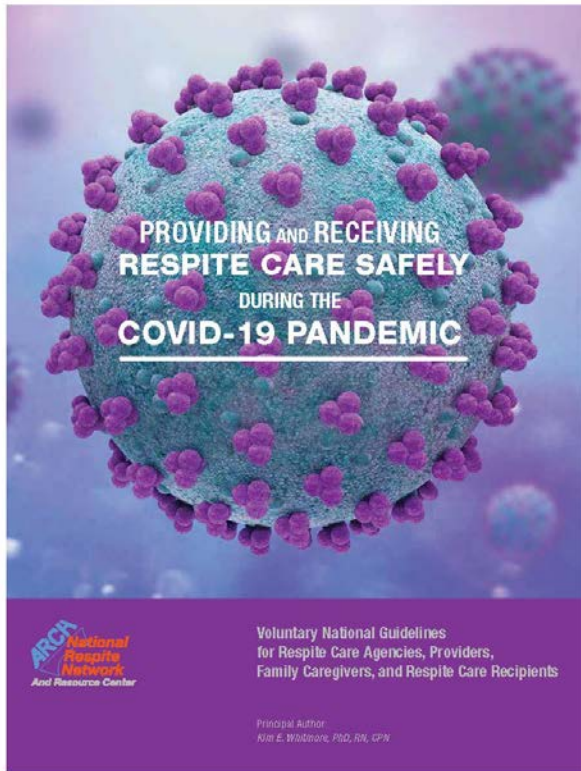


Using the LifeCourse Respite Tools during the Pandemic

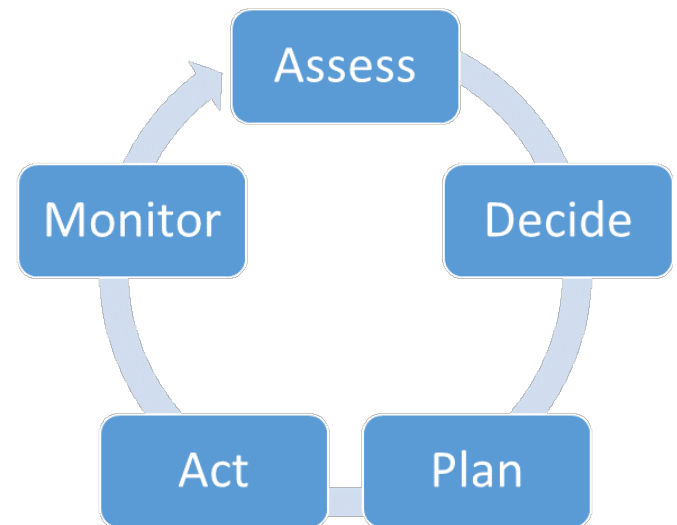
An ARCH Webinar
July 23, 2020



Voluntary National Guidelines for Providing and Using Respite Safely During the Pandemic



- Decision Guides for Respite Providers and Family Caregivers




<https://archrespite.org/national-respite-guidelines-for-covid-19>

<https://archrespite.org/national-respite-guidelines-for-covid-19#Decisions>

LifeCourse Respite Tools

Charting the LifeCourse




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

LIFE DOMAIN



ALL Life Domains

LIFE STAGE




ALL Stages

DEVELOPED BY

MISSOURI
FAMILY TO FAMILY
UMKC INSTITUTE FOR HUMAN DEVELOPMENT | UCEDD

IN PARTNERSHIP WITH



- Tools include:

Charting the LifeCourse: Respite Guide	My LifeCourse Respite Portfolio	Integrated Supports Schedule
--	---------------------------------	------------------------------

<https://www.lifecoursetools.com/lifecourse-library/exploring-the-life-domains/respite/>

- Webinar: Charting the LifeCourse Respite Tools, February 19, 2020

<https://archrespite.org/webinars-and-teleconferences/2017-05-19-18-17-05/charting-the-lifecourse-respite-tools>

- Exploring Respite Opportunities and Options

https://archrespite.org/images/Natural_Supports/STAR_Data_base.pdf

Featured Speaker

Jane St. John

Charting the LifeCourse Nexus
University of Missouri –Kansas City
Institute for Human Development
(UMKC IHD)
Kansas City, MO





UMKC Institute for
Human Development
Charting the LifeCourse Nexus

Charting the LifeCourse for Respite During COVID-19

July 23, 2020

About Jane....

- Mom of 3 sons, “Ben’s mom”
- UMKC-Institute for Human Development, UCEDD
 - Product Development and Training Specialist
 - Charting the LifeCourse Nexus Team
 - Co-developer of the CtLC framework and tools
 - Trainer/Coordinator of activities focusing on supported decision making

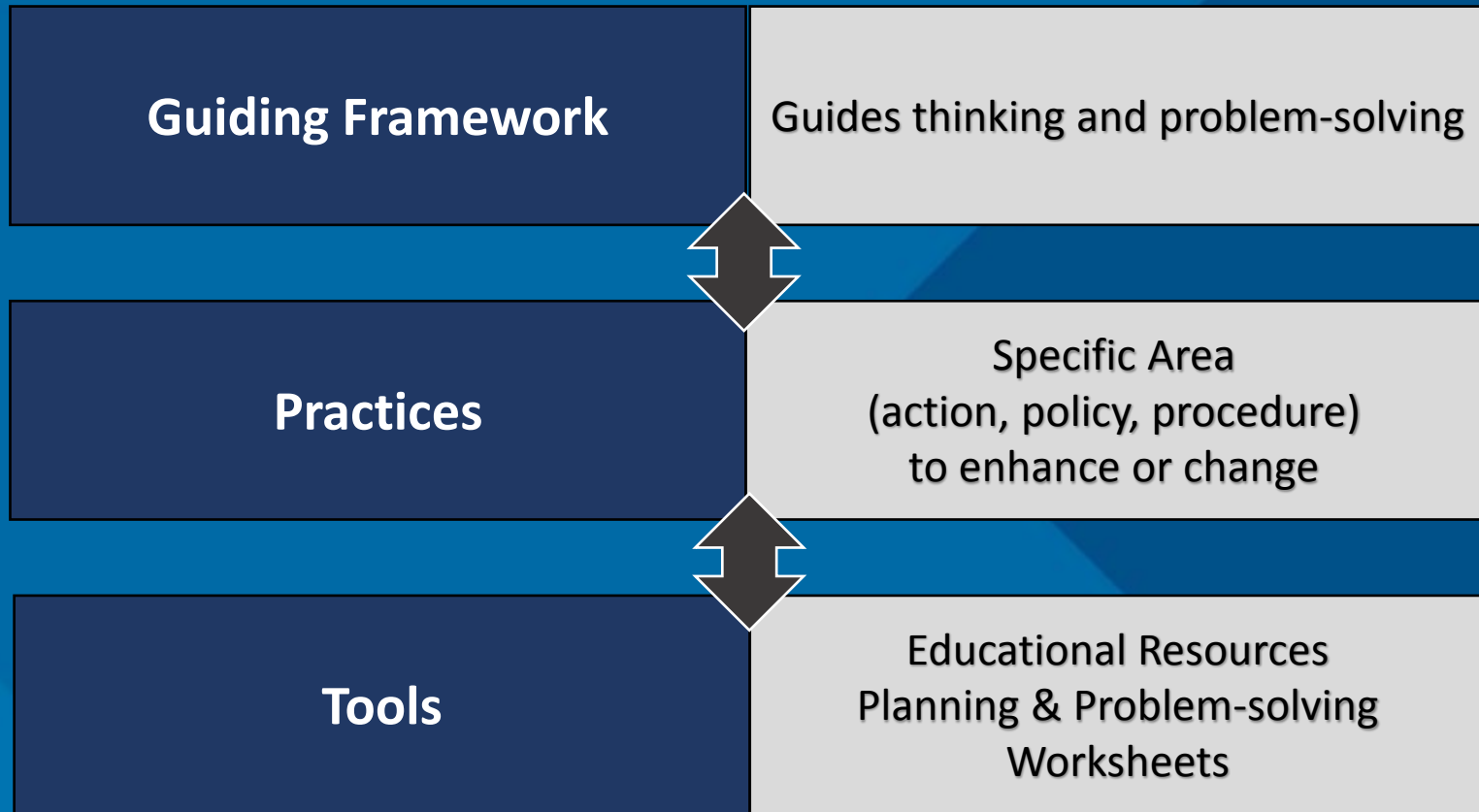




Charting the LifeCourse Framework



What is Charting the LifeCourse?





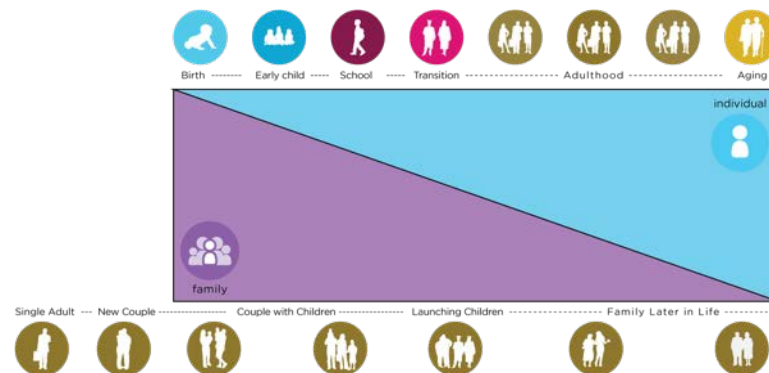
Core Belief:
All people and their families have the right to live, love, work, play, learn, and pursue their life aspirations in their community.



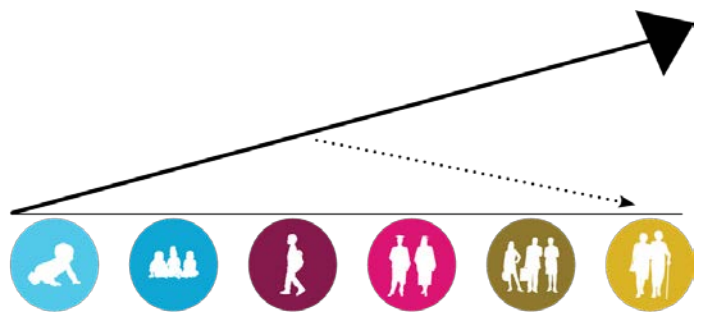
ALL Individuals Exist within the Context of Family



- Family is defined by the person
- Individuals and their family may need supports that adjust as roles and needs of all members change
- Not dependent upon where the person lives



Family Cycle Impacts Member Life Cycle



Family Life Experience Impacts Trajectory

Caring About	Affection & Self-Esteem
	Repository of knowledge
	Lifetime commitment
Caring For	Provider of day-to-day care
	Material/Financial
	Facilitator of inclusion and membership
	Advocate for support

Reciprocal Roles of ALL Family Members

“Good Life for ALL”

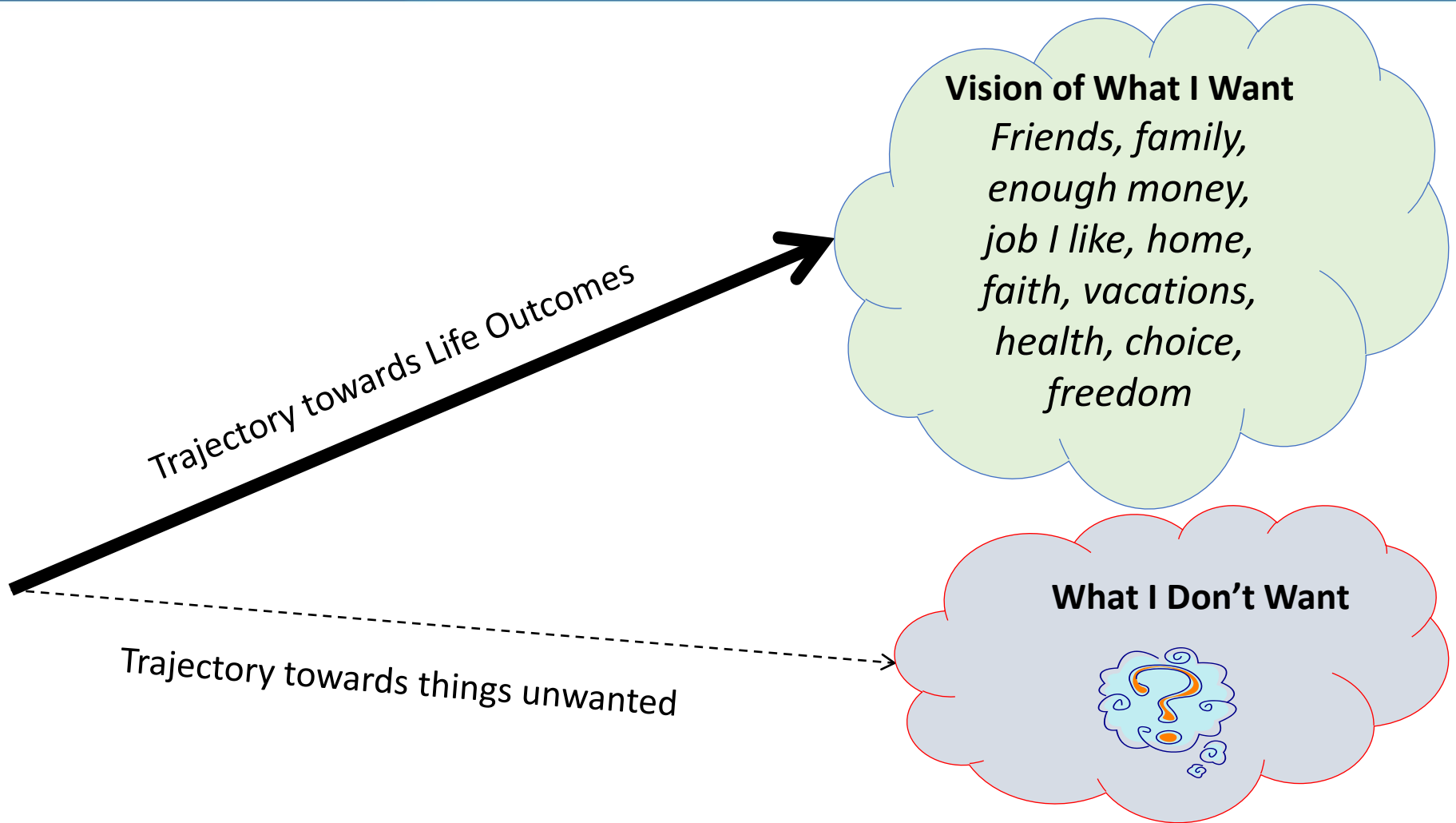


The Individual will achieve self-determination, interdependence, productivity, integration, and inclusion in all facets of community life

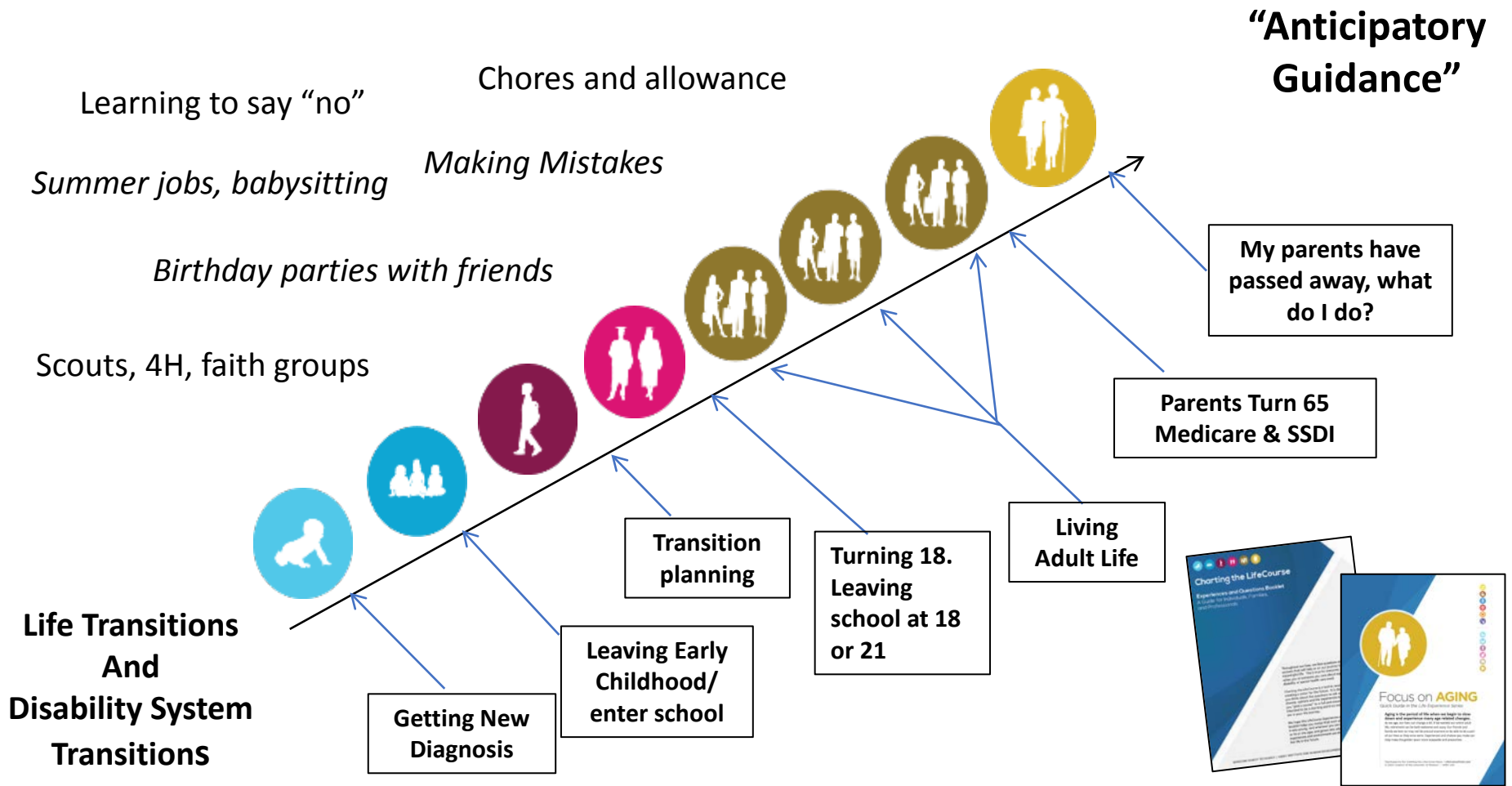


Families will be supported in ways that maximize their capacity, strengths, and unique abilities to best nurture, love, and support all individual members to achieve their goals

Vision & Trajectory for a Good Life



Trajectory Across Life Experiences, Life Transitions, and Life Stages



Achieving Outcomes for Connected 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)



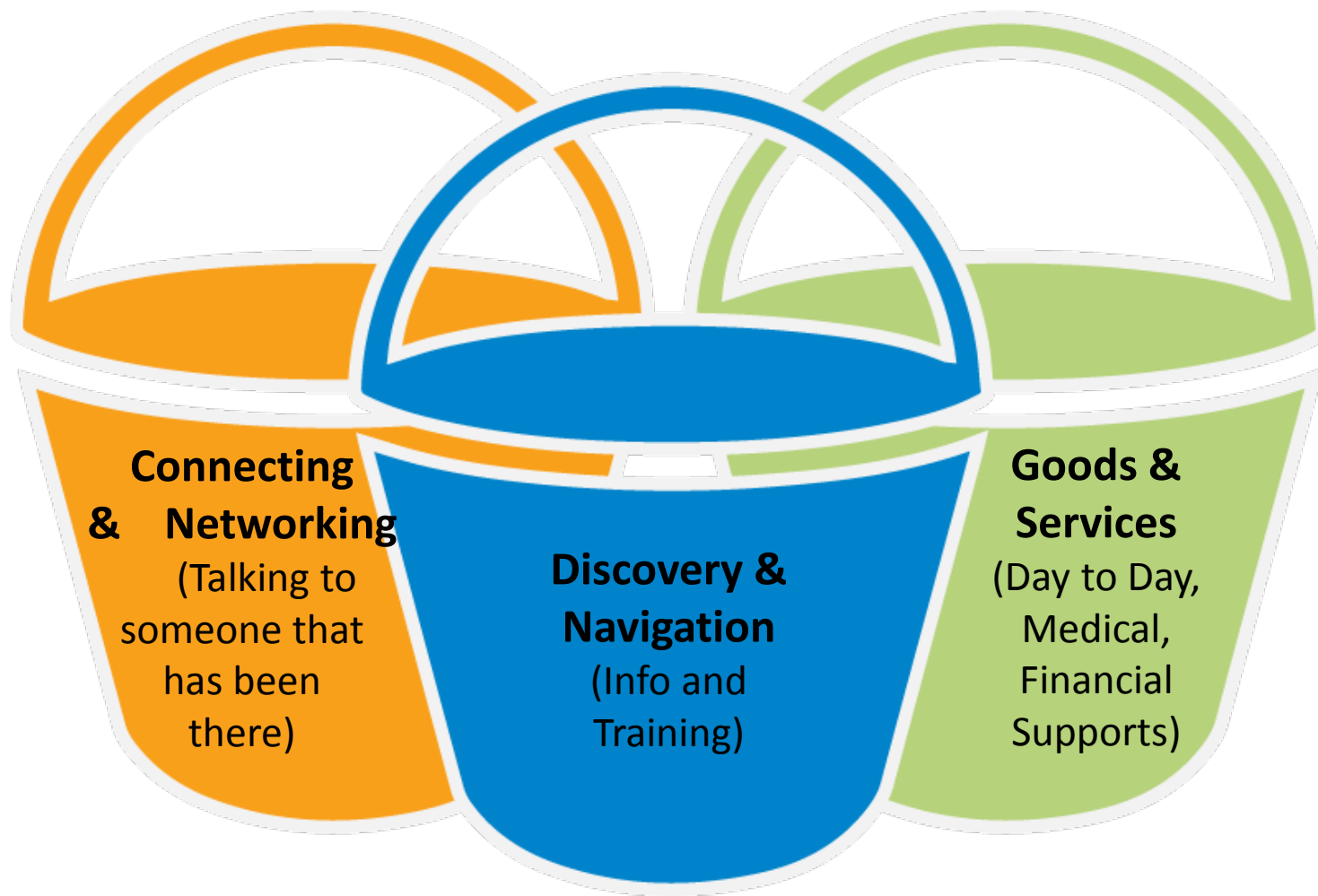
Social and Spirituality
(friends, relationships, leisure activities, personal networks, faith community)



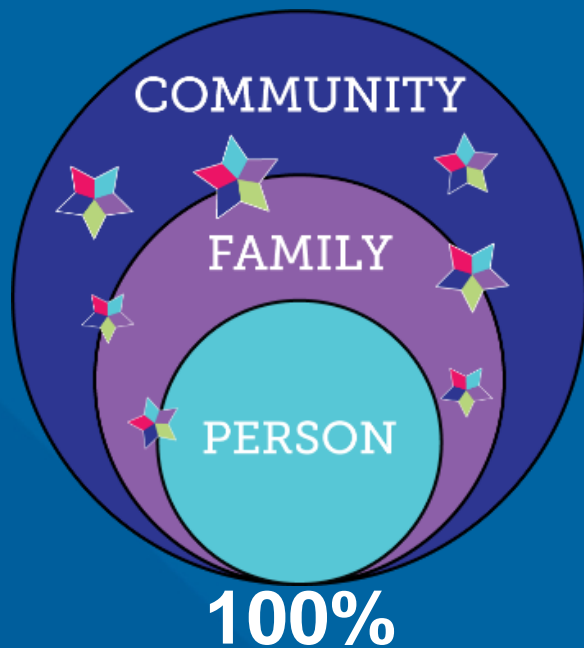
Advocacy and Engagement
(valued roles, making choices, setting goals, responsibility, leadership, peer support)

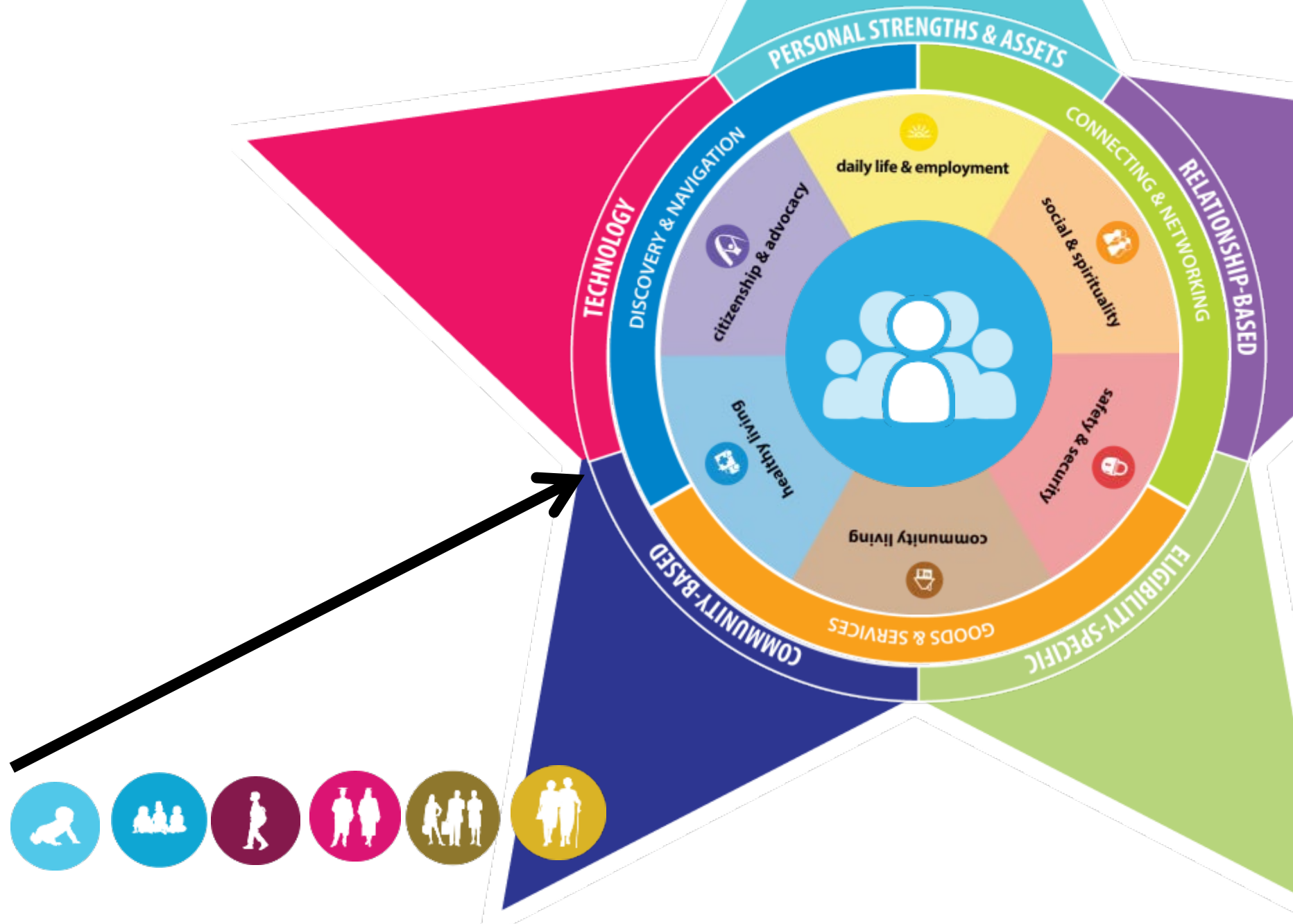
Types of Support

The “3 Buckets”



Charting the LifeCourse Integrated Supports Star





Charting the LifeCourse Respite Guide and Tools



www.LIFECOURSETOOLS.com

Browser address bar: <https://www.lifecoursetools.com>

Navigation menu: [LifeCourse Library](#) | [LifeCourse Learning](#) | [Network](#) | [About Us](#) | [Events](#) | [Contact us](#)

Header: **charting the LIFECOURSE NEXUS**

Phone: 1-800-773-8652 | Email: umkcctlc@umkc.edu

Hero Section: **Welcome to our Community of Learning**

Dropdown menu:

- LifeCourse Framework
- Foundational Tools
- Exploring the Life Domains
- Exploring the Life Stages
- Integrated Supports Star

Footer: <https://www.lifecoursetools.com/#>

System messages: Mozilla Firefox seems slow... to... start. | [Learn How to Speed It Up](#) | [Don't Tell Me Again](#)



CtLC Respite Tools on lifecoursetools.com

The screenshot shows the website interface with the following elements:

- Browser Address Bar:** <https://www.lifecoursetools.com>
- Navigation Menu:** LifeCourse Library | LifeCourse Learning | Network | About Us | Events | Contact us
- Logo:** charting the LIFECOURSE NEXUS
- Main Content Area:** "Welcome to our Community of Learning" with a background image of a smiling child.
- Navigation Path (indicated by red arrows and numbers):**
 1. Click on "LifeCourse Library" in the navigation menu.
 2. Click on "Exploring the Life Domains" in the dropdown menu.
 3. Click on "Respite" in the sub-menu.
- Sub-menu Items:** COVID-19, Daily Life and Employment, Healthy Living, Respite.
- Footer:** <https://www.lifecoursetools.com/lifecourse-library/exploring-the-life-domains/>



Charting the LifeCourse Respite Guide



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.

ALL Life Domains

LIFE STAGE



ALL Stages

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Planning for Respite in context of COVID-19

How can CtLC tools help?



www.LIFECOURSETOOLS.com

Impact of COVID-19 on Respite/Short Breaks

- Respite funds are still very limited, and likely to become more limited as budgets react to the economy and fallout from COVID-19 restrictions
- Caregivers may not want respite providers (formal or informal) in-home due to concern over care recipient or caregiver contracting COVID-19
- Respite opportunities in the community may be too risky
- Care recipient may not be able to take necessary precautions around others – physical distancing, wearing a mask, good hand-washing, not touching face, etc.
- Everyday life may be more complicated than usual



NAME: _____ DATE: _____

WHAT IS GOING ON IN MY LIFE?

HOW WOULD TAKING SHORT BREAKS HELP?

MAKING SHORT BREAKS HAPPEN:

<i>What would I do if I had a break from caregiving?</i>	<i>Who would I spend time with during a break from caregiving?</i>
<i>What needs to be in place so I am comfortable leaving the person I am caring for?</i>	



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NAME: JANE AND BEN

DATE: _____

WHAT IS GOING ON IN MY LIFE?

Jane is working from home for the past four months and for the foreseeable future. Ben has ceased his community volunteering, exploration, and other activities because of the COVID-19 virus. He is very social and is used to being out and about with lots of people. Ben's dad (Tom) is an essential worker so is out of the house during the day. This leaves Mom (Jane) and Ben home together 24/7, and sometimes we get on each other's nerves! We also are very careful about having anyone who doesn't live here inside our home, to minimize risk of getting the virus. Ben is high risk because of his IDD and medical diagnoses. Jane is also high risk due to several health conditions.

HOW WOULD TAKING SHORT BREAKS HELP?

Some times where we are each doing our own thing will help make the times when we are together more pleasant. We also don't want Ben to become completely dependent on being around Mom all the time, and not lose some of the skills he has worked so hard to gain (like spending some alone time or working out and staying fit, etc.) It also helps for Mom to have some time to get work done without Ben being right there and wanting to interact - so having some other options to occupy his time would be helpful.

MAKING SHORT BREAKS HAPPEN:

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

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

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



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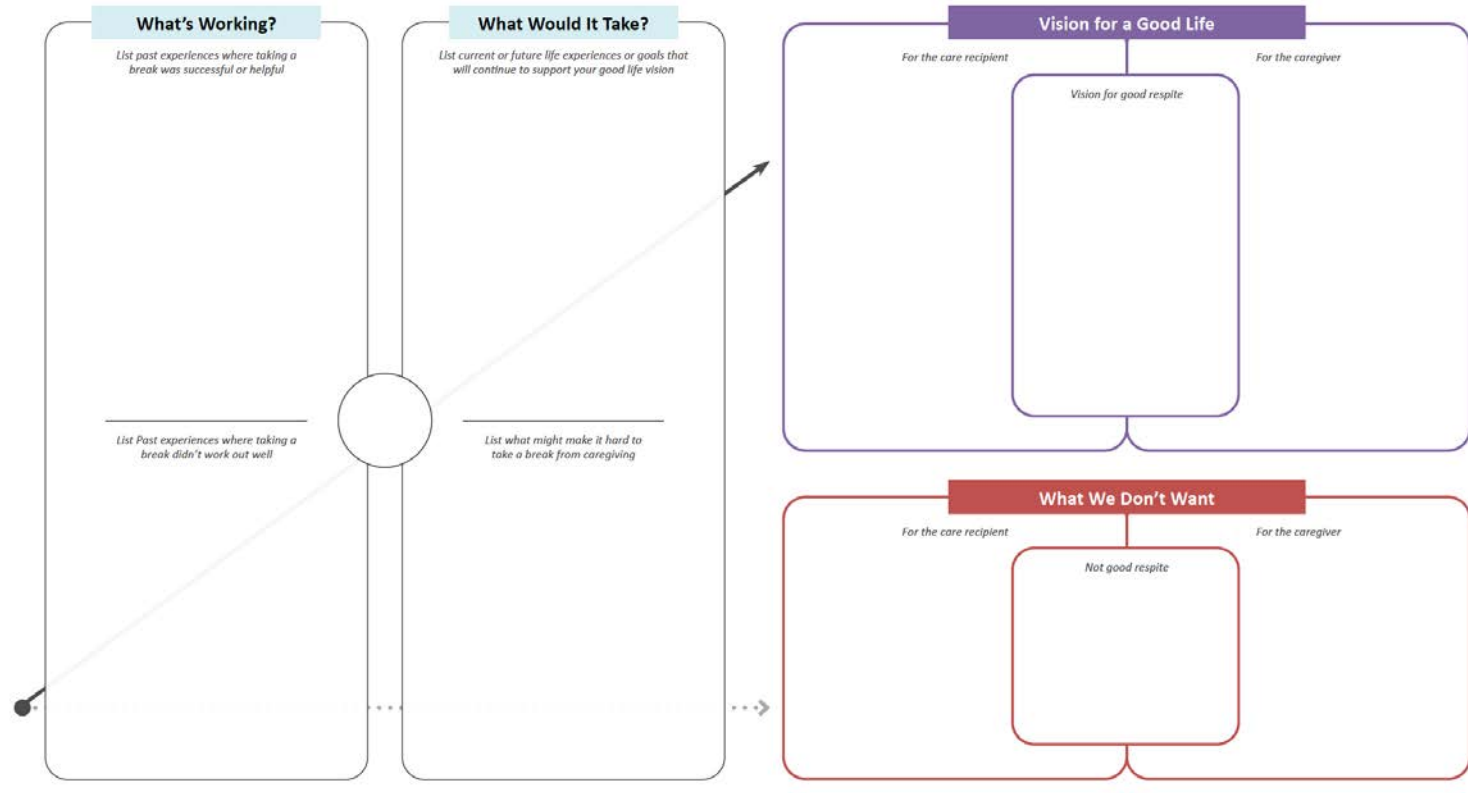
Jane and Ben's profile for respite during COVID



Respite Vision & Trajectory



LIFE TRAJECTORY | EXPLORING RESPITE



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Ben and Jane's Vision for Respite during COVID



LIFE TRAJECTORY | EXPLORING RESPITE

What's Working?

List past experiences where taking a break was successful or helpful

List past experiences where taking a break didn't work out well

What Would It Take?

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

List what might make it hard to take a break from caregiving

Vision for a Good Life



For the care recipient

- Spending time with family and friends, in person or virtually
- Volunteering at Fire Station
- Favorite food and drink - Pepsi is at the top of that list
- Watching wrestling or listening to music on I-pad
- Favorite TV shows - cooking shows, ER or medical shows, wrestling, music shows
- Playing basketball
- Swimming
- Tattoos (has one, wants more)
- Country music concerts
- Live wrestling shows
- Going to church on Sunday
- Playing Golf
- Going on vacations

Vision for good respite

- Mental health break for mom
- Time to run errands/shopping
- Someone or something to keep Ben occupied while I am in meetings or presentations
- "ME" time
- Ben is safe and secure and has something to keep him occupied
- Ben interacting with people he likes or cares about



For the caregiver

- Spending time/staying in touch with family and friends
- Having money to buy what I want and do what I want
- Getting my nails done every 2-3 weeks
- Mexican food and margaritas
- Having a safe, comfortable, upgraded house
- Traveling for fun and leisure
- Job I love (have one!)
- Izzi the dog
- Being healthy/keeping existing health issues under control
- Nice car with all the cool stuff
- Shoes - lots of them
- Eat without gaining weight
- Family safe and healthy

What We Don't Want

For the care recipient

- Being bored
- Being anxious or worried
- Getting sick/getting COVID19
- Seizures
- Hospital stay
- Health issues like diabetes or heart disease
- Being lonely or isolated
- In institution or group home
- No money
- Stuck at home 24/7
- Losing skills

Not good respite

- Ben exposed to COVID-19
- Ben upset, worried or scared
- Mom worried about Ben
- Ben is bored/not engaged
- Mom feels guilty for taking a break

For the caregiver

- Poor health/ current health issues deteriorating
- Ben or other family getting sick/getting COVID-19
- Ben or family members being hospitalized or dying
- Getting impatient or short-tempered due to over-exposure (Ben 24/7)
- Gain weight
- Not enough money

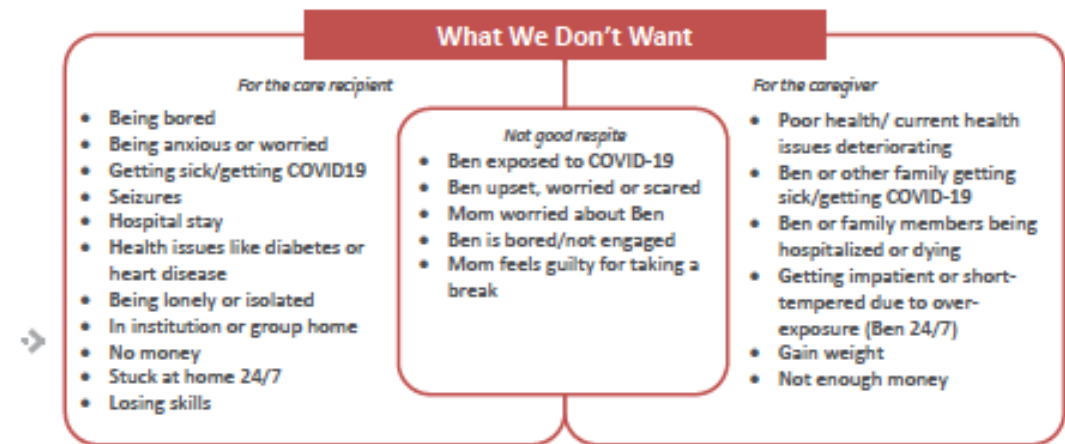
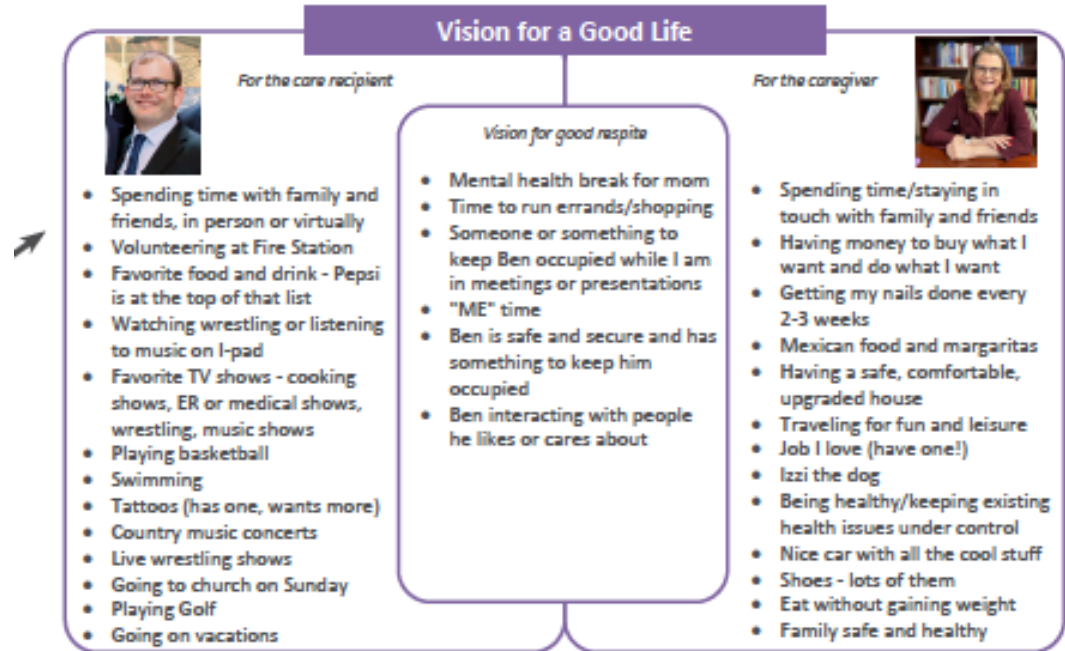


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Vision for Good Life and Good Respite

And what we DON'T Want



Coping with Impact of COVID-19


LIFE TRAJECTORY | EXPLORING
BEN COPING WITH/SURVIVING THE CO-VID19 CRISIS

STAY HEALTHY/ACTIVE

- Walk outdoors when it's nice weather
- Avoid contact with anyone other than Mom or Dad (social distancing)
- Get a list of other exercise ideas from Matt and Adam (weights, push-ups etc)--use ZOOM
- Clean up the driveway basketball goal
- Healthy but yummy food choices
- Good and frequent hand washing
- Purell
- Wipe down surfaces daily
- Cover coughs and sneezes
- Check temperature regularly

DAILY LIFE/ROUTINE

- somewhat consistent wake/sleep times
- shower daily
- Help with housework/cooking/etc daily "schedule" of things to do such as exercise, physical activity, get outdoors, etc

STAY CONNECTED

- Facetime Matt and other family
- Skype or Facetime Fire Dept shifts
- Make an encouraging video for ESHD
- Help Ben get on Facebook daily and "like" or comment on friends posts
- online church services on Sundays
- Front yard 10ft apart meet up with Steve

STAY BUSY/NOT BORED

- Ipad (WWE, music
- Remote control truck
- **see stay connected
- golf in basement
- Family Movie time
- explore e-books

POSSIBLE OBSTACLES/BARRIERS

- Dad still has to work - potential exposure
- CO-VID on the news and other media all the time
- Other people not complying with social distancing
- CABIN FEVER IS REAL
- Crappy weather/can't get outside

Vision for What I Want


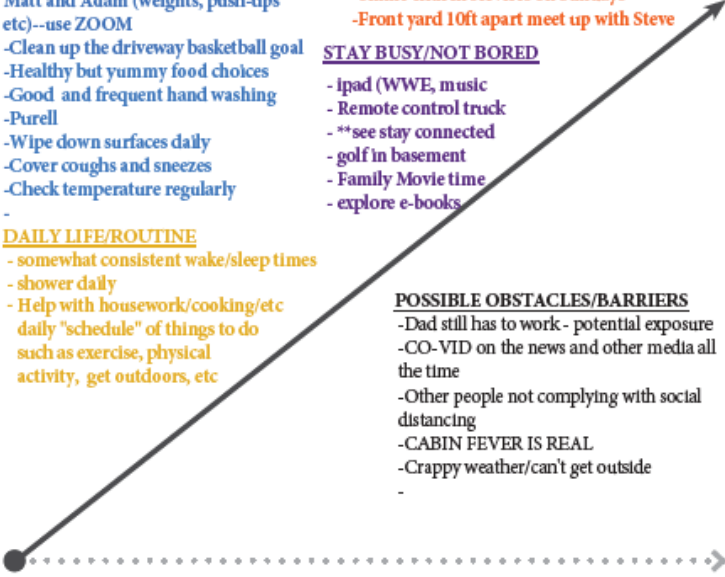
WHAT WE WANT FOR BEN DURING THE CO-VID19 CRISIS







- Keep busy
- Keep working on fitness while he isn't able to access his trainer or the community center
- Stay Connected with:
 - Fire department friends
 - Valued staff
 - Family who don't live with us (especially Matt)
 - St Ann friends
 - Coffee friends & other community acquaintances
- Stay healthy and active
- Dad and Mom stay healthy too
- Keep a positive outlook on life - BE HAPPY

What I Don't Want

WHAT WE DON'T WANT TO HAPPEN DURING THE CRISIS

- Boredom
- Get CO-VID19 or any other sickness
- Stress and worry
- Ben scared he will get sick
- Ben worried for parent's health
- Seizures or other diagnosis related health complications
- Sadness
- Missing family and friends
- Gaining weight/out of shape

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Ideas for Respite Resources and Supports During COVID-19

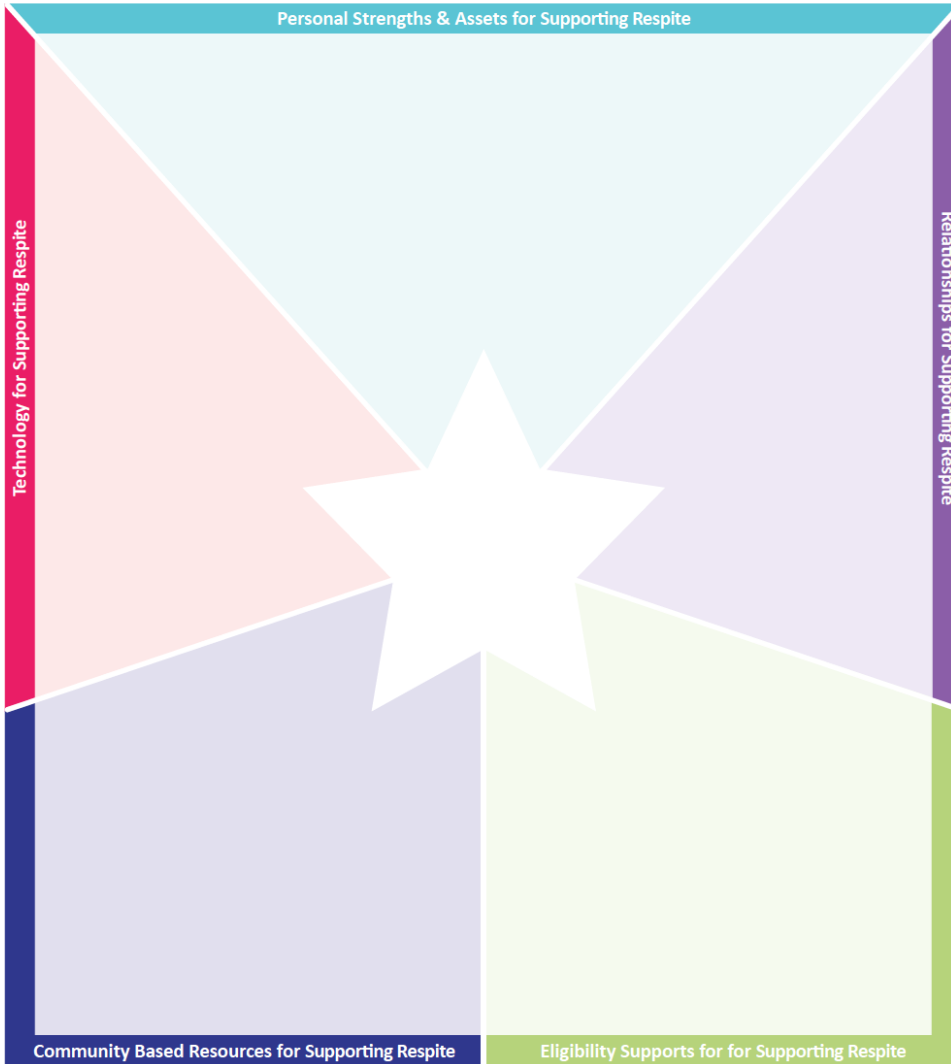


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INTEGRATED SUPPORTS STAR | RESPITE

This star will help families and individuals think about supports and resources available in each of the star categories that could help make respite possible or a better experience.



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Integrated Supports Star for Respite



Ideas for Respite or Short Breaks Anytime



INTEGRATED SUPPORTS STAR | RESPITE

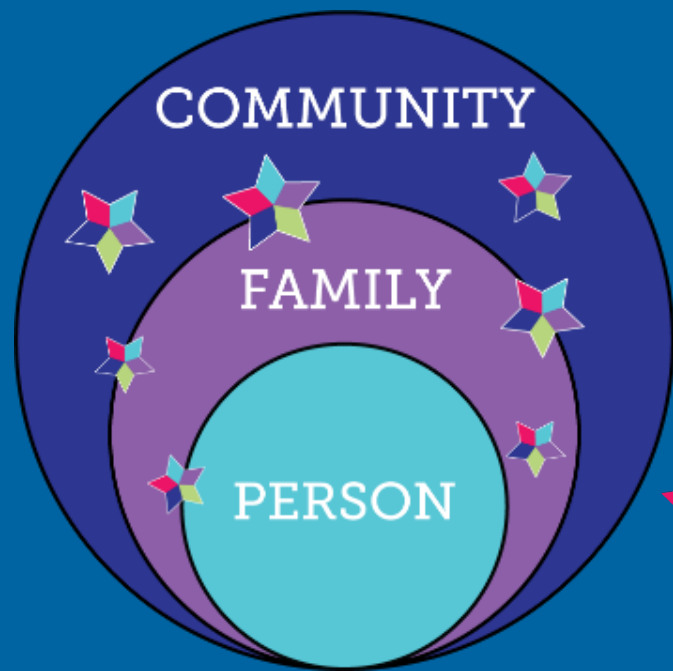
This star will help families and individuals think about supports and resources available in each of the star categories that could help make respite possible or a better experience.



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Relationship Supports for Respite During COVID-19



100%

People who can provide short breaks by doing any of the following with your child: video chatting, social distancing in the yard, texting or calling, playing video games online, etc.

- Immediate or extended family members
- Friends
- Teachers, coaches
- Co-workers
- Other caregivers
- Faith based community
- College students

Relationships

Personal Assets and Strengths for Respite During COVID-19



Personal Strengths & Assets

- Seek physical activity
- Find excuses to change rooms frequently
- Cook food that is new to you
- Learn a new skill or craft
- Make a wish list of “if I only had _____ min. to myself” ie. :15, :30, :60, a day etc. Be ready to execute your list as able
- Put positive memories in a jar and pull out as needed
- Create videos to share with others online
- Your child’s abilities:
 - can stay alone/in another room for short time
 - not a wanderer





Technology

- Electronic reminders
- Schedule to reduce anxiety
- Remote monitoring for short periods
- Cell phone/Texting – increase communication options for all
- Virtual conferencing
- iPad educational/life skills apps
- Virtual vacations for both parties
- Online classes or training
- Virtual Happy Hour after child's bedtime



Technology Supports for Respite During COVID-19



100%



Community Supports for Respite During COVID-19

- Online special interest groups (crafts, hobbies, sports)
- Meetup groups - online
- Faith-based resources – online services or groups
- Volunteering together - VolunteerMatch.org to find online opportunities
- Get involved in a volunteer project you can do from home
- Community Centers or Parks and Rec hosting online fun activities or exercise classes

Community Based



100%



Eligibility Supports for Respite During COVID-19



- Medicaid, Medicaid waiver, SSI, SSDI
- Family care homes or host homes
- Home-based service programs
- Self Directed Support Personal Care Assistant (PCA); Family as paid caregiver
- Personal Care Assistance Agencies
- State lifespan respite care programs
- Older Americans Act– Family Caregiver Support Program
- Respite voucher
- Consumer Directed Support

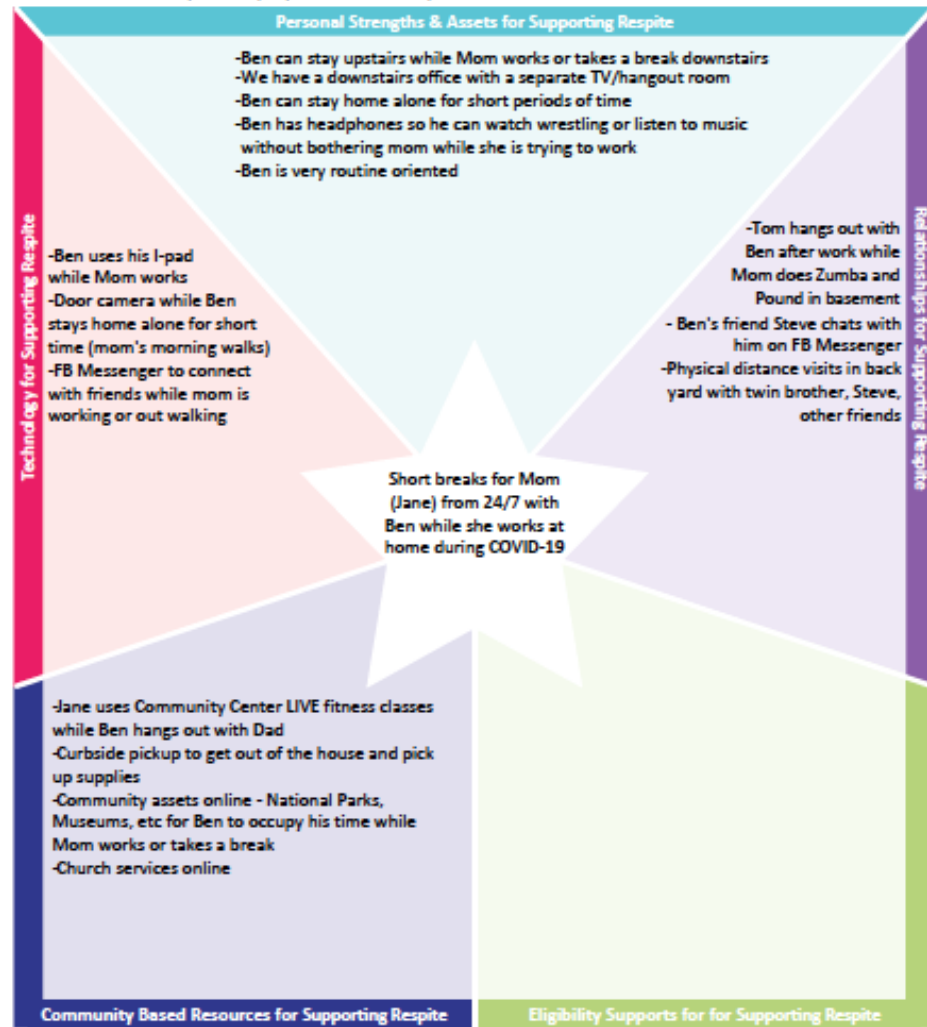
Eligibility Specific

Short Breaks or Respite for Ben's Mom



INTEGRATED SUPPORTS STAR | RESPITE

This star will help families and individuals think about supports and resources available in each of the star categories that could help make respite possible or a better experience.



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Information for Alternative Caregiver

If parents are hospitalized or unable to care for Ben



A Few Tips

- You might choose to only use one of the tools or one part of the Respite Portfolio
- Remember, it's more about the conversations and the process than it is about filling out a tool
- You might just use the tool to guide and organize your conversation with a caregiver – they might not even see the tool or know you are using it

Planning for Life Outcomes and/or Service Planning



Self-Advocate Tools & Resources

Family Perspective Tools

Formal Planning Tools and Forms

800-444-0821

Sharing and Questions

How have you used (or assisted someone to use) the CtLC Respite Tools or any CtLC tools during COVID-19?



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Charting the LifeCourse Nexus

Exchange Knowledge | Build Capacity | Engage Collaboratively
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