Testimony for the Office of the Healthcare Advocate

October 17, 2012

Anonymous

Good morning/afternoon:

I am the parent of a 23 year old son who has been insured for many years under his father's traditional health insurance plan. Recently, our son was hospitalized for a chronic mental health condition. At the same time, the medical insurance plan at his father's workplace is changing from a traditional health plan to a high deductible health plan. Father has decided to discontinue son on the family plan due to the large open ended nature of the deductibles for the plan.

At the time of transport to the hospital, I was asked whether my son had health insurance or not. The fact that he currently has health insurance through a traditional plan meant he could go to the facility requested. Next year, without health insurance, I am not sure where my son will be able to receive emergency and stabilizing treatment, if needed.

The shift in the private insurance industry from traditional health insurance programs to high deductible plans is not a cost sharing program, but a cost shifting program that has likely caused barriers for some people to receive needed care and is likely to increase the numbers of individuals who are foreclosed from services as more employers opt to offer only a high deductible health care plan.

Please submit anonymously as I do not want difficulty.

Thank you

A serious problem with commercial insurance is that they don't endorse/ cover EDT level of care, which is approx 6 months of 5 days a week treatment,3 hours a day. EDT provides intensive group, parent, family, psychiatric, and individual therapy as needed. EDT also includes an intensive level of collaboration with school, dcf, and outside providers. EDT is an important Level of care that both prevents costly hospitalizations, sub acute placements, and partial hospital programs. Hospitalizations, residential facilities, and partial hospital programs are emotionally costly to parents and young children and financially costly for insurance companies. They often occur outside of the child's community and can be difficult transitions into and out of these programs. EDT can also serve as an essential component of a successful discharge plan from a hospitalization. The use of EDT can shorten a hospital stay and it can prevent re-hospitalization. Husky covers this service and we see huge success with this treatment.

Commercial insurance has been paying for a shortened stay and then denying further days. We have had several children who continue to need this level of care. We have been absorbing the cost due to the on going psychiatric need of these children. If effect non profits and the state are subsidizing commercial insurance in order to provide the appropriate and ethical level of care.

Stephanie Ehrman

Testimony before the Office of the Healthcare Advocate
October 17, 2012
Nikkole Emmerich, Bridgeport, CT

Good morning/afternoon. My name is Nikkole Emmerich and I am 23 years old and suffer from a psychiatric illness.

I have been on psychiatric medications for most of my life. I was on psychiatric medications that were not brand names and were expensive to pay for. I couldn't afford them. Then I was put on name brand psychiatric medications that have co-pays that I also couldn't afford. I was then put on a psychiatric medicine that was a name brand and went to fill the prescription at my local pharmacy and later went to pick up my medicine and found out that even though the medicine was a name brand my insurance wouldn't pay for it.

I have been off of psychiatric medicines for more than a year now because my insurance won't pay for most psychiatric medications that I need to be on due to my illness.

Without the psychiatric meds I can't focus on anything and my behavior is unacceptable when I am off of them. I say hurtful things to people and go into rages that I can't control.

Sometimes, it is people like me who need the insurance to pay for psychiatric medicines to help keep things under control.

Thank you for your time and thank you for listening to me talk.

Nikkole Emmerich

Paul Gionfriddo
Our Health Policy Matters
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Office of the Healthcare Advocate
Mental Health and Substance Use: Access to Prevention, Treatment, and Coverage
Public Hearing
Legislative Office Building, Room 2C
October 17, 2012
10:00 AM to 4:00 PM
Hearing Notice: http://www.ct.gov/oha/lib/oha/Public_Hearing_Notice_10-17-12-_FINAL.pdf

TESTIMONY
SUBMITTED BY PAUL GIONFRIDDO

Thank you for the opportunity to make these comments. For many years, I worked on behavioral health policy as an 11-year member of the Connecticut House of Representatives. But I have had two experiences since then that have underscored (1) the importance of access for all to behavioral health services and parity in coverage and (2) how far we still have to go to achieve these things.

The first happened more than ten years ago, when my insurer said that my son Timothy had exhausted his lifetime mental health benefits while still a teenager.

Tim has given permission for his story – much of which took place in Connecticut – to be told publicly. And the September 2012 issue of the national health policy journal *Health Affairs* published an essay that tells it in some detail. The essay shows how poorly we have supported the community services needed to prevent and treat behavioral illnesses over the past 30 years. It also discusses problems in Connecticut and other states that persist to today. There is a link to the essay at the end of this testimony.

Tim was diagnosed with serious mental illness as a child, becoming one of the 6% of Americans who must live with such a condition. Serious mental illness has lifetime costs and consequences. The idea that someone could exhaust a lifetime of coverage in a few short years is astounding.

Fortunately, Tim was covered by a Connecticut insurer subject to Connecticut's state parity law. As a result – and only because of this – the insurer continued to pay for Tim's care for two more years.

Tim later lost his private insurance coverage. As a 20-something, he no longer met the criteria for physical or developmental disability his new insurer said he had to meet to remain on a parent's policy at the time.

In the past four years, we have come a long way toward making things better with the passage of both the Mental Health Parity and Addition Equity Act of 2008 and the Affordable Care Act.

But we haven't come as far as we think.

My second, more recent experience, explains why. It happened after both laws were passed.

I am now a resident of Florida, covered by a Connecticut insurer. I learned late last year that Blue Cross Blue Shield of Florida had sent nearly all of its behavioral health providers termination notices. It then offered to take them back, but only if they agreed to significant reductions in reimbursement. This only happened to behavioral health providers.

Here's what this meant. Before the reductions, a psychologist was receiving just under $52 for an hour counseling session. This is less than the $65 per hour earned by the average carpenter, the $75 per hour earned by the average electrician, the $90 per hour earned by the average plumber, and the $100 per hour earned by the average auto repair person.

After the reductions, today that same psychologist gets only $46 per hour.

You may wonder what this Florida example has to do with Connecticut.

This is it. Out-of-State Blues pay only in each state what the Blue Cross Blue Shield provider in that state decides to pay.

So the $46 is what Anthem Blue Cross Blue Shield of Connecticut – my current insurer - pays that psychologist. In this instance, "parity" for a Connecticut insurer is only as good as it is defined in Florida.

We must understand that what happens outside of Connecticut makes a difference in Connecticut. And, conversely, we must also understand – as do the insurers – that what is done in Connecticut can help build a wave that will travel through the rest of the country. We need Connecticut's leadership now more than ever.

Thank you.

Link to Health Affairs Narrative Matters Essay:
http://content.healthaffairs.org/content/31/9/2138.full.pdf+html

To: Office of the Healthcare Advocate
Public Hearing on Mental Health & Substance Use:
Access to Prevention, Treatment, & Coverage
From: Pamela G. Hine
Date: October 17th, 2012
Re: Testimony

Thank you for allowing me to speak today. I want to tell you what it has been like to try to access benefits for my son, Alex.

Alex is now 18, but he first showed atypical behaviors when he was 3. He first said he wanted "to be dead" at 6, the same age he was when he received his first psychiatric diagnosis. He was diagnosed as bipolar at 10, and by this past spring he was carrying six more labels and at various times had carried several others. He has had a very difficult life for one so young.

Alex entered a therapeutic residential school at 14, following his first hospitalization. He has been hospitalized 5 more times since. Every time I have had to tangle with Anthem over keeping him in long enough that he would be safe when released, never mind functional.

That first time, October 2008, he was released with a GAF score of 45, which as you may know indicates "Serious symptoms or impairment of functioning". Seven months later, in May 2009, he was released with a GAF of 40. If got worse every time.

The most egregious denials by Anthem were this past spring. Alex was admitted to Yale Psychiatric Hospital for 6 days in early February. When released he was still so unstable that he was unable to function in school. He came home to await an opening in a unique neuropsychological residential treatment program suggested by his school, our 1st hope in a long time. But the wait was too long.

Alex declined steadily over the next 5 weeks. There were threats of violence, holes in the walls, broken objects, and worse. This was more than living life walking on eggshells – it was more like treading lightly between closely spaced land mines.

On March 13th, in the quiet, wee hours of the morning, when he just could not take his hellish existence any longer, Alex attempted suicide – he swallowed 16,000 and 19,000mg of Tylenol, using a full bottle of Nyquil to wash it down. He chose Tylenol because he knew it couldn't be dialyzed from his blood.

For reference, taking 7,000mg puts a person at high risk of liver failure, while 10,000-12,000 is almost always fatal. I was taken aside in the ER and told that I should be prepared that Alex might well die.

Fortunately, Yale-New Haven's remarkable doctors gave him two new drugs, one experimental, and to everyone's astonishment, he not only survived, he has no liver damage. He was transferred once again to Yale Psychiatric Hospital.

Five days after his admission for the suicide attempt, when he was still suicidal and talking daily of how he was going to succeed next time, Anthem refused further treatment and said Alex should be released. I was told by multiple hospital staffers what I already knew from sad experience, that Anthem *never* allows a stay beyond 5 days – this refusal of benefits is standard procedure for Anthem in cases of psychiatric hospitalization.

We immediately appealed, and were, of course, once again denied. The supposed "Peer Review" of Alex's case trivialized his suicide attempt, portraying it as a childish gesture, the implication being that he was seeking attention. The review stated that Alex was "not actively suicidal"; when I asked about this, I was told that this indicated he had not tried to commit suicide *while in a psychiatric hospital*. This is a locked unit where patients are not even allowed to have shoe laces or go to the toilet alone, and the fact that Alex had not tried to commit suicide while under constant supervision was Anthem's reason for

saying he was ready for release. They further stated that Alex had "no suicidal ideation , harmful intent, or psychosis".

Alex's GAF at this point was a 10, meaning he was "In Persistent Danger of Severely Hurting Self or Others". The psychiatrist at Yale, Alex's own psychiatrist, and the Yale psychologist assigned to him all concurred on this score. Yet Anthem's "Findings and Recommendations / Rationale" claimed that Alex's case "does not show medical necessity" and, most unbelievable of all, "you have not harmed yourself to such a degree that has caused serious medical problems."

I find this incredible. A fleet of Yale's extraordinary doctors were able to pull off a miracle, Anthem was denying benefits apparently based of the fact that Alex managed to survive – he didn't manage to *permanently* harm himself (this time), so Anthem used that to claim he had not caused himself "serious medical problems".

Through the amazing help I received from the OHA, Anthem finally allowed Alex to enter a remarkable neuropsychiatric program in Texas. Teasing out rare neurological disorders takes time, but Meridell finally succeeded where no one else had ever been able to, and they found a frontal lobe dysfunction that explained why poor Alex had been unresponsive to 14 years of attempts to help him. Alex *finally* began to improve.

Anthem, of course immediately denied further benefits. This was *two days* after he had last voiced suicidal ideation, and tried cutting behaviors. It was before the second of the two medications needed to stabilize his newly-discovered neurological problem had even been started. This time they sent the appeal of Alex's case to one of the most notorious paid hacks in the insurance industry – Dr. Timothy Jack, of California.

If you ever have a moment, look this terrible man up on a reputable physician rating site, such as Vitals.com – he has the absolute lowest ratings possible. The comments section, limited to the last 18 months, is a litany of outrage, including eleven physicians encouraging complaints to California's medical and insurance boards. The most recent, on the 28th of last month, read: "Disgraceful. Actually appears to enjoy denying care to deserving patients. A complete sell out. Only positive I can see is that he is so blatantly incompetent and hostile that I, and many other physicians, are pursuing formal complaints with the medical board and attorney general's office." Dr. Jack's entire career appears to be denying claims for Anthem and other insurers. This is who Anthem pretends is an objective reviewer.

In Alex's case, on 5/26 – Dr. Jack wrote: "He (Alex) has had a tendency to have outbursts with suicidal behaviors, the last on 5/24. There is no report of Suicidal Ideation, Harmful Intent, or Psychosis." That's two sequential sentences that directly contradict one another. And these comments are just the beginning of a long list of distortions so massive that they are more honestly called lies. When Meridell's physician spoke with this odious, sham doctor, Dr. Jack said, and I quote (as Dr. Hageman wrote down every word) "If he (Alex) is better he should be released, and if he isn't, he needs custodial care."

Once again the OHA came to my rescue and helped me keep Alex at Meridell long enough for him to achieve enough stability that he can is now not only succeeding in school, he has straight A's and is talking about eventually going on to college in engineering, an ambition his school is encouraging.

Because the neurological problem underlying more than a decade of mental illness was finally teased out and treated, Alex is literally a new person, with real hope of a leading a good and productive life. Anthem stood in the way of every step and did everything they could to deny Alex the treatment he was fully entitled to, the treatment that made his future possible.

Does Anthem provide parity in mental health coverage? NO. Absolutely not.

On behalf of both Alex and myself, thank you for allowing me the opportunity to speak here today.

Office of the Healthcare Advocate

Public Testimony October 17, 2012

It is a shame that we have a claim submitted to Anthem BCBS for a child with a clear drug addiction/alcohol/depression problem, verified with not 1, not 2, but 4 attending physician statements, all stating that it is fully deemed medically necessary for my son to be admitted as an inpatient in order to receive the proper treatment for his disease. Instead the Anthem BCBS Ins. Co. feels they can diagnose the case without any consideration of the 4 doctor statements, who were the actual hands-on people treating the child for the disease. If someone were to come down with another disease such as diabetes would Anthem also disregard that patient's attending physician statements and determine the treatment of the condition to be not covered by the plan, even if you had 4 doctors stating it to be medically necessary. Each is a disease requiring long term treatment.

I certainly can see the public abuse in the area of alcohol/drug/mental & nervous disorders, but if the claim has been fully backed by a noted professional team showing the full necessity for the inpatient care, why isn't the claim recognized?

Thank you for your time and further thought to my claim and the many others you have received. Please advise me to your findings as soon as possible.

Vincent Mitchell

Brookfield, CT 06804

Testimony before the Office of the Healthcare Advocate
October 17, 2012
Barbara Sloan, Wallingford, CT

My name is Barbara Sloan. I am a retired mental health and addictions counselor and program manager. I have been disabled since 1994 and on Medicare since 1996. I also have a supplemental health insurance policy.

Despite this insurance coverage for mental health treatment, it is very difficult to get good treatment. When my former psychiatrist stopped accepting Medicare, I paid him a reduced out-of-pocket rate for several years until he downsized his practice. I had to find a new doctor.

Eventually, I ended up at a community mental health center because private doctors were either unavailable or wanted up-front payment that I could not afford to put out while waiting for reimbursement from Medicare.

This has not been satisfactory, since my community mental health center does not employ the specialists I need to treat Post-traumatic Stress Disorder, which is complicated by depression and several physical disorders that often cause severe pain. I have also experienced set-backs due to frequent staff turnover.

Last year, I learned of a private clinic that serves people with trauma-related mental illnesses. I started to attend this center that accepts Medicare and my supplement as full payment.

However, the reality has been that though the therapist was well trained, she had so many patients and duties that she was unable to see me on a regular basis. This is exactly the same problem I had with the community mental health center.

In both cases, every time I made progress, I became a loser: a loser of appointment times, a loser of regular treatment by the counselor I trusted and finally a loser of a counselor I knew. Starting over with a new therapist takes a lot of resources and time that could be better utilized in helping a patient make progress. It's not like getting a new dentist who starts where the former one left off.

Continuity is as vital to treatment success as access is. The "system" needs to support well-trained therapists with the time to work with their patients. Skilled therapists and doctors need to be available so that patients are not shuffled aside as soon as they feel a bit better.

It seems to be some doctors and therapists in small private practices who choose not to see patients without prepayment. Thus patients must continuously be out-of-pocket hundreds of dollars they can ill afford while waiting for Medicare and Medicaid to pay. I am not blaming these practitioners, who understandably want to maximize their own cash flow and are trying to see patients who need them. Still, it is a problem.

If these issues can be adequately addressed, patients will have better access and better continuity of care. The skills of doctors and therapists will be better utilized. Parity, in the sense of access to skilled practitioners, not just to some practitioners, will become a reality. And most importantly, patients will have a better chance at making a full recovery or at least improving their mental health.

Thank you for considering my remarks.

Barbara J. Sloan, M.Ed.
575 Pilgrim's Harbor
Wallingford, CT 06492

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.