



# A “Good Life” For the Whole Family

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National Community of Practice for Supporting Families

March 30, 2023

[www.lifecoursetools.com](http://www.lifecoursetools.com)

# Welcome from the CoP Leadership Team

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## Meet Jenny Wilson, LCSW

- Sibling of two sisters, one who is in her 30s with a disability & one who is 17 and adopted
- Licensed as a Clinical Social Worker
- Formerly a Support Coordinator and Director of a Provider Agency
- Co-Director of the National Community of Practice for Supporting Families
- Assistant Director of LifeCourse Nexus, Lead for Organizational and System Change Initiatives



# Meet Stephanie Mote



- Mom of two kids, plus an overgrown boxer and a tiny kitten
- More than 15 years working in field of disability and mental health services
- Formerly Director for provider agency
- 6 years with Commonwealth of VA; regulation and policy management, HCBS program development, waiver operations, and waitlist management
- Joined NASDDDS in July 2022

# Setting the Stage

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History of the CoP for Supporting Families



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# Evolution of Person-Centered and Family-Centered Services and Supports

1800s Exclusion---Segregation---Specialized---Inclusion---Self-Determination



1800s Blame---Damaged---Over-Burdened---Coping---Supported---Resilient



# Moving from Family Support to Supporting Families

Family Support	Supporting Families
Defined by eligibility, services or programs available, or funding	Not a program or based on eligibility, it is an approach to supporting families across the lifespan regardless of service provision and where a person lives
Caregiver or parent	Family is defined functionally by the person; inclusive of siblings, parents with disabilities, grandparents, friends who provide supports
Tension between self-advocacy and family support	Enhances opportunities for self-advocacy and self-determination
Crisis, immediate response	Preventative, long-term planning
Supporting caregiver in order to decrease demand on long-term services	Creates a quality of life for person with DD and their family by supporting their many reciprocal roles

# Achieve “Good Life for All”

## GOAL



### 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 the individual to achieve their goal



Recognizing that individuals exist within a family system

**DISCOVERY  
AND NAVIGATION**  
Knowledge & Skills

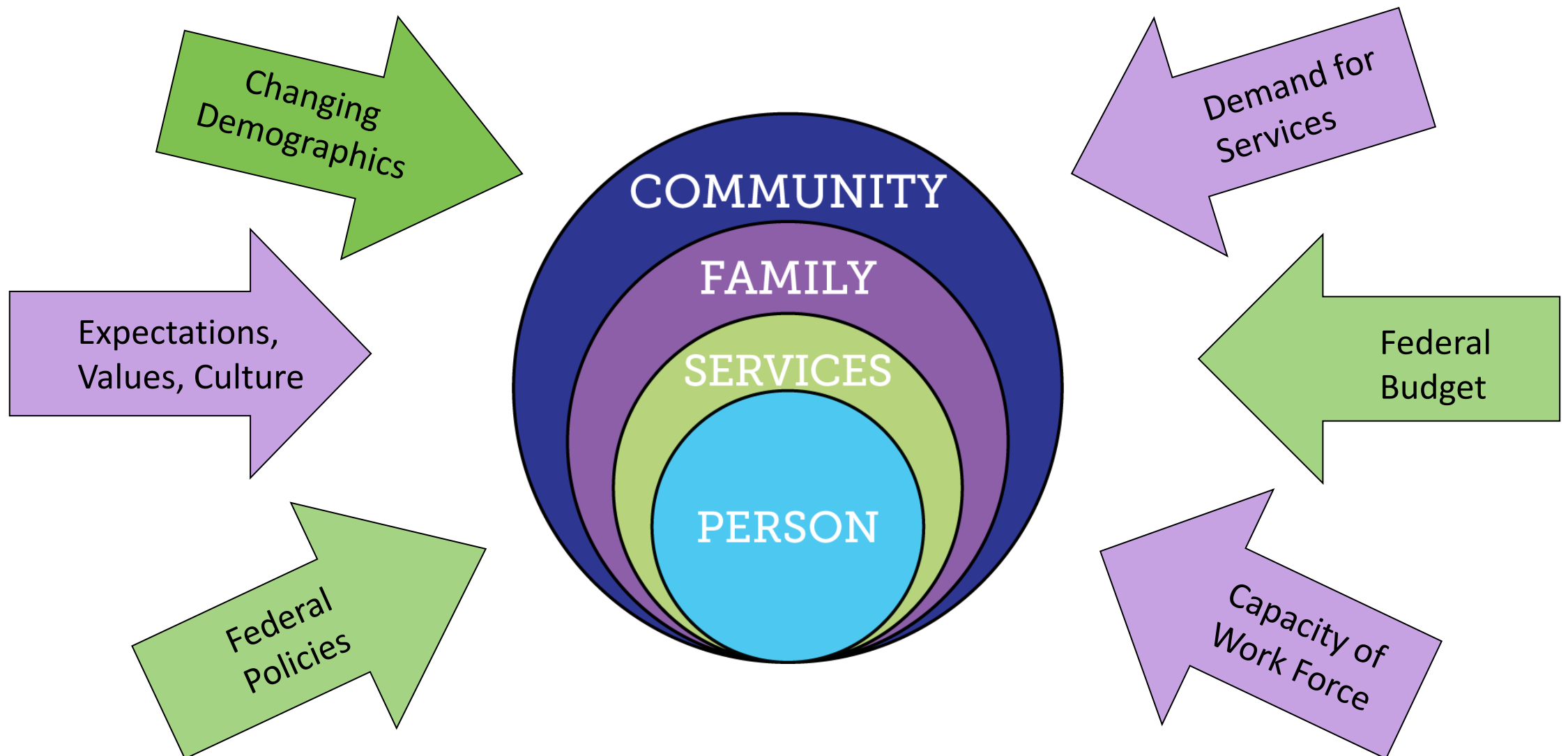
**CONNECTING  
AND NETWORKING**  
Mental Health  
& Self-Efficacy

**GOODS AND SERVICES**  
Day-to-Day  
& Caregiving/Supports

*\* Hecht, E., Reynolds, M., Agosta, J., & McGinley, K. (2011). Building an agenda for supporting families with a member with intellectual and developmental disabilities. Report of the Wingspread Conference on building a family support agenda, March 6-8, 2011. Racine, Wisconsin: Johnson Foundation.*



# Current Reality of Services and Supports



# Center for Medicaid Services - HCBS Final Rule: Settings

Federal  
Policy

**Individuals have the right to receive services in the community to the same degree as those not receiving home and community based waiver services:**

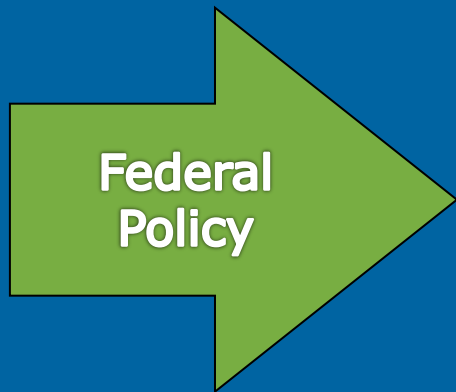
Individuals must be allowed to select the services they receive, where they live among available options, and the providers of those services.

Individuals have the freedom to control their own schedules, personal resources, and other aspects of their living arrangement.

Individuals must be treated with dignity and respect and be free from coercion or restraint.

*Home and Community Based Services (HCBS) Final Federal Rule Presentation, 11/10/18*

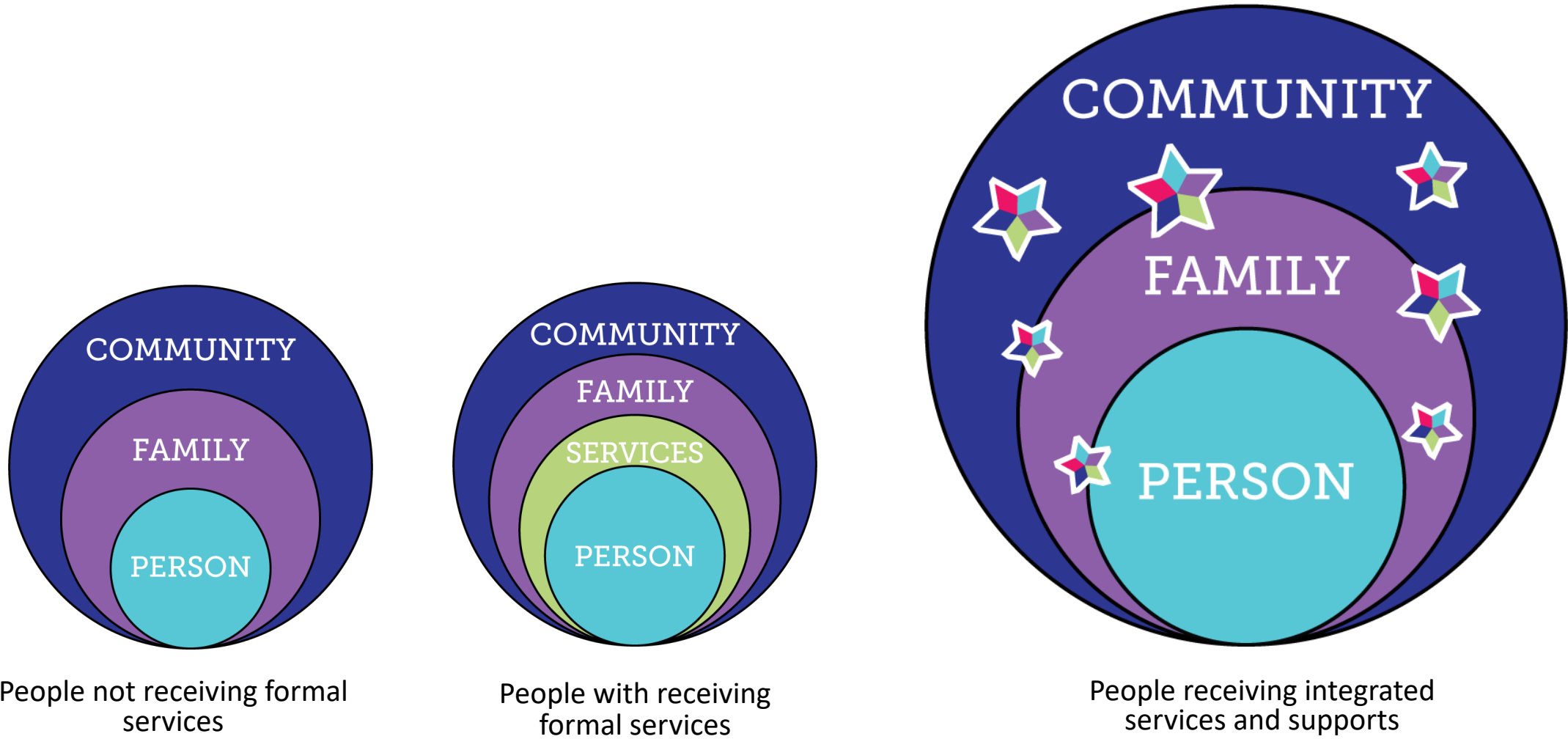
# Center for Medicaid Services- HCBS Final Rule: Person Centered



- Service plans for HCBS must be developed through a person-centered planning process that provides necessary information and support so that the individual can direct the process and make informed choices.
- The process must be directed by the individual and the individual's freely chosen representative and must reflect individual preferences and goals.
- The plan must be written so that the individual can understand the plan.

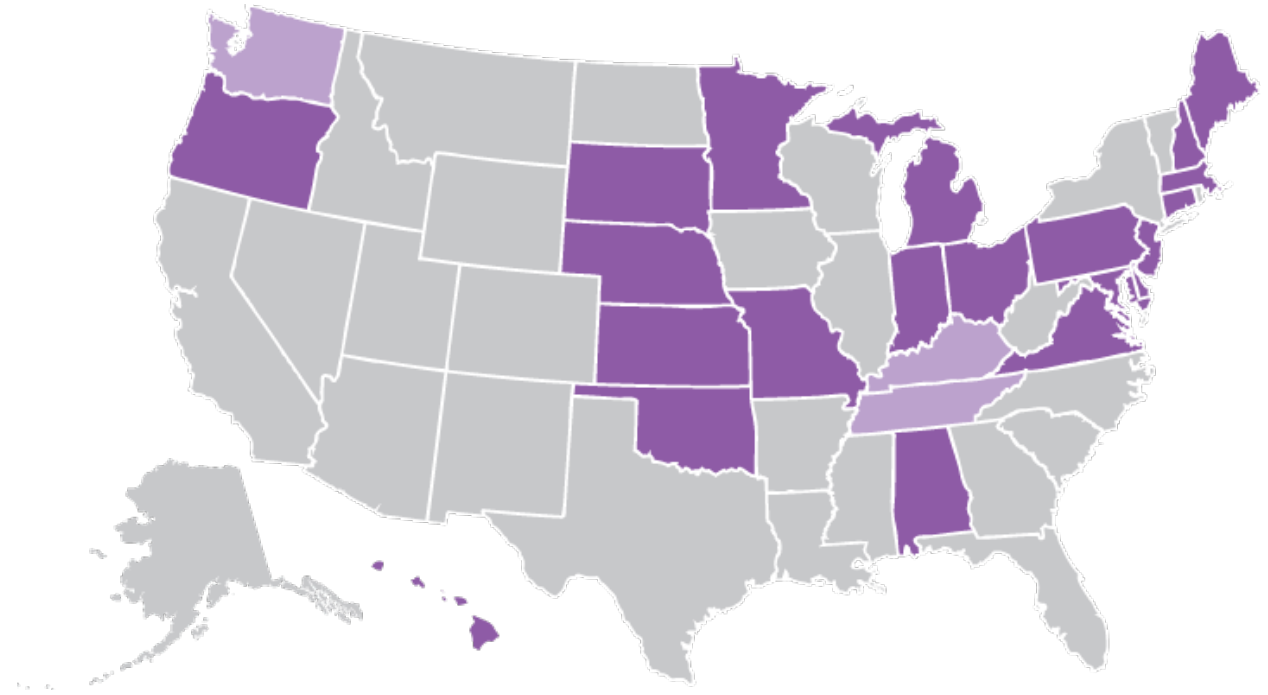
*From The Arc. National Policy Matters. The 2014 Federal Home and Community-Based Services Regulation: What You Need to Know* <http://www.thearc.org/document.doc?id=4596>

# Transforming Services and Supports



# The National Community of Practice for Supporting Families

Enhances and drives  
policy, practice,  
and system transformation  
to support the person within  
the context of their family  
and their community.



Collaboration Between:

**NASDDDS**

National Association of State Directors of  
Developmental Disability Services

**UMKC** Institute for  
Human Development  
A University Center for Excellence in Developmental Disabilities



# National Community of Practice on Supporting Families

## 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 intellectual and developmental disability across the lifespan.

## Outcomes

- State and national consensus on a national framework and agenda for improving support for families with members with I/DD
- Enhanced national and state policies, practices, and sustainable systems that result in improved supports to families
- Enhanced capacity of states to replicate and sustain exemplary practices to support families and systems

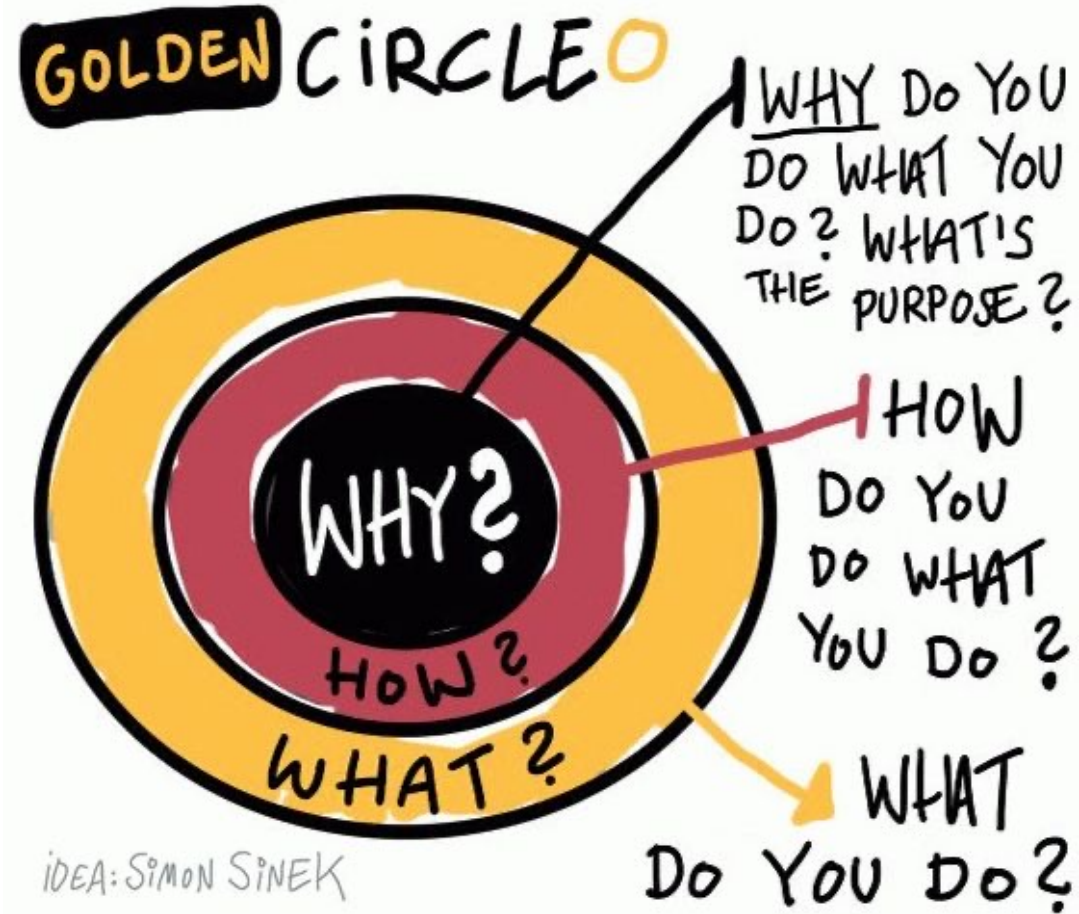
# Forming a National Community of Practice

A community of practice is a **learning environment** for an intensive exploration into current policy, practices, trends, and barriers.

The key to a community of practice is understanding that **the sum of the community knowledge is greater than the sum of individual knowledge.**



# Starting with Why





What is your  
**WHY?**

**Type in the chat or unmute and share:**

- What do you want for people and families?
- What don't you want?



# Go to [mentimeter.com](https://www.mentimeter.com)

- Type in the code on your screen
- Answer the question by typing in your response

# Thinking About How



# Charting the LifeCourse

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# What is Charting the LifeCourse ?

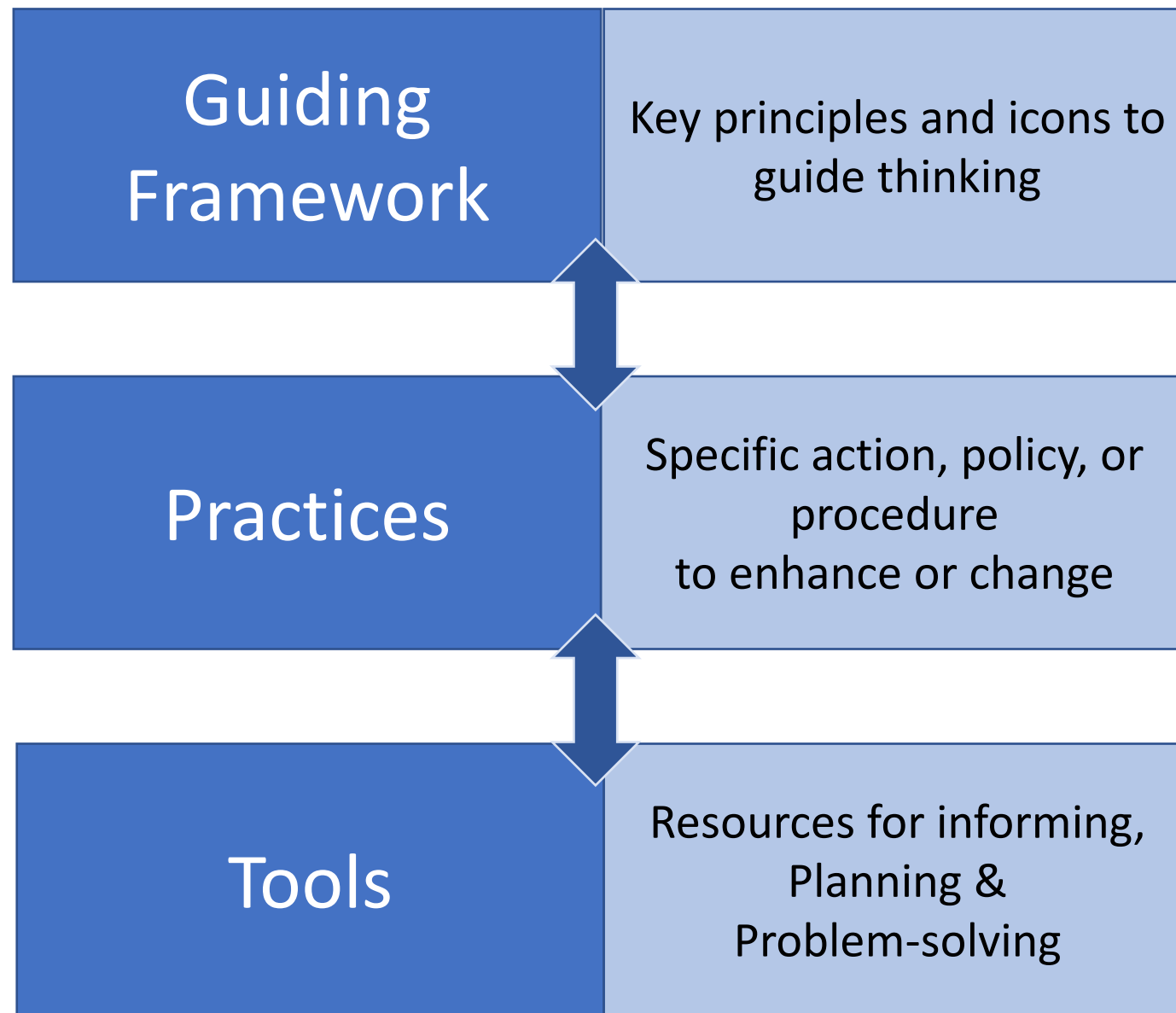
Created for people and families of all abilities and all ages to:

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

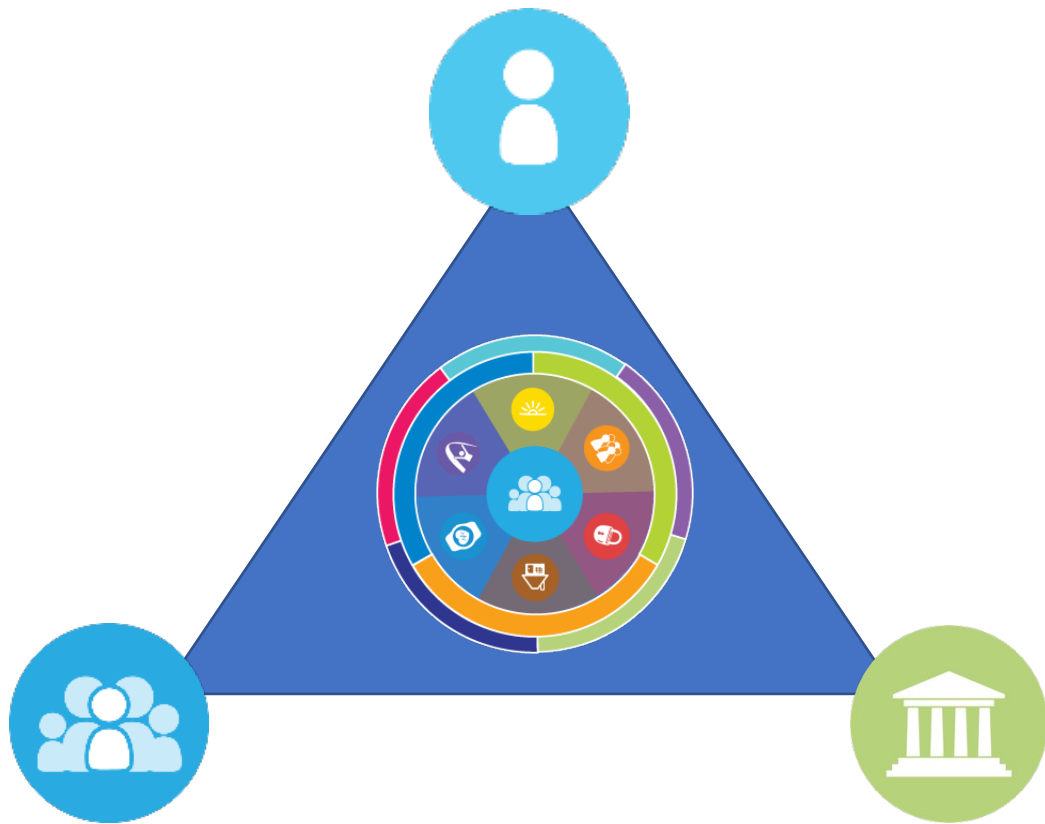




# What is Charting the LifeCourse



# CtLC Supports All Team Members



- **Individuals** will achieve self-determination, interdependence, productivity, integration, and inclusion in all facets of community life
- **Families** will be supported in ways that maximize their capacity, strengths, and unique abilities to best nurture, love, and support all individual members to achieve their goals
- **Professionals and Other Support Team Members** will have the capacity to provide person-centered services to support the individual and their family to achieve their good lives

# ALL People

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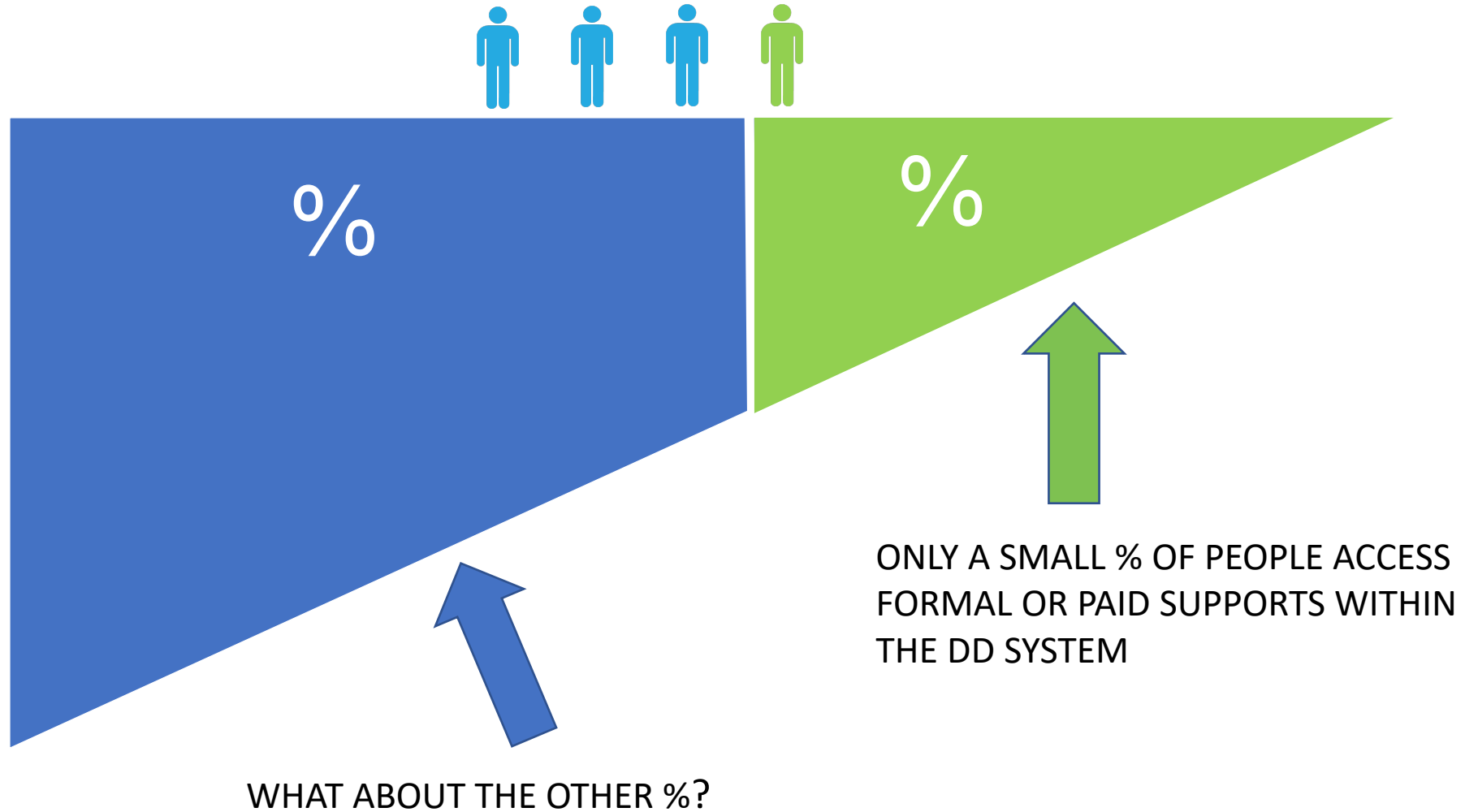
*All people, regardless of age, ability or family role, are considered in our vision, values, policies and practices for supporting individuals and families. All families have choices and should have access to the supports they need.*



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# WHY We Must Think Differently About Supports





# Person in Context of Family & Community

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*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.*



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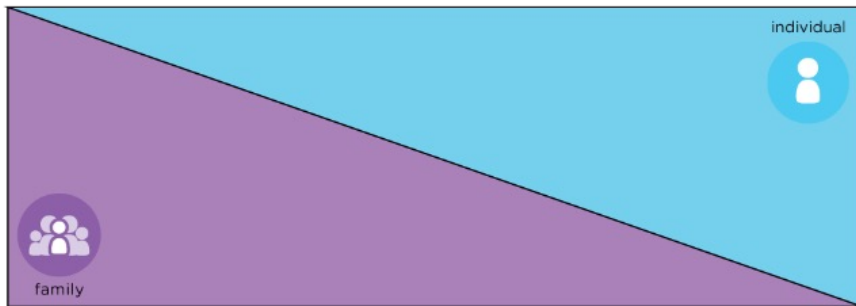
# ALL Individuals Exist within the Context of Family

- Family is defined by the individual
- Not dependent on where a person lives
- Includes the uniqueness of our relationships, culture, and family norms



# Life Long Impact of Family

## Individual Life Stages



## Family Life Cycle

**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

# Caring About



## CARING ABOUT

<b>Share Love, Affection, and Trust</b>	Trusted people that you may or may not spend a lot of time with but you care about and love each other. These are people such as immediate or extended family, close friends, significant others.
<b>Spend Time and Create Memories Together</b>	Friends and acquaintances that you spend time with and are important to you. You have shared experiences and memories that bring you both joy and laughter.
<b>Know About Personal Interests, Traditions, and Cultures</b>	People you trust to explain to others what is important to you, such as what makes you happy or sad, who is important to you, and your likes and dislikes. They also know about your habits, important family culture and celebrations.



# Caring For



## CARING FOR

<b>Supports Day-to-Day Needs</b>	People that provide for or make sure your self-care needs are met. People who make sure you have support for your safety, health and quality of life, such as helping with meals, dressing, medications and daily activities. This could be parents, family caregivers or paid staff.
<b>Ensures Material and Financial Needs are Met</b>	People that help you manage such things as your finances, housing, healthcare, transportation or technology needs. This could be a family member or someone in a formal role.
<b>Connects to Meaningful Relationships and Roles</b>	People that help you stay connected or develop new friendships. They may help you find and participate in hobbies, recreational or spiritual activities. This could be friends, family, community members, clergy or paid staff.
<b>Advocates and Supports Life Decisions</b>	People that help you with speaking up for yourself or that you trust to speak and advocate for you. They might also help you with making decisions by helping you understand choices, communicate what you decide, or following through with your decisions.





# 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 <u>Sarah</u> 's life	Looking Ahead	What's important to know, make sure continues, or make happen?
 <b>Caring ABOUT</b>	<b>Affection and Self-Esteem</b> Who loves and cares about him/her? Mom, Dad, Sisters, Boyfriend, Boyfriend's family	Who else makes him/her feel loved? Aunts/Uncles/Cousins, Friends Alisha and Marissa, some of her sister's friends (Andrea and Leia)	One on one /quality time is very important to Sarah. Building more relationships with friends will be important for the future, as well as making sure she has time with future nieces/nephews, etc.
	<b>Repository of Knowledge</b> Who else knows things that others don't know well? (celebrations, traditions, habits, history) Sarah, Mom, Dad, Big Sis Jenny	With whom does he/she have special memories or experiences? Aunts/Uncles/Cousins;	We need to write down all of Sarah's medical history and needs. This would be the piece that others would not know if something were to happen. Sarah knows and can communicate traditions/habits.
	<b>Lifetime Commitment</b> Who has a lifetime bond with him/her? Mom, Dad, sisters, Friend Marissa, longtime boyfriend/future husband Manny	Who else would step up when/if needed? Aunt Carol, Uncle Jim, Uncle Gary, Uncle Charlie, Cousin Ginny, Cousin Leigh, Manny's family	Emily & Sarah don't get along well now, but Emily would be there for her if she was needed. Working on their relationship is important, as Emily is significantly younger than Jenny
 <b>Caring FOR</b>	<b>Provider of day-to-day care</b> Who makes sure activities of daily living and healthcare needs are met? Sarah, Mom, Dad, Arc staff	Who else could provide oversight for these needs? Manny/Manny's family, Jenny's friends Andrea and Leia	Sarah is very independent with ADLs, but needs help with medical appointments/prescriptions, etc. Setting up automatic reorders and delivery may help.
	<b>Material and Financial Needs</b> Who makes sure his/her day-to-day basic and quality of life needs are met? Sarah, Mom, Dad, Jenny, Arc staff	Who else could help make sure this happens? Manny, Uncle Harvey, Uncle Jim, Uncle Gary, Jenny's friends Andrea and Leia	Managing money is an area where Sarah may be able to develop skills to become more independent, but financial support will always be important.
	<b>Facilitator of Inclusion and Membership</b> Who helps connect him/her to inclusive opportunities and maintain relationships? Sarah, Mom, Dad	Who would be good at helping him/her connect with and maintain inclusive activities? ??	Sarah wants to be involved in other organizations with more opportunities to meet people. Her current work schedule makes that really difficult – need to explore more opportunities for her to make connections.
	<b>Advocate for Support</b> Who helps him/her advocate in planning meetings? Sarah, Mom, Jenny	Who else could help advocate for/with him/her? Manny	Need to do an Integrated Support Star (divided) to explore this further. Not sure of options at this point.

Developed by the UMKC Institute for Human Development, UCEDD. More tools at [lifecoursetools.com](http://lifecoursetools.com)

MAY 2017



# Tools for Exploring Roles and Relationships



## MAPPING RELATIONSHIPS

CARING ABOUT	Who serves in this role now?	Looking Ahead	Next Steps
Shares Love, Affection and Trust			
Spends Time and Creates Memories Together			
Knows about Personal Interest, Traditions, Cultures			

CARING FOR	Who serves in this role now?	Looking Ahead	Next Steps
Supports Day-to-Day Needs			
Ensures Material and Financial Needs are Met			
Connects to Meaningful Relationships and Roles			
Advocates and Supports Life Decisions			



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## 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? _____	

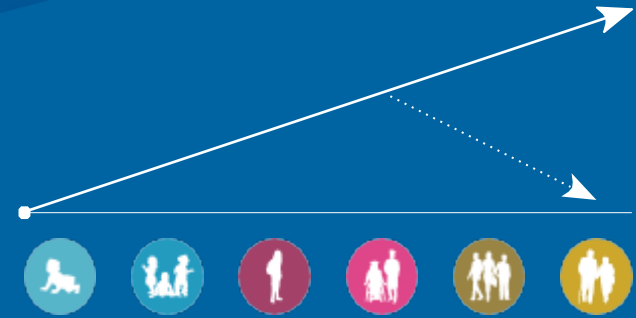


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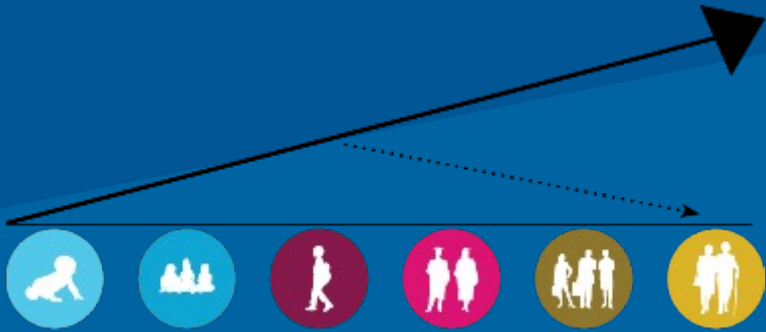


# Life Trajectory, Experiences and Life Stages

*Individuals and families can focus on a specific life stage, with an awareness of how prior, current, and future life stages impact and influence their trajectory. It is important to have a vision for a good, quality life and have opportunities, experiences, and support to move the life trajectory in a positive direction.*



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# Vision of a Good Life



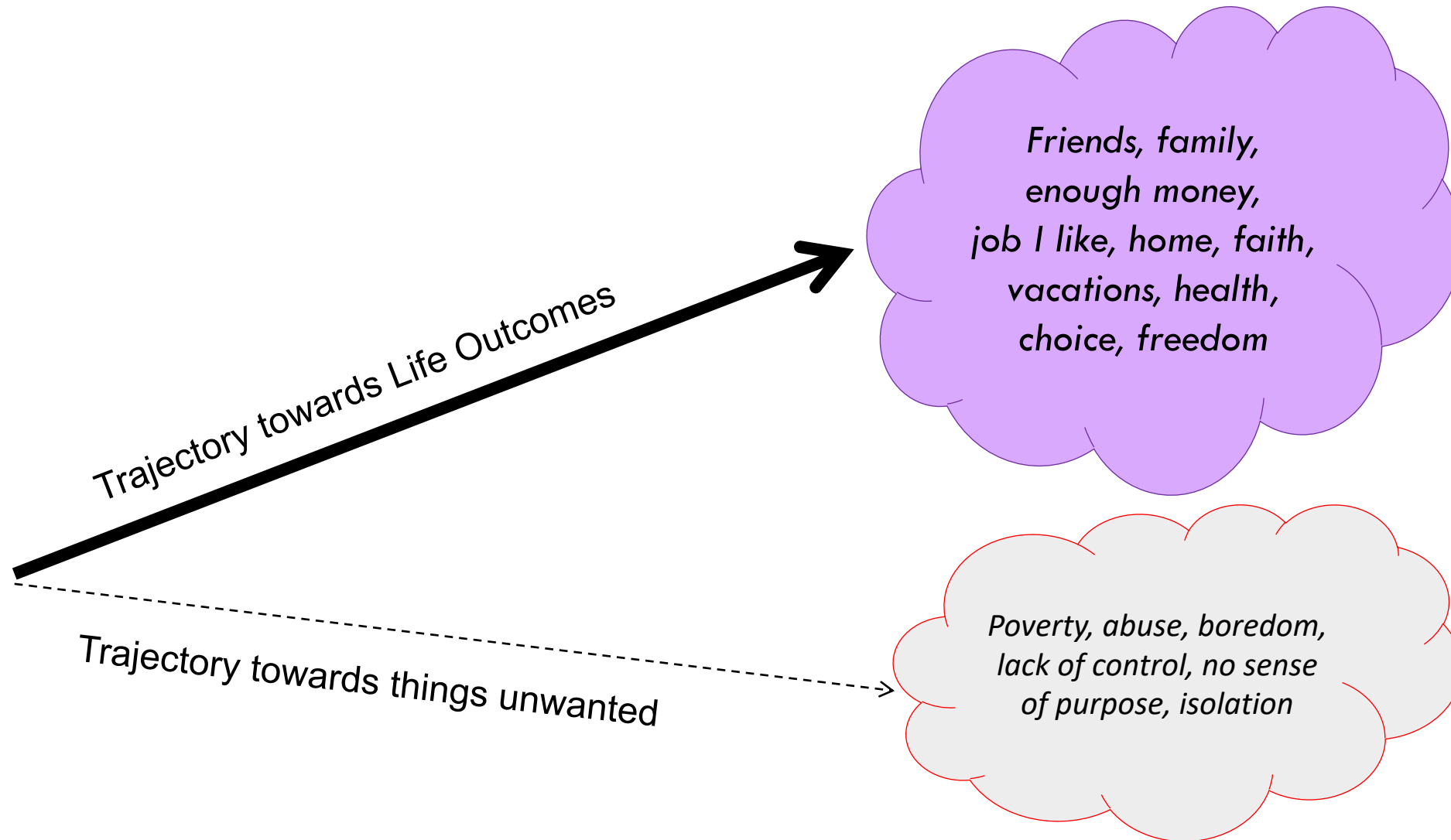
*The future is not something  
we enter. The future is  
something that we create.  
And creating that future  
requires us to make choices  
and decisions that begin with  
a dream*

# What DON'T You Want??

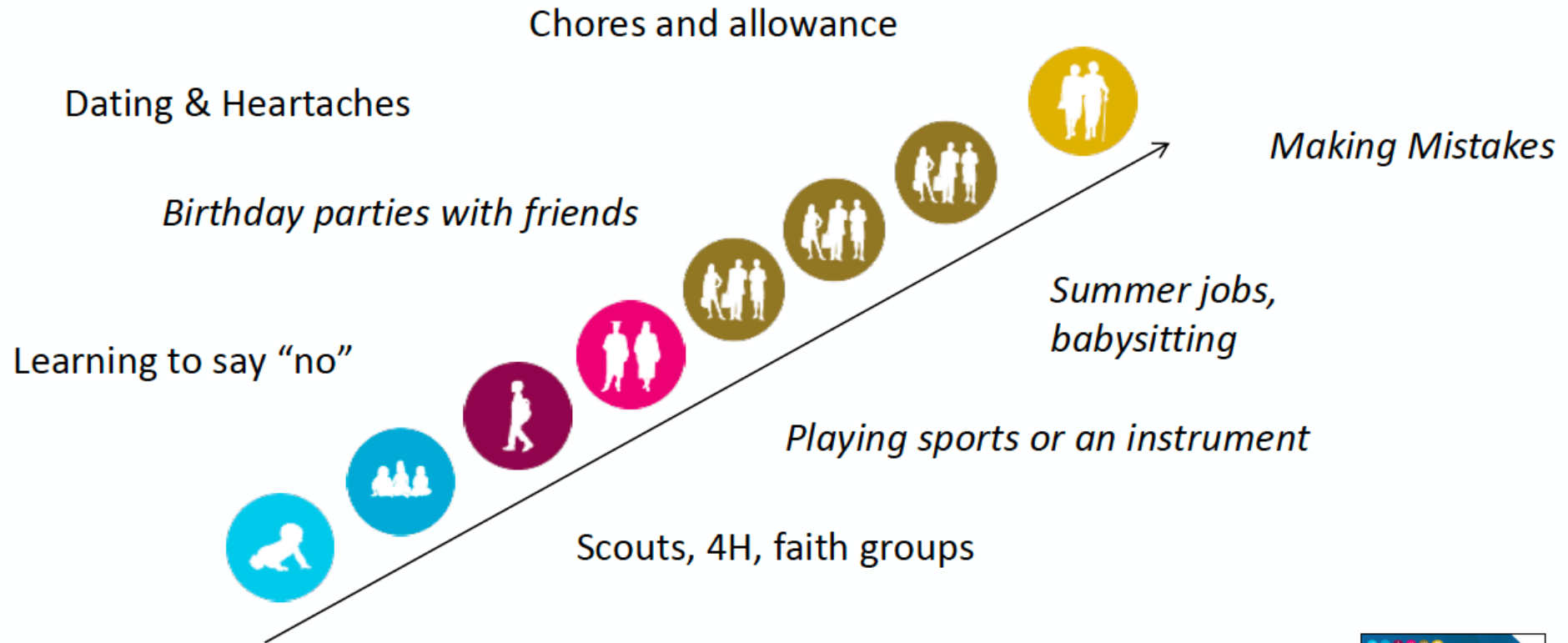
Vision of What  
I Don't Want



# Vision & Trajectory for a Good Life



# Trajectory Across Life Experiences



**“Anticipatory Guidance for Life Experiences”**



# How the Story Began: Sarah

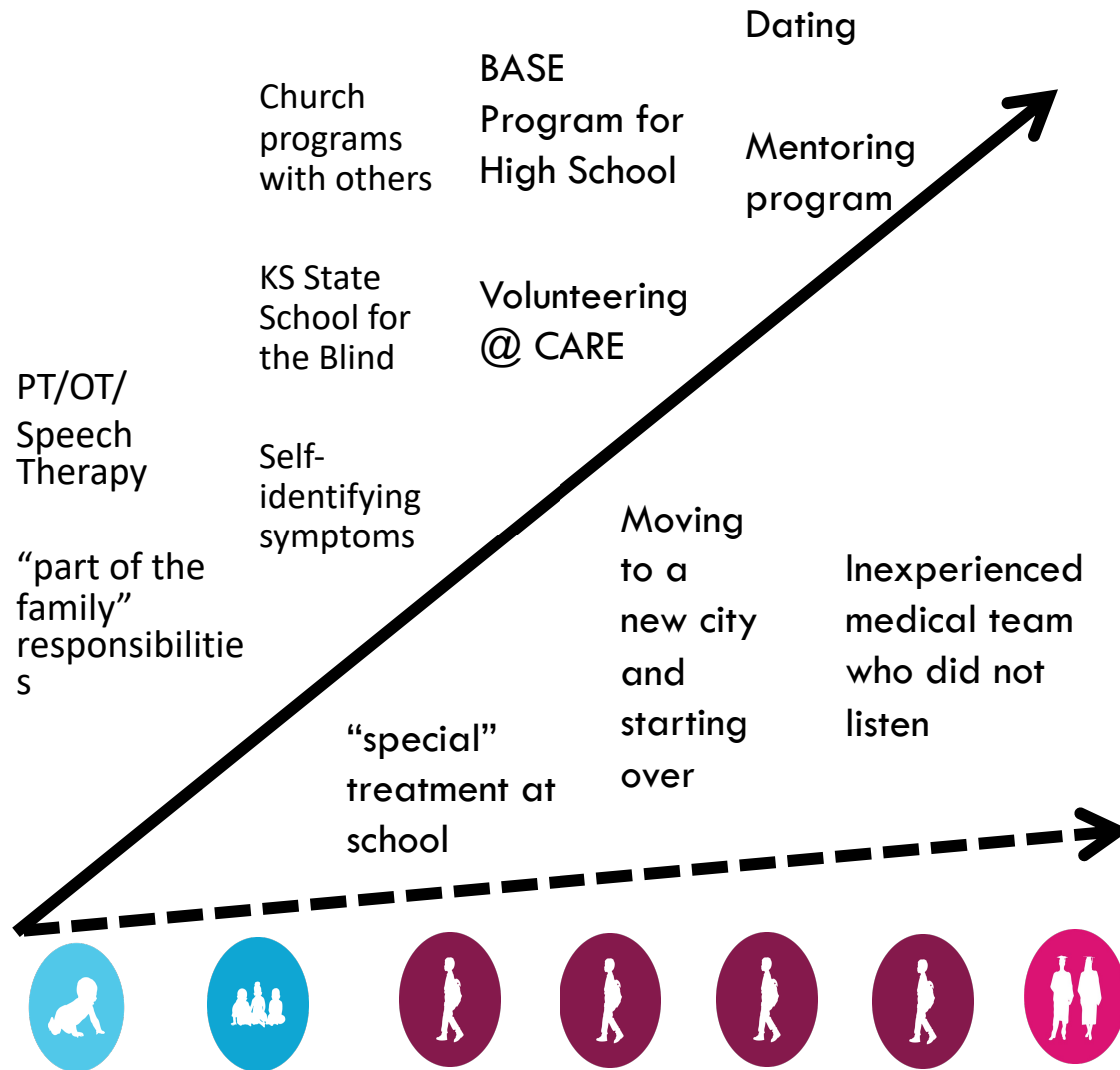
## How Others Described Sarah

- Cerebral Palsy: “mobility issues”
- Moderate Intellectual Disability: “requires significant support”
- Chronic Hydrocephalus with multiple shunts: “medically fragile”
- Low vision/hearing: “can’t navigate independently”

## Sarah’s Family’s View



# Shaping the Rest of the Story: Sarah



## What We Want

- Live independently
- Get married and have kids
- Work with animals or kids
- Close relationships with friends and family

## What We DON'T Want

- Reliant on others for medical care
- Taken advantage of
- Bored, low self-esteem
- Others make all decisions choices for her.

# Life Experiences = Life Outcomes = Good Life

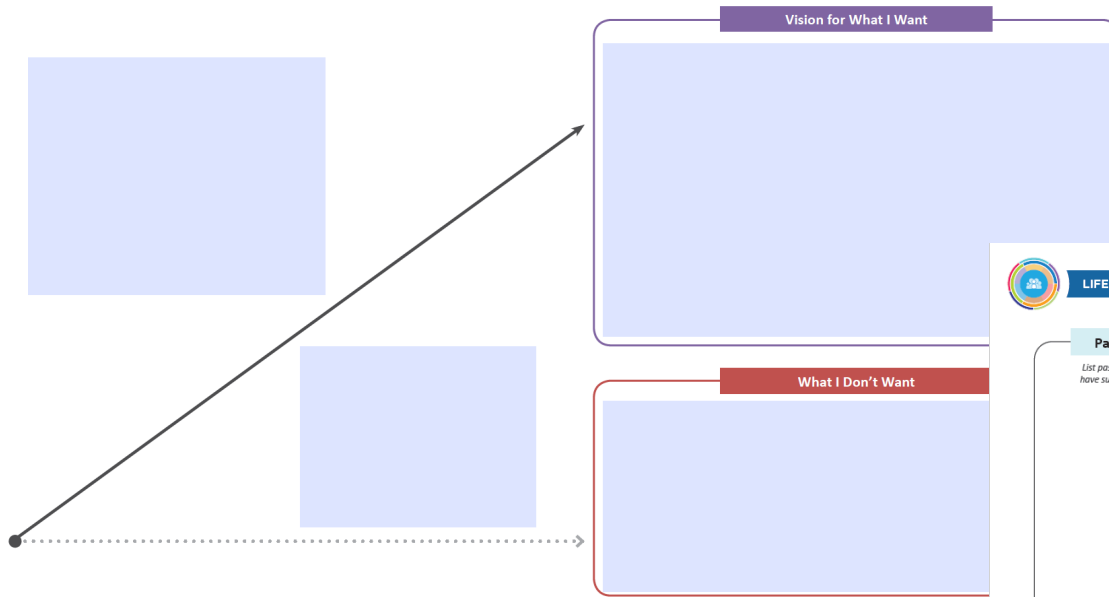




# Tools for Exploring and Planning



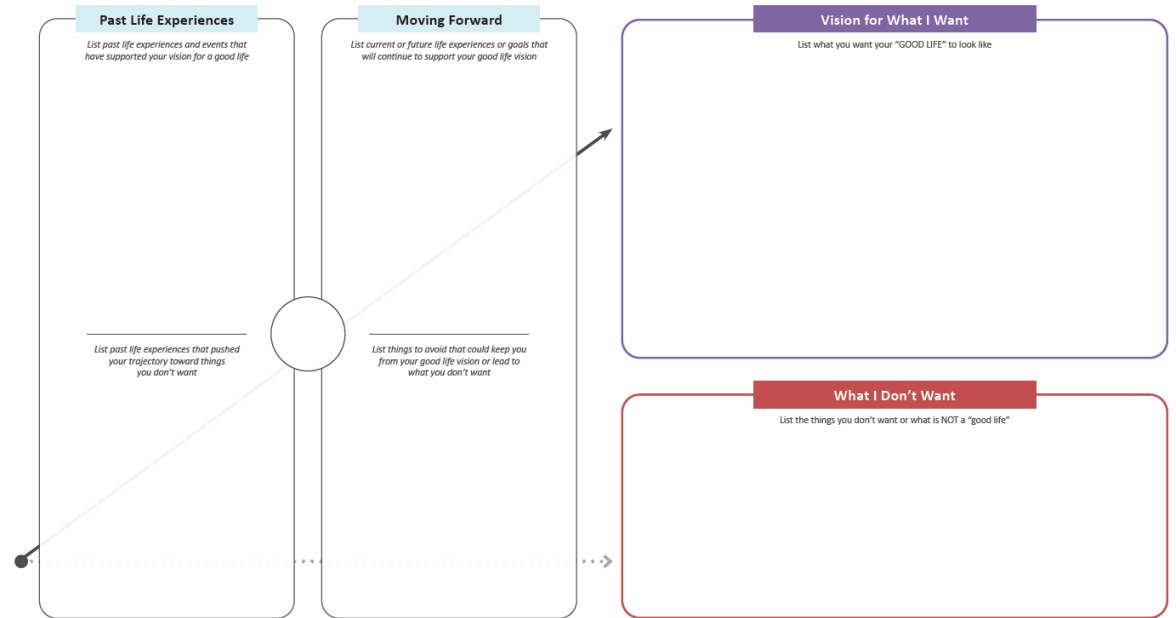
LIFE TRAJECTORY | EXPLORING



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LIFE TRAJECTORY | PLANNING



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# Distinguishing the Voice of All Family Members

**LIFE TRAJECTORY | PLANNING**

**Past Life Experiences**  
*List past life experiences and events that have supported your vision for a good life*

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*List past life experiences that pushed your trajectory toward things you don't want*

**Moving Forward**  
*List current or future life experiences or goals that will continue to support your good life vision*

---

*List things to avoid that could keep you from your good life vision or lead to what you don't want*

**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"*

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**LIFE TRAJECTORY | FAMILY PERSPECTIVE**

**Past Life Experiences**  
*List past life experiences and events that have prepared or supported my family member to move towards a vision for a good life*

---

*List past life experiences that pushed my family member's trajectory toward things they did not want or I did not want for them*

**Moving Forward**  
*List current or future life experiences or goals that will continue to support my family member to move towards a vision for a good life*

---

*List barriers or things to avoid that might get in the way of my family member taking steps to reach their goals*

**My Vision for My Family Member's Good Life**

**What I Don't Want**

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# Planning for a Good Retirement

## Life Trajectory Worksheet


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

Seeing my parents retire  
Seeing my friends that that already retired enjoying this time of their life  
Travel and vacation experience  
Volunteering

---

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

Observing the lifestyle of my family members and slightly older friends that were not / have not been able to retire  
Powdered Milk  
Unable to pay bills  
Unable to afford medical insurance



Write current age here  
52

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

Enjoy working, enjoy current work  
Vacation is inspiring  
Value insurance, healthcare, and income  
Appreciate time to be able to support my community  
Hope to be able to spend some time with my folks while they still live

---

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

Being a burden to my kids  
Unable to support self and assist others when in need  
Over-spending on non-necessities

**VISION for a GOOD LIFE**

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

- Retire... not sure when, might be 80...
  - Have medical insurance
  - Able to afford some travel
  - Able to pay all bills, and assist others in the family if needed
  - Able to stay healthy and relatively pain free
  - Time to volunteer and help others
  - Time to care for pet/s

**What I DON'T Want**

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

- To be dependent on others
- Lack of insurance
- Unable to pay bills
- A burden
- Unhealthy
- Unhappy
- Hungry
- Lonely



My LifeCourse Portfolio is a template of the UMKC IHD, UCEDD. More materials at [lifecoursetools.com](http://lifecoursetools.com)

OCTOBER 2016



# Joshua's Trajectory

## Meeting With His Waiver & Transition Teams

### Fixing the Broken CDCS Waiver Team for Joshua **Life Trajectory Worksheet**

#### Past Life Experiences

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

I have been able to use the CDCS option of my CAC waiver to complement the wages of my nursing and family DSP staff, so that they have a sustainable, competitive wage for my complex care needs.

This helps to mitigate some of the structural flaws inherent in home care, such as poor medical and dental benefits, weak, if any retirement options, and the risk of missed work if I am hospitalized.

The extra incentive has meant continuity of care for me, with safe staff who know the nuances of my cares, assessment and treatments. I have not had an unplanned hospitalization in 5 years!

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

I was forced to have a personal care planner by the county. However, the person has a very poor work ethic and her lack of effort has greatly damaged my coordination of care.

My family has had to do a lot of extra work to advocate for my needs, often re-writing parts of my plan, which were supposed to have already been included.

This has caused delays for many things I need for safety and comfort, and my family has had to carry the burden of the cost.

Outsourcing of case management has been a problem, too. Turnover, and lack of communication has meant that few get to know me and my needs, then make assumptions that impair my care. The results are stressful and cause my family so much anxiety, as well as put me at risk in so many ways. Too often, rules are capricious, petty, and not backed by DHS standards. This causes inequities in the delivery and quality of services I receive.

#### Future Life Experiences

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



amy stock photo

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

I want to have a team that works efficiently, but sees me as a person first. I want them to know the DHS rules, so my family is not made to fight for things on a Tuesday that were allowed on Monday, simply because of turnover in case management. I want a team that realizes how hard my family has worked to give me a good life, so that they don't try to make it more difficult for them, just because they have the power to do so, or because they simply don't do the work. They must realize that my life, my safety, my joy, depends, in large part, upon their cooperation, and upon their respect.



#### VISION for a GOOD LIFE

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



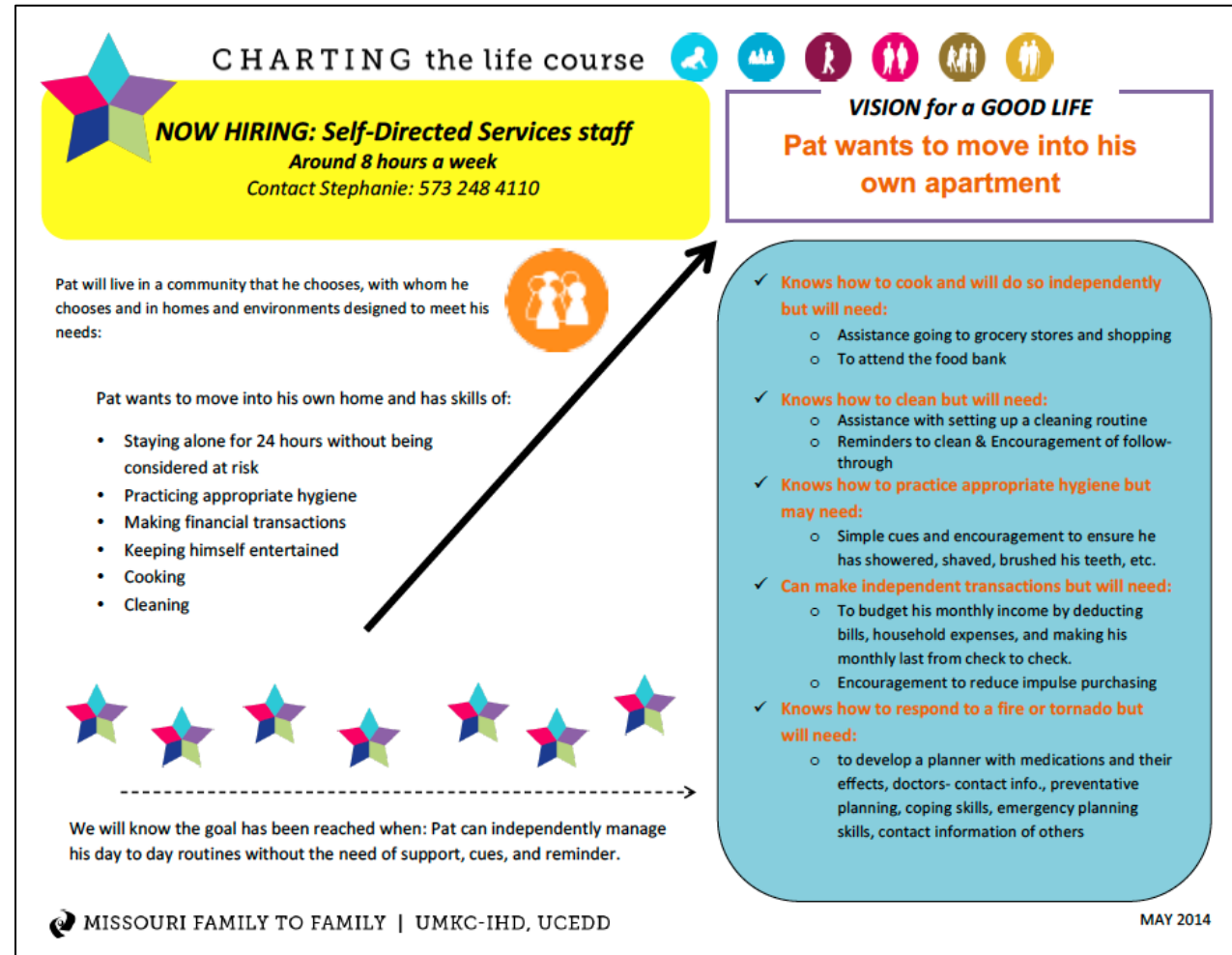
#### What I DON'T Want

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



As well as the notion that Josh is simply a document on someone's desk. He can be transferred as easily as a file, and disregarded in the same manner.

# Hiring for Self Directed Supports



# Life Domains, Outcomes and Possibilities

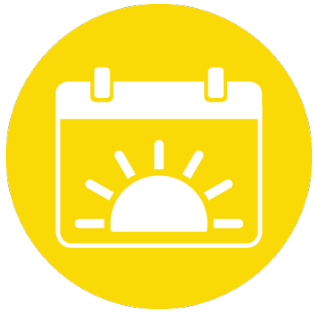
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*People lead whole lives made up of specific, connected, and integrated life domains that are important to a good quality of life. Life domains are the different aspects and experiences of life that we all consider as we age and grow.*



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# 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)



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

# Connect Person-Level Outcomes to SDoH




LifeCourse Domains	Social Determinants of Health (Healthy People 2030)	
	<b>Education:</b> <ul style="list-style-type: none"> <li>• High School Graduation</li> <li>• Enrollment in Higher Education</li> <li>• Language &amp; Literacy</li> <li>• Early Childhood Education &amp; Development</li> </ul>	<b>Economic Stability:</b> <ul style="list-style-type: none"> <li>• Poverty</li> <li>• Employment</li> <li>• Food Security</li> <li>• Housing Stability</li> </ul>
	<b>Neighborhood &amp; Built Environment:</b> <ul style="list-style-type: none"> <li>• Quality of Housing</li> <li>• Environmental Conditions</li> <li>• Access to Healthy Foods</li> </ul>	
	<b>Neighborhood &amp; Built Environment:</b> <ul style="list-style-type: none"> <li>• Crime &amp; Violence</li> <li>• Social &amp; Community Context</li> <li>• Discrimination</li> </ul>	
	<b>Health &amp; Health Care</b> <ul style="list-style-type: none"> <li>• Access to Health Care</li> <li>• Access to Primary Care</li> <li>• Health Literacy</li> </ul>	<b>Economic Stability:</b> <ul style="list-style-type: none"> <li>• Food Security</li> </ul> <b>Neighborhood &amp; Built Environment:</b> <ul style="list-style-type: none"> <li>• Access to Healthy Foods</li> </ul>
	<b>Social &amp; Community Context</b> <ul style="list-style-type: none"> <li>• Social Cohesion</li> <li>• Incarceration</li> </ul>	
	<b>Social &amp; Community Context</b> <ul style="list-style-type: none"> <li>• Civic Participation</li> </ul>	



# Using Life Domains to Understand, Narrow, Pinpoint the Vision












## Life Domain Vision Tool: Person Centered


**LIFE DOMAIN VISION TOOL | PERSON CENTERED**

Name of Person Completing: \_\_\_\_\_ Date: \_\_\_\_\_

On Behalf of: \_\_\_\_\_

LIFE DOMAIN	DESCRIPTION	MY VISION FOR MY FUTURE	PRIORITY
	<b>Daily Life &amp; Employment:</b> 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?		
	<b>Community Living:</b> Where would I like to live in my adult life? Will I live alone or with someone else?		
	<b>Social &amp; Spirituality:</b> How will I connect with spiritual and leisure activities, and have friendships and relationships in my adult life?		
	<b>Healthy Living:</b> How will I live a healthy lifestyle and manage health care supports in my adult life?		
	<b>Safety &amp; Security:</b> How will I stay safe from financial, emotional, physical or sexual harm in my adult life?		
	<b>Advocacy &amp; Engagement:</b> 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?		
	<b>Supports for Family:</b> How do I want my family to still be involved and engaged in my adult life?		
	<b>Supports &amp; Services:</b> 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](http://LifeCourseTools.com)  
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**Life Domain Vision Tool: Family Perspective**

LIFE DOMAIN		My Vision for My Future	priority
 <b>Daily Life Employment</b>	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?	I would like Sarah to work in a job that she enjoys, where she has co-workers who are supportive and friendly –not “taking care of her,” but really letting her be part of the team. I think working full time may be too tiring for her.	
 <b>Community Living</b>	Where and with whom do I think my family member will live in his/her adult life?	I would like Sarah to live in a home or apartment with her future husband, hopefully somewhere relatively close to me or to mom/dad in case of emergency.	
 <b>Social &amp; Spirituality</b>	How do I think my family member will connect with spiritual and leisure activities; have friendships & relationships in his/her adult life?	I want Sarah to find a group of friends who enjoy similar things – maybe a horse riding group, or a church Bible Study.	1
 <b>Healthy Living</b>	How do I think my family member will live a healthy lifestyle and manage health care supports in his/her adult life?	Sarah should learn her medical history a little bit better - she knows some things, but doesn't know the full picture. She is able to distinguish her symptoms. I think eating healthier/exercising would be helpful to her.	2
 <b>Safety &amp; Security</b>	How do I think my family member will be safe from financial, emotional, physical or sexual harm in adult life?	Sarah has decent boundaries, and does a good job to talk to her family/friends about situations that make her uncomfortable. She tends to think the best of people and be somewhat naive... we should continue to remind her about being aware of herself and her surroundings, and not trusting people too quickly.	
 <b>Citizenship &amp; Advocacy</b>	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?	Sarah is an important member of our family, and has a valued role. I think having opportunities to volunteer and be more connected in the community are important for her to feel greater value/control overall	
 <b>Supports for the Family</b>	What supports do I think our family unit needs now or will need in the future?	Assistance with transportation so that she can go where she wants/when she want; medical oversight for our peace of mind.	3
 <b>Supports and Services for Individual</b>	What do I envision for long term services and supports for my family member in the future?	I think she has a pretty integrated support system now... but I would like to do a trajectory with Sarah to make sure we are all working toward the same vision.	

Developed by Missouri Family to Family at the UMKC Institute for Human Development, UCEDD [mofamilytofamily.org](http://mofamilytofamily.org) | MAY 2017

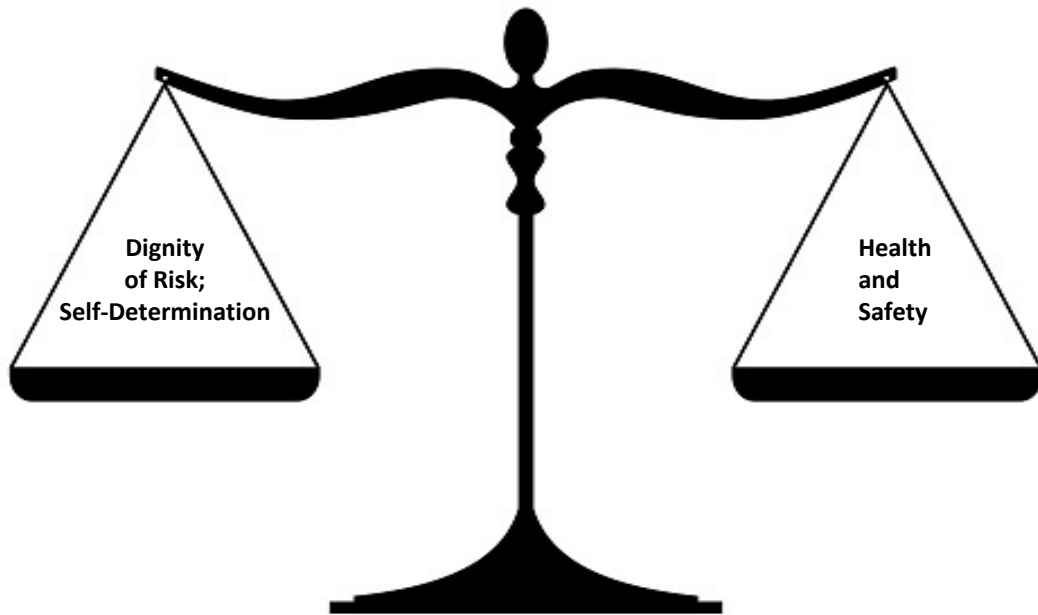
# Life Domain Vision Tool: Sarah's Example



# Balance Health/Safety with All Domains



# Life Experiences = Dignity of Risk



- Dignity of risk is the right to take risks when engaging in life experiences, and the right to fail in those activities.
- Lack of experiences and over-protection can result in lowered expectations, learned dependency, low self-esteem and underachievement

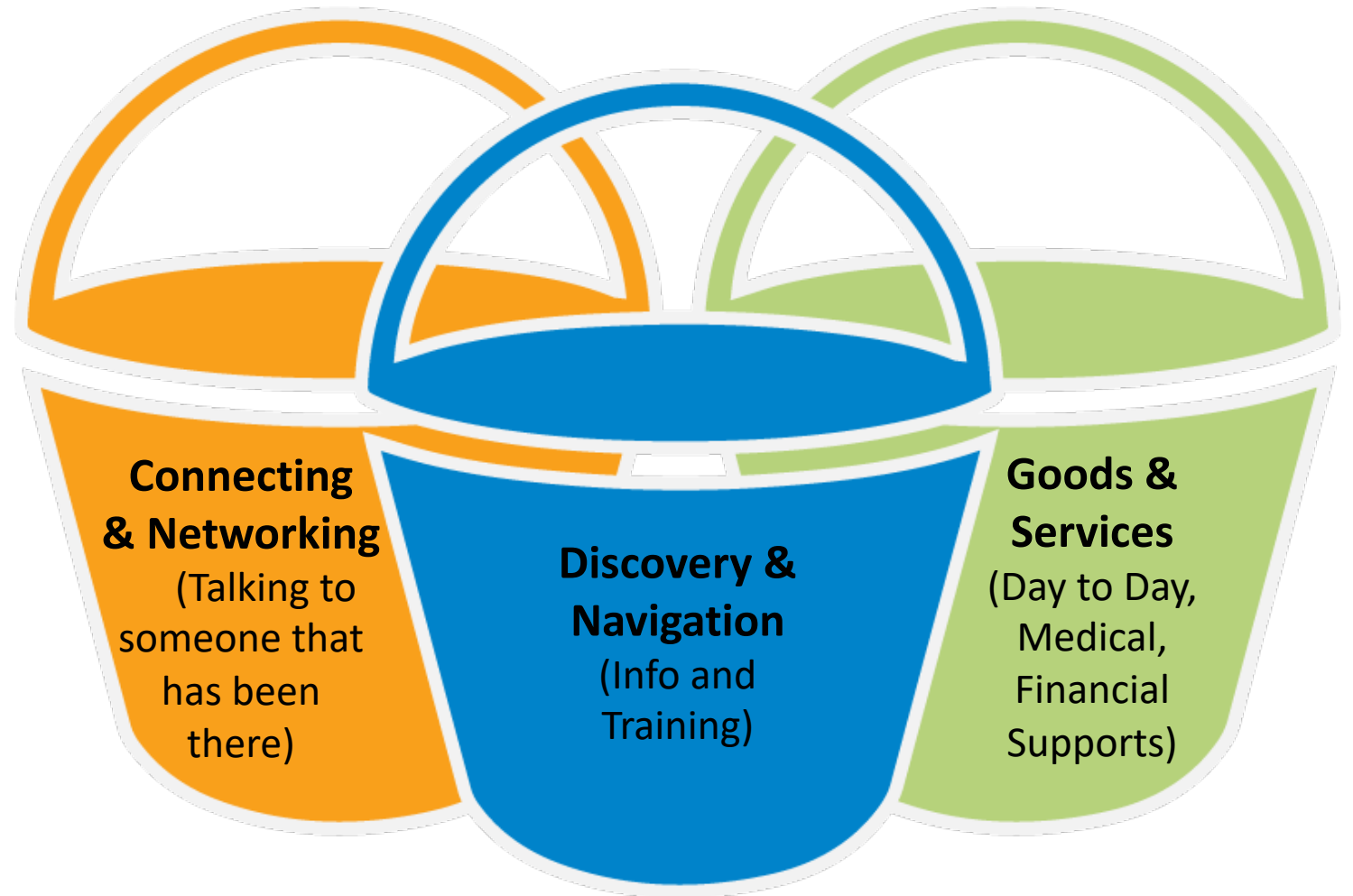
# Individualized Supports to Achieve a Good Life

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[www.lifecoursetools.com](http://www.lifecoursetools.com)

# Supporting the Needs of ALL People The “3 Buckets”



# The Three Buckets and Antarctica



# Filling All Three Buckets



*Information, education and training on best practices within and outside of formal services, accessing and coordinating community supports, and advocacy and leadership skills.*



*Connections and networks of family members connected with other family members with similar lived experiences and mutual partnerships with professionals that lead to empowerment*



*Services and goods that are specific to the daily support and/or caregiving role for person*



# Further Defined Family Supports

<b>Discovery &amp; Navigation</b> Knowledge and Skills	<b>Connecting &amp; Networking</b> Mental Health and Self-efficacy	<b>Day-to-Day Services</b> Instrumental Supports
<ul style="list-style-type: none"> <li>• Knowledge on best practices, values and life expectations</li> <li>• Skills for problem-solving and planning for now and future</li> <li>• Skills to advocate and navigate access services and supports</li> </ul>	<ul style="list-style-type: none"> <li>• Parent-to-Parent Support</li> <li>• Self-Advocacy Organizations</li> <li>• Family Organizations</li> <li>• Sib-shops</li> <li>• Support Groups</li> <li>• Professional Counseling</li> <li>• Non-disability community support</li> </ul>	<ul style="list-style-type: none"> <li>• Self/Family-Directed services</li> <li>• Transportation</li> <li>• Respite/Childcare</li> <li>• Adaptive equipment</li> <li>• Home modifications</li> <li>• Financial assistance</li> <li>• Cash Subsidies</li> <li>• Short/Long term planning</li> <li>• Caregiver supports and training</li> </ul>

\*National Community of Practice on Supports to Families, initiative of NASDDDS and UMKC-IHD, UCEDD originally funded by Administration on Community Living.

What do  
people and  
families  
need?



## Go to [mentimeter.com](https://www.mentimeter.com)

- Type in the code on your screen
- Answer the question by typing in your response



# Integrated Supports Star

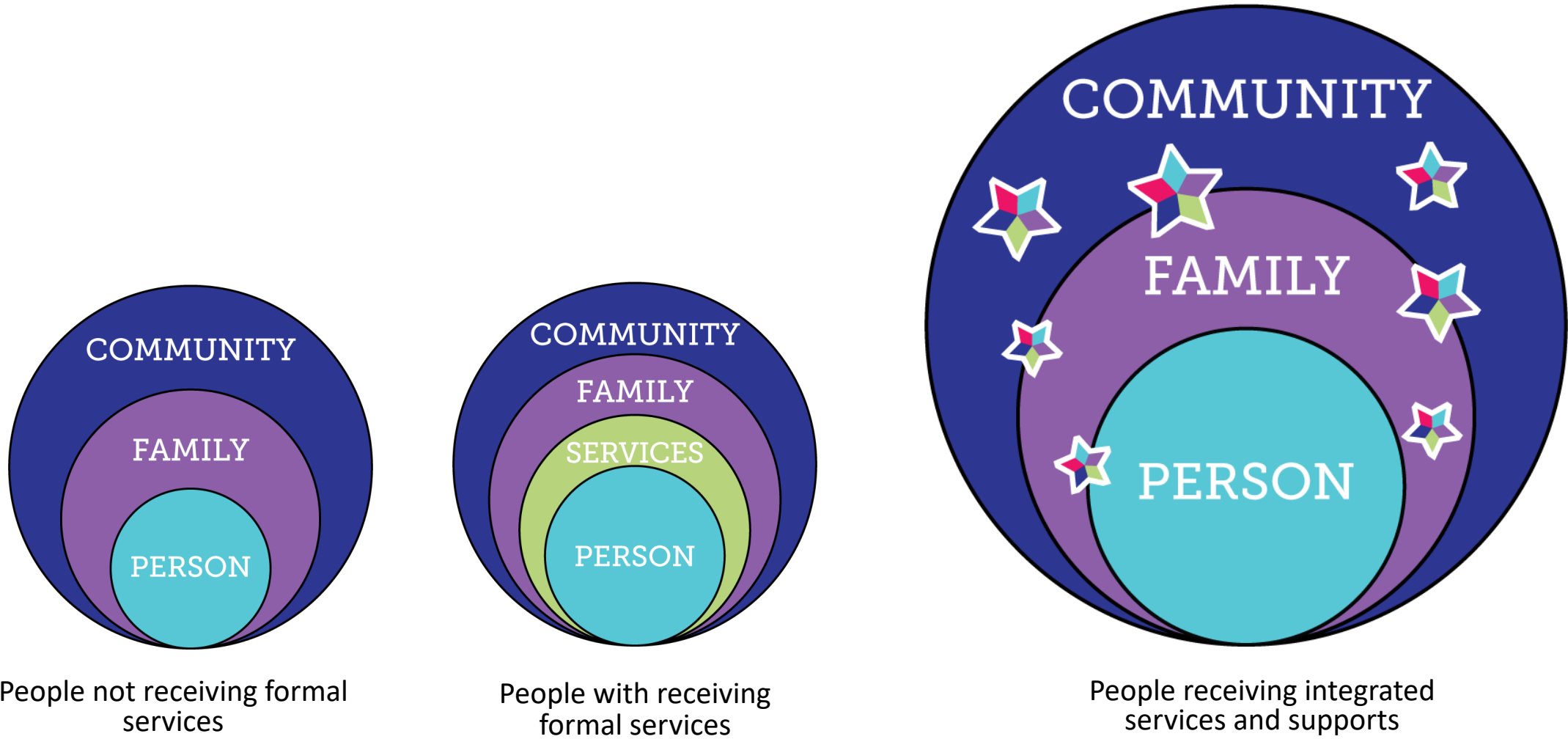
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*Individuals and families access an array of integrated supports to achieve their envisioned good life.*



[www.lifecoursetools.com](http://www.lifecoursetools.com)

# Transforming Services and Supports



# Charting the LifeCourse Integrated Supports Star



# Personal Assets and Strengths



## PERSONAL STRENGTHS & ASSETS

### Strengths:

Things a person is good at or others admire or like

### Assets:

Resources that are owned or can be accessed by the person

### Skills:

Personal abilities, knowledge or experience



# Relationship Supports



## RELATIONSHIPS

### Family:

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

### Friends:

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

### Acquaintances:

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

## TECHNOLOGY

**Personal Technology:**  
Common technologies  
used by anyone \*

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

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



# Technology Supports





# Community Supports



## COMMUNITY RESOURCES

### Places:

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

### Groups:

Civic and membership organizations

### Government Resources:

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



# Eligibility Supports



100%



## ELIGIBILITY-SPECIFIC SUPPORTS

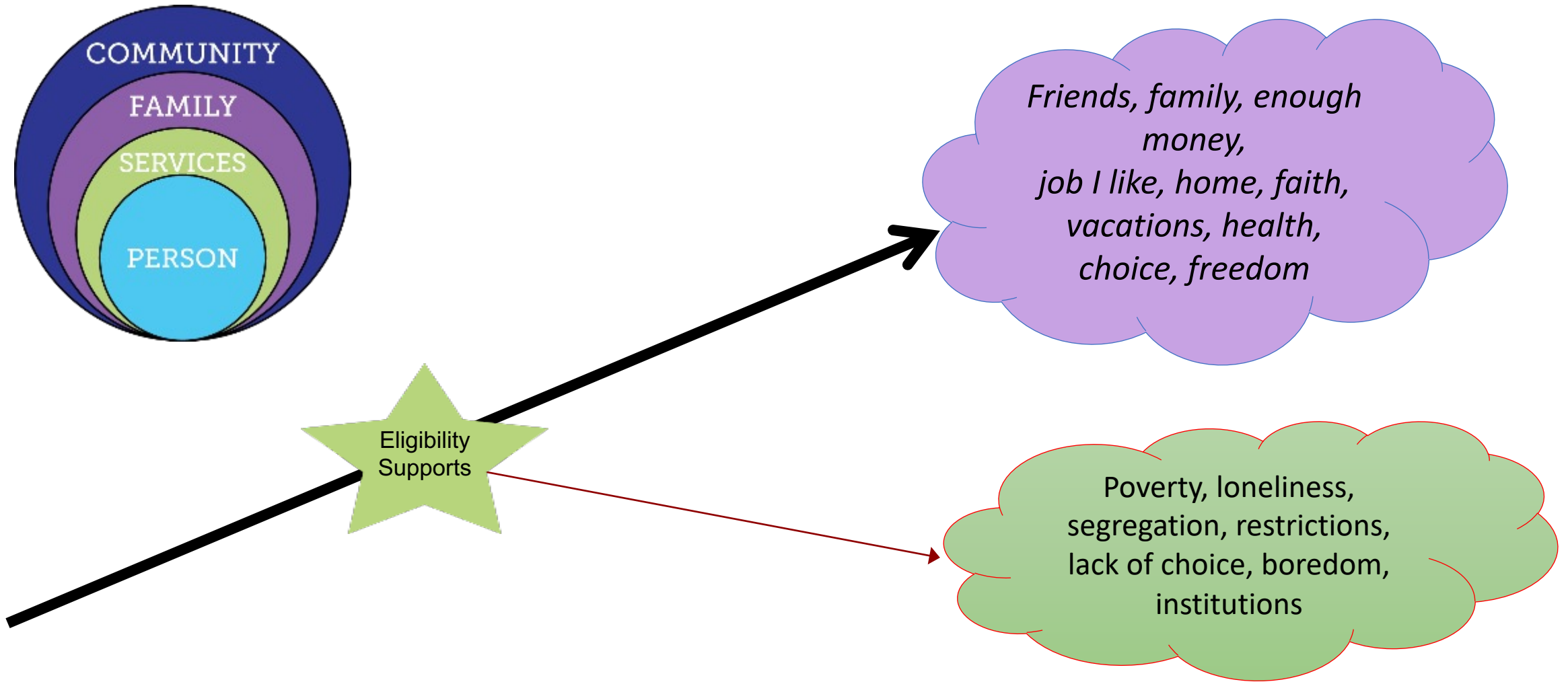
### Disability Specific:

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

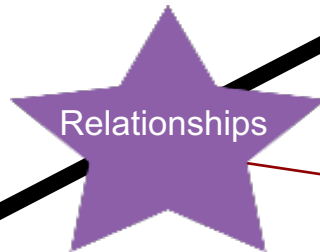
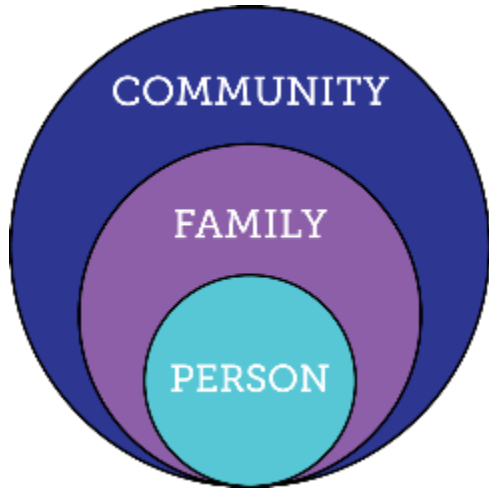
### Needs-based:

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

# Relying ONLY on Eligibility Supports



# Relying ONLY on Family & Friends



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

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

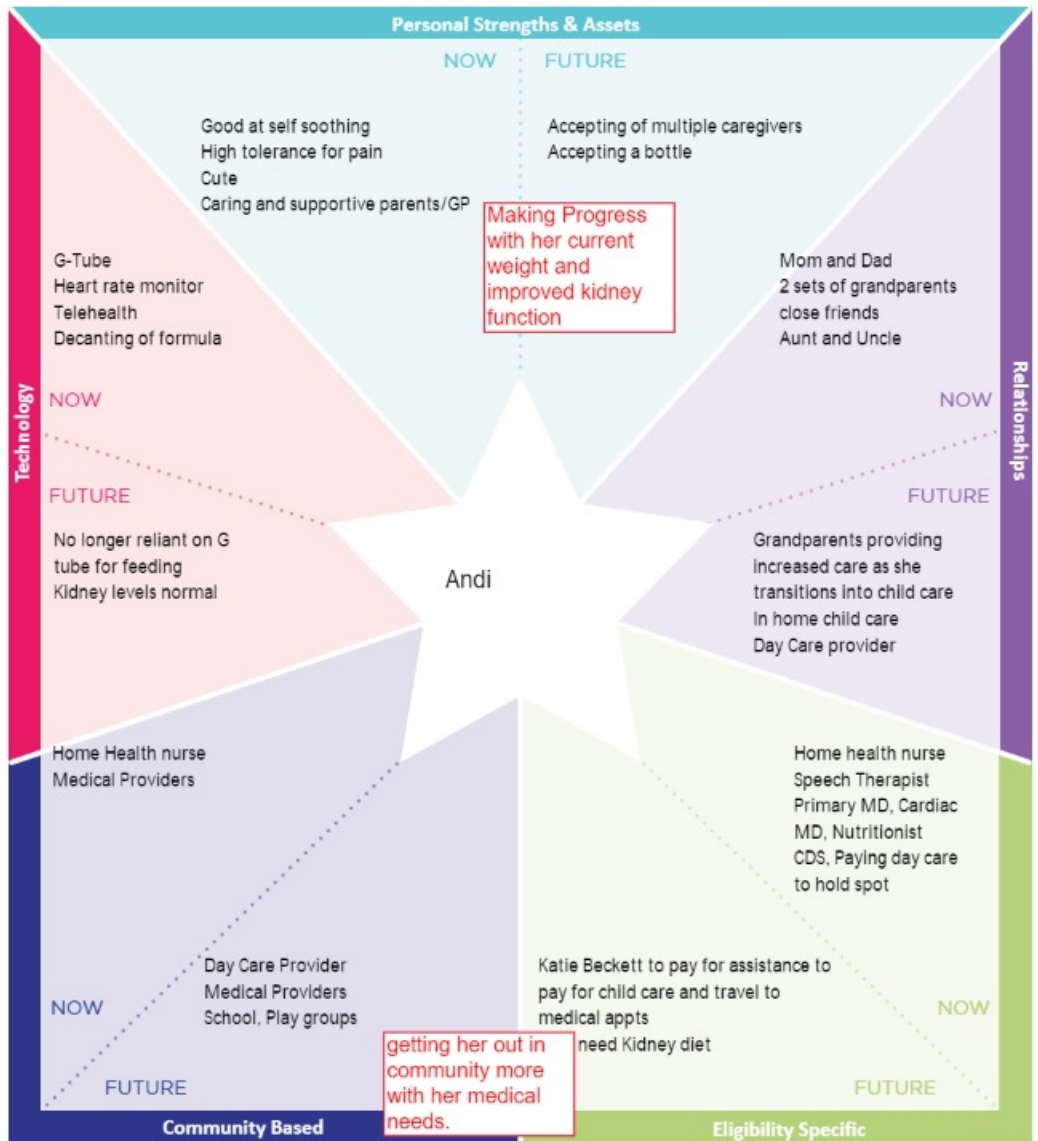
# Mapping Supports: Starter Stars for Life Domains



## INTEGRATED SUPPORTS STAR | HEALTHY LIVING

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



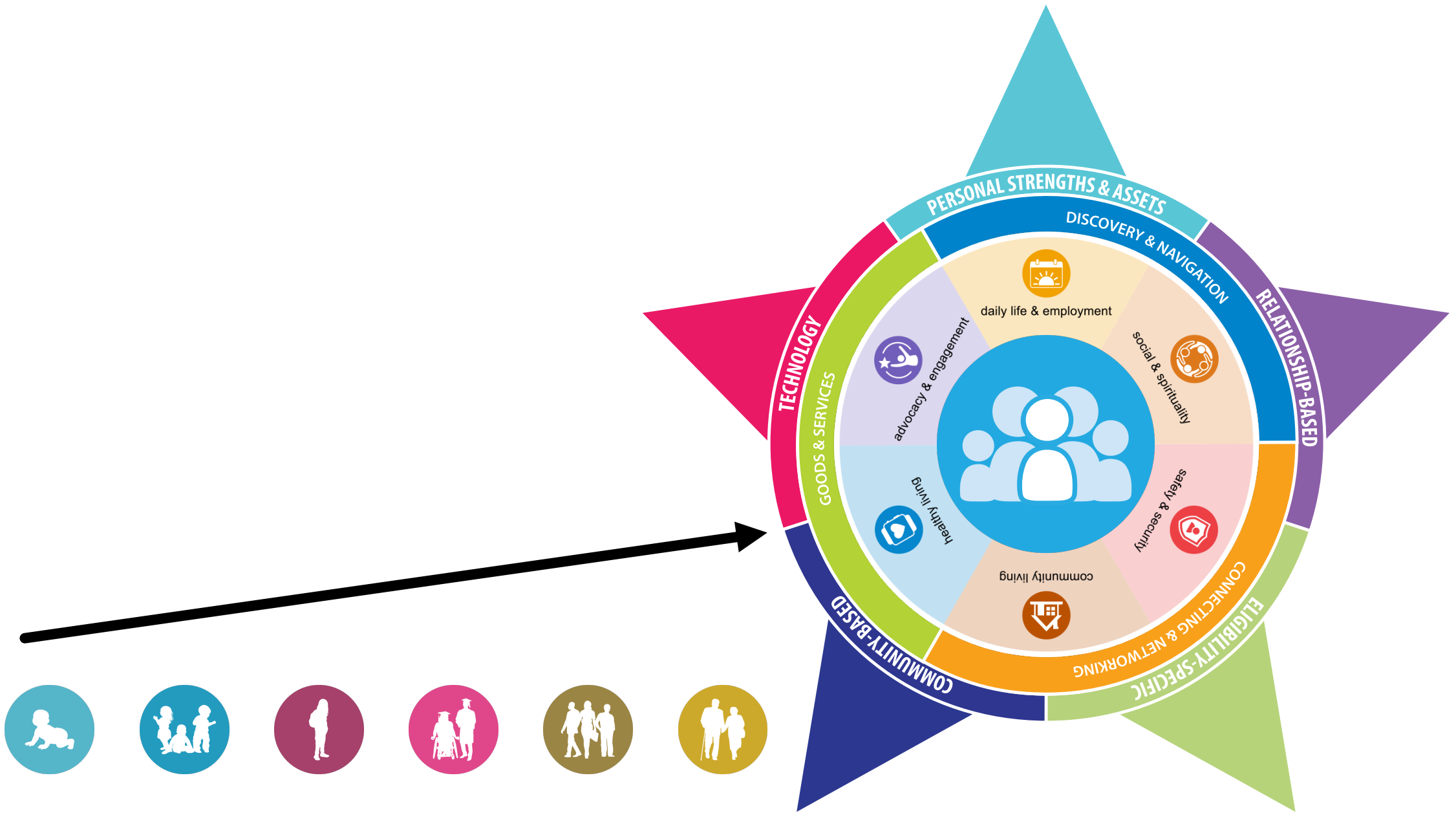


# Identifying Supports for Now and the Future



# Mapping Supports if a Caregiver is Not Available









## Go to [mentimeter.com](https://www.mentimeter.com)

- Type in the code on your screen
- Answer the question by typing in your response

# Thank You and Next Steps

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NATIONAL  
COMMUNITY  
OF PRACTICE





**Jennifer “Jenny” Wilson, LCSW**

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