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Schizophrenia and Its Effects on an American Family: A Call to Action for the 21st Century

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Good afternoon, ladies and gentleman. My name is Cynthia Captain, and this afternoon I will be sharing my Sr. Project, entitled “Schizophrenia and Its Effects on an American Family: A Call to Action for the 21st Century.

Our country’s healthcare system is at a moral crossroads. The way we treat those whom we call “the homeless” is deplorable. According to the National Alliance on Mental Illness, an estimated 26% of homeless adults staying in shelters live with serious mental illness and an estimated 46% live with severe mental illness and/or substance use disorders. We, as a nation, need to do a better job of treating those with the severe brain diseases of schizophrenia, schizoaffective disorder, and bi-polar disorder. These patients should be cared for just as we care for patients with Alzheimer’s disease and Parkinson’s disease, but instead, they are sent to live on the street. Effectively treating mental illness must become a national imperative. No American citizen should be forced to sleep in their own filth or be “warehoused” in jail for being sick. We must treat them with compassion, providing the mentally ill and their families with the tools necessary to be functioning members of society.

My Senior Project is based on my mother’s biography as seen through the lens of the treatment of mental illness, and the laws which affected her treatment. It is also the story of how her children coped with a seriously mentally ill mother, the foster care system, and the consequences of living in foster care. Due to the time constraints of this conference, I am focusing today’s presentation on my mother’s treatment and its outcome. For the entire story, please feel free to read my thesis.

Because of a broken mental healthcare system, my mother became homeless. Homeless mentally ill Americans are dying on our streets, and on December 15, 1999, one of them was my mother.
My mother’s parents had been born in the South, where they had both worked in cotton mills. In 1922, they made the arduous cross-country journey to the Wild West of California, where my grandfather found work in a logging camp in the Sierra foothills. My grandmother gave birth to my mother in the log cabin pictured above in February 1924.
The young family moved to a young Los Angeles the year my mother was born. Coincidentally, in 1924, Los Angeles opened its first clinic to care for children with mental and emotional issues – The Child Guidance Center – which is still going strong today. Had my mother exhibited any of the symptoms for which she was later treated, she wouldn’t have been taken to the new clinic though, because she didn’t fit the image it wished to portray to the public – a child of well-to-do, educated, professional parents, while my mother’s parents were working-class people who could barely read.

When my mother entered puberty, historically when the symptoms of mental illness first appear, she quit school and ran away from home. She was only 17 at the time, a bit of a wild child, and WWII was in full swing. She married the first of five husbands that year. She was also acting out, though no one thought much about her outbursts at the time. However, by the time she was 25, these outbursts became more serious.
In 1958, my mother entered the mental health system, as many mentally ill people do, through the Court System, when she was arrested for abusing a small baby in her care. The court placed her in custodial care and sent her for treatment to Camarillo State Mental Hospital. It was this same court’s recommendation that she was dangerous and should never be released.

This is Camarillo State Mental Hospital, now the home of UC Channel Islands. This is where my mother experienced “therapies” which were supposed to improve her mental health, and where she was diagnosed with severe schizophrenia. Patients who were in the care of Camarillo State Mental Hospital were treated with several experimental treatment modalities.
The most notorious, of course, is pre-frontal lobotomy. In 1936, Dr. Walter Freeman and his colleague, James Watt, performed the first prefrontal lobotomy. By the late 1950s, an estimated 50,000 lobotomies were performed (later, it was determined that the lobotomy had no positive therapeutic effect). Fortunately, my mother missed this intervention.
Another therapy, electroshock, also known as electro-convulsive therapy, was a treatment for schizophrenia which was invented in 1938 by Italian neurologist Ugo Cerletti. This therapy was used with relentless frequency on the patients of Camarillo, and it is very probable my mother experienced this treatment. Interestingly, this form of treatment is currently thought to be of benefit to patients with severe depression.
In addition to electro-convulsive therapy, hydro-shock therapy was also utilized – this “therapy” kept a volatile patient in a cold bath until they became comatose. I remember my mother telling my grandmother about how horrible this was, and why it was used. I also remember my grandmother responding, “Well, dear, why can’t you just be good?” This “therapy” was used on anyone the staff felt was a problem, and most severely mentally ill patients of that period were considered “problems.” There were no real therapies that actually helped the patient. Instead, what were considered therapeutic modalities were those which kept the patients in a state of torpor, making them “manageable.” A quiet patient was a good patient.
Another horror of the inpatient psychiatric hospital in California, was the practice of Eugenics. The first of several Eugenics laws was enacted on April 26, 1909, and remained largely unopposed for the next 70 years. This law, and those that came after, allowed the state to “prevent procreation of confirmed criminals, idiots, imbeciles, and rapists.” Eugenics, a movement founded by the English scientist, Sir Francis Galton in 1884, was meant to improve the human race, by weeding out anyone the State felt was “defective.” California, unfortunately, was an early leading force in the field of eugenics, and by 1921, California had accounted for 80% of the sterilizations nationwide, or about 20,000 forced sterilizations in California between 1909 and 1963. My mother was sterilized at Camarillo after giving birth to a healthy baby girl, who was placed up for adoption three days later.
In 1963, the Community Mental Health Act was signed into law by President John Kennedy. This law had a direct effect on my mother, and thousands of others hospitalized in state funded mental institutions. The Act was supposed to provide federal funding for the construction of community-based preventive care and treatment facilities. Between President Kennedy’s assassination, the Viet Nam War, and an economic crisis, however, the program was never adequately funded. In addition, in 1965, President Johnson enacted Medicaid, which incentivized the state to move its patients from institutions to nursing homes and general hospitals because it excluded coverage for people in “institutions for mental diseases.” This act also opened the door for President Reagan’s total deinstitutionalization.

In 1967, California passed the Lanterman-Petris-Short Act, which made involuntary hospitalization of the mentally ill a great deal more difficult. Interestingly, one year after the law passed, the criminal justice system saw the number of mentally ill inmates double.

Deinstitutionalization is the root cause of those human beings we now call “the homeless.” The sick person living on the streets has become a common sight in urban centers.
Even though my mother was severely ill, she was discharged from Camarillo following her sterilization in 1963. The State reunited her with her three younger children, who had not been placed up for adoption. She was not a good mother. She shouldn’t have been expected to be a good mother. She had no support system, no friends, no relatives; essentially no one to call for help. Because of her frequent erratic and abusive behavior, her children were in and out of foster homes, where they all suffered verbal and physical abuse. Amazingly, three of her five children grew up to become very responsible and productive citizens, but her two younger children have had great difficulty, and the whereabouts of her youngest son is unknown at this time.

The lack of effective treatment of my mother’s schizophrenia, and lack of any meaningful mental health care had a disastrous effect on my mother’s life. She was deemed not to be a threat to herself or to others, according to the last hospital psychiatrist who had evaluated her, though she was sitting in front of him with safety pins in her scalp, which she felt kept the aliens from reading her mind. And so, after her 72 hour hold ended, the door was opened and she was discharged. The hospital did not find a home for her. There were no inpatient hospitals available to her, and the shelter would not take her because she had misbehaved while staying there and had been asked to leave. The hospital who had been holding her, relieved of their responsibility, merely opened the door and asked her to leave. When my younger sister went to pick our mother up later that day, she had already gone. We never saw her again. She died on the street from exposure in December 1999. She was 75-years-old.

This is the street altar put up every year to remember those who died on the streets of Glendale, California.
It took me twelve years to find out where my mother was “buried.” First, though, she was taken here – the public crematorium.
The City of Los Angeles, allows religious leaders to come once a year for a public blessing of the ashes of the unclaimed dead. This is the spot where my mother’s ashes lie.
By amazing happenstance, I was able to find an image of my mother as a teenage girl, in her high school yearbook, before all her heartbreak started. She was still an amazingly bright, and spirited young woman in this photo. If she had had Parkinson’s Disease or Alzheimer’s Disease, she might have had a decent life, but the medical profession has not been able to figure out how to improve the lot of schizophrenics. I asked a very wise professor once, how he thought we should treat the mentally ill, and he replied “Treat mental illness just like any other illness or disease.” This sounds very simple, doesn’t it? But it isn’t. No other disease stigmatizes the sufferer to the extent that severe mental illness does. Those suffering from mental illness have to prove they are really sick, and they then enter a system that is unfit, and unable, to care for them.

I entitled my project “Schizophrenia and Its Effects on an American Family: A Call to Action for the 21st Century.” That call to action is personal – it’s to me. I will be entering a Masters Program in the Fall, where it is my plan to learn the skills necessary to be of service to the men and women who, like my mother, deserve to be treated just like any other sick person.

I have a handout from the National Alliance on Mental Illness with current statistics on the frequency and treatment of mental illness, since I didn’t have time to include that data in my presentation. Thank you all so much for attending my presentation.