A Person-Centered Approach to Defining, Collaborating, and Sharing to Support a "Good Life"

HCBS Conference 2019

University of Kansas City Institute for Human Development, UCEDD conducts and collaborates on a wide variety of **applied research projects to develop, implement, and evaluate new ideas and promising practices** that support **healthy, inclusive communities.**

UMKC Institute for Human Development
Charting the LifeCourse Nexus

Exchange
- Access to Resources and Tools
- Training
- Technical Assistance

Build
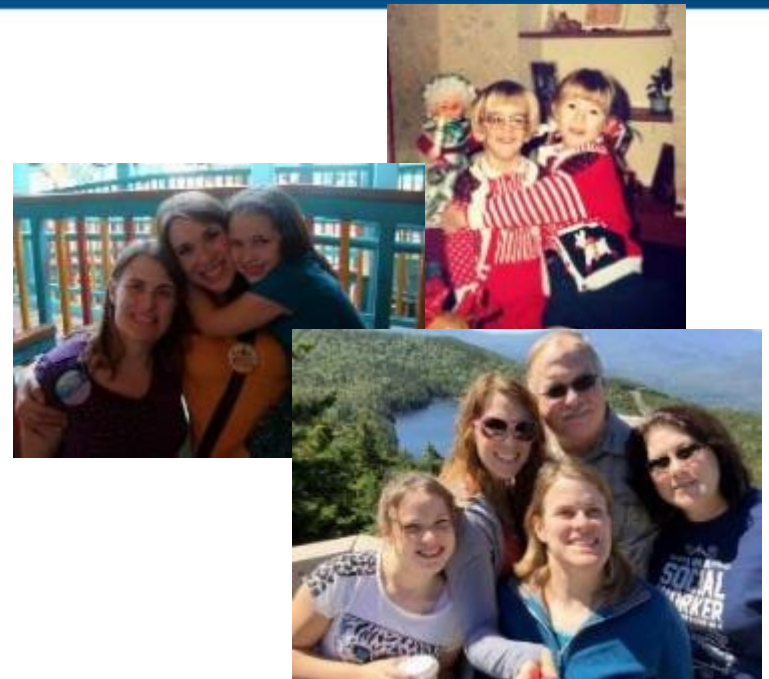- Innovate and Enhance
- Develop
- Research

Collaborate
- Network and Connect
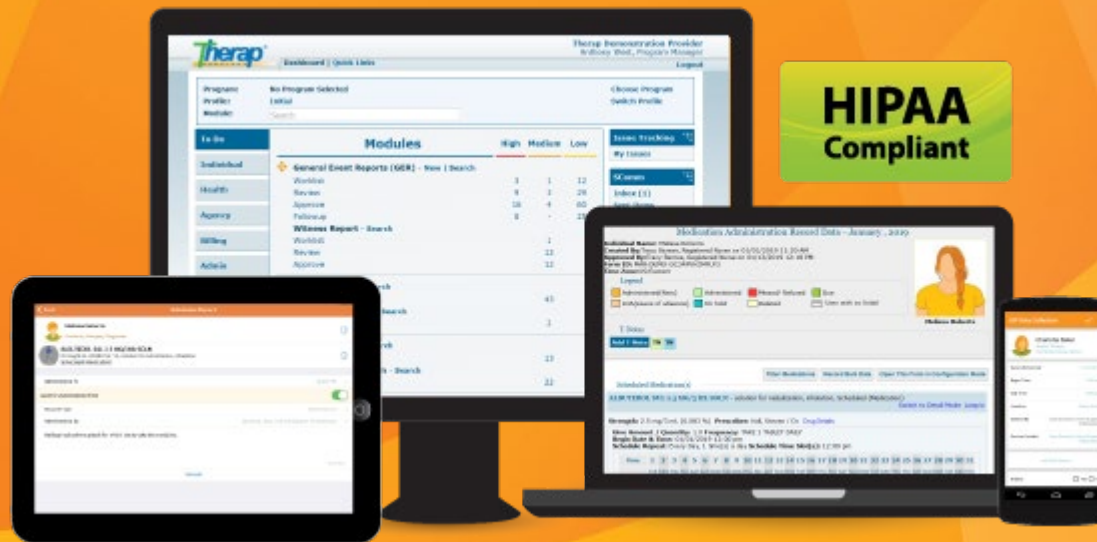- Share Learning
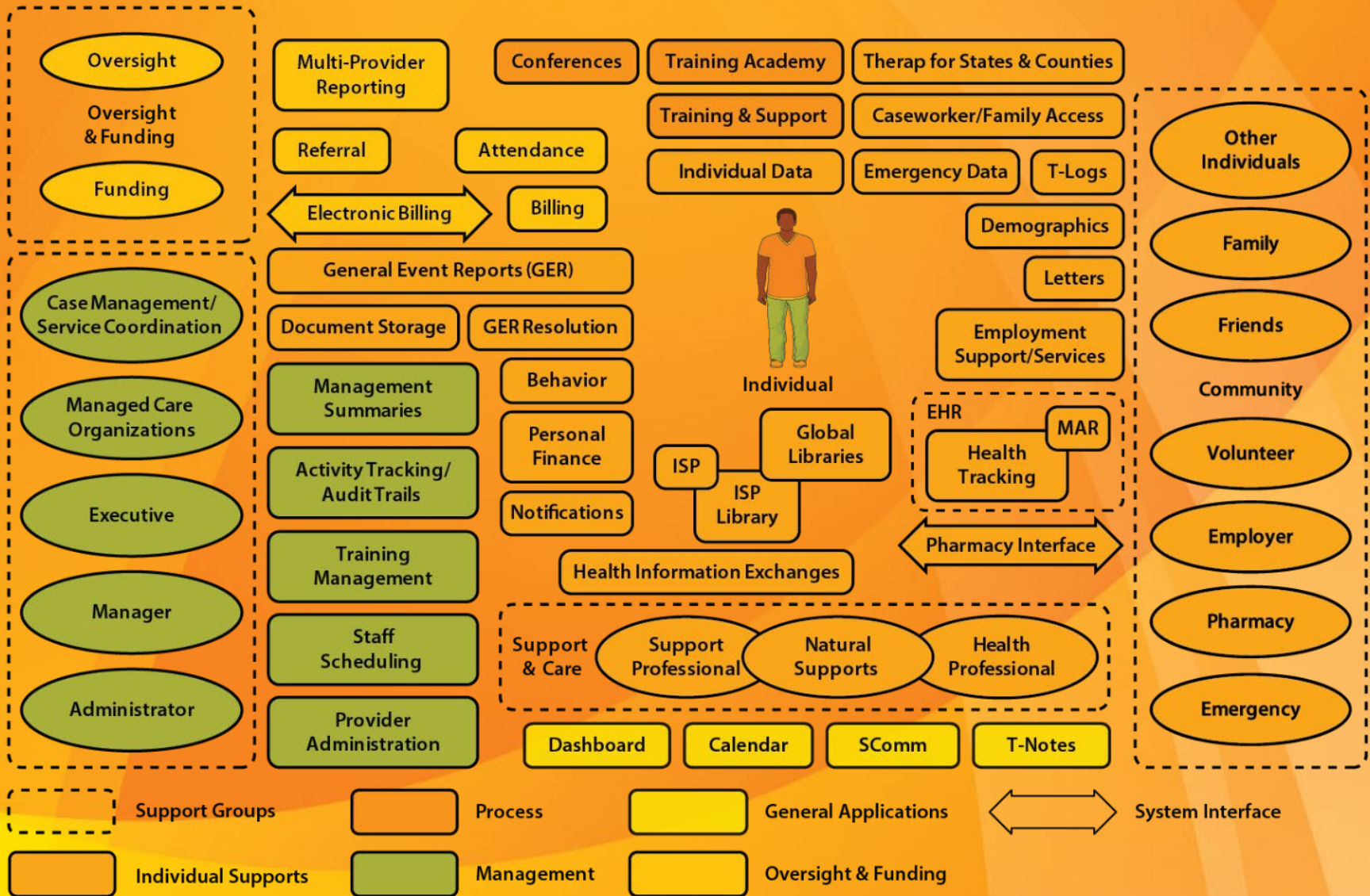- Share Stories

Jenny Turner, LCSW

- Sibling of two sisters, one who is in her 30s with a disability

- Licensed as a Clinical Social Worker

- Formerly a Support Coordinator and Director of a Provider Agency

- Senior Research Associate, UMKC Institute for Human Development

Therap was built on the concept of a paperless system that could save agencies' time and money, improving communication, accountability, and risk management while ultimately providing **Higher quality supports for individuals served.**

Person Centered Data

Therap®

Oversight & Funding
- Oversight
- Funding

Case Management/Service Coordination
Managed Care Organizations
Executive
Manager
Administrator

Multi-Provider Reporting
Referral
Attendance
Electronic Billing
Billing
General Event Reports (GER)
Document Storage
GER Resolution
Management Summaries
Behavior
Activity Tracking/Audit Trails
Personal Finance
Notifications
Training Management
Staff Scheduling
Provider Administration

Conferences
Training Academy
Therap for States & Counties
Training & Support
Caseworker/Family Access
Individual Data
Emergency Data
T-Logs
Demographics
Letters
Employment Support/Services

Individual

ISP
Global Libraries
ISP Library
Health Information Exchanges

EHR
Health Tracking
MAR
Pharmacy Interface

Support & Care
- Support Professional
- Natural Supports
- Health Professional

Dashboard
Calendar
SComm
T-Notes

Other Individuals
Family
Friends
Community
Volunteer
Employer
Pharmacy
Emergency

Legend:
- Support Groups
- Process
- General Applications
- System Interface
- Individual Supports
- Management
- Oversight & Funding

FCPER001 Last update: 06/19

Jeff Case

National Director of
Business Development

- Wife (Rebecca) and Jeff established Developing Potential Inc. in KCMO

- Leads a team that works with states, providers, and families to provide a documentation solution across the US and Canada.

Joining Forces for a New Vision

1950s Mom------------Parent-----Family Movement

1970s Self-Advocacy and Independent Living Movements (Nothing about me, without me!)

2000s Siblings Movement

1960s Medicaid and Medicare Established

1980s Medicaid Waiver (Community Supports)
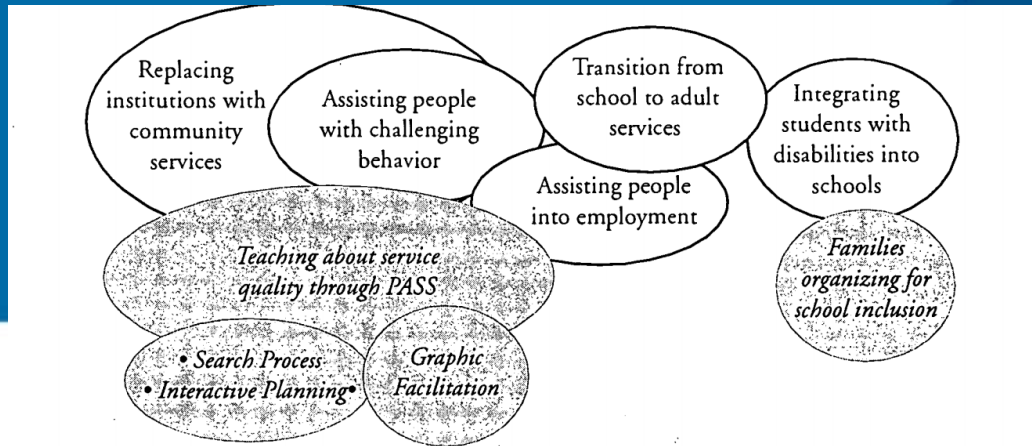
2010s Affordable Care Act

1970s Rehab Act: 504 Plans

1975s Education for All Children

1990s IDEA and ADA

2000's Community and Society

COMMUNITY

FAMILY
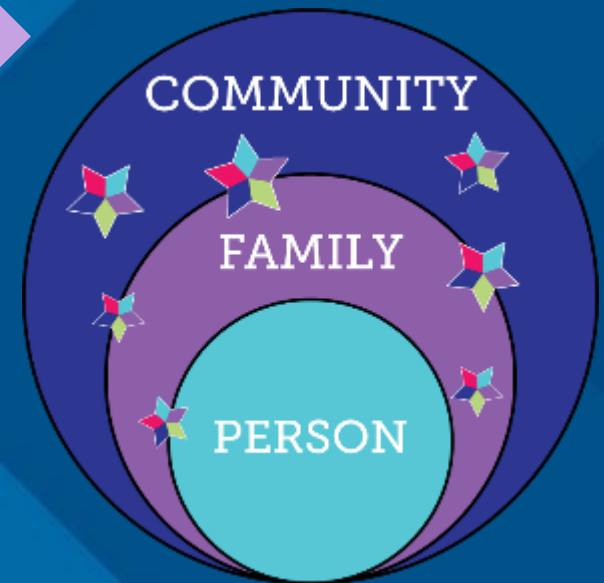
PERSON

The Development and Adoption of Person Centered Planning

from *The Origins of Person-Centered Planning: A Community of Practice Perspective,* 2000

1979

Initial Methodologies and Training Workshops

"normalization"

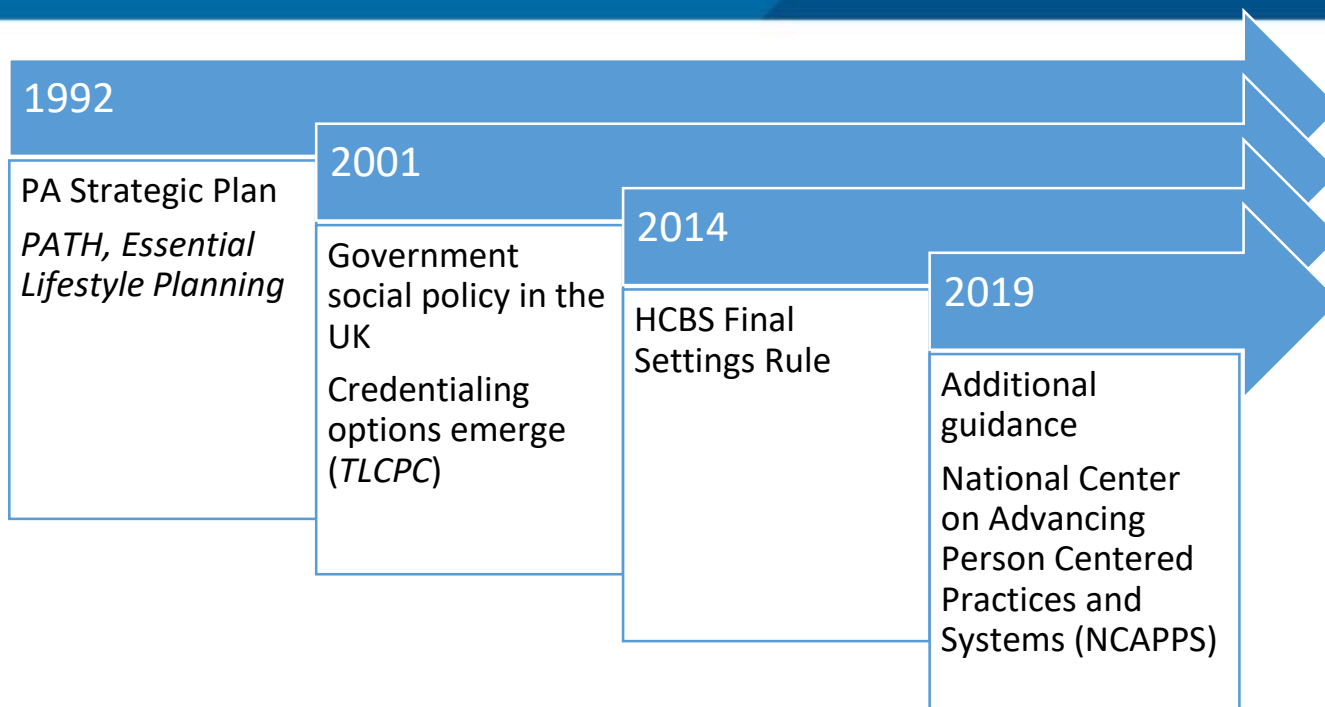*24 Hours Planning, Personal Futures Planning*

1985

Term "person centered planning" coined

People first, ordinary language, strengthening the voice of the person, valuing experiences, defining desirable changes

MAPS

1988

Some Regional and State Administrators exploring

Essential Lifestyles Planning

# The Development and Adoption of Person Centered Planning

Therap | UMKC Institute for Human Development — Charting the LifeCourse Nexus

1992
PA Strategic Plan

PATH, Essential Lifestyle Planning

2001
Government social policy in the UK

Credentialing options emerge (*TLCPC*)

2014
HCBS Final Settings Rule

2019
Additional guidance

National Center on Advancing Person Centered Practices and Systems (NCAPPS)

What is Person Centered Planning?

- a process directed by the person...
- ...identifies the person's strengths, goals, preferences, needs (medical and HCBS), and desired outcomes.
- ... enable and assist the person to identify and access a unique mix of paid and unpaid services
- ... creates a space of empowerment—a level playing field—that allows for consideration of personal preferences as well as health and safety needs
- ... helps people to live better lives, with support to do the things most important to them

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Charting the LifeCourse Nexus

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Current Reality of Services and Supports
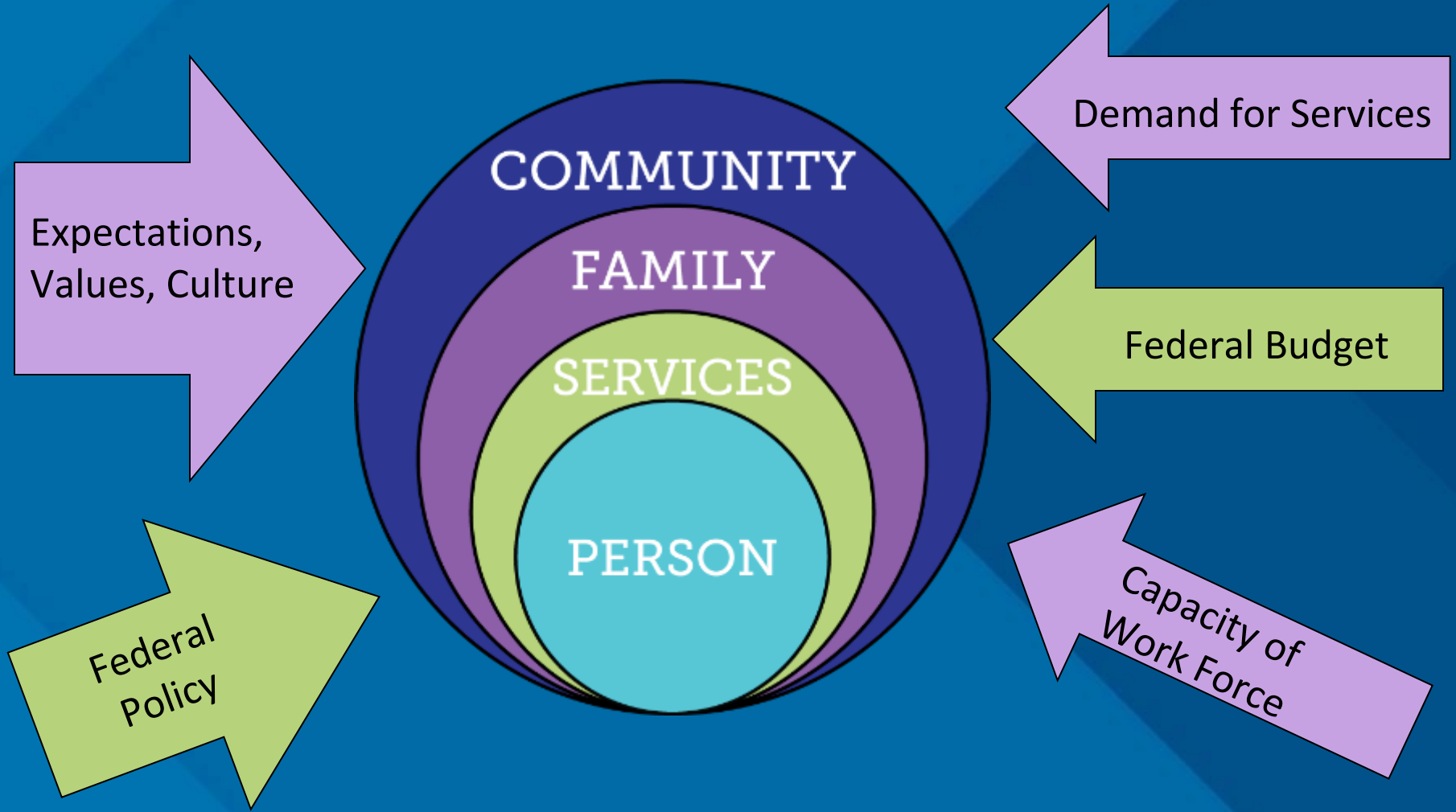
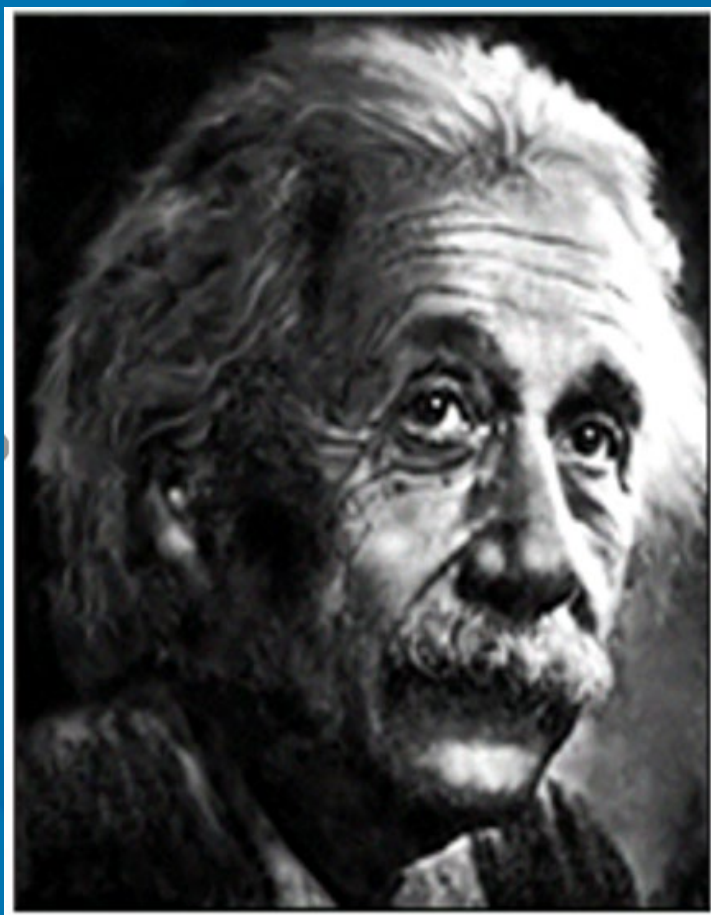# Services and Supports are Evolving
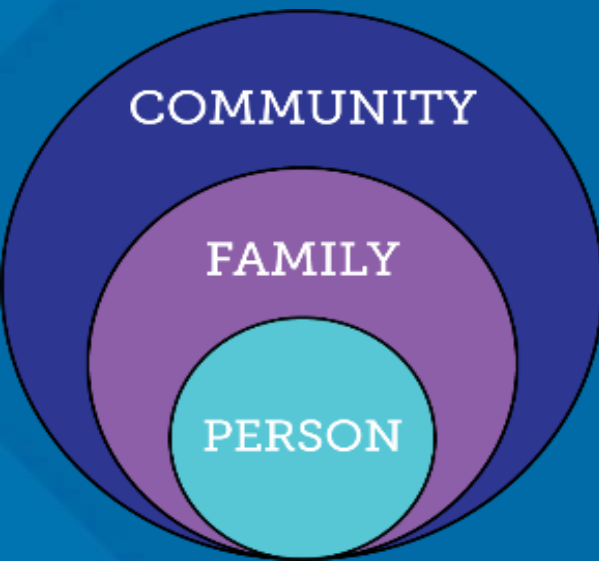
Everyone exists within the context of family and community

Traditional Disability Services

Integrated Services and Supports within context of person, family and community

The significant problems we face can not be solved at the same level of thinking we were at when we created them.

Albert Einstein

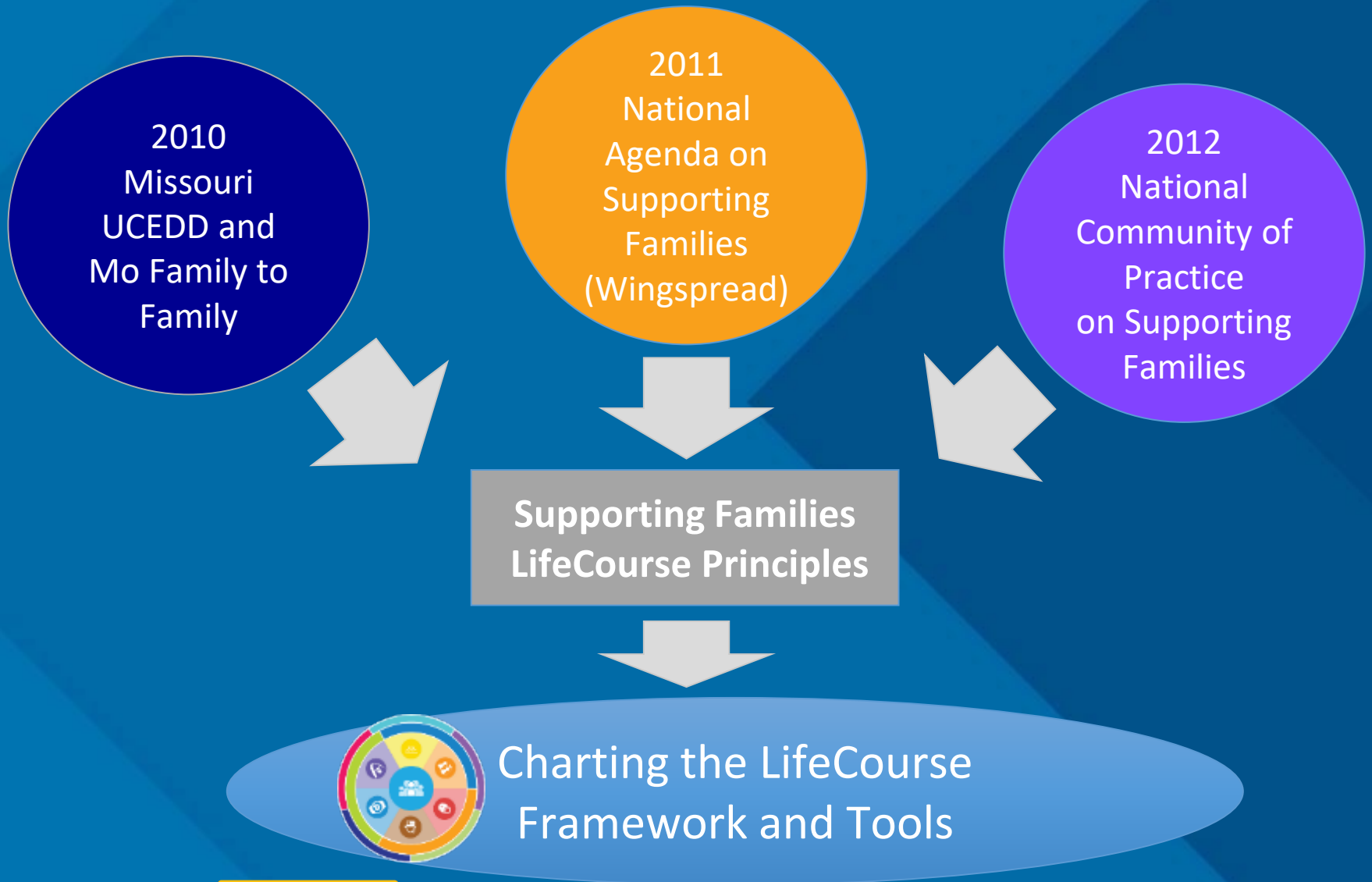# Type of Change that is Needed

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
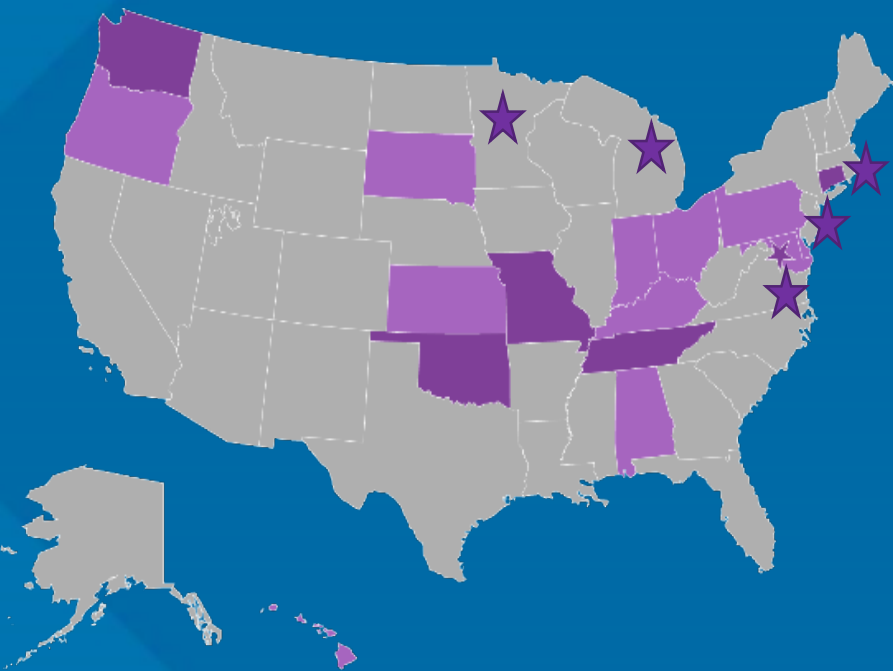
Creating Blue Space, Hanns Meissner, 2013

Evolution of CtLC Framework

2010 Missouri UCEDD and Mo Family to Family

2011 National Agenda on Supporting Families (Wingspread)

2012 National Community of Practice on Supporting Families

Supporting Families LifeCourse Principles

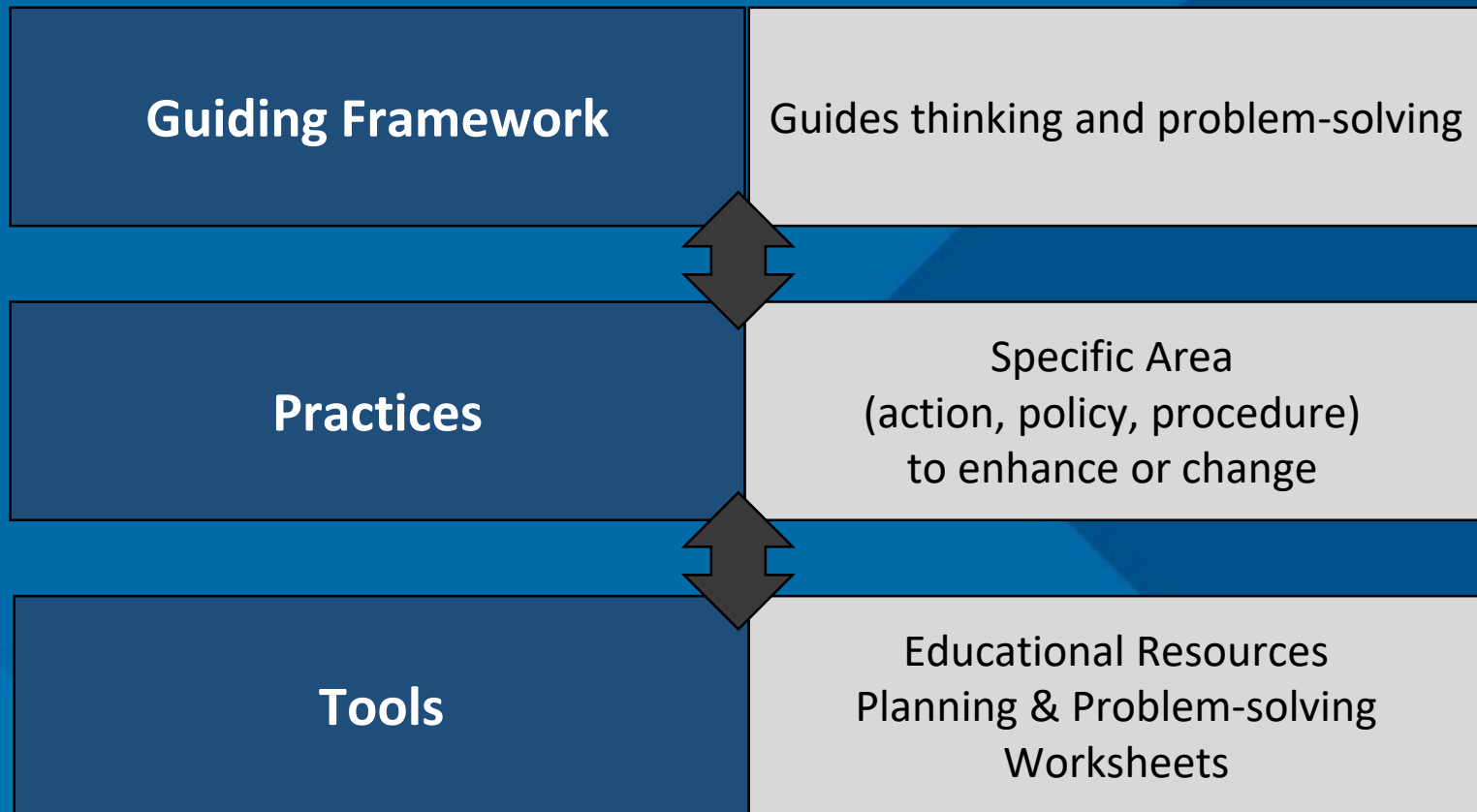Charting the LifeCourse Framework and Tools

Goal of the National CoP

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 an intellectual and developmental disability across the lifespan.

Application of Charting the LifeCourse

Guiding Framework	Guides thinking and problem-solving
Practices	Specific Area (action, policy, procedure) to enhance or change
Tools	Educational Resources Planning & Problem-solving Worksheets

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

Where do People with ID/DD Live?

4.7 million estimated People with Developmental Disabilities*

75%
3,500,000

Not Known to Services

12%
672,000

Living at Home

11%
528,000
Out of Home Services

RISP.umn.edu
RTC.umn.edu
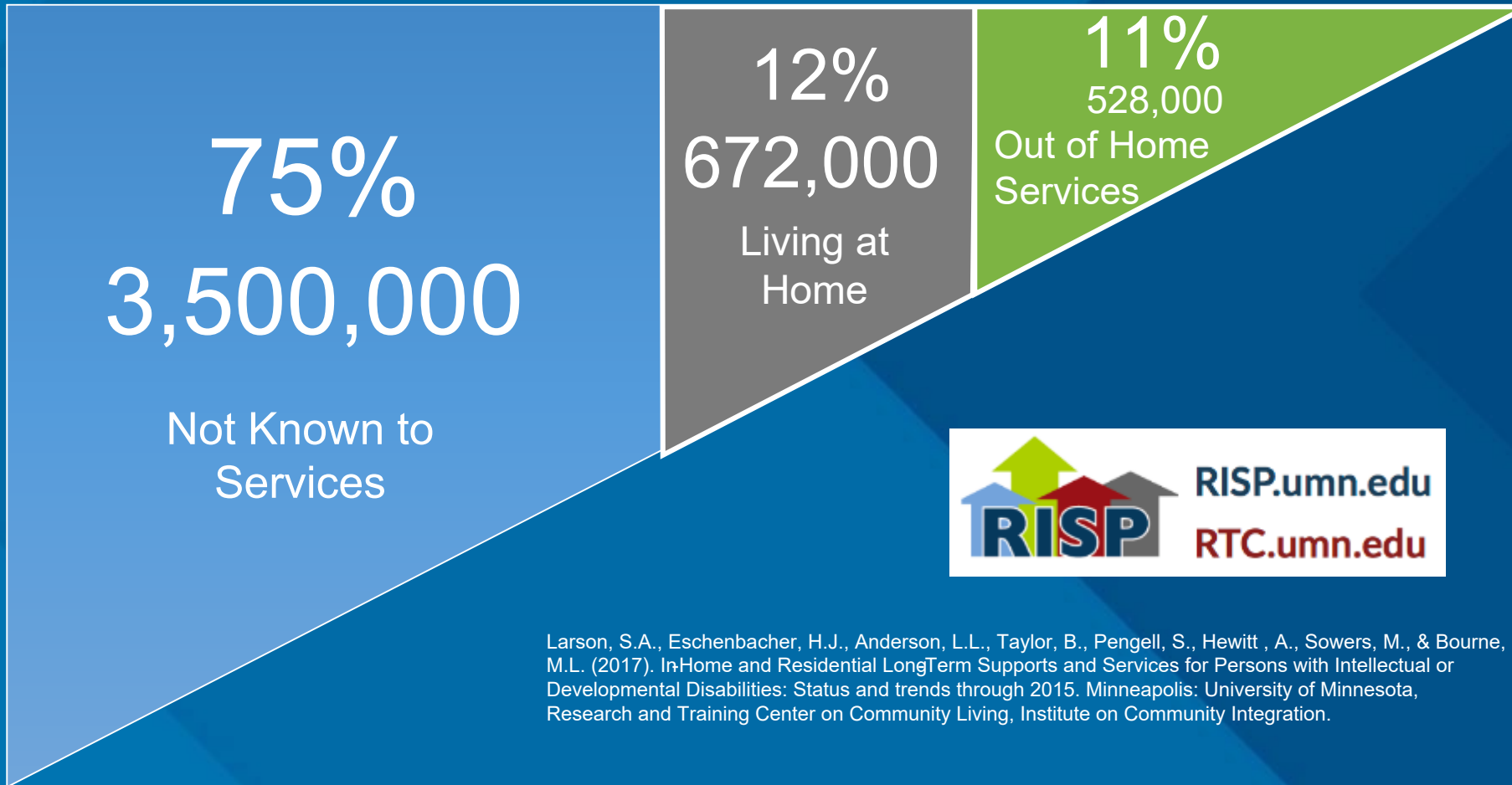
Larson, S.A., Eschenbacher, H.J., Anderson, L.L., Taylor, B., Pengell, S., Hewitt , A., Sowers, M., & Bourne, M.L. (2017). In-Home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities: Status and trends through 2015. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

All Individuals Exist in 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

Good Life for ALL

Individuals will achieve self-determination, interdependence, productivity, integration,

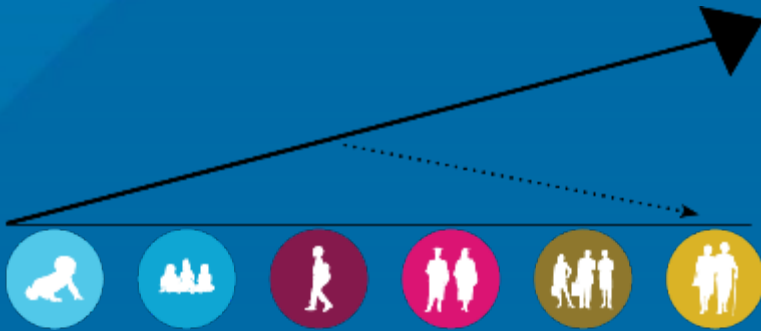and inclusion in all facets of community life

Families will be supported in ways that maximize their capacity, strengths, and unique abilities to best nurture, love, and support all individual members to achieve

their goals

What I Want for Quality of LIFE
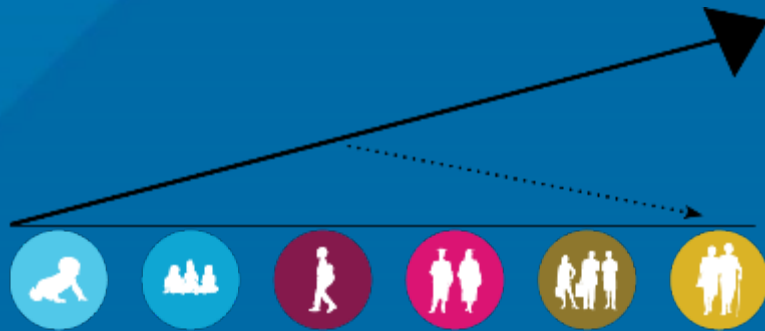
Vision of a Good Life

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

Trajectory Towards a Good Life

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

Trajectory towards Life Outcomes

Trajectory towards things unwanted

Vision of What I Don't Want

Trajectory Towards a Good Life

Chores and allowance

Learning to say "no"

Summer jobs, babysitting

Making Mistakes

Playing sports or an instrument

Birthday parties with friends

Scouts, 4H, faith groups

My parents have passed away, what do I do?

Parents Turn 65 Medicare & SSDI

Living Adult Life

Transition planning

Turning 18. Leaving school at 18 or 21

Leaving Early Childhood/ enter school

Getting New Diagnosis
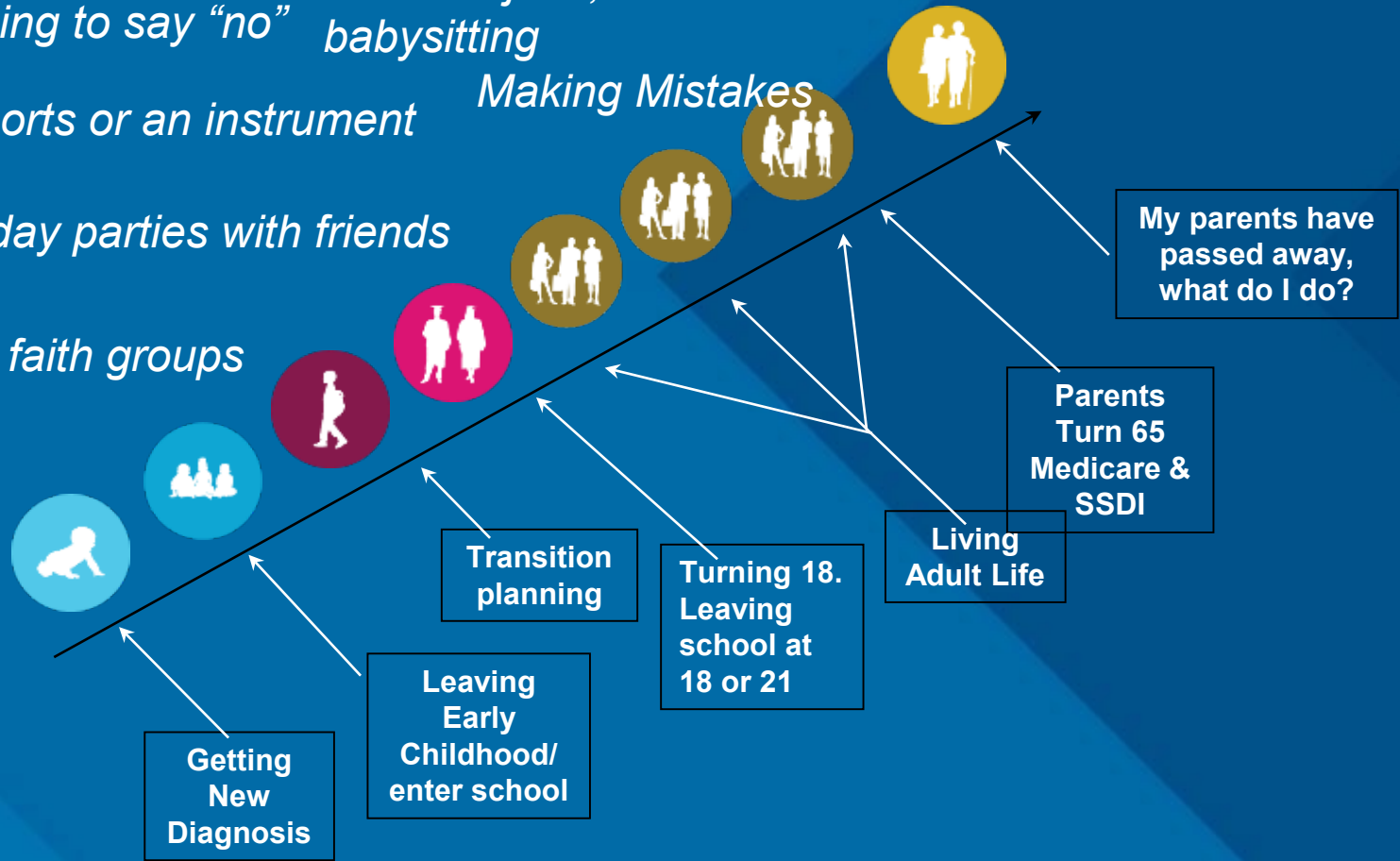
Integrated Life Domains

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 and issues, guardianship options and alternatives)

Social and Spirituality
(friends, relationships, leisure activities, personal networks, faith community)
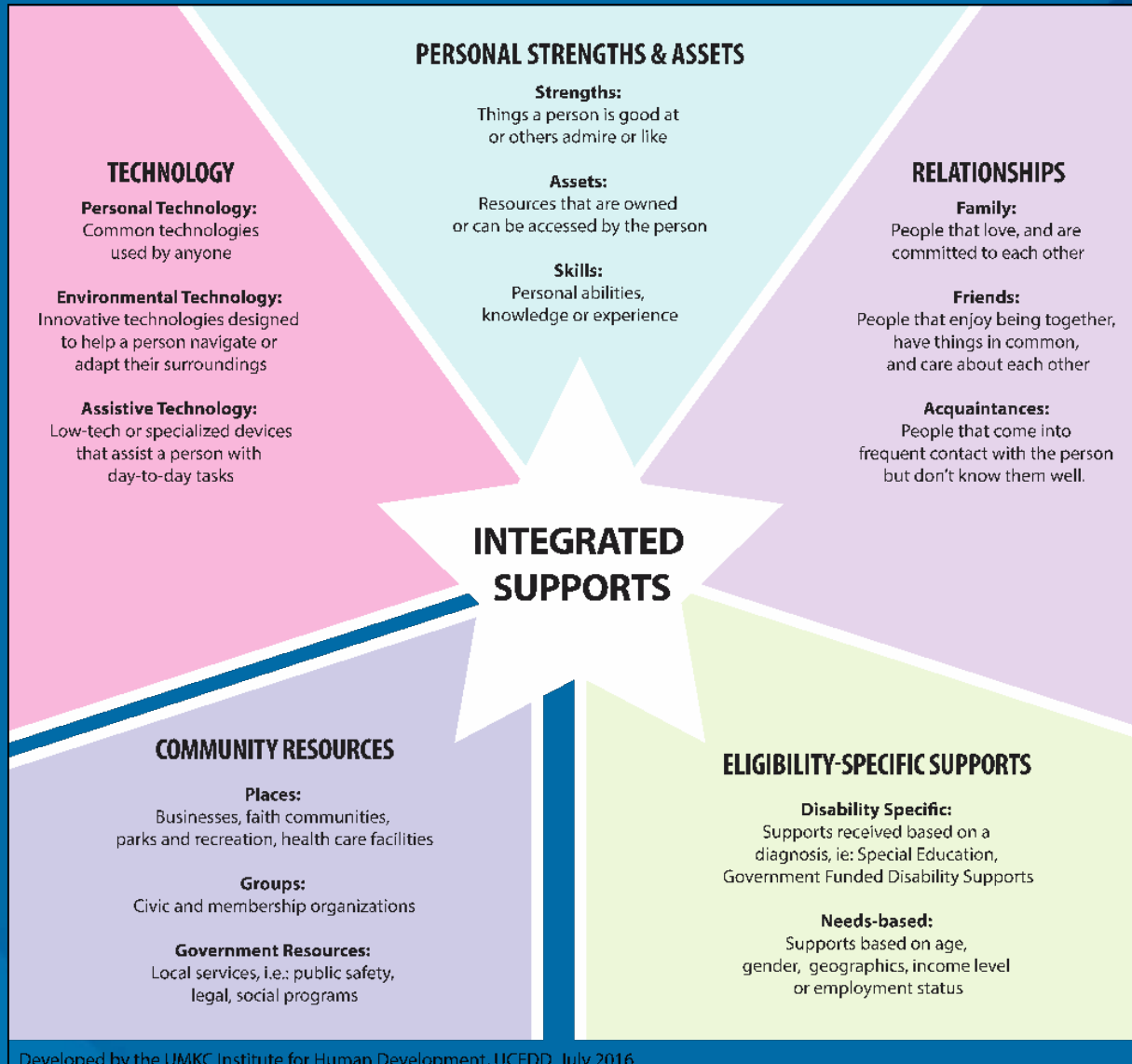
Citizenship and Advocacy
(valued roles, making choices, setting goals, responsibility, leadership, peer support)
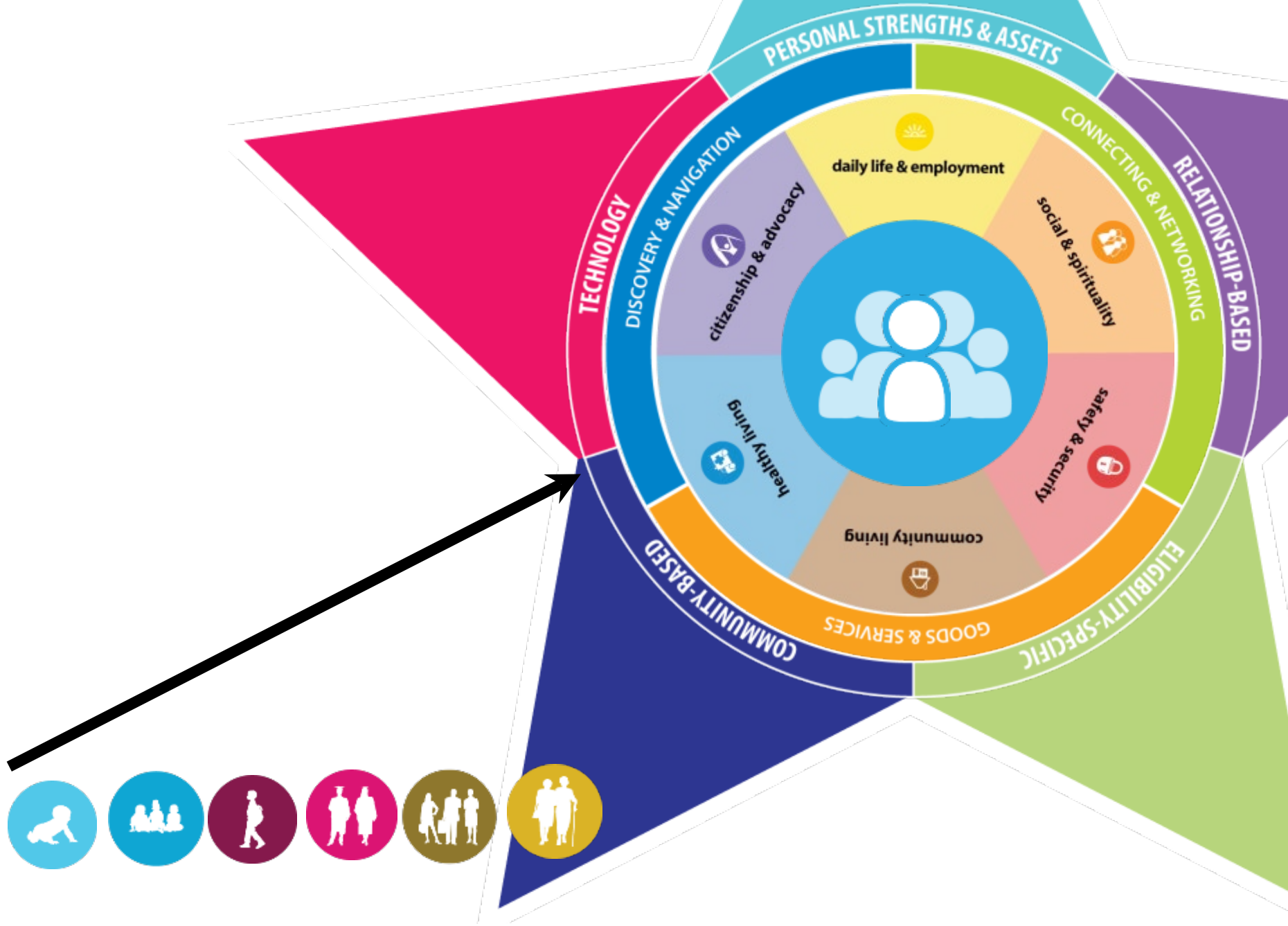
Integrated Services and Supports

More than "Natural Supports and Formal, paid developmental disability services and supports
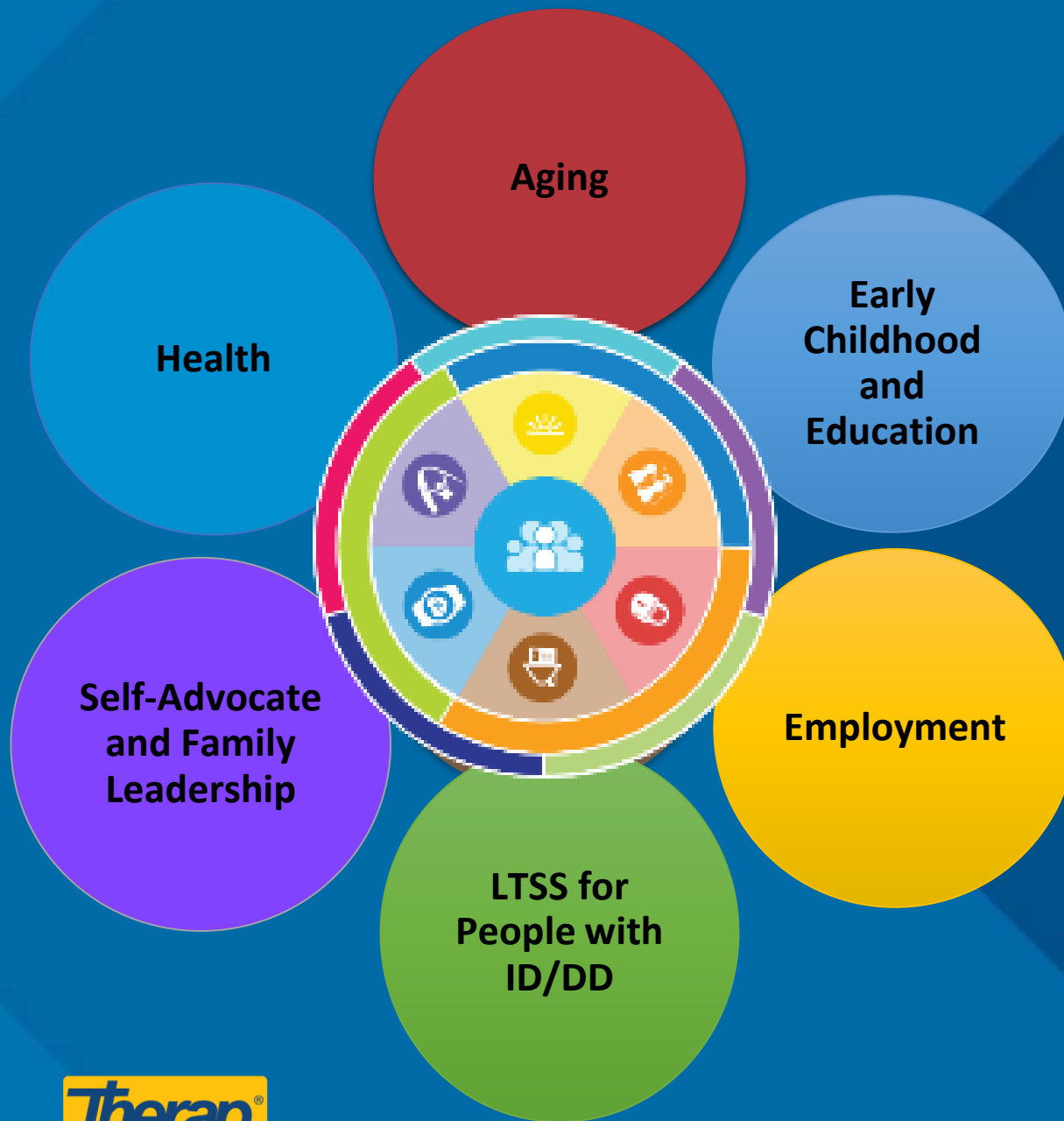
Integrated Support Star

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 surroundings

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

RELATIONSHIPS

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

Friends:
People that enjoy being 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.

INTEGRATED SUPPORTS

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

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PERSONAL STRENGTHS & ASSETS

CONNECTING & NETWORKING

RELATIONSHIP-BASED

TECHNOLOGY

DISCOVERY & NAVIGATION

ELIGIBILITY-SPECIFIC

COMMUNITY-BASED

GOODS & SERVICES

daily life & employment

social & spirituality

safety & security

community living

healthy living

citizenship & advocacy

Comprehensive, Integrated & Coordinated Across All Life Domains and 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

Elevating the Voice of All Team Members

Supporting Person's Self-Determination & Self-Advocacy

Supporting Families Across the Lifespan

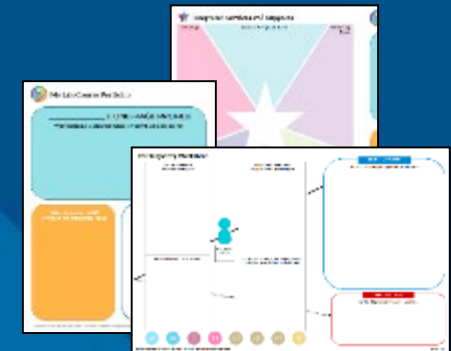Supporting Person-Centered Practices

Tools for All Team Members

Planning for Life Outcomes and/or Service Planning
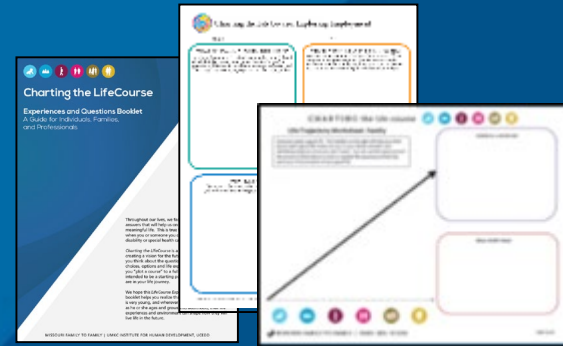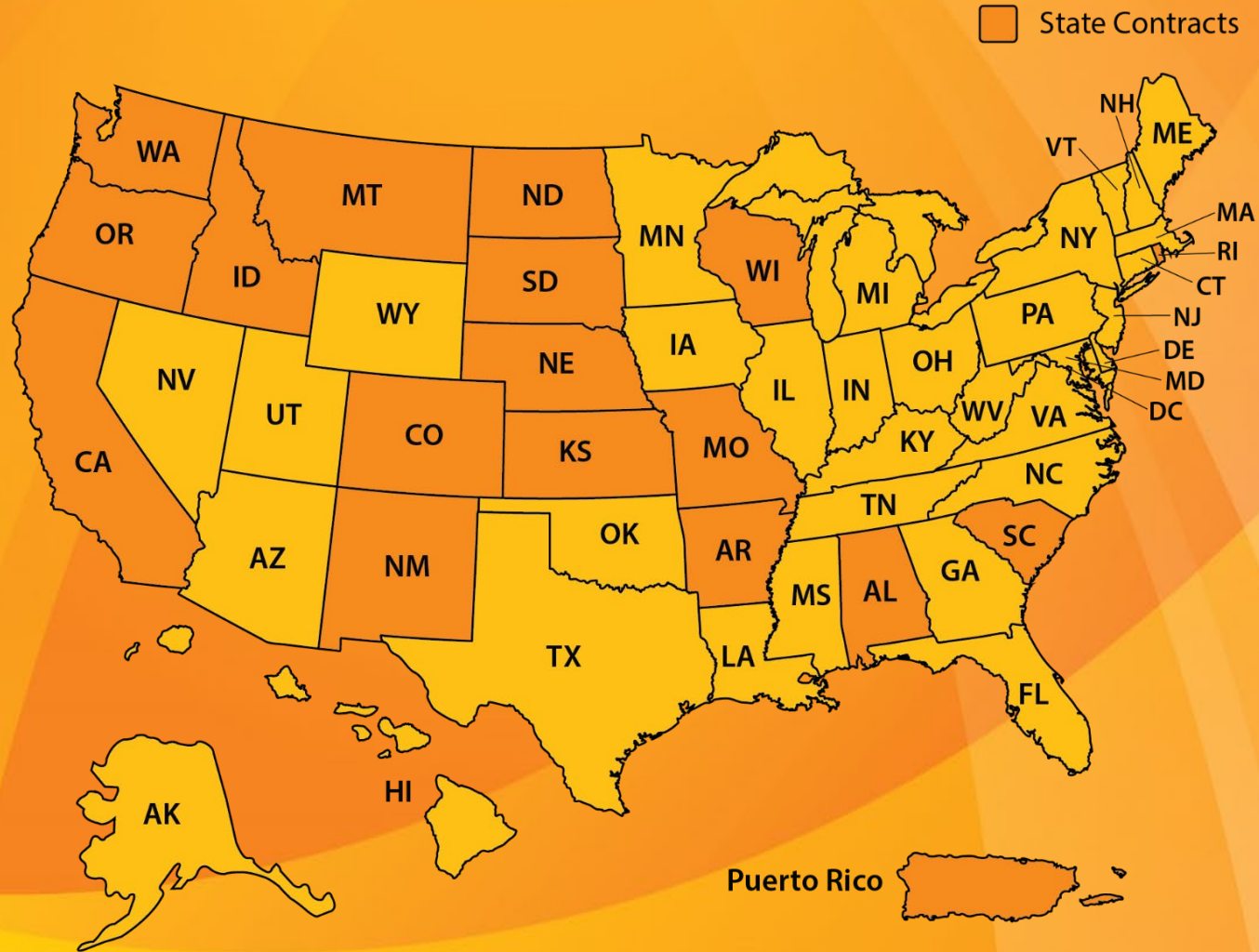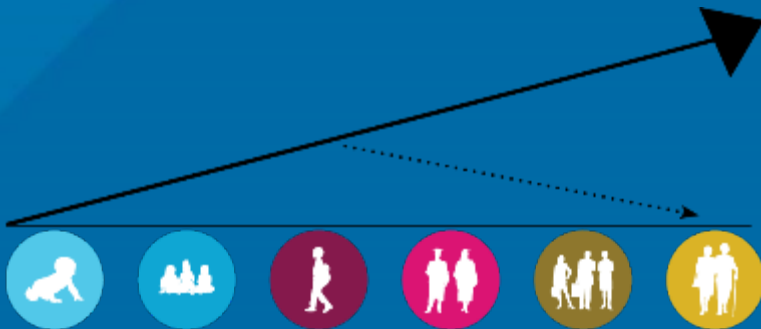

Self-Advocate
Tools & Resources
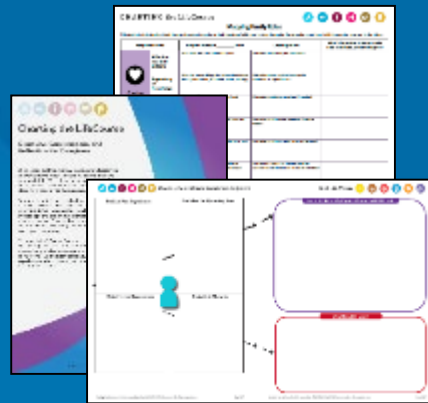
Family Perspective
Tools

Formal Planning
Tools and Forms

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Users in all 50 states and 18 state contracts

Trajectory

VISION for a GOOD LIFE

LIST what you want your "good life" to look like ...

What I DON'T Want

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

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Life Trajectory Worksheet

Past Life Experiences
LIST past life experiences and events that supported your vision for a good life.

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

Future Life Experiences
LIST current/ future life experiences that continue supporting your good life vision.

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

VISION for a GOOD LIFE
LIST what you want your "good life" to look like ...
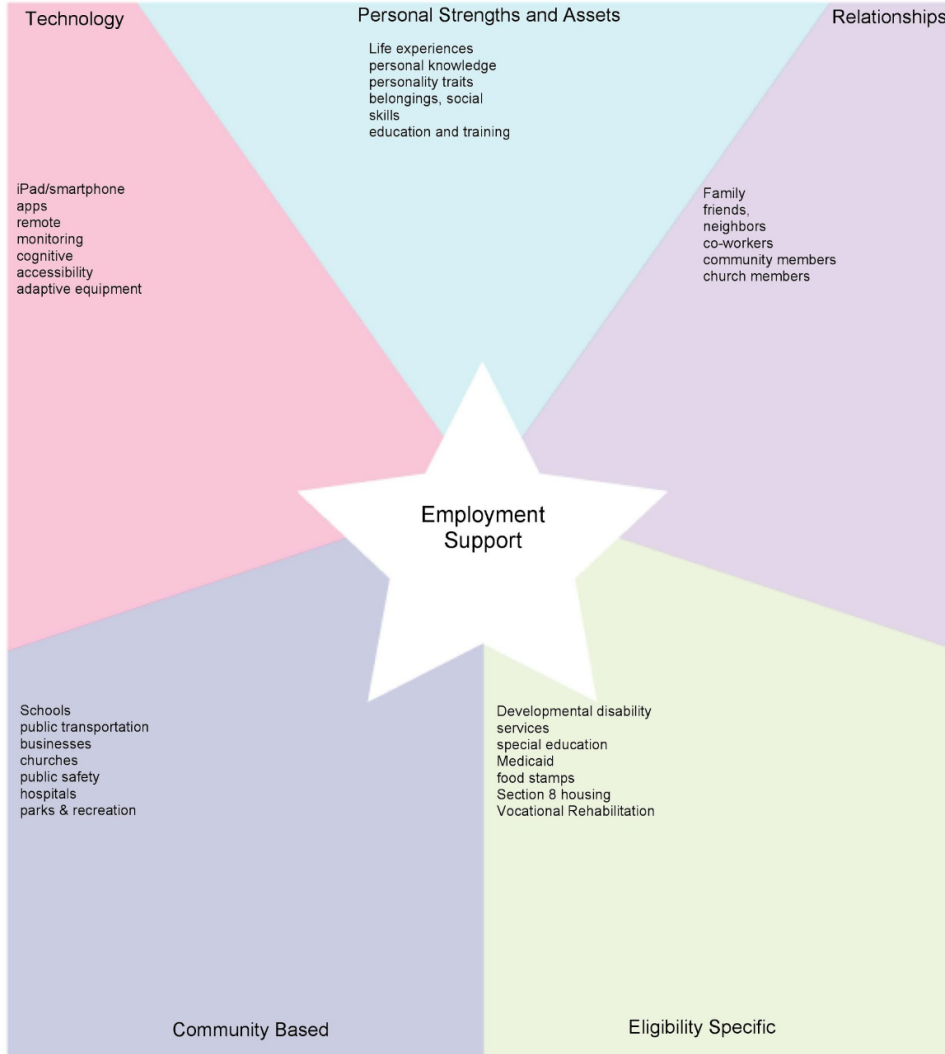
What I DON'T Want
LIST the things you don't want in your life...

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Charting the LifeCourse Nexus

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CHARTING the LifeCourse

Integrated Supports Apple orange, 1234 (Approved)

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

iPad/smartphone
apps
remote
monitoring
cognitive
accessibility
adaptive equipment

Personal Strengths and Assets

Life experiences
personal knowledge
personality traits
belongings, social
skills
education and training

Relationships

Family
friends,
neighbors
co-workers
community members
church members

Employment Support

Community Based

Schools
public transportation
businesses
churches
public safety
hospitals
parks & recreation

Eligibility Specific

Developmental disability
services
special education
Medicaid
food stamps
Section 8 housing
Vocational Rehabilitation

Access the LifeCourse framework and tools at lifecoursetools.com

Developed by the UMKC Institute for Human Development, UCEDD. More tools and materials at lifecoursetools.com   08/01/2019

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CHARTING the LifeCourse

Life Trajectory Worksheet: Individual   Apple orange, 1234 (Approved)

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.

- Participate unsocial events
- Use power services
- Need to socialize to meet people

- Getting Familliar with DART
- Changing my Major

Vision for

Good Life

- Job
- Wife
- Go Places (Trips)
- To discover more about skills
- Continue participating in recreational activities

What I don't want

- Be alone
- To not continue learn new skills
- To not have consistent supports
- To not discover skills

Life Trajectory Worksheet: Individual

Apple orange, 1234 (Approved)

Past Life Experiences

List past life experiences and events that supported your vision for a good life.

- Participate unsocial events
- Use power services

List past life experiences that pushed the arrow toward thing you don't want.

Future Life Experiences

List current/future life experiences that continue supporting your good life vision.

- Need to socialize to meet people

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

Write current age here

20

Vision for
Good Life

- Job
- Wife
- Go Places (Trips)
- To discover more about skills
- Continue participating in recreational activities

What I don't want

- Be alone
- To not continue learn new skills
- To not have consistent supports
- To not discover skills

08/01/2019

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Charting the Life Course

Life Trajectory   New | Search

Integrated Supports Star   New | Search

Life Trajectory

Individual	Matthew Thomas
* **Date** (mm/dd/yyyy)	07/01/2019 📅
* **Template**	Template 2 ▼
* **Perspective**	Individual ▼
* **Vision For**	Good Life

Back   Next

Integrated Supports Star Approved ⓘ

Individual	Hannah Ramirez
* Date (mm/dd/yyyy)	08/01/2019 📅
Type/Subject	Employment Support

Integrated Supports

Personal Strengths & Assets

Life experiences
personal knowledge
personality traits
belongings, social
skills
education and training

About 242 characters left

Relationships

Family
friends,
neighbors
co-workers
community members
church members

About 275 characters left

Eligibility Specific

Developmental disability
services
special education
Medicaid
food stamps
Section 8 housing
Vocational Rehabilitation

About 228 characters left

Community Based

Schools
public transportation
businesses
churches
public safety
hospitals
parks & recreation

About 252 characters left

Technology

iPad/smartphone
apps
remote
monitoring
cognitive
accessibility
adaptive equipment

About 263 characters left

📄 Print PDF

Cancel   Back   Update   Discontinue

Therap ®

Life Trajectory Approved ⓘ

Individual	Matthew Thomas
Date	08/01/2019
Template	Template 1
Perspective	Individual

Vision For a Good Life

Vision
- Job
- Wife
- Go Places (Trips)
- To discover more about skills
- Continue participating in recreational activities

About 880 characters left

What I don't want?
- Be alone
- To not continue learn new skills
- To not have consistent supports
- To not discover skills

About 293 characters left

Supporting Positive Life Trajectories
- Participate unsocial events
- Use power services
- Need to socialize to meet people

About 513 characters left

Preventing Negative Life Events
- Getting Familliar with DART
- Changing my Major

About 550 characters left

📄 Print PDF

Cancel	Back		Update	Discontinue

Life Trajectory Approved ⓘ

Individual	Charlotte Baker
Age	20
Date	08/01/2019
Template	Template 2
Perspective	Individual

Vision For a Good Life

Vision

- Job
- Wife
- Go Places (Trips)
- To discover more about skills
- Continue participating in recreational activities

About 880 characters left

What I don't want?

- Be alone
- To not continue learn new skills
- To not have consistent supports
- To not discover skills

About 293 characters left

Supporting Positive Life Trajectories

Past

- Participate unsocial events
- Use power services

About 349 characters left

Future

- Need to socialize to meet people

About 366 characters left

Negative Life Events

Past

About 400 characters left

Future

About 400 characters left

🅿 Print PDF

Cancel   Back   Update   Discontinue

Questions?

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(816) 522-3683