

Dear Governor Pritzker:

My name is Debra Ruesch. I am writing on behalf of my 32-year old son, Daniel, as well as many other Illinois citizens with developmental disabilities who continue to face a housing crisis. Daniel has autism, is non-verbal and requires 24/7 supports. He is loving, funny and helpful, a terrific son who “keeps us on our toes” and is an essential part of our family.

Dan is fortunate to live, for just over six years now, in a small group home near us in Champaign. I am writing to you because of the constant threat that Dan’s home will be forced to close. The impetus of my letter, however, is Ed McManus’s heartbreaking narrative about the criminally abusive treatment of residents at Choate SODC.

I say that Daniel is fortunate to live in a group home near us because far too many IL residents with developmental disabilities are forced, if they receive housing supports at all, to live far from their families and home communities. And too many of them, especially people with complex medical and/or behavioral needs, are living in institutions like Choate, where they are especially vulnerable to mistreatment and neglect. I can identify with the torment of those individuals, and that of their families.

Prior to moving to his current CILA, very challenging circumstances led to Daniel’s “temporary” placement at an SODC about 90 miles from us. His placement there was intended to be for six to eight weeks. He was stuck there for almost four years. It was as though he had been imprisoned. He lived on a “unit” with seventeen other guys. They had two bathrooms. The showers and toilets backed up regularly. It wasn’t uncommon for the bathrooms to have no hand soap or toweling. The “living room” was lifeless, hospital-like, cold. The guys spent their evenings seated in a large rectangle around one TV. A lucky few had comfortable seating; most were seated on hard-backed institutional chairs. Almost all shared bedrooms and had no personal space whatsoever. I think the incarcerated are better fed.

Staff direction to residents was typically bossy and sharp. The atmosphere was one of “crowd control”. Choice was almost never an option. The need to manage the group always took precedence over the needs of the individual. Some of the staff wore scrubs, which really added to the institutional flavor of the place. There were too many hard edges, not enough warmth, comfort and caring. It was a joyless place.

I can’t claim to have witnessed physical abuse, but Dan was miserable. We visited two to three times a week and were able to take him out to eat, shop and visit parks, but we worried about his well-being every minute that we weren’t there and we advocated continually to find him a way out. Sadly, we observed that most of the guys on Dan’s unit rarely left the SODC.

We are very grateful to Individual Advocacy Group, the agency that eventually committed to opening a home for Dan here in Champaign. Over the course of the six plus years that Dan has been “home”, his emotional and behavioral stability have improved dramatically. As an adult, we’ve never seen him happier. But, no exaggeration, the threat that IAG will not be able to “hang on” is with us every day.

CILAs are underfunded and chronically understaffed. Direct Service Providers (DSPs), those who REALLY support my son, are systemically undervalued and undercompensated. IAG is a small presence in our community. Even before COVID blindsided us all, we were aware that the cost of operating their three Champaign homes was becoming too burdensome to their organization. They closed one home in

January. So, we feel like we are living in limbo. The threat that it will all go away is very real and very scary.

My husband and I have been in recent contact with every local agency that we know of, in the hope that one of them could be persuaded to take over operation of Dan's home in the event that IAG ceases operations. Our search has been fruitless. One agency, Marion County Horizons, is in the process of opening a number of homes in rural communities within a 25-45 radius of Champaign, but they have more applications than available beds. Inquiries as to why they and others are not opening homes in Champaign County, where the PUNS list indicates there is a significant need for more CLAs, are met almost universally with the explanation that they cannot afford to do so.

So, the estimation is that the state spends 400 million dollars a year to keep the SODCs operating. That money should be providing better quality community-based supports for individuals with disabilities. These people are not criminals. They are wonderful people like my son. They deserve the opportunity to live near their families, to build friendships and develop interests, to volunteer, work and play in their communities, just like "regular" people do.

Below is a copy of Ed McManus's narrative regarding the terrible circumstances at Choate. It's disgraceful, disgusting and, I suspect, just one example of widespread systemic abuse. No system of care is perfect, but we can and absolutely must do better. Please, Governor, make humane treatment of our citizens with developmental disabilities a priority.

Thank you,
Debra Ruesch

EXCERPT BELOW IS FROM ED MCMANUS'S SPECIAL EDITION NEWSLETTER, MARCH 15, 2021

THE WORKERS AT CHOATE CENTER ARE ON THE ATTACK. THE TARGETS ARE THE RESIDENTS . . .

A total of 9 workers at Choate Mental Health & Developmental Center have been indicted on 16 felony counts during the past year in connection with attacks on residents of the institution.

The workers are accused of breaking one resident's arm and choking another person, among other things. In one incident last spring, four workers allegedly ganged up and attacked a resident. Another incident involved a worker "causing a patient to drink an entire cup of hot sauce."

You have heard of Choate, haven't you? It is located in far downstate Anna. 219 individuals with I/DD live there, and a psychiatric hospital is also located there.

The hot sauce incident? We don't know much about it, other than that it was found to be "an incident of physical abuse" by the Office of Inspector General, but the Union County Circuit Clerk's office said the perpetrator, Kipp Wilson, was not criminally charged. (We don't know why.) What we do know comes from the indictment of another Choate worker, Cody Barger. He was charged with official misconduct because he witnessed the incident and failed to report it.

LYING TO THE POLICE . . .

Barger also was charged with obstructing justice because, "with the intent to obstruct prosecution of himself, he furnished false information to the State Police, in that he denied all knowledge of his

involvement in the incident and then later admitted that he was with and witnessed Kipp Wilson” causing the resident to drink the sauce.

Barger also was indicted for misconduct and obstructing justice for another incident, along with a second worker, Jonathan Lingle. They were charged with “physically grabbing” a resident and then failing to report it “after they learned that the resident had a broken arm.”

If these descriptions seem sketchy, it’s because the only public information available on them is the indictments, and they do not go into detail.

Four workers were indicted for aggregated battery for ganging up on a resident last May 18. Bobby Lee is charged with striking the person in the face multiple times. Johnny Brimm is also charged with striking him in the face. Dalton Anderson is charged with “making contact of an insulting and provoking nature” by choking him with a shirt. Mathew Wiseman is also charged with choking him.

In addition, Brimm and Wiseman were indicted for obstructing justice for lying to the police about their contacts with other workers.

Kevin Jackson was indicted for battery for striking a resident multiple times with a belt. Teresa Smith was indicted for misconduct and obstructing justice for reading and reviewing a confidential report of the OIG investigation of Jackson, and then falsely denying to the police that she had done so, “with the intent to obstruct the prosecution of Jackson.”

And Sheri Fish, a security officer at Choate, was indicted for misconduct for violating confidentiality by disclosing the identity of a person who filed a complaint against other Choate employees.

All nine defendants are free on bail. Several have pre-trial hearings coming up next week.

Nine employees indicted in one year. Pretty awful.

‘A CULTURE OF FEAR’ . . .

Choate has been criticized severely in the past. Equip for Equality urged the State to shut it down in 2005. Their report was entitled “How an archaic system results in tragic consequences for people with disabilities.”

Equip said their investigation of Choate “revealed areas of tremendous concern, including deaths of residents due to the failure to provide adequate healthcare. . . . Discussions with residents revealed a culture of fear in which residents are afraid to exercise rights or express their needs for fear of retaliation or being ‘tied up’. The incidents and the records examined by the investigation unit, along with the documented observations as revealed by this report, clearly illustrate the systemic failure of this institution and the need for its closure.”

The Civil Rights Division of the U.S. Dept. of Justice conducted a study in 2009 and concluded:

“Choate does not adequately protect its residents from harm and risk of harm and does not provide its residents with a reasonably safe living environment. Specifically, individuals residing at Choate are subject to repeated injuries of similar nature, unchecked self-injurious behavior, abuse, and neglect. The harm Choate residents experience as a result of these deficiencies is multi-faceted and includes physical injury; psychological harm; excessive and inappropriate use of restraints; and inadequate, ineffective, and counterproductive treatment.

“This harm undermines the other care and treatment provided at Choate, prolongs the time period spent by individuals in the institution, and delays the movement of individuals to more integrated settings in violation of the U.S. Supreme Court’s Olmstead decision.”

THE RIGHT THING TO DO . . .

Choate is one of seven state-operated institutions for people with I/DD, serving a total of 1,649 persons. Only two states have more people in institutions; 17 states have no institutions at all. The U.S. 7th Circuit Court of Appeals has labeled Illinois “a laggard outlier” in the national trend to move people into the community.

Gov. Pat Quinn was able to shut down one facility, Jacksonville Developmental Center, in 2012, and planned to close others, but he was defeated for re-election by Bruce Rauner in 2014. When J.B. Pritzker replaced Rauner in 2018, there was hope that Quinn’s so-called “rebalancing” efforts would be renewed, but that hasn’t happened.

Advocates say there are two big arguments for rebalancing:

--One is funding. The institutional system is costing the State more than \$400 million a year; serving most of the residents in the community would save a ton of money.

--The other is that it’s the right thing to do. Institutions are no place to live. Individuals with disabilities deserve to live in real homes in real neighborhoods. Those other states have shown that it can be done.