

My Family Was Punished for Seeking Mental Health Care

My name is Kass, and I write to my state reps today for help because my family, like so many others, has been punished and financially devastated for daring to seek adequate mental healthcare and supports for my child who desperately needed it.

For background, my teen (P) has struggled with severe sensory issues, impulsivity, and elopement since toddlerhood in addition to a speech/developmental delay. I sought services and support for P from 16 months old, but our family was told P would "grow out of it". P did not receive any professional support until they began elementary school (once the issues could no longer be overlooked by providers) despite my ongoing efforts to secure early interventions for P. Like so many young neurodiverse girls, for most of their life P was incorrectly diagnosed and given therapies/medications that were not appropriate for their needs. They were refused accommodations in school and was even left unattended by school staff in 1st grade, resulting in a broken arm and traumatic emergency surgery, which left P dealing with debilitating anxiety and paranoia on top of pre-existing symptoms. Last year, at age 14, P was late-diagnosed with autism. School staff all these years later still refused to host an IEP meeting or provide accommodations, leaving P often unaccounted for, even missing off campus. Participation in public school is so dangerous for P that I was left with no choice other than to homeschool. To put it lightly, being heard and receiving appropriate referrals and services has been an uphill battle from day 1, to P's detriment. As P aged but still did not receive adequate care from providers or accommodations from school, things only continued to worsen.

P's behaviors, primarily elopement, increased in severity upon entering adolescence and re-entering public school after pandemic shutdowns. After a particularly dangerous elopement, I followed the advice of P's mental health and social work team, bringing P to Fairview Riverside ED. I was scared P would be kidnapped, killed, trafficked, get lost, or something horrible would happen if P was not in a secure environment where they could be monitored. I had asked for in-home supports and was told the only way to receive them was via hospital and county staff. I followed all the advice from providers but I'm here to say that things did not turn out the way P's providers said things would turn out back in 2022. After CPS/hospital/county referrals and involvement, our family did not ever end up with additional support. P ended up ping-ponged around different facilities like day treatments, other EDs, eventually a residential facility, and more EDs. These environments were not only inappropriate for P's needs but worse, they were all riddled with child abuse/neglect from staff. P's behaviors only increased as a result of exposure to these environments and peers with more severe behaviors. Aggressive tendencies increased, which decreased the amount of providers willing/able to work with P. It has been a vicious cycle. Additionally, P suffered educationally, often missing school and unable to focus while in school due to stress and institutional trauma.

Some of the treatment P experienced with hospitals over the past few years includes but is not limited to:

- Fairview Riverside refused to admit P to stabilize meds and decrease suicidality despite there being no outpatient meds provider (waitlisted). This hospital went on to allow P to elope from the campus multiple times consecutively - at one point police found P over 5 miles away from the hospital after midnight. I repeatedly asked hospital staff for referrals to other facilities or providers with immediate openings who could help stabilize or offer more support. I was open to providers in other cities and even other states nearby if needed. This support was withheld/refused by hospital staff who told me to coordinate with P's nearly nonexistent outpatient team. I brought P home even though it was dangerous to do so due to reasonable fear that P would lose their life in Fairview's negligent care, but also due to threats of CPS involvement from hospital social work staff and their overall unwillingness to coordinate or help even though there were no other available stabilization resources to my knowledge. Fairview also billed me over \$185,000 out of pocket despite P being a Medicaid recipient. During P's time at Fairview, hospital staff was less interested in discussing care planning for P and was more often than not only willing to discuss billing. They seemed to use the threat of billing me out of pocket as a means to get me to comply with their request to discharge P, un-stabilized, with no services despite me expressing reasonable fears about this. I asked for patient advocate assistance, financial assistance, P's records of care, and itemized bills - all of which were refused. I reported the facility and "no wrongdoing was found".

- Children's refused to admit P to stabilize after a severe reaction to new meds prescribed by new outpatient provider. P had become physically aggressive, self-injured, expressed suicidal ideations, and eloped. I did not feel comfortable with P being in another treatment setting, especially not an ED, but I felt it was unsafe to bring P home because there were no other resources that I could find and behaviors were severe. Children's staff refused to include me in any care meetings despite me repeatedly requesting information, updates, and coordination. They transferred P to St. Paul without informing me until afterwards. P was refused accommodations and was not given medical information in a way they could understand to make informed care decisions. Hospital staff continued to recommend discharge with no services or plan. I spent all of my waking hours, 15+ hours daily, on the phone/emailing with different providers coordinating, trying to find resources, and planning. P's mental health case manager and myself worked tirelessly to plan and find services. I was in constant contact with hospital staff giving play-by-plays. We were awaiting CADI in-home services still, as we had been for most of 2024. Despite knowing this, Children's refused to update P's medications or coordinate with outpatient providers to plan, and I was met with a report to CPS of "neglecting to provide shelter" to my child. I also received a call from staff at a shelter for child victims of sexual trafficking/abuse/torture, who had received a referral to place P there. She said it would be incredibly dangerous to place P there with their needs/vulnerability. I had not been made aware referrals to shelters were being made let alone considered for P especially as I was working so hard to find services for P to discharge home to so I was shocked, and neither CPS nor the hospital took responsibility for making this dangerous referral. CPS became involved and was included on all updates. CADI case management was unable to provide

any ETAs for any in-home services, so we recalibrated and decided to discharge with a lesser short term crisis stabilization service hoping for the best.

CPS worker was made aware via email that discharge was the following day, yet still this worker decided to file a CHIPS petition that very morning, interfering with P's safe discharge home. I was informed of this as I arrived at the hospital to pick up P. I had only spoken to unit staff 20 minutes prior who had planned to bring P down for discharge home to me, so they were as confused as we were. My younger child was bawling, confused, asking if their sibling had been kidnapped or killed. I called attorneys all over the city for help, most wanted \$10,000 or more. One attorney told me he'd just represented a client in the same situation who ultimately lost custody of their child, and then asked me for a \$15,000 retainer to represent me. I called and called the hospital trying to get in touch with P, knowing they would be so confused as they had been preparing to come home. Hospital staff wouldn't allow me to talk to P. Shortly after, I received a message from the CPS worker that P had eloped from the hospital and was missing. I called St Paul police asking what I could do, what was I even allowed to do? Am I allowed to be a parent anymore legally? I was frantic.

My 7yr old and I walked out to our car to head from our home in uptown MPLS to St Paul to try to find P, and THERE P WAS WALKING UP THE STREET WITH THEIR BAGS. How did they get here so fast? I only just found out they were missing from the hospital. I was so relieved but terrified, not knowing if I was even allowed to let P come home. P broke down sobbing on the street, said CPS and hospital staff told them I'm not their parent anymore and they weren't allowed to talk to me or call me. Apparently P became escalated at learning they couldn't be discharged home, told hospital staff they were leaving, hospital staff then helped P pack their belongings and walked them out to the street off hospital campus, discharging them to NO ONE. P was so lucky and fortunate to align with kind strangers who helped them navigate from unfamiliar St Paul all the way home to MPLS via train and bus. P is lucky to be alive and I am so grateful for their cunning and resilience and luck.

Despite CPS endangering P's life after which point CPS allowed P to stay home, our family still had to comply with their ongoing investigation, which I did not understand. I had to spend my life savings on legal representation to fight to not lose custody for reasons I didn't and still don't understand. For some months our family was subjected to constant schedule disruptions, arbitrary demands from CPS that required a Sisyphean effort to understand let alone meet, all while CPS workers made it known that they would not provide any resources or help for P or our family in any way. I still don't understand the purpose of their investigation or involvement, or why we had to go to such lengths and undue stress and financial burden.

In court, when our case was dismissed, the county's representation requested from the judge that our family not be awarded any county funding to assist with in-home supports that CADI still fails to provide to this day. Given that their representation could not provide sound logic for withholding funding from a child who desperately needs services, CPS'

treatment of our family feels retaliatory and punitive without justification. Children's staff will not speak to me on the phone to this day, I had to enlist the help of ombudspersons to retrieve P's records from them. Without the diligent help of the ombudspersons for mental health and disabilities I believe my family would have been treated much worse by CPS and hospitals alike.

- I wish that was the end of the story but following an elopement P was later brought against my request by MPD crisis response to Abbott. Responding LEO refused to allow P to work with their preferred crisis response Nexus and then put P in some kind of legal mental health hold I still don't understand because no one will give me paperwork or records. MPD then refused to tell me which hospital P was being transported to. I called around and located the hospital P was at, then sat at the hospital all night with my 7yr old, a friend, and Nexus crisis response, while hospital staff refused to engage with me or give me any records - only engaging with Nexus staff. The hospital failed to give P their meds and would not allow me to give them their meds or food I had brought. Later Abbott was supposed to transfer P to Prairie Care but admitted P to Abbott without explanation. Upon admission I brought paperwork to the hospital that included my contact info and all of P's outpatient team's info so that social work could coordinate. Social work never reached out. I called and called and called but could not get any information.

Later, unit staff called to tell me P had been restrained, cuffed to a chair and forcibly injected with sedative medication due to becoming escalated/aggressive on the unit. I could not and still don't understand would hospital staff would allow P to become escalated in this manner and find it appropriate to forcibly restrain/medicate them (causing undue fear, stress, and trauma) rather than adjust meds to begin with in an effort to help stabilize P's moods/decrease escalations. Why did Abbott admit P at all if they didn't intend to make any stabilizing meds adjustments or provide any services/coordinate care?

I reached out to the patient advocate at which point social work finally contacted me. For weeks, Abbott staff failed to make adequate efforts to coordinate with P's outpatient team, made no referrals whatsoever, did not make any medication adjustments, and allowed P to sit in the hospital with no services doing nothing with no plan, missing out on life and educational opportunities and even missing Christmas and New Year's. I had to repeatedly call the patient advocate, who often did not return my calls. I had to involve the ombudsperson in communications, at which point they finally began communicating more openly but still did not offer any referrals, resources, medication adjustments, or anything. Then, the provider who had been working with P went on vacation, at which time the provider who was filling in made medication adjustments. This provider was incredibly thorough and professional, which gave me hope. They had a plan that seemed safe and calculated, and they sounded knowledgeable about autism+meds. They said they'd coordinate with neurology to have P tested while in the hospital since P had been waiting for neuro tests to rule out any potential neuro/health issues. P responded well to the meds adjustments and was on a positive trajectory. When the original provider returned from

vacation, they immediately changed course with medications without notice, changing them much sooner than the other provider had recommended or planned, and they started pushing for discharge immediately, even though there had still been no effort made by their staff to coordinate with the outpatient team or referrals or discharge planning.

I was told we would have a virtual family therapy, but upon entering, I was surprised to find that the family therapist was absent. Instead, P's mental health case manager had been invited to the meeting, the meds provider Kelly and the social worker Heather were there, and they began talking about discharge, stating P needed to discharge pretty much immediately. This was contrary to the information I had received from the family therapist nor long before this meeting, who said they were still adjusting medications and wanted to work with P and me to safety plan and be cautious about discharge and not rush. I was surprised, blindsided, and confused. I repeated all the same information to the provider and social worker again that it was not safe to discharge at that time and that we were waiting on AuSM resources and other services, including CADI in-home services. Abbott staff disregarded this information and then brought P into the meeting, at which point the provider Kelly immediately asked P if they were ready to go home that day. I had to interject because that was not agreed upon or safe especially with no plan or supports in place, at which point P became understandably upset and walked out of the meeting. How confusing and awful of the providers there to put P through that!

After that, I made sure to include the case manager and ombudsperson or anyone I could in any communications with Abbott staff because they were behaving oddly. They had a last-minute meeting with the CADI case manager and the mental health case manager that I couldn't attend due to insufficient notice and other obligations, at which point apparently the hospital staff set a discharge date without informing, meeting, or safety planning with me or P, and then reported me to CPS when I failed to pick P up at the time they designated for discharge without my knowledge. Following this ensued a series of meetings and phone calls which included Abbott staff lying, falsifying records, withholding information/referrals, confusing and inconsistent information surrounding P's medications and treatment planning, denying ever saying they'd provide neuro testing or services and thusly refusing to do so, repeated attempts by staff to "entrap" via coercing me into saying/agreeing that I was refusing to pick P up or provide housing for P (which was never the case).

The CPS worker and Abbott staff cornered me alone in meetings and phone calls several times, used abusive language and leveraged threats at me, threatening multiple times to strip me of my parental rights not only of P but of my other child who was not even a part of the investigation, over-talking me in meetings and demeaning me so much so that efforts at coordinating care or planning were totally diminished as I was left in a position to defend and repeat myself due to being incessantly interrupted, threatened, accused, belittled, and attacked. I once sought mental health treatment at Abbott and as a patient I experienced similar behavior from staff who told me to "get over it" (the systemic barriers I was facing at the time) so I'm not shocked by the abuse - it seems to be Abbott's standard

of care. I can't imagine how they treat children in crisis if this is how they treat parents and families who just want to work together to find help for our kids. Additionally, during this time, the CPS worker called my abuser/stalker erroneously to talk about P, citing that they thought he was P's father (he isn't and records have absolutely no reason to indicate otherwise). This individual has weaponized false CPS reports against me in the past, so this directly endangers my family and puts us at risk. CPS has failed/refused to follow up with clarity surrounding errors in our records or what we can do to protect ourselves due to their mistake compromising our personal information and safety.

Why are hospitals allowed to weaponize CPS?

Why is CPS allowed to endanger the lives of children entirely unchecked?

Why are hospitals, treatment facilities, schools, county workers, and agencies who are contracted with the county permitted to have incorrect records that can negatively impact the course of people's lives or even potentially end people's lives?

Why does it seem that the only ones holding these agencies accountable are caregivers and children themselves?

Why must we live in fear of the agencies we are supposed to trust in and be able to turn to for help?

This whole experience was a repeated failure of hospitals. Hospitals that refuse to provide services when no other provider can.

This system is unsustainable and it is leaving children and caregivers to shoulder the burden of a broken system, as if we are somehow more capable than fully staffed hospitals. This system doesn't come with a handbook, yet children and caregivers are expected to navigate it without error, all the while we are seemingly the only ones reporting, checking, or holding these facilities and agencies accountable. It is as if we are being criminalized for needing support; for requesting accommodations and equity. We've been endangered and collectively traumatized, threatened, blacklisted, bankrupted, and stripped of resources and autonomy, all for daring to be low income and in need of resources. To hold children and their families accountable for policy and DHS/DCYF failures is unconscionable. As a taxpayer, not receiving any of the services I pay into for my child is just insult to injury, especially when so many case managers are paid from P's CADI waiver to do nothing while P sits for years needing services but not receiving any - and yet somehow I am also held responsible for that, too.

I can't even begin to imagine the things other parents and families who aren't as resourceful as myself are subjected to. This is causing generational hurt and trauma to families which is only going to burden the already overburdened system for decades to come if something doesn't change right now. This is a massive waste of resources. Among

other things, in going through this, my kiddos lost a lot of their childhood innocence, and I lost my livelihood along with the few non-grey hairs I had managed to retain. This system breaks down trust in community resources and further isolates ostracized marginalized and vulnerable populations. This system dehumanizes children, their families, and entire communities, summing us up as numbers and talking points. This system is killing people - killing children. Research-based changes that center brain development and the nervous system as well as whole-body, whole-person, and whole-family approaches to mental healthcare need to happen. I believe that hospitals shouldn't be the only resource for stabilization and that communities need other options, especially for autistic individuals. I'm not qualified to make suggestions about what that may look like... I just know from our abysmal experience that it really truly does not look like this.

Enough is enough.

Thanks for your time and consideration.

Kass Murphy