MDHHS Appropriations Subcommittee Hearing
March 16, 2022
Letter from Parents of Children with SED

March 16, 2022

The Honorable Representative Mary Whiteford, Chair,
MDHHS Appropriations Subcommittee

Members of the MDHHS Appropriations Subcommittee including
Representative Phil Green, Majority Vice Chair
Representative Felicia Brabec, Minority Vice Chair
Representative Sue Allor
Representative Ann Bollin
Representative Annette Glenn
Representative Greg VanWoerkom
Representative Timothy Beson
Representative Andrew Fink
Representative Rachel Hood
Representative Joe Tate
Representative Shri Thanedar
Representative Amos O'Neal

Lansing, MI

Dear Chair Whiteford and members of the MDHHS Appropriations Subcommittee,

These comments are directed toward the Executive Budget recommendations for fiscal year 2023. As you will see in the stories that follow, budgeting dollars for system wide mental health needs is critical if we are going to serve the children and families of Michigan. This letter represents the collective voices of those who have been attempting to navigate a complex, confusing and often “not very helpful” public and private mental health system in our state.

We are writing to you as parents that have children with the designation of serious emotional disturbances. Some of us have children with co-occurring developmental disabilities. Some of us have children that were adopted. Some of us utilize Medicaid as our medical and mental health insurance, others only have private insurance, and some families have primary insurance and Medicaid as secondary through SED Waivers. As diverse as we are as a group of parents, we have one thing in common. The mental health system in the state of Michigan has catastrophically failed our families over and over again.

Although our stories are painful and powerful, they are not new. The K.B. v. Lyon lawsuit was filed in 2018, and today, going on 4 years later, the same changes are needed in order to help some of the most vulnerable children in the state of Michigan.

The cycle is the same. Parents ask for help over and over again. Wait lists are long, and it doesn't seem to matter what county we live in, when it comes to the highest risk children, there is a comprehensive lack of quality of care. Community Mental Health eventually sends whoever they have available even if the team member has no clinical experience in the areas of the needs of the family.

Families cannot access core community mental health services. We are told there are no community living support staff available and the wait list is 6+ months long. We are told there are no respite providers, or that we cannot utilize respite because we really need community living support (even though no community living support staff is available), or we are finally given 3 hours of respite at a center that is a half hour away. Case managers tell us they have never heard of recreation therapy and it isn't offered.

Case managers are not requesting authorization for medically necessary services when the county doesn't have available providers, so parents do not get denials and adverse benefits notifications. We lose our right to due process, and our children continue going without.

The end result of these system failures is that situations escalate beyond our capacity to maintain safety in the home, and we take our children to the emergency room. We spend days, weeks, sometimes even months in the ER waiting for an inpatient bed. We sleep on the floor in the hospital waiting room, we have to take time off of work and we lose income, we don’t see our children for days, and still, the hospital cannot find a bed for our child in crisis. Our child in need of help is "safety planned" home when there are no open inpatient beds. Even when and if our children are admitted to an inpatient unit, the hospitals tell us we need intensive home based services, and our children are sent home to the same long wait lists and lack of quality care that led to our dependency on hospital emergency room in the first place.

We are coming to you with real stories of the ways the State of Michigan is failing our children. We are asking for this committee to recognize and validate the damage that is being caused. We are asking for answers. We know that the Executive Budget has 90 million dollars for the program being called, "MiKids Now," but there is still no help. We are asking you to see that this changes.

We need outpatient services that include therapies that are suited to the needs of the family/youth along with support services such as community living supports, youth peer supports, family supports, and home-based and wrap around services that are provided in fidelity to the model. We need respite options because parents cannot be there for their children if they never have a break themselves. We need meaningful and appropriate crisis response including 24 hour mobile crisis, crisis residential, and psychiatric residential treatment facilities. We absolutely need more inpatient beds, and we need system accountability.

I know this list is overwhelming, but please hear us out. I promise you the overwhelm that you feel hearing these stories is nothing compared to the overwhelm and devastation we feel living these experiences. The honest truth is that if these children don't get the help they need, it will negatively impact their lives for year to come, and it will break apart the family in irreparable ways.

Will you please listen to the families who are experiencing these system failures and budget so that real change can happen?

Most Sincerely,

Advocates for Mental Health of MI Youth—a grassroots parent organization

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MHA
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in Michigan

March 15, 2022

Honorable Mary Whiteford, Chair
Members, Appropriations Subcommittee on Health, and Human Services
Lansing, MI

Dear Representative Whiteford and Members of the Committee:

Thank you for the opportunity to provide information to the Committee as it prepares to hear testimony as to the proposed executive budget for FY ’22-23. The Mental Health Association in Michigan is pleased that the proposed budget includes additional funding for mental health-related services. Considering the pandemic, the need for mental health services for Michigan citizens is greater than ever before. However, despite the focus on increasing access to quality behavioral healthcare, services and supports, the mental health and wellbeing of Michigan’s children and youth with more serious emotional disturbances is in peril.

MHAM has been working with many families who are deeply worried about the mental status of their child/children. These families have stories about systemic failures in the public and private behavioral healthcare systems. To highlight their plight and to bring attention to what is “not working,” MHAM is providing the members of the committee with twelve (12) stories from families who are struggling mightily with accessing appropriate, effective mental health services and supports from the local community mental health. These stories represent the experiences of hundreds of other families whose children are at significant risk of suicide or of ending up in prison as adults due to the lack of available services.

Thank you for taking the time to read these twelve stories and the letter, signed by most of the families, which accompanies the stories. MHAM is working collaboratively with a core group of parents that has created a group called Advocates for Mental Health MI Youth. This is a grassroots organization comprised of parents of children with serious emotional disturbance that is sponsored by MHAM.
They look forward to hearing from the subcommittee members and appreciate the opportunity to share their stories with all of you.

The families are hoping that their advocacy on behalf of their own children will encourage legislators such as yourselves to take decisive action that will positively impact the dearth of mental health services in Michigan so that other children, youth and families will not have to endure the ongoing difficulties and heartbreaking consequences of not having access to appropriate mental health care that these stories represent. Some of these families will be testifying before the subcommittee tomorrow morning.

If you have questions, please contact me at 313-641-1109 or via email at: mhuffmham@gmail.com.

Sincerely,

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Marianne Huff, LMSW
President and CEO

To: Honorable Mary Whiteford, Chair
Members, Appropriations Subcommittee on Health and Human Services

From: Marianne Huff and Advocates for Mental Health MI Youth

DATE: March 15, 2022

RE: Mental Health Services “Wish List” compiled by parents with children with SED

This document was created by families who have children with Serious Emotional Disturbance and whose children receive services from the public mental health system. I asked that they let you know what would be most helpful to them as you consider systemic changes to the way that services and supports are provided to them and their children.

Children, Youth and Families Mental Health System Requests:

- Overall change in the ‘system’ to proactive, rather than the current reactive.

- Livable wages for mental healthcare workers to assist in staff retention; mandatory (paid) mental health trainings for staff.

- access to trauma assessments and neuropsychological evaluations.

- All services available to all kids regardless of what insurance covers them. *Example: quote “MI child adoption insurance has been a stumbling block for getting into ABA services.”

- Mental health service parity statewide: Crisis services; Not all counties offer all therapies such as DBT, TFCBT, EMDR

- full family supports: a child or youth with mental health challenges exists within a family setting; There is great impact on the entire family so ALL family members need supports and services.

- More providers so a parent can find a good fit instead of settling for wherever you can get in.

- **respite: safe facilities with trauma-informed, trained staff.**

-True accountability within the system. Concerns brought to local Office of Recipient Rights department are poorly investigated, authorized services aren't filled, and no one is willing to take responsibility for system failures.

-I would also add that CLS staff need training and mentoring provided by someone with the skills to guide treatment. This isn't happening because a) the training hours are nonbillable and b) even the CLS supervisors don't understand how to function as part of an overall treatment team.

- Appropriate emergency mental health services:

  - Pediatric mental health er (not medical er); if services are integrated, then mental health professionals staffed at all medical facility er's.
  - Emergency short-term respite care.
  - More residential beds.
  - Design a system where a family calling for help does not require calling the police – a child experiencing a mental health crisis is not a criminal.
  - Eliminate medical hospital stays that offer no mental health treatment yet discharge children/youth claiming the patient is 'better'.
  - Behavioral health services that allow options other than juvenile detention.

*IF 911 must be an option, create a mental health resources branch of the system with access to trained professionals.

**Quote: In no place should parents be told to call the police by mental health professionals. But especially in areas where police decline all training from mental health professionals.

- Access to psychiatry beyond stabilization. Often, once a child is stabilized, the psychiatry supports are closed. PCPs are often unable to prescribe/maintain the medications and the only way to retain the psychiatric service is to actively be engaged in therapy.

- Residential programs that don't require access through Juvenile Justice.

The following comments are direct quotes from families currently attempting to navigate systems and find effective, meaningful support for their children/family

* Quote: "Also, right now we don't get a psychiatrist for more than 12 weeks at a time because there aren't any available, so we depend on the residency program through pine rest. While we are thankful, I don't think it's the best quality of care to be switching with frequently and have to try to explain our situation and needs every 12 weeks."

1. Pediatric psych ER access so the hospital doesn't have to be utilized.
2. Better communication between major agencies like mental health/police/etc.
3. Better access to psychiatric facilities
4. Better preventative care
5. FASD/Trauma/mental health training for all state employees who would routinely be in contact with families."

"I have always said I wish services were offered to the whole family for counseling. The bio children do not go through the classes to understand what trauma kids bring to families. They get lost in the mental health shuffle trying to find a counselor that understands the stuff they are dealing with or helping them understand trauma."

"MANDATORY and immediate counseling for the child after being diagnosed with _________. Fill in the blank. Big, major, life-changing stuff. For us, it was epilepsy. I think things would have been very different for our family if we had more support after that diagnosis and all the events that followed. That may sound like it's not related to mental health, but it is absolutely related to mental health. She would have been way more healthy mentally with support like that. Family would have too. "

"More juvenile inpatient facilities (beds are always full, which impacts decisions on help).
The crisis line was an improvement, but if the person is not actively suicidal /homicidal by the time they arrive (even with an active attempt within a week) the child gets no emergency services. What's the point in calling?"

Stories from Parents of Children/Youth with SED
MDHHS Appropriations Subcommittee
March 16, 2022

Note: These stories are from twelve families and their children who want to let the members of this Committee that the current mental health system is not working nor has it been working in an effective manner for them or for their children. Each of these stories is written in the parents' own words. Some have requested that their names be withheld to protect the identity of their child/children while others have expressed worries about retribution for sharing their experiences with the public mental health system.

Story #1

Lexi's Story

Lexi is a 17 year old teenager who struggles to be successful in the home, school, and community, due to barriers presented by her complex diagnoses of Autism Spectrum Disorder, Level 1, Major Depressive Disorder, Generalized Anxiety Disorder, and Gender Dysphoria. She is currently waiting for additional psychological testing to rule out an emerging personality disorder and/or an emerging through disorder.

Lexi has private insurance and she access Medicaid through an SED Waiver. Her waiver started in fall of 2019 after her first hospitalization. She lives in Jackson County so her services are provided by Lifeways Community Mental Health.

In 2020, Lexi was treated at the emergency room or admitted to an inpatient unit 14 times. Placements included Michigan Medicine, Hawthorne, and Pine Rest. She would end up hospitalized every time the outpatient psychiatrist changed medication regimes. She also spent 4 weeks in a New Oakland partial hospitalization program.

In 2020, even through Lexi had wraparound services and home-based therapy with a 24-hour crisis therapist, there was never a single time that the crisis therapist came to us how to deescalate or attempt to stabilize. I was told by the provider that they first try to stabilize over the phone, then over zoom, and only if that does not work would they come to the home for in person stabilization.

Lexi had also been hospitalized in 2019. We did try calling the twenty-four-home based crisis line. We were initially told most of the time is it parents of young children that call send therapists were not used to talking directly to the beneficiary. It was so unhelpful that we stopped calling. We were well past the phone of needing phone coaching. Our child was dysregulating and punching holes in walls and eloping often running down the street. We needed on the ground help from a therapist well trained crisis intervention skills, and we most certainly were not getting it thought the 24-hour crisis response.

Lexi would sometimes call to talk to the On call therapist. She would call and say that everything was fine. The call would end, and we often would not even be notified that she had called. We quickly realized that the on-call therapists did not have skills working with neurodiverse populations and they were not able to work someone with expressive language difficulties.

The merry go round of hospitalization continued and we received very little crisis support. There were times that I begged and pleaded for an emergency medication review after Lexi 's psychiatrist took her off all her psychiatric medications because of suspected serotonin syndrome and then was out of the town the following week. Wraparound told me there was no way this could be done.

Every time Lexi was hospitalized, primary insurance would take over. The hospitalization would not even show in the Lifeways system because the authorization request went through private insurance and not through the county's access center. Wraparound meeting minutes (which I never received until 2021 when I requested Lexi 's full clinical record barely glossed over the fact that Lexi was hospitalized. Because we used the emergency room at Michigan Medicine, which is in Washtenaw County and not in Jackson County, and because Lexi was hospitalized out of county, home based therapists were never involved in safety planning Lexi home.

Lexi would get discharged, and there would not be a new safety plan designed to help with the transition home. We would go back to the same services and the same failures that aided in the previous hospitalization.

I felt that I should be able to access mobile crisis, ICSS, but because Lexi had home based therapy and they offered a 24-hour crisis line, I was told home-based kids could not access mobile crisis. I filed right complaints saying that home-based crisis was not a team of two nor did they have access to an on-call psychiatrist, and they were not even coming out to the house. The Office of Recipient Rights would not investigate my complaints. They felt that there were no rights violations because there was a policy preventing families with home based on utilizing mobile crisis. I now realize I should have gone back and filed the same complaints against the home-based provider, but at the time, I thought the home-based crisis response was a diluted version of ICSS that was more of a call line.

No one was listening to me as my family struggled. My concerns got swept under the rug as I was repeatedly told that if I wanted crisis support, I needed to call the home-based provider. I was calling the home-based provider! They were not doing anything. I would call and they would ask me what I wanted them to do. My family was in crisis. I wanted them to do their jobs!

Because private insurance was the payor, utilization for all these hospitalizations never hit the county's ledger. My child's cycle of hospitalizations was never brought up in Diversion

Committee meetings and recommendations were never made. When I pushed Lifeways on this, I was told,

> As to the Diversion Committee, the director of Utilization Management was brought into this case over a year ago through the diversion review… It is also important to know that with the coverage of the commercial insurance, LifeWays was not always made aware of the child's inpatient admissions. Diversion Committee is an internal review committee and not a service provided to individuals. The committee cannot direct the treatment of specific cases, but only provides recommendations. The records of committees assigned a peer review function are confidential internal documents and are not public records.

This response exactly identifies the problem while also illustrating there is nothing Lifeways was willing to do to fix their bokken system. "Lifeways was not always made aware of the child's inpatient admissions." It certainly was not because I was not telling the wraparound team.

At the end of December in 2021, parents made the decision to transfer Lexi to an out of state Residential Treatment Center that was paid for by primary insurance and out of pocket expenses. During her 6 months stay, Lexi was finally, out of crisis and finally beginning to stabilize and skill build. During her stay, she changed her preferred pronouns to she/they and she changed her preferred name to Lexi or Lexi anie. While in treatment, she underwent full neuropsychological testing, and many recommendations were made for continued care and support. In late June 2021, Lexi was discharged home.

Lexi was home for almost a months before authorized CLS services were provided. Our family left town multiple times to take Lexi to a location without home triggers so safety could be maintained. Meanwhile, there were problems identifying staff and getting staff in service on the treatment plan. We finally found three of our own CLS staff and the agency hired them to work specifically with our family. We advocated for weekly training meetings with case consultant Sharon Wilkes a BCBA and MSW to help CLS staff navigate challenges and learn about neurodiverse learning needs.

There were also treatment plan difficulties. Because the treatment plan was rushed and not presented to parents until the day before I flew out to pick Lexi up for Utah, further changes were requested as we did not feel the plan accurately identified the needs or specify the needed interventions. We wanted our treatment plan to be a roadmap of services so multiple providers could see how they would work together to create a needed support system. Instead, Dan Dedloff, customer service at Midstate Health Network, said that our plan was completely nonfunctional.

We tried to get the plan updated with specific staff interventions from June through September when we then brought in an independent facilitator. This is her personal explanation of the treatment planning process:

> "I was asked to facilitate a plan for Lexi , the child of _____. We started the preplanning process in September, with two preplanning sessions lasting two hours total plus some conversations that I had off to the side with Lexi . Then we had two planning meetings on Sept 29th and October 13th, lasting a total of 5.5 hours between the two meetings. Then on October 13th, I said I would help write the objectives and interventions because a draft that had been sent to me did not remotely resemble what we had discussed in the prior meeting (sept 29). I realized that there was a skill gap in writing objectives and interventions. On the following dates I met with the "writing team" to help them sort out the difference between an objective and intervention and to try to explain why interventions need to be specific and detailed enough for any of us to pick it up and know what to do with Lexi . The dates are October 18th for 1 hour, October 25th for 2 hours, October 27th for one hour, November 4 for 2 hours, November 8th for 1 hour, November 11th for 1 hour. Still when we received the draft plan, it did not describe the interventions. I can appreciate the desire to not have plans that drone on for pages and pages, but also there is no fidelity if you can hand it to two different people and they implement the plan in two entirely different ways and get different results. The plans need to be detailed enough for CLS staff to all be on the same page in how they implement an intervention."

The treatment plan was finally completed in December of 2022. I am not sure if it has been signed by parents or not.

In late fall of 2022, Lexi had started requesting a new therapist stating that she wanted to work with a female therapist. Conversations were had but in late December of 2021, Lexi said that she would not continue to meet with her current home-based therapist (a man) because she did not feel listened too. The provider initially suggested that the two should work to reconcile the relationships. Lexi made it clear in no uncertain terms (including many middle fingers) that she was not interested in continuing the relationship.

We advocated for a change in therapists. We started we wanted a home-based therapist that could address Lexi 's neurodiverse learning needs and we wanted the therapist to be QIDP. We were told none of the home-based therapists were QIDP, but the provider could continue send non QIPD therapists for crisis support. They also recommended looking for a qualified outpatient therapist through primary insurance even though this would be a step down from home-based therapy that violated medical necessity. The provider then "accidentally" sends us an adverse benefits notification terminating our services because they did not have a qualified therapist. We appealed and we won the appeal.

I do feel that the adverse benefits notification terminating services was mistakenly sent when a suspension of services was intended, but I expect a higher level or proficiency from a provider responsible for coordinating care for a complex case.

While all of this was going on, we were having difficulties with CLS and the identified agency not filling the number of authorized hours. We filed a rights complaint claiming failure to provide treatment suited to condition. The Office of Recipient Rights did not substantiate our claim stating that the CLS provider was not required to have a contingency plan. I wrote an appeal letter stating that with or without a contingency plan, the provider was still not providing authorized services.

I was told by Lifeways that we did not have access to incident reports that CLS staff completed when our child was injured with CLS. I wrote to cooperate compliance. I was again told these were internal records. I pushed back again. The provider sent the incident reports. Lexi was falling while at the skate park and her legs and arms were covered in bruises. Kids fall when they are skateboarding. I know that. I was not upset that she was falling. I wanted documentation of how the bruising happened in case were ever questions by a doctor or a psychiatric emergency room.

What I am saying is that we are experiencing endless chaos. Every day I make phone calls, send emails, call advocacy groups like Association for Children's Mental Health, Disability Rights of Michigan, the Arc, NAMI, Disability Connect, and Mental Health Association in Michigan and these groups nudge me along and try to help me produce the next step. I call the PIHP, write to the state, file rights complaints or grievances. I get passed around from department to department and no one takes responsibility and there is no accountability.

I endure these countless hours of phone calls, paperwork, and ongoing meetings that often result only in setting up more meetings trying to get help for my child, help that has already been authorized. It is soul crushing.

This is a widespread problem. According to a current class action lawsuit, the State of Michigan is responsible for "staggering failures" in its mental health system for children. It is allowing children to go with too little if any care until they spiral violently out of control and faced juvenile detection, psychiatric hospitalization and — as they approach adulthood — "permanent damage to their lives." I could not agree more.

But I will pick up the phone again today because we still do not have a home-based therapist and there is growing concern from members of the treatment team that our child might be experiencing a reemergence of a thought disorder or early psychosis.

The 24-hour crisis therapist was called out to the house over a weekend to assess and we were told this was not something she could do. We should instead call mobile crisis on Monday. We called mobile crisis on Monday, and they told us since we have home based, we must call their therapist. Round and round we go again. He said, she said, no one in the entire system knows what to do. The parents continue to push forward.

A new home-based therapist was appointment last week. She came out to the house when the family called for crisis support because she also happened to be the on-call therapist at the time.

When she arrived at the house, she told us that even though she does not have experience with delusional thinking, she felt that the best way to approach distortions/delusions was to "dive right into the distortions and make Lexi feel like there is someone on her side." We were told early that day that you treat distortions caused by trauma and you treat any distortion the same way (which we have since been told is not accurate).

Parents and the behavioral analyst (who was at the house at the time because she had just finished her apt with Lexi) all wanted to hit the pause button. We explained that our family and our team experiences significant problems with triangulation and we said that if not done correctly, she will take this to mean that you are on her side and against us. She assured us that she had researched delusions that afternoon, and she had a plan.

We were visibly recoiling because this plan was in such complete opposition to what the team has already determined to be helpful, and process defined in the safety plan for any situation requiring de-escalation. She assured us "this this is her level, and it is why they brought her in."

My husband clearly stated we were not looking for therapy nor did we want her to fix anything, we only wanted her to assess where Lexi was and documented if her thinking felt distorted. The therapist proceeded to engage in therapy. I knocked on the door and let myself in when Lexi was increasing in volume while talking about how controlling we are as parents. We asked to meet as a family in the dining room. We then gave Lexi her Chromebook and told the therapist goodnight.

We were concerned about triangulation, and we did not want Lexi getting worked up before bed because this would negatively be impacting her sleep. We did not want her ruminating, but we instead needed Lexi to relax and deescalate Our safety plan clearly states that when Lexi is not at baseline:

- Limit open ended questions and number of questions in general. Allow time for Lexi to respond, slow down the cadence of the conversation by slowing down your cadence and inserting pauses into the conversation.
- Sit down, talk more quietly and slowly, look relaxed and calm.
- Do not put more demands on Lexi (“Please do your homework now” or “In 5 minutes I need you to take off the garbage.”). Give Lexi space to process and become more relaxed before increasing expectations.

But instead, the conversation with the therapist was speeding up and picking up in intensity as Lexi started talking about all the reasons that she feels her parents control her. When we asked to meet in the kitchen as a family, the therapist suggested meeting in 5 minutes and told Lexi to set a timer. It was simply too much, too fast, and it not only did it run the risk of increasing agitation in Lexi , but it also undermined the work of the rest of the team to create a clear, consistent approach.

We recognize that this therapist was well intending and doing her best. The provider is simply providing therapy and crisis response that does not have the skill sets needed to meet the needs of our child. When therapists proceed without proper skills and/or training, they are operating outside of their scope of practice, and well-meaning intentions can inadvertently cause a setback in progress as well as overall disruptions to the current team approach.

The psychiatrist does not have up to date information regarding concerning behaviors, skill levels or current interventions. Changes in sleep, personal hygiene, and atypical thoughts are documented by the parents by not reported to the psychiatrist. Parents do not have direct access to the psychiatrist outside of the appointment, so we rely on the wraparound provider to pass this information on to the treating psychiatrist and it is not happening.

After again writing to the state, the PIHP, and to the Lifeways executive team, very small change is being made. Psychiatric appointments were changed from 30 minutes to 60 minutes. Neuropsychological testing is being recommended.

But we do not want more half promises and false starts. We want someone to see this across the finish line. We want Lifeways to identify both a Wraparound Provider and a Home-Based Therapy provider with 24 hours crisis support that is experienced in complex cases. We want providers with experience with the symptoms and challenges our daughter faces. We do not want a therapist has a plan after an afternoon of online research.

We want the correct skills brought to the table, and we want a treatment plan that specifically and concretely identifies therapeutic interventions in a measurable way. We want the data that parents have been collecting for 6 months incorporated in quarterly reviews and medical necessity. We most certainly want it communicated to the psychiatrist.

Lexi has an SED Waiver and as much as I hate the term “Serious Emotional Disturbance”, our daughter is actually struggling with a disability and mental health conditions that are not only serious, but also debilitating. We need providers that can rise to the challenge and lead the way.

If this cannot be found within the Lifeways network, we are asking Midstate to work with Lifeways to ensure that medically necessary services can be provided in ways that are suitable to condition even if Lifeways must look outside of their current network. The future of our daughter depends on the help she receives now.

Story #2

L.M.‘s Story

Community Mental Health experience

Hello, my name is L M, married 21 years, raising 3 boys, 17, 13, 10. I’m here to share about my 13 year old son. He is diagnosed with Attention deficit hyperactivity disorder; Oppositional Defiance Disorder; Reactive Attachment Disorder; pediatric Bi-Polar. Our days consist of defiance toward nearly every suggestion, reminder, or demand that we make of him - even as simple as washing hands with soap, brushing teeth - resulting in gingivitis, or ensuring he has clean clothing to wear. We deal with daily anger and aggression; anger often morphing in to destructive and aggressive raging. Nearly everything has been removed from his bedroom as anything he has becomes a projectile.

His walls and door are damaged and destroyed. We are on constant guard for assaultive behavior. It happens often. We have called 911 for safety assistance 9 times in recent months, handled countless situations on our own, and called his therapist or on-call services numerous times in an attempt to keep everyone safe. He is now on probation with Juvenile Justice due to his behaviors. The relentlessness and extreme level of these behaviors allowed us to qualify for the SED Waiver [Serious Emotional Disturbance], starting back in 2016, administered through CMH.

These are additional/enhanced services provided by Medicaid to support families in keeping our children in the home. A. “Promises” of supports provided by the SED Waiver: 1. Respite - (11 days/mo)the one time we used respite needed to p/u early d/t aggressive behavior. 2. Crisis respite - (3 days/mo) we couldn’t use as they didn’t feel he was aggressive enough. 3. Currently respite is 3 hours once a week; it also involves two hours of transportation time. 4. SED Therapy options - Art, Music, Sports. We were offered Equine therapy and CMH authorized one block of 8 sessions.

My son made significant connections, then we were told it is not covered under SED waiver so additional sessions denied. 5. Off the record, I'm told not to re-apply again. YOU have had the Waiver 'too long'-- Not that behaviors had improved. I was exhausted emotionally, physically... didn't have the energy to fight. We moved to the BehavioralHealthHome program where everyone could get services.

So far it is a complete failure. SED Waiver defines the youth as a "Family of One" I have TWO 'other' children. With the things they witness, overhear daily, things our family cannot do they DESERVE support also. Services he received through CMH: B. Therapy, Wraparound, CommunityLivingSupports met at our home, saving us significant drive time. 1. Therapies attempted include CBT CogBehavioralTherapy, DBT DialecticalBehavThera, TraumaFocused-CBT, EMDR -Eye movement Desensitization and Reprocessing -- unfortunately nothing helped. Music therapy made no positive impact on behaviors, despite over a year in the program.

II. Crisis Help

A. First attempt to get help outside of home
1. Medical Hospital - we did not know where else to go.
2. Dr on staff with hospital did not agree with the private psychiatrist's diagnosis of 'Pediatric Bi-Polar' so took him off meds and sent home unstable. When questioned this decision based on concern for the SAFETY of my other two children, I was threatened with CPS and child abandonment charges.
3. I was also informed that if a sibling was injured, CPS would be called d/t not protecting my other boys. They moved to grandparents for a MONTH while we worked to stabilize K.M. B. Recent hospitalization 1. After 3 continuous days of raging, culminating in violent/graphic descriptions of his plan to kill his youngest brother, attempt suicide, and kill my husband and me was called for outside help (Sheriff). K.M. threw a large rock at my husband; left a 5' x 3' hole in his bedroom wall. 2. He was admitted to PR, stayed 12 days. Less than 3 hours of getting home he was in to another rage. The following day we requested another emergency med review. A week later we received notice that the final three days of his stay were denied by CMH due to lack of medical necessity.

I was returning home from the hospital after being in the ICU with stroke-like symptoms and receiving TPa. I am not blaming my son for my health issues, rather level of challenges and stress in my home. The stress we have endured for last 12 years has taken its toll. My circle of support includes: My parents, in mid & late 70's as well as other families raising children with similar challenges. We are all at a dangerous level of frustration and exhaustion.

Conclusion: Raising a child with severe challenges is beyond difficult in itself. Having little support, ineffective services or no services, and learning to navigating systems adds exponentially to the burden. Legally our children and families are entitled to care and support based on need. Unfortunately we are denied and lied to at nearly every effort to gain those supports. Our goal is supposed to be to keep K.M. in our home and in our community. When appropriate services are withheld we do our best even as we are in constant mindfulness of the lack of safety in our home. The constant stress of the situation leaves us physically, mentally and emotionally exhausted. I don't know how much longer I can continue to push forward, even as I stand by watching my son destroy my home in both physical and emotional ways every day. My son is now in the juvenile justice system. My son is NOT a criminal. He is a youth with severe mental health challenges. The current system leaves me no option for help other than to pursue police involvement, which results with my son having a criminal record. We are told it is the only way to get him help. You are in a position to help us. Please hear my story and step up to help.

Story #3

SM's Story

CMH Fails

1. Does not meet clients' needs.
2. Provides minimal services, such as wrap around and case managers.
3. Does not provide services that are appropriate for client's cognitive and emotional levels.
4. Promises services and does not provide them, such as CLS and Respite. Continuously state that they cannot find workers.
5. Case manager changes every year or more frequently, leaving kids unable to connect or trust them as their counselors.
6. If a child needs hospitalization or treatment outside of the family home, CMH offers no assistance to help meet the child's or family's needs.
7. CMH workers have stated repeatedly that they expect us to run our home like a residential treatment facility, even though we have other children (ex. hide sharps, lighters, ropes, gasoline, etc. put up video cameras,….) It is just expected that we live in fear. Other family members are not considered.
8. It seems as though we parents make more calls and spend more time looking for help for our child than CMH does; actually, it seems as though they do a lot of paperwork. The plan never really changes even if it isn't working.
9. Crisis plan always includes mobile crisis hotline and they have never been mobile. They only want to talk to a raging person who has no intention of talking to anyone. We have always felt very alone during a rage and end up having to call the police.

10. CMH does not think out of the box to try to help a child. The process is the definition of insanity… keep doing the same thing repeatedly even if it isn't making a difference.
11. Promised family counseling and it's never happened.
12. The organization does not seem very trained or capable of treating Reactive Attachment Disorder (RAD), though they say they do.
13. CMH needs to provide services/placement between hospitalization and home. Kids should not go directly home after being discharged from the hospital. There should be a step-down option as appropriate.
14. Our son was diagnosed with high functioning autism, yet has never provided ABA therapy or treatment.
15. A fetal alcohol syndrome assessment was completed on our son. The worker said he met criteria for FASD. We repeatedly asked for a written report and we were told they do not provide reports with results. He was given a diagnosis of FASD by Easter Seals, but his treatment did not reflect the new diagnosis and nothing changed, again.
16. Repeatedly refused admittance to Hawthorn when our son was suicidal and homicidal. The denial forms were full of inaccuracies and did not reflect the situation, even though CMH was fully aware of the situation.
17. Possible treatments that could be implemented that are not provided: Service dogs, equine therapy, social activities such as a running club, ABA therapy.
18. Possible treatment alternative arrangements for outside of the home: therapeutic foster care, residential group homes, more psychiatric hospital beds. Every hospital should have a psychiatric floor that actually provides treatment.

Story #4

Mollie's and Aliyah's Story

Our story started in October 2020, since then our thirteen-year-old daughter Aliyah has spent 344 days and counting in one form of hospital or another due to continuing suicidal ideation and self-harming behavior. When we first started this journey with our daughter, we only had private insurance through Priority Health and state Medicaid received when we adopted our daughter and her brother in 2012. Since then, we have added services through Ottawa County CMH and a SED waiver.

Prior to October 2020 Aliyah as was succeeding at school, had friends and was on a traveling competitive tumbling and trampoline gymnastics team. She had some difficulties emotionally due to trying to process being adopted, what it meant to be removed from her biological parents care at the age of two and the beginning stages of remembering abuse in the foster care system. It wasn't until all of the covid shutdowns took her access to school, friends, and gymnastics away that we saw a drastic decline in her mental health that led to where we are now with almost constant suicidal thoughts, daily self-harm that has increasing gotten worse to the point where during her current hospital stay she is ripping her own fingernails out root and all.

Aliyah is currently on her sixth stay at Helen Devos Children's Hospital. This is her third stay that has been 30+ days and her fourth that will result in no placement in a mental health inpatient facility.

During Aliyah's first two stays in inpatient treatment at Pinerest she went from just having suicidal thoughts to self-harming and being very aggressive with staff resulting in being placed in soft restraints multiple times a day. She is unable to manage her emotions and acts very impulsively when her emotions get too big.
Since February 2021, all inpatient facilities within the state of Michigan have denied admission to our daughter due to a multitude of reasons: no beds; acuity; chronicity; long wait lists for 1:1 care; etc. We still cannot grasp how they can deny for acuity and chronicity since these two things contradict each other. Some short-term inpatient facilities deny stating she needs longer term residential care, however Priority Health states she needs ongoing home-based serves. Again, contradicting recommendations. With the large number of children needing inpatient care in today's world so many facilities can pick and choose which kids they admit and which ones they refuse care to. In too many instances they are choosing the cases that are easier to treat and declining admission to the kids that need help the most because they are the more difficult cases to manage.

In August of 2021 due to the lack of availability of beds within Michigan facilities we were able to look outside the state for placement and found a residential facility in Savanah Georgia that was willing to accept Aliyah into their 6-month program. We moved Aliyah from Helen Devos to Coastal Harbor residential on August 13, 2021, where she lived and went to all day therapy, DBT, school, etc. every day until Priority Health forced us to bring her home on December 5 three months short of competing the program. From October 2021 we had twice weekly meetings with Coastal Harbor staff, Priority Health and CMH to discuss Aliyah's placement at Coastal Harbor. Priority Health was always pushing for discharge home even when Aliyah was still not only voicing suicidal plans but also still actively trying to kill herself while at Coastal Harbor. Priority Health's reasoning for pushing for discharge was that she was failing at treatment so there was no reason for her to stay. We fought weekly with them to keep her in care. It took until mid-November for Aliyah to finally agree to try to participate in her treatment plan at the residential facility and start to show improvement. As soon as she started to show even the smallest improvement Priority Health changed their reason for wanting discharge from failing at treatment to succeeding at treatment. At first her doctor at Coastal Harbor was on the side of her needing to remain in treatment stating "it would be criminal to discharge Aliyah home in her current mental state" but due to Priority Health's continued pushing for discharge and threats to not pay for her residential stay the facility changed their minds siding with discharge after only two days of additional treatment.

After discharge, Aliyah made it home 30 days before attempting to hurt herself at school on January 5, 2022, resulting in another admission to Helen Devos. This time they didn't even try to get her admission into an inpatient facility, they didn't want to admit her at all despite the fact that Aliyah would tell every doctor and nurse who came into her room "you can't make me use the tools from therapy, if I want to die it's my choice and no one can stop me from killing myself." While in this five-day admission the psychiatrist at Helen Devos made the diagnosis that Aliyah is not safe to go to a traditional school setting because there is not enough supervision to keep her from hurting herself while at school. This resulted in her having to do online/virtual school. She is currently failing all her classes since she was placed in seventh grade classes based on her age not considering that fourth grade is truly the last year, she received a full education.

Fifth grade was done half at home due to covid shutdowns and little was learned because teachers did not know how to educate virtually since it was such a last-minute change due to the pandemic and then Aliyah was hospitalized for 90% of her sixth-grade year.

On February 8, 2022, Aliyah again tried to end her life while at home, she tried to jump off the back deck on the second story of the home multiple times resulting in the Ottawa County Sheriff having to come to our home to secure her until the ambulance could arrive to take her again to Helen Devos Children's hospital. While the Sheriffs were at our home, she attempted to take their firearms and continued to try to hurt herself by banging her head against the floor. The two sheriff's that were at our home were amazing at trying to keep her safe from herself while also trying to calm her down, unfortunately she had to be restrained to the stretcher when the ambulance arrived and again when we arrived at the Helen Devos children's ER. Aliyah was again admitted for observation to the Helen Devos Children's Hospital where she has been for over 30 days.

While she is at Helen Devos, she does not receive any psychiatric care, and very minimal medication management. When my husband and I along with her CMH therapist have requested med changes, supported by her outpatient psychiatrist we have been told by Helen Devos staff that they are a "medical hospital not a mental health facility." While at Helen Devos Aliyah is under 24-hour supervision by a nurse that sits outside her closed door and watches her through a window, she has only a mattress on the floor with no bed because she has in the past broken pieces of the bed off to self-harm with.

Aliyah is not allowed to use any utensils when she eats her meals because she will use them to self-harm, if there is a part of her meal that cannot be eaten with her fingers, they tear a piece off Styrofoam for her to use as a spoon. As I stated earlier, she has resorted to pulling her own fingernails out because it is the only way for her to self-harm now that they have restricted her so fully while at the hospital. Despite her continued success at harming herself under constant supervision Priority Health still recommends discharge home where it would be impossible to provide the same level of 24-hour constant supervision.
During this admission we have weekly care conferences with Helen Devos staff, Priority Health staff, CMH staff, her outpatient psychiatrist. During every care conference Priority Health has advocated for discharge home to the least restrictive environment despite CMH and originally Helen Devos advocating for continued inpatient care. We have not been able to find any inpatient facility that will accept Aliyah again they state she needs longer term care, more intense care than she can receive at the short-term inpatient settings, and they recommend residential care.

Aliyah's CMH therapist has continued her weekly visits with Aliyah through this current admission. This past week on Thursday March 10 the CMH therapist had the Helen Devos staff join her during her meeting with Aliyah because Aliyah has continued to voice a very thought-out detailed plan to end her life upon discharge. During the joint meeting Aliyah again voiced the plan to both Helen Devos and CMH staff. Aliyah's plan has times, dates, and the place she intends to end her life. Despite this joint meeting we received an email from Helen Devos on March 11 stating they are still seeking discharge home with the plan being those additional services through CMH is the proper path to take for Aliyah. Both I and her CMH therapist replied to this email requesting reconsideration of the discharge since no changes to the homebased services have occurred from prior to her admission to now due to lack of availability and Aliyah's continued active plan to end her life.

The homebased service treatment plan for Aliyah includes homebased therapy twice a week; CLS four hours a week; youth peer support; parent peer support; recreational therapy and a suggestion for DBT therapy which needs to be obtained outside CMH. Despite all these services being authorized through CMH the only services we are receiving are the homebased therapy and the peer supports. CLS has been referred to an outside provider because the need for CLS workers is so high the county cannot provide care to all the patients. We have spoken to the outside agency who also stated that after the initial meeting with the family they will need to hire staff to accommodate the needs of the community. Recreational therapy also has a waitlist. We have put Aliyah on two different waitlists for DBT however these lists are over six months long. The needs of the children in the community across the state far exceed the availability of services for these children.

It has been heartbreaking over the last eighteen months to fight so hard every day to get our child help that just is not available. We have reached out to attorneys; state representatives; congressmen; and many outpatient therapists. Everyone we speak to tells us the same thing "the system is broken;" how can so many people know a system is broken but no changes are being made to fix the system in a timely manner. I think the most heartbreaking thing we have been told throughout this process by numerous sources is that the only way to get out daughter the help she so desperately needs would be to relinquish our parental rights to our daughter back to the State of Michigan and put her back in the foster system.

Every time we are told this we have thought "this can't be an option" "this can't be true that foster kids get help faster than kids with families" however during this last admission to Helen Devos we found out that sadly this is true. We were told that the wait list for the state hospital is a yearlong for Aliyah, but Helen Devos placed a foster child into the state hospital within a week. In no world should the only option to help a child traumatized by her life in the foster system so badly that she wants to end her life be to place her back into the foster system. Just because she has an adoptive family who loves her should not mean she has to wait longer for care. There is so much more we could write but this summarizes our story well, we truly feel that if she is discharged from this admission without any real psychiatric treatment at either an inpatient short-term facility or another residential facility, we will lose our daughter to suicide.

Story #5

Karen Simon and D'Asha Jackson's Story

My name is Karen Simon, my daughter D'Asha Jackson (now 18) and I relocated to the great state of Michigan September 22, 2020, after being displaced during the pandemic. We choose to come to Saginaw because it is a beautiful region of the state, as well as it is racial diversity, and affordability. Unfortunately, I was not aware that it is one of the lowest funded counties in the state, making it terribly difficult to secure any type of decent services for someone with her neurological challenges. My daughter was born with hypoxic ischemic encephalopathy in 2003. She was oxygen deprived at birth and suffered brain damage – leaving her with a permanent brain abnormality and medically uncontrolled seizures. As well as executive function disorder, emotional dysregulation, intermittent explosive disorder, and dyspraxia. Chronologically she is eighteen, intellectually she is ten and emotionally she is four.

In October 2020, we attempted to enroll my daughter at Saginaw Public High. Unfortunately, their special education department was incapable of working with my daughter to medically care for her and educate her in the CI classroom. The instructor has a “certification” to teach special education. Clearly not enough knowledge to educate someone like my daughter with a multitude of neurological disorders. As her behaviors escalated, SPH referred us to Great Lakes Bay, who referred us to CMH.

My daughter was assigned a case manager at CMH the end of 202, and in January 2021 she had still not begun receiving services. She had a mental health break down in which I called 911. The Saginaw Police Department never came out for my very first call, instead they called me and hour and a half later to see if she had calmed down. The second time the police came to my home the ambulance took her to Covenant ER where she was evaluated and released within several hours. I advised Eddie ,the crisis worker, that was not a good idea to release her. He felt that it was just a mother daughter disagreement and that she would be fine to go home. I advised him, she is unstable, and I did not feel safe. I was advised the doctor made the final decision. She was discharged to come home, and on the way home began assaulting me in the car. I immediately called the crisis line to advise them what was happening. They NEVER told me to take her back to the hospital, instead they said someone would meet me at my home - meanwhile she was attempting to jump out of my moving vehicle. The crisis team met us at home and was able to deescalate her that night. My third time calling Saginaw police, they again had the ambulance take her to Covenant ER where she advised CMH that I had hit her, so they reported me to CPS for assaulting her - when in fact, I was the victim! Again, after this visit she discharged, and sent home to assault me.

At one of her therapy sessions my daughter became enraged, and the therapist called 911, the ambulance took her in, and the Covenant ER doctor still sent her home. The fourth time I called Saginaw Police they took her to Covenant ER where she again was assessed, and the crisis team advised me she would be discharged. I asked to speak with the ER doctor who came out to speak with me. This ER doctor looked me straight in the eye and said, "DO NOT bring her back here." The next time I called the police because she assaulted me, they took her to Saginaw jail where she ended up having a seizure and was sent home as "a liability."

In May 2021, our story was featured on the news here along with several other families. To this day nothing has changed.

Over the past 12 months my daughter has made numerous threats on my life and has caused bodily injury to me. I have had to install security cameras in my own home, and I still do not feel safe. On Thursday March 3, 2022, my daughter slowly began to spiral downward on Friday March 4, 2022, about 1:30pm my daughter became so enraged she threatened to kill me. She broke through my locked bedroom door and shoved me across the room. I called 911 and she left on foot. The police arrived about 30 minutes later after speaking with me, they located her near home. The police officer advised me he was taking her to the ER as she was a threat to me, herself, and her therapist. I went to Covenant ER to provide them copies of a Neuropsychological Evaluation which clearly states she needs placement in a facility and guardianship. As I wait for the guardianship process, I do have legal Power of Attorney - which was not being honored at Covenant ER that day. Brandon assured me he would include the neuropsych eval in the packet they sent for her when looking for placement. Sadly, no one ever sent the report, and she was placed at the lowest level facility here in Saginaw, which is voluntary. After having five seizures there, she discharged herself AMA. This is not okay. The staff at Saginaw Meadows was almost clueless to her life-threatening seizure disorder. They had no information about her antileptic medications, nor drug interactions. After being home 4 days, my daughter began to spiral again, at which time she charged at me wielding a screwdriver screaming she was going to kill me. I had to run out the door and call 911. I am thankful a great team came from the Saginaw city police and brought us straight to the ER. I spoke with Jenny and another young lady from CMH crisis and read the Neuropsychological evaluation to them. I feel if I had not read that report, my daughter never would have been sent to Havenwyck in Auburn Hills. I have had the opportunity to speak with the charge nurse who confirmed they only received five pages of information on my daughter, when typically, they receive about thirty. This is a tragedy for anyone with neurological disorders that is also experiencing mental health issues. I do not understand how CMH expects anyone to get the appropriate care when they fail to provide all relevant medical, psychological, and neuropsychological information to properly place their patients. CMH is doing a disservice to all their clients, they are completely failing anyone with Medicaid! This is completely unacceptable. My daughter is not a criminal, she has a mental health disorder and needs help.

We must do better for our most vulnerable people in society, they deserve better.

Thank you for your time and for reading our story.

Best Regards,
Karen Simon & D'Asha Jackson
183 Parkside Court
Saginaw, MI 48601
727-297-0726

Story # 6

Deidra and Lewis' Story

By Deidra Artecki 616-450-4826 email - dartecki@hotmail.com
I give you permission to share!

Lewis was born premature at 29 weeks and entered foster care with two older siblings shortly after being released from the NICU due to parental drug use and homelessness. He was adopted by his foster parents at 18 months and his siblings adopted by another family.
Lewis did not qualify for adoption subsidy benefits due to being under the age of three. He was put onto his adoptive parents' private insurance (BC/BS).

He has been diagnosed at a young age with ADHD, ODD, disruptive behavior disorder and sensory processing disorder. Lewis also has a history of violence directed mostly at close family members. He has struggled with behavioral/emotional issues for much of his childhood. Lewis has had long term psychiatric care and a long-term therapist. He has participated in Occupational therapy, neurofeedback, EMDR and music therapy.

Lewis is currently 15 years old and in the ninth grade. His negative behaviors at home and at school have increased dramatically and affecting his overall quality of life. Currently he has missed 32 days of school 15 days due to suspensions. He has had 3 days of in school suspension as well.

He has had two fights at school or on school property, one of which could/should have resulted in assault charges being filed (the parents of the other child decided not to press charges). He has also been suspended for not complying with school staff and using vulgar language towards staff. He failed all core classes in the first semester and is currently failing all this semester. Lewis refuses to comply with normal, safe requests at home, which makes day to day living very difficult for all involved. He has refused Psychiatrist appointments (Virtual), well child Doctor visit, routine eye appointments and therapy appointments were stopped due to aggressive behavior in route to the appointments and refusal to go. I have been trained in several parenting / therapeutic models and use those regularly.

As his parent I believe in home therapy and CLS services would be highly beneficial for him and help him to be able to function in a normal environment. Our private insurance will not cover the cost of in-home services and even if they did, there are no in home services available to children who do not receive Medicaid.

I have applied for an SED Waiver for him twice in the last year which would make him eligible for these services and have been denied both times. The last time I was denied Network 180 told me to allow him to be arrested and enter the juvenile justice system then he would qualify. This statement took my breath away, as a parent I would like to find proactive services and help for my child to keep him out if the justice system! They also noted that he seems to have behavioral issues as opposed to mental health issues (Are these not one and the same? What am I missing?) As his parent, I feel like I know best what might help Lewis to be successful and it is defeating to know it is not available to him.

I would like to see Mental Health/Behavioral Health services available to all children and families regardless of what insurance they are covered by as the children are our future!
In addition to my own experience, I also work for Adoptive Family Support Network and support families who have adopted and see parents struggling with the mental health system regularly.

Story #7

Mary’s Story

Our story: We moved to MI 5 years ago and purchased a 5 bedroom home, expecting to adopt one more time, a teen or sib group from MARE. We fostered for 17 years in TX and adopted 2 girls out of the foster care system, not biologically related to each other. Amanda was considered unadoptable and was going to be placed in a state mental institution until she turned 18. We were her 5th placement and her last chance. She had been born premature and drug addicted and had been tortured and starved. Her behavior was out of control. As she grew, she became more and more of a problem, running away, shoplifting, and lying about everything, things that mattered and things that didn’t. She never bonded to a toy, an animal, or a person. She married and left on her 18th birthday, accused her husband of attempted murder (a lie), got pregnant by a man twice her age while still married to her first husband, lost custody of her own children who were put up for adoption in Iowa, and disappeared into a world of prostitution, pornography, and drugs. Her life is so very typical of adopted children. Most of them come from generations of mental illness and/or addiction. This is no longer the day of the frightened unwed high school cheerleader who hides her pregnancy and puts her perfect newborn up for adoption. Most children who end up in the system have serious issues. They need help. And adoptive parents need more support than they get in this state.

Very few new foster or adoptive parents understand the complex issues that come with these kids. Many of the children can't bond, will never tell the truth, and will not have a good outcome, no matter how wonderful the new parents are. When it gets bad enough in the home, the parents can't find many answers. Some try to "unadopt". There has to be a better way.

Institutions weren't always bad places, and some children need that much supervision and structure. When an adoption fails or comes close to failing, there should be group homes or small institutions where these kids can live without the adoptive family being forced to cut ties. Just like the elderly who can't live alone but can have unlimited contact with friends and family in their assisted living apartment or nursing home.

Our other adopted daughter, Carrie, was alone with the body for 72 hours after her mother committed suicide. Carrie was 3. Then her father, a severely damaged Vietnam veteran, sacrificed her to Satan, raped her, forced her to watch while her brother was sodomized, and left her in an orphanage. She was moved twice before she came into our foster home where she lived for nearly 3 years, ages 5 to 7. By then she was self-hypnotizing and had some bizarre behavior. No one knew her history until she was hypnotized in therapy at age 14. By then she was in a locked psychiatric facility with a diagnosis of multiple personality disorder. Carrie left us at age 7 and was returned to her father, went through a failed adoption, attempted suicide, begged for us, and was locked up until she ran away at age 17. Her therapist called us in to help when she was 14, but she was considered too out-of-control to live in a family setting. She said our home was the only place she had ever felt safe, wanted, and loved. After she ran, we lost her until she was 32. She spiraled into a world of homelessness and drugs and told us later that she was too ashamed to contact us. We adopted her when she was 32 years old. She is doing very well but we have to be careful only to talk about the present and the future, never the past.

All that to point out that sometimes foster and adoptive families know the history of the children in their care, but sometimes even the children can't tell them what happened to them. The anger and frustration is often acted out with behavior and destruction that is beyond what many families can handle.

And the rest of our story: When we went through all the steps to be licensed in MI, they contacted both adopted daughters. Even though we had told them on day one what Amanda would say and how it would harm Carrie to talk about her past. They assured us that they only interviewed biological offspring. Their questions threw Carrie into a tailspin, and she begged them to let us help other kids like we had helped her. Then her anxiety got so high that we were afraid she would cut all ties with us. She was absolutely traumatized by their contact. Amanda told all the old lies, and because it was "our word against hers," MI chose to believe her and left us feeling like accused criminals with no license. In spite of the fact that my husband worked for years with a top secret government clearance, and I worked winters as a psychiatric nurse in locked facilities and summers as a camp nurse. We would have both lost our jobs instantly if there had been a hint of wrongdoing! Yet MI believed a mentally ill criminal, a product of the foster care system, over two well educated, successful professionals.

Back to the help that families need: These kids lie. The system teaches them that when they report abuse (as they should) dramatic things happen. Adults get punished and the kids get shiny new things, plenty of food, and a new life. But they learn that they have a lot of power. When they don't get their way, they often report false abuse or lie to get other people to turn against the new parents. The kids also learn that they can steal, destroy property, harm animals…. the list is endless… with no repercussions. Right now the answer is usually to move them to the next unsuspecting family.

There has to be more respite, fewer huge families doing this for the extra money and tax credit, safe places for the kids to live without cutting contact with their new friends and families…. And much, much more training for young people who think this is just like babysitting the kid next door.

Mary Grones RN, BSN

Sent from my iPhone

Story #8

Joy and Emily's Story

Joy Gallup
5087 Peachtree Ct. NE
Rockford, MI 49341

I have a child that I would like you to know about. Here is her story.

My daughter, Emily, is fifteen and a freshman in high school. To look at Emily, you would never know that she was born in hell, lived there for three and a half years, and still carries that hell around with her inside her mind and body.

Emily was born to her birth mother, a single parent with three older children all with different fathers. Emily was healthy at birth and the hospital sent her home with her birth mother. The next 3.5 years were horrific. Emily was sexually abused by her biological father and various aunts and cousins, she was fed formula laced with cocaine, she was neglected and abused in every way possible. CPS finally removed Emily from her birth home. Emily was placed in a foster home where the sexual abuse came to light and where her blood test results showed high levels of cocaine in her system. Emily also had milk rot on all her front teeth, and they had to be surgically removed. This is when I first met and chose to adopt Emily.

Emily survived the deplorable conditions into which she was born. However, they left lasting damage to her ability to function in the world. Academically and physically, Emily seems fine. However, emotionally, and behaviorally it is a different story. From the age of 3.5 until today, we have seen numerous therapists and been through various programs all meant to help Emily. Sadly, none of them have helped. Not really. Emily has been diagnosed with RAD, PTSD, major depression, and generalized anxiety disorders. All these boil down to trauma. Emily survived horrific trauma which cause her severe depression and anxiety enough to make her repeatedly attempt to take her own life, make her unable to attach to others in healthy ways leaving her constantly feeling alone, make her thrash out physically against all that try to help her. Emily cannot be successful in this world because of the trauma that she endured, unless we step up and give her the care that she needs and deserves.

What would that care look like? It would be a full continuum of care that addresses all aspects of her physical and mental health that need it. We went to the emergency room last week because Emily had, for the third time in her life, attempted to end her life. We were in the emergency room for 12 hours waiting for an inpatient bed at a crises center hospital. The hospital admitted us, and we waited another 27 hours for a bed to open at a crises center hospital. We need more crises center inpatient beds. Our kids deserve it.

Emily remained an inpatient for 10 days and she was discharged home to us. The psych hospital she was at had made a referral to a residential facility because they felt that Emily needed that to truly make progress. However, Emily never went for two reasons. First, the center turned her down because they did not feel they could handle the aggressive behaviors she presents at home. Secondly, Medicaid would not approve the stay at a residential facility because, as I was told by our case manager, “We just don’t do that.” When I asked our case manager (who works for the counseling center that is affiliated with Network 180 or Community Mental Health) what the plan was for Emily when she came home, how will we keep her safe, our case manager gave us no answer. That is because there is no plan.
Even though we have used every program and therapist available for Emily, and these programs have failed to help her to make progress; even though she has attempted suicide twice just this year, we are still only approved to have the same services. My greatest fear is the day I will walk into her room and see that I was too late and her attempts to end her life have been successful.

Emily needs residential care for a long period of time in order to learn how to function safely in society. This is what our therapists and counselors tell us. The constant self-harm, suicide attempts, physical attacks on family members, refusal to go to school, theft, vandalism of the home make it impossible for an at-home program to make progress with Emily. I try to keep my home safe for her by putting cameras in every room, alarms on every door and window, all sharps and dangerous materials locked away (sharps are not just knives and scissors but also pipe cleaners, mechanical pencils, the teeth on foil and wax paper packages, butter knives, and her latest weapon of choice staples pulled from pictures and anything that is a cord).

During the day, my thoughts cycle through the same process. What else is sharp? What else has a point? Are there cords left out? Shoot, I left my bathrobe in the bathroom, and she could hang herself with the belt. Emily needs residential therapy to learn how to live. I am a teacher. I am not equipped nor trained in how to teach her how to live without hurting herself. I do everything that I have been told will help and it has not helped. Emily needs residential therapy.

A residential facility for youth that have been through horrific trauma in the state would help youth like my daughter. Because there is only one of them in the state, then Medicaid should pay for children to go to a residential facility out of state.

Story #9

Molly’s Story

I am a parent of an 11-year-old son who has severe emotional impairment and behavioral problems, and these are the roadblocks that I have encountered while fighting for services in the state of Michigan:

1. Communication. There is a major lack of effective communication between agencies (judicial, mental health, education, medical). We have lots of misinformation and problems getting clarification.
2. Beds. There are not enough beds in mental hospitals or facilities. Our son has visited the ER something like 30 times in the last two years, and 90% of the time he is sent home after a couple of days because there are no beds available. He has been to two state hospitals and had 3-4 visits at Pine Rest, but it is still very hard to find a bed for him. We understand that staffing is also a problem. There needs to be well trained and valued staff in these facilities. It is a hard job, but lack of training can be disastrous.
3. Services that have age limits. There are limited services for a younger population with mental health problems. He is currently 11 and therefore does not qualify for the majority of programs intended for youth because of his age.
4. Detention. Our son is on probation for multiple charges of DV, assault, and assaults with deadly weapons. He is currently sitting in detention because we cannot find a safe placement for him anywhere else. Although he does have a lot of behavioral problems, detention will not benefit him as much as a residential program would.
5. Law enforcement. We have had the police over several times a month, every month, for the past year for anything from assault to eloping across town. Most of the time they are very helpful and aware there is a mental health component to this situation, but more mental health training for officers would probably be really effective. There have been times that our son as run from or physically fought with officers and thankfully they were aware of his situation and did not need to escalate the situation which could have easily been justified, but we worry about his future with law enforcement as he gets bigger and stronger.
6. Medicaid. We have been denied placements, services, and testing because we have Medicaid for our son and our private insurance cannot handle this level of needs. We know that with private insurance, it is much easier to get some of these services, but that is difficult or impossible for many families in situations like ours. Navigating insurance is overwhelming.
7. Respite. There are few options for respite for our family. While our son is home, we are all on high alert and live in constant chaos and danger. There are virtually no places where our son can go (like summer camps, events, even summer school) due to his level of severity. It is difficult to find options for him and as parents we are exhausted and overwhelmed by trying to keep him, our other children, our animals, and our community safe from him and to keep him safe from himself.
8. Diagnosis. At one point our son carried the ASD diagnosis, which was dropped after moving to Michigan. Simply dropping that diagnosis changed so many therapy or service options that would have been available to him. He has FASD which is little recognized, often ignored, and has no treatment centers, therapy programs etc. devoted to that disability. Although he has other comorbid diagnosis, the FASD is the one that should be recognized and treated primarily. There needs to be more training across the board for

FASD as it is the most common form of developmental disability, but it isn't recognized or understood across the broad spectrum of community services.

9. CMH. Network 180 is our CMH, and we spent the first 6 months after we moved to MI desperately trying to get services put in place, but no one in any place we called, told us that we had to go through 180 because we are on Medicaid. We spent hours on the phone trying to get it figured out, but all we needed was one person to tell us to go to 180 and we could have gotten into services much quicker. The system is very frustrating to parents.
10. Prevention. There needs to be more effort put into supporting family units to prevent foster placements, unmet mental health needs, and the disastrous effects on the family of living with a child with mental health problems. The earlier and easier it is to access services, the better the outcome in terms of long-term support. These children should not be held accountable for the choices of their parents or of the system that fails them. They need as much support as they can get so that they can heal and become productive members of society.

These are some of the frustrations that I have personally found while fighting for services and support for our family, but I know that I am not alone. I spend a lot of time talking with other adoptive parents who have similar struggles and who are just as frustrated and the thing I hear the most is "the system is broken and needs a major overhaul in all of its parts". It is an overwhelming task, but something needs to be done and quickly. We are fighting on our end, and we ask that the leadership in this state fights on their end to help ensure better future for our children.

Thank you for your time and consideration.

Respectfully,
Molly Dixon
weareontherock@hotmail.com
219-299-6564

Story # 10

Tim and Christine's Story

You need to shift the campaign to raise awareness of mental illness to one of funding mental illness treatment. No one the world over raises awareness of cancer as an effective treatment against it because that is absurd.

Therefore, mental illness treatment needs to be funded as a real disease, just like cancer. As a former teacher, I had many students whose confidential paperwork read, "depression" and I thought they must be depressed about the world, but this is way off. When my daughter became acute in 7th grade she told us parents, "my brain hates me and wants me to die." Kids, by and large, are not depressed about the world; their brains are attacking their own well-being.

Through our experience with the mental health treatment industry, we have learned the following, much of which needs to be improved.

Pediatric Emergency Services (PES) at the UofM, Ann Arbor are woefully inadequate. They have 16 beds for adolescents in crisis, 3 of which are reserved for the autistic leaving 13 for the general public. Thirteen beds at the preeminent research hospital in southeastern lower Michigan. No exclamation mark needed.

It gets worse. In order to get your child admitted to one of those 13 beds, you have to check into the waiting room and then just wait. You wait for hours; you wait for days. All you do is wait. Kids are draped in sheets. Parents are dazed in chairs. The TV on mute plays captioned Flip this House episodes *ad infinitum.* Your child is visited by social workers, residents and a psychiatrist and evaluated for admission but, that doesn't matter. You must wait and wait for a bed to become available. There's a certain day of the week where you have a better shot at admission because discharges typically happen the day before. I've forgotten the day, but it really doesn't matter because you still have to wait. Our daughter was admitted there twice, placed at Stonecrest, Detroit once and we walked away two other times. I know someone who waited 5 days for a bed. This means she and her kid could not leave the waiting room for five full days. If you leave, you lose your spot. I'm not sure whether this is draconian or barbaric.

My daughter and I were there recently. We're veterans now. It was easy to spot the newbie parents. One pulled out a laptop to plug in and get some work done– tisk, tisk. Staff came and took her cord because it is a suicide risk (how, with adults and staff at the ready, I'm not quite sure.) Another struck up a conversation with me because our kids looked similar. Later, she came to me exasperated after learning about the wait and the belief they do not diagnose or prescribe drugs there. She was a single mom, and her daughter was on a three-month waitlist for a psychiatrist, so she had no diagnosis and was not medicated. The mom swore and stormed off.

They do administer drugs there once your kid is admitted. But, they do not diagnose and pediatric emergency services, "psych wards" as the kids call them, are meant only to stabilize your kid. It is not long-term care, and it is not a cure. Typical stays for us were between 10-12 days. Parents the nation over have commented this does need to be advertised because so many of us were under the impression this is what you do– take your kid to the hospital for treatment but, the approach is just to stabilize. It's not to cure them and it's certainly not for follow-up at the hospital. You're not supposed to come back for further treatment or be referred to a specialist; once you're discharged, you're back to square one. The pediatric emergency service staff do not tell you this. They do not make referrals for continued treatment. Yes, there is continuation of care at discharge and safety plans drawn up and follow up appointments with your psychiatrist and therapist (if you're lucky enough to have them) but hospital emergency rooms do not refer their pediatric patients for long term care– this is left to the private industry: educational consultants.

Educational Consultants are private-pay individuals with no required educational background from what I can tell. From what I have seen, they are adults who have lived this nightmare with their own kids and now earn a living by placing the next generation of mentally ill adolescents. I don't know why this isn't regulated. Free market, I suppose. I'm glad Capitalism is in such good favor right now.

Anyway, they charge between $4,000-$6,000 out-of-pocket to place your kid at a Residential Treatment Center (RTC.) We didn't use one when we sent our child to an RTC in CA. Oh yeah, I would be remiss if I didn't mention that there is not a single adolescent residential treatment center in the state of Michigan. Therefore, all treatment beyond the hospital psychiatric ER is out of state, out of network and out of pocket. A lot of these facilities are in Utah because there's something about kids close to turning 18 and therefore able to walk away of their own accord but, somehow in Utah this isn't the case, so kids have to stay in treatment. Anyway, I can't really speak to this, but many parents sent their kids to Utah. I hear it's a beautiful state.

Both the EC and RTC are really expensive. Out of pocket costs ran us $55,000 for a 35-day stay and that is considered short-term treatment. It was recommended our daughter stay longer but we couldn't do it. Her grandmother can only die once to leave us the money to pay for it.

Our daughter has been home for 4 months now and still struggles mightily. Beyond RTC there is Therapeutic Boarding School (TBS) and Wilderness Training (WT). TBS was recommended for our kid. It's a 9–12-month stint where the client receives some therapy but mostly schooling. Apparently, insurance might reimburse for the therapy, but this is just a fraction of the cost. An EC we talked to but did not hire told us TBS costs $10-$15,000 a month so a nine-month stay can run up to nearly $150,000. I quit my teaching job when my daughter became acute, and my mother started her decline. My wife works but not enough, I guess.

In addition to the piecemeal, disjointed, fractured approach to mental illness treatment, there is, of course, the insurance industry. We've had pretty good luck with our carrier, Blue Care Network HMO. While sending our child to RTC for those 35 days and paying up front and out of pocket, we did receive "authorizations" for treatment. The RTC told us authorizations are good but do not mean you will get reimbursed because, "insurance authorizations department does not speak to billing."

There were multiple tear-filled phone calls among my wife, BCN and the RTC because insurance claimed the facility was billing using the wrong codes. The facility said it always used these codes and we parents were stuck in the middle, left to make all the phone calls, wait on hold and try to get consistent answers because you never talk to the same insurance representative twice. And no one was going to advocate for us– parents must do this leg work.

Our daughter uses drugs to cope with mental illness, cannabis mostly. However, she has gotten into pills and alcohol and now actually wants to go to addiction rehabilitation. Her social worker through the UofM adolescent treatment services (UMATS) referred us to 4 facilities. Guess what? They're all out of state and they're all out-of-network. The sticking point here is adolescence. MI has treatment centers in-state but not for kids.

We did an intake at Betty Ford Hazelden in MN, and they had a bed and they seemed to work out a "single-case agreement" wherein, although out-of-network, BCN would pay for this one 30-day treatment. Apparently, our luck has run out because BCN has denied the claim saying this facility was not appropriate for treating our daughter because she has an eating disorder. Our daughter does not have an eating disorder. Betty Ford Hazelden reviewed my daughter's intake information with me noting there was nothing on it to indicate an eating disorder. I said BCN must be going by her height and weight then. Betty Ford Hazelden said they did not take down her height and weight because the intake was done over the phone. This certainly looks like a fabricated pretense by BCN to deny coverage. And this for a 15 yr.-old girl who *wants* to go to drug rehab because she feels she needs to get addiction under control to use the skills she has learned in therapy to navigate life and get better.

In sum, the mental illness treatment industry in the State of Michigan is woefully inadequate. It simply does not function to the extent required to adequately service adolescent patients. Too many parents are left to their own devices to try to piece together treatment where none exists, pay for it by the grace of God, and hope for the best. We have been pretty damn lucky, but we are not out of the woods. No one is until legislation is drawn up, passed and funded to vastly expand the facilities to treat the mental illness epidemic, and make it affordable in this state and country.

Tim & Christine Peiter
Chelsea, MI
734 433 6564

Story # 11

Anonymous

Thank you for this opportunity to share our story. We are licensed foster parents in Washtenaw County, and two children in our care received mental health services through Community Mental Health (CMH) in the last three years. We are writing to express our concerns with the mental health services available to children with Medicaid, mainly a lack of available services to those with a Severe Emotional Disturbance Waiver (SEDW), a heavy reliance on psychotropic drug cocktails, no adequately trained respite workers, and a lack of FASD informed providers and programs. Due to privacy, we will only refer to the children in this testimony by their first initial.

Background

M was a 16-year-old girl who entered foster care at age ten. Like many kids in foster care, she bounced between several foster homes, started self-harming around age 13, and went through several inpatient and outpatient psychiatric programs until she ended up in a low secure residential facility. She was diagnosed with PTSD, Major Depression, Borderline Personality Traits, and Disruptive Mood Dysregulation Disorder. M was a Permanent Court Ward (PCW), and we took her in as pre-adoptive placement; she moved in with us in early January 2019. M went through intake at Washtenaw CMH and was assigned a therapist and psychiatrist.

During the six months she lived with us, she had six visits to the psychiatric ER due to self-harm, three inpatient psychiatric hospitalizations, and a week at an outpatient partial hospitalization program. Unfortunately, none of these services improved her mental health in any measurable way and only increased her frustration with the lack of control in her life. In addition, her therapist was often difficult to reach, didn’t return calls, and seemed very checked out in general.

E is 12 years old and has lived with us since May 2020 after a brief stay in a relative placement. He is a Temporary Court Ward (TCW), but the TPR (Terminating Parental Rights) trial is next month. Like M, he's experienced a tremendous amount of physical and emotional abuse and neglect in his young life. Since he's been with us, he has received the following diagnoses either by CMH or Michigan Medicine: PTSD, ADHD, Autism, Intermittent Explosive Disorder, Sensory Processing Disorder, and most recently, Partial Fetal Alcohol Syndrome (PFAS). In addition, he struggles with processing delays, executive functioning deficits, poor impulse control, and gross and fine motor control. He also struggles with social skills and has difficulty forming friendships with peers. We recently had to pull him out of public school because he was being bullied and was scared to go to school after another child attacked him. We enrolled him in a small private school for neurodivergent kids instead. He says the kids are much nicer, but he also struggles with emotional regulation, and we suspect he may eventually need homeschooling.

E is prone to aggression and rages when he is angry or triggered. He bites, hits, punches walls, and throws whatever is within reach. He also self-harms by punching himself in the face hitting his head against the wall, and in severe episodes, he will try to tie fabric or string around his throat. He has dented several walls in our house. The severity of his suicidal ideation has dramatically reduced since visits with his birth parents stopped. However, he still punches himself in the face several times a week and is aggressive towards us when dysregulated. He will also threaten us by making slitting motions across his throat while saying, "I'm going to kill you in your sleep!"

We understand that many of these behaviors are symptoms of his PFAS diagnosis. Because he struggles to communicate his needs and feelings with words, violence and threats are what he grew up with and is familiar with. When he is emotionally regulated, he is thoughtful, intelligent, funny, good with animals, and wants to help others. For example, he recently asked to donate his allowance to help children in Ukraine.

E started services through CMH in October 2020 after a private practice therapist discharged him from her service. We were reluctant after our experience with M, but it seemed it was our only option. He was assigned a home-based trauma-focused CBT therapist through CMH, and thankfully, she is fantastic, and E likes her.

Severe Emotional Disturbance Waiver (SEDW) and Wrap-Around

We learned about the SEDW program when M was living with us and asked her therapist if we could apply, but the therapist refused, despite the clear signs that M needed significant support. The therapist claims she denied services because M often refused to talk in therapy. The therapist also tried to convince us that M would not benefit from these services because she did not want the help.

Thankfully E's therapist suggested applying for a SEDW and wrap-around services immediately. Unfortunately, neither the waiver nor the wrap-around provided us or E with any helpful services. Wrap-around further adds another layer of bureaucracy that foster families are forced to schedule and coordinate with no actionable or tangible benefit for the kids. In addition, services covered under the SEDW are often unavailable or have a long waitlist, which we will discuss later.

We've also asked about alternative therapies, like art, music, sand tray, or play therapy. But unfortunately, to get those therapies, we would have to lose E's current therapist and be transferred to a different therapist, which is not something we want to do because they have established a good relationship. We would really like E to have access to these therapies in addition to his current therapist, not instead of.

Overreliance On Psychotropic Medications

M was already taking three psychotropic medications when she came to us; the CMH psychiatrist also added a mood stabilizer, but we noticed no improvement in M's mood. M recently expressed frustration that adults were putting her on multiple medications with no consideration for what she wanted, and she often felt worse on them.

Like M, E is now on four psychotropic medications with no real stabilizing effect other than helping with his insomnia. He's also experiencing metabolic side effects, increased blood pressure, daytime fatigue, weight gain, and blurry vision because of the medication. We expressed our concerns to his psychiatrist at CMH, and she said he is on a low dose and refuses to make changes. We asked to switch psychiatrists recently and are working with the new doctor to consolidate the medications and transition to ones that have less harmful side effects. We believe a lot of his aggression and defiance is because he is tired all the time from his medication.

Lack of Respite

E's SEDW will pay for 8 hours of respite a day, but we have yet to find a decent respite worker. We've had two respite workers through CMH, one of whom we had to fire after he continually canceled at the last minute. The other found a new job after a few months. We have not found a replacement. His therapist said we could find a respite worker on our own, and we did find a great candidate who was a college student studying child development. However, after several weeks of waiting on GT Independence to process her paperwork, we received the following email notifying us that they would not authorize the service:

"After looking into this further, it has been determined at the State level that in this situation of E being in a foster setting and on SED waiver that Self Directed Services will not be an option. Our State Director did ask the State if Michigan Agency with Choice was an option, and the answer was no."

The SEDW will also cover summer camps to give us respite. However, CMH only has contracts with Eagle Village and Youth Haven. Eagle Village is three hours away and doesn't provide transportation. E went to Youth Haven for a week last summer, and we will not send him again due to the religious trauma and racist comments he endured. We asked if CMH would pay for other camps they said no, they only pay for the camps they have contracts with.

We have not had any regular respite workers in 9 months and have resorted to asking friends and neighbors to take him for a few hours on weekends to get a break to recharge. Unfortunately, the lack of regular respite care makes us emotionally and physically drained to the point that we consider closing our license.

Lack of FASD-informed care

Traditional parenting and behavior modification techniques do not work for kids with FASDs and often worsen behavior. In our experience with E, punitive consequences result in rages, so we rely on natural and logical consequences. We have sought out training on FASD and, as a result, adopted a neurobehavioral approach at home, which helps reduce the episodes of rage, but E still gets aggressive and defiant when he is tired or hungry. We want training from a program like Families Moving Forward, an evidence-based intervention for families affected by FASD. Unfortunately, Washtenaw CMH doesn't have anyone trained in the program. We were offered Parent Management Training but have declined after talking to other families in the FASD community who said it did more harm than good.

E is also eligible for ABA therapy, but the centers that take Medicaid have a waitlist or aren't even adding names to their waitlist because it's so long. The quality of these centers is also not good compared to those that only take private insurance. There are no studies that show ABA improves behaviors in kids with FASDs, and we've heard from other FASD families that ABA backfired for their kids.

We recently learned that five counties were rolling out an FASD System of Care in 2021, and we have asked our wrap-around coordinator if we can get the Families Moving Forward program through a nearby county; we are still waiting on a response.

Crisis Support

There aren't many beneficial supports for kids in a mental health crisis. We've tried calling 911, going to psychiatric ERs, and calling the CMH crisis team. But none of them have been helpful, so we've learned how to manage the crisis on our own.

We have had police in our home several times due to M and E's mental health crises in the last three years. But for kids in foster care who've experienced trauma and emergency removals, having police in our home can be traumatizing. So, after the last time, I vowed never to call 911 again unless it was a true medical emergency.

We've also called the CMH crisis line many times. Once, they sent therapists out, but it took about an hour to arrive. And E refused to talk to them, so there wasn't much they could do to help. After getting wrap-around services, they transfer us to our wrap-around coordinator, who rarely answers her phone.

We've also frequented the psych ER at St. Joe's and Michigan Medicine multiple times, never provided meaningful help, and it is always an exhausting and uncomfortable experience. As a result, we no longer rely on it for crisis intervention.

Instead, we've learned to stabilize E by offering co-regulation, encouraging him to move his body, and giving him cold liquids to drink through a straw. We also have a PRN for Risperidone we can give him if needed. When he gets severely dysregulated, he will try to hurt me physically, so I used to block myself in our bedroom to stay safe while my husband attempted to manage him alone. However, I've learned he desperately needs me for co-regulation, so even though he's trying to hurt me physically, it makes his behavior worse if he can't get the co-regulation. It's exhausting, but we get through it. I've been asking for more training on crisis management techniques but have yet to receive any. Everything we have learned is from training and books that we have sought out and paid for on our own. E is about to be taller than me, though, so I’m not sure how much longer we can manage the episodes on our own. Fortunately, they happen less frequently now that he’s not doing visits with bio parents.

Outcomes

M ultimately sabotaged the placement after six months and ended up back in a residential facility; she eventually transferred to a Semi-Independent Living program. She went AWOL with her birth mother and stopped taking her medication, so DHHS discharged her from foster care at age 18 with no support. She reaches out to us every few months. She struggles to hold down a job and has experienced sexual assault, homelessness, and had a baby, which she put up for adoption. She claims she hasn’t self-harmed or had any suicide attempts since she is off medication, although she is still impulsive and puts herself in risky situations. M recently said she wished all the mental health providers had asked her what she needed instead of jumping to medication. She was frustrated and angry that she didn’t have much input in her care. Talk therapy was difficult for her. She wishes the adults gave her an alternative such as music, art, or animal therapy; and the opportunity to talk to someone whenever she needed it.

Life with E is difficult right now. We are trying to avoid terminating his placement because we know he would end up in residential facilities like M, but the lack of respite and FASD informed services makes life hard. We think he has a bright future if given more support. However, we can see how easy it might be for him to succumb to peer pressure, gangs, drugs, and violence. In addition, we worry about the aggression increasing as he gets taller and stronger.

Conclusion

In summary, we’ve witnessed firsthand our kiddos suffer from a lack of mental health resources, psychiatrists relying on cocktails of psychotropic medications that often worsen symptoms, and an inability to be flexible in care. This results in further suffering for traumatized kids and burnt-out caregivers who get secondary PTSD. Instead, mental health services should be robust, flexible, and implemented quickly, with respite care available on demand. We hope that more funding is provided for a full continuum of mental health services available to all families who need them. Thank you for your time and consideration.

Story #12

Rachel and Daniel’s Story

This letter is a desperate plea for help. As any parent would, I am trying to help my child survive his illness. I never thought such a simple thing could feel so impossible. My son, Daniel was born June 13, 2007. His birth-family lived in extreme poverty with a family history of mental illness and alcoholism. He spent his first months neglected in foster care and came to us at 7 months old, the back of his head flat from not being held enough and his motor skills delayed.

Daniel seemed to be happy in our home, but when he was six years old, we started him in therapy for lack of self-worth. We learned early that he needed an attachment therapist who specializes in adoption. As a result, for many years, we often paid out of pocket for specialized therapists and services because we were committed to getting him what he needed, regardless of whether it was covered by insurance. This included occupational therapy, physical therapy, neurofeedback, cranial sacral therapy, chiropractic care, an emotional support pet, academic intervention, an outpatient attachment therapist, a child psychiatrist, a total of five neuropsychological evaluations, and a naturopathic doctor with testing, supplements and dietary changes.

He tried a battery of medications including Wellbutrin, Fluoxetine, methylphenidate, Latuda, Benztropine, Clonidine, and Divalproex. This doesn't begin to touch on all of the other remedies and activities we were encouraged to enroll him in to support his ability to attach to us and support his brain function like language classes, karate, swimming, essential oils, special massage techniques, reconnecting with birth family, prayers, etc. We tried EVERYTHING to support Daniel's physical and mental health. During all of these years we had no idea that we could apply for assistance through a Medicaid SED waiver.

When we asked if help was available, we were always told Daniel wasn't eligible because of our income and because he wasn't adopted through Michigan's foster care system. So, we managed the best we could with what we had to work with. Unfortunately, Daniel's mental health deteriorated drastically in 2021 and the situation became unmanageable. His lack of self-worth turned to suicidal ideation and self-harm. He also became physically violent against everyone in our household, including his 9-year-old brother and emotional support dog. When Daniel spiraled, he destroyed things, stole, took his brother and younger neighbors on unsafe outings, and ran away, crossing the freeway on his bike.

We were faced with the fact that the support we were providing Daniel was clearly not enough to keep him and others safe. Daniel's therapist recommended that we reach out to Post Adoption Resource Center. A social worker came to our house and helped us develop a safety plan. If we weren't able to de-escalate a situation, we could call the CMH mobile unit. Over the next few months, I would call that number a dozen times and learn all the reasons why we couldn't get help from the mobile unit. For instance, the phone wasn't answered, or it was answered by a different agency who would pass along my message, and I didn't get a call back for hours or even until the next day. Also, the mobile service cut off at 10pm because it wasn't funded for 24-hour service son it wasn't an option for late night incidents.

Since we couldn't get the CMH mobile unit, and it was impossible to get Daniel in the car to drive him to the hospital, our other option was to call police and potentially expose Daniel to the criminal justice system. But everyone on our team agreed that calling 911was absolutely necessary. The first time I called 911, I came out of hiding to find Daniel on the roof, and several police officers in the snow below trying to talk him down. He was hospitalized that day. Once in the hospital (there were two hospitalizations), there were no beds at any of the mental health facilities in Michigan where Daniel could be kept safe. We were referred to CMH by the hospital for outpatient support. I was extremely skeptical because I had only heard really terrible reviews about our local CMH office. I had heard that there is high turnover in therapists, and most are new to the job and have little experience or training for complex cases like Daniel's. I also heard that we wouldn't be guaranteed that Daniel could meet with the same therapist every week despite the fact that stability and attachment are major drivers behind Daniel's mental illness.

Sure enough, when I did reach out to CMH, I was told that we would need to use their therapists and psychiatrist in order to access any services, essentially requiring us to end our long relationship with Daniel's highly qualified and experienced psychologist and psychiatrist in the middle of a crisis to start fresh with people who definitely didn't have the experience or training to address Daniel's unique situation. That's like switching to a general resident doctor program when you are facing stage 4 cancer and have been working with an oncologist at a cancer center. At this time, despite Daniel clearly exhibiting severe emotional disturbance, nobody ever mentioned an SED waiver, what it was for, how it could help, supports it would help us access or the fact that Daniel would probably qualify for it.

Through a chance encounter in a Facebook group, we learned about therapeutic consultants. Desperate for a path forward, we hired one and she thoroughly assessed Daniel's situation. She recommended a specific therapist with a specific therapy program in Wisconsin, known to help kids with Daniel's complex set of mental health issues. We moved forward with that plan and "celebrated" our 21st wedding anniversary by admitting Daniel to that intensive treatment program. After that, the treatment team and therapeutic consultant agreed that Daniel needed continued therapy and recommended a residential treatment program in Utah. We admitted Daniel to both of these programs with the expectation that our insurance would cover his care, per our policy.

However, we have encountered one obstacle after another and have been forced to pay out of pocket, requiring us to refinance our house, liquidate college savings, and now we are starting to liquidate our retirement savings. We have not received any help yet despite federal laws for mental health parity in insurance (We've learned Michigan is one of the few states with no parity law), FAPE in education, or the supposed availability of CHM and Medicaid in a situation like this. After all, Daniel is out of the state now so it doesn't matter that we have finally become more aware of the system, Daniel isn't eligible to enter it and it wouldn't pay for his care out of state, even if there isn't care available in the state. Furthermore, as I meet more parents in my situation, I am learning that he might not be approved for the SED waiver, despite his clear need. And, I am also learning that even if he was approved for the SED waiver, he likely wouldn't be able to access the supports anyway because there aren't enough appropriate facilities to help him in Michigan, there aren't enough beds available in those facilities (good luck even getting or staying on a waiting list), and there aren't enough qualified staff even for outpatient or in home services.

The first time I saw someone post in an adoption related Facebook group that she planned to abandon her child at the hospital and risk jail-time, a criminal record, and the threat of losing her other children to foster care in order to force the State to help provide care for her child, I thought she was a horrible mother. Since then, I have seen at least 20 more Facebook posts like that, and I understand now that this is a life-or-death situation. The only thing that separates us from those parents is our savings account.

What will happen to Daniel (and the rest of us) when our money runs out? Considering the recent declaration of a "National Emergency in Children's and Adolescents' Mental Health", and the rise in school shootings and suicides, the time to fix this situation is now.

Thank you for your help.

Sincerely, Rachel C.

Daniel's Diagnoses:
Attention Deficit Hyperactivity Disorder, Inattentive Type (ADHD)
Developmental Disorder of Scholastic Skills, unspecified (slow processing speed)
Specific developmental disorder of motor function (dysgraphia)
Unspecified Mood Disorder

Generalized Anxiety Disorder
Eating Disorder
Reactive Attachment Disorder (RAD)