

Disability Partners - IDD System Redesign Coalition
Center for Developmental Disabilities Advocacy & Community Supports
Year 1: 7/1/2025 – 6/30/2026

Olmstead and Illinois I/DD Services: User Choice, Oversight, and Reforms

Background: The Olmstead Mandate and Illinois' Response

In 1999, the U.S. Supreme Court's *Olmstead v. L.C.* decision established that unjustified institutionalization of people with disabilities is a form of unlawful discrimination under the Americans with Disabilities Act (ADA). The Court held that states must provide services in the "most integrated setting" appropriate to an individual's needs – typically, in community rather than institutions – when the person can handle and wants such a setting. In essence, *Olmstead* gave individuals with intellectual and developmental disabilities (I/DD) the right to live and receive services in the community if they do not require institutional care. They wish to live outside an institution. This landmark ruling set expectations for all states, including Illinois, to reduce reliance on segregated facilities and expand home- and community-based services (HCBS).

Illinois' initial response to *Olmstead* was slow. The state historically relied heavily on large institutions for people with I/DD and lagged behind national trends in deinstitutionalization. Illinois has long been an outlier, with one of the highest populations of individuals with I/DD living in state-run institutions in the nation. Early 2000s planning efforts (such as a 2002 executive order to develop a Disability Services Plan) yielded few immediate changes. It wasn't until lawsuits and enforcement actions that Illinois began substantive reforms:

- **Ligas v. Hamos (formerly Ligas v. Maram)** – a 2005 class-action lawsuit alleging that Illinois violated *Olmstead* by underfunding community services and thereby forcing individuals into large facilities or leaving them on wait lists. This case resulted in a consent decree in 2011, with Illinois agreeing to expand community-based options so people in institutional settings (or at risk of entering one) could move to more integrated settings of their choosing.
- **Williams v. Quinn (2010)** – a similar consent decree (though focused on adults with mental illness in IMD nursing facilities) underscored the state's obligation under *Olmstead* to offer integrated housing and support.
- **Colbert v. Pritzker (2012)** – another Illinois consent decree (targeting older adults and people with disabilities in Cook County nursing homes) further reinforced the push for community living.

These *Olmstead*-related cases compelled Illinois to develop an "Olmstead Plan" of sorts through court orders. By settling *Ligas* in 2011, Illinois promised a "*major expansion of its community-based services*" for people with I/DD. The state committed to moving *thousands* of individuals into community settings or providing services at home, and to enrolling a minimum number of people from the waiting list each year. In short, the *Olmstead* decision and subsequent litigation placed **user choice** – the individual's right to choose community living – at the forefront, and imposed court-ordered oversight to hold Illinois accountable.

Illinois' I/DD Service System and Settings

Over the past two decades, Illinois has maintained a broad but imbalanced continuum of I/DD services. Understanding these settings is crucial to understanding how *Olmstead* impacts the day-to-day life of individuals (user experience) and their ability to choose where and how to live (user choice), as well as the challenges in state regulatory oversight of each.

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- **Community Integrated Living Arrangements (CILAs):** CILAs are small-group homes or apartments in the community (serving eight or fewer unrelated adults) with staff support. They are Illinois' primary HCBS residential option. CILAs can be 24-hour (round-the-clock staff) or Intermittent, where staff provide supports on a scheduled or as-needed basis for individuals who can live more independently. CILA residents receive individualized habilitation and personal support, usually under a person-centered plan. As Olmstead prompted the expansion of community living, Illinois substantially grew its CILA program – the number of people served in family homes or group homes increased from approximately 13,500 in 2011 to over 23,000 by 2023. This reflects significant progress in giving people opportunities outside of institutions. However, challenges remain. Many CILA group homes in Illinois house 6 to 8 people, an older model that advocates say does not truly meet modern standards for being “integrated” or home-like. Best practice now is homes of 3 or fewer residents, to maximize independence and privacy. The court monitor in the Ligas case noted Illinois' group home model is “outdated”, with too many larger homes, and urged development of smaller settings more consistent with what individuals desire. Another issue is geographic gaps – in some regions, families report that the only available CILAs have eight residents and may not be suitable for those with higher medical or behavioral needs. From a user experience perspective, quality of life in CILAs can be very positive when homes are truly integrated – residents attend community events, make choices in their daily routines, and build relationships. However, the user experience suffers when staffing is inadequate, activities are limited, or when individuals are placed in a home based on availability rather than personal preference. In recent years, Illinois increased wages for direct support professionals in CILAs. It invested more in community providers, aiming to improve care quality (e.g., reduce high staff turnover that disrupts residents' lives). Continued investment is needed, as low pay and workforce shortages still impact many CILAs, resulting in vacancies in services and sometimes inadequate oversight of care.
- **Home-Based and Family Supports (Intermittent Services):** Many Illinois adults with I/DD live in their family's home or their own home and receive supports through the Adult Home-Based Support Services (HBS) program or intermittent CILA services. Under HBS (a component of the HCBS waiver), individuals (or their families) manage a yearly budget to cover the costs of staff, therapies, respite care, and other supports necessary to maintain their living at home. This option maximizes personal choice – the individual can remain in their community and avoid facility placement. Olmstead's influence is evident here: Illinois had to recognize that integrated services include not only group homes but also supporting family caregivers and independent living. User experience in HBS is often characterized by greater autonomy, as individuals or their families can schedule staff as needed and tailor services accordingly. However, a significant issue is access: until recently, HBS and other waiver slots were limited and subject to a lengthy waiting list (the PUNS list – Prioritization of Urgency of Need for Services). There are still thousands of individuals on Illinois' waitlist, hoping to receive HBS or CILA services. As of the end of 2024, approximately 6,711 adults were actively seeking services on the PUNS list. Many wait 5+ years for funding. This undermines Olmstead's promise because people at risk of institutionalization might not get timely support to prevent it. Illinois, under the Ligas decree, has agreed to add at least ~600–630 people from the waiting list into services each year. While this has gradually chipped away at the list, the “reasonable pace” requirement still leaves many waiting several years. Strengthening state oversight of the waiting list process (ensuring it is fair and moving efficiently) and dedicating more state funds could improve user choice, so that

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individuals aren't effectively forced into a nursing facility or large ICF/DD simply because their community-based support wasn't available when needed.

- **Community Day Services (CDS):** Formerly known as “Developmental Training” programs, these are day programs for adults with I/DD, typically operated in community settings (resource centers, workshops, or out in the community). Illinois’ HCBS waiver offers CDS to provide skill-building, recreation, and community integration opportunities during the day. According to the state’s description, Community Day Services should include activities for “community exploration, inclusion, and integration”, tailored to each person’s interests and goals. In practice, many individuals in CILAs or family homes attend a day program or sheltered workshop on weekdays. Olmstead’s integration mandate applies here too – it’s not just about where one lives, but how one spends their days. Over the last decade, there has been pressure to improve the quality of day services: to move away from segregated, purely facility-based programs toward more inclusive models (such as supported employment, volunteer work, or classes in typical community settings). Illinois’ court monitor and advocates have highlighted the need for “meaningful day services”, noting that simply placing people in a program is not enough – they should be gaining skills, forming relationships, and accessing the broader community. A challenge has been funding rates for CDS, which have historically been low, potentially limiting the variety of activities and staff support available. The state’s *HCBS Settings Rule* compliance effort (required by CMS in 2014 and finalized by 2023) also pushed providers to ensure day programs are not isolating. As a result, many Illinois CDS providers are now expanding community outings and supported employment options. From a user experience perspective, improving day services is crucial – a person living in the community should have an engaging day, not just sit in a center doing repetitive tasks. Some progress is evident, but ongoing oversight by state agencies and perhaps higher reimbursement are needed to realize truly person-centered daytime opportunities.
- **Intermediate Care Facilities for Individuals with Developmental Disabilities (ICF/DDs):** These are Medicaid-licensed facilities (typically 24-hour care) for people with I/DD who need more structured support than a small home may provide. Illinois has both state-operated ICF/DDs (the SODCs, discussed separately below) and private ICF/DDs (run by non-profits or companies, often larger group homes or campus-based settings). Many private ICF/DDs in Illinois serve 10, 16, or even 100+ residents in a facility, making them institutional. Unlike HCBS waivers, ICF/DD admission does not require going through the PUNS waiting list – if a facility has a bed and the person is eligible, they can be placed immediately. This policy disparity has often meant that families in crisis may turn to an ICF/DD placement when they cannot obtain timely community-waiver services, effectively creating an “institution first” bias. Olmstead affects ICF/DDs by requiring that these placements be “necessary, not just convenient” – i.e., only those who truly cannot be served in community or who choose an ICF should be there. Illinois’ Ligas consent decree specifically included class members residing in ICFs/DD who *want* to move to the community. The state must offer those individuals the opportunity and necessary funding to relocate. Since the decree, Illinois has worked with ICF providers on voluntary downsizing or closures. From FY2013 to FY2024, there have been 89 voluntary ICF/DD closure or downsizing agreements, resulting in about 1,419 people moving out of ICF/DDs – the vast majority (over 1,200 individuals) transitioned into CILA homes in the community. This is a significant shift, showing Illinois’ slow pivot toward community integration. Nevertheless, around 4,000–5,000 individuals still live in private ICF/DD facilities in Illinois (exact figures vary), and many of these settings have nine or more residents together, a level of congregate living that can limit

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personal autonomy. User experience in ICF/DDs can vary widely – some smaller ICFs (6-8 bed) feel similar to group homes, but larger ones can resemble nursing homes or institutional campuses. State regulatory oversight for ICF/DDs is performed by the Illinois Department of Public Health (IDPH), which conducts inspections for federal certification. While health and safety regulations exist, ICFs are not governed by the HCBS integration rules; therefore, they may have more restrictive routines (e.g., fixed meal times, limited community access) without jeopardizing funding. For Illinois to fulfill Olmstead, the regulatory focus has been on encouraging individuals to move out of ICFs. The state reports data on Ligas class members in ICFs and their transitions, and even after a decade, dozens of residents remain in ICF/DDs *despite expressing interest in community services* (some had not yet received waiver slots or were awaiting appropriate community placement). This indicates gaps in capacity and transition planning that the state is still working to address.

- **Medically Complex Developmental Disability Facilities (MC/DDs):** MC/DD facilities (created under the Illinois MC/DD Act of 2016) are a category of skilled nursing facilities tailored for individuals with developmental disabilities who have complex medical needs. They evolved from specialized units that served children or adults with severe medical conditions (such as ventilator dependence, feeding tubes, etc.) alongside developmental disabilities. Examples in Illinois include facilities like Alden Village, Marklund, and the Swann Special Care Center in Champaign. These centers offer intensive nursing care in a hospital or institutional setting. Some primarily serve children, though adults may reside there if they need ongoing medical care. The Olmstead principle applies to individuals with MC/DDs, in that if they can be supported in a smaller community setting with medical support, they should not be segregated in a nursing facility. Illinois officials have acknowledged the need for more community-based medical supports (for example, allowing in-home nursing under waivers, or specialized small-group homes for medically fragile individuals) so that MC/DD placement is a last resort. User experience in an MC/DD is often akin to a hospital or nursing home environment – it can provide vital medical stability. Still, it may lack opportunities for a regular community life. State oversight for MC/DDs is again conducted through IDPH licensure, and these facilities must meet the same standards as nursing homes. Illinois has a relatively small number of MC/DD facilities (roughly a dozen statewide), but some have a history of serious quality issues. For instance, past investigations into Alden Village North (a pediatric facility) uncovered safety issues, prompting reforms in oversight. To improve outcomes, Illinois will need to invest in community alternatives for medically complex individuals – such as in-home technology, better reimbursement for nursing in community settings, and training for group home providers to handle medical needs – so that choice isn't between living in a hospital-like setting or receiving inadequate care.
- **State-Operated Developmental Centers (SODCs):** These are large state-run ICF/DD institutions managed by the Illinois Department of Human Services (DHS). Illinois currently operates 7 SODCs located around the state (e.g., *Choate, Shapiro, Murray, Ludeman, Kiley, Mabley, Fox Center/Lincoln*). SODCs house individuals with developmental disabilities who often have the most severe behavioral or medical challenges. Historically, Illinois relied heavily on these centers; as of early 2025, about 1,600 people lived in SODCs. Admissions today are supposed to be limited to cases where no community option can manage the person's needs. In theory, SODCs offer intensive services with the goal of stabilization and return to community living "as quickly as possible". In practice, however, many residents have lived in SODCs for years or decades. User experience in an SODC is the most institutional: these centers are campus hospitals (some built in the 19th century)

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with dozens or hundreds of residents. While they provide structure and specialized care (and some families prefer them for safety), they also come with significant drawbacks – regimented schedules, lack of community integration, and in several cases, severe abuse and neglect problems. Oversight of SODCs is complex: the DHS internally manages them, and the DHS Office of Inspector General (OIG) is tasked with investigating allegations of abuse and neglect in state facilities. Federal DOJ oversight has also come into play (discussed below). Over the last 10–15 years, Illinois has closed several SODCs as part of its rebalancing efforts (e.g., the Howe Developmental Center was closed in 2010 due to repeated federal violations, and the Jacksonville Developmental Center was closed in 2012, with residents relocated to community settings or other facilities). Governor Pat Quinn attempted to close additional centers (e.g., Warren G. Murray Center) to comply with Olmstead, but political and family resistance halted further closures. Thus, Illinois still runs seven centers, and the conditions within them have become a central Olmstead concern. Investigative journalism in 2022–2023 (the “*Culture of Cruelty*” series) exposed “horrific instances of abuse and neglect” at multiple SODCs, especially Choate in southern Illinois. Staff at Choate were found to have beaten, choked, and even sexually assaulted residents, while supervisors covered it up. These reports echoed problems that the DOJ had identified back in 2009, indicating systemic failures that had persisted over decades. The fallout has been significant: In 2023, Governor JB Pritzker called the situation “awful and deeply concerning,” announcing a “transformational” plan to relocate roughly half of Choate’s 240 residents from that facility. However, executing this plan proved difficult – by the end of 2024, of the 81 residents who moved out of Choate, more than half were transferred to other SODCs (not into community living). Only a handful of individuals (nine) actually transitioned to community group homes or returned to their families. This outcome highlights the shortage of community placements for individuals with high needs, as well as the influence of guardians who may opt for an alternative institution. From an Olmstead perspective, SODCs are viewed as an “antiquated and oppressive model” that Illinois continues to rely on. Indeed, advocates note that thousands of individuals are still served in institutions in Illinois, when many could thrive in smaller, more supportive homes. The presence of ~1,600 people in SODCs, and others in private facilities, represents lives that are less integrated than they could be. For now, state oversight efforts at SODCs include increasing staffing and training, adding security cameras in common areas, and heightened scrutiny by independent monitors. But meaningful reform likely requires *downsizing* these centers and bolstering community alternatives, which we will explore in recommendations.

User Choice Under Olmstead: Progress and Continuing Barriers

Olmstead’s core promise is “**choice**” – specifically, the individual’s choice to live in an integrated setting. Illinois has gradually shifted its policies to honor that promise, but tensions and barriers remain regarding who actually gets to choose and what options are available.

Empowering individuals to choose community living: The Ligas consent decree explicitly aimed to ensure that any qualifying person with intellectual and developmental disabilities (I/DD) who *wants* to live in the community can do so. Since 2011, Illinois has assisted thousands of people in transitioning out of institutional settings. By late 2023, Illinois reported it had moved or newly served about 10,000 additional people in community settings compared to 2011 (a rise from ~13.5k to ~23k served). These include class members who left ICF/DD facilities for CILAs, as well as those who were taken off the waiting list and provided with home-based or residential services. Each of those transitions represents an individual (or family) exercising a choice for a more independent life, which is a direct effect of Olmstead and the

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enforcement litigation. Consent decrees have also led Illinois to adopt person-centered planning approaches across its DD system, ensuring that services begin with the individual's preferences and goals. Since 2018, Illinois' Division of DD requires a Personal Plan for each waiver participant, replacing older service plans. This personal plan is built from a "Discovery" process to learn what is *essential to and for* the individual. Person-centered planning, when done correctly, elevates the person's voice in deciding where to live, with whom they live, and what daily activities they pursue, among other decisions. This represents a culture change in services, aligning with Olmstead's emphasis on the individual rather than fitting people into whatever slots are available.

Despite these improvements, significant barriers to true choice remain in Illinois:

- **Waiting List and Crisis Admissions:** If a person cannot obtain community services due to the PUNS wait list, their "choice" is constrained. Some individuals feel pressure to enter a facility to receive any services at all, because ICF/DDs have open admission, whereas waivers do not. This is inherently at odds with Olmstead. Illinois has attempted to mitigate this by prioritizing individuals in crisis for immediate waiver slots (and by creating a "Crisis Criteria" in Ligas). However, advocates argue that many still fall through the cracks. For instance, Equip for Equality (Illinois' protection & advocacy organization) reported in 2023 that **lack of crisis support and specialty services** often forces individuals into SODCs in moments of instability. Once institutionalized, regaining independence can be challenging, so the initial lack of community capacity effectively overrides the individual's choice to remain in the community. Illinois acknowledged in court that **wait times for services have been reduced, especially for those in crisis**; however, the issue is not yet fully resolved. As of the end of 2024, hundreds of adults on PUNS had been waiting 4–5 years or more for services. Until the state fully funds services "on demand" (or at least at a reasonable pace), many individuals have limited practical choice. Improving this is essential for user experience – being stuck at home with no supports for years, or feeling you must accept a nursing facility bed to get care, are scenarios Olmstead intended to prevent.
- **Role of Guardians and Family Preference:** A unique challenge in the I/DD field is that many adults have legal guardians (often parents or relatives) who make decisions on their behalf. This has led to debates about whose choice Olmstead protects. Legally, Olmstead focuses on the individual with a disability. However, Illinois (like other states) defers to guardians in most placement decisions if the person is adjudicated to be incapacitated. Some guardians strongly prefer institutional care – they may feel their loved one is safer or better served there – and thus oppose community placement even when professionals suggest it. Advocacy groups representing families (such as VOR and some Illinois parent associations) argue that *guardian choice* must be respected, and that Olmstead shouldn't force someone out of a facility against family wishes. They cite federal policy that families are "the primary decision-makers" regarding services for individuals who can't decide themselves. Indeed, federal judges have acknowledged guardian objections in cases like *U.S. v. Arkansas*, where the court declined to order deinstitutionalization at a facility largely because nearly all guardians wanted their wards to stay put. In Illinois' own Ligas case, a group of guardians intervened during the litigation to ensure that those *content* in ICF/DDs could remain (the consent decree ultimately allowed individuals who *choose* to stay in facilities to do so, focusing relief on those who wanted out). The user choice principle thus cuts both ways: it means the state must offer community options, but it also means no one should be *forced* into the community if they truly do not consent. In practice, Illinois must balance these situations through person-centered planning and regular

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review of each individual's desires. There is also a growing movement to implement supported decision-making in Illinois, giving individuals with intellectual and developmental disabilities (I/DD) more say, even if they have a guardian, or avoiding full guardianship so that the person's preferences carry more weight. The 2025 Equip for Equality monitoring found that "decisions made by guardians rather than the individuals themselves" were slowing transitions out of Choate and causing frustration. To improve Olmstead compliance, Illinois will likely need to educate guardians about community successes and possibly provide trial visits or peer mentorship (family-to-family) to address their concerns. The bottom line: user choice should mean the individual's authentic choice. Illinois' system redesign could incorporate policies to ensure, for example, that individuals in SODCs are regularly asked (in an accessible manner) where they want to live. If a guardian's decision contradicts an adult individual's stated preference, there should be a process in place to advocate for the person's wishes.

- **Information and Options Counseling:** Another aspect of choice is knowing what alternatives exist. Historically, many Illinois families were never informed about community living possibilities – especially decades ago, professionals might tell parents of a child with severe disabilities that an institution was the only option. Even as late as 2007, DOJ found that Choate (a state facility) failed even to identify or inform residents of opportunities to move to community settings, calling it a "profound inattentiveness" to Olmstead's requirements. Today, Independent Service Coordination (ISC) agencies are supposed to present all options to individuals and families, including CILAs, supportive housing, etc., and update the discussion annually. Illinois' compliance with the federal HCBS Settings Rule by 2023 also mandated that any provider-owned setting have a residency agreement and policies guaranteeing rights, such as the right to privacy, the right to receive visitors, the right to control one's schedule, and the right to move to another setting if one chooses. These measures collectively aim to enhance personal autonomy. The goal, as Illinois DHS itself states, is to ensure people live "*in the least restrictive setting of their choosing*." In the future, strengthening options counseling (for example, when someone is considering placement in a large facility, ensuring they meet peers who live successfully in the community) could further improve how user choice is exercised.

In summary, Olmstead has encouraged Illinois to provide individuals with more choice and person-centered control over their lives. Thousands have benefited by moving from segregated settings to community living. Yet, barriers such as waitlists, guardianship dynamics, and a lack of specialized community supports mean that choice is not yet fully realized. The state still hears stories of people who want to leave an institution but "can't find suitable group home placements" for their complex needs. Addressing these gaps is central to improving the *user experience* – it means people can actually live where and how *they* prefer, with appropriate supports.

State Oversight, Quality of Care, and Investigations

Ensuring a positive user experience and protecting the rights of individuals with intellectual and developmental disabilities (I/DD) in services requires robust state oversight and effective regulatory enforcement. Illinois' oversight has been under intense scrutiny, especially in the past 10 years, due to incidents of abuse, neglect, and non-compliance with required standards. Below, we discuss oversight mechanisms and notable investigations/findings that have driven calls for reform.

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- **Regulatory Structure:** Multiple agencies share oversight of Illinois' I/DD system. The Illinois Department of Human Services (IDHS) Division of Developmental Disabilities is the primary authority for program funding, policies, and monitoring of community services (CILAs, CDS, etc.). Licensing of community residential programs (like CILAs and 16-bed group homes) is handled by IDHS's Bureau of Accreditation, Licensure and Certification. Intermediate Care Facilities (ICF/DD) and MC/DD nursing facilities are licensed and inspected by the Illinois Department of Public Health (IDPH) because they are medical facilities under Medicaid rules. The IDHS Office of Inspector General (OIG) has jurisdiction to investigate allegations of abuse, neglect, and exploitation in any facility or program funded by DHS, including state-run centers and community agencies. The Independent Service Coordination (ISC) agencies also play an oversight role at the individual level, as they are expected to monitor the well-being of each person on their caseload, facilitate annual service planning, and raise concerns if a provider isn't meeting standards. Finally, court-appointed monitors (in the Ligas, Williams, and Colbert consent decrees) oversee Illinois' compliance with those settlements, which effectively makes them watchdogs over certain aspects of the system (like whether people are getting off the waitlist or whether individuals are safe and thriving in placements).
- **Findings of Abuse and Neglect:** Unfortunately, Illinois has a track record of high-profile failures in protecting individuals with I/DD from harm. State-operated developmental centers have been particularly prone to problems. The DOJ Civil Rights Division investigated two Illinois developmental centers in the late 2000s under the federal Civil Rights of Institutionalized Persons Act (CRIPA):
 - **Howe Developmental Center (Tinley Park)** – before its closure in 2010, Howe had its Medicaid funding revoked due to numerous care deficiencies (deaths, medical neglect, etc.). The DOJ's findings letter on Howe (November 2009) noted that even as Illinois prepared to close the facility, systemic failures in ensuring safe transitions and care continued to persist.
 - **Choate Mental Health and Developmental Center (Anna)** – DOJ's investigation in 2007-2009 found constitutional violations at Choate: lack of adequate healthcare and psychiatric services, failure to protect residents from harm, and failure to provide "*proper transition planning for those wanting to move into the community.*" In other words, Choate was not meeting Olmstead obligations nor ensuring basic safety. The DOJ cited that Illinois was not placing residents in the most integrated setting and did not have a process to reconsider whether each person could live in the community regularly. Illinois entered an agreement to remedy these issues, and DOJ monitored Choate until 2013. However, once federal oversight ended, the problems persisted.

The 2022-2023 "Culture of Cruelty" investigation by *Capitol News Illinois* and *ProPublica* revealed that at Choate, abuse by staff had become rampant and was often covered up by a "code of silence." Staff members were arrested for brutalizing residents – e.g., beating a man for not pulling up his pants, and threatening to break another resident's finger, an incident caught on a 911 call recording. There were cases of sexual assault and humiliation of residents. The OIG confirmed many of these cases, and found facility leaders frequently failed to take action. Shockingly, the investigative reporters noted that the horrors they uncovered at Choate in 2022 mirrored those documented by DOJ 15 years earlier. This indicates that state oversight mechanisms failed – either the reforms were not implemented or not sustained. In response to the public outcry, state officials

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promised personnel changes and new safety measures at Choate. By 2023, the plan (as mentioned) was to downsize Choate significantly. However, this plan's early phases drew criticism when monitoring showed many residents were shuffled to other institutions where oversight might not be much better.

Notably, these investigative reports spurred the U.S. Department of Justice in 2025 to open a fresh, wide-ranging civil rights investigation into Illinois' treatment of people with developmental disabilities. The DOJ announced it would examine "whether the state unnecessarily institutionalizes, or puts at serious risk of institutionalization" adults with I/DD, and whether Illinois is protecting people from abuse in the facilities. The scope includes not only Choate but also other SODCs (such as Shapiro and Mabley), as well as the overall system of services. This is a serious development – it essentially means the federal government suspects that Illinois may be violating Olmstead (for over-institutionalization) and possibly the ADA/CRIPA (for hazardous conditions). Governor Pritzker's administration has pledged full cooperation with the investigation. Advocates, such as Equip for Equality, welcomed this DOJ action, calling Illinois' reliance on institutional models "antiquated" and expressing hope that federal involvement will bring the needed expertise and resources to reform the system.

- **Office of Inspector General (OIG) Oversight:** The Illinois DHS OIG publishes annual reports tracking abuse/neglect allegations in both state-run and community settings. The latest data (FY2024) show a troubling trend: OIG received over 15,000 complaints of abuse/neglect/exploitation in DD or mental health services in one year – a 24% increase from the previous year and an 80% increase since FY2020. This spike could partly indicate improved reporting, but it undoubtedly also reflects genuine increases in incidents or, at the very least, increased detection of incidents. The OIG noted it is struggling to keep up with investigations, even after growing its staff from 73 to 91 investigators; by their estimate, they need at least 120 staff to handle the caseload appropriately. Delays in OIG investigations or lack of capacity can directly harm user experience – if abusive staff are not promptly removed, individuals remain at risk; if neglect issues aren't addressed, they fester. It is a positive sign that the state has recognized the staffing issue, but funding those positions is critical. Another concern is that while OIG can substantiate complaints and recommend corrective actions, enforcement is sometimes weak. Community agencies found to have violations might get cited, but license revocations are rare. Similarly, in state facilities, discipline of employees has historically been inconsistent (with strong public employee unions adding complexity to firing abusive staff). Strengthening the OIG's authority and ensuring that facilities implement corrective actions are areas that need attention.
- **Independent Monitors and Court Oversight:** Under the Ligas decree, an independent court monitor (currently Ronnie Cohn) provides regular reports. In 2024, as Illinois sought to terminate court oversight, the monitor opposed ending the decree, citing numerous ongoing problems. She testified that Illinois' services remain "in stark contrast to national best practices." For example, Illinois still had 200 Ligas class members living in six of the seven SODCs in 2024, which ideally should not be the case after a decade of supposed community expansion. The monitor and plaintiffs' attorneys (Equip for Equality) highlighted persistent safety concerns in those institutions – reinforcing that avoiding new placements into SODCs and expediting the removal of people from them is crucial. They even documented that some individuals who had moved from community homes *into* institutions during crises suffered "tragic outcomes" like abuse or decline in those facilities. This

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underscored a failure in the crisis response system: instead of helping people stabilize in the community, the system defaulted to an institution, with dire results. In denying Illinois' motion to exit the consent decree, the federal judge (in September 2024) agreed that the state "still hasn't met its decade-old promises" under Ligas. The judge acknowledged "*significant progress*" had been made, but unequivocally ruled that oversight must continue because mandates were not fully met. This is a clear signal that Illinois' regulatory oversight and service delivery have not yet met the requirements of Olmstead, particularly in terms of ensuring timely community access and minimizing institutionalization. The judge's decision keeps Illinois under court supervision, meaning the state must accelerate reforms and regularly report outcomes—a form of external oversight that complements internal monitoring.

- **State Audits and Reports:** Illinois' Auditor General has also turned attention to DD services oversight. A 2024 performance audit examined DHS's oversight of Independent Service Coordination (ISC) agencies, which are pivotal in linking individuals to services. The audit (mandated by House Resolution 66) found areas for improvement in how DHS manages the ISCs, such as consistency in following up on clients' needs and ensuring ISCs are helping transition people promptly out of institutions when appropriate. (For example, one responsibility of ISCs is to visit SODC residents regularly and attend annual staffings to discuss discharge possibilities. If that isn't done well, opportunities for community placement might be missed.) The audit made a dozen recommendations to DHS to strengthen its oversight of ISCs, indicating that better training, more straightforward guidelines, and accountability measures are needed. Additionally, at the behest of legislators and advocates, the Auditor General's office began a new audit of the CILA program in 2025. This audit will likely evaluate licensing, incident reporting, and DHS monitoring of community group homes. The fact that such audits are happening shows legislative concern that state oversight might be falling short and needs independent review.
- **Funding and Rate Oversight:** Quality oversight is tightly linked to funding adequacy. Illinois has ranked near the bottom of states in funding for developmental disability services (primarily community-based services) for many years. Low reimbursement rates led to chronic staff shortages, program closures, and a decline in program quality. The Ligas Court Monitor's reports repeatedly pointed out that "low rates for community services" were undermining Illinois' ability to expand and improve those services. In response, Illinois convened a Rates Oversight Committee in 2018-2019, which developed recommendations for more sustainable funding of programs, including increasing wages for direct care workers and funding "meaningful day" activities. In recent state budgets (FY2023 and FY2024), Illinois implemented significant rate increases for DD services – for instance, raising the starting wage benchmark for direct support staff (DSPs) and funding new programs, such as DSP training. Governor Pritzker and DHS have touted "unprecedented investments in home and community-based options" in the last few years. These investments are part of oversight in a broad sense, because without proper funding, the best regulations or monitoring can fail. It is too early to assess the impact fully, but one positive sign is the state's report that by 2023, it had "*raised pay for workers who assist with daily tasks like eating and bathing*" in community settings, which should help with retention. Continued oversight by the court and advocates will encourage the state to ensure that these dollars translate into improved outcomes (e.g., more consistent staffing, fewer crises, enhanced skill development) for individuals.

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In summary, Illinois' oversight of its I/DD system has been under a microscope. Federal investigations, court monitors, media exposés, and state audits have all identified serious issues: abuse and neglect in facilities, slow transitions or lack of community capacity, inadequate monitoring of providers, and workforce shortages affecting care. The user experience for Illinoisans with intellectual and developmental disabilities (I/DD) has varied widely – some enjoy good lives in the community. In contrast, others have endured harmful conditions or long waits. Strengthening regulatory oversight is not just about writing stricter rules; it's about ensuring accountability and continuous quality improvement at every level, from state agencies down to direct care staff. Illinois is now facing heightened pressure (with DOJ's 2025 probe and ongoing court supervision) to correct course and better protect the rights, safety, and dignity of people with I/DD.

Recommendations for Improving User Experience and Choice in Illinois

Based on the historical and ongoing issues detailed above – spanning community services (CILAs, day programs, etc.), intermediate facilities (ICF/DD, MC/DD), and state institutions (SODCs) – there are several targeted changes that Illinois can pursue to improve the user experience and uphold Olmstead principles. These recommendations focus on bolstering user choice and enhancing state oversight/quality, as part of a comprehensive plan to redesign Illinois' I/DD system.

- **Expand Community Capacity and Crisis Supports:** A key Olmstead challenge in Illinois is the lack of suitable community placements for individuals with complex needs. The state should invest in creating new models of small-scale, high-support housing. For example, develop specialized CILAs or supervised apartments for people with intense medical or behavioral needs – perhaps with enhanced staffing ratios or on-call clinical supports. This could be achieved by providing incentive grants or higher rate tiers to agencies that serve individuals transitioning out of SODCs or those who avoid SODC admission. Alongside housing, Illinois must bolster its crisis response system. The goal should be that no one is forced into an institution due to a temporary behavioral crisis or caregiver burnout. Illinois can establish mobile crisis teams trained in I/DD, short-term crisis respite homes, and emergency in-home supports. By addressing crises in the community, the state can prevent the revolving door of emergency SODC or ICF placements. These measures directly improve user experience by delivering help at the moment of need and keeping the person in their chosen environment. Equip for Equality's recent report noted that long wait times and lack of providers were hindering community living, and recommended "far more effort and resources" to make community living a *real* choice. Funding these supports is part of that effort.
- **Reduce Institutional Reliance (Downsize SODCs and Large ICFs):** Illinois should set a clear plan to reduce the census of its large institutions over time responsibly. This does *not* mean overnight closures, but a phased approach. For SODCs, implement a moratorium on new long-term admissions (except for truly short-term treatment stays), allowing the population to decrease naturally over time. Strengthen transition planning for each current resident by assigning dedicated transition coordinators who work with the individual (and their guardian) to identify or develop community solutions. Utilize some SODC resources to create community services – for example, repurpose unused campus buildings as community agency offices or training centers, or retrain willing SODC staff to work in community programs where a workforce is needed. The state has already begun relocating some Choate residents; it should replicate this approach at other centers, taking lessons learned (such as avoiding the simple transfer of people to other institutions). To address guardian resistance, involve families in planning and offer them opportunities to visit

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community homes and talk to other families who have transitioned – thereby demystifying the change. Similarly, for large private ICF/DD facilities, Illinois can expand its voluntary closure/downsizing program, which has moved over 1,400 people since 2013. Providing financial and technical assistance to providers to convert large facilities into small homes or alternative services will further integration. The resulting savings from closing expensive institutional beds (Illinois spends a very high amount per person in SODCs, often over \$200,000/year each) can be reinvested into community services, creating a virtuous cycle. Importantly, all these efforts must be paced to ensure no individual is left without appropriate care – for example, building up capacity *before* closing a unit. The end goal is a system where institutions are truly the last resort. This aligns with DOJ’s inquiry into unnecessary institutionalization: by proactively reducing institutional use, Illinois demonstrates compliance with Olmstead’s mandate to serve people in the most integrated setting.

- **Prioritize Small, Personalized Settings:** In redesigning services, Illinois should explicitly prioritize small settings that maximize autonomy. This means encouraging “micro-CILAs” or supported living arrangements of 2-3 people, and even supporting individuals in their own apartments with drop-in supports if possible. The court monitor has pointed out that many Illinois group homes are larger than ideal. State policy may cap new community residences at four or fewer residents (some states have adopted a maximum of four residents to ensure homelike environments). Illinois might also explore host family or shared living programs, where an adult with a disability lives with a family or roommate who provides support (this model can be very person-centered and stable). By expanding the range of residential options, individuals can select the living arrangement that best suits their personality and needs. Notably, smaller settings have been associated with better outcomes and satisfaction. However, they must be funded adequately – a group of two people will need sufficient funding to cover the staffing that was previously shared among six to eight people. Thus, adjusting reimbursement formulas is part of this recommendation. The benefits will include a more individualized user experience, increased privacy, and enhanced community integration.
- **Strengthen Person-Centered Planning and Transition Processes:** Illinois should double down on person-centered planning (PCP) training and implementation. Every individual (whether in a family home, CILA, ICF, or SODC) should have a PCP process that truly listens to their goals (or, for those with significant communication challenges, uses tools to discern preferences). The state can invest in training independent facilitators or using tools like supported decision-making agreements to involve the person to the maximum extent. A concrete improvement would be to ensure that residents of SODCs and large ICFs are provided with information about community options in a regular, structured manner, perhaps through peer-to-peer programs (where someone who has successfully transitioned returns to share their experience). The DOJ’s 2009 finding that residents weren’t informed of their Olmstead rights should never be true again – Illinois could require a standardized “Know Your Options” presentation to be given to each resident annually (and documented). Alongside PCP, the transition planning when someone agrees to move out must be bolstered. The Ligas monitor noted Illinois lacked crisis support and help with building independent living skills, which led to people struggling or declining after moving out. Therefore, adding “transition support teams” that work with individuals for, say, 6-12 months post-move could improve stability. These teams can troubleshoot issues (such as the person needing additional behavioral therapy or a change in their day program) to prevent failed placements. Overall, the philosophy should shift from

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a “one and done” approach to providing continual support throughout the person’s journey, ensuring their choice to move actually results in a better life.

- **Improve Oversight and Accountability Mechanisms:** Several steps can be taken to tighten oversight.
 - **Fully Staff and Empower OIG:** As the OIG data showed, more investigators are needed. The state should allocate funding to increase the OIG's staffing to the recommended 120 investigators (or more if complaints continue to rise). Additionally, ensure OIG has enforcement teeth – for example, if patterns of abuse are found at a particular facility or CILA provider, there should be consequences such as fines, probationary licenses, or management changes. Public transparency can also help: Illinois could publish an annual digest of abuse/neglect *trends* (without violating privacy), highlighting system-wide issues and responses.
 - **Licensing Reviews and Unannounced Visits:** Increase the frequency of unannounced inspections of CILAs, ICF/DDs, and MC/DDs. Surprise visits often uncover issues that planned surveys may miss. The state might hire additional quality assurance staff to do random spot-checks on group homes (beyond the routine annual licensing). This can be framed as a supportive measure – the goal is to identify problems early (such as safety hazards or staff training deficits) and implement fixes, thereby improving the daily experience for residents. Family members often worry that nobody is watching what happens in a home at 10 pm on a Saturday; more random checks could address that concern.
 - **Use Technology for Oversight:** As planned for SODCs, video cameras in common areas can deter abuse. Illinois can pilot this in state facilities (with appropriate privacy considerations) and even consider encouraging it in common areas of larger group homes or day programs. Moreover, implementing electronic health records and incident reporting systems that flag concerning patterns in real-time would allow for quicker intervention by the state.
 - **Quality Measures and Feedback:** Oversight shouldn’t only be about catching negatives; it should also measure positives. Illinois should define quality of life indicators (e.g., community participation hours, employment rates, satisfaction surveys) for its DD services and require providers to report on them. This shifts focus to outcomes that matter to users (not just health/safety compliance). Publishing provider scorecards could empower individuals and families to choose high-quality services (market accountability). The state could convene a Quality Council, including self-advocates and families, to review systemic data and recommend continuous improvements.
- **Enhance Training and Workforce Development:** A well-trained, stable workforce is fundamental to good user experience. Illinois should continue raising DSP wages until they are competitive with similar jobs in other industries (to attract talent). However, beyond wages, improvements in training are also needed. Every staff member working in I/DD (whether in an SODC, CILA, or day program) should receive training in person-centered approaches, communication (including for non-verbal individuals), positive behavior supports (to manage challenging behaviors safely), and human rights. Following the abuse scandals, DHS has started providing additional training on abuse prevention

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and reporting. This could be expanded into a certification program for DSPs, offering professional development and perhaps tying completion to wage enhancements. When staff are better equipped and feel valued, individuals receive more respectful and effective support – improving their daily experience. The state can also partner with community colleges or universities to create a pipeline of trained caregivers, including specializing in high-need areas (for example, a certificate in “Supporting Individuals with Dual Diagnosis” to help those with I/DD and mental illness, who are often the ones in institutions).

- **Focus on Meaningful Daytime Engagement:** Life is more than just where you live – it’s how you spend your time. To truly fulfill Olmstead’s vision of inclusion, Illinois must ensure that community services are not limited to 9 am-3 pm in a sheltered workshop and then return to a group home without community contact. The state should promote initiatives for competitive, integrated employment for individuals who wish to work. This might include expanding supported employment services, incentivizing businesses to hire individuals with intellectual and developmental disabilities (I/DD), and phasing out sub-minimum wage programs in favor of fair wages and equal opportunities. For individuals with significant disabilities who may not have access to work, volunteer, or recreational opportunities in typical community settings, these opportunities should be integrated into their plans. The HCBS Settings Rule requires that day programs facilitate access to the broader community; therefore, compliance with this rule by 2023 must be sustained. The DHS could track and report the percentage of day program time that participants spend integrated with non-disabled peers, aiming to increase it annually. Additionally, individual choice in daily activities should be honored – some people might prefer to spend an afternoon at a library or park rather than at a program site. Self-directed day programming (where an individual, with support, creates their own schedule of community-based activities) could be an innovative option. By enriching daytime experiences, Illinois will vastly improve overall quality of life – people will build relationships beyond the service system and develop skills and interests, which is precisely what community integration means.
- **Address Housing and Transportation Needs:** A practical aspect of choice is having somewhere to live and a way to get around. Illinois should collaborate with housing authorities and developers to increase the availability of affordable and accessible housing for individuals with intellectual and developmental disabilities (I/DD). For example, set aside units in new developments for those coming out of SODCs or ICFs, coupled with mobile support services. This can facilitate more independent living (for those who don’t need full 24-hour care but still need some supports). On transportation, many individuals rely on paratransit or agency-provided rides. The state could invest in improving transportation options (perhaps expanding travel training, subsidizing Uber/Lyft-type accessible services, or funding vehicles for agencies) to ensure that living in the community truly means access to the community. Without mobility, a person’s “community” life can be very limited to their home.
- **Collaboration with the Department of Justice and Advocates:** Given DOJ’s current investigation, Illinois has an opportunity to collaborate proactively. Embracing technical assistance from DOJ or other states that have successfully complied with Olmstead could accelerate reforms. For example, other states have effectively closed all their institutions (Ohio, for instance, went from over a dozen state DD centers to just a few in recent years by boosting community supports). Illinois can learn from those models. The state should also maintain transparency with stakeholders, including self-

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advocates, families, providers, and advocacy organizations, regarding its plans and progress. Regular public reports on the Ligas implementation (which Illinois already publishes semiannually) and updates on steps taken in response to the “Culture of Cruelty” findings will help build trust and maintain momentum. Advocates like Equip for Equality and The Arc of Illinois should continue to be partners in crafting solutions, as they possess deep knowledge of the system's pain points.

By pursuing these recommendations, Illinois can move toward a redesigned system that is person-centered, well-resourced, and rights-driven. This will translate to measurable improvements in user experience: individuals will have more choice in where and how they live, will be safer from harm, and will have richer lives in the community. At the same time, the state will better fulfill its regulatory responsibilities and likely satisfy the court and DOJ that it is meeting its obligations under Olmstead and the ADA.

Summary and Conclusion

Since the Olmstead decision in 1999, Illinois has been challenged to transform its I/DD services from an institution-heavy system to one focused on community living, personal choice, and quality oversight. Significant progress has been made – the state has relocated thousands of people into community settings under the Ligas consent decree, and the number of individuals supported in family or small home environments has climbed from approximately 13,500 in 2011 to over 23,000 by 2023. Illinois also closed at least two large developmental centers (Howe and Jacksonville) and downsized many private facilities, signaling a shift toward integration. These changes have given many people with I/DD the opportunity to live more typical lives in their communities, in line with Olmstead’s mandate that services be provided in the “*most integrated setting*” appropriate.

However, the last decade – and especially the last few years – have also highlighted persistent shortcomings that negatively affect the user experience for Illinoisans with I/DD. The state continues to operate seven SODCs with ~1,600 residents, and investigative reports have uncovered appalling abuse and neglect in some of these institutions. At the same time, thousands remain on waiting lists for community services, and some individuals who want to live in the community are stuck in facilities due to a lack of specialized community options. Illinois’ independent monitor acknowledged that services are still “*in stark contrast to national best practices*,” noting outdated group home models (many with 6-8 people) and ongoing safety issues in larger settings. The attempt by Illinois in 2024 to terminate the Ligas court decree was rejected by a federal judge, who ruled that the state has not yet met its obligations to enable people to live outside large institutions. In early 2025, the U.S. Department of Justice launched an investigation into whether Illinois is unnecessarily institutionalizing people and failing to protect those in its care, a stark reminder that Illinois still falls short of full Olmstead compliance.

To truly improve user choice and quality of life – the heart of the user experience – Illinois must address these gaps with decisive action. This means continuing to shift resources into community-based services, so that every individual, including those with complex needs, has a viable community living option. It means empowering individuals (and their families) with information and support to make their own life choices, whether that’s pursuing a job, living with a roommate, or trying a new community activity. It also requires strong state oversight and accountability to ensure that all settings, from small homes to large facilities, are safe and uphold individuals’ rights. The state needs to invest in its oversight infrastructure – more OIG investigators, more rigorous licensing inspections, better training and wages for staff – to prevent abuse and

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substandard care. As one advocate put it, Illinois must shed its “*antiquated and oppressive*” aspects of service delivery and replace them with modern, person-centered supports.

In concrete terms, the following steps for Illinois could include developing more small-scale housing, enhancing crisis intervention services to avoid institutional admissions, reducing the size of group homes for a more home-like feel, and ensuring everyone’s voice is heard in service planning (including moving toward supported decision-making in lieu of overreliance on guardians). The state’s ongoing collaboration with the court monitor and the pressure of DOJ oversight offer an impetus to make these changes swiftly and sustainably. Advocacy efforts – such as this proposal – will be crucial in holding the state accountable and providing solutions informed by past lessons and successful models elsewhere.

In conclusion, the Olmstead decision set forth a vision of freedom and inclusion for people with disabilities. Illinois has embraced that vision in principle and has taken many steps forward; however, the journey is not yet complete. By focusing on user choice (expanding real options for integrated living and meaningful days) and strengthening state regulatory oversight (to assure safety, rights, and quality), Illinois can resolve the long-standing issues in its I/DD system. The outcome would be a system redesigned around the individual – one where, regardless of the level of disability, each person has the opportunity to live, work, and thrive in the community with the necessary supports. Such a system would not only fulfill Illinois’ legal obligations under Olmstead and various consent decrees, but more importantly, it would enable people with I/DD to lead richer, self-determined lives as fully included members of society. This is the ultimate measure of “user experience” – that individuals feel empowered, respected, and integrated – and it should be the guiding principle for Illinois’ reforms in the years ahead.

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