Social Services ("DSS") to deny access to Applied Behavioral Analysis for children with autism, in violation of federal Medicaid law. This policy improperly denies medically necessary services to needy children, and the rationale which the agency has applied in doing so indicates a misinterpretation of the long-standing requirements of the governing federal law. The Department's interpretation also renders Medicaid coverage more restrictive than commercial insurance coverage in Connecticut, and is ultimately wasteful for Connecticut's taxpayers.

DSS' Position

The specific services at issue concern applied behavioral analysis ("ABA") services for children with autism spectrum disorders. In denying coverage for these services, there has been no claim by DSS that the particular services are not medically necessary for the individuals requesting them; rather, the Department has simply stated that the services are not even **covered** under Medicaid, regardless of medical need. For example, in a denial letter issued by former Medicaid Director Mark Schaefer, in June of 2011, he provided the following rationale:

> The services your provider requested are "habilitation" services. This means they are meant to help you get new skills, ***not to restore skills or abilities that you once had but lost due to an illness or health condition***. A habilitation service that is provided by an unlicensed individual cannot be covered under the Medicaid state plan or as an EPSDT special service.

Dr. Schaefer subsequently confirmed that his position is that DSS will not pay for any therapy services to bring a child up to his or her mental or physical potential – for **any** medical condition -- unless the child previously had that level of function (or the services are provided by a licensed provider, which is extremely unlikely for ABA services). No statutory or regulatory authority for this distinction has been provided except for the assertion that the "rehabilitation"

Medicaid option under 42 U.S.C. § 1396d(a)(13) inherently applies only to individuals who are seeking to regain a function or a previous level of function.

DSS's Position Violates Federal Medicaid Law

The refusal to pay for ABA services under Medicaid is premised upon a fundamental misinterpretation of long-standing federal law. Under the Early, Periodic, Screening, Diagnosis and Treatment provisions of the Medicaid Act, otherwise known as the "EPSDT" provisions, all Medicaid enrollees up to age 21 are entitled to:

> Such other necessary health care, diagnostic services, treatment, and other measures described in subsection (a) of this section [42 U.S.C. § 1396d(a)] ***to correct or ameliorate defects*** and physical or mental illnesses and conditions discovered by the screening services, **whether or not such services are covered under the State plan**.

42 U.S.C. § 1396d(r)(5).

But DSS is attempting to draw a distinction between services needed to bring a child up to a level of functioning he or she never had because of being born with a medical condition, which is it calling "habilitative services," and services to restore a function that the child had but lost, which it is calling "rehabilitative." It asserts that only the latter are covered under 42 U.S.C. §1396d(a)(13) and thus required for children under EPSDT. This proposed distinction is premised upon a discredited set of proposed regulations promulgated by the Bush Administration near the end of its term, which were blocked by Congress and then formally withdrawn. The two court decisions which dealt directly with the issue also rejected the distinction as being unfounded under federal Medicaid law.

Indeed, if there were any merit at all to DSS' claim, the states could routinely deny services to address functional limitations of children born with cerebral palsy, spina bifida, learning disabilities, mental retardation and other congenital "defects," since, after all, any improvements that services provided to these children produced would "help [the child] get new skills" which they ever had at birth. No such distinction exists under federal Medicaid law.

DSS's Position is Contrary to State Public Policy and Will Be Costly for Taxpayers

The Department's misinterpretation of federal law in this case must be contrasted with the broad public policy reflected in the legislature's recent enactments specifically concerning commercial insurance coverage for ABA services. As a matter of state law, since 2009, commercial insurers in Connecticut have been required to provide ABA services when medically necessary. *See* Conn.Gen.Stat. § 38a-514b. The legislature made the determination that it is

critical that commercial insurers provide these services, where medically necessary, because the failure to provide these services on a timely basis has lasting negative consequences for affected children. Since the passage of that requirement, commercial insurers in Connecticut have routinely approved properly prescribed and supervised ABA services. It is inconsistent with state public policy to treat poor children with autism spectrum disorders less favorably than we treat commercially-insured children.

If the Department's suggested fundamental alteration to the long-standing interpretation of EPSDT were allowed to prevail, it would be costly to Connecticut's taxpayers. If these services are not provided, in the end, the taxpayers will all pay much more as the lack of appropriate behavioral training, at a time when it would have made the most impact, results in far more costly state-subsidized services-- from costly institutional placements to involvement in the justice system-- down the road. Under the Department's misinterpretation of federal law, the taxpayers will be saddled with the long-term costs of failing to provide timely remedial services necessary to allow vulnerable children to overcome learning and other disabilities and develop the basic skills which they need to become productive members of society.

In light of the seriousness of this matter, if DSS will not reverse its position, the legislature may have to act to do so.

Thank you for the opportunity to testify today about this matter of great concern to needy children with autism, and their families, throughout the state.