

Weaknesses in Access to Care Highlighted at Press Conference

By JANET SUSIN

On December 11 a major study regarding access to mental health and addictions care was released at a press conference hosted by North Shore Child & Family Guidance Center. I was pleased to be a speaker at that event and have been on the committee that helped develop and promote the study. The press conference was featured on News 12 Long Island and in the article below that appeared in local papers published by *The Island Now*.

North Shore Child and Family Guidance Center's 'Project Access' shows struggles of finding mental health care

By AMELIA CAMURATI

The Island News, December 12, 2017



Janet Susin spoke at the press conference about the struggles her son had faced after being diagnosed with

schizophrenia.

(photo courtesy of North Shore Child and Family Guidance Center)

Janet Susin said during her family's first visit to the emergency room after her 16-year-old-son was diagnosed with schizophrenia, the hospital staff had only one concern.

"The first question we heard wasn't, 'how's he doing?', it was, 'do you have insurance?'" Susin said.

North Shore Child and Family Guidance Center held a press conference Monday to discuss the results of their year-long Project Access study examining the ease or difficulty with which patients and their family have accessing mental health and substance

abuse care, especially through insurance providers.

Susin, a past president of the Nassau-Queens chapter of the National Alliance on Mental Illness, was a teacher, and her husband was a doctor at North Shore Hospital during that hospital visit 30 years ago, and she quickly learned that while her policy had \$1 million worth of mental health coverage, her husband's only offered \$40,000 for the family for life.

Soon after, her son, now 46, was prescribed an antipsychotic medication and has not been in the hospital since, thanks to the care of an excellent psychiatrist, Susin said — a psychiatrist who charges \$250 per visit and does not take insurance.

Susin said while their psychiatrist was willing to try working with her insurance company, the agreement ended less than a year later because the psychiatrist believed the rates were too low and receiving payments from the insurers was a hassle.

Susin said she has paid out of pocket for subsequent psychiatrists as well ever since.

"We're lucky we can afford to pay for good care for our son and as a result, he's remained stable all these years," Susin said. "Every person struggling with a psychotic disorder or any mental condition should have the same opportunity."

Social worker Kerry Eller spoke about the struggles of her teenage sister, who has dealt with mental health and substance abuse issues since she was 11.

Her mother was a single parent, trying to manage two younger boys while fighting to get her daughter the care she needed. Eller said her mother often blamed herself, asking if she caused these problems for her daughter and whether she was enough of a mother to care for her children.

"When anyone in my family had some kind of physical ailment, there were no issues getting care," Eller said. "When I needed my tonsils removed, I wasn't directed to multiple doctors just to find one that was willing to provide me with the medically necessary treatment that my condition required. There is such a stigma related to psychiatric and substance abuse related disorders, which makes it scary to reach out in the first place.

"When you finally build up enough courage to reach out for help and then your efforts are thwarted, it feels defeating," she said.

North Shore Guidance Executive Director Andrew Malekoff said the 41-question survey was completed by 644 people who answered questions about demographics and experiences as well as an open-ended question for personal stories about the process.

Malekoff said fewer providers accept commercial health insurance plans because their rates are often lower than Medicare rates.

Dear Friend:

We're pleased to provide you with a link to the results of a year-long research undertaking called Project Access, which has been supported by the Long Island Unitarian Universalist Fund of the Long Island Community Foundation.

We surveyed almost 650 respondents across Long Island about their experiences regarding the ease or difficulty with which they were able to access mental health and addictions care. As the results of our study show, far too many people are having trouble finding timely, affordable, quality care for themselves and their loved ones. Access delayed is access denied.

A few key findings:

- Almost half of the participants said that it was more difficult finding help for mental health or substance abuse problems than finding help for physical illnesses, especially when they were in crisis.
- Nearly 40% said that their insurance company did not have an adequate number of providers.
- Two-thirds told us that their insurance company was not helpful to them in finding a suitable provider for themselves or a loved one.
- Almost 40% of participants reported that stigma and affordability were impediments to seeking care.
- And almost 25% of participants reported that they felt their attempts at accessing care were futile.

We hope that you will find this report affirms what many of us know anecdotally regarding the impediments we and our neighbors experience when seeking to access care. Please feel free to forward this and to make your legislator aware of it.

We are calling for the New York State Department of Financial Services to launch an investigation of the problem of access to care. Please join us in spreading the word. Please contact the Governor at the following address:

The Honorable Andrew M. Cuomo, Governor of New York State
NYS State Capitol Building, Albany, NY 12224

Sincerely,

ANDREW MALEKOFF, Executive Director
North Shore Child & Family Guidance Center

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Memories from Greg Barber

I wrote this to a Manhasset resident, but decided to send it to a few Manhasset supporters of mine.

We met at a networking lunch on Long Island. I used to live on Kensett Road in Manhasset. My son was a lacrosse star there. He became mentally ill with schizophrenia starting in his Junior year. Life changed for everyone.

But I started a charity in my son's name., Neil Barber, with Hall of Fame lacrosse player and Manhasset coach, Bob Rule. The charity is www.neilswheelsny.com.

I made my son into a hero in Manhasset for raising food and for destigmatizing mental illness. We have raised over 70,000 cans and boxes of food in eight years. We started in 2009. My website has all the info on how and why we began, but this is a story about battling back from the depths of despair, and not about how many goals he made in lacrosse at Manhasset, where he was a star.

I once made a speech at the Swan Club before the annual NAMI Walks at Jones Beach and I didn't talk about Neil. I said I wanted all the team captains of this walk to stand up, and give all 230 people there a round of applause. For being a caregiver to a mentally ill family member is the toughest role in life. The applause went on a good two minutes.

I am not sure why I decided to write all of this to you, but I think it was because you live in Manhasset and holidays are really tough for me, and memories keep me going. It has been 25 years since Neil became ill. He had it all and then it was gone.

But, Neil is remembered by his classmates and friends in Manhasset because of our charity, and I feel his life is not in vain.

Thanks for inspiring my letter to you. It helps to open up.

Greg Barber & Neil Barber

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According to Project Access results, almost half the participants said it was more difficult to find help for mental health or substance abuse

problems than care for physical ailments, 40 and two-thirds said their insurance company was not helpful in finding a mental health care provider.

State senators Todd Kaminsky (D-Long Beach) and Elaine Phillips (R-Flower Hill) provided a bipartisan front from the state Legislature, both sharing stories of family members who suffered from mental health issues and struggled to receive help.

"The founder of the Nassau-Queens National Alliance on Mental Illness chapter was my cousin Arnold Gould, who passed away last year," Kaminsky said. "He devoted his life to this issue, and for a long time, Arnold had a son who was the cousin in my family no one talked about or knew existed. We have to turn the page on that. We can do better."

Kaminsky and Phillips both said they would write letters to Gov. Andrew Cuomo and the state Department of Financial Services with the Project Access data and their concerns about the issue.

"I am extremely proud to be supporting Project Access and to be supporting the mental health industry because it is going to take research like this when we do write the governor and the New York State Department of Financial Services," Phillips said. "We have data behind it to say that this isn't happening in low socioeconomic areas of one part of the state; this is a rampant problem that is happening throughout New York and especially here on Long Island."

Phillips also said if needed she would support legislation to make mental health care more accessible and affordable across New York.

North Shore Child and Family Guidance Center partnered with LIU Post for the research, and social work professor Elissa Giffords said the school received approval from their institutional review board before administering the survey to human subjects and placed surveys in waiting rooms and posted flyers with a link to the survey as well.

"People who completed the survey, it's likely they already accessed care," Giffords said. "This is quite important, particularly because although they could access treatment, they still reported impediments when seeking this care. This also means there's a

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NYS Senators Elaine Phillips and Todd Kaminsky with Andrew Malekoff, Executive Director, NSC&FGC

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