

January 16, 2023

Ms. Gina Bull (Sent via email to Gina.Bull@ag.ny.gov)  
Assistant Attorney General and Special Assistant to the 1<sup>st</sup> Deputy  
NYS Office of the Attorney General / Executive Division  
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Dear Ms. Bull:

Thank you and Attorney General James for your attention to the mental health supports for the citizens of New York State. This letter is going to be a very honest commentary on our personal perspective on the challenges with mental health supports and the ineffective and limited mental health services in Western New York.

By way of background, I would like to provide a quick introduction to our family. My husband and I adopted our first child in California before we moved to Buffalo, New York. We added to our family in 2010 when we adopted a sibling set of 3 children from Ohio. This sibling set spent 3 and a half years in foster care in 5 different homes. There was limited information about their parents and their mental health history. None of this is uncommon in adoptions. We fostered and adopted our fifth child in 2015 and then in 2017 we received a call about our fifth child's biological sister and we eventually adopted our sixth and final child in 2020. During this same time we experienced the tragic loss of our second oldest child due to suicide.

#### Sibling set adoption

Since adopting the sibling set of three in 2010, these children have been in specialized classrooms and in counseling. While they made progress in their education, their mental health counseling had limited success. The main reason is that they are on Medicaid and counseling supports for children on Medicaid is limited. Any interventions requiring specialized support is not covered by the Medicaid

program and thus, children on Medicaid cannot get the specialized mental health support they need because they do not have the access to providers which are mainly private pay. Since 2010, mental health support has only grown worse as service providers have had to deal with reduced reimbursement rates and a changing workforce who simply do not want to go into counseling professions for low wages. The wait list for supports is months long and staff turnover is high. Establishing a relationship with a mental health counselor is a key to a successful outcome. You cannot establish a relationship with a counselor if they are constantly changing. From our experience, 75% of the counselors have changed to get other positions and opportunities that pay more. If not leaving for better pay, the staff feels unappreciated by their employer and leave to go to a different company, in most cases a private pay provider.

After our son committed suicide our children's needs for mental health supports increased and the void of mental health supports became even more apparent. We have used the services of Spectrum Cares, CFTSS services, WNY CPC, CPEP, OLV RTF and currently our son is at a Gateway Longview RTC. I will describe our experience with each of these services.

#### Spectrum Cares

This is the only service that can be used for mental health support for children under the age of 18. This is mainly telephone support and you never know who is going to answer the phone. This support also requires the individual in crisis to get on the phone and that is rarely the case. Most of the time the response from Spectrum Cares has been, "Lock the younger children in a room so that they are isolated from the crisis and then let the crisis play out". If you are in crisis, you have to prove that you are in crisis before they will send a mobile response team and it is rare that they send a team. When a mobile response team does arrive, their evaluation process is, "Is the individual a lethal threat to themselves or others". They say that they have to evaluate this way because that is the way New York State law is currently written. There have been some good engagements but most engagements have been disappointing and many have been awful with us begging them for support and them saying they cannot help or send a response team.

### CFTSS Services (Additional Supports in General)

With most interactions with mental health professionals and especially as evaluated by Erie County and OMH, is “How many services do you have in place?” Erie County and OMH continue to say that “services” are the answer and when you respond with “We are on a 6 month wait list”, their reaction is, “I know, the system is broken and overwhelmed”. When you respond with “My child will not engage with the service provider” their response is, “There is nothing we can do”. So if a minor is not going to participate in their self-care and additional supports that the family is directed to, the “There is nothing they can do” is not helpful and not an answer. We were very lucky that we had a great CFTSS worker because this worker held our child accountable for their actions. Unfortunately, she moved on to another position that was not covered by Medicaid.

Recommendation: Pay service providers more so that they can keep quality staff. If a minor is refusing services that are determined are needed they should be held accountable by needing to complete a treatment program or some other type of program so that they know that they need to participate in their self-care or there will be a choice made for them to hold them accountable.

### ECMC CPEP

This is absolutely the worst service available in Erie County and unfortunately it is the only service available for citizens in mental health crises. We cannot tell you the chorus of voices (including mental health professionals and providers) that also share our disappointment in/disgust with ECMC’s CPEP program. Their one criteria is, “Is the individual a lethality concern?” If the individual does not meet that concern, they tell the family to come pick them up. In our case when we identified that our child’s aggressive and unpredictable behavior presented a safety concern for the family and the younger children, their response was, “That is not our concern”. On the most recent incident where our child physically attacked us requiring us to get an order of protection, ECMC CPEP still was calling to have us pick up our abusive child. Baffling isn’t it. Their social work staff is abusive.

Recommendation: Establish another service for Erie County that will evaluate mental health crises and not just lethality concerns. Make sure that this service has the ability to work with the individuals and

families on a safety plan before returning home and then most importantly, hold the individual to the requirements of the safety plan. If the individual does not comply with the requirements of the safety plan, then they will need to be transferred to a treatment program. (See note below on collaborative mental health clinic)

#### OLV RTF

After several engagements with additional services, CPEP and the WNY CPC, our son was placed in residential treatment. This was our first engagement with residential treatment. During his 12 month stay, his medication increased from 2 pills per day to 12 and we did not have one successful family session. At the 12 months, we were told that he could not stay there any longer and that we needed to take him home. We were introduced to the health homes team for additional services once he was released but as mentioned above there are long wait lists for these services and there were little transitional interventions. By the second month after his release, we were already calling the police for disturbances in the home. At the 3<sup>rd</sup> month after his release he was back at CPEP but again released because he was a lethality concern and by month 6, we were assaulted in our home because we asked him to turn in the computer at 9:30 and when he did not we turned off the internet. He spent a year in residential treatment and NOTHING had changed with the exception of the additional medication that caused him to gain weight and made him more self-conscious of his appearance.

Recommendation: No facility should have the ability to increase medication at this alarming rate so quickly. There should be a double check system within the State to prevent this level of increase. Mikey's behavior changed only because he was over medicated. Every month the facility should evaluate if there has been successful family engagement including a direct question to the family with a family response. Do you feel that your child has had successful family engagements? Do you feel that your child is ready to return home? The minor should be put on an enforceable safety plan that if they don't follow they will be returned to the facility. Currently they do write a safety plan but if the minor does not follow the plan nothing happens and again we as parents are told, "There is nothing we can do". Finally, intensive support should be in place before returning the child home and these supports should identify if the transition is working or has additional challenges that need a return to

the facility. I discussed this with the service provider OLV and they said that they could not do this because it would be seen as “double dipping”. We cannot let the billing mechanisms get in the way of proper transitions for those in mental health care. I will share that a month after our child was released from the RTF they had to close down 2 wings of the facility (approx. 50% of the facility) because there was not enough staff to support the facility.

Because of our order of protection after the assault, our child could not return home and Erie County was “forced” into taking him on a voluntary placement agreement. It should be noted that both ECMC CPEP and Child Protective Services supported his return to our home even after the assault. It should also be noted that during the process of getting the order of protection that many “advisors” said that we should get him in to the juvenile justice system. This is really where our system is failing mentally challenged individuals. They just want to push them into the justice system. Once they are there, they are lost.

#### Gateway Longview RTC

Erie County had access to place our child in an RTC. Why RTC’s cannot be accessed by the general population is a problem. Our child did not make contact with us for the first 5 months and continues to refuse his supports and services. Our child has been there for 8 months with little to no improvement. Many times the mentally challenged individual does not want to take accountability for their actions and our child is no different. That compounded with him being 17 years old and the immaturity that comes with being a teenager.

In addition to the above recommendations, we offer the following:

#### Central Mental Health database

We will use our son as the example. We placed numerous calls to Spectrum Cares (over 20), numerous police visits (over 20), 6 stays at CPEP, a three month stay at WNY Children’s Psychiatric Clinic, 1 year stay at OLV Residential Treatment Facility. There should be some way for all these service

actions/activity to be captured in a consolidated database so that our son would be on the “mental health radar”.

#### Collaborative Mental Health Clinic / Resource

In an ideal world, after the several calls to the police and/or Spectrum Cares we should have received a call from an empowered mental health clinic to say, “We have noticed you have had a lot of activity with your son, what can we do to help”. This clinic could also work with the wonderful organizations in our area NAMI and WNY MHA to help families negotiate the mental health system which is current fraught with challenges. By working together under one umbrella in a centralized environment families would be better able to serve their loved ones with better supports and services. This clinic/resource would be better equipped to evaluate the mental health of an individual versus the current lackluster services provided by ECMC. As the second largest city in New York State we should have more and better services for our community members who are in crisis. Service providers should be challenged on how they could work better together rather than in isolation.

#### Equity

Minors on Medicaid should have the ability to access specialized services versus going to complete private pay, even if there is a copay needed your insurance should not prevent them from getting the services they need. Private pay providers should not have the ability to automatically reject Medicaid.

Care providers at facilities, particularly staff at RTF’s and RTC’s should get paid more than a fast food worker. The pay is horrible and that leads to turnover and poor support for individuals who are struggling. Pay people for what they are worth based on the job that they do. Support professionals deserve more than what they get because their job is emotional and hard.

#### Accountability

Minors, like their adult counterparts, MUST be accountable for their self-care and families (parents) need the empowerment to keep them accountable for their self-care until they are an adult. If the minor has gone through professional treatment and they have been identified as needing medication,

then the minor needs to take the medication. If there is a second opinion needed, then access the professional talent of the consolidated mental health clinic noted above. If the minor is not attending their needed services and support appointments, then there is a level of accountability that they will face. Right now there are no accountabilities for a minor's actions of not participating in their own self-care. That is not how life works and we need to change that. As an adult, those accountabilities will be different and potentially not very pleasant. We need to ensure that minors know that they are accountable and need to proactively work on their self-care. That will prepare them to be an adult.

If you take a hard look at where the funding for services is currently going I am 100% sure you will find that implementing these solutions would not cost incremental funds. Organizations just have to start working together instead of trying to "play in their own sandbox."

Thank you for taking the time to read this letter. We hope that your work will spark change. It is not going to be easy, but it is not impossible. It just needs to start somewhere instead of everyone saying, "The system is broken." If we had a nickel for every time we heard that.....

Respectfully,

Mark Mortenson and Curt Maranto