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The Long Road to Nowhere:
A Daughter's Journey Through the Mental Health System
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(Mother of a child with Serious Mental Illness)

I would like to introduce you to my daughter, Michaela Thomas

- **We, her family and friends, all have known Michaela as a very bright, musically, artistically and academically talented person with major curiosity, and an understanding of the larger world. She grew up without a lot of frills. She overcame many obstacles in her journey through school. I'll never forget the day she finally got her acceptance to Smith College in May of 2014!**

- **Michaela is an amazing person. She played her first violin recital at MSU School of Music at 4 years old. She was shorter than the grand piano that accompanied her!**

- **Michaela loved to swim and play softball. At 9, she earned three belts in Tae Kwan Do in one year! She presented a proposal to the St. Louis Lion's Club and City Council that same year to plant trees at the Lion's Club park where she played to create shade and provide homes for wildlife.**

- **Michaela was a Michigan Youth Symphony Orchestra member for three years, took numerous awards in academics, science and music, and achieved National Merit Scholarship Finalist standing, as well as National Honor Society.**

- **She was invited to join a mission group to teach English in Haiti at 17. She not only taught English, but also started a music class. She hauled donated violins, along with a few of her own, with her to Haiti, where she introduced the violin to mission students, presenting the violins to them.**

- **Then, all too soon, she went off to college. Like every Mom, my heart was full and broken at the same time. I missed her terribly, but she had to begin her journey to find out who she was and what she had to give back to the world.**

- **You see the life and vigor, the intelligence and energy in these photos. This is how Michaela charged into life at Smith! In her last semester, she was given an internship to Jordan to study water systems. This was to be her last achievement as an aspiring environmental engineer...**

- **...because something went wrong.**

CRISIS

- Michaela experienced her first crisis hospitalization in November, 2016. It started in the spring o that year. She sensed something was not right—she kept trying to figure it out. Her FB posts went from activist-artist-literary commentator to muddled, unintelligible ramblings. She stopped eating—a pure adventurous delight for my daughter! She stopped going to classes, stopped bathing, sleeping, socializing. Back at home, she became paranoid and aggressive. She would sit catatonic for hours. Her aggression won her a ride in a patrol car to the hospital, where she was finally certified by doctors to be placed in a psychiatric unit. That was three long years and more than 6 hospitalizations ago. And I have been fighting ever since to get her appropriate and effective treatment.

- Everyone who experiences a family member spiraling into psychosis will tell you that the experience is so unbelievable and utterly foreign that words fail to describe the experience. Like someone experiencing gun violence, or a car accident, you are in shock, but in this case, there is no clear path from 911 to the emergency room, where a competent triage team wheels your loved one into a highly trained and organized theater of surgery, and a hospital liaison takes you firmly to the family waiting room to explain what is happening, and what comes next. There is no hand book, not even a google site to tell you exactly what to do and where to go to get help. You are simply on your own to figure out how to get your loved one the help they need to get well.

- Michaela, having no private insurance, was shuttled back out of the hospital and sent by ambulance to Clinton-Eaton-Ingham Community Mental Health's Crisis Clinic. There, she had to wait for three days, living in a room, sleeping in a chair, until she could be re-certified by CMH psychiatrists. An application for Medicaid was expedited, and when it was approved, they began looking for a bed for her. In the middle of the night on the third day, she was transported to Saginaw to White Pines. There she stayed for 3 weeks while her psychiatrist struggled to determine her diagnosis.

DISCHARGE: the CEI CMH Millwheel

- Armed with a diagnosis of Catatonic Schizophrenia and Bi-Polar Disorder, a paper prescription to be filled, and a plastic garbage bag of all of her personal effects, she came home on Thanksgiving Eve. There was no way to fill the prescription, and she went for two days before it could be filled.

- From the start, Michaela insisted that there was nothing wrong with her. She still has what is termed anosignosia, lack of insight into her illness.

- Because Michaela could not be left home alone, I took FMLA and all of my vacation time to be home to try to figure out what steps to take get the continued help she needed. The problem was that I didn't know myself what she needed, or who might know. She just came home and . . . nothing. She needed constant attention to her activities of daily living. She resisted taking meds, she wandered, would not sleep or would sleep too much. She set fires in the kitchen, left messes, food and water everywhere. She couldn't talk or read or watch TV or engage in any former activity.

- She was admitted back to CEI-CMH for community based treatment—case management, therapy, psychiatric care. Her first appointment was a week after she came home. Intake. She was asked what kind of help she would like from CMH. I was dumbfounded. I asked if the intake staff had read her file from White Pines. She stated that they take their information from the patient because this process is person-centered, and she had the right to speak for herself. Michaela's answers all indicated that she was doing very well, and she didn't need any help really. What CEI-CMH fails to acknowledge is that Michaela's condition robs her of her ability to understand her situation, the danger she puts herself in, her lack of judgment, and her utter inability to care for herself.

- Her next appointment was two weeks later. She met with another social worker who filled out an assessment to determine her level of services. A few weeks after that we were told that she was assigned to a case manager, and that it would be February before she could see a psychiatrist because they were short staffed.

- Running out of FMLA, I called everyone who had any experience with mental health to find out what I could do. I was referred to ETCH, a community-based therapy clinic that accepted Medicaid. She was screened and accepted as a patient, and began seeing a psychiatrist immediately. ETCH provided many activities and types of therapy for clients. But unfortunately, due to Michaela's resistance to treatment and the lack of early comprehensive medication management, she did not respond well. After three months, she began to refuse to take her meds, deteriorated, and ended up in Northwestern Hospital in Chicago after attempting to run away.

- By April, in desperation, I borrowed over $75,000 to place Michaela in a private treatment center, Rose Hill in Oakland County. There, she lived in a highly structured setting with a daily routine which included, regular meals times, morning work teams, afternoon classes and therapy, evening activities, socialization, outings, step-up independence as able, supported volunteering, supported work in the community and college. Michaela is so medically resistant to medications that she was 4 months into her stay when the lead psychiatrist initiated gene testing to get a better picture of

what class of medications she might better respond to. She began a new regimen, but the funds ran out, and she had to be discharged back to CEI-CMH. Within 2 months, Michaela had stopped taking her medications again, and declined anymore services. Nine months after that, she was back in the hospital. In 2018, I met a 30 year veteran in the mental health profession who explained that CEI-CMH does in fact have the option to provide residential-level services. Yet, after all she has been through, CEI-CMH continues to deny her this vital step toward stability and independence.

- Michaela has attempted suicide twice, run away and hitchhiked in Michigan, Illinois and Minnesota. In the 3 years since she has been a patient with CEI-CMH, she has never been relieved of her psychotic symptoms. I have fought for 3 years to get CEI-CMH to place Michaela on a more intensive level of treatment, with close psychiatric supervision for medication management and community living supports, but they have refused every request. Michaela has lost 3 years, with each episode causing more brain damage that may never heal. I have spent over $150,000. Of borrowed money on private options for her. I have had to leave a good job in 2017 to stay home to care for her, while continuing the fight to keep her safe, and get appropriate treatment.

- Because of my persistence, CEI-CMH has gone to great lengths to shut me out of the process. They have not listened to me as a family member and care-giver. They have used Michaela's paranoia (a symptom of her psychosis) and her resistance to treatment to encourage her to deny me access to her treatment and to provide inputs as to her behaviors that could be mitigated by appropriate med management and therapy. When I petitioned for guardianship, which would give me the right to participate, they encouraged her to contest it, costing me thousands in legal fees to represent my position as her mother and care-giver. When guardianship was granted initially to an outside agency, Michaela lost more ground when she aged out of Medicaid MyChild, and neither guardian nor CMH was tracking her insurance. They failed to keep her safe from a predatory relationship that began when CMH placed Michaela in a homeless shelter because they didn't have an adult foster care home placement open. When she was evicted from the shelter, she was placed in an old hotel room with no money, and access to only breakfast for 5 days, before she finally landed in a low-level Adult Foster Care home in an area of Lansing known for drug activity and high crime. There, she shared a room for which she was to pay $884 per month of her SSD that she had not begun to receive. She was allowed to roam and wander at will, and not monitored for safety.

- Most recently, after admitting Michaela without any explanation to their Crisis Bridges Inpatient Center for 9 days, she was driven by a case manager to my

neighbor's home to request that she file a Personal Protection Order against me on Michaela's behalf, and failing that, to the Probate Court to file a petition to have me removed as guardian. The petition was ultimately denied, but the cost for representation for 3 of the 4 court hearings is over $15,000.

- **All this came about because I finally began filing complaints against CEI-CMH for their neglect of my daughter, and showing up to meetings with an advocate who knows the system, and can point out when they are violating Michaela's and my rights.**

- **After 3 years, only in response to a PIHP complaint inquiry, Michaela is finally being placed on Assertive Outpatient Treatment, but their responsiveness is "too little, too late". Michaela's ability to keep herself safe and take care of her daily needs has not improved with her years of inadequate treatment through CEI-CMH. Due to her continuous psychosis. She requires residential treatment where she can be in a safe environment with 24 hour oversight, which was noted and recommended by Bridges staff in her recent stay. Ironically, though, CEI-CMH *management* still insists that Michaela does not meet qualifications for residential treatment.**

POLICE AS INTERVENTIONISTS

- **During these 3 years, we have gotten to know the East Lansing Police through the many calls to assist when Michaela has become violent or has wandered away. Many of the ELPD officers are Crisis Intervention Team trained and know how to work with a SMI person in crisis. Our ELPD officers are kind, they listen, and they have assisted Michaela in taking her meds as well as transporting her to the hospital when she has gone into crisis. While this is not what they became police officers to focus on, they find themselves in the same position as every community in the country—the crisis intervention that CMH's and the medical community should be providing. I bless these officers every day for their compassion and insight.**

- **When community police are obliged to get involved in a mental health crisis, it is a direct result of mental health services that are underfunded, under-monitored, and disconnected from other medical and community services. Our police forces become first responders in a medical crisis that should be handled by trained mental health professionals and the medical community. Why is this? Answer: 1) The underfunded and disconnected system lacks the personnel and coordination to respond to crises. 2) This same system chooses to apply scarce resources to the average, which leaves persons with Serious Mental Illness exposed, vulnerable and unstable.**

OUTCOMES?

- Michaela to date does not receive any community living supports, a clearly outlined feature of CMH services and a requested part of her Person Centered Treatment Plan. She is expected to find and fund her own housing, keep track of her daily living needs, organize herself, get herself to all of her appointments and willingly refrain from using tobacco, drugs and alcohol. In other words, live independently, self-monitor and "carry her own load". Worse, to leave Michaela to her own devices is a conscious choice CEI-CMH is making.

- To expect persons like Michaela to take care of themselves and make healthy, appropriate decisions for themselves is, in my opinion, what defines insanity—the insanity of a broken system that continues to be structured and funded in such a way as to NOT respond to the needs of those it is designed to meet. The human cost as well as the cost to society in the revolving door of hospitalizations, court cases, jail sentencing (or housing patients in jails due to lack of hospital beds) is astronomical. It's time that we decide that our precious children and other family members are no longer going to be the dross of funding cuts, and bad legislation. It is no longer acceptable to discriminate against the mentally ill where Medicaid parity should exist. It is no longer justifiable to house mentally ill patients in jails (in isolation, no less) for any reason. I thank God that my daughter has so far avoided this aspect of the mental health system.
  How can this be fixed?

<u>RECOMMENDATIONS:</u>

1) Develop better, and adequately fund and monitor *ALL* MH services to reverse today's poor and inadequate treatment options:

~ re-design community-based treatment (CMH's)

~ provide residential treatment (long-term, inpatient step-up-to-independence programs)

~ develop housing (SIP's, AFC's and group homes with range-of-intensity services)

~ implement home-based (to include case management, Community Living Supports and caregiver respite).

2) Legislate Medicaid parity and include access to private clinics. Need every county to adopt and fund "wrap-around" model of Assisted Outpatient Treatment, to reduce revolving-door hospitalization, homelessness, recidivism and suicide for persons with serious MI who lack insight into their illness and who are resistant to treatment.

3) Treat psychiatric illnesses in *psychiatric hospitals* and *increase* beds.

COMPARRISON OF CURRENT VS. PROPOSED MODELS

	CURRENT MODEL	**PROPOSED MODEL
Crisis	3-7 day hospitalization	14 day hospitalization—with longer hospitalization if needed (pref. in psychiatric hospital setting)
Discharge	Community-based - CMH/private pay ~ACT case management-- limited access ~SIP-limited access ~Basic case management -Jails—increasingly used to house MI -Jails—arrests (attributable to MI) -Homeless—without treatment	Residential (where needed): -Step-up to Community-based independence programs (include public agency for oversight) Community-Based: -Medicare utilize private pay clinics (VA model—in areas with limited CMH supports) -CMH ~ ACT-Current intensive program—increase access with CLS and add *AOT ~SIP—increase access with range of supports ~Basic low-level case management for persons able to self-engage in treatment

**Research-supported Proposed Model = avoid hospitals and jails, saves dollars

* AOT: court-supported mandated treatment helps avoid criminal hospitalization and/or being released to inadequate CMH treatment or self-monitoring

LEARNING THE SYSTEM

What I had to learn to help my daughter: Wow! It is a long list; I did the following:

-The day of her initial hospitalization—found out who treats people in a mental health crisis
-Dozens of phone calls to find clinics that are taking new patients, and that take Medicaid
-Hundreds of hours researching Schizophrenia and Bi-Polar disorder

-Read many text books on how to deal with Schizophrenia as a family member
-Talked to experts in a variety of agencies to get answers to why Michaela is not being treated according to her illness
-Learned parts of the Mental Health Code to find out what Michaela qualifies for under Medicaid and within the court as a "person requiring treatment".
-Learned the exact jargon because if you don't use the correct terms, you will not get what you ask for.
-Learned that, although you are filling out legal forms at the probate courthouse to gain guardianship so that you can be legally involved in the treatment process, the staff will not guide you to the correct response you need to get what you are asking for. If you make a mistake, you will have to re-file—at $150. per petition. Or you can hire a lawyer at $350. to $450. per hour to file the forms correctly. (I had to petition 3 times before hiring a lawyer.)
-Hundreds of hours researching anti-psychotic medications, their chemical interactions, side effects and how they reduce life span by 25% (Most persons with SMI have a three quarter life expectancy of typical persons due to medication-caused diabetes, heart disease, liver disease, reduction in cognition, onset-parkensonian symptoms, and a variety of other negative onset health outcomes.)
-Hundreds of hours researching alternative treatments after finding out about, and witnessing, the horrific side effects caused by the medications
-NAMI—I sought out our local chapter, and took a 10 week class to learn more about mental illness and the mental health system. Here, I met a dozen other families going through the same ordeal. These classes are run year-round. They are often the first exposure families have to vital, often life-saving information.
-Dozens of hours sitting in the SSA and MDHHS offices to find out about SSI, SSDI and the payee-ship application process, and filing dozens of forms and documents to re-apply for Medicaid.
-Thousands of miles driven to visit in hospitals from Saginaw to Flint to, Holly, Owasso, Chicago and locally
-30 to 40 hours per week managing my daughter's treatment, keeping her in the system, keeping her from self-destructing.

CONCLUSIONS

- Finally, as I sorted through my photos of Michaela over the years in putting this narrative together, I realize that I begin to fail to see who she had the potential to become. I know that she also looks through her photos and sees who she was. I know Michaela grieves for that young woman who had friends, a wonderful college experience, talent and a kernel of plans for a future. When mental illness strikes them down, is this the kind of treatment our family members deserve? And believe me, mental illness is the single most equal opportunity disease going. It does not discriminate on the basis of age, sex, socio-economic, educational, racial, postal, and

other demographic considerations. We need to have a clear, structured, funded path to treatment and recovery in place for these individuals so that they do not have to suffer the journey of neglect and abandonment that Michaela continues to endure.

WHAT THE FUTURE HOLDS?

- **My hopes and prayers are that a type of treatment that Michaela will respond to is found through intensive collaboration of professionals. That she gains insight—significantly increasing her ability to recover. That she returns to some level of her former life activities and goals, or is able to independently live, pursuing new goals. That she has friends and is able to resume relationships with the rest of her family. This is also what I hope and pray for all of the individuals whose lives have been reduced by mental illness and a system that has left them behind.**