

# Supporting Families LifeCourse Framework: *Building Leadership Capacity of Families, Organizations and Systems, to Drive Change*

*AUCD Annual Conference  
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# About UMKC-IHD

UCEDD/LEND with longstanding focus on Family Support, Self-Advocacy and Self-Determination

State and National Systems and Policy Change:  
National Community of Practice for Supporting Families

Statewide Family Resource Center, Family-to-Family HIC, for over 25 years with evolving and on-going statewide partnership


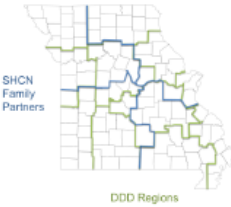
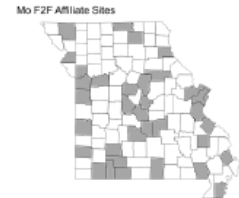
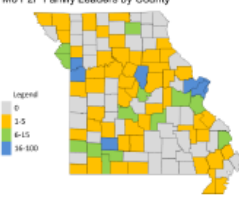


# Supporting Families LifeCourse Framework

## Activities: Local, State and National Levels



### Missouri LifeCourse Network Overview

LEVEL	MEMBERS
<p><b>National Partners</b></p> 	<ul style="list-style-type: none"> <li>National Community of Practice on Supports to Families (partner with NASDDDS &amp; HSRI)</li> <li>Parent to Parent USA (p2pusa.org)</li> <li>HRSA/MCHB &amp; Family Voices- National Family to Family HIC (familyvoices.org/states)</li> <li>The Learning Community on Person Centered Practices (learningcommunity.us)</li> </ul>
<p><b>Statewide Partners</b></p> 	<ul style="list-style-type: none"> <li>DMH Division of Developmental Disabilities</li> <li>DHSS SHCN Family Partnership</li> <li>DESE/First Steps/VR</li> <li>Show Me Careers Project</li> <li>Missouri state Supports to Families CoP team</li> <li>MACDDS</li> <li>Missouri Protection &amp; Advocacy Services</li> </ul>
<p><b>Local Partners</b></p> 	<p><u>171 Affiliate Organizations</u></p> <ul style="list-style-type: none"> <li>12 - Regional Initiatives</li> <li>6 - Project Specific Initiatives</li> <li>75 - Active Affiliates</li> <li>78- Info. Dissemination Affiliates</li> </ul>
<p><b>Self-Advocate &amp; Family Leaders</b></p> 	<p><u>1023 Family Leaders in Network</u></p> <ul style="list-style-type: none"> <li>699- Family Volunteers</li> <li>550 - Trained SOS peer mentors</li> <li>35 - Family Leadership Certificate Series Trained</li> </ul>

October 2015

# Outcomes for Today

- Provide overview of the Supporting Families LifeCourse Framework
- Share examples of how families and self-advocates are using LifeCourse Tools
- Discuss how Support Coordinators are using LifeCourse Tools with individuals and families they support
- Explore how states in the Community of Practice for Supporting Families are using the LifeCourse Framework to transform policies and systems

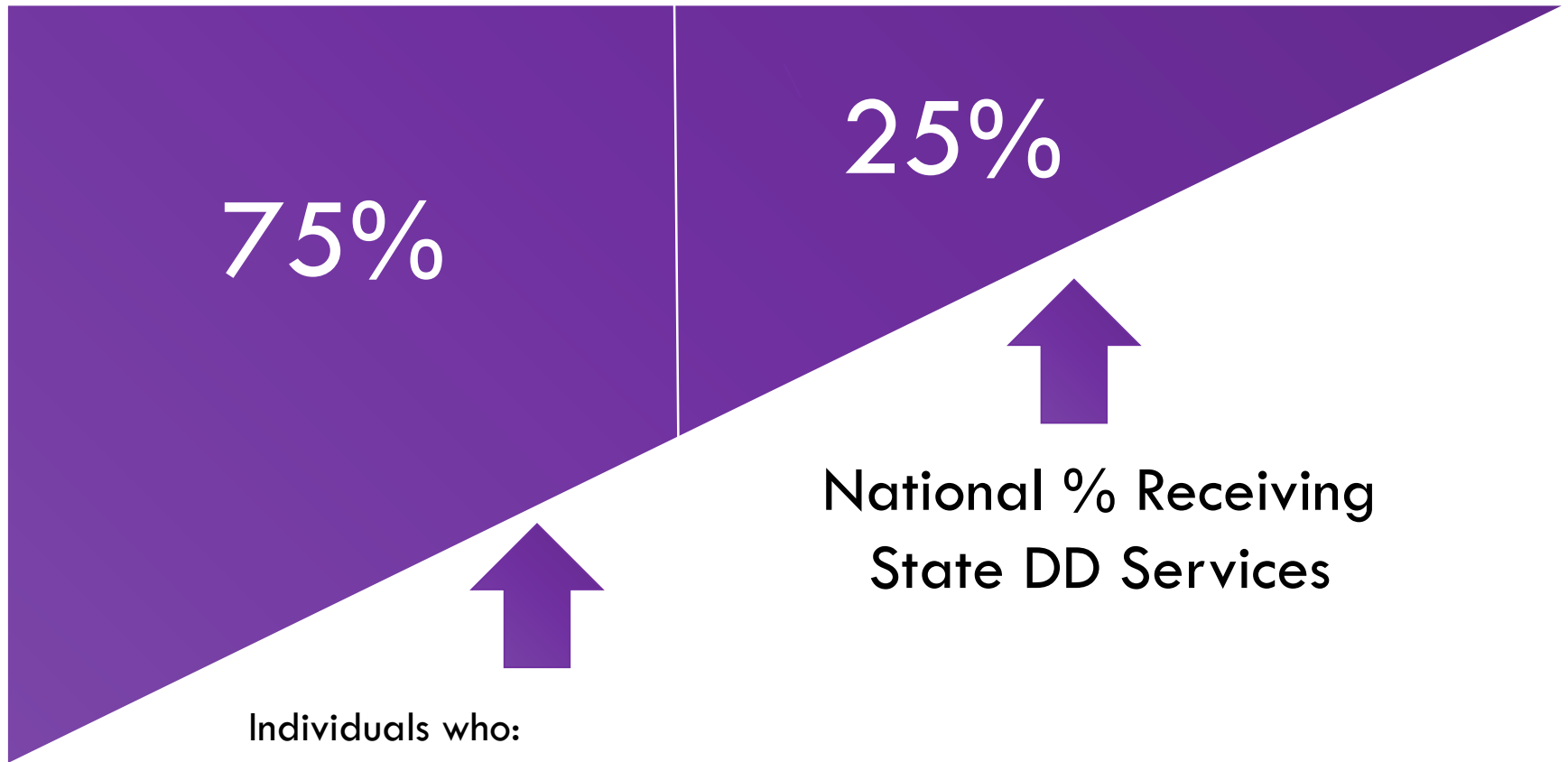


People with disabilities and their families have the right to live, love, work, play and pursue their life aspirations just as others do in their community.



# Focusing on ALL

ALL 4.9 Million people with developmental disabilities



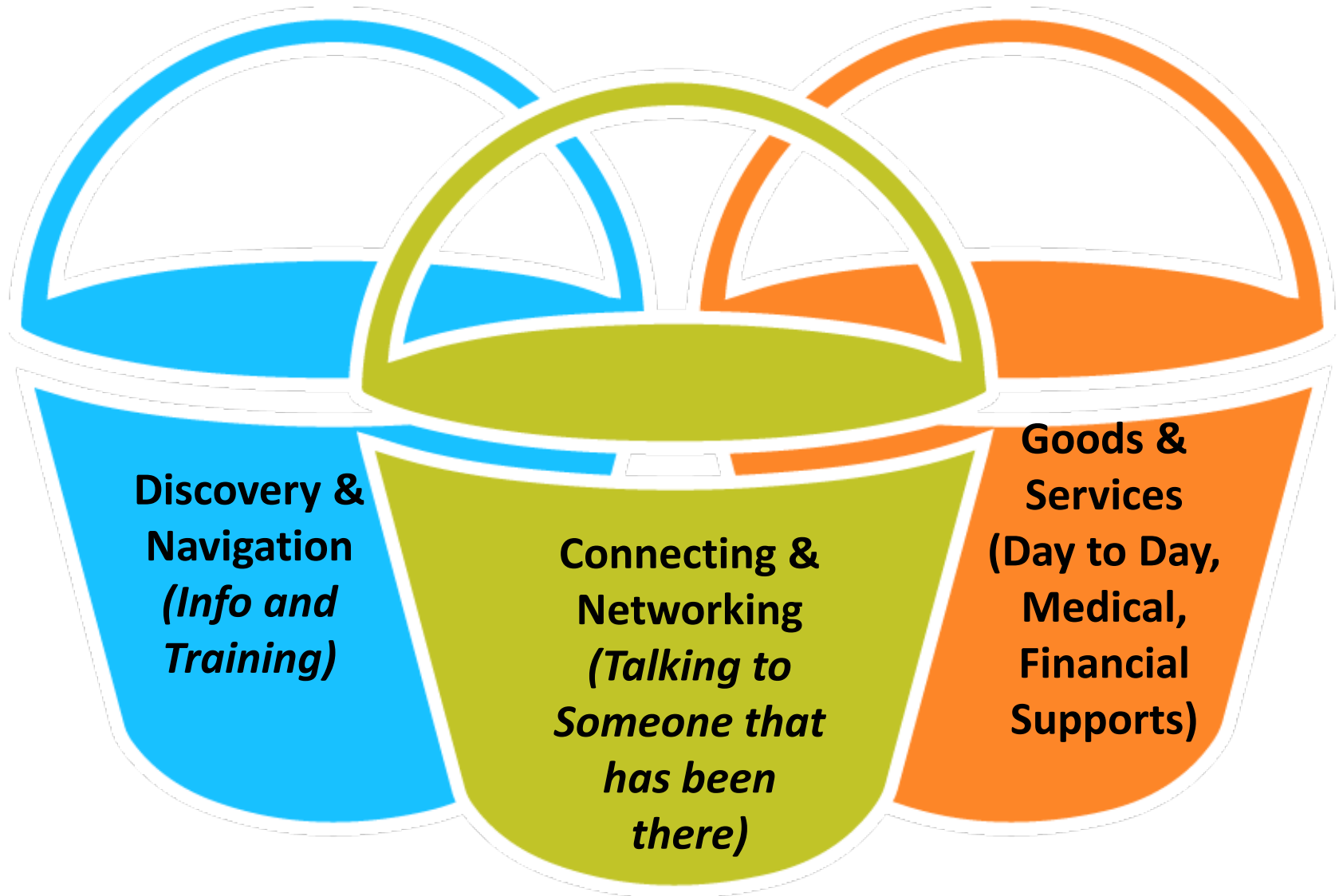
Individuals who:

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

# LifeCourse Framework

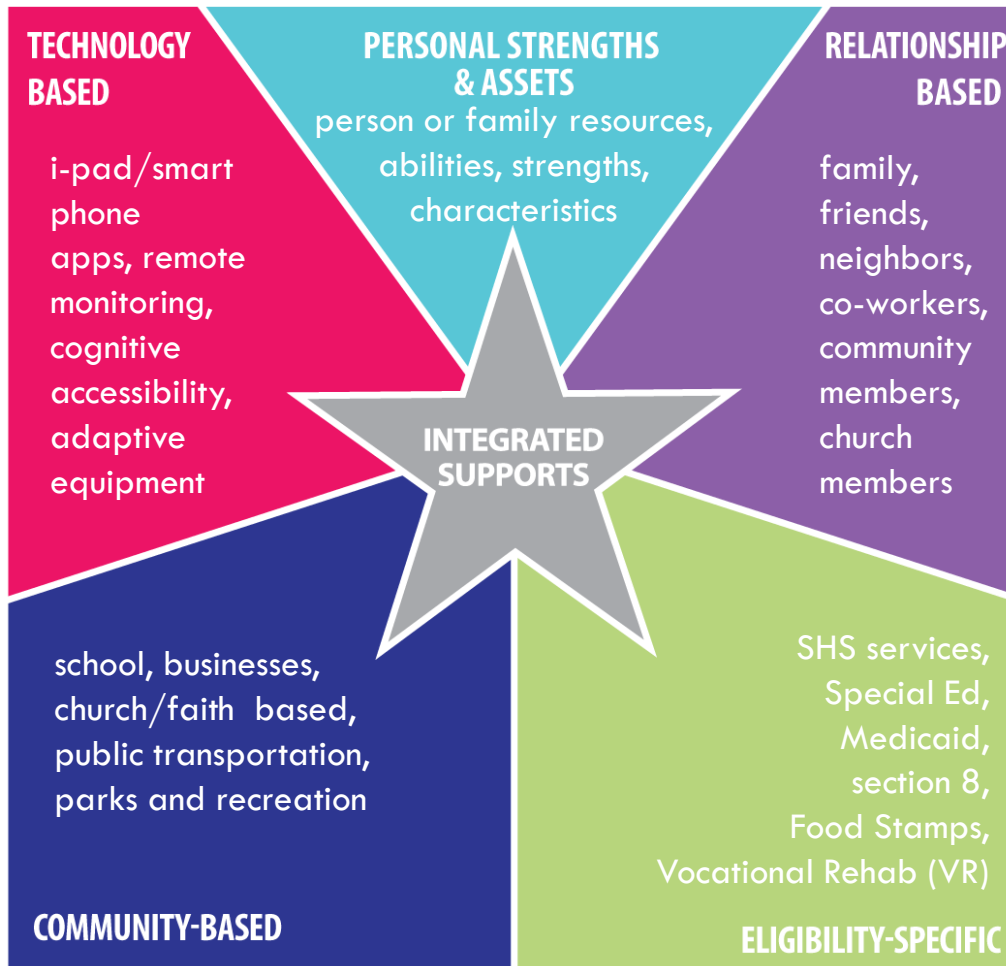


# Three Types of Supports





# Integrated Supports STAR



# Life Trajectory, Life Experiences, Life Stages & Outcomes

*Volunteering at church*

*"Birthday parties with friends"*

*"Playing sports or an instrument"*

*"Making mistakes"*

*"Chores and allowance"*

*Learning to say "no"*

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

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

Trajectory towards Life Outcomes

Trajectory towards things unwanted



***Focusing on Past, Present and Future Life Experiences***

# People with DD and Families Engage, Lead and Drive Policy and Systems Change



# Tools for Reframing

**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 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 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 "take 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.

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**Charting the LifeCourse**

Transition

LIFE DOMAIN: [Icons for Education, Employment, Relationships, Technology, Community, Eligibility] LIFE STAGE: [Icons for Childhood, Youth, Adulthood]

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, or matter. For you and your child, transition means that he/she 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. Chosen and declared you and your son/daughter make during this time can help to positively shape the future and the life they will live as an adult. This guide is based on Charting the Life Course Experiences & Questions.

Charting the Life Course Experiences & Questions presents questions to ask or consider in different life 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.

The LifeCourse Framework was created to help individuals and families of all abilities and all ages.

**Charting the LifeCourse**

Daily Life & Employment

LIFE DOMAIN: [Icons for Education, Employment, Relationships, Technology, Community, Eligibility] LIFE STAGE: [Icons for Childhood, Youth, Adulthood]

Before you know it, school will be ending and adult life will be beginning. Transition is a time to think about what you want to do and explore what you will be doing in more of your life when the school bus stops coming? You will have many 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.

DEVELOPED BY  
**MISSOURI FAMILY TO FAMILY**  
MISSOURI INSTITUTE FOR HUMAN DEVELOPMENT | UMKC  
IN PARTNERSHIP WITH  
**SHOW-ME CAREERS**

**ELIGIBILITY-SPECIFIC**

TECHNOLOGY

RELATIONSHIPS

STRATEGIES FOR THE GOOD LIFE

INTEGRATED SUPPORTS ACROSS THE LIFECOURSE

COMMUNITY-BASED

PERSONAL ASSETS & STRENGTHS

**Charting the LifeCourse**

VISION for a GOOD LIFE

What I DON'T Want

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MAY 2014

**CHARTING the life course**

Integrated Services

Technology

Personal Strengths & Assets

Relationship Based

Community Based

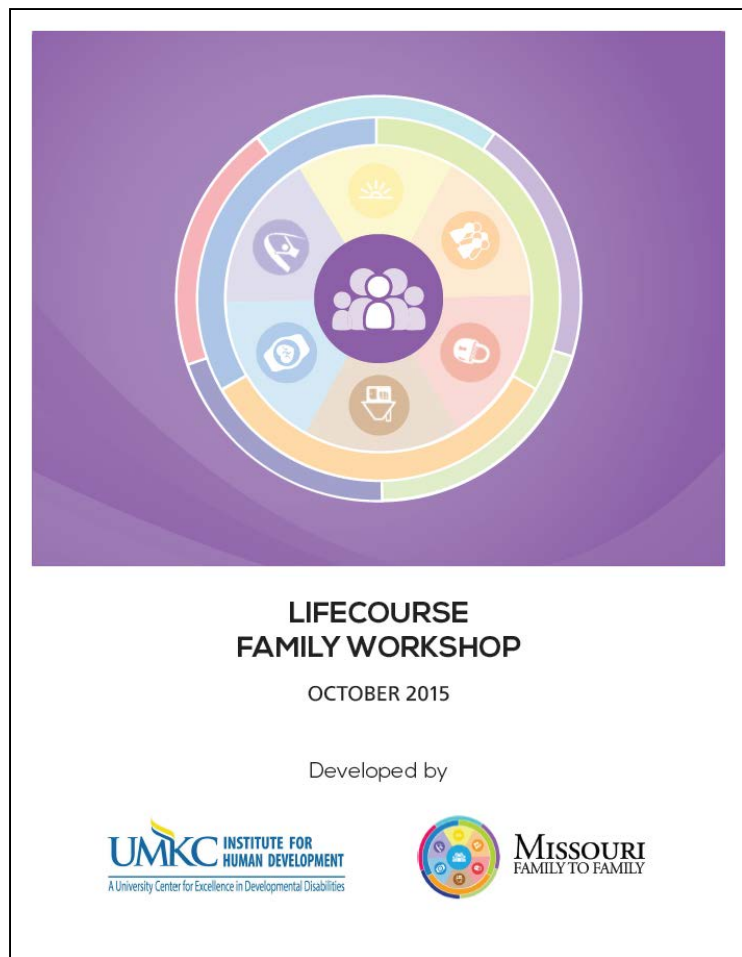
Eligibility Specific

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# LifeCourse: Families & Self-Advocates Drive Change

# LifeCourse Curriculum for Families and Self-Advocates



- 4 hour interactive workshop
- Developed using Plan-Do-Study-Act
- Families and self-advocates learn to use LifeCourse tools for having conversations and driving plans
- Trained family facilitators
- Evaluation and Family Aspiration pre-survey

# Evaluation & Family Survey

**CHARTING the life course** 

**Family LifeCourse Workshop Evaluation**

Location \_\_\_\_\_ Date \_\_\_\_\_

**About You**  
Please tell us about yourself (check all that apply)


I am a self-advocate with a disability, special health care need, mental health needs, etc.  
 I am a family member  
 I am a professional

**Quality of this Workshop Series.** We would like to know your opinions about this workshop. Please mark one best response for each feature.

	Excellent	Good	Fair	Poor
Presenter's Skills				
Information in Presentations				
Handouts and Other Materials				
Opportunities for Participation				
Overall Quality of the Series				

**Change in Your Skills and Confidence.** We would like to know whether you think the information activities in the LifeCourse Family Workshop improved or changed your skills and confidence in the following areas. Please circle the number that best describes your answer.

As a result of this workshop:	Strongly Agree	Agree	Disagree	Strongly Disagree
1) I am confident in my ability to use LifeCourse tools to think about and have conversations about my family member's future, or in my professional role working with individuals and families.	4	3	2	
2) It is likely that I will use LifeCourse tools when exploring possibilities, planning or having life conversations with my family member(s), in my own life, or in my professional role.	4	3	2	
3) I gained skills to use the Life Trajectory Worksheet to help my family member, myself and other supporters develop and articulate a vision for a good life.	4	3	2	
4) I have a better understanding of the importance of accommodating and adapting a variety of life experiences for people with disabilities in achieving their life goals.	4	3	2	
5) I have increased expectations about what is possible in the lives of people with disabilities.	4	3	2	
6) I feel more confident in my ability to navigate and make life expectations a reality for my family member or in my role as a professional working with individuals and families.	4	3	2	
7) I gained skills to use the Integrated Supports Start to problem solve or plan for needed supports from a variety of sources now and in the future.	4	3	2	
8) I have learned skills I can use to advocate for what I want or what a person with a disability or a family wants in other formal meetings (IEP, IFSP, IFSP, etc.)	4	3	2	

**CHARTING the life course** 

**LifeCourse Family Survey**

Date: \_\_\_\_\_

Please answer the following questions to the best of your ability. There is no right or wrong answer, we are just trying to get an idea of your current situation and your ideas about what adult life might look like for your son or daughter. \*If you have more than one child with a disability, please base your answers on your oldest child with a disability.

**I. Please answer the following questions to help us learn a little about you and your family.**

**Basic Information**

**A. My primary role in attending this workshop is as:**

Person with a disability/special healthcare need  
 Mother of a person with a disability/special healthcare need  
 Father of a person with a disability/special healthcare need  
 Sibling of a person with a disability/special healthcare need  
 Foster Parent  
 Friend  
 Guardian (non-family) \_\_\_\_\_  
 Other relative: \_\_\_\_\_  
 Professional (please specify (ie support coordinator, education, medical, etc.) \_\_\_\_\_

**B. Ethnicity:**

Hispanic/Latino  
 Not Hispanic/Latino  
 Unknown  
 Prefer not to say

**C. Race (check all that apply):**

White  
 African American  
 American Indian/Alaska Native  
 Native Hawaiian/Other Pacific Islander  
 Other: \_\_\_\_\_  
 Unknown  
 Prefer not to say

**D. Total Number of Children in Household** \_\_\_\_\_

**E. Number of Children with Disability/Special Healthcare Need** \_\_\_\_\_

**II. Please answer the following questions based on what you think your son or daughter's life will be like when they are an adult.**

**Daily Life Employment**

**A. When my son/daughter is an adult, I believe during the day he/she will:**

Continue their education at college or technical school  
 Volunteer or work in the community  
 Stay home alone and/or go out in the community on their own  
 Have paid support staff while I work  
 Go to a day program

**B. When thinking about adult employment for my son/daughter, I believe he/she will:**

Be employed in a job in the community without paid supports  
 Be employed in a job in the community and will need paid supports on the job to be successful  
 Be employed in a job specifically for people with disabilities  
 Probably not be employed

**Community Living**

**C. When my child is an adult, I believe he/she will need:**

No paid supports  
 Minimal paid supports such as personal care assistance  
 A lot of support, but less than 24 hour paid supports  
 24 hour paid staff

**D. When my child is an adult, I believe he/she will:**

Live in our family home  
 Live alone in a house or apartment  
 Live in a house/apartment with a roommate that he/she chooses  
 Live in a house/apartment with a paid roommate  
 Live in a group home or other system supported housing

**Healthy Living**

**E. When my child is an adult, I believe he/she will:**

Be able to take care of own daily care needs (shower, toileting, preparing meals/snacks)  
 Need some support with daily needs  
 Need 24 hour care for daily needs

**F. When my child becomes an adult, in order to be/stay healthy, I believe he/she will need:** (check all that apply)

Physical, occupational, speech or other therapies  
 Community based fitness classes  
 To exercise or work out at a gym or at home  
 To learn about the importance of healthy eating and exercise

# Partnered with Organizations to Host LC Curriculum for Families

- **Arc of St Louis**
  - Transition age families
  - Elementary school age families
- **St. Louis Special School District**
  - Families, Transition Coordinators, other school personnel
  - Held 1<sup>st</sup> “train the family facilitator”
- **Progressive Community Services (county board/TCM)**
  - Families served in Buchanan County



# Peyton's Good Life Trajectory

**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

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MAY 2014

# Peyton's Integrated Supports

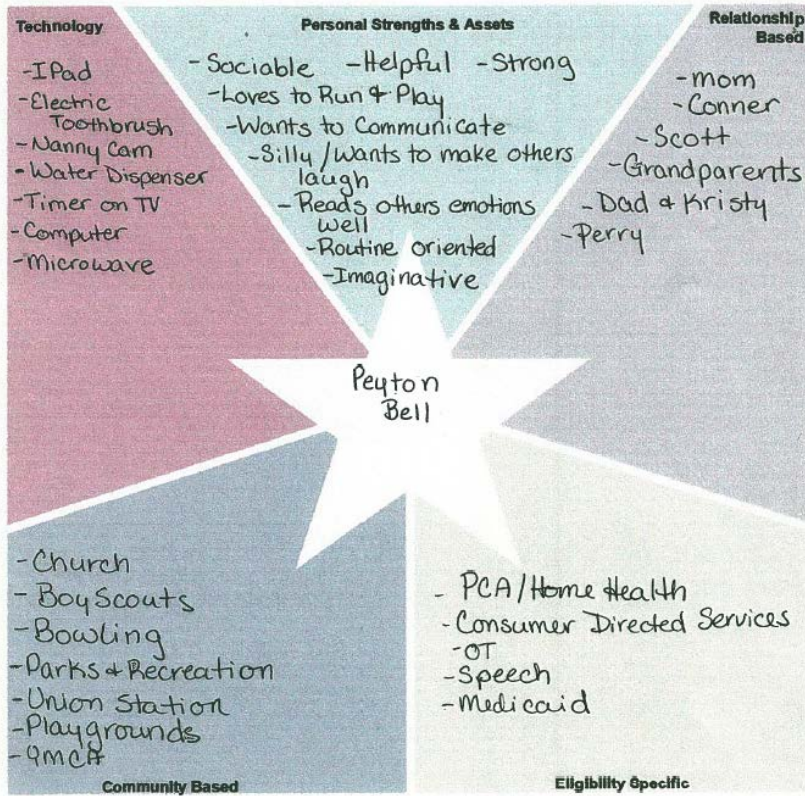
## CHARTING the life course



### 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 special ed classrooms				
11-11:30 AM							
11:30-12 PM							
12-12:30 PM							
12:30-1 PM						PCA /	Time with family
1-1:30 PM							
1:30-2 PM						Home Health	
2-2:30 PM							
2:30-3 PM							
3-3:30 PM							Mom provides support
3:30-4 PM							
4-4:30 PM	PCA /	PCA /	PCA /	PCA /	PCA /		
4:30-5 PM	Home Health	Home Health	Home Health	Home Health	Home Health		
5-5:30 PM							
5:30-6 PM							
6-6:30 PM			Mom provides support			Sports	
6:30-7 PM							
7-7:30 PM	Boy Scouts	sports			Parks		
7:30-8 PM							
8-8:30 PM							
8:30-9 PM							
9-9:30 PM							
9:30-10 PM							
10 PM-6 AM							



# Jessica's Transition Plan: *Self-led IEP Meeting*

# Jessica's Trajectory

## MY TIMELINE



Early Intervention,  
Pre-K & Lots of Play  
Therapy (0-5)

Elementary  
2004-12 (13 )

Middle School  
2012-13 (14 )

High School  
2013 - 17 (14-18)

I am  
here

Transition  
2017-20  
(18-21)

Adult Living  
2020... 21+



# Vision for a Good Life

## MY PLANS AS AN ADULT

- ❖ I want to be independent and make good choices for myself.
- ❖ After I graduate, I want to:
  - Go to college
  - Live in my own home with a friend
  - Work at a good job like the movie theater or Starbucks like my big sister!
  - Go to church
  - Have fun with my friends and family
- ❖ I need caregivers and staff to help me.
- ❖ I want to have a boyfriend and then some day get married in a wedding too.



# What Jessica Doesn't Want

## WHAT I DON'T WANT

- ❖ I don't want to work in a sheltered workshop or in some boring place making less than minimum wage.
- ❖ I don't want everyone else to assume they know what I want and make all my choices for me.
- ❖ I don't want to live in a group home or an institution with a whole bunch of other people.
- ❖ I don't want to be lonely, isolated, or "lumped in" either with everyone else with a disability.





# Support Coordination:

*Tools for Exploring and Planning with  
People with Disabilities and their Families*

# Enhancing Skills of Support Coordinators

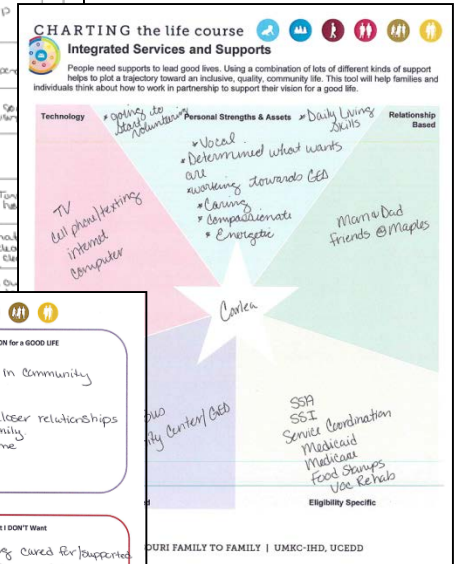
- Updating DDD Statewide Support Coordinator Manual
- Hosting LifeCourse Training Workshops and Coaching Sessions
- Participation in LifeCourse Tools and Practice Workgroup

**CHARTING the life course**

Tool for Developing a Vision - Family Tony 7/20/15

Forming a vision and beginning to plan for the future in each of the life domains helps plot a trajectory for a full, inclusive, quality life in the community. This tool is to help families of all ages - from with a very young child, an adult or somewhere in between, start to think about a vision for how their family member will live their life as an adult.

LIFE DOMAIN	My Vision for My Family Member's Future	rank	Current Situation/Things to Work On	rank
Daily Life	become a chef	3	Tony likes to help cook	
Community Living	I think Tony will program and host parties on his own (entertainment)		Tony likes to be in the car	
Social & Spirituality	I think if Tony understood more he can make friends and do activities		let me work on his to the gym to do water activities	
Healthier Living	I am trying to get Tony to eat different healthy foods			
Income & Security	will do the best I can to help Tony be employed by his own business	2	I monitor what Tony plays with what he has adults talk about	
Citizenship & Advocacy	I can have Tony speak at events and help with the community		I remind Tony that keeping his room clean helps him improve his focus on class	



**CHARTING the life course**

Life Trajectory Worksheet - Family Staff Jeffrey

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.

going to help participating in activities in the community going to the community  
work on safety for alone time  
Voc Rehab for employment  
building relationship w/ family

**VISION for a GOOD LIFE**

- involved in community
- Jobs
- Active
- Have closer relationships with family
- Alone time
- Health


**What I DON'T Want**


- Not being cared for/ supported
- Not having anything to do
- Not seeing family/Aunt
- Not going to UCB
- Sick

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# Developing Person-Centered Guidelines & Templates in Response to HCBS Person-Centered Rule


  
**Learning Opportunities Quality Works, Inc**  
**Initial and Annual Assessment**

 Consumer Name (first, middle initial, last name):   
 Date of birth:

*Instructions for use: Mark if this assessment is annual or initial assessment. Meet with the individual and support members of their choice, ask each question in succession. Answers should be recorded in full sentence form so that when they are read in succession the answers create a story, without need to summarize.*


Initial Assessment                       Annual Assessment

Contributing staff or family:

 **Community Living**  
**Living Arrangement:**  
 Do you like where you live and who you live with? Are there any modifications in your home needed to (rails, staff, stairs, etc.)? Do you feel safe when you are at home?

**Transportation and Community Access:**  
 Are there nearby places you like/need to go and how do you get there? What support do you need, if any, to access your community?

Is there anything you would like to learn how to do as a hobby or a special interest to you?

 **Social and Spirituality**  
**Communication:**  
 Who are your family and friends that are most important to you and what do you enjoy doing together?

How do you communicate with your family and friends (Verbal/ Nonverbal, letters, phone, email, sign language, communication device) and is there a way you could make more frequent contact?

All Charting the Life Course category logos and graphics from the Missouri Family to Family Resource Guide, and can be found at: <http://mofamilytofamily.org/?cid=62>.

**Missouri Quality Outcome**  
**Citizenship & Advocacy**

**People Have Opportunities to Advocate for Themselves, Others and Causes They Believe In, including Personal Goals and Dreams**



**ABOUT THIS OUTCOME**

This outcome emphasizes the importance of self-advocacy. Training and ongoing support are often time requires to assist an individual in developing their self-advocacy skills.


**Icons\***  
Each MOQO has a correlating "Charting the Life Course" icon to assist in using the guides together.

-  Daily Life
-  Community Living
-  Social Spirituality
-  Healthy Living
-  Safety & Security
-  Citizenship & Advocacy
-  Supports to Families

16

Life Trajectory

LIST past life experiences that pushed the arrow toward things you don't want.




Write current age in the STAR

LIST life experiences to avoid because they push you toward things you don't want.

What I DON'T Want

LIST the things you don't want in your life...



# Self-Directed DDD Services: 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 Good 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

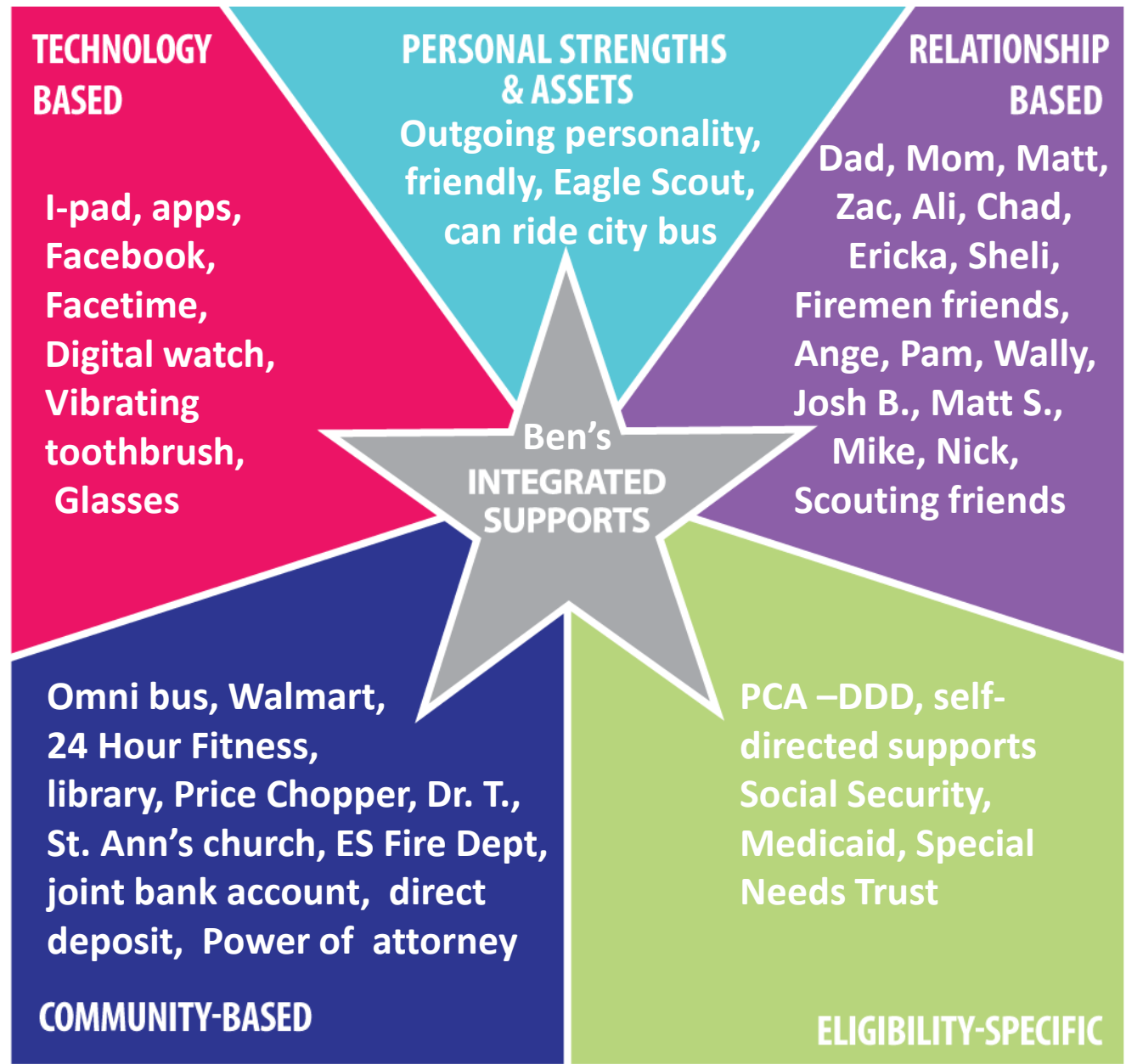
Friends  
Job/financial security  
Fun/interesting stuff to do  
Continue to learn new things  
Ben own his own home or condo  
Live on his own or with a friend  
Vacations  
Getting a Tattoo

### What I DON'T Want

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



# Ben's Integrated Services and Supports Star



# 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	Mom and Dad provide all support, including meals, transportation and support for activities, etc.						
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 Dad are overnight staff						
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							

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	Home alone while Mom walks										
8:30-9 AM																
9-9:30 AM																
9:30-10 AM																
10-10:30 AM																
10:30-11 AM		St. Ann's w/ mom														
11-11:30 AM																
11:30-12 PM																
12-12:30 PM																
12:30-1 PM		Waiver Self-Directed PCA	Waiver Self-Directed PCA	Home alone while Mom walks												
1-1:30 PM																
1:30-2 PM	Volunteer at high school, supported by coaches and friends	Volunteer at high school, supported by coaches and friends	Home alone while Mom walks													
2-2:30 PM																
2:30-3 PM																
3-3:30 PM	Mom and/or Dad prepare meal and assist as needed					Home alone while Mom walks										
3:30-4 PM																
4-4:30 PM																
4:30-5 PM																
5-5:30 PM																
5:30-6 PM								WWE With Matt	Home alone while Mom walks			Dinner w/ Roy & Carol & family				
6-6:30 PM																
6:30-7 PM																
7-7:30 PM														Horseback Therapy w/ Dad	Nick's Birthday Party with Matt and friends	
7:30-8 PM																
8-8:30 PM																
8:30-9 PM																
9-9:30 PM	Mom and Dad are overnight staff					Home alone while Mom walks										
9:30-10 PM																
10 PM-6 AM	Mom and Dad are overnight staff															

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

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: *Personal Assistant Plan*

# Shay's Life Trajectory

## 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 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**

Live in own place w/ limited supports  
 Maintain a Job Become his own person  
 (no more guardian)  
 Have friends that "hang out" Get married  
 Play for Team USA Football in Special Olympics  
 Maintain healthy habits

**What I DON'T Want**

Live in a REF forever  
 Be admitted into a psych hospital or locked facility  
 Mom's side of the family involved in personal life  
 To walk w/ a walker or wheel chair  
 To work in maintenance or cleaning job

Put ME FIRST!!!

Meal planning to help w/ healthy eating and budgeting

Build relationship w/ employer so I feel comfortable discussing work related issues

Learn budgeting plan that works for me

Learn/keep daily hygiene routine

Look into qualifications for Team USA football

Consult w/ therapist & keep up w/ medical management

Maintain leg and back pain - therapy, dr. appis.

Request ISL placement for more individualized supports

Go back to UCP for employment services

Exercise regularly

Be more social to make new friends - try new activities in the community

Renew/learn healthy food options

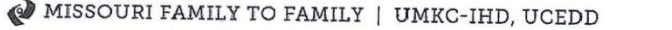
Current in REF

Not making media appearances

Missing doctor appointments

Letting others take advantage of me

Not bathing or picking up after myself








# LifeCourse: Organizational Change

# Organizational Strategic Thinking: LOQW and PCS



**PROGRESSIVE  
COMMUNITY SERVICES**

**Strategic Plan 2015 to 2018**

**MISSION:**  
Build relationships to inspire social change,  
empower people and challenge the status quo.

**VISION:**  
An inclusive  
community where all  
people have value.

**VALUES:**

- Person-centered supports.
- Embracing innovation to empower individuals and employees.
- Ethically driven decisions and actions.\*
- Enabling meaningful lives through integrated supports, inclusion and relationships.
- Ensuring health and safety while promoting freedom of choice.

\*Pursuant to Personnel Policy 232, available upon request.

### Expectations of Persons Served

Our consumers are our livelihood. LOQW must provide quality services and always strive to exceed the expectations of persons served.

Objective	Goal	Responsible Parties	Resources Needed	Timeline	Status	Comments
LOQW consumers will remain satisfied with services	Input regarding services will be gathered on the consumer's monthly review as well as random monthly quality assurance calls	Managers, Records Technicians	Computer, phone	Ongoing	I	
LOQW consumers will receive services in a safe & healthy environment	Provide employment, community, personal, and social opportunities to LOQW consumers that meet their needs and reflect their choices and social capital	Director of Community Services, Managers, All direct care staff	Funding, community resources & connections	Ongoing	I	
LOQW consumers will receive services in a safe & healthy environment	Staff will receive specialized training on specific medical needs of consumers with whom they work	Dir. of Community Services, HR, Managers, All	S, computer/ internet, access to basic information	Ongoing	I	
LOQW consumers will receive services in a safe & healthy environment	Safety drills will be held with consumers living in their own homes at least annually	Managers, Direct care staff	NetWorks	1-2016		
LOQW will maintain a safe and adequate fleet of vehicles to support the daily operations of the organization	Continue to complete monthly vehicle safety checklists on each vehicle	Managers, Safety Director, Technicians	\$	Ongoing	I	
	Report all needed repairs or concerns & follow up for completion					
	Report vehicle problems, accidents to the business office within 24 hours					

## Charting the Life Course

VISION for a GOOD LIFE

What I DON'T Want

### Life Trajectory :

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.

• ○ ○

**HEADING ONE**

Embracing innovation to empower employees and individuals.

[READ MORE](#)

**HEADING TWO**

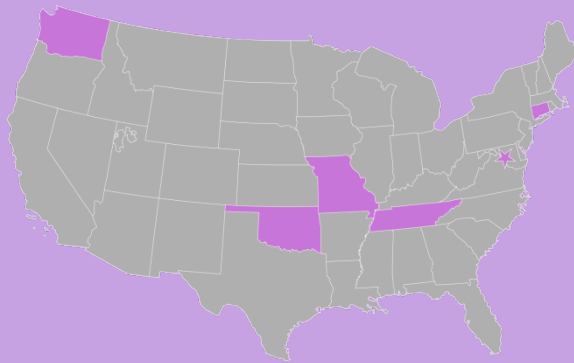
Embracing innovation to empower employees and individuals.

[READ MORE](#)

**HEADING THREE**

Embracing innovation to empower employees and individuals.

[READ MORE](#)



# LifeCourse: DD Systems Change

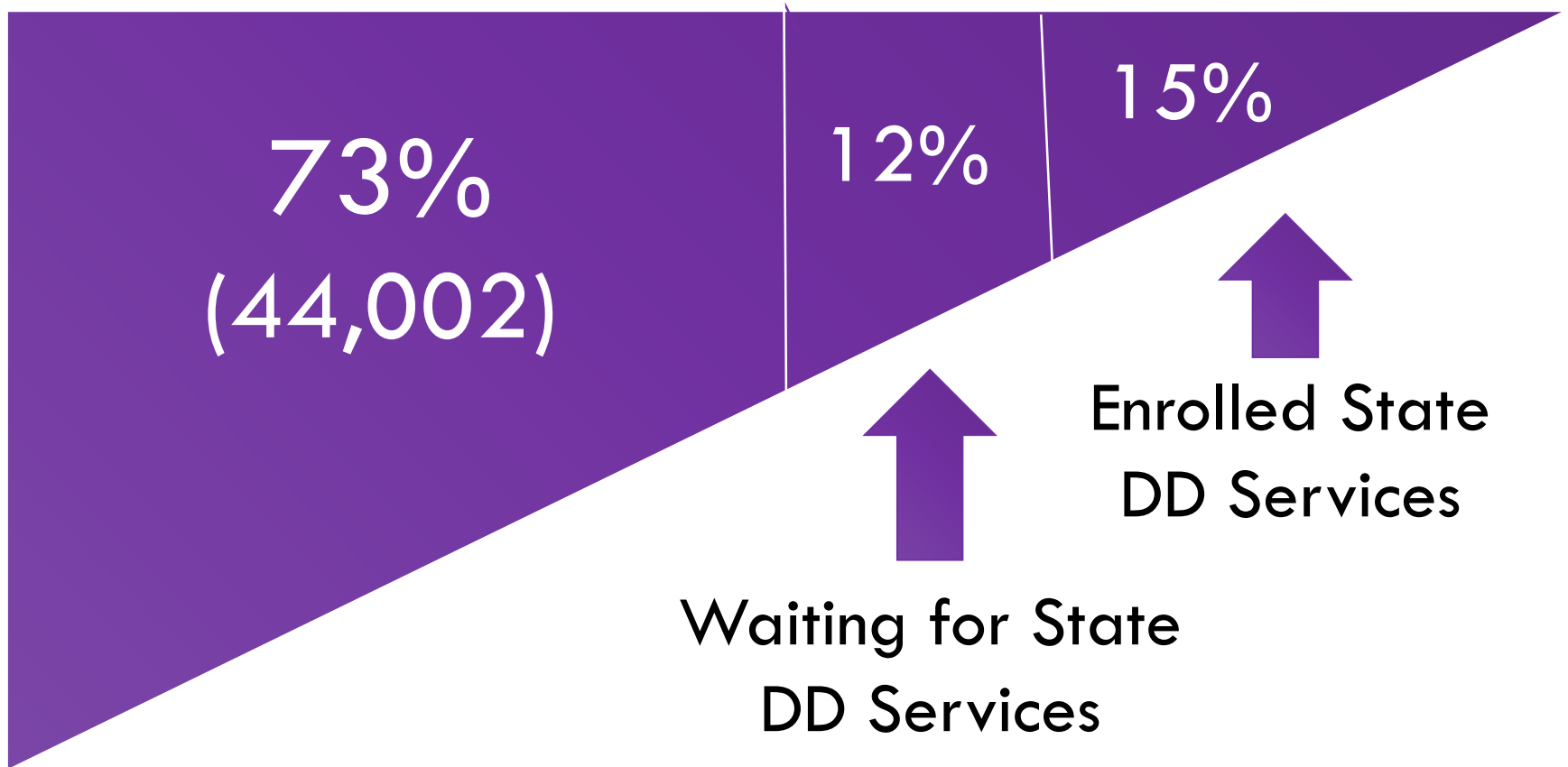
- **State DD System**
  - Existing initiatives focused on person centered planning
  - Enhance role of case managers and intake workers to focus on support to families
- **Governors Blue Ribbon Task Force using LifeCourse framework to guide conversations and plan development**



Oklahoma

# Oklahomans with I/DD

60,277 estimated Oklahomans with Developmental Disabilities

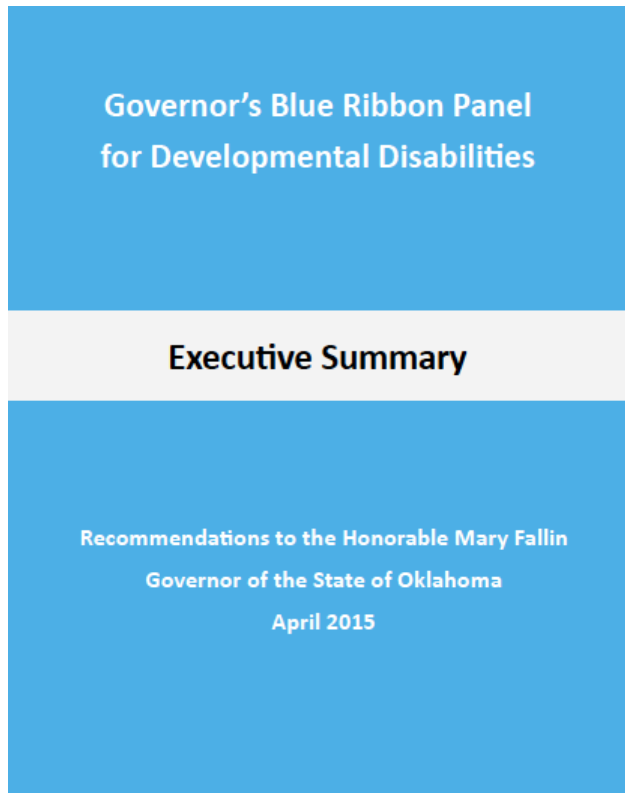


Based on 1.58% prevalence of 3.815 million citizens, US Census

# Reframing Wait List Discussion

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

# Governor's Blue Ribbon Task Force



## Strategies:

1. Strengthen Information Access
2. Provide Resource Navigation and Improve Inter-Agency Service Coordination
3. Provide family-to-family support to individuals and families who are currently on the Waiting List or who apply for Waiver Services.
4. Assess needs of families currently on the Waiting List.
5. Build capacity of services and supports outside of those provided through DDS waivers.

# Self-Advocate and Family Educational Training

- **Statewide Joining Forces Family Leadership Conference**
- **Rural Leadership Institutes**
- **Partners in Policymaking**



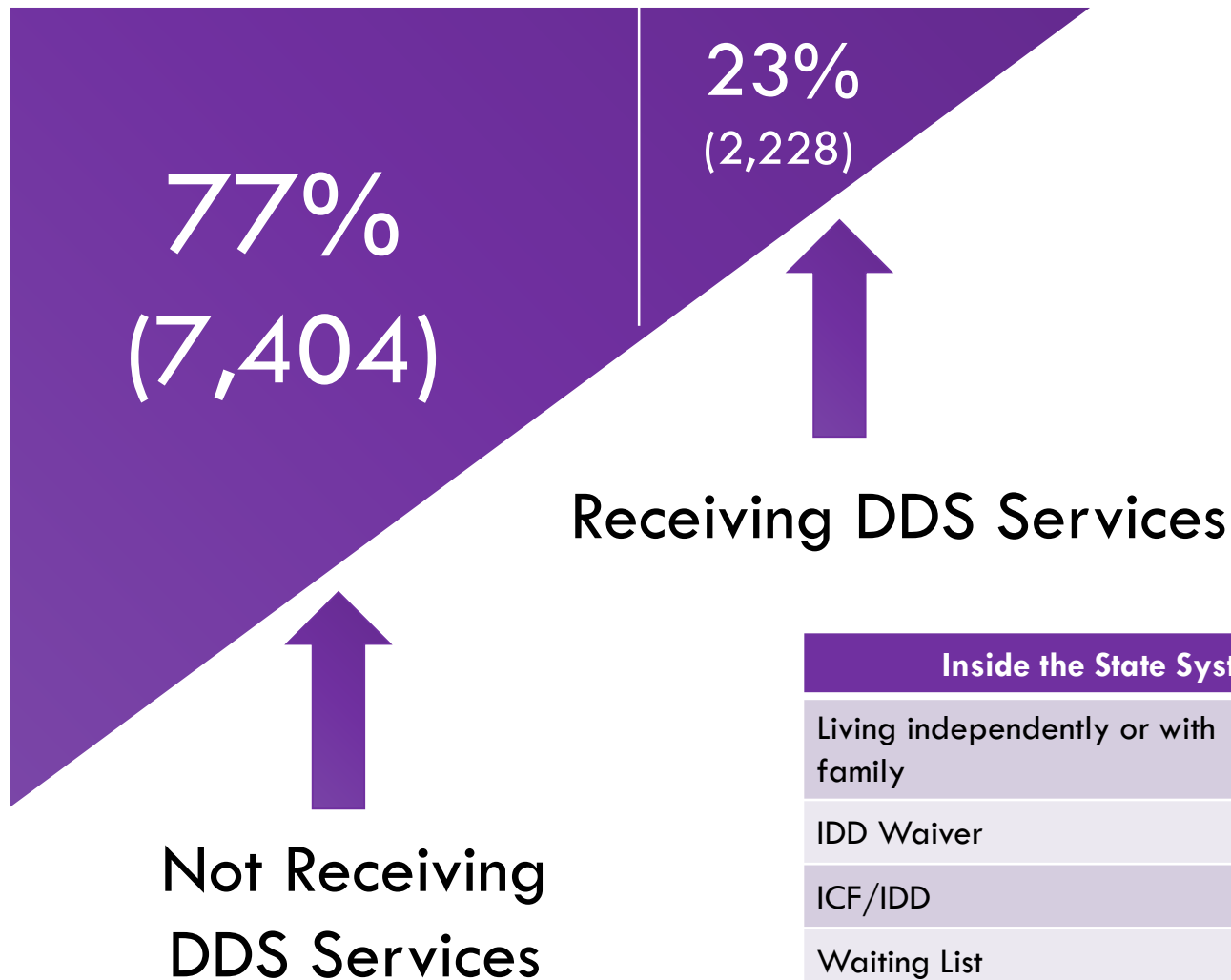
- ***Currently Legacy System***
  - ***Adults with Intellectual Disabilities only***
  - ***Commitment to community based supports***
  - ***Stalled at reforming the law***
- Developing new Legislation for DD Services
- Budget Line Item for Supports to Families
- Initiated Supporting Families Advisory Council
- Connecting System Reform Initiatives Together (Employment First, Person Centered Thinking: Trained Family Facilitators, Supporting Families CoP)



District of  
Columbia

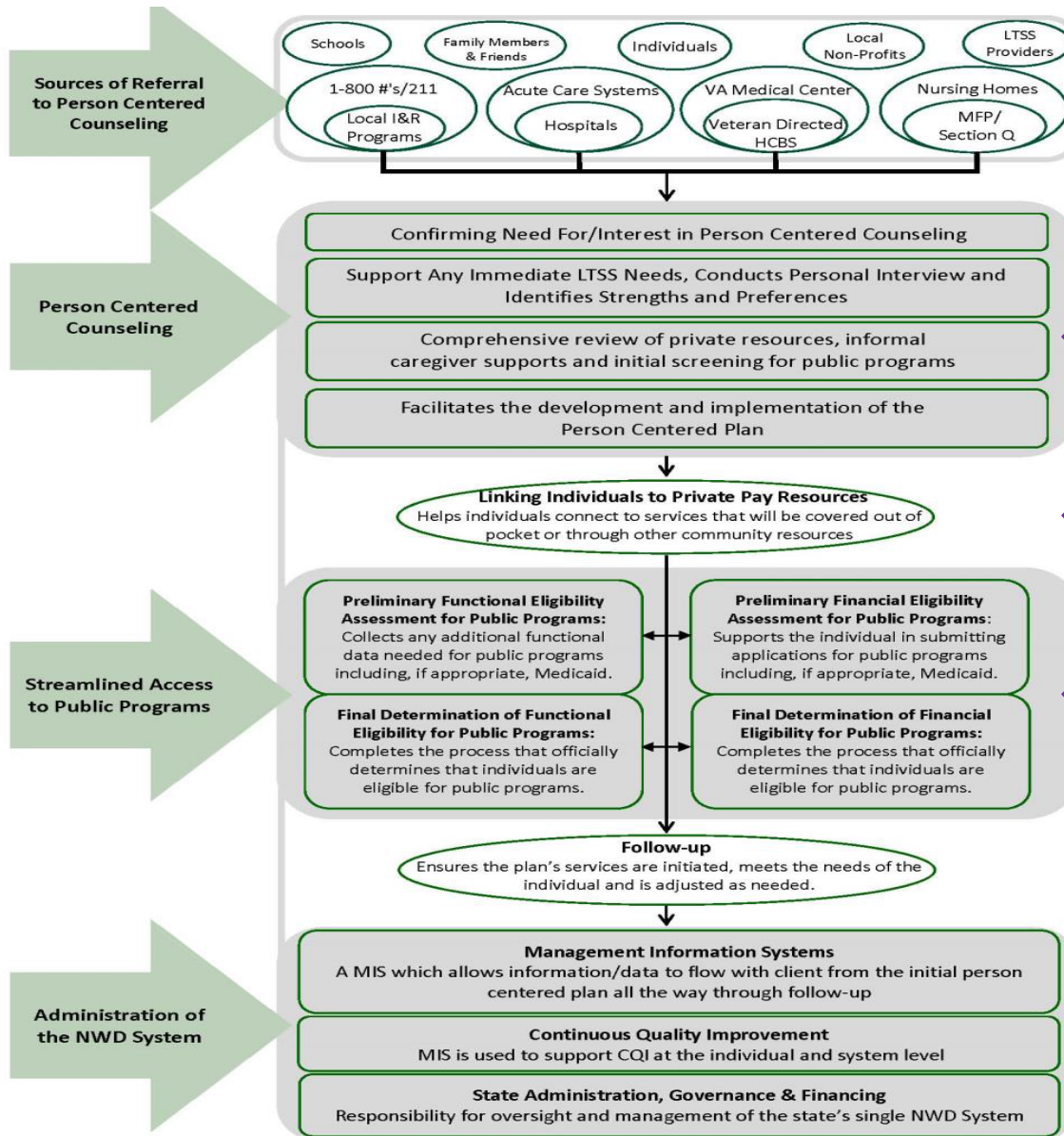
# Individuals in DC with I/DD

9,632 individuals estimated to have Developmental Disabilities\*



\*Based on 1.49% prevalence, S. Larson, University of Minnesota (2013)

# No Wrong Door SYSTEM

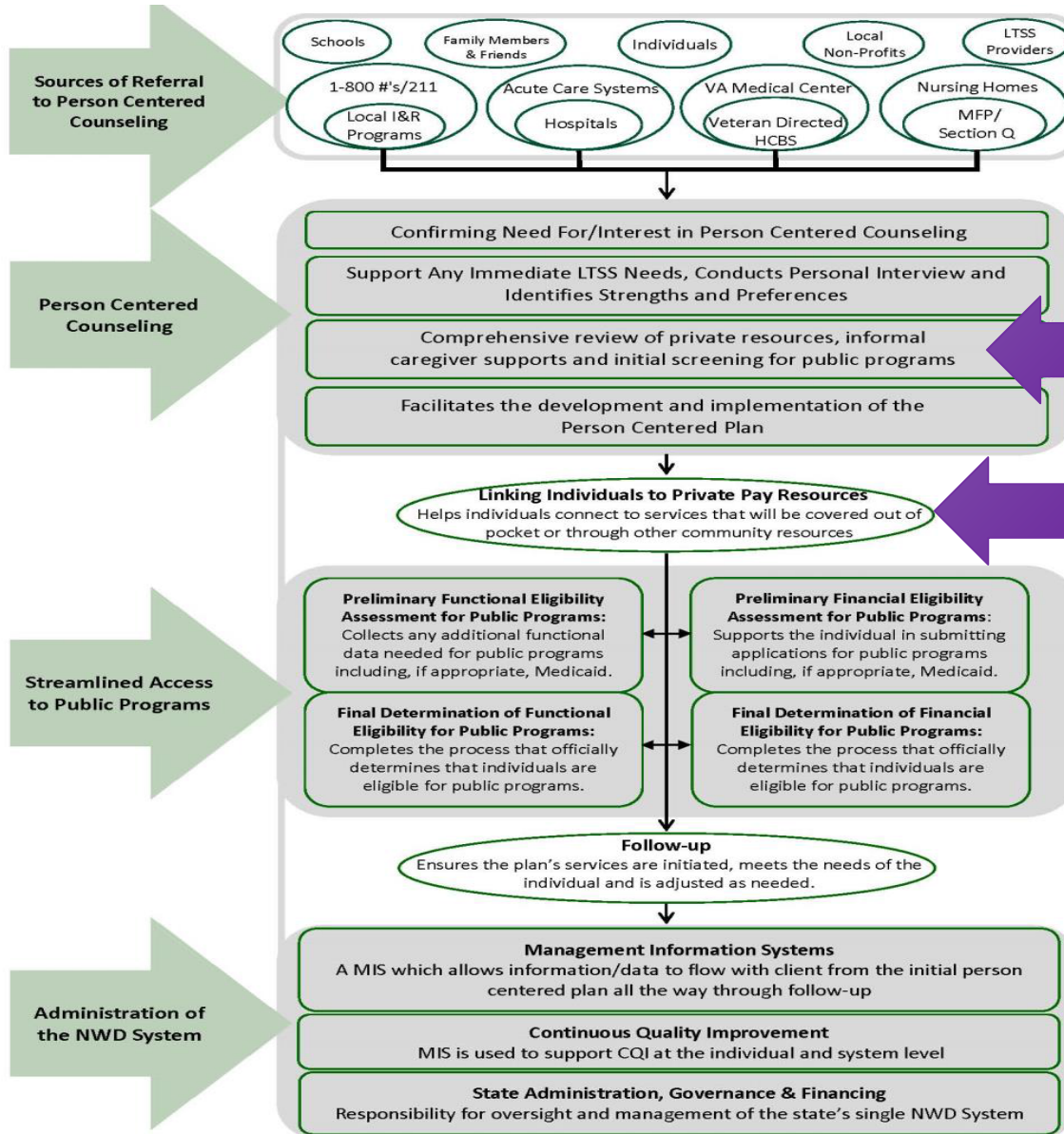


## Focus of CoP Supports to Families and DD System:

- Support Coordination
- Person Centered Thinking, Planning, and Facilitation
- Family Navigation and Family Networks
- LifeCourse Framework and Tools
- Responding to new CMS HCBS rule
- Focusing on Front Door of DD Services

*Developmental Disability Field has been evolving from an institutional based to system to a person centered system for many years*

# No Wrong Door SYSTEM



## LifeCourse Tools focusing on Adapting, Accommodating and Integrating Supports:

- Own Strengths, Assets and Resources
- Technology
- Relationships
- Community Resources
- Eligibility Specific Services and Supports

*Planning may require identifying, developing and adapting supports beyond private and public supports*



# LifeCourse: Domain Specific

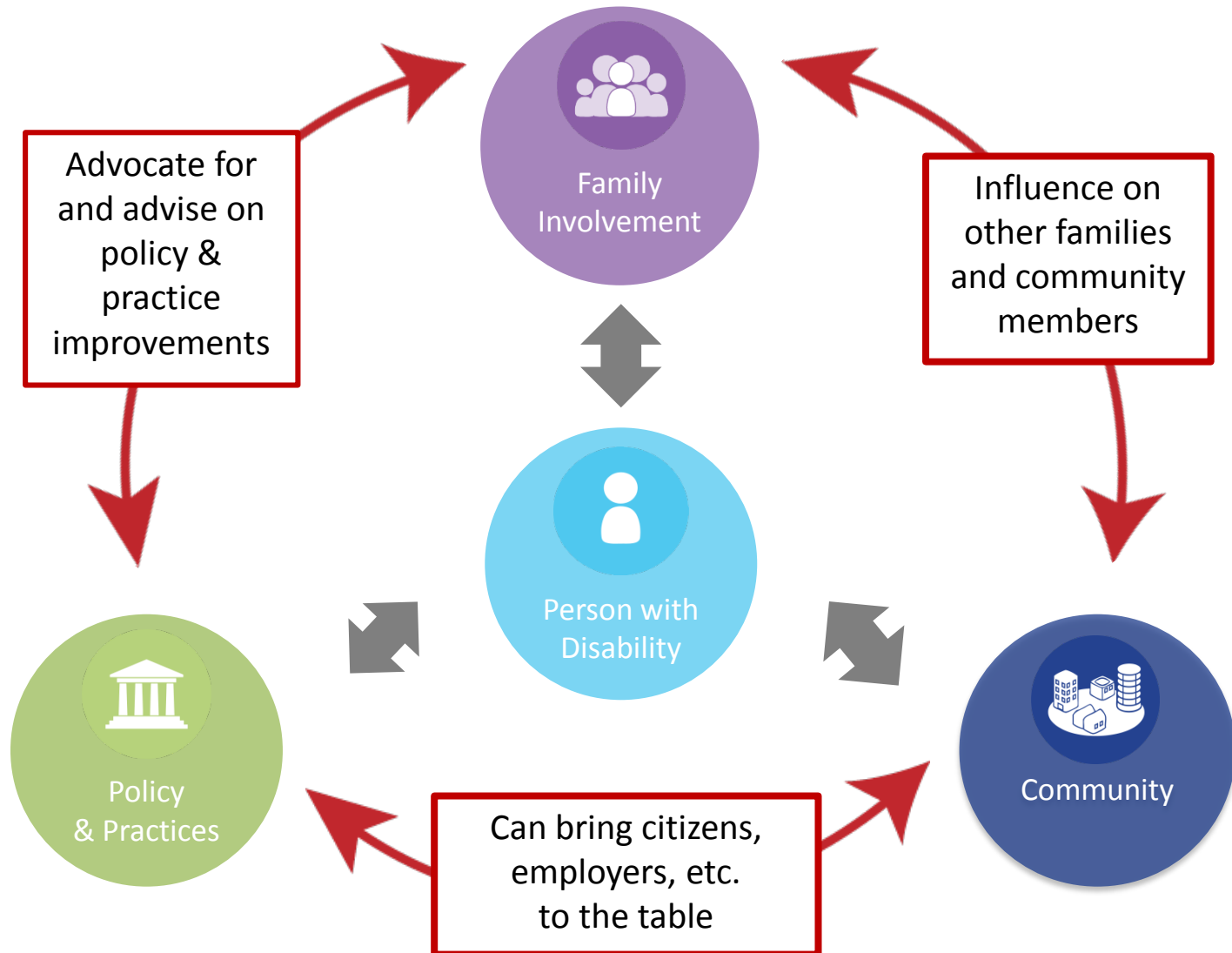


# Daily Life: *Focus on Employment*

# Connecting the Dots and Integrating Missouri Initiatives



# Family Involvement and Employment Outcomes







# SHOW-ME-CAREERS: Family Involvement Initiative

*Develop materials to enable local pilot community teams to:*

- *Enhance family expectations related to integrated employment and post-secondary education as a preferred outcome*
- *Increase family capacity to effectively utilize available resources that support movement toward integrated employment and post-secondary education*

- **Awareness of expectations** of employment for people with disabilities (federal/state policies, cultural shift)
- **Knowledge about possibilities** for employment, career and post secondary education options for people with disabilities
- **Access to resources and supports** to learn about, plan for and make employment a reality

## 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.

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#### LIFE DOMAIN



##### Daily Life & Employment

*What a person does as part of everyday life— school, employment, volunteering, communication, routines, life skills.*

#### LIFE STAGE



##### Transition

*Transitioning from school to adult life (14-22)*

#### DEVELOPED BY

**MISSOURI**  
FAMILY TO FAMILY  
UMKC INSTITUTE FOR HUMAN DEVELOPMENT | UCEDD

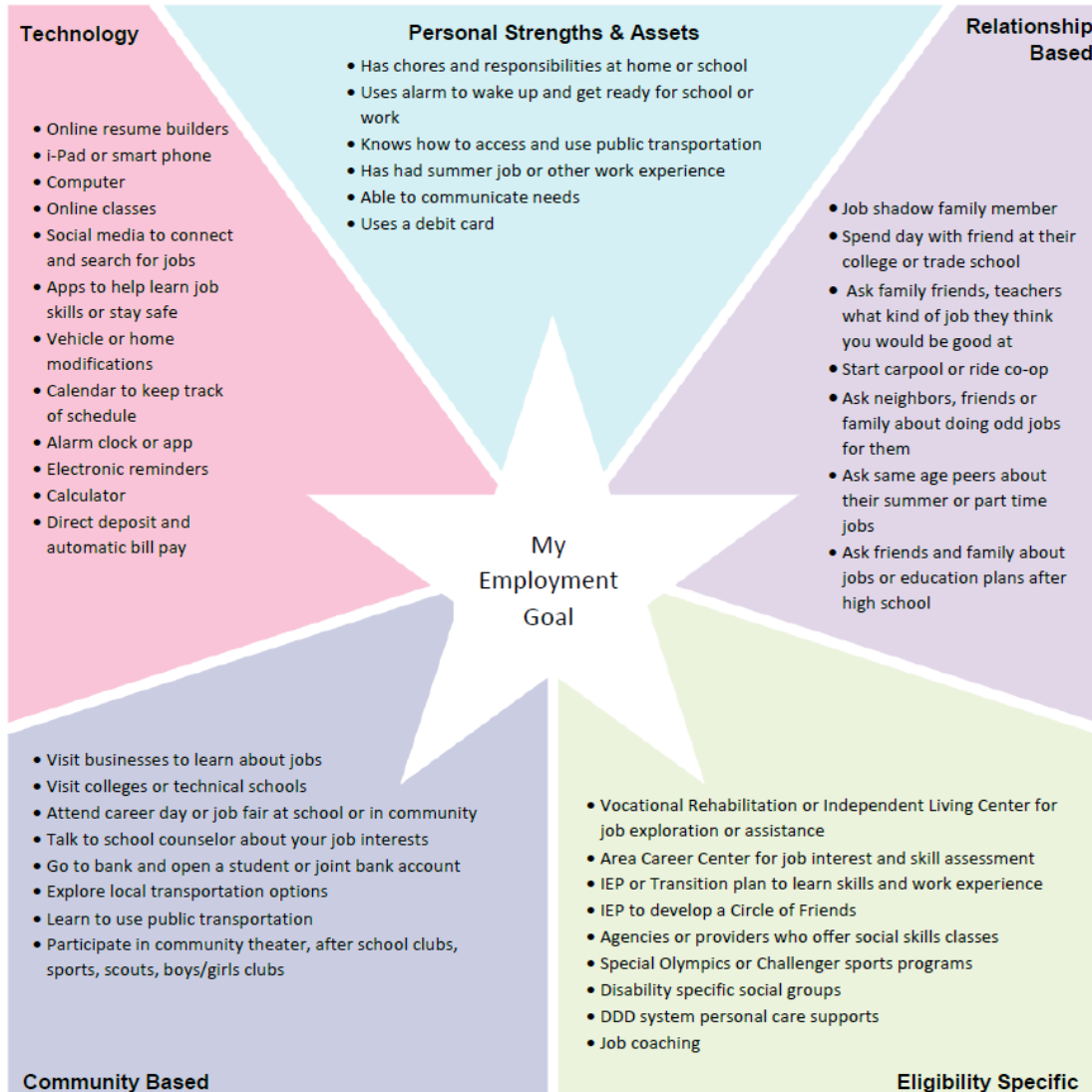
#### IN PARTNERSHIP WITH

**SHOW-ME-CAREERS**  
Missouri's Department of Economic Development

# Daily Life: *Focus on Employment*

## Domain Booklet





# Daily Life: Focus on Employment

## Integrated Supports Star



# Who is Using LC Employment Tools?

- **Vocational Rehabilitation**
  - PETS (Pre Employment Transition Specialists)
  - Employment Specialists
- **School Districts**
  - Special Ed Teachers
  - School Counselors
- **State DD System**
  - Employment & Youth Transition Specialists
  - Support Coordinators

# Adult Employment Trajectory

**Employment Trajectory Worksheet:**

**Contributions:**  
Skills, Experience, Attributes, Talents

- Hard Working
- On time / prompt / reliable
- Wakes up around 6 am
- Motivated by money
- Will pick up extra shifts
- Knows what cleaning supplies are used while cleaning the restroom and how to use them safely
- Showers and wears clean clothing each day
- Will work weekends

Before 1996    '96-'01    2010    2014    2014    2015

**What I DON'T Want**

- To work near kids because it is not safe
- Sheltered Workshop employment- Kenny does not want to work with "those people" and dislikes the job because it does not pay well
- Overnight shifts because he likes to go to bed early and wake up early
- Full time employment because of the need for Medicaid to maintain a healthy living environment
- Frequent changes in staff, unexpected job task changes

**VISION for good employment and a GOOD LIFE**

**Long term employment desires and goals:**

Kenny would like to find a job that he is good at and enjoys for long term employment. Kenny enjoys custodial work and finds that it is a good match for him. He finds it very important that the factors under "What I DON'T Want" are respected when job seeking.

Kenny's ultimate goal is to find full time employment with benefits and to live independently. Kenny understands that this can only happen when it is considered safe for himself and everyone else.

**Conditions:**

- Part-time employment
- Line-of-site supervision at all times
- Make at least minimum wage
- Co-workers / staff are respectful to him

**Preferences:**

- Would like to work indoors when the weather outside is too hot
- Custodial employment
- Cutting grass

**Support Needs:**

- Assistance learning the routine and new job tasks
- Reminders to be clean shaven
- Transportation to and from work from Carrs
- Audio learner with demonstration as needed

(May include: Schedule, Salary, Benefits, Appearance, Learning Style, Supervisor Interaction, Environment, etc.)

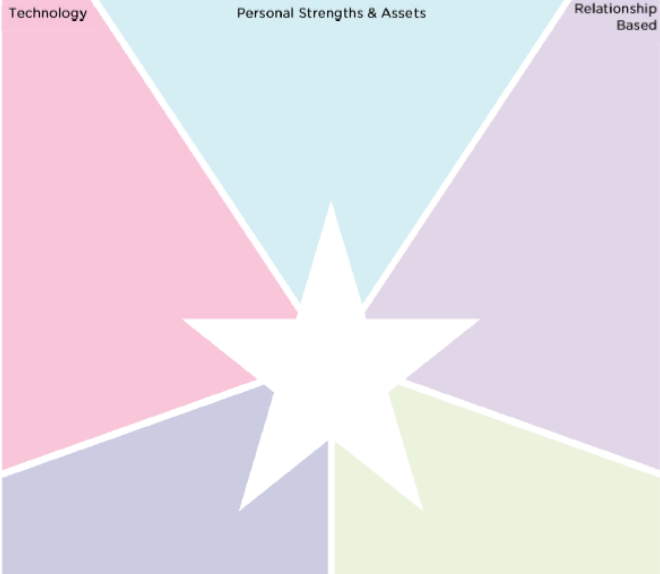
MISSOURI FAMILY TO FAMILY | UMKC-IHD, UCEDD

MAY 2014



### 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.



TURNING ABILITIES INTO OPPORTUNITIES  
GREENE COUNTY RESOURCE BOARD FOR  
PEOPLE WITH DEVELOPMENTAL DISABILITIES

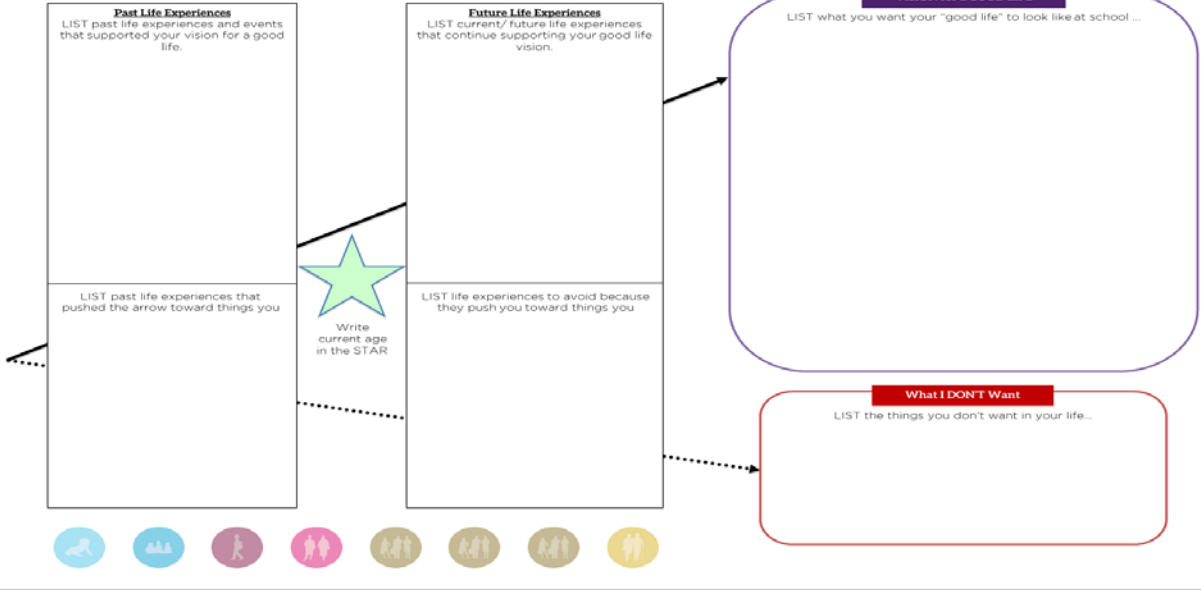
## \_\_\_\_\_ 's ONE-PAGE SCHOOL PROFILE

What people like & admire about me

What's Important to ME

How to Best Support ME

### Journey through School



# Abilities First One Page School Profile



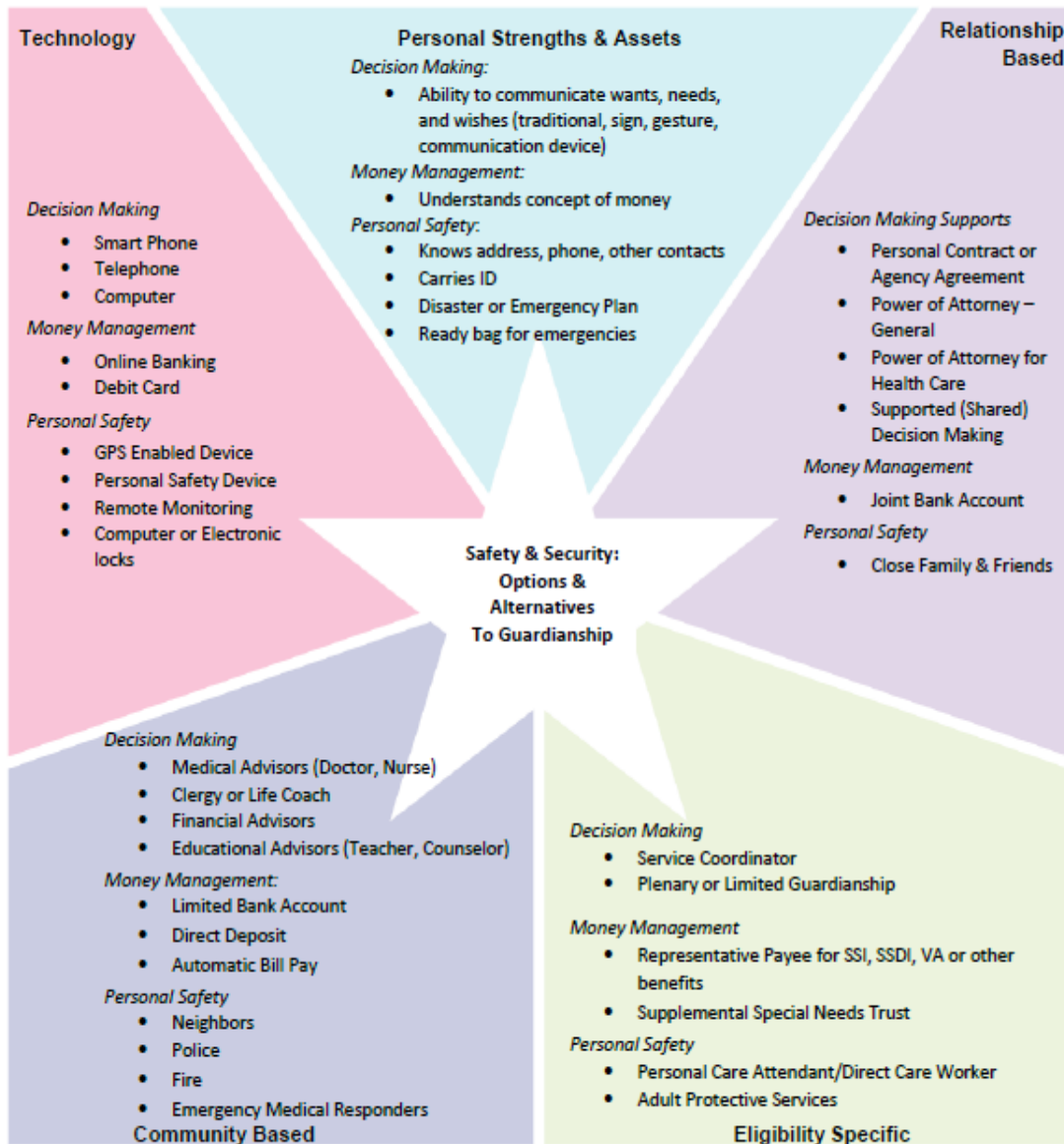
# Safety and Security: *Focus on Supported Decision Making*

# Mo Guardianship: Understanding Options and Alternatives

- Developed and launched in 2009/2013
- Workshops for families, self-advocates, and professionals
- Promoted making informed decisions about guardianship with emphasis on supported decision making

IDENTIFYING ALTERNATIVES TO GUARDIANSHIP			
Name of Individual: _____			
Name of person completing this form: _____			
Relationship to individual (circle one): Self Family Friend Guardian Other: _____			
How long have you known the individual? _____			
<p>This checklist is a tool designed to be used <b>only</b> for the purposes of the training program.</p> <p><b>MO Guardianship:</b> <i>Understanding Your Options &amp; Alternatives.</i> It is designed to assist with identifying a person's ability to make decisions and manage key areas of the individual's life. It is intended to assist with exploring alternatives and less restrictive options to plenary or full guardianship.</p> <p>The questions listed below are <b>not</b> exhaustive and are <b>not</b> intended to provide a final determination of what a person should (or should not) do in their unique circumstances.</p>	<p><b>LEAST RESTRICTIVE:</b> Individual Makes Own Decisions</p> <p>"YES"</p> <p>If the answer is "YES," place a ✓ in the box.</p> <p>If the answer is "NO," go to next column.</p>	<p>Individual Needs Support With Making Decisions</p> <p>"NO"</p> <p>If there is an <b>ALTERNATIVE</b> that meets the need, list it below.</p> <p><b>NO</b> Alternative meets the need, go to next column.</p>	<p><b>MOST RESTRICTIVE:</b> Individual has NO RIGHTS to Make Decisions</p> <p>Place a ✗ in the box and indicate whether you need to address the need through use of the <b>GUARDIANSHIP OPTIONS.</b></p>
	<p><b>EMPLOYMENT</b></p> <p>Can the person make and communicate choices in regard to employment?  <small>(Can the person look for and find a job (go to employer agency, instead to ask, see contact)?</small></p>		
	<p><b>MONEY MANAGEMENT</b></p> <p>Is the person able to manage their money (a. invest financial commitments, such as savings bills)?</p> <p>Is the person able to manage the monetary benefits he or she is supposed to receive?</p> <p>Is the person able to identify and resist financial exploitation?</p>		
	<p><b>HEALTH &amp; NUTRITION</b></p> <p>Does the person make decisions about where, when, &amp; what to eat?</p> <p>Can the person follow a prescribed diet and/or take medicines as directed?</p> <p>Does the person understand the need to maintain personal hygiene and dental care?</p> <p>Can the person make and communicate decisions regarding medical treatment, including understanding the consequences of not accepting treatment?</p> <p>Does the person understand health consequences associated with high risk behaviors (alcohol use, smoking, high risk sexual activity, etc)?</p> <p>Can the person seek others and seek medical help for serious health problems?</p>		
<p><b>Alternatives to Guardianship</b></p>			
<p><b>GENERAL SUPPORTS</b></p> <p>Family/Friends                      Advocacy Organizations &amp; Community Supports</p>			
<p><b>DECISION-MAKING</b></p> <p><b>Personal Contract/Agency Agreement:</b> An agency agreement is a legal contract creating a fiduciary relationship whereby one party (the "principal") agrees that the actions of another party ("the agent") binds the principal to agreements made by the agent as if the principal had himself personally made the agreement. A formal agreement is usually signed setting out the commission (pay the agent will receive, the duration, and other terms on which the principal and agent will do business together.</p> <p><b>Power of Attorney:</b> Power of Attorney is a written legal document that lets a competent individual designate another person to act on his/her behalf, as stated in the document. Often, this is used to give authority to act for another person in specified or all legal or financial matters. Power of Attorney can be given to more than one person, and a succession can be designated, in the event that one person is no longer willing or able, or if the power is revoked, the next designated person will assume the authority to act on the other person's behalf.</p> <p><b>Durable Power of Attorney for Health Care:</b> A health care power of attorney (HCPOA) is a legally enforceable document in which you authorize another person to make health care decisions when you cannot do so. The document must be prepared and signed while you are competent, and is not affected by your later disability or incapacity. The document can give your attorney-in-fact authority to make specific health care decisions or the authority to make any and all health-care decisions you could make, if you were able. However, as long as you can make your own decisions, you, and not your attorney-in-fact, have the authority to make your own treatment decisions.</p> <p><b>Living Will:</b> A living will (treatment directive) is a written declaration directing your doctor to withhold or withdraw death-prolonging procedures should you lack the capacity to make the decisions. It does not apply to any other health-care decisions. A living will directs your doctor's actions when the use of death-prolonging procedures would serve only to postpone the moment of death, but would not provide a cure for the condition.</p>			
<p><b>MONEY MANAGEMENT</b></p> <p><b>Limited and/or Joint Bank Accounts, Direct Deposit, and Automatic Bill Pay</b> - Joint bank accounts enable monitoring of account activity and transfer of funds as needed. Limits can be set so that in a specified period of time (day, week, month) no more than the set amount will be authorized for purchases.</p> <p><b>Representative Payee:</b> A representative payee is an individual or organization designated by you, a government agency, or the court to receive your money to use on your behalf. A Representative Payee is available for Supplemental Security Income (SSI), Social Security Disability Insurance (SSDI), Veterans' Affairs (VA) benefits, Railroad Retirement Benefits, and Stock Lung benefits.</p> <p><b>Living Trust:</b> A living trust is a trust created while you are still alive. A living trust is a legal entity completely separate from you. If you establish a trust, you are a grantor or trustee. If you are managing a trust, you are a trustee. You can be both a grantor and a trustee. If another individual established a trust for you, you are the beneficiary. A living trust will continue after the death of the grantor, and does not require involvement of the Probate Court. Because the trust is recognized as a separate entity, the trustee can continue to make distributions to the beneficiary without any involvement from the court.</p> <p><b>Special Needs Trust:</b> A special needs trust or supplemental benefits trust is a trust established to provide supports for a beneficiary without causing the beneficiary to lose public benefits such as Supplemental Security Income (SSI) and Medicaid. A special needs trust can be established by a grandparent, parent, sibling, son or daughter, or a friend. Additionally, the trust can establish a special needs trust. However, the special needs trust cannot be established by the intended beneficiary, the individual with special needs. A special needs trust can be used for such things as purchasing, setting or repairing a home; paying utilities and taxes; vacations; recreation or entertainment; personal items; medical costs not covered by Medicaid; or attorney fees.</p>			
<p><b>PERSONAL SAFETY</b></p> <p><b>Adult Protective Services:</b> The Missouri Department of Health &amp; Senior Services investigates abuse, neglect and exploitation, and provides protective services to vulnerable persons living in the community or in a long-term care facility, who are unable to protect their own interests. The Hotline number is 1-800-392-0230.</p> <p><b>Protection Orders (TRO):</b> A Court can order an individual who is hurting or threatening to hurt you or a loved one, to stay away from you.</p>			





# Safety and Security: Focusing on Supported Decision Making

## Integrated Supports Star



# IDENTIFYING ALTERNATIVES TO GUARDIANSHIP

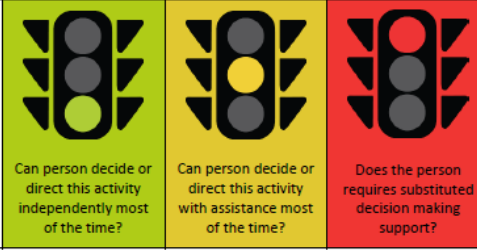
This tool was designed to assist with identifying a person's ability to make decisions and manage key areas of life. It is intended to assist with exploring alternatives and less restrictive options to plenary or full guardianship.

Name of Individual: \_\_\_\_\_  
 Name of person completing this form: \_\_\_\_\_  
 Relationship to individual (*circle one*): Self Family Friend Guardian Other: \_\_\_\_\_  
 How long have you known the individual? \_\_\_\_\_

**Step 1:** Decide for each question if the answer is yes or no. If yes, put a checkmark in the GREEN column – this means the person is good to go. If NO, put a mark in the yellow column.

**Step 2:** When you have completed all the questions, explore alternatives to guardianship to meet the supported decision making need for all questions marked in the yellow column.

**Step 3:** ONLY if NO alternative can be identified, then limited guardianship might be considered for those specific areas of need.



## DAILY LIFE & EMPLOYMENT

Can the person make and communicate choices in regard to employment?			
Can the person look for and find a job ( <i>go to employment agency, respond to ads, use contacts</i> )?			
Is the person able to manage their money (i.e. meet financial commitments, such as regular bills)?			
Is the person able to manage the monetary benefits he or she is supposed to receive?			
Is the person able to identify and resist financial exploitation?			

## HEALTHY LIVING

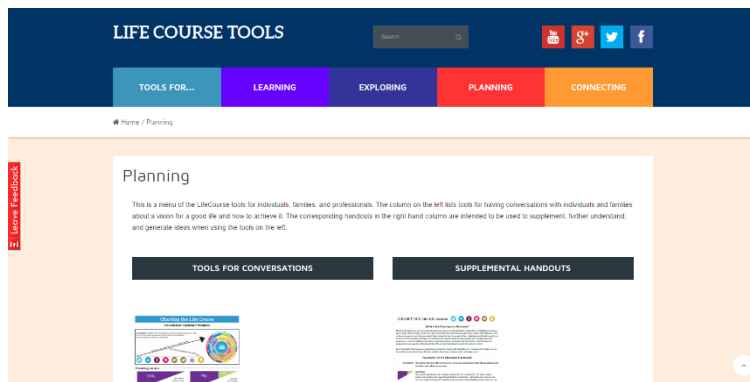
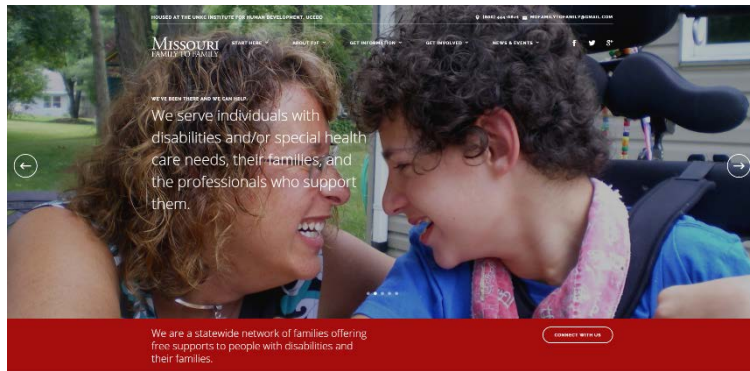
Does the person make decisions about where, when, & what to eat?			
Can the person follow a prescribed diet and/or take medicines as directed?			
Does the person understand the need to maintain personal hygiene and dental care?			
Can the person make and communicate decisions regarding medical treatment, including understanding the consequences of not accepting treatment?			
Does the person understand health consequences associated with high risk behaviors ( <i>substance abuse, overeating, high-risk sexual activities, etc.</i> )?			
Can the person alert others and seek medical help for serious health problems?			
Is the person able to decide and direct what kinds of support they need or want and select who provides those supports?			

Safety and Security:  
 Focusing on Supported Decision Making

The Stoplight Tool



# CONNECT WITH US ONLINE



# Questions, Reflections and Discussion