

# Personal Outcomes Across the Life Course

# About me...

- Sibling of three brothers, one who is 32 year old with developmental disability
- Director of Individual Advocacy and Family Support, UMKC UCEDD
  - Supported the Self-Advocacy Movement for 12 years
  - Director of Mo Family-to-Family Health Info Center
  - Co-Director of National CoP on Supports to Families



# About UMKC-IHD

UCEDD/LEND has longstanding focus on Family Support, Self-Advocacy and Self-Determination State and National Systems and Policy Change Statewide Family Resource Center, Family-to-Family HIC, for over 25 years with evolving and on-going statewide partnership





# SUPPORTING FAMILIES

of individuals with intellectual & developmental disabilities

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



ADMINISTRATION ON  
INTELLECTUAL AND  
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 intellectual and developmental disability across the lifespan.



# Funded by



# National Partners



# Outcomes for Today

Overview of the LifeCourse framework guiding the work of the National Community of Practice on Supports to Families

Connections between Personal Outcomes and LifeCourse principles

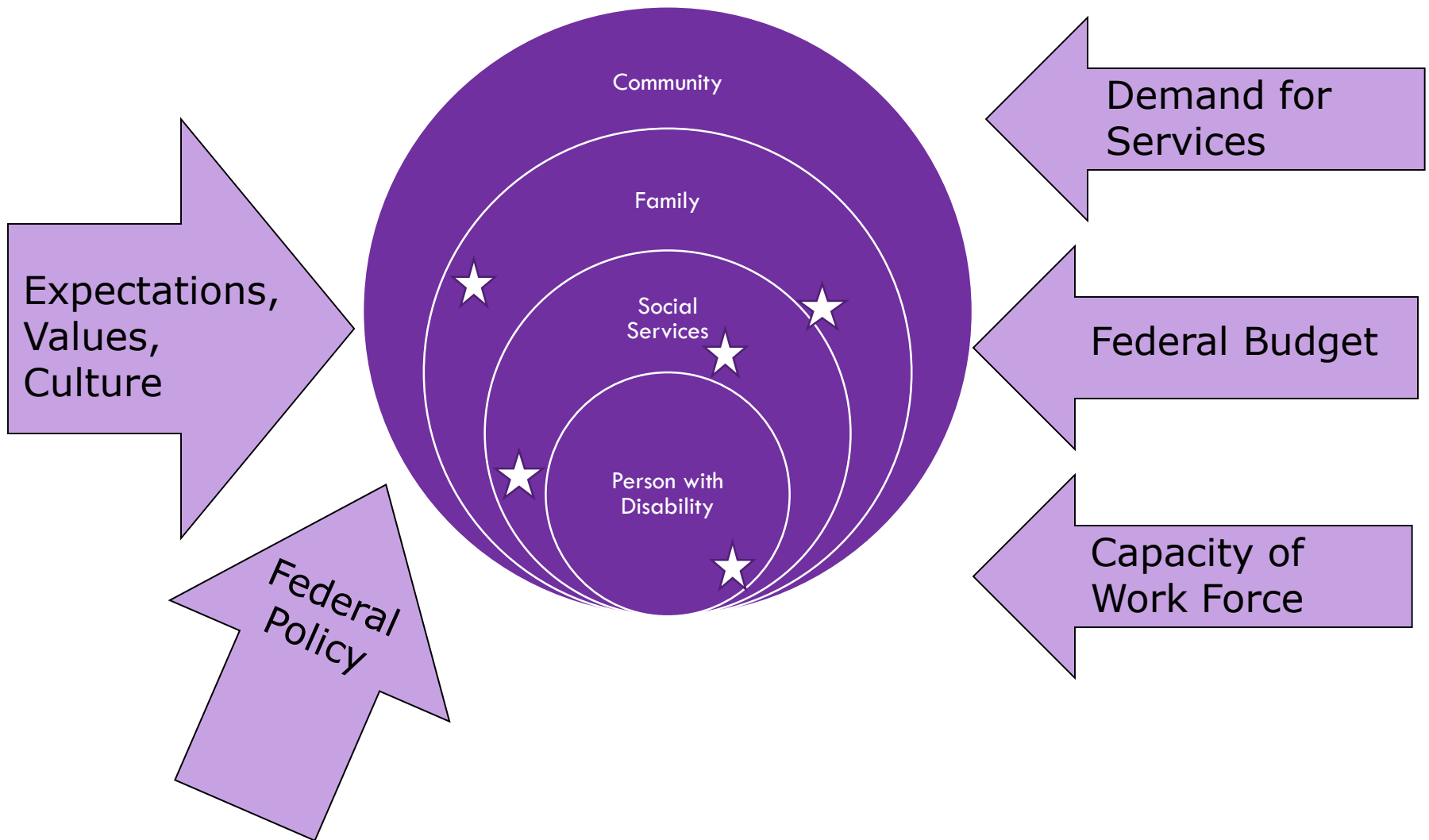
Introduction to LifeCourse tools and resources with concrete examples for how to use





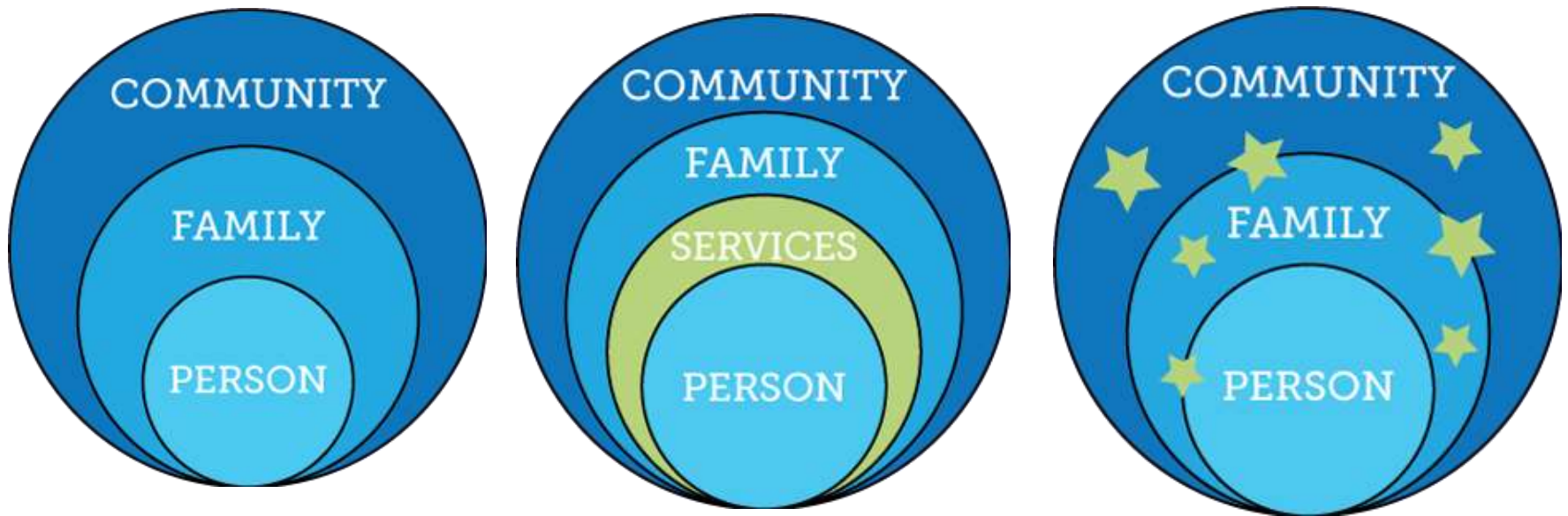
# Setting the Stage

# What we know about current realities?





# Services and Supports are Evolving



# Type of Change that is Needed

## TRANSITIONAL CHANGE

“Retooling” the system and its practices to fit the new model

Mergers, consolidations, reorganizations, revising systematic payment structures, creating new services, processes, systems and products to replace the traditional one

## TRANSFORMATION CHANGE

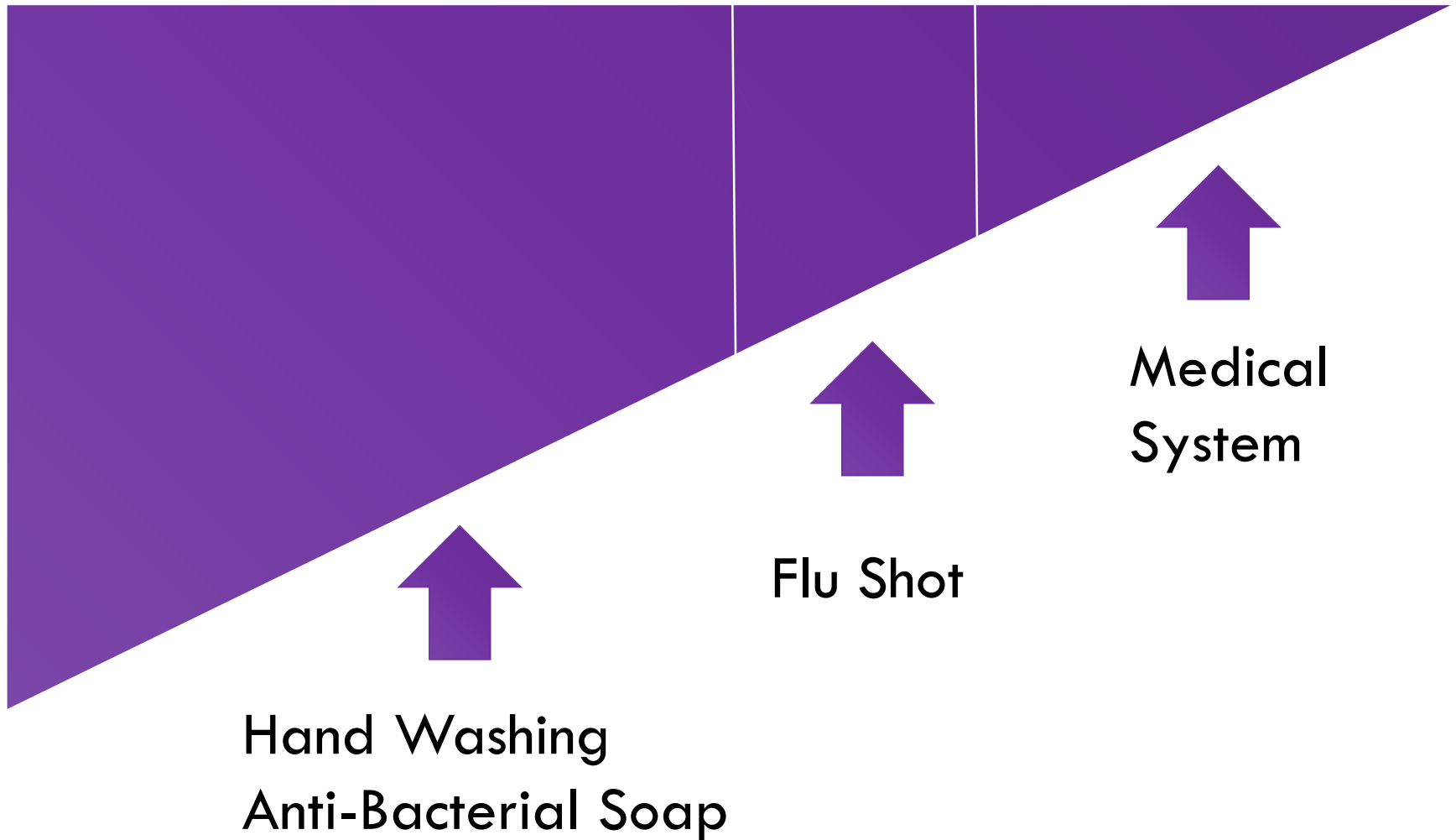
Fundamental reordering of thinking, beliefs, culture, relationships, and behavior

Turns assumptions inside out and disrupts familiar rituals and structures

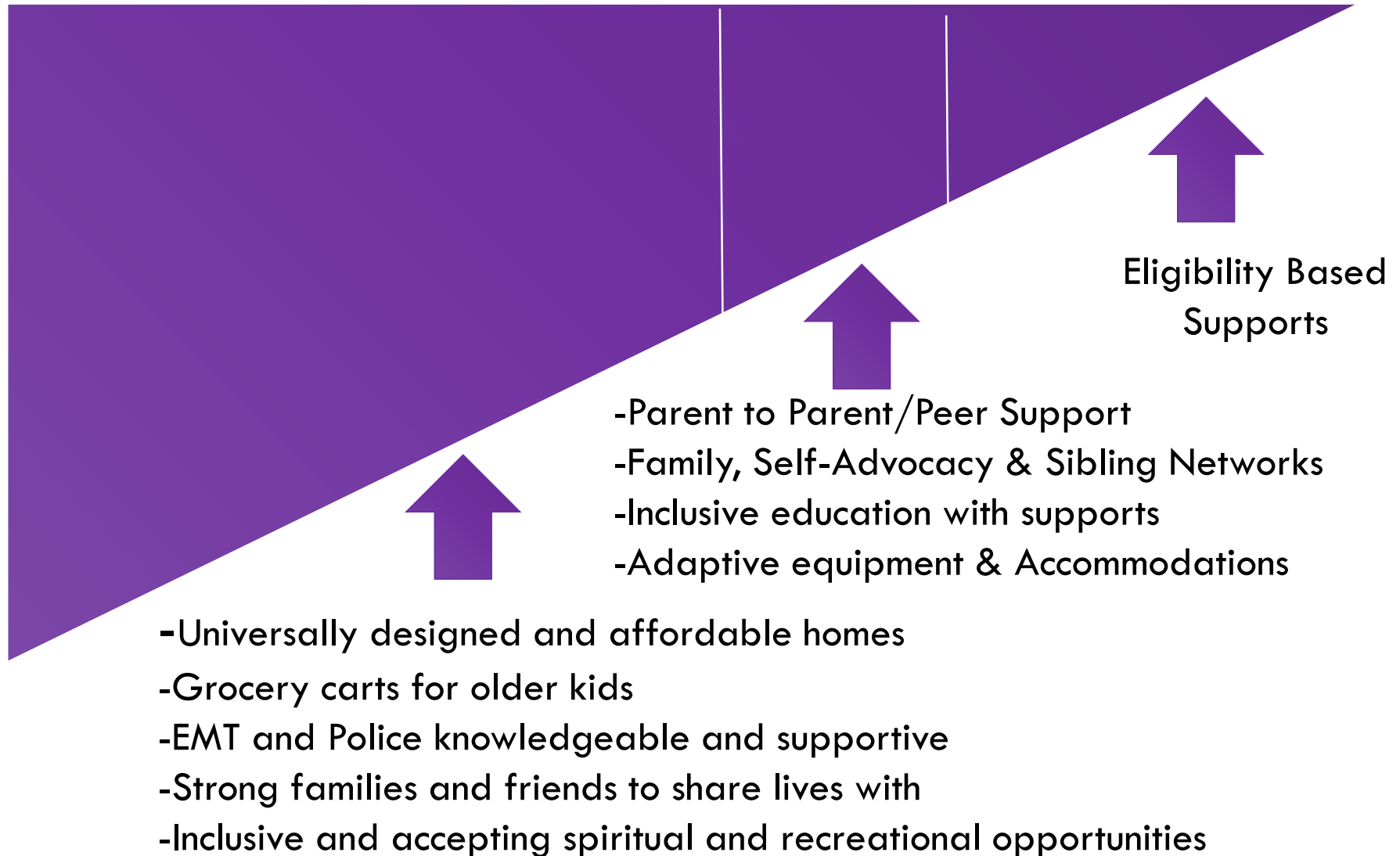
Rejects command and control relationships in favor of co-creative partnerships

Creating Blue Space, Hanns Meissner, 2013

# ALL: Public Health Framework



# Universal Strategies for Change





# LIFECOURSE FRAMEWORK AND TOOLS





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





# “Good Life for All ”



**The 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 all individual members to achieve their goals





ALL People

100%

# Focus on “ALL”

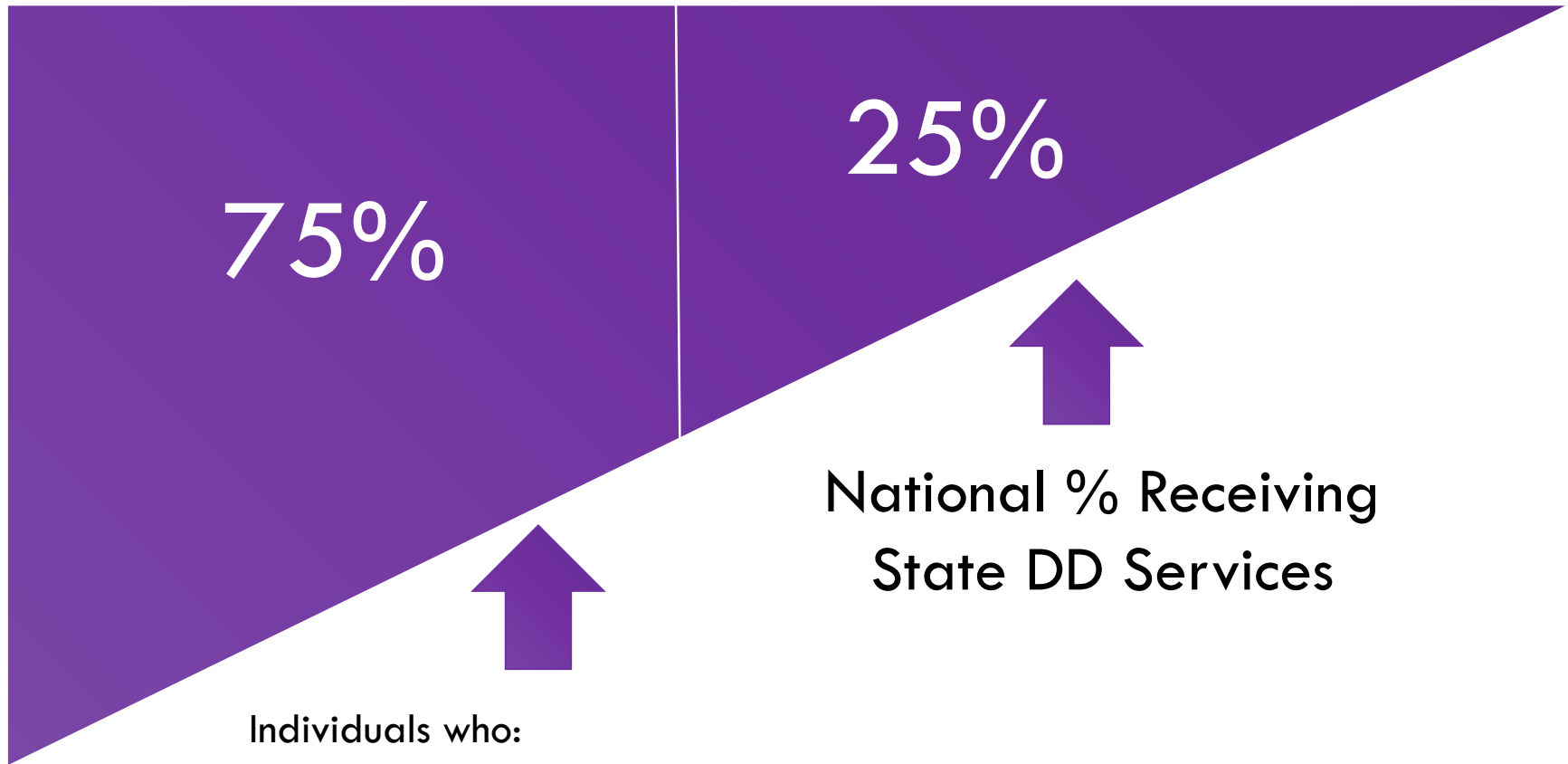
***ALL individuals*** (including those with intellectual and developmental disabilities or special health care needs) ***and their families*** ***are considered in our values and vision.***



*(Family is defined by the individual)*

# Focusing on ALL

ALL 4.9 Million people with developmental disabilities

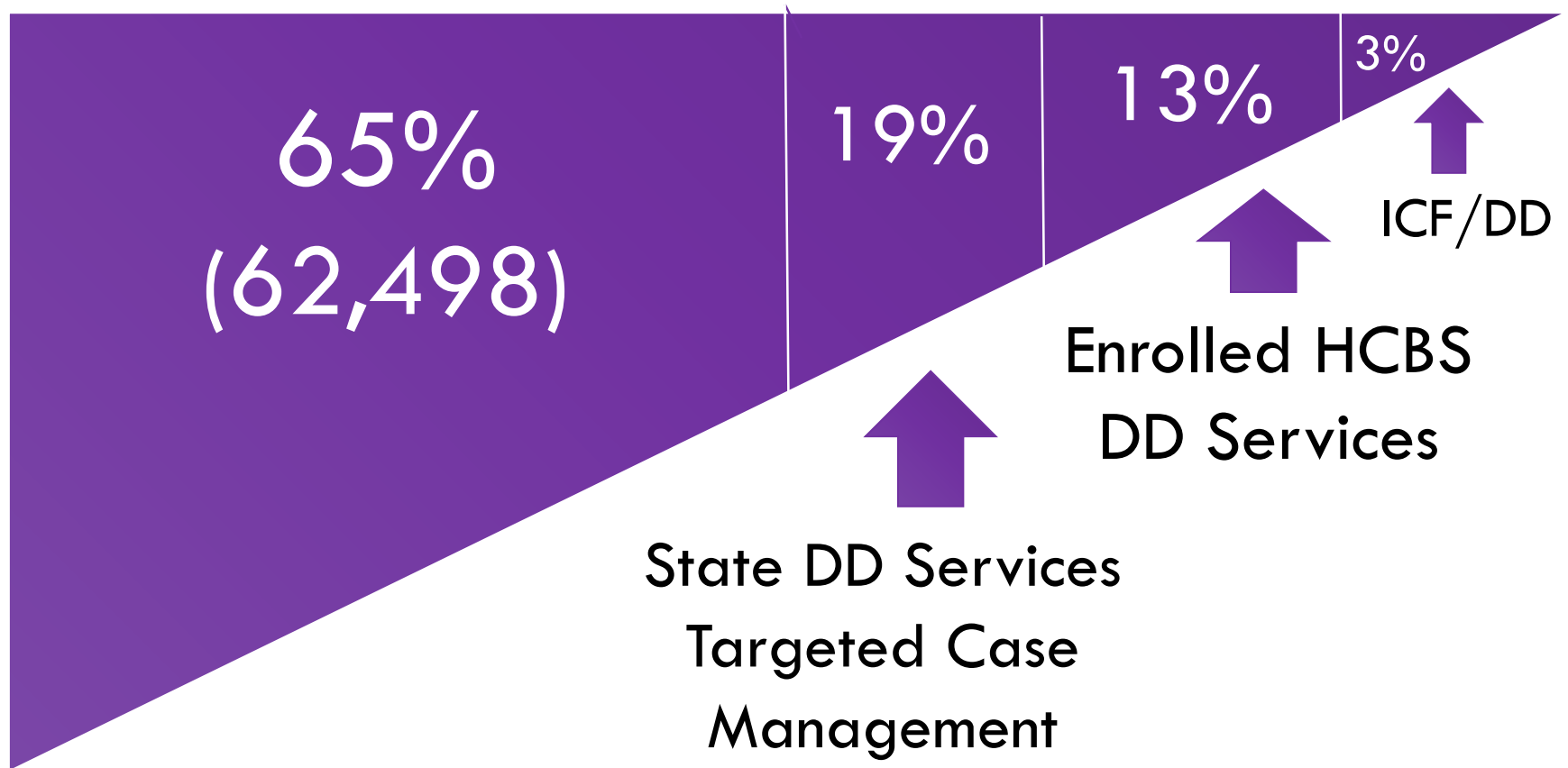


Individuals who:

- Unaware of disability specific services
- Do not want disability specific services
- Have a diagnosis but don't meet "eligibility criteria"

# Missourians with Disabilities

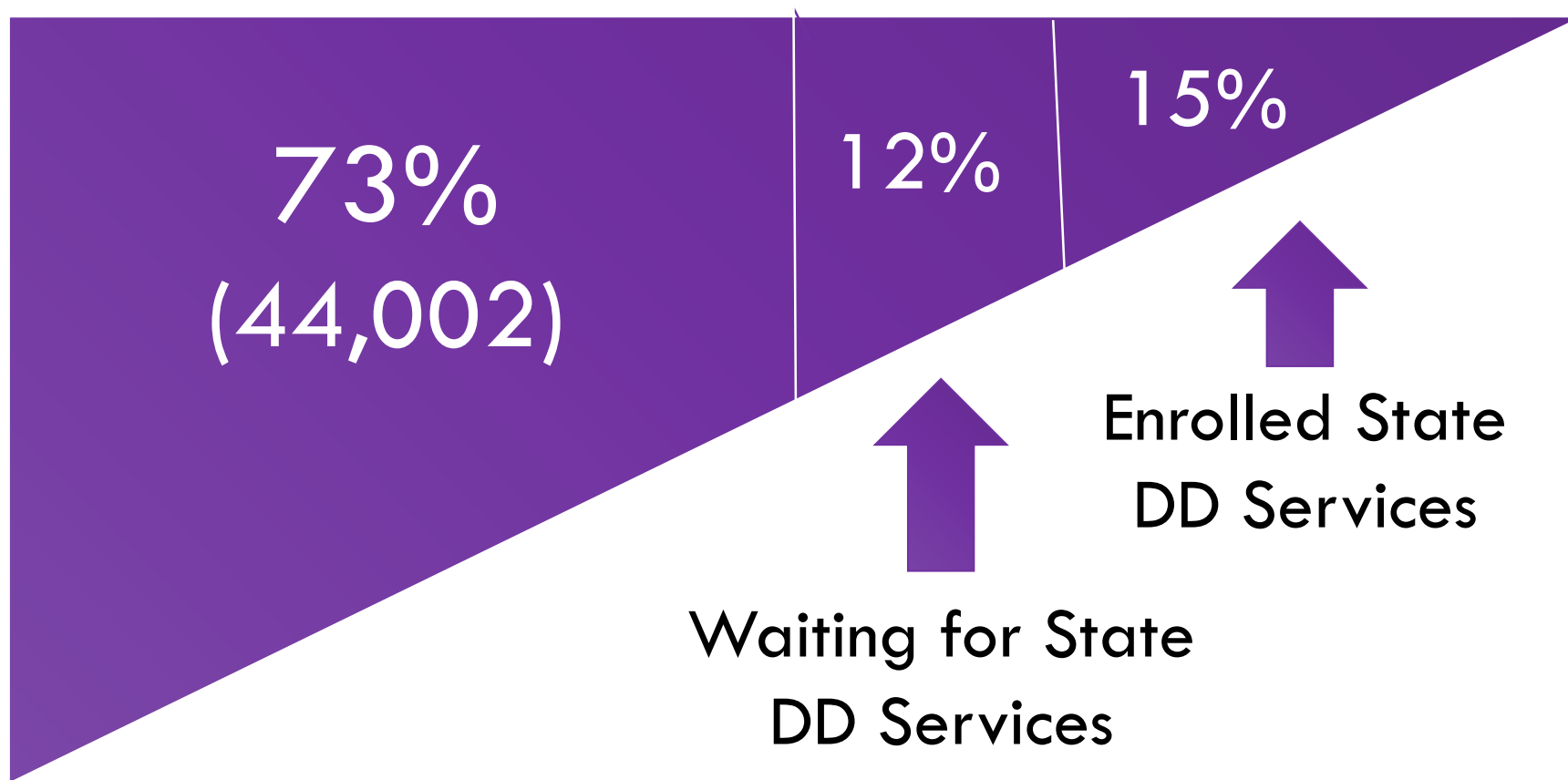
95,498 estimated Missourians with Developmental Disabilities



Based on 1.49% prevalence of MO citizens, US Census

# Oklahomans with I/DD

60,277 estimated Oklahomans with Developmental Disabilities



Based on 1.49% prevalence of OK citizens, US Census





Person Within Context  
of Family & Community



# All individuals exist within the context of family

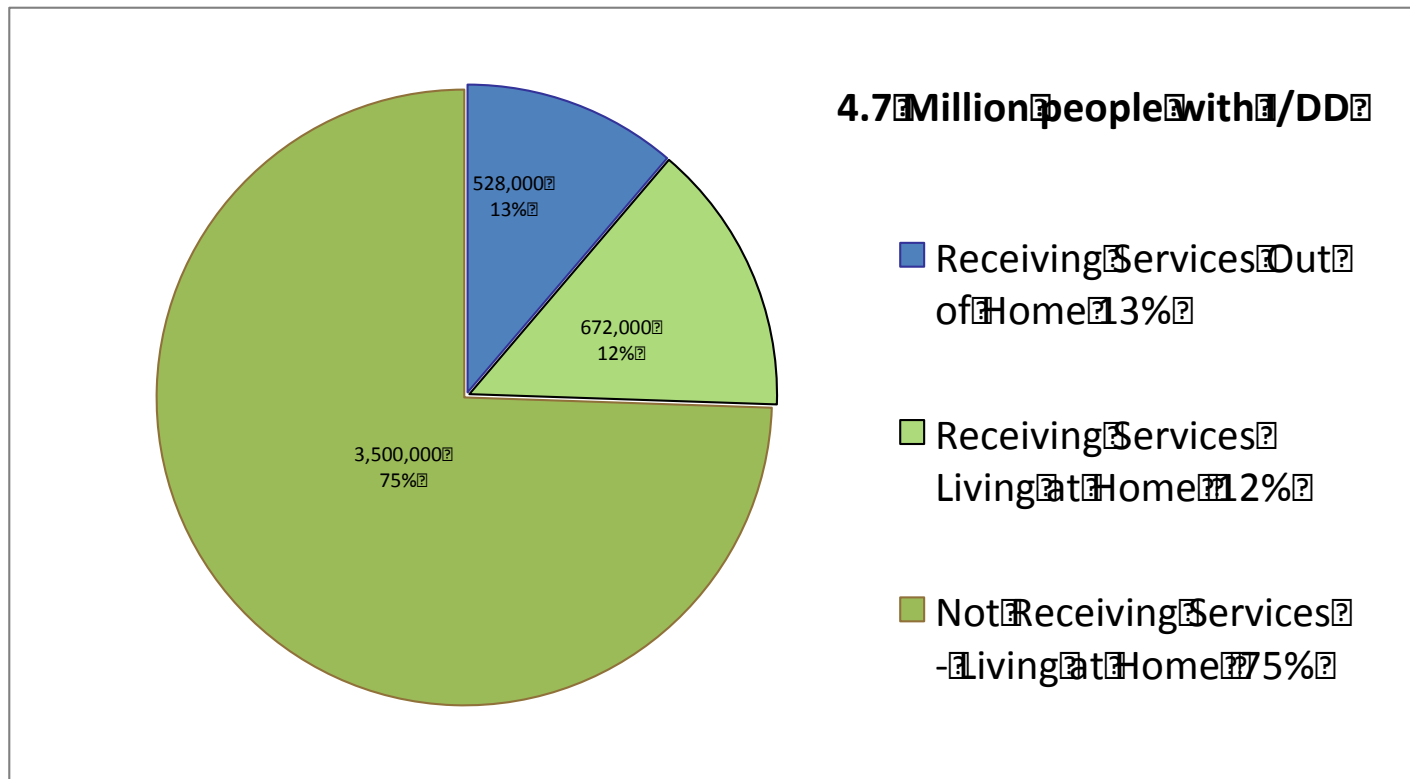
*Individuals and their family, as a whole, may need supports that address different facets of life and that adjust as roles and needs of all members change through both the life cycle and the family cycle.*



*(Regardless of where a person lives)*

# Where Do People with Disabilities LIVE and Receive Services?

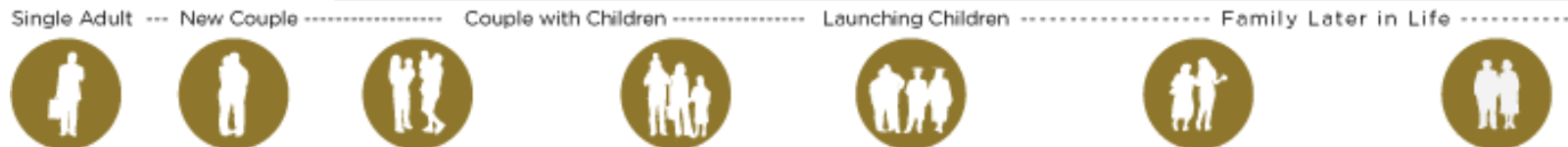
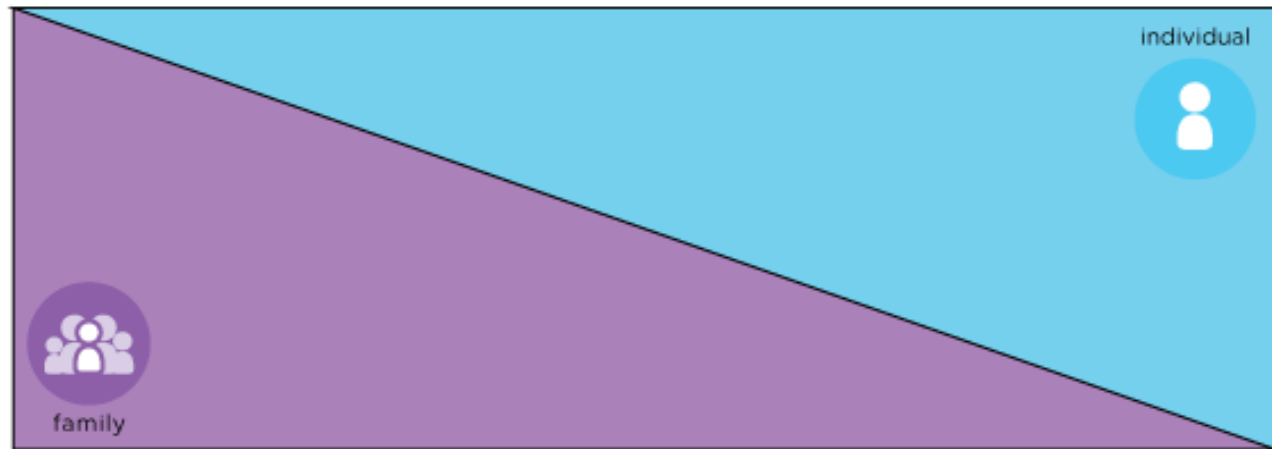
*89% of People I/DD receiving services are Supported by Family*



Larson, S. A., Lakin, K. C., Anderson, L., Kwak, N., Lee, J. H., & Anderson, D. (2000).

# Recognition of Individual and Family Cycles

## *Individual Life Cycle*



## *Family Life Cycle*





Aging Parents

Siblings with  
Disabilities

Children

## Siblings: The 'Club Sandwich' Generation

Siblings often juggle multiple roles for support and caregiving, which can seem overwhelming



# Reciprocal Roles between 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 al (2011)*



# Lifelong Impact of Family on Individual

**Biologically:** Likes, dislikes,  
skills, abilities

**Socially:** Family and friend  
network, connection with  
community members



**Environmentally:**  
Neighborhood, socio-economic,  
education

**Policy:**  
Dreams, Aspirations,  
House rules, cultural rules,  
expectations



# Life Trajectory, Experiences and Life Stages

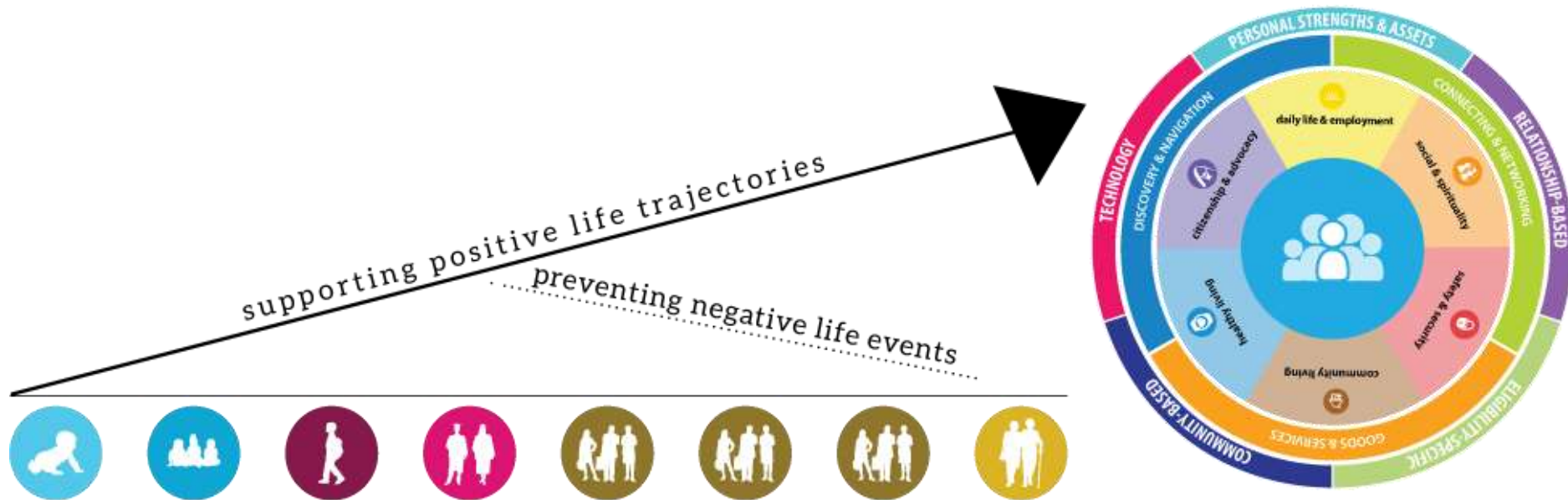
# Vision for a Good Life



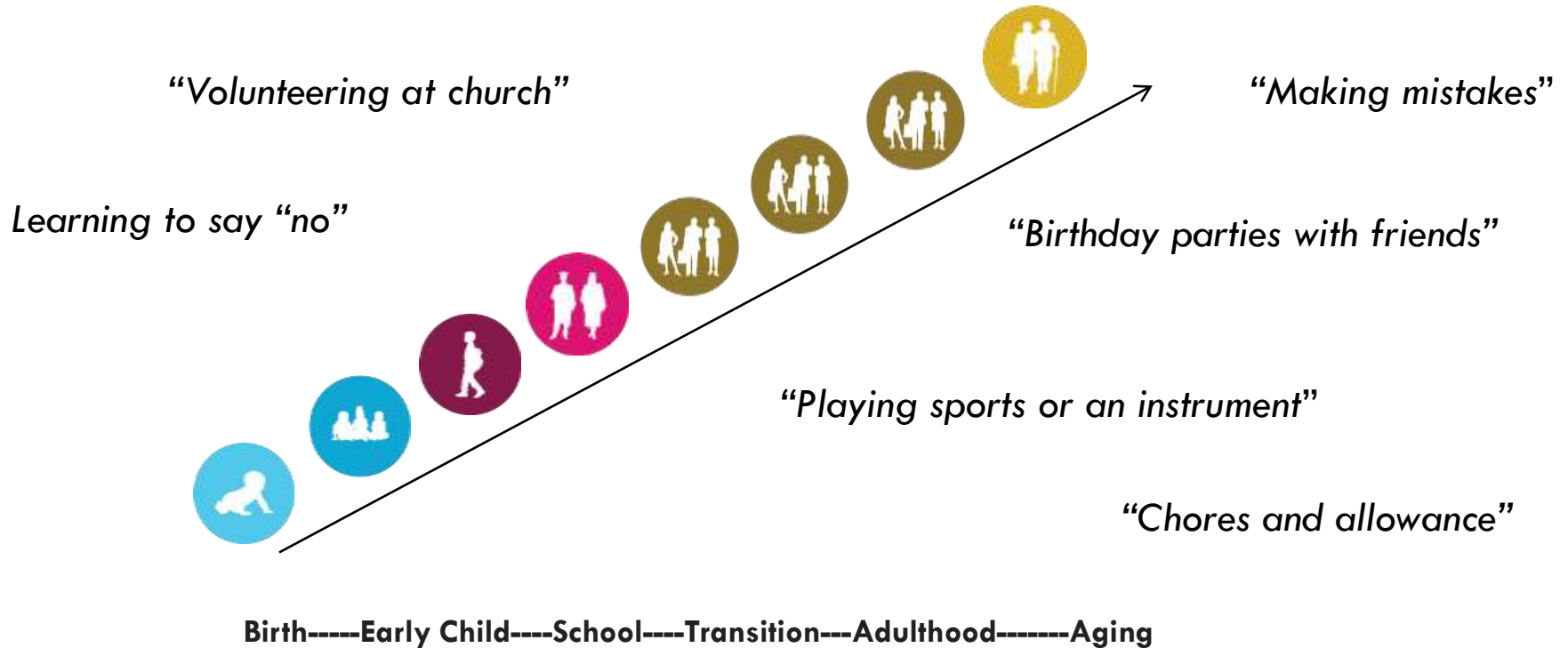
*The future is not something we enter.  
The future is something that we create.  
And creating that future requires us to  
make choices and decisions that begin  
with a dream.*

-Leonard L. Sweet

# Vision and Trajectory



# Focusing on Life Experiences



**“Anticipatory Guidance for Life Experiences”**

# Life Stages: Think Across Generations

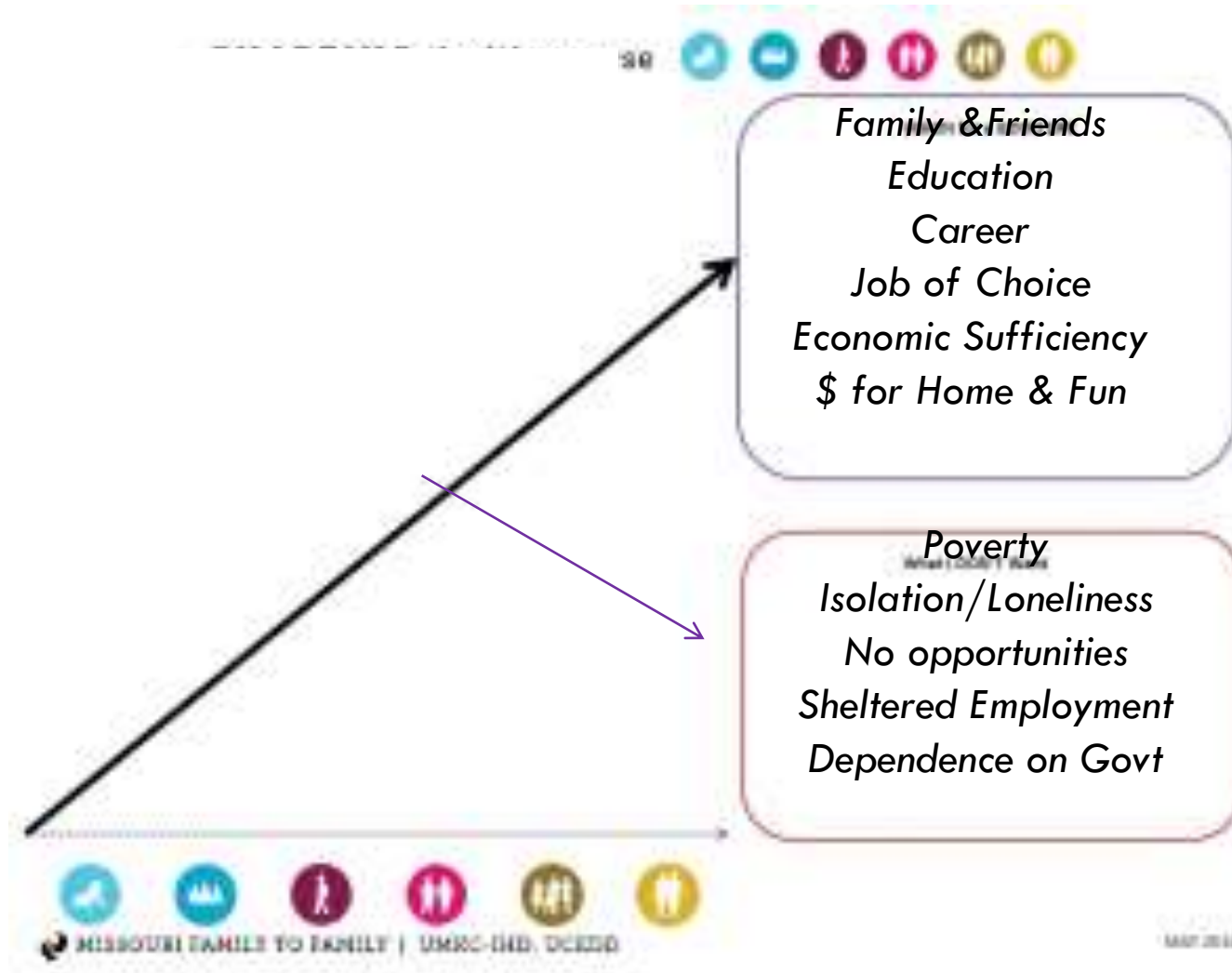
Age	0-5	6-18	19-64	65
Total MO Population	362,650 (6%)	1,045,641 (17.3%)	3,747,386 (62%)	888,537 (14.7%)
Approx. DD (1.58%)	5729	16,521	59,209	14,038

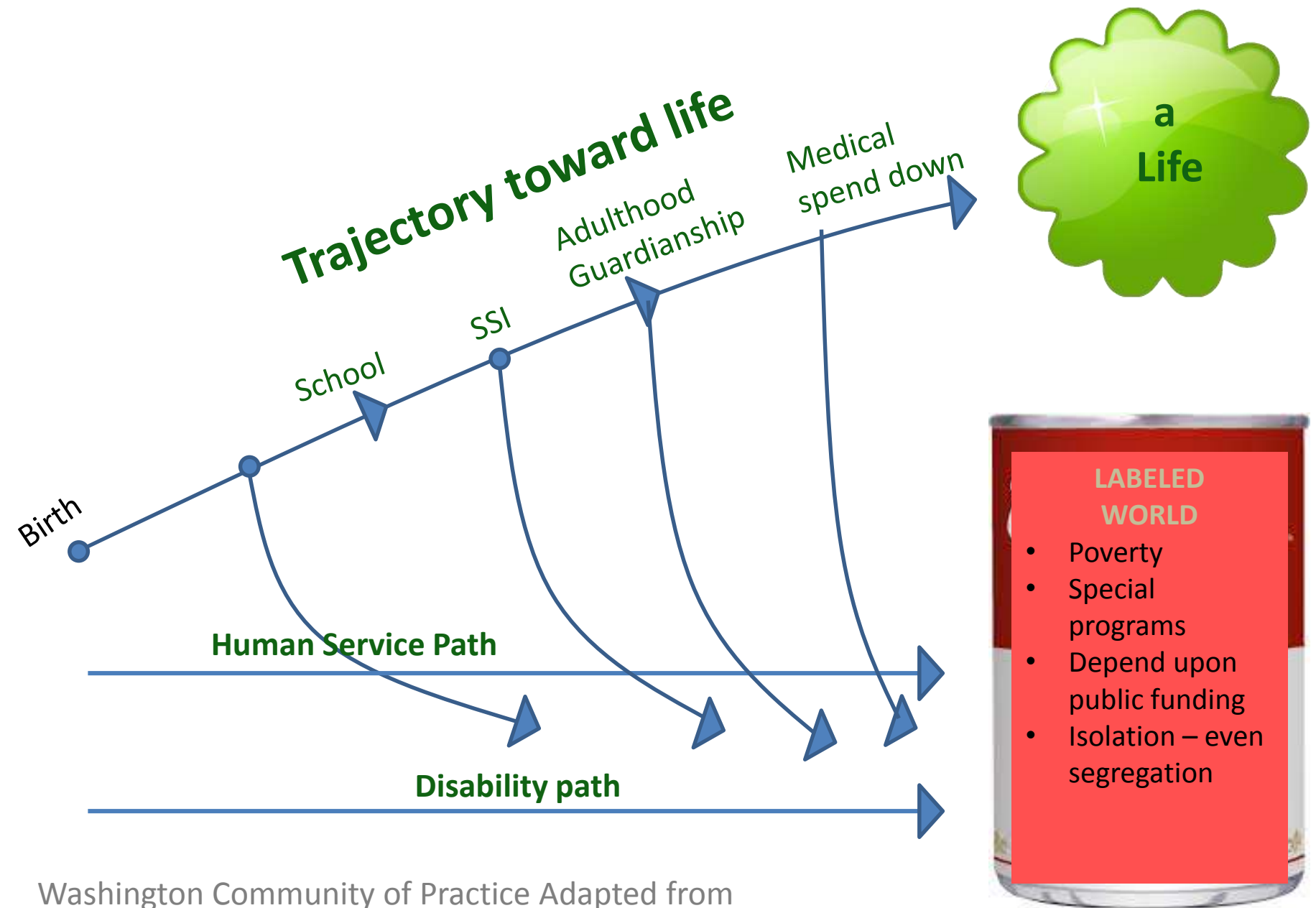




# ACTIVITY:

## Charting Life Experiences





Washington Community of Practice Adapted from  
National CoP Supports to Families, 2015



# Life Domains and Outcomes

# Thinking Across All Life Domains



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



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



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



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

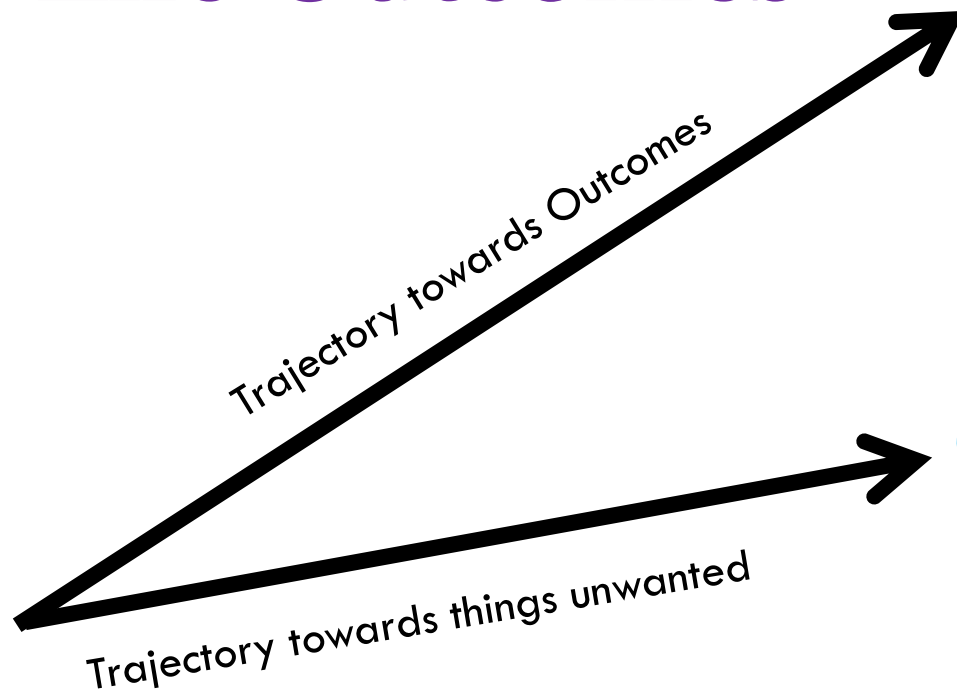


**Social and Spirituality**  
(friends, relationships, leisure activities, personal networks, faith community)



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

# Trajectory toward Positive Life Outcomes



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

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



*Across the Lifespan*





Individualized Supports  
to Achieve a Good Life



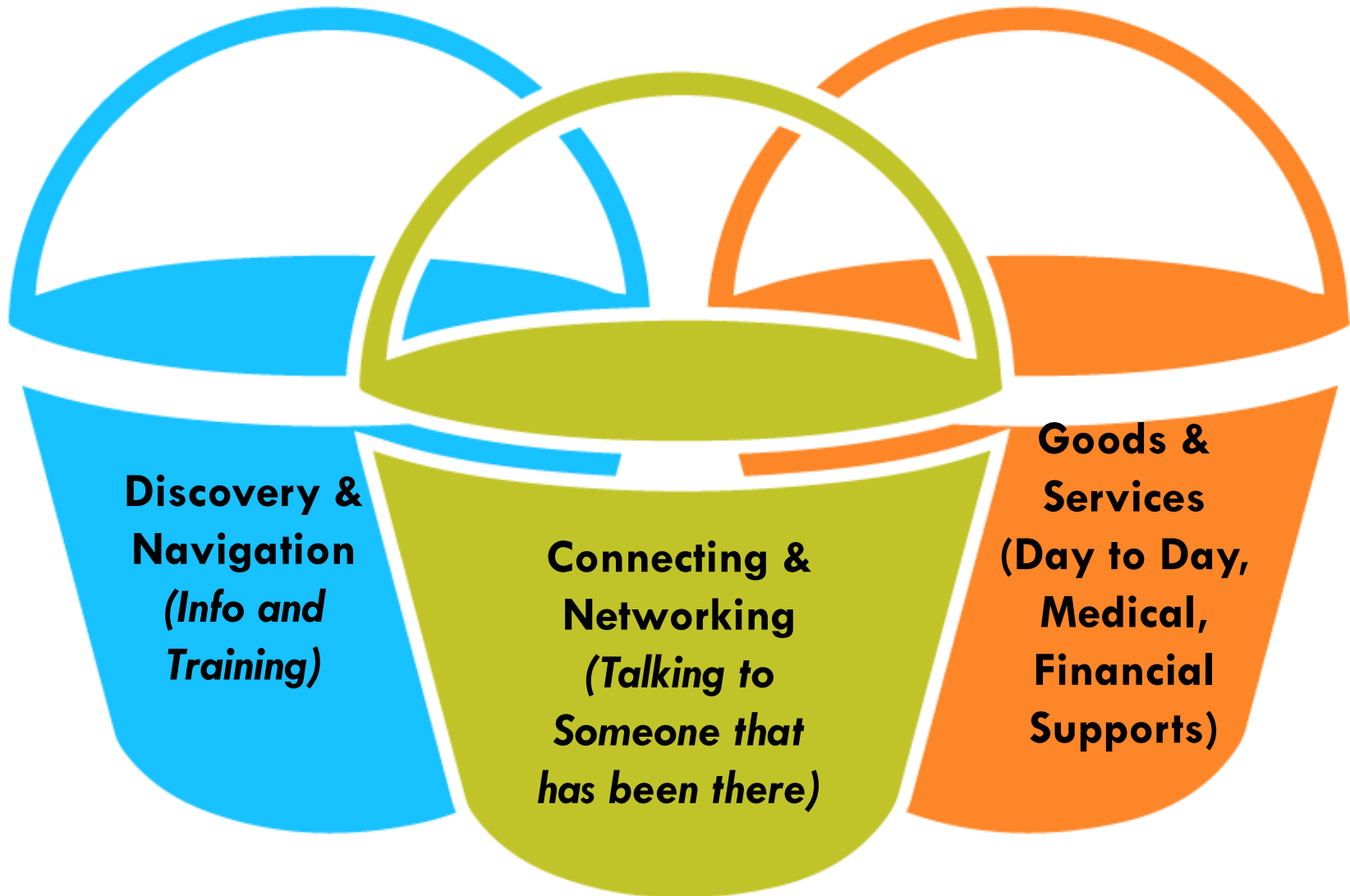
# People with disabilities and their families...

have **access to resources  
and supports**, that are  
person and family  
centered and directed,  
that **enhance individual  
lives and maintain the  
family well-being.**

What  
People  
Need to be  
Supported



# Three Types of Supports





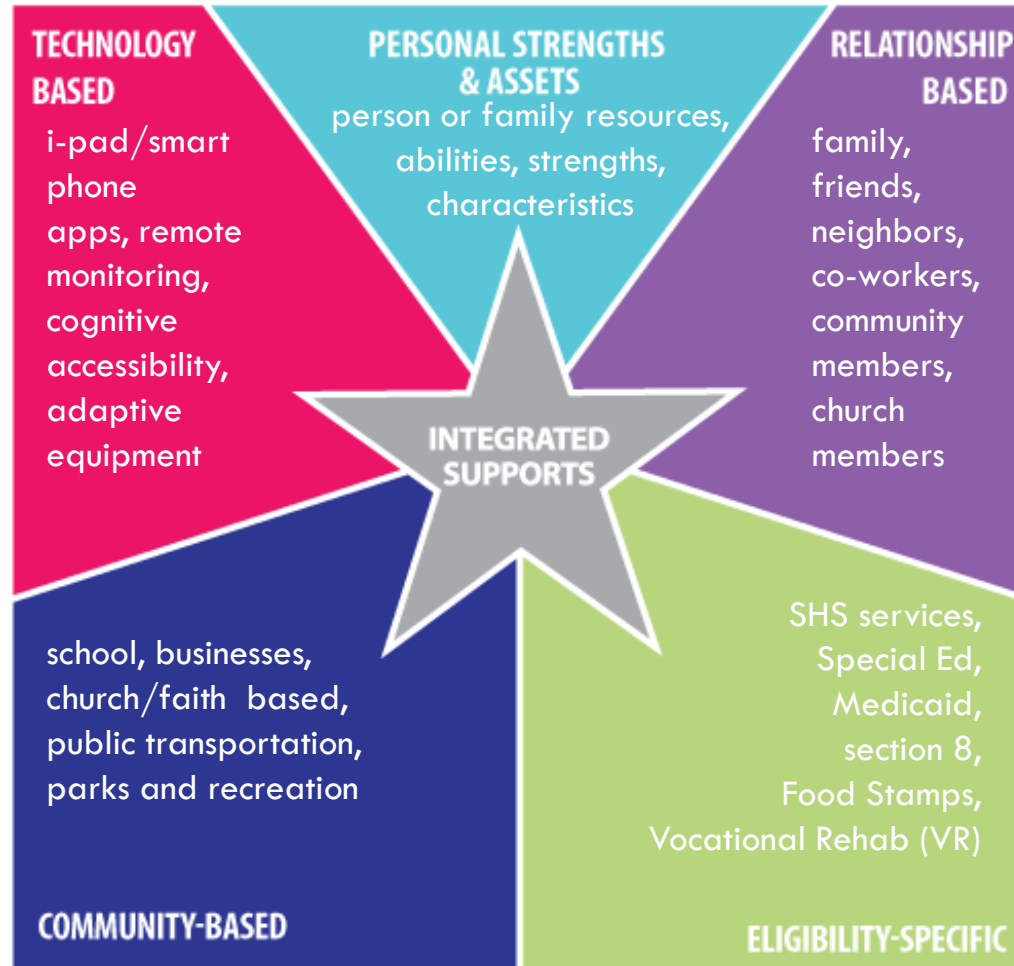
# Types of Supports

<b>Discovery &amp; Navigation:</b> Knowledge & Skills	<b>Connecting &amp; Networking</b> Mental Health & Self-efficacy	<b>Day-to-Day Services</b> Instrumental Supports
<ul style="list-style-type: none"><li>• Information on disability</li><li>• Knowledge about best practices and values</li><li>• Skills to navigate and access services</li><li>• Ability to advocate for services and policy change</li></ul>	<ul style="list-style-type: none"><li>• Parent-to-Parent Support</li><li>• Self-Advocacy Organizations</li><li>• Family Organizations</li><li>• Sib-shops</li><li>• Support Groups</li><li>• Professional Counseling</li><li>• Non-disability community support</li></ul>	<ul style="list-style-type: none"><li>• Self/Family-Directed services</li><li>• Transportation</li><li>• Respite/Childcare</li><li>• Adaptive equipment</li><li>• Home modifications</li><li>• Financial assistance</li><li>• Cash Subsidies</li><li>• Short/Long term planning</li><li>• Caregiver supports &amp; training</li></ul>



Integrated Star  
for Problem Solving & Exploring Options

# Identifying, Developing and Integrating Supports & Services







# LifeCourse Framework and Tools in Action





# Peyton's Plan for Inclusion in School

Using the  
LifeCourse Tools  
to Transform the  
Way the School  
Thinks about  
Inclusion for  
Peyton

# Peyton's Good Life

## CHARTING the life course *Peyton* Life Trajectory Worksheet: Family

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 arrows to think about current or needed life experiences that help point you in the direction of your good life.



### VISION for a GOOD LIFE

Friends  
Family  
Productive Employment  
Happiness  
Living Independently  
Meaningful Relationships  
Love  
Community Involvement  
& Inclusion

### What I DON'T Want

Sheltered workshop  
Group home  
Isolation  
Dependency on paid supports  
Lonely  
Unhappy  
Unproductive  
Bored  
Poverty





# Peyton's Integrated Good Life

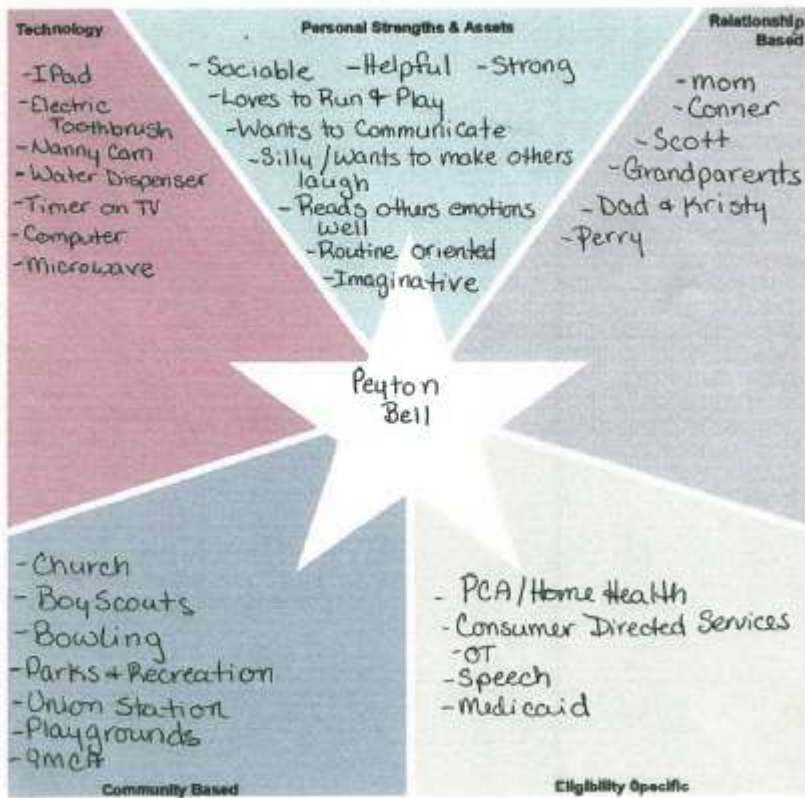
## CHARTING the life course



### Integrated Services and Supports



People need supports to lead good lives. Using a combination of lots of different kinds of support helps to plot a trajectory toward an inclusive, quality, community life. This tool will help families and individuals think about how to work in partnership to support their vision for a good life.



## CHARTING the life course



### Long Term Support Needs

TIME	MON	TUES	WED	THURS	FRI	SAT	SUN
6-6:30 AM							
6:30-7 AM			Mom				
7-7:30 AM			provides				
7:30-8 AM			support				
8-8:30 AM							
8:30-9 AM	School	providing	supports				
9-9:30 AM	through	various	means:				
9:30-10 AM	- Social	support	from	peers			Church
10-10:30 AM	- Tech	support	through	AT device			
10:30-11 AM	- Aid	supports	in	Reg Ed and			
11-11:30 AM	special	ed	classrooms				
11:30-12 PM							
12-12:30 PM							
12:30-1 PM						PCA /	Home Health
1-1:30 PM							
1:30-2 PM						Home Health	
2-2:30 PM							
2:30-3 PM							
3-3:30 PM							
3:30-4 PM							
4-4:30 PM	PCA /	PCA /	PCA /	PCA /	PCA /		
4:30-5 PM	Home	Home	Home	Home	Home		
5-5:30 PM	Health	Health	Health	Health	Health		
5:30-6 PM							
6-6:30 PM							
6:30-7 PM							
7-7:30 PM	Boy	sports					
7:30-8 PM	Scout's						
8-8:30 PM							
8:30-9 PM							
9-9:30 PM							
9:30-10 PM							
10 PM-6 AM							

# Ben's GOOD LIFE





I PITY THE FOOL  
WHO DOESN'T LIKE



BEN'S ONE PAGE  
PROFILE!

### WHAT PEOPLE LIKE & ADMIRE ABOUT ME

- I like to make other people feel good and be happy.
- I have a great smile and a contagious laugh. I frequently "get the giggles"!
- I'm fun, silly and friendly!
- I am a dedicated volunteer in my community
- I am an Eagle Scout and an adult leader in scouting - been involved in service through scouting since first grade.
- I am a man about town!
- My tattoo!!
- My great hugs!
- I am willing to try new things...
- I remember songs and who sings them
- I am not usually a complainer, even though sometimes I am in pain or uncomfortable

### WHAT'S IMPORTANT TO ME

- My family and friends
- Volunteering at the Fire Station, wearing my uniform and badge
- Going to the library
- Going to church
- My TV, DVR, and radio/CD player (I like to play them all at once sometimes)
- My iPad
- WWE wrestling – I love when my brother Matt takes me to live shows
- Nascar Racing (Jeff Gordon is my favorite driver)
- Going to country music concerts
- Feeling like I belong
- Being like everybody else, not being treated differently
- Getting a tattoo (already planning my next tattoo)
- Having control over my life as much as possible
- My Excelsior Springs Tigers – especially football
- Riding horses at NTRC
- Facebook friends
- Having an occasional beer with friends
- Having a purpose and being productive

### HOW BEST TO SUPPORT ME

- I need help remembering things, like what I did or who I saw today.
- I get confused easily so I need help not getting lost or turned around when I am out and about.
- I know what times I am supposed to take my meds, but I need help getting them out and getting refills.
- I get anxious sometimes, need to be reassured that people I care about will be there for me.
- I don't like to spend time alone, but I am working on it, help me not be so anxious when I am alone for short periods of time.
- I sometimes need someone to steady me if I get off balance.
- I need to rest or extra support if I have to do a lot of walking or standing. If I am shopping, it helps if I am the cart-pusher.
- I need support keeping in touch with friends and family and practicing having good conversations.
- I'm friendly even though I may not look you in the eye at first

# Tools Used for Planning and Day-to-Day Supports for DMH Division of DD

## *(Ben's One Page Profile)*

# Ben's Life Trajectory

CHARTING the life course



## Ben's Life Trajectory Worksheet

Chores  
Boy Scouts  
School Inclusion  
Riding bike  
Swimming  
Circle of Friends  
T-ball  
Shooting hoops  
Birthday parties  
Family vacations  
Brothers  
Cousins  
Music  
Going to brother's games

Football Manager  
Gen Ed Classes  
Inclusion  
Church group  
Volunteering  
Homecoming King  
Riding Omni bus  
Shopping at Walmart and PC  
Using Debit Card  
Fire Station  
Good Sam  
Hanging out with friends  
Graduation

SPED negativity & low expectations  
Segregated classes  
Scoliosis  
Seizures  
Physical barriers  
Surgeries  
Side Effects of Meds

### VISION for a GOOD LIFE

Friends  
Job/financial security  
Fun/interesting stuff to do  
Continue to learn new things  
Ben own his own home or condo  
Live on his own or with a friend  
Vacations  
Getting a Tattoo

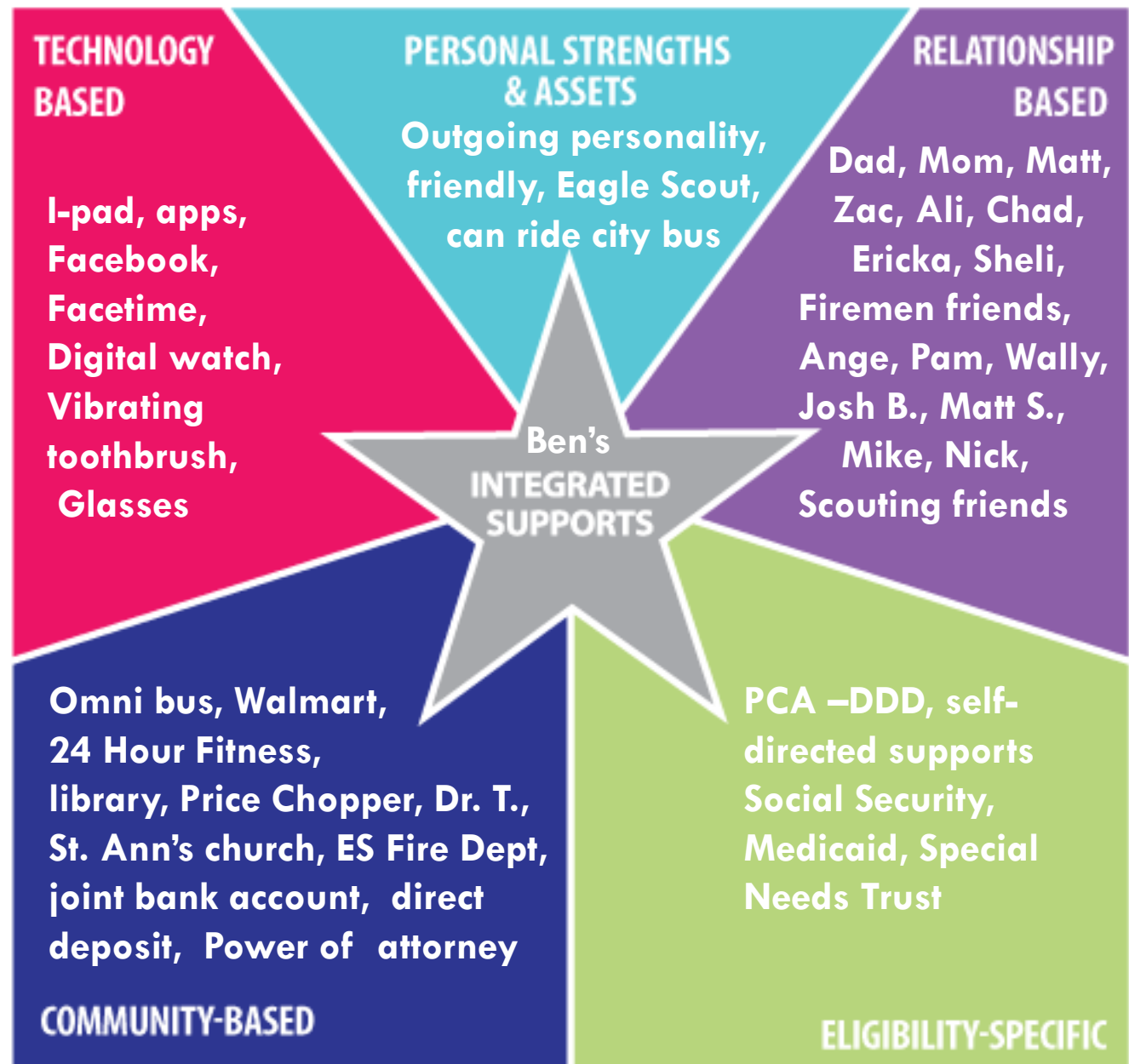
### What I DON'T Want

Sheltered Workshop  
Group Home or Institution  
Segregation or Isolation  
Loneliness  
Guardianship  
Poverty





# Ben's Integrated Services and Supports Star





## CHARTING the life course

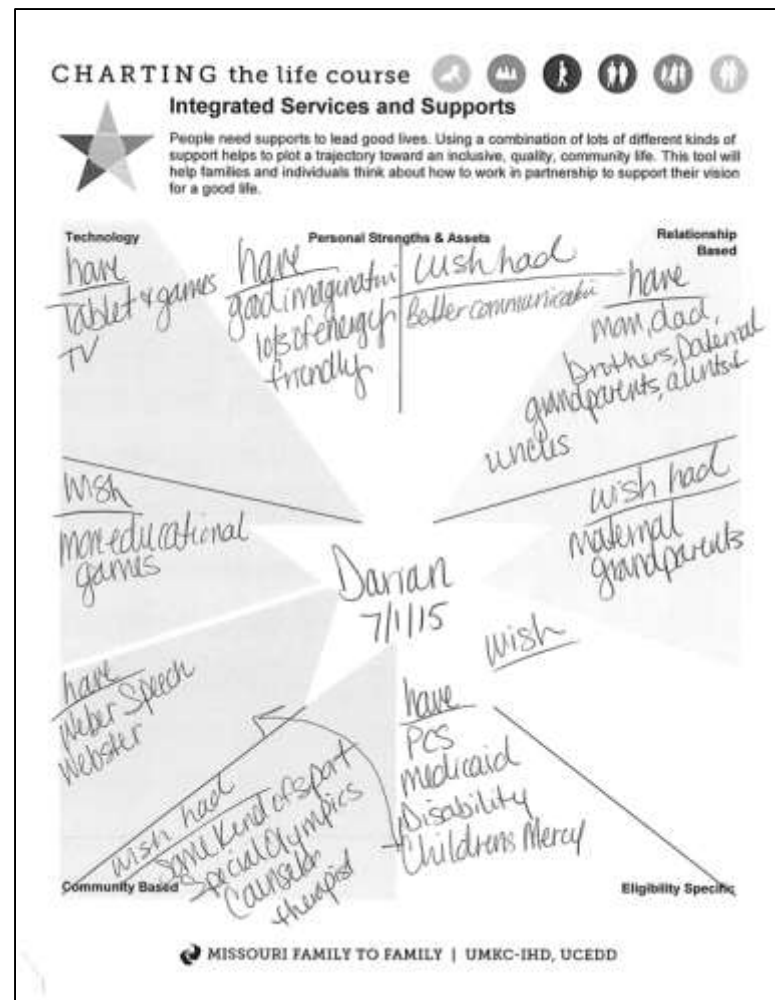
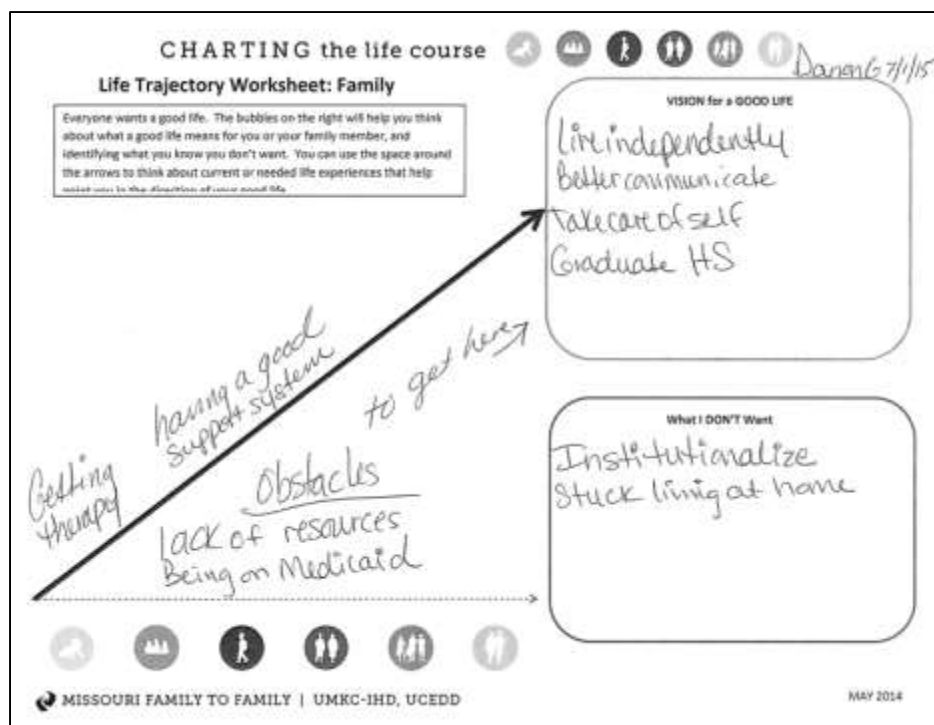


### Integrated STAR Activities

TIME	MON	TUES	WED	THURS	FRI	SAT	SUN
6-6:30 AM	Breakfast	Breakfast	Breakfast	Breakfast	Breakfast		Spend
6:30-7 AM	I-pad while	I-pad while	I-pad while	I-pad while	I-pad		Night with
7-7:30 AM	Mom walks	Mom walks	Mom walks	Mom walks	Mom walks		Matt
7:30-8 AM							
8-8:30 AM		Volunteer		Volunteer	Workout		
8:30-9 AM		Fire Station		Fire Station	@ Gym		
9-9:30 AM	Go for walk	8-Noon	Buy food	8-Noon	Get ready		
9:30-10 AM			& take to		& go to IHD		
10-10:30 AM	Workout		Good Sam.		Volunteer		Church @
10:30-11 AM	@ Gym		Center		At IHD		St Ann's
11-11:30 AM	Watch TV		Watch TV		with PCA		
11:30-12 PM		↓	Lunch with	↓			
12-12:30 PM	Lunch with	Lunch with	PCA help	Lunch with	Lunch @		
12:30-1 PM	PCA help	Firemen @	Workout	PCA help	Crown Cntr		
1-1:30 PM	Library	El Maguey	@ Gym	Wal-Mart			
1:30-2 PM		Watch TV		With PCA			
2-2:30 PM	Watch TV	& chill until	Sonic drink	Watch TV	Get ready		
2:30-3 PM	& chill	football	Chill time	& chill	for game		
3-3:30 PM	Football	Football	Football	Football	ESHS		
3:30-4 PM	Practice	Practice	Practice	Practice	Tigers		
4-4:30 PM					Football		
4:30-5 PM					Game		
5-5:30 PM	↓	↓	↓	↓		Dinner with	
5:30-6 PM		Go visit				Matt (twin)	
6-6:30 PM		Twins, Chad	McDonalds				Watch
6:30-7 PM		& Ericka in				Music	PayPerView
7-7:30 PM		Lawson				Concert	with
7:30-8 PM	I-pad when	I-pad while	Northland	I-pad while		with Matt	Firemen
8-8:30 PM	Mom walks	Mom walks	Therapeutic	Mom walks			friends
8:30-9 PM			Horseback				
9-9:30 PM			Riding				
9:30-10 PM					↓	↓	
10 PM-6 AM						Spend night with Matt at his apartment	

# Ben's Integrated Activities

# Darien – age 3





## CHARTING the life course



### Integrated Services and Supports

People need supports to lead good lives. Using a combination of lots of different kinds of support helps to plot a trajectory toward an inclusive, quality, community life. This tool will help families and individuals think about how to work in partnership to support their vision for a good life.

#### Technology

- Computer that she has
- Digital watch
- TV
- Home phone

#### Personal Strengths & Assets

- Great cook
- Very knowledgeable about everything and others
- Awesome advocate for herself
- Her own person
- Loves promoting good causes
- Does laundry dishes

#### Relationship Based

- Likes to read
- Nick - like a grandson
- Nathan - like a grandson
- Bill - man she likes
- Keith - childhood friend & preacher
- Autumn - Nick's daughter - like a granddaughter

Debbie T

- Computer
- Internet
- Cell phone

That she wants

That she wants

- Somewhere she can be around cattle

- East Hills Church of Christ
- TOPS
- Cabs

Community Based

that she has

- SSA
- Medicare
- Section 8 housing
- PCS
- DHSS
- Blue Skies
- Mental health net
- Primary doc
- Eye doc
- Mosaic for legs therapy

Eligibility Specific

that she has

That she wants

None to add

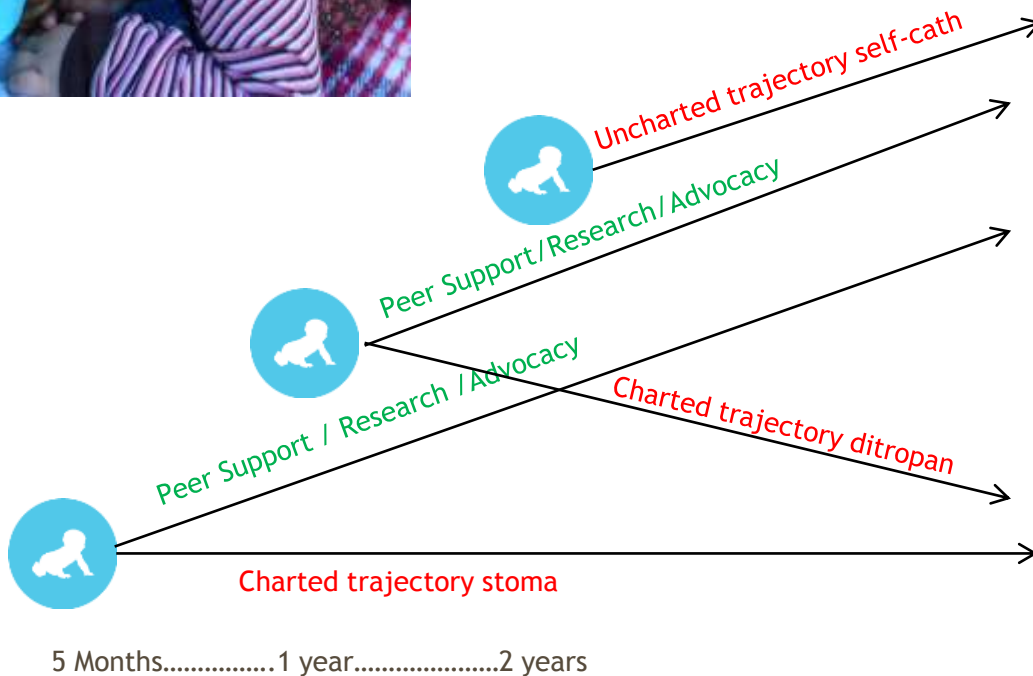
## CHARTING the life course



### Long Term Support Needs

TIME	MON	TUES	WED	THURS	FRI	SAT	SUN
6-6:30 AM	Up at 5:30 am					Up at 5:30	
6:30-7 AM						laundry, dishes, hygiene	
7-7:30 AM	Does laundry, dishes, & writes					Breakfast	
7:30-8 AM						Merch	
8-8:30 AM	DHSS Supports					East Hills Church	
8:30-9 AM	Breakfast					watch news	
9-9:30 AM	Shower					Keith	
9:30-10 AM	House Cleaned					Keith	
10-10:30 AM	Pay bills						
10:30-11 AM	makes her own lunch					!!!	
11-11:30 AM	NAPS					!!!	
11:30-12 PM	TV					TV	
12-12:30 PM	SC visits					TV	
12:30-1 PM	Read newspaper					snack	
1-1:30 PM	makes her own dinner					Keith	
1:30-2 PM	Read Books					East Hills Church	
2-2:30 PM						Keith	
2:30-3 PM	Any sports on TV					TV	
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							
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	Bed at 12:30 am					Bed at 12:30	

# Elizabeth's Health and Wellness Trajectory



## VISION for a GOOD LIFE

Self determination  
Choice  
Privacy

## What I DON'T Want

Unnecessary medications  
Unnecessary procedures  
Limiting choices  
Limiting self-determination



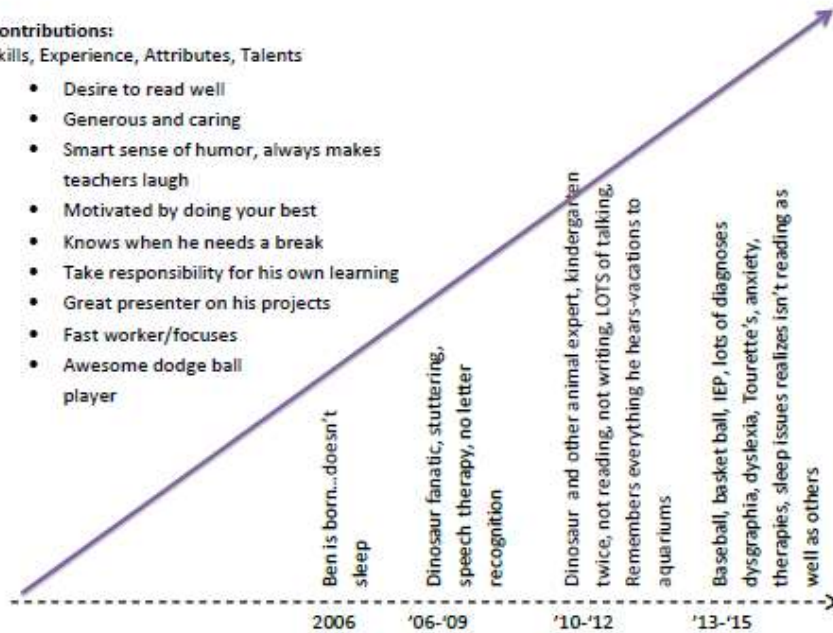
# Elementary School Trajectory

## Elementary School Trajectory Worksheet:

### Contributions:

#### Skills, Experience, Attributes, Talents

- Desire to read well
- Generous and caring
- Smart sense of humor, always makes teachers laugh
- Motivated by doing your best
- Knows when he needs a break
- Take responsibility for his own learning
- Great presenter on his projects
- Fast worker/focuses
- Awesome dodge ball player



### What I DON'T Want

- To be bullied
- For other kids to know I am below grade level in reading
- Not be able to be a marine biologist or paleontologist
- A teacher that corrects my reading and tells me I can read better if I just try harder, a teacher that tells me to stop doing a tic, but I can't stop it

### VISION for successful school experience and a GOOD LIFE

#### Long term education desires and goals:

Ben is currently considering a career as a marine biologist or paleontologist. He wants to meet people that have dyslexia and Tourette's that have chosen these careers.

Educate his classmates on Tourette's

He is determined to be able to read on grade level

#### Conditions:

- Access to de-stressing supports (ball pit, alone time, talking it through with trusted teacher)
- Modification for reading assignments and home work
- Having a teacher that "gets" Tourette's, dyslexia and anxiety
- LOTS of activity at recess

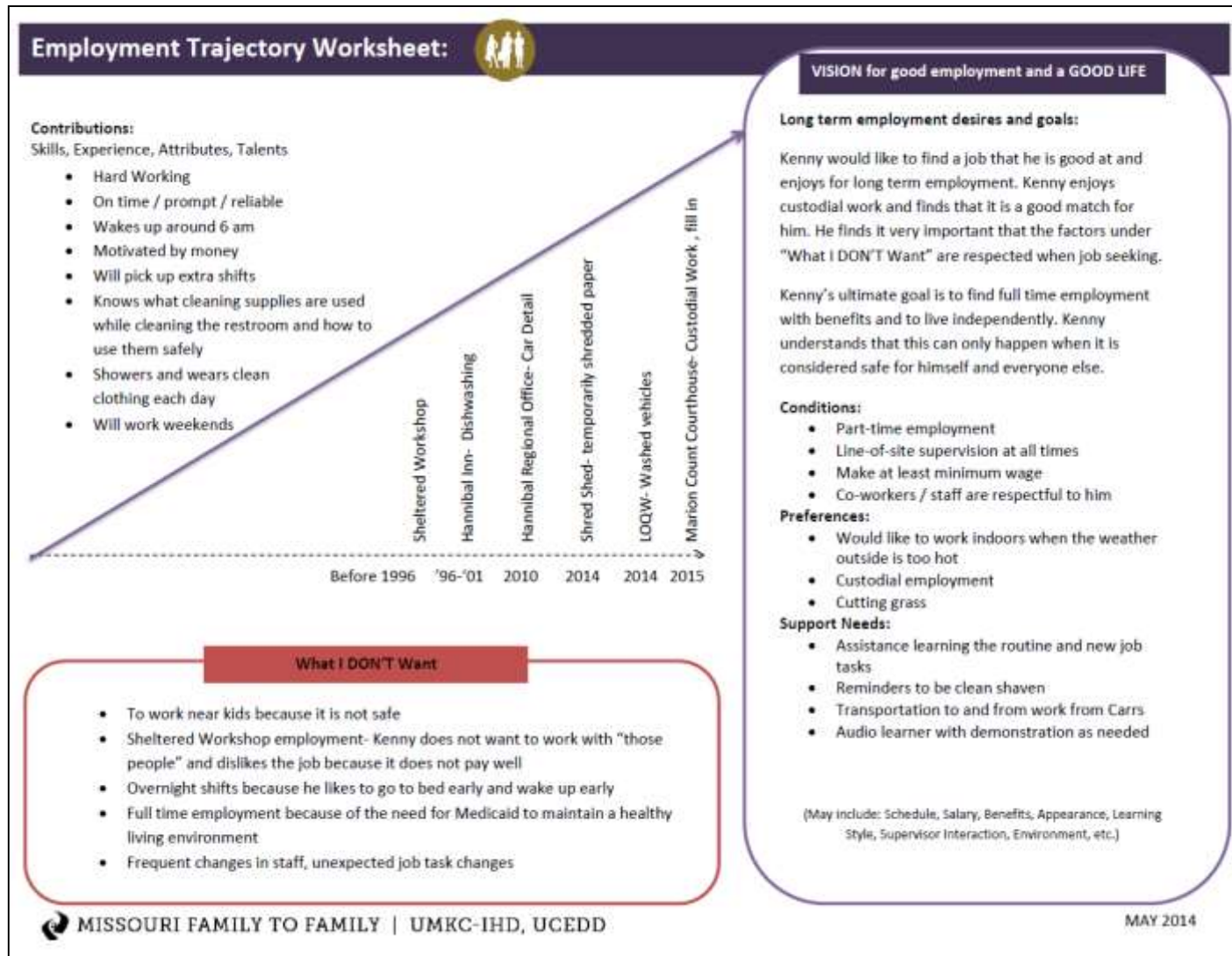
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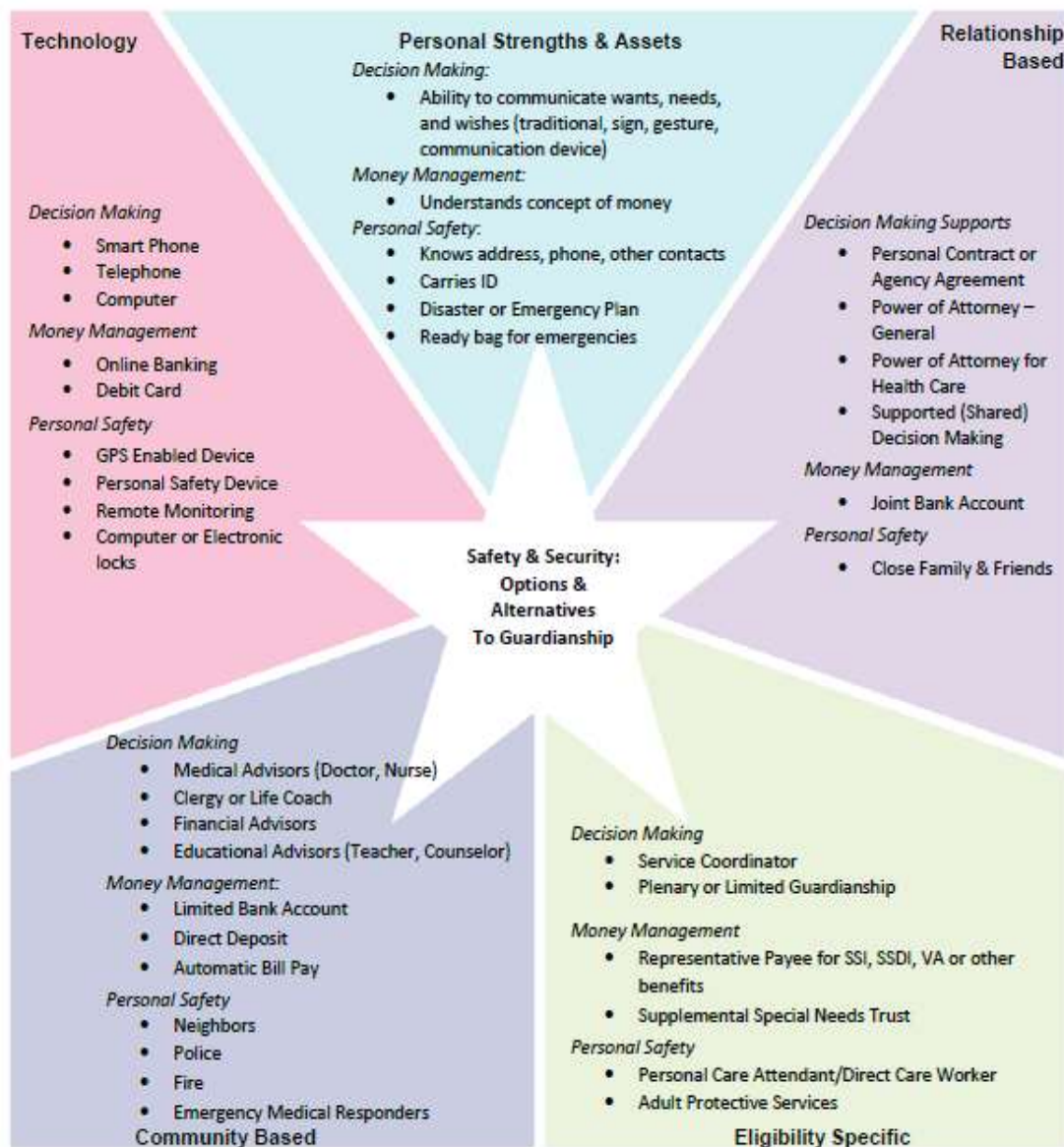
- Teacher – nice, not a lot of home work, funny
- Loves social studies and science best!
- Recess!!!!!!

#### Support Needs:

- Visual schedule
- Regular routine
- Opportunities to explore his passions in projects
- Audio learner with demonstration as needed

# Adult Employment Trajectory





# Domain Specific

## Safety and Security:

### *Focusing on Supports Beyond Legal Guardianship*



# Eric's Focus on Social and Spiritual

## TECHNOLOGY BASED

I-pad  
Smart  
Phone



## PERSONAL STRENGTHS & ASSETS

Happy, Funny and loving; Likes to help  
people, Likes to try new things, Police  
cars, tow trucks, fire engines and  
racecars, Golf Cart

## RELATIONSHIP BASED

See his  
girlfriend  
more  
Connect with  
his family  
Spend more  
time with  
friends



## INTEGRATED SUPPORTS

Scouts  
Red Robin  
Race Tracks

## COMMUNITY-BASED



Companion  
Supports  
day-to-day

## ELIGIBILITY-SPECIFIC







Community & Person/Family  
Centered & Driven Policy & Systems



# Comprehensive, Integrated & Coordinated Systems Across Life Domains & Stages

Pediatrician, Families and Friends,  
Faith based

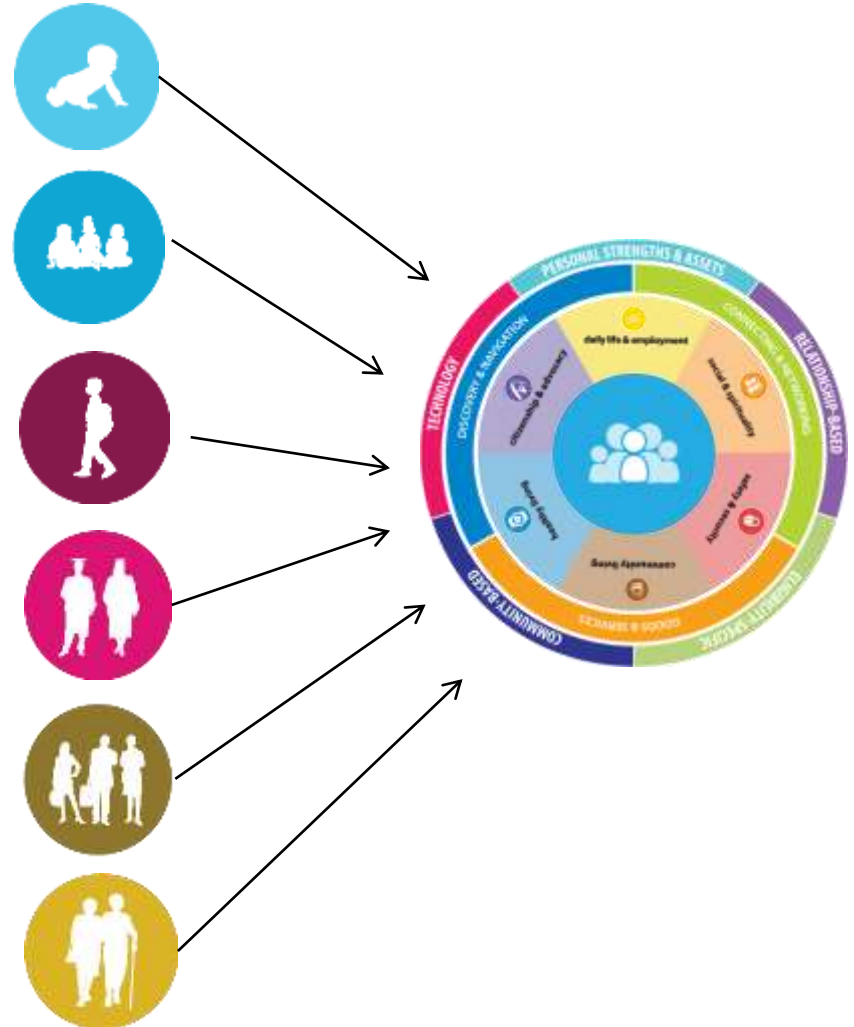
IDEA Part C, Parents as Teachers,  
Health, Headstart

School, Special Education, Health,  
Recreation

Vocational Rehab, Health Employment,  
College, Military

Disability Services, Health, Housing,  
College, Careers

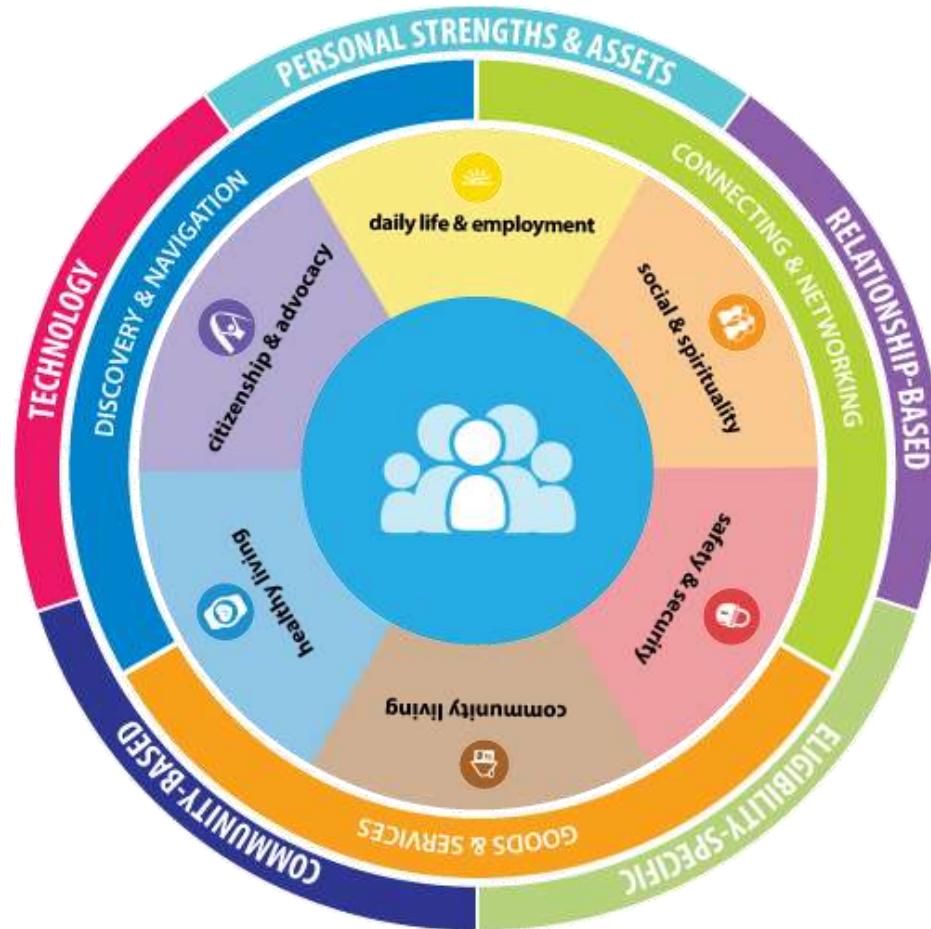
Retirement, Aging System, Health



# Partnering with People with Disabilities and their Families so they can Engage, Lead, and Drive Policy and Systems Change



# Putting the Framework Together!



# Questions, Reflections and Discussion

# Contact Information

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