



Characteristics and Outcomes of Young Adults With ID/DD Receiving Services

Sarah Taub Webinar Series
May 22, 2018

What is NCI?

- NCI is a voluntary effort by public developmental disabilities agencies to measure and track their own performance.
- Collaboration began in 1997
- Currently 46 states and Washington D.C. represented plus 2 sub-state entities (regional centers in California)
- Coordinated by HSRI and NASDDDS



NCI Goals

- Establish a nationally recognized set of performance and outcome indicators for DD service systems
- Use valid and reliable data collection methods & tools
- Report state comparisons and national benchmarks of system-level performance



Selected Findings

Outcomes and Characteristics of Young Adults Receiving Services



In-person Survey

- Formerly the Adult Consumer Survey
- Adults who receive at least one service beyond case management from the IDD agency
- Face-to-face survey with the person receiving services
- Survey includes three main parts:
 - Background information
 - largely collected from state records
 - Section I – Subjective questions *only* the person can answer
 - Section II – Objective questions can be answered by a proxy when needed



Where Do the Data Come From?

- In-person Survey data from 2015-16 data collection cycle
 - Includes data from 35 states and Washington D.C.
- Two sub-groups were created for comparison using age variable from the Background Information section
 - Data on individuals for whom age information was not available were excluded from analysis
- The total number of individuals in each group was:
 - 2,726 in the 18-25 age range
 - 14,732 who were 26 and older
 - Total sample of 17,458 individuals.



How were the Data Analyzed?



- Chi-squared analyses were conducted to assess significance between age cohorts
- All reported differences in this data brief are significant at the $p \leq .01$ level
- Statistical significance means that the result cannot be attributed to chance but in fact is a true reflection of actual differences



Nature of Disability

Has an ID Diagnosis

18-25

- 88%

26 and older

- 96%

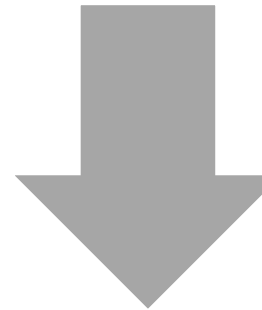
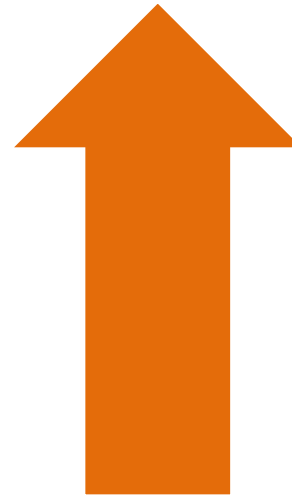
Has ASD

18-25

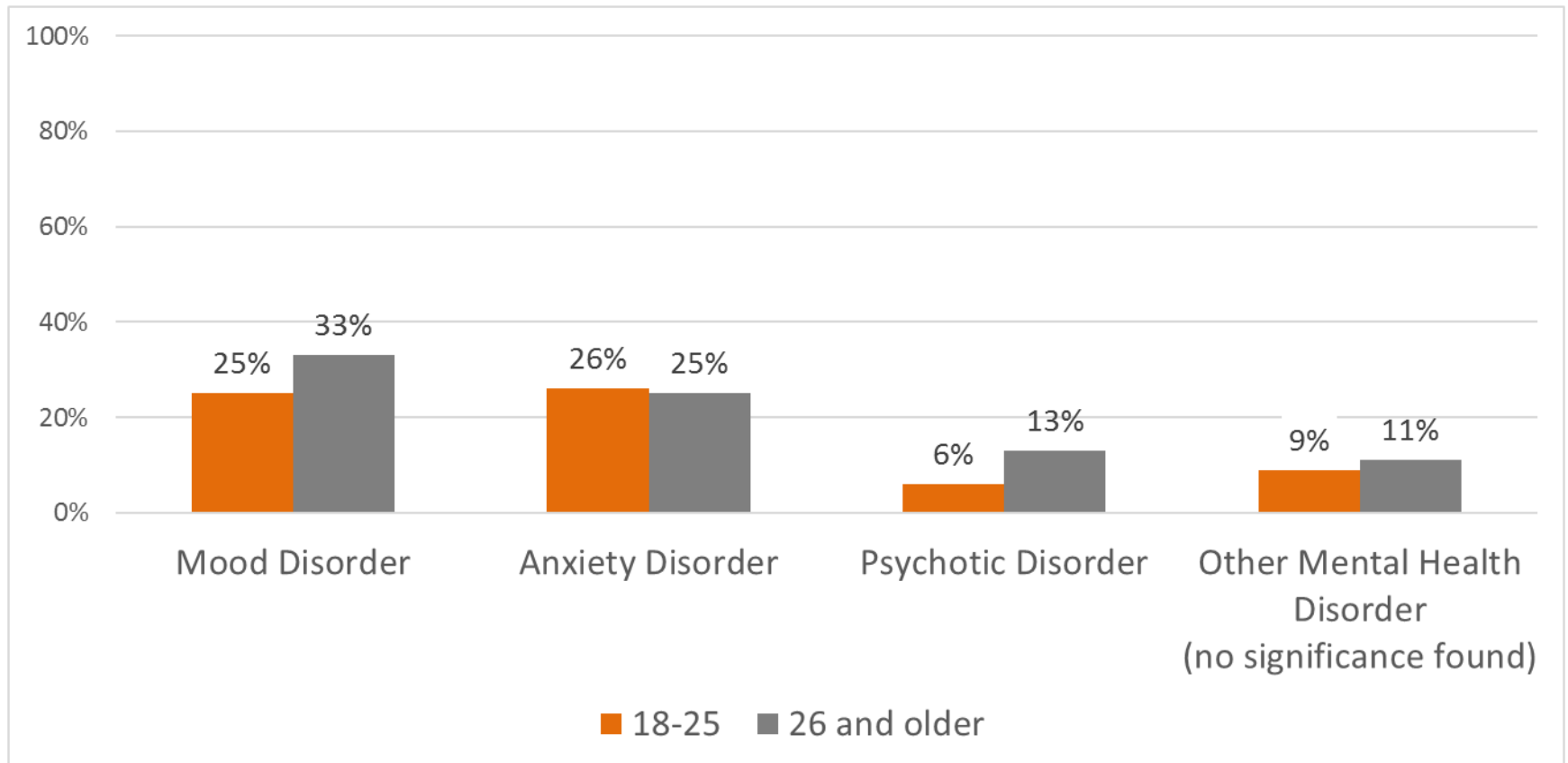
- **39%**

26 and older

- **13%**



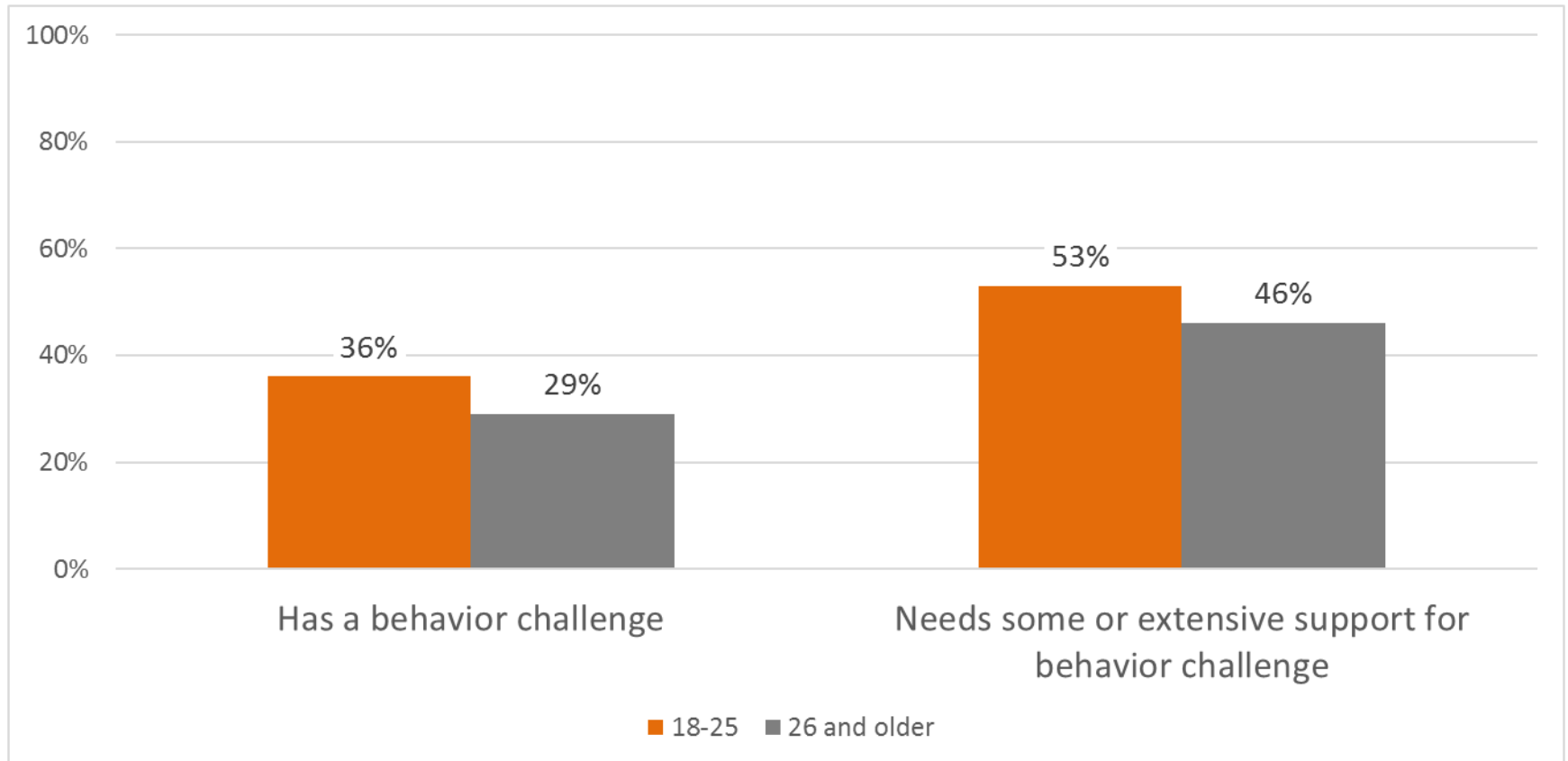
Presence of Mental Health Diagnosis



42% of 18-25 year old versus **50%** of those 26 and older had at least one mental health diagnosis



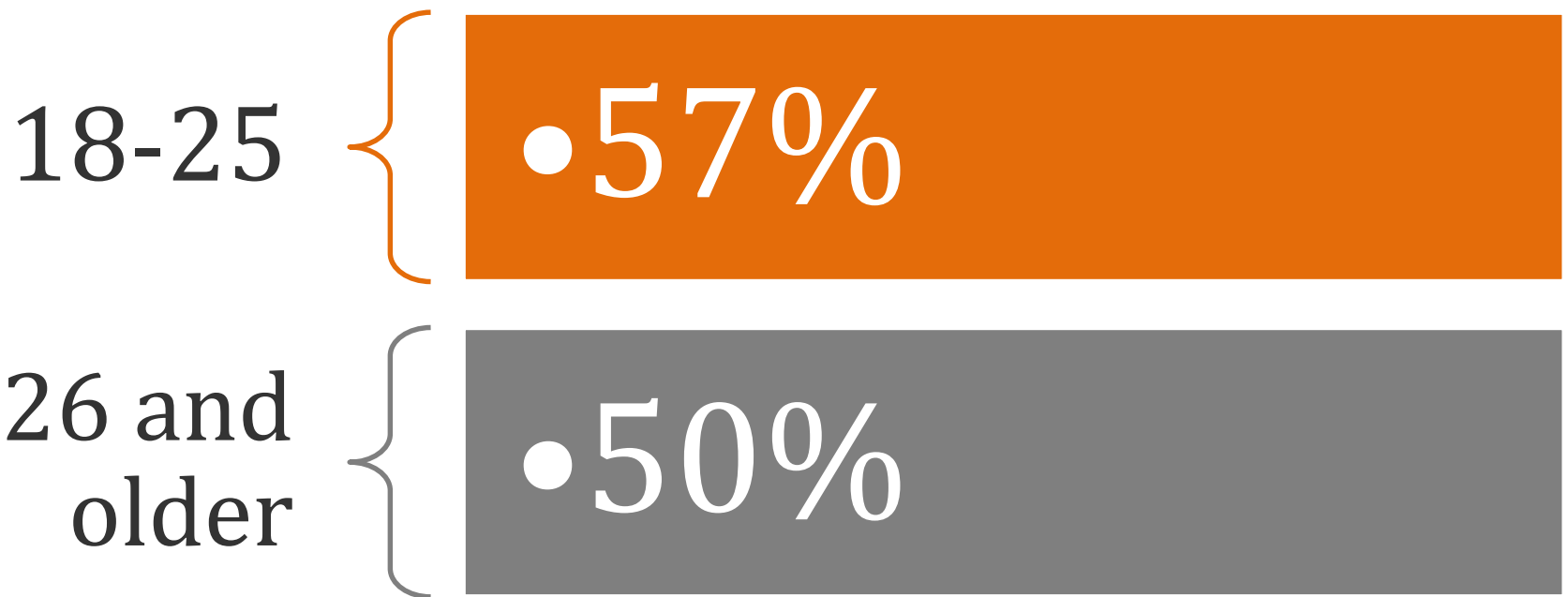
Behavior Challenge(s)* Requiring Support



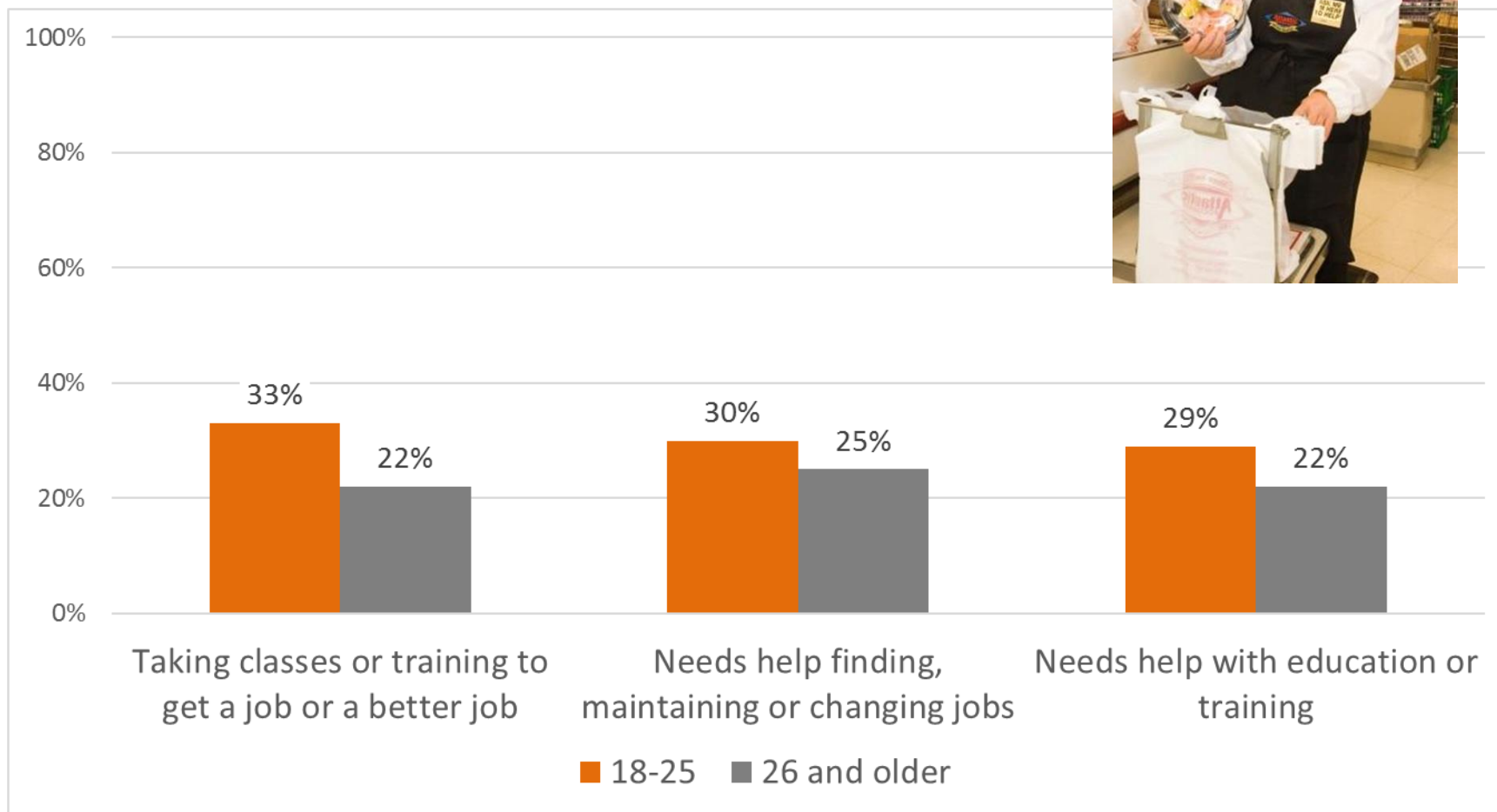
*Self-injurious, destructive, and/or disruptive behavior



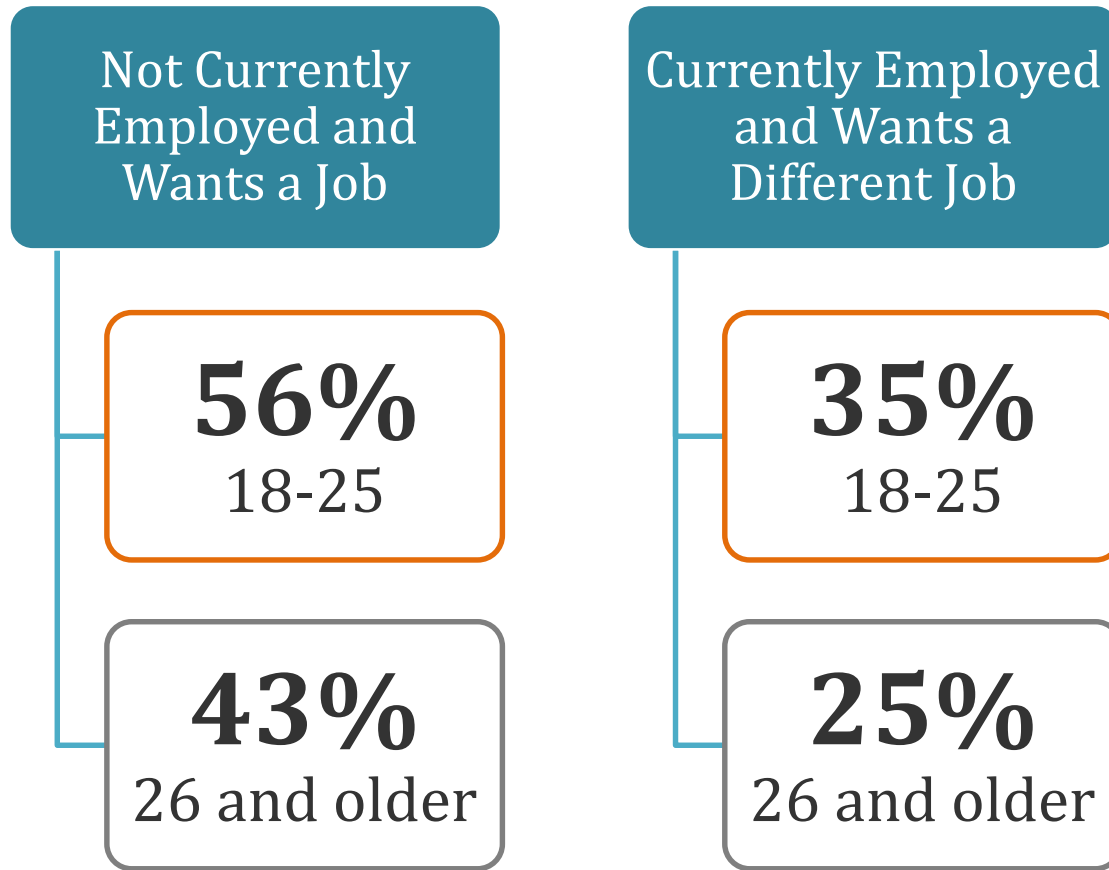
Has a Guardian or Conservator



Training, Employment and Education



Employment

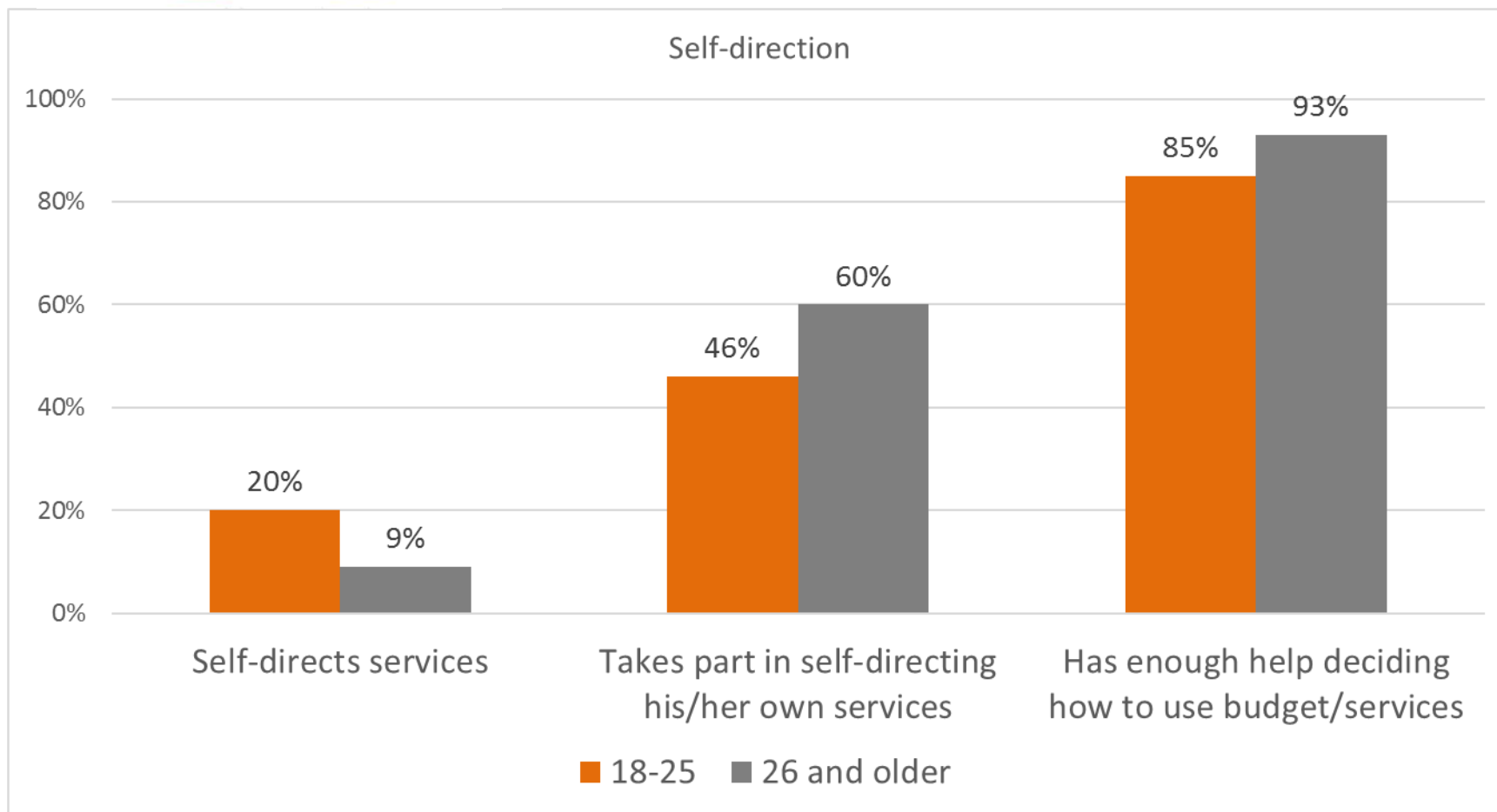


18% in both cohorts had a paid community job





Self-Direction



Additional Findings

- 18-25 years were *more* likely to:
 - Live at home and want to live elsewhere
 - Have rules and restrictions in their everyday lives
- 18-25 years were *less* likely to:
 - Make choices in their everyday lives
 - Have attended a self-advocacy group, meeting conference or event
 - Have voted in a local, state or federal election



Questions for Policy Makers

- Do you carry the transition process beyond the person's graduation from school to ensure a seamless move from adolescence to a productive and empowered adulthood?
- Do you include person-centered expectations during the transition regarding community and civic involvement, postsecondary education, vocational training, self-direction?
- Do you address family expectations during transition?
- Do you make provision for work experience even before the preparation of the transition plan to enhance the possibility of post-graduation employment?



Questions for Policy Makers

- Are alternatives to guardianship explored during the transition process?
- What does your state NCI data tell you about the frequency of guardianship among young adults?
- Is information about supported decision-making broadly disseminated?
- Are you tracking results on the NCI Child Family Survey to detect trends in the numbers of children diagnosed with autism (2015 – 2016 data indicate that 56.2% of children are on the spectrum)?



Young Adult Data Brief

Full data brief can be found here:

[https://www.nationalcoreindicators.org/upload/core-indicators/NCI Young Adult Data Brief Final 1.pdf](https://www.nationalcoreindicators.org/upload/core-indicators/NCI%20Young%20Adult%20Data%20Brief%20Final%201.pdf)

Or by going to:

nationalcoreindicators.org → Resources → Data Briefs





Charting the LifeCourse

Sheli Reynolds, PhD

May 22, 2018



About Sheli Reynolds, PhD

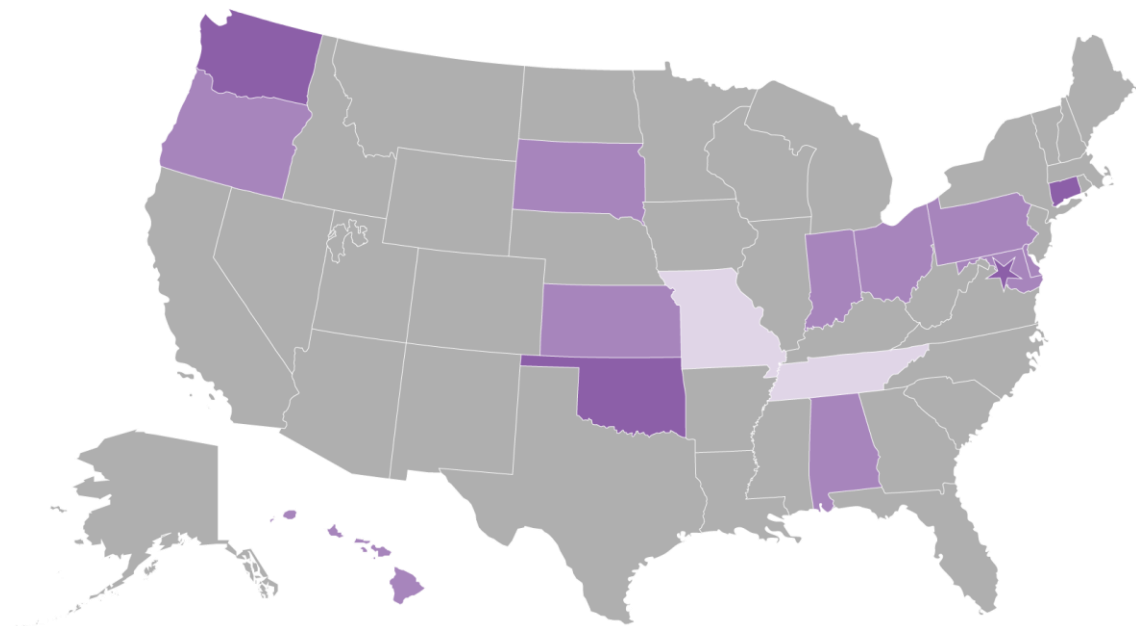
- Associate Director, UMKC Institute for Human Development, University Center on Excellence in Developmental Disabilities
- Research Associate Professor, Department of Biomedical and Health Informatics, UMKC School of Medicine
- Citizen Member, Presidents Committee for Persons with Intellectual Disabilities Appointed by President Obama
- Sibling of three brothers, one who is 35 years old with developmental disability



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.



NASDDDS

National Association of State Directors of
Developmental Disability Services

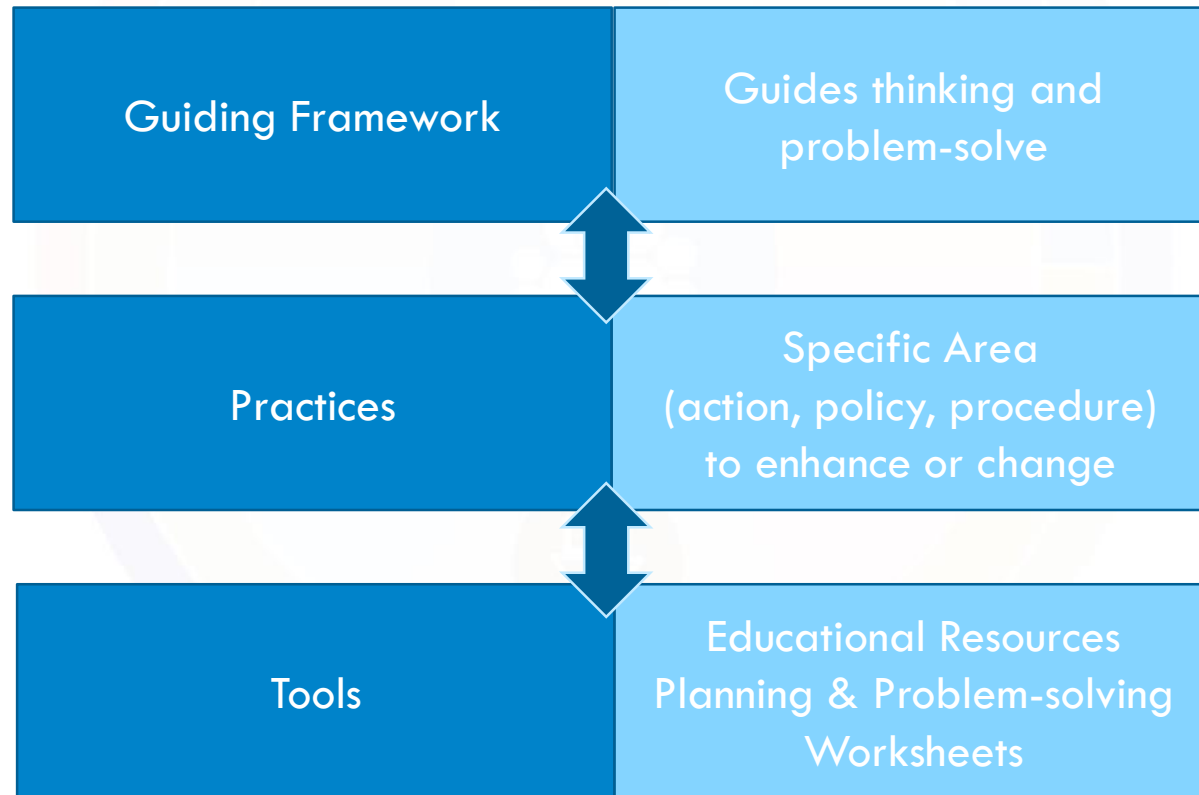
UMKC

INSTITUTE FOR HUMAN DEVELOPMENT
A University Center for Excellence in Developmental Disabilities (UCEDD)

Original Funding Source

ACL
Administration for Community Living

What is Charting the LifeCourse??



Thinking that Guides the Framework

Family Systems Theory

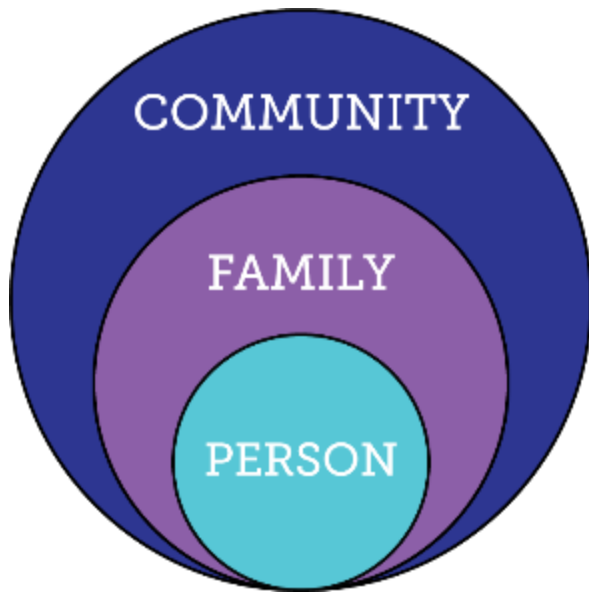
Life Course Theory Social Capital
Person-Centered Practices
Socio-ecological Model
Family-Centered Practices
Community Integration Public Health Model
Anticipatory Guidance
Self-Determination





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





Everyone exists
within the context
of family
and community



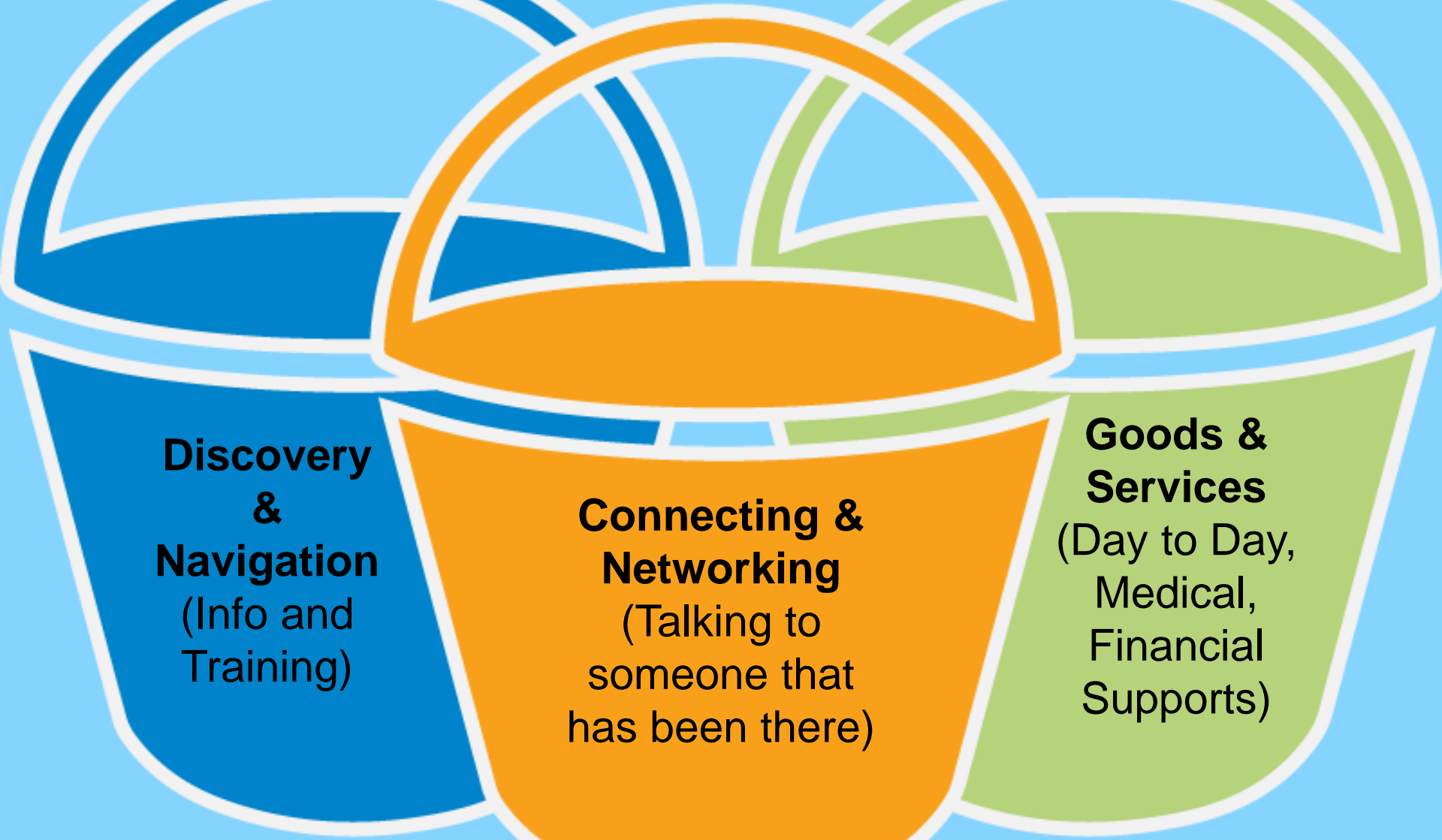
Traditional
Long Term Services
and Supports



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

Charting the LifeCourse Key Principle:
**Person within the Context of the Family
and Community**





Charting the LifeCourse Key Principle:
**Supporting Informational, Social Emotional and
Day-to-Day needs**





Charting the LifeCourse Key Principle:
Holistic Focus across Interconnected Life Domains



Vision for a Good Life



*The future is not something we enter.
The future is something that we create.*

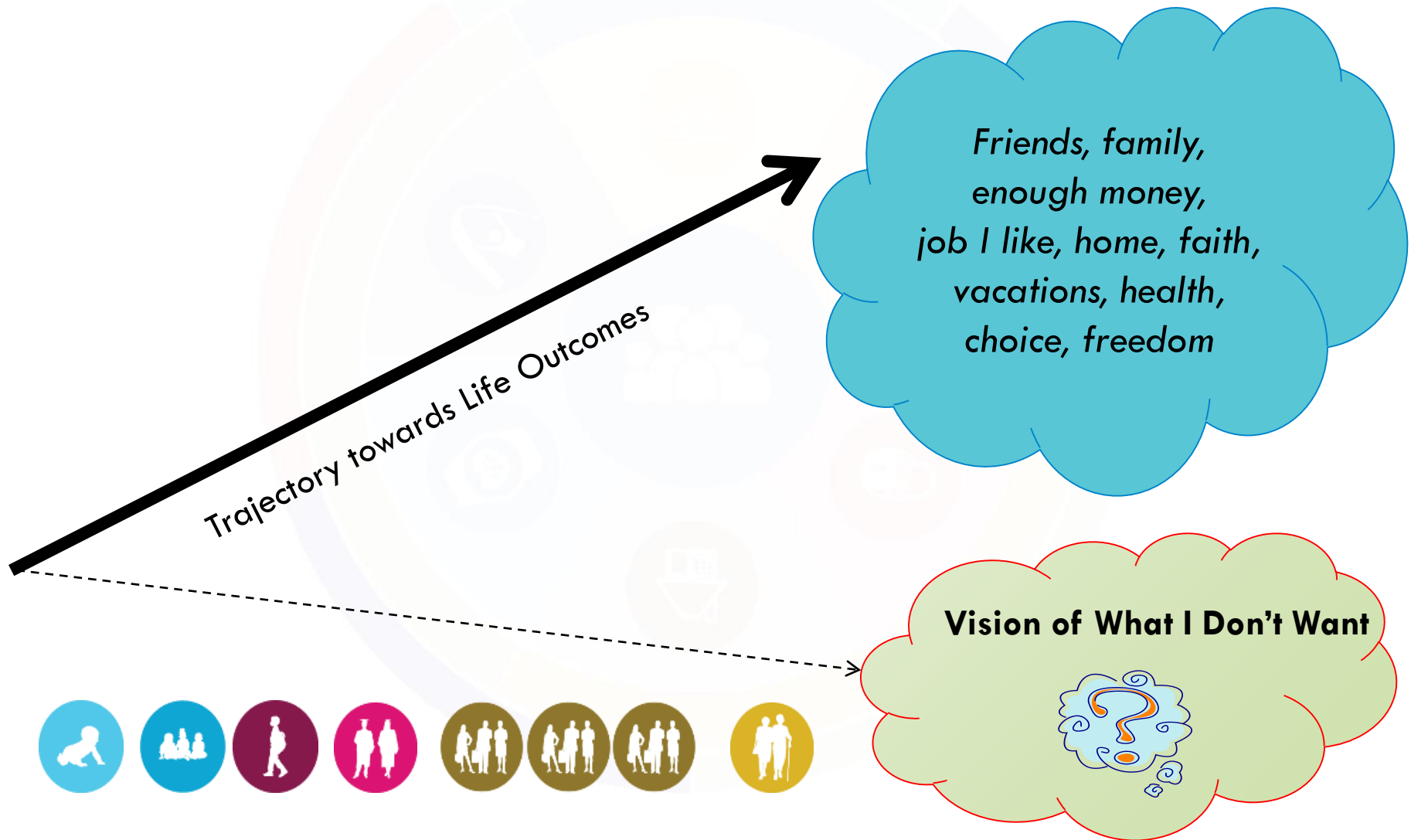
*And creating that future requires us to make choices and
decisions that begin with a dream.*

-Leonard L. Sweet

Charting the LifeCourse Key Principle:
Trajectory for Enhancing Life Experiences

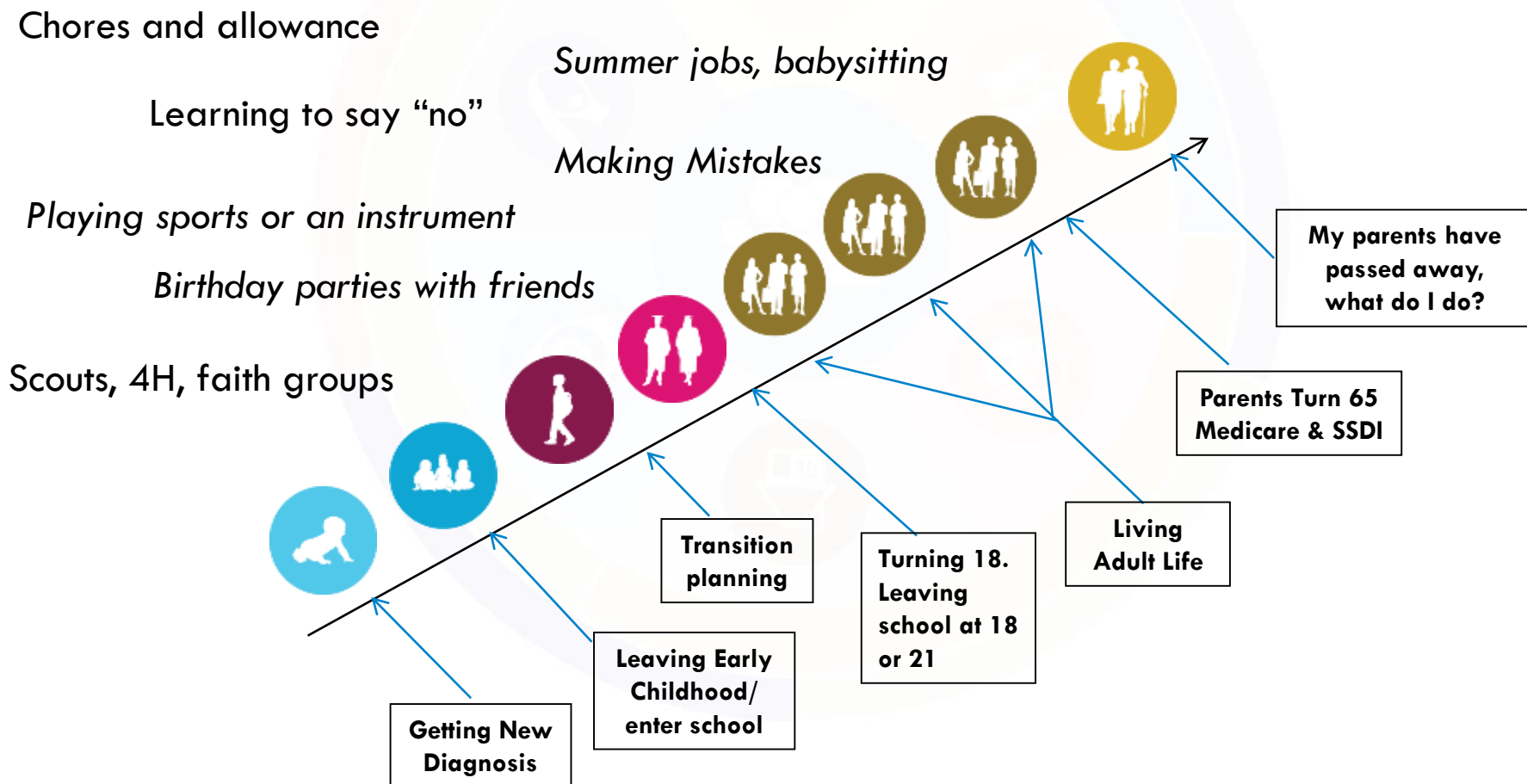


Trajectory towards Good Life



Formal Services & Life Experiences

“Anticipatory Guidance for Life Experiences”



Intentional Supports that Focus on “Life Experiences”



Not known to System

Receiving State DD
Services

ISP

IEP

Health Plan

Financial Plan



CtLC Portfolios

Focus Person & Family Perspective

The image displays two worksheets from the CtLC Portfolio. The primary worksheet is the 'Life Trajectory Worksheet', which features a central figure icon with a box to 'Write current age here'. To the left of the figure are two boxes for 'Past Life Experiences': the top one for experiences supporting a vision for a good life, and the bottom one for experiences pushing away from things one doesn't want. To the right of the figure are two boxes for 'Future Life Experiences': the top one for experiences supporting a good life vision, and the bottom one for experiences to avoid. Arrows connect the past and future experience boxes to a large purple box on the right titled 'VISION for a GOOD LIFE' (with the instruction 'LIST what you want your "good life" to look like ...'). Below this is a red box titled 'What I DON'T Want' (with the instruction 'LIST the things you don't want in your life...'). At the bottom of the worksheet are icons for various life domains and the text 'Charting the LifeCourse Portfolio is a template of the UMKC IHD, UCEDD. More materials at lifecoursetools.com' and 'OCTOBER 2016'.

Charting the LifeCourse Integrated Supports Star: Mapping

Technology Personal Strengths & Assets Relationships

Charting the LifeCourse Portfolio: Planning

Name: _____

What Do People Like and Admire About Me?

What Is Important to Me?

What Are The Best Strategies To Support Me?

OCT 2022

Life Trajectory Worksheet

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

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

Write current age here

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

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

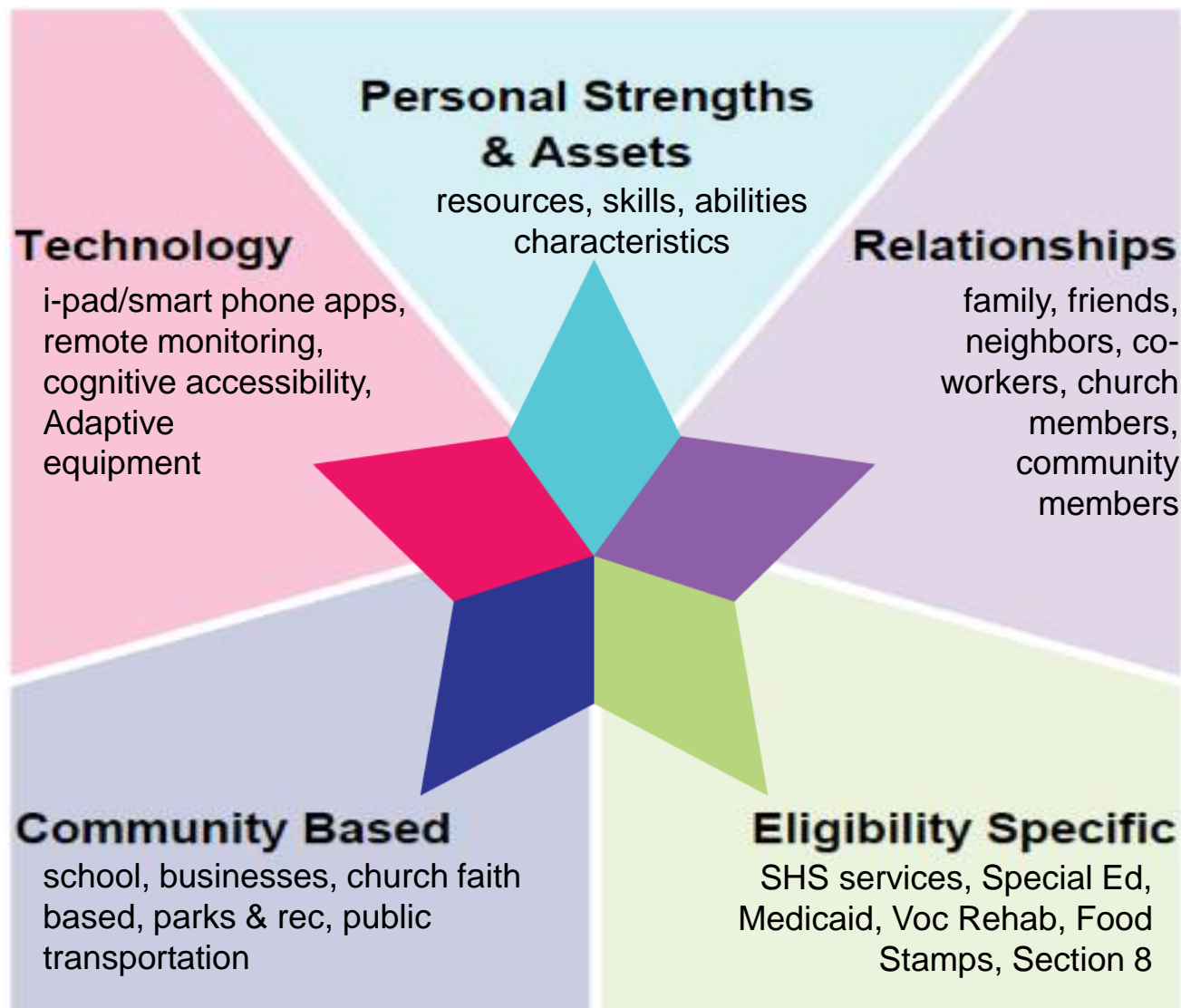
VISION for a GOOD LIFE
LIST what you want your "good life" to look like ...

What I DON'T Want
LIST the things you don't want in your life...

Charting the LifeCourse Portfolio is a template of the UMKC IHD, UCEDD. More materials at lifecoursetools.com

OCTOBER 2016

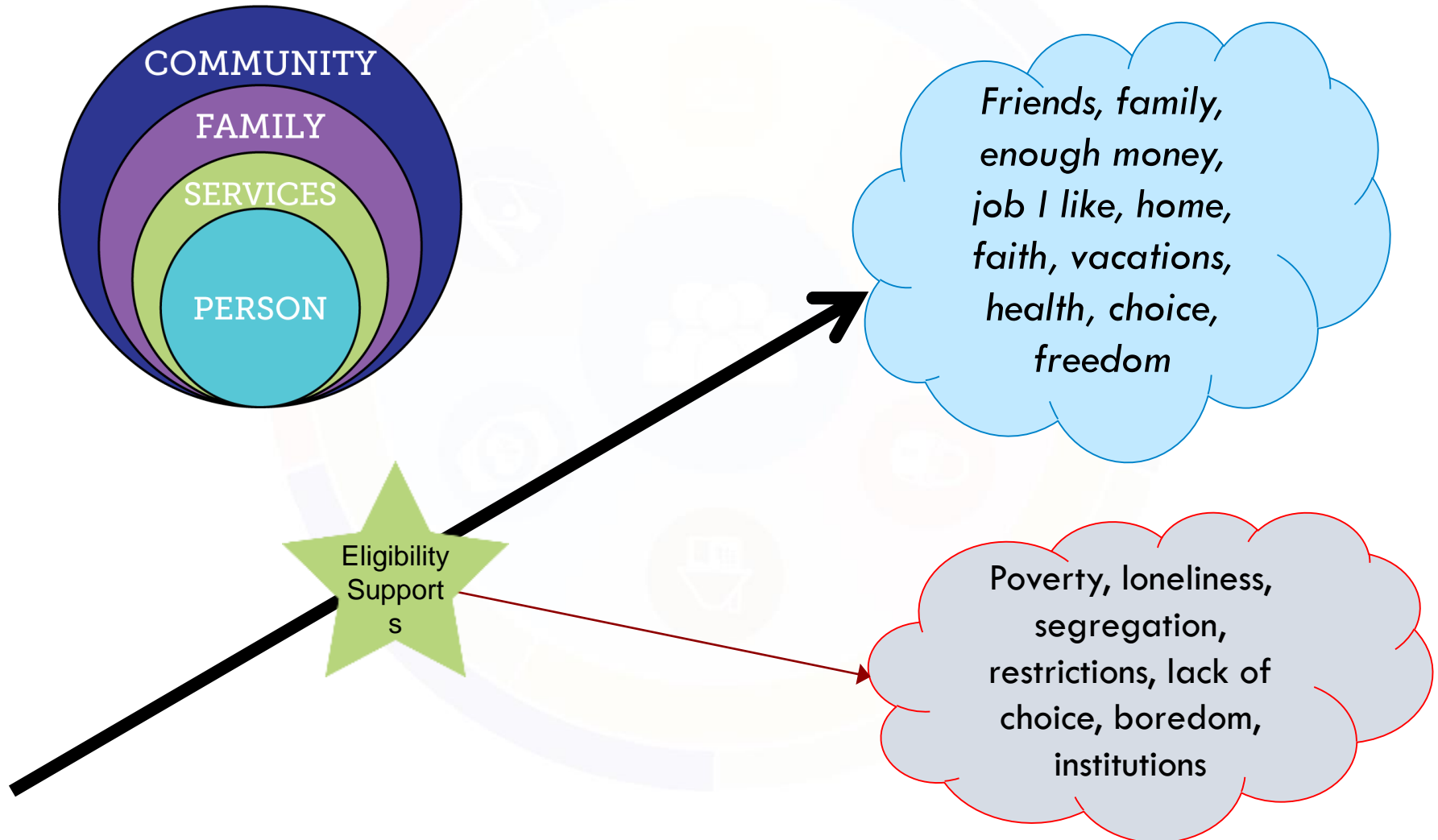




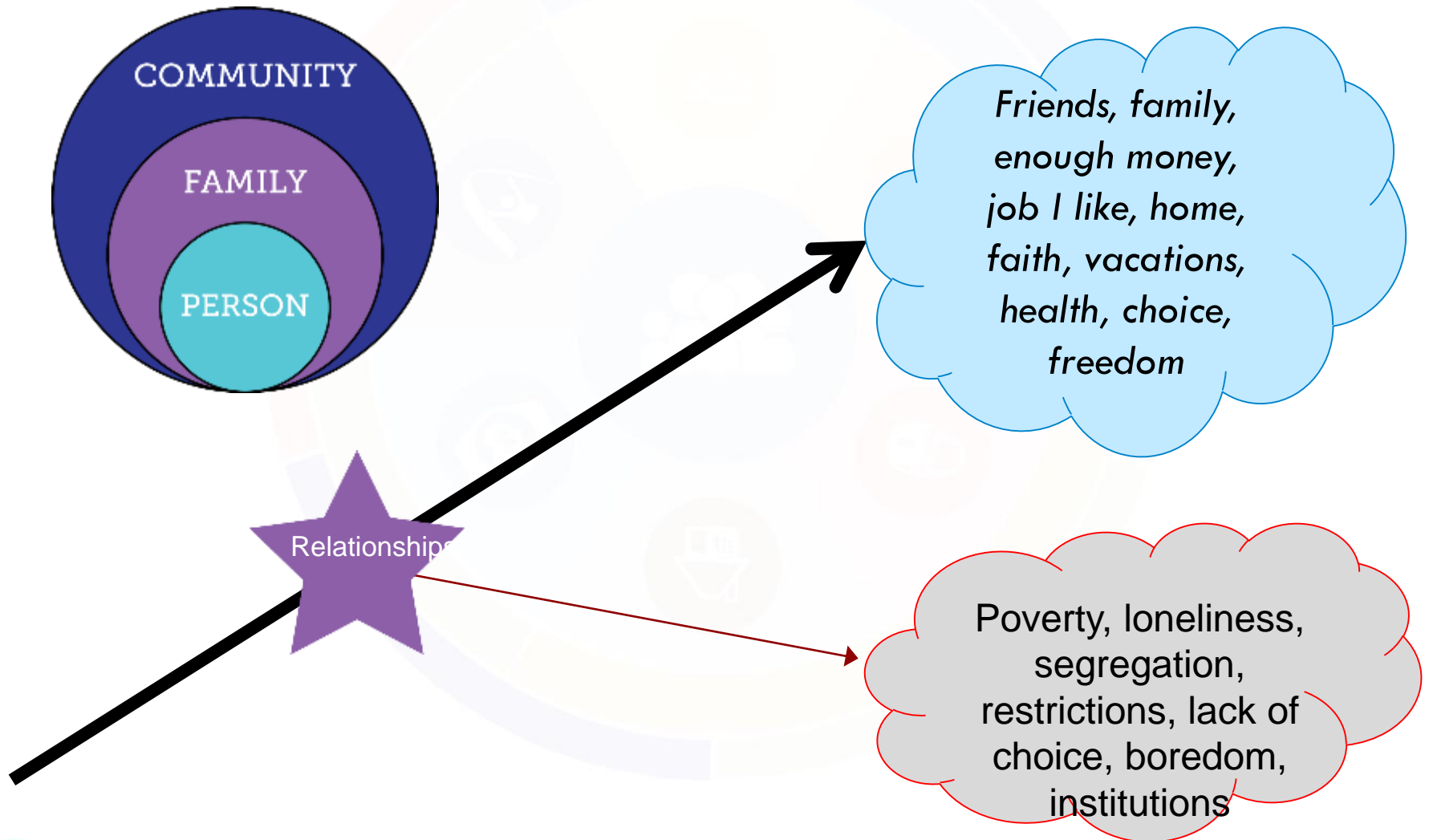
Charting the LifeCourse Key Principle:
**Integrating Services and Supports
Across the Life Span**



Focusing ONLY on Eligibility Supports



Relying ONLY on Family & Friends





The Garcias Good Life



Family,
home, work
health, keep
culture,

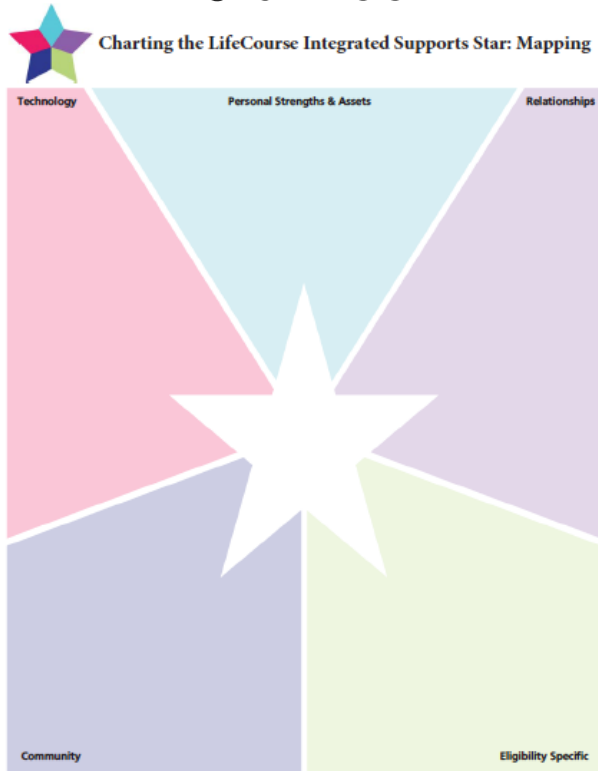
Moving
away to get
supports, not
staying
together



CtLC Integrated Problem Solving Stars

Star Tool

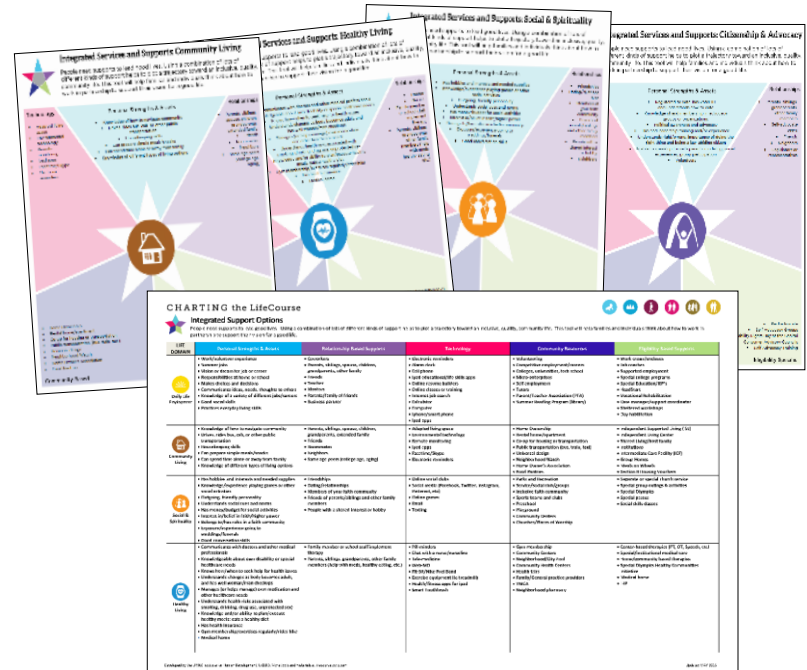
Integrated Star Educational Resources



Access the Charting the LifeCourse framework and tools at lifecoursetools.com

Charting the LifeCourse Portfolio is a template of the UMKC IHD, UCEDO. More materials at lifecoursetools.com

SEPT 2017













Charting the LifeCourse: Achieving Personal Outcomes





Tool for Developing a Vision - Family

LIFE DOMAIN		My Vision for My Family Member's Future	priority	Current Situation/Things to Work On
 Daily Life Employment	What does I think my family member will do during the day in his/her adult life?	Continue to volunteer at Fire Station because he loves it and he belongs. We want to help Ben start his own small business, based on his interests, using the Micro-Enterprise model. We want him to be active /not sit home all day.	1	Priority #1: We need to help Ben figure out how one of his interests can be used to help him start a small business and make money. We also need to explore how to do this and maintain his eligibility for Medicaid. We also need to work with his daytime staff and help them with ideas on ways to get him out of the house more.
 Community Living	Where and with whom do I think my family member will live in his/her adult life?	Ideally, we want Ben to either rent or own an apartment, condo or house, and have a roommate or live-in companion. For now, we are looking at options for him to be more independent within our family home.	4	
 Social & Spirituality	How will he/she connect with spiritual and leisure activities, have friendships & relationships in his/her adult life?	Ben loves going to weekly mass and a lot of people there talk to him. The fire department is so is a source of friendships for him. We want him to keep in touch with friends via social media and invite friends over or out and about with him. We would like him to have a girlfriend and maybe get married.	2	Priority #2: We need to take a more active role to help Ben invite friends to do things with him, especially the firemen outside the station.
 Healthy Living	How will he/she live a healthy lifestyle and manage health care supports in his/her adult life?	Ben would work out at least 3-5 times/week, eat healthy food choices, and limit caffeine (Pepsi). We want to get a pill dispenser so he can be more independent taking his meds. We want him to be able to talk to his health care providers and be supported to make choices about his medical care.	3	Priority #3: Explore buying a medication dispenser that he can start learning how to use while we are around to supervise and help him. We also think it is a good idea for him to start a small container garden to grow some of his own vegetables.
 Safety & Security	How will he/she protect from financial, emotional, physical or sexual harm in adult life?	We want Ben to have lots of friends and family members who keep in touch with him regularly and will notice if something is wrong. He has a trust committee for his SN Trust, and he has family who are his Powers of Attorney. Use available banking options for financial security.		Priority #4: We would like to finish our basement as a possible apartment for Ben or at least a hangout space where he can spend time with friends away from mom and dad.
 Citizenship & Advocacy	How can I make sure he/she has valued roles and responsibilities, and has control of how his/her own life is lived as an adult?	We would like to see Ben have more active roles at church – maybe ushering or joining the men's group. Maybe find some other volunteer opportunities. Ben should be supported by family and trusted friends to make his own decisions and choices.		
 Supports for Family	What will our family need to help support him/her in his/her adult life as needed?	Helping Ben self direct his services is helpful so we can continue to work while still being able to hire people we know or that are highly recommended. We need coaching and mentoring for future options.		
 Supports & Services	How will he/she be supported in adult life to live the kind of life he/she wants as independently as possible?	By using a combination of technology, family and friends, community options, paid supports, and building on Ben's own skills and abilities, we think he can have the good life he wants.		

Working with Families to Capture Vision for their Son

Getting more specific in each life domain



Creating a Shared Vision for Parents and Team Members

Used during Early Childhood Transition Planning Meeting

CHARTING the life course
MAX's ONE-PAGE PROFILE

What people like & admire about me

Funny
Cute
Little

Complimentary
Affectionate
Energetic

What's Important to ME

Attention
Family
Toys
Food
Cooking with mom

How to Best Support ME

- Boundaries
- Consistency
- Appropriate affirmation

MISSOURI FAMILY TO FAMILY | UMKC-IHD, UCEDD

AUGUST 2015

Integrated Services and Supports

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

Technology

Personal Strengths & Assets

Relationship Based

- likeable
- social
best - affectionate
no entime

- he was in pre-school/peer relationships (childcare)

Goal for Academic readiness

res neighbor kid - good relationship

- Biological Mother bases a lot of decisions on scheduling needs - but feels full time pre-k/childcare is the answer

MISSOURI FAMILY TO FAMILY | UMKC-IHD, UCEDD

AUGUST 2015

Home with Family

- Social skills
with parents/family

- Play with TV and toys
in the house

- Different reactions
due to being the baby

- Time of transitioning
from home to school

- Missing Mom
as things are not
the same

- Supporting the
transition of the
family

- Getting ready
for school

- School Success

- Friends

- appropriate behavior and
social functioning

- positive relationships

- consistent expectations

- Support and Praise

- Support in home
to give him different
experiences and to
strengthen his behavior
appreciating his skills

MISSOURI FAMILY TO FAMILY | UMKC-IHD, UCEDD

AUGUST 2015



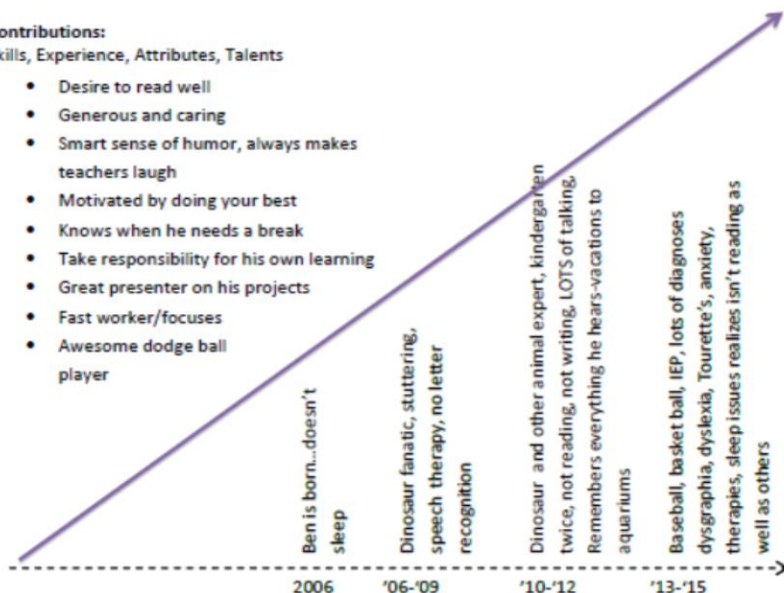
Educate School Team on Vision

Elementary School Trajectory Worksheet:

Contributions:

Skills, Experience, Attributes, Talents

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



What I DON'T Want

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

VISION for successful school experience and a GOOD LIFE

Long term education desires and goals:

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

Educate his classmates on Tourette's

He is determined to be able to read on grade level

Conditions:

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

Preferences:

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

Support Needs:

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

Mapping Experiences for 6th Grade Year

Personal Strengths & Assets

Sean is easy to wake up in the morning. Although he doesn't pick out his clothes he does share when he doesn't want wear something that has been picked out for him by his mom. Sean enjoys school, which is a great asset to his education. He gets good grades (All A's & B's) and in the last couple of years has figured out that he thrives more in the regular classroom than in the resource room with other with special needs. Sean's handwriting is improving, he excels in science, and has gained several new friendships this year.

One of Sean's favorite times of school is Advisory Time which he is able to finish homework, play games, hang out in the gym, and partake in his favorite sports.

School Technology

Digital Clock
Chrome Book
School Bell
Locker Combination Lock

Home Technology

I-Pad
Clock
Game systems

Relationship Based

Sean likes his teachers, especially Mrs. Skaggs because she likes him & his love for science.

Some of his friends are Michael, Jackson, Cameron, Colby, James & Oakley

Sean's immediate family also helps him with excelling in school and contributes to his love of education

Short term goal

An AWESOME science project

My 6th
Grade Year

Long term goal

Science teacher focusing on fossils

Community Based

Mom drives to and from school

LOQW Summer YES Program- helped maintain safety skills and opportunities for future employment. Sean is greatly looking forward to being able to participate in this program again.

Eligibility Specific

IEP guided education
Floating paraprofessional
Speech Therapy
Service Coordination

Vision for a Good Life

Spending time with my friends
Going to the YES Program
Doing an awesome science experiment, one with potions and explosions

What I Don't Want

To get in trouble
To forget anymore school work, it is embarrassing

My new friend came over to play

Relationship building outside of school

LOQW Summer YES Program

Building of school relationships

Regular Class with Peers

Advocating at IEP

Motivational teacher

Resource Room



Self-Lead IEP Transition Plan

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" with a disability.



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.



MY TIMELINE



Elementary
2004-12 (13)

on,
Play

Middle School
2012-13 (14)

High School
2013 - 17 (14-18)

I am
here

Transition
2017-20
(18-21)

Adult Living
2020... 21+



Career Planning Star



Future Career Planning Caleb

Relationship Based

Decision Making:

Caleb's family farms

Caleb can express his

preferences.

Caleb needs support to

understand the situation to

make choices.

There are some situations he will not

comprehend and will need more input

from trusted family or friends.

Skills:

Caleb has been trained to understand how

to pick and handle produce in the garden.

He is interested in learning more about animals.

Caleb has support to try new opportunities.

Money Management:

Caleb is learning more about money.

He needs help with significant monetary decisions.

Personal Safety:

Caleb is known by some other school district

students in our community.

He is known in our church community.

He needs to be with a trusted adult at all times.

Personal Strengths & Assets

Decision Making:

I can accurately choose from lists of activities.

I have definite preferences for what I like to do.

Skills:

I have a very positive attitude. People like to be around me.

I will try to do any activity that I am challenged to do.

I like to do anything outside and I work hard.

I have been working outside all my life.

Money Management:

I can use a debit card and cash.

Personal Safety:

I follow directions well.

I can tell a person of authority who I am,

where I live and who my parents are.

I might get bored but will get back

on task with reinforcement.

Technology

Decision Making:

I can learn on line or in person.

Missouri Assistive Technology

-What equipment do I need?

-What is available?

-AgAbility grants?

Money Management:

Can I buy it at a regular store?

How can I pay for it?

-Private funding

-Charity

-Public funding eligible

Personal Safety:

Decision making apps

Decision Making:

Caleb needs substantial support in regards to public sector resources.

Money Management:

-Substantial family involvement and planning

-Financial Planner

-Can use traditional savings to pay for school/career

-Tax status – can I get tax deductions and credits?

Personal Safety:

-Lawyer - Special Needs Trust, Alt. Guardianship tools, Living Will

-I have private health insurance as well as Medicaid

Community Based

Decision Making:

Use a CWIC to understand my SSI/SSDI benefits options.

Use Vocational Rehabilitation for job readiness planning.

Use CIL to understand community options of all kinds.

Money Management:

Determine how to use Student Earned Income Credit benefit

Medicaid – access waiver, medical insurance, support, job coach,

equipment, PCA

Determine how my services will be effected and eventually replaced as

my income increases?

Determine what financial tools are available based on my eligibility ABE,

PASS, IDA, grants,

Increase cash flow and keep/get private insurance - HIPP

Personal Safety:

Good relationships with family, providers and case managers learn about

P&A/DHSS rights to protection

Eligibility Specific



NASCAR

HS Football
Coach



Going to country
music concerts



Eagle Scout Leader

Going to the Library and other
places around town.



What is important to me?

The Good Life

By: Ben St John

Cognitively Accessible Tools for Self- Advocacy



Diverse Array of Implementation

- ⊙ Educating self-advocates and families on possibilities, problem-solving and planning
- ⊙ Early Childhood and School Transition Planning
- ⊙ Information and Referral/Options
Counseling/Navigation Support/Futures Planning
- ⊙ Long Term Services and Supports Planning Formal
Planning Process and Requirements
- ⊙ Aging, Social Services, Employment, Retirement,
Health
- ⊙ Etc, etc, etc.



LIFECOURSE Tools

LIFECOURSE TOOLS

LIFECOURSE PRINCIPLES

LIFECOURSE IN ACTION ▾

CONNECT ▾

ABOUT



chartingthelifecourse.org
LifeCourseTools.com



Contact Information

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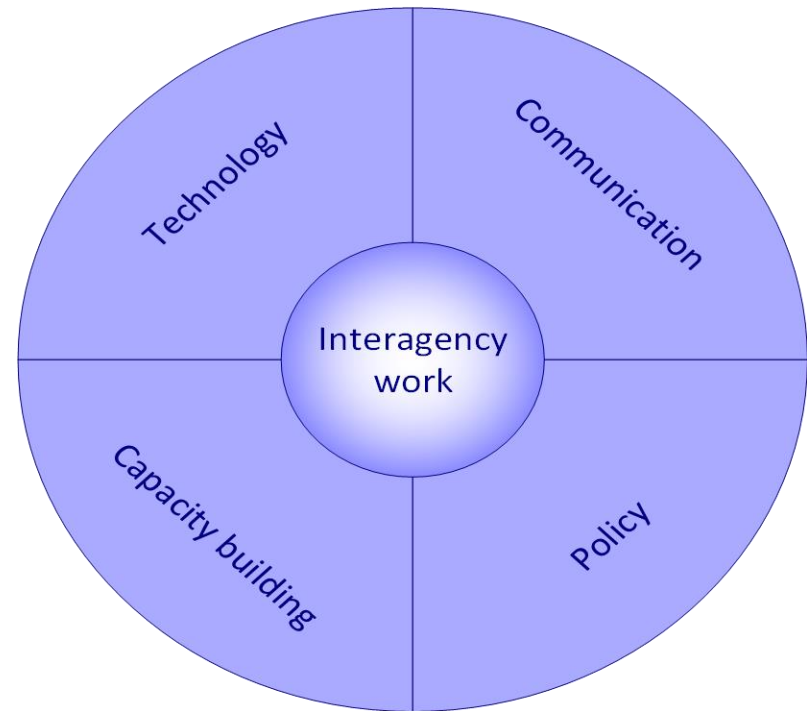
816-235-1759



Minnesota's Interagency Efforts

Core Inter-Agency Partners

- Minnesota Department of Human Services (DHS)
- Minnesota Department of Vocational and Rehabilitation Services (VRS)
- Minnesota Department of Education (MDE)



Technology Tools

Central Launch Pad: Disability Hub MN

Disability HUB MN

Welcome to the Hub.
We can help you plan your best life, your way.

Select Language ▼

My options ▾ My voice My tools Hub partners

Search Disability Hub MN...

What is the Hub?

Disability Hub MN is a free statewide resource network that helps you solve problems, navigate the system and plan for your future.

At the Hub, we focus on your needs — helping you understand your options, connect to resources and find solutions. We're here to help you get the answers you need. We'll help you think through additional options and identify new paths toward creating the life you want.

Read more [about the Hub](#).

Introducing Disability Hub MN: Your best life, your way.

Watch a [video](#) or [audio described video](#), or read video [transcript](#).

Tools – DB101 and HB101

Disability Benefits 101

work • benefits • you

Home Your Situation Programs Estimators Glossary Videos My Vault Partners

Disability Benefits 101 gives you tools and information on health coverage, benefits, and employment. You can plan ahead and learn how work and benefits go together. > More

Welcome to DB101 (1.5 min video)

Your Situation
Take a personal approach to benefits planning. Find information that applies to you. > More

Programs
Just the facts. Get details about benefit programs. > More

Going to Work
Cash Benefits

Housing Benefits 101

Your Home. Your Choice.

HOME MY SITUATION PROGRAMS & SERVICES MY VAULT GLOSSARY PARTNERS

Plan for Your Home, with the Services You Need
Explore your housing options. Discover what works for you. Make a plan to get there.

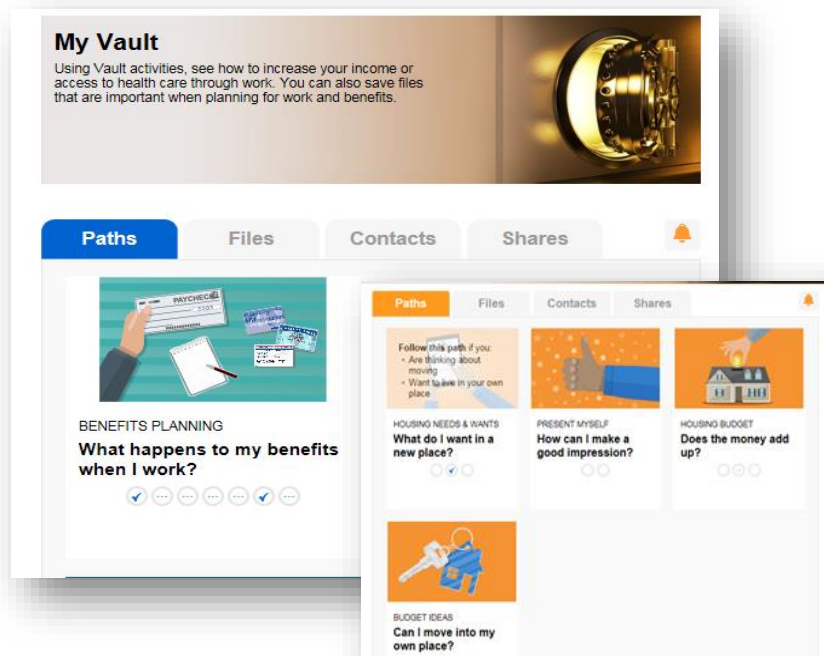
BUILD YOUR PLAN

Get Help Now
Do you have a disability?
Are you 60 or older?
Are you a veteran?
Are you homeless?
Other?

Moving Out of a Facility, Group Home, or Foster Care
Changing Your Home
Keeping Your Housing
Homeless Services in Minnesota

The “Vault” – supports person centered practice and coordination

Shared vault between DB101 and HB101



Current list of activities

