October 17, 2012

BEFORE THE OFFICE OF THE HEALTHCARE ADVOCATE

Testimony of Alijah Cafro concerning the Denial of ABA Services to Children with Autism by Medicaid in Violation of Federal Medicaid Law

Good afternoon . My name is Alijah Cafro. My son, Judaea, is autistic. He is diagnosed with sensory integration disorder, PDD-NOS and has OCD tendency. He is three years old. I am writing to you today to ask for your assistance in correcting a systemic breakdown between current legislation, insurance companies and the state agencies that are responsible to provide services and protection for all citizens, including low-income children with autism on Medicaid.

Judaea was receiving treatment for his medical diagnoses from Beacon Services of Connecticut under the Birth to Three Program. He was receiving 15 hours of applied behavioral analysis (ABA) as well as speech and occupational therapy (OT) as prescribed by his neuro-developmental specialist.

While Judaea was receiving these services the advancements that he made were incredible. In the past, he could not effectively communicate his needs, fears, or emotions. Within just a short time after the services began, he was able to really communicate for the first time. This was amazing to see as a parent. He continued to progress day after day. Then he reached his third birthday and the services stopped.

On his third birthday July 22, 2012, he "aged out of the Birth to Three program". I was told that the only way he could continue to receive these services was if I paid Beacon or another agency like them, out of my own pocket. Even though Jude is on Medicaid, and I have been told by various advocates that, as a matter of federal law, Medicaid must cover for low-income kids any treatment "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 [Medicaid] State plan" (42 U.S.C. § 1396d(r)(5)), I was told by state representatives that the Husky A/Medicaid program would not cover these services under any circumstances.

While trying to navigate my way through the many denials, I applied for SSI for Jude and he was approved. This only provides $700.00 dollars per month, and while that might sound like a lot, 6 hours of ABA services a week for a period of one month costs nearly $2,000.00 dollars. Six hours is less than half of the hours he was receiving under the Birth to Three program. The only way I was able to pay for a month of therapy was because I had saved his SSI money for the three months leading up to his third birthday.

That money has since run out. Even while I was self paying, the significantly reduced hours proved to be inadequate and his regression began. Judaea stopped progressing. He stopped answering questions. He stopped making as much eye contact. He began to show less affection towards others and he started using inappropriate behavior instead of language to communicate. It has become almost unbearable at times. He was doing so well before and now his regression is heart-wrenching to watch as a parent.

Because of this blocked access, I decided to try and get an individual healthcare policy with help from my family, even though Jude is on Medicaid. Even this has proven impossible. As a matter of state law, since 2009, commercial insurers in Connecticut have been required to provide ABA services to kids with autism when medically necessary. Conn. Gen. Stat. § 38a-514b. The legislature made the determination that it is critical that these services be provided because the failure to provide them in a timely manner has lasting negative consequences not just for the individual child and his or her family, but the broader society. Unfortunately, however, §38a-514b only mandates that insurance companies provide ABA services for **group** policy plans of 50 or more through an employer.

A simple amendment to the wording of this law should suffice to rectify the issue here for families able to buy individual policies. It should state that **all** insurance plans, individual and group, not restricted to larger companies, must provide ABA and the autism therapies recommended by each affected person's treatment team, where medically necessary. It should also say that the insurance company must pay a reasonable, competitive and fair rate to the providers of such treatment so that the children of lesser fortune will not be compromised by sub-level treatment.

However, for many families, including my own, whose incomes are so low that they qualify for Medicaid, this legislative change would not help: the only place they can get health insurance is through the Medicaid program. The Department of Social Services (DSS) persists in denying ABA services to Jude and other kids with his illness, claiming that ABA services will not "restore" him to a level of functioning he already had, that these services are "habilitative" not "rehabilitative," and that the former do not need to be provided to children under Medicaid, despite the broad federal law protections for these vulnerable kids. DSS is just plain wrong in its interpretation of the rehabilitation provision of federal Medicaid law. Children born with Autism Spectrum Disorder (ASD) are born with a genetic defect and lack some of the innate abilities that are inherent to the general population. They are born with a disorder that requires rehabilitative therapy to improve functioning and put them on track with their peers. If a child was born with a broken hip, that child would require rehabilitation even though that child never knew the world without the pain of that ailment. ASD children are born with a broken gene of sorts, and they will not know the world as we do without intensive therapies.

It has been scientifically proven that ABA, along with other methodologies, can improve functioning of ASD children to the point (in many cases) that they could even lose their autism diagnosis. They can function in the neuro-typical world with little or no support if they are given intensive intervention at an early age. This intensive therapy will not only "rehabilitate" a genetic disorder, but also save the individual, the insurance companies, the school systems and the tax payers from providing greater support to these children in the future. Therefore, whether ABA services are classified as "rehabilitative" or "habilitative" treatment is beside the point. The erroneous DSS interpretation of federal Medicaid law renders services needed to improve functioning, and thus avoid a lifetime of costly dysfunction, completely unavailable to Jude and thousands of others like him, and needs to be legislatively reversed.

The physicians and supervisors from the Behavioral Health Partnership have not returned my calls to them about this issue. It has been two months since I requested ABA, speech therapy and OT for Judaea, and, though I have called, filed complaints and begged for Jude's therapies to be approved, I haven't even received a call back. I believe that this is all because they are acting under the direction of DSS, which does not want

to pay for these services in defiance of federal law.

You should also know that other states which have been challenged for applying a similar erroneous interpretation of Medicaid law have righted this wrong. Two federal courts, in Ohio and Florida, have struck down the very same "habilitation"/"rehabilitation" dichotomy being erroneously used by DSS here to deny ABA services, and ordered these services to all children with autism for who have a medical need for them. See *Parents League for Effective Autism Services v. Jones-Kelley*, 565 F. Supp. 2d 905, 916-17 (S.D Ohio 2008), *affirmed*, 339 Fed. Appx. 542 (6th Cir. 2009); *K.G. v. Dudek*, Case No. 11-20684-CIV-LENARD/O'SULLIVAN, slip opinion at 9-11 (S.D.Fla. March 26, 2012)(Amended Permanent Injunction Order). No court which has heard the argument being put forth by DSS has accepted it; all have rejected it.

ABA services have been recognized for decades to be an effective treatment for many children on the autism spectrum, but DSS resists the great weight of authority by persisting in categorically denying these services. In Connecticut, there have been many attempts to correct this. In September 2011, the Office of the Healthcare Advocate wrote to Commissioner Bremby at DSS. In January, 2012, the Office of the Child Advocate wrote to Commissioner Bremby in a joint letter with other organizations asking for action. And the Office of Protection and Advocacy for Persons with Disabilities, which is responsible for protecting vulnerable Connecticut residents with disabilities from discrimination, also wrote to the Commissioner on March 5th. All of these efforts have been to no avail, with DSS exhibiting a remarkable insensitivity to the needs of the low-income children it is responsible for serving, even as Governor Dannel Malloy asserts that he is committed to preserving the safety net and says he himself greatly benefited from receiving special services to address his own disability as a child.

To a mother of a child suffering it seems so simple that an amendment to a law that was specifically written to help these children when enrolled in commercial insurance must be made, and, similarly, that DSS must be instructed to provide ABA therapy and other therapies needed by the lowest income kids with autism, those on Medicaid, just as other states' Medicaid agencies have been instructed to do. In urging this legislation, I am not unmindful of the costs of providing ABA services. But if these services are not provided now, at the critical developmental stage, the taxpayers will ultimately end up paying a much higher price, for special education services, social work services, and, sadly, in some cases, even the child welfare agency and criminal justice services.

I have exhausted every resource available to help my son. My plight is far too lengthy to explain. Truly every state agency and even private programs have been unable to assist Jude. However, since we are on Medicaid, DSS is the ultimate obstacle blocking Jude's access to these services, and the legislature can override this obstructiveness. Any help that you could provide would be appreciated beyond measure. Time is the enemy for my son. The longer he goes without his prescribed services the greater the risk to his development and the less likely it is that he will be able to function in the neuro-typical world. Connecticut was the leader in this battle at one time. Please help to make Connecticut a leader in combating autism spectrum disorders again.

Thank you.

Sincerely,

Alijah B. Cafro

cc: David Cafro
Healthcare Advocate Victoria Veltri
Acting Child Advocate Mickey Kramer
James McGaughey, Office of Protection and Advocacy for Persons with Disabilities
Rep. Catherine Abercrombie