



Charting the LifeCourse

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Massachusetts



About Sheli

- Sibling of three brothers, one who is 35 years old with developmental disability
- Member, Presidents Committee for Persons with Intellectual Disabilities Appointed by President Obama
- Associate Director, UMKC Institute for Human Development
 - Lead Developer of Charting the LifeCourse framework and tools
 - Co-Director of National CoP on Supports to Families
 - Director of Mo Family-to-Family Health Info Center
 - Supporter of the Self-Advocacy Movement for 12 years



MISSOURI
FAMILY TO FAMILY
UMKC INSTITUTE FOR HUMAN DEVELOPMENT | UCEDD

UMKC INSTITUTE FOR
HUMAN DEVELOPMENT
A University Center for Excellence in Developmental Disabilities



I PITY THE FOOL
WHO DOESN'T LIKE



BEN'S ONE
PAGE PROFILE!

WHAT PEOPLE LIKE AND 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.

Introducing Ben



Outcomes

- ◎ Underscore the significant role families play across the lifespan in supporting their family members with disabilities.
- ◎ Illustrate how the LifeCourse Framework can be used as a foundation for assisting individuals with disabilities and their families in creating a vision at different life stages, such as transition from school to adult life, aging, etc.
- ◎ Highlight the use of the Charting the LifeCourse framework and tools to support problem solving and decision making.
- ◎ Learn about the experiences and different ways staff are putting the LifeCourse tools and strategies into practice.
- ◎ Lay the groundwork for future efforts to integrate and apply the LifeCourse Tools in our ongoing work and engagement with individuals and families.





Setting the Stage



Recognizing Our Role

Navigator

Detective

Solution finder

Encourager

Emotional Support

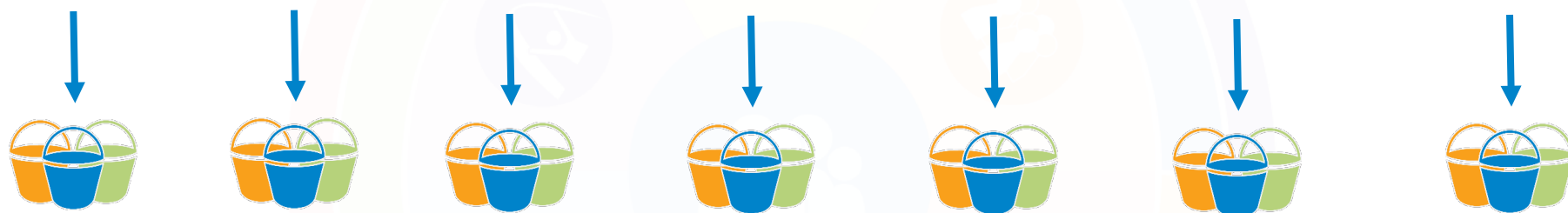


Kingsley, Emily P. (1987) *Welcome to Holland*.

*What is Your role in Supporting
the “Journey of Life”*

Human Needs vs. System Needs

Human Needs of Person and their Family



Touchpoints between Person/Family and LTSS

Front Door
Interaction

Intake &
Assessment

Person Centered
Plan Process

Accessing
Supports

Delivering
Services

Check-In &
Monitoring

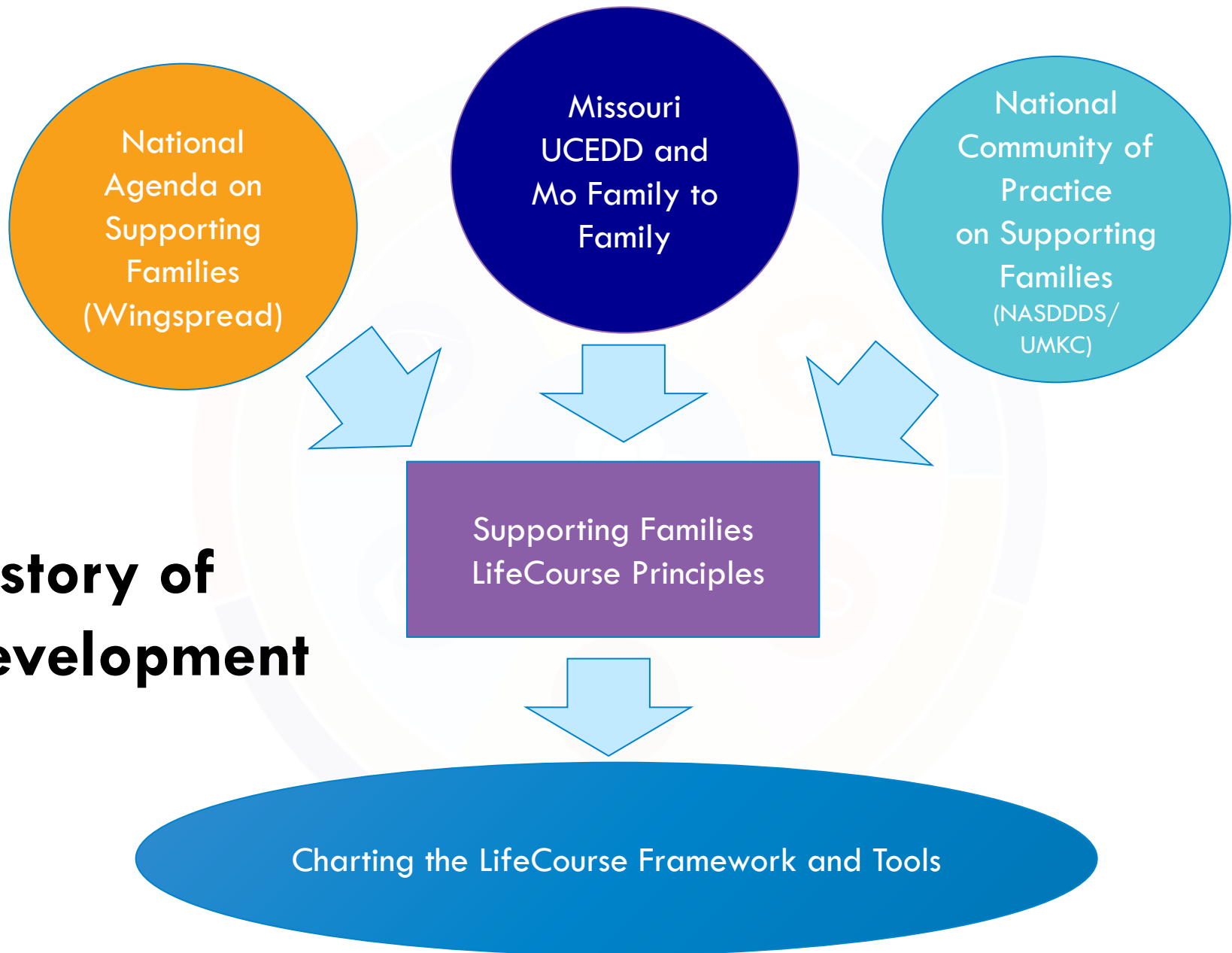
Annual
Meeting



System Requirements (Federal, State, Organizational)



History of Development



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



Thinking that Guides the Framework

Family Systems Theory

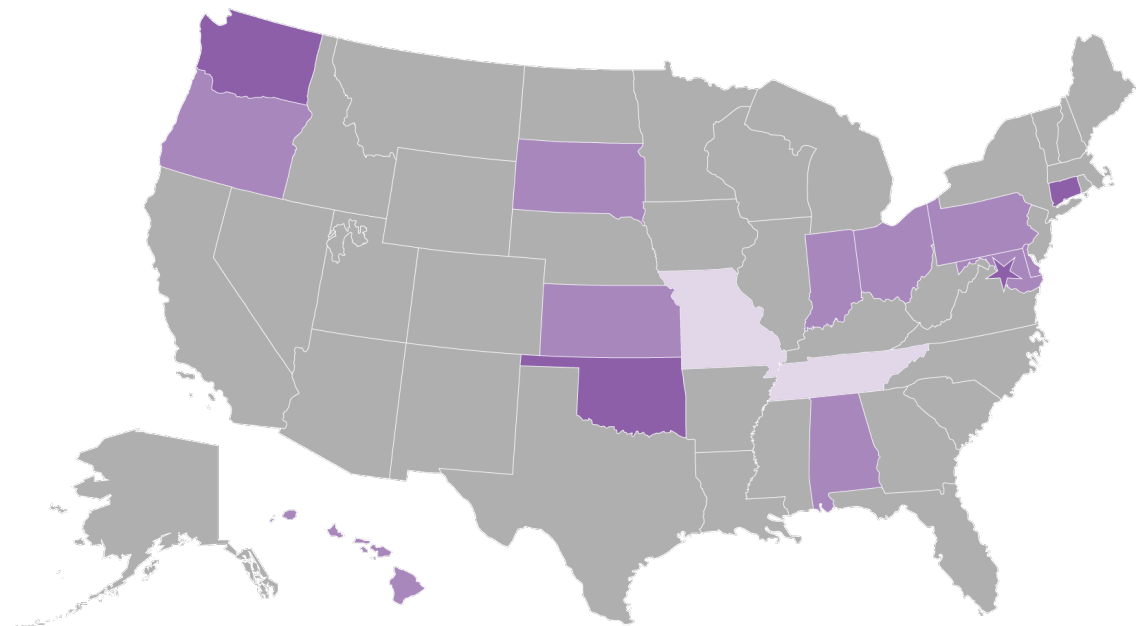
Life Course Theory Social Capital
Person-Centered Practices
Socio-ecological Model
Family-Centered Practices
Community Integration Public Health Model
Anticipatory Guidance
Self-Determination



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

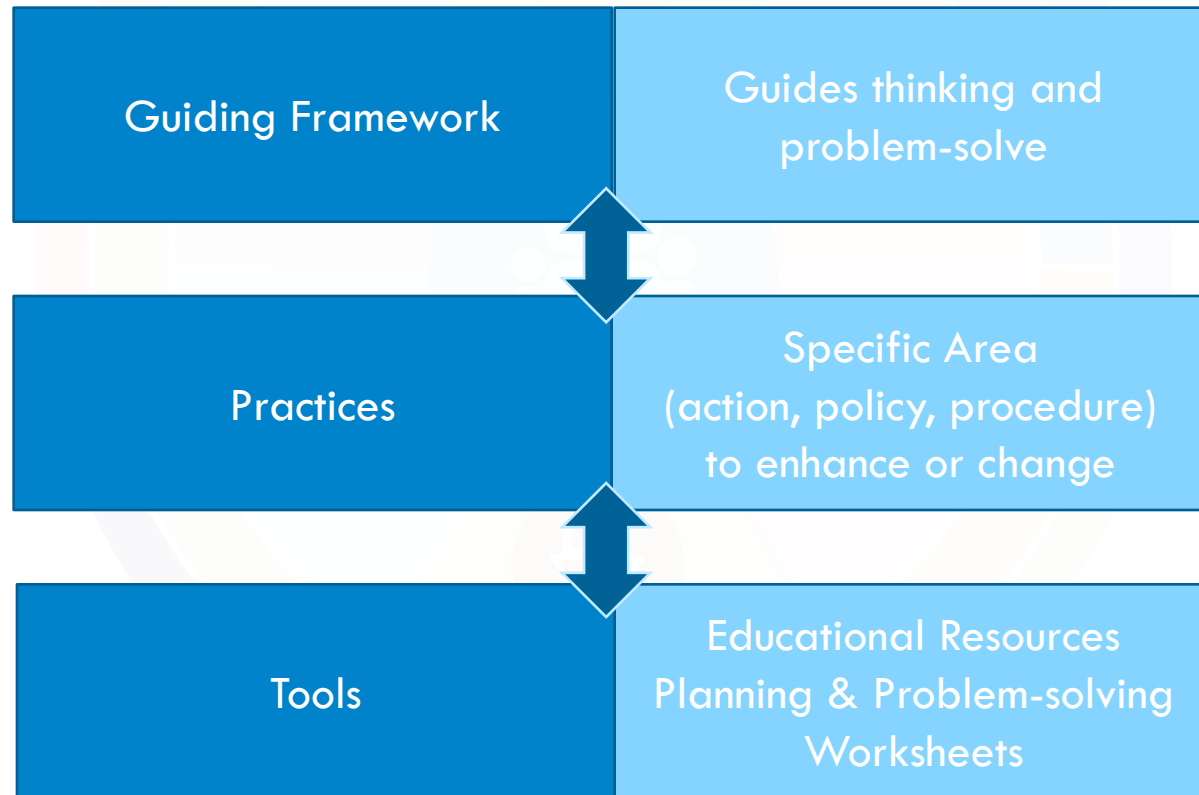
INSTITUTE FOR HUMAN DEVELOPMENT

A University Center for Excellence in Developmental Disabilities (UCEDD)

Original Funding Source



What is Charting the LifeCourse??





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.



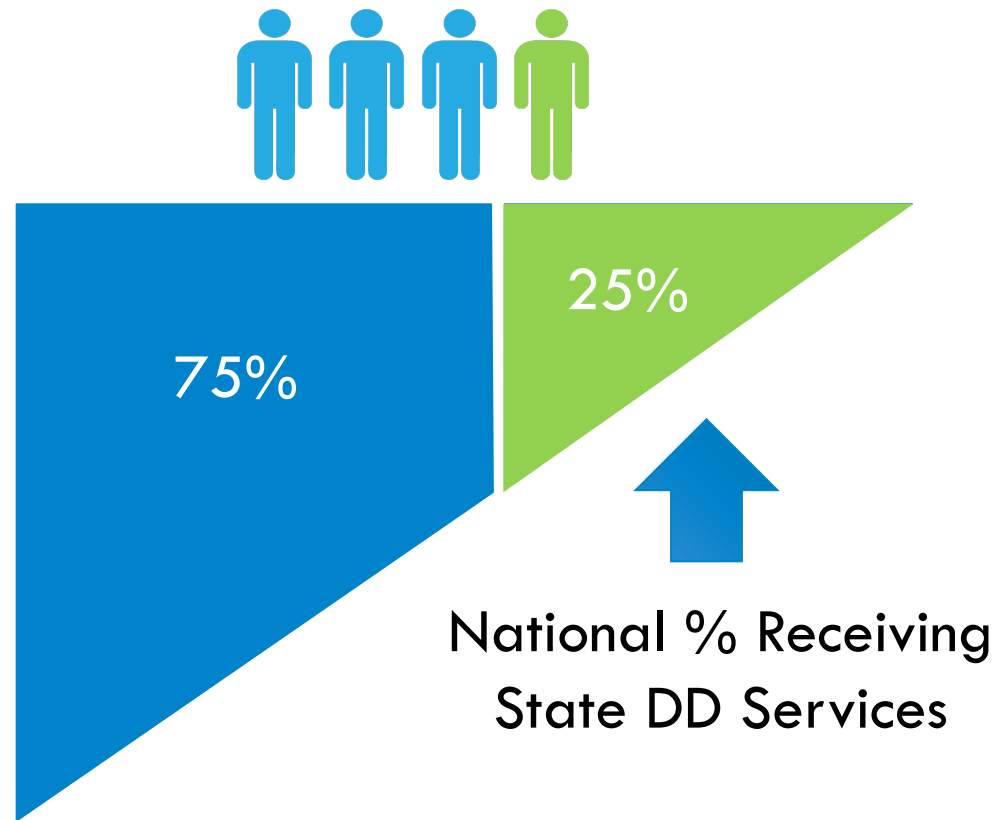
All People

ALL people, regardless of age, ability or family role, are considered in the framework.

ALL people with disabilities and their families have choices and access to supports they need, whether they are known to the disability service



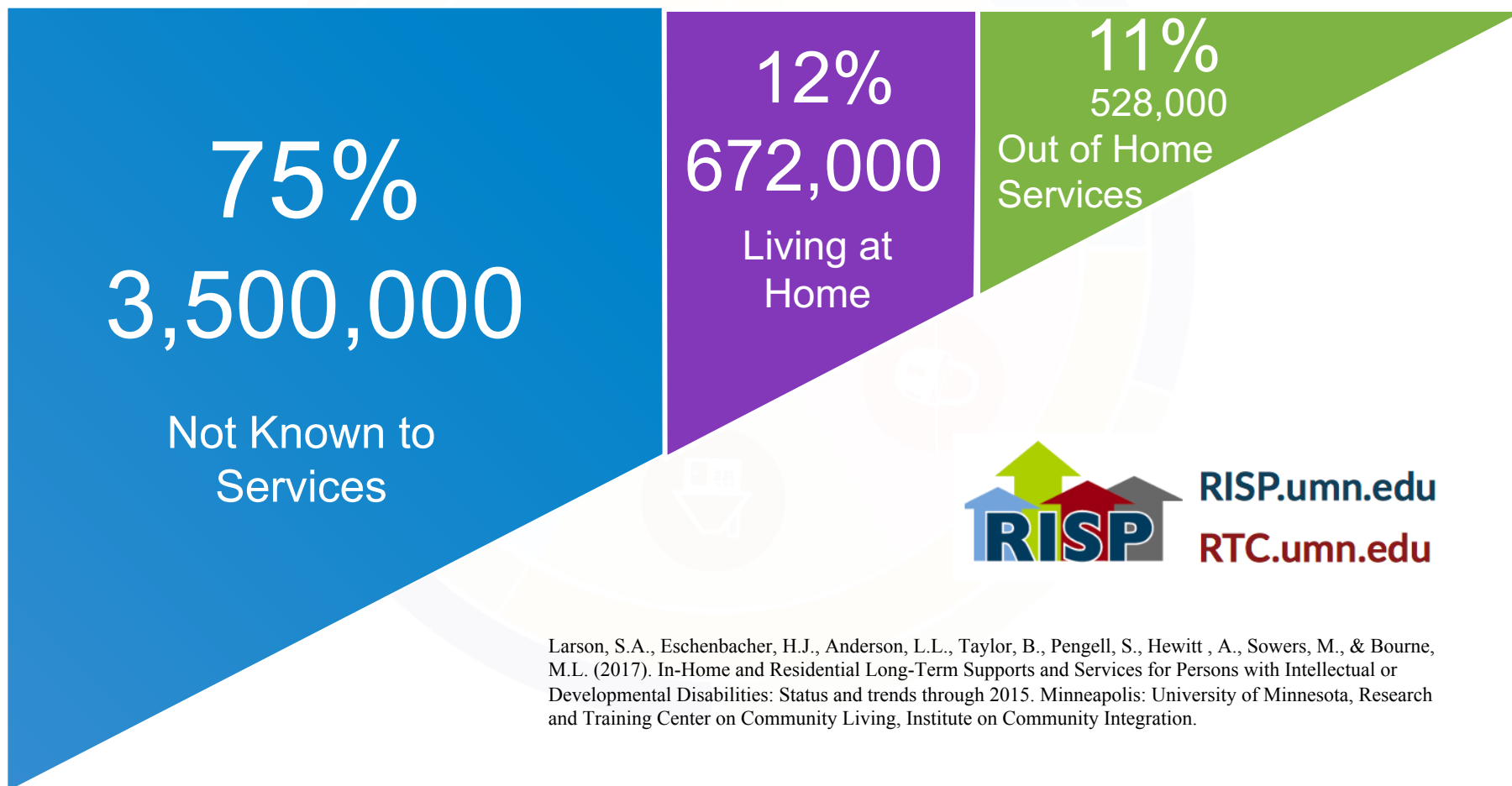
1 in 4 Persons with I/DD Receive
Formal State DD Services



**** Based on national definition of developmental disability with a prevalence rate of 1.49%**

Where People with I/DD Live

4.7 million estimated People with Developmental Disabilities*



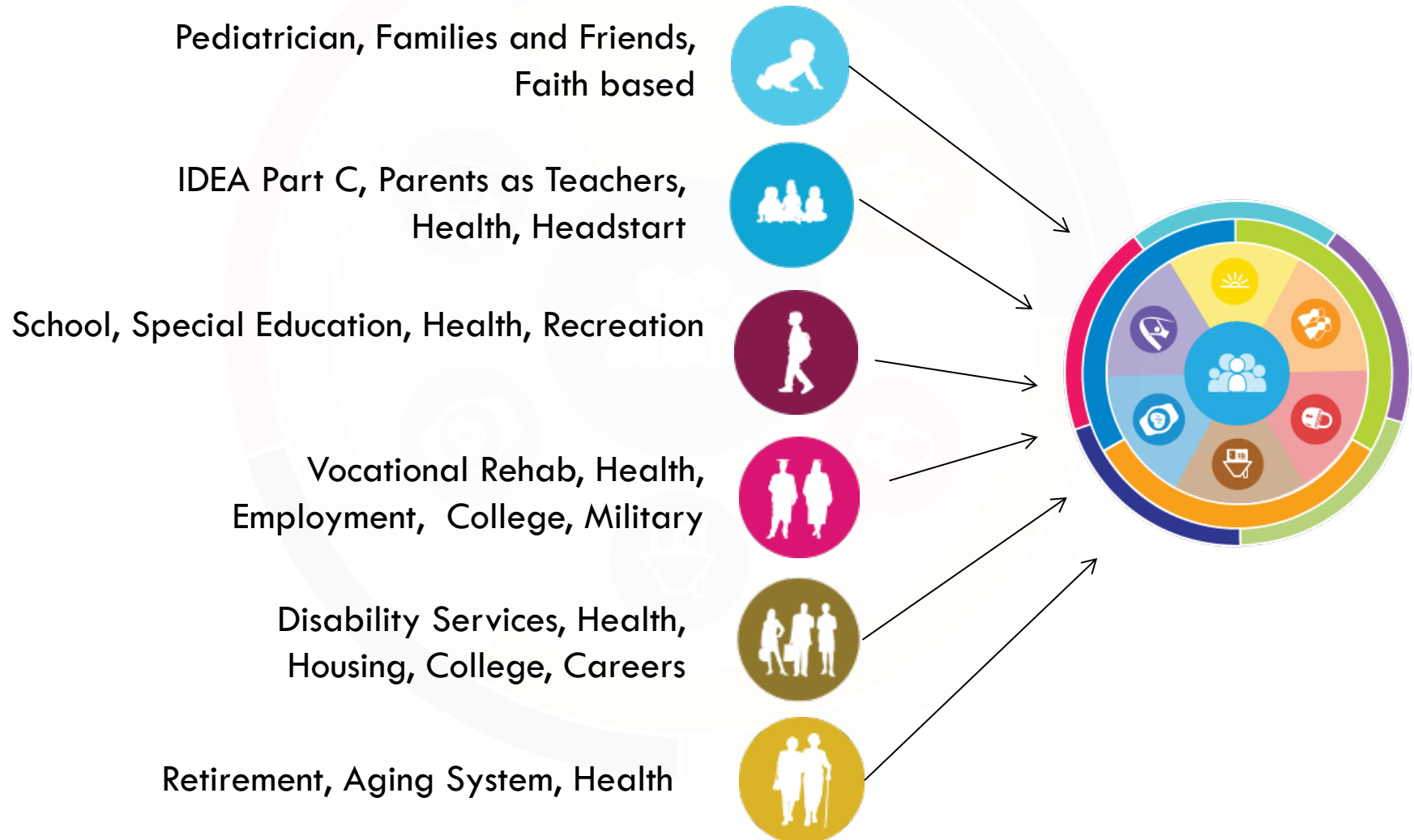
RISP.umn.edu

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.



Supporting All Ages, Across All Systems

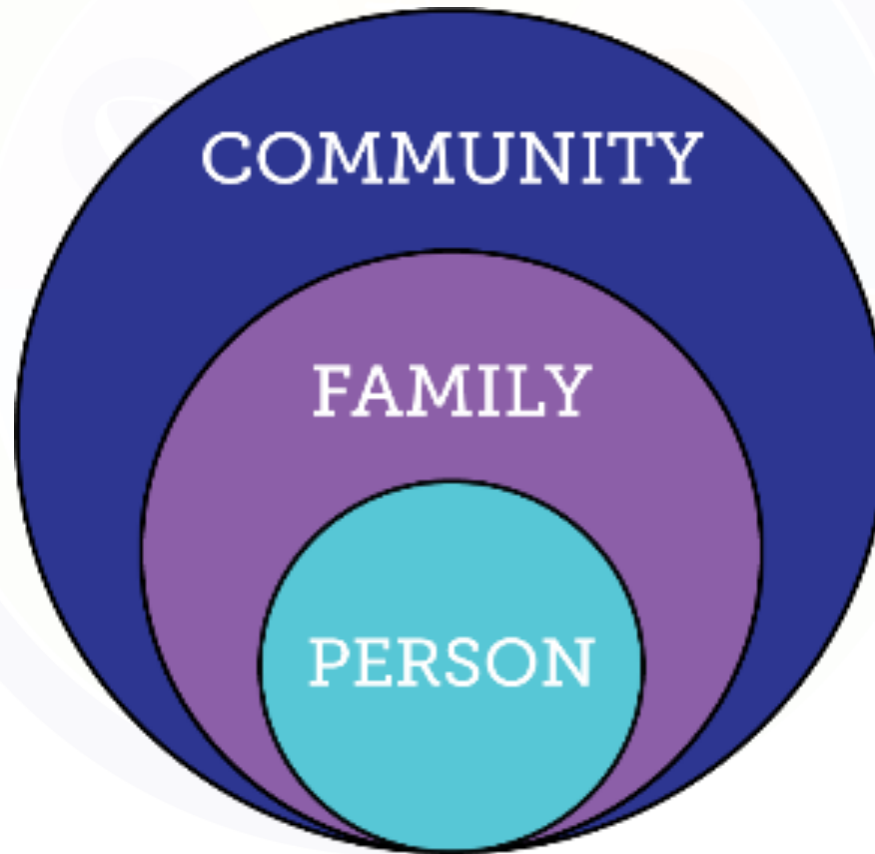




Individuals
live within the
context of their
Families and
Community



Everyone exists within the context of family and community



Draw Your
Circles





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



Lifelong Impact of Family on Individual

Biologically: Likes, dislikes, skills, abilities

Socially: Family and friend network, connection with community members

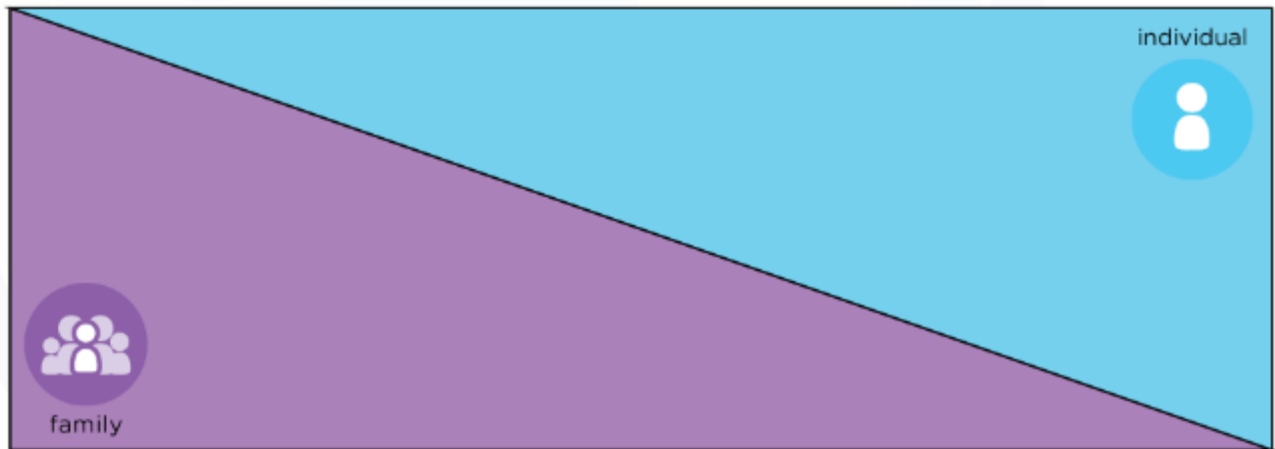
Environmentally: Neighborhood, socio-economic, education

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



Connected Stages and Cycles

Individual Life Stages



A Traditional Family Life Cycle





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 & membership

Advocate for support

**Adapted from Bigby & Fyffe (2012), Dally (1988), Turnbull et al (2011)*





Mapping Reciprocal Roles

CHARTING the LifeCourse



Mapping Family Roles

This tool is to help families think through the roles they play in their loved one's life, and to help them plan for who else could help fulfill those roles now and in the future.

Reciprocal Roles	People's Roles in _____'s life	Looking Ahead	What's important to know, make sure continues, or make happen?
 Caring ABOUT	Affection and Self-Esteem Who loves and cares about him/her?	Who else makes him/her feel loved?	
	Repository of Knowledge Who else knows things that others don't know well? (celebrations, traditions, habits, history)	With whom does he/she have special memories or experiences?	
	Lifetime Commitment Who has a lifetime bond with him/her?	Who else would step up when/if needed?	
 Caring FOR	Provider of day-to-day care Who makes sure activities of daily living and healthcare needs are met?	Who else could provide oversight for these needs?	
	Material and Financial Needs Who makes sure his/her day-to-day basic and quality of life needs are met?	Who else could help make sure this happens?	
	Facilitator of Inclusion and Membership Who helps connect him/her to inclusive opportunities and maintain relationships?	Who would be good at helping him/her connect with and maintain inclusive activities?	
	Advocate for Support Who helps him/her advocate in planning meetings?	Who else could help advocate for/with him/her?	



Developed by the UMKC Institute for Human Development, UCEDD. More tools at lifecoursetools.com

MAY 2017

Handout in Folder



Mom Mapping Roles in Son's Life

Reciprocal Roles		People's Roles in <u>Ben</u> 's life	Looking Ahead	What's important to know, make sure continues, or make happen?
 Caring ABOUT	Affection and Self-Esteem	Who loves and cares about him/her? <i>Mom, Dad, Matt, Zac</i>	Who else makes him/her feel loved? <i>Chad, Ericka, Lauren, Landon, future in laws and nieces and nephews</i>	Birthdays and holidays celebrated and personal (gifts both ways); not alone for special occasions; Important holidays: Christmas, Easter
	Repository of Knowledge	Who else knows things that others don't know well? (celebrations, traditions, habits, history) <i>Mom, Dad, Matt</i>	With whom does he/she have special memories or experiences? <i>Zac, Matt Spohn, Sheli, Brad, Stalder</i>	Church on Sundays-10:00 mass; Consistency with medical and other professional appointments
	Lifetime Commitment	Who has a lifetime bond with him/her? <i>Mom, Dad, Matt, Zac</i>	Who else would step up when/if needed? <i>Mike A, Ericka, Chad, Twins when older,</i>	Really important that Ben knows who is there for him and who he can count on. Also needs people in his life that will "reminisce" with him about people that are no longer alive and events
 Caring FOR	Provider of day-to-day care	Who makes sure activities of daily living and healthcare needs are met? <i>Mom and Dad, Staff (Steve)</i>	Who else could provide oversight for these needs?	Ben has staff he is comfortable with and he is active in the community and not just sitting home all day
	Material and Financial Needs	Who makes sure his/her day-to-day basic and quality of life needs are met?	Who else could help make sure this happens? <i>Matt, Zac, Ange (has a "Trust" committee)</i>	Need people aware of his "service" dollars and how to find other sources of support (STAR)
	Facilitator of Inclusion and Membership	Who helps connect him/her to inclusive opportunities and maintain relationships? <i>Mom, Dad, Matt, Zac, Staff</i>	Who would be good at helping him/her connect with and maintain inclusive activities? <i>Matt, Matt Spohn, Zac Mr. Allgaier at church; Ernie</i>	Must keep going to ESFD and being involved with the fire fighters. Do age appropriate things with people he likes and cares about.
	Advocate for Support	Who helps him/her advocate in planning meetings? <i>Mom</i>	Who else could help advocate for/with him/her? <i>Matt, future SIL,</i>	Ideally, Ben will keep gaining skills to be his own best advocate with just a little support from family and friends



Changing Roles of Family

Family Roles

Caregiver and Family
Behavior Therapist
Spiritual Guide
Psychiatrist or Counselor
Social Planner
Life Coordinator
Protector and Advocate

Family Members Are
Cared about and Loved
Self-determined
Independent/interdependent
Integrated and Included
Productive



Birth-----Early Child---School-----Transition-----Adulthood-----Aging





Aging Parents

Siblings with
Disabilities

Children

Siblings: The 'Club Sandwich' Generation

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

-Sibling Leadership Network



Supporting the Needs of the Person and All Family Members

Individual and family supports address all facets of life and adjust as roles and needs of all family members change.



**Discovery &
Navigation**
(Info and
Training)

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

**Goods &
Services**
(Day to Day,
Medical,
Financial)

Overarching Area (3 Buckets)	Focus Area of Enhancement	Examples of Services or Supports
Discovery and Navigation	Informational Support Instructional Skills Development Navigation and Advocacy Skills	<ul style="list-style-type: none"> • Informational Support (<i>specific disability or health condition, options and possibilities for employment, community living, relationships, recreation, future planning</i>) • Skill Building Support (<i>navigating and access services, behavioral supports, medical tasks</i>) • Interventions that enhance the ability to advocate for services and policy change
Connections and Networking	Emotional Support Affirmational Support Relationships and Social Capital	<ul style="list-style-type: none"> • Support Groups • Professional Counseling • Peer-to-peer interventions and programs (<i>Parent-to-Parent, Sib-shops, Self-advocacy organizations</i>)
Goods and Services	Physical Support Financial Material/Instrumental	<ul style="list-style-type: none"> • Individual and Family-Directed Supports • Cash Subsidies and Financial assistance • Transportation • Respite/Childcare • Adaptive equipment and Home modifications





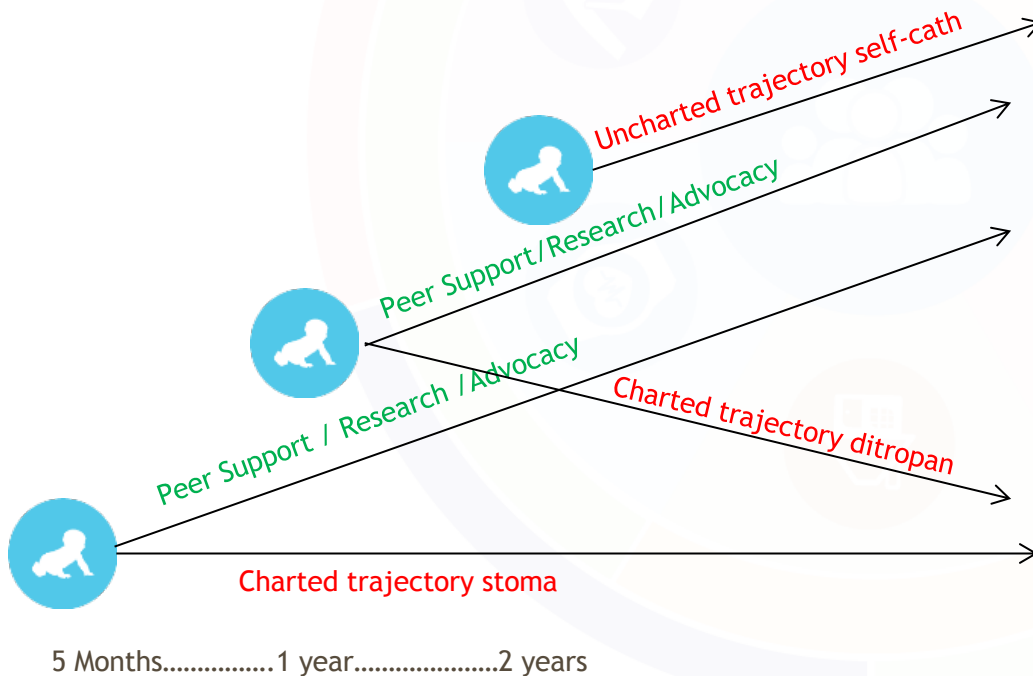
Elizabeth's Health Trajectory As Told by Her Mother

VISION for a GOOD LIFE

Self determination
Choice
Privacy

What I DON'T Want

Unnecessary medications
Unnecessary procedures
Limiting choices
Limiting self-determination





The focus is on the “person with a disability”
this does NOT mean that “Family
Engagement” supersedes the INDIVIDUAL

It is not.....
family involvement VS person centered

Family Engagement is a component of a holistic approach to person centered supports that recognizes the context and impact of the family in practice and policy implementation.



Families are complex, but we know that families.....

- Help each other; they sacrifice for one other;
- Hurt each other; they apologize and forgive;
- Have fun and celebrate with each other;
- Have routines, customs and habits – they have their way of doing things;
- Have secrets and things they don't talk about;
- Have troubles, get tired and discouraged;
- Do the impossible;
- Might commit abuse and take advantage of other families members;
- Can't do everything;

*The family is the context for the person;
personal outcomes are influenced by the family*



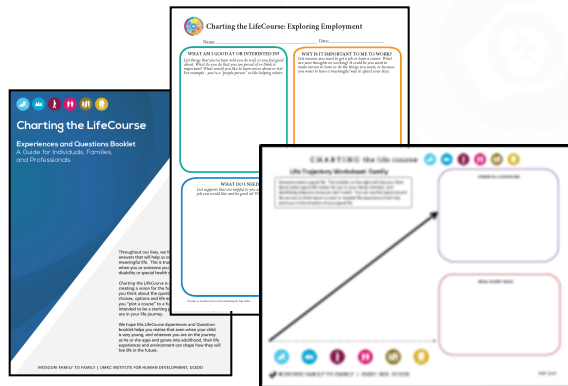
Challenging Our Thinking About Families

- ◎ *“the families I work with are often a barrier”*
- ◎ *“families are too tired and overwhelmed”*
- ◎ *“families expectations are too high”*
- ◎ *“families expectations are too low”*
- ◎ *“the people I support don’t have any family”*

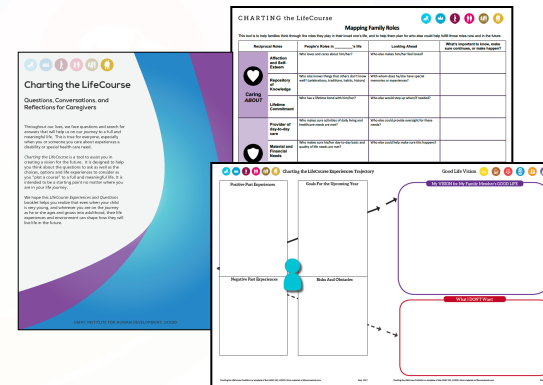




Massachusetts CtLC in Action

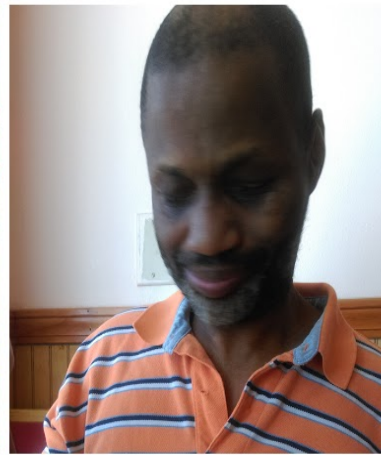


Person Centered Planning



Family Futures Planning





Trajectory of Life Experiences

Individuals and families can reflect on prior and current life stages and experiences while focusing on the future.

A vision creates opportunities for life experiences along the life trajectory.



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



What is YOUR Vision for a Good LIFE?

**Vision of What I Want for a
Quality of Life**

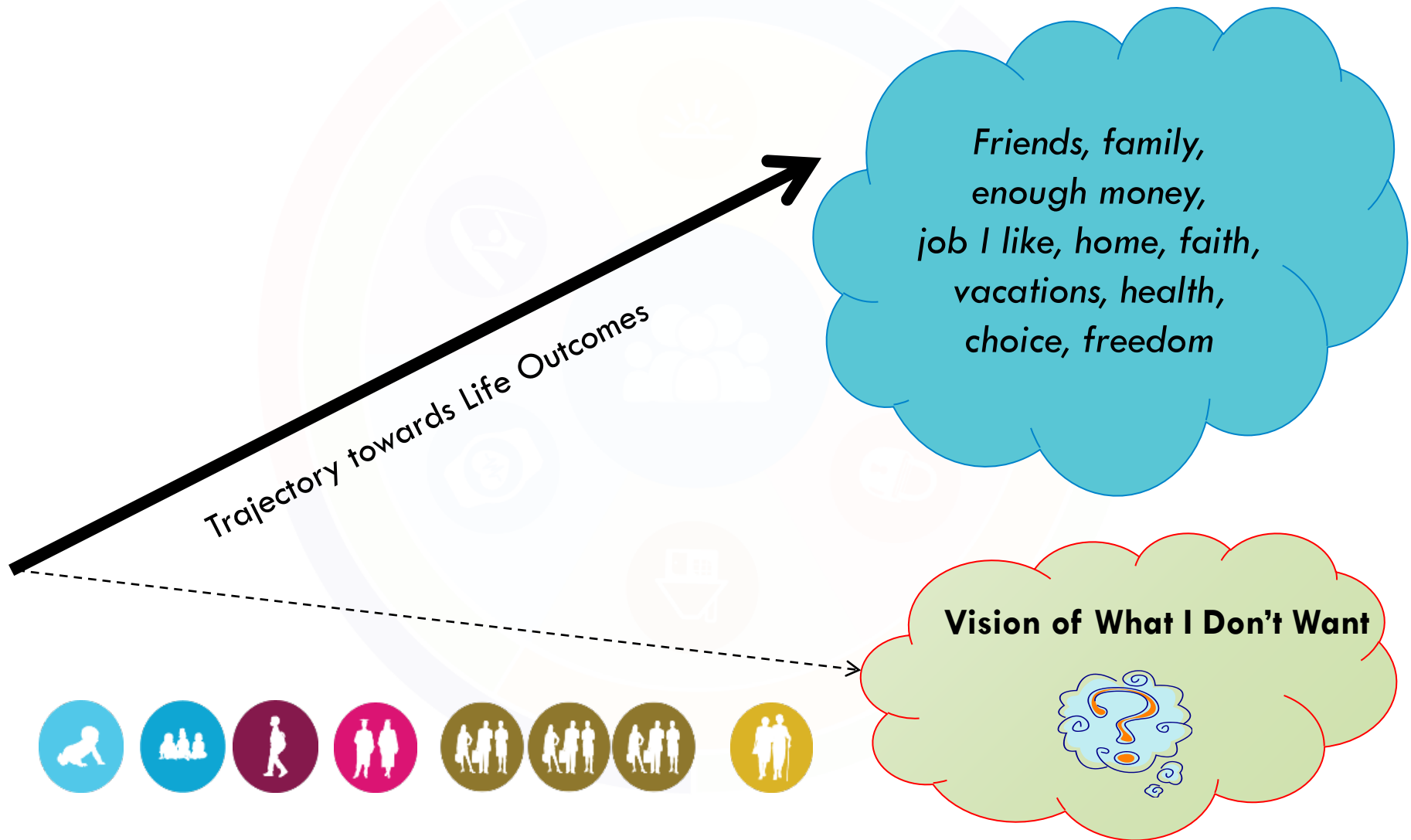


What DON'T you want??

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



Trajectory towards Good Life



Trajectory towards 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

WHAT I DON'T WANT

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

Trajectory towards Life Outcomes

Trajectory towards things unwanted



“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



Person and Family Level Quality of 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)





Life Domain Vision Tool: Family Perspective

LIFE DOMAIN		My Vision for My Future	priority
 Daily Life Employment	What do I think my family member will do during the day in his/her adult life? What kind of job/career might they have?		
 Community Living	Where and with whom do I think my family member will live in his/her adult life?		
 Social & Spirituality	How do I think my family member will connect with spiritual and leisure activities; have friendships & relationships in his/her adult life?		
 Healthy Living	How do I think my family member will live a healthy lifestyle and manage health care supports in his/her adult life?		
 Safety & Security	How do I think my family member will be safe from financial, emotional, physical or sexual harm in adult life?		
 Citizenship & Advocacy	How do I think my family member will have valued roles, responsibilities, and control of how his/her own life is lived as an adult?		
 Supports for the Family	What supports do I think our family unit needs now or will need in the future?		
 Supports and Services for Individual	What do I envision for long term services and supports for my family member in the future?		









Handout in Folder

Family Perspective Life Domain Vision Tool





Life Domain Vision Tool: Family Perspective

LIFE DOMAIN		My Vision for BEN's Future	priority
 Daily Life Employment	What do I think my family member will do during the day in his/her adult life? What kind of job/career might they have?	Continue to volunteer at ES Fire Dept because he LOVES it and he belongs. We want to help Ben start his own business, based on his interests, and also be something that his brothers could also be involved or interested in. We want him to stay active and not sit around the house all day.	HIGH
 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, house or condo, and have a roommate if he wants one, or a live-in companion. For now, we are looking at options for him to be more independent within our family home. We are currently working on him being able to come home alone and get settled (change clothes, get a snack, let the dog out, get his iPad, etc.)	Medium
 Social & Spirituality	How do I think my family member will 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 know him and talk to him. The fire department is also 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 find love and maybe even get married someday.	HIGH
 Healthy Living	How do I think my family member will live a healthy lifestyle and manage health care supports in his/her adult life?	Ideally, 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 and learn to use while we are still around to help him. We want him to be able to talk to his health care providers and be supported to make choices about his medical care.	Medium
 Safety & Security	How do I think my family member will be safe from financial, emotional, physical or sexual harm in adult life?	We want Ben to have lots of friends, family members and acquaintances who keep in touch with him regularly or see him out and about and will notice if something is wrong or seems "off". Ben has a trust committee for his Special Needs Trust, and he has family who serve as his Powers of Attorney. We use available banking options for financial security. We do NOT want Ben to <u>EVER</u> have a guardian.	HIGH
 Citizenship & Advocacy	How do I think my family member will have valued roles, responsibilities, and control of how his/her own life is lived as an adult?	We would like to see Ben have more active roles at church - he has been working on learning to usher, and maybe he could join a men's group or the Knights of Columbus. We would like him to explore other volunteer opportunities. Ben should be supported by family and trusted friends to make his own decisions and choices.	Medium
 Supports for the Family	What supports do I think our family unit needs now or will need in the future?	Helping Ben self direct his services is helpful so we can continue to work while still being able to hire people we know are highly recommended by someone we know. We need coaching and mentoring for future options and problem solving issues.	
 Supports and Services for Individual	What do I envision for long term services and supports for my family member in the future?	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 and that we want for him.	

Family Perspective Life Domain Vision Tool for Ben

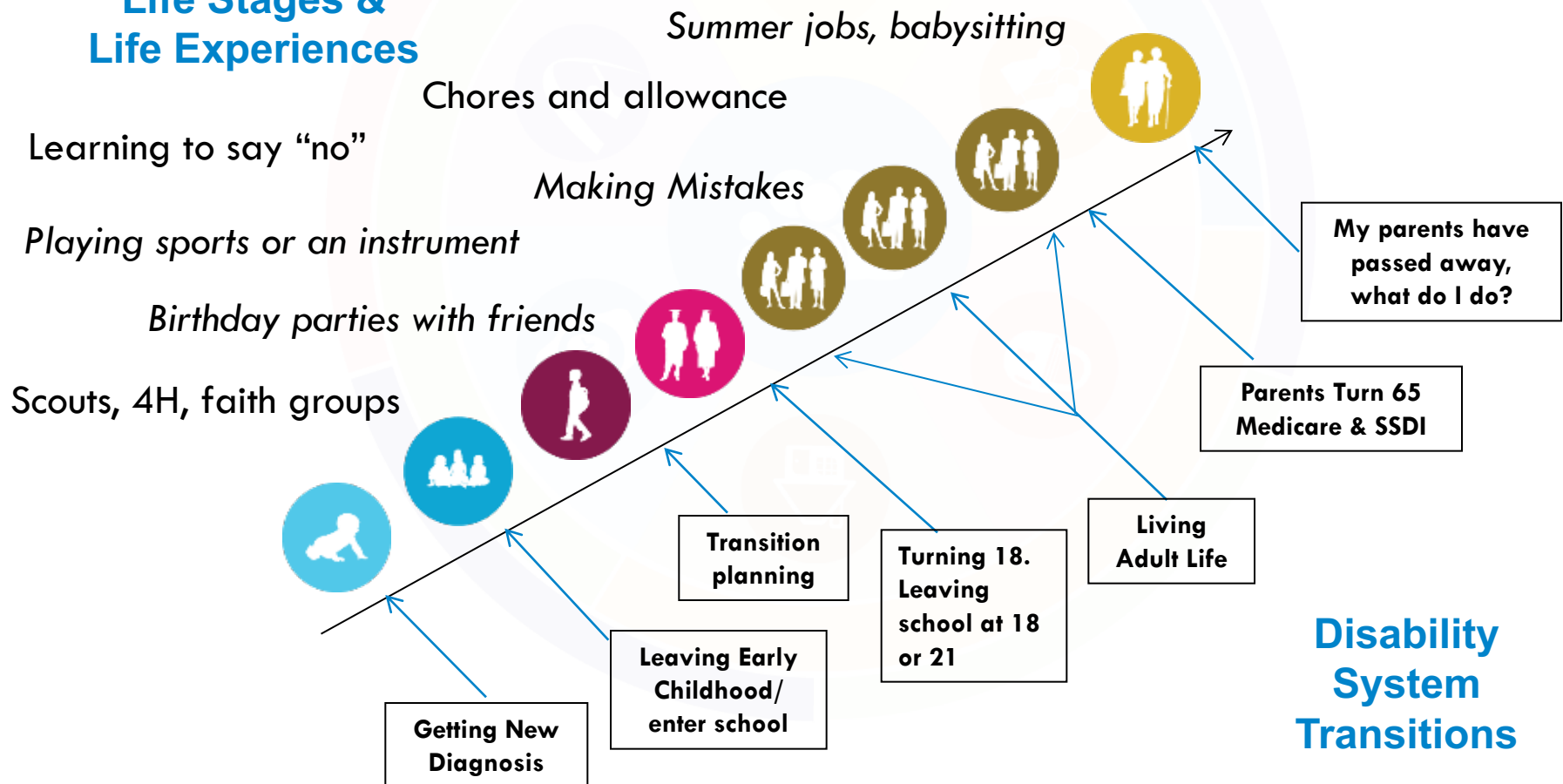
*Getting more
specific in each
life domain*



Trajectory Across Life Transitions

“Anticipatory Guidance for Life Experiences”

Life Stages & Life Experiences

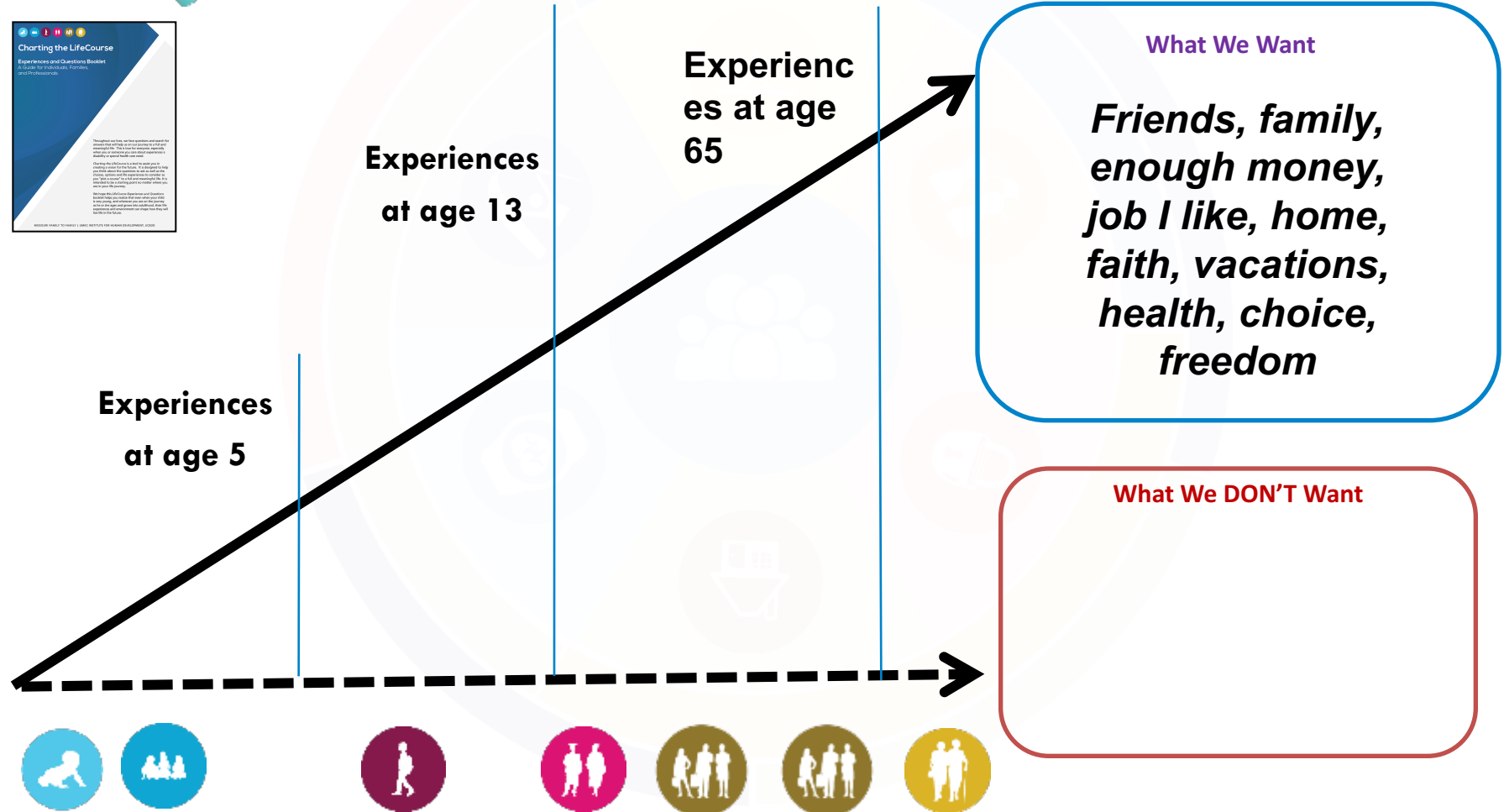


Disability System Transitions





Life Experiences = Life Outcomes



Dignity of Risk and Mistakes

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



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

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



Ben's Life Trajectory

Life Trajectory Worksheet

Past Life Experiences	Future Life Experiences	VISION for a GOOD LIFE
<p>LIST past life experiences and events that</p> <p>Chores; boy scouts; School inclusion/circle of friends; Birthday parties; Riding bike; Family vacations; Church youth group; Debit card; Football manager; Homecoming king; Volunteering High School diploma</p>	<p>LIST current/ future life experiences that continue supporting your good life vision.</p> <p>Volunteer at fire station; Find more volunteer ops; Workout regularly; Keep in touch w/ friends; Increase alone time; Go out with friends; Spend daytime hours out of the house; Explore micro enterprise;</p>	<p>LIST what you want your "good life" to look like ...</p> <p>Family and friends Girlfriend Vacations Concerts; WWE; Nascar Tattoos Money; job or my own business Volunteer at fire station Being Tiger football manager Church Healthy & fit Good food; Pepsi Basketball Royals baseball Staying active</p>
<p>LIST past life experiences that pushed the arrow toward things you don't want.</p> <p>Special education low expectations; Para glued to Ben's side; Pressure to segregate; Medication side effects; Scoliosis; Seizures; Physical barriers;</p>	<p>LIST life experiences to avoid because they push you toward things you don't want.</p> <p>Sitting at home watching TV all day; Rely on paid supports; Gain weight; Eat unhealthy foods or drink too much Pepsi (caffeine);</p>	<p>What I DON'T Want</p> <p>Poor health, heart disease, diabetes; Poverty/no money; Guardianship; institution/group home; Segregation/isolation; being lonely Being treated differently;</p>



Write current age here

25





Massachusetts CtLC in Action



CtLC Healthy Living



King James



- Kernicterus (brain damage due to severe jaundice)
- All motor control affected, cognition not impacted
- Non ambulatory
- Non verbal
- G tube fed
- Little to no volitional movement
- Hearing impaired
- Baclofen pump, **DBS**, spinal fusion



Our New Reality!





Charting the LifeCourse Portfolio: Healthy Living

Name: James

Date:

Why is it important to ME to be healthy and well?

Motility
sore prevention
climate control
DBS management
Baclofen pump management

What is happening NOW with my life and health?
What specific health issues or concerns are there?

DBS programming
Medication weans
spinal fusion
recovery

What SUPPORTS do I need to help me be healthy and well?

What are specific supports that work well for me and what does not?

Access to Tobii
ASL

How do I learn best?

Visual learner—
ASL

What helps me stay motivated?

ASL

What is the best way to encourage me?


ASL

Supporting Healthy Living



Supporting Healthy Living



 **Charting the LifeCourse Integrated Supports Star:
Healthy Living**

Technology	Personal Strengths & Assets	Relationships
<p>How can I use technology to help me be healthy?</p> <p>Tobii Alexa CVS app Sign for Me app</p>	<p>What are my own assets and strengths that could help me with being healthy?</p> <p><u>CAN</u> communicate! Persistent</p>	<p>Who are people in my life who can help me with being healthy?</p> <p>Gillette drs Laney drs Tufs drs Mm, Maritza CREAT team PCAs</p>
<p>SUPPORTING MY HEALTHY LIVING GOALS</p>		
<p>What community assets can I use to help me with being healthy?</p> <p>Fidelity House DDS Medically Complex Program AAC Group</p>	<p>What supports am I eligible for that could help me with being healthy?</p> <p>DMZ - Connor, Byrum, Aperia DDS supports IHCP</p>	
Community	Eligibility Specific	

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

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

JULY 2018

Life Trajectory Worksheet: Healthy Living

What's Working?

Things in the past that helped me be healthy and make good choices about my health

effective partnership
with doctors

What Would It Take?

What needs to happen to improve my health, support my vision for a healthy life, and make healthy choices

unconventional
communication
• Tobi
• ASL

VISION for What I WANT

What do I want my HEALTHY "good life" to look like?

sore free
spain free
effective motility

My Overall Good Life

What health issues am I having or am I worried about?

spine, motility

What are disability or diagnosis specific concerns

DBS

Are there issues around fitness, nutrition and wellness?



Write date or age here

What's Not Working?

Things in the past that caused me to be unhealthy or make poor choices about my health

being unheard
by medical
professionals

Barriers to Overcome or Avoid?

What might make it hard to reach my healthy living goals or make healthy choices

AMCWB
TIME to
communicate
inaccessible forms
(medical)

What I DON'T Want

What are things I don't want to happen with my health?

STORMING

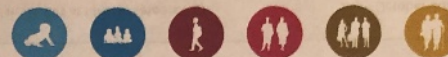
Overall NOT Good Life



Today's Health Care Visit



CHARTING the LifeCourse



TODAY'S HEALTH CARE VISIT

COMPLETE BEFORE THE VISIT

My Name: James Bostic

Today's Date: 4/16/18

Who is with me today? Mom, Mike (PCA)

Current list of my medications, pills, and vitamins
(attach it for the doctor or nurse)

Do I have a plan or card that pays for my medicine?

☒ Yes ☐ No (list) _____

Did I recently go see any other doctor or dentist?

☒ YES (who?) Dr. Rosenquist NO

What was the reason?

Pre-op

Why am I at the doctor's or clinic today?

(Things like illness, check-up, follow-up from previous visit, need forms filled out, need medication change or refill, etc.)

- follow up on spinal fusion surgery
- help with adaptive seating and positioning

Questions I want to ask today

why do I spasm when I lay down?
how can I adjust my position in my chair

Answers to my questions

MY TAKE-AWAY INFORMATION

Were there any Medication or Diet Changes?

YES or ☒ NO If YES:

Medication Name: _____

I am to take this _____ times per day, at _____

I am to stay on this for _____ days (or specify _____)

Why do I need to take this?

Medication Name: _____

I am to take this _____ times per day, at _____

I am to stay on this for _____ days (or specify _____)

Why do I need to take this?

Are there medications I don't need to take anymore, or anything else I should know?

Information about today's treatment plan, recommendations, and/or follow-up

(for ME, my family, caregivers, or other supporters)

4 months- follow up x-ray

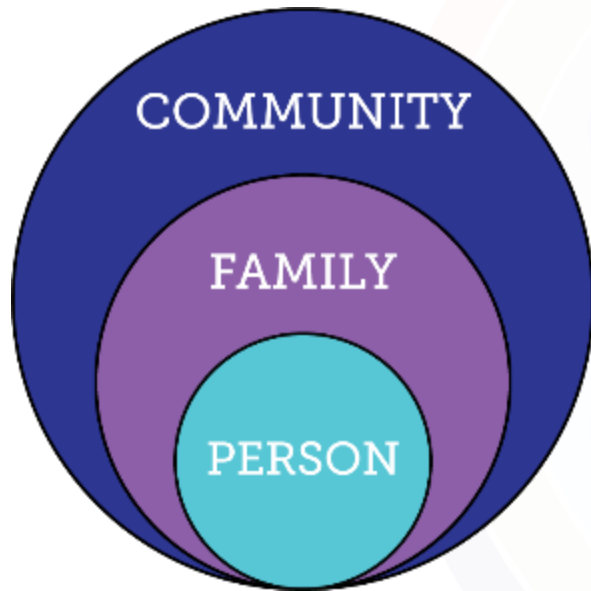
possible additional surgery

Integrated Service and Supports

Individuals and families utilize
an array of integrated
services and supports to
achieve the envisioned good
life



Services and Supports are Evolving



Everyone exists
within the context
of family
and community



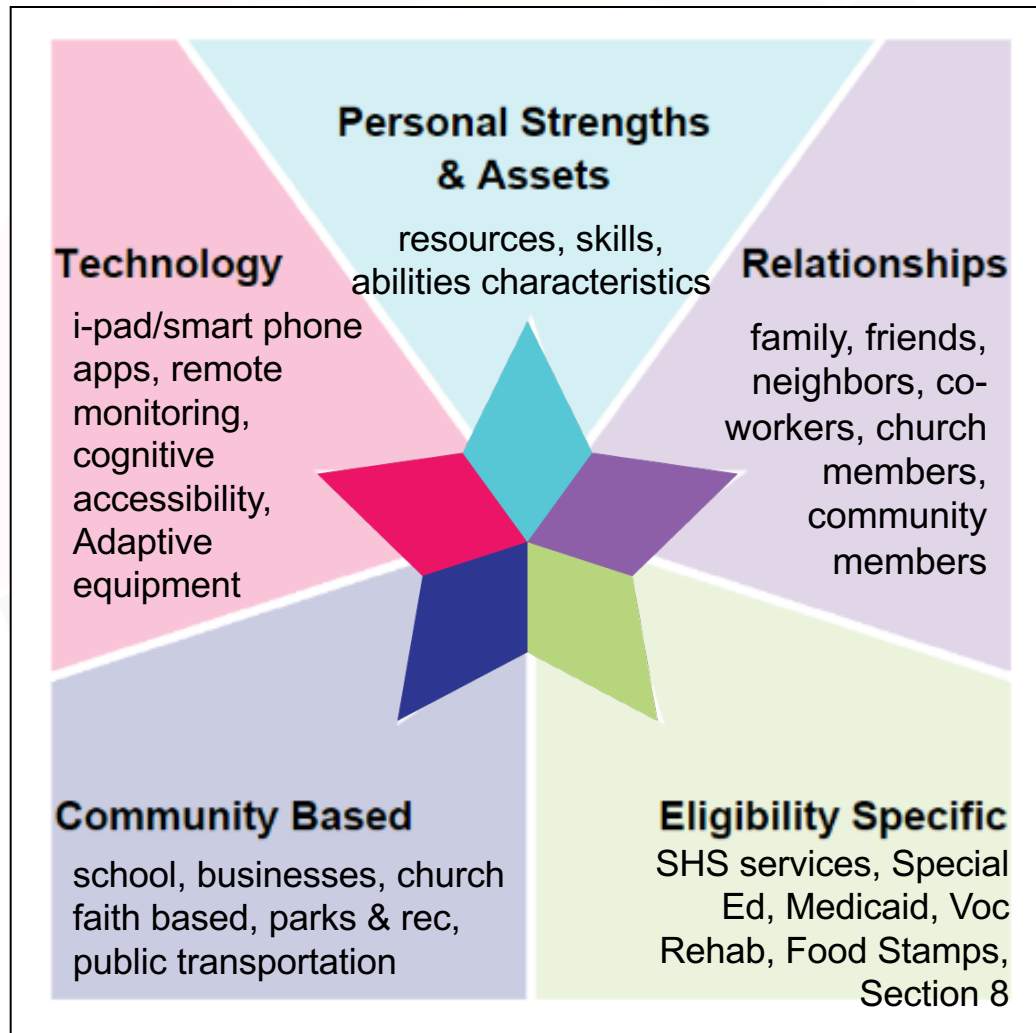
Traditional
Long Term Services
and Supports



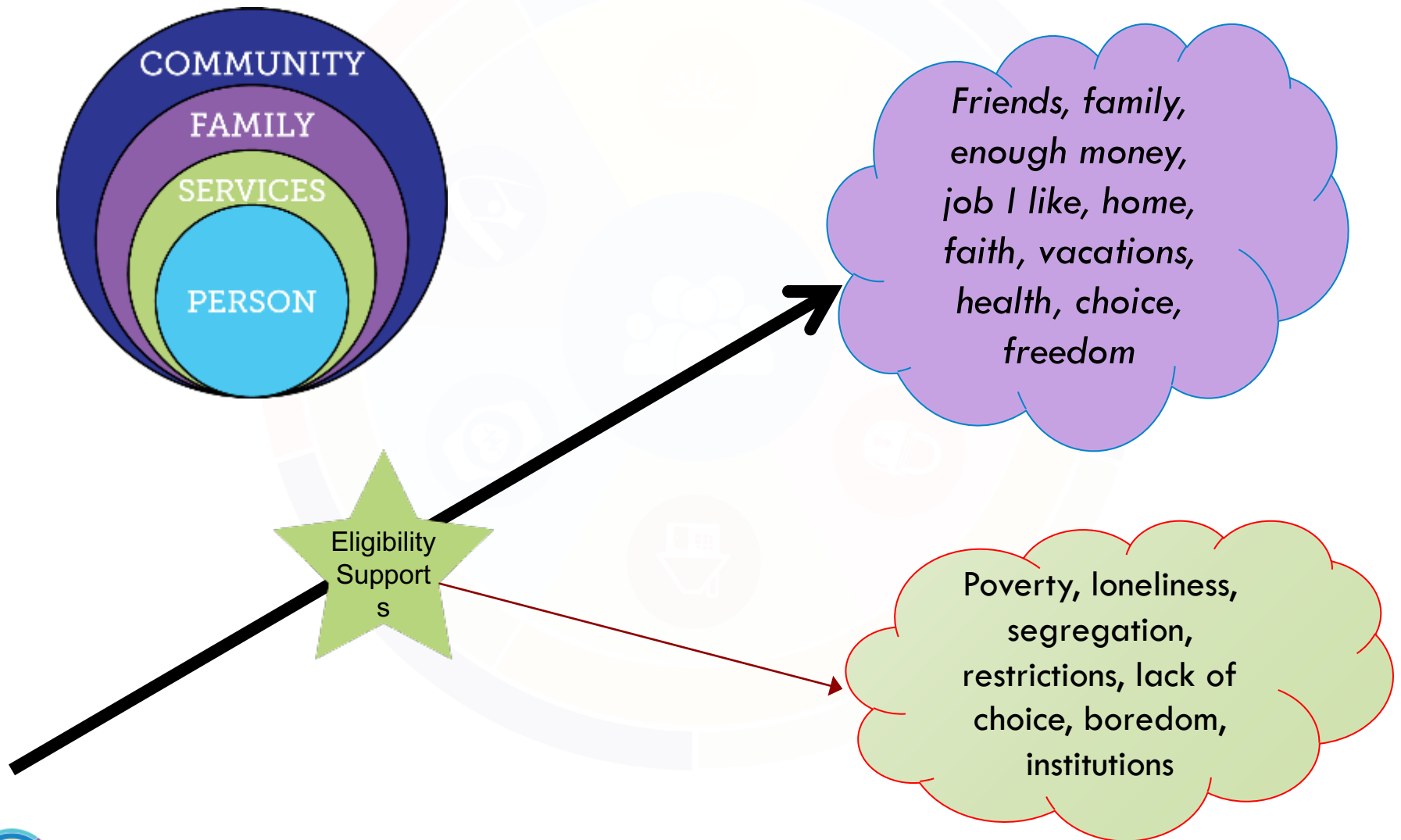
Integrated Services
and Supports within
context of person,
family and community



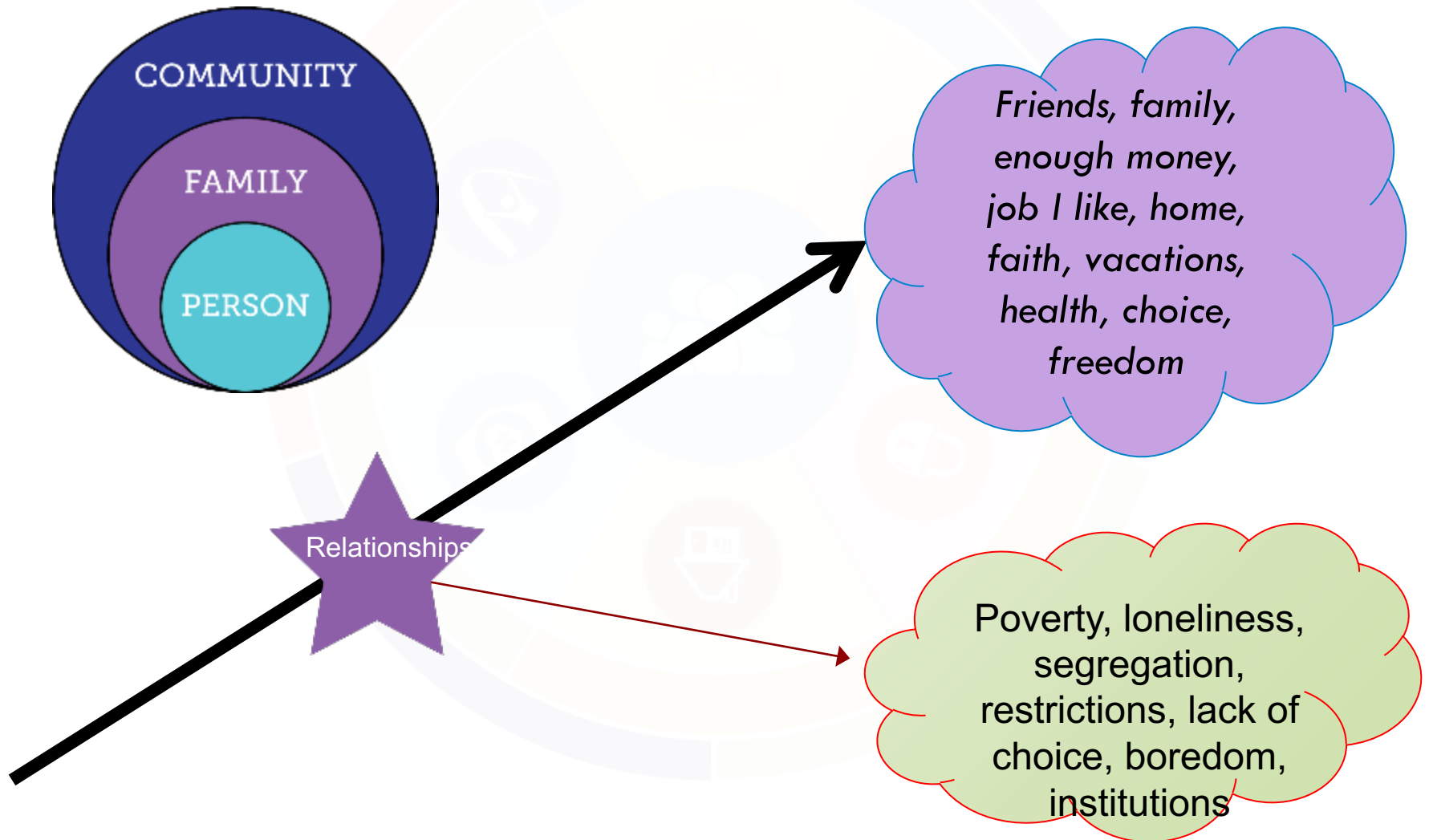
Integrated Supports STAR

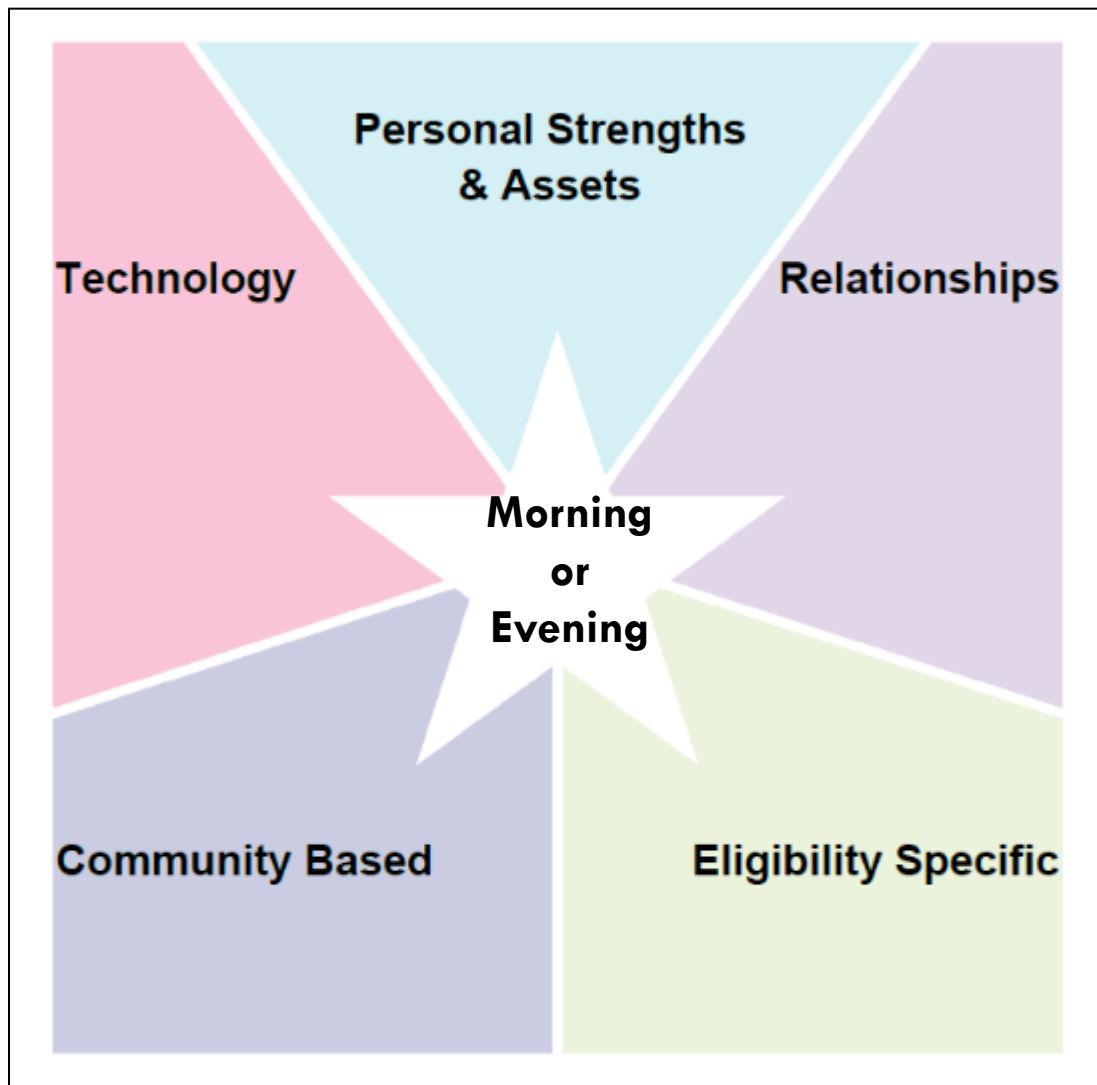


Focusing ONLY on Eligibility Supports



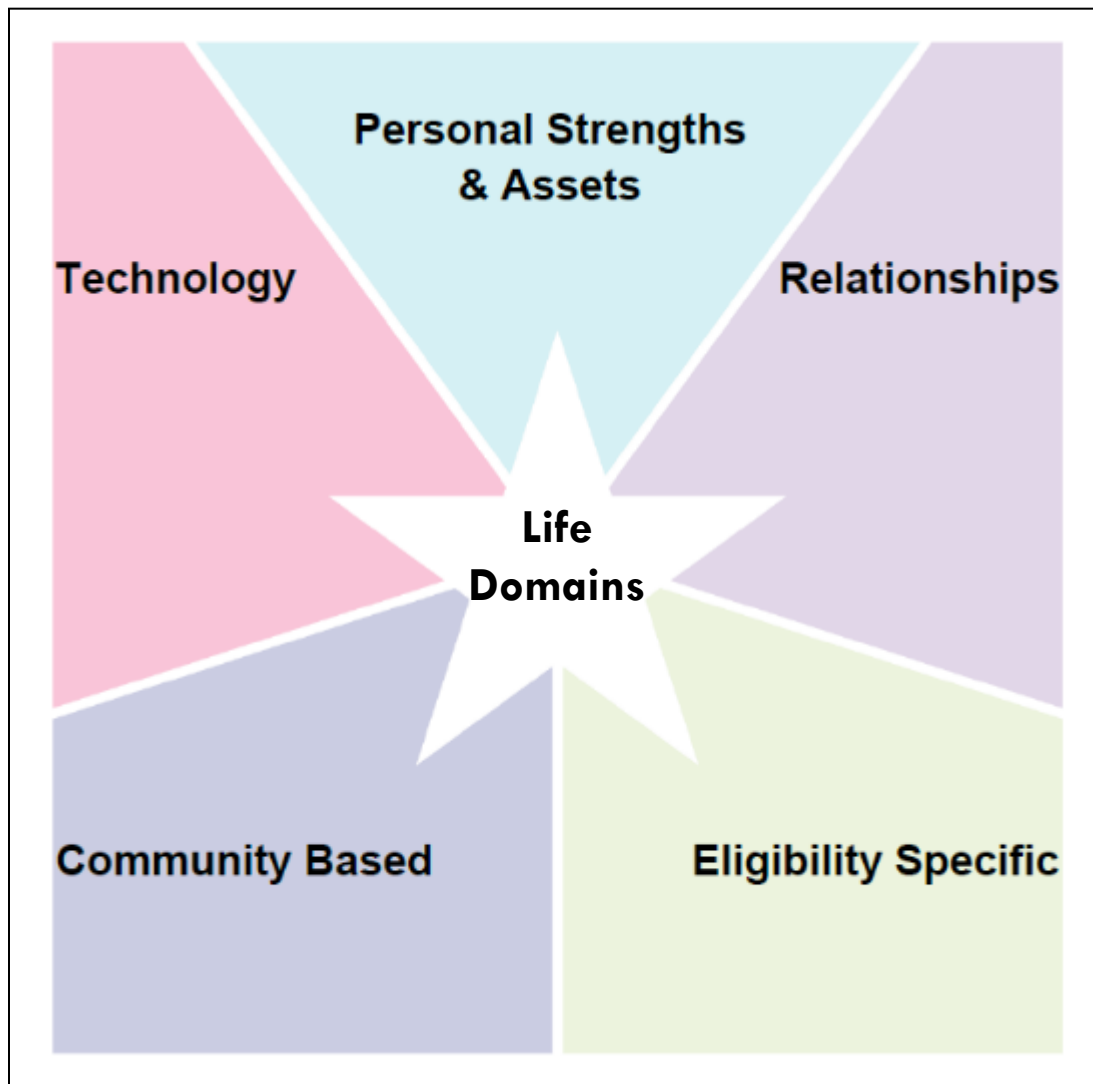
Relying ONLY on Family & Friends





Integrated Supports: Daily Routine





Integrated Supports: Domain Specific

CHARTING the life course
Integrated Services and Supports

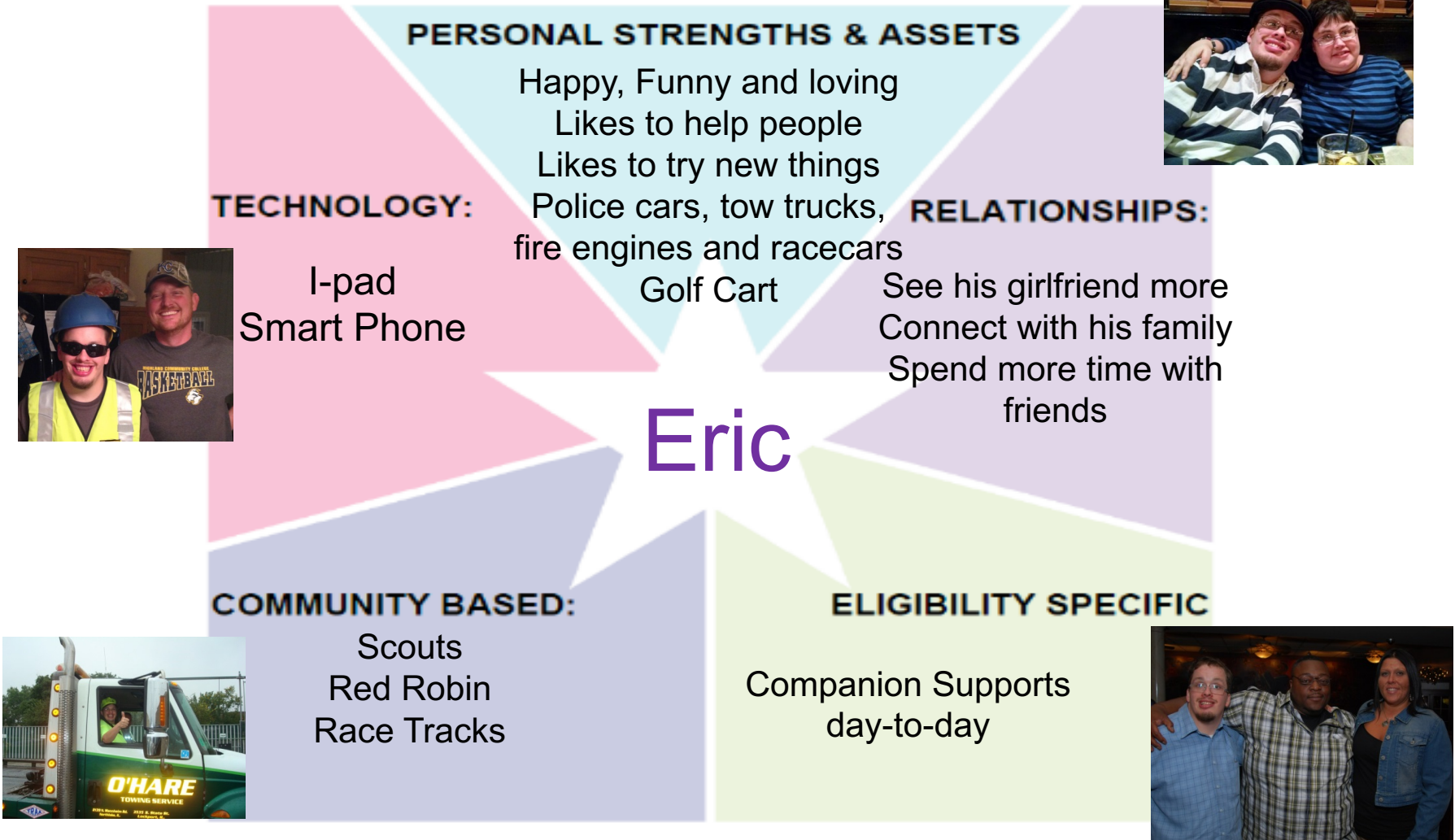
Charting the life course is a process of identifying and documenting a person's life course, including their strengths, needs, and goals, to inform the development of integrated services and supports. The charting tool is a template that can be used to document a person's life course, including their strengths, needs, and goals, to inform the development of integrated services and supports.

Category	Personal Strengths & Assets	Relationships	Eligibility Specific	Community Based	Technology
Personal Strengths & Assets	<ul style="list-style-type: none"> Individual's strengths, skills, and abilities Individual's interests and passions Individual's values and beliefs Individual's cultural and linguistic background Individual's education and training Individual's work experience Individual's social and emotional well-being Individual's physical and mental health Individual's financial resources Individual's housing and transportation Individual's access to community resources Individual's access to social support Individual's access to information and communication technology Individual's access to transportation Individual's access to food and nutrition Individual's access to healthcare Individual's access to legal services Individual's access to financial services Individual's access to housing and transportation Individual's access to food and nutrition Individual's access to healthcare Individual's access to legal services Individual's access to financial services 	<ul style="list-style-type: none"> Individual's family and social network Individual's community and social connections Individual's relationships with service providers Individual's relationships with peers and friends Individual's relationships with community organizations Individual's relationships with government agencies Individual's relationships with religious and spiritual communities Individual's relationships with cultural and linguistic communities Individual's relationships with educational institutions Individual's relationships with workplaces Individual's relationships with healthcare providers Individual's relationships with legal services providers Individual's relationships with financial services providers Individual's relationships with housing and transportation providers Individual's relationships with food and nutrition providers Individual's relationships with healthcare providers Individual's relationships with legal services providers Individual's relationships with financial services providers Individual's relationships with housing and transportation providers Individual's relationships with food and nutrition providers Individual's relationships with healthcare providers Individual's relationships with legal services providers Individual's relationships with financial services providers 	<ul style="list-style-type: none"> Individual's eligibility for federal, state, and local programs Individual's eligibility for federal, state, and local benefits Individual's eligibility for federal, state, and local services Individual's eligibility for federal, state, and local housing Individual's eligibility for federal, state, and local transportation Individual's eligibility for federal, state, and local food and nutrition Individual's eligibility for federal, state, and local healthcare Individual's eligibility for federal, state, and local legal services Individual's eligibility for federal, state, and local financial services Individual's eligibility for federal, state, and local housing and transportation Individual's eligibility for federal, state, and local food and nutrition Individual's eligibility for federal, state, and local healthcare Individual's eligibility for federal, state, and local legal services Individual's eligibility for federal, state, and local financial services Individual's eligibility for federal, state, and local housing and transportation Individual's eligibility for federal, state, and local food and nutrition Individual's eligibility for federal, state, and local healthcare Individual's eligibility for federal, state, and local legal services Individual's eligibility for federal, state, and local financial services 	<ul style="list-style-type: none"> Individual's access to community resources Individual's access to social support Individual's access to information and communication technology Individual's access to transportation Individual's access to food and nutrition Individual's access to healthcare Individual's access to legal services Individual's access to financial services Individual's access to housing and transportation Individual's access to food and nutrition Individual's access to healthcare Individual's access to legal services Individual's access to financial services Individual's access to housing and transportation Individual's access to food and nutrition Individual's access to healthcare Individual's access to legal services Individual's access to financial services 	<ul style="list-style-type: none"> Individual's access to information and communication technology Individual's access to transportation Individual's access to food and nutrition Individual's access to healthcare Individual's access to legal services Individual's access to financial services Individual's access to housing and transportation Individual's access to food and nutrition Individual's access to healthcare Individual's access to legal services Individual's access to financial services Individual's access to housing and transportation Individual's access to food and nutrition Individual's access to healthcare Individual's access to legal services Individual's access to financial services



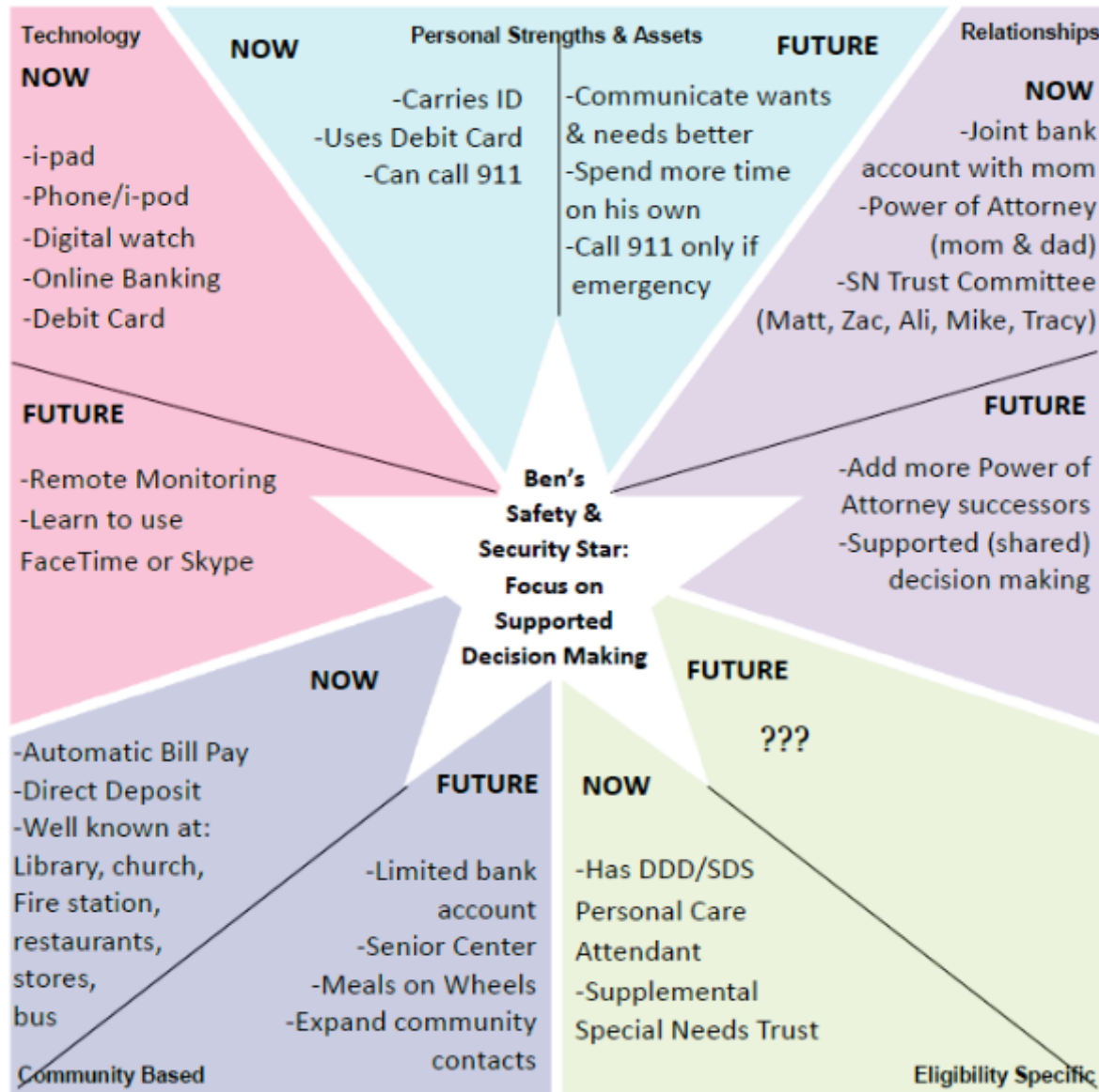


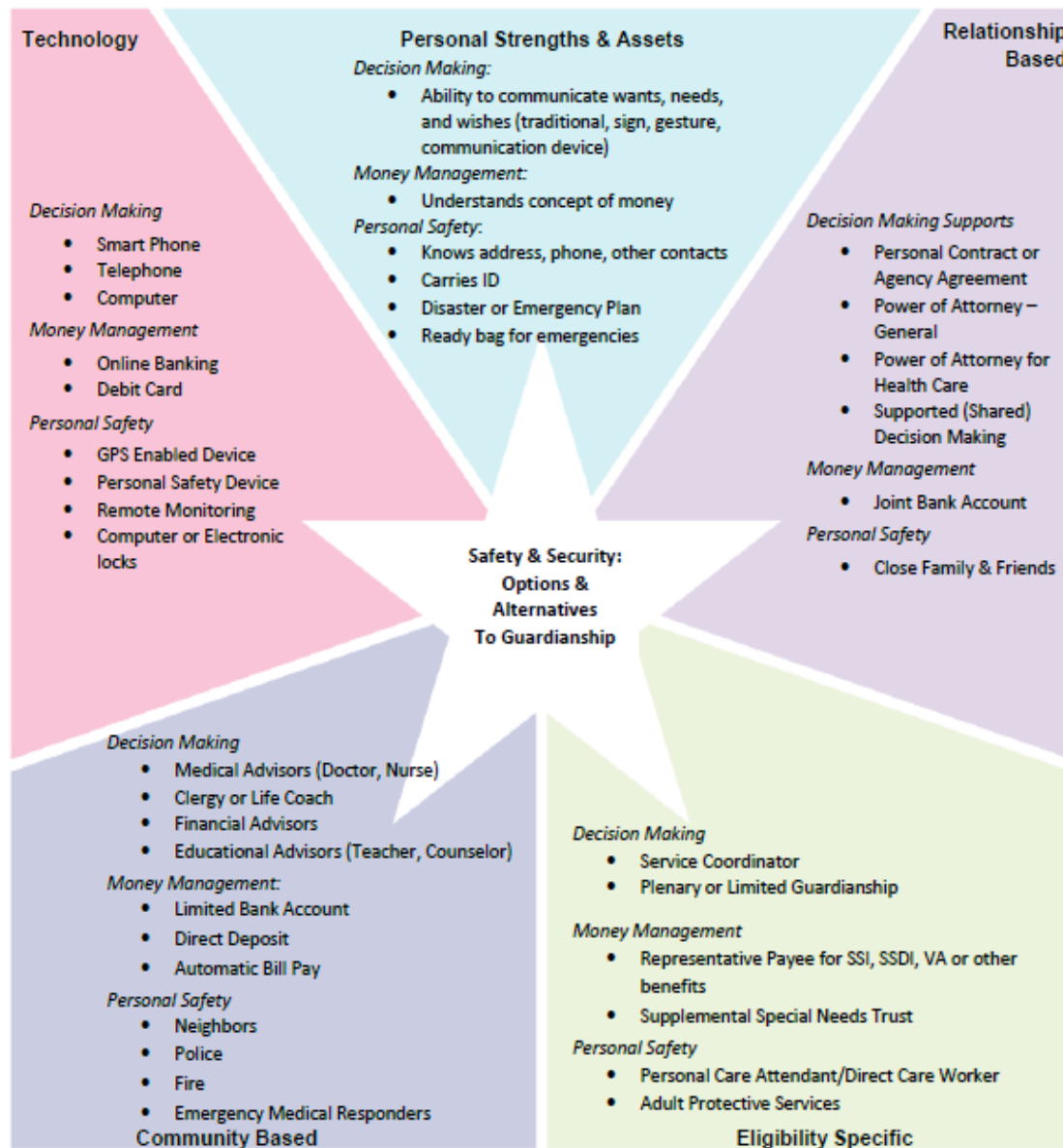
Focus on Social and Spirituality



Ben's Safety & Security Star

Focus on
Supported
Decision Making



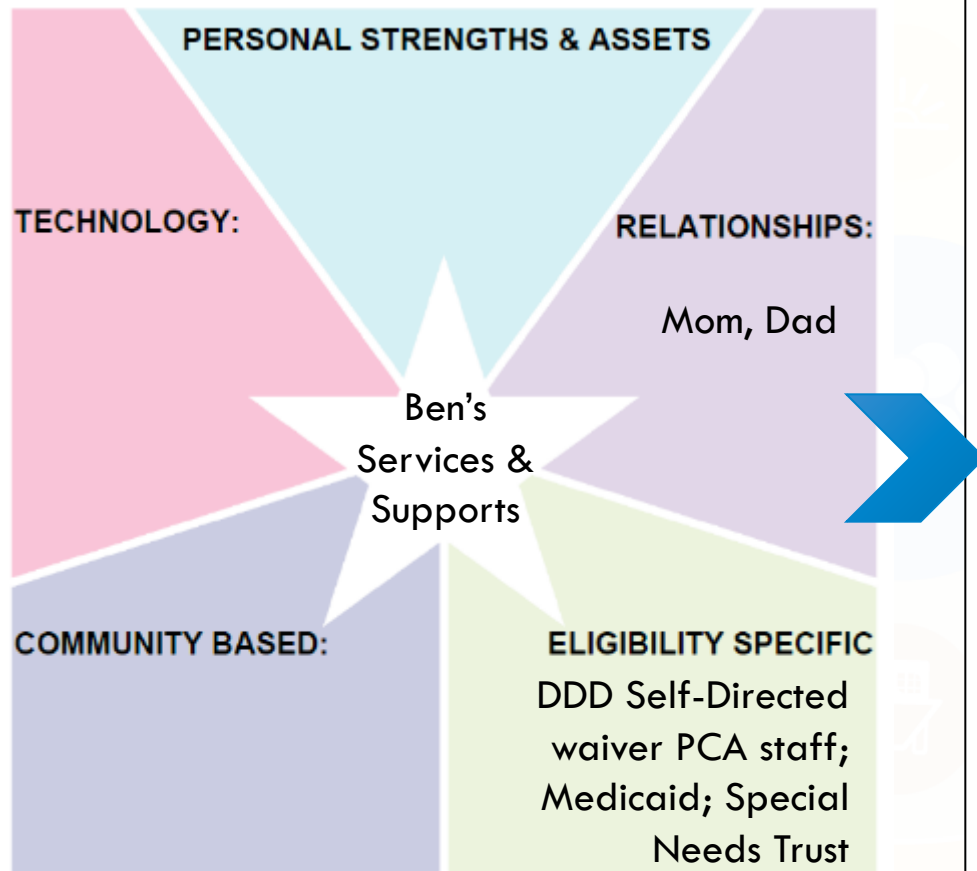


Safety and Security

Focus on Supported Decision Making



BEFORE: Integrated Supports



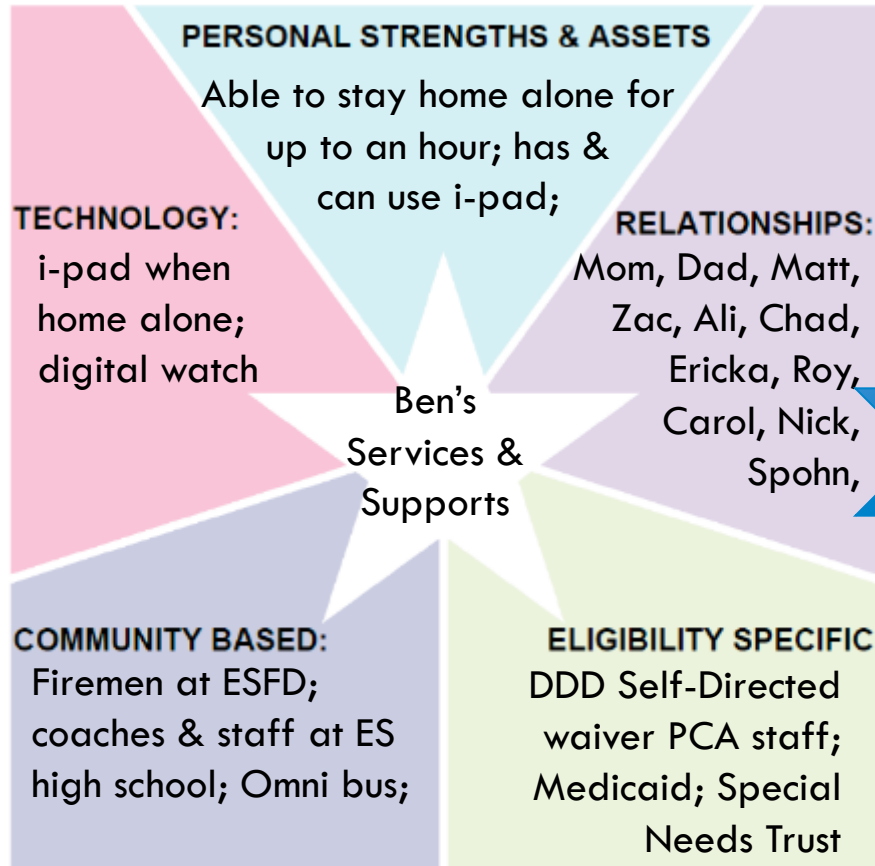
Long Term Service and Support Needs							
Time	Mon	Tues	Wed	Thurs	Fri	Sat	Sun
6-6:30 AM	Parents get Ben out of bed, assist with breakfast, shower, getting dressed and ready for his day						
6:30-7 AM							
7-7:30 AM							
7:30-8 AM	<div> <div>Waiver Self-Directed PCA</div> <div>Parents are weekend support</div> </div>						
8-8:30 AM							
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	<div> <div>Mom and Dad provide all support, including meals, transportation and support for activities, etc.</div> </div>						
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	<div> <div>Mom and Dad are overnight staff</div> </div>						
6-6:30 PM							
6:30-7 PM							
7-7:30 PM							
7:30-8 PM							
8-8:30 PM							
8:30-9 PM							
9-9:30 PM							
9:30-10 PM							
10 PM-6 AM							

Template by Missouri Family to Family @ UMHC-HD, UCEDD

December 2014



AFTER: Integrated Supports



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													
10-10:30 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		St. Ann's w/ mom						
10:30-11 AM													
11-11:30 AM													
11:30-12 PM													
12-12:30 PM	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							
12:30-1 PM													
1-1:30 PM													
1:30-2 PM													
2-2:30 PM													
2:30-3 PM	Volunteer at high school, supported by coaches and friends												
3-3:30 PM													
3:30-4 PM													
4-4:30 PM													
4:30-5 PM													
5-5:30 PM													
5:30-6 PM	WWE With Matt	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				Nick's Birthday Party with Matt and friends							
7-7:30 PM		Horseback Therapy w/ Dad											
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-IND, UCEDD

January 2015



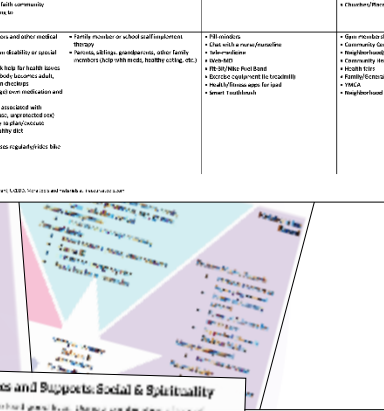
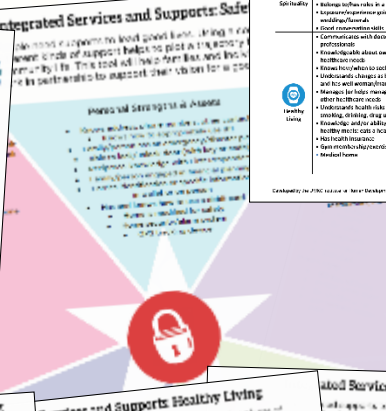
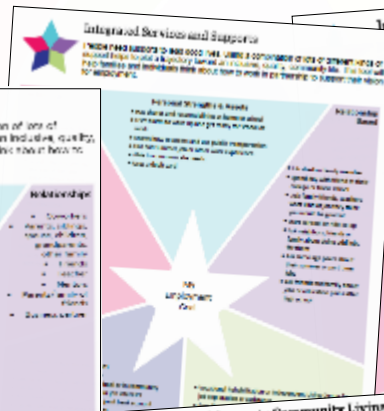
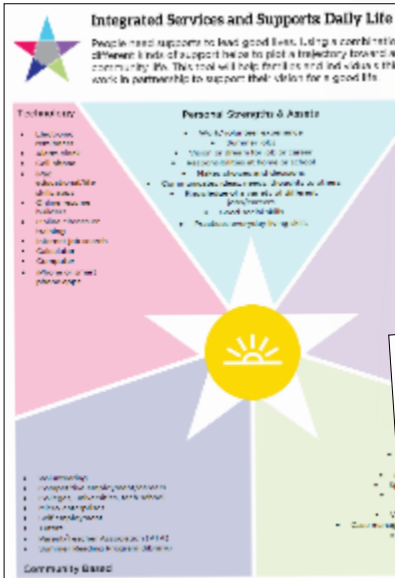
Integrated Options & Star Cheat Sheets

CHARTING the LifeCourse

Integrated Support Options

People need supports to live good lives. There is a combination of different kinds of support to help a person live a good life. This tool will help you think about how to work together to support a person to live a good life.

LIFE DOMAIN	Personal Strengths & Assets	Relationship Based Supports	Technology	Community Resources	Eligibility Based Supports
Only the Employee	<ul style="list-style-type: none"> Work/education experience Interests, hobbies, talents, skills Values or interests (e.g. career) Knowledge of how to live Knowledge of a variety of different cultures Good work ethic Remember everything being able 	<ul style="list-style-type: none"> Co-workers Family, friends, spouse, children, grandchildren, other family Neighbors Teacher Religious Parents/Family of friends Religious pastor 	<ul style="list-style-type: none"> Electronic resources Smart phone Cell phone Smartwatch/fitness tracker Tablet computer Smart TV Internet access Computer Smartwatch Smartphone 	<ul style="list-style-type: none"> Volunteering Employment opportunities Religious, educational, health care After-school programs Adult education Tutoring Parent/Teacher Association (PTA) Summer Reading Program (SRP) 	<ul style="list-style-type: none"> Work area changes Job changes Supportive employment Specialized training Specialized education Specialized health care Specialized housing Specialized transportation Specialized support services
University Student	<ul style="list-style-type: none"> Knowledge of how to live Interests, hobbies, talents, skills Values or interests (e.g. career) Knowledge of how to live Knowledge of a variety of different cultures Good work ethic Remember everything being able 	<ul style="list-style-type: none"> Co-workers Family, friends, spouse, children, grandchildren, other family Neighbors Teacher Religious Parents/Family of friends Religious pastor 	<ul style="list-style-type: none"> Electronic resources Smart phone Cell phone Smartwatch/fitness tracker Tablet computer Smart TV Internet access Computer Smartwatch Smartphone 	<ul style="list-style-type: none"> Volunteering Employment opportunities Religious, educational, health care After-school programs Adult education Tutoring Parent/Teacher Association (PTA) Summer Reading Program (SRP) 	<ul style="list-style-type: none"> Work area changes Job changes Supportive employment Specialized training Specialized education Specialized health care Specialized housing Specialized transportation Specialized support services
Adult & Senior	<ul style="list-style-type: none"> Knowledge of how to live Interests, hobbies, talents, skills Values or interests (e.g. career) Knowledge of how to live Knowledge of a variety of different cultures Good work ethic Remember everything being able 	<ul style="list-style-type: none"> Co-workers Family, friends, spouse, children, grandchildren, other family Neighbors Teacher Religious Parents/Family of friends Religious pastor 	<ul style="list-style-type: none"> Electronic resources Smart phone Cell phone Smartwatch/fitness tracker Tablet computer Smart TV Internet access Computer Smartwatch Smartphone 	<ul style="list-style-type: none"> Volunteering Employment opportunities Religious, educational, health care After-school programs Adult education Tutoring Parent/Teacher Association (PTA) Summer Reading Program (SRP) 	<ul style="list-style-type: none"> Work area changes Job changes Supportive employment Specialized training Specialized education Specialized health care Specialized housing Specialized transportation Specialized support services
Family	<ul style="list-style-type: none"> Knowledge of how to live Interests, hobbies, talents, skills Values or interests (e.g. career) Knowledge of how to live Knowledge of a variety of different cultures Good work ethic Remember everything being able 	<ul style="list-style-type: none"> Co-workers Family, friends, spouse, children, grandchildren, other family Neighbors Teacher Religious Parents/Family of friends Religious pastor 	<ul style="list-style-type: none"> Electronic resources Smart phone Cell phone Smartwatch/fitness tracker Tablet computer Smart TV Internet access Computer Smartwatch Smartphone 	<ul style="list-style-type: none"> Volunteering Employment opportunities Religious, educational, health care After-school programs Adult education Tutoring Parent/Teacher Association (PTA) Summer Reading Program (SRP) 	<ul style="list-style-type: none"> Work area changes Job changes Supportive employment Specialized training Specialized education Specialized health care Specialized housing Specialized transportation Specialized support services





Massachusetts CtLC in Action



CtLC Self-Direction





Person with Disability and their Families
Engage, Lead, and Drive
Policy, Practice and Community Change

Partnering at Every Level for Change

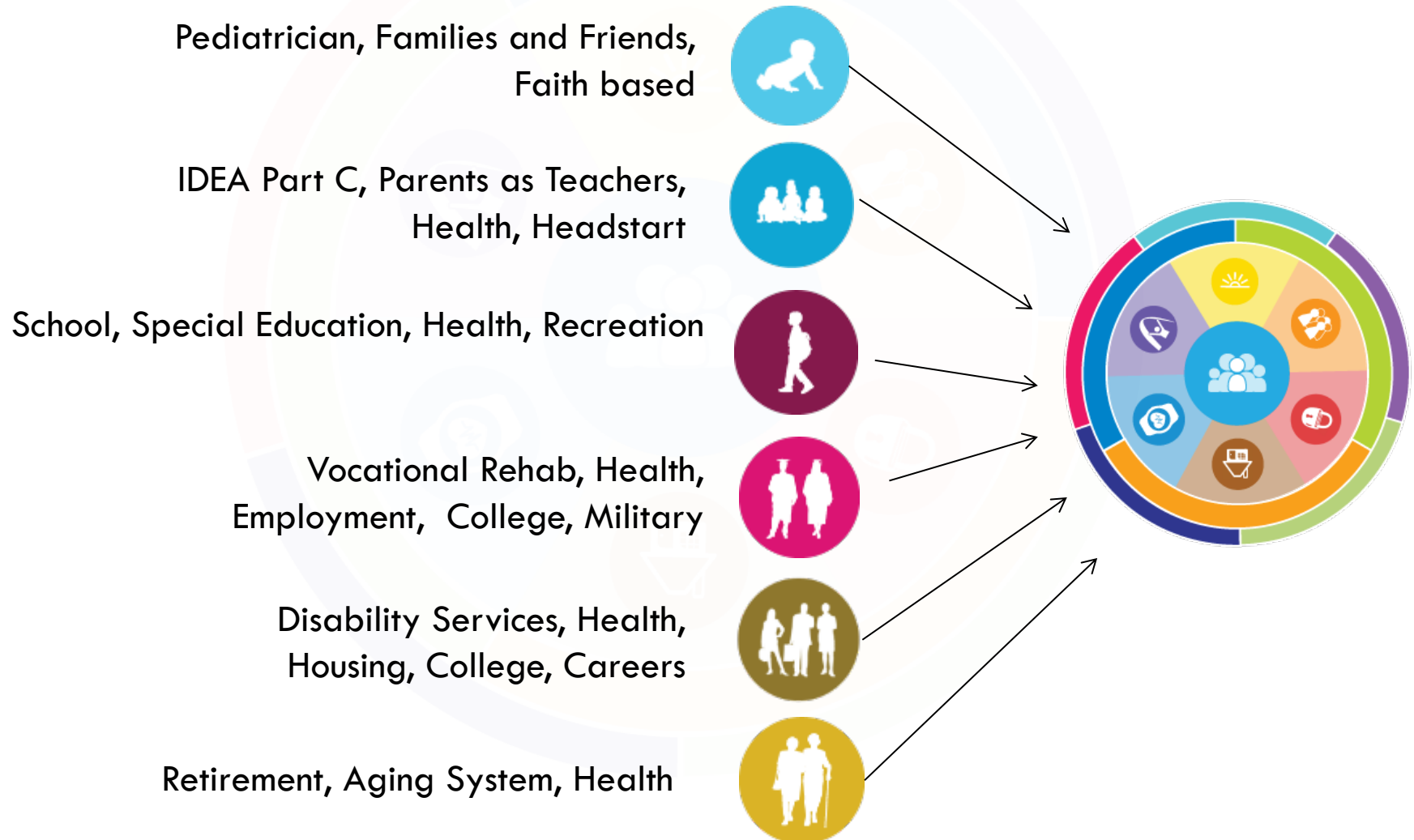
Every program, organization, system and policy maker must always think about a person in the context of family

Individuals and families are satisfactorily involved in policy making so that they influence planning, policy, implementation, evaluation and revision of the practices that affect them.

.



Comprehensive, Integrated & Coordinated Systems Across Life Domains & Stages





CtLC in Action



Human Needs and System Needs

Human Needs of Person and their Family



Touchpoints between Person/Family and LTSS

Front Door
Interaction

Intake &
Assessment

Person Centered
Plan Process

Accessing
Supports

Delivering
Services

Check-In &
Monitoring

Annual
Meeting

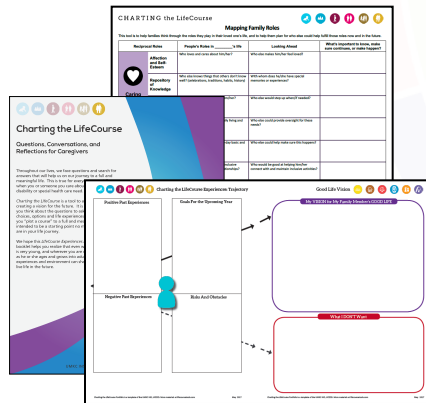


System Requirements (Federal, State, Organizational)

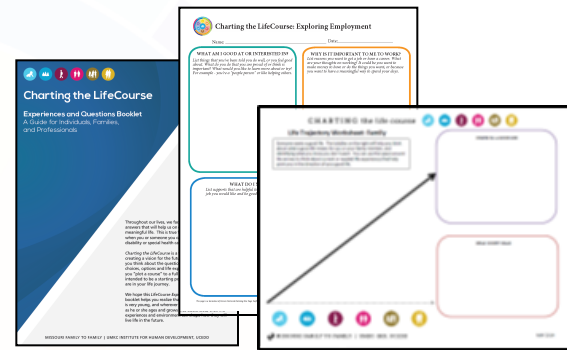


Tools for All Team Members

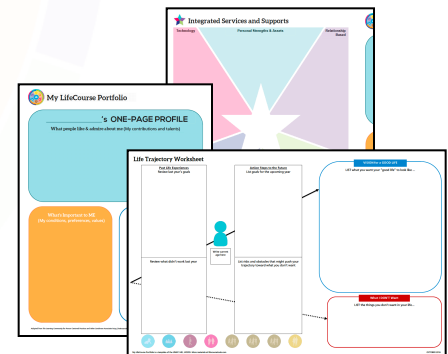
Planning for Life Outcomes and/or Service Planning



Family Perspective Tools & Resources



Self-Advocate Tools & Resources

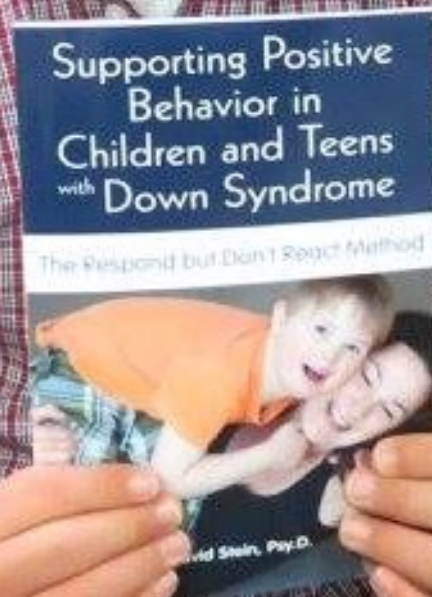


Support Team Tools & Resources



Peyton's Plan for Inclusion in School

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



Peyton's Good Life 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

MISSOURI FAMILY TO FAMILY LIVING AND WORK



Peyton's Integrated Supports

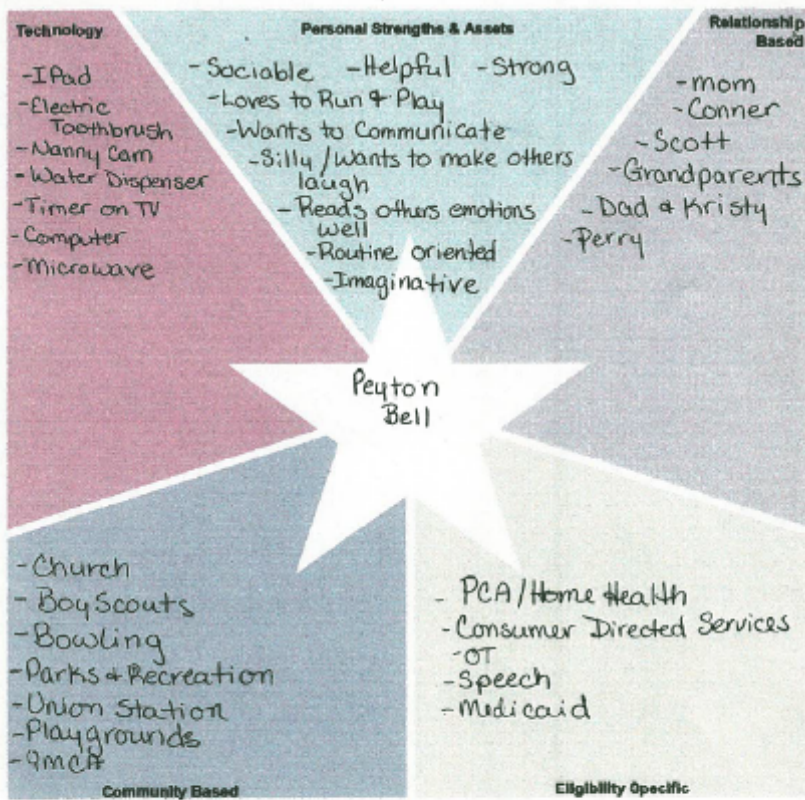
CHARTING the life course



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 through various means:						
9-9:30 AM	- Social support from peers						Church
9:30-10 AM	- Tech support through AT device						
10-10:30 AM	- Aid supports in Reg Ed and special ed classrooms						
10:30-11 AM							
11-11:30 AM							
11:30-12 PM							
12-12:30 PM						PCA /	Home Health
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	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							
6:30-7 PM							
7-7:30 PM	Boy Scouts	sports					
7:30-8 PM							
8-8:30 PM							
8:30-9 PM							
9-9:30 PM							
9:30-10 PM							
10 PM-6 AM							

Conner's Trajectory for IEP Meeting

Life Trajectory Worksheet

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

- Inclusion in Gen Ed Learning
- Education of support staff and students to provide understanding
- Exposure to various activities
- Riding the Reg Ed Bus
- Providing schedules and set expectations
- Help building friendships
- Educating my peers
- Letting me advocate for myself

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

- Seclusion in Special Education Classrooms
- Aids helping me in every situation
- Riding the Special Education Bus
- Low expectations
- Being punished for bad behaviors
- Making excuses for my behavior

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 ...


- Have a job (Gainfully Employed)
- Make Friends (Have Quality Relationships)
- Make Money (Be Financially Independent)
- Have a Girlfriend (Find Love)
- Have Kids
- Live on My Own (Independently)
- Go Bowling (Participate in Community)
- Build things in the forest next to New York City (Have hobbies he enjoys)

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

- No Friends (Unhealthy Relationships)
- Get fired (Unstable Employment)
- No Girlfriend (Isolation)
- No Kids
- Stigmatized

Conner

Write current age here
2016-2017
6th Grade



Impact on All Family Members



My LifeCourse Portfolio
Lilly's ONE-PAGE PROFILE

Integrated Services and Supports

People need supports to lead good lives. Using a combination of lots of different kinds of help, people can develop meaningful activities, quality relationships, and a sense of purpose. This page is a place to describe how you work in partnership to support your child for a good life.

Technology
iPad
iPhone
TV
DVD Player

Personal Strengths & Assets
Happy
Smart
Curious
Adventurous

Relationships
Mom
Dad
Payton
Conner
Elizabeth
Susan
Dale
Mom Paw
Grandma Kathy
Grandpa Ralph
Erica
Tenley
Jordan
Cameron
Katie

Lilly

Integrated Services and Supports

People need supports to lead good lives. Using a combination of lots of different kinds of help, people can develop meaningful activities, quality relationships, and a sense of purpose. This page is a place to describe how you work in partnership to support your child for a good life.

Technology
iPad
iPhone
TV
Treadmill
Computer
Mixer
Apps
Crockpot
Skillet
Coffee maker
Outlet timer
Car
Habit
Facebook

Personal Strengths & Assets
Determined
Devoted
Ambitious
Happy
Hard Worker
Resourceful
Helpful
Honest

Crystal

Community
Gym
Grocery Stores
Church
TOPS group
Races
Health Department
Daycare

Across the LifeCourse framework and levels of representation

November 2018

Adapted from the LifeCourse framework and levels of representation

Life Trajectory Worksheet

Positive Life Experiences
LST and life experiences that supported your vision for a good life.
-Acknowledging and responding to my child's needs, desires, and wishes
-Playing with me to help me learn and grow

Barriers to Life Experiences
LST and life experiences that hindered your vision for a good life.
-Lack of time to help me learn and grow
-Positive struggles for the car, not

VISION for a GOOD LIFE

LST and life experiences that supported your vision for a good life.

Happy
Financially Independent
Educated
Friends
Healthy Relationships
Positive Life Experiences
Balanced/Adaptable
Accepting/Open-minded
Independent
Healthy

What I DON'T Want

LST and life experiences that hindered your vision for a good life.

Lonely
In Poverty
Financially dependent on government/parents

VISION for a GOOD LIFE

LST and life experiences that supported your vision for a good life.

Successful/Fulfilling Career
Financially Stable
Travel
Happy
Good Health/Fit
Respected
Independent
Valued
Close Friends
Active Retirement/My Choice
Affordable/Adequate Healthcare

What I DON'T Want

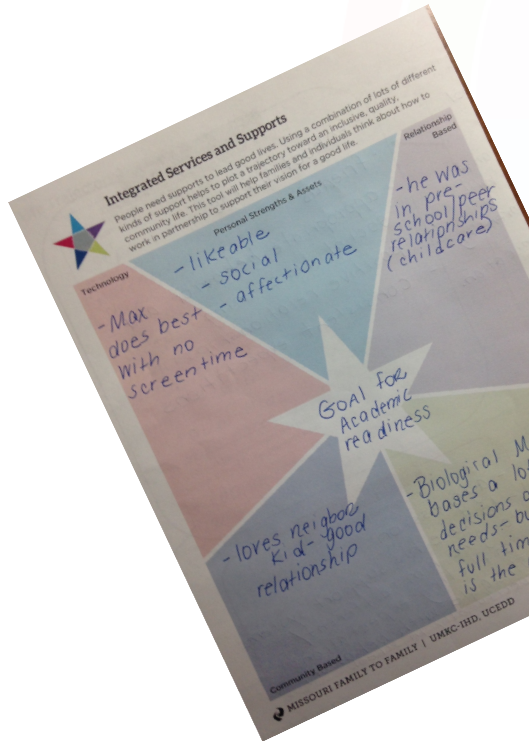
LST and life experiences that hindered your vision for a good life.

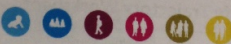
Unhealthy/Fat
Living like a failure
Living from day to day/no vision
Living with family making an impact
Poverty
Dependent



Max

Early Childhood Transitions



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

AUGUST 2015

MISSOURI FAMILY TO FAMILY | UMKC-IHD, UCEDD

Maxwell

Identifying strengths

- Identifying Max's strengths
- Identifying Max's interests
- Identifying Max's abilities
- Identifying Max's preferences
- Identifying Max's communication

School Success

- friends
- appropriate behavior and social functioning
- positive relationships
- consistent expectations

Support Systems

- support systems
- more support systems to give him different/consistent expectations
- consistent expectations

MISSOURI FAMILY TO FAMILY | UMKC-IHD, UCEDD



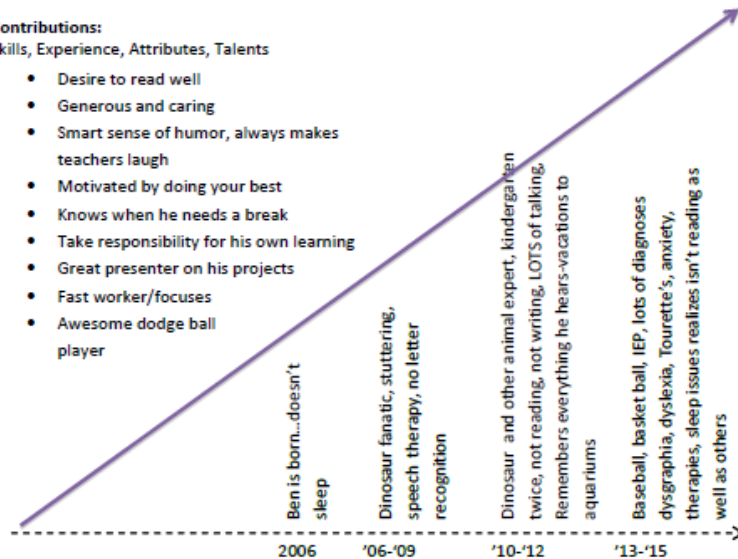
Elementary School Trajectory

Elementary School Trajectory Worksheet:

Contributions:

Skills, Experience, Attributes, Talents

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



What I DON'T Want

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

VISION for successful school experience and a GOOD LIFE

Long term education desires and goals:

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

Educate his classmates on Tourette's

He is determined to be able to read on grade level

Conditions:

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

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

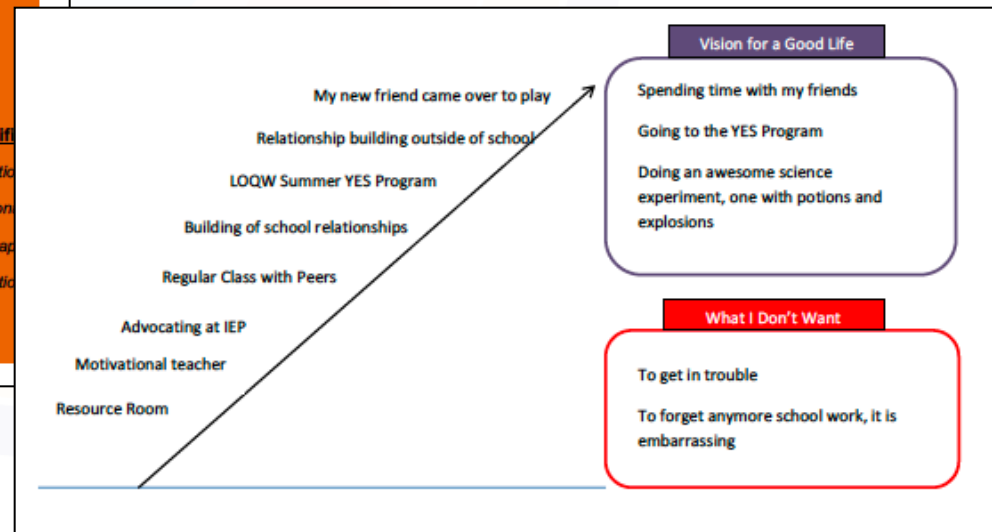


MISSOURI FAMILY TO FAMILY | UMKC-IHD, UCEDD

MAY 2014



Mapping Supports for 6th Grade Year



Jessica Planning Her Future for Success

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" with a disability.

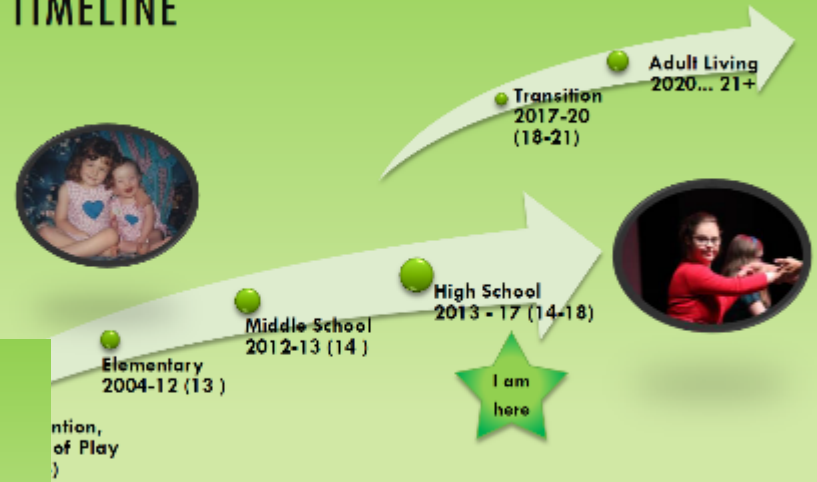


MY PLANS AS AN ADULT

- ❖ 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



Caleb's 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?
-Are Ability 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:

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 ABLE, 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

Community Based

Decision Making:

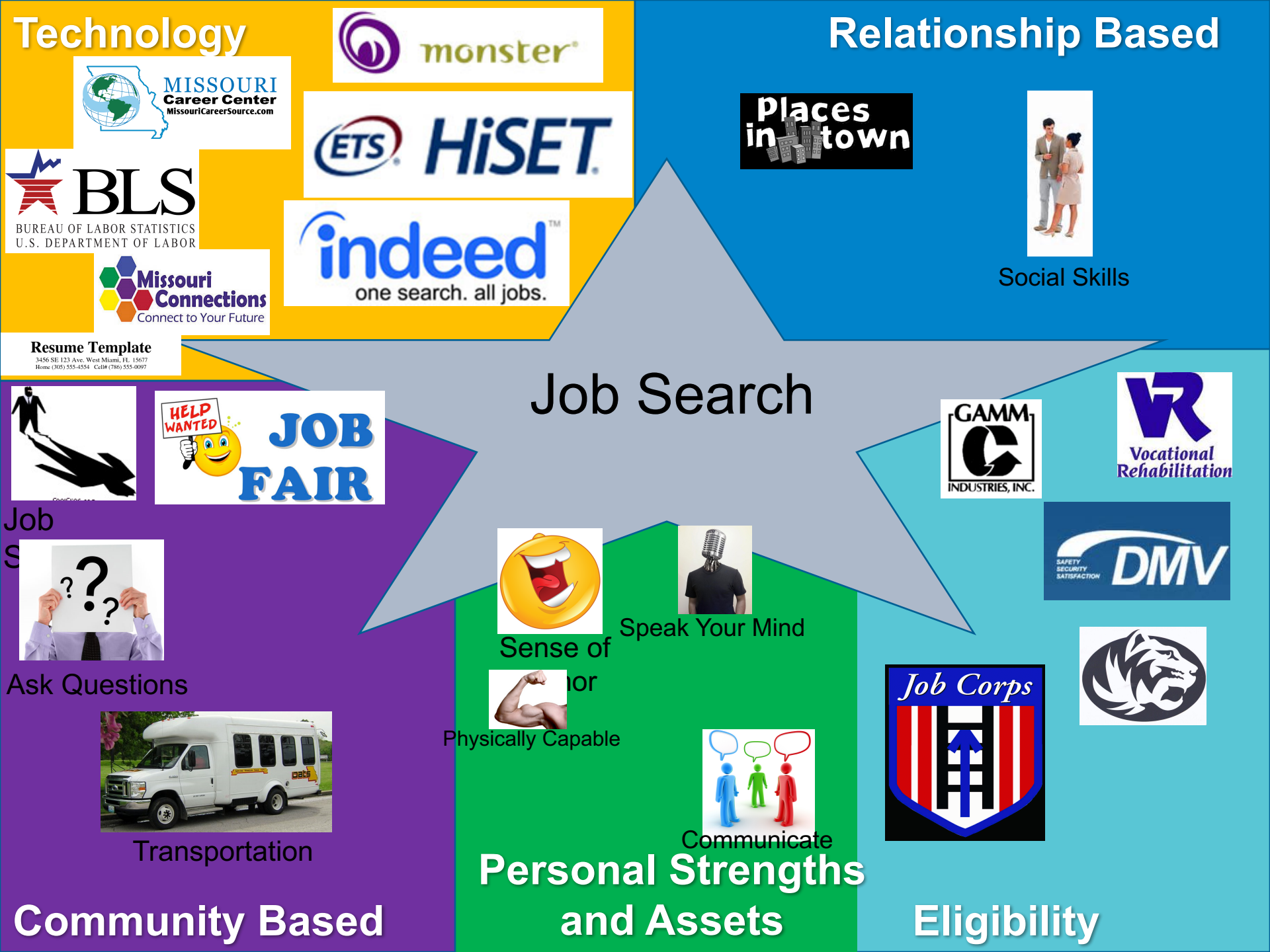
Caleb needs substantial support in regards to public sector resources.

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

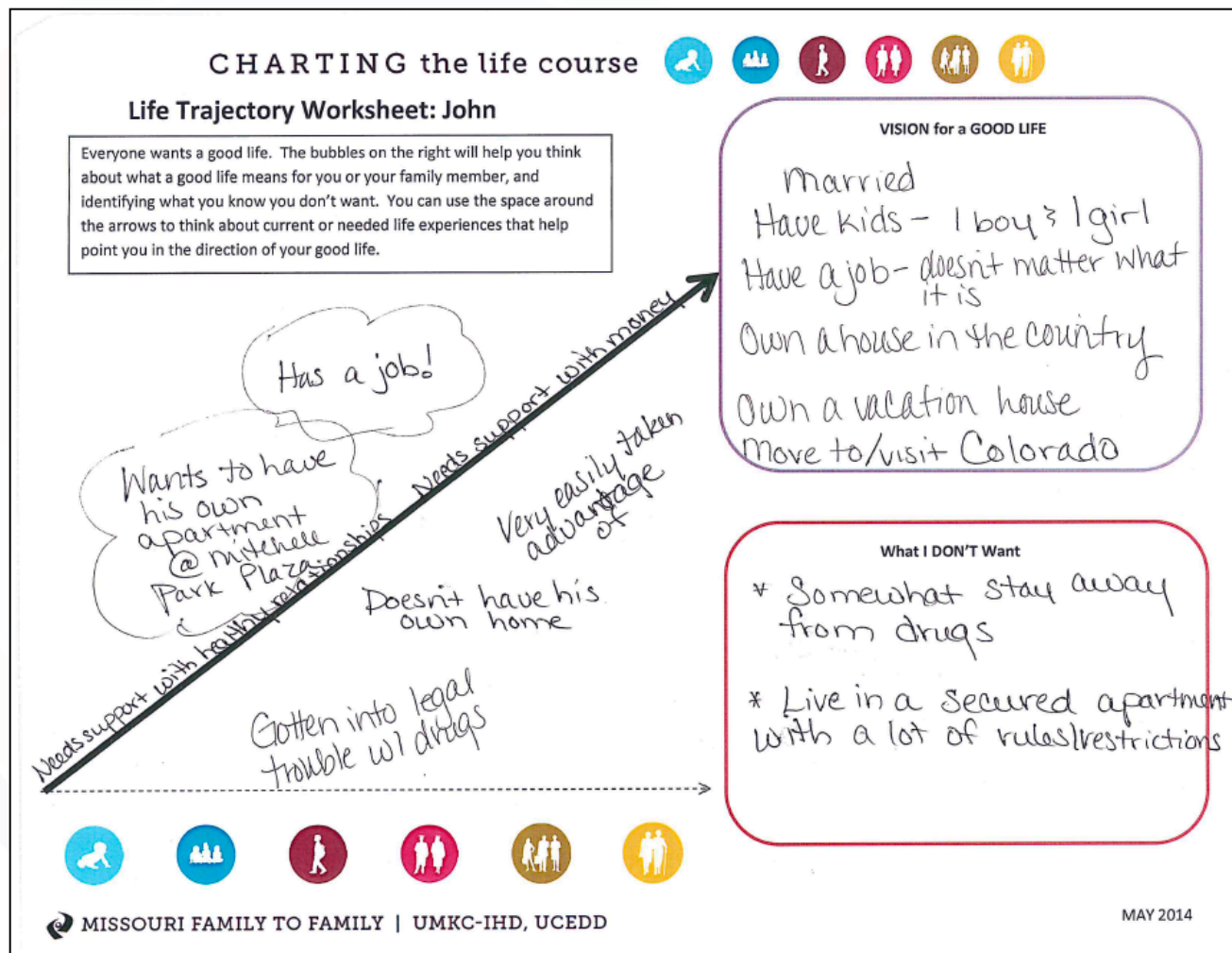


John

26 yrs old

Homeless

Moves from house to house of others



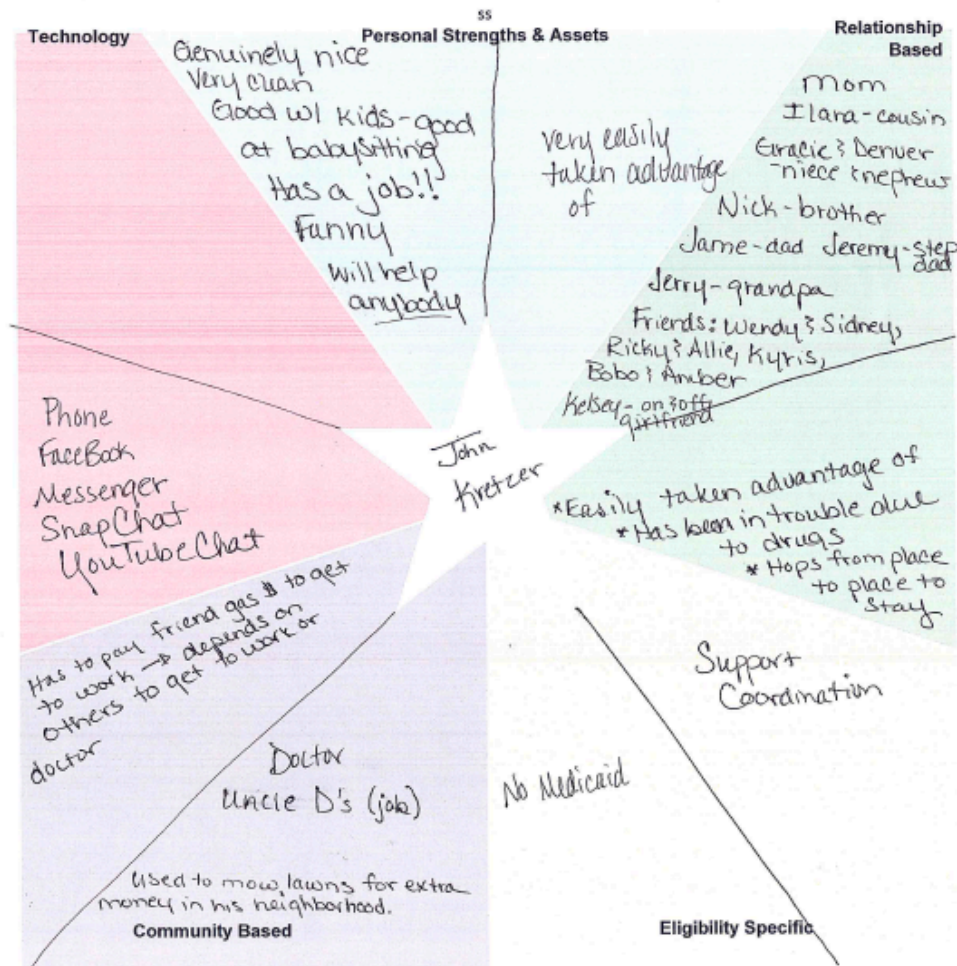
CHARTING the life course



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.



John

TCM only









Sylvia
Lives with mom
Never leaves the
house

TCM only

CHARTING the life course

Life Trajectory Worksheet: SYLVIA MOSHER

WHAT WOULD SUPPORT SYLVIA'S VISION?

Receiving personal assistant services to help her develop confidence performing daily tasks and activities.

Volunteering at an animal shelter.

Voc Rehab

WHAT IS CURRENTLY SUPPORTING SYLVIA'S VISION?

Sylvia walks to the library by herself every day.

Sylvia attends church activities.

There are places that Sylvia likes to go to that are within walking distance from her home.

WHAT DOES NOT SUPPORT SYLVIA'S VISION?

Sylvia does not leave her home often.

Sylvia will not ride the bus by herself.

Sylvia becomes afraid and anxious when she attends places by herself.

Sylvia believes that her anxiety makes it hard for her to get out into the community.

SYLVIA'S VISION of a GOOD LIFE

"I want to work with animals."

"I want to be confident enough to go on a bus by myself and not be scared of getting lost."

"I would like to have a place of my own."







"I would like to be more independent."

"I want to gain more confidence in myself."

"I want to do things without being afraid of what could happen."

What SYLVIA DOESN'T want

- "I don't want to be scared of what happens when I'm on the bus."
- "I don't want to be scared of getting lost."

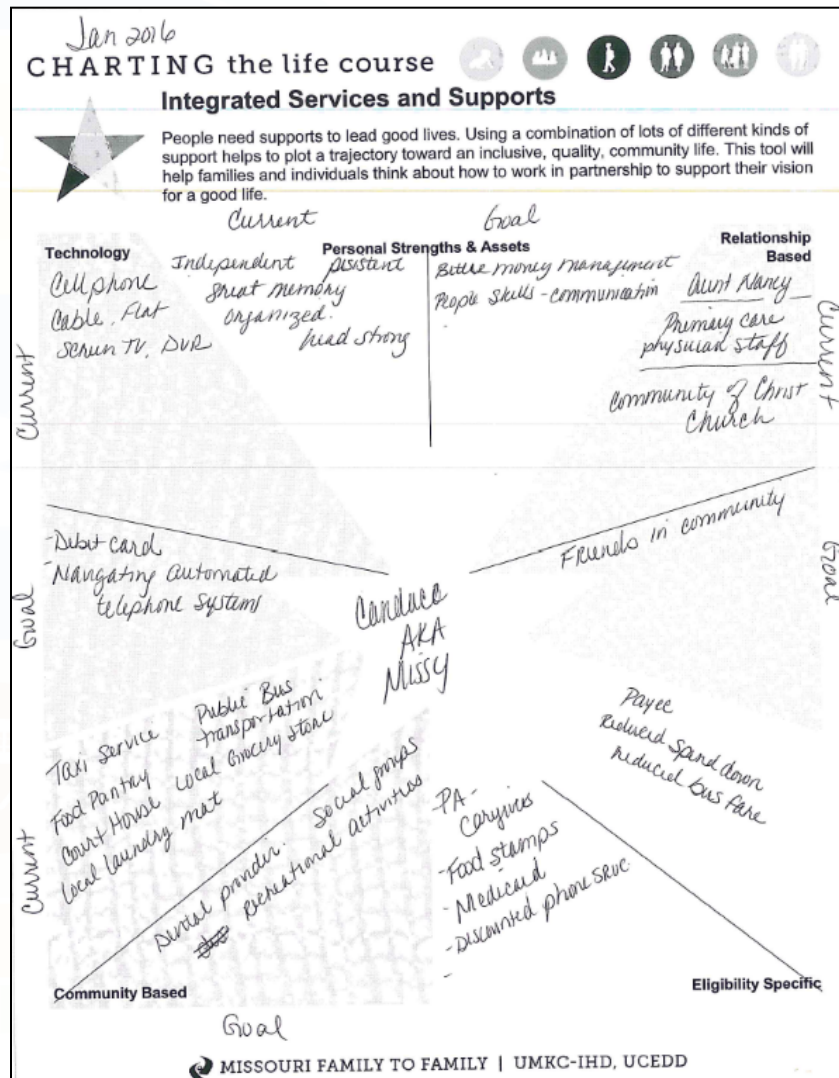
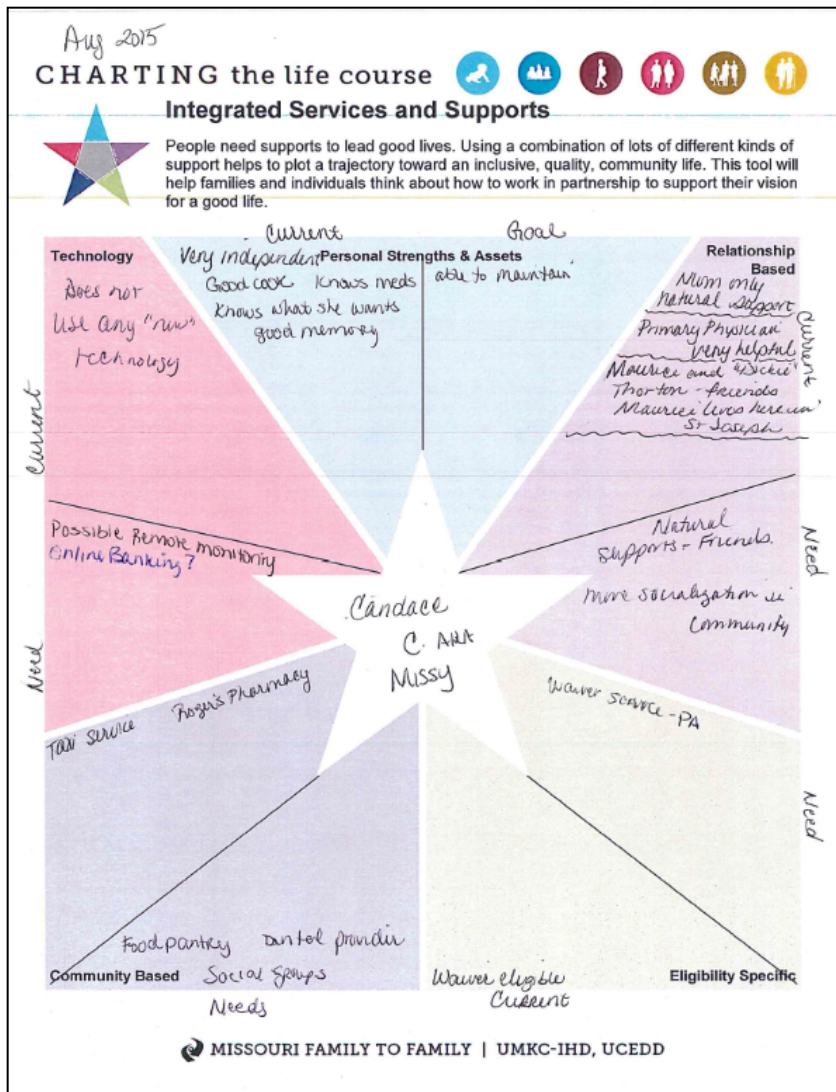







MISSOURI FAMILY TO FAMILY | UMKC-IHD, UCEDD

MAY 2014



Star plus 6 months later



Taylor - 2015

CHARTING the life course



Tool for Developing a Vision - Individual

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 individuals with disabilities of all ages start to think about a vision for how they want to live their life as an adult.

LIFE DOMAIN	My Vision for My Future	rank	Current Situation/Things to Work On	rank
 Daily Life Employment	What do I think I will do/want to do during the day in my adult life? What kind of job/career do I think I might like?		work part time play on iPad go swimming	
 Community Living	Where would I like to live in my adult life? Will I live alone or with someone else?		wants to live in a house w/ a roommate	
 Social & Spirituality	How will I connect with spiritual and leisure activities, and have friendships and relationships in my adult life?		mom & dad will help her	
 Healthy Living	How will I live a healthy lifestyle and manage health care supports in my adult life?		mom will take her to appt.	
 Safety & Security	How will I stay safe from financial, emotional, physical or sexual harm in my adult life?		unsure	
 Citizenship & Advocacy	In my adult life, what kind of valued roles and responsibilities do/will I have, and how do/will I make sure I have control of how my own life is lived?		- wants to have job working w/ cooking or animals - wants a roommate / friend	
 Supports for Family	How will my family still be involved and engaged in my adult life?		- They will take her new places, help w/ everything	
 Supports & Services	What types of support will I need to live as independently as possible in my adult life, and where will my supports come from?		- hygiene - making some - shopping meals - transportation - money	



Taylor 2015 Mom's vision

Taylor Woffe
CHARTING the life course

realization - awesome
hygiene - needs help
showing legs
wants to move 5 years



Tool for Developing a Vision - Family

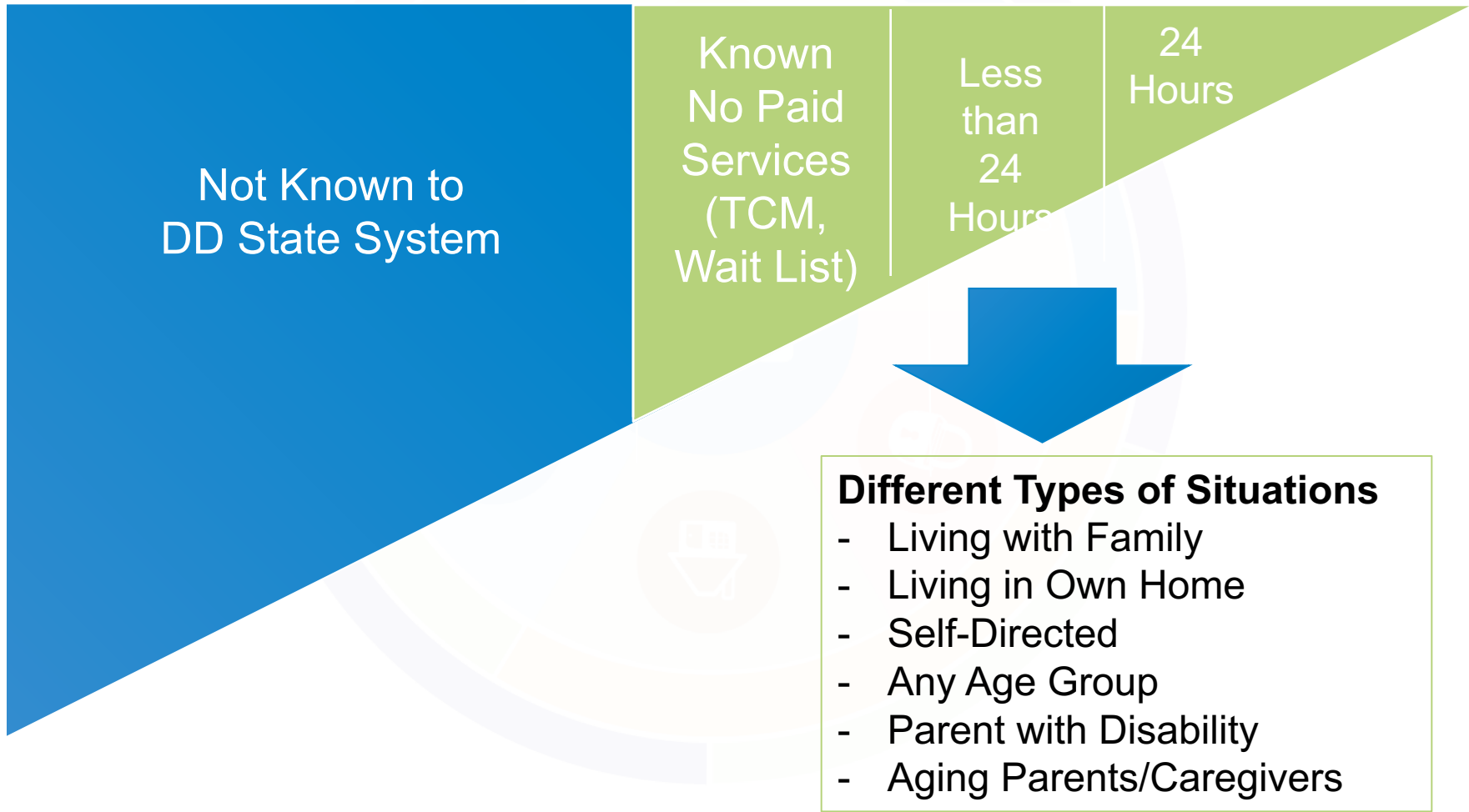
Forming a vision and beginning to plan for the future in each of the life domains helps plot a trajectory for a full, inclusive, quality life in the community. This tool is to help families of all ages - those with a very young child, an adult or somewhere in between, start to think about a vision for 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 Employment	What do I think my child will do during the day in his/her adult life?		would like her to have a job if possible	
Community Living	Where and with whom do I think my child will live in his/her adult life?		Mom thinks she would always live w/ them, sister when they are gone	
Social & Spirituality	How will my child connect with spiritual and leisure activities; have friendships and relationships in his/her adult life?		- Mom supports w/ driving - hope Taylor will make friends through work	
Healthy Living	How will my child live a healthy lifestyle and manage health care supports in his/her adult life?		- will need support w/ tracking Dr. visits, health needs - good w/ medications	
Safety & Security	How will I ensure the safety of my child from financial, emotional, physical or sexual harm in his/her adult life?		- mother will remain payee - sister will take care for mother	
Citizenship & Advocacy	How can I make sure my child has valued roles and responsibilities, and has control of how his/her own life is lived as an adult?		- stay connected to family	
Supports for Family	What will our family need to help support my child to live a quality life as an adult?		Someone they trust working w/ Taylor - especially sister needs so much help w/ hygiene	
Supports & Services	How will my child be supported in his/her adult life to lead the kind of life he/she wants as independently as possible?		Mom would do whatever to help Taylor have a meaningful life.	

MISSOURI FAMILY TO FAMILY | UMKC-IHD, UCEDD

February 2014

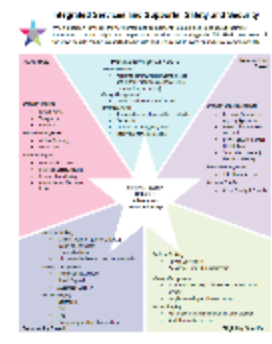
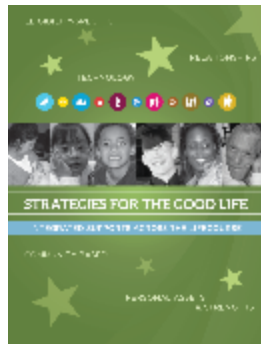
Specific Application of LifeCourse



Reframing for All Stakeholders: Developing Materials



- ◎ Family to Family at Missouri UCEDD
 - ◎ Early Childhood, Part C
 - ◎ School Districts, Special Education
- ◎ PNS Show Me Career Grant Pilot Sites
- ◎ State Division of Developmental Disability
 - ◎ Special Health Care Needs
 - ◎ Dept. Health and Senior Services
 - ◎ Vocational Rehabilitation



Educating Self-Advocates and Families



- ◉ Disseminating LC Materials and Tools
- ◉ Developing New Materials using LC framework
- ◉ Organizing Websites using LC Framework



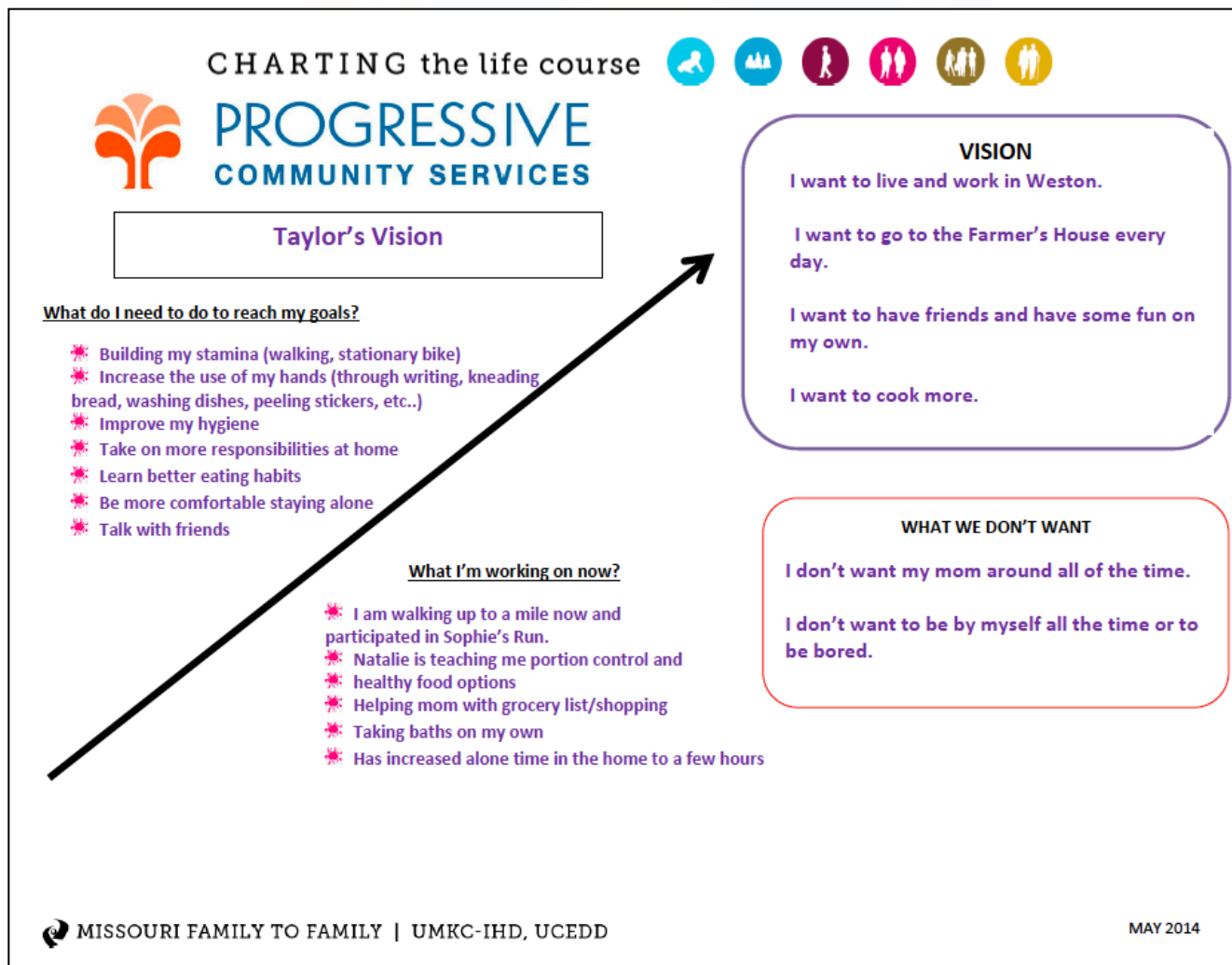
Supporting Self-Advocates and Families to Problem Solve and Plan on Own



- ⊙ Hosting Family and Self-Advocate training workshops
- ⊙ Providing 1-1 support to coach on using tools for different reasons



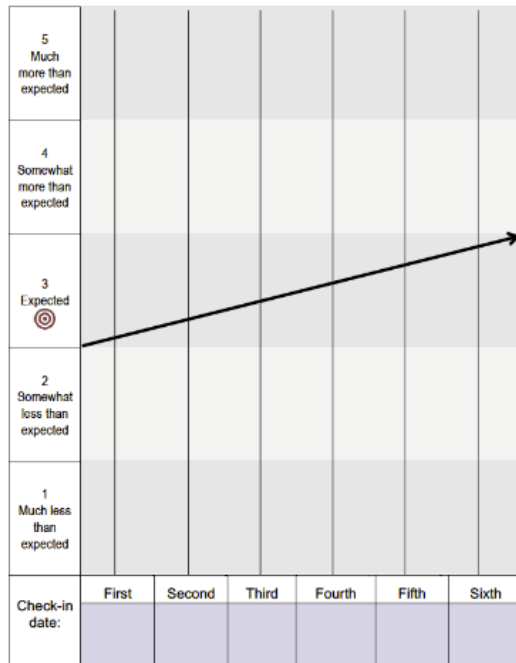
Taylor – one year later



CHARTING the life course



Goal Attainment Scaling



Successes

Please describe what you did that made you successful in this action step.

Barriers and Challenges

Please describe any difficulties you had working on this goal.

CHARTING the life course



LifeCourse Action Plan



Target Goal:

5 Much more than expected			
4 Somewhat more than expected			
3 Expected	Action Step A:	Action Step B:	Action Step C:
2 Somewhat less than expected			
1 Much less than expected			

How can I use technology to help me achieve my goal?

What are my assets and strengths that will help me achieve my goal?

Who are the people in my life who can help me reach my goal?

What community assets can I use to help achieve my goal?

What kind of eligibility supports could I access and how will they help me reach my goal?

LifeCourse Action Plan is a template of the Family to Family LifeCourse Network | UMKC IHD, UCEDD. More materials at lifecoursetools.com June 2016

Enhance monitoring to
focus on quality
outcomes



Brandie – Plotting Outcomes

ACTION PLAN

Past/Current Goals and Progress:

Outcome A: I will participate in meaningful daily activities of my choice.

Continue working at the Monroe City Sheltered Workshop.

Develop a system to keep my apartment clean.

Plan my own activities I would like to participate in.

Practice what to say and ask before going to the bank.

Develop a simple budgeting system.

Vision for Daily Life

Keep my apartment clean and organized.

Work at the Monroe City Sheltered Workshop

Participate in community activities.

Manage my own money.

What I Don't Want

Having LOQW support forever.

To be unemployed.

To never leave my home.

Staff planning activities.
Too complex of budgeting system .

LOQW pushing me to use all my authorized hours.
No system developed to teach me to clean by myself.



4 yr old quarterly service monitoring

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.

SCANNED
169-1746

Steps To Take:

Look into ABA therapist for home
Research social activities to engage w/
Other kids more
Talk to doctor/Therapist about other
tools/resources/services that
will be beneficial for Jane
Find resources for potty training
and introducing new foods
School is linking to ABA Therapist for school
Enjoying school! seems to want to go
* He is using more words to request things, not just echolalia
IEP in place - 1hr of speech therapy, 5 days a week
Began Preschool w/ Camden Point Elementary
Completed Hippotherapy - posture and task follow through improved

Progress Made:

VISION for a GOOD LIFE

Able to verbally communicate with
Others, hold a conversation
Have Friendships, improve social skills
Be successful w/ school
Know and use manners

What I DON'T Want

In a segregated classroom
Not able to talk at all, regression in
skills
Bullied or taken advantage

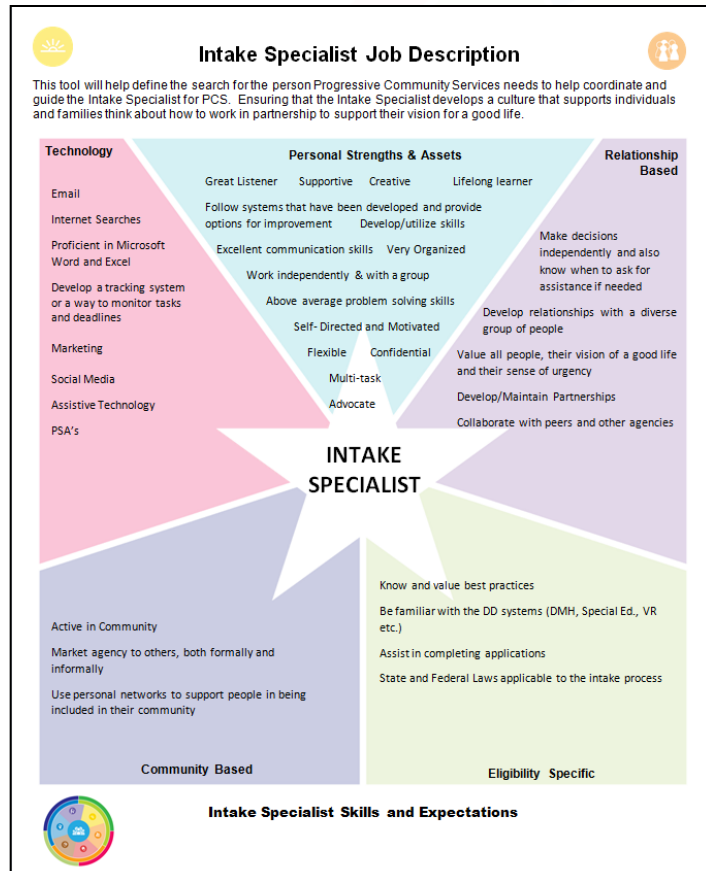


Other Examples of LifeCourse Application

- Job Descriptions
- New Positions
- Hiring & Interviews
- Performance Reviews
- Team Meetings



Job Descriptions



CHARTING the life course

**PROGRESSIVE
COMMUNITY SERVICES**

Intake Specialist Trajectory

VISION for Intake Specialist

- People will receive personalized support with the Intake process to DMH/DD Supports
- More people will complete the process in a shorter amount of time
- The process will be easier for individuals/families
- Work closely with the Family Navigator to address immediate needs

What to avoid

- Individuals and Families feeling overwhelmed and/or confused by paperwork
- Individuals/families not finishing the process
- The process taking so long that people are frustrated

Human Resource: Hiring and Performance Reviews

Family Navigator Job Description

Technology	Personal Strengths & Assets	Relationship Based
Email Internet Searches	Great Listener Supportive Creative Lifelong learner Follow systems that have been developed and provide options for improvement Implement new skills	

Integrated Supports – Family Navigator Interview

Technology	Personal Strengths & Assets	Relationship Based
What forms of technology do you currently use and for what purpose? What computer programs do you/can you use? What is the relationship between technology and people with disabilities?	What personal strengths & assets do you have that make you a good fit for this job? What life experiences have you had that will be helpful in this position? What words would your family, friends, Co-workers use to describe you? What do they like about you?	What are some relationships that are most important to you? What experience do you have with building professional or volunteer networks? How do you nurture and maintain your relationships with friends, family, neighbors, co-workers, etc.?

FAMILY NAVIGATOR

Community Based	Eligibility Specific
How do you use your community? Schools, parks, etc. How active are you in your community? What social roles do you have?	What eligibility specific programs/services are you aware of? What is your comfort level with completing detailed applications? Ex: Medicaid

PROGRESSIVE COMMUNITY SERVICES

PERFORMANCE STAR – LULA BELLE

PERSONAL STRENGTHS & ASSETS

- New Software
- Strong Communicator
- Dependable
- Mover and shaker

Name of Employee: Lula Belle Hire Date: 9/30/15
Supervisor Signature: _____ Date: _____
Employee Signature: _____ Date: _____

Trajectory Worksheet for Employees

Use this sheet to talk about goals the employee should be working towards for the year. Use the steps on the arrows and the attached sheet to list a couple of steps to reach the goal. Use the obstacles to identify issues that are keeping the employee from the Vision and Goals.

Consider these areas when identifying goals:

- More meaningful lives for the people we support
- Competencies and requirements of the job
- Attitude, attendance and professionalism
- Philosophy and Actions
- Development through training and coaching

GOAL 4 STEPS

- Help leadership identify reports they can use to manage their departments
- Look at quality
- Help implement new technologies that can create efficiencies
- Continue to work on implementing an internal audit plan for RS and TCM departments.

GOAL 3 STEPS

- Develop a realistic training plan for SC's – from new hire to one year.
- Work with supervisor to develop training plan for each position at PCS with built-in training/competencies for advancement.

GOAL 2 STEPS

- Keep momentum going with pilot group.
- Continue meeting and reflecting
- Develop training and plan for training new SC's
- Keep connected with LifeCourse community and learning about new ideas/concepts.
- Continue to share our success.

GOAL 1 STEPS

- Develop plan for POM's process
- Change plan as we learn what works vs. what doesn't work
- Incorporate POM into training

VISION AND GOALS for the Year

- POM's are integrated into our practices. The POM team is interviewing each month and we are analyzing the data from interviews.
- We continue to move forward with using LifeCourse framework with families we support.
- We have a training curriculum/development plan for each position at PCS.
- Leadership has data systems and a functioning audit plan and can use those resources to make informed decision and look at quality.

Obstacles / What We Don't Want

- Managers hesitant about Quality leading training plan.
- Follow up's when she identifies issues – are things getting resolved?
- Feedback from RS and RSM about internal audits

PCS MISSION
Build relationships that will inspire positive social change, empower people and challenge the status quo.

PCS VISION STATEMENT
An inclusive community where all people have value.



LIFECOURSE Tools

LIFECOURSE TOOLS

LIFECOURSE PRINCIPLES

LIFECOURSE IN ACTION ▾

CONNECT ▾

ABOUT



WEBSITE: LifeCourseTools.com



SELF-DIRECTING SUPPORTS VIDEO SERIES

Video: Charting the LifeCourse (CtLC) Overview – watch if you need to learn the basics or need a quick refresher before beginning

Module 1: Planning for Self-Directed Supports

Lesson 1: Discovering What a Good Life Looks Like

Lesson 2: Exploring the Path to a Good Life

Lesson 3: Developing a Personal Overview

Lesson 4: Exploring Supports for a Good Life

Lesson 5: Preparing for the Self-Directed Supports Plan Meeting

Module 2: Setting Goals to Achieve a Good Life

Lesson 1: Going from a Plan to Action

Lesson 2: How Will I Know When I've Achieved My Goal?

Lesson 3: See How One Person Sets and Achieves Their Goals

Module 3: Day-to-Day Strategies for Success in Self-Directing

Lesson 1: Maximizing Limited Funds for a Good Life

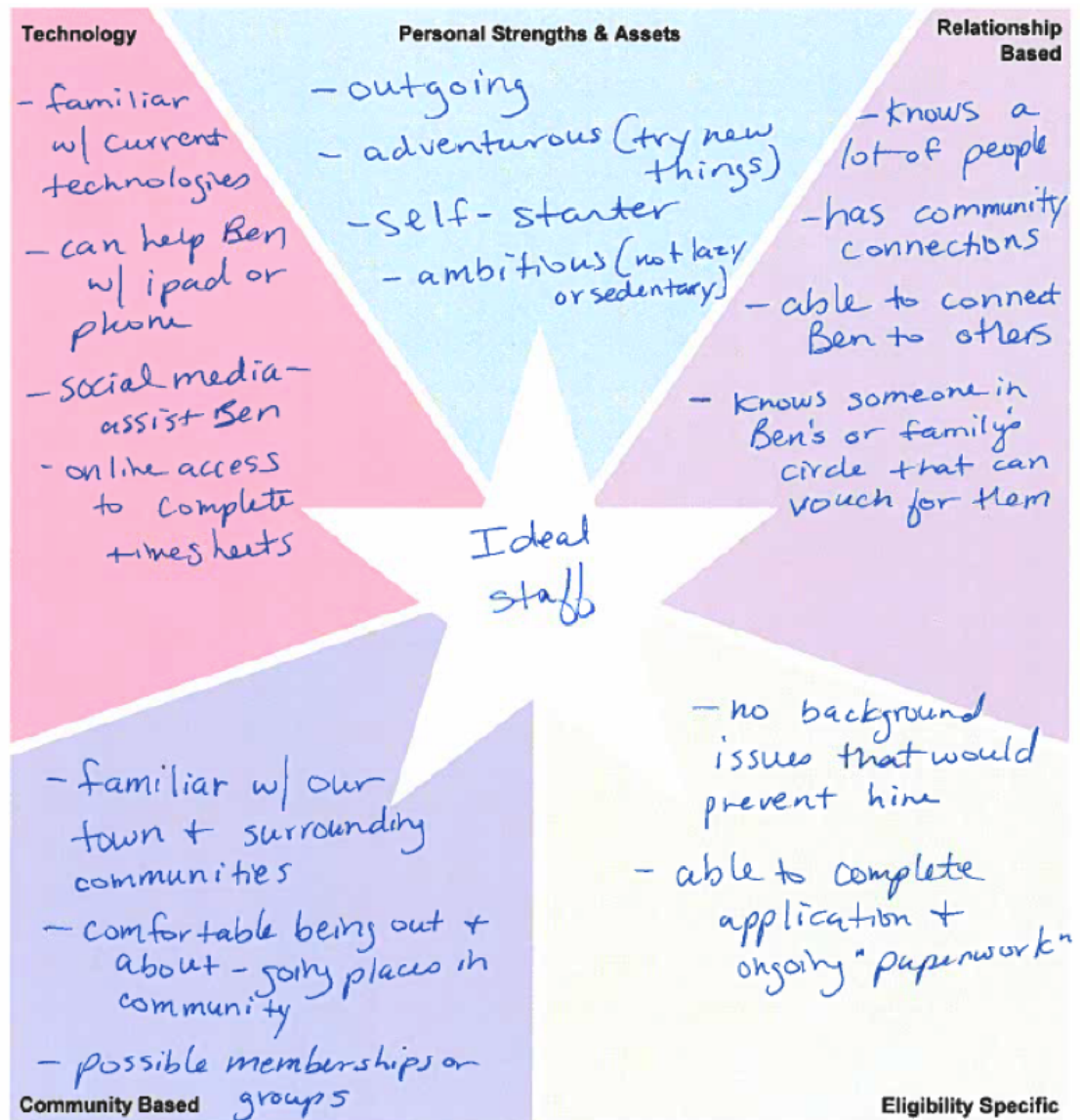
Lesson 2: Identifying and Hiring Self-Directed Staff

Lesson 3: Scheduling Staff and Planning Activities

www.lifecoursetools.org



How Family Supports Ben to Hire Self-Directed Staff

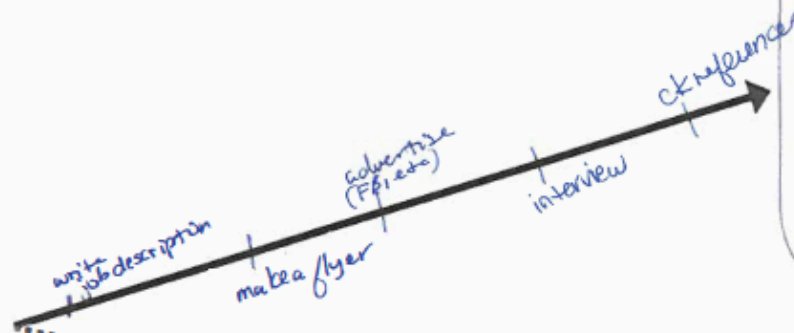


Family using Vision and Trajectory for Supportin g Ben to Hire Staff

Charting the LifeCourse: Life Trajectory Worksheet

Past (+) experiences w/ staff

- staff helped Ben shop + cook meals + snacks
- introduced Ben to new people / facilitated friendships
- Staff kept Ben busy



PAST experiences (to avoid moving forward)

- Staff who was too bossy + forgot she worked FOR BEN!
- Staff created division instead of connections
- staff was on social media instead of interacting w/ Ben
- Staff quit w/ short notice

MY VISION

VISION for GOOD S.D. STAFF:

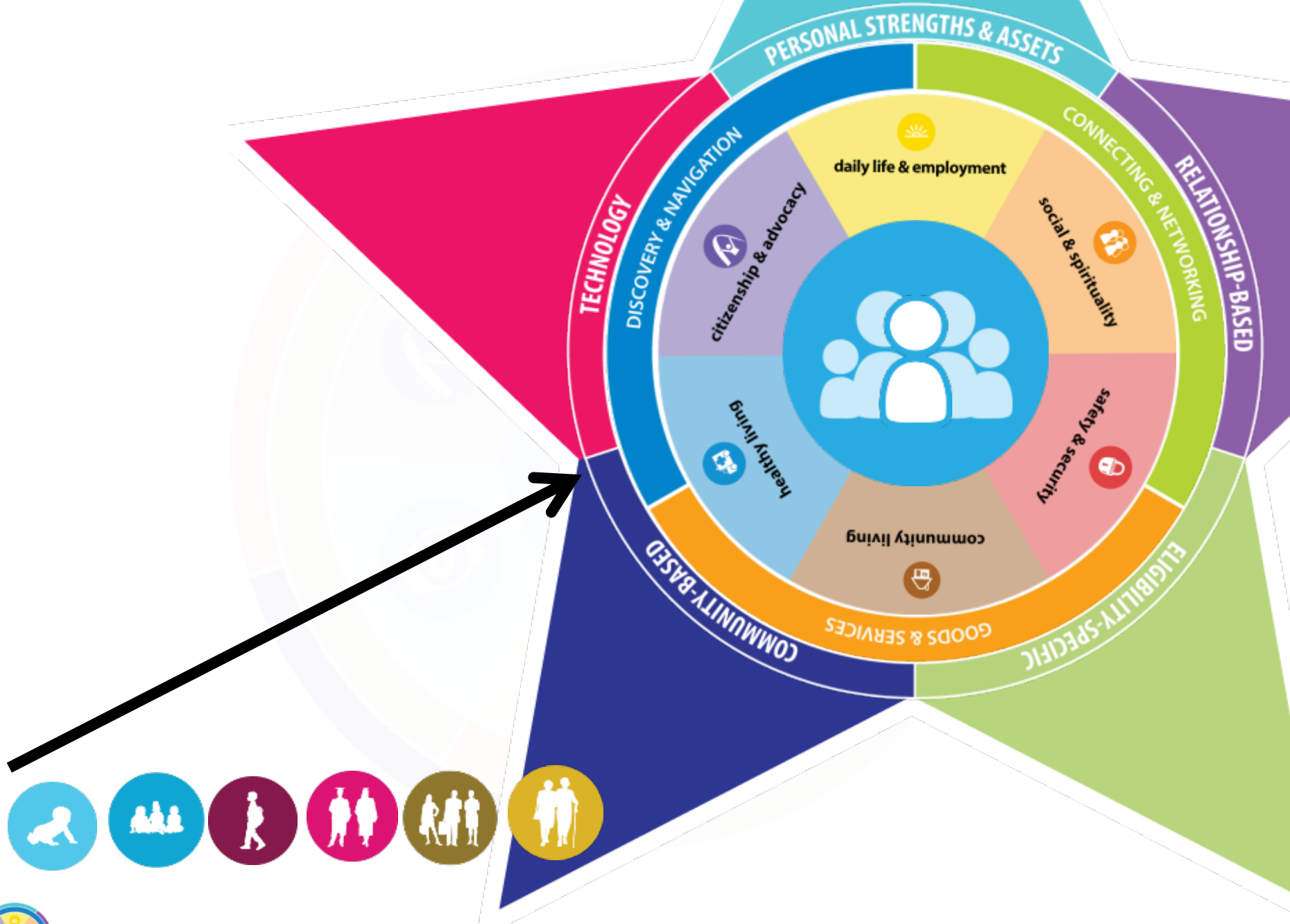
- | | |
|--|--------------|
| Creative | FUN! |
| Kind | Happy person |
| NOT a pushover | |
| Self-starter | |
| Young or "young at heart" | |
| Someone we ^{Ben} know or is highly recommended by someone we know | |
| A "connector" (to people, opportunities to learn, gain skills) | |
| Energetic | |
| Flexible | |
| Shares interests and things in common with Ben | |

DISLIKES

what is NOT good staff: (what we don't want)

- Lazy Staff
- Old school thinking
- Bossy
- Group home mentality
- Couch Potato





Contact Information Sheli Reynolds

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816-235-1770

