



# Charting the LifeCourse for Respite

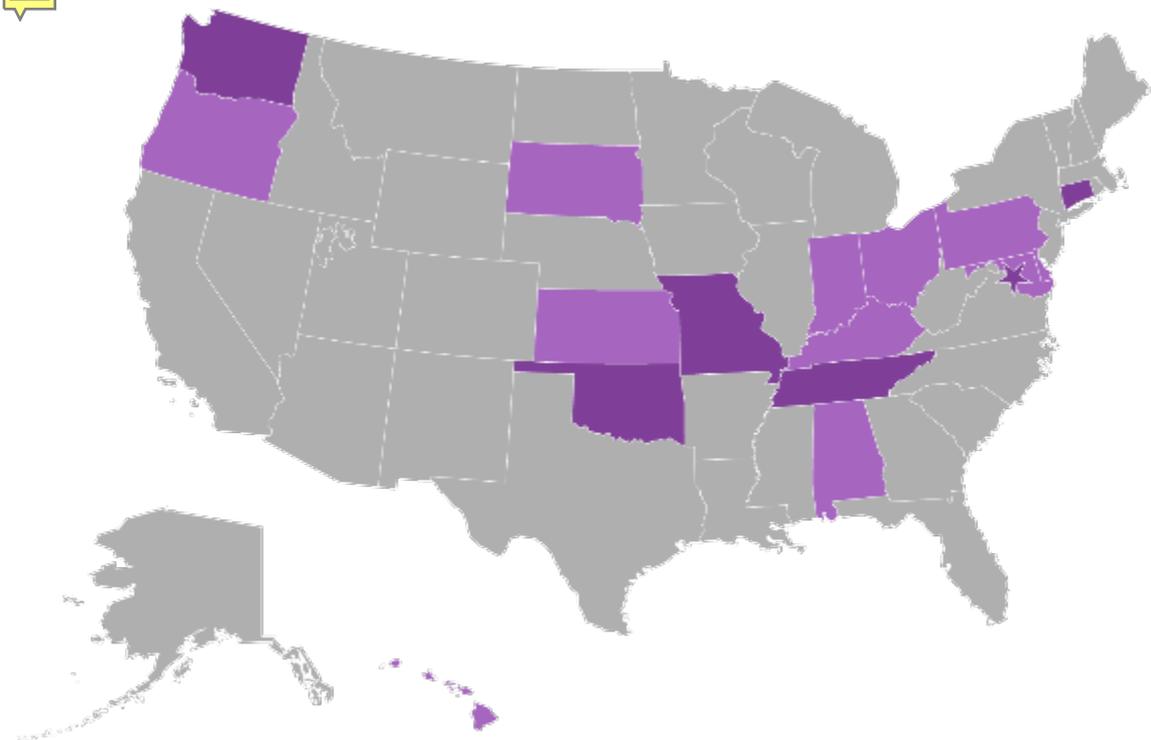
October 13, 2017



# About Jane....

- Mom of 3 sons, “Ben’s mom”
- Partners in Policymaking Graduate
- Community Inclusion and Field Research Specialist
- National Community of Practice on Supporting Families Staff
- Missouri Family-to-Family HIC staff
- Coordinator of activities focusing on supported decision making





## Project Outcome

- 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.

# 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.





# Outcomes for Today

- Basic overview of the Charting the LifeCourse Framework
- How to use the Charting the LifeCourse Respite Guide, Portfolio and Calendar
- Tips and hints from the pilot group
- Share real life examples

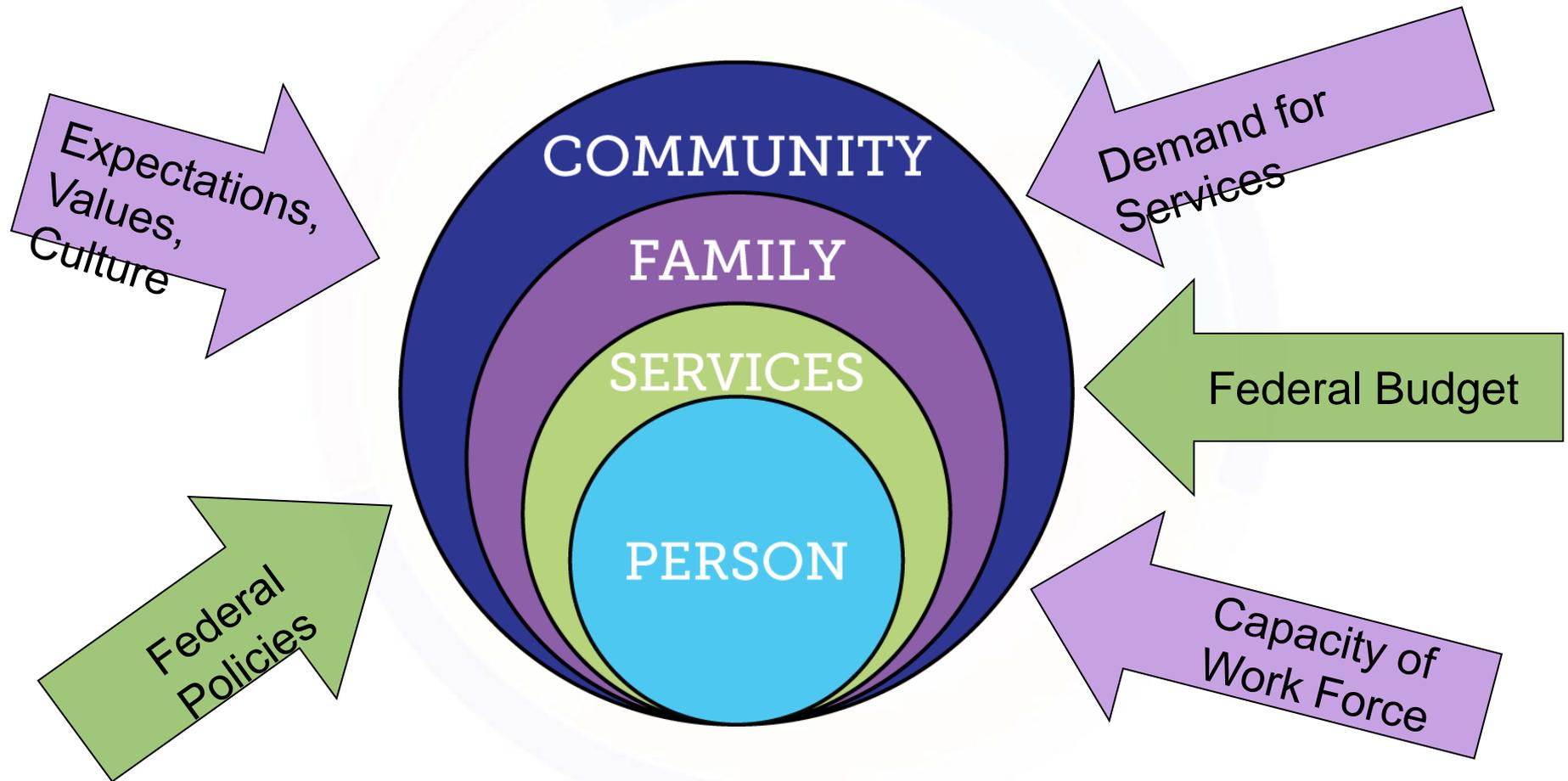




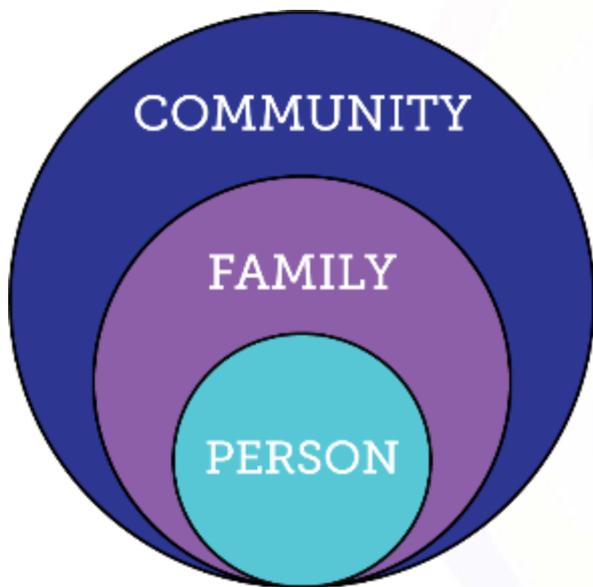
# Guiding Principles of the Charting the LifeCourse Framework



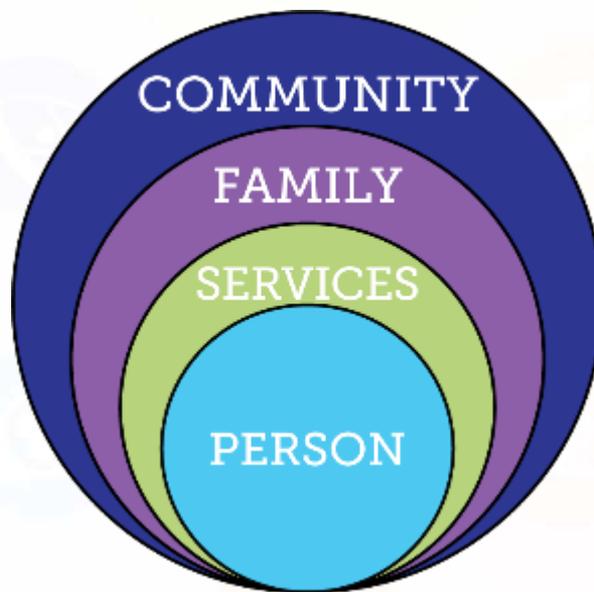
# Current Reality of Services and Supports



# Services and Supports are Evolving



Everyone exists within the context of family and community



Traditional Services

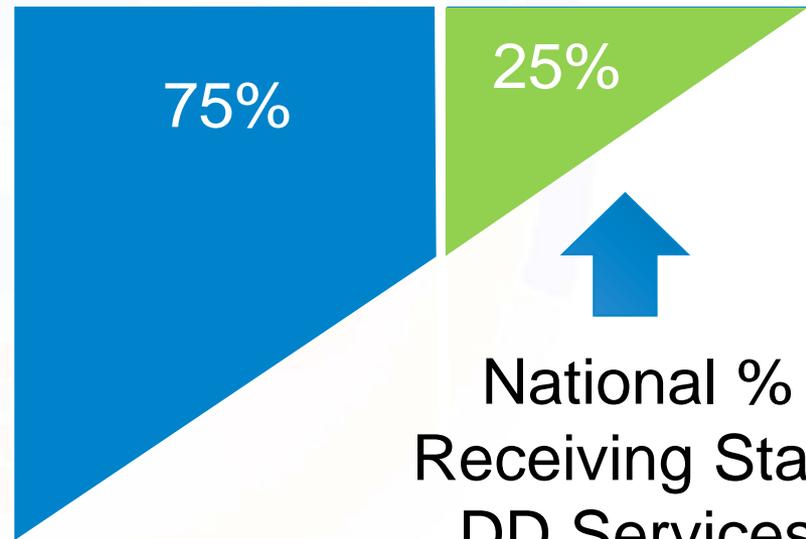
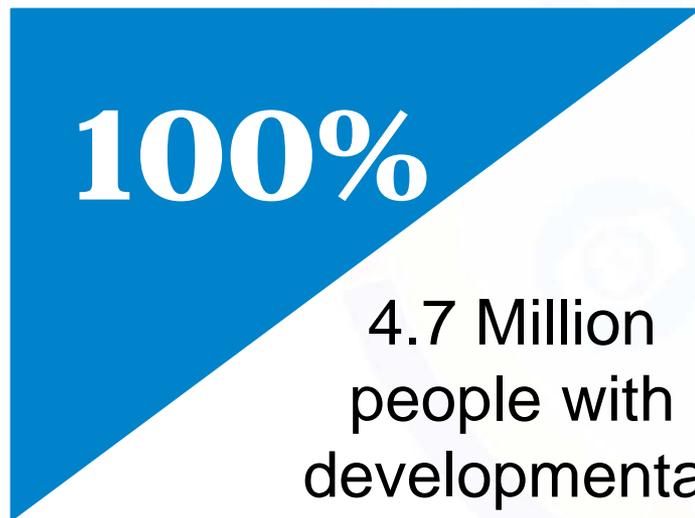
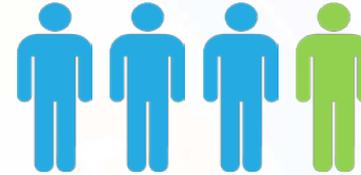


Integrated Services and Supports within context of person, family and community



# National “All” People with I/DD

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%*



# Expanding the Framework to “All”

100%

- All Disabilities
- All Socio-economics
- All Members of Family
- All People Across the Lifespan
- All Types of Organizations
- All Systems

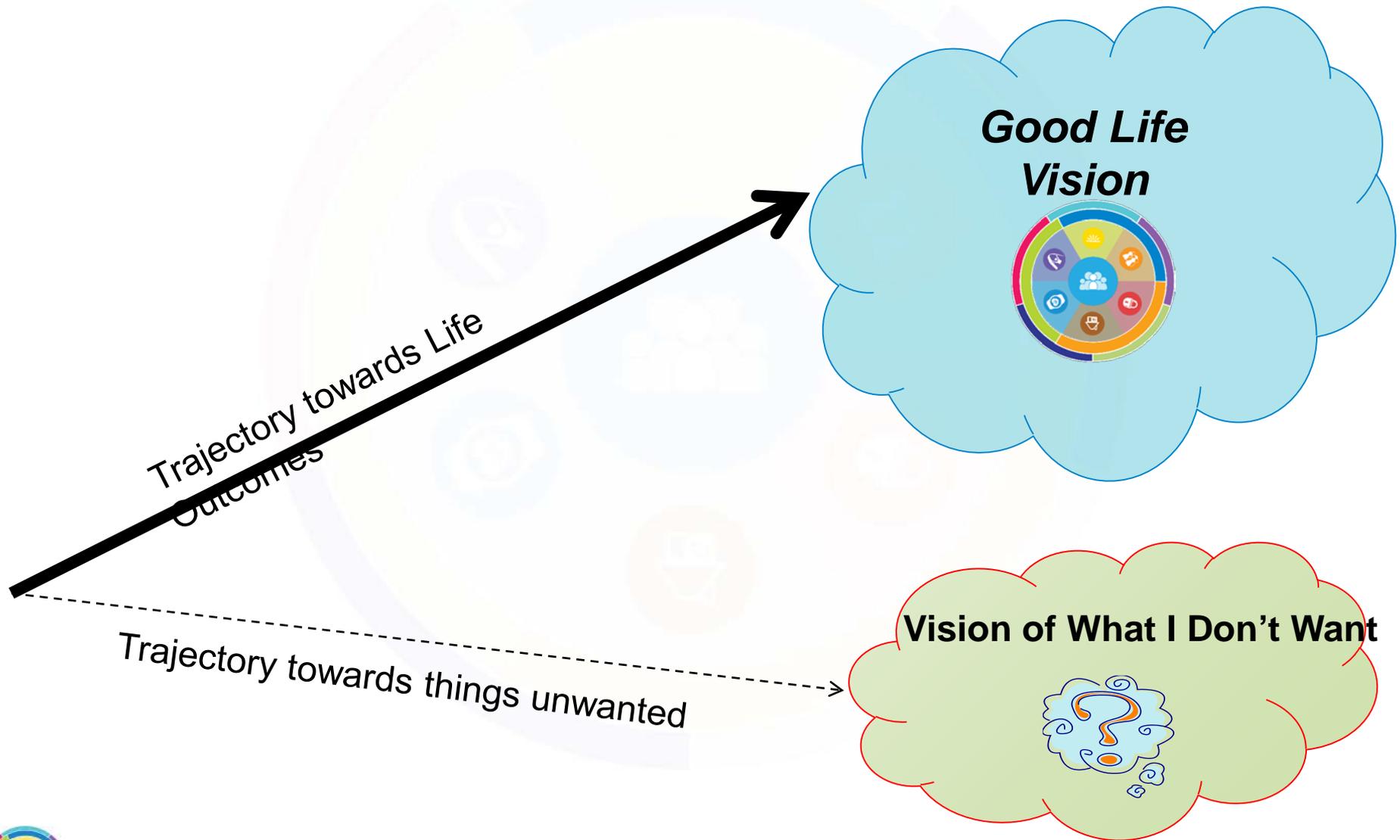




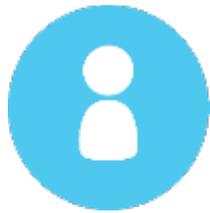
***Core Belief:***  
***All people and their families have the right to live, love, work, play and pursue their life aspirations in their community.***



# Trajectory towards Good Life



# “Good Life for All”

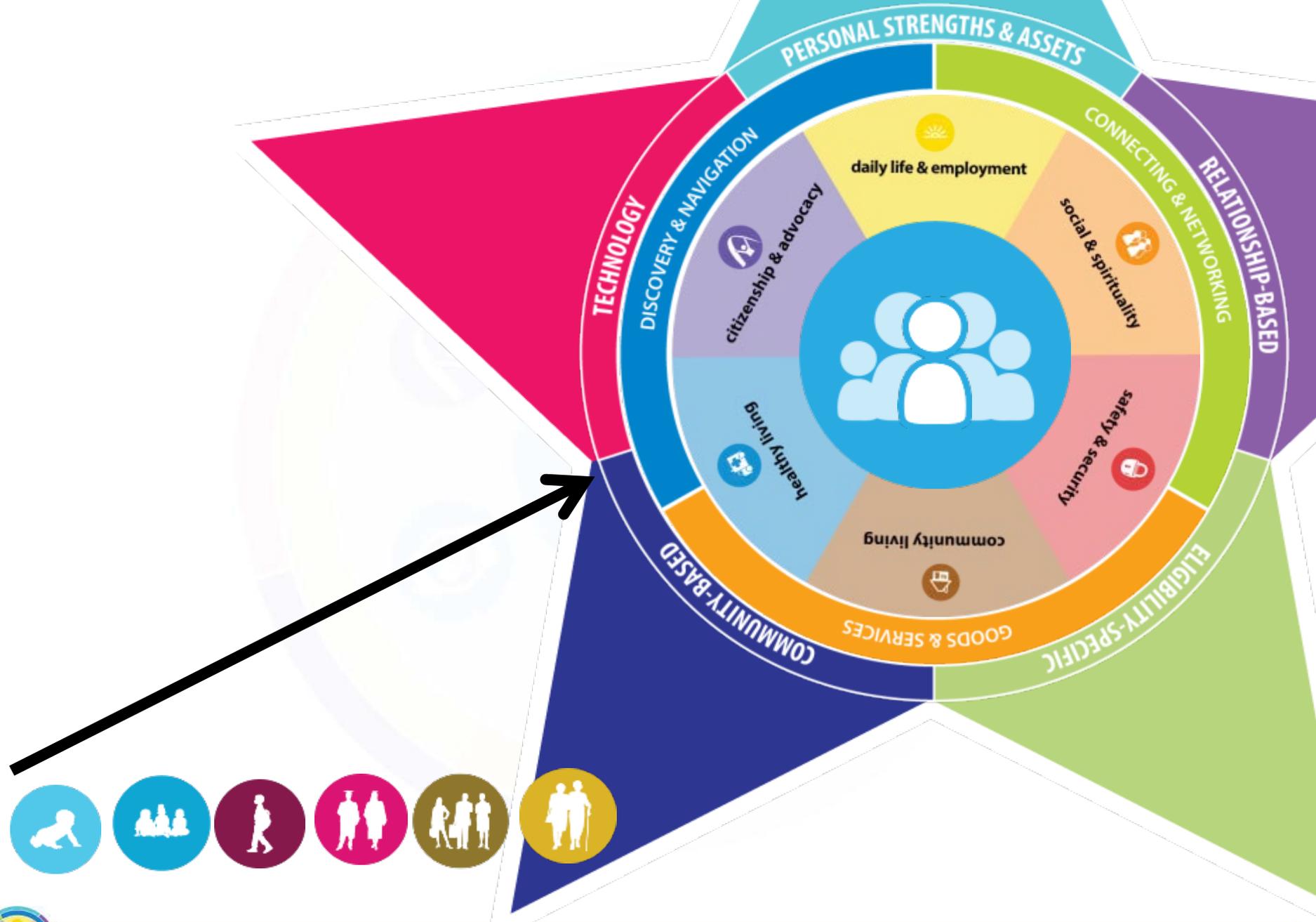


**The Individual** will achieve self-determination, interdependence, productivity, integration, and inclusion in all facets of community life

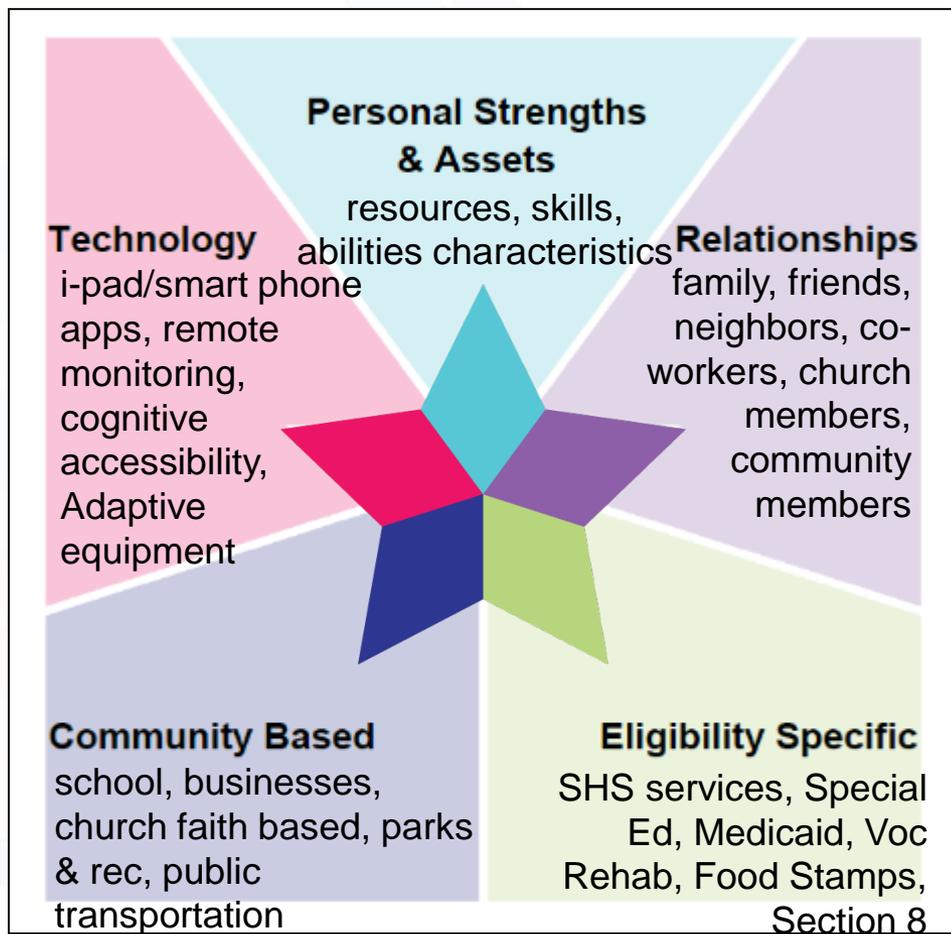
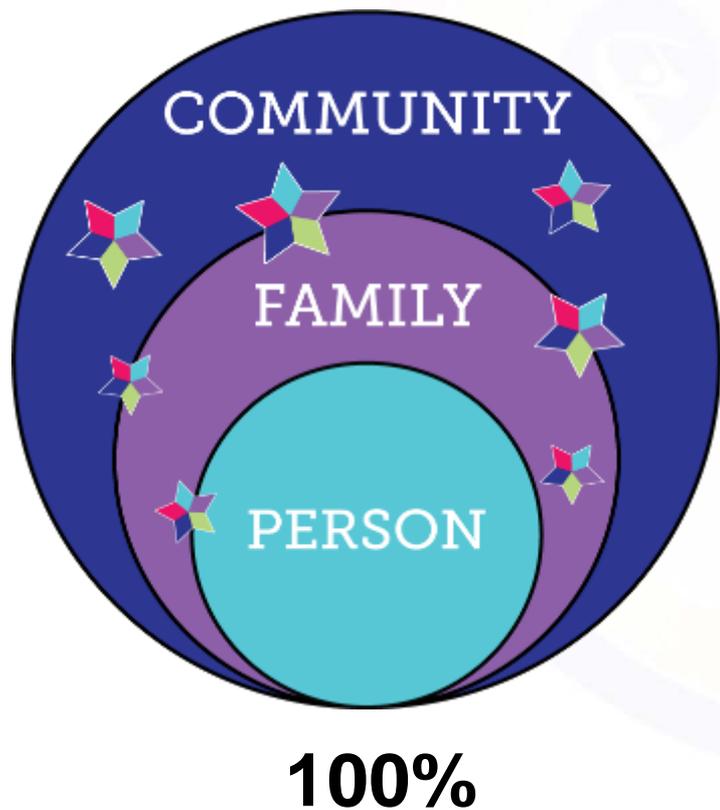


**Families** will be supported in ways that maximize their capacity, strengths, and unique abilities to best nurture, love, and support all individual members to achieve their goals

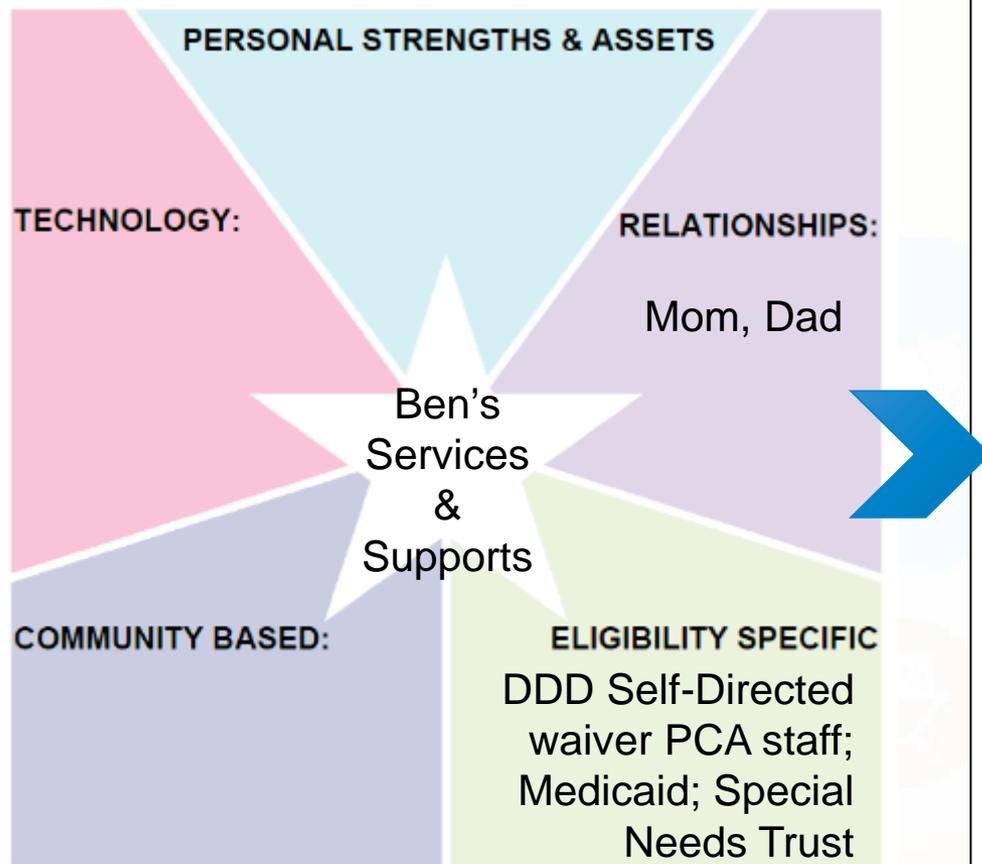




# LifeCourse Integrated Supports STAR



# BEN – before Integrated Supports



**Long Term Service and Support Needs**

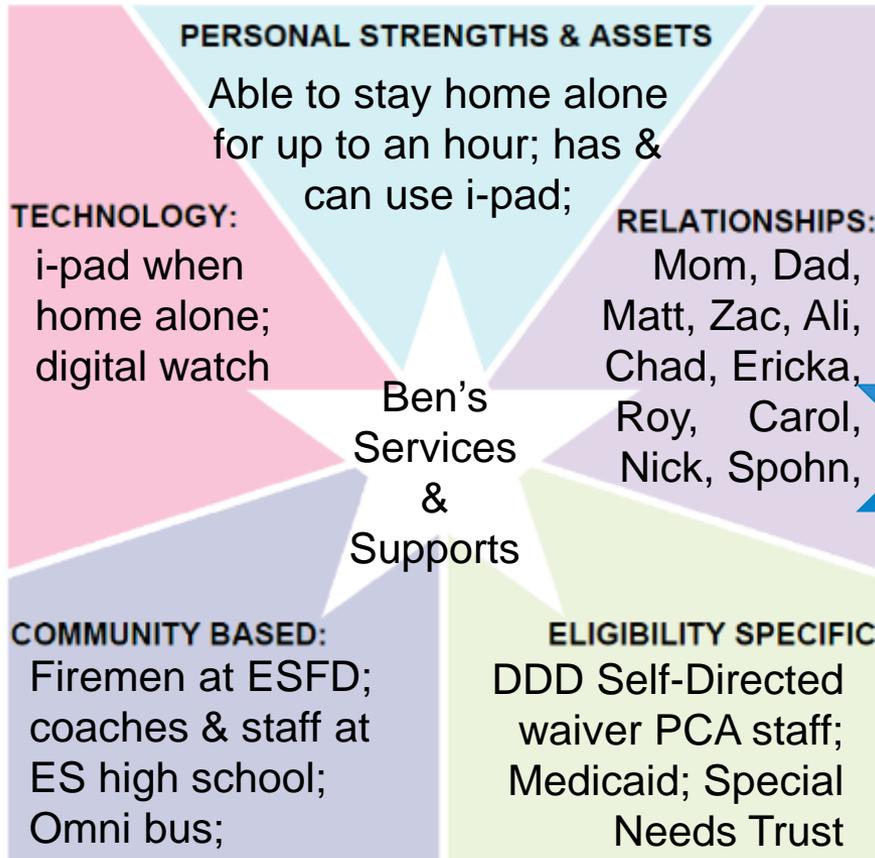
Time	Mon	Tues	Wed	Thurs	Fri	Sat	Sun
6-8:30 AM	Parents get Ben out of bed, assist with breakfast, shower, getting dressed and ready for his day						
8:30-7 AM							
7-7:30 AM							
7:30-8 AM							
8-8:30 AM	Waiver Self-Directed PCA					Parents are weekend support	
8:30-9 AM							
9-9:30 AM							
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							
1-1:30 PM							
1:30-2 PM	Mom and Dad provide all support, including meals, transportation and support for activities, etc.						
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							
6-6:30 PM							
6:30-7 PM	Mom and Dad are overnight staff						
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 @ UMKC-HD, UCEDD

December 2014



# BEN – After Integrated Supports

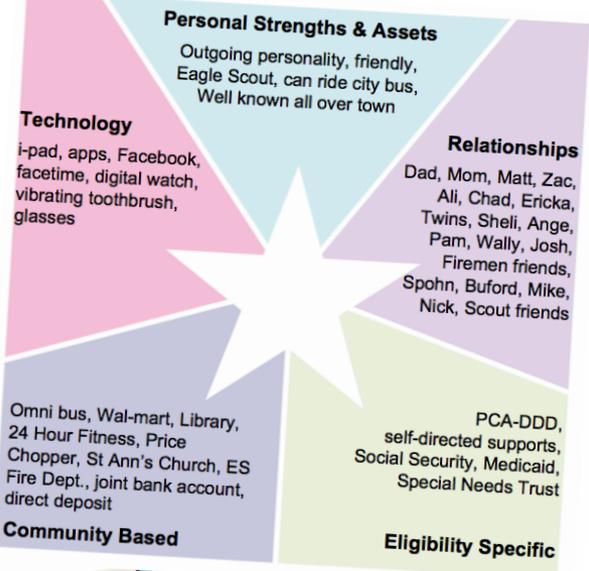


**Long Term Service and Support Needs**

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	Parents support Ben						
7-7:30 AM	Parents support Ben						
7:30-8 AM	Parents support Ben						
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	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
10-10:30 AM							
10:30-11 AM							
11-11:30 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		Home alone while Mom walks
11:30-12 PM							
12-12:30 PM							
12:30-1 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
1-1:30 PM							
1:30-2 PM							
2-2:30 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
2:30-3 PM							
3-3:30 PM							
3:30-4 PM	Volunteer at high school, supported by coaches and friends						
4-4:30 PM	Volunteer at high school, supported by coaches and friends						
4:30-5 PM	Volunteer at high school, supported by coaches and friends						
5-5:30 PM	Volunteer at high school, supported by coaches and friends						
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		Home alone while Mom walks					
6:30-7 PM		Home alone while Mom walks					
7-7:30 PM	WWE With Matt	Horseback Therapy w/ Dad					Nick's Birthday Party with Matt and friends
7:30-8 PM							
8-8:30 PM							
8:30-9 PM	WWE With Matt	Horseback Therapy w/ Dad					Nick's Birthday Party with Matt and friends
9-9:30 PM							
9:30-10 PM							
10 PM-6 AM	Mom and Dad are overnight staff						

Template by Mission Family to Family @ UMKC-IND, UCEDD  
January 2015





**Life Trajectory Worksheet**

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

Chores; Boy Scouts; School Inclusion/Circle of Friends; Birthday parties; Riding bike; Debit card; Family Vacations; Church youth group; Football manager; Homecoming king; Volunteering; High School Diploma

**Special Education low expectations;**  
**Para glued to Ben's side;**  
**Pressure to segregate;**  
**Medication side effects;**  
**Scoliosis;**  
**Seizures;**  
**Physical barriers**

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

Volunteer at fire station; Find more volunteer ops; Work out regularly; Keep in touch w/ friends; Increase home alone time; Go out with friends; Spend daytime hours out of the house; Explore micro-enterprise

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

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 and fit  
Good food; Pepsi  
Basketball  
Royals baseball  
Chiefs football  
Staying active

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

health, heart disease, diabetes;

Write current age here  
**26**

A GOOD LIFE  
The School Bus Stops Coming  
The LifeCourse in Ben's Life  
Ben St. John & Jane St. John  
June 25, 2014



I PIT WHO DO

**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

**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.
- 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.

**WHAT'S IMPORTANT TO ME**

- My family and friends
- Volunteering at the Fire Station, wearing my uniform and badge
- Going to the library
- 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

**Tool for Developing a Vision - Family**

LIFE DOMAIN	My Vision for My Family Member's Future	priority	Current Situation/Things to Work On
Daily Life Employment	What do I think my family member will do during the day in his/her adult life?	1	Priority #1: We need to help Ben figure out how one of his interests can be used to help him start a small business and make money. We also need to explore how to do this and maintain his eligibility for Medicaid. We also need to work with his daytime staff and help them with ideas on ways to get him out of the house more.
Community Living	Where and with whom do I think my family member will live in his/her adult life?	4	Priority #2: We need to take a more active role to help Ben invite friends to do things with him, especially the firemen outside the station.
Social & Spirituality	How will he/she connect with spiritual and leisure activities like friendships & relationships in his/her adult life?	2	Priority #3: Explore buying a medication dispenser that he can start learning how to use while we are around to supervise and help him. We also think it's a good idea for him to start a small container garden to grow some of his own vegetables.
Healthy Living	How will he/she live a healthy lifestyle and manage health care supports in his/her adult life?	3	Priority #4: We would like to finish our basement as a possible apartment for Ben or at least a hangout space where he can spend time with friends away from mom and dad.
Safety & Security	How will he ensure safety from financial, emotional, physical or sexual harm in adult life?		
Citizenship & Advocacy	How can I make sure he/she has the skills, responsibilities, and has control of how his/her civic life is lived as an adult?		
Supports for Family	What will our family need to help support him to live a quality life as an adult?		
Supports & Services	How will he/she be supported in adult life to lead the kind of life he/she wants as independently as possible?		





# Charting the LifeCourse.....

- ⦿ Is about having different conversations
- ⦿ Is a different way of thinking
- ⦿ Is about encouraging high expectations
- ⦿ Is about having life experiences to move the trajectory in the desired direction
- ⦿ Is about integrating LOTS of different kinds of support, and not just having an “all green life”
- ⦿ Isn't JUST about the “tools”
- ⦿ Isn't a “program”



# The Respite Guide: Thinking through “Short Breaks”

**Charting the LifeCourse**

**LIFE DOMAIN**  
ALL Life Domains

**LIFE STAGE**  
ALL Stages

**Respite:  
Short Breaks for Caregivers**

Being a caregiver can be one of the most rewarding and most challenging times we face. In order to continue to care for family members who require additional support, we must remember to care for ourselves as well.

This guide is meant to help caregivers and those who support them to understand the meaning and importance of respite/short breaks, see real life examples, understand the possibilities and options that exist for respite, within and outside the formal, paid service system, and create a successful plan that uses these short breaks to enhance the lives of all family members.

UMKC INSTITUTE FOR HUMAN DEVELOPMENT, UCEDD

DEVELOPED BY  
**MISSOURI  
FAMILY TO FAMILY**  
UMKC INSTITUTE FOR HUMAN DEVELOPMENT | UCEDD

IN PARTNERSHIP WITH  
**ARCA** National Respite Network  
*And Resource Center*





# Benefits to ALL family members

Some benefits of taking short breaks include<sup>1,2,3,4</sup>:



## FAMILY UNIT

- More time spent together
- Improved relationship quality with other children, spouse or partner
- Improved relationship with, and better able to relate to, the care recipient
- Ability to live 'a more ordinary life'



## CAREGIVER

- Have time for everyday activities, like sleeping or running errands, and for taking care of own health
- More time to spend with other family members, such as a spouse or partner or children
- Freedom to do something for themselves, like visit friends or read a book
- Better overall physical and emotional health
- Reduced stress, exhaustion, and anxiety
- Feeling a 'sense of renewal' or relief



## CARE RECIPIENT

- Meaningful, and potentially new, experiences
- Greater independence by spending time away from the caregiver
- Socialization and keeping active (depending on activities during respite time)
- Improved interactions with caregiver (because caregiver is less stressed)
- Increased happiness and self-esteem
- Improved physical and mental health

1. Harper, A., Dyches, T. T., Harper, J., Roper, S. O., & South, M. (2013). Respite care, marital quality, and stress in parents of children with autism spectrum disorders. *Journal of autism and developmental disorders*, 43(11), 2604-2616.

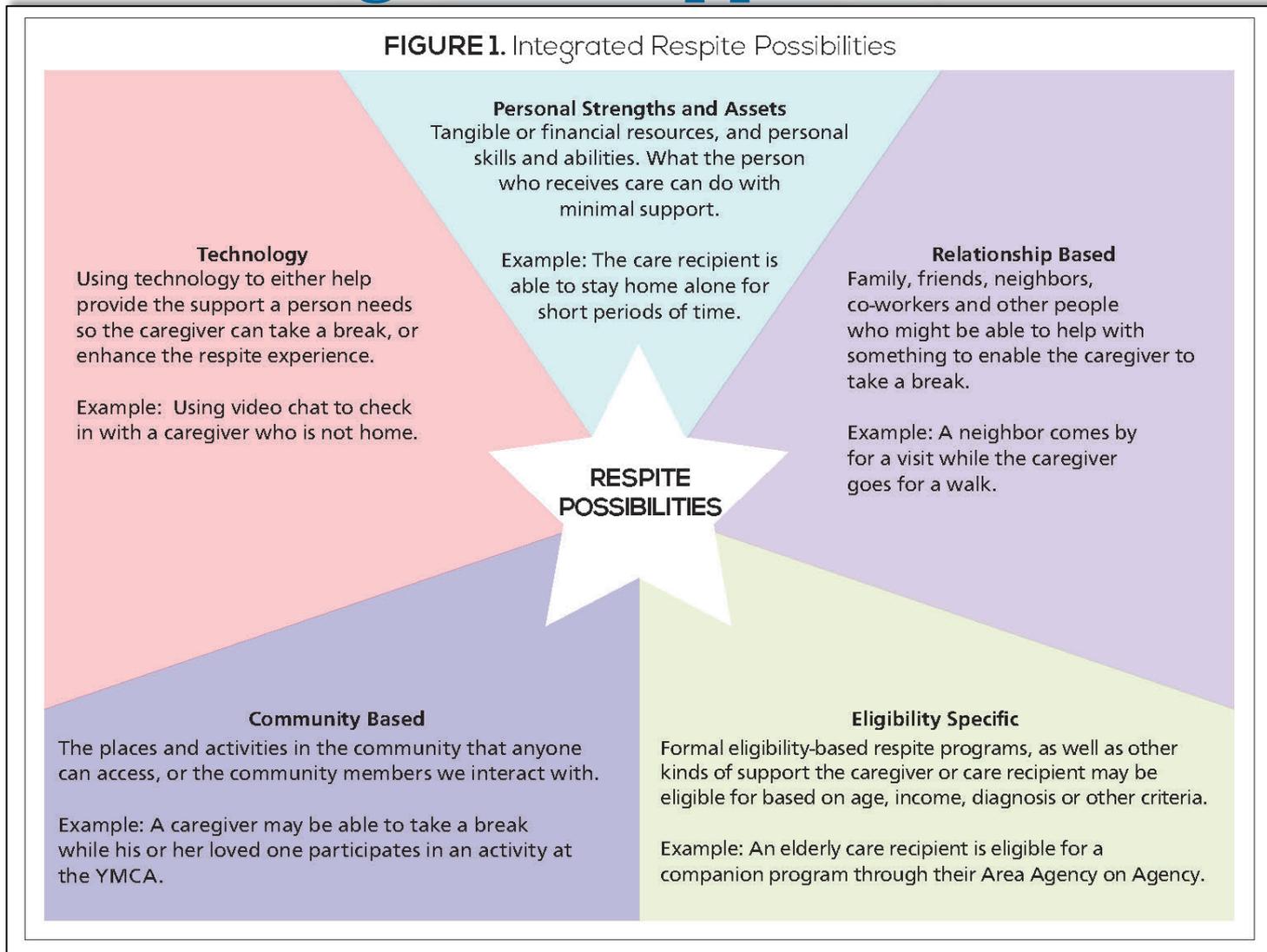
2. Neville, C., Beattie, E., Fielding, E., & MacAndrew, M. (2015). Literature review: use of respite by carers of people with dementia. *Health & social care in the community*, 23(1), 51-63.

3. Robertson, J., Hatton, C., Wells, E., Collins, M., Langer, S., Welch, V., & Emerson, E. (2011). The impacts of short break provision on families with a disabled child: an international literature review. *Health & social care in the community*, 19(4), 337-371.

4. Theis, S. L., Moss, J. H., & Pearson, M. A. (1994). Respite for caregivers: An evaluation study. *Journal of Community Health Nursing*, 11(1), 31-44.



# Exploring Respite Possibilities with the Integrated Supports Star





### Life Trajectory Worksheet: Exploring Respite

<p><b>What's Working?</b> Past experiences where taking a break was successful or helpful</p>	<p><b>What Would It Take?</b> What would need to happen to have a positive caregiver break?</p>
<p><b>What's Not Working?</b> Past experiences where taking a break didn't work out well</p>	<p><b>Barriers to Overcome or Avoid?</b> What might make it hard to take a break from caregiving?</p>

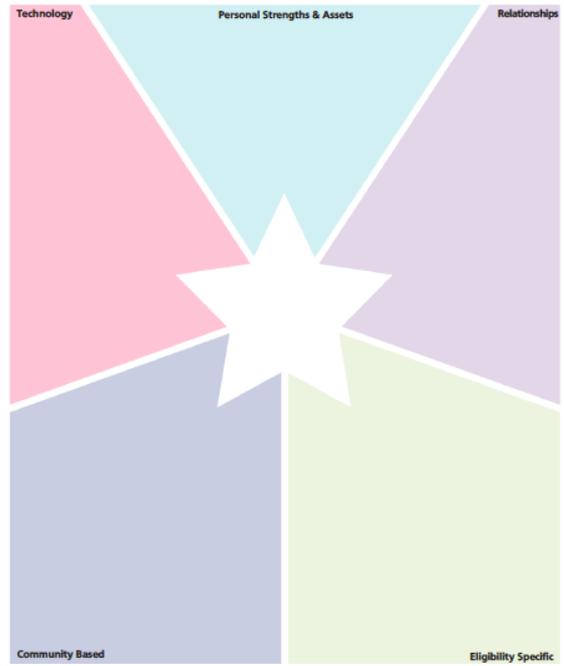
VISION FOR A GOOD RESPITE

For the Care Recipient	VISION FOR GOOD RESPITE	For the Caregiver
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WHAT WE DON'T WANT

For the Care Recipient	NOT GOOD RESPITE	For the Caregiver
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### Charting the LifeCourse Integrated Supports Star: Mapping Respite Supports



Access the LifeCourse framework and tools at [lifecoursetools.com](http://lifecoursetools.com)

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

OCTOBER 2017

### Charting the LifeCourse: Exploring Respite

**What is going on in my life?**

**How would taking short breaks HELP me and the person I provide care to?**

**Making short breaks happen**

<p>What would I do if I had a break from caregiving?</p>	<p>Who would I spend time with during a break from caregiving?</p>
--	--

What needs to be in place so I am comfortable leaving the person I am caring for?

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

OCTOBER 2017





# How can the Respite Portfolio be used?

- ⦿ Problem solve during planning meetings on how to meet needs of all (loved one, caregiver, other family members)
- ⦿ Train/coach person(s) providing respite (in/out of home)
- ⦿ Plan or coordinate logistics of day-to-day activities
- ⦿ Help educate community members on how to support loved one



# Caregiver “Snapshot”



## PLANNING RESPITE

What's going on now?



Having a clear picture of your current situation can help you know where you are starting, how using respite could improve your life, think about what you would do with a short break, and identify what needs to change.

To begin, you will need the blank LifeCourse Respite portfolio that came with this guide or you downloaded at [lifecoursetools.com/respites](http://lifecoursetools.com/respites).

The first page of the portfolio is designed to provide a snapshot of your current situation related to respite as well as help you identify the benefits of respite to you, your loved one and other members of your family, if you are able to take a break from your caregiver role while your loved one is in trusted care. Take a few moments to reflect or even have honest conversations with other family members about the impact of caregiving and consider your own needs as well as those of others in your family. Try to let go of any guilt and think factually about your unique situation.

### What is going on in my life?

List some of the ways that caregiving impacts you, your loved one, and your family as a whole. Think about factors that are unique to your situation.

Examples: loved one requires 24/7 care; being sole caregiver; juggling care-giving with full time job; lack of sleep; caregiver health issues.

### How would taking short breaks HELP me and the person I provide care to?

List some of the SPECIFIC benefits to you, your loved one, and your family.

Examples: relieve stress; improve caregiver mental health; improve relationship of caregiver and loved one; caregiver keeping their job.

### Making Short Breaks Happen

#### What would I do if I had a break from caregiving?

List ideas of places you might want to go, activities in which you'd like to participate, or hobbies you might pursue.

Examples: attend faith or other community events; host sleepovers or family events; take a yoga class.

#### Who would I spend time with during a break from caregiving?

Think about who you would like to spend time with if you had respite from caregiving.

Examples: reconnect with family or friends; make a new friend; have some alone time.

#### What needs to be in place so I am comfortable leaving the person I am caring for?

List some of the conditions/specific supports that you and your loved one feel are necessary to feel comfortable being apart and truly enjoying a short break from caregiving.

Examples: specific training needed; unique care needs; preferred way of being supported.



# What's going on now?

## What is going on in my life?

List some of the ways that caregiving impacts you, your loved one, and your family as a whole. Think about factors that are unique to your situation.

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# How can Respite help us?

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# Planning what I could do if I had a respite break

## Making Short Breaks Happen

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# Who would I spend time with?

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# “Must Haves” to make it work

## Making Short Breaks Happen

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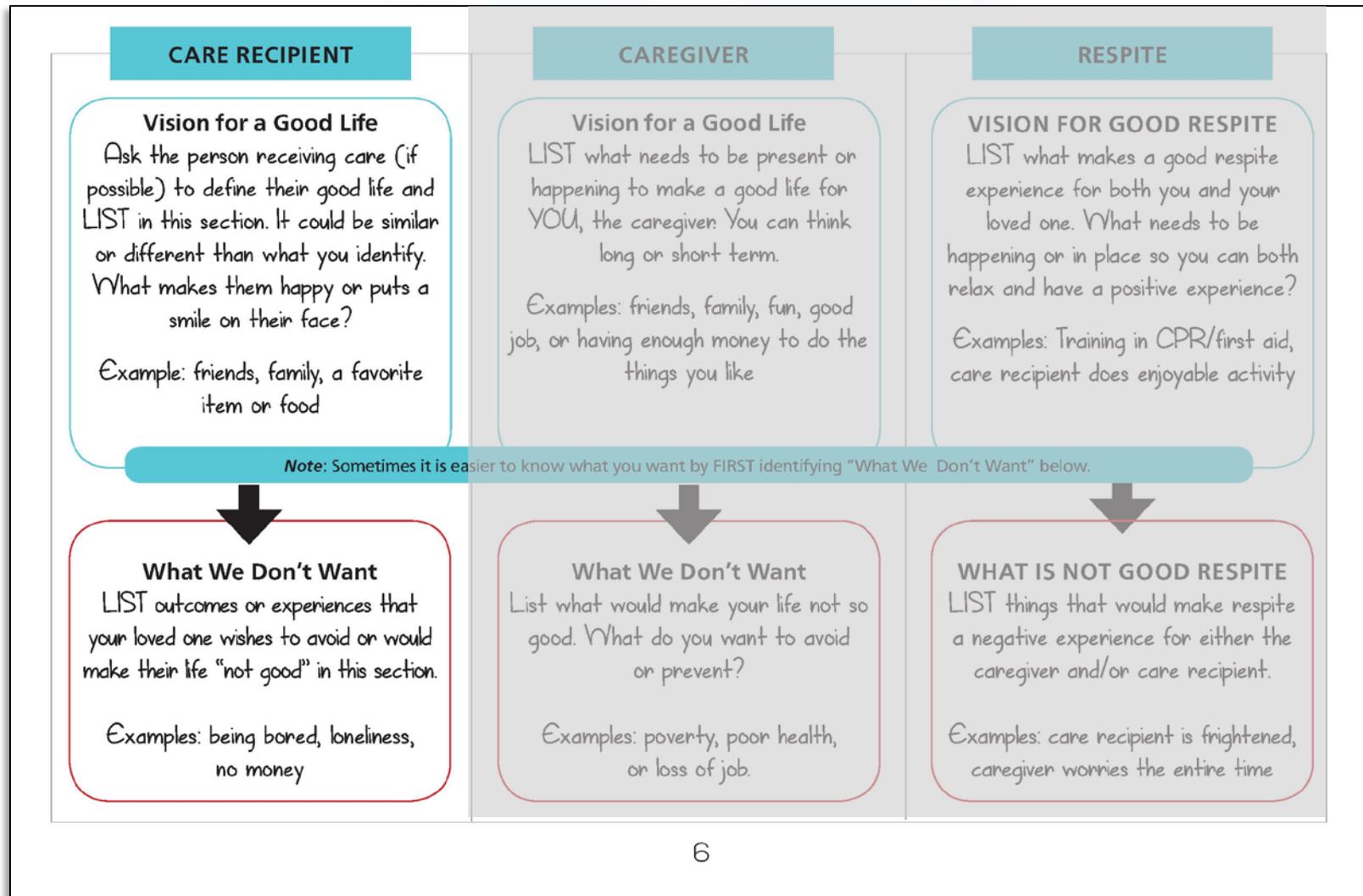
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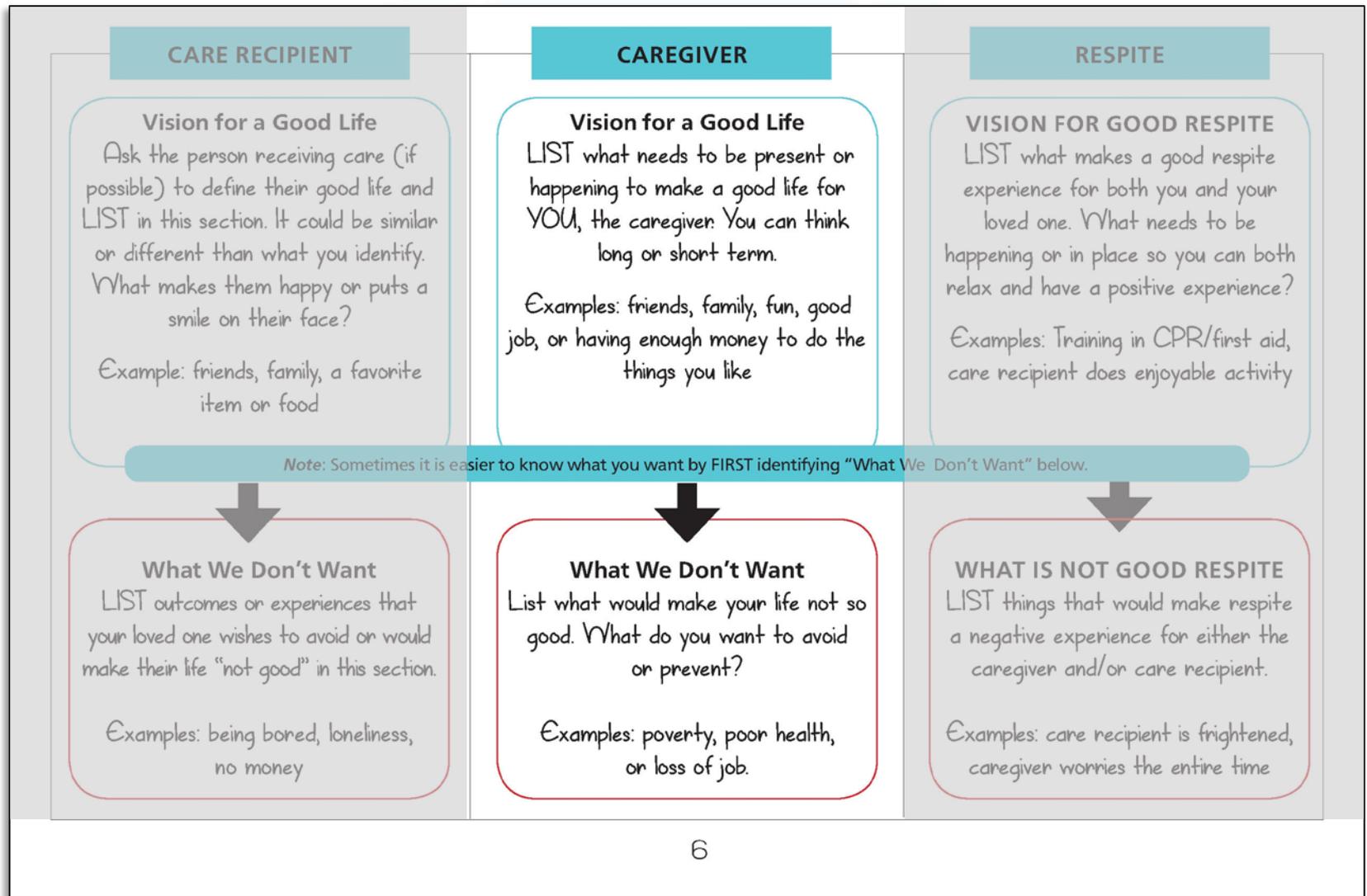
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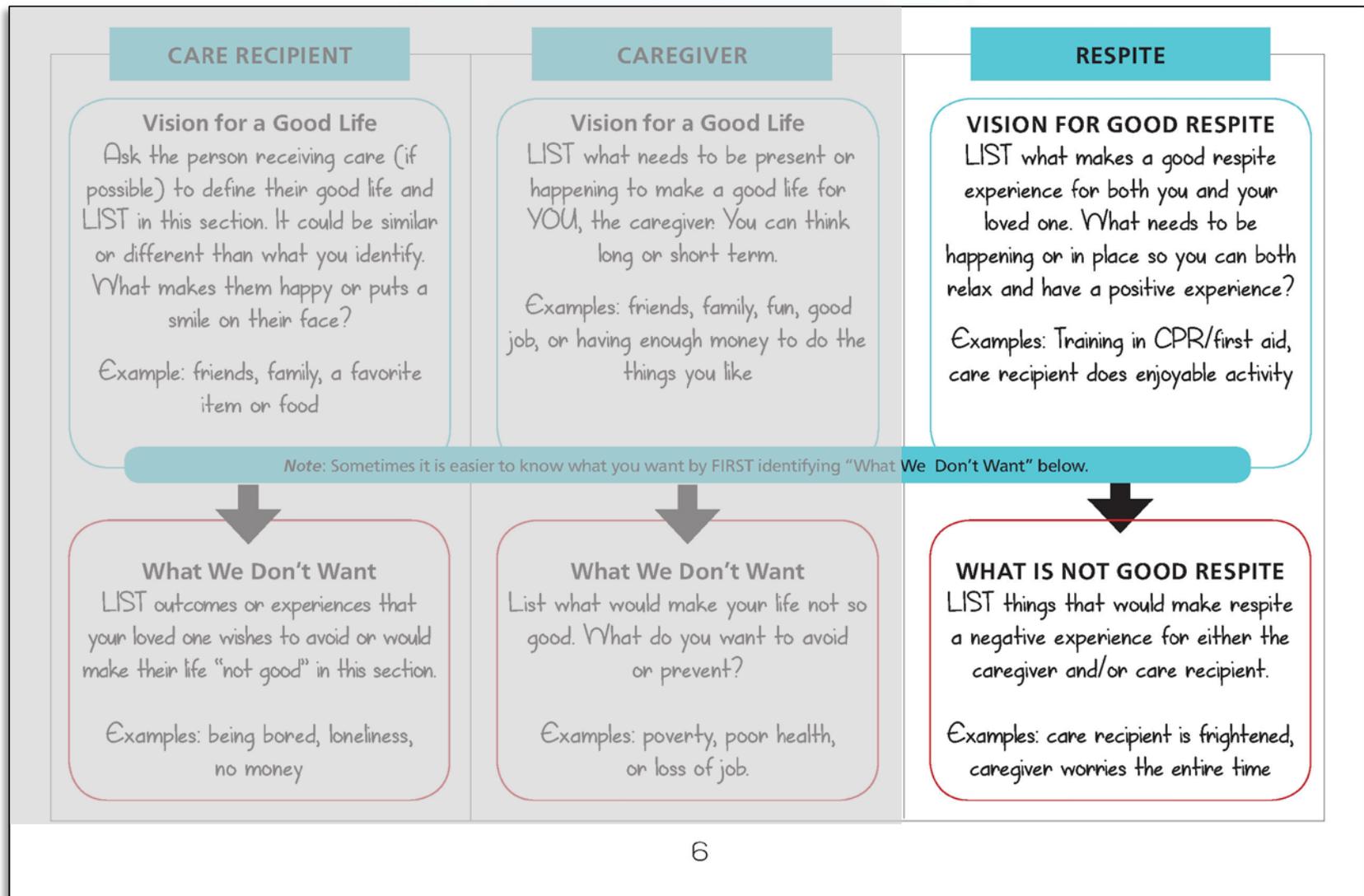
# Care Recipient Vision



# Caregiver Vision



# Vision for Respite



# Trajectory

## PLANNING RESPITE

What is our trajectory?



### Trajectory

The 'trajectory' is the path in life that will either lead you toward your good life or push you toward what you don't want. Life experiences and events effect the trajectory. Some experiences help move the trajectory toward the desired good life outcomes. Others might move the trajectory toward unwanted results. It's important to reflect on past life experiences, both positive and negative, to know what to continue or build upon, and what to avoid or stop doing. With every choice, decision, experience, or interaction with others, consider which direction it nudges the trajectory. You will need your Respite Trajectory Worksheet (pictured).

Planning is beneficial at any age. First, on your Respite Trajectory Worksheet, write your loved one's current age or the date in the box under the icon of the blue person.

**FIGURE 3. RESPITE TRAJECTORY WORKSHEET**

The worksheet is divided into four quadrants around a central icon of a blue person. The top-left quadrant is titled 'What's worked?' and contains a large red 'X' and the text 'Start Here'. The top-right quadrant is titled 'What's not a take?' and contains a box for 'What's your goal?'. The bottom-left quadrant is titled 'What's not worked?' and contains a box for 'What's your goal?'. The bottom-right quadrant is titled 'WHAT WE DON'T WANT' and contains two boxes for 'For the Care Recipient' and 'For the Caregiver'. At the bottom of the worksheet, there are several icons representing different aspects of care and support.



# Life Experiences

## Past Experiences

### What's working?

Reflecting on past experiences that were positive can help you to know what worked well and plan more positive experiences in the future. LIST times you felt comfortable taking a break, things that resulted in a positive respite experience, or situations where your loved one was successfully supported by someone other than you, the caregiver.

### What's not working?

It is also important to acknowledge past barriers to good respite or what has moved you or your loved one toward unwanted results. By knowing what didn't work in the past, you can identify situations to avoid. LIST past negative experiences, situations that made you feel uneasy about taking a break, or resulted in a stressful situation for you or your loved one.

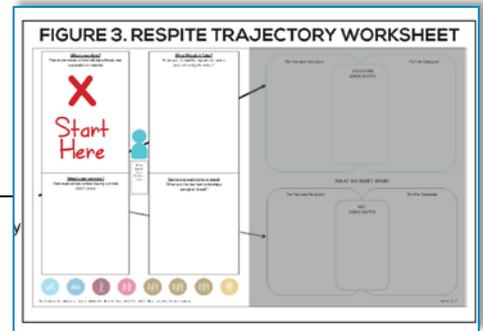
## Current and Future Experiences

### What would it take?

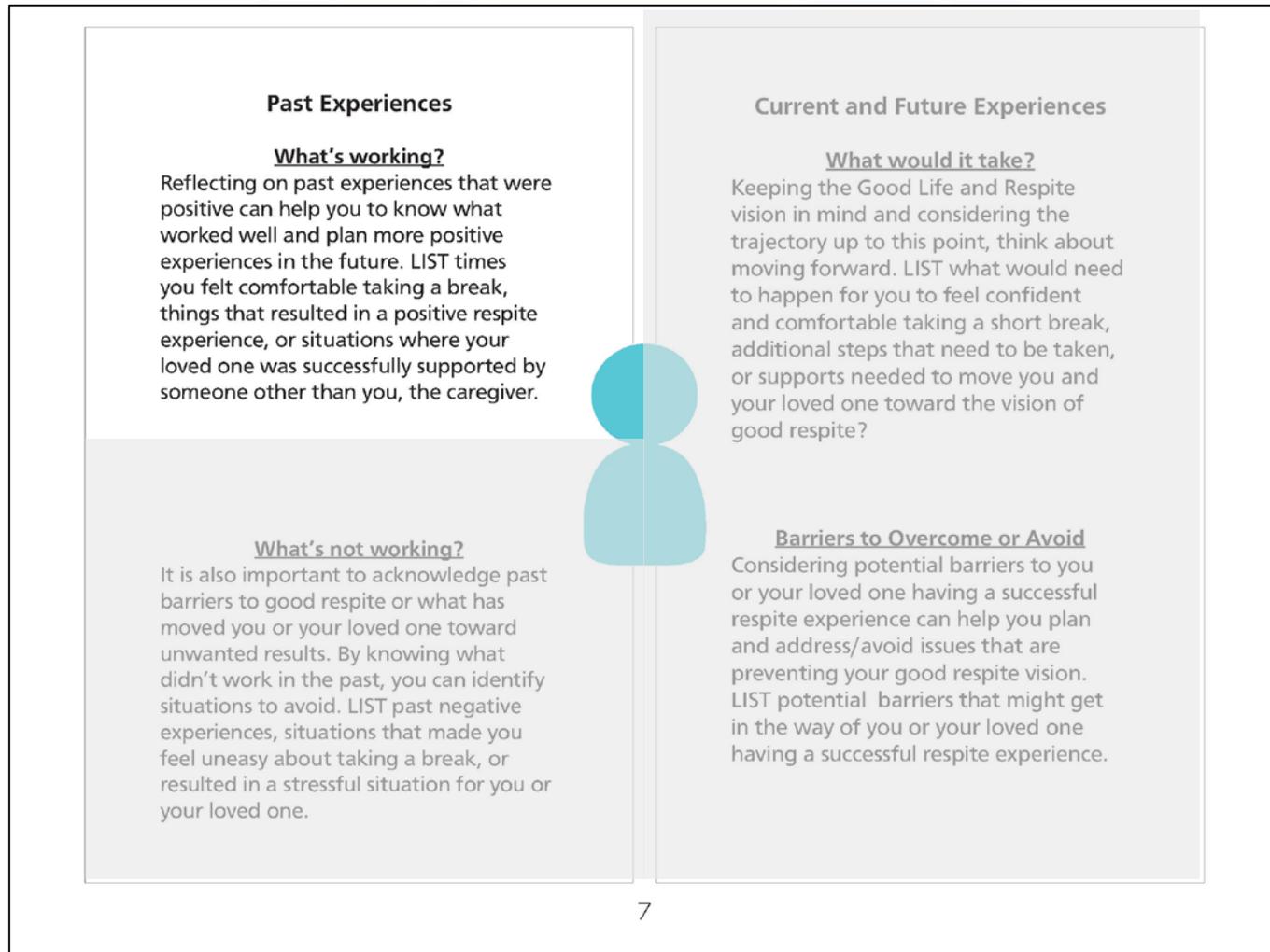
Keeping the Good Life and Respite vision in mind and considering the trajectory up to this point, think about moving forward. LIST what would need to happen for you to feel confident and comfortable taking a short break, additional steps that need to be taken, or supports needed to move you and your loved one toward the vision of good respite?

### Barriers to Overcome or Avoid

Considering potential barriers to you or your loved one having a successful respite experience can help you plan and address/avoid issues that are preventing your good respite vision. LIST potential barriers that might get in the way of you or your loved one having a successful respite experience.



# Past Experiences: What's Working



**Past Experiences**

**What's working?**  
Reflecting on past experiences that were positive can help you to know what worked well and plan more positive experiences in the future. LIST times you felt comfortable taking a break, things that resulted in a positive respite experience, or situations where your loved one was successfully supported by someone other than you, the caregiver.

**What's not working?**  
It is also important to acknowledge past barriers to good respite or what has moved you or your loved one toward unwanted results. By knowing what didn't work in the past, you can identify situations to avoid. LIST past negative experiences, situations that made you feel uneasy about taking a break, or resulted in a stressful situation for you or your loved one.

**Current and Future Experiences**

**What would it take?**  
Keeping the Good Life and Respite vision in mind and considering the trajectory up to this point, think about moving forward. LIST what would need to happen for you to feel confident and comfortable taking a short break, additional steps that need to be taken, or supports needed to move you and your loved one toward the vision of good respite?

**Barriers to Overcome or Avoid**  
Considering potential barriers to you or your loved one having a successful respite experience can help you plan and address/avoid issues that are preventing your good respite vision. LIST potential barriers that might get in the way of you or your loved one having a successful respite experience.

7



# Past Experiences: What's NOT Working

## Past Experiences

### What's working?

Reflecting on past experiences that were positive can help you to know what worked well and plan more positive experiences in the future. LIST times you felt comfortable taking a break, things that resulted in a positive respite experience, or situations where your loved one was successfully supported by someone other than you, the caregiver.

### What's not working?

It is also important to acknowledge past barriers to good respite or what has moved you or your loved one toward unwanted results. By knowing what didn't work in the past, you can identify situations to avoid. LIST past negative experiences, situations that made you feel uneasy about taking a break, or resulted in a stressful situation for you or your loved one.

## Current and Future Experiences

### What would it take?

Keeping the Good Life and Respite vision in mind and considering the trajectory up to this point, think about moving forward. LIST what would need to happen for you to feel confident and comfortable taking a short break, additional steps that need to be taken, or supports needed to move you and your loved one toward the vision of good respite?

### Barriers to Overcome or Avoid

Considering potential barriers to you or your loved one having a successful respite experience can help you plan and address/avoid issues that are preventing your good respite vision. LIST potential barriers that might get in the way of you or your loved one having a successful respite experience.



# Current and Future Experiences: What would it take?

## Past Experiences

### What's working?

Reflecting on past experiences that were positive can help you to know what worked well and plan more positive experiences in the future. LIST times you felt comfortable taking a break, things that resulted in a positive respite experience, or situations where your loved one was successfully supported by someone other than you, the caregiver.

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## Current and Future Experiences

### What would it take?

Keeping the Good Life and Respite vision in mind and considering the trajectory up to this point, think about moving forward. LIST what would need to happen for you to feel confident and comfortable taking a short break, additional steps that need to be taken, or supports needed to move you and your loved one toward the vision of good respite?

### Barriers to Overcome or Avoid

Considering potential barriers to you or your loved one having a successful respite experience can help you plan and address/avoid issues that are preventing your good respite vision. LIST potential barriers that might get in the way of you or your loved one having a successful respite experience.



# Current and Future Experiences

## Barriers to Overcome or Avoid



Past Experiences	Current and Future Experiences
<p><b><u>What's working?</u></b></p> <p>Reflecting on past experiences that were positive can help you to know what worked well and plan more positive experiences in the future. LIST times you felt comfortable taking a break, things that resulted in a positive respite experience, or situations where your loved one was successfully supported by someone other than you, the caregiver.</p>	<p><b><u>What would it take?</u></b></p> <p>Keeping the Good Life and Respite vision in mind and considering the trajectory up to this point, think about moving forward. LIST what would need to happen for you to feel confident and comfortable taking a short break, additional steps that need to be taken, or supports needed to move you and your loved one toward the vision of good respite?</p>
<p><b><u>What's not working?</u></b></p> <p>It is also important to acknowledge past barriers to good respite or what has moved you or your loved one toward unwanted results. By knowing what didn't work in the past, you can identify situations to avoid. LIST past negative experiences, situations that made you feel uneasy about taking a break, or resulted in a stressful situation for you or your loved one.</p>	<p><b><u>Barriers to Overcome or Avoid</u></b></p> <p>Considering potential barriers to you or your loved one having a successful respite experience can help you plan and address/avoid issues that are preventing your good respite vision. LIST potential barriers that might get in the way of you or your loved one having a successful respite experience.</p>



# Mapping Respite Support Options

## Integrated Star Worksheet

In this section, you will create your own Respite Integrated Supports Star “bank.”

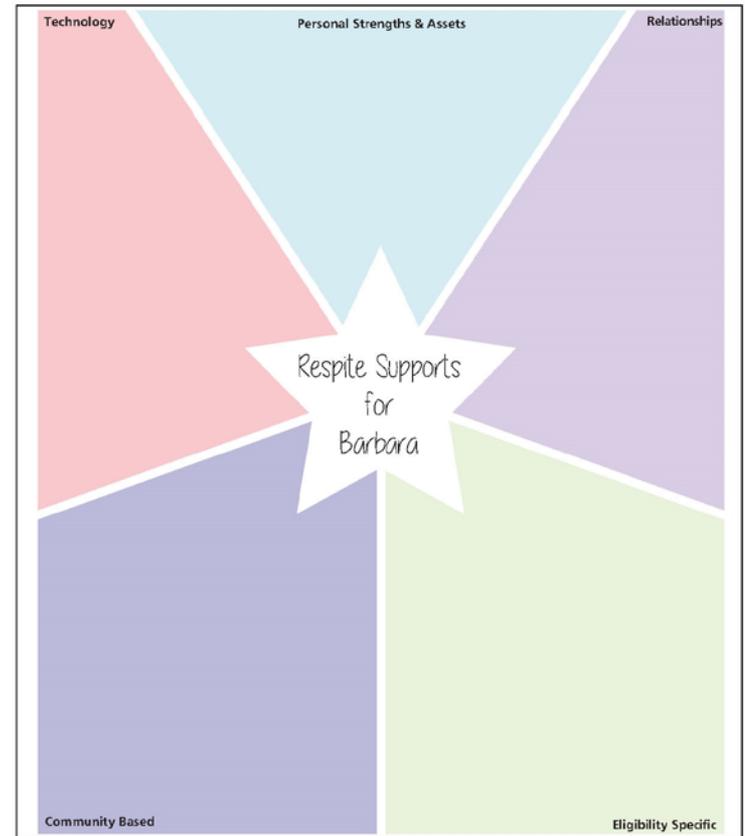
Completing the star will help you think about your own life and the supports and resources you have available in each of the star categories that could help make respite possible or a better experience for you and your loved one.

You will need your LifeCourse Respite Portfolio, turning to the Integrated Star Worksheet on the back page.

First, in the center of the star, write “Respite Supports for” and the care recipient’s name.

The descriptions and examples that follow in this section will guide you through each part of the Integrated Supports Star.

FIGURE 4. MAPPING SUPPORTS FOR RESPITE



# Personal Assets and Strengths

## Personal Assets and Strengths

It's important to consider what the caregiver and the person receiving care bring to the table – what are the possessions, assets, skills, traits, knowledge and talents of you and your loved one that could make respite possible and a positive experience?

List you and your loved one's knowledge, skills, personality traits, and material or financial resources that enable or could enable you to take a break in the light blue part of the star.

### Examples:

- ability to stay home alone
- ability to dial 911
- doesn't wander
- knows/communicates address
- ability to use public transportation
- money to pay for respite



# Technology

## Technology

Everyone uses technology as part of daily life these days. How can technology be used to help make respite possible for you and a positive experience for your loved one?

List the technology you and/or your loved one have available or use now in the pink part of the star. Remember, technology can be high tech, like a smart phone, or low tech, like a digital watch.

### Examples:

- Medical Alert or Safety ID
- Remote monitoring
- Facetime/Skype
- GPS locator
- Smart device (phone or tablet)
- Computer



# Relationships

## Relationships

Most of us rely on others in our life to give us advice, lend a hand, or be there for us when we need some support. How can relationships help you take a respite break and/or make it a positive experience for the care recipient?

List the people in your life (and if you'd like, their relationship to you or your loved one) right now that either do or could do even one thing that would enable you to take a short break in the purple part of the star.

### Examples:

- Immediate or extended family members
- Friends
- Volunteers/ Mentors/Interns
- Teachers/Coaches
- Spiritual leaders and fellow worship congregants
- Co-workers, employers, carpool participants
- Other caregivers



# Community-Based Resources

## Community-Based Resources

There are many places and activities that can be accessed simply by being a member of that particular community. Could participating in a community activity provide an opportunity for a caregiver break?

In the dark blue part of the star, list the places you and/or the person receiving care go and activities you participate in.

### Examples:

- Parks and recreation, community center
- Public transportation
- Schools, camps, faith-based resources
- Hospice
- Parent/family cooperative
- Sitter-companion services



# Eligibility Specific

## Eligibility Specific

Eligibility specific supports are resources the caregiver or care recipient may be able to receive because of income, age, diagnosis, disability, or other criteria. This might include formal respite supports, but can also consist of other options either or both of you might be eligible to receive based on various factors.

List the supports both you and the person receiving care are eligible for or currently receive in the green part of the star.

### Examples:

- Medicaid, Medicaid waiver, SSI, SSDI
- Rehabilitative services
- Center-based respite, ie: adult day centers
- Family care homes or host homes
- Home-based service programs, home health aides
- State lifespan respite care programs
- Older American's Act – Family Caregiver Support Program
- Respite voucher
- Consumer directed respite



# PLANNING RESPITE

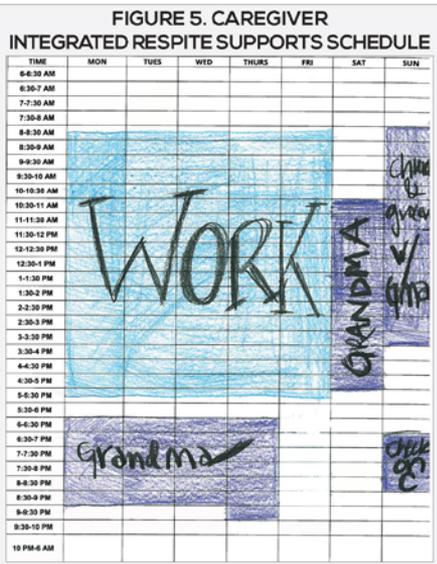
Can we find time?



You and your loved one have worked hard to make plans for successful respite and identify resources that can help you reach your vision of good respite. With today's busy lifestyles, you may feel it is difficult to fit respite time into your schedule. Sometimes, you may not even realize how much you could really use some respite time in your life. This section will show you two ways you can use the Integrated Respite Support Schedule. If you don't already have one, download a copy for free at [lifecoursetools.com](http://lifecoursetools.com). Since the colors used to color the schedule are the same as the Integrated Supports Star colors, you may want to have your Respite Integrated Star bank closeby.

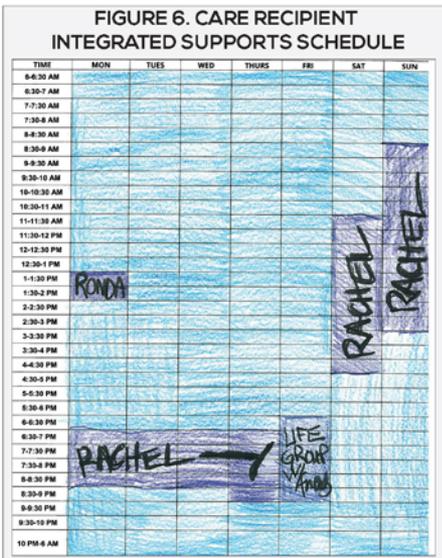
The schedule can help you see the need to take a break as well as find time to incorporate respite into your life. Fill out your own schedule as it is now so you have a good visual of when you are providing care and when you are meeting other life obligations.

The schedule can also help you see how and when your loved one is supported by yourself and others, and find windows of time when it might make sense for you to create respite opportunities. Fill in your loved one's schedule and write who supports him/her during specific times. It is helpful to shade the timeslots the same color as the type of support it corresponds to on the Integrated Supports Star.



Example: If you work 8:30am to 5:00pm each day, color in those times as shown in the example above on the left. If you provide care for your loved one evenings and weekends, shade those times as shown. Maybe you have other family that you need to do something with. Add those times to the schedule (and if it overlaps some of the other times, that's okay), as that will help identify times when you need support with caregiving.

You can see in this example, the caregiver has little time to do other things she needs to do, and illustrates the need for finding time and supports for respite.



Example: If your loved one stays home by themselves during the day Monday through Friday, shade that time light blue, as that shows a personal strength. If they have a weekly meeting (like a Bible study or card game), shade that time based on who is supporting them.

Once filled in, you can look for times and ways to incorporate different supports so you can take a break, and your loved one can be supported to have good respite experiences and a good life.

# Finding Time for Respite



# Integrated Support Schedule

CHARTING the LifeCourse



## Integrated 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							
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							
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							
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							





# Introducing Barbara and Rachel

*Finding time  
for Respite*



# Barbara's Trajectory

## Vision for a Good Life

- Live in my **own** home
- Go to church and get out in the community
- Spend time with granddaughter
- Country and gospel music
- Gardening and flowers
- Crossword puzzles, game shows, and soap operas

## What I DON'T Want

- Live in a nursing home
- Be alone
- Sick, go to hospital
- Financial problems
- Personal drama & stress



# Before the hospital (as of May 2015)

CHARTING the life course



## Barbara's Long Term Support Schedule

May 2015

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							
9-9:30 AM							
9:30-10 AM		Volunteering at Impact		Volunteering at Impact			Church & Sunday School
10-10:30 AM							
10:30-11 AM							
11-11:30 AM							
11:30-12 PM							
12-12:30 PM							
12:30-1 PM							
1-1:30 PM						Rachel comes over for lunch	
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							Night church
6-6:30 PM							
6:30-7 PM					LifeGroup with friends		
7-7:30 PM				Fun night at church			
7:30-8 PM							
8-8:30 PM							
8:30-9 PM							
9-9:30 PM							
9:30-10 PM							
10 PM-6 AM							

# After the hospital (September 2015 through February 2016)

CHARTING the life course



## Barbara's Long Term Support Schedule

September 2015

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 comes over	Rachel comes over
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							
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							
6-6:30 PM							
6:30-7 PM							
7-7:30 PM	Rachel comes over						
7:30-8 PM							
8-8:30 PM							
8:30-9 PM							
9-9:30 PM							
9:30-10 PM							
10 PM-6 AM							



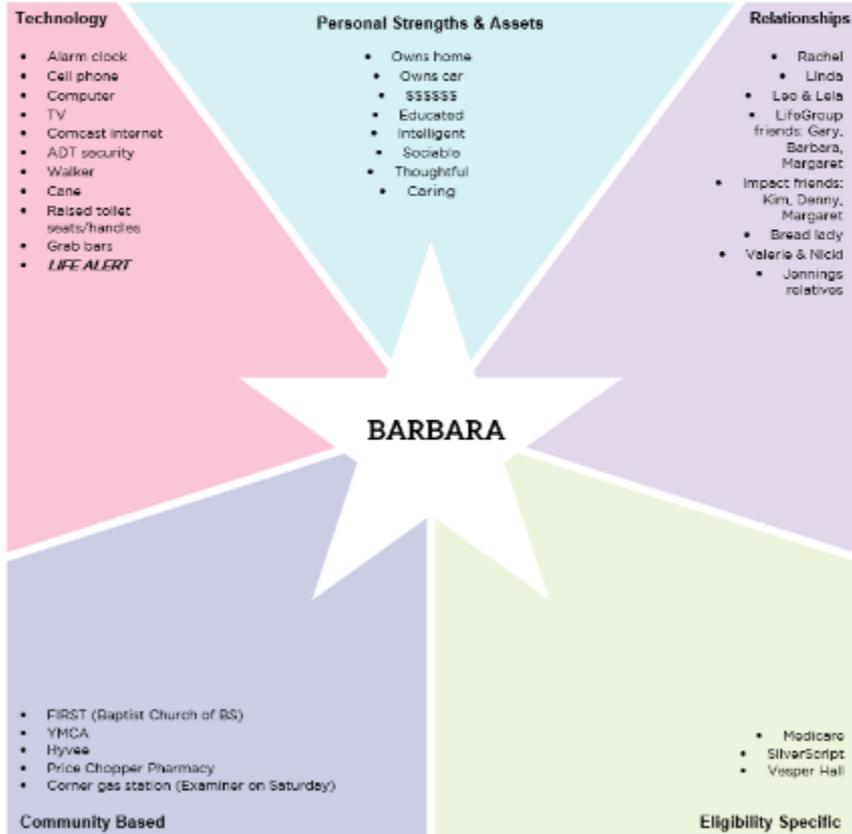
# Now - AFTER INTEGRATED SUPPORTS

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.



MISSOURI FAMILY TO FAMILY | UMKC-IHD, UCEDD

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							Rachel takes Grandma to church and attends
8:30-9 AM							
9-9:30 AM							
9:30-10 AM							
10-10:30 AM		Sherry Blyler - bread					
10:30-11 AM							LifeGroup with friends
11-11:30 AM							
11:30-12 PM	Ronda						
12-12:30 PM		Chaney		Chaney			
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							
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							



# Example Care Recipient Schedule

FIGURE 6. CARE RECIPIENT  
INTEGRATED SUPPORTS 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							
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							
1-1:30 PM	RONDA						
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							
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							

Handwritten annotations on the schedule:

- RONDA**: 1-1:30 PM (Monday)
- RACHEL**: 11:30-12 PM (Saturday)
- RACHEL**: 12:30-1 PM (Sunday)
- RACHEL**: 6:30-7 PM (Monday)
- LIFE GROUP w/ Andy**: 6:30-7 PM (Friday)



# Example Caregiver's Schedule

FIGURE 5. CAREGIVER  
INTEGRATED RESPITE SUPPORTS 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	WORK	WORK	WORK	WORK	WORK	GRANDMA						
8:30-9 AM												
9-9:30 AM												child
9:30-10 AM												&
10-10:30 AM												given
10:30-11 AM												v/
11-11:30 AM												gma
12-12:30 PM												
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												
4:30-5 PM												
5-5:30 PM												
5:30-6 PM												
6-6:30 PM	Grandma	Grandma	Grandma	Grandma	Grandma	Grandma						
6:30-7 PM												
7-7:30 PM												check
7:30-8 PM												on
8-8:30 PM							C					
8:30-9 PM												
9-9:30 PM												
9:30-10 PM												
10 PM-6 AM												



# Portfolio is completed, now what?

The Charting the LifeCourse Respite Portfolio can be used:

- To help others provide good supports to your loved one while you are taking a break or are not around. Paid staff, volunteers, family, friends, or others who might be providing care in your absence can use the front page of the portfolio as a quick reminder about what's important and how to best support the person receiving care.
- To train and coach people on how to best provide support when you are taking a respite break, and understand your vision for a good life and a good respite experience for your loved one. It could be kept in a notebook that can be easily accessed and used as a reminder when someone new or who hasn't spent time with the care recipient recently is providing support.
- To help people know how to best support your loved one when he/she is participating in an activity or event in the community.
- To advocate with professionals in formal planning meetings for your loved one's support needs and your needs as a caregiver and family member. The vision and trajectory pages can help you articulate to others what is important, what has worked or not worked in the past, and how you and your loved one want to move forward. The Integrated Star can be used to help both you and professionals think about how paid services can be enhanced by using some of the other types of supports you identified in the LifeCourse Respite Integrated Supports Star, or if paid services aren't available, decide how to best meet the support needs of your loved one, and your need to have some time for yourself.
- As a good organizing tool. It can help with planning and coordinating the logistics of everyday life for you and your loved one. The Integrated Schedule can be used when planning and scheduling who is providing support and when. It can help you find time for yourself to get a break from caregiving. The Integrated Supports Star Worksheet can help you find solutions when challenges arise around respite and other life issues.



# Introducing Daniel and his caregiver



## My LifeCourse Respite Portfolio



What is going on in my life?

Health issues  
mine and his  
juggling life, work,  
teens alone as a  
single parent  
Daniel's new sleep  
habits  
additional caregiving  
with the addition of  
the great grand baby  
into my life

How would taking short breaks HELP  
me and the person I provide care to?

Spending time with  
my daughter and  
her school activities  
My own stress level  
Visiting my Family  
since he often refuses  
anyway

### Making short breaks happen

What would I do if I had a break  
from caregiving?

massage  
date  
just be home in my  
own house alone

Who would I spend time with during  
a break from caregiving?

Friends  
boyfriend

What needs to be in place so I am comfortable leaving the person I am caring for?

Someone Daniel and I are both comfortable  
with, that cares for him and he will have  
fun too.



# Vision for Good Life, What is NOT Wanted, and Vision for Good RESPITE

## VISION FOR A GOOD LIFE

For the Care Recipient

Daniel does not want Mommy to leave. He does like to play with animals and go out to eat at his fave restaurants.

### VISION FOR GOOD RESPITE

He needs to be content and not call me 25x's a day. Provider has to give him attention and keep him engaged so he doesn't miss me so much. Then I can relax

For the Caregiver

Sometimes getting a break is just a bath with him not coming in to tell me he loves me. I need to spend time away from him with my friends to decompress. I want to do Daniel's safety is the most important factor.

## WHAT WE DON'T WANT

For the Care Recipient

"I don't want Mom to leave" Someone to be mean to me.

### NOT GOOD RESPITE

Daniel worries about me all the time when I am gone. Daniel not having fun or feeling lonely. Daniel not being safe

For the Caregiver

↓ health  
↑ stress  
Daniel not being safe or injured by someone I ask to care for him



## Respite Trajectory Worksheet

### What's working?

Past experiences where taking a break was successful or helpful

The right provider  
Daniels "buy in"  
Plan activities while gone  
Play pokeman or video games with him

### What Would it Take?

What would need to happen to have a positive caregiver break?

Daniels continued buy in and compliance

### What's not working?

Past experiences where taking a break didn't work

medical issues occurring  
provider emergency

### Barriers to overcome or avoid

What are the barriers to taking a caregiver break?

Not liking provider  
Daniel doesn't like Mom being away  
Paying for care for both kids to be away



Write Age of Care Recipient Here

20

Thinking about What's Worked or Not Worked in the Past, and Thinking about how to Move Forward



## ★ Mapping Supports for Respite

### Technology

IPAD  
 Phone  
 Laptop  
 Video games  
 hearing aid  
 cochlear implant  
 alert necklace

### Personal Strengths & Assets

Knows 911, likes to be home  
 Can be alone for a couple  
 of hours  
 Calls & texts Mom if  
 he needs something

### Relationships

neighbors  
 Jim & Judee  
 + Pat & Amanda  
 Brother  
 Cathy - respite  
 provider  
 Friends

Daniel

Rec. Center  
 Church (he refuses)  
 Parks  
 Camp  
 Open Door  
 Library  
 Bowling Alley

Medicaid w/ spend down  
 Social Security  
 Community Support  
 Waiver

Community Based

Eligibility Specific

Access the LifeCourse framework and tools at [lifecoursetools.com](http://lifecoursetools.com)

# Mapping Daniel's Integrated Supports



# Karen's Story

- ⦿ Had a yearly allotment of respite funding
- ⦿ Was using it up fast and was going to run out many months before year end
- ⦿ Used the Respite Portfolio to think through other kinds of supports and what might help moving forward
- ⦿ Discovered new ways to have respite without using funding
- ⦿ Side benefit of daughter's friendship outside of school setting



## RESOURCES FOR RESPITE



The ARCH National Respite Network includes the National Respite Locator, a service to help caregivers and professionals locate respite services in their community, the National Respite Coalition, a service that advocates for preserving and promoting respite in policy and programs at the national, state, and local levels, and the Lifespan Respite Technical Assistance Center which is funded by the Administration for Community Living in the US Department of Health and Human Services.

The resources below, arranged by the categories of the Integrated Supports Star you just learned about, are just few examples of national resources to get you started, and help you to make respite happen.

To find even more resources, visit [archrespite.org](http://archrespite.org).

### PERSONAL ASSETS & STRENGTHS

#### [VolunteerMatch.org](http://VolunteerMatch.org)

Search engine with hundreds of thousands of opportunities for individuals to give back and share their time and talents with their community.

#### National Center for Creative Caregiving

[creativecaregiving.org](http://creativecaregiving.org)

Free resource providing creative lessons to address the needs of family and caregivers of adults living with Alzheimer's disease and related cognitive disorders.

### COMMUNITY RESOURCES

#### [YMCA.net](http://YMCA.net)

YMCAs offer recreation and exercise programs for individuals of all ages and abilities.

#### Public Libraries [usa.gov/libraries](http://usa.gov/libraries)

Public libraries lend books, movies, music, and offer recreational and educational programs year round.

### TECHNOLOGY

#### State Assistive Technology Projects [ataporg.org](http://ataporg.org)

Listing of statewide programs helping people with disabilities and their families select and acquire assistive technology devices for all types of settings.

#### [LotsaHelpingHands.com](http://LotsaHelpingHands.com)

Manage care schedules online for individuals of all ages.

#### AARP Technology [aarp.org/technology](http://aarp.org/technology)

Provides information, webinars, and resources for older Americans and their caregivers to learn more about technology for entertainment, support, and more.

### RELATIONSHIP-BASED

#### Parent to Parent USA (P2PUSA) [p2pusa.org](http://p2pusa.org)

Find your state P2P to connect with someone who's 'been there' and find out how they made respite happen for their family.

#### AARP.org Caregiving [aarp.org/caregiving](http://aarp.org/caregiving)

Tips and advice for caregivers at all stages, including articles, online discussion boards for caregivers to connect, and links to resources.

### ELIGIBILITY SPECIFIC

#### ARCH National Respite Locator Service

[respitelocator.org](http://respitelocator.org)

Search engine of local respite programs and providers serving family caregivers of individuals with any disability or chronic condition, or of any age.

#### ARCH Respite Fact Sheets

[archrespite.org/productspublications/arch-fact-sheets](http://archrespite.org/productspublications/arch-fact-sheets)

Provides an overview of the different types of respite programs available and how to access them.

#### [Eldercare.gov](http://Eldercare.gov)

Find your local Area Agency on Aging or Senior Center and additional resources.

#### Family-to-Family Health Information Centers

[fv-ncfpp.org](http://fv-ncfpp.org)

Federally funded centers that provide information and referral, training through workshops, and family-friendly materials to help you navigate life.

# Resource page

More resources at  
[archrespite.org](http://archrespite.org)



# THE Charting the LifeCourse FRAMEWORK



This guide was developed using the *Charting the LifeCourse*, a framework 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, and discover what it takes to live the lives they want to live. Individuals and families may focus on their current situation and stage of life but may also find it helpful to look ahead to think about life experiences that will help move them toward an inclusive, productive life in the future.

Even though it was originally created for people with disabilities, this universally-designed framework may be used by any person or family making a life plan, regardless of life circumstances.

## FOUNDATION OF THE LIFECOURSE FRAMEWORK

The following are the building blocks of the LifeCourse framework. They are the core principles and values that are important as we begin to think differently about what it means to support individuals with disabilities and their families to have good lives.

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



### ALL People

ALL people, regardless of age, ability or family role, are considered in our vision, values, policies and practices for supporting individuals and families.



### Life Stages and Trajectory

Individuals and families can focus on a specific life stage, with an awareness of how prior, current and future life stages and experiences impact and influence life 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.



### Life Outcomes

Individuals and families plan for present and future life outcomes that take into account all facets of life and have life experiences that build self-determination, social capital, economic sufficiency and community inclusion.



### Family System and Cycles

People exist and have give-and-take roles within a family system. Roles adjust as the individual members change and age. Individuals and families need supports that address all facets of life and adjust as the family ages through family cycles and the roles and needs of members change.



### Life Domains

People lead whole lives made up of specific, connected, and integrated life domains that are important to a good quality of life. These include daily living, community living, safety and security, healthy lifestyles, social and spirituality, and citizenship and advocacy.



### Individual and Family Supports

Supports address all facets of life and adjust as roles and needs of all family members change. Types of support might include discovery and navigation (information, education, skill building); connecting and networking (peer support); and goods and services (daily living and financial supports).



### Integrated Delivery of Supports

Individuals and families access an array of integrated supports to achieve the envisioned good life, including those that are publicly or privately funded and based on eligibility; community supports that are available to anyone; relationship-based supports; technology; and that take into account the assets and strengths of the individual and family.



### Policy and Systems

Individuals and families are truly involved in policy making so that they influence planning, policy, implementation, evaluation and revision of the practices that affect them. Every program, organization, system and policy maker must always think about a person in the context of family.

To learn more about the LifeCourse framework, visit [lifecoursetools.com](http://lifecoursetools.com).

# The Charting the LifeCourse Framework Overview



# Tips and Tricks

- ⦿ You don't have to FILL IT OUT in front of family/caregiver
- ⦿ You don't have to complete the Portfolio in the order that's in the guide if it doesn't make sense for a particular person or circumstance (find what works best for your style and the person you are working with)
- ⦿ Could use it to take notes as you talk to caregiver
- ⦿ Don't have to "fill out" the whole portfolio – do what makes sense
- ⦿ Sometimes you just use the framework to have conversations
- ⦿ Could give it (in person or send ahead of time) to the caregiver and ask them to follow the guide and fill out the tools and get back with you to discuss



# www.lifecoursetools.com/respite

HOUSED AT THE UMKC INSTITUTE FOR HUMAN DEVELOPMENT, UCEDD

INFO@LIFECOURSETOOLS.COM

## LIFECOURSE Tools

LIFECOURSE PRINCIPLES

LIFECOURSE RESOURCES

LIFECOURSE IN ACTION

VIDEOS

CONNECT

ABOUT

SHOWCASE

SHORT BREAKS FOR CAREGIVERS

### RESPITE

Videos, tools, and resources for Respite



Leave Feedback

Charting the  
LifeCourse: Respite  
Guide



My LifeCourse  
Respite Portfolio



# Feedback Form



## Charting the LifeCourse Respite Guide and Tools Pilot: Feedback form

Please complete to submit your example of how you have implemented the Charting the LifeCourse Respite tools

1. Your Name: \_\_\_\_\_
2. Your Email: \_\_\_\_\_
3. Your Organization: \_\_\_\_\_
4. What do you see as your role?

<input type="checkbox"/> Family member - parent	<input type="checkbox"/> Public Health Staff
<input type="checkbox"/> Family member - sibling	<input type="checkbox"/> State system - I/DD Staff
<input type="checkbox"/> Respite Provider	<input type="checkbox"/> State System - Education staff
<input type="checkbox"/> Lifespan Respite Grantee	<input type="checkbox"/> Support coordinator or case manager
<input type="checkbox"/> State Respite Coalition Representative	<input type="checkbox"/> Nurses and Medical staff
<input type="checkbox"/> Respite Provider - administration/management	<input type="checkbox"/> University staff (UCEDD, faculty)
<input type="checkbox"/> State Unit on Aging	<input type="checkbox"/> Other: _____
<input type="checkbox"/> Area Agency on Aging Staff	
5. When using the Charting the LifeCourse Respite material or tool in this example, who was your focus person(s)?

Role of Focus Person:

<input type="checkbox"/> Parent Caregiver
<input type="checkbox"/> Spouse Caregiver
<input type="checkbox"/> Adult Child Caregiver
<input type="checkbox"/> Other Family Member Caregiver (specify) _____
<input type="checkbox"/> Non-Family Caregiver
<input type="checkbox"/> Other (specify) _____

Age of Care Recipient:

<input type="checkbox"/> Under 18
<input type="checkbox"/> 18-64
<input type="checkbox"/> 65 and over





# Questions? Comments?



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Ways to  
Learn More:

- *Webinars*
- *CoP Listserv*
- *Website Links*

[supportstofamilies.org](http://supportstofamilies.org)

[lifecoursetools.org](http://lifecoursetools.org)

[mofamilytofamily.org](http://mofamilytofamily.org)





Thank you!!

