

Statement for the Joint Committee on Child Welfare System Oversight

Wednesday, November 16, 2022

Members of the committee, thank you for the opportunity to be here today. My name is Deacon Godsey and I am here today to share my experience caring for a youth with significant behavioral health needs.

In early March of 2020, just before schools released for Spring Break, my wife Jill, our teenager, and I became emergency foster parents for a then 7yr old girl who we'll identify as J. J and her siblings had been removed from their home for safety reasons, and J needed a home where someone knew of her developmental and behavioral challenges, as she is non-verbal autistic (though she hadn't been officially diagnosed at the time.) We were considered a viable option only because Jill had been a para educator in J's specialized autism room at Quail Run Elementary School in Lawrence for several years.

The first few weeks of fostering were definitely challenging, especially in light of I, and our teenager, not being trained or experienced in caring for someone with J's level of support needs. All three of us were doing the best we could to adjust to our new situation, meanwhile holding out hope for school to reconvene and provide some brief relief during the school day. Then, of course, the world came to a halt.

Now, clearly a global pandemic made everyone's life more difficult, on almost every conceivable level; this was painfully true for first time participants in the Kansas foster care system, to say nothing of those providing care for a child who - through no fault of her own - required 1-on-1 or 2-on-1 care at every waking moment, and who desperately needed a wide variety of professional services she never had access to, much less the chance to utilize.

To make matters even more challenging, the case workers we interacted with had never fully navigated a case for a child with the breadth and depth of evaluative and palliative care J required; at one point it became clear that some of them, despite good hearts and right motives, were not even familiar with the *Americans with Disabilities Act (ADA)* or how it related to J's rights, or care.

Thus began a multi-year odyssey of navigating a labyrinth of acronyms and agencies, all of which were absolutely necessary to help Josie's behavioral and intellectual development, and none of which were affordable or accessible until J was officially diagnosed as autistic (which only happened after 1yr and 3mos of effort on our part, and on J's third case manager who came on the scene a year into her case), and until she qualified for the I/DD waiver.

As I'm hopeful you're aware, said waiver "serves individuals age five and older who meet the definition of intellectual disability, having a developmental disability or are eligible for care in an Intermediate Care Facility for Individuals with Intellectual Disabilities...Those with a developmental disability may be eligible if their disability was present before age 22 and they have a substantial limitation in three or more areas

of life functioning.” Of course, all that sounded great to us at first, and was a momentary source of hope in our process, until we were told the waiting list for I/DD services was 9 years long. NINE. YEARS.

Eventually, after months of searching, working with multiple individuals and agencies, and filling out more paperwork than I could have previously imagined, J was finally able to access med management through Children’s Mercy Hospital in Kansas City, a short stint of occupational therapy in Baldwin City, and in-home *Applied Behavioral Analysis* - ABA therapy - for a helpful-but-insufficient number of hours each week. After nearly two years, and some steadily increasing (and much needed) financial assistance from J’s designation as a “super-tiered” child, we were finally in the position to hire consistent, reliable in-home assistance, as well as pay for several professional therapeutic services. We also had the opportunity to get J screened for the SED (Severely Emotionally Disturbed) waiver through Lawrence’s Bert Nash, in hopes other therapeutic services would become available.

Unfortunately, due to J’s high level of support needs, and a steady-but-dramatic increase of physical aggression, J’s existing ABA firm determined it was unsafe for their staff to continue working with her. Following their withdrawal, extensive efforts were made to secure a new provider, but these efforts proved fruitless, as literally every single provider J’s case workers reached out to arrived at the same conclusion: J’s needs were greater than what any network of community-based services could provide.

This was subsequently echoed by the team at Bert Nash who also denied J services, stating that her level of functioning was not what they were capable of serving.

You see, despite a variety of medical interventions, ongoing ABA therapy, an incredibly supportive school environment, and all the love we had, we simply weren’t equipped or trained to provide the kind of constant, hand-on care required for J’s level of unpredictable aggression. During her time with us J used the back of her head to put roughly 75 holes in our drywall, smash a hole in the tile wall of our shower, and shatter a backdoor car window; she also regularly head-butted us and other caretakers, along with hitting, kicking, hair pulling, and her own daily self-harm from head banging on every conceivable surface (wood floors, doors/frames, carseatbacks, windows, brick, concrete...)

Ultimately, after just under 2 ½ years of fostering, two emergency hospital stays due to unmanageable physical aggression and property destruction, and an admittedly high toll on our mental and emotional health, it was determined - despite all our efforts to the contrary - that J required a stay in a PRTF (Psychiatric Residential Treatment Facility) with round-the-clock professional care and observation to determine what would be best for her long-term health and safety.

It is important to state with absolute clarity here: J ending up in a PRTF was never the option we truly hoped for. We made every effort possible, on every level possible, to make J’s stay in our home a realistic, safe possibility, for her and for us, and the system we worked with provided every possible financial resource to make that happen. Unfortunately, despite all that working in our favor, the lack of in-home/ community services ultimately made this impossible.

It should also be noted that after two years of court proceedings, the Judge on J's case realized it was not her biological parents - or we, as her foster parents - who made it unwise for J to return home or stay in the foster care system, but it was the level of difficulties involved with J's care - and the lack of necessary community services available - that revealed both possibilities to be non-viable long-term options. J's parents have six other children (at least one of whom has also been identified as likely being on the autism spectrum), owns only one vehicle, and is not in the financial or logistical situation to safely care for J and their other children in the same environment.

In light of all this, and after a two month stay at the KVC hospital in Wichita this summer, J was finally admitted to the Lake Mary PRTF in Paola, KS, where she has since been screened and deemed qualified for potential residency at Parsons State Hospital, as her unpredictably aggressive behaviors have continued despite daily, round-the-clock supervision from professionally trained and rotating staff, and ongoing clinical med management.

Was this result for J's long-term care inevitable in light of being so far behind the curve from early on in her development? Possibly. But it is also possible that had she been screened at the proper age, the necessary community services been made available early in her development - or, at the very least, during her stay in the foster care system - and had the necessary funding been made available to staff, administer, and access such services, J's case - and so many others like hers - could have taken a much different path.