

# INNOVATIONS IN SUPPORTING FAMILIES COMMUNITY OF PRACTICE FRAMEWORK FOR SYSTEMS CHANGE WEBINAR SERIES

## LifeCourse in Action:

Scaling up the  
LifeCourse at Every  
Stage in Connecticut



NASDDDS

UMKC  
INSTITUTE FOR HUMAN DEVELOPMENT  
A University Center for Excellence in Developmental Disabilities (UCEDD)





# SUPPORTING FAMILIES

of individuals with intellectual & developmental disabilities

THE NATIONAL COMMUNITY OF PRACTICE • FUNDED BY THE ADMINISTRATION ON INTELLECTUAL & DEVELOPMENTAL DISABILITIES

## Project Goal

To build capacity through a community of practice across and within States to create policies, practices and systems to better assist and support families than include a member with I/DD across the lifespan.

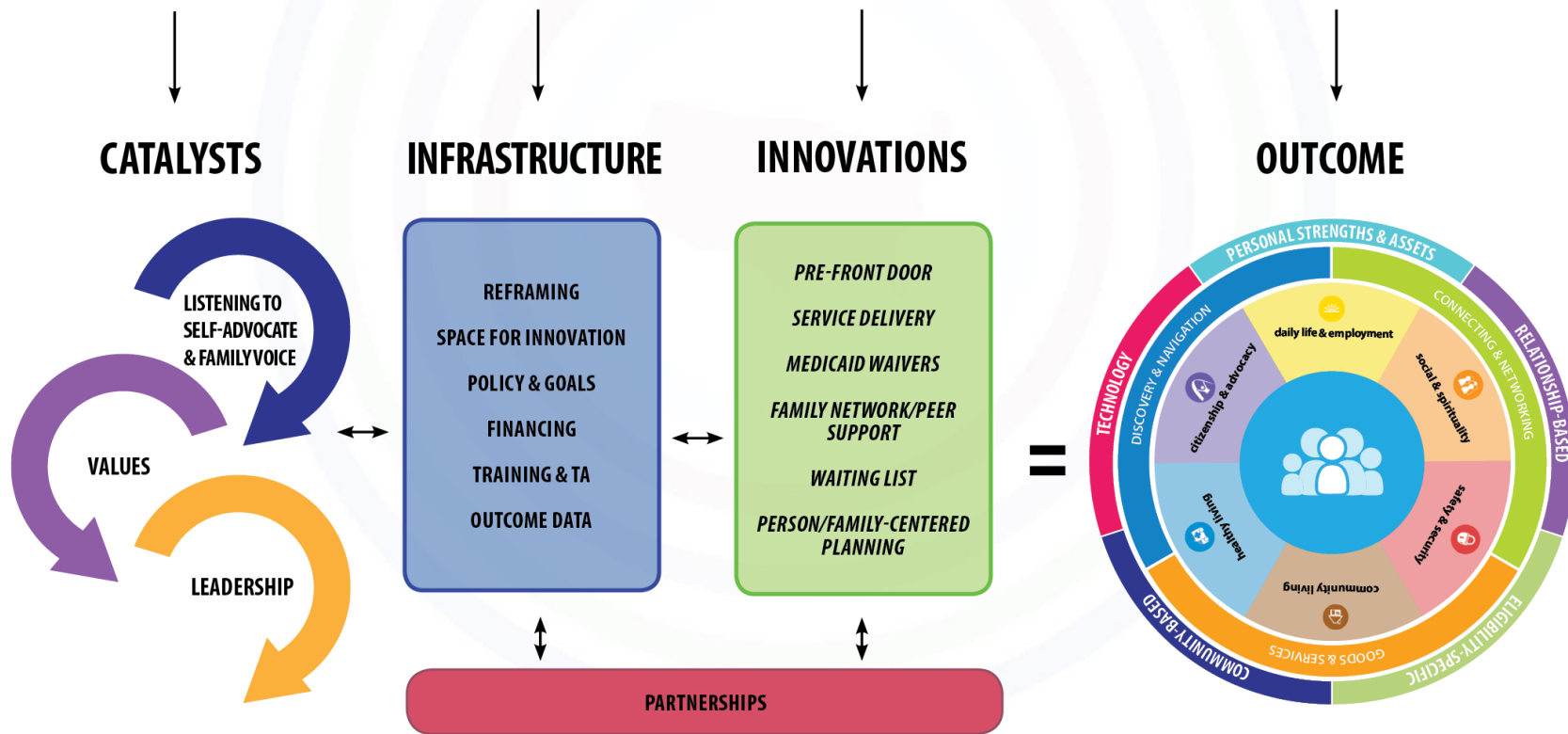


ADMINISTRATION ON  
INTELLECTUAL AND  
DEVELOPMENTAL  
DISABILITIES



# National CoP for Supporting Families Framework for Systems Change

## Life Course Guiding Principles



Michelle "Sheli" Reynolds, PhD. UMKC Institute for Human Development, UCEDD. Revised June 2014. Adapted from Hall et al, 2007





# The LifeCourse Framework

Introduction



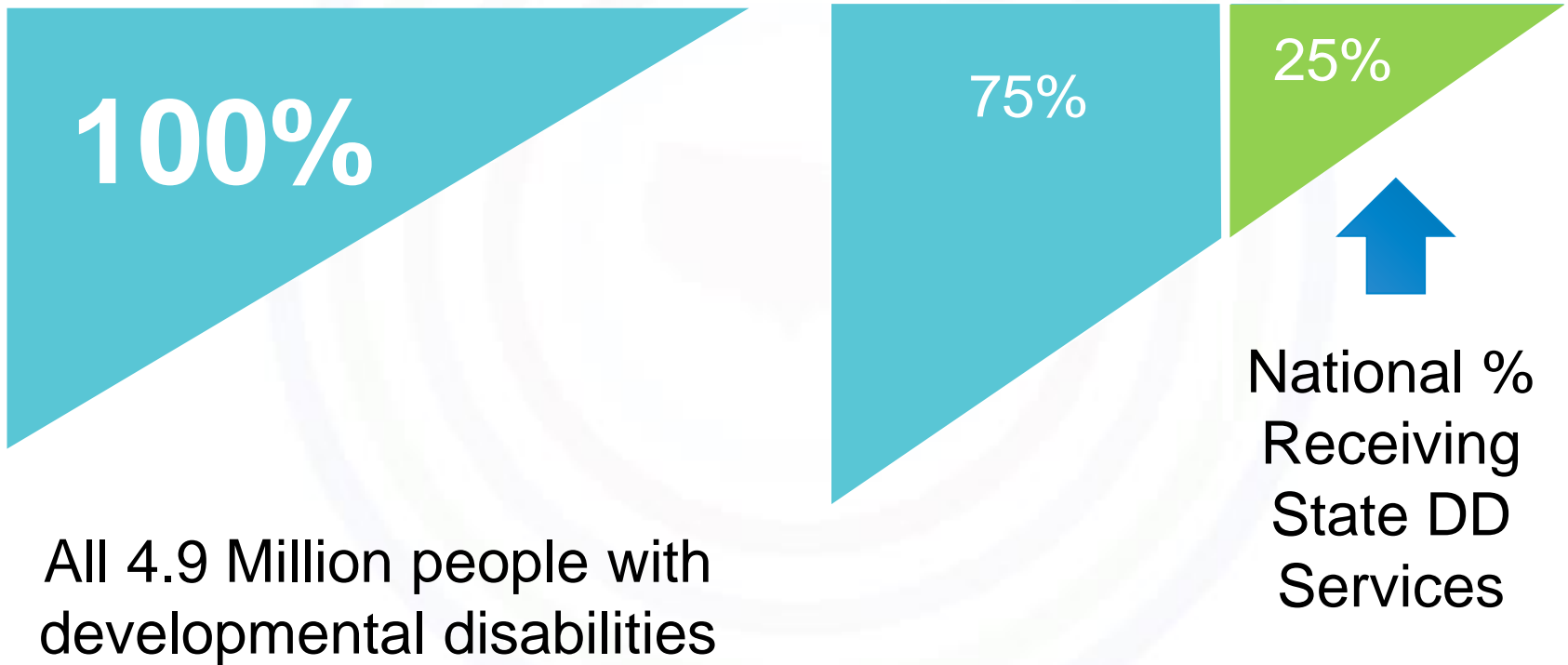




All people have the right to live, love, work, play and pursue their dreams in their community.



# Focus on “ALL”



*\*\* Based on national definition of developmental disability with a prevalence rate of 1.49%*



# LifeCourse Framework



# LifeCourse Framework

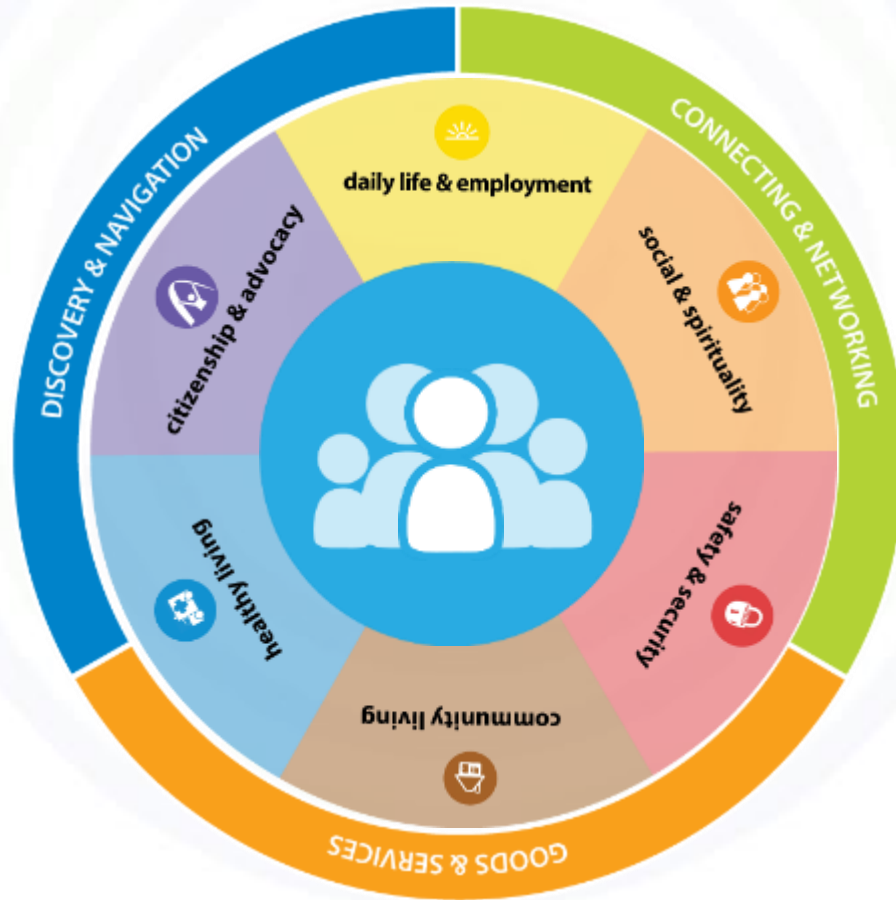




# LifeCourse Framework



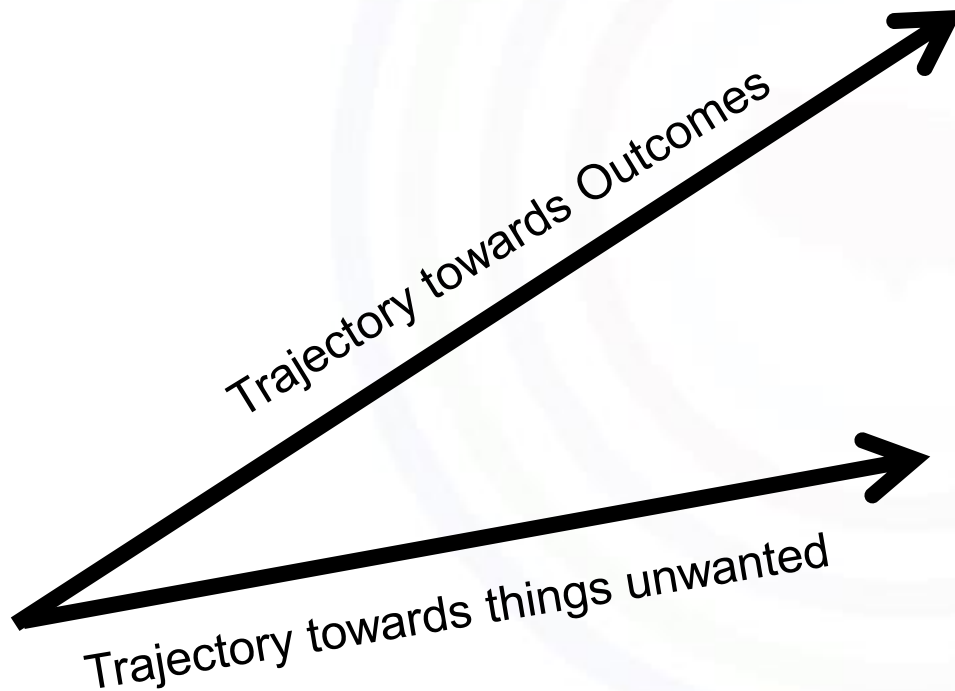
# LifeCourse Framework



# LifeCourse Framework



# Trajectory towards Life Outcomes



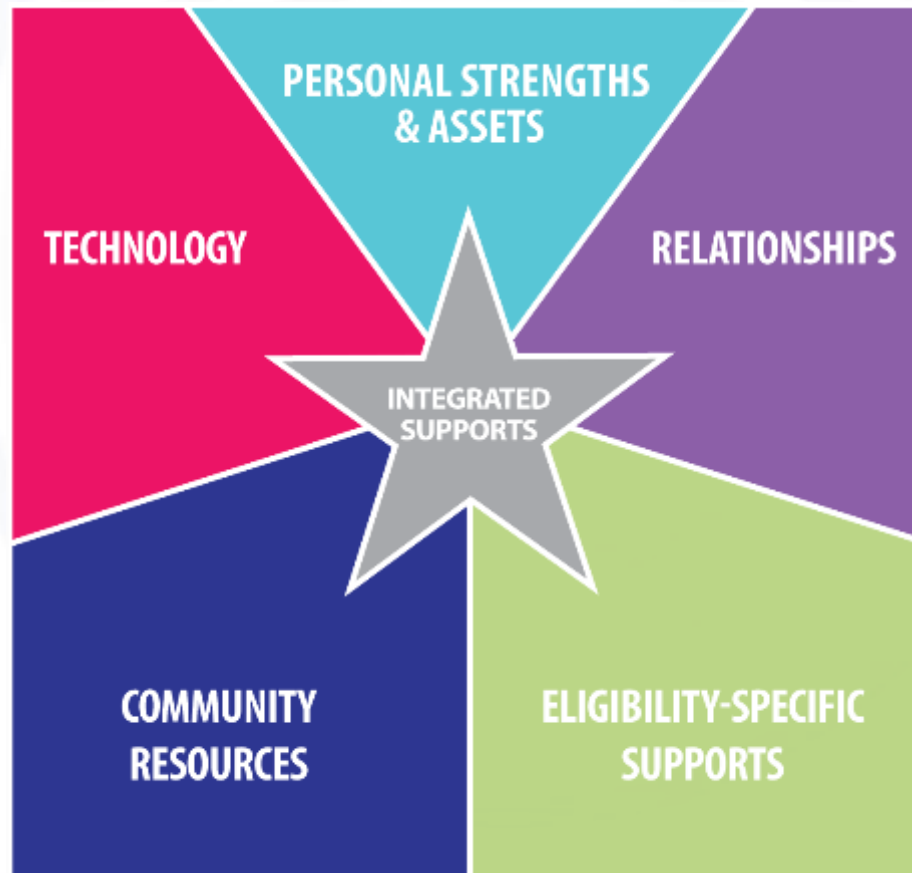
*Friends, family, self-determination, community living, social capital and economic sufficiency*

**Vision of What I Don't Want**

*Both in practice with individuals and in policy changes for systems*



# Identifying Integrated Strategies for Delivery of Supports



**Not only  
DD Services**





# Outcomes for Today's Webinar

1. Understand the principles of the LifeCourse framework,
2. See concrete examples of how the LifeCourse framework and tools are being used to support individuals throughout the entire lifespan
3. Hear how the Connecticut Community of Practice team is incorporating Life Course principles and practices across the state









# LAND OF STEADY HABITS

**Connecticut**



# Re-evaluating Current Services – How many could we serve?

Type of Service	Cost per Person	Cost to Serve the Waiting List 122,870	People Served with \$5 M
ICF/MR	\$128,275 CT \$383,316	\$15,761,114,925	 39 CT 13
Non-family HCBS	\$70,133 CT \$140,199	\$8,617,241,710	 71 CT 36
Host Family	\$44,122 CT \$51,687	\$5,421,270,140	 113 CT 97
Own Family	\$25,072 CT \$30,390	\$3,080,596,640	 200 CT 165

Data Source: Lakin, K.C. MSIS and NCI data from 4 states (1,240 Individuals)

National Association of State Directors of Developmental Disabilities Services (NASDDDS)



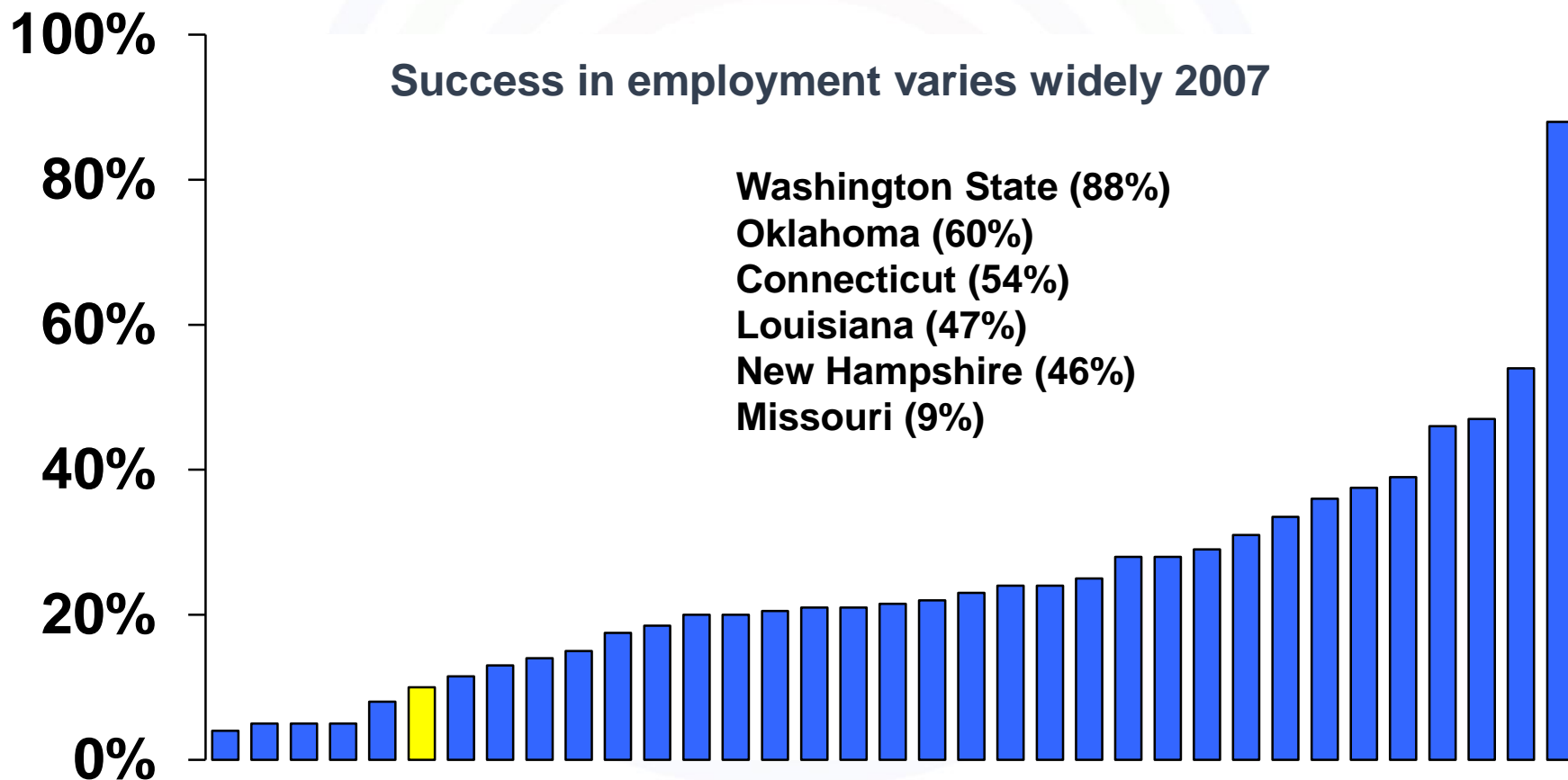
# Thinking for the Long Term

Type of Service	Cost per Person	20 yrs. Cost	30 yrs. Cost
ICF/MR Institution	\$128,275	\$2,565,600	\$3,848,250
HCBS 24hr staffed Residential	\$70,133	\$1,402,660	\$2,103,990
Shared Living (Adult Foster Care)	\$44,122	\$882,440	\$1,323,660
Supports in Own or Family Home	\$25,072	\$502,440	\$752,160

National Association of State Directors of Developmental Disabilities Services (NASDDDS)



# What People Do During the Day



Source: 2009 –UMass Boston ICI ID/DD Agency Survey

National Association of State Directors of Developmental Disabilities Services (NASDDDS)





# What has “Caught On” in CT



+ Life Span Partnerships



+ PCP/Life Course Planning



+ Expanded vision of Family Supports



# CONNECTICUT COMMUNITY OF PRACTICE FOR SUPPORTING FAMILIES

DDS



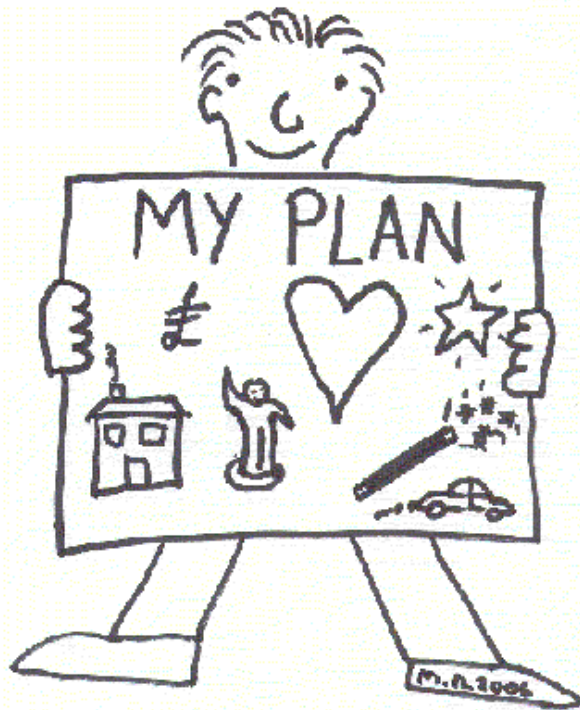
PATH  
Parent-to-Parent  
Family Voices  
of Connecticut



Building a **Life Span Partnership** for Supporting Families with a  
Member with Intellectual and Developmental Disabilities



# PCP & Life Course Planning



Person-Centered Planning



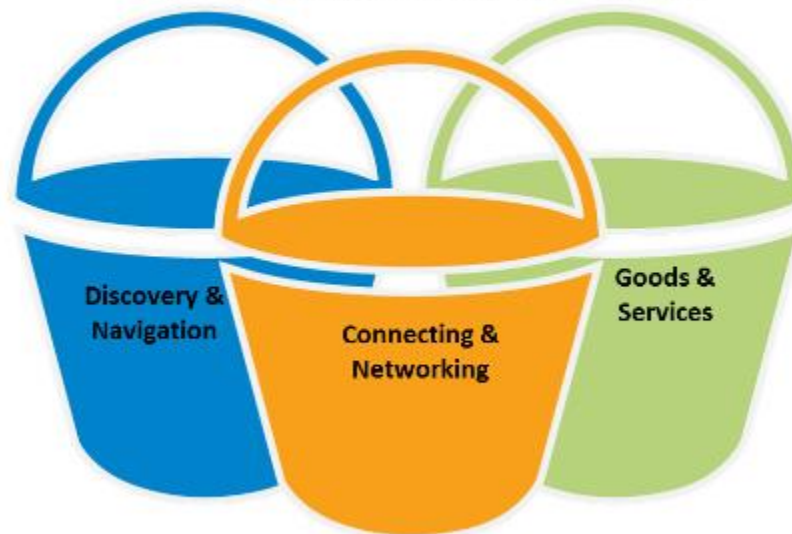
Life Course Planning





# Community of Practice for Supporting Families of Individuals with Intellectual & Developmental Disabilities

## Mapping Strategies for Supporting Families Across the LifeCourse



**Discovery & Navigation:**  
Helping families find and understand the information they need to better support their child

**Goods & Services:**  
Helping families get the supports they need for their child

**Connecting & Networking**  
Helping families connect to other families for support & mentoring





# Planning Tools

Open Romblad 's ONE-PAGE PROFILE

I am hilarious, Quick witted, Treat others nicely, Sweet and Kind, Competitive. Really good at video games, Entertaining.

Family, Friends, Milo my dog, Ziggy my guinea pig, Getting things right the first time, Free running, Exercise, Staying organized, Time  
People ask me what I want to do. Drawing

How to Best Support ME  
Extra Time  
Organizers  
Beetle reminders

\_\_\_\_\_ 's ONE-PAGE PROFILE

What people like & admire about me

What's Important to ME

How to Best Support ME





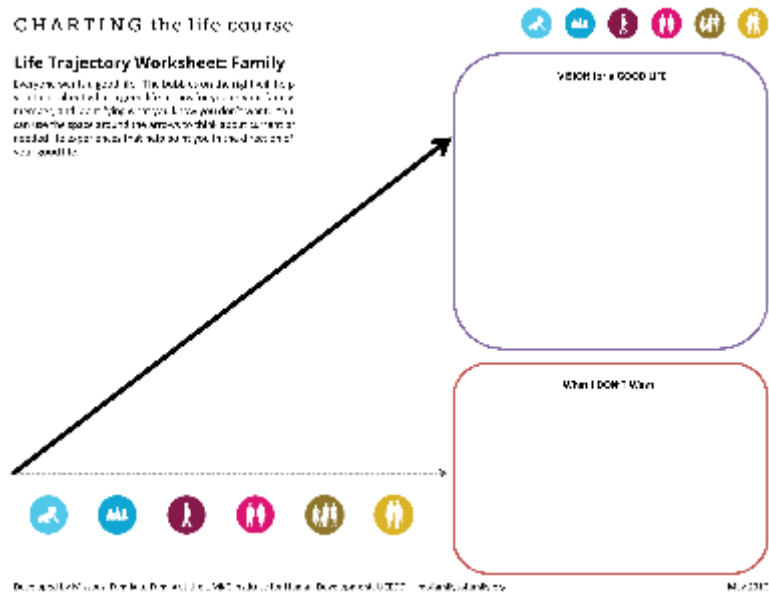
# Planning Tools

## FAMILY-CENTERED VISION OF THE FUTURE

CHARTING the life course

### Life Trajectory Worksheet: Family

Describe what you would like the future to look like for all the people who are important to you. Use the icons to help you think about the people you want to include in your vision. You can use the space at the bottom to write about the people you want to include in your vision.

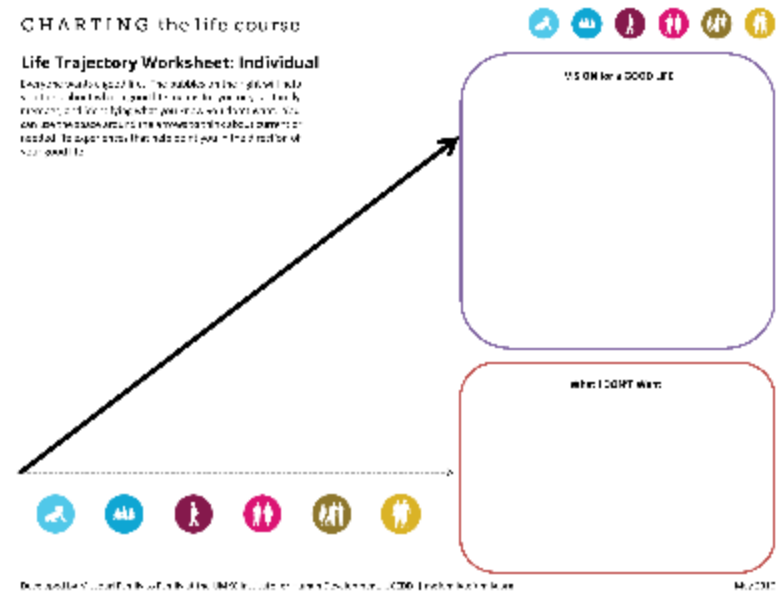


## PERSON-CENTERED VISION OF THE FUTURE

CHARTING the life course

### Life Trajectory Worksheet: Individual

Describe what you would like the future to look like for you. Use the icons to help you think about the people you want to include in your vision. You can use the space at the bottom to write about the people you want to include in your vision.







# Changes Across the Life Span

## Life Span Approach



## Bucket Thinking

### Mapping Strategies for Supporting Families Across the LifeCourse



## PCP/LifeCourse Planning

### PCP & Life Course Planning



Person-Centered Planning



Life Course Planning



#### OUR MISSION

The Americans with Intellectual and Developmental Disabilities (I/DD), the Developmental Disabilities Assistance and Bill of Rights Act (DD Act) provides for the protection and support of the fundamental rights afforded to all U.S. citizens. As a nation, it is our responsibility to not only recognize those rights but to transform our communities so that this is a reality in the everyday lives of individuals with I/DD. This requires the systems that support individuals with I/DD to transform the way they provide services and to recognize the family as a critical source of support that ensures these rights." *Winged Report*

#### OUR VISION

All Connecticut citizens with intellectual and developmental disabilities are valued contributors to their communities as family members, friends, neighbors, students, employees, volunteers, members of civic and religious associations, voters and advocates.

#### OUR GOALS

- Individuals**  
Will achieve self-determination, interdependence, productivity, integration, and inclusion in all facets of community life.
- Families**  
Will be supported in ways that maximize their capacity, strengths, and unique abilities to best nurture, love, and support the individual to achieve their goal.



#### QUALITY OF LIFE CORE AREAS

- VISION & VALUES**  
Vision for the future of an amenable life
- CONNECTIONS & RELATIONSHIPS**  
Social circles, personal networks, and links to opportunities
- RESPONSIBILITY & SELF-DETERMINATION**  
Control of and responsibility of life
- STRENGTHS & CONTRIBUTIONS**  
Having valued roles and giving back





# Prenatal & Infancy



- DDS Central Office Life Span Coordinator
- B3 Provider as a PCP/LifeCourse Ambassador



## PCP & Life Course Planning



Person-Centered Planning



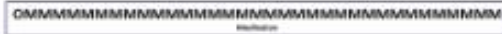
Life Course Planning





# Prenatal & Infancy Family Partnerships

Mapping Strategies for Supporting Families Across the LifeCourse



CAREGIVER SUPPORTS







# Early Childhood

B3 move to OEC

Great Expectations

Independence & Respite



Connecticut Office of  
Early Childhood

**Great Expectations:**  
Preparing Your Child with Developmental Disabilities  
for Employment Success

September 2011

**What families are saying...**

27% of all families with a child with a disability in America...  
 44% of all families with a child with a disability in order to...  
 70% of all families with a child with a disability in order to...  
 70% of all families with a child with a disability in order to...

Respite is not a luxury,  
it is a vital necessity.

The Transition Course

**WHAT FAMILIES NEED TO KNOW ABOUT**

**Respite**

The best respite is intentional, regular, and a favorite activity.

By Douglas Westcott

It is essential that respite be...  
 The Department of Developmental Services  
 2011



**PCP & Life Course Planning**

Person-Centered Planning

Life Course Planning







# Early Childhood Positive Behavior Supports

## WHAT FAMILIES ARE SAYING....

What do families need to know about positive behavior supports in early childhood? We are working on this question and following parents, child care providers, and community organizations to answer and follow-up on this. Do you have any questions about the Positive Behavior Support program? We would love to hear from you. Please email us at [info@supportstofamilies.org](mailto:info@supportstofamilies.org) or call us at 860-426-2222.

What do you as parents need to know about positive behavior supports in early childhood? We are working on this question and following parents, child care providers, and community organizations to answer and follow-up on this. Do you have any questions about the Positive Behavior Support program? We would love to hear from you. Please email us at [info@supportstofamilies.org](mailto:info@supportstofamilies.org) or call us at 860-426-2222.

### Who Can Author Positive Behavior Support Plans and Provide Consultation?

People who write Positive Behavior Support plans and offer consultation to families should have appropriate training and supervision in providing behavior supports to persons with developmental disabilities. This includes education, training, and experience, and must include a minimum of 100 hours of training in the development of Positive Behavior Support plans, and a minimum of 100 hours of training in the development of Positive Behavior Support plans, and a minimum of 100 hours of training in the development of Positive Behavior Support plans.

**Positive Behavior Support Resources:**  
[www.supportstofamilies.org](http://www.supportstofamilies.org)  
 860-426-2222  
 860-426-2222

This product was developed through the National Community of Practice for Supporting Families of Individuals with Disabilities ([www.supportstofamilies.org](http://www.supportstofamilies.org))

## WHAT FAMILIES NEED TO KNOW ABOUT Positive Behavior Supports

The goal is to help you identify challenging behaviors that are most important to your family and help you and your family learn strategies to help.

**DBS**  
Division of Developmental Disabilities

CT Department of Developmental Disabilities

## Children's Behavioral Health Plan

General Assembly Public Act 13-178

[plan4children.org](http://plan4children.org)

[About](#) | [Final Plan](#) | [Implementation](#) | [CT Opistol Response](#) | [Provide Input](#) | [News](#) | [Contact Us](#)

The State of Connecticut developed a plan to improve children's behavioral health services and systems across the state.

In developing this plan, we sought input from parents, community members, mental health experts, and other interested people who offered ideas and shared their experiences related to children's behavioral health issues. The completed plan will guide the State's efforts to build a comprehensive and integrated behavioral health system that benefits all of Connecticut's children.





# School Age

*Get Your FUTURE Started*  
**FOCUS ON TRANSITION**  
 CONNECTICUT TRANSITION TIMELINE

- Birth to Five
- Elementary
- Middle School
- High School
- Post-Secondary

The Connecticut Transition Timeline provides information beginning at birth, and continues throughout the school age years.

The Connecticut Transition Timeline provides a list of programs, services and activities to help your child or young adult prepare for the future.

The Connecticut Transition Timeline provides resources and information on post-secondary educational and employment opportunities.

The Connecticut Transition Timeline provides families, students, educators and community members opportunities to empower and promote a "great life" for all!

**SERC** STATE EDUCATION RESOURCES CENTER

HOME ABOUT BUDGET NEWS STATE RELEASES SERVICES EQUIPMENT LIMITED CONTACT US

Teacher Professional Learning Opportunities

READ

RESEARCH-BASED READING EDUCATION ASSISTANCE (REBE) PROGRAM

PARENT LEADERSHIP TRAINING GRANT

## SDE Transition Timeline

## PCP/LifeCourse Teacher Training

PCP & Life Course Planning

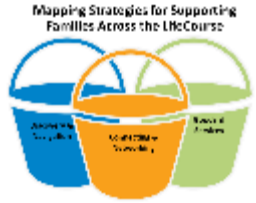
Person-Centered Planning

LIFE COURSE PLANNING





# School Age Information Dissemination



**Charting the LifeCourse**  
Experiences and Questions Booklet  
A Guide for Individuals, Families, and Professionals

Throughout our lives, we face questions and search for answers that will help us in our journey to a full and meaningful life. This is true for everyone, especially when you or someone you care about experiences a disability or special health care need.

Charting the LifeCourse is a tool to assist you in creating a vision for the future. It is designed to help you think about the questions to ask as well as the choices, options and life experiences to consider as you "plot a course" to a full and meaningful life. It is intended to be a starting point no matter where you are in your life journey.

We hope this LifeCourse Experiences and Questions booklet helps you realize that even when your child is very young, and wherever you are on the journey as he or she ages and grows into adulthood, their life experiences and environment can shape how they will live life in the future.

CONNECTICUT COMMUNITY OF PRACTICE FOR SUPPORTING FAMILIES

Charting the LifeCourse

**Daily Life & Employment**

Before you know it, school will be ending and adult life beginning. Transition is a time to think about what adult life will look like and explore what you will be doing as part of daily life when the school bus stops coming! You will likely make choices based on what you like and what you want to do. This guide is designed to help you and your family think about questions to ask, things to do, and resources to lead you to a job, career, volunteering, college or continuing education, and ultimately, the life you want.

**LIFE DOMAIN**  
Daily Life & Employment (What a person does as part of everyday life - school, employment, volunteering, concentration, routines, etc.)

**LIFE STAGE**  
Transition (moving from school to adulthood (14-21))

To find out more about how to use the LifeCourse employment materials please contact:  
Connecticut Family Support Network (CTFSN) [ctfn.org](http://ctfn.org)  
1-877-458-4DAY (1-877-375-4329)  
or  
PATH Parent to Parent/Family Voice of Connecticut [ctpfv.org](http://ctpfv.org)  
1-800-89-8000 (1-203-254-9900)

CONNECTICUT COMMUNITY OF PRACTICE FOR SUPPORTING FAMILIES

State of Connecticut  
**DEPARTMENT OF DEVELOPMENTAL SERVICES**  
**DDS**  
Individual and Family Support Resources  
and  
**HELPLINE Information**

Providing assistance to individuals who are eligible for DDS services and reside at home with families

**\*Eligibility Unit**





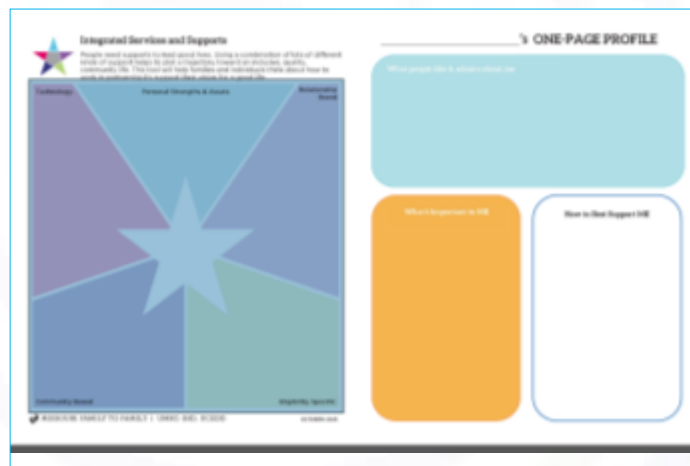
# Transition

## WIOA LEVEL UP

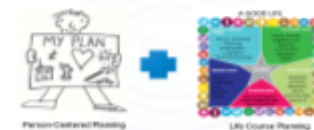
## LifeCourse Profiles

## DDS

## DDS Regional Transition Advisors



PCP & Life Course Planning







# Transition



WHAT FAMILIES NEED TO KNOW ABOUT

## assistive technology

**What is Assistive Technology?**

Assistive Technology (AT) refers to any item or piece of equipment that is used to increase, maintain or improve the functional capabilities of individuals with disabilities in all aspects of life, including at school, at work, at home and in the community.

Assistive technologies range on a continuum from low-tech to high-tech devices or equipment. Low-tech devices are usually less expensive, don't require a lot of training and have less features. High-tech devices tend to be more expensive, may require more in-depth training but will also likely have multiple features and are more adaptable for multiple purposes.

**DDS**  
CT Department of Developmental Services  
dgs.nh

CT Research on Developmental Disabilities  
rdgs.nh

State of Connecticut  
Department of Social Services

## Community First Choice

Revision date 2/4/16

**My Service Planning Tool Kit**





# Adulthood



## PRAT Allocation



## PCP LifeCourse Ambassadors







# Adulthood

Mapping Strategies for Supporting Families Across the LifeCourse



Department of Developmental Services

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**Parents with Intellectual Disability**

"Parents with a Voice" –Support and Advocacy Groups

North - [North Region Parents with a Voice Advocacy Group](#)  
 South - [Norwich Area Support Group for Parents with ID and Their Children](#)  
 West - [Parents with a Voice Advocacy Group](#)

**Resources:**

[Norwich Area Support Group for Parents with ID and Their Children \(PDF, 241 KB\)](#)  
[The ARC Resources](#)

**Happenings in Connecticut:**

[2015 – 2016 Partners in Policymaking Class- Brochure and Application](#)  
**NEW**

[Norwich Area Support Group for Parents with ID \(children welcome\) celebrates its 2 year anniversary!](#)  
[North Region Parents with a Voice Advocacy Group](#)  
[PWID 2nd Annual Family Picnic – May 31, 2014 \(PDF, KB\)](#)  
[Previous Picnic \(PDF, 273 KB\)](#)

Content Last Modified on 11/20/2015 11:00:12 AM

## Parenting Support Services

Peer<sup>2</sup>Peer

**PEER SUPPORT**

Getting support from people I trust!

"If I Can Do it, SO CAN YOU!"

## Peer Supports



## Shared Living Supports





# Aging



[Home](#)

[About The Technical Assistance Exchange \(TAE\)](#)

[No Wrong Door \(NWD\)](#)

[All Resources](#)

Search

[Go!](#)

Information on assistance in your community for seniors and/or persons with a disability.

## Welcome To The No Wrong Door Website

PCP & Life Course Planning



Person-Centered Planning



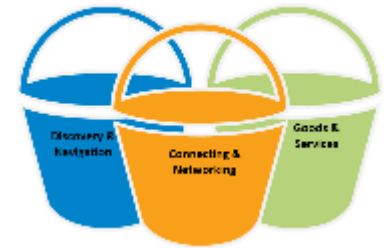
Life Course Planning





# Aging

Mapping Strategies for Supporting Families Across the LifeCourse



## Money Follows the Person



# Expanding Partnerships



Youth



Providers

**\*\*Are you an adult sibling of an individual with disabilities?\***

**The Connecticut Sibling Connection  
Invites You  
To The First Sibling Connection Meeting!**

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Thursday, June 9, 2016  
6 - 8 PM  
Allied Community Services, Inc.  
Three Pearson Way  
Enfield, CT 06082

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The Connecticut Sibling Connection is an organization with the mission to support siblings of individuals with disabilities in the State of Connecticut by providing the information, tools, and community to enrich their lives and the lives of their siblings.

Please join us at our first networking and information meeting to learn:

- Overview of Who We Are and What We Hope to Achieve
- Meet Other Siblings of Individuals with Disabilities in the State of Connecticut
- Learn How You Can Join CT Sibs and Create a Network of Support

For more information, please visit [cfsibs.org](http://cfsibs.org) or contact Mary at [mary@cfsibs.org](mailto:mary@cfsibs.org) or 860-266-4428.  
RSVP is not required, but appreciated for planning purposes.

**CONNECTICUT SIBLING CONNECTION**  
cfsibs.org



**ALLIED COMMUNITY SERVICES**

Siblings



# Q&A



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# LIFECOURSE TOOLS

LIFECOURSE TOOLS

LIFECOURSE PRINCIPLES

LIFECOURSE IN ACTION ▾

CONNECT ▾

ABOUT



LifeCourseTools.com





# Innovations Webinar Series

## Next webinar:

LifeCourse in Action: Connecticut – 9/29/16

## Archived webinars:

- Overview of the LifeCourse Framework
- Focusing on the Front Door of Long Term Services & Supports
- We're All in This Together: Uniting the Movements for a Good Life
- Reframing the Conversation at All Levels: Tools for Change
- Technology & Strategies for Supporting Families
- LifeCourse in Action: Implementation at all Levels in Missouri
- LifeCourse in Action: Reaching the All in Tennessee





# SUPPORTING FAMILIES

of individuals with intellectual & developmental disabilities

THE NATIONAL COMMUNITY OF PRACTICE • FUNDED BY THE ADMINISTRATION ON INTELLECTUAL & DEVELOPMENTAL DISABILITIES

- About
- The States
- Resources
- News & Events
- Contact

2016 Supporting Families 0

### LATEST NEWS

Next «Innovations webinar announced!  
 «LifeCourse Tools in Action: A Good Life for All in  
 «Oklahoma



FUNDED by



ADMINISTRATION ON INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

NATIONAL partners



### Welcome!

The **Community of Practice for Supporting Families of Individuals with Intellectual & Developmental Disabilities** involves working with six states to develop systems of support for families throughout the lifespan of their family member with intellectual and developmental disabilities (I/DD).

The **Supporting Families** project is operated under a five-year grant awarded to NACDDDC by the Administration on Intellectual and Developmental Disabilities (AIDD) beginning October 2012. Grant partners include University of Missouri-Kansas City-Institute on Human Development (UMKC-IHD), Human Services Research Institute (HSRI) and the National Association of State Directors of Developmental Disabilities Services (NASDDDS).

### MAILINGlist

Get updates about the national project, state teams, and supporting families!

First Name

Last Name

Email Address

# Visit us online at supportstofamilies.org