

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



OVERVIEW OF THE LIFECOURSE FRAMEWORK

JANUARY 22, 2015

About Us....

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NASDDDS, Co-Principle Investigator CoP and National Core Indicators

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IHD, Mo UCEDD, Director of Individual Advocacy and Family Supports

Co-Principle Investigator CoP



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 that include a member with I/DD across the lifespan.

Project Outcome

- State and national consensus on a national framework and agenda for improving support for families with members with I/DD.
- Enhanced national and state policies, practices, and sustainable systems that result in improved supports to families.
- Enhanced capacity of states to replicate and sustain exemplary practices to support families and systems.

Funded by



National Partners





SUPPORTING FAMILIES

of individuals with intellectual & developmental disabilities

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



National CoP Structure

Y1-2: Technical Assistance from National Staff

Monthly Calls with All States

One on One TA calls with Teams or Facilitator

Yearly Face to Face Meeting

Annual TA visit in states

Topical Specific Webinars (Family Networks, Framing)

Y3-5: TA and Knowledge Translation

National Webinars on Learning

Issues Briefs

E-newsletter

Increased Social Media Presence

GOAL



Individual

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

Recognizing that individuals exist within a family system

DISCOVERY & NAVIGATION

Knowledge & Skills

CONNECTING & NETWORKING

Mental Health
& Self-Efficacy

GOODS & SERVICES

Day-to-Day &
Caregiving/Supports

Defining Supports to Families



Wingspread Conference: Center Racine, WI
Sunday, March 6, 2011 - Tuesday, March 8, 2011

BUILDING A NATIONAL AGENDA FOR SUPPORTING FAMILIES WITH A MEMBER WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES



Integration of All Movements

1950s Parent-----Family-----Siblings

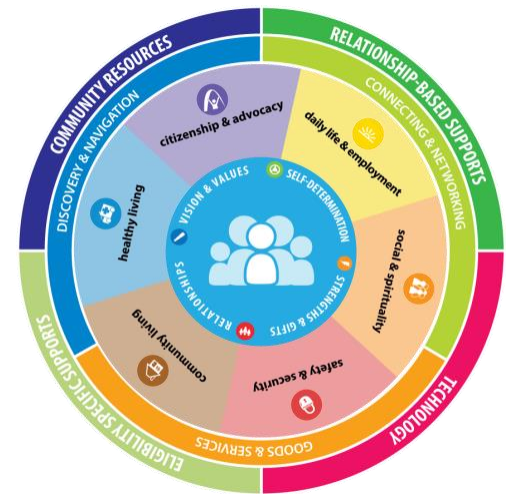
1960s State Service Systems

1970s Education for Children with Disabilities

1980s Medicaid Waiver

1970s Self-Advocacy-----Youth

2010s Community



**LifeCourse
Framework**

Guiding Principles & LifeCourse Framework

Reframing the Conversation at All Levels



People with disabilities and their families have the right to live, love, work, play and pursue their life aspirations just as others do in their community.



Focus on “ALL”



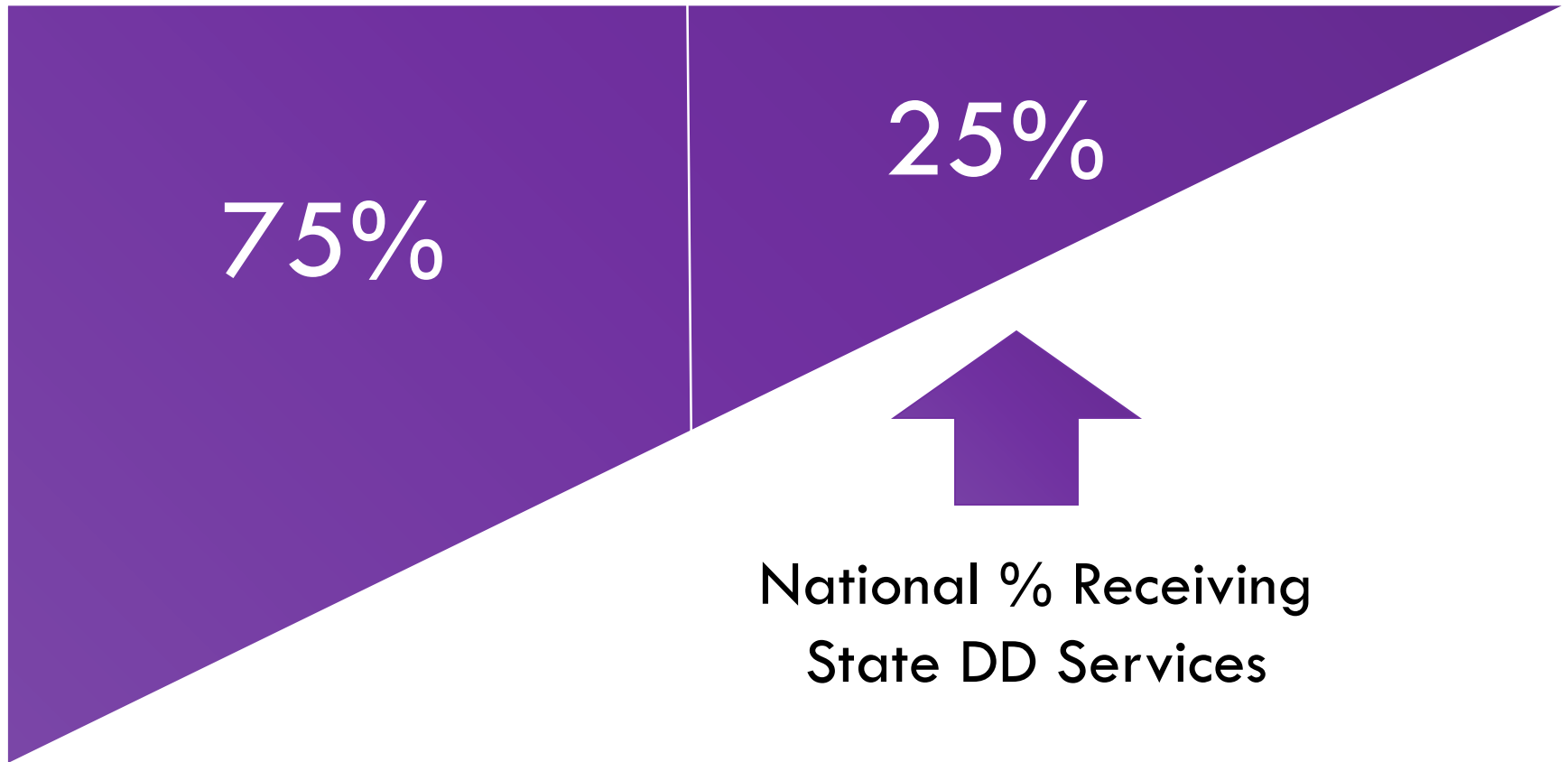
100%

ALL individuals with disabilities and families are considered in our values and vision.

(Family is defined by Individual)

Focusing on ALL

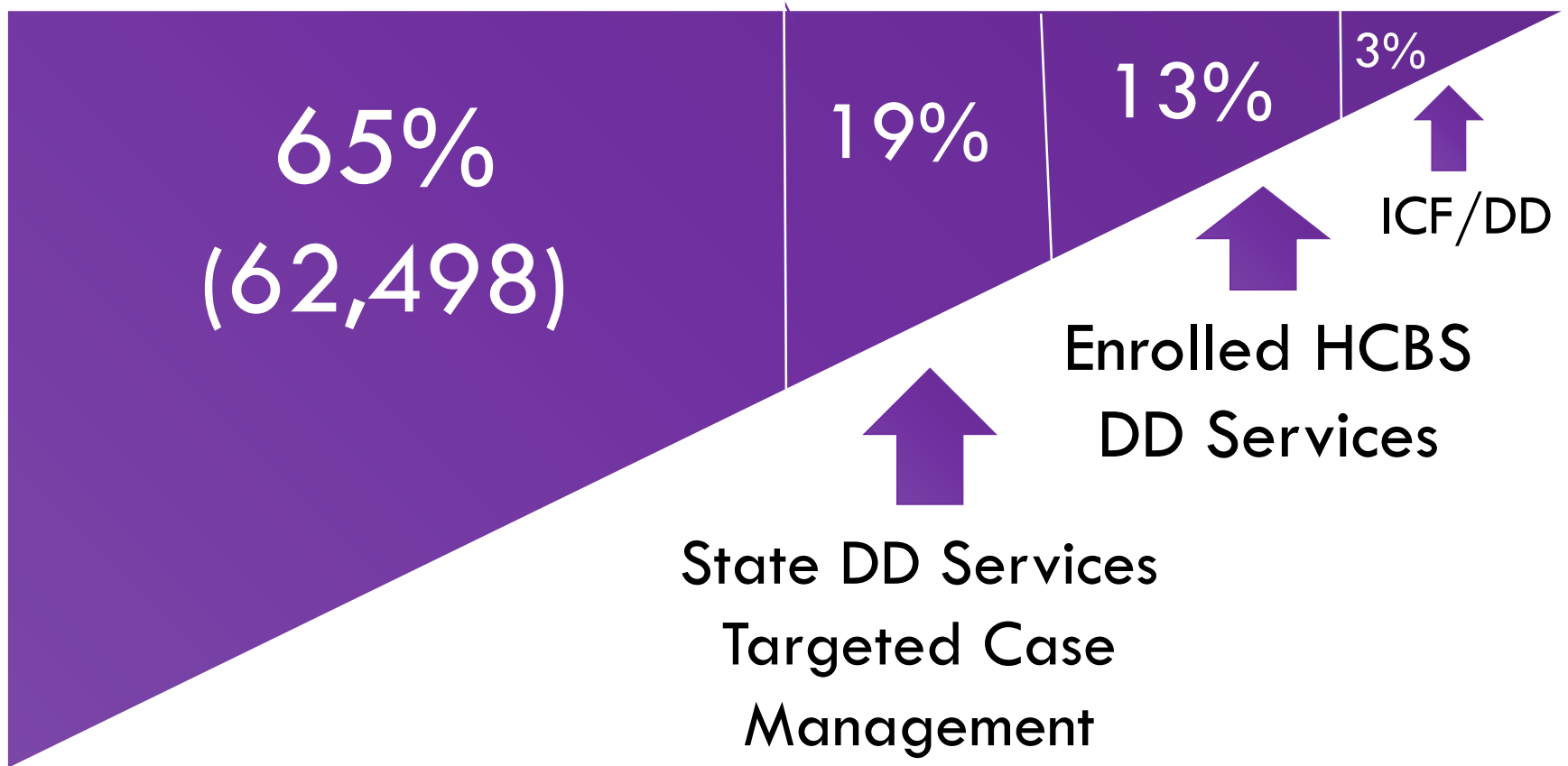
All 4.9 Million people with developmental disabilities



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

Missourians with I/DD

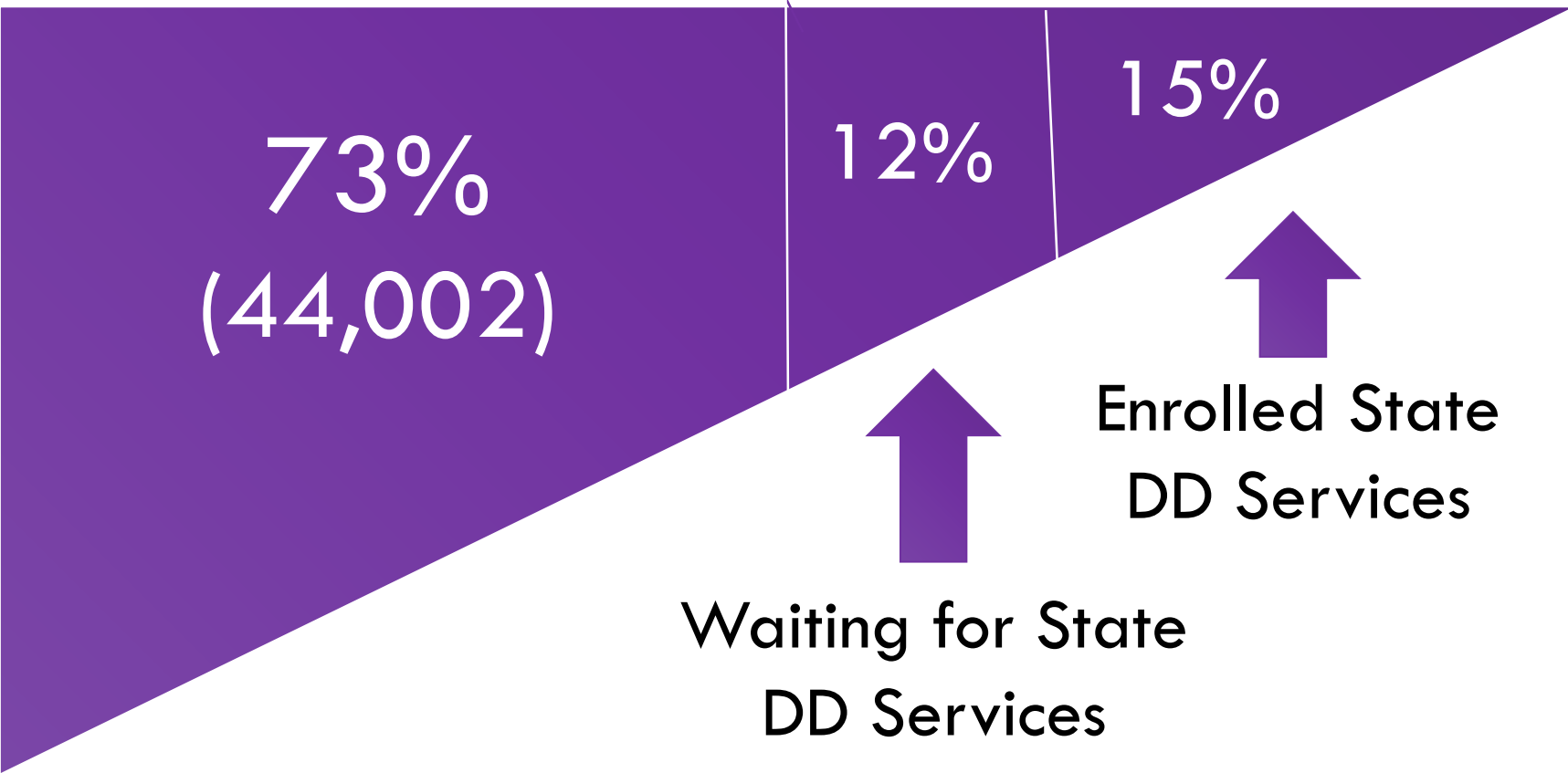
95,498 estimated Missourians with Developmental Disabilities



Based on 1.58% prevalence of 3.815 million citizens, US Census

Oklahomans with I/DD

60,277 estimated Oklahomans with Developmental Disabilities



Based on 1.58% prevalence of 3.815 million citizens, US Census

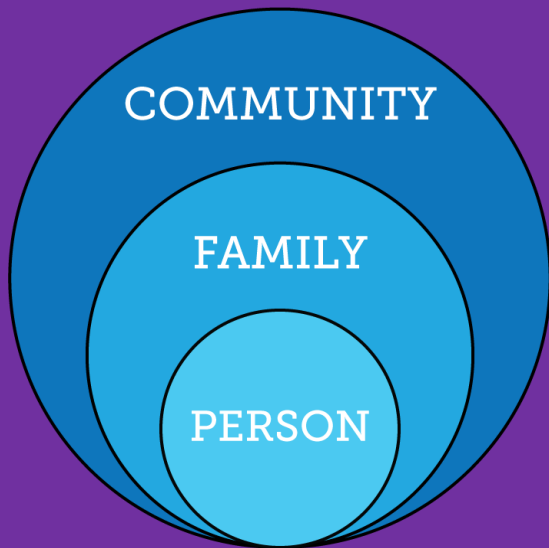


All individuals live within the context of a family

Individual members and their family, as a whole, may need supports that address different facets of life and that adjust as roles and needs of all family members change as they age through both the life cycle and the family cycle.

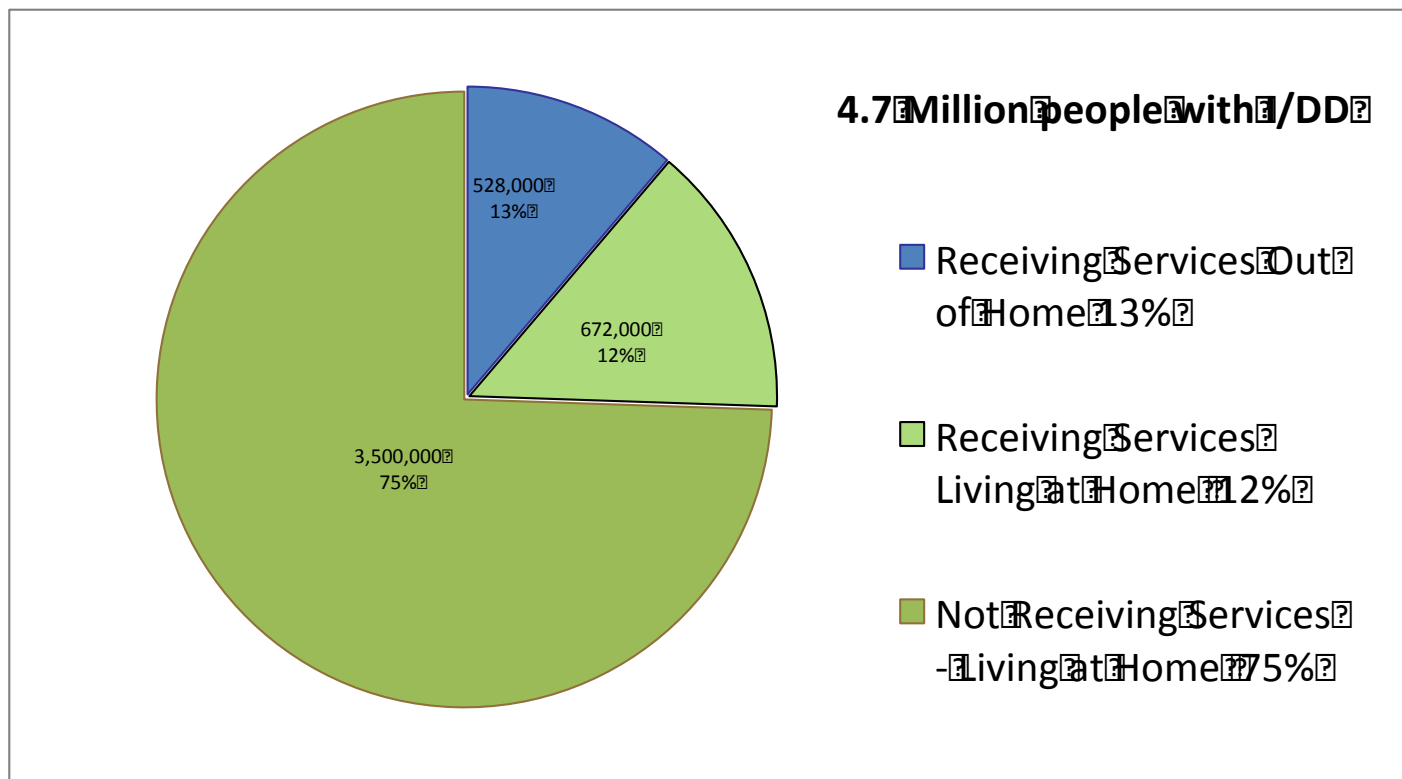
(Regardless of where a person lives)

Importance of Family within the Context of Disability Services: Our History



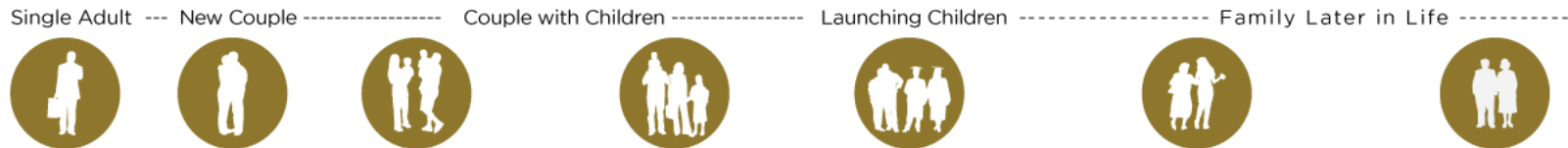
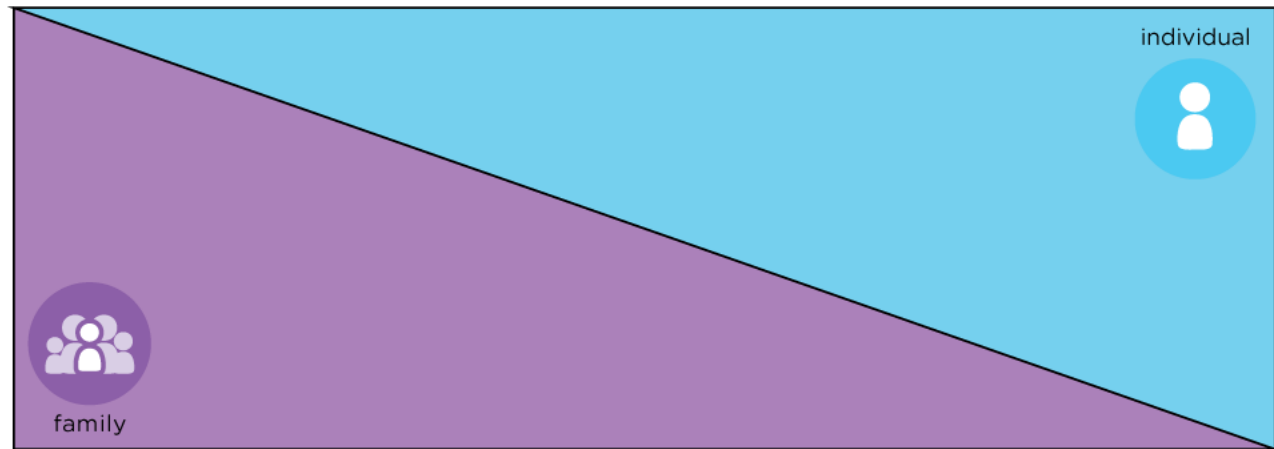
Importance of Family within the Context of Disability Services: Current Supports

89% of People I/DD receiving services are Supported by Family



Recognition of Individual and Family Cycles

Individual Life Cycle



Family Life Cycle

Reciprocal Roles of ALL Family Members

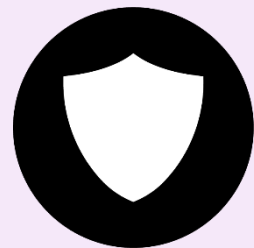


Caring About

Affection & Self-Esteem

Repository of knowledge

Lifetime commitment



Caring For

Provider of day-to-day care

Material/Financial

Facilitator of inclusion and membership

Advocate for support

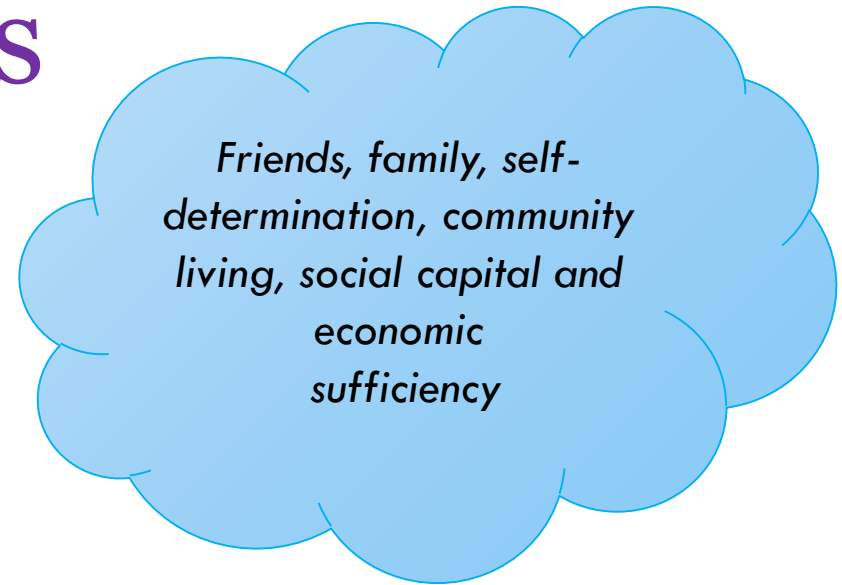
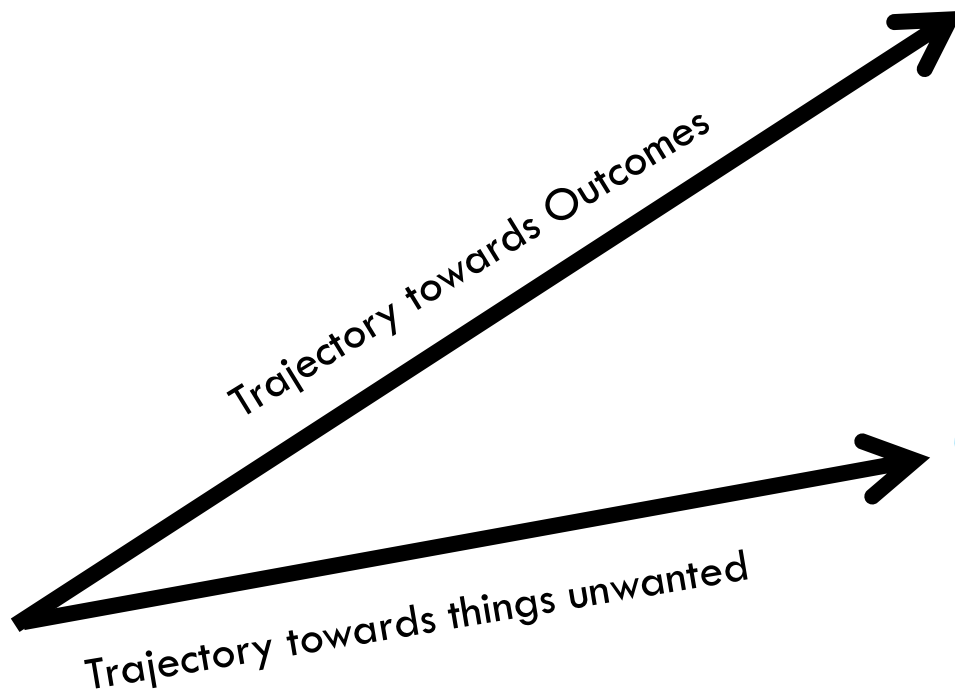
**Adapted from Bigby & Fyffe (2012), Dally (1988), Turnbull et all (2011)*

Life Stages: Think Across Generations

Age	0-5	6-18	19-64	65
Total TN Population	406,659 (6.3%)	1,084,425 (16.8%)	4,047,231 (62.7%)	916,597 (14.2%)
Approx. DD (1.59%)	6,465	17,242	64,350	14,573

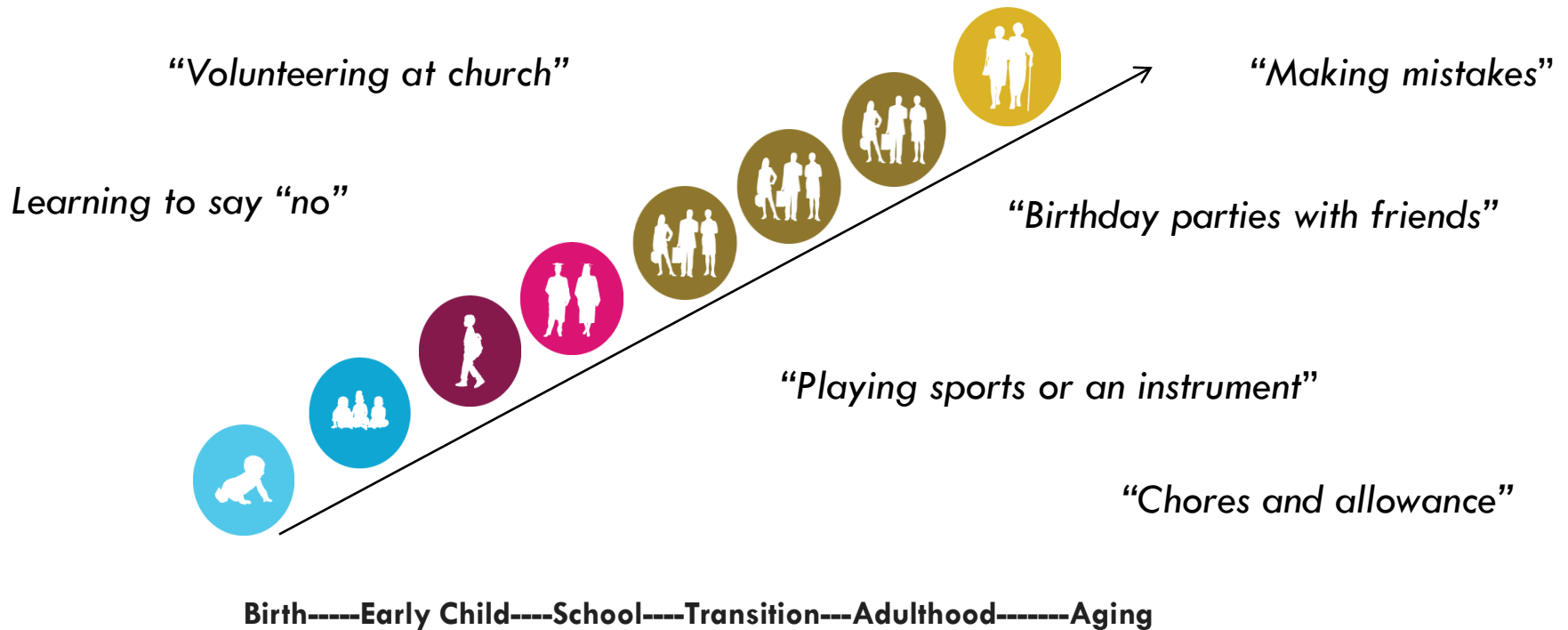


Trajectory towards Life Outcomes









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

Focusing on Life Experiences

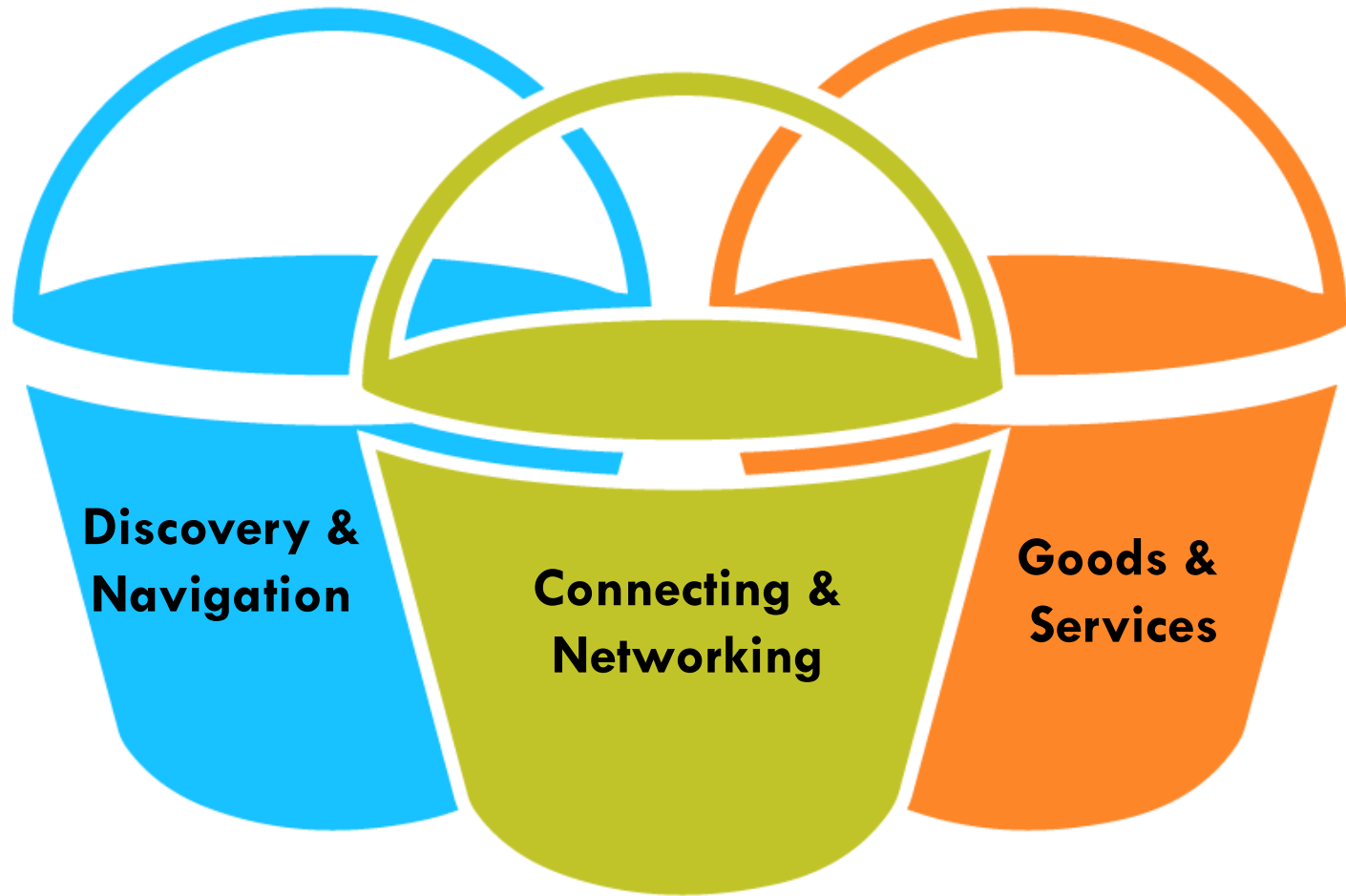


“Anticipatory Guidance for Life Experiences”

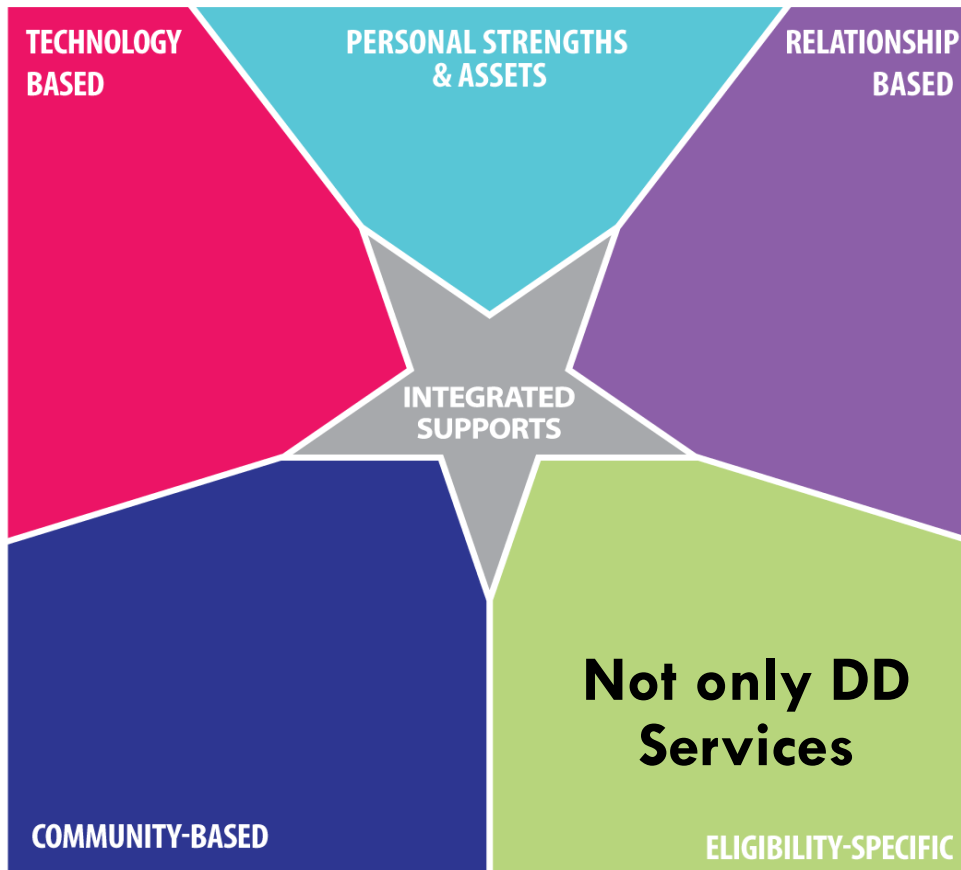
Thinking Across All Life Domains

 <p>Daily Life & Employment</p>	<p>What a person does as part of everyday life – school, employment, volunteering, routines, life skills</p>	 <p>Healthy Living</p>	<p>Managing and accessing health care & staying well – medical, mental health, behavioral health, developmental, wellness & nutrition</p>
 <p>Community Living</p>	<p>Where and how someone lives – housing and living options, community access, transportation, home adaptations & modifications</p>	 <p>Safety & Security</p>	<p>Staying safe and secure – emergencies, well-being, guardianship options and alternatives, legal rights and issues</p>
 <p>Social & Spirituality</p>	<p>Building friendships and relationships, leisure activities, personal networks, faith community</p>	 <p>Citizenship & Advocacy</p>	<p>Building valued roles, making choices, setting goals, assuming responsibility and driving how one's own life is lived</p>

Three Types of Supports



Identifying Integrated Strategies for Delivery Supports



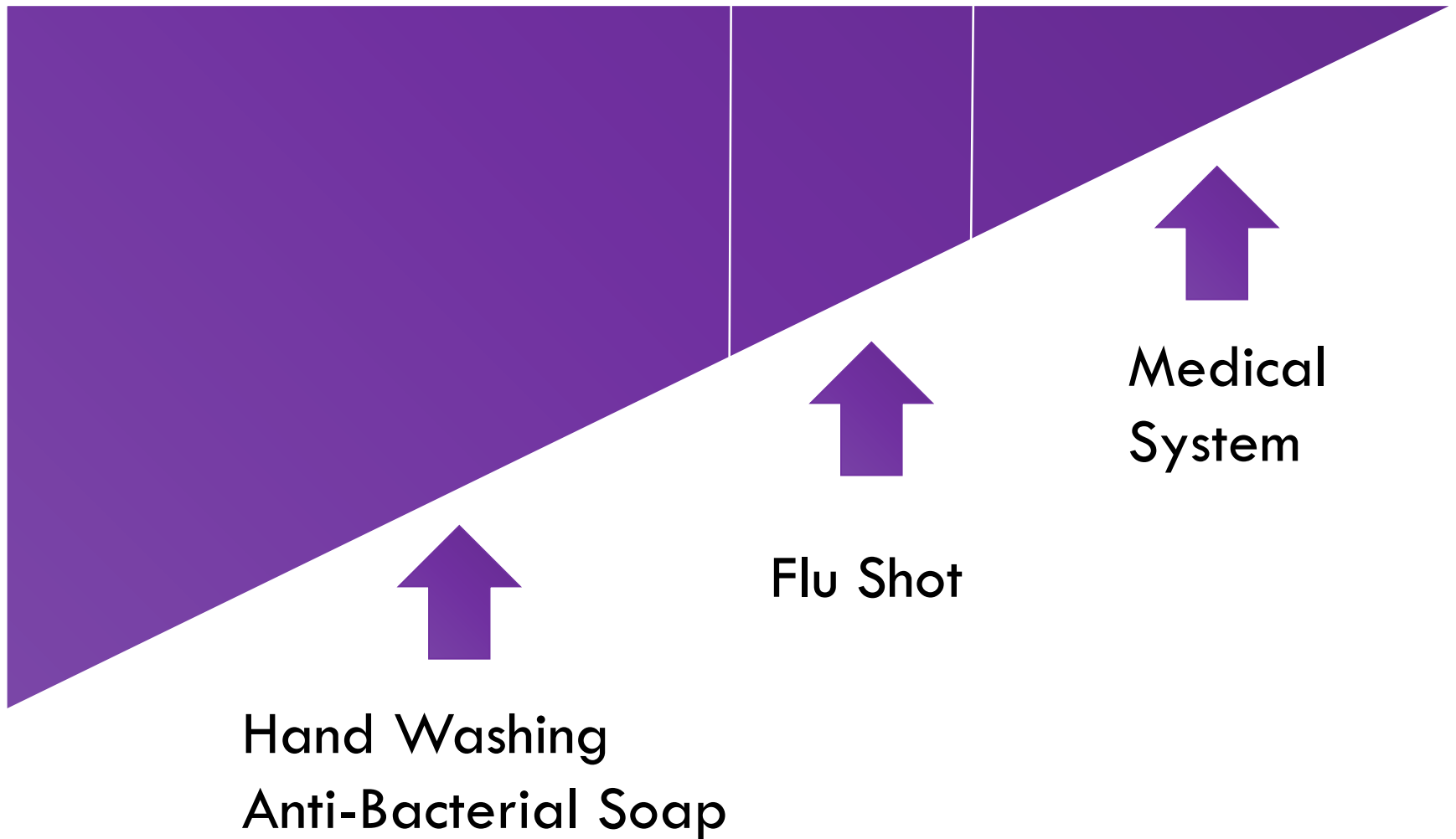
Self-Advocates and Families Must Engage, Lead, and Drive Policy and Systems Change



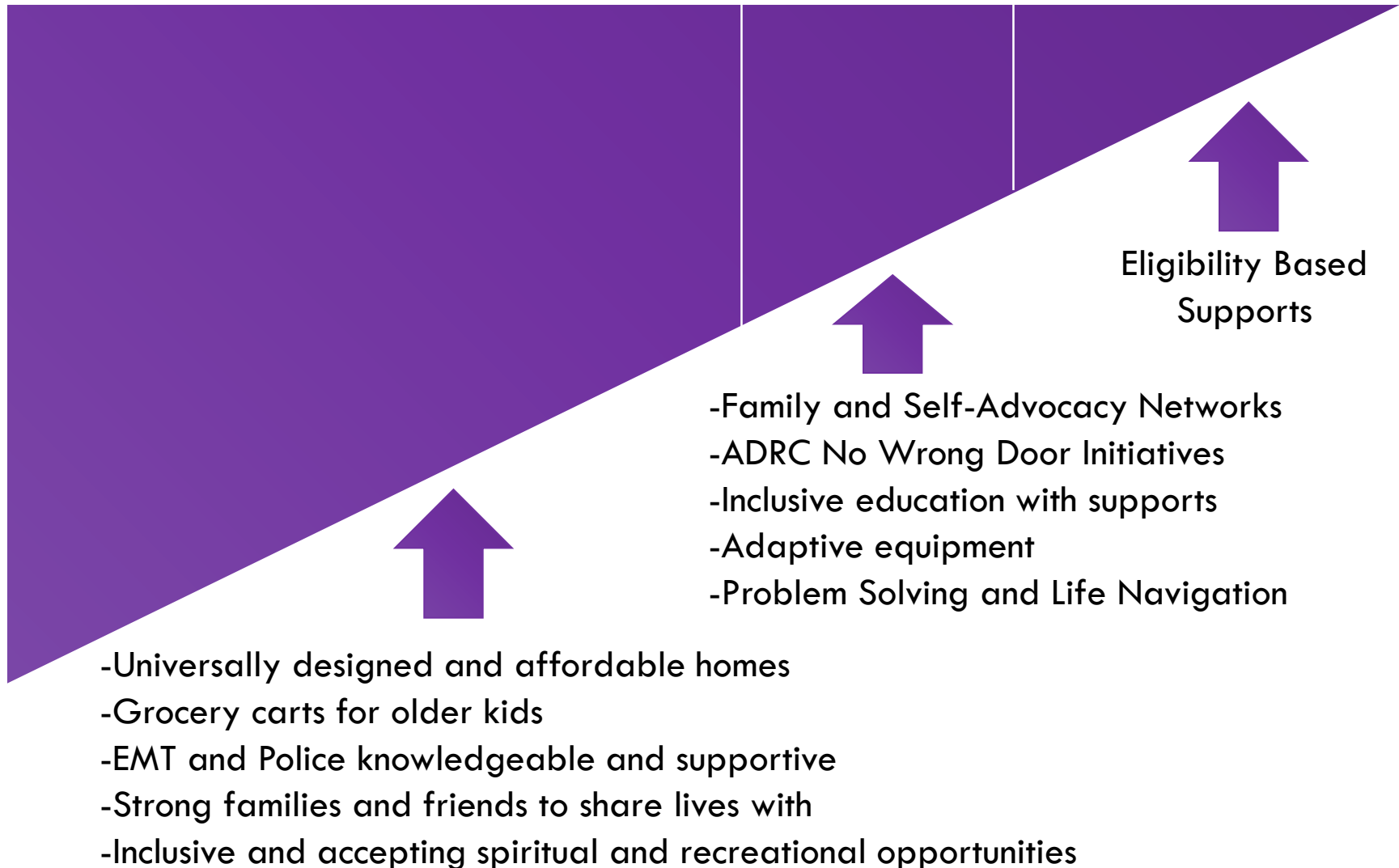
Applying the Framework to Transformational Change

“Creating Space for Innovation”

ALL: Public Health Framework



Developing Innovative Strategies for Transformation within and outside DD



Building Family & Self-Advocacy Networks



Missouri:

- Statewide Family to Family Network consisting of 150 affiliates and over 900 self-advocate and family leaders
- State agency contracted with Family to Family Health Information Center for seamless front door



District of Columbia:

- State is partnering with other state agencies and has contracted with P2P USA to start DC chapter
- Training Family Facilitators on One Page Profiles

Applying Life Trajectory: Systems

CHARTING the life course



Life Trajectory Worksheet: Individual

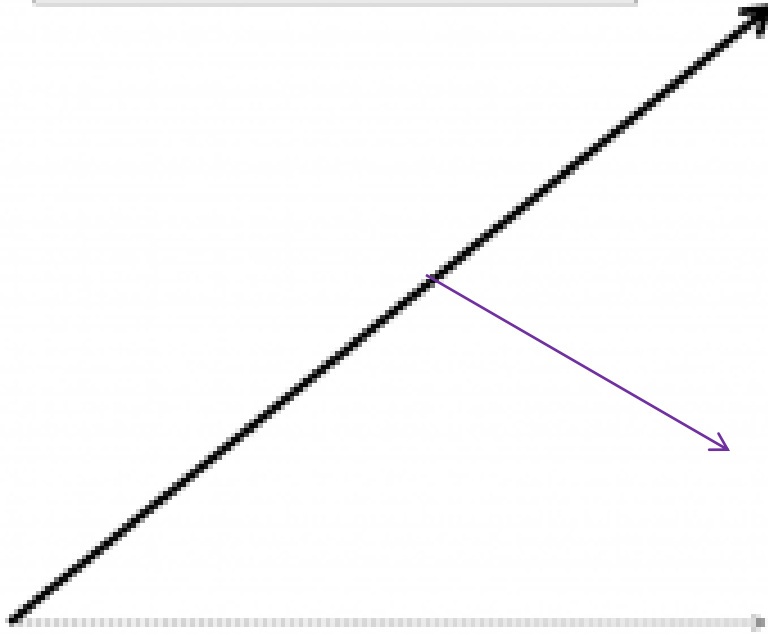
Everyone wants a good life. The bubbles on the right will help you think about what a good life means for you or your family member, and identifying what you know you don't want. You can use the space around the arrow to think about current or needed life experiences that help point you in the direction of your good life.

VISION for a GOOD LIFE

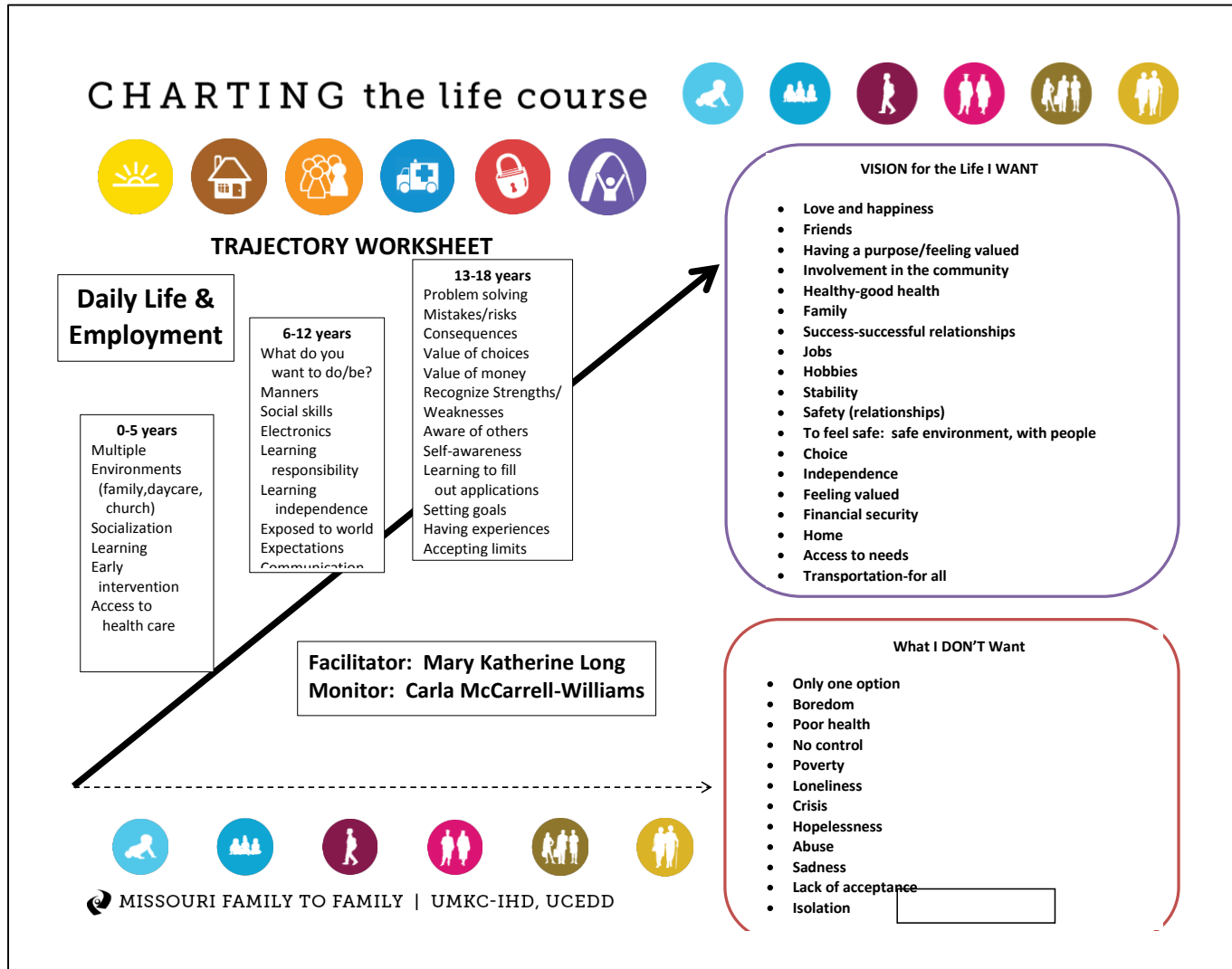
Education
Career
Job of Choice
Economic Sufficiency
\$ for Home & Fun

What I DON'T Want

Poverty
No opportunities
Sheltered Employment
Dependence on Govt




Applying Life Trajectory: Practice



Applying Life Trajectory: John

Vision for a Good Life

- * Visit Mom / spend time as she gets older
- * Making good \$, job I Love
- * Moving forward → , Internet
Being my own guardian - don't want to rush, being in control of \$, not having
- * Living alone - no roommate - ^{lots of} growing staff
- transportation + ^{check}
- * Doing more lawn/snow blowing business
- * Not getting bored - ever!
Getting support on my own terms

What I DON'T Want

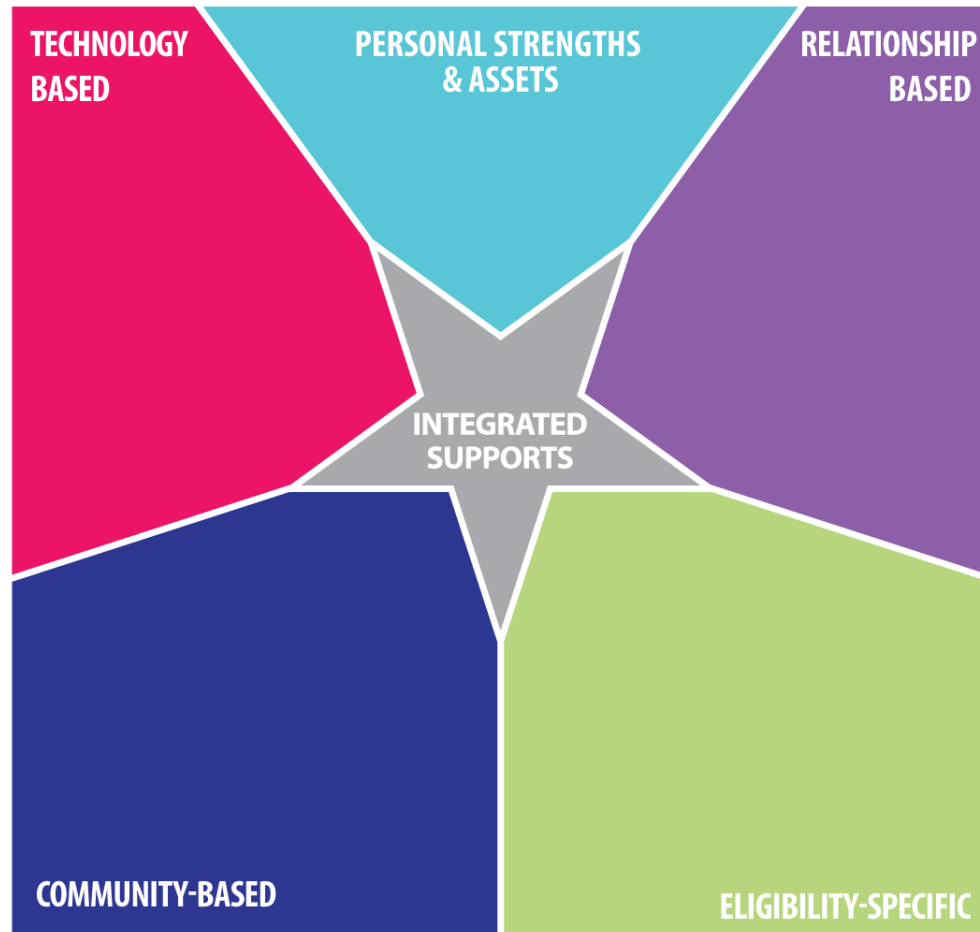
Lose job

Not having reliable transportation
not feeling trapped, restricted, stuck

Not being in placement ^{→ staff} rest of your life.

Others making the rules/decisions

Application of the Integrated Supports Star



System Level: Connecticut



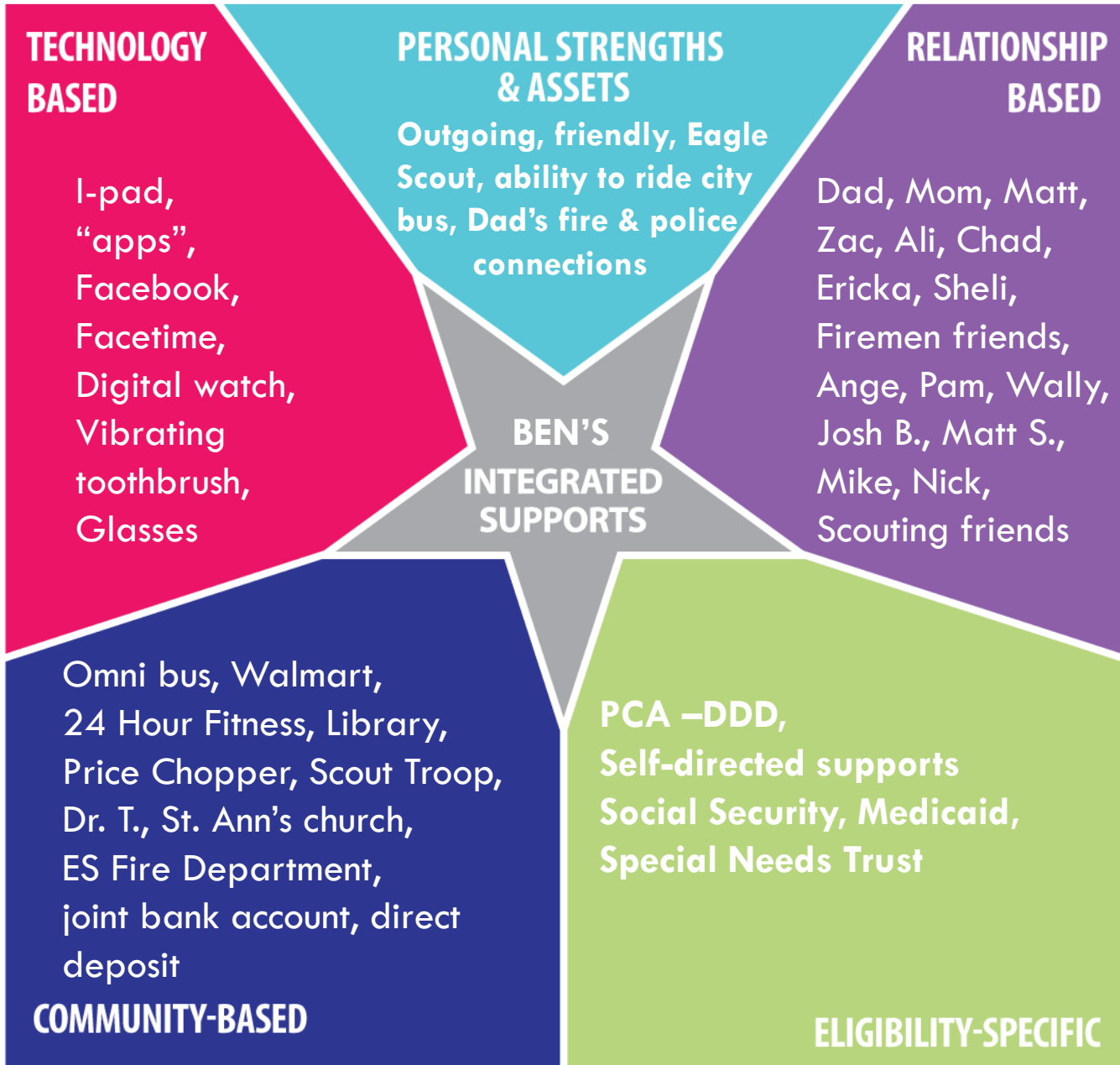
Organizational Level: Connecticut





Individual Level: Ben

The GOOD LIFE is getting tatted up!



Integrating Supports into Real Life

Long Term Service and Support Needs								
Time	Mon	Tues	Wed	Thurs	Fri	Sat	Sun	
6-6:30 AM	Parents get Ben out of bed, assist with breakfast, shower, getting dressed and ready for his day							
6:30-7 AM								
7-7:30 AM								
7:30-8 AM								
8-8:30 AM	Waiver Self-Directed PCA					Parents are weekend support		
8:30-9 AM								
9-9:30 AM								
9:30-10 AM								
10-10:30 AM								
10:30-11 AM								
11-11:30 AM								
11:30-12 PM								
12-12:30 PM								
12:30-1 PM								
1-1:30 PM								
1:30-2 PM								
2-2:30 PM								
2:30-3 PM								
3-3:30 PM								
3:30-4 PM								
4-4:30 PM	Mom and Dad provide all support, including meals, transportation and support for activities, etc.							
4:30-5 PM								
5-5:30 PM								
5:30-6 PM								
6-6:30 PM								
6:30-7 PM								
7-7:30 PM								
7:30-8 PM								
8-8:30 PM								
8:30-9 PM								
9-9:30 PM								
9:30-10 PM								
10 PM-6 AM	Mom and Dad are overnight staff							

Template by Missouri Family to Family @ UMKC-IHD, UCEDD
December 2014

Long Term Service and Support Needs														
Time	Mon	Tues	Wed	Thurs	Fri	Sat	Sun							
6-6:30 AM	Parents get Ben out of bed, assist with breakfast, shower, getting dressed and ready for his day													
6:30-7 AM														
7-7:30 AM								Parents support Ben						
7:30-8 AM														
8-8:30 AM	Waiver Self-Directed PCA	Volunteers Fire Dept Supported as needed by firemen	Waiver Self-Directed PCA	Volunteers Fire Dept Supported as needed by firemen	Waiver Self-Directed PCA	St. Ann's w/ mom								
8:30-9 AM														
9-9:30 AM														
9:30-10 AM														
10-10:30 AM														
10:30-11 AM														
11-11:30 AM														
11:30-12 PM														
12-12:30 PM														
12:30-1 PM														
1-1:30 PM	Volunteer at high school, supported by coaches and friends					Home alone while Mom walks								
1:30-2 PM														
2-2:30 PM														
2:30-3 PM														
3-3:30 PM														
3:30-4 PM														
4-4:30 PM														
4:30-5 PM														
5-5:30 PM														
5:30-6 PM														
6-6:30 PM	Mom and/or Dad prepare meal and assist as needed					Dinner w/ Roy & Carol & family								
6:30-7 PM	Home alone while Mom walks													
7-7:30 PM														
7:30-8 PM														
8-8:30 PM	WWE With Matt	Horseback Therapy w/ Dad				Nick's Birthday Party with Matt and friends								
8:30-9 PM														
9-9:30 PM														
9:30-10 PM	Mom and Dad are overnight staff													
10 PM-6 AM														

Template by Missouri Family to Family @ UMKC-IHD, UCEDD
January 2015

Building Teams: Life Stages and Life Domains

Pediatrician, Families and Friends,
Faithbased

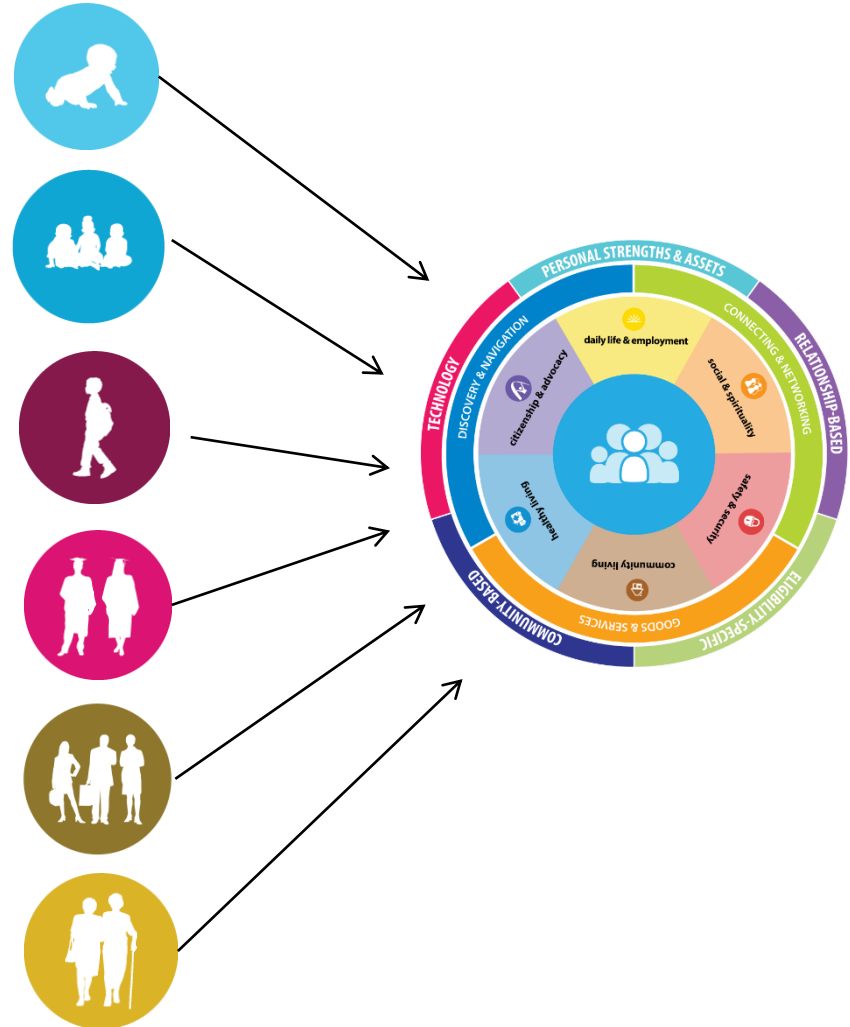
IDEA Part C, Parents as Teachers,
Health, Headstart

School, Special Education, Health,
Recreation

Vocational Rehab, Health Employment,
College, Military

Disability Services, Health, Housing,
College, Careers

Retirement, Aging System, Health

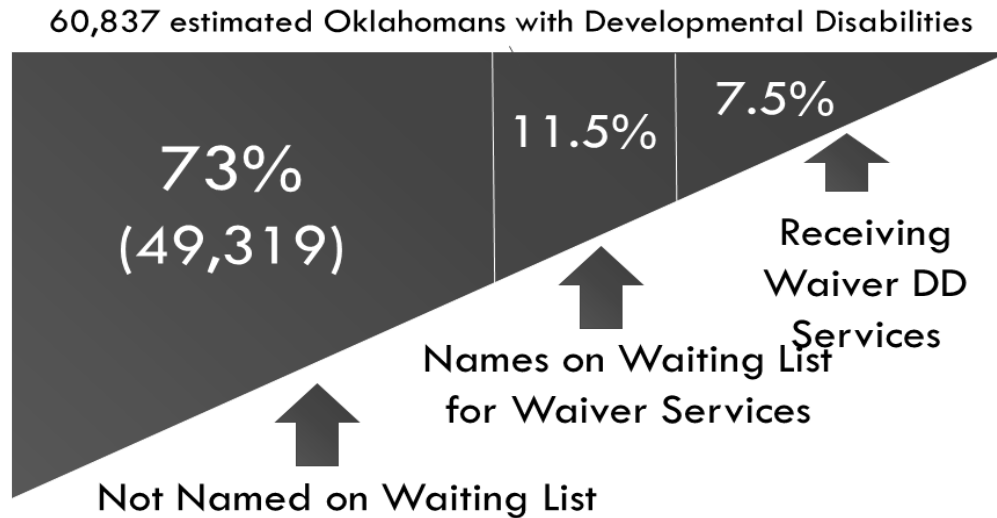


CoP Teams: Connecting Initiatives

- Employment First
- Alternatives to Guardianship/Supported Decision Making
- No Wrong Door Initiatives
- Aging and Disability Resource Center
- CMS Balanced Incentive Program
- CMS Community Settings and Person Centered Rule
- Family Information Systems Project
- NIDRR newly funded RRTC on Family support
- IDEA Performance Outcomes
- HRSA Home Visiting



Applying to Wait List Discussions



Information about Oklahomans with DD on Waiting List

0-5	6-18	19-64	65+	Total	Details
624	2579	3714	59	6,976	Names on Waiting List
114	620	850	11	1,695	On list, No known public benefits
510	1959	2864	48	5281	On list, Getting Some Public benefits

Putting Framework Into Action



Partnering to Disseminate a Consistent Message

- Early Childhood and Part C
- School Districts, Special Education
- PNS Show Me Career Employment Grant State
- Division of Developmental Disability
- Special Health Care Needs

STRATEGIES TO SUPPORT REAL LIVES
RESOURCES & SERVICES ALONG THE LIFE COURSE

1-800-444-0821 • MOFAMILYTOFAMILY.org

MISSOURI FAMILY TO FAMILY RESOURCE CENTER

STRATEGIES TO SUPPORT REAL LIVES

Charting the Life Course: A Guide for Individuals, Families, and Professionals

Throughout our lives, we face questions and search for answers that will help us on 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 healthcare need.

Charting the Life Course 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 and options to consider as you "plot a course" for a full and meaningful life. It is intended to be a starting point no matter who you see in your life journey.

We hope the life course approach helps you realize that even when your child is very young and so far in the age and growth into adulthood, their experiences and environment can shape how they will live their life in the future.

MISSOURI FAMILY TO FAMILY RESOURCE CENTER
University Center for Excellence in Developmental Disabilities
Division of Developmental Disabilities, University of Missouri
1000 University Blvd., Room 1000, Columbia, MO 65211
Phone: (573) 487-1000, Fax: (573) 487-1001, Email: info@mofamilytofamily.org
www.mofamilytofamily.org

CHARTING the life course

Focus on Transition

Your child is entering a point in time, filled with change, growth, excitement, and sometimes fear and confusion, called TRANSITION. Transition is defined as movement, passage, or change from one position, state, stage, subject, concept, to another. For you and your child, transition means that his/her is moving from childhood to young adulthood, and from school to adult life. There are many things to think about and do to prepare for this change. This guide is to help you think about some of the questions to ask, options to consider, and things to talk about with your transitioning youth. Choices and decisions you and your son/daughter make during this time can help to positively shape the future and the they will live as an adult.

This guide is based on Charting the Life Course: A Guide for Individuals, Families and Professionals. Charting the Life Course is a framework that was developed to help individuals with disabilities and families at any age or stage of life do:

- Think about what they need to know
- Identify how to find or develop supports
- Discover what it takes to create the life they want to live

Charting the Life Course presents questions to ask or consider in different the domains. Life domains are the different aspects and experiences of life that all people consider as they age and grow from childhood into adulthood and eventually the senior years of life.

Individuals and families can focus on their current situation and stage of life, but may also find it helpful to look ahead and start thinking about what they can do or learn now that will help build an inclusive, productive life in the future. It is also important to consider questions and options regarding supports and services, especially when considering about living.

MISSOURI FAMILY TO FAMILY | UMKC-IHD, UCEDD

APRIL 2014

CHARTING the life course

Tool for Developing a Vision - Individual

Forming a vision and beginning to plan for the future is each of the life domains helps plot a trajectory for a full, inclusive, quality life in the community. This tool is to help individuals with disabilities of all ages start to think about a vision for how they want to live their life as an adult.

LIFE DOMAIN	My Vision for My Future	rank	Current Situation/Things to Work On	rank
Daily Life	What do I want to do to help me in living the life I want to live as an adult? What kind of job/career do I want to get into?			
Community Living	What would I like to do that is my child's job? Will I be able to work outside the home?			
Social & Spirituality	How will I connect to spiritual and social activities, and how important are relationships to my child's life?			
Healthy Living	How will I stay healthy, physically and mentally, and what will I do to stay healthy as an adult?			
Safety & Security	How will I stay safe, and what will I do to stay safe as an adult?			
Education & Advancement	In my adult life, what kind of education and opportunities do I want to have, and how important are they to my child's life?			
Family	How will my family life be in the adulthood and what will I do to make it so?			
Supports & Services	What type of support will I need to be as independently as I can in my adult life, and what will my supports look like?			

MISSOURI FAMILY TO FAMILY | UMKC-IHD, UCEDD

MAY 2014

Overall Themes: What are we learning?

- Balancing Focus on Person with Disability as we try to increase supports to families
- Concept of “all” has made a major impact
- Family support vs. supporting families
- Aging families or “traditional mindset” families comfortable with the current system



Overall Themes: What are we learning?

- Thinking about integrated supports
 - *Technology is really exciting*
 - *Increased focused on what are “natural or informal supports”*
- People are “ready” and excited for the message and concrete, practical tools
- The skill of “partnering” with other entities and with self-advocates and families is hard



Learning: System Level

- Initial focus within State Developmental Disability system policies and practices
- Partnering and integrating framework within other systems (VR, Education, Aging)
- Integrating Person Centered Thinking and Planning with LifeCourse Framework



Learning: Practice Level

- Development and piloting of LifeCourse training materials and tools for different target audiences (Self-Advocates/Family, Case managers, Options Counselors, Teachers, Family Navigators)
- Initial phase of developing an implementation structure of facilitators and trainers to ensure competency and fidelity of practices



Questions, Reflections and Discussion



Innovations Webinar Series

Next Webinar:

Focusing on the Front Door of Supports

Future topics:

Emotional/Navigational Peer Support

National & State Data Projects

Person-Centered & LifeCourse Planning

Medicaid Waivers and Other Funding Sources

Waitlist for Services

Contact Information

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