



Person Centered Care for Aging Individuals with Intellectual/ Developmental Disabilities

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student and parent**



December 2020



charting the
LIFECOURSE
NEXUS AFFILIATE

Affiliates are committed to enhancing outcomes for:

- People and their families to reframe their understanding and expectations in order to **plan, problem-solve, navigate, and advocate for integrated supports that lead to quality of life.**
- Staff and professionals to use **person and family centered practices** for reframing **conversations, problem-solving and planning** to support individuals and their families to have a “good life.”
- **Organizational cultural change** at every level by using the Charting the LifeCourse framework for **strategic thinking and planning, training and coaching staff, driving policy change, and engaging with stakeholders**



Why Charting the LifeCourse



Member Focus

We organize our response to the life the member wants to lead, recognizing people are more than a set of health needs.

Complimentary to Aetna's care planning model

**Whole
Person
Approach**

**Bio, Psycho,
Social
Model**

**The right
supports at
the right
time**

**Incorporates
Social
Determinants
of Health**

**Person
centered
planning
approach**



Comments from Care Managers about CTLC:

- 1) Helpful in initiating difficult conversations with members.
- 2) Helpful in guiding conversations with members.
- 3) Has helped keep the member's vision in the forefront of all we do.
- 4) Has helped us think differently about supports.

Nuts and Bolts of implementation

Partnership with UMKC

Curriculum and training development

Training

Aetna colleagues and community partners trained

Community partners

Kansas Council on Developmental Disabilities; local County Boards for Developmental Disabilities

Internal Capacity building

Community of Practice groups



Benefits from using CTLC



Person centered focus



Tools for members



Universal Language



Enhance communication



Difference between services and vision of a good life

Future Plans

Continue to Pave the way

1st Managed Care Organization to have graduating Ambassador class

Increase member and family involvement

Increase community trainings on CTLC

Increase Stakeholder partnerships

Develop innovative partnerships around CTLC

Research

Partnership with UMKC on SDoH, Charting the LifeCourse and health outcomes





Charting the LifeCourse

- Framework for Driving Transformational Change
- Icons and Language for Engaging Others
- Tools and Strategies for Implementing into Practice
- Network for On-going Learning and Sharing



charting the
**LIFECOURSE
NEXUS**

Transformation at All Levels

Explore life possibilities
Share ideas, hopes, and fears
Set higher expectations
Navigate Future
Advocate for Vision
Problem-Solve and Plan

Individuals
Family Members
Professionals
Organizational Leadership
Systems Change Agents
Community Members



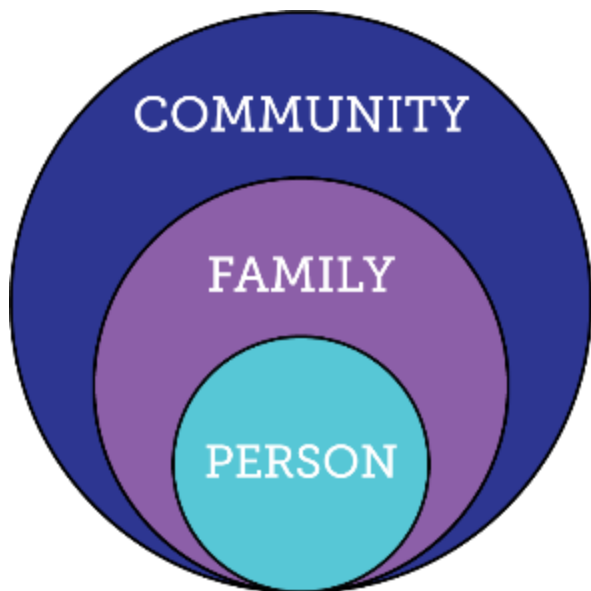


charting the
LIFECOURSE
NEXUS

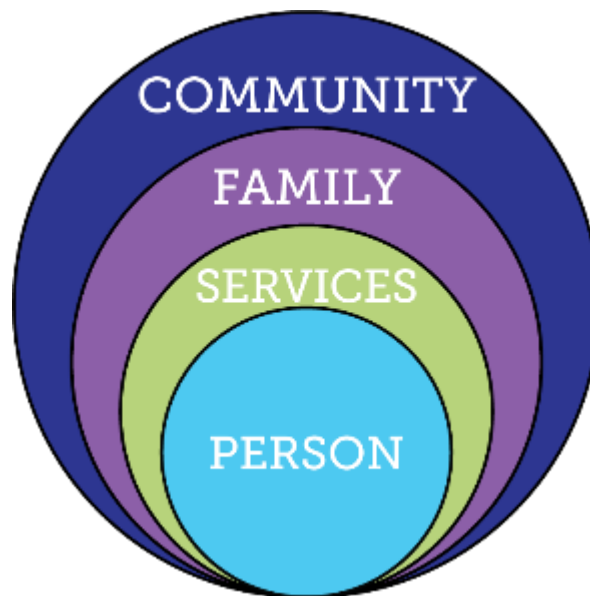
A central location for the intersection of ideas, collaboration, and transformation. The LifeCourse Nexus supports the growth, expansion and spreading of the innovations.



Transforming Services and Supports



Everyone exists within the context of family and community



Person in relation to Traditional Disability Services



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

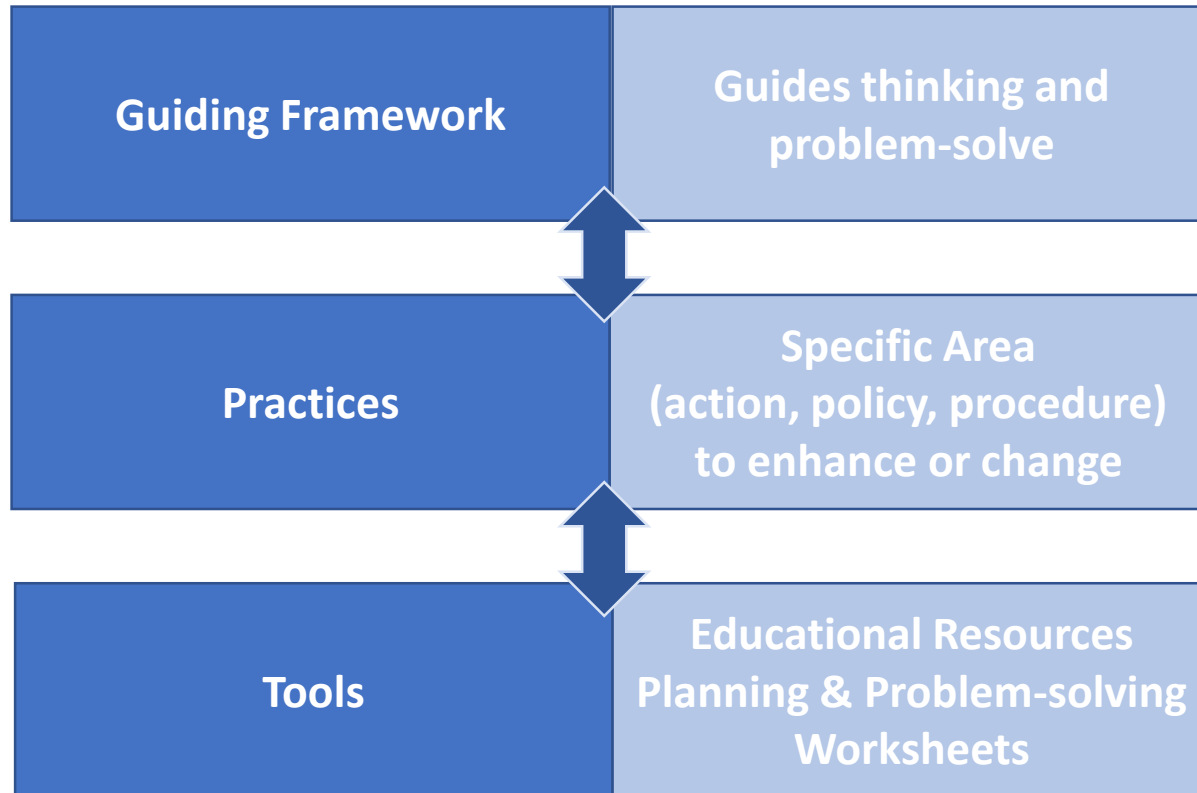
What is Charting the LifeCourse

Created to help individuals and families of all abilities and all ages

- *develop a vision for a good life*
- *think about what they need to know and do*
- *identify how to find or develop supports*
- *discover what it takes to live the lives they want to live.*



What is Charting the LifeCourse??





Core Belief

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

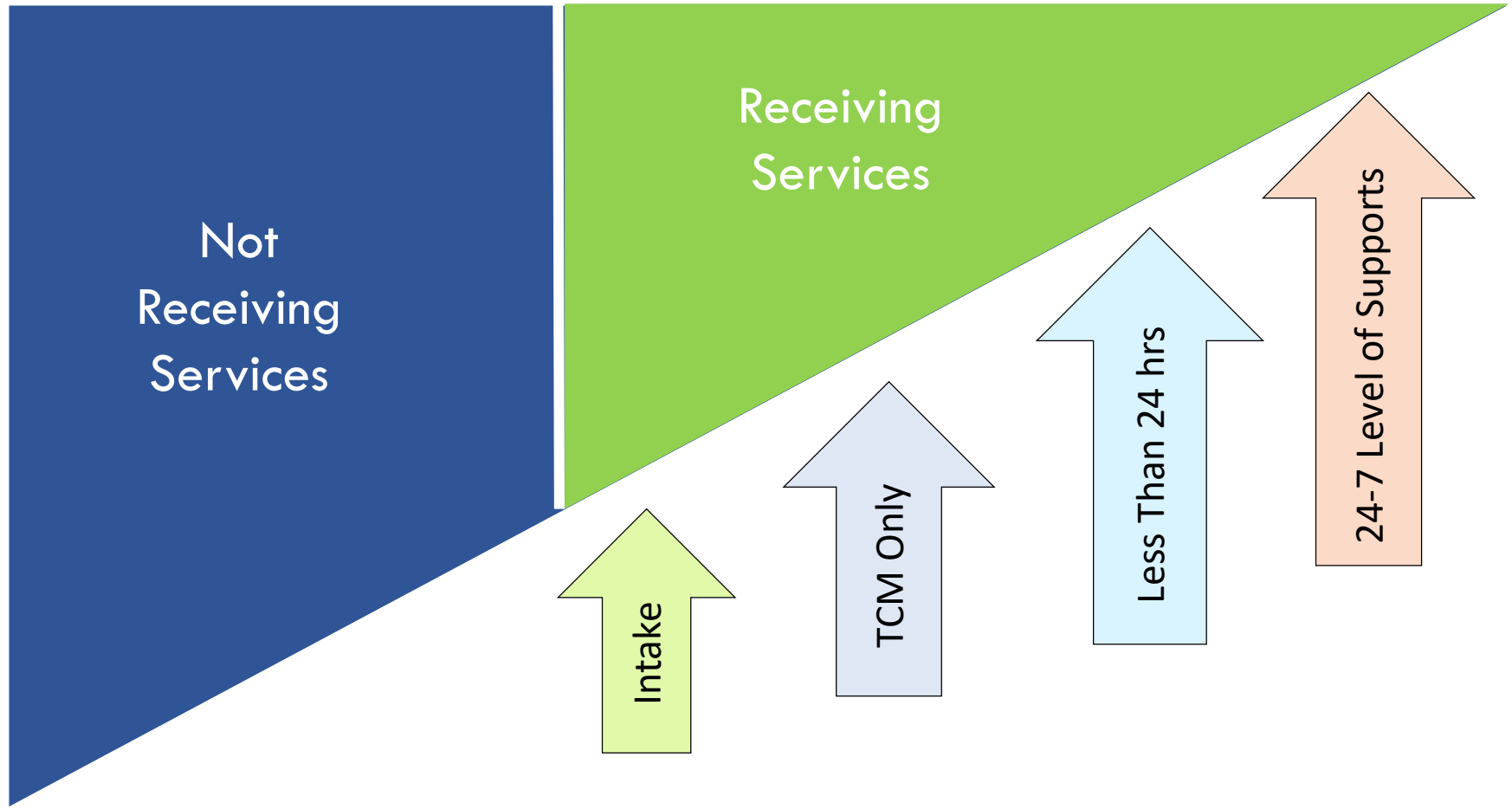


Focusing on the All

All people, regardless of age, ability or family role, are considered in our vision, values, policies and practices for supporting individuals and families. All families have choices and should have access to the supports they need.



Enhancing Practices: Support Coordination





Person in the Context of Family

People exist and have reciprocal roles within a family system, defined by that individual. Roles adjust as the individual members of the family system change and age. The entire family, individually and as a whole, needs support to ensure they all are able to successfully live their good life.



Family Functions and Roles



Caring
About

Share Love, Affection and Trust

Spend Time and Create Memories Together

Know About Personal Interests, Traditions, and Cultures



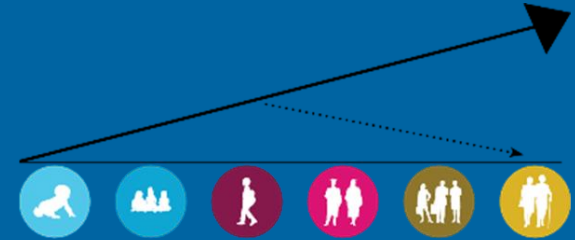
Caring
For

Supports Day-to-Day Needs

Ensures Material and Financial Needs are Met

Connects to Meaningful Relationships and Roles

Advocates and Supports Life Decisions

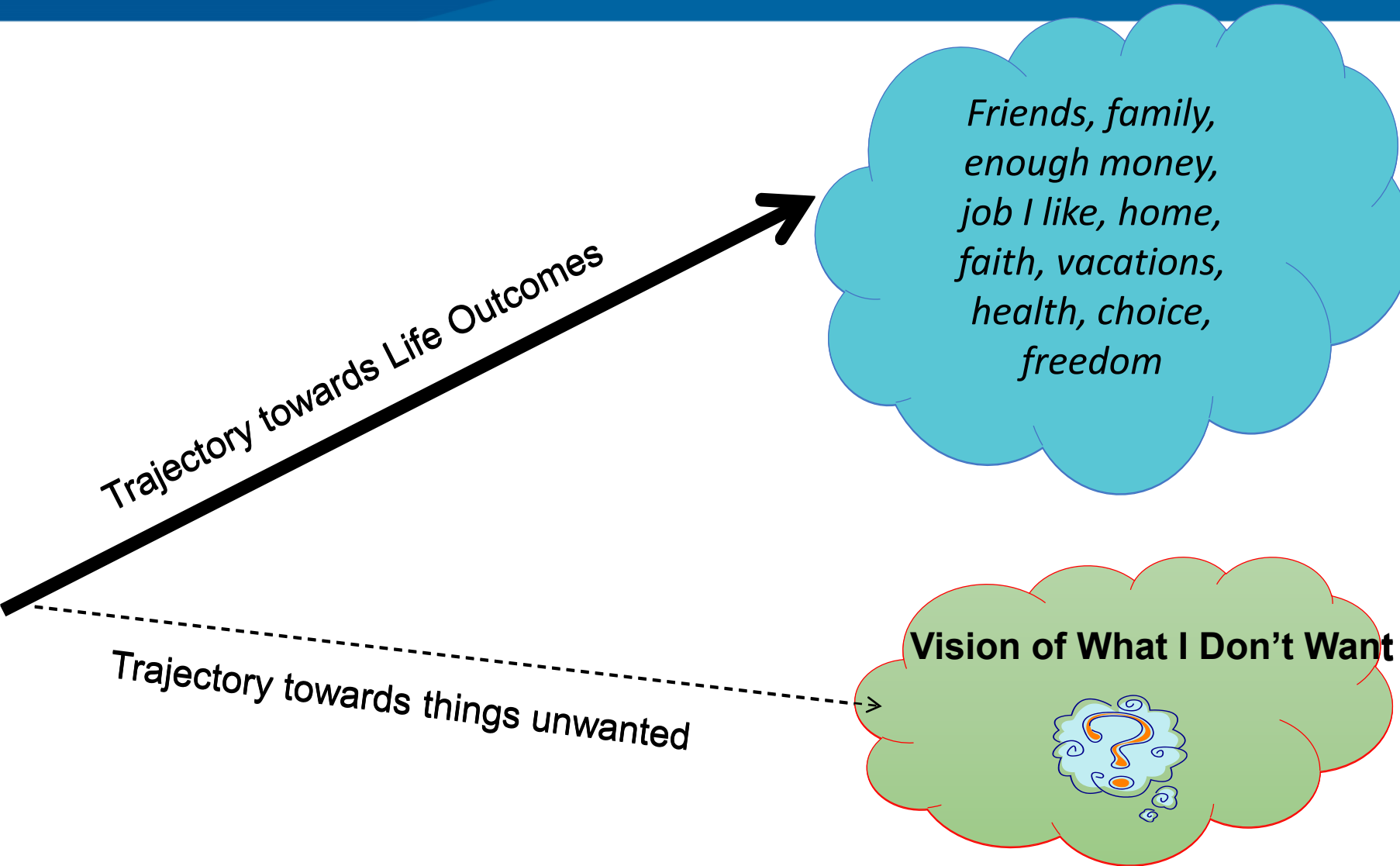


Trajectory and Life Experiences

All people, regardless of age, ability or family role, are considered in our vision, values, policies and practices for supporting individuals and families. All families have choices and should have access to the supports they need.



Trajectory Towards a Good Life



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

Vision of What I Don't Want



Trajectory towards Life Outcomes

Trajectory towards things unwanted



Holistic Focus across All Life Domains

People lead whole lives made up of specific, connected, and integrated life domains that are important to a good quality of life. Life domains are the different aspects and experiences of life that we all consider as we age and grow.



Focusing on Life Domains



Daily Life and Employment
(school/education, employment, volunteering, routines, life skills)



Healthy Living
(medical, behavioral, nutrition, wellness, affordable care)



Community Living
(housing, living options, home adaptations and modifications, community access, transportation)









Safety and Security
(emergencies, well-being, legal rights & issues, guardianship options & alternatives)



Social and Spirituality
(friends, relationships, leisure activities, personal networks, faith community)



Citizenship and Advocacy
(valued roles, making choices, setting goals, responsibility, leadership, peer support)

LifeCourse Domains	Social Determinants of Health Domains (Healthy People 2020)	
	Education: <ul style="list-style-type: none"> • High School Graduation • Enrollment in Higher Education • Language & Literacy • Early Childhood Education & Development 	Economic Stability: <ul style="list-style-type: none"> • Poverty • Employment • Food Security • Housing Stability
	Neighborhood & Built Environment: <ul style="list-style-type: none"> • Quality of Housing • Environmental Conditions • Access to Healthy Foods 	
	Neighborhood & Built Environment: <ul style="list-style-type: none"> • Crime & Violence • Social & Community Context • Discrimination 	
	Health & Health Care <ul style="list-style-type: none"> • Access to Health Care • Access to Primary Care • Health Literacy 	Economic Stability: <ul style="list-style-type: none"> • Food Security Neighborhood & Built Environment: <ul style="list-style-type: none"> • Access to Healthy Foods
	Social & Community Context <ul style="list-style-type: none"> • Social Cohesion • Incarceration 	
	Social & Community Context <ul style="list-style-type: none"> • Civic Participation 	

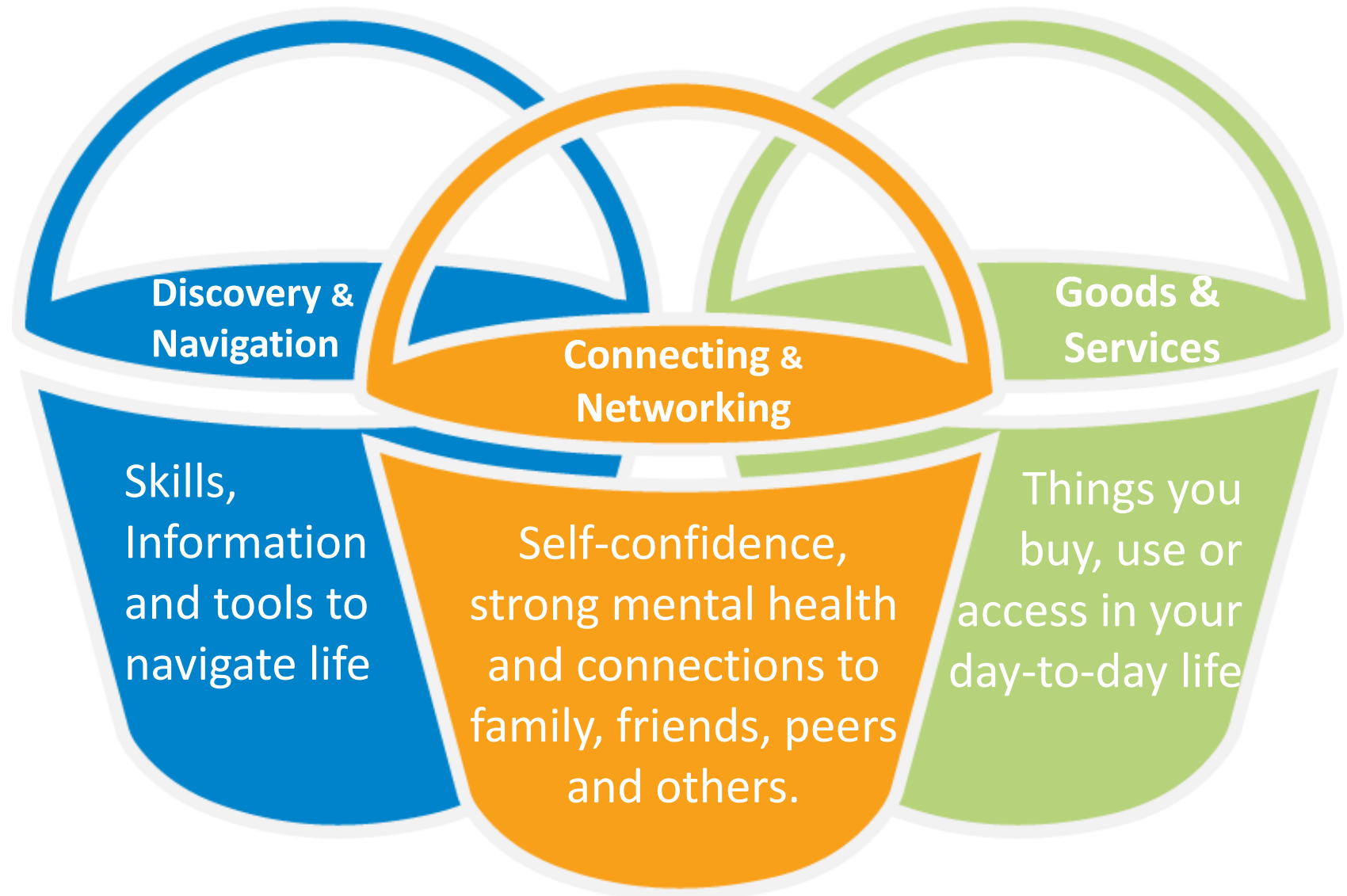


Individualized Supports and Services

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



Supporting Persons Three Buckets of Needs





Integrated Supports and Services

Individuals and families access an array of integrated supports to achieve their envisioned good life.



LifeCourse Integrated Supports STAR

PERSONAL STRENGTHS & ASSETS

Skills, personal abilities, knowledge or life experiences;
Strengths, things a person is good at or others like and admire;
Assets, personal belongings and resources

TECHNOLOGY

Personal technology anyone uses;
Assistive or adaptive technology with day to day tasks;
Environmental technology designed to help with or adapt surroundings

RELATIONSHIPS

Family and others that love and care about each other;
Friends that spend time together or have things in common;
Acquaintances that come into frequent contact but don't know well

COMMUNITY BASED

Places such as businesses, parks, schools, faith-based communities, health care facilities;
Groups or membership organizations;
Local services or public resources everyone uses

ELIGIBILITY SPECIFIC

Needs based services based on age, geography, income level, or employment status;
Government paid services based on **disability or diagnosis**, such as special education or Medicaid



Returning Home from the Hospital

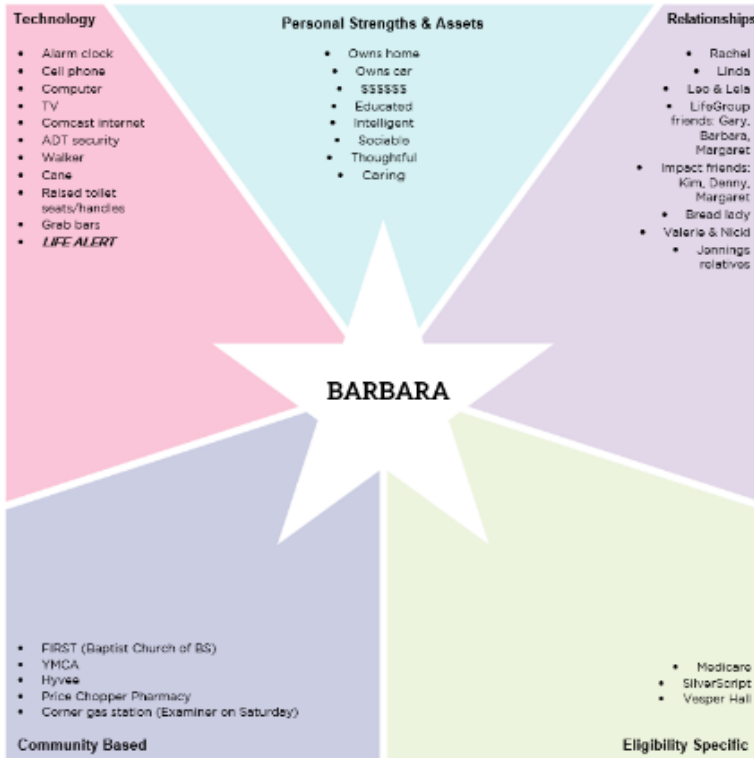
CHARTING the life course



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.

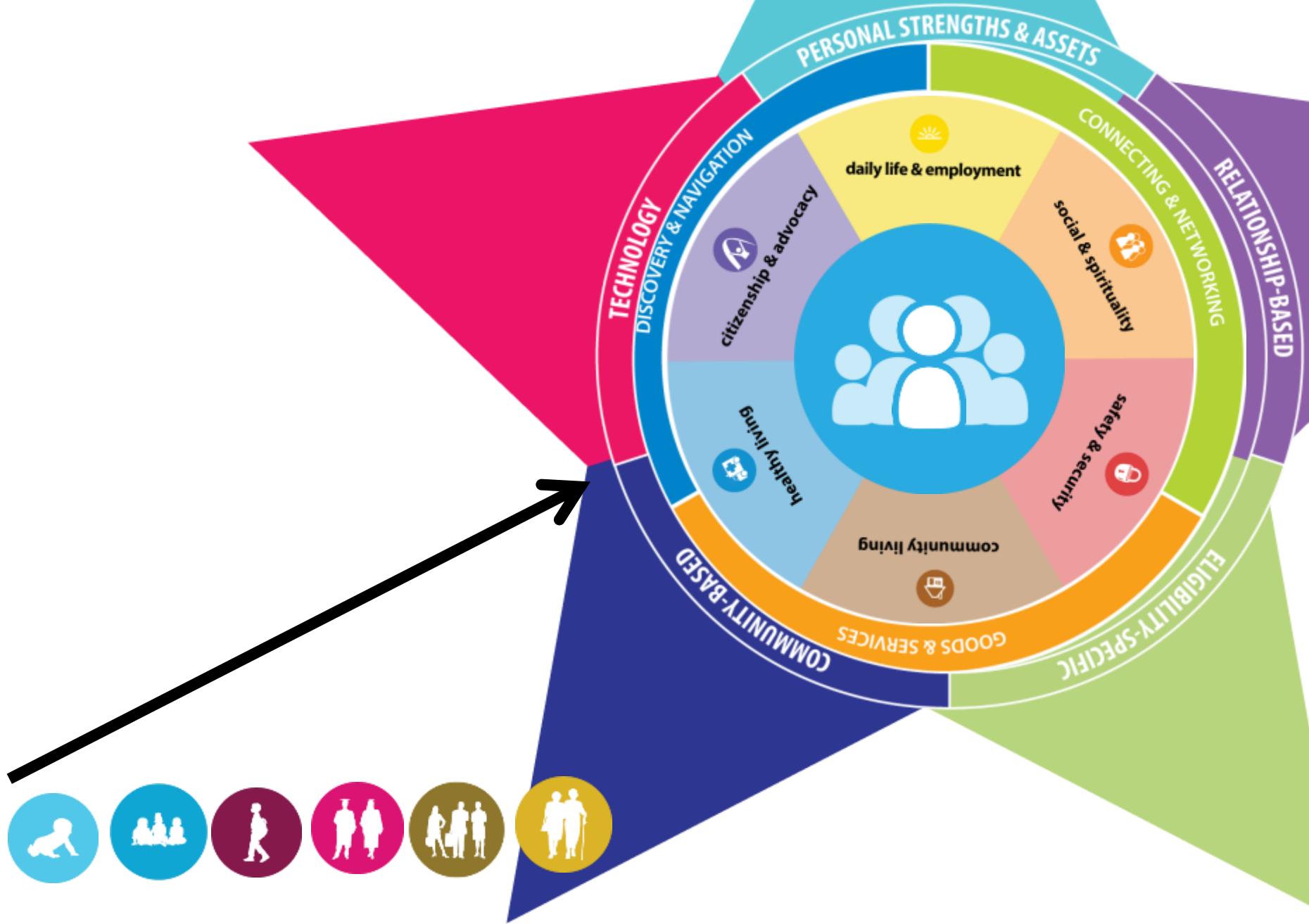


CHARTING the life course



Barbara's Long Term Support Schedule

TIME	MON	TUES	WED	THURS	FRI	SAT	SUN
6-6:30 AM							
6:30-7 AM							
7-7:30 AM							
7:30-8 AM							
8-8:30 AM							
8:30-9 AM							Rachel takes Grandma to church and attends
9-9:30 AM							
9:30-10 AM							
10-10:30 AM		Sherry Blyler - bread					
10:30-11 AM							
11-11:30 AM							
11:30-12 PM	Ronda						
12-12:30 PM		Chaney					
12:30-1 PM				Chaney			
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					Chaney		
4:30-5 PM							
5-5:30 PM							
5:30-6 PM							
6-6:30 PM							
6:30-7 PM	Rachel	Rachel	Rachel	Rachel	LifeGroup with friends		
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							



Strategies and Tools for Implementing LifeCourse into Practice



Person
Centered
Tools



Family
Perspective
Tools



Planning Tools
for
Professionals

LifeCourse Foundational Tools



Tools for the Person: lifecoursetools.com/person-centered/

INTEGRATED SUPPORTS STAR

Personal Strengths & Assets

Technology

Relationships

Community Based

www.LIFECOURSETOOL

LIFECOURSE PORTFOLIO | EXPLORING

NAME: _____ DATE: _____

WHAT PEOPLE LIKE AND ADMIRE ABOUT ME:

WHAT'S IMPORTANT TO ME:

Life Domain Vision Tool | Individual

Name of Person Completing: _____ Date: _____

On Behalf of: _____

LIFE DOMAIN	DESCRIPTION	MY VISION FOR MY FUTURE	PRIORITY
	Daily Life & Employment: What do I think I will do or want to do during the day in my adult life? What kind of job or career would I like?		
	Community Living: Where would I like to live in my adult life? Will I live alone or with someone else?		
	Social & Spirituality: How will I connect with spiritual and leisure activities, and have friendships and relationships in my adult life?		
	Healthy Living: How will I live a healthy lifestyle and manage health care supports in my adult life?		
	Safety & Security: How will I stay safe from financial, emotional, physical or sexual harm in my adult life?		
	Advocacy & Engagement: What kind of valued roles and responsibilities do I or will I have, and how can I have control of how my own life is lived?		
	Supports for Family: How do I want my family to still be involved and engaged in my adult life?		
	Supports & Services: What support will I need to live as independently as possible in my adult life, and where will my supports come from?		

Developed by the Charting the LifeCourse Nexus - LifeCourseTools.com
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Moving Forward
or future life experiences or goals that rise to support your good life vision

Vision for What I Want
List what you want your "GOOD LIFE" to look like

What I Don't Want
List the things you don't want or what is NOT a "good life"

ings to avoid that could keep you your good life vision or lead to what you don't want

Tools for the Family: lifecoursetools.com/family-perspective/



INTEGRATED SUPPORTS STAR

Personal Strengths & Assets

My Vision for My Family Member's Good Life

Relationships



LIFECOURSE PORTFOLIO | FAMILY PERSPECTIVE

NAME OF PERSON COMPLETING: _____ DATE: _____

ON BEHALF OF: _____

WHAT PEOPLE LIKE AND ADMIRE ABOUT MY FAMILY MEMBER:

WHAT I BELIEVE IS MOST IMPORTANT TO MY FAMILY MEMBER:



LIFE TRAJECTORY | FAMILY PERSPECTIVE

Past Life Experiences

Moving Forward

My Vision for My Family Member's Good Life



LIFE DOMAIN VISION TOOL | FAMILY PERSPECTIVE

Name of Person Completing: _____ Date: _____

On Behalf of: _____

LIFE DOMAIN	DESCRIPTION	MY VISION FOR MY FAMILY MEMBER'S FUTURE	PRIORITY
	Daily Life & Employment: What do I think my family member will do during the day in their adult life? What kind of job or career might they want?		
	Community Living: Where and with whom do I think my family member will live in their adult life?		
	Social & Spirituality: How will they connect with spiritual and leisure activities, and have friendship, and relationships in their adult life?		
	Healthy Living: How will they live a healthy lifestyle and manage health care supports in their adult life?		
	Safety & Security: How will my family member be safe from financial, emotional, physical or sexual harm in their adult life?		
	Advocacy & Engagement: How do I think they will have valid roles, responsibilities, and control of how their own life is lived as an adult?		
	Supports for Family: What supports does our family will need now or will need in the future?		
	Supports & Services: What supports and services might my family member need in the future to lead the kind of life they want as independently as possible?		

What I Don't Want



RECIPROCAL ROLES | FAMILY PERSPECTIVE

CARING ABOUT	People's Roles in _____'s life.	Looking Ahead.	What's important to know, make sure continues, or make happen?
Share Love, Affection, and Friendship	Who loves and cares about them?	Who else makes them feel loved?	
Spend Time and Create Memories Together	Who else knows things that others don't know well? (habits, history, celebrations)	With whom do they have special memories or experiences?	
Know About Personal Interests, Traditions, and Cultures	Who has a lifetime bond with them?	Who else would step up when/if needed?	

CARING FOR	People's Roles in _____'s life.	Looking Ahead.	What's important to know, make sure continues, or make happen?
Day-to-Day Needs	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 day-to-day basic and quality of life needs are met?	Who else could help make sure this happens?	
Meaningful Relationships and Roles	Who helps connect them to inclusive opportunities and maintain relationships?	Who would be good at helping them connect with and maintain relationships and valued roles?	
Advocacy and Life Decisions	Who supports them in planning meetings and with decision making?	Who else could help with making decisions and advocating?	

Family Member:

The LifeCourse Nexus - LifeCourseTools.com
University of Missouri | UMKC 810 • March 2020



Member/Family Perspective

Jon and Brenda Jackson

brendajeffjackson@earthlink.net

Changing the conversation

Strengths not
Deficits

Planning for life
transitions
earlier

Easy to
understand
and use

Independence
not residential
supports

Jon's
vision for
his life

Don't sign me
up for stuff
without asking

Employment
and education
not enclave
work

Jon

What do People Like & Admire About Me?

- Unique Personality
- Play D&D
- Eagle Scout
- Good at science and Math
- Friends at Church
- Brother, cousins and family
- Good sense of humor
- Nice

What is Important to Me?

- Brother and family
- Going to college and getting a job
- Friends
- Going to church
- Living at home
- Being healthy (maybe)
- Scouts and D&D
- Video games

What Are the Best Strategies to Support Me?

- Dekeysha/Dillon, parents, church friends, and scout leaders
- Driving me around
- Brother – emotional support
- Food, medicine, house, clothes – Parents
- Exercise – Regina, Dillon
- Family Calendar



Jon's Quality of Life Domains



Daily Life and Employment

- Summer Job at Juniper Farms
- Chores at Home
- Food Prep
- College



Community Living

- Practice riding the bus
- Go to the library and Game stop
- Practice driving and get license



Social and Spirituality

- Friends
- Read emails and surf the web
- Go to D&D, scouts, church



Healthy Living

- Make good decisions and follow diet
- Learn to manage medications
- Talk to doctors
- Exercise more (swim, run, bike)
- Go shopping with a list



Safety and Security

- Debit card



Citizenship and Advocacy

- Volunteer at Harvestors
- Scout leader
- Vote
- Get Driver's license

Jon's Life Trajectory

Past Life Experiences

LIST past life experiences and events that pushed you toward the things you want

Chores;
 Boy scouts;
 School inclusion;
 Birthday parties;
 Family vacations;
 Church youth group;
 Debit card;
 Volunteering;
 High School diploma;
 Job experience:
 • Nature Center
 • Camp Counselor
 • Juniper Hills Farm
 Two years of college

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

Special education low expectations;
 Pressure to segregate;
 Medication side effects;
 Seizures;

Future Life Experiences

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

Find more volunteer ops;
 Workout regularly;
 Keep in touch w/ friends;
 Continue to do well in college;
 Job at Juniper Farms next summer

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

Sitting at home watching TV all day;
 Rely on paid supports;
 Gain weight;
 Eat unhealthy foods or drink too much

Vision for a GOOD LIFE

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

Job

Live with family or on my own

Friends

Go to church

Go to Scouts and D&D

Be more independent

- Chores
- Lifeskills
- Driver's
- Income/bills



What I DON'T Want

Death
 Diabetes
 Hospital
 Live in a group home
 Not have a job



Jon: Integrated Supports

