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
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.

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.
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

COMMUNITY

FAMILY

SERVICES

PERSON

Expectations, Values, Culture

Demand for Services

Federal Budget

Federal Policies

Capacity of Work Force
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
1 in 4 Persons with I/DD Receive Formal State DD Services

100%

4.7 Million people with developmental disabilities

75%

25%

National % Receiving 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 Vision

Vision of What I Don’t Want
“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

PERSON

FAMILY

COMMUNITY

100%

Personal Strengths & Assets
- resources, skills, abilities characteristics

Technology
- i-pad/smart phone apps, remote monitoring, cognitive accessibility, Adaptive equipment

Relationships
- family, friends, neighbors, co-workers, church members, community members

Community Based
- school, businesses, church faith based, parks & rec, public transportation

Eligibility Specific
- SHS services, Special Ed, Medicaid, Voc Rehab, Food Stamps, Section 8
BEN – before Integrated Supports

Mom, Dad

Ben’s Services & Supports

DDD Self-Directed waiver PCA staff; Medicaid; Special Needs Trust

Long Term Service and Support Needs

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Parents get Ben out of bed, assist with breakfast, shower, getting dressed and ready for his day.

Parents are weekend support.

Waiver Self-Directed PCA.

Mom and Dad provide all support, including meals, transportation and support for activities, etc.

Parents are overnight staff.
Able to stay home alone for up to an hour; has & can use i-pad; i-pad when home alone; digital watch

RELATIONSHIPS:
Mom, Dad, Matt, Zac, Ali, Chad, Ericka, Roy, Carol, Nick, Spohn

COMMUNITY BASED:
Firemen at ESFD; coaches & staff at ES high school; Omni bus;

ELIGIBILITY SPECIFIC
DDD Self-Directed waiver PCA staff; Medicaid; Special Needs Trust

BEN – After Integrated Supports
Impact on All Family Members
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”

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

IN PARTNERSHIP WITH

ARCA National Respite Network
And Resource Center
Charting the LifeCourse: Respite
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RESpite: What is it and why is it important?

What is it?
Respite in the context of caregiving can be described as a child or adult with special needs spending time away from the home environment in the care of another individual. It is a planned break for the primary caregiver, providing needed support to the caregiver in the role of providing care. In the context of family care, the primary caregiver is the person providing the majority of care, help, or support to the care recipient.

Why is it important?

- Reduces caregiver stress and fatigue
- Increases quality of life for both the caregiver and the care recipient
- Improves caregiver satisfaction
- Provides an opportunity for the care recipient to develop new skills and activities
- Provides a break for the caregiver, allowing them to rest and recharge

RESpite: What do caregivers need to know?

- Caregivers are essential to the well-being of care recipients
- Caregivers need support and resources to continue providing care
- Caregivers can benefit from respite services

RESpite: How can it help?

- Respite can help caregivers manage stress and improve their own health
- Respite can provide a break for caregivers, allowing them to attend to their own needs
- Respite can give care recipients a chance to experience new activities and develop new skills

RESpite: How can I find respite services?

- Contact local respite agencies or organizations
- Check with local hospitals or community centers
- Ask for recommendations from family members or friends

RESpite: What are the benefits of respite?

- Improved quality of life for both the care recipient and the caregiver
- Increased caregiver satisfaction
- Improved health outcomes for both the care recipient and the caregiver

RESpite: Who is eligible for respite?

- Caregivers of children or adults with special needs
- Family members, friends, or volunteers who provide care

RESpite: What should I expect from a respite service?

- A call from a respite service provider
- Information about available respite services
- Assistance in arranging for respite services

RESpite: What is respite planning?

- The process of preparing for and arranging for respite services
- Includes identifying respite needs, finding respite services, and planning for respite

RESpite: What is the role of the caregiver?

- The caregiver is responsible for providing care to the care recipient
- The caregiver should plan for and arrange for respite services

RESpite: What is the role of the care recipient?

- The care recipient is responsible for participating in the planning and arrangement of respite services
- The care recipient should be involved in the decision-making process

RESpite: What is the role of the respite service provider?

- The respite service provider is responsible for providing respite services to the care recipient
- The respite service provider should coordinate with the caregiver and care recipient to ensure the best possible care
Benefits to ALL family members

Some benefits of taking short breaks include:\textsuperscript{1,2,3,4}:

\textbf{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’

\textbf{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

\textbf{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


Exploring Respite Possibilities with the Integrated Supports Star

**FIGURE 1. Integrated Respite Possibilities**

- **Personal Strengths and Assets**
  - Tangible or financial resources, and personal skills and abilities. What the person who receives care can do with minimal support.
  - Example: The care recipient is able to stay home alone for short periods of time.

- **Technology**
  - Using technology to either help provide the support a person needs so the caregiver can take a break, or enhance the respite experience.
  - Example: Using video chat to check in with a caregiver who is not home.

- **Relationship Based**
  - Family, friends, neighbors, co-workers and other people who might be able to help with something to enable the caregiver to take a break.
  - Example: A neighbor comes by for a visit while the caregiver goes for a walk.

- **Community Based**
  - The places and activities in the community that anyone can access, or the community members we interact with.
  - Example: A caregiver may be able to take a break while his or her loved one participates in an activity at the YMCA.

- **Eligibility Specific**
  - Formal eligibility-based respite programs, as well as other kinds of support the caregiver or care recipient may be eligible for based on age, income, diagnosis or other criteria.
  - Example: An elderly care recipient is eligible for a companion program through their Area Agency on Agency.
Download your own LifeCourse Respite Portfolio at lifecoursetools.com/respite
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
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/respite.

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 caregiving 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/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.

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.
How can Respite help us?

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Planning what I could do if I had a respite break

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<thead>
<tr>
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</thead>
<tbody>
<tr>
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Who would I spend time with?

Making Short Breaks Happen

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“Must Haves” to make it work

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# Care Recipient Vision

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<th>CAREGIVER</th>
<th>RESPITE</th>
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<tbody>
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*Note: Sometimes it is easier to know what you want by FIRST identifying “What We Don’t Want” below.*
Caregiver Vision

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**Respite**
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Vision for Respite

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List things that would make respite a negative experience for either the caregiver and/or care recipient.
Examples: care recipient is frightened, caregiver worries the entire time
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.
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.
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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.
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

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

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

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 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
Finding Time for 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 lifecourse tools.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 book close by.

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.
## Integrated Support Schedule

<table>
<thead>
<tr>
<th>TIME</th>
<th>MON</th>
<th>TUES</th>
<th>WED</th>
<th>THURS</th>
<th>FRI</th>
<th>SAT</th>
<th>SUN</th>
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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)

**Barbara’s Long Term Support Schedule**

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### After the hospital (September 2015 through February 2016)

**Barbara’s Long Term Support Schedule**

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Now - AFTER INTEGRATED SUPPORTS

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.

Personal Strengths & Assets:
- Owns home
- Owns car
- Educated
- Caring

Relationships:
- Rachel
- Linda
- Lee & Lea
- LifeGroup friends: Gary, Barbara, Margaret
- Impact friends: Kim, Dewayne, Margaret
- Bread lady
- Valerie & Nicci
- Jennings relatives

Barbara's Long Term Support Schedule

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Rachel takes Grandma to church and attends LifeGroup with friends
### Figure 6. Care Recipient Integrated Supports Schedule

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- RONDA
- RACHEL

*Life Group*
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<th>TIME</th>
<th>MON</th>
<th>TUES</th>
<th>WED</th>
<th>THURS</th>
<th>FRI</th>
<th>SAT</th>
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</table>

*WORK*

*GRANDMA*

*GRANDMA*
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 Supportst 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 grandbaby 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
### Thinking about What’s Worked or Not Worked in the Past, and Thinking about how to Move Forward

**Respite Trajectory Worksheet**

<table>
<thead>
<tr>
<th>What’s working?</th>
<th>What Would it Take?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Past experiences where taking a break was successful or helpful</td>
<td>Daniels’s “buy in” continued, buy-in, and compliance</td>
</tr>
<tr>
<td>The right provider</td>
<td>Daniels’s “buy in” continued, buy-in, and compliance</td>
</tr>
<tr>
<td>Daniels’s “buy in”</td>
<td>Daniels’s “buy in” continued, buy-in, and compliance</td>
</tr>
<tr>
<td>Plan activities while gone</td>
<td>Daniels’s “buy in” continued, buy-in, and compliance</td>
</tr>
<tr>
<td>Play Pokemon or video games with him</td>
<td>Daniels’s “buy in” continued, buy-in, and compliance</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>What’s not working?</th>
<th>Barriers to overcome or avoid</th>
</tr>
</thead>
<tbody>
<tr>
<td>Past experiences where taking a break didn’t work</td>
<td>Not liking provider</td>
</tr>
<tr>
<td>Medical issues occurring</td>
<td>Daniel doesn’t like Mom being away</td>
</tr>
<tr>
<td>Provider emergency</td>
<td>Paying for care for both kids to be away</td>
</tr>
</tbody>
</table>

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[Image of a person drawing a stick figure and writing notes about respite planning.]
# Mapping Supports for Respite

<table>
<thead>
<tr>
<th>Technology</th>
<th>Personal Strengths &amp; Assets</th>
<th>Relationships</th>
</tr>
</thead>
<tbody>
<tr>
<td>iPad, phone, laptop</td>
<td>Knows 911, likes to be alone for a couple hours, calls/texts mom if brother needs something</td>
<td>Cathy, respite provider</td>
</tr>
<tr>
<td></td>
<td>Can be alone for a couple hours</td>
<td></td>
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<tr>
<td></td>
<td>Laptop calls/texts mom if brother needs something</td>
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<td></td>
<td>Video games</td>
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<td>Hearing aid</td>
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<td>Cochlear implant</td>
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<td>Alert necklace</td>
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</table>

**Daniel**

- Three Center Church (benefits)
- Parks
- Camp
- Open Door
- Library
- Bowling Alley

**Community Based**

**Eligibility Specific**

- Medicaid with spend down
- Social Security
- Community Support Waiver

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

*My LifeCourse Portfolio is a template of the UWACD, LDCCD. More materials at lifecoursetools.com*
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 a few examples of national resources to get you started, and help you to make respite happen. To find even more resources, visit archrespite.org.

PERSONAL ASSETS & STRENGTHS

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.creativeaging.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.

RELATIONSHIP-BASED

Parent to Parent USA (P2PUSA) 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
Tips and advice for caregivers at all stages, including articles, online discussion boards for caregivers to connect, and links to resources.

COMMUNITY RESOURCES

YMCA.net
YMCA plans recreation and exercise programs for individuals of all ages and abilities.

Public Libraries usa.gov/libraries
Public libraries lend books, movies, music, and offer recreational and educational programs year round.

ELIGIBILITY SPECIFIC

ARCH National Respite Locator Service
respite locator.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-factsheets
Provides an overview of the different types of respite programs available and how to access them.

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

TECHNOLOGY

State Assistive Technology Projects atap.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
Manage care schedules online for individuals of all ages.

AARP Technology aarp.org/technology
Provides information, webinars, and resources for older Americans and their caregivers to learn more about technology for entertainment, support, and more.

More resources at 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 LIFE COURSE 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.

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.
- 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
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?
   - Family member - parent
   - Family member - sibling
   - Respite Provider
   - Lifespan Respite Grantee
   - State Respite Coalition Representative
   - Respite Provider - administration/management
   - State Unit on Aging
   - Area Agency on Aging Staff
   - Public Health Staff
   - State system - I/DD Staff
   - State System - Education staff
   - Support coordinator or case manager
   - Nurses and Medical staff
   - University staff (UCEDD, faculty)
   - Other: ________________________________

5. When using the Charting the LifeCourse Respite material or tool in this example, who was your focus person(s)?
   Role of Focus Person:
   - Parent Caregiver
   - Spouse Caregiver
   - Adult Child Caregiver
   - Other Family Member Caregiver (specify) ________________________________
   - Non-Family Caregiver
   - Other (specify) ________________________________

   Age of Care Recipient:
   - Under 18
   - 18-64
   - 65 and over
   Lifecoursetools.com

UMKC IHD, UCEDD
Questions? Comments?
Ways to Learn More:
- Webinars
- CoP Listserv
- Website Links

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stjohnj@umkc.edu

- supportstofamilies.org
  lifecoursetools.org
  mofamilytofamily.org
Thank you!!