

What Do We Do Now?

Disability Service Systems Past 2020

Arc of Illinois

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AGENDA

01

Hope,
Belief &
Resolve

03

Concluding
Remarks

Taking Stock
and Setting
Our Sights

02

The Way
Forward

04

1. Our Sights Hope, Belief, and Resolve



Standing Back...

- Much was accomplished and learned over the past 50 years
- Thousands of people and their families depend daily on supports received through developmental disability systems. And the bar was forever raised. People expect that they will get the help they need to participate in their community... To live a life.
- Yet in so many ways we seemed stuck, ensnared by our founding origins... and so we make our past our future.
- ***But together we understood the challenge in front of us***



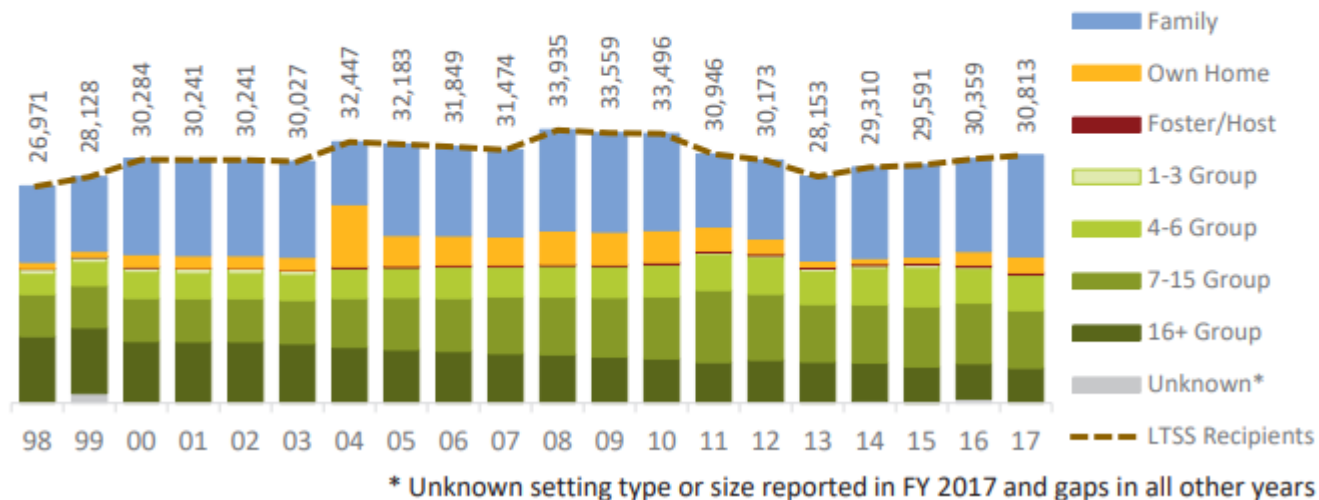
Illinois

Fiscal Year 2017

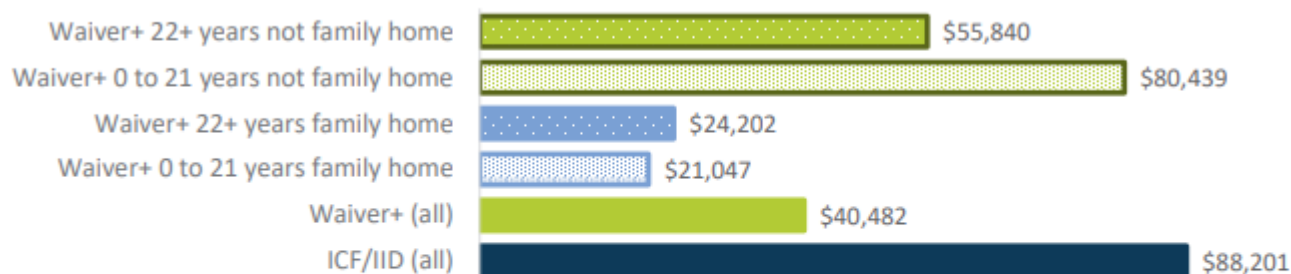
Residential Information Systems Project



IDD Agency Long Term Supports and Services Recipients by Residence Type



Average Spending Per Person by Medicaid Authority in Fiscal Year 2017



Intellectual or Developmental Disabilities (IDD); LTSS: Long-Term Supports and Services

ICF/IID: Intermediate Care Facilities for Individuals with Intellectual Disabilities

Group: Number of people with IDD in a setting (ICF/IID, group home or other)

Waiver+: Medicaid Authorities 1115, 1915 (a)(b) or (b)(c), 1915(c)

For more see risp.umn.edu

People Served

State population is 12.74 million

served is 30,813

served per 100k in IL 241

USA 393

IL is at 61% of the national average

IL will need to serve 19,700 more to reach the national average

Amount Spent

\$40,482 per person receiving

community waiver services

That's \$72 per state resident

In the USA the average is \$44,983

That's \$119 USA resident

A Word About Employment

About 1,740 received employment services. That's 6%.

The national average is 21%.

Illinois Data Basics

Considering Disruptive Systems Change

Population demographics **change**
Generational thought and belief **change**
Service recipient expectations **change**
Employees and their availability **changes**
Technology **changes**
Service practices **change**
The economy **changes**



Just because we “have done things the same way for years” doesn’t mean we aren’t affected by **disruptive change**.

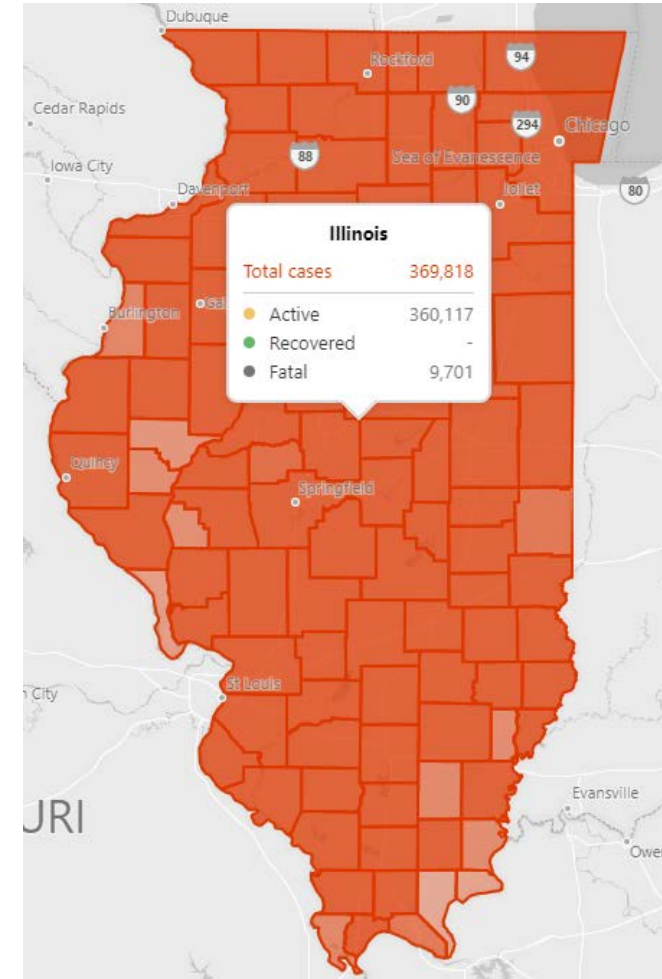
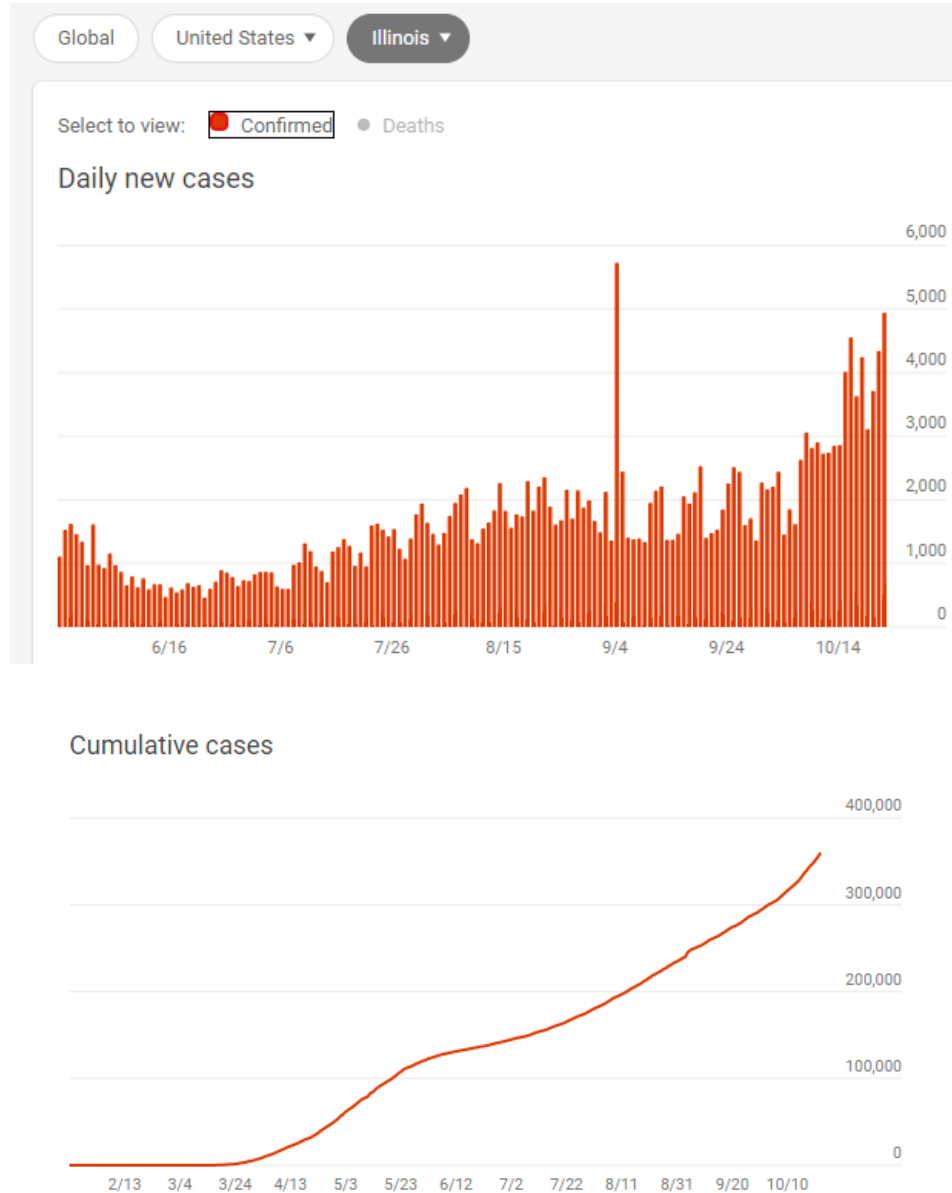
Let's do a quick gap analysis in our heads

A gap analysis is an assessment that compares the actual to potential or desired performance.

- Consider how money is spent per person right now
- Consider how things have changed
- Especially consider the expectations today of self-advocates and their families



Along Comes a Virus



COVID-19 Impacts

- We are concerned for our individual and collective health and safety
- Past ways of life are disrupted, including previous service use patterns
- We are tired and stressed
- We share an enduring uncertainty for the future



Community integration and self direction versus health and safety

Calm consensus versus impassioned conflict

Difficulties with delivering services, yet day to day life goes on

Anticipated budget shortfalls

There is a toll taken on each of us and all of us.

The story itself overwhelms what the numbers alone tell us.

2. Hope, Belief, and Resolve



Thinking About Hope...

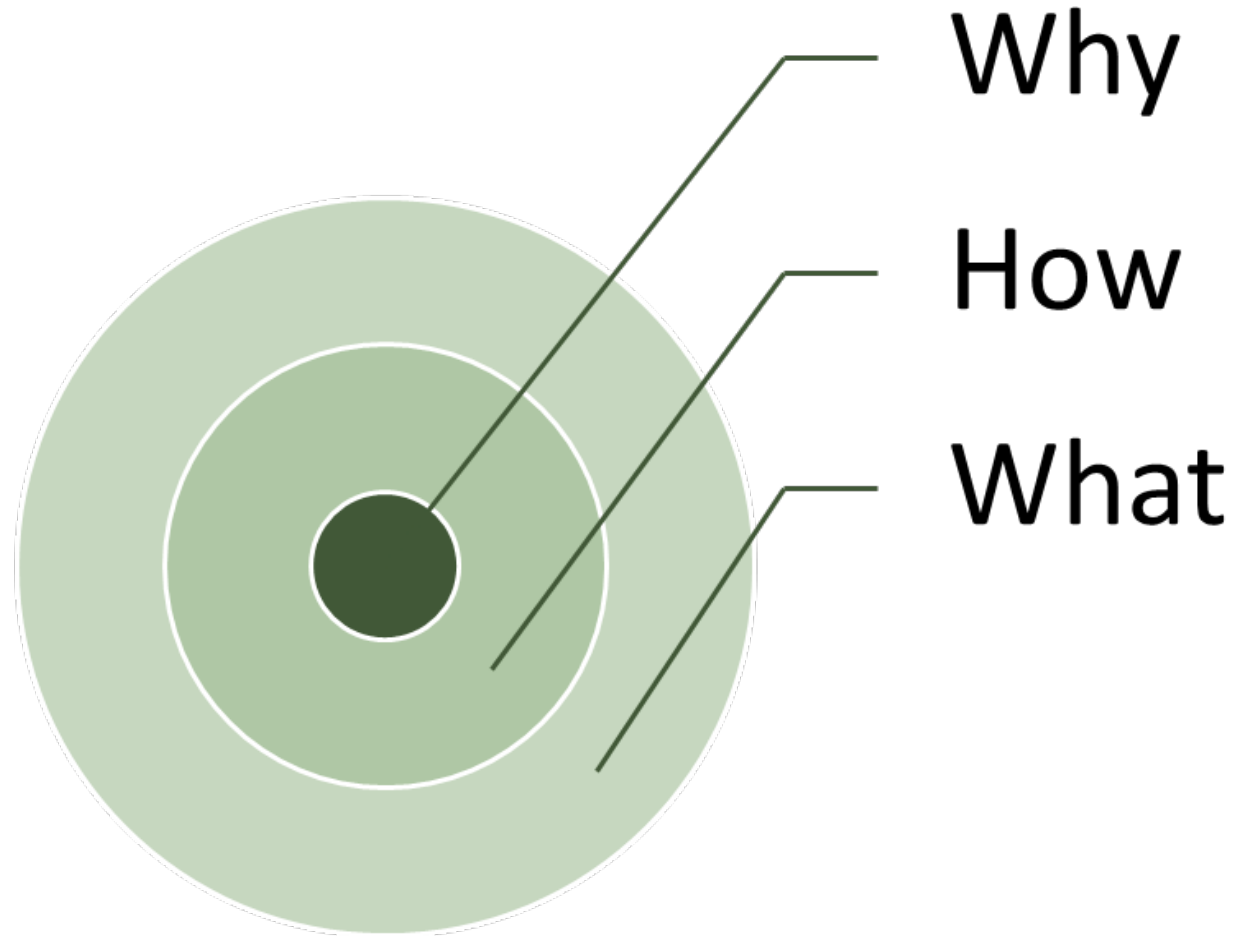


“Hope is not blind optimism. It's not ignoring the enormity of the task ahead or the roadblocks that stand in our path. It's not sitting on the sidelines or shirking from a fight.

Hope is that thing inside us that insists, despite all evidence to the contrary, that something better awaits us if we have the courage to reach for it, and to work for it, and to fight for it.”

Barack Obama

A place to start



We believe that...

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



MISSOURI FAMILY TO FAMILY AT UMKC IHD, UCEDD | LIFECOURSETOOLS.COM



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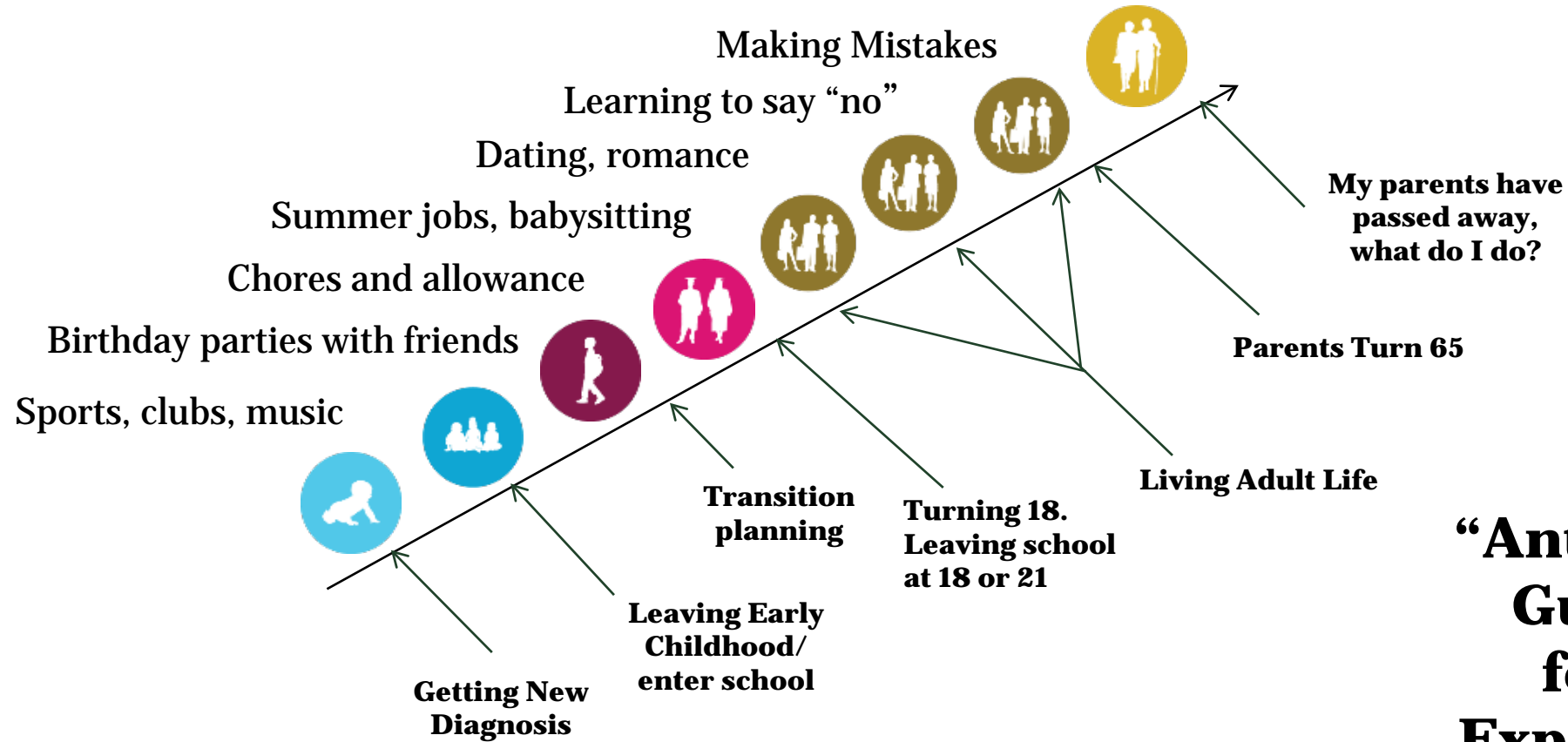
Complementing principles

A person-centered, community-oriented approach to deliver services for people with disabilities. The approach emphasizes:

- That people with IDD be 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.



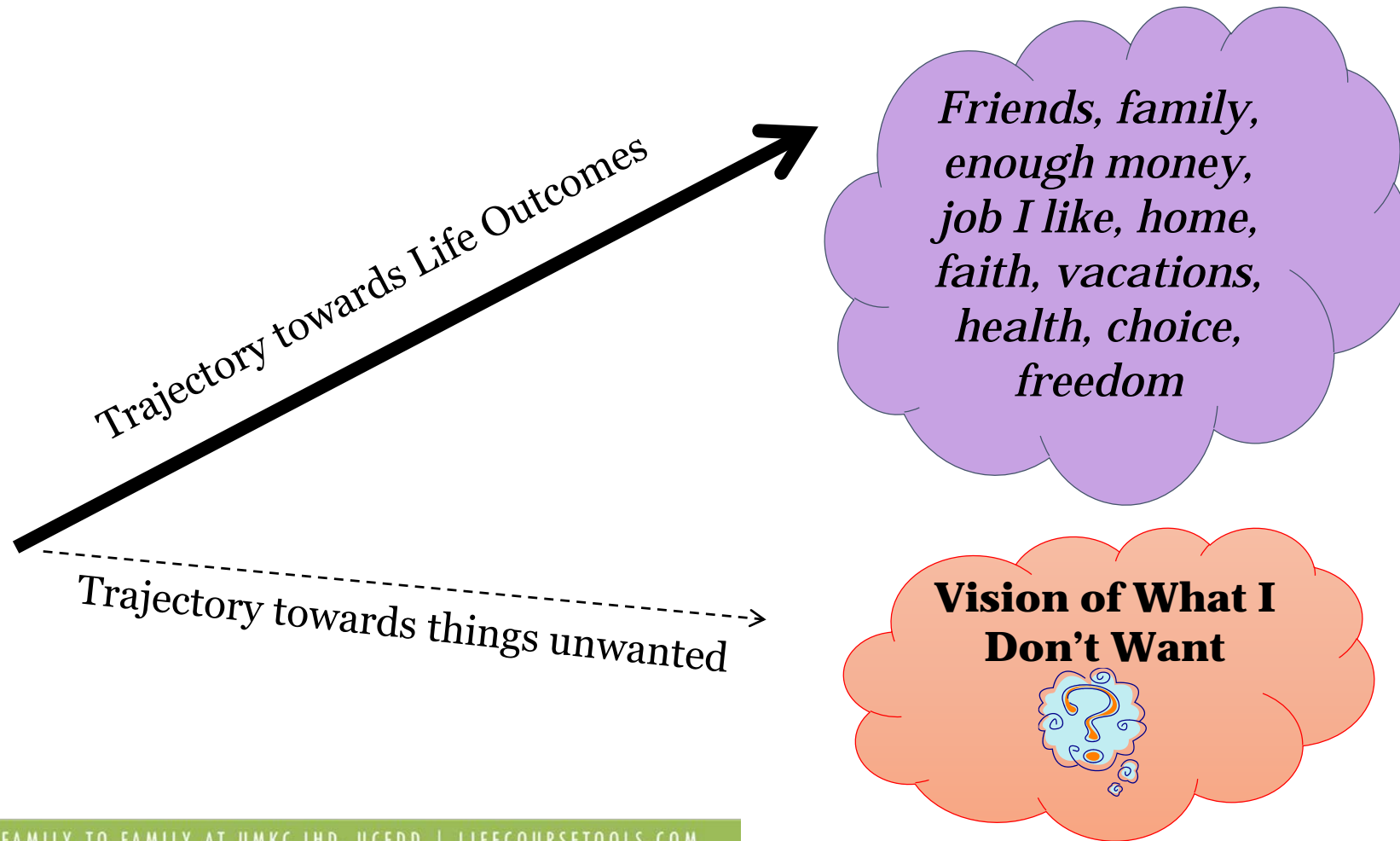
Focusing on Life Experiences and Life Transitions



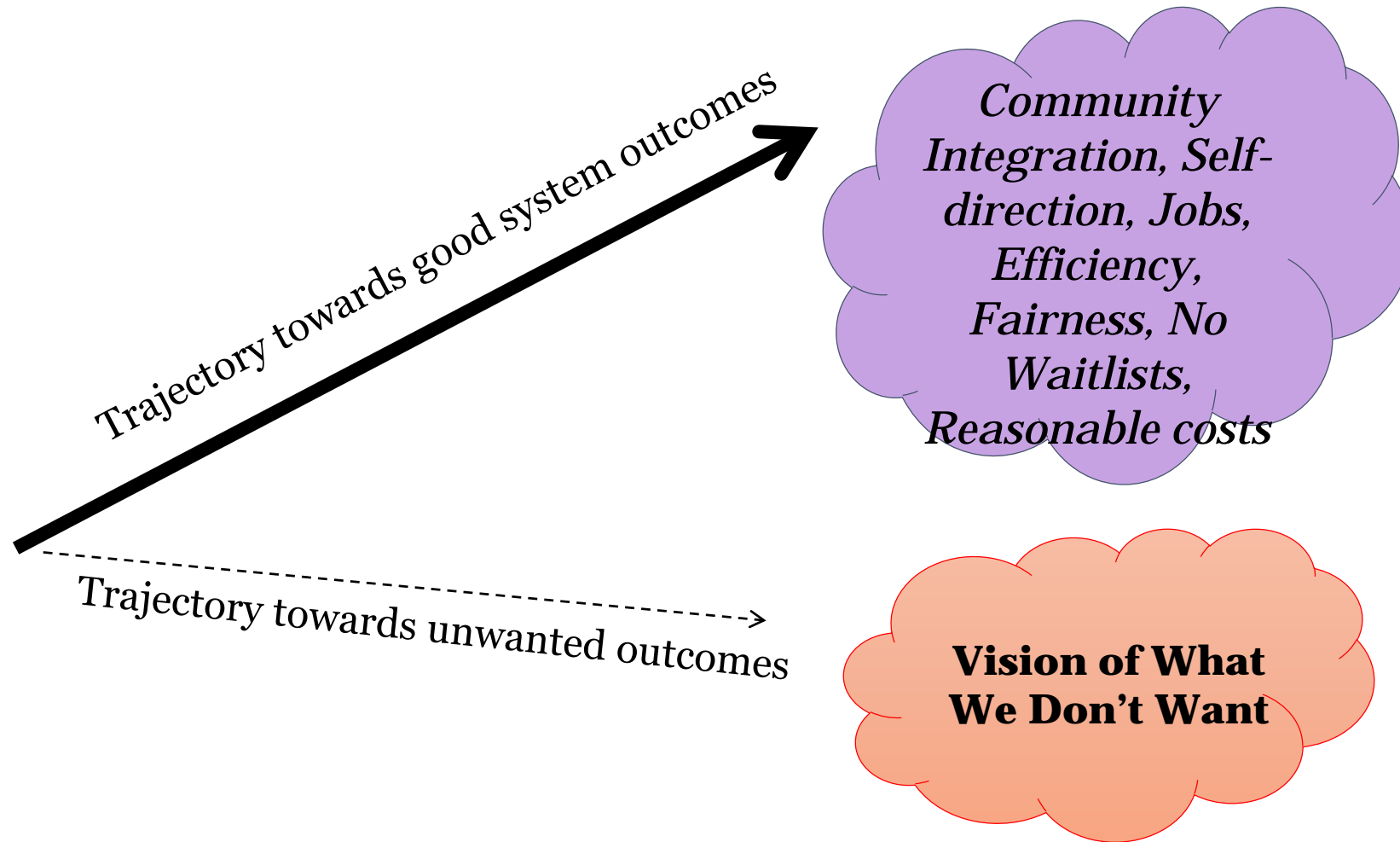
**“Anticipatory
Guidance
for Life
Experiences”**



Trajectory toward a good life



Trajectory toward a good system



3. Thinking About the Way Forward



System Re-Design

LifeCourse Principles



Service Array
Rates
Assessment &
Supports Budgets
Service Mixes



Support Planning
Exceptions



Provider Network
Supports Delivery



Quality Outcomes
- Person
- System

Finance Strategy

Summertime Canvass of a Few Leaders

During this past summer, Valerie Bradley led discussion with a few individuals about the way forward

- John Agosta
- Sue Swenson
- Nancy Thaler
- Nancy Weiss
- Michael Smull
- Mary Sowers
- Rud Turnbull
- Ann Turnbull
- Holly Riddle
- Robin Cooper
- Steve Eidelman
- Gerry Morrissey
- Ruth Luckasson
- Marty Ford
- Ari Ne'eman
- Julia Bascom
- Amy Hewitt
- Cathy Ficker-Terrill
- Alison Barkoff
- Celia Feinstein

“It is always wise to look ahead, but difficult to look further than you can see”

Winston Churchill



Most important...

We must listen to what people with IDD and their families have learned during this period and what *they* want their lives to be in the future.

Afterall...

Where imagery leads, policy follows and behavior results.



System Re-Design

De-emphasis on

- Anticipating a return to previous expectations about systems
- Using the past as a definitive guide for solving problems going forward
- A need for buildings, including further reduction in facility-based options (sheltered workshops, congregate residential systems)

Emphasis on

- More equitable system design and allocations of resources especially in face of budget shortfalls
- Assistance to families
- Better pay and protection for essential workers (DSPs)
- Increased emphasis on technology (telehealth, remote supports) to support people in smaller settings and with their families
- New day service models without walls
- Emphasis on creating more inclusive communities to reduce the isolation of people with IDD and to expand friendships
- Increased attention to trauma informed supports in healing settings given the trauma that people are experiencing
- New emergency planning requirements that include accommodations during a pandemic

4. Concluding Remarks





Lead On!

Justin Dart

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

From Rud Turnbull: *"When it's too dark to see"*

Blow on the coal of the heart.
The candles in the churches have gone out.
The lights have gone out in the sky.
Blow on the coal of the heart
And we'll see by and by....

We'll see where we are.
The wit won't burn and the wet soul smolders.
Blow on the candle of the heart and we'll know...
We'll know.

*Sarah responding to her husband, J.B., in
Archibald MacLeish's 1956 play entitled J.B.*

