

# What Do We Do Now?

## *COVID-19 and how policy makers may respond to reshape service systems*

Statewide Best Practices and Home-Based Services Conference

Arc of Illinois and Family Support Network  
October 29, 2021

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# PRESENTED BY



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he/him

The Human Services Research Institute is a national non-profit that was founded in 1976 to improve the availability and quality of supports for children and adults with disabilities and other vulnerable populations.

We have worked for the federal government, in all 50 states, in multiple Canadian provinces, and further abroad. Underpinning our work is a simple belief:

*All people and their families have the right to live, love, work, play and pursue their life aspirations in their community.*

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# AGENDA



- Welcome, reflections, & purpose



- How things work and taking stock



- System redesign issues to consider



- Four key decision points

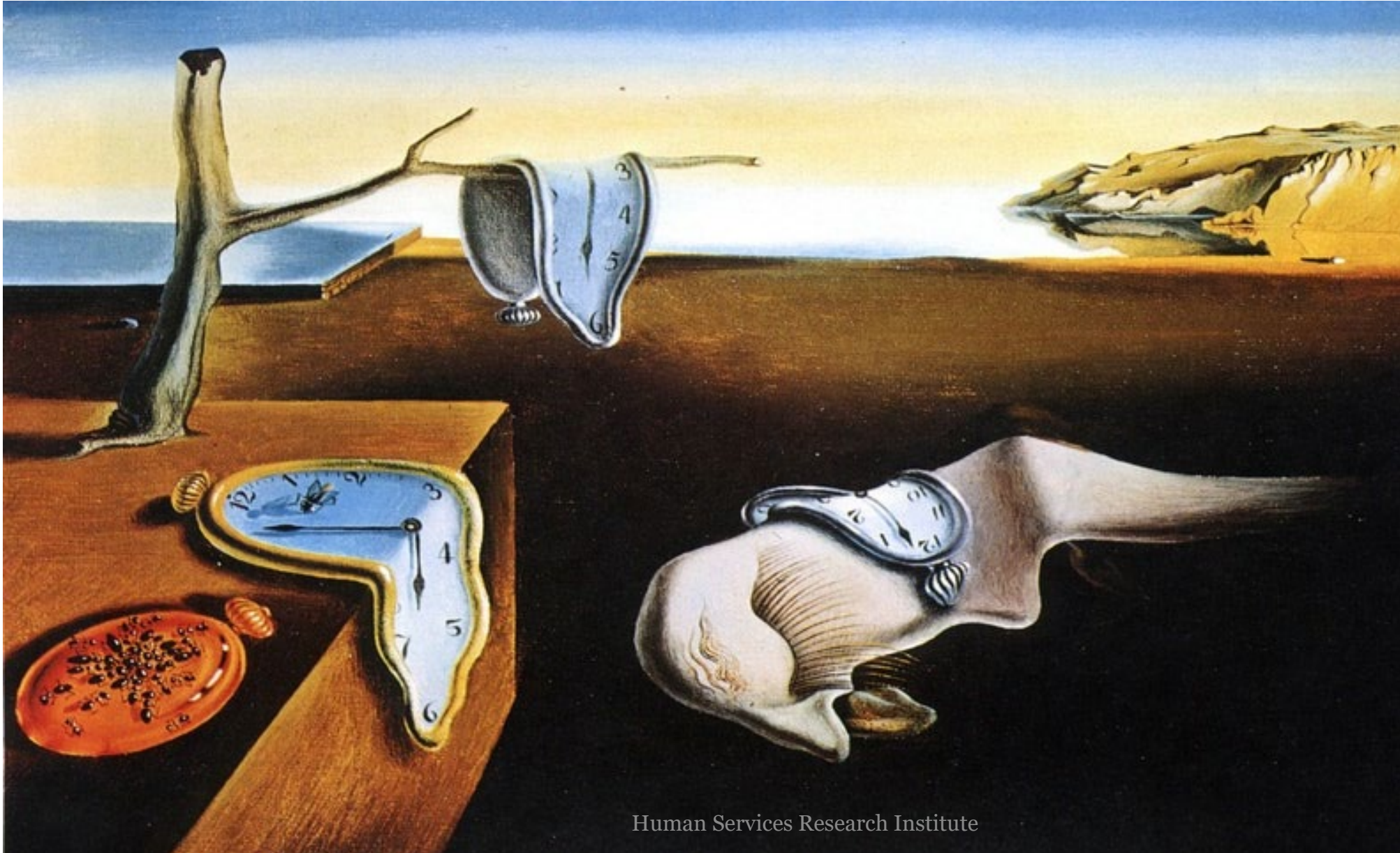


- What do you think?

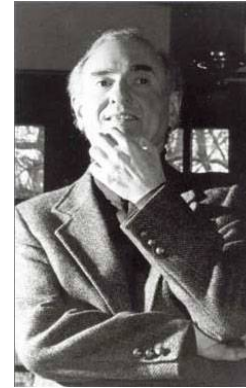
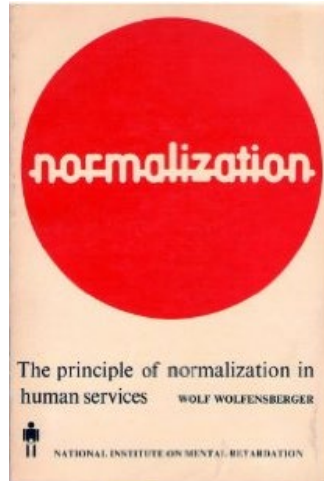


- Concluding thoughts

# Welcome, reflections and purpose



# Thinking Back...



“enter the functioning sphere of [people with intellectual disabilities] to teach culturally normative behavior.”

Wolf Wolfensberger

*“Where imagery leads, policy follows and behavior results.”*

Ellen Goodman



Marc Gold when he taught...  
“try another way...”

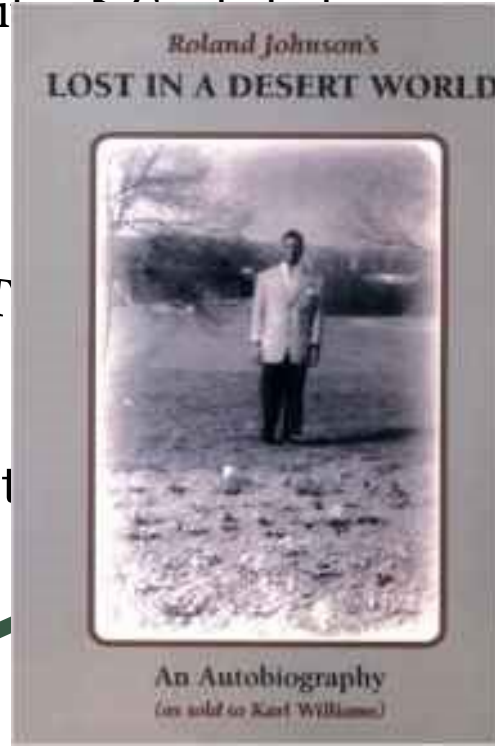
# What do you believe? And when did you believe it?

Integration → Inclusion  
Independence → Interdependence  
Productivity → Creativity



1960's

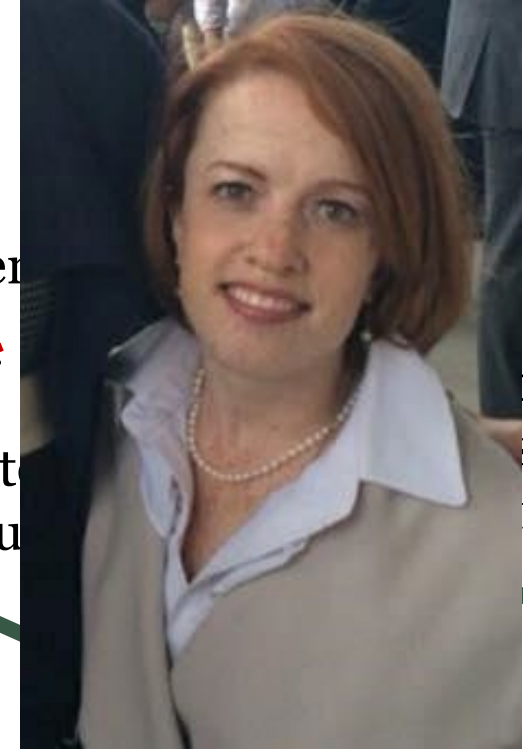
“Label jars,  
not people!”



“Who's in  
charge?”



“Nothing about  
me without me”



2021

“Thank you, but what  
you built we don't want”

# Just Wondering...

## Two World Views To Think Through

### Choice

Is the primary consideration so that...

Choices that exemplify community integration or facility-based segregation are equally acceptable.

### A Community or Society for All

Is the primary consideration so that...

Policy favors options that promote community integration and discourages, even eliminates, options that segregate people from their community.

**What about...**

Gated Communities?

Farmsteads?

Sheltered Work?

Day Habilitation?



# Noah's Ark of Central Florida

Empowering people who have developmental disabilities to live, laugh and love

HOME ABOUT US ACTIVITIES RESIDENTIAL IMPORTANT INFO FORMS NEWS WAYS TO D

CONTACT US

Enter search

**The Villages at Noah's Landing**



BUY A BRICK

Construction Is Well Underway

## 15 Farm & Ranch Communities For Individuals With Special Needs

3.6K SHARES

Facebook Twitter Google+ Pinterest LinkedIn Email



### New Concept in Housing For Disabled to Emerge



RENDERING SHOWS the pool and clubhouse, above, at The Villages at Noah's Landing, a gated community for the developmentally disabled.



# And so, here we are!

- We DID seem to agree that individuals with disabilities should receive the supports they need to live, work, participate, and play in their communities just as others do.
- We DID seem to agree that their families should receive the support they need as well to offer effective support to their loved one.
- Over time, states have surely made great progress to translate this expectation into practice. But progress has varied across the nation.
- We have not been completely true to our best intentions
- Now we face an array challenges -- including those posed by COVID-19
- **So.... What do we do?**



# How things work and taking stock



# Assessment in the Context of System Design

*“Every system is perfectly designed to get the results it gets.” (attribution disputed)*

The service system, developed over decades, reflects the countless policy decisions made by those advancing a cause and others building a response.

Advocacy to address a need  
*Those with numbers, connection, standing, money, presence, persistence*

Publicly financed allocations in response  
*Those making policy decisions*



<b>Driving Principles &amp; Goals</b>	Beliefs & principles Goals and objectives Balance of ideology with fiscal discipline
<b>Opportunity to be served</b>	Eligibility rules Outreach practices Admissions practices (“level of care criteria”) Demographics regarding what people are served Responsiveness (wait lists)
<b>Availability and Accessibility</b>	Services available (e.g., services in HCBS waiver) Availability & distribution of providers by type and proximity Availability of direct support professionals Funds available (individualized budgets, reimbursement tiers) Allocative equity
<b>Support Planning</b>	Feeling welcome, heard, empowered (self-direction) Building a Plan of Support (e.g. <i>LifeCourse domains</i> ) Daily life & Employment    Safety & security Community living            Social & spirituality Healthy living                 Advocacy & engagement
<b>Service Delivery and Acceptability</b>	Service use/spending • Practice aligns with principles and best practices • Where people live and what people do in the day Quality of services and consistency in quality across age, gender, race, ethnic, and linguistic differences
<b>Quality of Life Impacts</b>	<i>Example: National Core Indicator domains</i> Access, community participation, work, rights, respect, relationships choice, control, self-direction Other personal and locally referenced outcomes

**Financing strategy, including state funds, Medicaid, or other sources**

**Quality monitoring, assurance, and improvement across all aspects**

# Flash back a few years

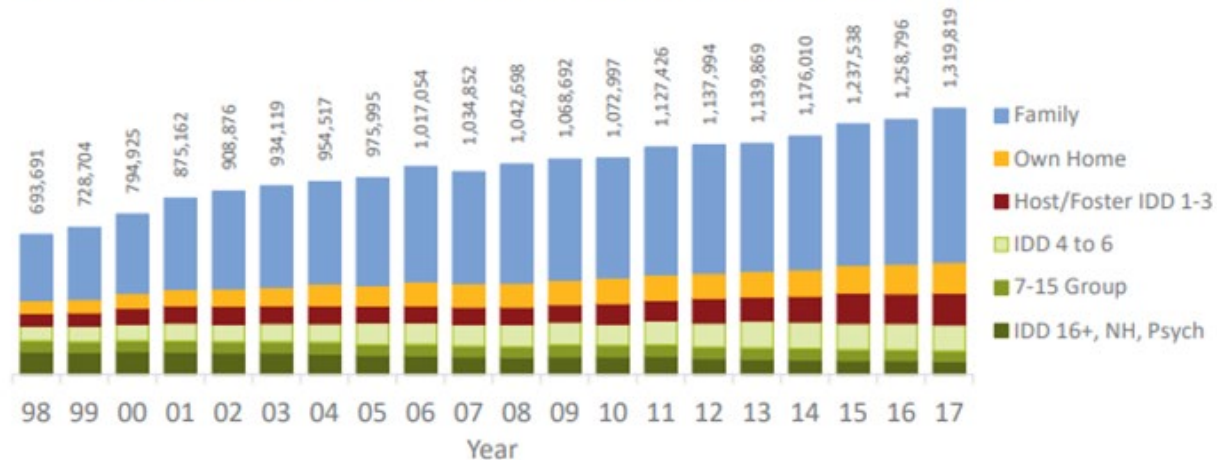
## United States

Fiscal year 2017

Residential Information Systems Project [risp.umn.edu](http:// risp.umn.edu)



### Long Term Supports and Services Recipients with IDD by Residence Type and Year



- Much accomplished and learned over past 50 years
- Thousands of people and their families receive services through developmental disability systems
- People now expect they will get the help they need to participate in their community... To live a life

### But together we understood the challenge in front of us

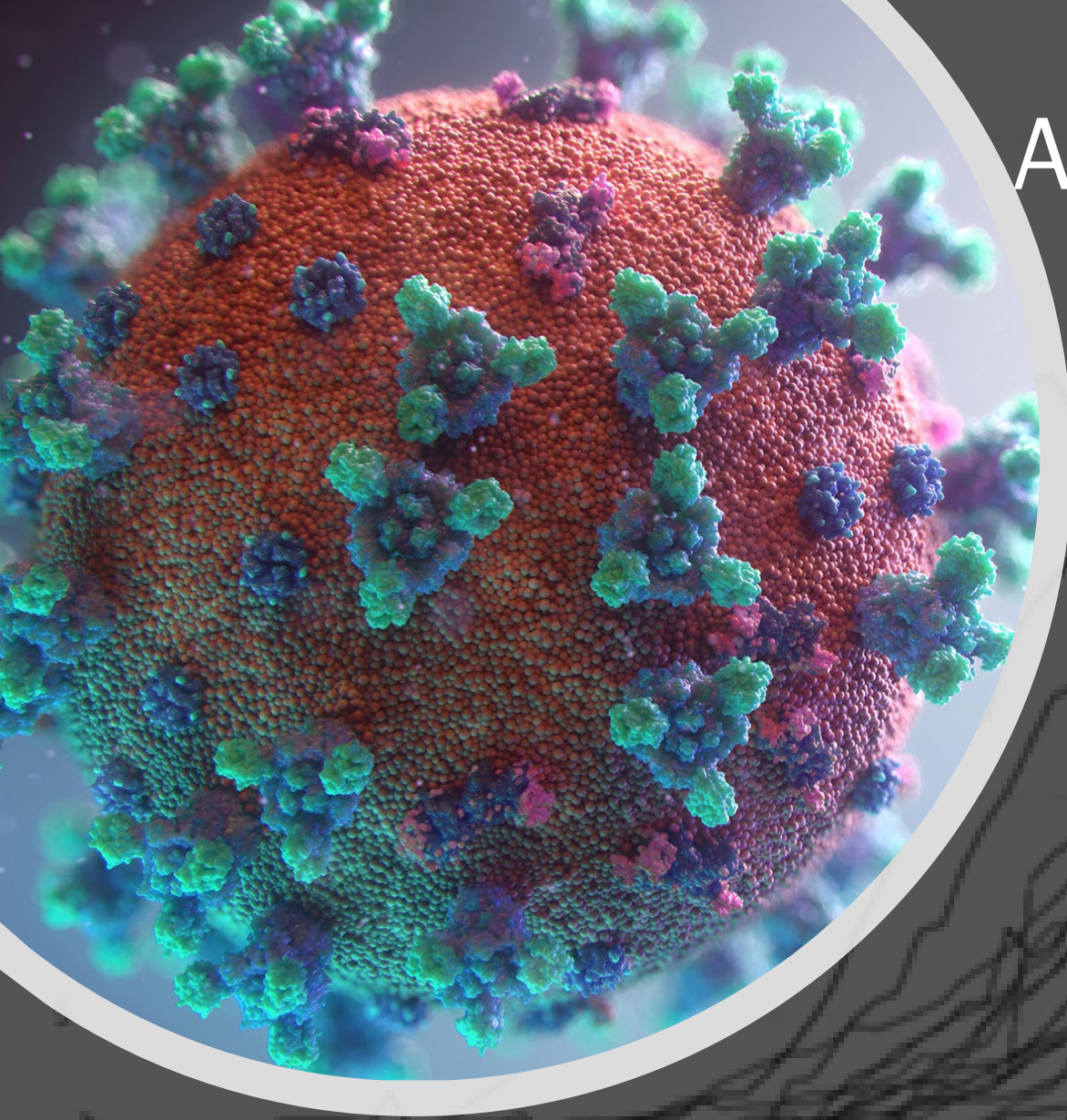
- We seemed ensnared by our founding origins
- We spoke about person-centered service systems, but change was not always so easy

# Disruptive change drivers were already in play

- Population and expectations are **changing**
- Employees and their availability is **changing**
- Technology is forever **changing**
- Service practices are **changing**
- The availability of public funds is **changing**



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# A Virus Comes Into Our Lives

Concern for our individual and collective health and safety

Ways of life & service use patterns disrupted

Tired and stressed

Shared enduring uncertainty for the future

Community integration/self direction versus health/safety

Calm consensus versus impassioned conflict

Difficulties with delivering services, yet daily life goes on

Anticipated budget shortfalls

# A Moment To Pause

October 27, 2021

#	Country, Other	Total Cases	New Cases	Total Deaths	New Deaths
	World	245,616,406	+354,290	4,984,463	+6,136
1	<a href="#">USA</a>	46,505,496	+7,777	760,143	+211
2	<a href="#">India</a>	34,231,161	+16,296	456,416	+732
3	<a href="#">Brazil</a>	21,748,984		606,293	
4	<a href="#">UK</a>	8,897,149	+43,941	140,041	+207
5	<a href="#">Russia</a>	8,352,601	+36,582	233,898	+1,123
6	<a href="#">Turkey</a>	7,936,007	+26,896	69,769	+210
7	<a href="#">France</a>	7,140,294	+6,528	117,589	+34
8	<a href="#">Iran</a>	5,888,100	+10,644	125,716	+197
9	<a href="#">Argentina</a>	5,283,000		115,866	
10	<a href="#">Spain</a>	5,006,675	+2,532	87,289	+51

<https://www.worldometers.info/coronavirus>

In Illinois...

There have been 1,690,274 total COVID cases, including 25,707 deaths in the state since the pandemic began.

More than 69% Illinoisans received one dose; 54% Illinoisans fully vaccinated - Public Health Officials Announce 15,131 New Cases of Coronavirus Disease Over the Past Week

Illinois is reporting its lowest number of people hospitalized with COVID-19 in nearly three months, according to new state data released Monday.

If you experienced a loss of a loved one or other hardship, we offer our condolences.

Indeed, numbers like this give us all pause.

We are thankful to the many in our field who continued to manage systems, keep doors open, and offer the direct supports that people needed.

# Direct impacts of COVID-19

- Individuals, families, friends, community, and supports were affected
- Constant fluctuating information, regulations, fears, and anxieties about living daily life
- COVID-19 posed graver risks for people who utilize long term services and supports, especially
  - Those with underlying health conditions (hypertension, obesity, chronic lung disease, diabetes mellitus, and cardiovascular disease)
  - Older people
  - Those living in large congregate living settings



# Direct impacts of COVID-19

- State leaders adjusted administrative and service delivery practices
  - e.g., Day programs, including employment services, suspended operations
- People living on their own or with family lost crucial in-home staff supports
- Community residences restricted comings and goings at these homes
- Some ancillary services (e.g., therapies) were suspended
- Case managers ceased personal visits
- Remote technologies grew in popularity across the service realm

# System redesign issues to consider



# As we *re-open* service systems

Now, as the pandemic eases – or becomes more a part of ongoing life (*“endemic”*) – policy makers are considering how to re-normalize service delivery,

That is, how to reopen service systems to some semblance of pre-pandemic status.

**Are we really going to go back to  
pre-pandemic service delivery systems?**

# As we *re-open* service systems

We understand that:

- COVID-19 posed graver risks for people who utilize long term services and supports.
- State leaders adjusted administrative and service delivery practices to keep service recipients, providers, and the larger community safe.
  - Day programs, including employment services, suspended operations.
  - People living on their own or with family lost crucial in-home staff supports.
  - Community residences restricted comings at goings at these homes.
  - Ancillary services (e.g., therapies) were suspended.
  - Case managers ceased personal visits.
  - Remote technologies grew in popularity across the service realm.



# 3 Considerations for moving forward

Personal health and well-being

What health related risks, real or perceived, to individuals, families, staff, and communities will persist and influence policy?

Service system design

What system adjustments will endure and what new reforms will be enacted?

Allocation of resources

Who gets what, how much, and to what ends?

What will we do?

# Focus on 3 considerations

- **What health related risks, real or perceived, to individuals, families, staff, and communities will persist and influence policy?**
  - How will systems cope with a population that is not altogether vaccinated?
  - What health and safety protocols regarding service practices will persist?
- **In the context of normalizing service delivery, what system adjustments will endure and what new reforms will be enacted?**
  - Will day programs be reopened to match pre-pandemic service use?
  - What impacts will there be on employment supports for people with IDD?
  - Will the present investment in congregate residential services be reduced or more?
  - Will there be greater investment in arrangements where people live on their own or with families?
  - How might we better invest in remote technologies?
- **Who gets what, how much, and to what ends?**
  - What can people get?
  - How much will it cost?
  - Is it going to be enough?
  - Will people have control of their allocation?
  - Will it be fair?
  - What happens to “me”?



# Four Key Decision Points in Response



# 1. What do we believe?



“Nobody ever comes along because of what you do or how you do it. They come along because of why you do it.

And because you believe in why you are doing it. And if they can find a way to believe in the same thing, then they will come along with you. Not for you, but for themselves.

Because they believe it too. It’s not what you do or how you do it. It’s why you do it.

Remember Martin Luther King Jr. did not give an “I have a plan” speech. He told people he had a dream. He told them what he believed. And they believed too. Not for him but for themselves.”

-Simon Sinek



# Do we believe that...

*All people and their families have the right to live, love, work, play and pursue their life aspirations in their community.* (From *Charting the LifeCourse*)

With an approach emphasizing:

- That people with IDD are in charge of their lives as much as possible.
- That people with IDD have opportunities to use resources in ways that enhance their lives and help them participate in their communities.
- The contribution that people with IDD and their families may make.
- A shared responsibility for the wise use of public dollars.
- That the system be managed in a way that is efficient and fair to everyone.



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People with disabilities  
still live in institutions?



What the...? It's 2010 People!

The Shelteredworkasaurus



**STOP FEEDING THE DINOSAUR**

We want real jobs!

[www.theriotrocks.org](http://www.theriotrocks.org)

# Focusing on Quality of Life Domains



**Daily Life and Employment**  
(school/education, employment, volunteering, routines, life skills)



**Community Living**  
(housing, living options, home adaptations and modifications, community access, transportation)



**Social and Spirituality**  
(friends, relationships, leisure activities, personal networks, faith community)



**Healthy Living**  
(medical, behavioral, nutrition, wellness, affordable care)



**Safety and Security**  
(emergencies, well-being, legal rights & issues, guardianship options & alternatives )

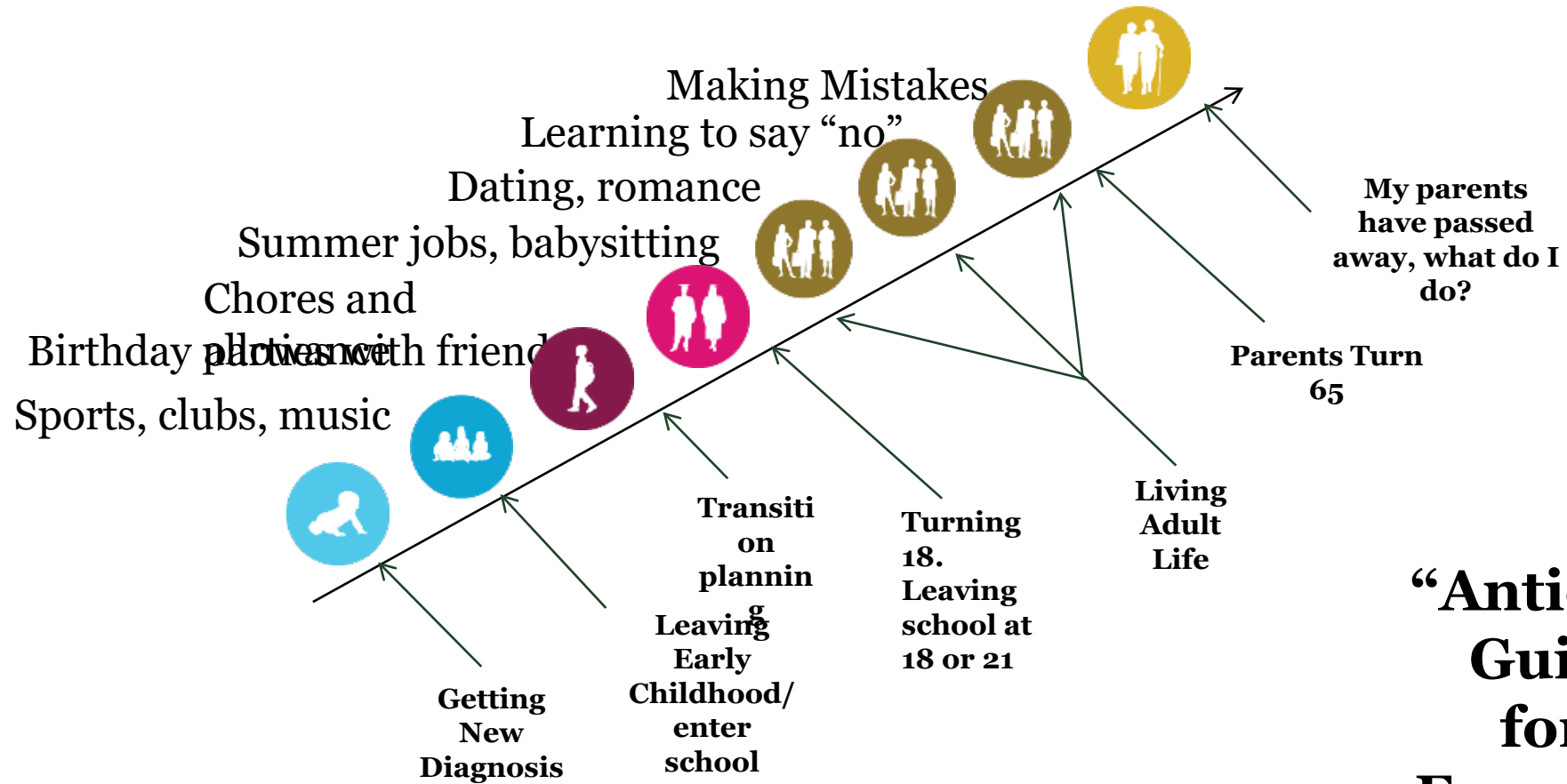


**Citizenship and Advocacy**  
(valued roles, making choices, setting goals, responsibility, leadership, peer support)



MISSOURI FAMILY TO FAMILY AT UMKC IHD, UCEDD | [LIFECOURSETOOLS.COM](http://LIFECOURSETOOLS.COM)

# Focusing on Life Experiences and Life Transitions

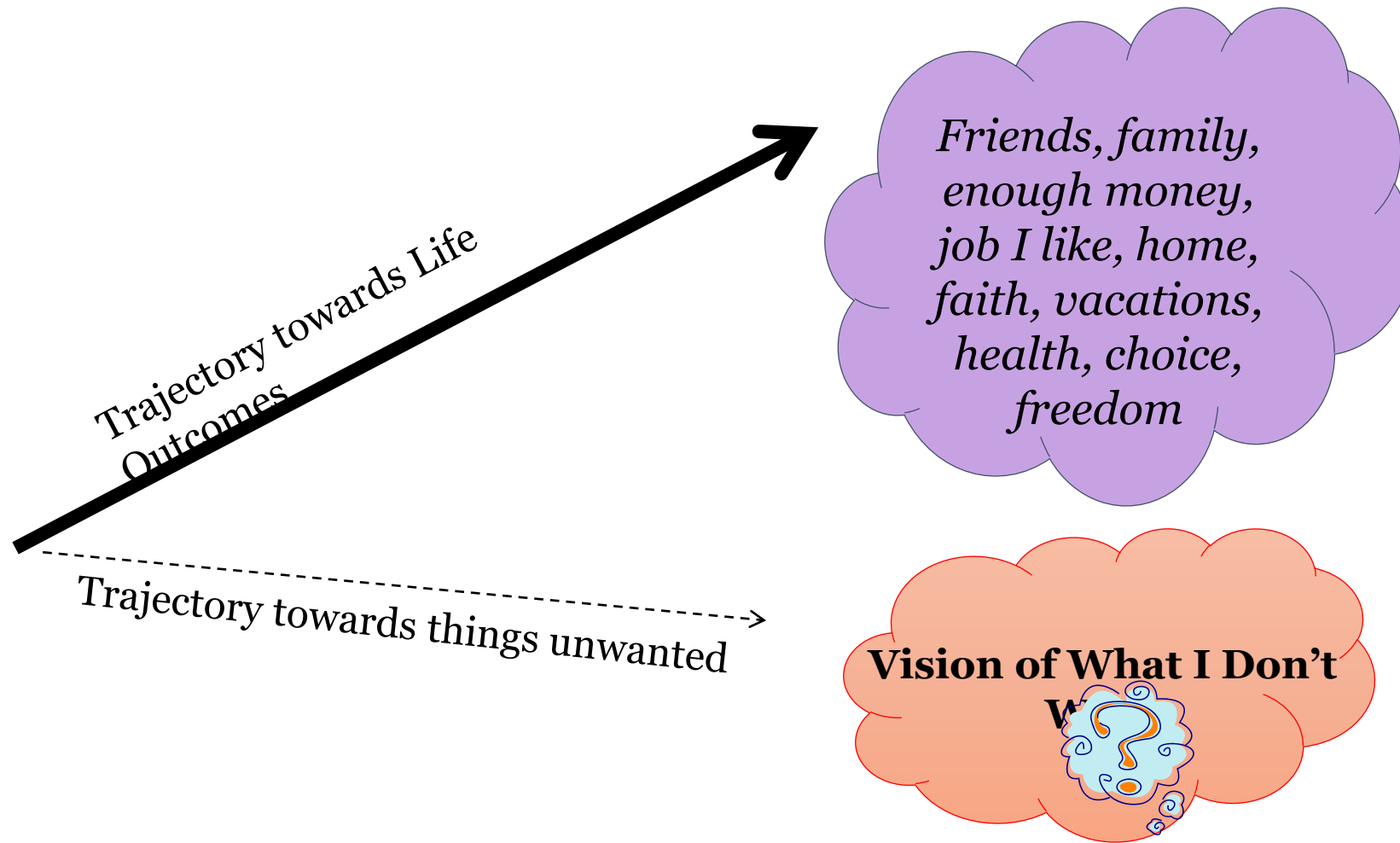


**“Anticipatory  
Guidance  
for Life  
Experiences”**



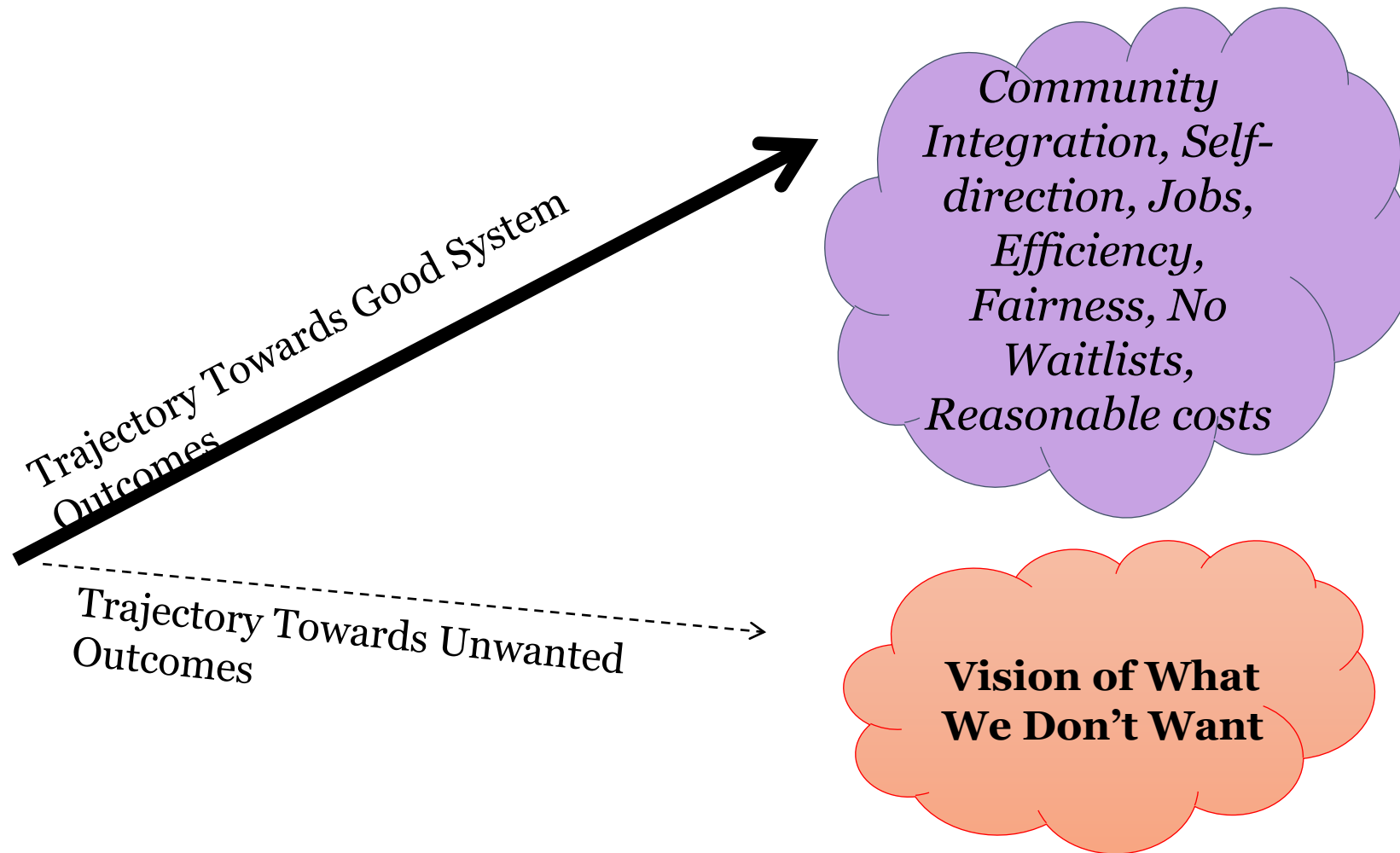
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# Trajectory Towards a Good Life

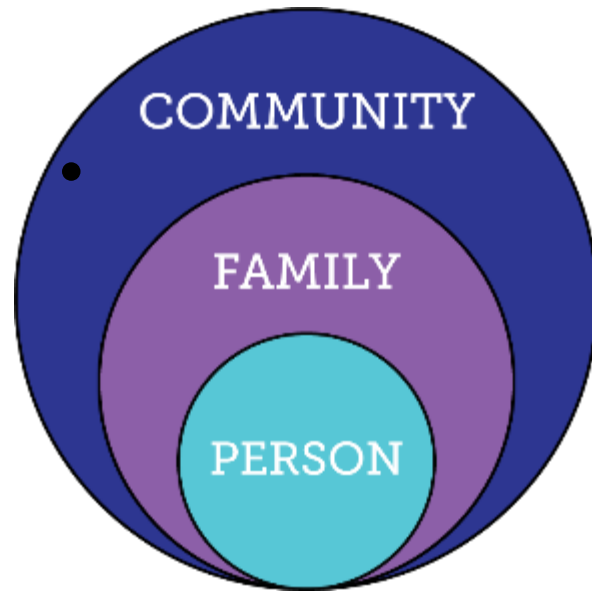


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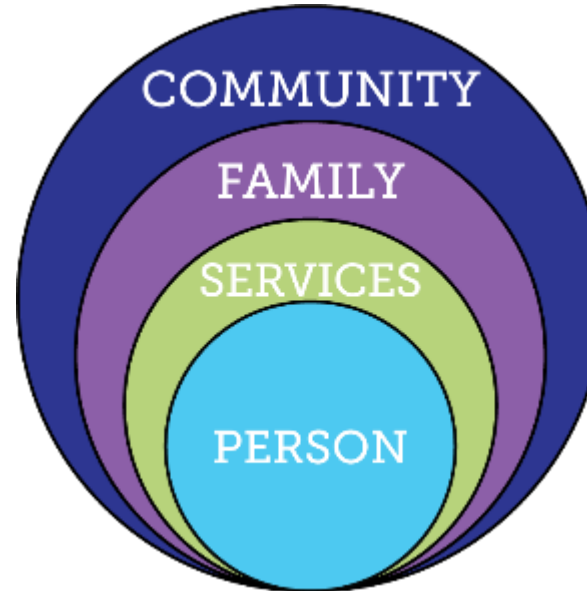
# Trajectory Towards a “Good System”



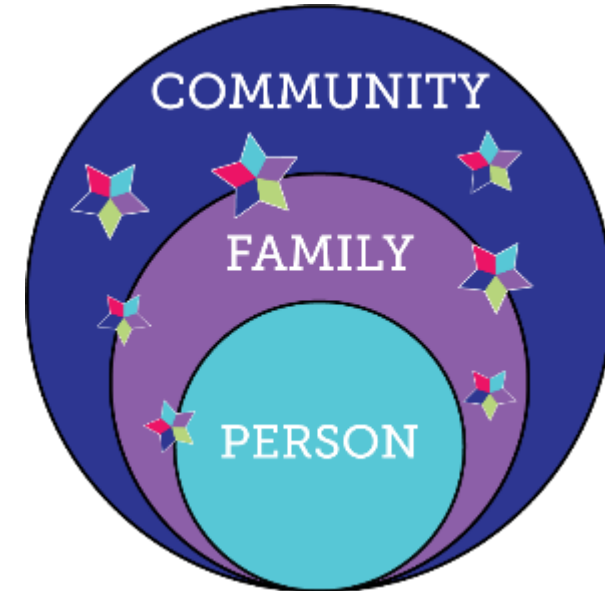
## 2. What services will be available and sought post COVID?



Everyone exists within the context of family and community



Traditional Disability Services

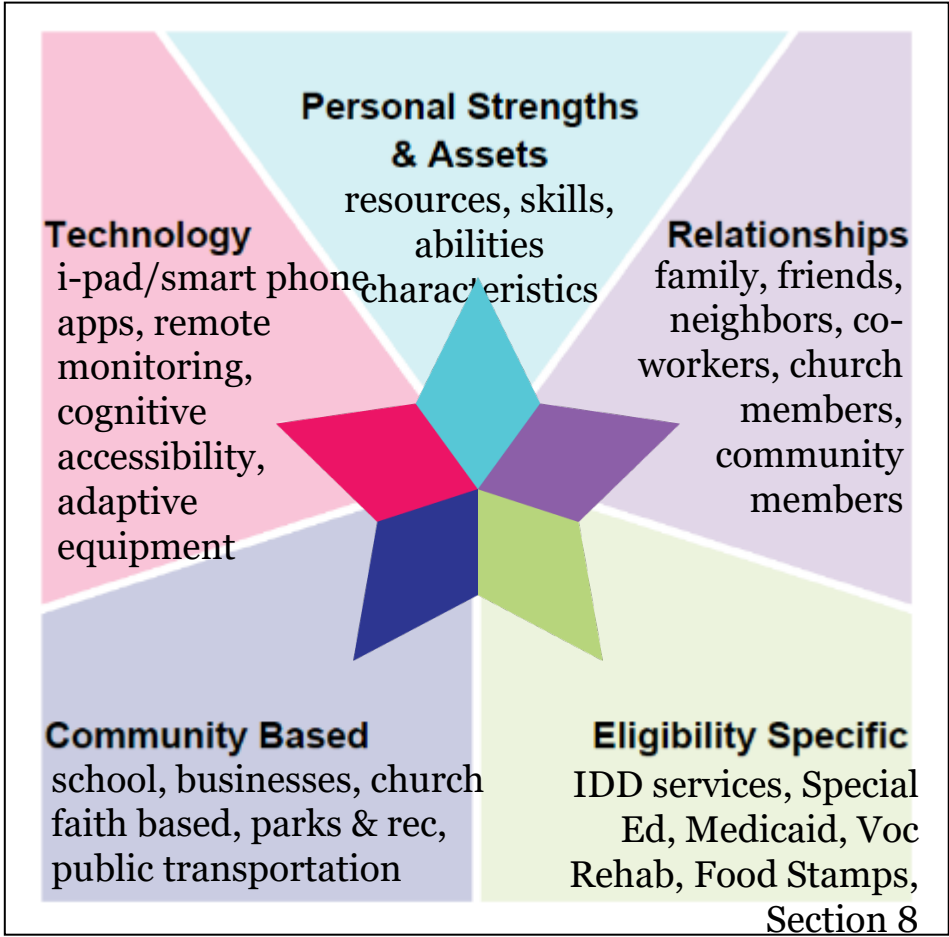


Integrated Services and Supports within context of person, family and community



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# LifeCourse Integrated Supports STAR





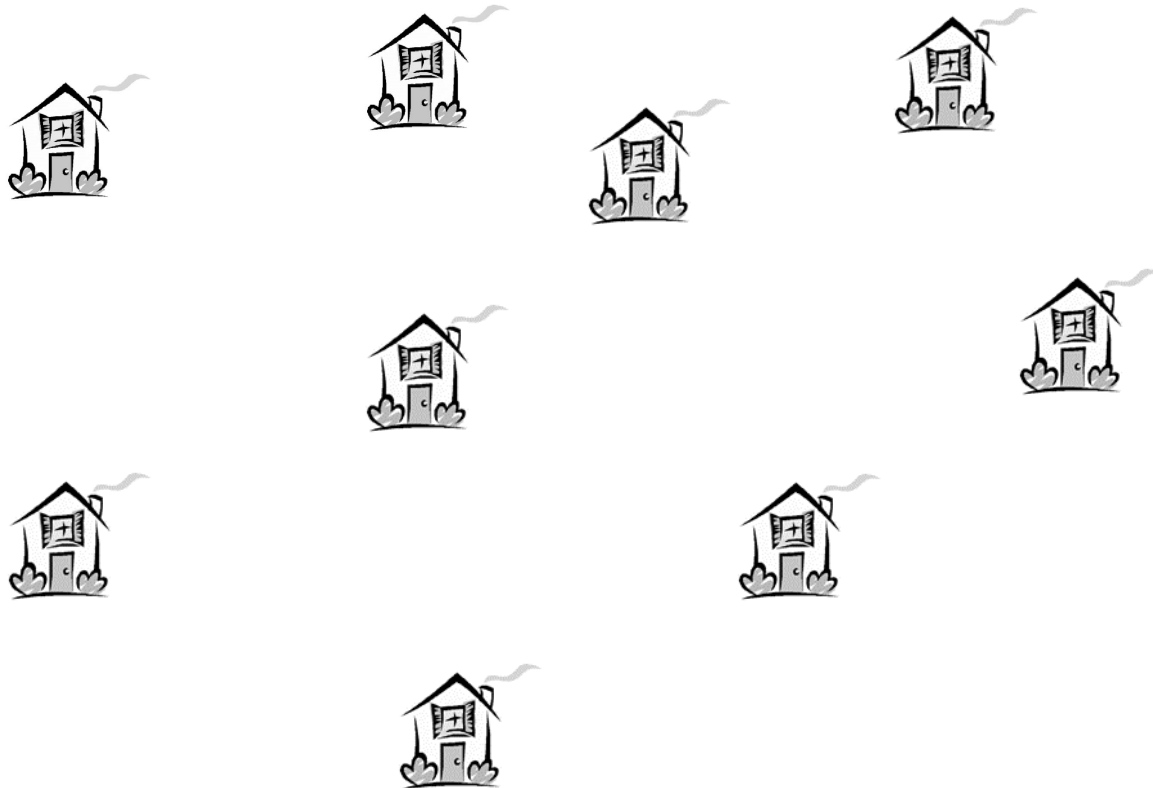
# What's in your service array?

Residential	Home with Family	Day Supports	Capacity Building
Host Home	Family Caregiver	Center-Based	Community Guide
Group Community Residence	Education and Training Parenting Support (for parents with IDD)	Employment	
Shared Living	Respite	Center-Based Habilitation Services	
Supported Living	-Center-based -In Community -Home Based In home Support	Employment -Discovery -Support -Follow along	
		Community Integration/Volunteer	Peer Support Peer Support Network Organizing

**Add Ons....** Therapies, home barrier removal, behavioral support, remote technology, assistive technology, nursing, special diet, stipends, transportation

# Focus on alternative supports

The Way Things Are...



Services are provided to people living in individual households.

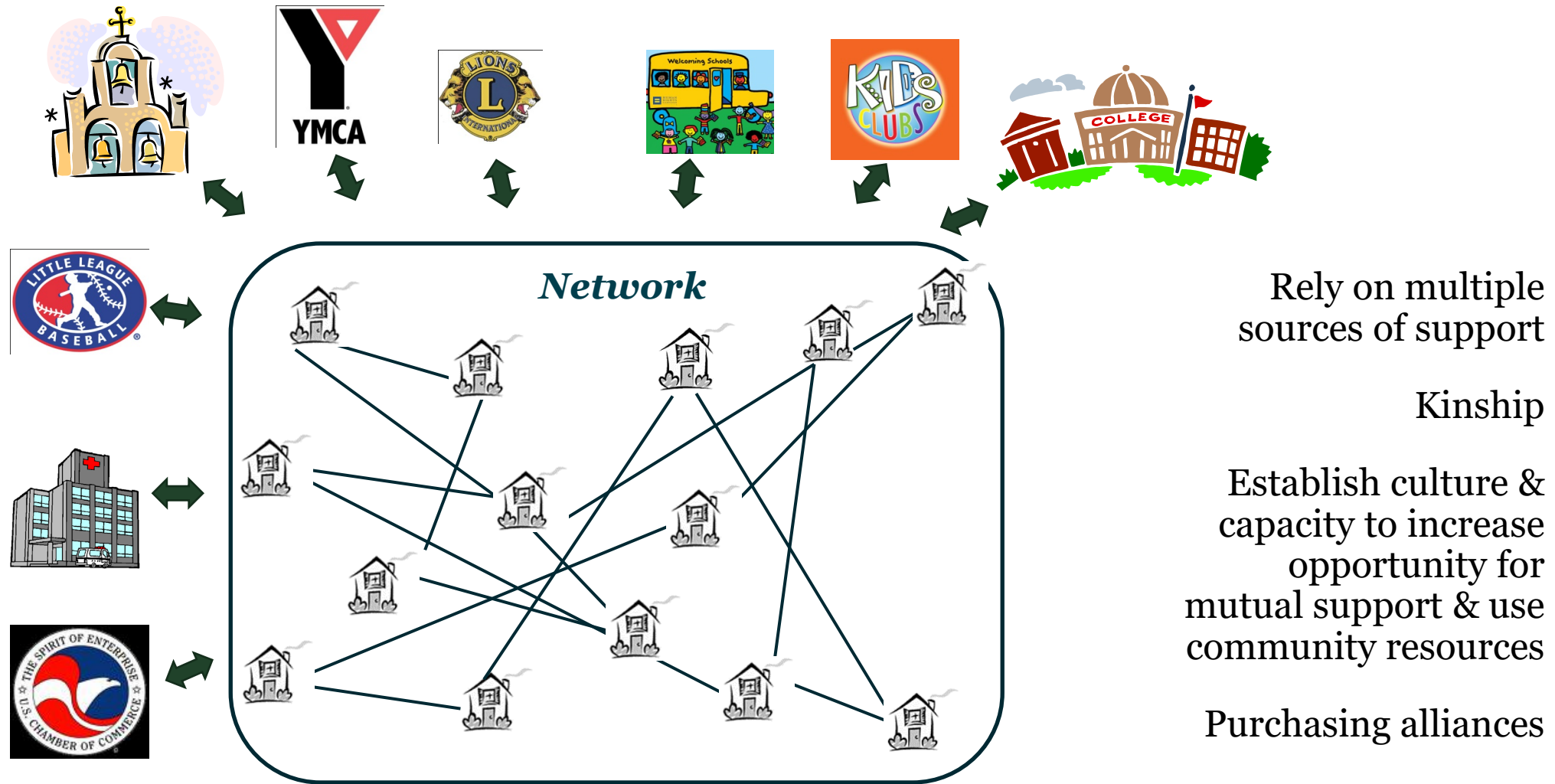
Dependency on services

Isolated households

Fail to build culture & capacity to increase opportunity for mutual support & use community resources

# The Way Forward...

Public services work together to use community assets with mutual support.



# 3. Who gets what and how much

Consider how money is spent per person

- Systems over many years come to allocate money in ways per person and/or per provider.
- The result is a distribution of resources that may be reviewed
- Consider how money is spent in relation to assessed support need and type of residence
- We have reviewed several jurisdictions in this way.

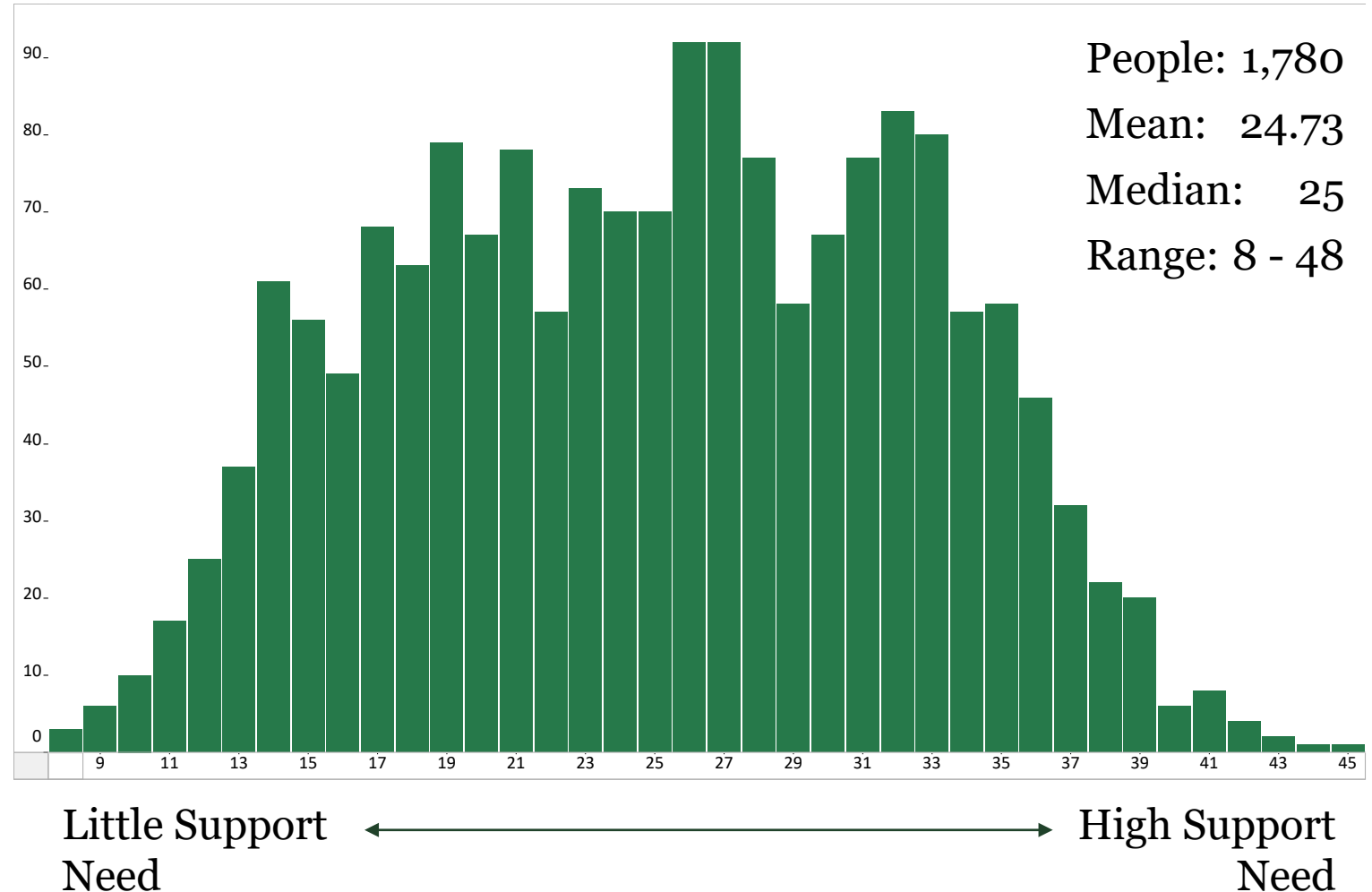


# Let's look "support need" across people

Using data from the  
*Supports Intensity Scale*

Sum of 3 SIS sub-scales:  
Home Living (A),  
Community Living (B) and  
Health & Safety (E)

Combined scale (Sum A-B-E)  
ranges from 8 (low support  
need) to 52 (high support  
need)



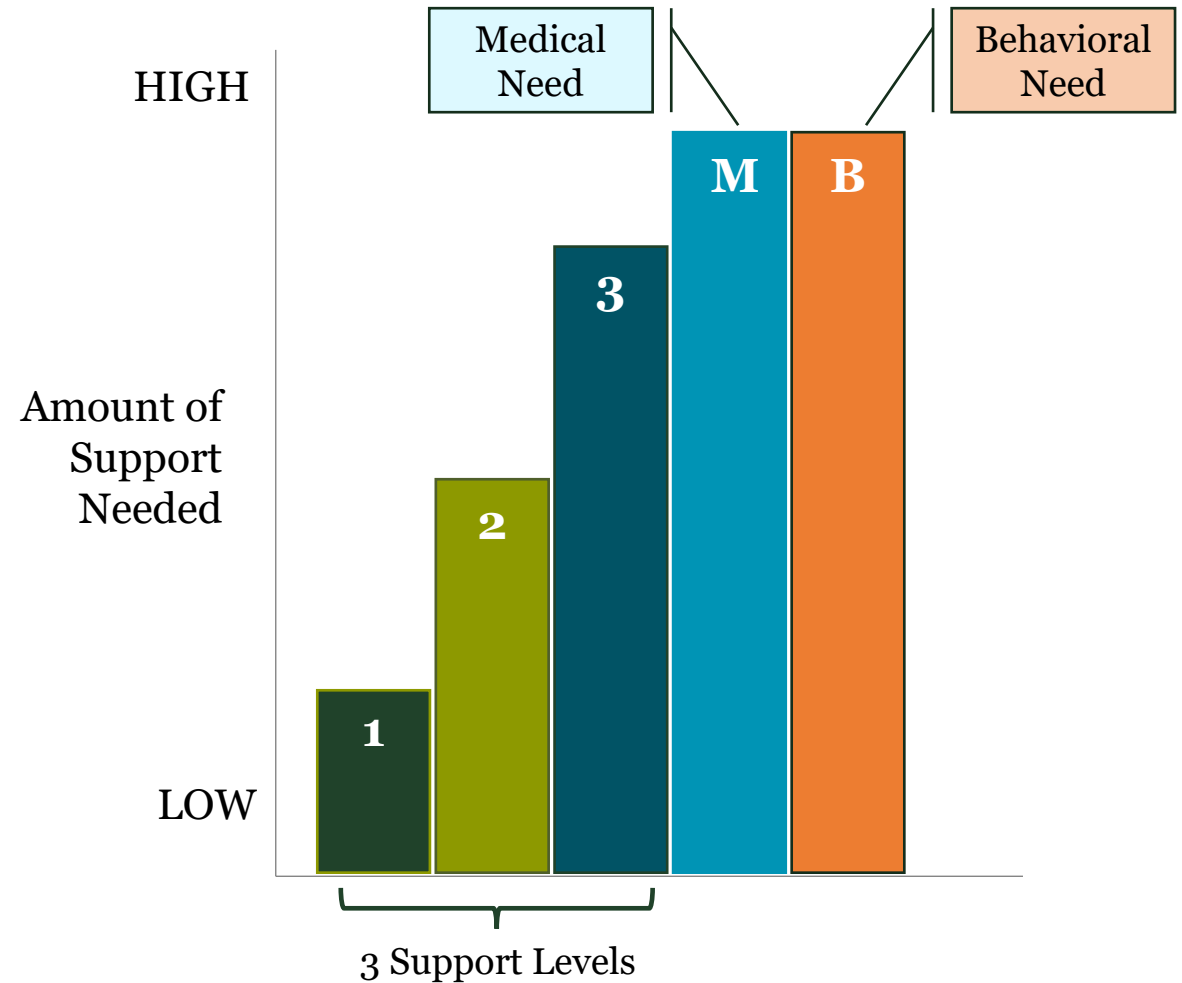
# We can assign people to support levels

*Applying a support level framework to help allocate resources*

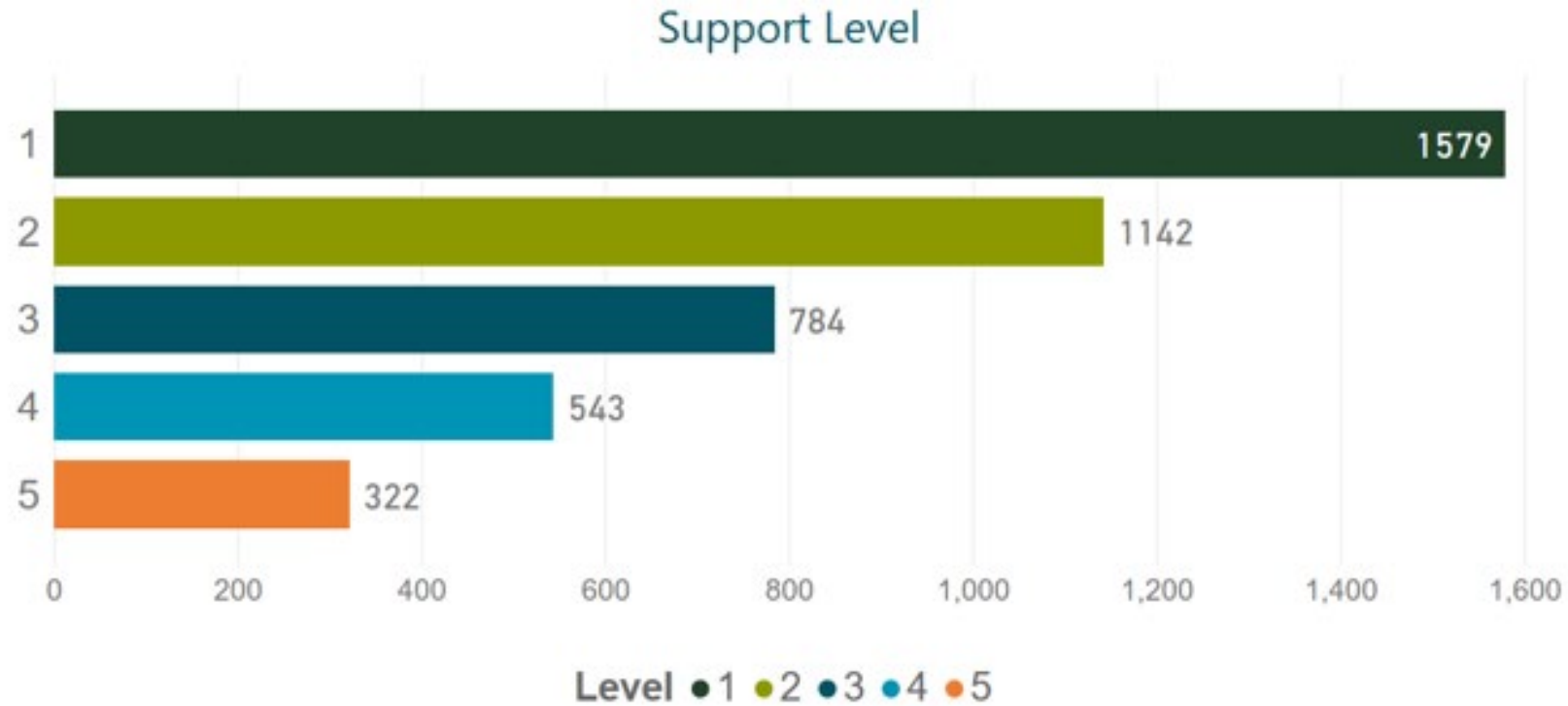
The support level framework includes

3 levels of support need (1,2,3)  
from low to high and

2 specific levels for people with  
high medical and behavioral needs



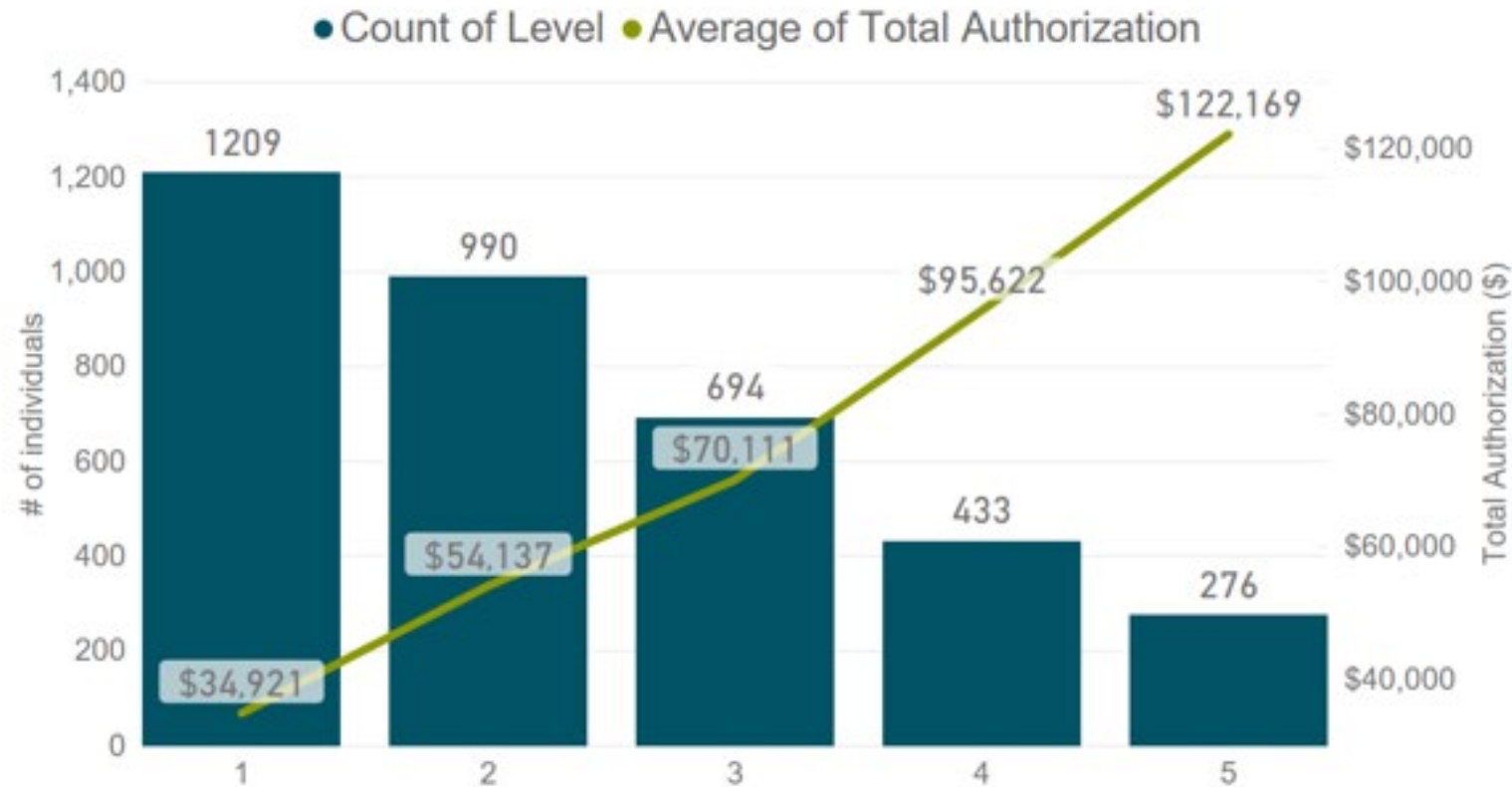
# We can look at a service population



People: 4,370



# We can look at Past Authorizations by support level

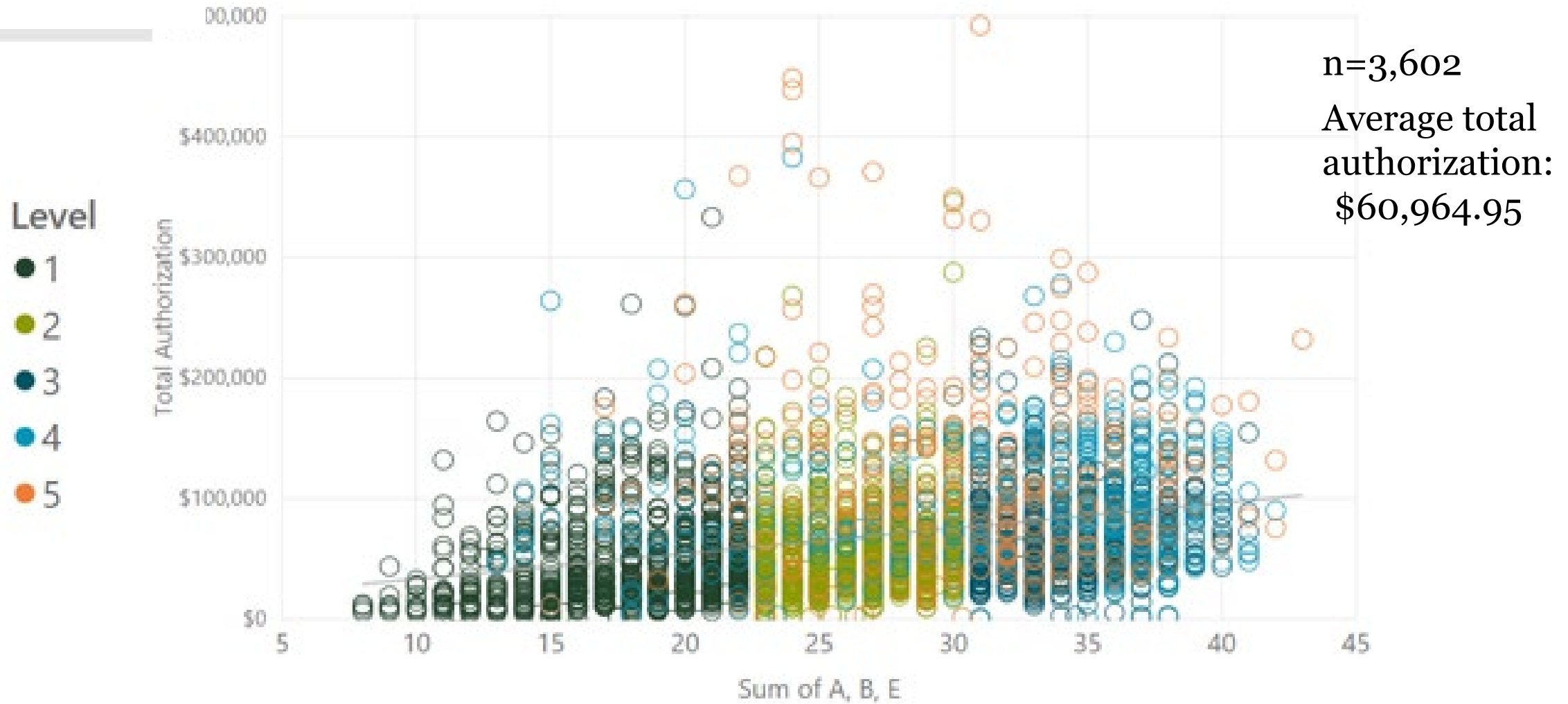


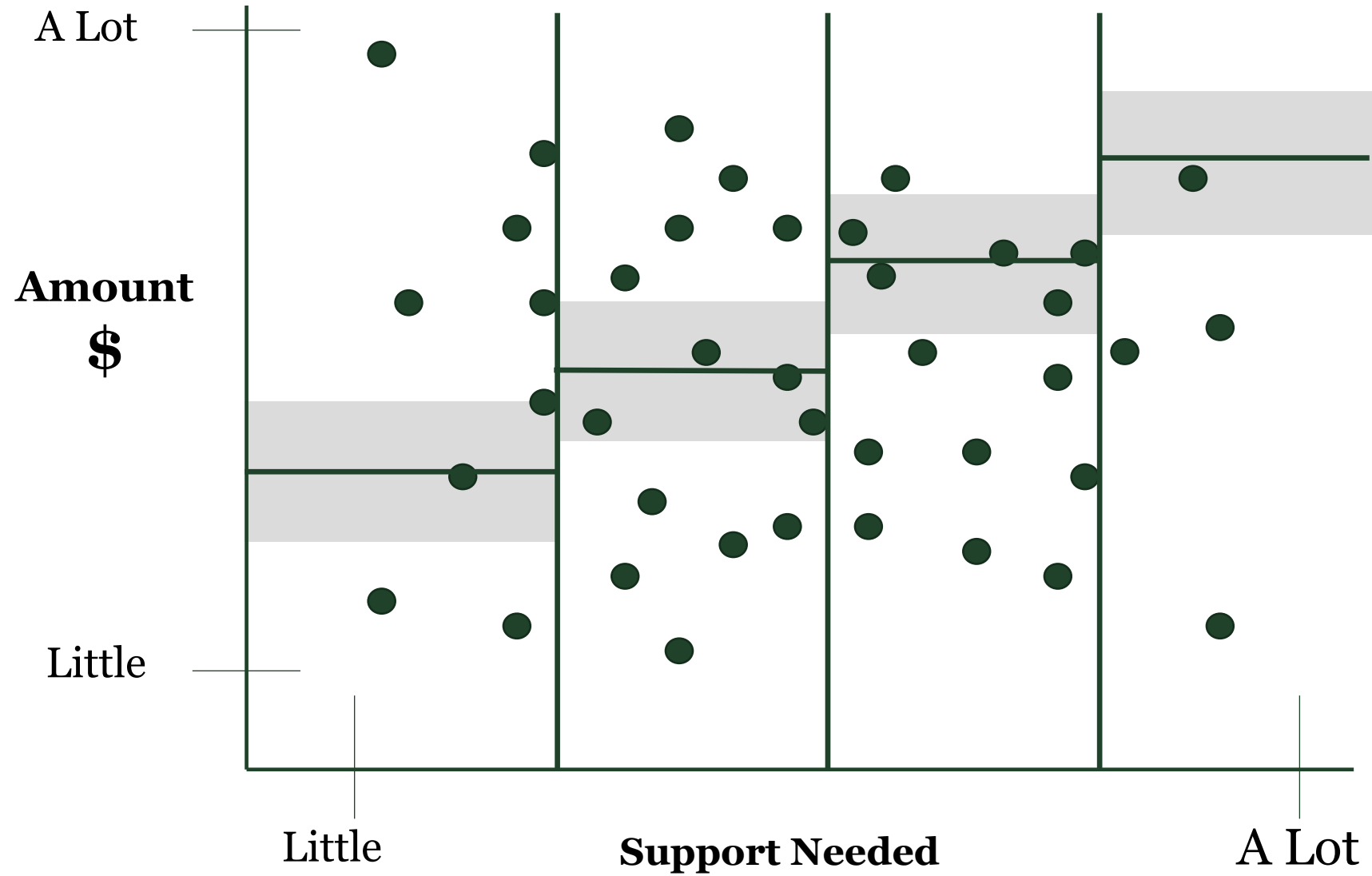
n: 3,602

Average total authorization:  
\$60,964.95



# Another look at authorizations by Support need scores (Sum of A,B,E)





# 4. To what ends?

We can think of **outcomes** in terms of how things turn out for people, but overall for systems too.

- We can look at the **performance metrics** - the numbers – that tell us how things are going.
- But it's not just about the numbers that tell us what services are being delivered to what number of people.

It's also about **how people experience** the services they receive. For people, personal and family outcomes concern access to support, control over life, and direct impacts on life.





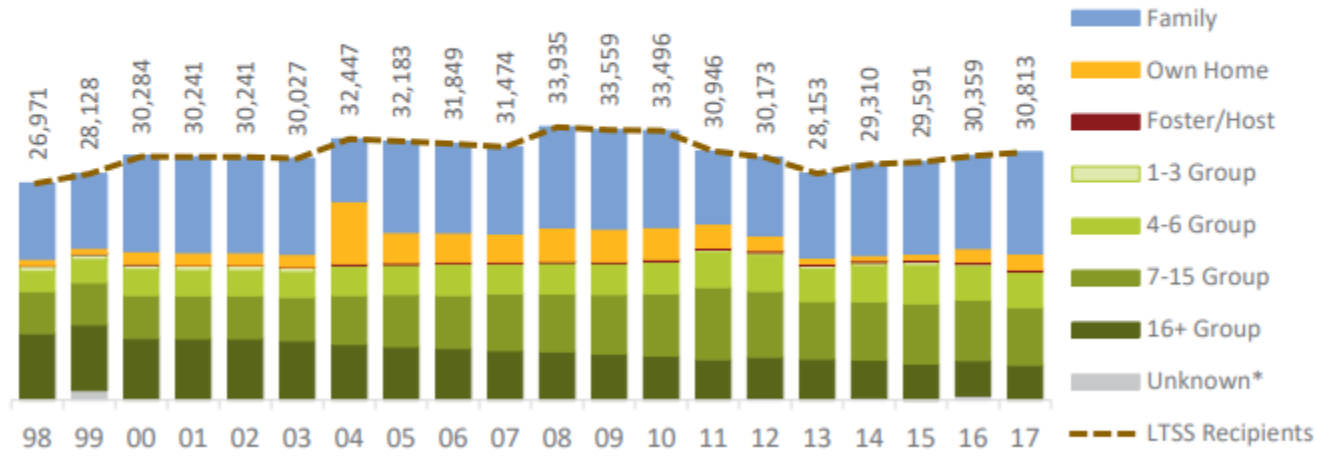
# Illinois

Fiscal Year 2017

Residential Information Systems Project



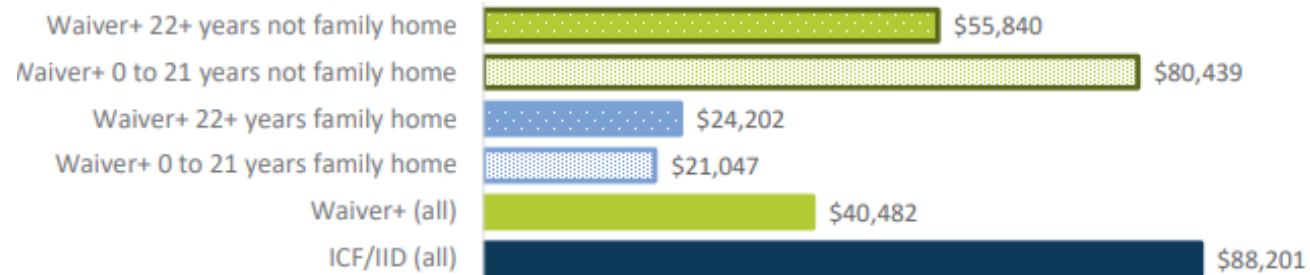
### IDD Agency Long Term Supports and Services Recipients by Residence Type



\* Unknown setting type or size reported in FY 2017 and gaps in all other years

# Illinois Data Basics

### Average Spending Per Person by Medicaid Authority in Fiscal Year 2017

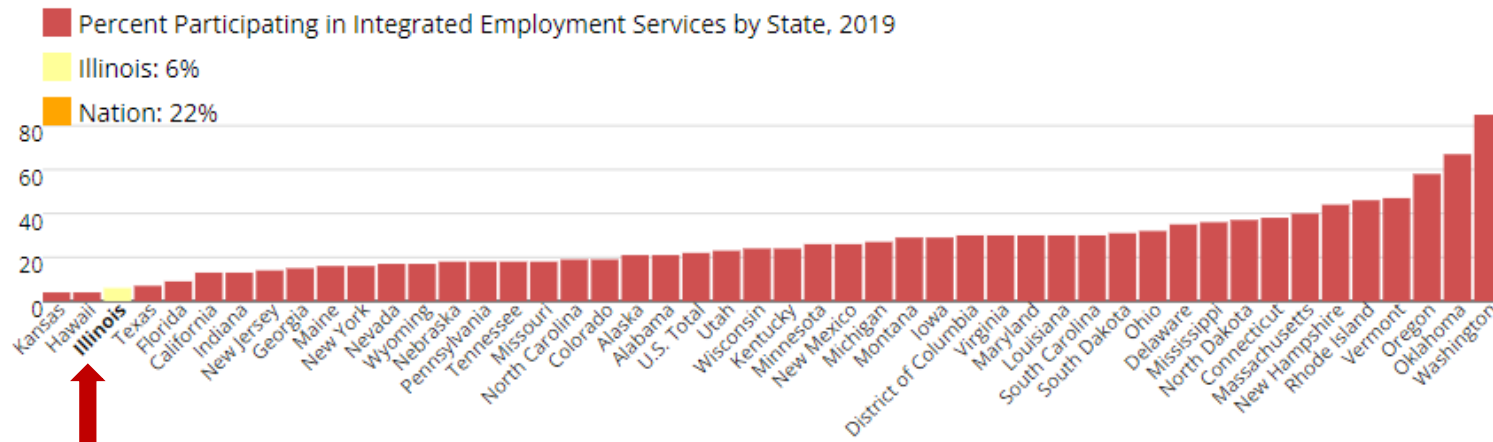


[https://ici-s.umn.edu/files/aCHyYaFjMi/risp\\_2017](https://ici-s.umn.edu/files/aCHyYaFjMi/risp_2017)

# Focusing on employment

	Illinois 2019		Nation 2019	
	Number	Percent	Number	Percent
<b>Total in day and employment services</b>	23,300		657,826	
<b>Total in integrated employment services</b>	1,301	6%	141,678	22%
<b>Total funding for day and employment services</b>	\$194,627,115.00		\$9,639,272,494	
<b>Total funding for integrated employment services</b>	\$7,636,567.00	3.9%	\$892,111,994	11.3%

\* = Data not available



<https://www.statedata.info/statepages/Illinois>

# But it's not just about numbers, it's all so about "how"

*Do people with Disabilities and their families receive...*

## **Information**


1. Information so they may make informed decisions about the supports they choose.

## **Access To Support**

2. Supports that respect cultural, ethnic, economic and spiritual differences.
3. Supports that address all facets of life and change as their needs change, they age through the life cycle or roles change.
4. Supports that include combinations of supports that are publicly or privately funded or involve natural supports
5. Supports that address their health-related needs
6. Access to everyday technology, as well as specialized technology and environmental adaptations to meet their needs.
7. Access community supports available to any other citizen, including supports offered by community serving organizations, houses of worship, and community businesses.
8. Supports that result in the achievement of valued outcomes identified by individuals and families

## **Control**

9. Design and direct the supports they receive to the extent possible.



*Do policy makers ensure that...*

**Alliance with  
Service  
Users**

10. Individuals and families are satisfactorily involved in policy making so that they influence planning, policy, implementation, evaluation and revision of the practices that affect them.

**System  
Management**

11. Individuals and families access and receive necessary publicly funded services and supports with reasonable promptness.
12. Public funding is sufficient to ensure that those who seek support receive the support they need.
13. Public funding is allocated to individuals and families in ways that are fair to all.

# What do you think?





# Concluding Remarks

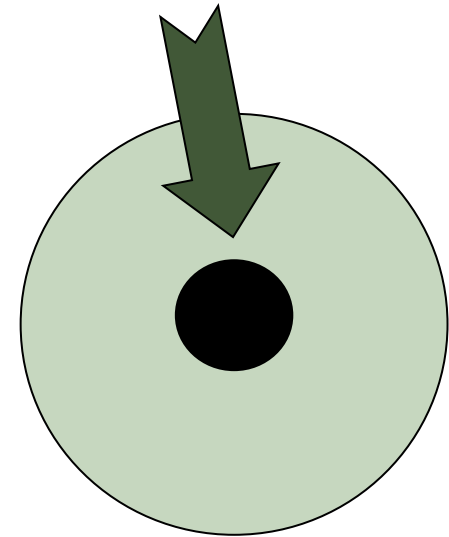


# In the end... Can we...

## Admit to ourselves that...

- We must settle in on what we believe -- our north star.
- We must decide on what services we want to invest in and... disinvest in.
- We must learn to distribute resources in ways that are effective and fair to all.
- We must hold ourselves accountable for the outcomes we produce and how we manage systems

We can't stay  
on this spot





## *Lead On!*

Justin Dart

- Change imposes choice.
- Choice imposes ambiguity.
- Ambiguity promotes discussion.
- Discussion promotes deliberation.
- Deliberation forms opinion.
- Opinion leads to action.

# Look forward, not backward

A service system for [people with disabilities] and others in need of support will have to be a system in constant change. It has to be continuously developed, if the 'customers' are not to be left behind and to become hostages of an outdated way of doing things."

Alfred Dam (undated)  
Denmark

