

# Respite Needs Survey: Butler County

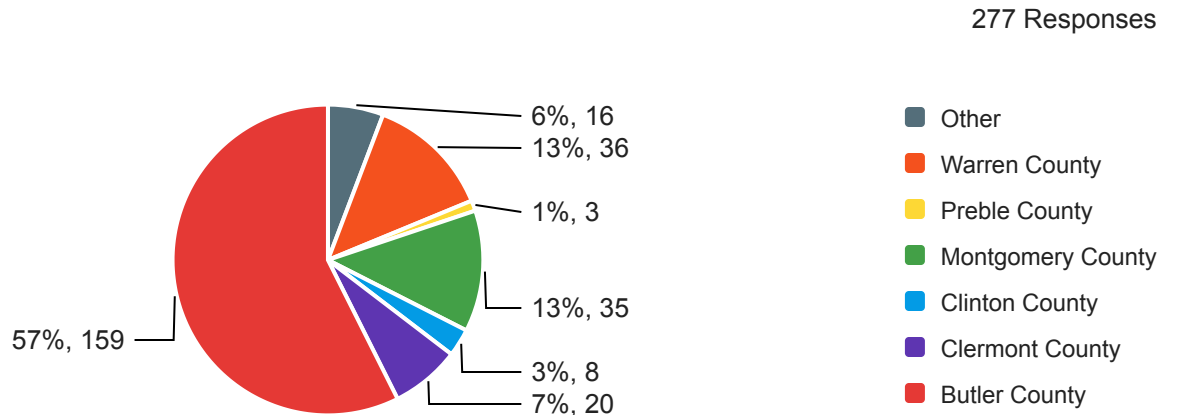
Survey Responses Received via Qualtrics: November 4, 2024 through March 7, 2025  
Report prepared by: Heather Wells, LISW OCPS

- Page 1: Respondent Characteristics
- Page 4: Impact of Caregiving
- Page 8: Opportunities for Respite Care
- Page 14: Caregiver Recommendations

## Respondent Characteristics

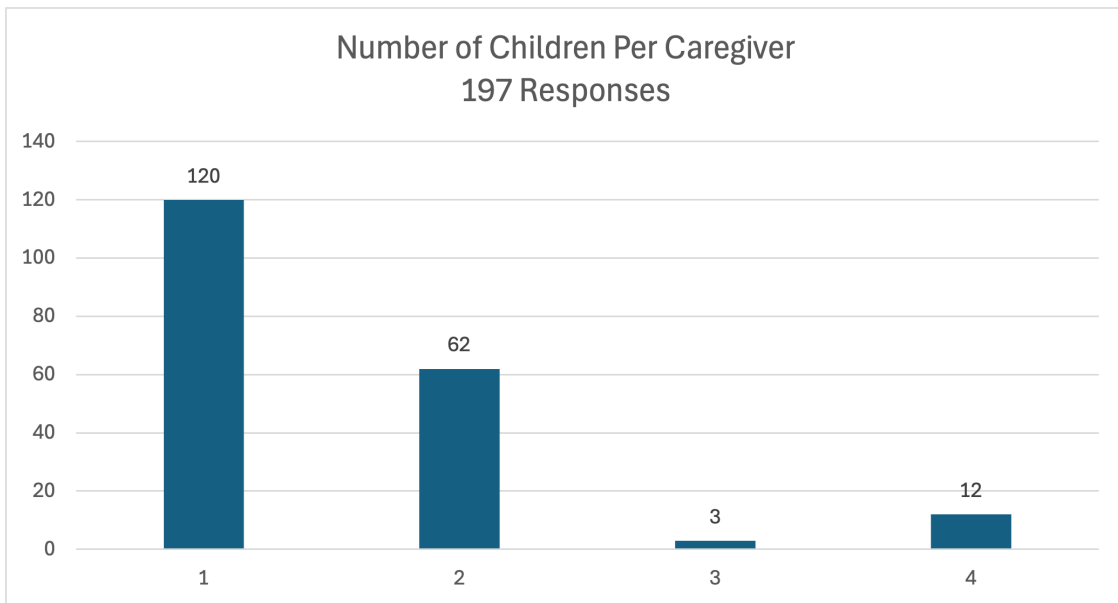
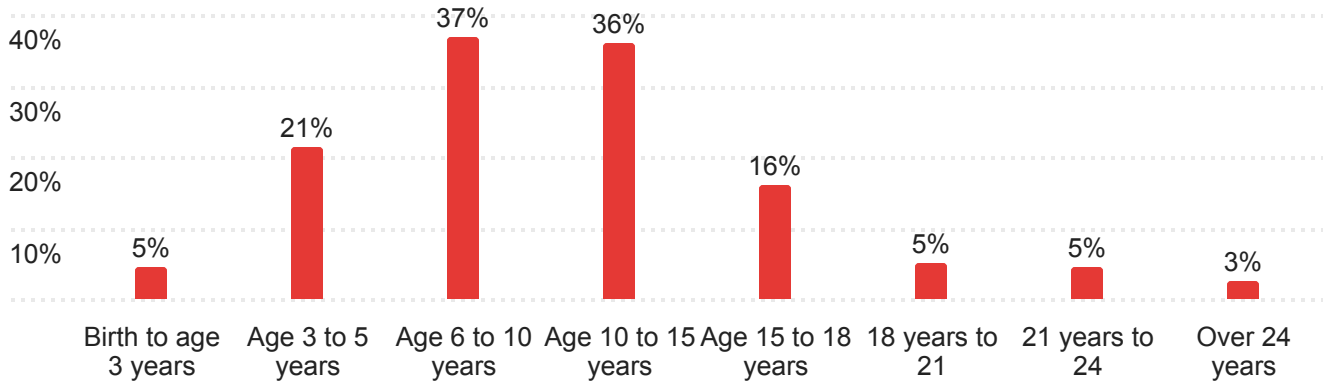
The survey targeted caregivers in southwest Ohio who care for a child or young adult (ages birth through 21) who requires extra caregiving time because they have special needs. Special needs could include developmental, emotional, behavioral or chronic medical needs, among others.

County of Residence:



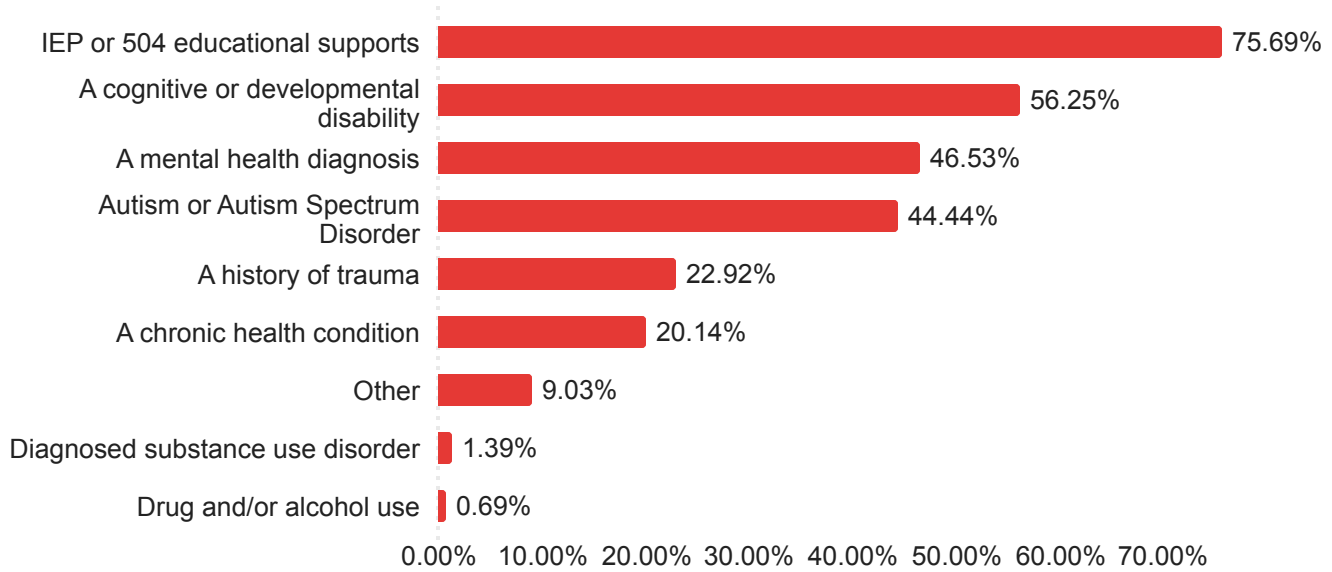
### Age of the Child Cared For (Respondents Could Select More than One) Percentage of Responses

155 Responses



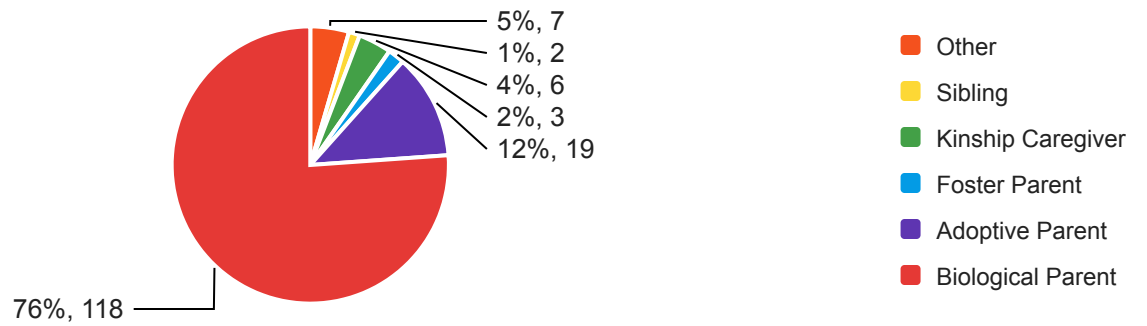
Child's Conditions/Supports: Respondents could select all that applied  
Percentage of Responses

144 Responses



Caregiver Relationship

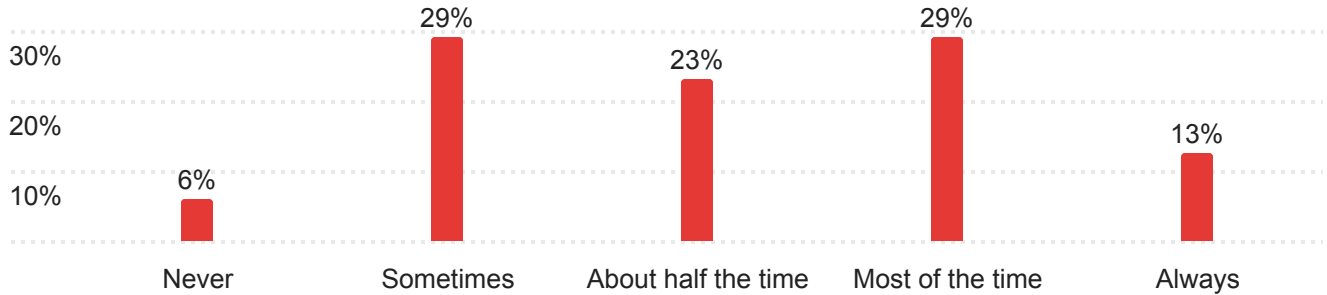
155 Responses



## Impact of Caregiving

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

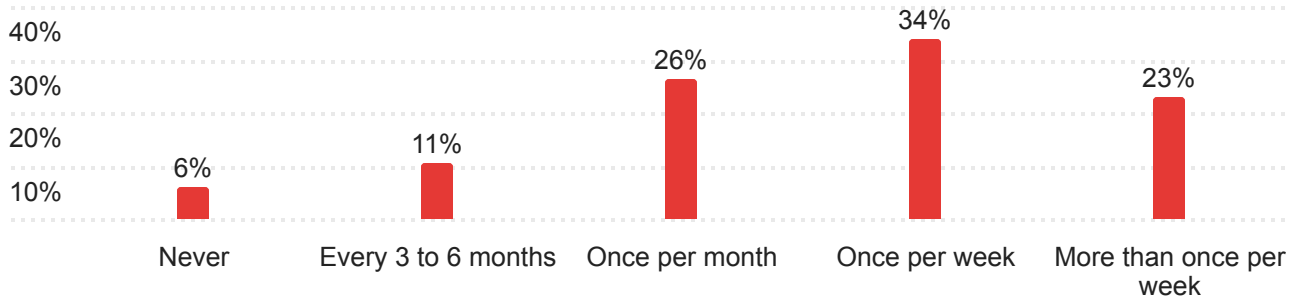
151 Responses



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	3.13	1.14	1.31	151

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.)?

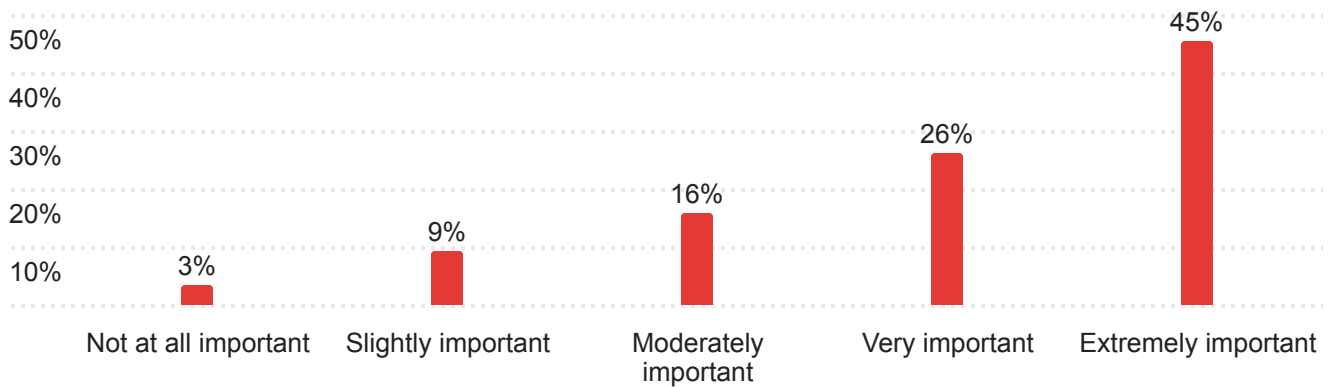
151 Responses



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	3.58	1.13	1.28	151

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

152 Responses

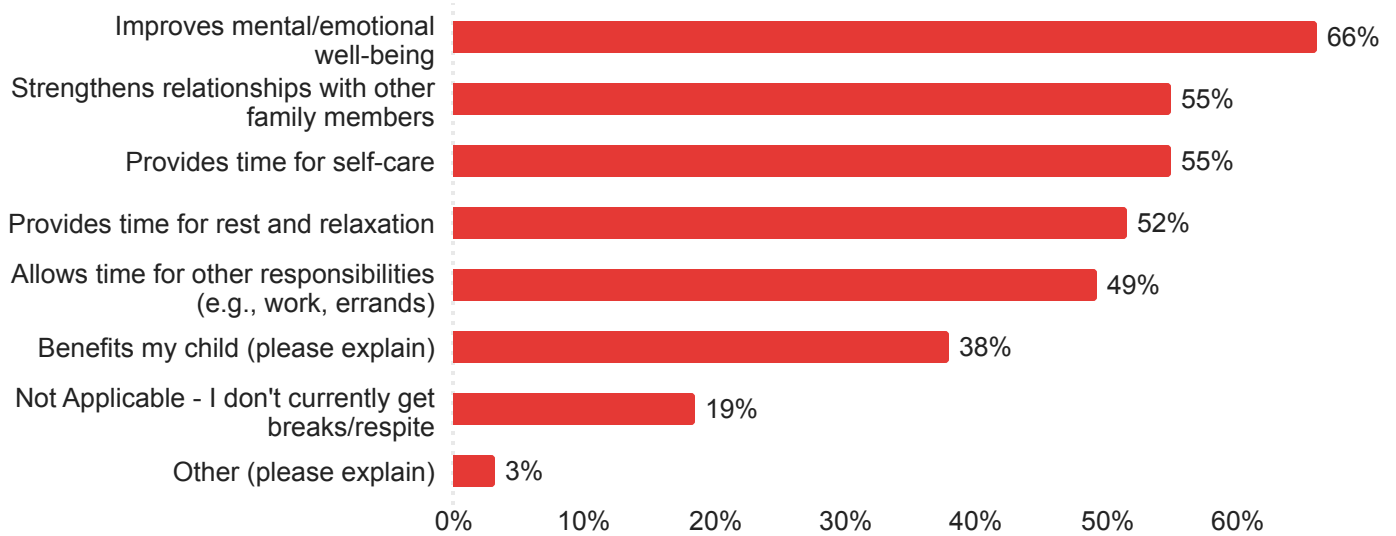


Field	Min	Max	Mean	Standard Deviation	Variance	Responses
How important is getting a break from caregiving (respite) to your family's overall well-being?	1.00	5.00	4.01	1.13	1.28	152

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

Percentage of Responses

124 Responses



## Benefits my child (please explain)

Benefits my child (please explain) - Text

He gets to be around children with similar disabilities who understand him. My daughter gets to be around other sibs who know what she's going through.

My children like to venture out and be social and do other activities with children their own age, they play and grow and make friends...

My child really enjoys the times he is at Pause and The Boys & Girls club

To get to know other families in the area and to build social skills for her

My child lives in an only-child home - being in the community with others is helpful to build relationships.

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 and an "escape" from their mundane routines.

Helps with practicing transitions and social interactions. Also helps because he gets a recharged parent afterwards .

He enjoyed being able to engage and socialize with other kids around his age

He loves going to pause which is not always the case with other places

The only current respite is the pause events that my son enjoys

Allows her to temporarily focus on something else

Child receives professional services such as therapy which I cannot provide.

We have a provider who spends 3 hours once a week most weeks. She makes Sam feel included and she encourages and builds on his goals for community involvement.

It's been hard to try to have quality time in 3 hours because we are still cleaning up and resetting from before he left. If we wanted to do an activity, there isn't enough time to travel to do this since most things are 30-45 mins away.

I am a better parent and more patient. I also have more time to think and reflect and can then engage them in activities to support them.

He loves PAUSE. Gives him a place I know he's safe that he enjoys going to

If they can do something that interests them, it makes them happy and more well-rounded (i.e. - dance, art club, community service, engineering club, etc.)

They're forming bonds with trusted family members.

Socializing with others

Gives him time away from the same old too.

It allows me to spend time with my other children, on getting home tasks done, errands, etc.

## Other (please explain)

Other (please explain) - Text

---

ALL of these honestly (I could only pick one)

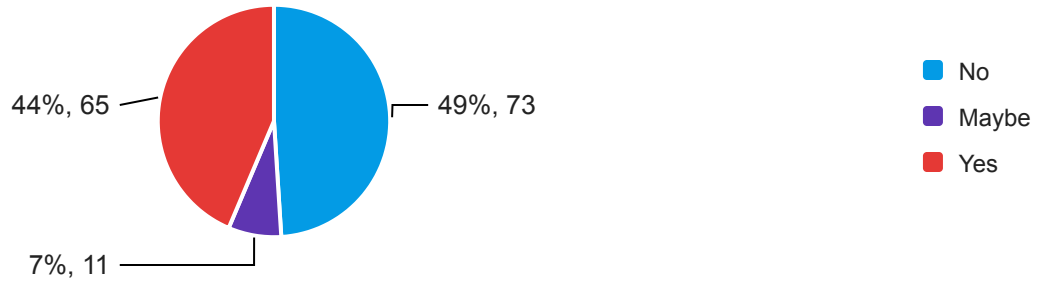
Enables some individual time on occasion with my teenager if she is not volunteering or doing something else, and we can drop the two younger children off at Pause.

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

## Opportunities for Caregiver Respite

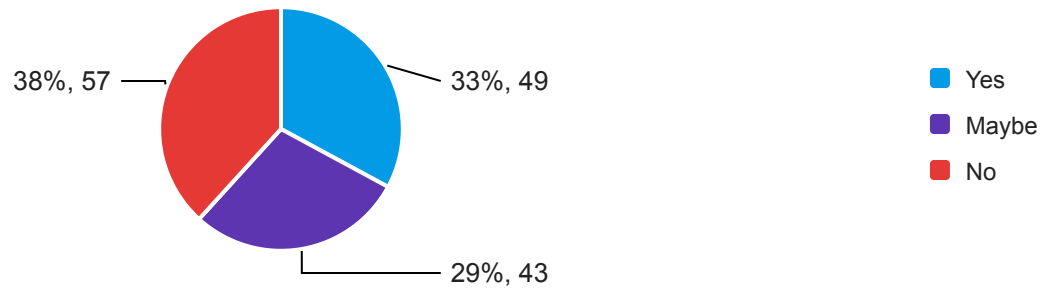
Has "respite care" ever been suggested or offered to you an agency or professional serving your family?

149 Responses



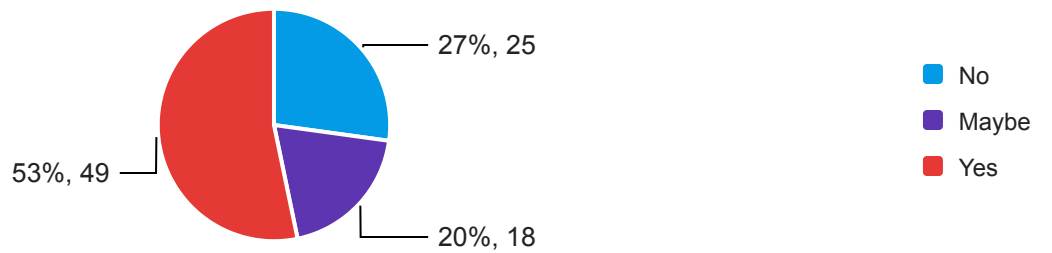
Do you currently have a way to get a break from your caregiving responsibilities when needed?

149 Responses

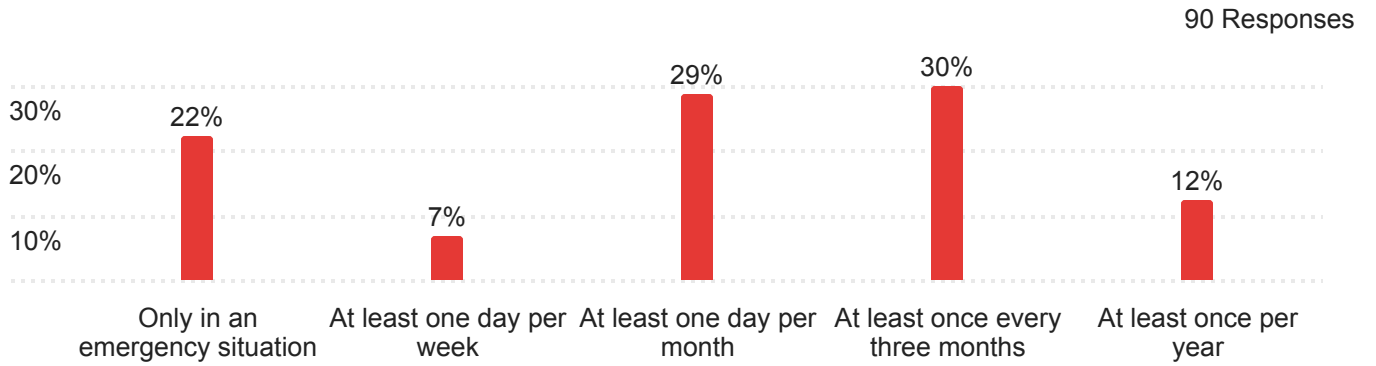


Do you feel that you need more respite (breaks) than you currently have available?

92 Responses

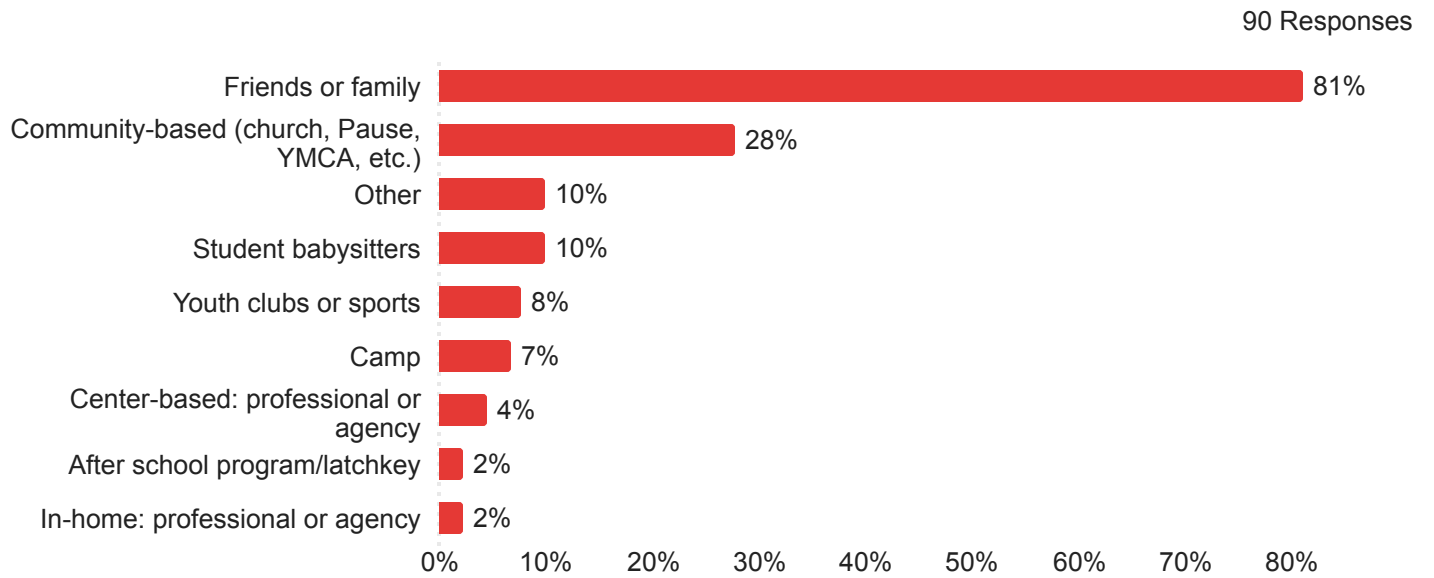


How often do you typically access respite (get a break)?



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

Percentage of Responses



Other - Text

husband

Baseball

hubby

Pause

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

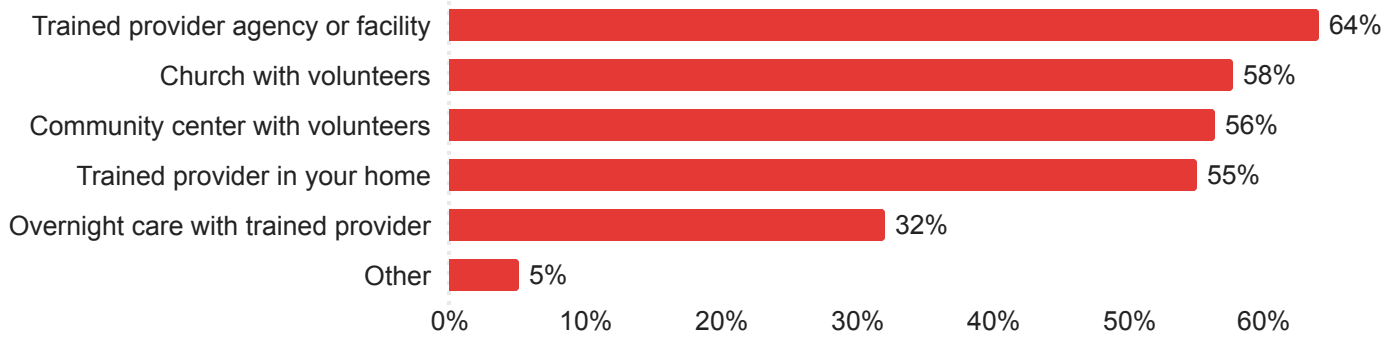
Pause

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

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

Percentage of Responses

78 Responses



Other - Text

at a church with paid staff

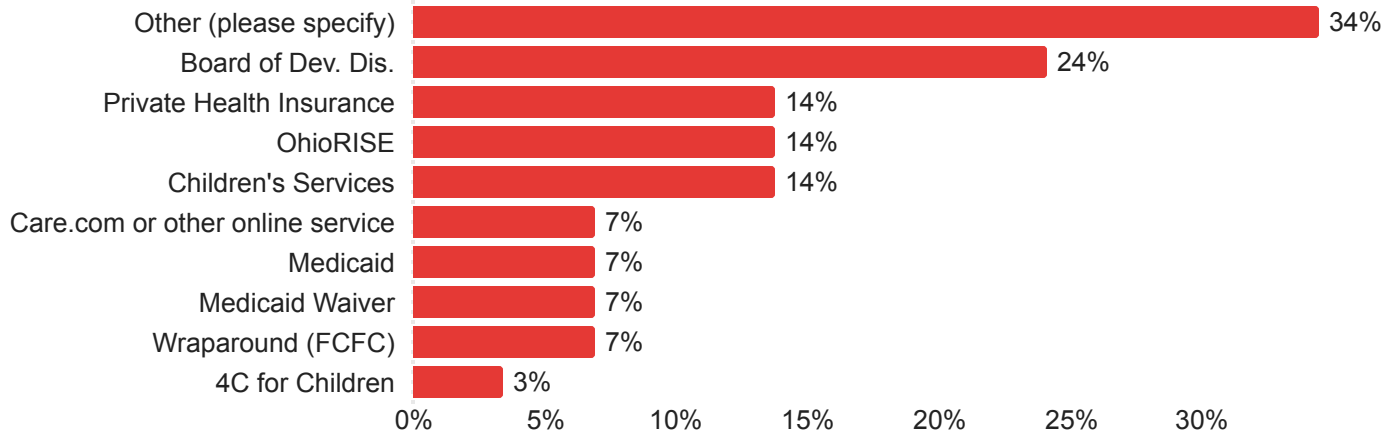
No

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

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

Percentage of Responses

29 Responses



Other (please specify) - Text

Maybe health insurance

none

Family support system.

None

Pause

Pause

ARC

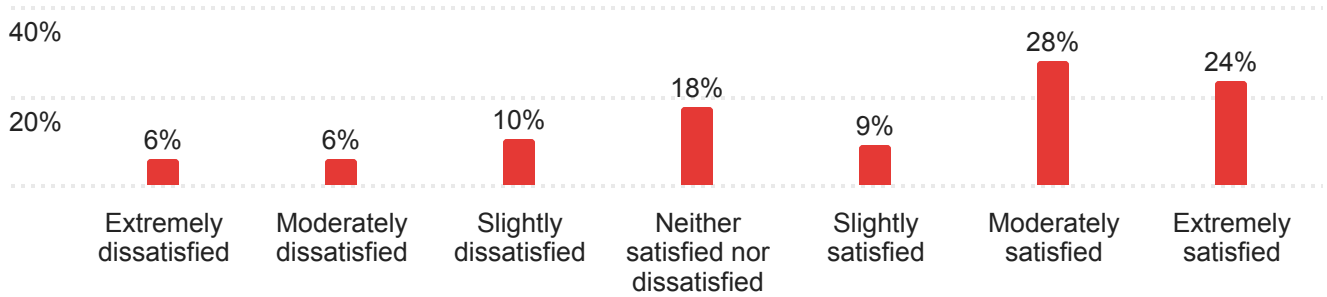
N/A

Me with a Google search

None

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

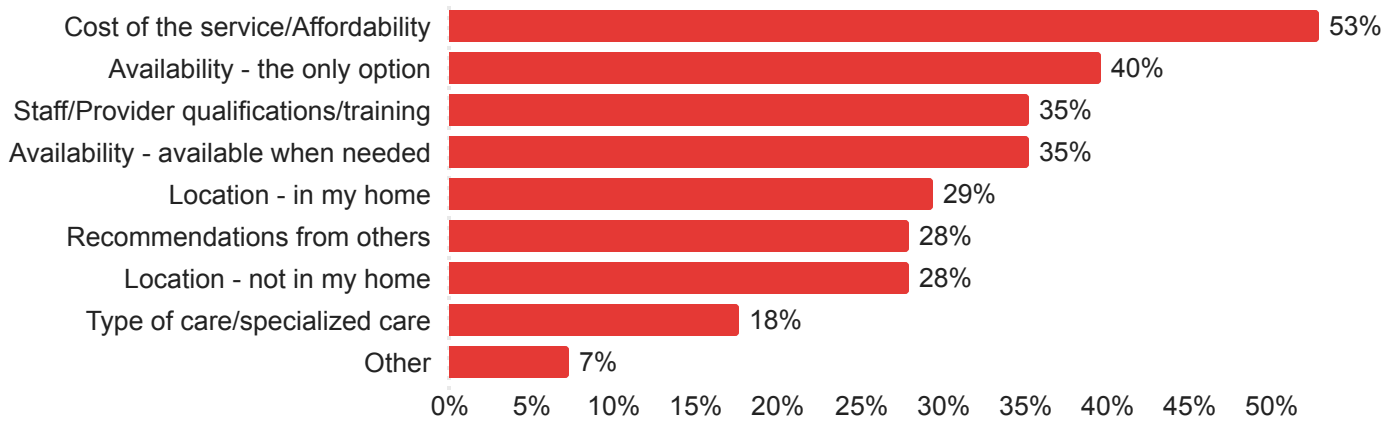
68 Responses



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

Percentage of Responses

68 Responses



Other - Text

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

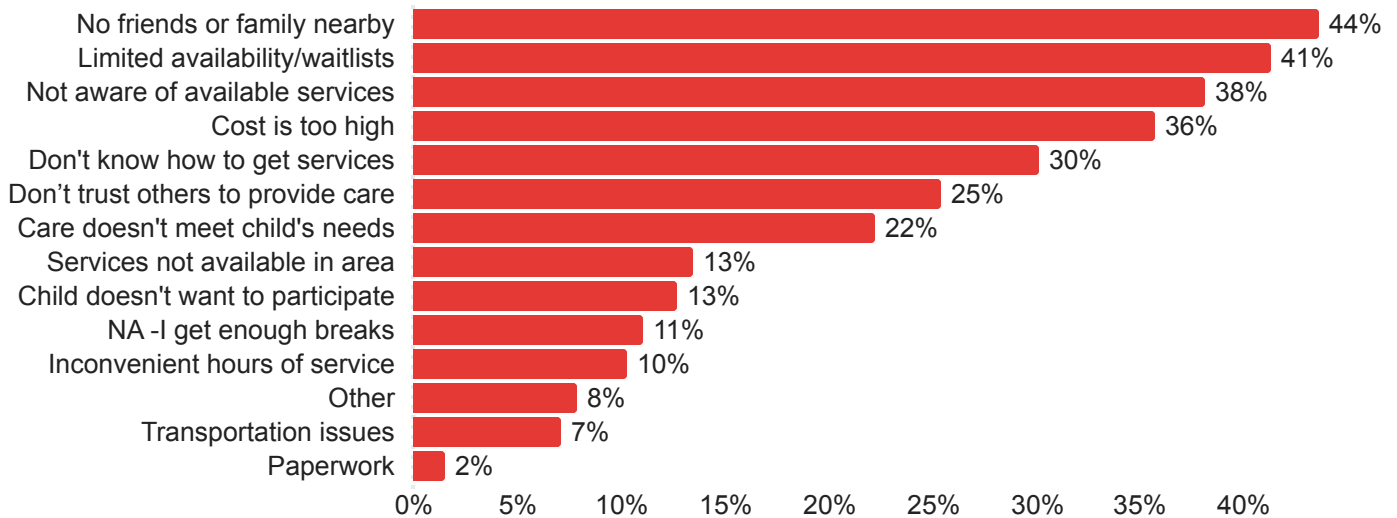
Other grandparents than myself

My overnight respite care is provided by family members.

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

126 Responses



Other (please explain) - Text

Limited family nearby to help

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.

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

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.

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



More funding for Pause, their programs are great and really help us with Thrive nights and Holiday events.

More options

If we could find people who can watch level 3 autism.

List of opportunities available in Butler County

To be accepted

More funding for Pause to get off the waitlist.

More availability and affordability

A playgroup that provides respite care even once every other month that my child would enjoy vs. a sitter

Would love for the Pause program to open up to new families again. Their programs are exactly what we would be interested in for respite.

Care providers who understand children with difficult behaviors

Resources available

More availability

Take children to their appointments or after school events.

I really don't know what's available, beyond the limited care I'm already using.

We would love more of pause. I don't trust many people with my children.

Weekend program during the school year and summer day camp or service during the summer. Also day program during long school breaks

Transportation to and from respite events or simply home based

Accessibility, costs, and no age caps.

Availability of school-based therapy groups focused on mental health and healthy peer relationships.

An over night provider who doesn't take more than one or two children total at a time.

Maybe some how have a provider who could go on an outing with us but be there specifically for my special needs child so we could do things as a family and have the support needed to do such activities.

our future, being calm

I like the idea of a fun day camp space. Currently we have limited funding and because my son is on the spectrum he is timid about going to new places with new people. If his older sister could be with him that would help.

More frequent events

Before school care especially if the elementary school start time is moved to a later time

Don't know

I've always thought a sports program would be excellent, it would allow the kids to be active and burn off some extra energy. The kids have always wanted to be in a sport however I myself have a disability and committing to all the driving back and forth as well as attending the games and practices on a regular basis is more than I can provide.

Knowledge of resources/lower costs

Just having more access to after school safe space at school where kids can do homework or be a part of a club for a while and parents can have a little flexibility with pick up time. 2:30 pick up is not conducive to most working families.

Camps and day camps to be actually affordable to middle class families.

Actually offer them

Opportunities for summer and day camps that are equipped to care for my child. Respite opportunities closer to home.

I would like more respite care. My family only gets it once every 6 months

We were late to the game with both a diagnosis and with getting help. The first help we really got was from Pause. We used their services, but son is really too old for some of it. We were desperate for respite, but I found Pause truly by accident. If it weren't for Lisa and Melody, I don't know where we'd be.

More opportunities like Pause offers.

Instead of continually telling me that I need to take a break and I need respite, actually link me to resources. Everybody I contact doesn't service our area or doesn't take our insurance or is full.

More opportunities, more places (esp summer day camp) that could accommodate all of my children's needs

People who are certified to do respite.

Not having to be on waitlists to receive respite care

Free care by trained staff

Open pause in more counties it's amazing!!!!

Having people capable of handling our autistic kiddos needs is hard to find. PAUSE is the only one that can help us right now. Family is too old to help when things could get physical with one kiddo. They aren't high functioning enough to do regular programs. Even stepping stones no longer takes high needs kids in their summer program, if you need potty help etc you aren't allowed to go anymore. My kid still asks me when he gets to go there and he hasn't been in almost two years. Doing fun things with peers is a desperate need for him and I can't provide it myself.

Have a school day type of respite Where my child could be gone for a school day time period from 8-4 pm so I can have more free time to get important things done

Overnight care

More services in my area

No waitlists

How to get it. Pause is the only access we have because we have private insurance that won't cover respite care.

I am satisfied at this time with Help I am receiving

Reinstating policies in camps like Stepping Stones and Camp Campbell Gard serve those more impaired who had successfully participated before they decided to cherry pick the more independent campers. Instead of encouraging parents of high needs kids to find and create their own solutions, the system needs to support those parents far more because life is objectively harder to care for those who need to be diapered, hand fed and bathed by another person for the rest of their life compared to those who are cognitively disabled but can do self-care activities and also hold a job.

NA

Access to low cost after school care for middle school children at Fairfield.

I have not ever used respite care. I think it is extremely important to those who need it. When my grandson was growing up Respite care was not that available or even really known about at that time. He is now 18 years old and does very well on his own for a few hours.

More resources available for at-home support. Pause was great but it became too chaotic the bigger it go and than it became too much for our family to attend.

Affordable, reliable care and transportation

qualified, trained providers available when needed

Building respite opportunities during foster care placements would maybe help bridge the gap of feeling shuffled from one family/environment to another. By the time you realize respite is well overdue, it's too late to try to build the network at that point. That is the space we currently occupy.

I would have liked to have more independent Care providers who offered respite care but only agencies have been available so far. I just would like a more personal and direct connection with an individual and consistency of care instead of having to work through an agency with high turnover.

Access to resources that do not include relying on family and friends. I have no family living locally and no friends available to provide respite. Pause is not taking new members and I don't know of any other options

More availability. There seems to be no available respite care for my son. The one respite provider we had was also very inconsistent. She would no show for her scheduled visits.

Caregivers that can attend to ADLs (help with feeding, bathing, dressing, toileting, medication administration) and caregivers that can keep my children safe in the community (ie: eloping).

The availability

More options available for families with private insurance. We have less services available to us as opposed to families with government insurance

Teen summer programs

Be more aware of any programs

I'd love to have once a month options for the PAUSE type respite. We are a bit strapped financially so we just can't pay a babysitter as often as I'd like to have a break.

More information about resources available

Better resources

Having the ability to get respite care

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. It is still helpful, valuable, and a part of our routine, but we are not with the same families month after month to build relationship and the family isn't getting the same dosing. Programming also only goes October-April, so there is time in the Summer when families really need other options.

We would like to have emergency respite care. Our 2 grandson each have different difficulties. 12 year old has mental issues. 15 year old has ADHD with serve impulsivity.

More spots in programs/camps & more respite providers able to handle higher needs kids (elopement, incontinence, behavior issues)

More options and dates available -- one weekend day per month would be ideal for 3-4 hours

Increased availability, increased ease of finding and securing care

Quality activities for older children. Just because she is 23, she still desires outings

I would love to have a list of affordable, vetted, reliable care givers that can handle four kids at once. We have my husband's mother that helps occasionally but she is elderly and not able to handle all four kids at the same time.

A comprehensive lists of available activities or camps for every month would also be nice.

More trusted people available to help a nonverbal child

Making respite more available- more choices/options/help/ resources/ give therapy sessions for parents to help express emotions/emotional support/having more events that offer disability times/days. I feel more stressed going to events with my child but our family enjoys these types of activities. Child does fine but it's more personal since people look at him - makes me anxious.

I need a respite caregiver (or caregivers) that can handle many different ages and disabilities. Pause helps with the four youngest but I am still caring for another adult who has additional needs.

Honestly, my son is 19, and I highly doubt he would want services, so I filled it out based on how I felt in the beginning of needing it. My issue is that there probably are services out there that we do not qualify for because we have private insurance. We were not able to get into 2 outpatient programs because of it. The other issue is communication. The SSA that we had when things were really bad was not helpful at all. I found Pause for Parents by total accident, and I would have thought this would be a no-brainer because we were DESPERATE for respite at the time. I know that there's not a playbook for being a parent with a special needs child; however, I would have thought that it would be easier knowing the services available, including respite. The isolation with this is rampant.

More trained services available that don't cost so much you can't afford it

Make the community more aware of respite options. Post things on FB or other social media sites. Create groups on social media for local families to join and learn about what options are available.



I think this would be very helpful.

We are doing ok, and it gets better with time, as the child grows older.

People need more respite care, but they need more respite care with people who wants to work with kids. I haven't seen many situations where someone is complaining about their position and helping with special needs kids and it makes me afraid to leave my kid places too often. Pause is the only place that I will leave my children other than their nursery at church

My son does have a waiver with butler county I'm wondering if it could be used at pause if programs were opened

None

If quality respite care was, provided in my area. I'd like, be able to keep consistent employment and not have to change jobs often. In order to accommodate to my boy's school schedules.

Often Respite care is associated with people who are caring for someone ill or with various mental or physical needs... sometimes just your average family needs help, especially if they don't have family in the area. Nothing major - just a safe place for kids to be able to hang out after school to get a snack, be with friends, and maybe do something fun or just do homework - just letting kids be kids in a safe space.

No

Actually offer thrm

This service is extremely important to our family.

Respite care gives me a time to distress. It gives me time to be with my husband for a few hours. We need more of it.

The struggle we've had all along is two-fold. First, we don't fit into a nice diagnostic category, so I know that people haven't known what to suggest. I have been very discouraged about the system because there weren't clear-cut answers to our questions about what services are available to help us. The services that were suggested were N/A because we have private insurance. Honestly, the system stinks and I have never felt so alone. Pause has been the first group that has really helped and listened. I now volunteer with them, and the need is unreal. I talk to parents who are as discouraged as I was, and still am at times. I have one child with a disability, some who I have talked to have multiple children with differing needs.

The hypervigilance we need to care for our kids produces a large amount of stress! The fact that care doesn't end when they turn 18 & that pur kids will never reach total independence is a heavy burden for us. The mental load of parents like us is higher than your average family. We have a much harder time finding respite because we have 3 children with varying needs. We have been fortunate to be involved with PAUSE for many years! They are great with accommodating our family but even there we have limited access because we need the more specialized care.

There is funding available for my daughter to get respite services but there is no one to do it. I've been waiting years. I had one lady last summer that I trusted and she lied about where she was taking my daughter and I haven't found anyone since.

County headcount not enough to follow up or service family. Pause has been a godsend

We love and trust PAUSE to give the kids a good time and most importantly keep them safe. It's the only break we get and worth the world to us.

It's needed and more affordable Also there needs to be alternative to day camp options like an open gym type option

It's an amazing thing thank you for considering.

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.

No

Respite for those families caring for high needs individuals has been in a crisis mode in our state for the past 5 years at least yet the system won't even acknowledge that fact. Transition planning only provides information about jobs and activities for those less impaired. High needs individuals have to pray their parents are educated, savvy and wealthy enough to create solutions with nonexistent information and to know where to eke out what limited resources there are. Otherwise, those individuals are trapped at home with families who have no breaks. This has been an outrage.

NA

I am happy to offer feedback and suggestions or sit on a board if that would be helpful.

I truly love the resources that Butler County Children's Counsel & Butler County ECS provides!

The process to pay a babysitter through Family Fund resources is very labor intensive unless you have a consistent family member you can sign up for this sort of thing. It is not an easy process for outside caretakers who want to be paid when services are provided not after the fact.

Stronger support groups or more options for groups are needed to build organic respite opportunities. For main stream kids, invitations to a birthday party or sleepover is organic respite for caregivers. For kids with medical needs or big behaviors birthday parties and sleepover invites are few and far between. These kiddos also limit family and friends being able to pitch in as the needs are too high for the faint of heart. This is very isolating and hard to dig out of when you wait to long for help. And often times there just isn't any help.

Respite care for after school or babysitting are not accessible in my area of Butler County

I think the people that are hired need to be aware how important these services are. When you care for your loved one 24/7, when you think a break is coming and it doesn't, it can make you feel alone.

I am the grand parent but I know how important respite care is.

We have services that say they provide respite, but the caregivers don't have availability when we need, are not able to take care of ADLs, have long wait lists, are only available for 2 or 3 hours every few weeks.

My child has a mental health disorder. As I stated above, more services should be available to families with private insurance.

I just appreciate the opportunity to share my experience. I am thankful for the resources we have and would just love a few more.

#### Special needs training

It is hard to find people that can appropriately work with children with mental health disorders, such as OCD. It is a debilitating disorder that significantly impacts the entire household and more funds need to be directed at children with mental health diagnosis only (OCD, ADHD, Anxiety combos) because there is a lot behind the scenes at homes with these nuanced disorders as well that don't get enough support. These kids have 504's and IEP's in the schools, and they need access to more community funding and respite as well.

Respite is crucial for families like ours. Everything is harder for us. We have a much higher mental load than other families. We have 3 boys with varying needs. It is hard to find programs that can accommodate all of their needs. It seems the first thing cut is services for higher needs kids & yet we are the caregivers who most need a break!

I would love to send my daughter to different camps and other experiences that we currently don't send her to because of the extra needs she has.

Groups that support those with special needs ie special Olympics do not accept us because we don't have the right diagnosis.

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

Pause has been great. We've been with them since my son was in help me grow. The need for them far outweighs their capacity though which reduces the help all families receive (we really appreciate it when we can get in though).

Love Pause respite services, but can not receive it if I do not register in time.