



# FAMILIES LEADING THE WAY:

## Transforming Supports for Adults with Complex Disabilities

The Arc of Illinois - April 29, 2026

## **What We'll Cover**

- Who is IPACD
- The current system
- How it works in practice
- How Illinois compares nationally
- What's missing and the solution
- How we build this in Illinois

# **Illinois Partners for Adults with Complex Disabilities**



## Who is **IPACD**

- A grassroots, family-led effort
- Families navigating the same system
- Built from lived experience
- United by one shared reality:

**The system wasn't designed for adults with complex support needs.**



# Our Purpose

**Ensuring people with  
complex support needs  
can live with dignity and choice  
in their own homes  
and communities.**

# What are Complex Support Needs

- Significant medical and/or clinical support needs
- Requires continuous 24-hour support for daily living
- May include behavioral or mental health support needs
- May rely on specialized equipment or technology
- High risk without consistent support
- Requires coordinated, integrated supports and services

**This is the group most impacted by system gaps.**

# **The System As It Exists Today**

**This is what families are expected to navigate.**

# What Exists Today

- Primary service pathways within the Adults with Developmental Disabilities Waiver
  - Community Integrated Living Arrangements (CILA)
  - Intermittent Community Integrated Living Arrangements (iCILA)
  - Home-Based Services
- Independent Service Coordination (ISC) agencies and Qualified Intellectual Disability Professionals (QIDPs) coordinate and oversee supports
- Institutional settings are often used when support needs exceed community capacity
  - State Operated Developmental Centers (SODCs)
  - Intermediate Care Facility for Individuals with Developmental Disabilities (ICF/DD)
  - Nursing Homes

**The system that exists falls short for those with high support needs.**

# What Happens in Practice

- Choices are limited to what is available
- Families often take a significant role coordinating and managing services
- No clearly defined 24-hour in-home supported living service
- Supports can be fragmented and difficult to coordinate
- Providers often can't, or choose not to, accept higher-acuity needs
- Staffing gaps shift burden to families as backup

**Without a viable option, higher cost institutional settings are used.**

# The System Is Built on Aging Caregivers

- Most adults with complex disabilities live at home with family
- Caregivers are aging—many in their 60s, 70s, and beyond
- When parents can no longer provide care and coordination → **crisis**
- There is often no clear plan for what comes next
- This creates significant risk over time.

**This is not sustainable and families know it.**

# What Happens When the System Falls Short

- Staffing gaps shift responsibility to families who often step in to provide round-the-clock support
- Many primary caregivers are aging, often without a clear long-term plan
- Short-term crisis placements often become long-term realities
- System defaults to institutions when no sustainable community option exists
- People don't have meaningful choice among options
- Individual civil rights under the ADA, Olmstead Decision, and Ligas Consent Decree are potentially violated

## Families Pay The Price

# **Illinois Is Not Keeping Pace Nationally**

**This isn't just about Illinois  
It's about where Illinois stands compared to other states**

# It's Not Just What You Spend

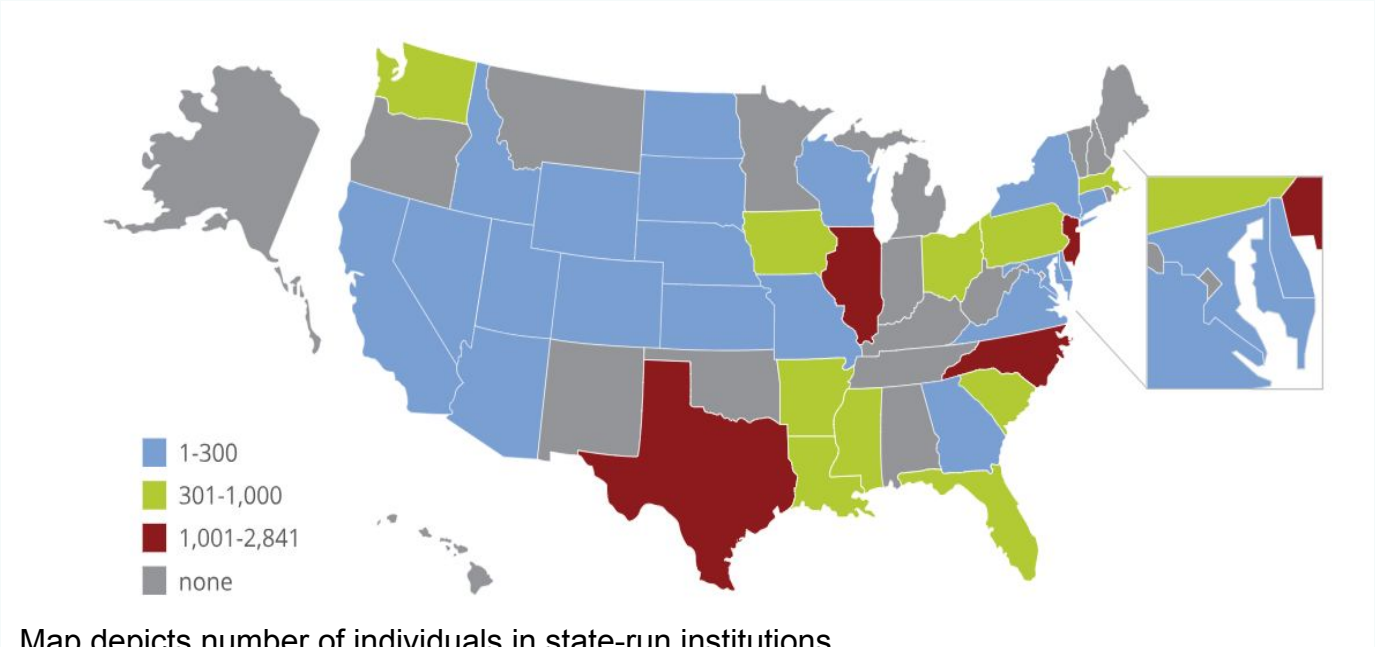
Spending must be viewed in **context**

- Compared to the **state's total budget**
- Compared to the **size of the population**
- Compared to **other states**

**It's how resources are prioritized.**

# National Practice

As of recent national data, **17** states and the District of Columbia have eliminated state-run institutions and support individuals with complex needs in the community<sup>(1)</sup>.



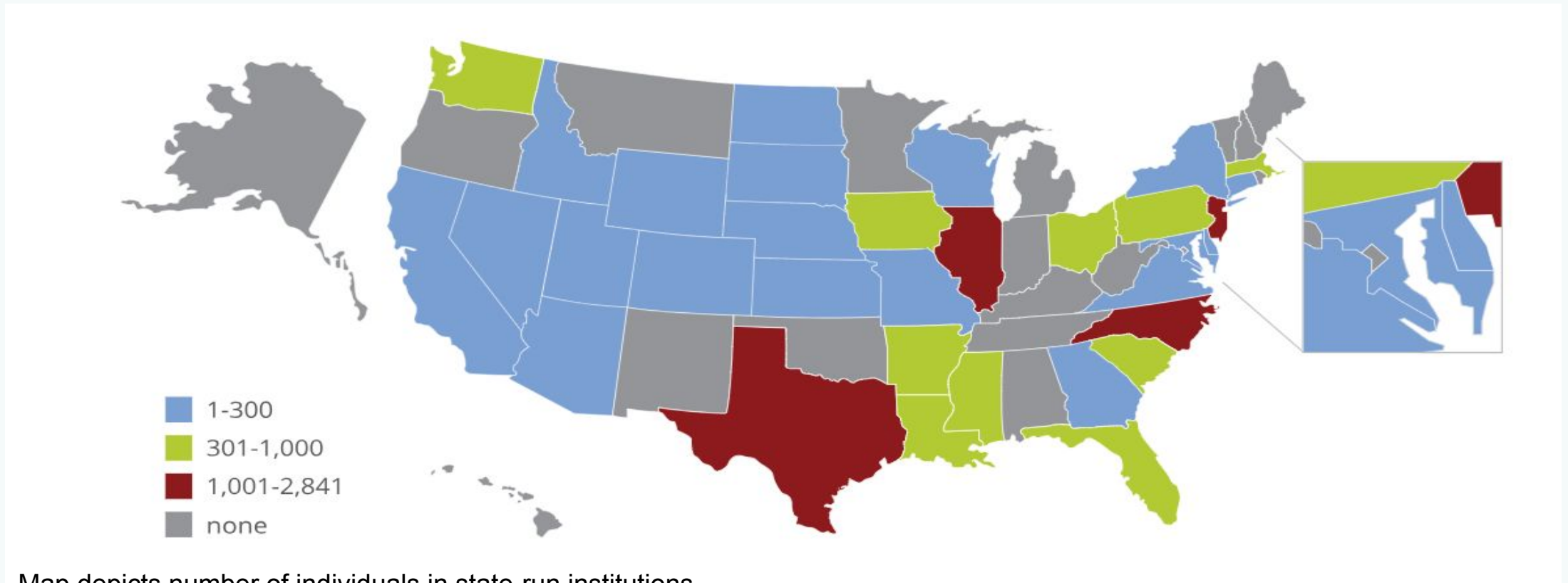
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- New Hampshire
- New Mexico
- Oklahoma
- Oregon
- Rhode Island
- Tennessee
- Vermont
- West Virginia
- District of Columbia

<sup>(1)</sup>Residential Information Systems Project (2020). Minneapolis: University of Minnesota, RISP, Research and Training Center on Community Living, Institute on Community Integration. Retrieved from: <https://risp.umn.edu>

# Illinois is an Outlier

Only four states have over 1,000 people still living in large state-run institutions<sup>(1)</sup>.

- Illinois still has over **1,500** SODC residents
- Many nearby states have drastically reduced or eliminated their use of these facilities



<sup>(1)</sup>Residential Information Systems Project (2020). Minneapolis: University of Minnesota, RISP, Research and Training Center on Community Living, Institute on Community Integration. Retrieved from: <https://risp.umn.edu>

# Illinois Is Out of Step with National Trends

## Fiscal Effort: Spending per \$1,000 Personal Income<sup>(2)</sup>

	National Average	Illinois	
<b>Total</b>	\$4.65	\$3.11	67% of National average
<b>HCBS Funding</b>	\$4.30	\$2.12	49% of National average
<b>Institutions</b>	\$0.35	\$0.99	

**Illinois invests **less than half** the national average on community-based supports.**

<sup>(2)</sup>State of States report 2025, U Kansas – Fiscal Effort for IDD LTSS (Does not include Health Care Expenses) Spending per \$1,000 Personal Income.

# Illinois Falls Behind

Ranks **near the bottom (40<sup>th</sup>) nationally** in **total** fiscal effort for people with I/DD

- Illinois ranks **near last** in the nation—**48th in community investment.**
- Ranks near top for investment in institutional settings (**6th**)

• Leads to:

- ✓ Long waitlists
- ✓ Limited service options in the community
- ✓ Institutional reliance

**Illinois ranks near the bottom and the results reflect that.**

# **What's Missing — and What Solves It**

**System changes are not only about funding, but structure also plays a key role**

# The Gap in the System

- No clearly defined 24-hour supported living service in a person's own home
- Options not consistently structured to support higher-acuity needs
- No scalable solution for individuals with the most complex support needs

**We don't lack services – we lack the right services.**

# Community Supported Living (CSL-24): Shifting from “Where” to “How”

- **History**

- 1987: Congress authorized Community Supported Living Arrangements (CSLA)
- 1990s: States began developing Supported Living through HCBS waivers
- Available to states, including Illinois, for decades

- **What was different**

- Separated housing from supports
- Support funding tied to the person, not the facility or provider
- Person-centered which allowed people to:
  - Choose where they live
  - Choose if they live with someone
  - Control daily routines

**Illinois has had the option to develop this service but has not.**

# Community Supported Living (CSL-24): A Federally defined 24-hour in-home support option

- **Home & Choice**

- The home is controlled by the person—not the provider (full tenancy rights)
- Choice of up to 2 housemates (if any)

- **Structure & Accountability**

- Separation of housing from services
- One designated provider holds continuous 24-hour responsibility

- **Support**

- Person-centered planning that drives supports
- Full community integration, inclusion, and belonging
- Adjusts as needs change—without forcing someone to move

**Provides 24-hour support for individuals with complex needs.**

# This Service Option Already Works

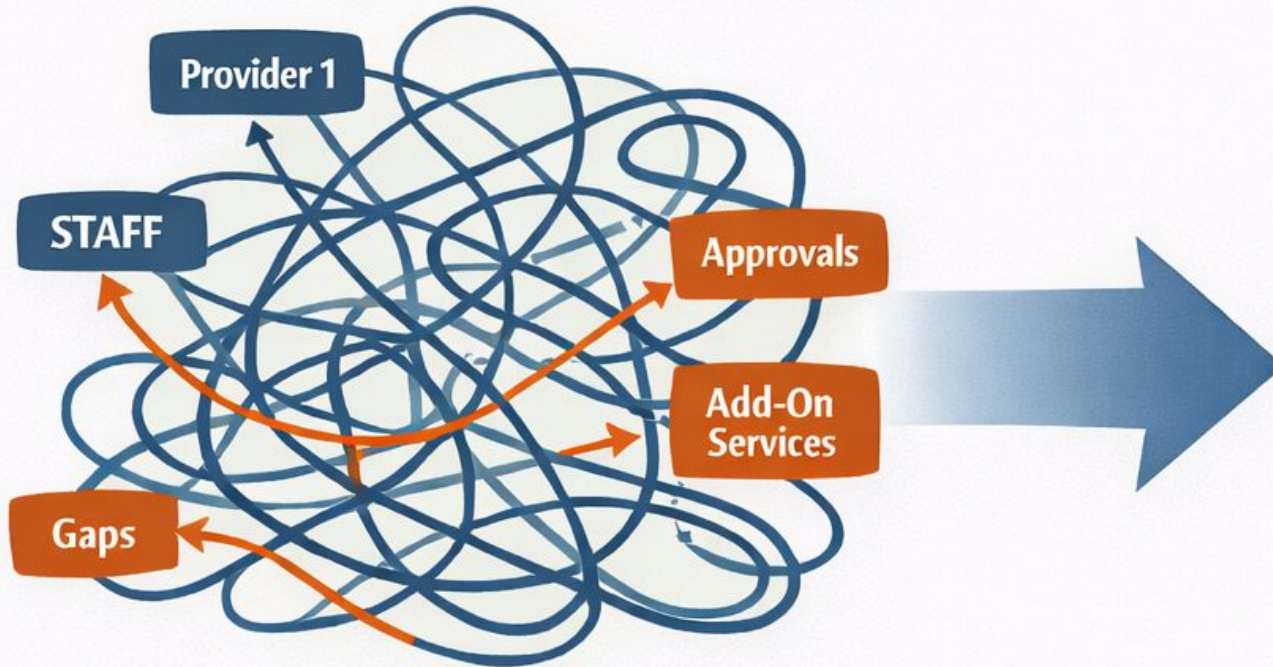
- Implemented in many other Midwest states
  - Wisconsin, Missouri, Iowa, Michigan, Indiana, North Dakota, Kansas, Minnesota
- Supports individuals with complex needs
- Helps prevent institutional placement
- Separation of housing from services/supports
- Built for clinical and behavioral complexity
- One provider holds continuous 24-hour responsibility

**This is not a new idea.**

**The principles have been reflected in Federal policy for over 30 years.**

# From What Families Face Today → To What's Possible

## Today's Journey



Families are left to navigate and piece this together

## Future with HB5605



Support is designed around the person from the start

# From System-Centered → Person-Centered

## Today

- Fragmented supports
- Placements and settings often provider controlled
- Gaps in accountability
- Crisis driven → institutional placement

## CSL-24

- Single accountable provider 24-hour support
- Individual controls their home and choice of housemates
- Person-centered supports with individual choice and direction
- Stable supports in the community
- Supports adjust as needs change reducing the need for disruptive moves

# **How We Build This In Illinois**

## **HB5605**

**A Defined 24-hour Community Supported Living Service**

# The Policy Solution

## **HB5605: The Community Supported Living Arrangement Services Act**

Created to:

- To fill a long-standing gap in the current service system
- To support individuals whose needs are not fully met by existing options
- To create a consistent, statewide approach for complex support needs
- To ensure supports are reliable, coordinated, and continuous
- To strengthen long-term system sustainability

# What HB5605 Does

- ✓ Adds a defined 24-hour supported living service
- ✓ Establishes provider accountability for continuous support
- ✓ Expands the ability for people to live in their own homes
- ✓ Keeps housing separate from services even as needs change
- ✓ Helps reduce costly crises and institutional placements
- ✓ Phased implementation, prioritizing highest needs first

**Closes a long-standing service gap in Illinois.**

# What HB5605 Does Not Do

- ✘ Does not create a new waiver
- ✘ Does not eliminate or replace existing services
- ✘ Does not reduce current services
- ✘ Does not require anyone to move
- ✘ Does not expand eligibility beyond current waiver criteria

**This is additive - not disruptive.**

# The Opportunity: A More Sustainable Approach

- Shift investment toward planned, community-based support
- Reduce reliance on higher-cost institutions over time
- Support people in stable, home-based settings
- Improve outcomes while managing long-term costs

**Targeted investment now sets the foundation for long-term savings and better outcomes.**

# The Cost of Doing Nothing

- Reactive, crisis-driven supports cost more over time
- High-cost institutional care remains a major investment
- Families continue to fill system gaps
- Demand grows without sustainable solutions.

**This isn't a neutral choice -  
doing nothing has real financial and human costs.**

# Why This Matters

## For Individuals/Families:

- Stability and continuity
- Dignity and choice
- Fewer crisis placements
- Ability to plan for the future
- Peace of mind
- Better quality of life

## For Illinois:

- Strengthens accountability
- Reduces institutional reliance
- Helps reduce legal and fiscal risk
  - Strengthens compliance with ADA, Olmstead (most integrated setting requirement)
  - Aligns with **Ligas Consent Decree commitments**
- Uses public dollars more effectively

**This is not innovation for Illinois.  
It's playing catch-up in Policy and Practice.**

# Momentum Is Building

- Bill is assigned to House Human Services Committee
- 840+ witness slips in support for the first round
- Growing legislative support
- Growing stakeholder engagement

**This is moving forward.**

# Collective Action is How Change Happens

- Advocacy works
- Messaging matters
- Change takes persistence
- Legislating change takes time

**Together we're a powerful force for change.**

# How We Rise Together

- Join IPACD
- Learn about the bill
- Follow updates on Facebook
- Submit witness slips every time requested
  - Written testimony is even more powerful
- Meet with legislators
- Share your story

**This isn't about whether it can be done —  
there is clear evidence that it works.**

**It's about whether we choose to build something  
that truly supports people and families,  
in a way that reduces long-term costs and  
supports better outcomes.**

**It's a Choice.**

**Shirley Sains**

**Paul Blobaum**

**[IPACDD@gmail.com](mailto:IPACDD@gmail.com)**

**[www.SupportTheComplex.org](http://www.SupportTheComplex.org)**



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