

PLANNING & PERMANENCE



2025 ANNUAL REPORT

ILLINOIS COUNCIL ON DEVELOPMENTAL DISABILITIES

Value People | Invest in Success



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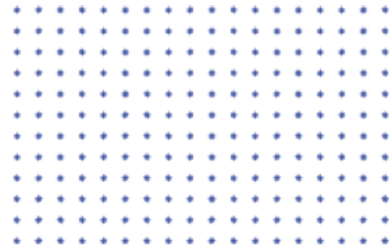
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DIRECTOR'S NOTE



In 2025, the Illinois Council on Developmental Disabilities (ICDD) delivered results that matter to the developmental disabilities community. We helped move Illinois from ideas to action resulting in lasting systems change.

This year marked a clear shift. Illinois began implementing the Dignity in Pay Act. Housing Navigation moved from a Council pilot to a permanent statewide service. Cross-agency coordination strengthened across employment, housing, health, transition, and the justice system. These changes did not happen by chance. They happened because people with disabilities, families, advocates, providers, and state partners worked together with focus and intent.

We also remained honest about the work ahead. Illinois continues to rely too heavily on institutional care. Workforce instability puts pressure on services statewide. Too many people still face barriers based on race, geography, income, or immigration status. In 2025, we did not look away from these realities. We studied them. We named them. We used data and lived experience to understand where systems fall short.

At the same time, we prepared for the future. Much of 2025 was spent building the foundation for our next Five-Year State Plan. We conducted a statewide landscape analysis. We examined gaps. We centered equity. This work ensures the next plan is grounded in evidence, accountability, and the voices of people most affected by the system.

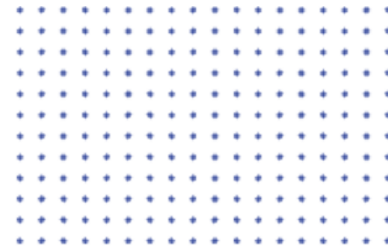
ICDD's role is clear. We convene. We challenge. We help Illinois build systems where people with developmental disabilities can live, work, and thrive in their communities. 2025 strengthened our ability to do exactly that.

Warm regards,

Director Kimberly Mercer-Schleider

Illinois Council on Developmental Disabilities

ILLINOIS' 2025 LANDSCAPE ANALYSIS



In Illinois, some things are getting better for people with developmental disabilities (DD) and families. More people can live and work in their communities instead of institutions. State agencies are working together more often to support jobs, housing, health care, and community life. These agencies share goals about fairness, inclusion, and helping people live full lives. Agencies are also using information and data to inform their work. Illinois now tracks how systems are changing and how employment is improving. This helps the State see what is working and what needs to change, especially as the Dignity in Pay Act moves forward. At the same time, there are still serious challenges.

Illinois still relies heavily on large institutions:

- Illinois operates 7 [State Operated Developmental Centers \(SODC\)](#).
- 1,523 people with DD live in those centers.
- 272 residents and families are currently exploring community placement options.
- Illinois is one of only four states with more than 1,000 people living in large state-run facilities.

By comparison:

- 18 states have zero people in these facilities.
- 22 states have fewer than 500 people.

Living in the community also costs less and gives people more choice:

- The average annual cost per person in an SODC is just under \$350,000.
- The average annual cost per person receiving 24-hour Community Integrated Living Arrangement supports is \$128,084.

Intermediate care facilities remain common.

- Illinois has 196 [Intermediate Care Facilities](#) serving about 3,800 residents.
- Large congregate settings continue to be a major part of the service system.
- 123 residents were identified for transition from the Choate SODC.

The Early Intervention system faces high demand and limited resources:

- Illinois has about 458,421 children under age 3.
- About 20 %, or 92,446 children, are estimated eligible for [Early Intervention](#).
- 43,893 children were served in FY24.
- FY24 spending totaled about \$208.5 million.
- An estimated \$432.2 million is needed to serve all eligible children.

There are not enough workers to meet current needs:

- 20% of Early Intervention providers reported they would not stay in the system without improvement within one year.

- Workforce shortages affect [Home and Community-Based Services \(HCBS\)](#), Early Intervention, and employment supports statewide.
- Low wages and burnout limit service access for people with DD and families.

🔍 Some people face more barriers than others:

- People of color, people living in rural areas, and people with lower incomes often have a harder time finding information, housing, jobs, and supports.
- Families report confusion navigating:
 - Education systems
 - Vocational rehabilitation
 - Medicaid eligibility and services
 - Adult service systems
- These systems are fragmented, especially during major life transitions.

In 2025, the Council did not ignore these challenges. We named them clearly. We studied them using data and real experiences. This work prepared Illinois to respond with focus, accountability, and a clear plan for the future.



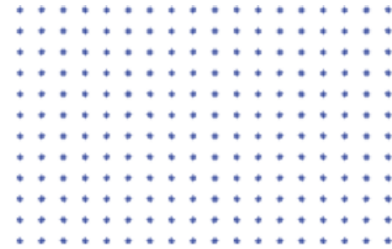
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As a mom, this makes a lot of sense to me. I see the progress Illinois is making, and I appreciate the focus on community living and jobs. But I also see how hard it still is to find clear information and steady support for my daughter. Reading this helped me understand why things feel so complicated and why change takes time. I'm glad we are able to name the problems and that we are able to plan for a better future for families like mine.

- Parent, Champaign, Illinois

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2025 AT A GLANCE: IMPACT & OUTCOMES



Dignity in Pay Act Leadership and Coordination:

ICDD played the central coordinating role required in statute for the [Dignity in Pay Act](#). The Director and a Council Member co-chaired the Dignity in Pay Workgroup under the [Employment and Economic Opportunities for People with Disabilities Task Force](#) (EEOPD). Staff convened and supported seven full workgroup meetings and extensive subgroup work, totaling more than 60 hours of facilitated planning. The result was the on-time submission of a comprehensive [Multi-Year Plan](#) to the [General Assembly](#) by July 1, 2025, containing 46 formal recommendations across people, providers, systems, results, and employer engagement. The process also included a public comment period that generated 75 discrete comments and the creation of a dedicated public resource website. This work positioned Illinois for full implementation through December 31, 2029, and reflects a major systems-level milestone rather than a one-time deliverable.

Targeted Investments to Support

Implementation: ICDD approved \$354,673 in new Federal Fiscal Year 2026 funding to support technical assistance, provider transformation, and implementation of the [Dignity in Pay Act](#). This included a major investment in statewide, cohort-based technical assistance to support providers transitioning away from subminimum wage practices. These investments were explicitly tied to gaps identified through EEOPD workgroups and national technical assistance, ensuring funds were targeted, time-limited, and aligned with measurable systems-change outcomes rather than duplicative services.

National Technical Assistance Leveraged at No

Cost: As a [National Expansion of Employment Opportunities \(NEON\) Core State](#), Illinois received approximately 300 hours of targeted national technical assistance at no cost to the Council. ICDD staff strategically aligned this assistance with state priorities, using it to inform the Dignity

in Pay Multi-Year Plan, strengthen interagency data infrastructure, advance Employment First coordination, and address reentry-related employment barriers. NEON subject matter experts directly informed recommendations embedded in the plan, accelerating readiness for implementation.

Provider Readiness and Early Practice Change:

ICDD used coordinated technical assistance to move providers from planning to early practice change. Through [Marc Gold & Associates](#) and related efforts, seven provider organizations participated in structured discovery and Customized Employment coaching. A total of 177 professionals participated in training and coaching activities, including 12 provider staff receiving intensive support and 165 provider and [Division of Rehabilitation Services](#) staff participating in broader trainings. Providers reported improved documentation, stronger alignment with customized employment principles, and increased staff confidence, demonstrating early but meaningful progress toward readiness for competitive integrated employment.

From Pilot to Permanent Systems Change:

ICDD intentionally designed initiatives so successful pilots transition to permanent ownership by state agencies. The [Housing Navigator model](#) is a clear example. After demonstrating effectiveness, the [Division of Developmental Disabilities \(DDD\)](#) fully adopted the program, funding Housing Navigators statewide and embedding the model into policy and waiver infrastructure. In 2025 alone, Housing Navigators supported 412 individuals exploring community housing and helped 36 people move into their own homes.

Education on Federal Budget Cuts and the One

Big Beautiful Bill Act (OBBBA): ICDD provided targeted education on the potential impacts of federal budget proposals, including the [OBBBA](#). Staff, Council Members, and community partners

analyzed how proposed changes could affect [Medicaid](#), [Supplemental Nutrition Assistance Program \(SNAP\)](#), and other critical supports relied on by people with DD and their families. ICDD worked to explain these impacts in clear, accessible language so advocates, providers, and policymakers could understand the real-world consequences of federal decisions. This education strengthened statewide awareness of how federal budget actions can directly threaten community-based services, employment supports, and family stability, and helped position Illinois to respond in an informed and coordinated way.

Education on the Importance of Home and Community-Based Services: ICDD increased education on the value and necessity of HCBS across Illinois. This included collaboration with [Access Living](#), the [Going Home Coalition](#), and other community partners to elevate the role of HCBS in supporting independence, equity, and cost-effective services. The Council emphasized the cost and quality advantages of community living over institutional care and highlighted HCBS as a cornerstone of disability rights, [Olmstead](#) compliance, and long-term system sustainability. This work laid the groundwork for a broader HCBS protection agenda in the next [Five-Year State Plan](#).

Self-Advocates continued to lead the way: ICDD strengthened self-advocacy by investing in leadership development, accessible information, and meaningful participation in policy and systems change. These efforts increased the ability of people with DD to understand issues that affect their lives, speak for themselves, and influence decisions at the local and state level.

- The Illinois Self Advocacy Alliance trained 108 self-advocates statewide, focusing on transition, employment, financial literacy, and community participation.
- 14 new leaders graduated from Partners in Policymaking, including people with disabilities, family members, siblings, and professionals committed to systems change.
- Two self-advocates were appointed to boards and commissions as a direct outcome of Council-supported leadership development.

- The [Speak Up Speak Out Summit](#) reached 1,514 participants, the highest participation in the program's history.
- A hybrid format expanded access for people in rural areas and for those who needed virtual participation options.
- Self-advocates played central roles in planning, presenting, and leading sessions, reinforcing peer-to-peer leadership and shared learning.

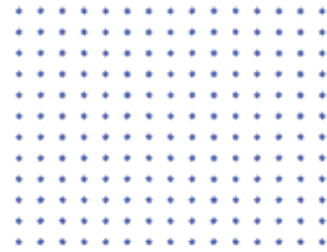
Information access and advocacy readiness:

- 175 people with DD received targeted education during the Dignity in Pay Act legislative period through action alerts and [plain language](#) updates.
- 380 family members and 657 professionals and allies were also educated during this period, strengthening aligned advocacy across groups.
- Over 8,000 subscribers received ongoing updates through ICDD listservs and briefings, increasing access to timely and understandable information.

Knowledge and decision-making outcomes:

- Across Individual and Family Advocacy activities, data showed that 80% of participants increased their knowledge and took part in decisions affecting their lives, their families, or broader systems.
- Self-advocates reported increased confidence in understanding policy issues, sharing lived experience, and participating in discussions with providers and state agencies.
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ADDITIONAL SYSTEMS CHANGE & POLICY IMPACT



Systems Change and Policy Impact:

- Housing Navigation became a permanent statewide service.
- 100% of Independent Service Coordination agencies now employ a Housing Navigator.
- Dignity in Pay Act Multi-Year Plan formally adopted in July 2025.
- Customized Employment and Discovery established as core implementation strategies.
- Employment & Economic Opportunities for People with Disabilities Task Force Dignity in Pay Act Workgroup fully operational.
 - Three standing subgroups established to drive implementation.
- 100+ members engaged across agencies, providers, self-advocates, families, and national partners.



Community Living and Housing Outcomes:

- 412 people with DD were supported to explore community housing options.
- 36 individuals moved from institutional or unstable settings into their own homes.
- 58 individuals used transition funds to secure housing, furnishings, or accessibility supports.



Self-Advocacy and Leadership Outcomes:

- 108 self-advocates trained statewide through the Illinois Self Advocacy Alliance.
- 1,514 participants attended Speak Up & Speak Out.
- Hybrid format expanded access for rural and underserved communities.
- 14 new [Partners in Policymaking](#) graduates.
- Nearly 8,000 individuals reached through leadership briefings, trainings, and action alerts.



Cross-System and Justice Impact:

- [Illinois Department of Corrections \(IDOC\)](#) education and employment access improved.
- Council-supported advocacy contributed to passage of school records legislation effective January 1, 2026.
- [Test of Adult Basic Education \(TABE\)](#) waiver policy advanced to improve access to vocational and educational programs for incarcerated people with DD in IDOC.

THE COUNCIL IN ACTION

In 2025, Council members played an active and visible role in advocacy across the State of Illinois. Their involvement went beyond advisory participation and reflected direct engagement in policy education, systems change, and public advocacy grounded in lived experience.

Council members used their voices to inform state and national decision-makers. During the legislative session, members participated in meetings, hearings, and public events related to employment, Medicaid, and disability rights.

Several Council members shared personal stories to help lawmakers understand how policy decisions affect people with DD and their families in real life. This advocacy helped translate complex policy issues into human impact.

Council members also contributed directly to the implementation of the Dignity in Pay Act. Members served on and co-chaired workgroups under the Employment and EEOPD Task Force, providing lived experience input that shaped recommendations related to employment expectations, choice, and equity. Their participation helped ensure the Multi-Year Plan reflected the priorities of people most affected by subminimum wage practices.

At the federal level, Council members engaged in national advocacy efforts related to 14(c) reform. Members participated in the U.S. Department of Labor public comment process, submitting written statements informed by their experiences as self-advocates and family members. This ensured Illinois voices were represented in



national conversations about employment equity and wage reform.

Council members also played a role in educating policymakers and the broader community about Medicaid and HCBS. Through participation in Medicaid Office Hours and related advocacy activities, members helped explain how proposed federal budget changes could affect access to services, community living, and family stability. Following these sessions, Council members and participants took additional action by writing letters, recording videos, and sharing stories to support HCBS protection.

In addition to external advocacy, Council members strengthened their own advocacy capacity. Members participated in Development Days and policy briefings that increased understanding of legislation, systems change strategies, and effective advocacy approaches. This investment supported informed participation in Council decision-making and external advocacy efforts.

Through these activities, Council members helped advance individual and family advocacy outcomes in 2025. Their leadership increased awareness of disability issues among policymakers, informed systems change efforts and strengthened the role of people with DD and their families in shaping policies that affect their lives.

- Self-Advocate, DuPage County

Being on the Council means my lived experience matters. In 2025, I did more than attend meetings. I helped shape policy, spoke directly to lawmakers, and made sure decisions reflected real lives, not just paperwork. I saw how my voice helped move Illinois forward, especially on jobs, community living, and protecting Medicaid. That matters to me, and it matters to families like mine.

FINANCIAL REPORT & IMPACT



From October 1, 2024 through September 30, 2025, ICDD received **\$2,707,402** in federal funding to support its work.

The Council used these funds carefully and as planned. About **\$1.27 million** was spent during the year on approved activities.

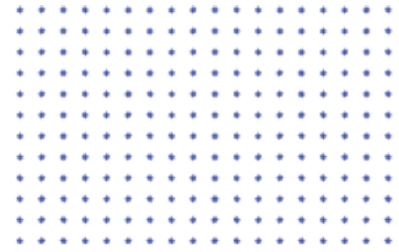
The remaining **\$1.43 million** was already committed to projects that continue into the next year. This means all funds were planned for and no federal money was left unused.

No additional state funds were used for Council activities during this period.

This approach allows the Council to support long-term projects, avoid gaps in services, and stay focused on lasting systems change rather than short-term spending.



PREPARING FOR THE NEXT 5 YEARS



In 2025, ICDD intentionally focused on preparing Illinois for the next Five-Year State Plan. While the Council continued to deliver measurable impact, this year also served as a bridge between implementation and long-term planning.

The Council conducted a comprehensive statewide landscape analysis to better understand how Illinois' service systems are working for people with DD and where gaps persist. This analysis examined community living, employment, health, transition, and access to services across the state.

Special attention was given to populations that are often unserved or underserved. The Council analyzed barriers faced by people of color, people living in poverty, undocumented individuals, and people in rural communities. This work helped clarify where access breaks down and where targeted strategies are needed.

The landscape analysis also incorporated data from the Comprehensive Review and Analysis. This included information on institutional reliance, workforce instability, Early Intervention system strain, and the rising cost of maintaining segregated systems compared to community-based services. These findings helped ground future planning in real conditions rather than assumptions.

Throughout 2025, findings from this work were shared with the full Council. Council members used this information to discuss priorities, test assumptions, and shape early direction for the next plan. This ensured planning was informed by data, lived experience, and statewide context.

In parallel, the Council strengthened its systems-readiness work. The adoption of the Dignity in Pay Act Multi-Year Plan provided a clear implementation roadmap through December 31, 2029. Housing Navigation transitioned from a pilot to a permanent statewide service, allowing the Council to shift from direct management to monitoring and targeted technical assistance. These milestones create a stronger foundation for future work.

The Council also used 2025 to prepare for emerging risks. Education on federal budget proposals, including the One Big Beautiful Bill, helped communities and policymakers understand potential threats to Medicaid, SNAP, and HCBS. This work positioned Illinois to respond more quickly and strategically if funding or policy changes occur.

By the end of 2025, the Council was positioned to enter the next Five-Year State Plan cycle with clarity and purpose. The groundwork was laid through research, planning, and systems alignment. This approach ensures the next plan will be evidence-based, equity-focused, and designed to produce measurable results for people with DD and their families.

Onward...



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