

CAREGIVING AND RESPITE

Report of Findings from a 2025 Survey of Caregivers in Southwest Ohio

Prepared by Heather Wells, LISW OCPS, for the
Butler County Family and Children First Council
March 2025



www.ButlerFCFC.org

TABLE OF CONTENTS

PURPOSE METHODOLOGY AND KEY FINDINGS..... 1

Purpose 1

Methodology 1

Findings Overview 3

Key Findings 4

SURVEY DATA 7

PURPOSE

METHODOLOGY AND KEY FINDINGS

PURPOSE

In November 2024, the Butler County Family & Children First Council developed a survey of caregivers in Southwest Ohio to inform their **understanding of the impact of caregiving** for those parenting children and adolescents with special needs as well as caregiver's **experiences with respite care**, including **access, satisfaction, barriers** and **recommendations**.

METHODOLOGY

An English only on-line survey was created using Qualtrics. An introductory screen detailed the purpose of the survey, anonymity of responses and an explanation of the term "respite."

"What is Respite Care? Respite care provides temporary relief for primary caregivers by offering short-term care for children or adults in need, allowing caregivers time to rest, attend to personal matters, or recharge. Respite care ensures that the individual in need (a child or adult with additional needs) receives safe attention, either at home, at a care facility, or in a community setting, while the caregiver has a chance to prioritize their own well-being. It's a valuable way to maintain a sustainable balance between caregiving and self-care."

The survey consisted of 24 quantitative and qualitative questions. Demographic variables collected included the county of residence, status as a caregiver of a child(ren) with special needs ages birth through 21, and the caregiver's relationship to the child(ren).

*Q2. Do you care for a child or young adult (ages birth through 21) who requires extra caregiving time because they have special needs?
Special needs could include developmental, emotional, behavioral or chronic medical needs, among others.*

Only respondents who selected “yes” or “maybe” to being caregivers for the targeted population were able to move through the survey questions. Those indicating they were not caregivers were taken to an exit screen.

Respondents who indicated they receive respite care were asked questions about their experience with this service. These questions were not asked of those who indicated they receive no respite services.

Distribution

The survey link was shared via email and social media by the Butler County Family and Children First Council (FCFC). Council member and partner agencies were asked to distribute the link to families they served. The link was also forwarded to FCFCs in Montgomery, Preble, Clermont, Warren and Clinton Counties for inclusion of families across the Southwest Ohio region. Responses were collected from November 4, 2024, through March 7, 2025.

Sample Size

- 545 individuals initiated the survey
 - The survey was completed by 77.7% of individuals who opened it
- 265 respondents identified themselves as a caregiver of a child with special needs, birth through age 21
 - 12 indicated they “may be” a caregiver
 - 199 respondents selected “no” to this screening question and were directed to the end of the survey

Limitations

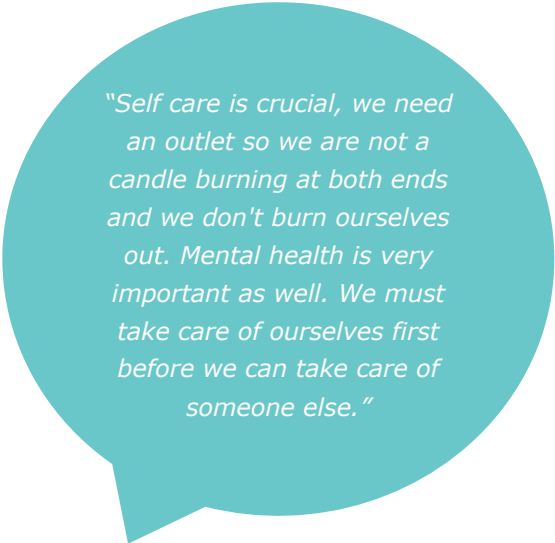
- The survey was only available in English, making it inaccessible to non-English speakers. Future surveys should be available in multiple languages to ensure accessibility.
- Race, gender and income of the respondents was not collected, limiting our understanding of the diversity of the sample or able to identify any trends that relate to these demographic variables. Future surveys should include one or all these variables to allow communities to better understand the unique needs of caregivers based on these factors.
- There is an over-representation of Butler County caregivers in the sample which may limit other counties’ ability to interpret and use the information collected. In the future, better engagement of key stakeholders and leaders in all targeted counties to create a plan for broad dissemination could result in a more consistent response rate.
- Inclusion of a definition of respite that implied a benefit may have biased the responses of some respondents. The definition was included to ensure that all respondents had the same understanding of a word they may never have heard before. Future surveys should include a more neutral definition to avoid influencing responses.

as ongoing support like monthly or biweekly care, would significantly ease the strain on caregivers.

Additionally, better communication about available resources and funding for respite care, especially for families with private insurance, is needed. Many also wish for more inclusive, age-appropriate activities for older children and adults, such as sports programs, camps, or events that can accommodate their needs. Finally, families are requesting more opportunities for care that don't require waitlists or navigating complex waiver systems, and a more personalized, consistent approach to respite care would be greatly appreciated.

KEY FINDINGS

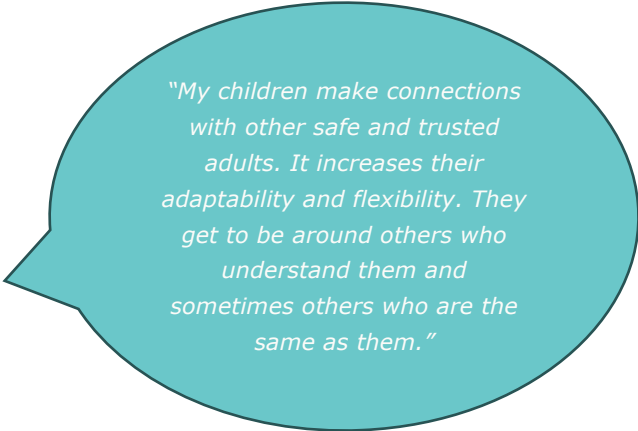
1. **The role of caregiving is complicated.** Many reported parenting multiple children with special needs (up to 4) of diverse ages and with multiple diagnoses. Caregivers may have a combination of biological, step, kinship, foster and adopted children in their home.
2. Caregivers of children with special needs in Southwest Ohio **experience frequent strain** that impacts their emotional or physical well-being: 96% report feeling strain while 44% report strain most or all the time.
 - Those with children with intellectual or developmental disabilities, autism and/or receiving special education services reported the most frequent strain
3. Caregivers find respite **beneficial to their family's well-being**: 27.4% state it is "very important," 49% state it is "extremely important." Benefits are tangible (can take care of tasks and responsibilities), emotional (time for self-care) and relational (spending time with spouse, other children, friends)
 - 62% reported that respite care improves their mental and emotional well-being, provides time for self-care (52%), rest and relaxation



"Self care is crucial, we need an outlet so we are not a candle burning at both ends and we don't burn ourselves out. Mental health is very important as well. We must take care of ourselves first before we can take care of someone else."

(47%) and time to strengthen relationships with other family members (48%)

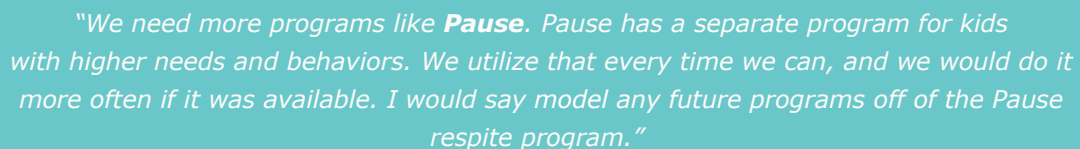
- 34% of caregivers report their children benefit from new experiences, socialization, fun and independence



"My children make connections with other safe and trusted adults. It increases their adaptability and flexibility. They get to be around others who understand them and sometimes others who are the same as them."

4. Many caregivers expressed **satisfaction** with and **thanks** for the services they receive

- 49% state they are moderately to extremely satisfied
- Pause for Parents Play for Kids was mentioned frequently as a model of respite care to which caregivers wish they and others had greater access



*"We need more programs like **Pause**. Pause has a separate program for kids with higher needs and behaviors. We utilize that every time we can, and we would do it more often if it was available. I would say model any future programs off of the Pause respite program."*

5. Caregivers **struggle to get information** they need to access respite. Only 49% reported that a professional had suggested respite care as an option.

- Boards of Developmental Disability were most frequently cited (33.3%) as helping access respite

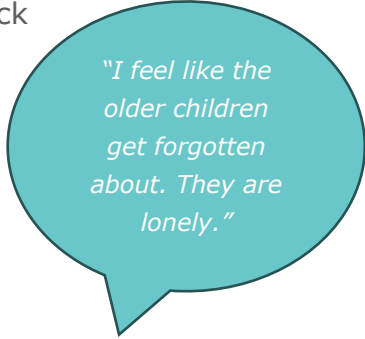
6. **Friends and family** are the primary sources of respite care being provided (79%).

7. Caregivers are **not getting the frequency of respite** that they feel would benefit them, their family and their children.

- 69% report needing more breaks than they have available
- 18% of those receiving respite only get it in a crisis; 10.4% only get a break one time per year
- 60.5% want to get a break one or more days per week but only 7.6% report currently having access that frequently

8. Caregivers are struggling to access **individuals and programs to provide the care** they need.

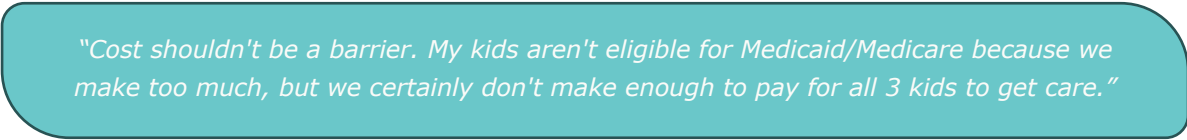
- Waiting lists, cost, lack of family and friends, and lack of knowledge of available services were the most frequently cited barriers to access
- The actual or anticipated inability of care providers to meet the complex needs of their child(ren) was cited frequently
- Families with multiple children of various ages and needs struggle to find providers to care for all the children; many report fewer available options as their child ages
- Willingness to trust their child to the care of others is a significant psychological barrier



"I feel like the older children get forgotten about. They are lonely."

9. **Financial support for respite is limited** and cost creates a significant barrier

- Only 62% of caregivers reported receiving help paying for respite
- Boards of Developmental Disabilities and Medicaid waivers were most frequently cited as assisting with payment



"Cost shouldn't be a barrier. My kids aren't eligible for Medicaid/Medicare because we make too much, but we certainly don't make enough to pay for all 3 kids to get care."

10. Caregivers want access to **many types of care** from both trained providers and volunteers

- Babysitter services were the most frequently requested (57.7%) followed closely by community-based programs (56.7%), camps (53.4%), and day programs (50.5%)
- Caregivers indicated they would access care offered by trained providers at a facility (70%) or in their home (65%) or by volunteers at a church (63%) or at a community center (57%)
- 37% requested overnight care

SURVEY DATA

Appendix A: 2025 Respite Needs Survey Results – All Responses
Appendix B: Qualitative Thematic Analysis

Appendix A

2025 Respite Needs Survey Results - All Responses

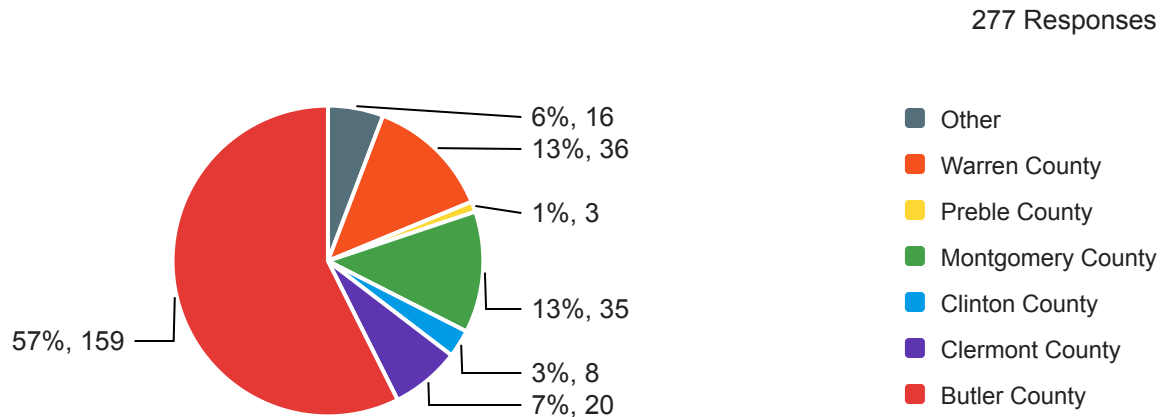
Survey Responses Received via Qualtrics: November 4, 2024 through March 7, 2025
Report prepared by: Heather Wells, LISW OCPS

- Page 1: Respondent Characteristics
- Page 6: Impact of Caregiving
- Page 9: Opportunities for Respite Care
- Page 18: Caregiver Recommendations

Respondent Characteristics

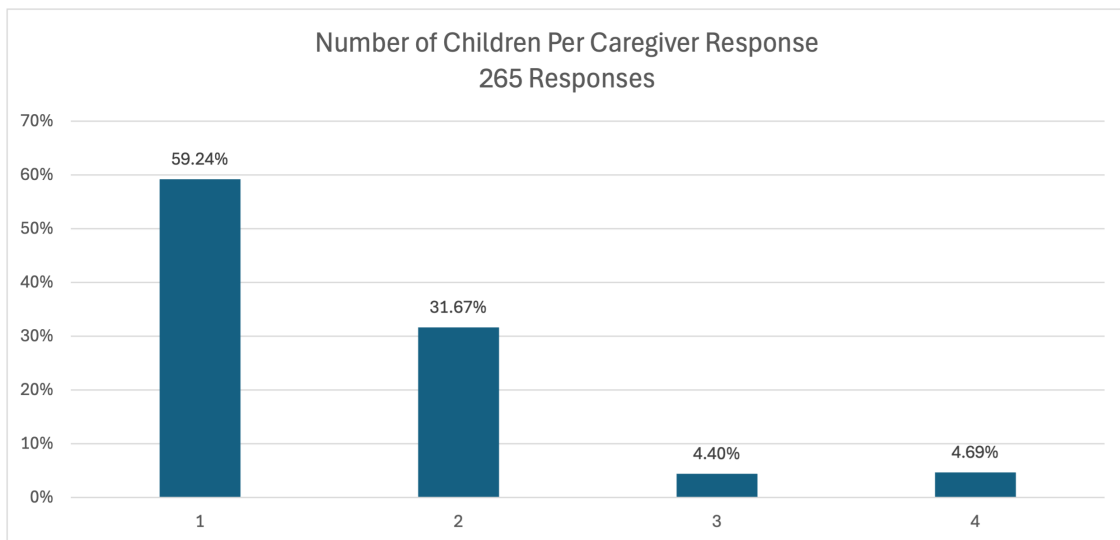
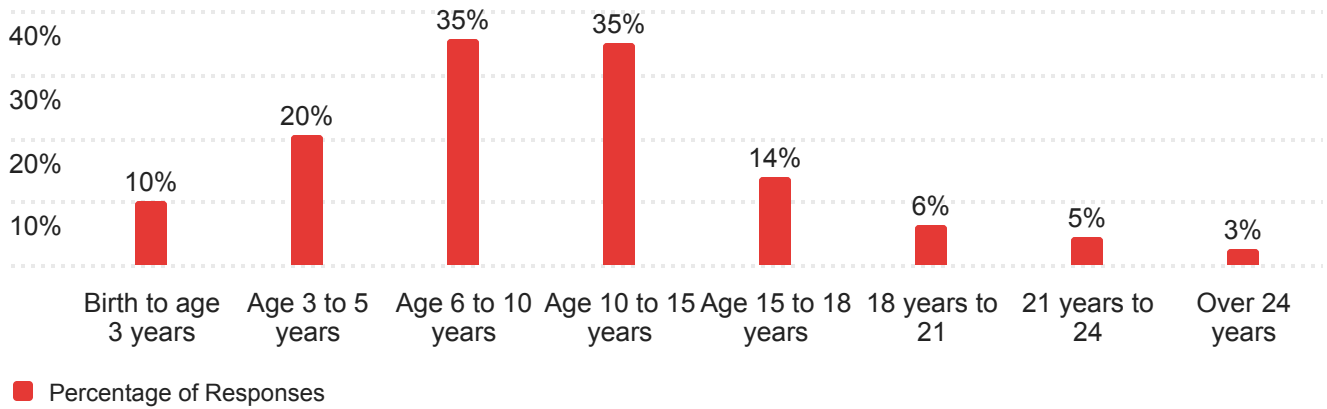
The survey targeted caregivers in southwest Ohio who care for a child or young adult (ages birth through 21) who requires extra caregiving time because they have special needs. Special needs could include developmental, emotional, behavioral or chronic medical needs, among others.

County of Residence:



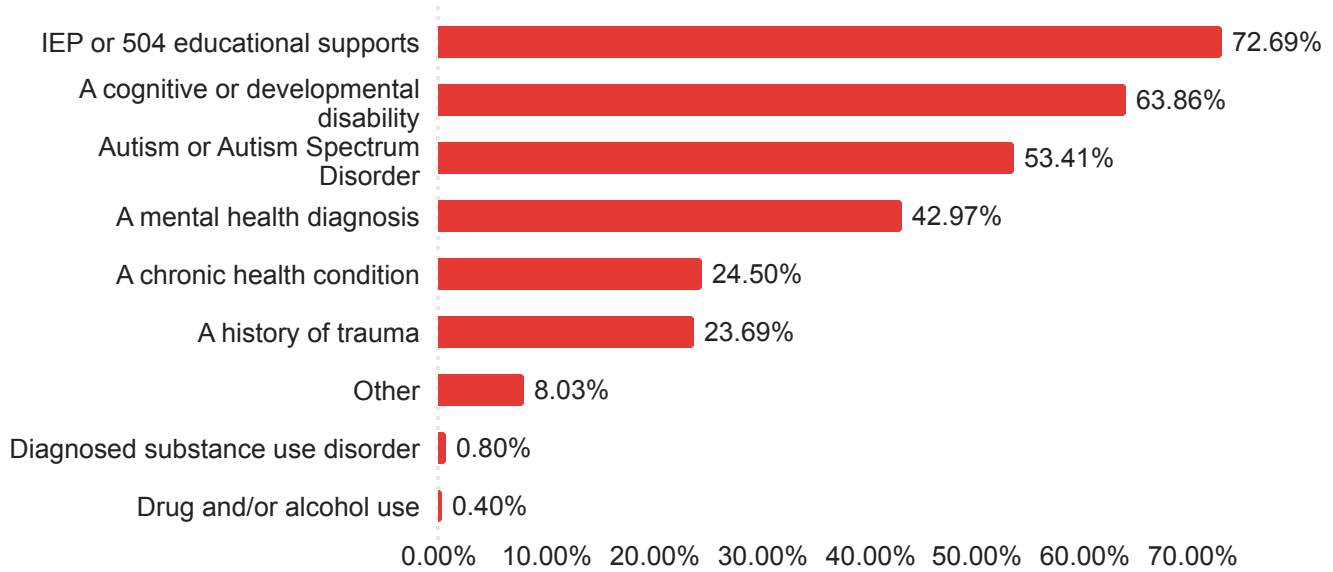
Age of the Child Cared For (Respondents could select more than one) Percentage of Responses

265 Responses



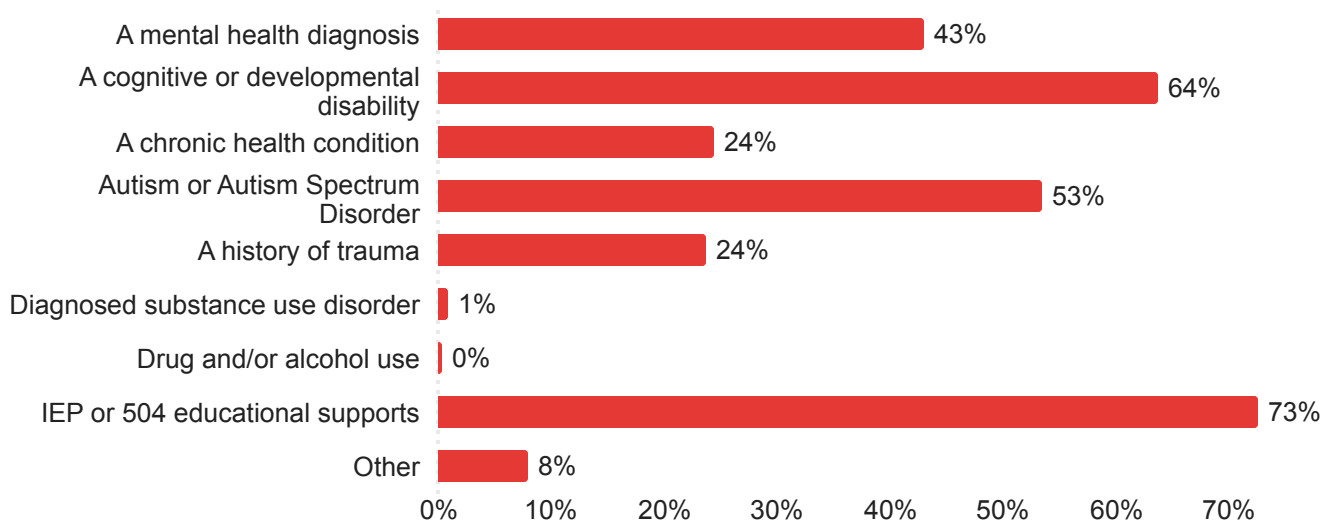
Child's Conditions/Supports: Respondents could select all that applied
Percentage of Responses

249 Responses



Child's Conditions/Supports: Respondents could select all that applied
Percentage of Responses

249 Responses



Percentage of Responses

Other - Text

Speech disorder

ADHD

Type 1 diabetic

Down syndrome

ADHD

Asthma

Developmental and Speech Delay

Developmental delay with speech

behavioral issues

Sensory processing disorder, mixed expressive-receptive communication disorder

Intermittent Explosive Disorder

Speech language processing issues

Severe speech and language disorder

Her throat isn't fully developed

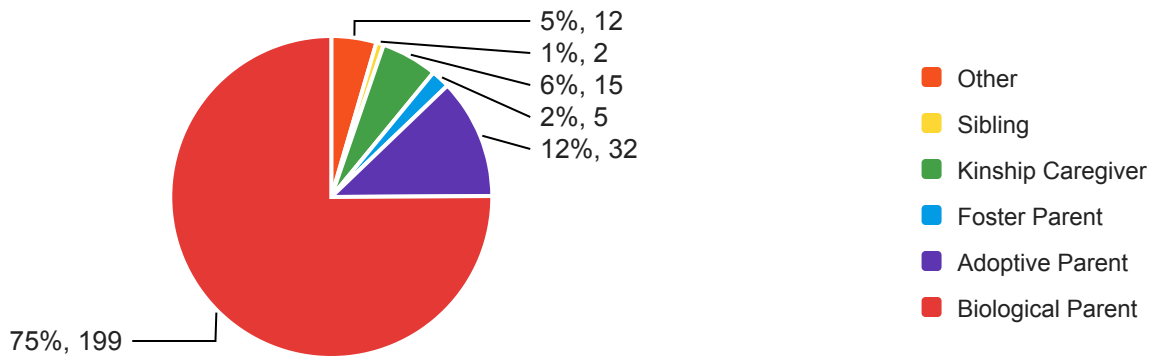
bi-lateral hearing loss

High risk for falls and bone fractures, multiple visual impairments, incontinence

Pans/pandas

Caregiver Relationship

265 Responses



Other - Text

Step parent

Daughter

I have adoptive and kinship kids

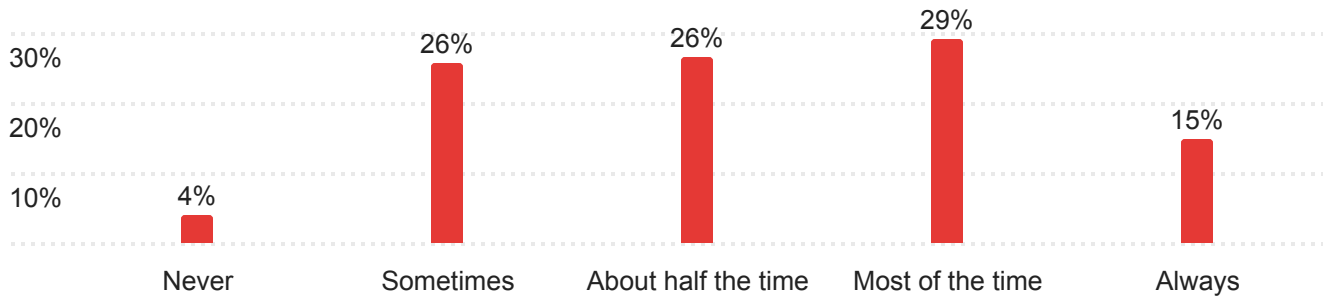
Step-mother/primary care

Both bio and foster

Impact of Caregiving

How often do you feel physically or emotionally strained by your caregiving responsibilities?

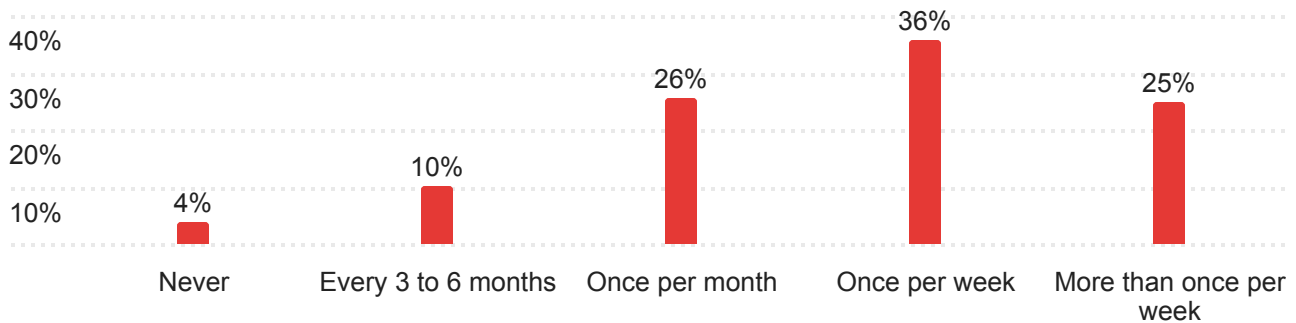
257 Responses



Field	Min	Max	Mean	Standard Deviation	Variance	Responses
How often do you feel physically or emotionally strained by your caregiving responsibilities?	1.00	5.00	3.25	1.11	1.23	257

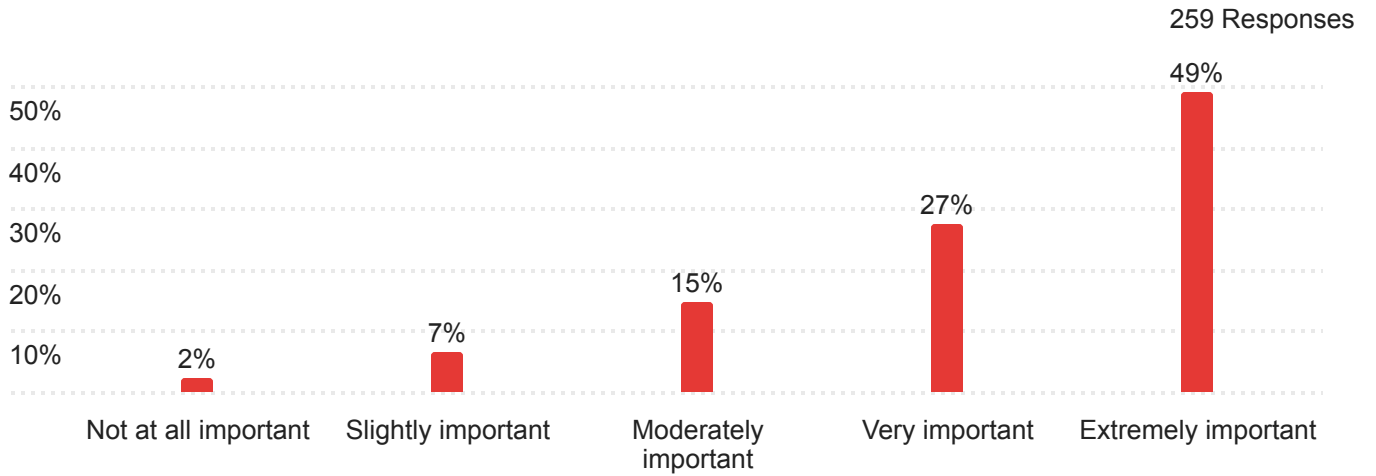
How frequently do you feel the need to take a break from your caregiving responsibilities in order to take care of yourself (self-care) or accomplish personal tasks (cleaning, shopping, etc.)?

258 Responses



Field	Min	Max	Mean	Standard Deviation	Variance	Responses
How frequently do you feel the need to take a break from your caregiving responsibilities in order to take care of yourself (self-care) or accomplish personal tasks (cleaning, shopping, etc.)?	1.00	5.00	3.67	1.07	1.15	258

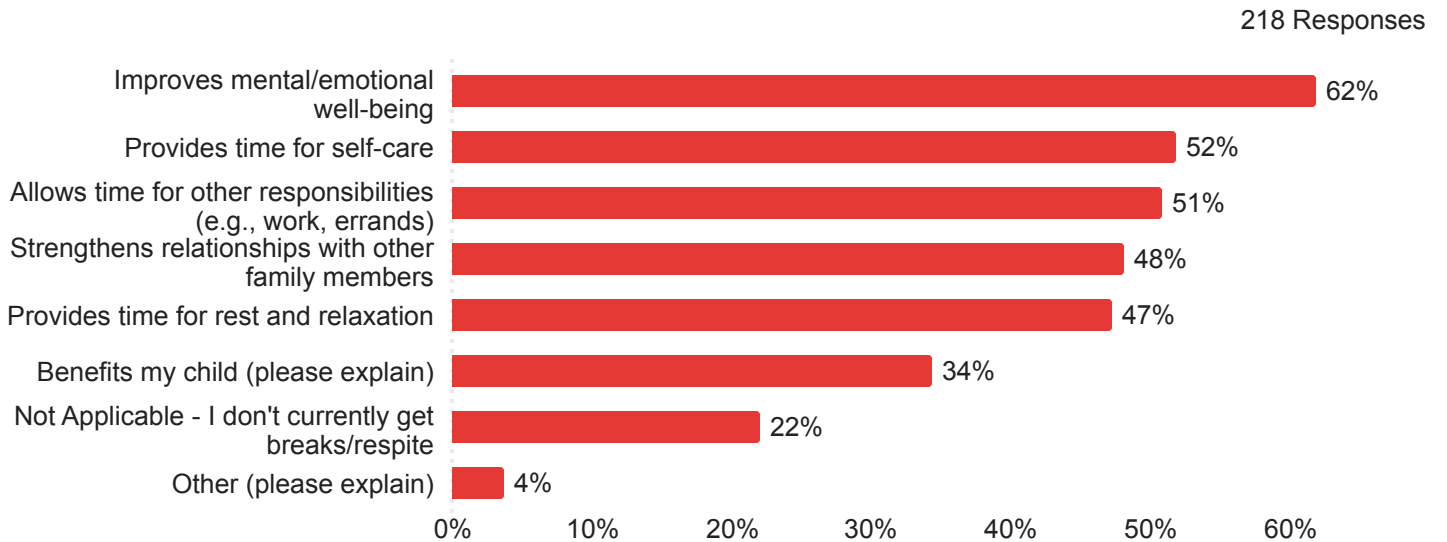
How important is getting a break from caregiving (respite) to your family's overall well-being?



Field	Min	Max	Mean	Standard Deviation	Variance	Responses
How important is getting a break from caregiving (respite) to your family's overall well-being?	1.00	5.00	4.14	1.04	1.09	259

When you use respite care, how does it benefit your family? (Select all that apply)

Percentage of Responses



Other (please explain) - Text

We have not used respite care

We have other children who have events that we would like to attend that aren't accessible or enjoyable for him to join.

ALL of these honestly (I could only pick one)

Enables some individual time on occasion with my teenager if she is not volunteering or doing something else, and we can drop the two younger children off at Pause.

Allows me to run errands, rest because I'm exhausted, build my relationship with my husband and fun for kids

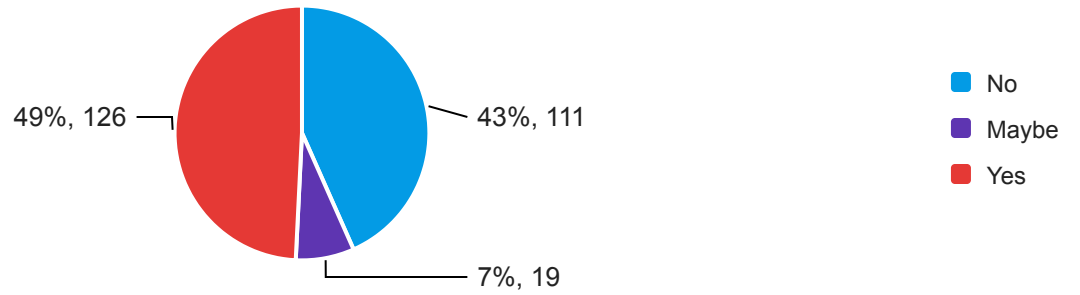
Does both - relax and also time with siblings and spouse.

Not able to do more than one but it's like a reset

Opportunities for Caregiver Respite

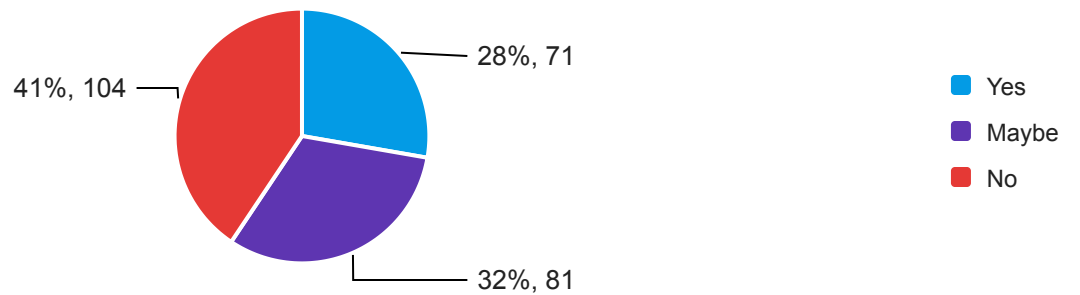
Has "respite care" ever been suggested or offered to you an agency or professional serving your family?

256 Responses



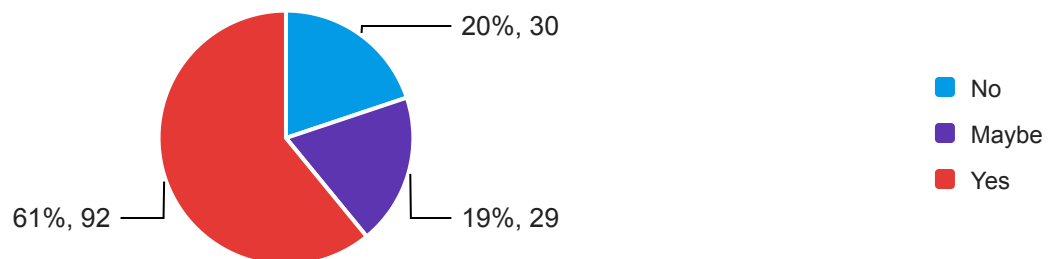
Do you currently have a way to get a break from your caregiving responsibilities when needed?

256 Responses



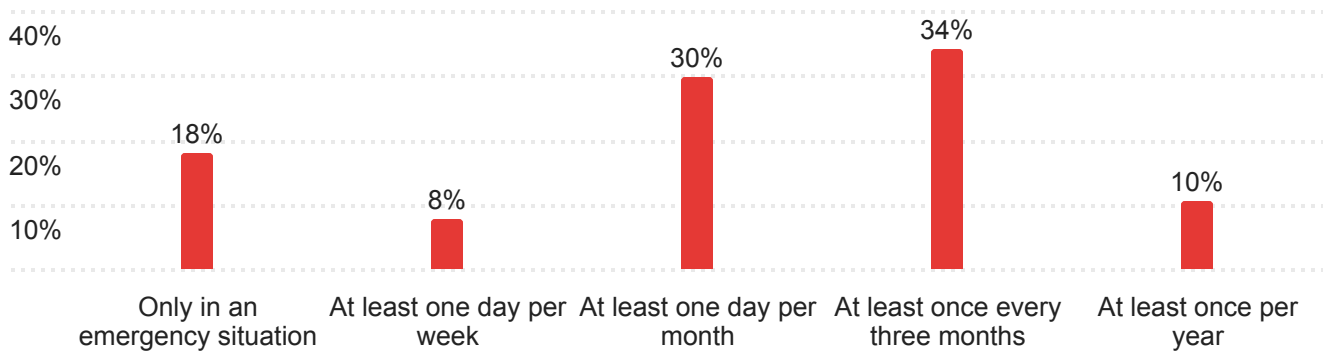
Do you feel that you need more respite (breaks) than you currently have available?

151 Responses



How often do you typically access respite (get a break)?

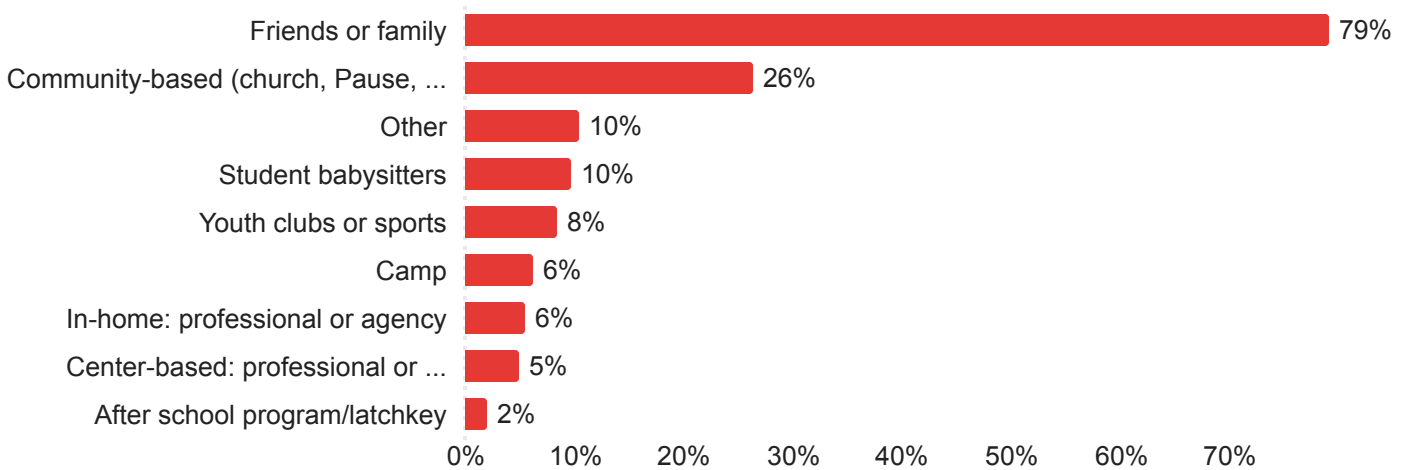
144 Responses



Who provides the care that gives you a break (respite)? (Select all that apply)

Percentage of Responses

144 Responses



Other - Text

Private home daycare

husband

Baseball

Pause

hubby

Independent provider paid through the waiver

Pause

He is now old enough (18) to stay alone for a few hours if need be

school transition program

Pause

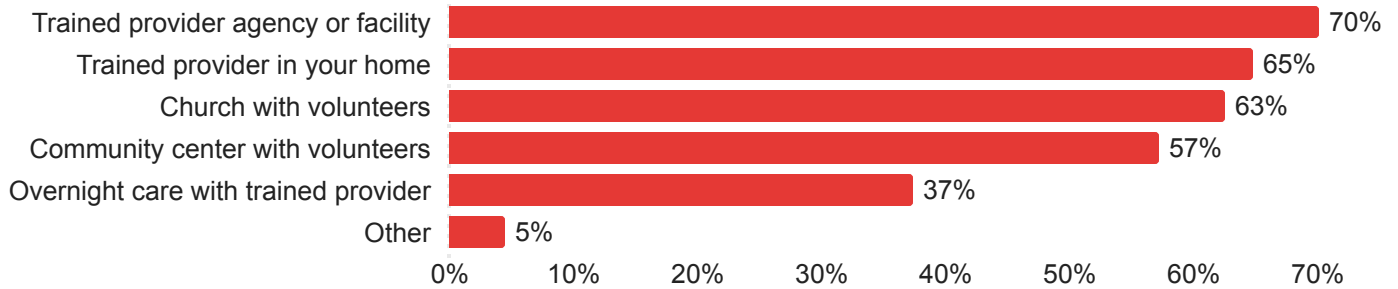
Vacation day from work while child is at school. No after school weekend options

Pause

Would you access respite care if it were offered in the following ways? (Select all that apply):

Percentage of Responses

131 Responses



Other - Text

at a church with paid staff

No

None don't need my kids older. They go to school. That's when I get a break

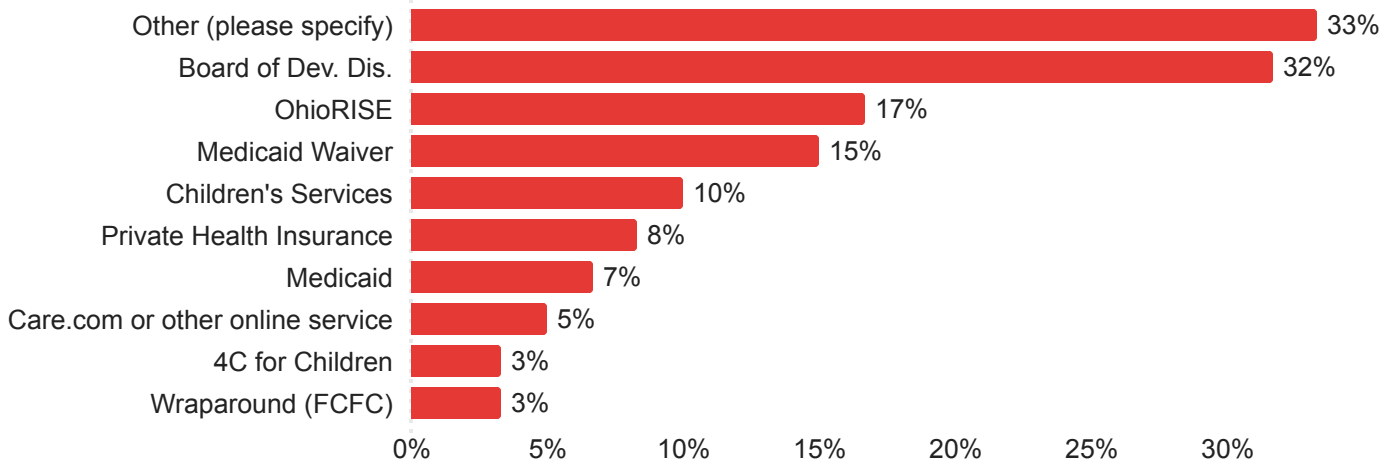
The setting isn't as important for us as someone who can handle our kids behaviors & needs

Due to my son's limited communication skills and willingness to do whatever is asked of him, I'm hesitant to leave him with anyone I don't know or haven't built trust with. I wouldn't do it just because they had a certification, I would need to have time to build trust with them. I have seen several instances where providers have taken advantage of their non-speaking client.

Do any of the following assist you in **finding** a respite care provider? (Select all that apply)

Percentage of Responses

60 Responses



Other (please specify) - Text

Ohio KAN

Maybe health insurance

none

No

Family support system.

None

No I don't need it. I know it's available.

I want to clarify that "help" in this context means "try." Like they put your name up for any providers that are looking for work. This hasn't yielded results in many years or they send someone super sensitive who feels "uncomfortable" being left alone with my daughter, so I don't get the break!

Pause

None

Pause

ARC

N/A

Me with a Google search

No

I depend on family and friends. There are also a few staff members at school who have provided respite for us. Most times, my husband and I switch off staying home with our son.

Air Force EFMP

None

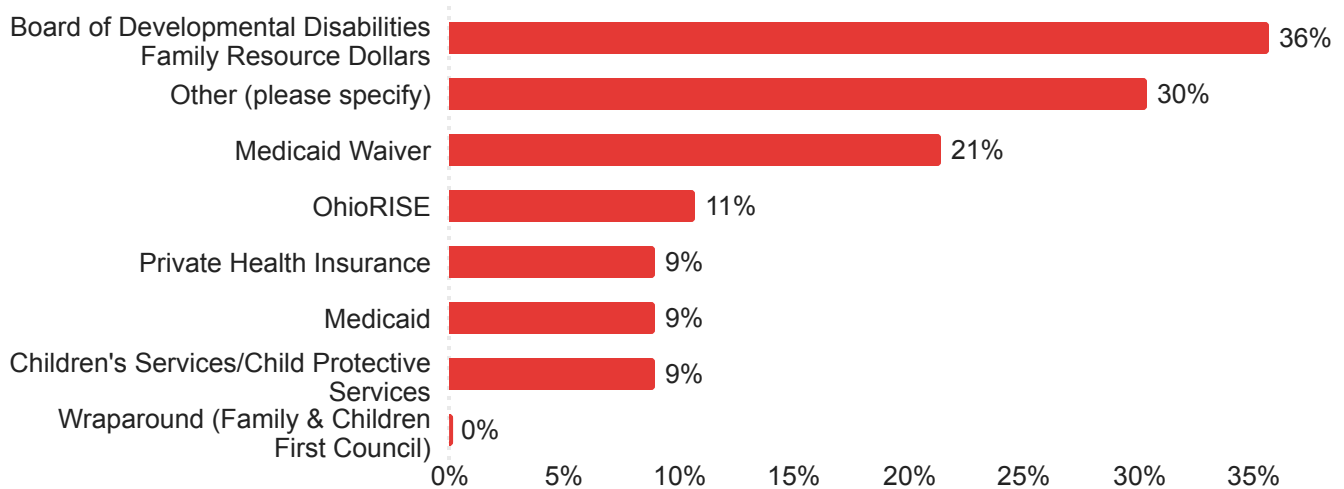
none

No

Do any of the following assist you in paying for respite care? (Select all that apply)

Percentage of Responses

56 Responses



Other (please specify) - Text

Ohio KAN

While we get money from the county most of it goes to making sure my kid gets Speech, OT sessions and covers the cost of child care during the summer. There isn't any left over to pay someone to give us respite.

no

No

No

No family asks to spend time with them.

No

PASSS - Post Adoptive Special Services Subsidy

None

N/A

Not sure if Aetna is the same payer as OhioRISE. Child also has CareSource Medicaid.

Care House

No

Air Force EFMP

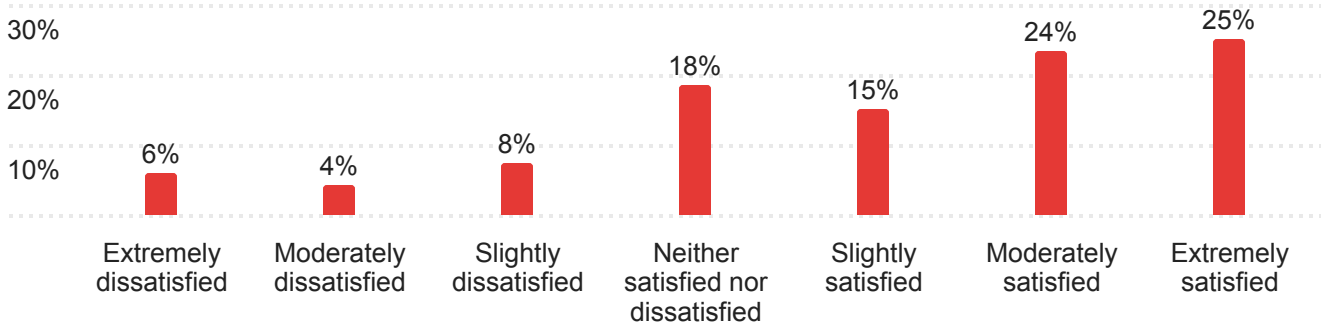
No

none

No

How satisfied are you with the respite care services you currently use?

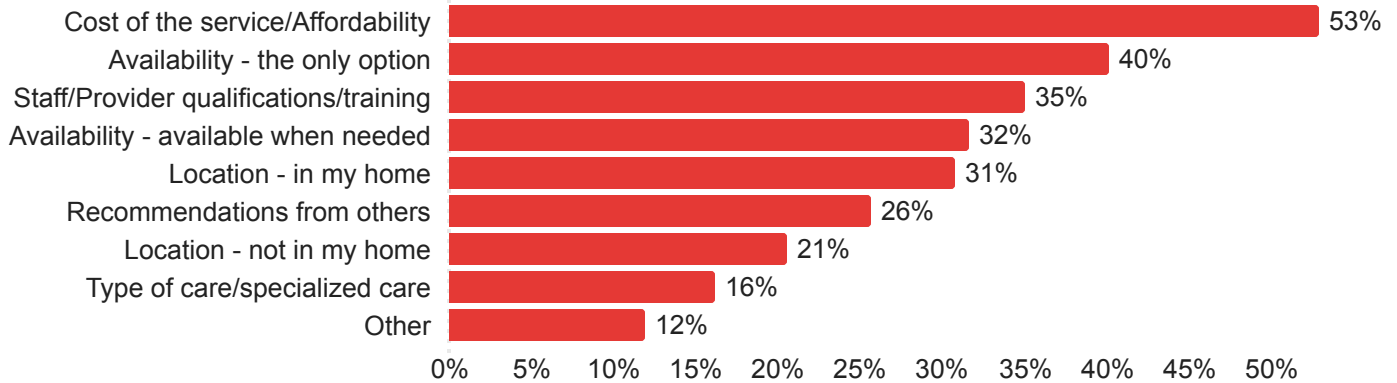
119 Responses



What factors influenced your choice of respite care service? (Select all that apply)

Percentage of Responses

117 Responses



Other - Text

Not currently receding respite care

I don't currently use respite care from an outside source, but these would be my priority for choosing respite care.

Other grandparents than myself

Right now don't respite care.

Right now we only use a family friend whom we know very well and Pause and cost was a consideration. We now have a waiver and will research trustworthy providers.

Trust-so far have only used family.

My overnight respite care is provided by family members.

Offered to me

Trust. The people who have provided services through the waiver were family and friends who became certified to specifically care fo Jack.

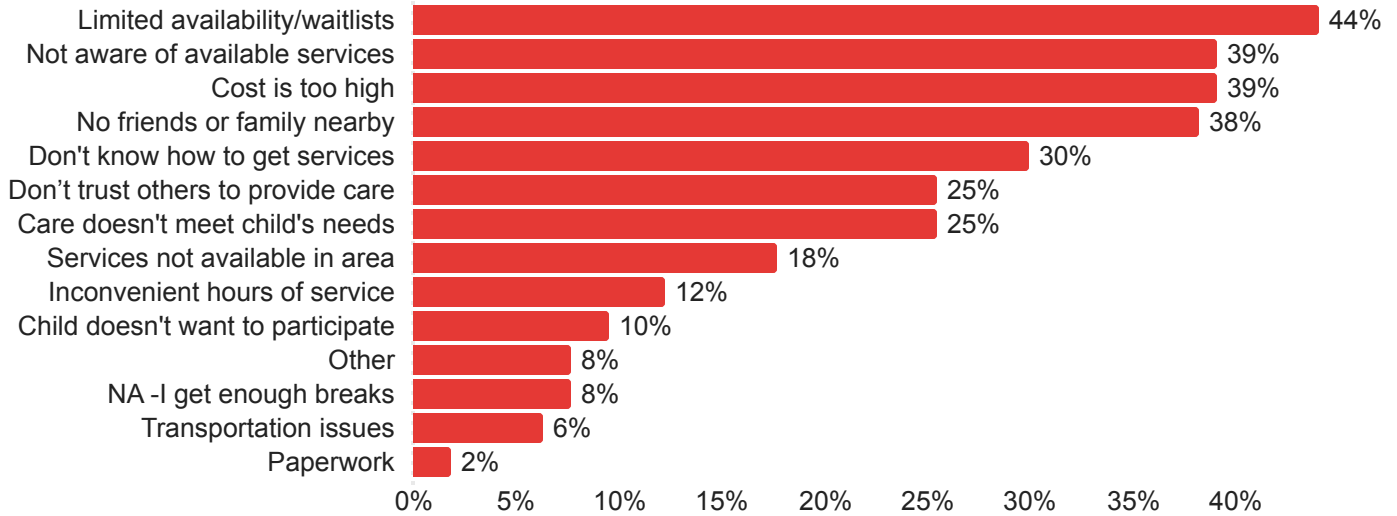
Personality, good match for loved one

Won't let me select more than one cost and availability are huge

If you are not able to get as much of a break (respite) as you need, what are the reasons? (check all that apply)

Percentage of Responses

220 Responses



Other (please explain) - Text

Limited family nearby to help

We don't have a waiver nor receive Family Support Dollars so we don't necessarily get info - not sure we qualify

I am a single parent who's mother is 82 and can only help at certain times. My best friend works 3rd shift and helos her elderly 90 year old mother. My other friend works at our small business and it is hard to take her awsy from work. I have to do it but also want too. I just get tired and overwhelmed.

Don't qualify for most programs, because of having private insurance.

My sons caregiving needs are more than a typical babysitter can accomodate.

Guilt over needing a break from a child I willingly chose to adopt. And leaving child who is manipulative and the ramifications of coming back from respite.

I was hoping to find an Independent Care Provider instead of an agency, but could not find one with the availability I needed.

I feel bad paying to take time to myself.

When my child was younger, I needed way more and got fewer breaks.

Child does not qualify on mental health diagnosis alone for services but has been under continual care of DDBP for 8 years at CCHMC

My children have various high needs. It's hard time find caregivers or programs that can accommodate all 3 of them.

Need care for child with extra needs and siblings. Finding someone for 4 kids including 1-2 high needs kids is hard.

Service hours that get with waiver are not enough to attract a respite caretaker

Limited availability/waitlists, high costs, I don't know how to get the services I need.

Having difficulty finding babysitters with experience or even want to help with my child.

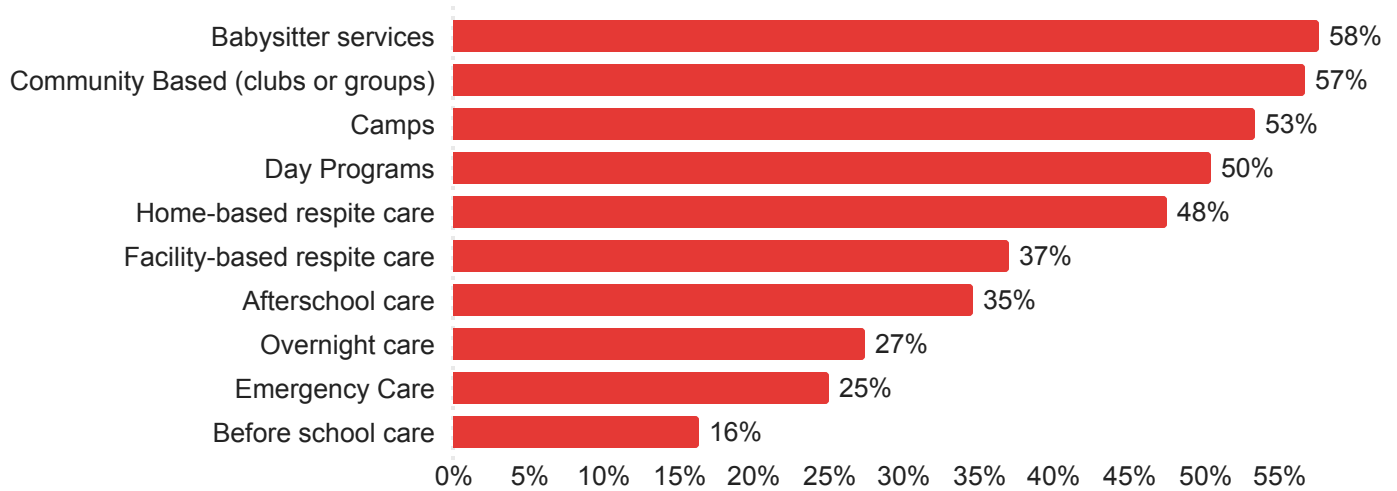
Again not able to select more then one but availability in our area is key , we go pretty far out sometimes

Caregiver Recommendations

What types of respite care would you like to have more access to? (Select all that apply)

Percentage of Responses

208 Responses



Other - Text

Church is the biggest thing for us

I dont know whatis available

Anything that would allow him to feel like he is cared for and maybe make a friend or connection.

Hard to describe since my son is 19. He doesn't need a playgroup, camp, etc. He needs someone to hang with or just check in on him if we go out.

Summer programming that won't throw us out because of behavior

I would love to have access to after school care for middle school students at Fairfield. Most services don't include children this age. My son is in 8th grade and would benefit from an after school program.

Out of home or care with "strangers" can be more traumatizing for a kiddo who has already been removed from bio home and/or spent time in residential care. This is a very difficult predicament for all involved!

Church based programs in our community

Many of these would be helpful. Our child has high support needs, and it's harder to find family and friends able to care for him as he gets older. There are very few summer options, as he is not toilet trained.

Summer options!

Support for sports/arts programs

Not able to select more than one but anything is helpful

All of the above. This question does not allow one to select multiple choice even though the question wording suggests it should be.

2025 SURVEY OF RESPITE NEEDS IN SOUTHWEST OHIO

QUALITATIVE THEMATIC ANALYSIS

PREPARED FOR THE BUTLER COUNTY FAMILY & CHILDREN FIRST COUNCIL

Prepared by: Heather Wells LISW OCPS

March 2025

The following thematic analysis was conducted to summarize responses to qualitative survey questions asked of caregivers in Southwest Ohio who are parenting children (ages birth through 22) with special needs. The survey sought to understand the impact of caregiving, families' access to respite care and recommendations for system leaders to improve the services available to their family.

The survey was completed by 272 caregivers residing in 8 counties across Ohio.

THEMES THAT EMERGE FROM THE CAREGIVER RESPONSES ABOUT THE BENEFITS OF RESPITE CARE FOR THEIR CHILD/CHILDREN:

1. Socialization and Building Relationships (25 responses)

One of the most frequently mentioned benefits of respite care is the opportunity for children to develop social skills and build relationships with peers and trusted adults. Many caregivers emphasized that their children have limited opportunities for social interaction outside of respite programs. Respite care provides a structured and supportive environment where children can engage with others, make friends, and feel included.

- "They get to participate in fun activities & interact with other children & adults."
- "My children make connections with other safe and trusted adults. It increases their adaptability and flexibility."
- "My child builds relationships with other trusted caregivers and peers at Pause."
- "He gets to experience new people, activities, and places, which I believe help him to grow overall."

- "Gives my child time and space to make friends and have kids the same age to play."

2. Parental Well-being and Capacity (10 responses)

Caregivers consistently expressed that respite care allows them to recharge, manage stress, and be more present and patient when caring for their child. Many noted that when they have time for self-care, their ability to parent improves, benefiting both themselves and their children.

- "When my mental health is good I am a better parent, which benefits my child!"
- "I'm more equipped to parent in a positive way. It gives me hope to be able to continue to care in the future."
- "I am a better parent and more patient. I also have more time to think and reflect."
- "Helps because he gets a recharged parent afterwards."
- "As much as we need a break, our kids need a break from us."

3. Independence and Exposure to New Experiences (12 responses)

Respite care offers children the opportunity to interact with different caregivers, navigate new environments, and build confidence in their ability to function independently. Some caregivers highlighted that their children have difficulty separating from them, and respite care provides a safe space to practice independence.

- "Shows my children via action that they can rely on more than just me to care for them and to meet their needs."
- "He likes being with someone other than me."
- "Different people and surroundings—loves to explore, so he likes new people and places!"
- "He loves his independence and this state needs to offer more opportunities locally."
- "Being around kids like them and being around other siblings of kids with disabilities."

4. Opportunities for Fun and Engagement (9 responses)

Many caregivers emphasized that respite care provides their children with a chance to have fun and participate in activities they enjoy. Some children may not otherwise have access to recreational opportunities that align with their interests, making respite care a critical outlet for enjoyment and personal growth.

- "Gets them out and about in a safe space where people care about their happiness."

- "The activities Pause provides build my child's self-esteem, and he makes/keeps friends there."
- "He enjoyed being able to engage and socialize with other kids around his age."
- "Benefits my child—he can do fun things socially with kids similar to him."
- "He loves PAUSE. Gives him a place I know he's safe that he enjoys going to."

5. Preparation for Future Transitions (8 responses)

Respite care helps children practice skills necessary for future independence, including adjusting to new routines, engaging with different caregivers, and learning social norms outside of their immediate family. Some caregivers see respite as a steppingstone to greater autonomy as their children grow.

- "Helps with practicing transitions and social interactions."
- "Forming relationships with other people is crucial for a future when parent caregivers are no longer living."
- "It gave him a different environment to be in. He had the opportunity to realize that the rules we had were not set up just for him, but for society."
- "If respite is with other children—day camp, etc.—it is good practice for my son to be around peers."
- "My child loves his independence, and this state needs to offer more opportunities locally to give my child overnight camp to set him up for success in a group home."

6. Family Connection and Balance (7 responses)

Respite care allows caregivers to dedicate time to other family members, complete necessary household tasks, and maintain balance in their lives. Several caregivers noted that they struggle to give attention to their other children while caring for a child with high needs, and respite care provides that necessary time.

- "It allows me to spend time with my other children, on getting home tasks done, errands, etc."
- "Time with his grandma who lives an hour away."
- "Enjoy being out of the house but with 3 kids, not physically able to safely go out."
- "He struggles with self-regulation and relationships—time to be with others helps strengthen his skills."
- "He gets a break too!"

7. Community Inclusion and Belonging (6 responses)

Several caregivers shared that respite care helps their child feel like a valued part of the community. Whether through structured activities or simply being in a space designed for their needs, respite care fosters a sense of belonging.

- "She feels included and valued by the community."
- "Gets a break from the same old routine and experiences new places and people."
- "My children deserve to have a life outside of school and the home. They should know that they can have friends and live a life full of friends."
- "Being around others who understand them and sometimes others who are the same as them."
- "Allows her to temporarily focus on something else."

8. Safe and Supportive Environment (9 responses)

Caregivers value respite care as a trusted space where their children are cared for, understood and supported.

- "He loves PAUSE. Gives him a place I know he's safe that he enjoys going to."
- "He does not have many friends outside of Pause. When he is there, I know he is cared about as well as cared for."
- "Forming relationships with other people is crucial for a future when parent caregivers are no longer living."

THEMES RELATED TO THE QUESTION

“WHAT COULD BE IMPROVED TO BETTER MEET YOUR FAMILY’S RESPITE CARE NEEDS?”

1. Increased Availability of Respite Care (51 responses)

Caregivers expressed a strong need for more frequent, reliable, and accessible respite care opportunities.

- "Pause respite is only 3 times a year now. It is not enough anymore to make the same regular impact it used to when it was regular and monthly."
- "More availability. There seems to be no available respite care for my son."
- "We would like the opportunity to have respite. Even monthly would be beneficial."

2. Expanded Program Options (42 responses)

Families requested additional program types, including weekend and summer care, emergency respite, and options for older children.

- "Weekend program during the school year and summer day camp or service during the summer."
- "Teen summer programs."
- "Opportunities for summer and day camps that are equipped to care for my child."

3. Qualified & Trustworthy Providers (37 responses)

Many caregivers emphasized the need for trained, experienced, and dependable providers who understand the specific needs of children with disabilities.

- "Qualified, trained providers available when needed."
- "More trained services available that don't cost so much you can't afford it."
- "Having someone trustworthy."

4. Financial Accessibility & Funding (32 responses)

Many families struggle with the cost of respite care and need additional funding support without sacrificing other essential therapies.

- "We need a way to pay for respite that isn't taking money away from speech or OT."
- "More funding for Pause to get off the waitlist."

- "Money for respite care and after-school care available for kids with special needs."

5. Better Outreach & Communication (27 responses)

Some caregivers were unaware of available respite services or found it difficult to navigate the system to access them.

- "I really don't know what's available, beyond the limited care I'm already using."
- "Instead of continually telling me that I need to take a break and I need respite, actually link me to resources."
- "More information on how to access respite care."

6. Inclusive & Specialized Care (24 responses)

Caregivers highlighted the need for services that accommodate children with higher support needs and those with complex medical or behavioral challenges.

- "My son is medically fragile. Group activities like camp are not an option. I need respite in my home."
- "More spots in programs/camps & more respite providers able to handle higher needs kids (elopement, incontinence, behavior issues)."
- "A program where my other child could also be included. He is not autistic but does have ADHD and sensory modulation disorder."

THEMES RELATED TO THE QUESTION

“ARE THERE ANY OTHER COMMENTS OR SUGGESTIONS YOU WOULD LIKE TO SHARE ABOUT YOUR EXPERIENCE OR NEED FOR RESPITE CARE SERVICES?”

1. The Critical Need for Respite to Support Caregiver Well-being (36 responses)

Caregivers emphasized how essential respite is for their mental health, relationships, and ability to provide quality care.

- "When we are able to receive respite, it recharges us in a way that nothing else can."
- "Respite care gives me a time to de-stress. It gives me time to be with my husband for a few hours. We need more of it."
- "Self-care is crucial. We need an outlet so we are not a candle burning at both ends and we don't burn ourselves out."

2. Lack of Availability and Accessibility of Respite Services (31 responses)

Many families shared their frustration with long waitlists, limited providers, and not being able to utilize existing funding due to a lack of available caregivers.

- "There is funding available for my daughter to get respite services, but there is no one to do it. I've been waiting years."
- "We have an allowance through the state and can't even utilize it."
- "We are on the waiting list for Pause but currently unaware of any other options."

3. The Need for More Specialized and Consistent Care Providers (28 responses)

Families struggle to find providers who are trained, reliable, and willing to work long-term with their children's needs.

- "We are looking for someone who loves to do the work, is an advocate for people with disabilities, and has the training required to do the job well."
- "Respite care is very much needed. A lot of individuals are not qualified or comfortable providing care to special needs children."
- "It is hard to find people that can appropriately work with children with mental health disorders, such as OCD."

4. Financial Barriers to Accessing Respite Care (24 responses)

Families shared concerns about the cost of respite, the complexity of financial aid, and the lack of options for those who don't qualify for Medicaid or waivers.

- "Cost shouldn't be a barrier. My kids aren't eligible for Medicaid because we make too much, but we certainly don't make enough to pay for all three kids to get care."
- "We need money for it and qualified people to provide it. Training for volunteers is important."
- "The process to pay a babysitter through Family Fund resources is very labor-intensive."

5. A Greater Need for Inclusive & Expanded Respite Options (21 responses)

Caregivers noted the need for respite services beyond standard models, including after-school programs, summer camps, and care for children with high behavioral needs.

- "There isn't an option for after-school care for special needs kids."
- "We need more programs like Pause. They have a separate program for kids with higher needs, and we utilize that every time we can."
- "There are far fewer opportunities for children with behavioral issues, and that means we get virtually no respite."

6. The Emotional & Social Isolation of Caregiving (19 responses)

Many caregivers expressed feelings of loneliness and a lack of organic respite opportunities, such as social events or informal community support.

- "Not having help feels very lonely."
- "Stronger support groups or more options are needed to build organic respite opportunities."
- "For mainstream kids, invitations to birthday parties or sleepovers are organic respite. For kids with medical needs or big behaviors, those invitations are few and far between."