

Illinois HB5605 – Community Supported Living Act

Frequently Asked Questions

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Common Terminology

ADA – The Americans with Disabilities Act

BALC – Bureau of Accreditation, Licensure and Certification

CILA – Community Integrated Living Arrangement

CSL-24 – Community Supported Living-24 Hour

DDD – Division of Developmental Disabilities

HCBS – Home and Community Based Services

ICF/DD – Intermediate Care Facility for Individuals with Developmental Disabilities

I-CILA – Intermittent Community Integrated Living Arrangement

IDHS – Illinois Department of Human Services

IPACD – Illinois Partners for Adults with Complex Disabilities

SODC – State Operated Developmental Center

Overview and Purpose

Q1. Does this bill create a new system or replace existing services?

No. HB5605 works within the existing Illinois Adults with Developmental Disabilities Medicaid waiver and does not replace or eliminate existing services.

Instead, it creates a more clearly defined Community Supported Living option for individuals whose needs are not consistently supported through intermittent, shift-based, or disconnected support arrangements, often referred to as fragmented supports.

Many families are currently coordinating multiple services themselves and function as the long-term “backup system” when supports break down. Individuals requiring continuous supports struggle to access stable community services because current structures are not consistently designed around long-term coordination, accountability, continuity, and sustainable community living over time.

Illinois continues to lack sufficient community support infrastructure specifically designed to consistently support individuals with the most complex needs in integrated community settings.

HB5605 is intended to be additive rather than disruptive within the existing waiver system.

Q2. Does it comply with federal HCBS rules?

Yes. The bill is designed to operate within existing federal HCBS requirements, including the HCBS Settings Rule, the ADA, Olmstead, and the Ligas Consent Decree, supporting individuals with disabilities in the **most integrated** setting possible.

Q3. Does this bill change eligibility for the waiver?

No. HB5605 does not change who qualifies for services under the Adults with Developmental Disabilities Medicaid waiver.

Instead, it establishes service-specific criteria used to determine whether CSL-24 is an appropriate support option for an individual within the existing waiver system.

Q4. Will Community Supported Living affect the PUNS wait list?

No. This bill does not change the PUNS wait list or create a separate entry process. It adds an additional service support option within the existing waiver system.

How CSL-24 Differs from Existing Services

Q5. Does this duplicate existing services like CILA and I-CILA?

No. Current I-CILA services have functioned as intermittent staffing structures rather than continuous, coordinated 24-hour community supports.

I-CILA services have functioned as intermittent support structures and have not consistently been designed or implemented as comprehensive provider-accountable 24-hour living support models for individuals requiring continuous supports. As a result, extending intermittent support structures to individuals requiring continuous supports may still result in instability because the underlying service structure was not originally designed around continuous provider responsibility.

CSL-24 is designed around individualized supports, person-directed living, and ongoing provider responsibility for maintaining stable supports over time within a home selected by the individual.

CSL-24 also differs structurally from traditional CILA settings, which often rely on shared staffing structures, provider-controlled housing, and licensing requirements associated with the physical CILA setting. CSL-24 is designed around separation of housing and services, allowing individuals to retain greater control over where and with whom they live.

HB5605 does not eliminate or replace existing CILA services. It adds an additional option for individuals whose needs may require a more continuous, coordinated and provider-accountable support structure in their own home.

Q6. Why does HB5605 place so much emphasis on person-centered planning?

Federal HCBS rules require services to be built around the individual's goals, preferences, strengths, and support needs.

HB5605 strengthens person-centered planning by requiring staffing, housing decisions, health, safety supports, and community participation to be guided by the individual's Person-Centered Plan rather than standardized residential program models.

Person-centered planning also helps ensure supports can adapt as needs change over time.

Q7. Doesn't Illinois already have a "Supportive Living" program?

Illinois does have a Supportive Living program, but it is a different system that primarily serves older adults and people with physical disabilities in licensed supportive living facilities. It is not designed as an individualized 24-hour community living service for people with developmental disabilities living in their own homes.

Community Supported ed Living is different. It is a Medicaid HCBS waiver service option designed to support individualized community living for people with developmental disabilities who require continuous supports

within their own homes and communities. Community Supported Living is not tied to a facility and emphasizes person-centered planning, individualized staffing, and ongoing coordination.

Q8. Would the home have to be licensed? How is oversight ensured?

No. The individual's home itself would not be licensed as a facility or require BALC review.

However, providers would remain subject to certification, monitoring, oversight, and compliance requirements established by the Department.

Providers would also remain responsible for maintaining health and safety, staffing stability, continuity of supports, and compliance with applicable Department requirements and oversight processes.

Q9. Does this increase costs?

Yes and no. HB5605 will require an initial targeted, phased investment to help build more stable community support infrastructure, provider capacity, staffing models, and coordinated support systems for individuals requiring continuous supports.

However, Illinois already incurs substantial costs through crisis response, emergency utilization, failed placements, workforce instability, caregiver collapse, and continued reliance on institutional systems. Illinois also continues to maintain costly, aged institutional infrastructure while many individuals with complex needs still lack sustainable community-based options.

Over time, expanding stable community-based supports should reduce reliance on higher-cost crisis and institutional systems while allowing resources to be more effectively rebalanced toward sustainable community living.

HB5605 is intended to improve continuity, accountability, and long-term system stability rather than repeatedly rebuilding staffing, provider relationships, housing arrangements, and support systems after breakdowns occur.

Housing, Choice, and Daily Living

Q10. Do families have to own a home to use this service? What is the family role?

No. Families are not required to provide housing or coordinate services, although many may choose to remain actively involved in planning and community life for the individual with a disability.

CSL-24 is intended to support living arrangements in homes that are not required to be provider-owned or provider-controlled.

Providers may assist individuals in locating and coordinating community housing, but the housing itself remains under the individual's control and separate from the service. The goal is to support greater residential choice and control for individuals requiring continuous supports.

Q11. Will Community Supported Living help only individuals with the highest support needs?

HB5605 is intended for individuals whose needs require continuous or 24-hour availability of supports to live safely and successfully in the community.

This includes individuals currently living with aging caregivers, individuals receiving insufficient waiver supports, and individuals residing in or at risk of placement in institutional or congregate settings, including state-operated developmental centers (SODCs), ICF/DD settings, nursing facilities, or other restrictive environments — because sustainable long-term community options capable of supporting complex needs remain limited.

Individuals with significant medical, behavioral, or physical support needs may also experience difficulty locating community providers or residential settings capable of consistently supporting their needs.

Implementation will be guided by evaluation and is intended to occur in a phased manner focused initially on individuals with the most complex needs while remaining available to others meeting service criteria as capacity develops.

Q12. Are roommates required?

No. Shared living is an option, not a requirement. Individuals may choose to live alone or with up to two housemates of their choosing.

Shared living may help individuals access affordable or accessible housing by sharing a portion of housing costs while maintaining individualized supports and community integration. Smaller home settings are frequently recognized nationally as an important quality indicator associated with greater individualization, autonomy, and community integration.

Research has often associated smaller individualized living settings with improved quality of life, increased choice, and greater community engagement.

Q13. How does someone access Community Supported Living?

Access remains through the existing PUNS process and Independent Service Coordination agencies. HB5605 does not create a new entry point into services.

Workforce, Oversight, and Eligibility

Q14. Why does HB5605 place so much emphasis on workforce development and training?

Individuals requiring continuous supports often depend on highly skilled and stable support teams.

HB5605 emphasizes workforce stability, training, coordination, career development, and relationship-based supports because continuity may directly affect communication, health, safety, behavioral stability, and long-term community stability.

More stable staffing structures may improve staff retention, reduce staff turnover, strengthen communication, and improve long-term outcomes for both individuals and providers.

HB5605 is intended to strengthen and modernize community support structures, not replace existing providers or services.

Q15. Is this only for people with medical needs? Why is HRST included?

No. HB5605 is intended for individuals with significant support needs that may include physical, behavioral, or health-related complexities. It is not limited to a medical diagnosis.

HB5605 operates within existing Medicaid waiver authority and does not create a new institutional level of care or a separate medical eligibility category.

HRST is already widely used within Illinois developmental disability services as a standardized tool to assess health and support complexity. Additional assessments and person-centered evaluation would continue to be part of the planning and authorization process.

Q16. Why is “one accountable provider” important?

Many families currently coordinate across multiple staffing, oversight, crisis-response, and support systems with no single entity fully responsible for maintaining long-term stability.

In many Home-Based or self-directed arrangements, families themselves often remain responsible for managing staffing, scheduling, training, oversight, emergency backup coverage, and long-term coordination of the support system.

Community Supported Living is designed around one accountable provider responsible for coordinating and maintaining continuous supports based on the individual’s Person-Centered Plan. This includes integrating direct supports, coordination, oversight, and backup systems rather than shifting gaps and disruptions back onto families.

The goal is to create clearer long-term responsibility for maintaining stable community supports rather than fragmented responsibility that changes across staffing shifts or service systems.

Individuals would continue to retain choice and control over services, including the ability to change providers if supports are not meeting their needs.

Person-Centered Planning and Independent Service Coordination responsibilities would continue consistent with existing waiver oversight requirements.

Q17. How will this be implemented?

HB5605 includes phased implementation, evaluation, workforce development, and ongoing review to help Illinois build sustainable community infrastructure over time. Initial implementation is intended to prioritize individuals with the most complex and urgent support needs while allowing provider capacity, oversight systems, and workforce supports to develop responsibly.

The bill is intended to support careful development and long-term system stability rather than immediate large-scale expansion.

HB5605 is also intended to help Illinois build the long-term community infrastructure necessary to support individuals with the most complex needs in integrated community settings.

Why Families Are Asking for This

Q18. Why not just add more hours to existing services?

For many individuals requiring continuous supports, the issue is not simply the number of authorized hours. The larger challenge is whether supports are structured to function continuously, reliably, and sustainably over time.

Current services are often fragmented across multiple staffing, coordination, oversight, and crisis-response systems. Many families remain responsible for coordinating staffing, filling service gaps, responding to emergencies, training new staff, and maintaining long-term stability when systems break down.

Simply increasing hours does not necessarily create a support structure capable of remaining stable when families are no longer able to coordinate and sustain the system themselves.

Some families rely on Home-Based or self-directed services not because they are the ideal long-term structure, but because more coordinated community options may not consistently exist or may not consistently support individuals with the most complex needs.

CSL-24 is intended to create a more coordinated and accountable support structure where responsibility for maintaining continuous supports does not rely primarily on unpaid family management.

In addition, individuals with significant physical or medical support needs may face limited access to appropriate accessible housing within existing community residential structures.

Some individuals may also experience limited access to meaningful day, employment, or community participation opportunities when individualized supports are unavailable.

Q19. Would anyone be forced to move into Community Supported Living?

No. Community Supported Living is intended to expand options, not replace existing services or require anyone to move.

Individuals and families would continue making choices based on their own goals, preferences, and support needs.

Q20. Is Community Supported Living only for people living with family?

No. Community Supported Living is intended for individuals requiring continuous supports in the community, regardless of their current living situation.

Some individuals may currently live with aging caregivers, while others may be at risk of institutionalization, repeated crisis utilization, or unstable community placements.

Q21. Does this create mini-institutions or more group homes?

No. HB5605 is designed around individualized community living in integrated community settings rather than larger congregate service structures.

Individuals may choose to live alone or with a limited number of housemates of their choosing in homes integrated within the broader community.

The bill emphasizes person-centered planning, individualized supports, separation of housing from provider ownership or control, and greater residential choice and control.

The goal is to build supports that adapt around the individual over time rather than requiring disruptive moves, loss of housing, or repeated changes in providers and living arrangements as support needs evolve.

Q22. What would Community Supported Living change for families?

Many families currently remain responsible for coordinating staffing, filling service gaps, responding to emergencies, training new staff, and maintaining long-term stability when systems break down.

For many individuals with complex needs, the long-term goal is not simply receiving more service hours but building support structures capable of remaining stable and functional over time — including when parents or family members are no longer able to coordinate, stabilize, or sustain the system themselves.

For many families, long-term stability also means creating supports that can remain with the individual over time rather than repeatedly rebuilding supports or requiring disruptive moves as needs change.

Many individuals also want the opportunity to live outside the family home while remaining connected to their community, relationships, and daily life — the same expectation most adults have for adulthood.

CSL-24 is designed to create a more coordinated and accountable support structure where one provider remains responsible for organizing and maintaining continuous supports around the individual's Person-Centered Plan.

Families may still choose to remain actively involved, but the goal is to reduce dependence on unpaid family crisis management as the primary stabilization system.

Q23. What happens if nothing changes?

Without more sustainable community support structures, Illinois will continue experiencing repeated cycles of crisis utilization, staffing instability, preventable hospitalizations, caregiver burnout, placement disruptions, and continued reliance on institutional and emergency systems.

HB5605 is intended to support long-term community stability rather than continued reliance on crisis response and unstable support arrangements.

Q24. What happens when parents age or can no longer provide support?

Many families currently continue providing extensive coordination and crisis management well into adulthood because stable long-term community supports are difficult to secure.

Community Supported Living is intended to help create more sustainable support arrangements that can remain stable over time, including when aging caregivers are no longer able to continue serving as the primary support system.

This is especially important as many family caregivers continue aging while remaining the primary coordination and stabilization system for adult supports.

HB5605 is intended to help build community support structures that remain stable even when families can no longer continue serving in that role.

Getting Involved

Q25. What can I do to help support HB5605?

You can help by:

- Joining IPACD or participating in advocacy efforts supporting individuals with complex support needs
- Filing witness slips and written testimony for Illinois House and Senate committee meetings and hearings
- Talking to your state legislators about HB5605 – find your state legislators here:

<https://www.elections.il.gov/electionoperations/districtlocator/districtofficialsearchbyaddress.aspx>

- Writing letters to your local newspapers or submitting letters to the editor
- Sharing information with others
- **Consulting with and providing updates to IPACD leadership regarding advocacy activities, outreach efforts, and related initiatives to support coordination, communication, and overall outreach efforts. Email IPACDD@gmail.com**

More information is available at:

www.SupportTheComplex.org