

**Nancy Jensen, Person with Lived Mental Health Experiences and Author  
Testimony on HR 3717 before the House Energy and Commerce Subcommittee on  
Health**

*Mr. Chairman, Ranking Member, and other distinguished members of the  
Subcommittee:*

Thank you for this opportunity to testify. My name is Nancy Jensen. I am the author of the book, "The Girl Who Cried 'Wolf'", which chronicles my lived experiences as a person with a mental illness and a survivor of the horrific conditions of the Kaufman House in Newton Kansas. You've heard of the old TV show "Little House on the Prairie," right? Well the conditions in the Kaufman House were so terrible that it could be called the "Little House *OF HORRORS* on the Prairie."

The story the Kaufman House vividly shows why the Subcommittee must remove the parts of this bill which destroys the funding and effectiveness of both the Protection and Advocacy for Individuals with Mental Illness program (known as the "PAIMI" program) and the recovery programs (such as the Alternatives conference and others).

This bill pretty much destroys funding for the PAIMI program and takes away its ability to hold abusers accountable and protect the rights of people with mental illness, including the right to treatment. The PAIMI program helped finally shut down the Kaufman House, freed my friends, and helped us get justice. If this bill was the law only a few years ago, Arlan and Linda Kaufman would still be in the business today of terrorizing, abusing and enslaving people with mental illness. More people with mental illness would be suffering in terrible places like the Kaufman house.

I know how terrible the Kaufman House was. I was unfortunately a resident of that evil place. Arlan and Linda Kaufman ran an abusive group home in Newton, Kansas, for over 20 years. They called what they did "therapy." It was not therapy. It was cruel. It was horrible. It was sexual and emotional abuse. The Kaufmans forced their so-called patients to be nude, to do housework, and tend the farm in the nude. The Kaufmans forced residents to do bizarre sex acts while videotaping it. They billed Medicare for these so-called "therapy services." They treated us worse than dogs. I was forced to be naked, to sleep on the filthy floor, and to use a bucket for a toilet. I was degraded and told that I will never wed, never have a child, never join a church,

and that I would never get a job. Well, as a proudly married mother with both faith in God and a job, I proved the Kaufmans wrong!

The PAIMI program shut down this house of horrors when no one else would or could. I was the first former resident to tell the State of Kansas about the evil happening there. Over a 20-year period, three more former residents and 11 Kansans joined me in telling Adult Protective Services (APS) and the State of Kansas about the Kaufman's reign of terror. APS and the State failed.

How did the PAIMI program get in and shut down the Kaufman House when the State could not? Three key reasons:

First, the federal PAIMI Act gives the Protection and Advocacy systems (called "P&As" for short) monitoring powers and independence to protect people's rights, including talking to the victim without others in the room, even in an unlicensed place like the Kaufman House and even when PAIMI does not have a client. Without a court order, APS was turned away.

Second, the PAIMI funding provided the P&A enough resources so that it could properly investigate the Kaufman House. PAIMI could then provide legal services to the victims for their rights and treatment as well as press for important and needed policy changes to stop future problems.

Third, and perhaps most importantly, with the PAIMI program the individual with a mental illness, the victim, is the client. The client is in charge. The victim decides what justice is. APS serves the interests of providers and the State.

As you can see in on page seven of my testimony, prosecutors praised the P&A and the PAIMI program for its ability to get into the Kaufman House when the State could not and to help ensure treatment for people with mental illness. For example, the Kansas Attorney General's office said at the time that the P&A through its PAIMI program "had the ability to go in and do some things under their authority that we [the state of Kansas] were not able to do...". Long story short, thanks to the PAIMI program working with prosecutors, the Kaufman House was shut down, people with mental illness obtained treatment, and Arlan and Linda Kaufman were found guilty on over 60

charges, including involuntary slavery. Thanks to the help of the PAIMI program, the Kaufmans are in prison today and I am here testifying. How cool is that?

This bill takes away the PAIMI program's ability to educate policymakers. The PAIMI program worked with me as a survivor to change laws to prevent future Kaufman houses. With PAIMI by our side we changed the law. Places like Kaufman House must now get licensed. Together with PAIMI we fixed guardianship laws. We started an Abuse and Neglect Unit. If this bill would have been the law, the PAIMI program could not have done all that, and similar situations would have continued to occur throughout the state. Systemic work protects people's rights and prevents abuse and neglect in an efficient and effective way.

Also, PAIMI does not just help victims of abuse and neglect. PAIMI protects the rights of people with mental illness. Because HR 3717 slashes funding for the PAIMI program it will make it harder people with mental illness to find housing, employment, and education. HR 3717 will prevent individuals with mental illness from receiving treatment. PAIMI serves people with disabilities in all these areas, not just preventing abuse and neglect. Since President Ronald Reagan signed the PAIMI program into law in 1986, it has been vital in securing appropriate treatment. This includes but is not limited to youth with severe mental health issues, adults with mental illness, as well as youth and adults with autism and other developmental disabilities who also have co-occurring mental health issues.

Another important lesson learned from the Kaufman House is the need to support recovery programs. Until I worked with PAIMI in 2006, I did not know that recovery was possible. Now I am an advocate for recovery. You need to have hope to recover. I fear this bill will take away the hope to recover by slashing funding to recovery programs.

I am also concerned that this bill would decrease the privacy protections of individuals with mental illness under HIPPA in order to provide families more access to information when it is not needed. Families of course are important to people with mental illness and their ability and opportunity to recover. Families already have access to a lot of information about their loved ones. The individual's right to privacy is what should be most important.

Finally, I believe that this bill has been misnamed “The Helping Families in Mental Health Crisis Act.” I want to respectfully point out to the Subcommittee that the focus should be on helping individuals with mental illness in crisis and through recovery. While families are an important support, the focus must be on the person and their recovery.

## **Extended written testimony about HR 3717, more background on the Kaufman House case, the PAIMI program and Recovery Programs -**

### ***Who ran the Kaufman House?***

The Kaufman House was owned and managed by husband and wife Arlan and Linda Kaufman. Arlan Kaufman was the so-called therapist, landlord, service provider, and guardian/conservator of one of the residents.

### ***How the State of Kansas Served Its Own Interests, and Not the Interest of People with Mental Illness ... or how to make \$75,000 while abusing people with mental illness:***

The State of Kansas had investigated the Kaufmans several times. However, the State served its own interest, not the interests of the residents. The State would show up, knock at the door and get turned away because Mr. Kaufman was a guardian for at least one resident and the State wrongly assumed he was guardian for all of us. The State has an interest to have people with mental illness served somewhere. They do not always care where. The State of Kansas and its APS program did not want to go against that interest, even when former residents, like me, told them the truth. You have heard the phrase money speaks louder than words, right? Mr. Kaufman pushed back against the State of Kansas for looking into his group home. Mr. Kaufman sued the State. The State of Kansas paid Mr. Kaufman a settlement of over \$75,000 to make this problem go away. That alone tells you all you need to know about the fact that the State serves its own interests. They paid off Mr. Kaufman to make him stop litigating in court. People with mental illness continued to suffer. Only the independent P&A and PAIMI program has the legal authority and funding to serve the interests of all the victims of abuse in a systemic way.

### ***How did the P&A Help Prosecutors Find the Kaufman's Guilty? How did PAIMI help the victims? How did the case unfold?***

The P&A got a report of the terrible abuse from former Kansas Attorney General, Phil Kline. General Kline was frustrated that the State agencies could not do anything. The deadline for the State to file charges had passed.

The US Attorney for Kansas, Eric Melgren, had originally turn down prosecuting the Kaufmans because he did not have enough evidence or a witness free from the

Kaufman's influence. The State of Kansas and Adult Protect Services (APS) was not able to help or obtain a resolution over a 20 year period. Unlike the State, the P&A represented us. The P&A believed us. They were OUR attorneys. The P&A used its "reasonable, unaccompanied access" under the PAIMI Act to do a full investigation. Because of this "reasonable, unaccompanied access" the P&A through its PAIMI program talked to a friend of mine, Barb, without the Kaufmans in the room. Barb told the P&A attorney "I don't want to be forced to be naked anymore. Please help me." The P&A attorney represented Barb and what she wanted. Not what the State wanted. The victims were now in charge.

The P&A got Barb out of that house of horrors. The P&A represented her in a court of law to get an emergency change of guardianship – Mr. Kaufman was also her guardian! The victims wanted to pursue criminal prosecution and restitution. As the attorney for the victims, that is exactly what the P&A did. The P&A provided information and a witness free from the Kaufman's influence to prosecutors. Prosecutors who had before would not press charges, finally had enough evidence to go forward. Thanks to the PAIMI program's "reasonable unaccompanied access," the P&A was able to ensure that justice prevailed. For 20 years, nothing happened. Six months after the P&A got involved, the P&A accompanied the FBI on a raid of the Kaufman house. The FBI seized over 30 videotapes from the Kaufman's bedroom, which vividly showed sexual abuse perpetrated on patients. The P&A was asked by the FBI and US Attorney's office to be on hand when the FBI executed its raid in order to ensure effective services and treatment for the residents of the Kaufman House. With the Kaufman's arrested and pending a trial, the P&A stepped in to ensure proper services and treatment for the now former residents of the Kaufman House.

The P&A and PAIMI program stepped in and protected the rights of the victims. The P&A obtained emergency change of guardianships for the rest of the residents. The P&A helped establish services and treatment for the residents. The P&A represented the victims civilly to ensure we were effective witnesses for the prosecution. The P&A represented the victims to obtain restitution. The Kaufman's were found guilty on over 60 federal charges, including involuntary slavery of people with mental illness and Medicare fraud. I am happy to report that Arlan and Linda Kaufman are in a federal prison as I speak here today. This group advocacy is an important and cost effective way to ensure positive changes for a large group of people.

***What did Prosecutors say was Important about the P&A and its PAIMI program in Obtaining Justice for the Victims of the Kaufmans:***

The main prosecutors of Arlan and Linda Kaufman were the US Attorney's office and the Kansas Attorney General's office. Below are quotes of what these Prosecutors had to say about the P&A and its PAIMI program. The direct quotes come from a documentary film about the P&A (called the Disability Rights Center of Kansas). It was the incredibly diligent and professional work of prosecutors along with the P&A through its PAIMI program that ensured a prosecution and enabled justice to prevail in this case.

The full documentary film on the Kaufman House can be found at:

[www.drckansas.org/abuse](http://www.drckansas.org/abuse)

Loren Snell, Office of the Kansas Attorney General:

“DRC [as the P&A with its PAIMI program] had the ability to go in and do some things under their authority that we were not able to do or weren't able to do as quickly as they [the P&A] could get it done. They were able to step in and work on behalf of those individuals, the victims in that case a lot quicker than we could under the state system because they had other authority other regulations and rules that they could operate under that were going to allow them to do things and do them a lot quicker.”

Eric Melgren, US Attorney for Kansas:

“One of the things that was unique about the Kaufman's approach was that we knew when we went in to execute search warrants and to make arrests of both Arlan and Linda Kaufman, that we were going to face the situation of having to have to have a plan in place to deal with the residents of the house. As I indicated, there were a number of adults who lived there who had various forms of mental illness or mental disabilities who either because they couldn't take care of themselves or had been conditioned to rely on others, weren't going to be in a situation to immediately provide for their own living and housing arrangements. Through the assistance both through referral to the Kansas Attorney General's office and to the assistance of the Disability Rights Center we managed to get court orders freeing the residents from those houses then we filed criminal charges both civil rights and health care fraud and abuse charges against both Arlan and Linda Kaufman.”

***Is this an Isolated Incident? Does Kansas differ in the way it conducts Adult Protective Services from Other States?***

The Kaufman House is not an outlier. It is not an isolated incident. All across the nation, State Adult Protective Services and other State investigation programs are failing people with mental illness. Simply put, these investigative systems continue to represent the State's interests. The attorneys for APS represent and serve the needs of the State. The attorneys for the P&A represent and serve the legal needs to the person with a mental illness who is the abuse victim. The P&A can investigate and monitor facilities and where people with disabilities get services. The P&A can represent groups of individuals, instead of only one person at a time. H.R. 3717 would not allow this type of systemic advocacy.

***The P&A and PAIMI Program Is the Premier System Fighting for the Rights of People with Mental Illness and Their Right To Receive Treatment:***

Supporters of HR 3717 misconstrue what the PAIMI program does and how it helps obtain treatment for people with disabilities. I fear that some advocacy groups supporting HR 3717 are only focused on expanding institutionalization at any cost. The underlying bill will increase the need for expensive institutionalization. It redirects federal money away from innovative community based and recovery programs and towards involuntary commitment. Committing people with mental illness against their will is both expensive and ineffective. The focus needs to be on recovery, community-based services and protecting individual's rights. The PAIMI program helps people with mental illness, including those with the most serious mental health problems, obtain the treatment and support that they want as individuals. It protects our rights. Supporters of HR 3717 apparently do not like the PAIMI program and the systems change it performs. Well, they have not walked a mile in my shoes. I have seen first-hand how the PAIMI program and the P&A works with individuals with mental illness, to be their advocate, and to help pass laws enhancing our rights and increasing access to treatment, services and supports.

PAIMI helps people with mental illness all over the nation. The National Disability Rights Network can provide this committee numerous examples of how PAIMI helps people through both individual advocacy and systemic work. For example, the Arizona Center for Disability Law (who has the PAIMI program) reached a settlement to help



increase services for people with seriously mental illness in Arizona. Thanks to this settlement, services including everything from medications to housing and supportive employment will now be more readily available to these individuals with mental illness. Governor Brewer credited the mental health advocates, including the P&A, with providing "the hammer" to ensure the state lives up to its legal obligations.

***PAIMI Program Helps Millions of Americans:***

The Kaufman House case is just one example of the work occurring every day across the country by the nationwide network of P&A agencies implementing the PAIMI program. Last year alone, over 15,000 individual cases, over 35,000 Information and Referrals, over 80,000 stakeholders were trained on rights and other topics, along with over 39 million people positively impacted through systemic advocacy by the PAIMI program. Think of the millions of people, families and society as a whole that have been positively impacted by the PAIMI program since it started in 1986.

***HR 3717 harms the Mental Health Block Grant and Pushes Involuntary Outpatient Commitment:***

This bill places negative strings on the federal mental health block grant money, hurting innovative programs and pushing involuntary outpatient commitment. This is bad policy. As I understand it, this bill would stop states from receiving federal mental health block grant funds (used to support innovative, evidenced-based services) unless they are forcing involuntary, court-ordered outpatient commitment. This is both ineffective and costly. It is also not based on the recovery model. It infringes on the independence and choice of Americans with mental illness. It would also have the effect of reducing funding for important and innovative community-based services in favor of involuntary treatment.