

# A Supported Living Model

## Team 209

*Presented by  
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September 24, 2025*

# SHE NEEDED ....

Living

Flexible Innovative Supported

## Ashley's Story

**When Ashley's mom passed away with her dad already gone, she was scared she would have nowhere to live.**

**She was in crisis.**

**It was suggested she move to Springfield. To a State Operated Developmental Center there.**

**An institution.**



# **SHE NEEDED ....**

*Model*

*A Flexible Innovative Supported Living*

## **Ashley's Story**

**Luckily, her mom had many close friends who said, “NO!”**

**Together they formed a Circle of Support with help from new Champions in her life, Vicki, Nancy, Chris and Anna who said, “We can help you think about a NEW future Ashley, and we will be there to guide you!”**

**Ashley learned to dream again. A new chapter began to fold.**



# Illinois Choices

## **Box A:**

Agency Managed  
CILA, ICILA

## **Box B:**

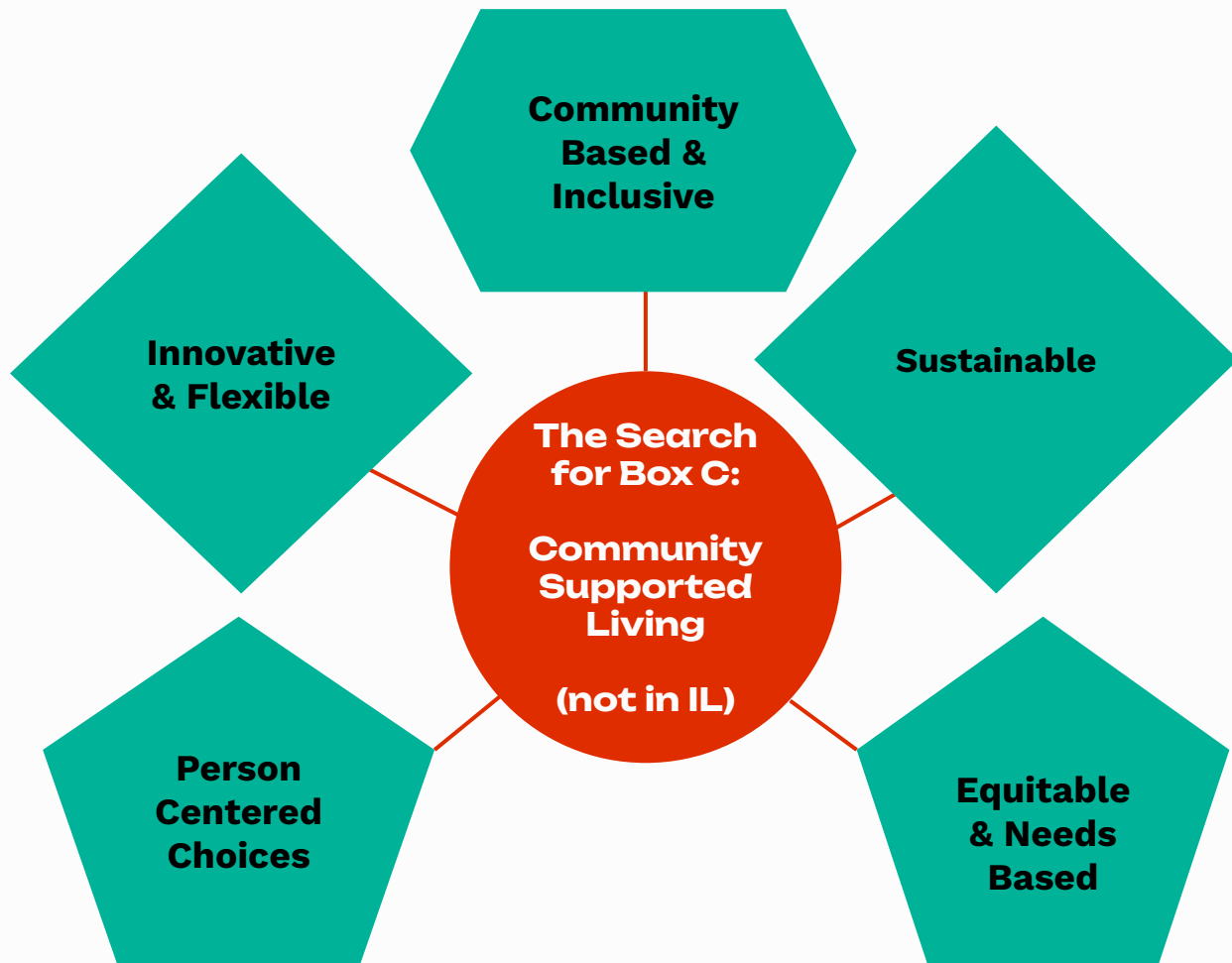
Home Based  
Self Directed Home Based  
Funding

## **Defaults:**

SODC (Institutions-7)  
State Operated  
Developmental Center

ICF/DD

16 bed nursing care



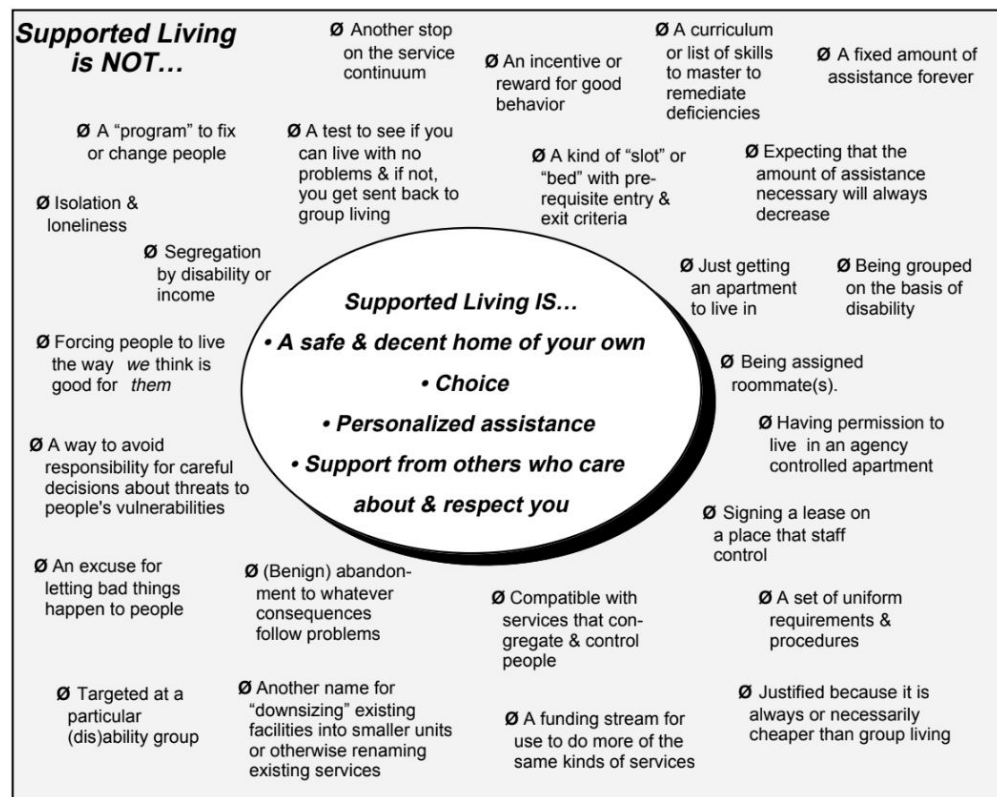
# SUPPORTED LIVING IS.... Not

- Creating a life for someone based on the person's preferences, interests, needs and choice.
- Building the scaffolding they will need to pursue these interests.
- Having the opportunity to live in the community of their choice.
- Ability to decide if they want to live alone or with someone.

*"It is helpful to define the edges of Supported Living by saying as clearly as possible what it is not."*

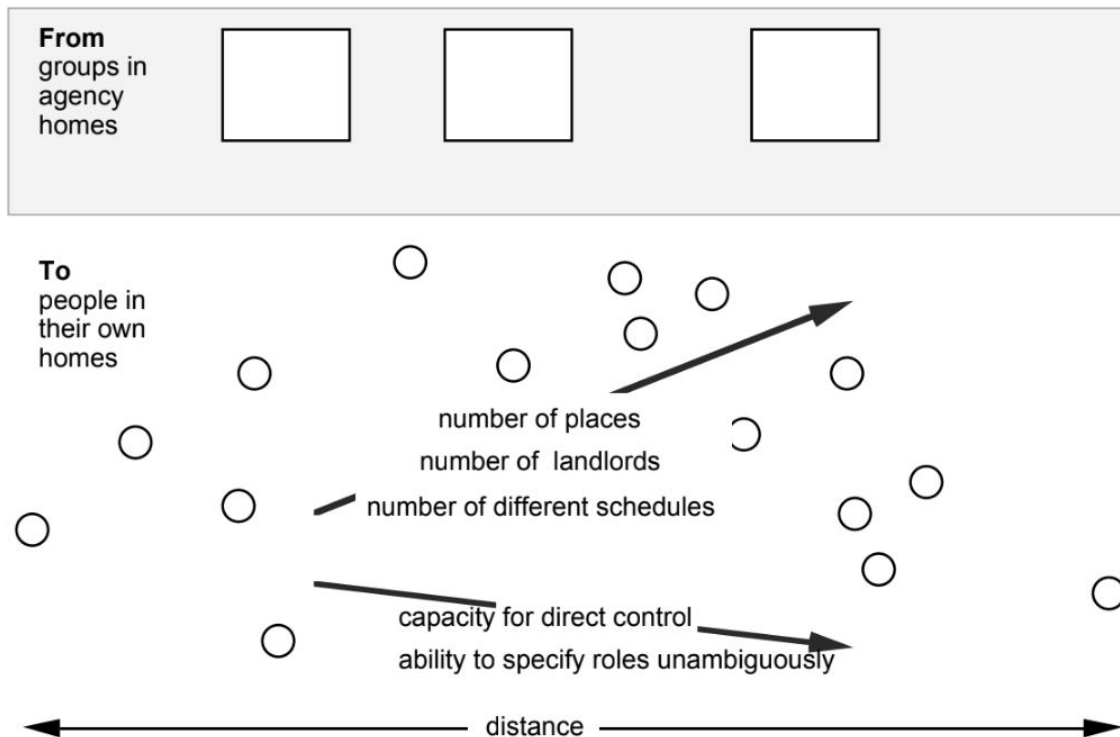
*Supported Living: What's the Difference*

*John O'Brien*



# SUPPORTED LIVING IS....

*Equity, Dignity & Choice*





# THEY NEEDED....

Model

A Flexible Innovative Supported Living

With  
Just a Dollop of  
**EVERYTHING**

Dreaming  
Fun Ideas  
Choice  
Routine  
Friendships  
Outings  
Working  
Community



# THEY WANT ....

To Make plans



## RACHEL:

- I love to make plans for our Just a Dollop business.
- I search for new recipes to try out.
- I look for pictures of foods that look like fun to make.
- I love finding new desserts to share with family and friends.
- I really like to plan business trips together.





# THEY WANT ....

To Try Things Out

## RUTH:

- I like to test out new recipes with friends.
- We take our cookbooks to places to sell them.
- My mom helps us with payments for our cookbooks and other things we sell.
- I like to travel to talk about the work we do
- I love to take business trips with my Just a Dollop Team!



# THEY WANTED TO .... To start their own

## Business

And our staff supported them in doing just that! Check out their website at:



*If you happen to be near Naperville in November, pop into one of several Just a Dollop OPEN HOUSES that month. The ladies will be selling their merchandise and you can get a peak at Supported living In action!*

*(check the website for details)*



# SUPPORTED LIVING IS... *Doing all of these things* *Together*



Advocating to  
Live your Life!





# LIFE AT THE 209 HOME ....

*Jumpstarts*

## Changes

- **Sept 2023**
  - Creative Housing Network formed
- **May 2024**
  - Families & IDD lead change with Strategic Planning in Springfield Key stakeholders (70)
  - Northstar Plan developed with goals and timelines
- **Jan 2025**
  - Establish Engage IL 1st goal
  - Coleman Grant Infrastructure
  - Steering Committee formed
  - Sub Committees identified
    - Outreach- Build coalition
    - Legislative strategy
    - Communications
- **Sept 2025**
  - Building the Coalition & Networking





Our Vision

**INDIVIDUALS WITH DISABILITIES  
DESIGNING LIVES IN THE  
COMMUNITY OF THEIR CHOICE**



Our Mission

# UNITING INDIVIDUALS AND FAMILY VOICES FOR EQUITY, DIGNITY AND CHOICE





# A LITTLE HISTORY

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- Federal Government developed institutions to educate people with IDD to become ‘productive’ members of society.
- Over the years, institutions shifted from educational schools to custodial settings
- Functioned as locations of care and medical practice rather than education. And here is where IL got stuck.

# ILLINOIS COMPARED TO OTHER STATES

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- A disproportionate amount of allocated dollars goes to 'brick and mortar' and not services in the community.
- Illinois has seven state-run institutions. Most states have none.
- Institutions are the default placement in Illinois when there is no other option.

# FUNDING MODELS

<b>Federally Funded</b>	<b>Waiver Programs</b> Matching funds from Federal Government and State	<b>More Progressive Models</b>
<ul style="list-style-type: none"><li>• Institutions</li><li>• ICF-DD</li></ul>	<ul style="list-style-type: none"><li>• CILA (group homes)</li><li>• Home Based Program</li></ul>	<ul style="list-style-type: none"><li>• More flexible, needs-based funding program</li></ul>

# FEDERALLY FUNDED MODELS

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## Institutions

- State Operated Developmental Centers
- Est annual cost: \$350K per person

## ICF-DD (Intermediate Care Facility for Developmentally Disabled)

- Est annual cost: \$150K per person

# WAIVER PROGRAMS

## CILA (Community Integrated Living Arrangement)

- Established in 1981, the model hasn't changed in 40 years.
- Needs based but not person centered
- Group homes run by licensed providers
- Est annual cost: \$80 - 100K
- Rules and regulations have not been updated in 40 years.

## Home Based Program

- Stipend 3 times x Social Security \$34K/year
- Intended to provide funds to keep loved one at home until moving into CILA
- Not sufficient funds to create a person-centered self-directed life.
- 80% of individuals choosing Home-Based by default as no other options are available.

# WE ARE ADVOCATING FOR: A MORE FLEXIBLE AND PERSONALIZED PROGRAM



## HOME BASED PROGRAM

- Case management provided by ISC with large caseloads. Meetings are once a quarter.
- PSWs are family members or individual family hires and trains
- Monthly allotment of \$2900 provides 4 – 6 hours of support a day (5 days).

## NEW PROGRAM

- Robust, wrap around case management based on person-centered plan. Weekly, monthly and quarterly check-ins.
- Finding, hiring and training PSW part of case management.
- New program should be needs based and consider multiple times throughout the day when support is required.



# WE ARE ADVOCATING FOR: A MORE FLEXIBLE AND PERSONALIZED PROGRAM (PG 2)

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## HOME BASED PROGRAM

- Transportation, nursing, emergency and employment support all must come from same monthly allotment.
- No funding available for flexible programming in the day

## NEW PROGRAM

- To allow for more flexibility
- Needs should be a part of an overall needs-based funding program.
- Individuals should be able to choose what programs, classes and community-based activities they want to attend, where and when.

# STRONG PARENT VOICE NEEDED

Currently, the strongest unified voices oppose moving away from institutional and congregate living models, which is the most expensive option for the State.

**We need to advocate with louder voices for community-based programs that yield evidence-based, positive outcomes.**



**WE NEED A NEW  
STRONG FAMILY  
VOICE IN  
SPRINGFIELD  
REPRESENTING  
THE DEMAND FOR  
BETTER COMMUNITY  
BASED OPTIONS.**



# WE NEED A STRONG COALITION



...of thousands of voters to move  
the Governor's office, the  
legislators and the Division of  
Developmental Disabilities



# TOGETHER WE HAVE THE POWER ....

To create Equity, Dignity, and Choice







# JOIN US!



**Join Us**



**Donate**



**Connect  
Us**

A coalition of individuals with  
disabilities, their families, and allies