Testimony submitted by
Diana Leyden
79 Spruce Lane
Glastonbury CT
(860)633-1132

How insurance companies have betrayed the intent of parity of coverage for eating disorders.

Hello, my name is Diana Leyden. I am here to testify that insurance companies, in particular Anthem, are not living up to the rule of parity when it comes to behavioral health issues. In particular, when it comes to eating disorders, which are mental health issues with physical manifestations, they are hiding behind the physical benchmarks to argue that they cover all that is medically necessary. As I will show with my story, not only are they denying much needed care for mental illnesses, but they are also doing it at a cost to both the patient and to themselves. As I will show, by refusing 4 years in a row to cover residential treatment for my daughter, they ended up prolonging her illness, putting her a greater risk for serious complications, and ended up paying more than if they had authorized longer residential care in the first case. The insurance companies end up pointing to minimal weight statistics that eating disorder providers uniformly agree are not the indicator of stability or recovery. Why do the insurance companies use this benchmark? Because that is when the body is generally outside of danger of physical collapse- heart attacks, complications of dehydration, etc. It is not, however, any indication of the mental stability of the eating disorder patients.

What I would like you to keep in mind as you listen to my story are two cases. Case No. 1- a patient has kidney problems that require an operation and dialysis until the doctor determines if the kidney can function on its own or the patient needs a transplant. Case No. 2- a severely anorexic teenager who refuses to eat, causing her heart to beat too slowly. This leads to hospitalization until the heart can be stabilized. The prognosis for recovery however, is uncertain because it depends on the mental state of the teenager. In the first case, I am sure that the insurance company would not stop paying for dialysis once the kidney is functioning at 85%. However, in the second case the insurance company does stop paying for residential care once the teenager reaches 85% of a minimal weight. Why the difference? Surely this is not parity. In fact, the insurance companies appear to be hiding behind physical milestones in the case of patients with mental health in the disguise of parity. I urge you to deliver the message to insurance companies that parity means paying for medically necessary care as that is determined by mental health providers, not insurance company reviewing doctors.

Further, insurance companies deny nutritional counseling and nutritional therapy beyond 3 visits per year despite the uniform opinion of eating disorder providers that such counseling must be provided weekly until the patient is in recovery. The insurance companies will only pay for such counseling if it is provided by a hospital or residential care facility, much more expensive options. The reason for limiting it is that that is the same coverage provided to diabetics or obese patients. However, an eating disorder patient has a mental illness, manifested by physical deterioration. The legislature when it adopted the rule of parity did not mean, and could not have meant, that parity is achieved as soon as the insurance companies

pays for similar treatment of physical conditions of a person with a mental illness and a person with out a mental illness. Rather, what the legislature meant is that persons with mental illness must receive care that is medically necessary to treat that illness in the same way that a person with a physical disease such as cancer or a stroke must receive medical care that is necessary to treat that disease. As you will learn from my story, the insurance companies are not living up to the intent of the law. As a result, they are putting many patients with eating disorders at risk for more entrenched eating disorders, more physical problems, and unfair higher costs to families whose loved ones suffer from these mental illnesses.

In 2007, our family was thrown into the nightmare world of anorexia when my then 16 year old daughter was hospitalized with severe anorexia. At only 75% of her minimal body weight and with a heartbeat lower than 50 beats per minute, she was admitted to the Connecticut Children s medical center. Of course the first concern was slowly introducing nutrition into her body. Most people think it is as easy as hooking up a feeding tube and delivering nutrition. However, for most anorexics with severely low body weight, nutrition has to be reintroduced slowly because the body can be thrown into shock with the fast introduction of food. This in turn can cause heart problems. But an added problem with an anorexic is the mental barriers that must be overcome. My daughter, at 71 lbs. truly believed herself to be obese. When she looked at her image in a mirror her mind displayed that image of a 300 lb person. As a result, as food was introduced, she countered it by excessively exercising. Unless watched 24.7 she would do situps, push ups, pace up and down the house or corridor and bounce her leg at a rate of 2 ever second.

After being hospitalized for 2 weeks, her team- which unlike a person with just a physical illness, included a psychiatrist, nutritionist, and physician- called us in to talk about the next steps. Of course, the insurance company signaled to us that it would be covered if she came home, went to a 6 hour day program, where she would be weighed, served a breakfast and lunch she would be encouraged to eat, and attend group counseling sessions.

Her team, however, encouraged us to admit her to a residential facility. For eating disorder patients, such facilities are a step up form a hospital. Patients, mostly girls, are housed in a locked house like a dormitory which has a kitchen on site. Food is measured and monitored, medication is administered, and staff are on site 24.7 to watch for unhealthy behavior such as excessive exercising or in the case of bulimic patients, purging. Therapy consists of group sessions and individual sessions.

This being our first experience with this deadly illness, we opted for the day program. However, in less than 3 weeks, we were told that her illness was so severe, that residential treatment was the only chance of not sending her back to the hospital. The first program she went to was Klarmans in Belmont, MA. Please be aware- Connecticut does not have any residential treatment facility for eating disorders. This means that Connecticut residents must travel to other states (Mass is the closest. Many of theses facilities are in the mid west.) It also means that medical dollars are going out of state. As a side note, I urge the panel to encourage the development of a residential facility, perhaps connected with CCMC or UConn.

My daughterwas there for almost 8 weeks- sounds like a long time, no? Her team, who saw her

everyday told us that based on sound medical studies a patient with severe anorexia should be in a residential facility a minimum of 3 months and in Libby's case would probably need to be there for 6 months. The reason for this is that while a severe anorexic might begin to gain weight (a mile stone that is not only crucial for physical health but also necessary to nourish the brain so she could begin to make some rational choices), soon after gaining a few pounds the starved brain and the mental illness kicks in and the patient becomes very resistant to additional weight gain. Thus, the patient needs intense counseling and therapy, and many times psycho pharmacy, to be able to lower the resistance and restore the weight. However, as soon as My daughterreached the weight of 85 lbs. Anthem denied coverage. This meant we had to appeal the denial within 24 hours and if we did not succeed we would have to pay until a 2nd appeal or litigation occurred. These facilities cost between $2,000 and $7,500 a week. We could not afford that. We were able to get My daughtermore time until she was 92 lbs but she was still well below her minimal target weight of 110 lbs. We estimate that if My daughterhad been approved for continued residential care in this first facility for 3 months more, the costs to the insurance company would have been about $40,000. As I discuss next, over the next 4 years My daughterrequired admission into 4 more residential treatment facilities and in an inpatient facility, the total cost to the insurance company being around $200,000. So even from the financial perspective of an insurance company, the current interpretation of parity does not make sense.

But the current interpretation of parity has other more long lasting and harsh consequences. The denial of medically necessary care early on leads to other physical problem (bone loss that can lead to early osteoporosis), depression of the patient and her family, strains on marriage, and tremendous financial costs.

Over the next 4 years we would repeat this process, admitting My daughter to 3 more residential facilities and ultimately, obtaining a guardianship over her in Massachusetts where she lived while enrolled in school. At one point, we had to take a cash advance from our credit card to pay $12,500 to pay for care while the insurance company made us appeal the third denial. (In each case, the coverage was denied because her weight was above 85lbs. The doctor used by the insurance company never looked a Libby, never interviewed her, and came to the conclusions over the reasoned objections of her treating team.) Her college had denied her to continue until she was at a weight of 100 lbs. (at one point in her journey she went as low as 61lb.s) It took the guardianship, which cost us $10,000, and a forced stay in an inpatient facility (a higher level of care than a residential facility but lower than a hospital) to finally help her turn it around.

We are happy that she has been above her minimal weight now for almost 2 years, is going to school again, and is in a safe place. But we know that anorexia never leaves. It can remain dormant for many years and be triggered by a seemingly innocuous event. That is why it is still very important to us that we make your aware of the importance for true parity.

Parity can only mean that a person with a mental illness must receive sufficient care that is medically necessary to put her in a safe place, ideally in recovery. Parity must mean that the medical team's determination of medically necessary must be followed because the factors to be considered cannot be classified into commonly understood statistics such as weight, blood

pressure, or blood work statistics. Parity must mean that what is the commonly accepted as the standard of care for mental health illnesses must be used not the standard of care for physical illnesses that are manifested by persons with mental illness. Parity should encourage insurance companies to pay for the care at the earliest stages when the chance for recovery is greatest.

I urge you to press insurance companies to live up to the intent of the parity rule, not just the window dressed interpretation of parity.