Charting the LifeCourse Virginia

March 2019

Outcomes for Today

- Basic overview of the Charting the LifeCourse Framework

- Practice using the Charting the LifeCourse Framework and tools

Setting the Stage

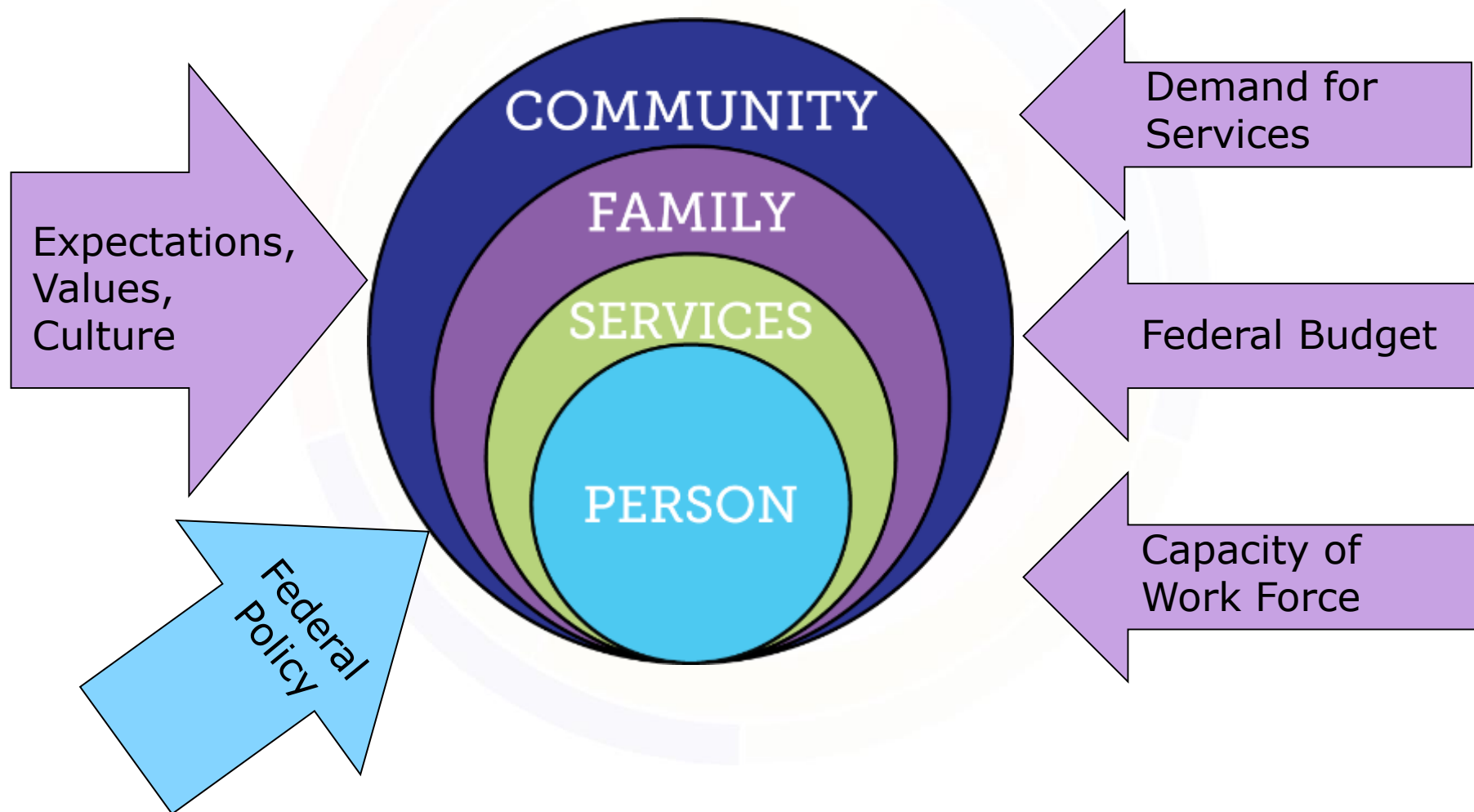# National Community of Practice for Supporting Families

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.
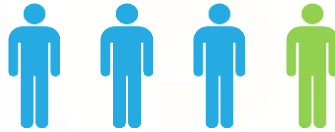
Project Outcome

- 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.

Current Reality of Long Term Services and Supports

COMMUNITY

FAMILY

SERVICES

PERSON

Expectations, Values, Culture

Federal Policy

Demand for Services

Federal Budget

Capacity of Work Force

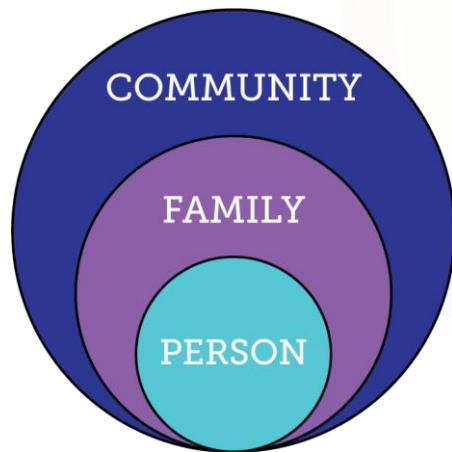# WHY We Must Think Differently About Supports

75%

25%

ONLY 25% OF PEOPLE WITH IDD ACCESS FORMAL OR PAID SUPPORTS WITHIN THE DD SYSTEM

WHAT ABOUT THE OTHER 75%?

What We Want to See...

75%
People with I/DD not receiving formal DD services

25%
People with I/DD receiving formal DD services

100%
People with I/DD receiving integrated services and supports

Charting the LifeCourse.......

◎ **IS:**

◎ About having different conversations

◎ A different way of thinking

◎ Encouraging high expectations

◎ Having life experiences to move the trajectory in the desired direction

◎ Integrating LOTS of different kinds of support, and not just having an "all green life"

◎ **ISN'T:**

◎ JUST about the "tools"

◎ A "program"

◎ *Is for ANYONE, regardless of AGE or ABILITY!*

GUIDING PRINCIPLES OF THE CHARTING THE LIFECOURSE FRAMEWORK

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

Person Within Context of Family & Community

ALL individuals Exist within the Context of Family

- Family is defined by the individual
- Individuals and their family may need supports that adjust as roles and needs of all members change
- Not dependent upon where the person lives

Family is anyone who loves you unconditionally.

Spirit Science

Where do People with I/DD Live?

TOTAL 4.7 MILLION PEOPLE WITH IDD

■ Own or With Family ■ Residential Supports

89% living in own homes and/or are supported by family

Anderson, L.L., Larson, S.A., Kardell, Y., Hallas-Muchow, L., Aiken, F., Hewitt, A., Agosta, J., Fay, M.L., & Sowers, M. (2015). Supporting Individuals with Intellectual or Developmental Disabilities and their Families: Status and Trends through 2013. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

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 and Individual and Family Cycles

Individual Life Stages

Birth --------- Early child ----- School ----- Transition ------------------ Adulthood ------------------ Aging

individual

family

Single Adult --- New Couple ------------------ Couple with Children ------------------ Launching Children ------------------ Family Later in Life -----------
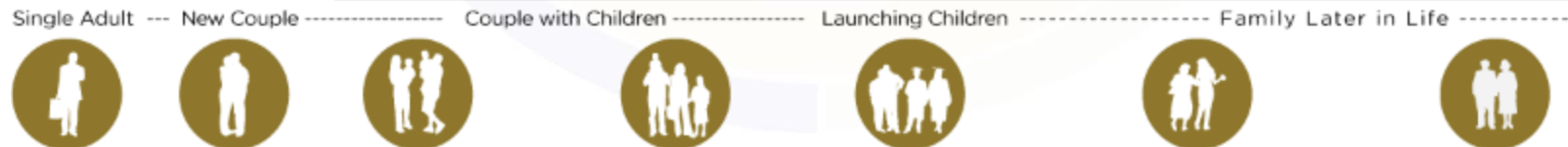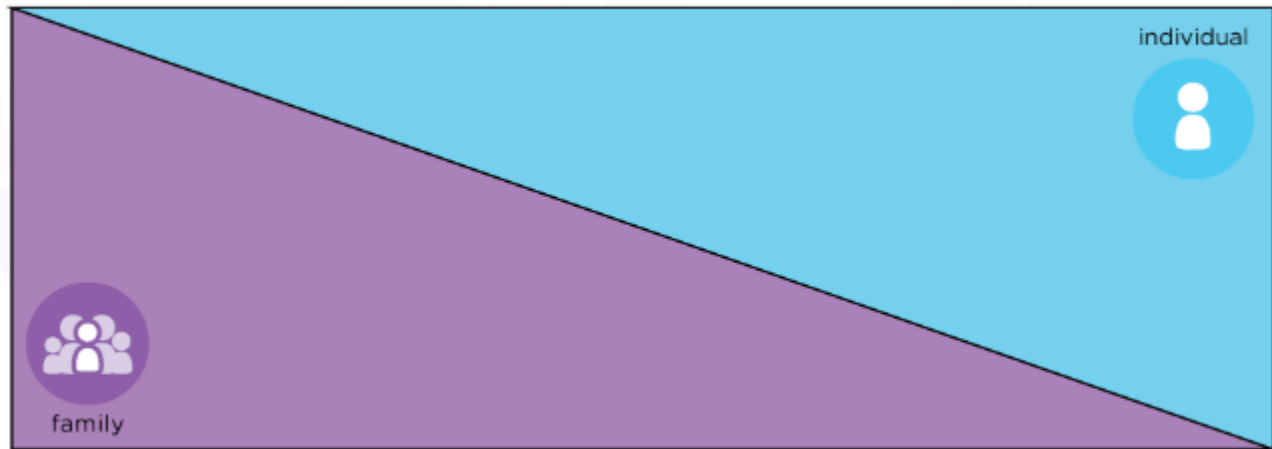
Family Life Cycle

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

Siblings: The 'Club Sandwich' Generation

Aging Parents

Siblings with Disabilities

Children

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

"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

Supporting All Team Members

Supporting Person's
Self-Determination
& Self-Advocacy

Supporting
Families
Across the
Lifespan

Supporting
Person-Centered
Planning

Policy, Systems & Community Change: Person-/Family- Centered and Driven

Partnering with People with Disabilities and their Families

So they can Engage, Lead, and Drive
Policy and Systems Change

Life Trajectory, Experiences and Life Stages

What is YOUR Vision
for a Good LIFE?

Vision of What I Want

What DON'T you want??

Vision of What I Don't Want

Vision & Trajectory for a Good Life

Trajectory towards Life Outcomes

Friends, family, enough money, job I like, home, faith, vacations, health, choice, freedom

Trajectory towards things unwanted

Vision of What I Don't Want
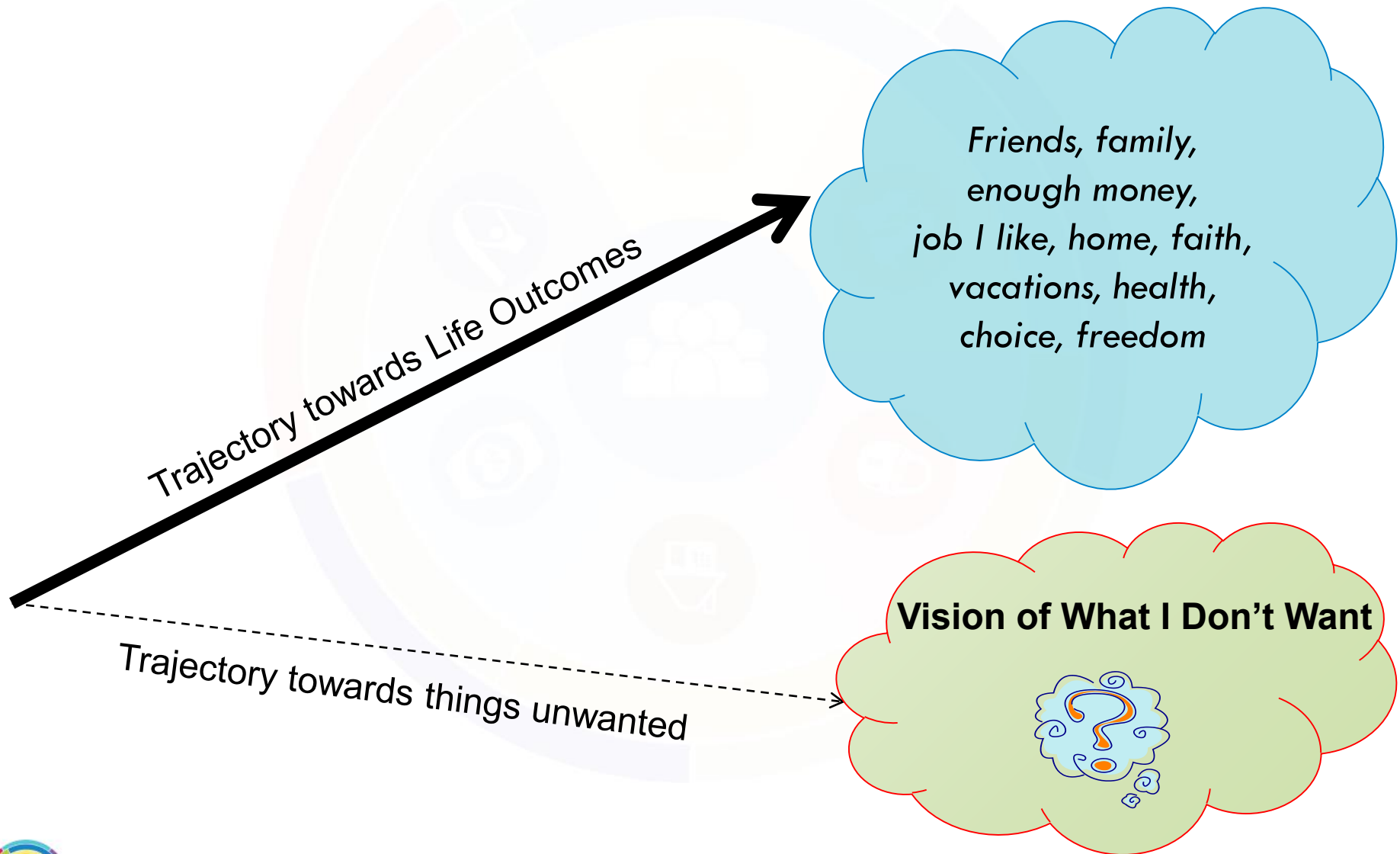
Ben's Good Life Vision

Family Friends TATTOOS
Vacations   Girlfriend
Concerts   WWE   Nascar
Money Job/own business
Fire Station   Church
Tiger Football   Royals
Good Food   Pepsi   Beer
Active   Healthy & Fit

Poverty/No Money
Poor Health Diabetes
Heart Disease Guardian
Isolated/Segregated
Institution/group home
Treated Differently

Trajectory Across Life Stages and Life Transitions

Life Transitions And Disability System Transitions

Getting New Diagnosis

Leaving Early Childhood/ enter school

Transition planning

Turning 18. Leaving school at 18 or 21

Living Adult Life

Parents Turn 65 Medicare & SSDI

My parents have passed away, what do I do?
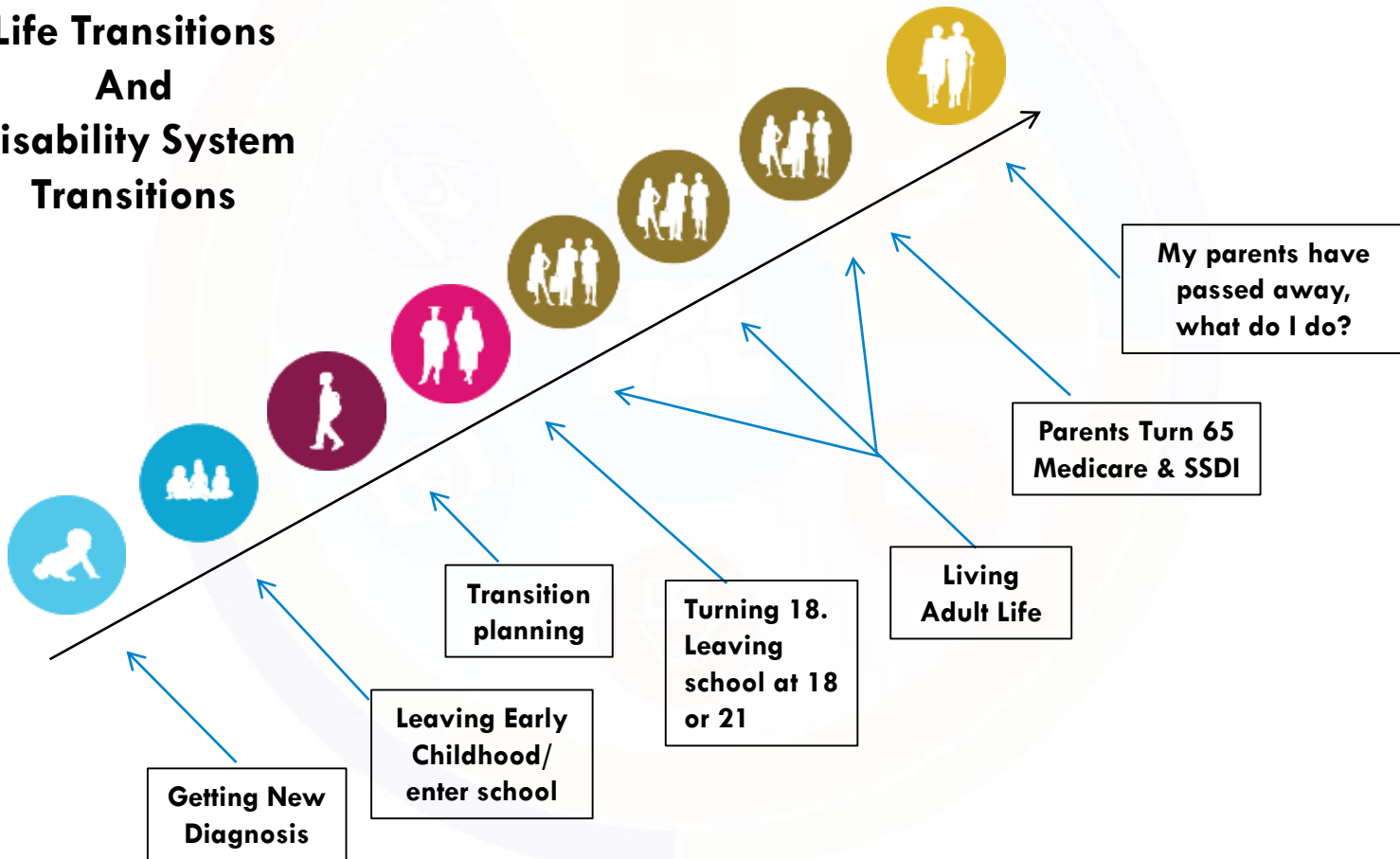
Trajectory Across Life Experiences

Chores and allowance

Dating & Heartaches

Birthday parties with friends

Learning to say "no"

Making Mistakes

Summer jobs, babysitting

Playing sports or an instrument

Scouts, 4H, faith groups
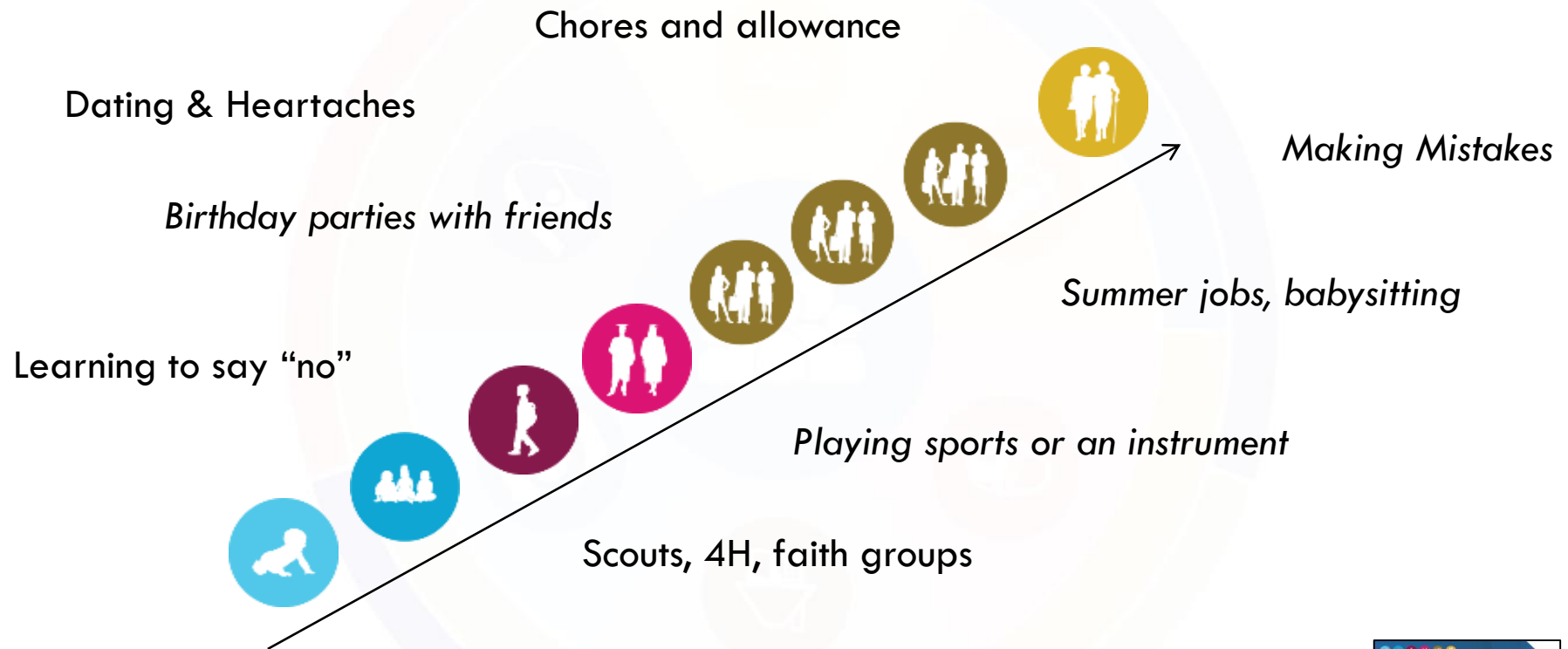
"Anticipatory Guidance for Life Experiences"

Life Experiences = Life Outcomes

Experiences at age 65

Experiences at age 13

Experiences at age 5

What We Want

Friends, family, enough money, job I like, home, faith, vacations, health, choice, freedom

What We DON'T Want
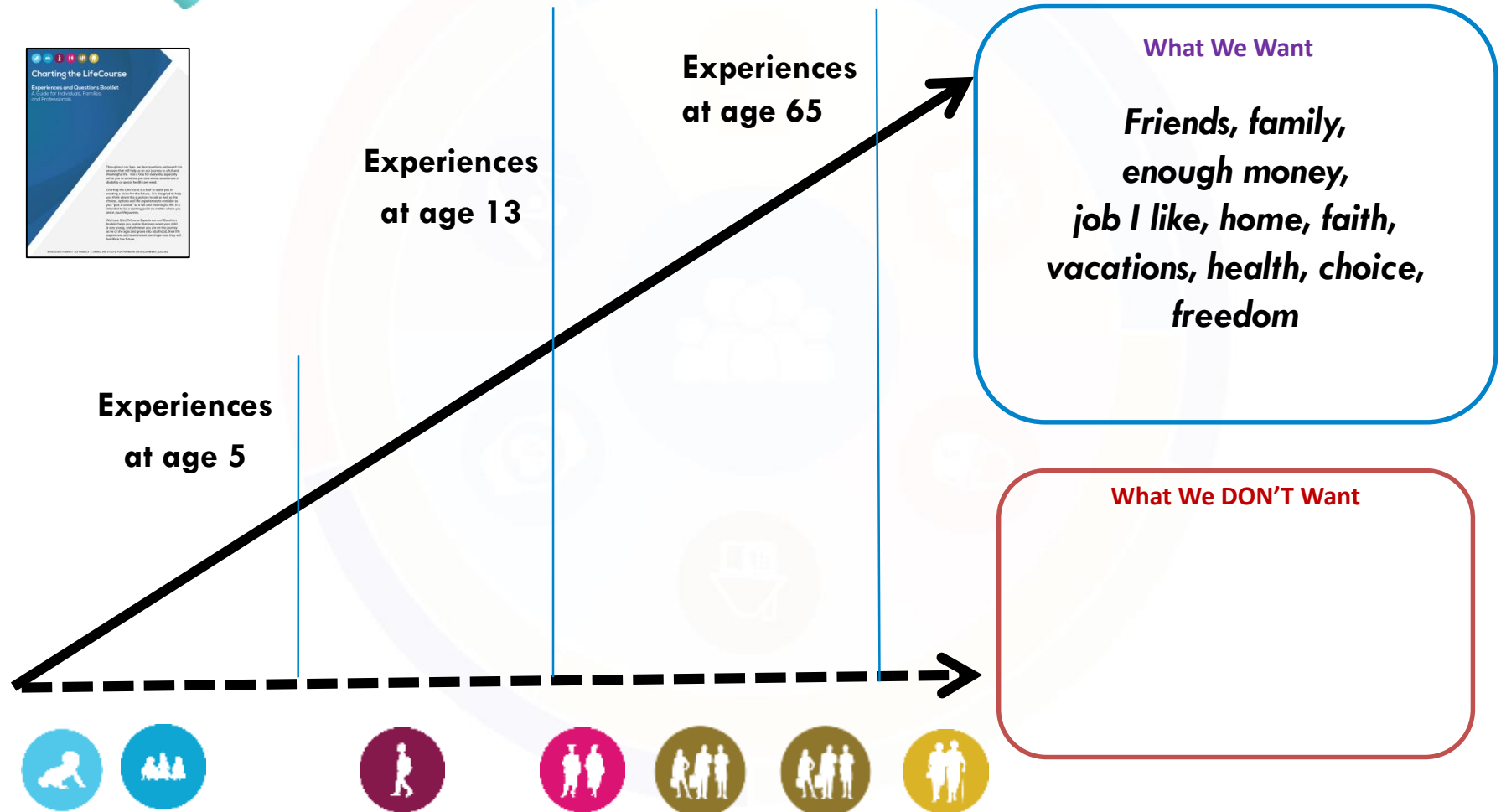
Dignity of Risk and Mistakes

Never be defined by your past. It was just a lesson, not a life sentence.

Spirit Science

Friends, family, enough money, job I like, home, faith, vacations, health, choice, freedom

Poverty, loneliness, segregation, restrictions, lack of choice, boredom

Life Domains, Life Outcomes, and Life Possibilities

Achieving Outcomes for Connected 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)

Looking at Life Possibilities

Innovative	*Very new or undiscovered*
Islands of Excellence	*Exists in a lot of places but not everywhere*
Traditional Options	*Services that have existed for a long time*
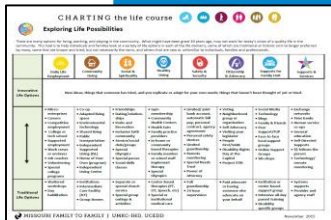
Individualized Supports
to Achieve a Good Life

Types of Support
The "3 Buckets"

Connecting & Networking
(Talking to someone that has been there)

Discovery & Navigation
(Info and Training)

Goods & Services
(Day to Day, Medical, Financial Supports)
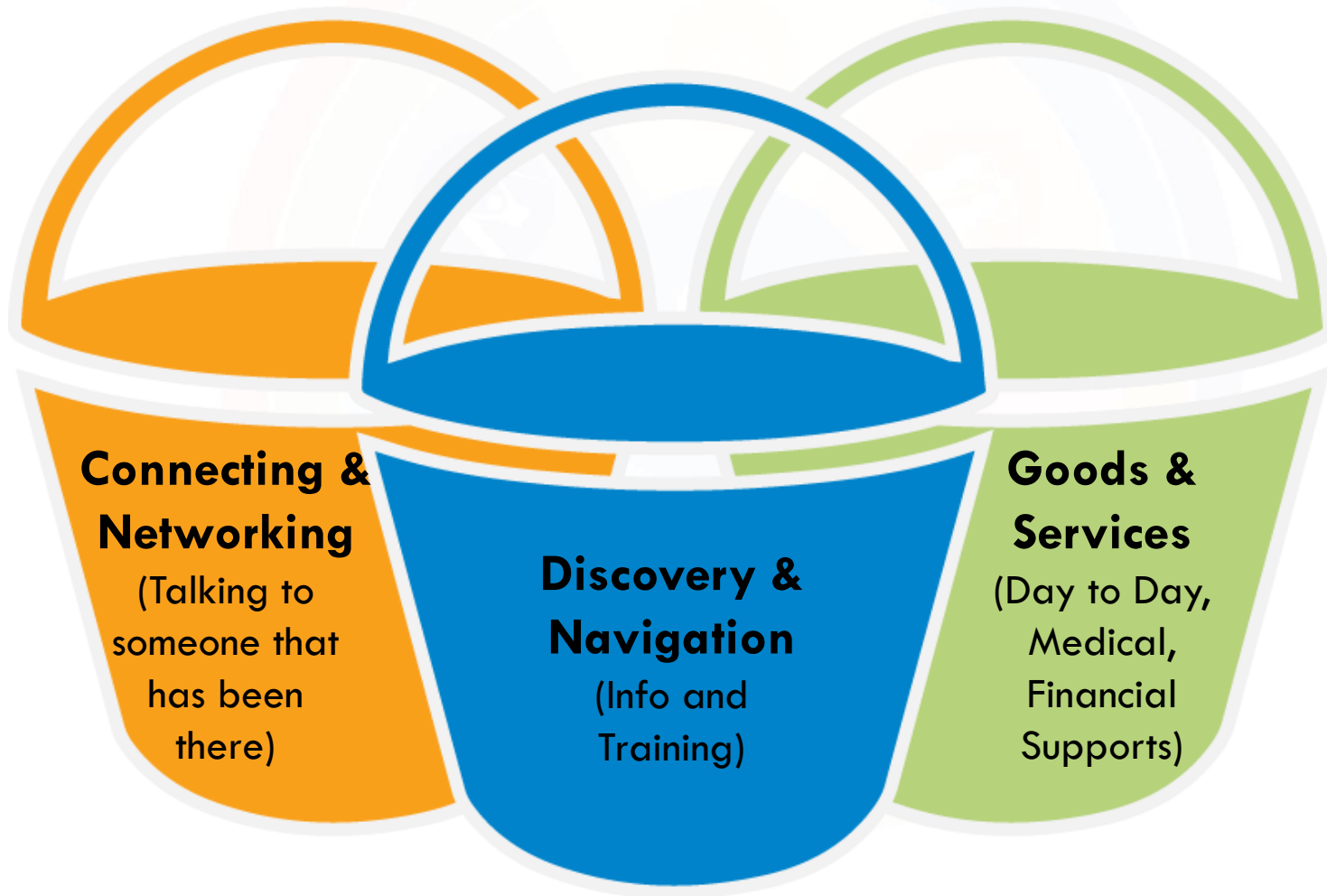
Integrated Star for Problem Solving
& Exploring Options

Charting the LifeCourse Integrated Supports STAR

COMMUNITY

FAMILY

PERSON

100%

PERSONAL STRENGTHS & ASSETS

Strengths:
Things a person is good at
or others admire or like

Assets:
Resources that are owned
or can be accessed by the person
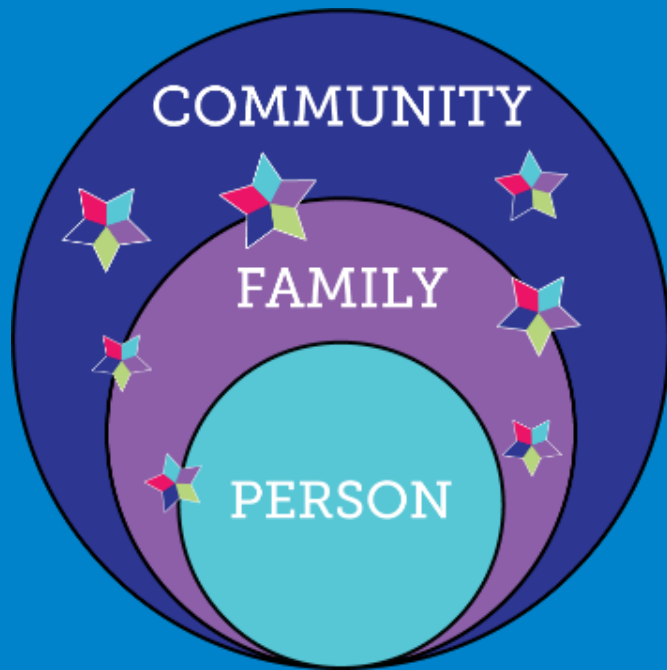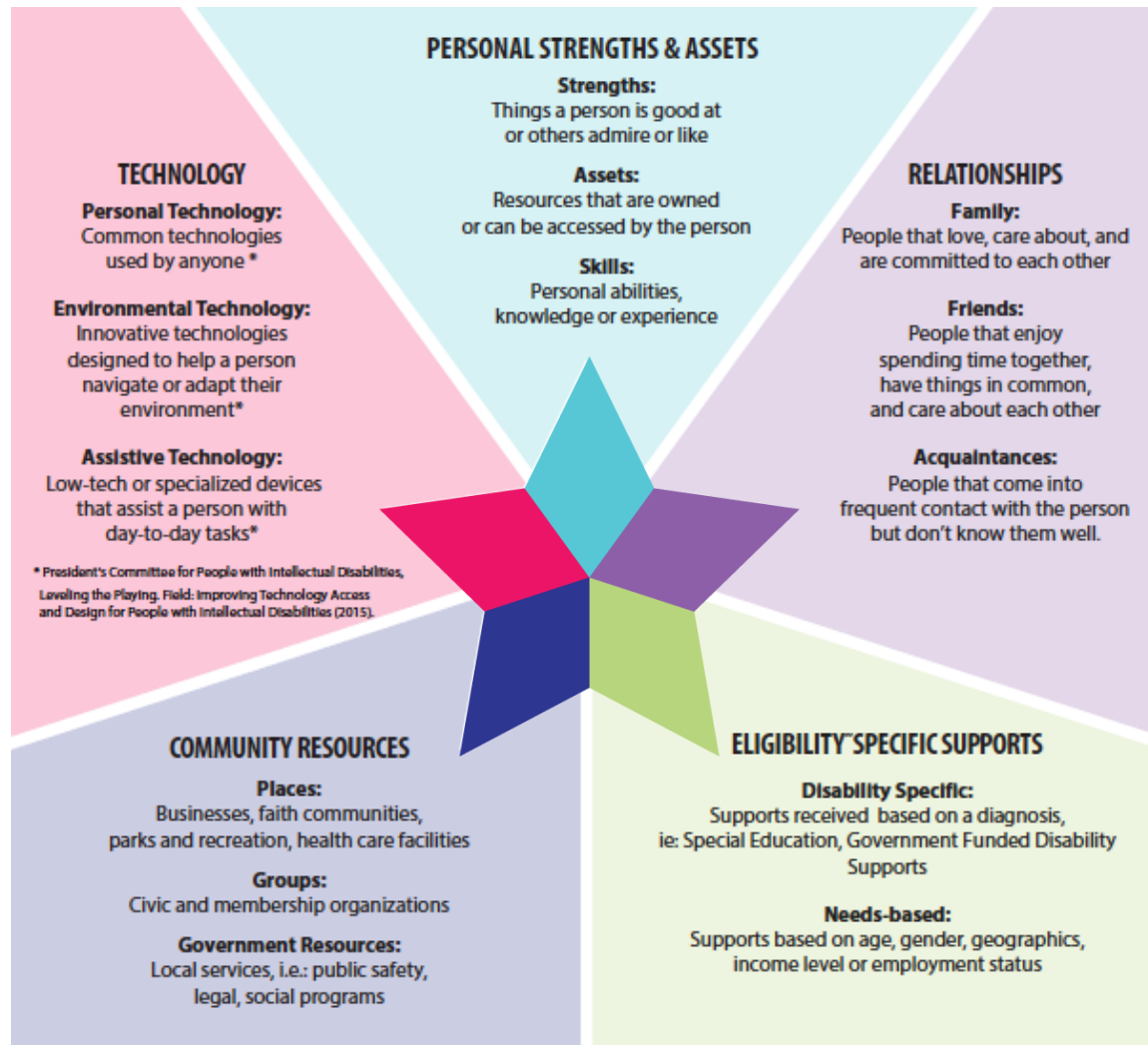
Skills:
Personal abilities,
knowledge or experience

TECHNOLOGY

Personal Technology:
Common technologies
used by anyone *

Environmental Technology:
Innovative technologies
designed to help a person
navigate or adapt their
environment*

Assistive Technology:
Low-tech or specialized devices
that assist a person with
day-to-day tasks*

* President's Committee for People with Intellectual Disabilities,
Leveling the Playing. Field: Improving Technology Access
and Design for People with Intellectual Disabilities (2015).

RELATIONSHIPS

Family:
People that love, care about, and
are committed to each other

Friends:
People that enjoy
spending time together,
have things in common,
and care about each other

Acquaintances:
People that come into
frequent contact with the person
but don't know them well.

COMMUNITY RESOURCES

Places:
Businesses, faith communities,
parks and recreation, health care facilities

Groups:
Civic and membership organizations

Government Resources:
Local services, i.e.: public safety,
legal, social programs

ELIGIBILITY SPECIFIC SUPPORTS

Disability Specific:
Supports received based on a diagnosis,
ie: Special Education, Government Funded Disability
Supports

Needs-based:
Supports based on age, gender, geographics,
income level or employment status

Developed by the UMKC Institute for Human Development, UCEDD, July 2016

Charting the LifeCourse Integrated Supports STAR

COMMUNITY

FAMILY

PERSON

100%

RELATIONSHIPS

Family:
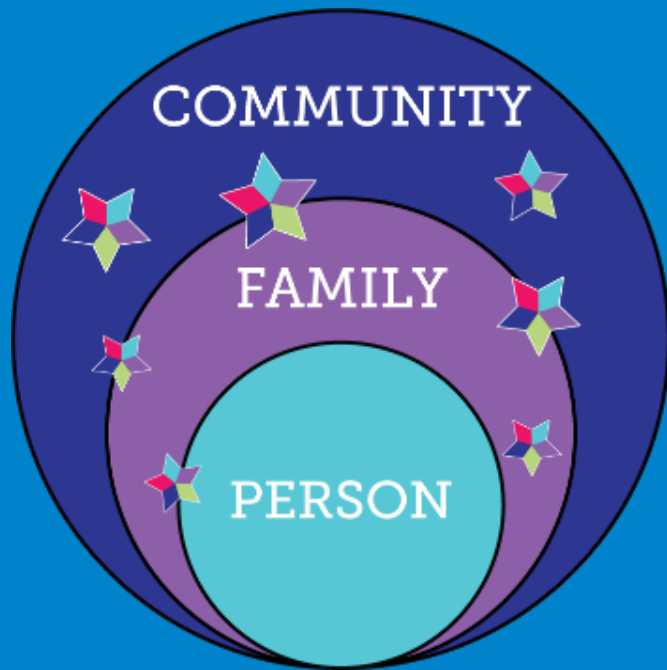People that love, care about, and are committed to each other

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Charting the LifeCourse Integrated Supports STAR

COMMUNITY

FAMILY

PERSON

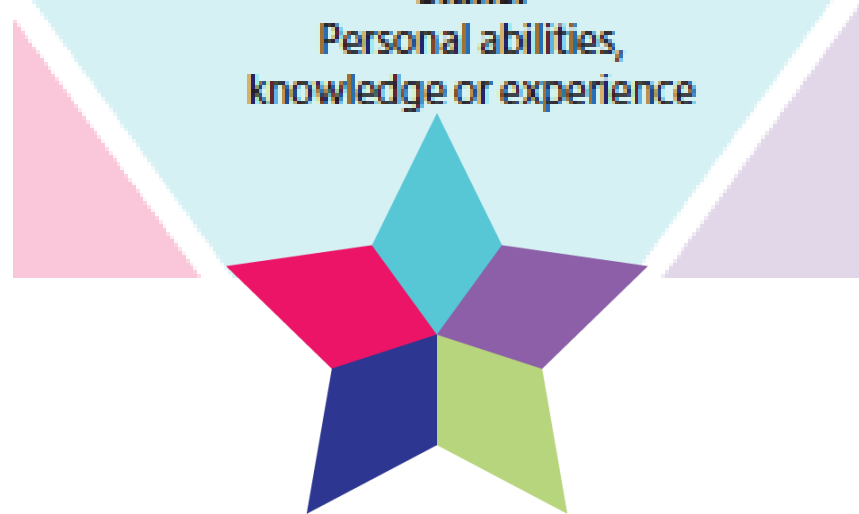**100%**

PERSONAL STRENGTHS & ASSETS

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Things a person is good at
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Skills:
Personal abilities,
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Charting the LifeCourse Integrated Supports STAR

COMMUNITY

FAMILY

PERSON

100%

TECHNOLOGY

Personal Technology:
Common technologies
used by anyone *

Environmental Technology:
Innovative technologies
designed to help a person
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Assistive Technology:
Low-tech or specialized devices
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Charting the LifeCourse Integrated Supports STAR

COMMUNITY

FAMILY

PERSON

100%

COMMUNITY RESOURCES

Places:
Businesses, faith communities,
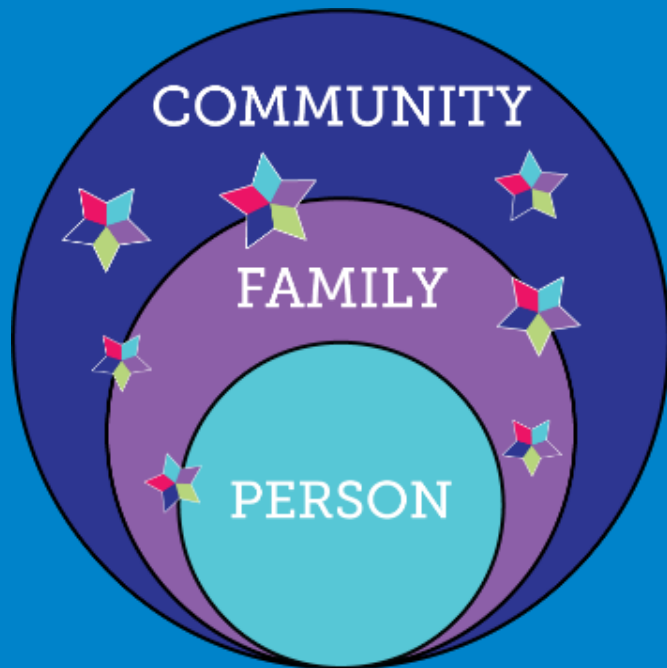parks and recreation, health care facilities

Groups:
Civic and membership organizations

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Local services, i.e.: public safety,
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Charting the LifeCourse Integrated Supports STAR

COMMUNITY

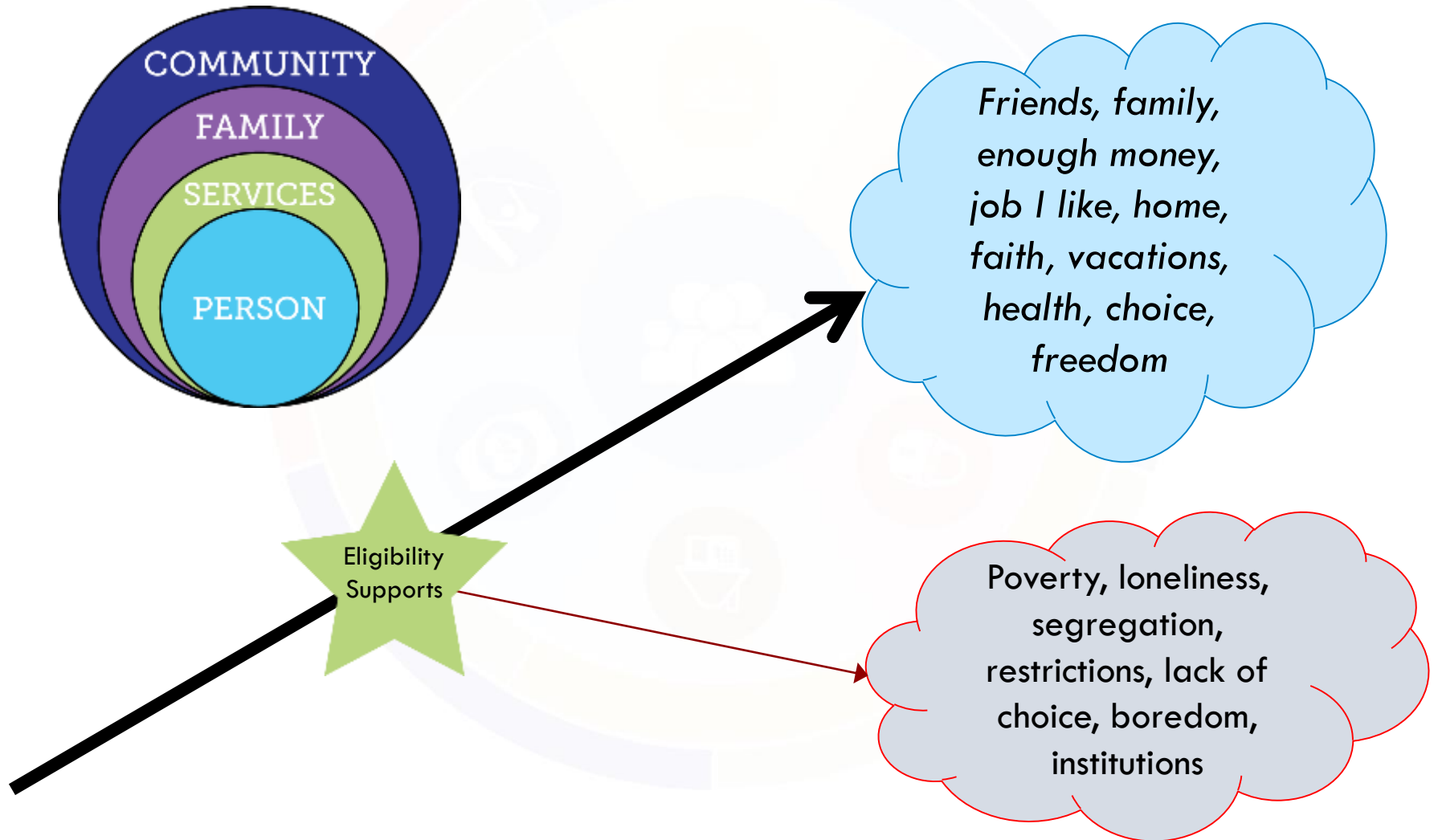FAMILY

PERSON

100%

ELIGIBILITY SPECIFIC SUPPORTS

Disability Specific:
Supports received based on a diagnosis,
ie: Special Education, Government Funded Disability Supports

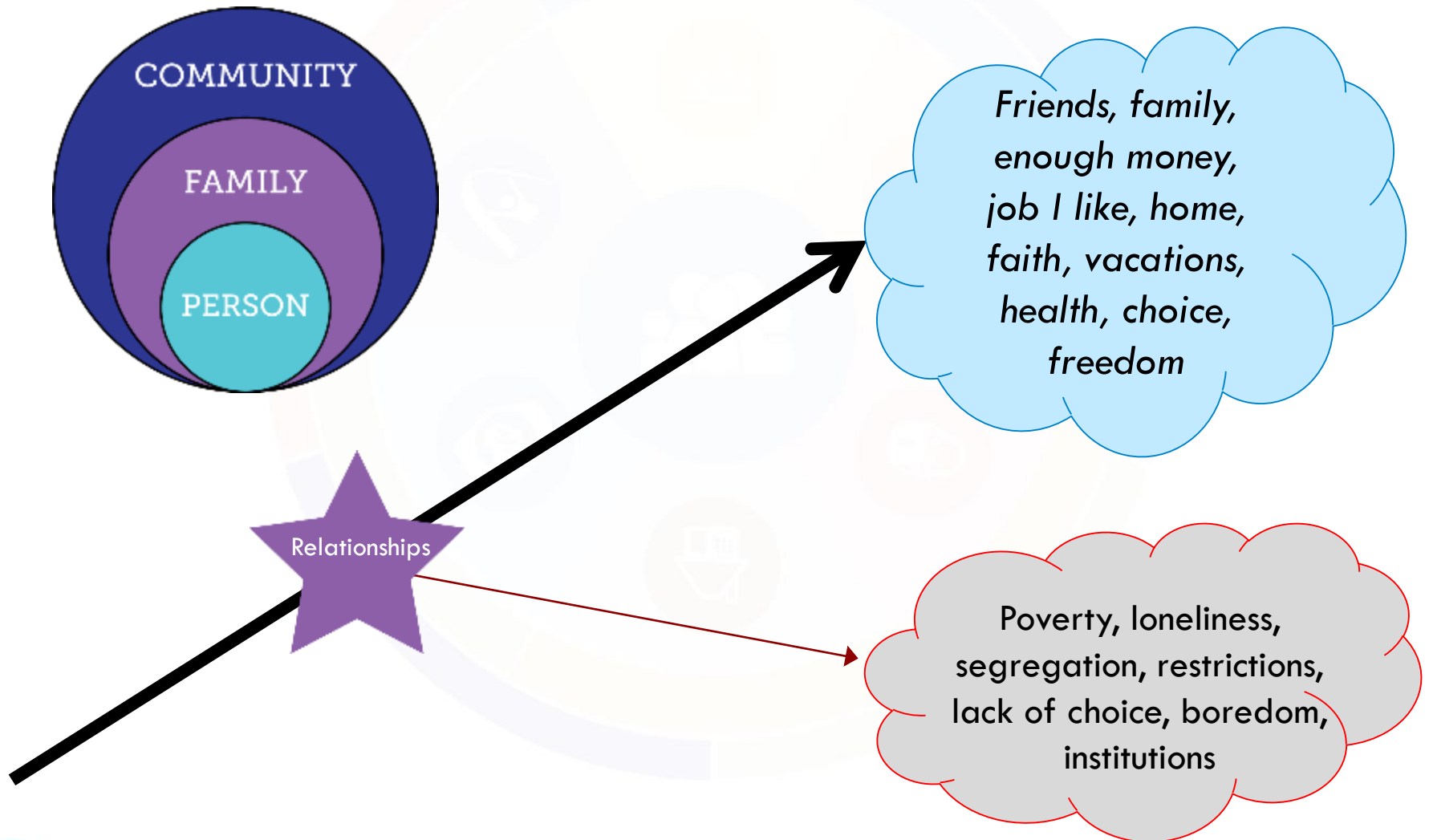**Needs-based:**
Supports based on age, gender, geographics,
income level or employment status

Focusing ONLY on Eligibility Supports

COMMUNITY
FAMILY
SERVICES
PERSON

Eligibility Supports

Friends, family, enough money, job I like, home, faith, vacations, health, choice, freedom

Poverty, loneliness, segregation, restrictions, lack of choice, boredom, institutions

Relying ONLY on Family & Friends

COMMUNITY
FAMILY
PERSON

Relationships

Friends, family, enough money, job I like, home, faith, vacations, health, choice, freedom

Poverty, loneliness, segregation, restrictions, lack of choice, boredom, institutions

LifeCourse Star to Calendar

Ben - BEFORE Integrated Supports

PERSONAL STRENGTHS & ASSETS

TECHNOLOGY:

RELATIONSHIPS:

Mom, Dad

Ben's Supports

COMMUNITY BASED:

ELIGIBILITY SPECIFIC

DDD Self-Directed waiver PCA staff; Medicaid; Special Needs Trust

Long Term Service and Support Needs

Time	Mon	Tues	Wed	Thurs	Fri	Sat	Sun
6-6:30 AM							
6:30-7 AM							
7-7:30 AM	Parents get Ben out of bed, assist with breakfast, shower, getting dressed and ready for his day						
7:30-8 AM							
8-8:30 AM							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	Waiver Self-Directed PCA						
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							
4:30-5 PM							
5-5:30 PM							
5:30-6 PM							
6-6:30 PM							
6:30-7 PM	Mom and Dad provide all support, including meals, transportation and support for activities, etc.						
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

Ben - AFTER Integrating Supports

PERSONAL STRENGTHS & ASSETS

Able to stay home alone for up to an hour; has & can use i-pad;

TECHNOLOGY: i-pad when home alone; digital watch

RELATIONSHIPS: Mom, Dad, Matt, Zac, Ali, Chad, Ericka, Roy, Carol, Nick, Spohn,

Ben's Supports

COMMUNITY BASED: Firemen at ESFD; coaches & staff at ES high school; Omni bus;

ELIGIBILITY SPECIFIC DDD Self-Directed waiver PCA staff; Medicaid; Special Needs Trust

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		
8:30-9 AM							
9-9:30 AM							
9:30-10 AM							St. Ann's w/ mom
10-10:30 AM							
10:30-11 AM							
11-11:30 AM							Home alone while Mom walks
11:30-12 PM							
12-12:30 PM		Waiver Self-Directed PCA		Waiver Self-Directed PCA			
12:30-1 PM							
1-1:30 PM							
1:30-2 PM							
2-2:30 PM							
2:30-3 PM							
3-3:30 PM	Volunteer at high school, supported by coaches and friends						
3:30-4 PM							
4-4:30 PM							
4:30-5 PM							
5-5:30 PM							
5:30-6 PM		Mom and/or Dad prepare meal and assist as needed					Dinner w/ Roy & Carol & family
6-6:30 PM							
6:30-7 PM		Home alone while Mom walks					
7-7:30 PM	WWE With Matt						
7:30-8 PM			Horseback Therapy w/ Dad				Nick's Birthday Party with Matt and friends
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   January 2015

PERSONAL STRENGTHS & ASSETS

RELATIONSHIP-BASED

ELIGIBILITY-SPECIFIC

GOODS & SERVICES

COMMUNITY-BASED

TECHNOLOGY

DISCOVERY & NAVIGATION

CONNECTING & NETWORKING

daily life & employment

social & spirituality

safety & security

community living

healthy living

citizenship & advocacy

Missouri Quality Outcomes

◎ The Missouri Quality Outcomes (MOQO) were developed in the 1990's, in an effort to emphasize quality of life for individuals receiving services and supports from the Missouri Division of Developmental Disabilities

◎ In 2015 Missouri Division of Developmental Disabilities adopted the Charting the Life Course Domains into statewide Missouri Quality Outcomes

MO Quality Outcomes were changed in 2015

◎ More user friendly and can be used in conjunction with "Charting the Life Course" guide developed by UMKC Institute for Human Development;

◎ New Federal regulations around Self-Determination and Home and Community Based Services
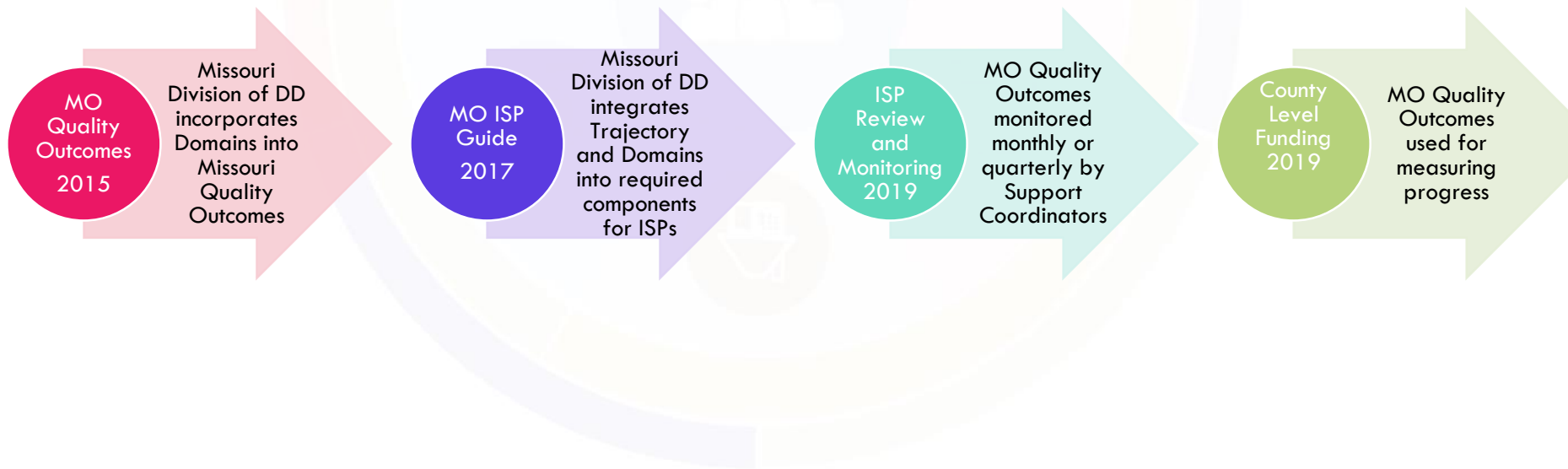
◎ Missouri Quality Outcomes

ISP Guidelines 2017

◎ Require the team to explore the Vision of a Good Life of each person

◎ Require the Missouri Quality Outcomes to be addressed in all ISP's in Missouri

◎ Intentionally connect Personal Outcomes to the MO Quality Outcomes.

Charting the Life Course System Impact in Missouri

MO Quality Outcomes 2015 → Missouri Division of DD incorporates Domains into Missouri Quality Outcomes

MO ISP Guide 2017 → Missouri Division of DD integrates Trajectory and Domains into required components for ISPs

ISP Review and Monitoring 2019 → MO Quality Outcomes monitored monthly or quarterly by Support Coordinators

County Level Funding 2019 → MO Quality Outcomes used for measuring progress

lifecoursetools.com

**Planning for Life Outcomes
and/or
Service Planning**

Self-Advocate
Tools & Resources

Family Perspective
Tools

Formal Planning
Tools and Forms

800-444-0821

Please fill out the Post-Survey and Evaluation - Thank You!