

FINDING GOOD RESPITE: PART 3



FACT:

Every parent needs a break from their caregiving role.

Respite care is one way to get a break.

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Charting the LifeCourse Ambassador, 2019

Objective:

Increased satisfaction/benefit from the breaks you receive

You will need: Plenty of paper to write on and a pen or pencil

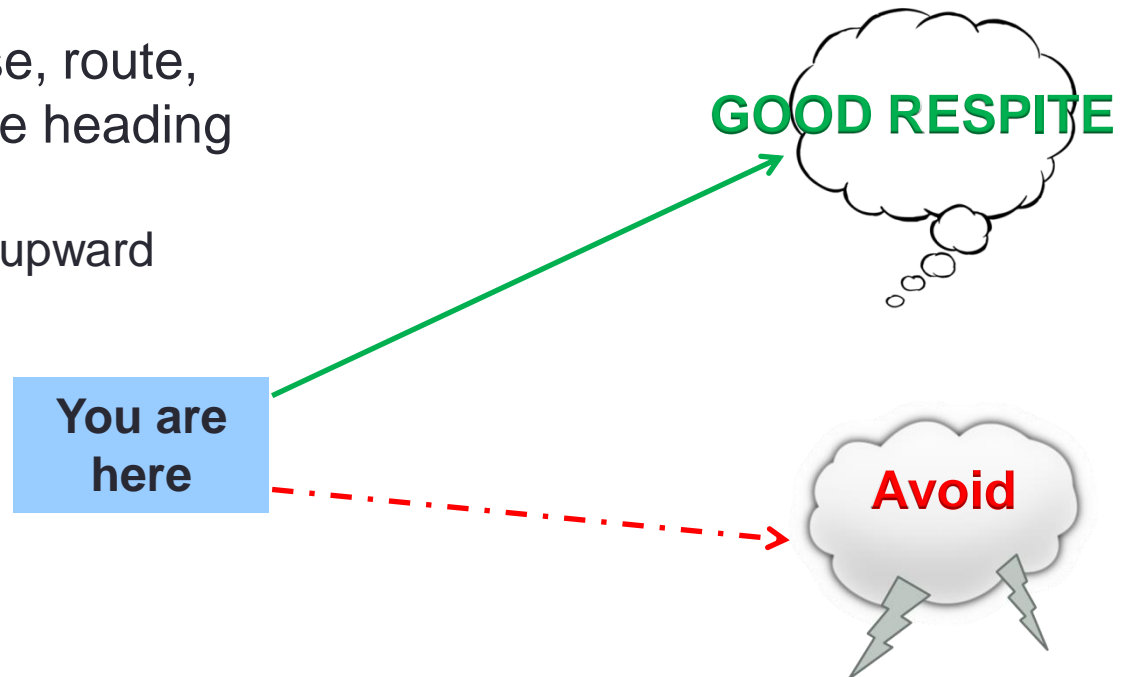


Quick Review of Part 1

- In the first part of this series you were introduced to the Charting the LifeCourse tool often called the **TRAJECTORY**.
- You identified what **GOOD RESPITE** would look like for you.
- You identified the things you want to **AVOID** when seeking **GOOD RESPITE**.

Trajectory = your course, route, direction, where you are heading

Your desired trajectory is upward toward **GOOD RESPITE**!



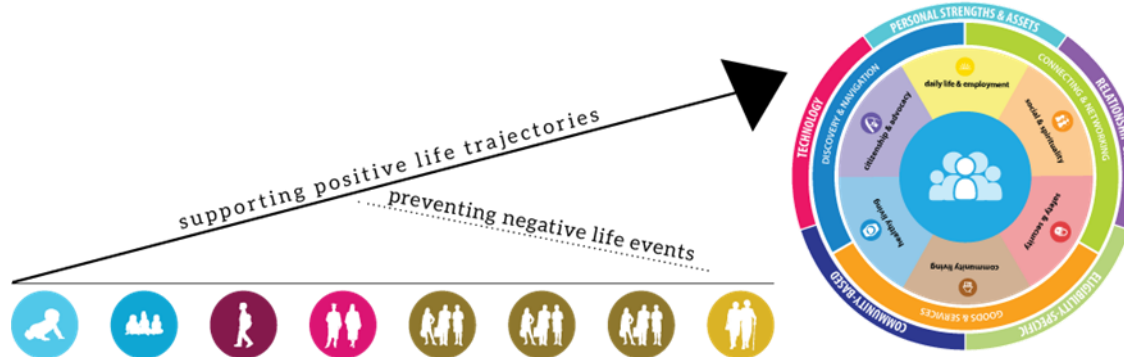
Quick Review of Part 2



- In this session you learned about the STAR tool.
- The STAR helps you identify 5 different types of resources that you currently have or could use in the future.
- The 5 categories are color coded and represent one point each on the STAR.

Putting it all together for GOOD RESPITE!

- You now have a vision for GOOD RESPITE and you've identified the resources available to you. Use all of these resources when looking for a break.
- Don't depend on just one type of resource.
- A more satisfying life is often one that integrates all 5 areas of support.
- Look to technology, friends, family, the community, and within your own personal resources to get a break. You don't always need to pay someone.



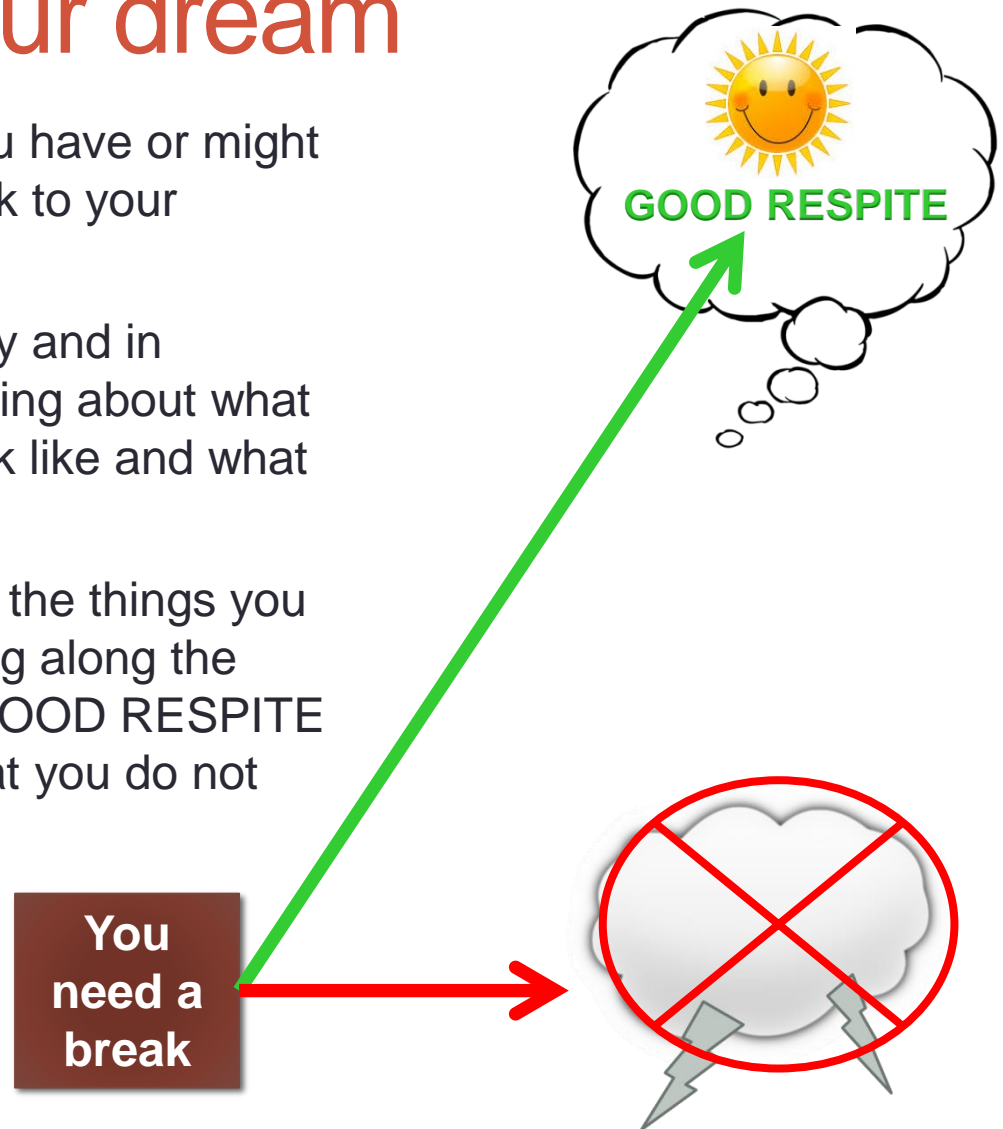
Putting it all together for GOOD RESPITE



- You and your family member are unique so everyone will have a different mix of resources to use.
- MyCare was designed to help when you need financial assistance in order to get a break.
- Use the personal and community resources you've identified to get the breaks you need and if they don't work or are not enough, MyCare funding can help fill in the gaps.

Circle back to your dream

- After identifying the resources you have or might have available you can circle back to your dream.
- LifeCourse talks about a trajectory and in Session 1 we talked about dreaming about what you want GOOD RESPITE to look like and what you want to avoid.
- You now need to identify some of the things you will need to do to keep you moving along the green arrow (trajectory) toward GOOD RESPITE and avoid the red line toward what you do not want.

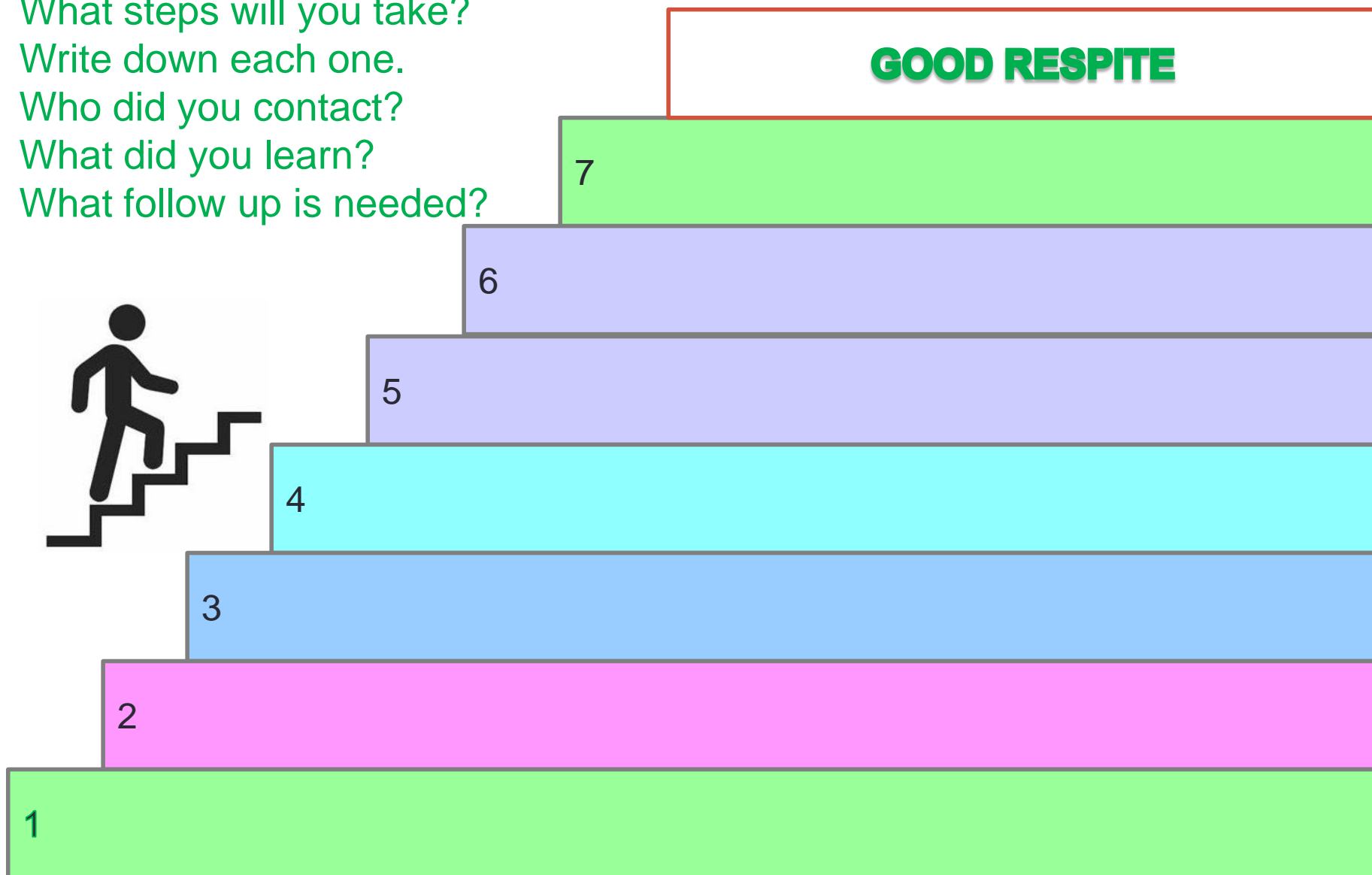


Circle back to your dream

- You need to write down some steps to take.
- Write them down and keep track of your progress.
- Make notes of what worked, who helped, what you learned.
- Your trajectory is not always going to be a straight line.
- It might look a lot like the gray line.
- Don't be discouraged. Keep your eye on where you want to be.



What steps will you take?
Write down each one.
Who did you contact?
What did you learn?
What follow up is needed?



Avoid a life only in the GREEN! Why?

- Using all the colors on the LifeCourse star creates a more integrated life, a balanced life.
- This can be more satisfying for your family member. It enriches their life.
- This is more like the life lived by their peers without disability.
- There is no ideal percentage of how supports should be spread over the different points of the star because every person and every family is unique.
- Avoid wait lists: Using integrated supports helps avoid over dependency on public funding that may be limited.
- This empowers you and your family to be more in control of the supports received.
- There are some families who simply have no other options and must rely heavily on the eligibility-specific supports.



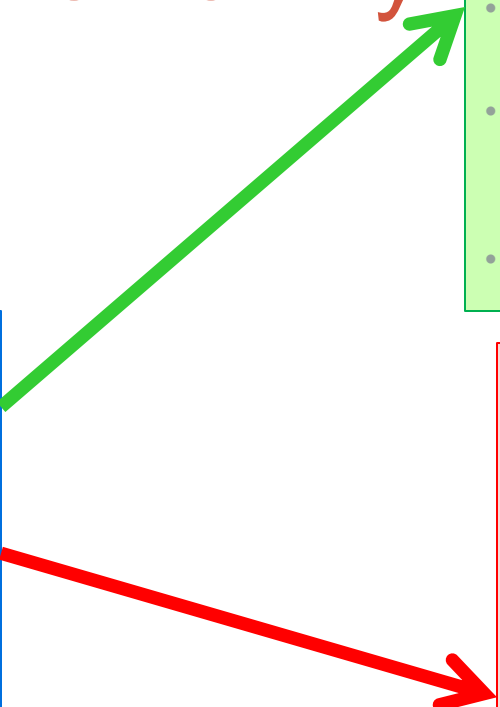
Finding providers is the #1 problem reported by MyCare families.

- There is currently a national crisis and shortage of individuals interested in providing direct care.
- Pay is too low & state/federal rates are not increasing to provider agencies.
- Some agencies are cutting back on services because they cannot hire or retain adequate staff.
- Families who want to hire their own staff are also feeling the impact of this crisis.



- 1. How might you use the LifeCourse framework to get a break?**
- 2. Will you always need to pay someone in order to get a break?**

Let's see an example. Meet Sarah and her family.



WHERE THEY ARE AT:

Sarah is 20 year old woman with Down syndrome who lives with her parents and her younger brother. Her parents work full time & Mom also helps her aging parents.

GOOD RESPITE:

- One weekend 4x a year
- Mom--2 hr on Wed for yoga
- Go with son to visit colleges
- A college-aged female or someone energetic
- In my home or the community
- Sarah is safe, feels comfortable, & likes the person
- Husband & I have time together to relax; have fun; self-care; & not worry about Sarah
- Affordable

AVOID:

- Male or someone physically unable to keep up with Sarah or unreliable
- Her to be harmed physically or emotionally
- House a mess or visitors
- Items stolen as in past
- Too Expensive

Technology

- video doorbell
- use tablet to video chat
- Computer to research
- Care.com for help finding someone

Personal Strengths & Assets

- Sarah can stay home ½ hr alone & can call 911 & Mom's cell. She is well liked.
- She volunteers at church nursery during services
- Dad used to work in HR interviewing & hiring
- Can afford \$100/day
- Mom used to hire babysitters

Relationships

- Mom's friend Ann has daughter in college & nieces
- Sarah's teacher
- Mom's & Dad's coworkers
- Paternal Grandparents
- Aunt Betty
- Neighbor Jessie
- Sister of brother's friend
- Brother

Respite for Sarah's Parents

- Family's church for Sunday School & Young Adult Club on Wed nights
- Community Center down the street
- YMCA

Community Based

- Sarah:
- gets SSI
 - has ABLE account
 - has Service Coordinator at DDA
 - is enrolled in MyCare at Pony Bird

Eligibility Specific

Circle back to trajectory

Things To Do:

- Talk to Ann to introduce her daughter to Sarah
- Ask Grandparents if she could stay with them
- Ask Brother to hang out with her during yoga
- See if YMCA has anything
- Ask if MyCare will pay when need more than \$100/day. Use voucher to see how it works.
- Etc Etc Etc

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GOOD RESPITE:

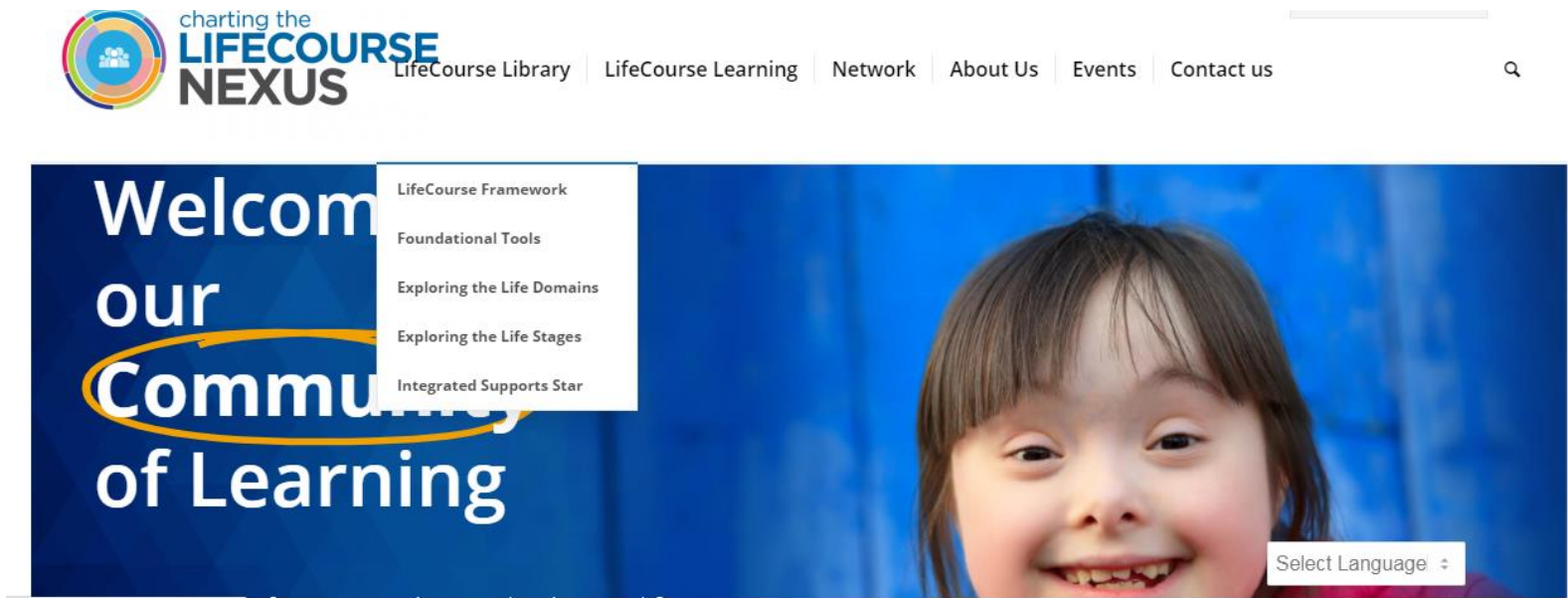
- One weekend 6x a year
- 2 hr on Wed for my yoga
- Go to things with Sarah's brother
- A college-aged female or someone energetic
- In my home or the community
- Sarah is safe & likes the person
- Husband & I have time together to relax; have fun; & not worry about Sarah
- Affordable

AVOID:

- Male or someone physically unable to keep up with Sarah or unreliable
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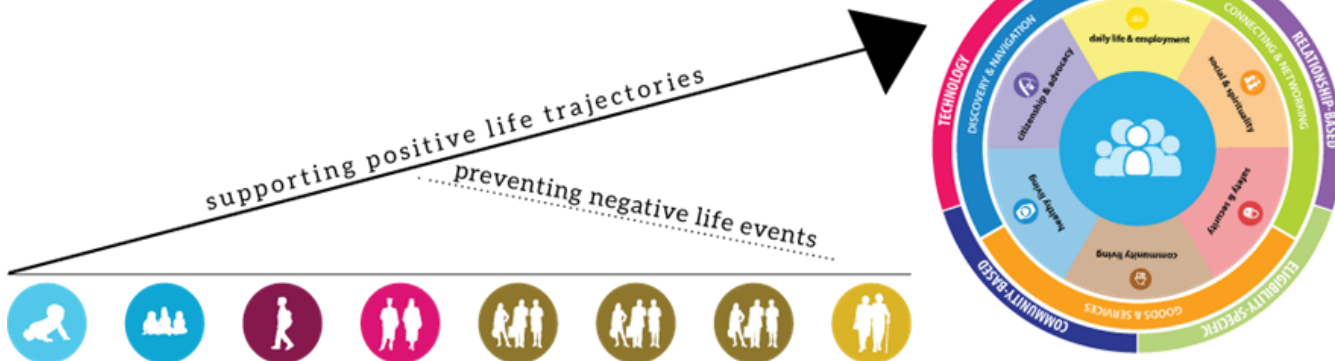
For more information online...

- Visit <https://www.lifecoursetools.com>.
- Drop down the menu for the “LifeCourse Library” then
- Slide over to “Exploring-the-life-domains” then
- Click on “Respite.”
- You will find videos and tools to use to continue your search for GOOD RESPITE.



Charting the LifeCourse

- Pony Bird can also mail you color copies of the Charting the LifeCourse tools that could be used to accompany this session.
- Request the tools by emailing or calling Pony Bird's Family Support office.
- FamilySupports@ponybird.org
- 636-282-1414 or 636-933-3764



Final Words of Wisdom

- ✓ Value all of your breaks not just paid services.
- ✓ Short respites can also refresh you.
- ✓ Any break can be meaningful.
- ✓ Be grateful and cherish every moment.
- ✓ Make getting a break a habit.
- ✓ Plan your breaks but take advantage when opportunities present themselves.
- ✓ If you keep your eye on GOOD RESPITE and identify your resources, you might be surprised how many opportunities come along. BE READY!



QUESTIONS

If you have any questions, email them to

LSWolf@ponybird.org

Or call and speak with someone in our office at
636-282-1414 or 636-933-3764



Pony Bird

