

STATEMENT OF
J. MICHAEL JONES, FATHER OF A SON WITH PSYCHIATRIC DISABILITIES
OCEAN COUNTY, NEW JERSEY

SUBMITTED TO
HOUSING TRANSPORTATION, AND COMMUNITY DEVELOPMENT SUBCOMMITTEE OF THE
SENATE BANKING, HOUSING, AND URBAN AFFAIRS COMMITTEE
UNITED STATES SENATE

OCTOBER 29, 2009

Senator Menendez and Members of the Subcommittee –

As the father of someone with psychiatric disabilities I appreciate your invitation to provide testimony to this Subcommittee on the behalf of the many families in the same situation. Also as a father I can tell you that about two out of every five families are affected by mental illnesses.

Mr. Chairman, I thank you and this Subcommittee for your work to sustain, improve, and increase the number of units available for low-income people with disabilities. As the only federally funded housing program aimed at providing low-income people with disabilities with affordable rental subsidies the Department of Housing and Urban Development's Section 811 program is very important to the recovery of many with mental illnesses. This program also provides people the opportunity to live independently within their own communities by providing affordable rental options. Today I will share some of my son's experiences as a mental health services consumer in obtaining and living in several types of supported housing.

First I would like to provide you with a little history of my family's journey into mental illness, treatment, and recovery. My 28 year old son, Michael, was diagnosed with Attention Deficit Hyperactive Disorder when he was four. When he started school the child study team determined that he also had learning disabilities. He was placed into special education, where he

remained throughout elementary, middle, and high school. When he was a freshman in high school he was diagnosed with Depression, but he had other behavioral problems as well that periodically caused trouble in school. He was first hospitalized for treatment of mental illness when he deliberately cut himself on the cheek with a box cutter while in shop class. He was subsequently tentatively diagnosed with Schizoaffective Disorder, then Bipolar. Reevaluated in his senior year, he was found to have Schizophrenia shortly before he was first hospitalized in the state hospital. As you can imagine, high school was not enjoyable for him. He graduated in 2000, although it was not with his classmates. He completed his senior year at a therapeutic academy for students with psychiatric disorders. His current diagnosis is again Schizoaffective Disorder with co-occurring substance abuse. His learning disabilities still limit what he is able to do if it involves concentration, reading comprehension, planning, or short term memory. For example, he cannot decipher even simple medical instructions.

Mr. Chairman, as a father, the first response to a mental illness; after the shock of discovery, diagnosis, and denial is to learn all that you can to try and fix your child's problem. I started looking for that "silver bullet" that we all hope to find as a cure any major illness and found that there were none, but I did discover hope and support from other families and friends that had gone before us and that are going through this. As my family became increasingly involved in learning about what we could do, who we needed to know, and where we needed to go to help our son I discovered that there were many support systems besides the mental health systems that could be needed. In order to learn more about these and to help others I sought, and was selected, to be on the Ocean County Mental Health Board and the New Jersey State Planning Council as a family member. These two organizations have helped me learn about new programs and details of existing programs that could help my son and many other families.

When I found out that the National Alliance on Mental Illness (NAMI) was founded by families supporting other families, educating each other and advocating for improved treatment and services I decided that I had found my support. NAMI is the nation's largest non-profit organization representing and advocating on behalf of persons living with chronic mental health challenges. Through over 1,100 chapters and affiliates in all 50 states and over 200,000 members, NAMI supports education, outreach, and advocacy on behalf of persons with schizophrenia, bipolar disorder, major depression, severe anxiety disorder, post-traumatic stress disorder (PTSD), and other chronic mental illnesses that affect children and adults.

However, we didn't discover NAMI until 2002. I became very active in our local affiliate in 2003 and I am currently the President of NAMI-Ocean County. I was also elected to the NAMI New Jersey Board of Trustees and, because I'm a veteran, asked to be on the NAMI National Veterans Council where I support Veterans and their family with mental illnesses. I also became a teacher in the Family-to-Family Education Program where I learn from and facilitate support groups for families in crisis in their journeys to recovery.

While I will talk about my son's experiences I have found that they are similar to many other families' situations. One key thing I have learned is that those who contract mental illnesses seem to be stuck developmentally at the level of maturity where they are when they get sick. The saying is, "They are stuck where they are struck." The knowledge of when one gets ill should be helpful to those trying to tailor services to their needs. My son's mental maturity is such that he still reacts and thinks like a very young person much of the time. Another thing I have found is that many times those providing services, providing information, or giving directions, which are then not followed by the consumer, do not seem to be able to empathize

and brand the consumer as noncompliant or nonresponsive when it is simply the inability to remember.

Michael always wanted to be on his own, but had no financial means or living skills to do so. After graduation from high school he tried living with friends but ended up in crisis and in the state hospital again. By then we had learned that if he had no place to go upon being released he would likely be placed into a group home. He needed structure, but he also needed to be away from his family in order to develop skills for independence. We told his treatment team the day he arrived in the hospital that he could not come home after release. During this hospitalization he first admitted to taking substances other than prescribed medicine and started rehabilitation at another facility. He was quickly sent back when he became psychotic due to the treatment methods. After his hospitalization he was released to a group home for mentally ill chemical abusers (MICA). He did well for a while, but eventually started to try to find a way to leave. He finally did after almost three years. But he left to live with his girl friend and her mother. His girl friend was pregnant.

My wife took the couple to apply for Section 8 housing in May of 2006. Our son was informed after a few months that he was eligible, but he never heard anything further.

The day treatment program he and his girlfriend both attended referred them to their supported housing office. This office provided them with a listing of several apartment complexes where they could look. None had vacancies. They were still living with the girlfriend's mother when the baby was born, however there was a fire in the apartment the day before the baby was to come home, thus they all went to live with relatives. Because they were now homeless, the housing office was able to get them into an apartment in about two months. The new family was provided support to get the lease established and transportation to obtain

utilities and deposit payments. The case manager also picked out and had furniture delivered before they moved in. They initially were visited by their case manager several times a week, but this soon slowed to only sporadic visits.

My son discovered that their cable had pay-per-view movies and unwittingly ran up their bill to well over \$400 the first month. In addition to having to adjust to living pretty much on his own, and to being a father he also had a very difficult time with the routine of daily life and had zero ability to manage finances.

In less than a year our son and his girlfriend split up. He then briefly came back home to live with us. Shortly thereafter visitation and child support arrangements were made and he started having supervised visits with his daughter in our home. However, the first time he went to pick her up he was handed a note stating that his former girlfriend was leaving the county with his daughter when the lease was up. After the second visit by his daughter he suddenly packed up some things and left to live with friends.

During this timeframe a New Jersey Division of Mental Health Services program called Residential Intensive Support Teams (RIST), originally established for providing intensive supported housing for those leaving the state hospitals, was expanded in Ocean County to provide housing for those at risk of becoming homeless and who also needed more intensive services. Our son was referred and selected to participate.

A major difference between this program and supported housing is that RIST initially holds the lease and acts as the Representative Payee for social security benefits. This is beneficial because clients may need to be hospitalized periodically and/or have real problems managing finances and spending. This way the clients do not lose their homes and someone is there to help keep their benefits and affairs as straight as possible.

The stated goals of RIST are to support and encourage the development of life skills required to sustain successful living in the community and to provide housing in a community setting environment which allow opportunities to learn the skills necessary for more independent living. Within this setting they provide each consumer with the maximum possible autonomy, independence and self-determination. This program does constantly strive to empower consumers to relocate to less restrictive living arrangements.

My son moved into the apartment to live on his own, a very nice second floor apartment that RIST had help him furnish, in early 2008; he started living skills training and a new day program. RIST provided evening “life skills” groups for the RIST supported clients in the apartment complex. Michael volunteered to help others to learn from his experience on how to use the bus system. He also had plans to become a peer support counselor, but never carried through.

However it didn’t take him long to make friends and to throw his first loud party. He ran up his electric, cable and telephone bills very quickly. His case manager tried to help by having his phone limited to the local exchange only and canceled his cable. At this point, he had no one to take up the slack in paying for food and quickly found that his food stamps didn’t buy enough each month. He would eat lunch at his day program and would sometimes cook easy-to-prepare meals, but would go for days with one meal a day at program. He started using money he obtained from selling things he either owned or stole to buy food and drugs.

He got to the point of deciding, with his case manager, that living on his own was really not appropriate for him yet and that he needed go into the hospital to get into a long-term drug rehab program then back into a group home. The hospital case manager found that there were no

long term rehab programs available. He then made the correct decision to go to the state hospital again for treatment and so that he could get into a group home.

At his initial attempts, Michael was not ready for supported housing. He had never developed the skills and habits needed to build on to start to live independently. His girlfriend, whose mental illness hit her much later in life, has continued to do very well in supported housing. While he was very fortunate to be afforded the opportunities and to have caring case workers he wasn't ready. I am very proud to say that he came to the realization, and knowing enough to talk it over with his case managers, he decided that he should to return to the MICA group home so he could learn and pursue skills he needs to live independently. The lesson here is that the providers of supported housing must understand that those with mental illnesses may require much more than periodic support. They may need very intensive case management to guide and reinforce living skill development for as long as a year, perhaps longer.

Mr. Chairman, this concludes my formal testimony. I hope you are able to take our views into consideration as you conduct the important work of this Subcommittee. Again, I appreciate the opportunity to testify. I would be honored to answer any questions that you might have.