Choate Developmental Center Repurposing Plan: **Why No One Should be Left Behind**

August 2023

EXECUTIVE SUMMARY

In the spring of 2023, Governor Pritzker announced the downsizing and repurposing of Clyde L. Choate Developmental Center (Choate), stating that people with "intellectual and developmental disabilities deserve respect, dignity, and the highest quality of care to assist them in living healthy, fulfilling lives." While Equip for Equality supported much of Governor Pritzker's decision, which included transitioning individuals living on four units out of Choate, we have strong concerns about the people on the four units under consideration to remain at Choate, described as the dual diagnosis, forensic and step-down units. This report by Equip for Equality focuses on, and includes recommendations for, the people who must not be left behind.

Equip for Equality's recent intensive, two-year monitoring effort comes almost two decades after Equip for Equality's 2005 report on Choate, which was followed by the Department of Justice's 2009 report. These previous extensive reviews established that people at Choate were living in unsafe conditions and that the facility was incapable of providing people with the services they need to become more independent and address the reasons that lead to their isolation in an institutional setting. What we still see today is very reminiscent of conditions that existed twenty years ago.

Choate currently houses approximately 222 residents. Equip for Equality's independent monitors spent over 2,000 hours evaluating the status of Choate's care and treatment of individuals with developmental disabilities through activities consisting of in-person and off-site reviews that included interviewing individuals who reside there, staff and administration; communicating with guardians; observing physical plant conditions; and conducting chart, incident, and restraint reviews.

Our findings show that individuals on the units under review – Redbud, Dogwood, Sycamore Lower and Sycamore Upper – should not remain at an institution that has failed to meet their needs and exposed them to abuse and neglect. Requiring individuals to remain at Choate is antithetical to their well-being and the reason for their placement, i.e. to receive intensive treatment that assists them to timely progress and move to less restrictive settings that do not isolate them from the broader community. Long-standing efforts to address problems at Choate have not resulted in meaningful change, and the entrenched cover-up culture among staff leaves people at continued risk. As a result, Equip for Equality is calling for **all individuals with developmental disabilities to be removed from Choate**.

SYSTEMIC PROBLEMS PLACE INDIVIDUAL SAFETY AND WELL-BEING AT RISK AND RESULT IN THEIR CONTINUED ISOLATION FROM SOCIETY.

Multi-level, systemic problems contribute to the simple fact that Choate is not meeting the Department of Human Services' stated purpose for institutions, which is to provide intensive services to help people achieve their personal goals of living where they want. Indeed, many individuals at Choate want community placement – including ninety-one that Equip for Equality interviewed in late October 2022 through early July 2023, plus an additional thirty-one who we did not interview but were included on a list of people interested in community transition before the Governor's announcement. Yet, individuals' progress to the community is slow or, for those not on the transition list, non-existent. The barriers to community placement vary, but "behavioral" and "mental health" concerns predominate, and there is an absence of intensive, therapeutic and coordinated care to help address their emotional health needs.

In addition, most individuals we interviewed reported experiencing one or more problems, many of which directly impact wellness and safety. Chart reviews also revealed continued problems with the quality of medical services and treatment team follow-up. Choate's physical plant also remains in a poor condition and there are continuing problems with cleanliness and availability of basic supplies, like toilet paper.

This is not to say that all staff at Choate are bad. Staffing challenges and the COVID-related restrictions had an impact on care and there are, of course, some good and committed staff at Choate. However, the presence of good staff has not and cannot overcome the facility's long-standing culture and quality problems. As further described below, the end result for the individuals living at Choate is an atmosphere and treatment model that is coercive, non-therapeutic, and unnecessarily institutionalizes individuals for long periods without providing the required array of services needed to ensure the shortest stay possible.

- **Choate Fails to Provide Federally Required Treatment and Adequate Programming to Assist People with Developmental Disabilities Live in Their Communities.**

    - Monitoring activities over the past two years demonstrated that the fundamental lack of federally mandated treatment and adequate programming remains a significant problem. In addition, the lack of active treatment leaves individuals stuck in a restrictive setting, with multiple providers rejecting their applications for placement, and subject to a sometimes-chaotic environment that leaves them at risk of harm and deterioration – all of which is in direct conflict with federal requirements.

- This outmoded model of care is not therapeutic and prevents individuals with developmental disabilities from living a full life in their communities. It also adds to the multiple traumas many of them have experienced. Individuals with developmental disabilities on **all** units at Choate are harmed by these conditions.

- **Choate Staff Continue to Use Restraints as a Mechanism for Control and Without Adequate Oversight.**

  - Equip for Equality's ongoing monitoring activities reveal that restraint is often used as a mechanism for control as opposed to a last resort and is not subject to adequate oversight. That the use of restraints remains a continued problem is not surprising given the lack of active treatment. People sitting around, doing nothing, with their needs otherwise not being adequately addressed leads to chaos. Moreover, the facility's treatment style continues to be reactive rather than proactive, with Equip for Equality monitors frequently observing staff sitting around, ready to respond to a problem but not otherwise engaging residents.

  - In repeated interviews, multiple individuals further reported that they are threatened with restraint if they do not comply with direction (even when the legal standard for restraint – imminent risk of serious physical harm to self or others – was not present). We also received multiple reports of people being hit and verbally abused while in restraints, and that restraints were applied in a manner that was physically painful.

  - Choate's continued problems with restraint usage is harmful to all individuals with developmental disabilities, and **no** unit at the center is exempt.

- **Continued Incidents of Staff Abuse Against Individuals at Choate, as Well as Peer-to-Peer Abuse, Leave Individuals at Risk of Physical and Emotional Harm, and Perpetuate an Environment of Fear and Coercion that are Antithetical to Therapeutic Services and Basic Human Rights.**

  - The abuse history at Choate has been well-documented over the past two years, with multiple OIG reports exposing incidents of staff abusing residents, witnessing abuse and not intervening, or helping cover-up abuse.

  - In total, we received thirty-nine reports of abuse from individuals interviewed during eleven site visits from Fall 2022 through Summer 2023. These individuals reported experiencing staff abuse or witnessing staff abuse their peers. These more recent reports of abuse follow the uptick in substantiated OIG abuse findings from June 2021 to May 2023. There were fourteen substantiated abuse cases during this period. While some of the cases involved older incidents, three were from fiscal year 2021 and four were from fiscal year 2022. Six of fourteen

cases arose out of Redbud, Dogwood, and Sycamore Lower / Upper. Staff mental or physical abuse in place of care and treatment was also a theme of substantiated OIG reports.

- The combination of the cover-up culture, both individuals' and staff fear of retaliation, and many individuals with limited or no ability to adequately communicate what they have experienced, ensures that abuse often goes undetected or unsubstantiated. The numbers speak volumes on this front. For individuals who were able to express their desires, ninety-one people told Equip for Equality that they desired to leave Choate, and an additional thirty-one individuals who we did not interview were on the community transition list before the Governor's announcement. Only two individuals expressed a desire to stay at Choate.

- Many residents do not feel safe or supported at Choate and remain at risk of harm, including on the Redbud, Dogwood, and Sycamore Lower and Upper units under review for continued use for individuals with developmental disabilities. Residents there are no safer there than on the Cedar and Cypress units that are closing and, given people's history with abuse at Choate whether directly or witnessed, Choate simply cannot offer therapeutic care given the damage already done.

- **Individuals at Choate Continue to Live in an Environment Where Their Right to Dignified, Respectful and Compassionate Care is Not Recognized or Fulfilled.**

  - Equip for Equality's 2005 report found that Choate does not afford individuals basic dignity. These concerns continue. During resident interviews conducted from October 2022 through July 2023, forty-one individuals shared concerns regarding lack of staff attention and twenty-five reported feeling disrespected by staff. Also, during on-site monitoring activities, Equip for Equality monitors observed individuals disrobing on the unit, or wearing clothes that expose their bodies, without staff noticing or responding; an individual wearing clothing that was so large that it created a fall risk without staff noticing; and poor living conditions that do not lend themselves to high quality care and reflect that this population of people is somehow not deserving of something better.

  - The reports Equip for Equality regularly received from individuals, as well as substantiated OIG reports, reflect a culture where individuals' rights to be treated with respect and dignity, and receive compassionate care, are not paramount. Here too, the control-based treatment practices at Choate dehumanize individuals resulting in harm. Again, people on **all** units at Choate experience these untenable conditions.

- **Choate Continues to Fall Short in Meeting Individuals' Medical, Monitoring and Communication Needs.**

    - As was true of Equip for Equality's and DOJ's reviews many years ago, Choate continues to have multiple systemic treatment failures that result in harm to the individuals in their care. Equip for Equality's review of twenty-five individuals' charts revealed incomplete and disorganized files with outdated information, failure to track and adjust to individuals' changing needs, and/or lack of or delay in follow-up on necessary medical and communication services. These findings applied to **all** units.

    - Further, regarding the units under additional review for continued use, 75% of the twenty OIG cases substantiated for neglect since September 2019 arose on Redbud, Dogwood and Sycamore Lower / Upper. Some examples of the neglect findings that reflect on-ongoing issues with meeting individuals' medical and monitoring needs include staff failing to provide required supervision while an individual who is blind and deaf used the bathroom, resulting in injuries; staff encouraging an individual to punch a chair when she was frustrated; and staff failing to provide supervision which led to an individual eloping, only to be found outside at 3:45 a.m., naked in December.

    - IDPH has also cited the facility on multiple occasions for issues involving quality of care. In its May 2022 Annual Certification Survey, IDPH found (among other findings) failure to ensure staff were properly trained, failure to implement adequate supervision and assistance during meals, failure to implement an individual's behavior plan, and failure to consistently and accurately document data for treatment programs.

    - The people living on the units under review are not exempt from these problems and, given the long history of these problems after repeated efforts to correct them, there is no reason to believe that there can be meaningful and lasting change.

CONCLUSION AND RECOMMENDATIONS:

Equip for Equality has engaged in significant monitoring at Choate Developmental Center, two decades ago and the past two years, and has not seen meaningful, positive change – all to the detriment of individuals who deserve better. In our recent monitoring we heard from almost one hundred individuals who want to leave Choate and become part of their communities – mostly consisting of individuals who are not court-ordered to be there – yet they are institutionalized without being offered community options or even the opportunity to explore them.

In addition, any action on the SIU School of Medicine's July 14, 2023 Phase One report, which stemmed from the Governor's March 2023 announcement on Choate, must not result in any units for people with developmental disabilities remaining on the Choate campus. The Phase One report failed to analyze why the units subject to review should remain despite the facility's long troubled history, or why any individual with a developmental disability should be required to stay in a setting that has long failed to meet their needs and operated in a manner that is directly contrary to their well-being. Individuals should not have to wait to see if meaningful, sustained change can occur.

We remain committed to working with the Department of Human Services to ensure that all individuals who want to transition to the community from Choate have meaningful options consistent with their wishes, and to help ensure resident safety while repurposing efforts are underway. This must include the dual diagnosis (Redbud / Dogwood) and Sycamore Lower and Upper units. Those living arrangements have not and cannot provide therapeutic care, both due to the history of abuse and neglect on those units and the lack of specialized services being provided. Like Cedar and Cypress, people on these units need a fresh start, with intentionally and individually designed care in the least restrictive setting possible.

Therefore, Equip for Equality recommends that the Department of Human Services take the following steps:

- Immediately end new placements in all units other than Sycamore Lower (the forensic unit, and only until such time as the forensic unit can be opened in another location).
- Develop a plan to create a forensic and step-down unit in a safe environment where the individuals' service needs, including their psychological needs, can be fully addressed.
- Continue and intensify efforts to transition people from Choate to the least restrictive environment of their choosing, including individuals on the dual diagnosis units (Redbud and Dogwood) as well as individuals on the step-down unit (Sycamore Upper) who do not have legal barriers preventing their transition from an institutional setting.
- While individuals remain at Choate, implement meaningful programs and individualized treatment to ensure the provision of supports and services to both meet individuals' needs and ensure their success in the community.
- Implement OIG's recommendations as detailed in its June 9, 2023 Report, which includes the installation of security cameras, a top to bottom analysis of all processes relating to reporting abuse and neglect, review the facility's staffing levels to ensure there are an adequate number of staff to meet individual needs, comply with

directives related to root cause analysis, and address resident care needs in an individualized fashion.

- Maintain on-site monitoring at Choate during this transitional period, including Equip for Equality's current monitoring activities and oversight by the Department's Division of Developmental Disabilities' SODC Operations staff and the Chief Resident Safety Officer. The Department's oversight role must include ensuring Choate administration is effectively addressing problems and implementing solutions to ensure resident safety and rights. (Our recommendations purposefully do not take a position on replacing facility leadership. While additional oversight at the facility is necessary, Choate's current problems are not new and are reflective of a culture problem that developed over the course of decades. Taking time to appoint new leadership could serve as a distraction that only delays the timely transition of all individuals with developmental disabilities away from Choate.)
- Monitoring and oversight must also include the Illinois Department of Public Health, the Centers for Medicare and Medicaid Services' state survey agency. They have previously played this role when state-operated centers have experienced problems but have not yet done so at Choate in recent years.

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