



Advancing the human and civil rights of people with disabilities

SELF-ADVOCACY ASSISTANCE ★ LEGAL SERVICES ★ PUBLIC POLICY ADVOCACY ★ INDEPENDENT FACILITY MONITORING

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Equip for Equality:
Midpoint Assessment of Choate's 3-Year Transition Plan
(March 8, 2023 to September 9, 2024)

On March 8, 2023, the Governor announced his intention to repurpose Choate Developmental Center. As part of that plan, all individuals on the four “certified” units are to move to community-based settings or other state-operated developmental centers (SODCs) within three years. Through this announcement, the Governor expressed the State’s commitment to meeting its “legal duty to ensure residents with disabilities have a full opportunity to live in the least restrictive environment of their choosing” which he noted was consistent with “nationwide, research-informed best practices...” As such, he further committed that these efforts were not limited to Choate and would “reshape the way the State approaches care for individuals with intellectual and developmental disabilities (I/DD).”

We are now at the midpoint of the three-year plan. As of September 9, 2024, of the 123 people on the identified units, 10 people have moved to community settings, 3 have moved to family homes, 2 have moved to private institutions, and 33 have moved to other SODCs. Of those remaining at Choate, 33 are waiting to move to community settings, 31 are waiting to move to other SODCs, and 6 are on the undecided list. That over 50% of individuals have or are slated to move to other SODCs is not a good bellwether for the State meeting its commitment to ensure people live in the least restrictive setting of their choosing or that the current service system will be transformed.

First, for those who have or are slated to move to other SODCs, 31% had previously told Equip for Equality that they want to live in community settings. At times, the SODC transfer occurred because the individual grew frustrated with waiting to identify a community setting or, very rarely, due to individual preference. More frequently, it was because a guardian, not the individual, decided that the individual went or will transfer to an SODC. Many of these individuals have limited ability to communicate their wishes and are going to other SODCs regardless of whether their needs could be met in a less restrictive environment.

Second, regarding the 33 individuals waiting to move to a community setting, 91% have been waiting over 9 months without identifying a provider, with 27 of the 33 waiting a year or more. The long delays have consequences, including people transitioning to

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other SODCs or private institutions due to the lack of available community options, and people feeling rejected and frustrated, and experiencing increased anxiety – all of which negatively impacts their stability, which then hinders their efforts at finding a community provider. And, while the people on the four certified units have been targeted for transition, the pace of community transitions from Choate Developmental Center’s other units are nearly identical, with 12 individuals moving from those units to community settings as compared to 13 individuals on the certified units during the same period.

As a result, it is clear that far more effort and resources are required if the State intends to deliver on its commitment to transform Illinois’ historical reliance on institutional care and make least restrictive options a reality for those who want them. Equip for Equality urges the Governor and legislature to take action to ensure that individuals leaving Choate truly have access to the community options promised them. Further, the State must take full advantage of this opportunity to create a strong model that addresses long-standing and substantial barriers that prevent people from leaving SODCs and achieving their stated desire to live as part of the community. Relying on current practices for securing community placement is not going to achieve that result. Instead, there must be a plan to remedy these historical barriers, including strategies that incorporate best practices, provide necessary funding, and require a reasonable timeframe for placement to occur.

As shared with the Department of Human Services, Division of Developmental Disabilities (the Division), Equip for Equality’s monitoring of people on the transition list has revealed a pattern of universal barriers that negatively impact timely moves from Choate (and other SODCs) to a community setting. Those barriers can be found within the community system, the current structure of the placement efforts, and for Choate transitions, at Choate itself:

Barriers in the Community – Urgent need for community provider expansion, including:

- More homes that meet individuals’ needs / preferences such as having their own bedroom, living in a smaller setting (1–3 person apartments / homes), and home-based services; and more homes in Central / Southern Illinois;
- Opening transition / stabilization homes, which has already received legislative approval (405 ILCS 80/7A-1 et seq.);
- Specialized homes that can assist people with increased needs related to diabetes, feeding tubes, other complex medical needs, hearing impairments, sex offender status, and significant mental health needs;
- Supported work opportunities; and
- Access to crisis mental health services in the community, and in a timely manner.

Barriers in the current placement system –

- The State contracts with seven Independent Service Coordination (ISC) agencies, serving twelve areas of the state, to assist with matching individuals to potential providers. These ISC agencies are directly involved with transitions from the SODCs, which is good, but the system is not set up to ensure coordination between these agencies (or with Division personnel) when an individual in one area of the state would like to move to another area.
- Despite the lengthy transition list at Choate (33 on certified unit and 30 on non-certified unit), there continues to be only one ISC staff member assigned to help individuals locate a provider. This is also a problem at Shapiro Developmental Center, which similarly has a lengthy transition list but only one assigned ISC staff to help people find a new home.
- The absence of enhanced services to secure community placement for those having difficulty finding a provider.

Barriers specific to Choate Developmental Center – Despite the well-publicized problems at Choate and as described in Equip for Equality’s August 2023 report (www.equipforequality.org/choate), there continue to be treatment gaps that result in lengthy stays and difficulty finding a provider, including:

- Not providing or delays in individuals receiving comprehensive mental health treatment and other active treatment to help them progress;
- Absence of necessary treatment for individuals with inappropriate sexual behavior and personality disorders;
- Treatment teams serving as a barrier to people being added to transition list by delaying decisions, encouraging other SODC placement, or placing more emphasis on the guardian’s wishes than the individual’s;
- Failing to prepare individuals for community living;
- Treatment files in disarray leading to long delays in preparing referral packets (sometimes months);
- Referral packets containing outdated, inaccurate and/or unverified information that does not sufficiently address the progress the individual has made, what supports have helped, and/or what supports the person needs to be successful in the community.

Although the Division has taken steps to address historical barriers, including incentivizing 3-bed group homes, increasing wages for front-line staff in community settings, increasing mental health and behavioral resources at Choate, and starting to rework individual service plans and transition packets to better reflect the individual’s strengths and needs, it will take the full support of the Governor and legislature to truly transform Illinois’ system of care for people with I/DD.

We welcome the opportunity to partner with the Governor's office, the Department of Human Services and the Division of Developmental Disabilities to develop strategies to address the above-listed barriers. In addition, we have the following immediate recommendations:

Improve Matching System -

- When the current system does not result in timely identification of a provider, or difficulties securing placement are anticipated, the Division must provide a more robust referral / matching system outside of the standard referral system, and such system must include development of community resources for the individual where needed. Initially, this process should focus on people who have been waiting the longest with an end goal of ensuring that no one is waiting more than six months to find a provider, with most people finding a provider within a few months.

Make Community Choice a Reality -

- For people at Choate who have expressed interest in living in the community but have instead transferred to an SODC or private institution, or are on the list to transfer to an SODC, an ISC should provide outreach to educate such individuals and explore community options if consistent with their wishes. In addition, for all instances where there is disagreement between the individual and their guardian about placement, there also must be a formal conflict resolution process, with the individual being provided an independent advocate. If the conflict cannot be resolved, the Division must provide a mechanism for individuals to access their right to appear before a court under sections 5/4-305 and 308 of the Mental Health Code (which then must also be available at other SODCs). Finally for all individuals transferring from Choate to other SODCs, and for everyone living in SODCs, the State must ensure compliance with federal law and the Mental Health Code's requirement that individuals are provided services in least restrictive environment, regardless of guardian preference to the contrary. 405 ILCS 5/2-102(a).

Ensure Access to Mental Health Care -

- The State must take steps now to address inequities in the mental health care system for people with I/DD. Far too often such individuals are refused mental health care based on their I/DD diagnosis. Ensuring timely access to crisis mental health services will both increase provider confidence in serving individuals who have mental health challenges and help ensure individuals continue to live in their communities rather than going or returning to an SODC. Although there are current initiatives to improve mental health services for various populations through the Behavioral Health Workforce Center, people with I/DD with a co-occurring mental health disorder do not appear to be an area of focus.