



Building Healing Systems: Trauma-Informed/Healing-Centered Organizational Transformation

Behavioral Health Caregiver Survey

Behavioral Health Administration & Universities Partnership



UM SOM Psychiatry Department

- Division of Child and Adolescent Psychiatry (DCAP)
- Systems Evaluation Center (SEC)



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- Department of Behavioral Sciences and Services



Key Take Aways



- **Caregiver Positive Childhood Experiences (PCEs) and Difficult Childhood Experiences (DCEs)**
 - 97% of caregivers experience one or more PCE
 - 74% of caregivers report experiencing one or more DCE with 8% having 4+ DCEs.
 - 4+ DCEs were reported by a higher proportion of caregivers who support children (14%) or transitional aged youth (16%) compared to those supporting adults (5%)
- **Almost half of caregivers report their DCEs impact their lives today (21-46%), and there are several activities that have helped them in adulthood (13-39%)**
- **Almost a quarter of the caregivers reported *most of the time* or *always* experiencing emotional distress about the trauma or adversity experienced by the individuals they support (23.5%)**



Key Take Aways



- Caregivers report experiencing difficulties with physical health (24%), mental health (17%) or substance use challenges (14%) in the past 30 days
- Caregivers are comfortable with discussing their difficult childhood experiences in general (80%) and with behavioral health providers (74%)
 - Providers can facilitate discussing caregivers difficult childhood experiences by asking directly or providing information to facilitate disclosure
- Caregivers made several suggestions for ways they could be better supported
 - **Providers:** provide training especially regarding behavioral health services, increase caregiver involvement in treatment planning, maintain open and transparent communication, and offer access to support and resources such as support groups, crisis intervention services and respite care.
 - **BHA:** funding training, establishing support networks and technology platforms for resources, advocating with policy makers for increased resources, ensuring that caregiver supports are included as a part of treatment planning, promoting healthy work environments and healthy communication, collecting feedback from caregivers using that information to implement change.



Surveys

- **The BHS surveys aim to gain an understanding of**
 - The prevalence of Adverse Childhood Experiences (ACEs) and trauma exposure within the Maryland Public Behavioral Health System (PBHS) and associated outcomes or experiences
 - ACEs and trauma screening procedures currently in use by behavioral health Caregivers
 - Caregiver training and support needs when working with individuals with ACEs
 - Other information to inform BHS Initiative activities
- **The results will be used to:**
 - understand the impact of childhood trauma and ACEs on associated health and behavioral health outcomes
 - to develop strategies aimed at supporting the integration of trauma informed approaches at the state, local, and Caregiver levels



Surveys

- **The panel surveys will include a similar set of items asked across three target populations within the Maryland PBHS, with one survey conducted during each of the three years of the BHS initiative:**
 - Year 1: Behavioral health service Caregivers
 - Year 2: Caregivers of individuals receiving services
 - Year 3: Transition Age Youth receiving services
- **This approach will enable the collection of prevalence information from three different perspectives, providing a multi-faceted estimation of ACEs prevalence within the system.**



Caregiver Survey Goals

1. Assess Caregiver Positive Childhood Experiences (PCEs)
2. Assess Caregiver Difficult Childhood Experiences (DCEs)
3. Understand the impacts of DCEs on Caregivers in adulthood
4. Learn about factors that help individuals in adulthood who have experienced DCEs
5. Understand which services and supports caregivers have received or would like to receive
6. Learn about caregivers' comfort with talking about DCEs and how to reduce barriers in communicating with behavioral health providers about caregivers' DCEs.



Building Healing Systems:

Caregiver Survey Methods



Methods: Survey Development

- This project has Institutional Review Board approval.
- BHS developed a web-based survey tool in collaboration with BHA
 - Topics from the Brief Risk Factor Surveillance Survey (BRFSS) and the Youth Behavioral Risk Survey / Youth Tobacco Survey (YRBS/YTS) were included
 - This allowed comparisons with Maryland and national data.
 - A literature review was conducted to inform questionnaire development, sources included:
 - Primary care pediatric surveys regarding ACEs prevalence and screening (Bright, Thompson, Esemio-Jenssen, Alford & Shenkman, 2015)
 - Impact of ACEs (Quizhpi et al., 2019)
 - Positive Childhood Experiences (Bethell, Jones, Gombojay, Linkenbach & Sege, 2019)
 - Other questions developed by the BHS team as needed to capture information needed to address project goals



Methods: Definition of Caregiver

- **Caregiver:** individuals who provide support (physical, social, emotional or financial) to anyone who has received behavioral health services in Maryland.
- **Behavioral health services** included mental health and /or substance use treatment services.
- **Excludes:** professional caregivers (e.g. nurses, social workers, health home aides) unless they provide unpaid support to someone in their life who has received behavioral health services.



Methods: Language for Childhood Experiences

- **Valuable review and feedback contributed by**
 - National Alliance on Mental Illness Maryland (NAMI Maryland)
 - Maryland Coalition of Families (MCF)
- **The survey uses “difficult childhood experiences” when asking about Adverse Childhood Experiences for constructs from:**

Kaiser-Permanente^a

1. Emotional Abuse
2. Physical Abuse
3. Sexual Abuse
4. Emotional Neglect
5. Physical Neglect
6. Parental Separation or Divorce
7. Household Domestic Violence
8. Household Substance Abuse
9. Household Mental Illness
10. Household Incarceration

Philadelphia Urban Expansion^b

1. Witnessed Violence
2. Felt Discrimination
3. Adverse Neighborhood Experience
4. Bullied
 1. Bullied at School
 2. Electronic Bullying
5. Lived in Foster Care

^aFelitti, et al., (1998). Relationship of childhood abuse and household dysfunction to many of the leading causes of death in adults: The adverse childhood experiences (ACE) study. *American Journal of Preventive Medicine*, 14(4), 245–258.

^bSource: [FindingsfromPhiladelphiaACESurveyandComparedACEQuestions.pdf](#)



Methods: Sample

- **2248 Survey responses were received. The following responses were dropped from the analysis:**
 - 327 non-Caregiver and incomplete responses
 - 1,264 potentially invalid survey responses (separate survey interference summary available)
- **657 responses from Caregivers included in the analysis**
- **Three open ended questions were included in the qualitative analysis. Topics included:**
 - Barriers to discussing Caregiver Difficult Childhood Experiences (DCEs) with behavioral health providers (n=327)
 - What other things can treatment providers do to better support Caregivers? (n=475)
 - Anything else you think BHA should know about how to provide services or supports to Caregivers? (n=444)
- **Additional Methods for Eligibility, Invitation, Data Collection and Analysis, and Survey distribution can be found in the Appendix.**



Methods: Limitations

- The survey was distributed via multiple stakeholder partners online; therefore, it is not possible to fully describe the populations to which they were distributed.
- The survey was distributed online, therefore individuals without internet access are not represented.
- Online surveys are subject to the biases of the respondents, since individuals self-select participation.
- The survey offered the chance to receive an incentive. It is possible that some non-caregiver individuals completed the survey to obtain the incentive.
- Data collected through open-ended text questions is subject to alternative interpretations.
- The results of this survey cannot be generalized.



Building Healing Systems:

Respondent Characteristics

Percentage and number of caregivers responding to survey by age, gender, sexual orientation, race, and ethnicity (n=599-609)

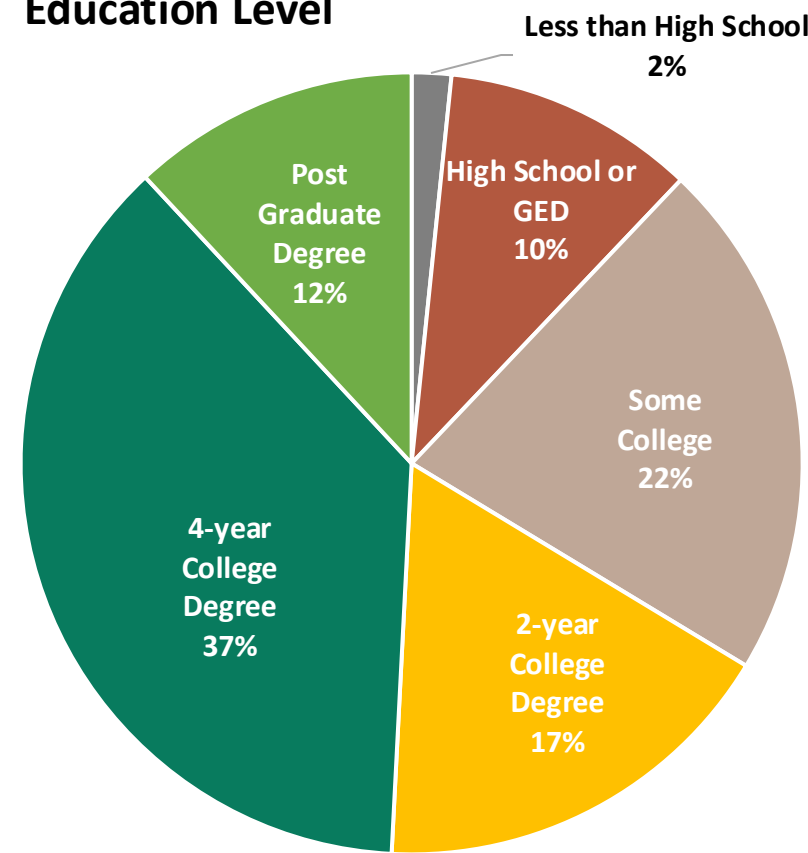
Demographic Characteristic	Caregivers % (n)
Age Range	
18-25 Years	3.8% (23)
26-34 years	45.2% (274)
35-64 years	48.7% (295)
65 years or older	2.3% (14)
Gender	
Male	46.1% (281)
Female	53.2% (324)
Transgender	0.3% (2)
I don't know	0.3% (2)
Sexual Orientation	
Heterosexual / Straight	94.3% (566)
Lesbian, Gay or Bisexual	5.4% (32)
Other	0.3% (2)

Demographic Characteristic	Caregivers % (n)
Race	
Black or African American	16.0% (105)
White	45.2% (274)
Asian	3.2% (21)
American Indian / Alaskan Native	7.5% (49)
Native Hawaiian / Pacific Islander	1.4% (9)
Other	1.1% (7)
Spanish, Hispanic / Latinx	18.7% (113)

Caregiver Demographic Characteristics

Percentage and number of caregivers responding to survey by education and household income

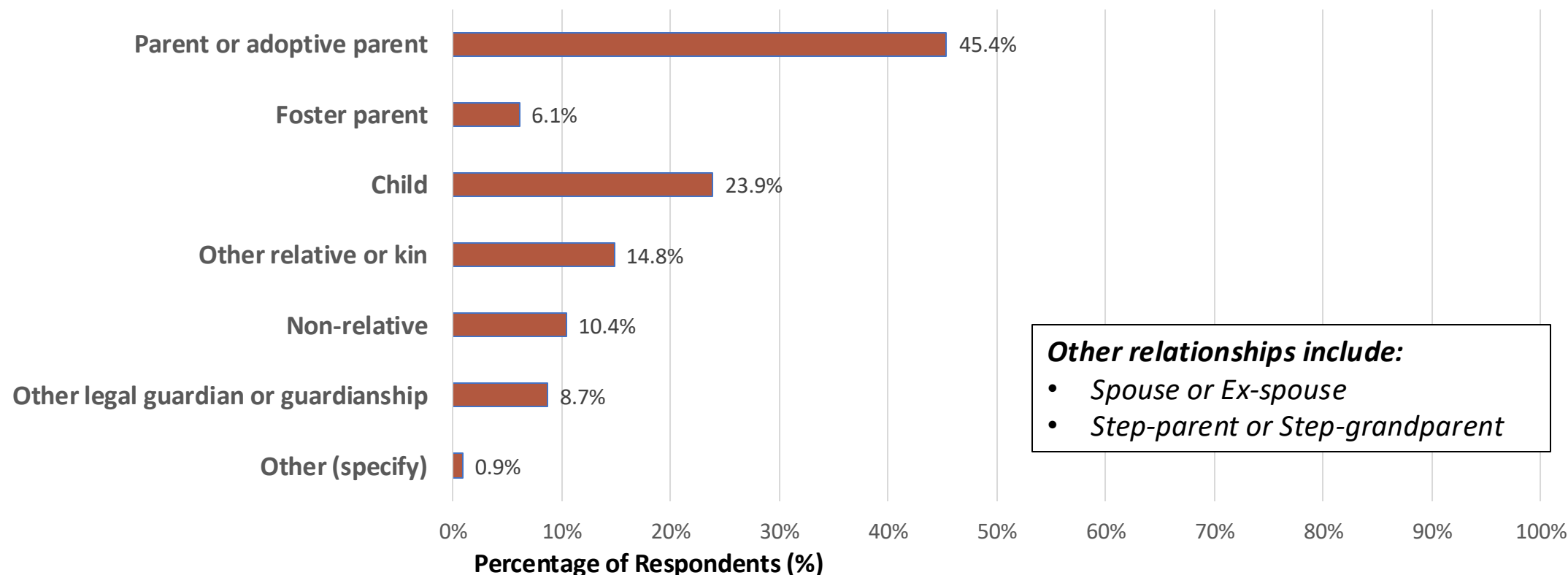
Education Level



Household Income	Caregivers % (n)
Less than \$10,000	1.2% (7)
\$10,000 to < \$15,000	3.3% (20)
\$15,000 to < \$20,000	4.1% (25)
\$20,000 to < \$25,000	2.8% (17)
\$25,000 to < \$35,000	2.8% (17)
\$35,000 to < \$50,000	20.8% (126)
\$50,000 to < \$75,000	30.6% (186)
\$75,000 to < \$100,000	16.0% (97)
\$100,000 to < \$150,000	10.4% (63)
\$150,000 to < \$200,000	6.4% (39)
\$200,000 or more	1.6% (10)

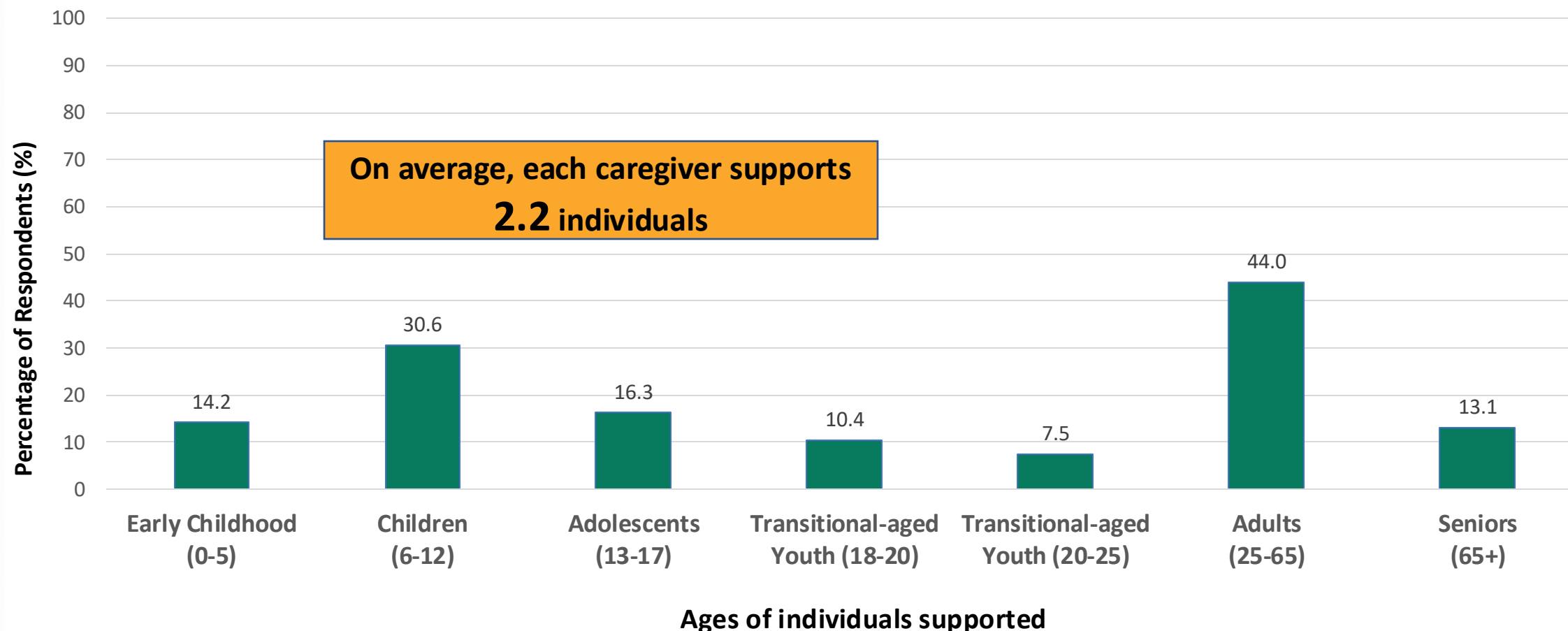
Relationship to individual(s) receiving support

Percentage of caregivers by their relationship to the individual(s) who receive support (n=657)



Ages of individuals supported by Caregivers

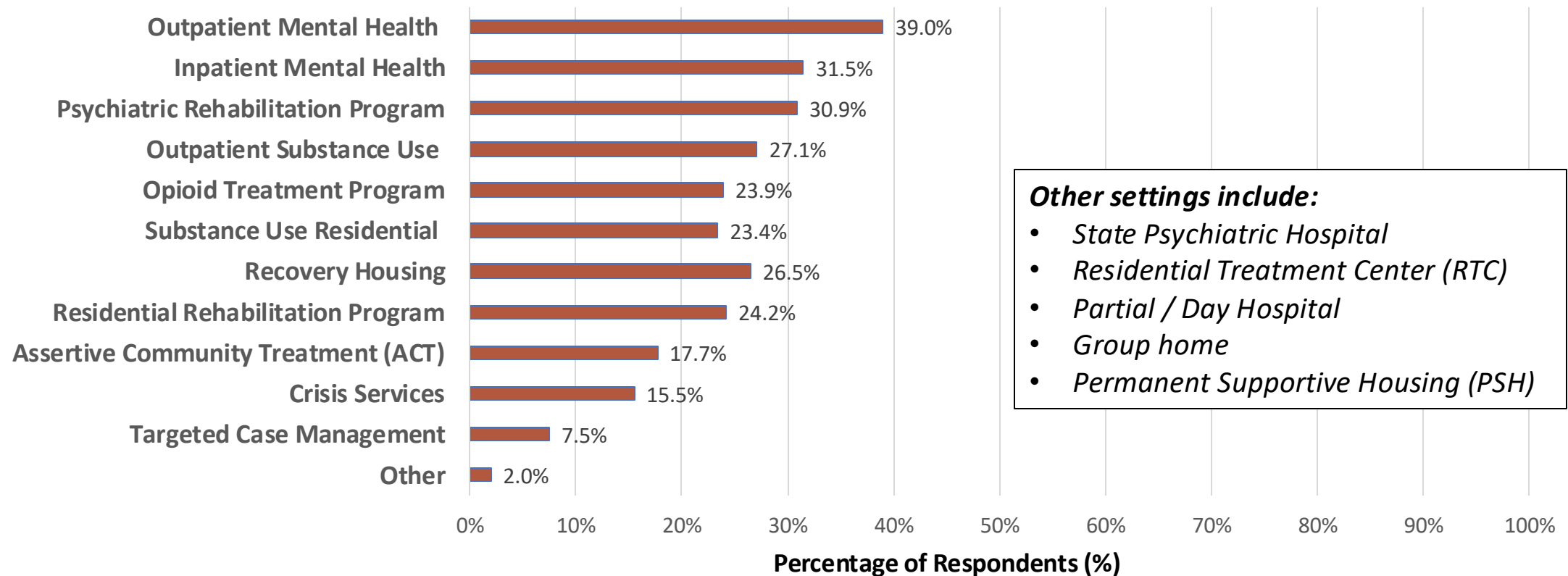
Percentage of caregivers by the age of the individual(s) who receive support (n=657)



Note: Caregivers may support individuals in multiple age categories

Behavioral Health Treatment Settings

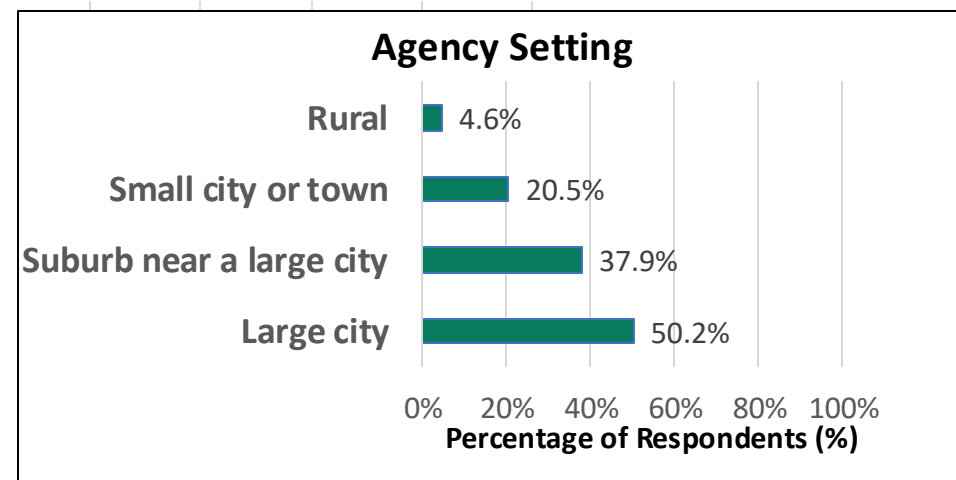
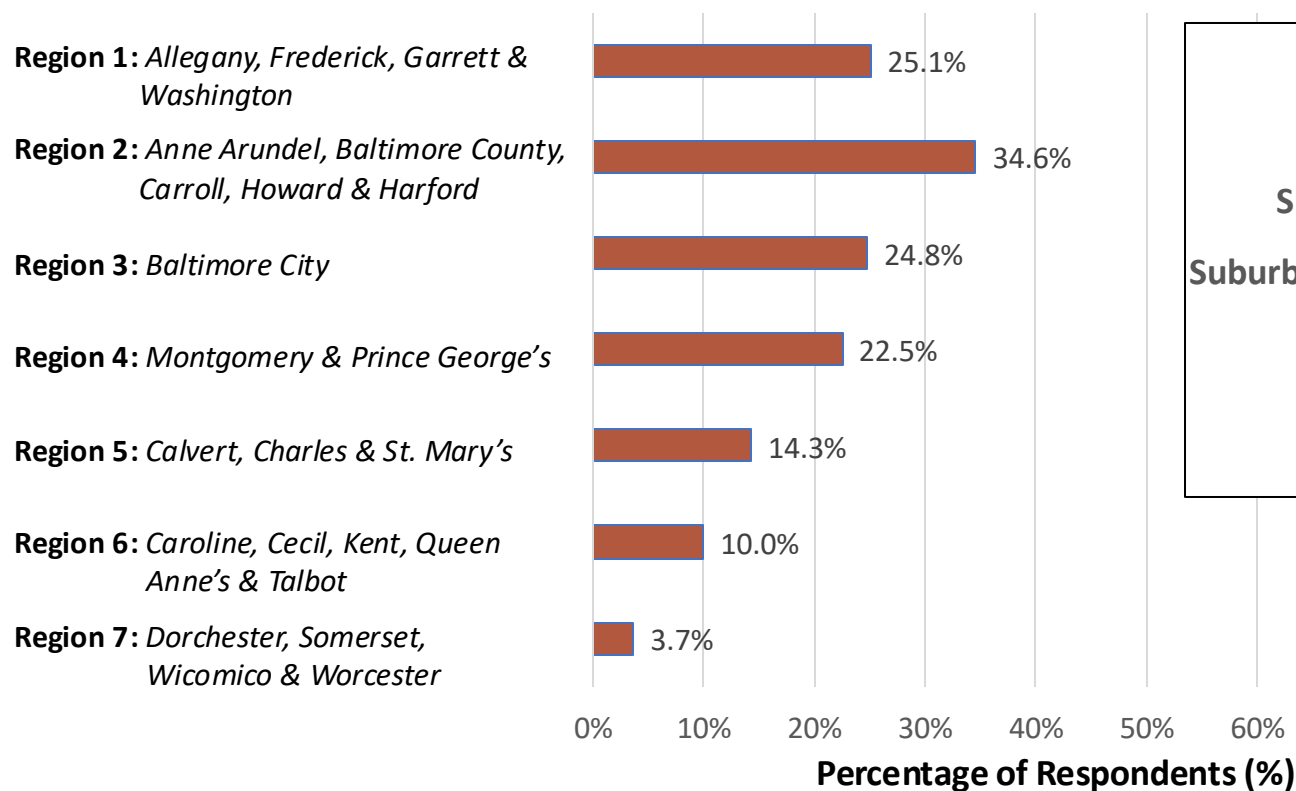
Percentage of caregivers by the settings where the individual(s) they support receive behavioral health treatment (n=657)



Location of Treatment Services

Percentage of caregivers by region and agency setting where the individual(s) supported receive behavioral health treatment
(n=657)

By Region





Building Healing Systems:

Positive Childhood Experiences
Difficult Childhood Experiences

Impact of Positive Childhood Experiences

- PCEs can counteract the impact of Adverse or Difficult Childhood Experiences in adulthood
 - 72% lower levels of adult depression and/or poor mental health
 - 3.5 times more likely to get social and emotional support (Bethell, et al, 2019)
- When parents shared ideas and talked about things that mattered with their child, the child had a 1,200 percent greater chance of flourishing (Bethell, Gombojav & Whitaker, 2019)

Impact of Positive Childhood Experiences

Household PCEs

- Being able to talk openly to a family member or as a family about feelings and feel heard, accepted and supported.
- Belief that family stood by them during difficult times.
- Feeling safe and protected by an adult in the home.

Community PCEs

Feeling supported by friends.

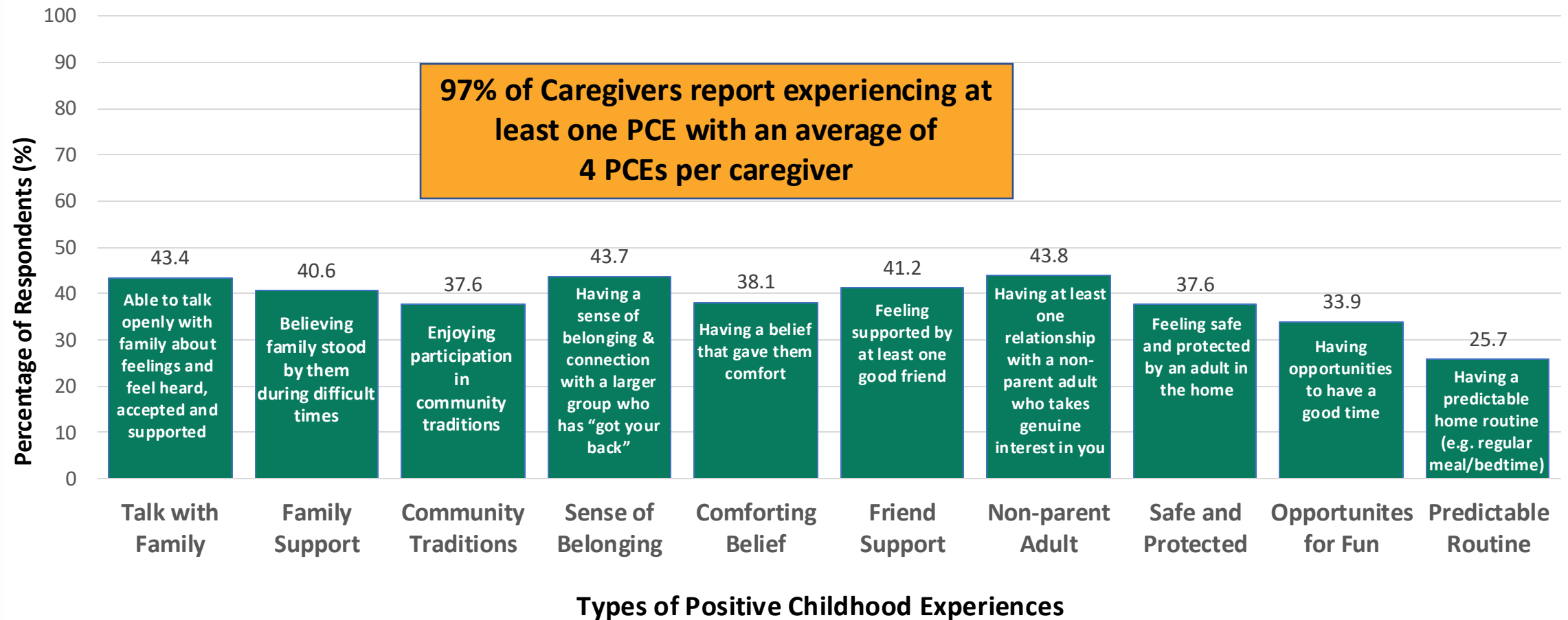
Having a sense of belonging and connection with a larger group who has “got your back” (e.g. school, church, clubs, neighborhood, etc.).

Enjoyment of participation in community traditions.

Relationship with at least one non-parent adult who takes genuine interest in you.

Positive Childhood Experiences (PCEs)

Percentage of caregivers reporting positive childhood experiences during their childhood (n=657)



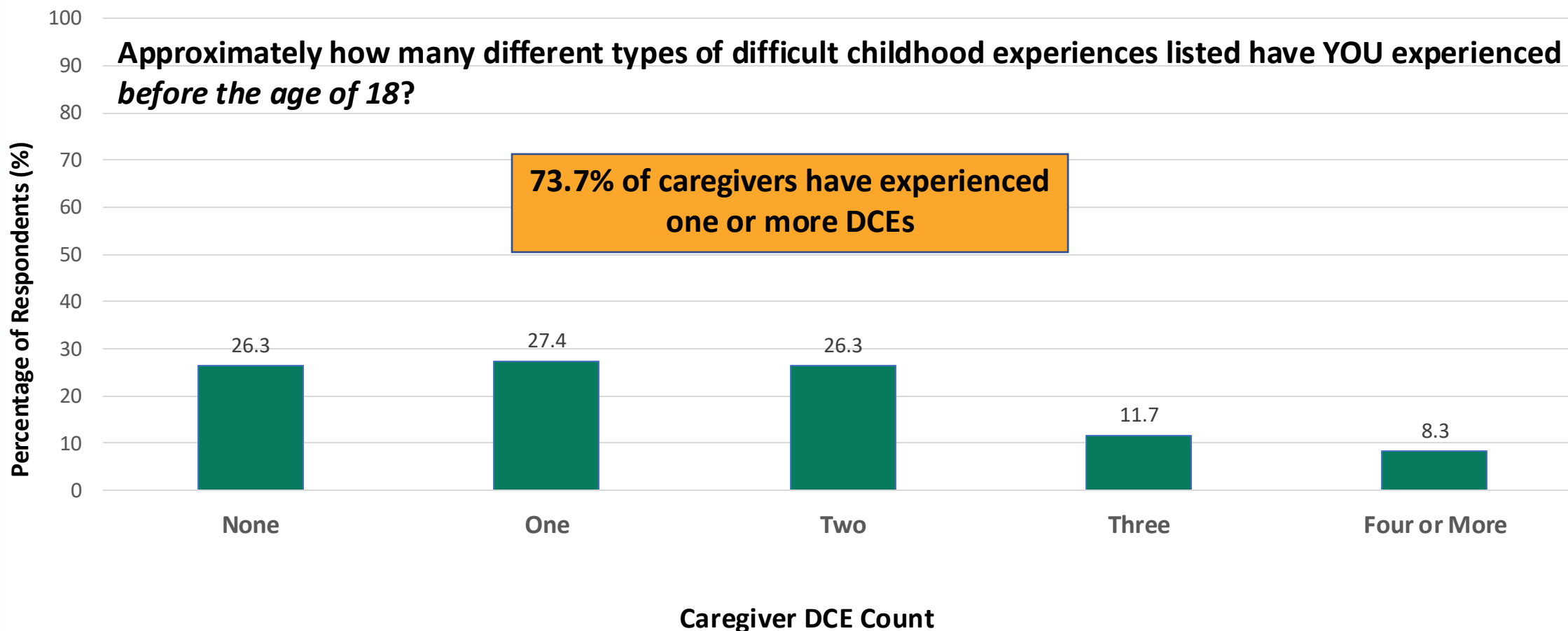
Caregiver Difficult Childhood Experiences (DCEs)

Using the list below, approximately how many different types of experiences listed have YOU experienced *before the age of 18*?

- **Experiencing discrimination because of your race, ethnicity, or any other aspect of your identity or culture** (e.g., age, developmental/acquired disability status, religious/spiritual orientation, sexual orientation, gender identity, socio-economic status, Indigenous heritage, national origin and/or immigrant status)
- **Feeling unsafe in your community, or feeling that people in your community didn't look out for one another and/or couldn't be trusted**
- **Witnessing someone get seriously injured, physically attacked, beaten, stabbed, or shot in your neighborhood**
- **Being bullied or electronically bullied** (e.g., through texting, Instagram, Facebook, or other social media)
- **Living with someone who was depressed, mentally ill, or suicidal**
- **Living someone with substance use problems** Including problem drinker or alcoholic, used illegal street drugs or abused prescription medication
- **Living with someone who served time or was sentenced to serve time in a prison, jail, or other correctional facility**
- **Experiencing the separation, divorce or death of a parent, guardian, or close family member**
- **Living with domestic violence or abuse** Adults in household hit, beat, kicked, or physically hurt one another OR adults in household sworn at, insulted, or put down by one another
- **Living in foster care**
- **Experiencing physical neglect** Basic needs unmet, such as safety, clean clothes and enough to eat
- **Experiencing emotional neglect** Lack of adult in household to help you feel safe and protected
- **Experiencing emotional abuse** Adult swore at, insulted, put down or behaved in a way that made you afraid that you would be physically hurt
- **Experiencing physical abuse** Adult in home hit, beat, kick, or physically hurt you. Do not include "spanking" that does not result in evidenced physical or emotional injury
- **Experiencing sexual abuse by someone more than 5 years older than you** including sexual touch and/or forced sex

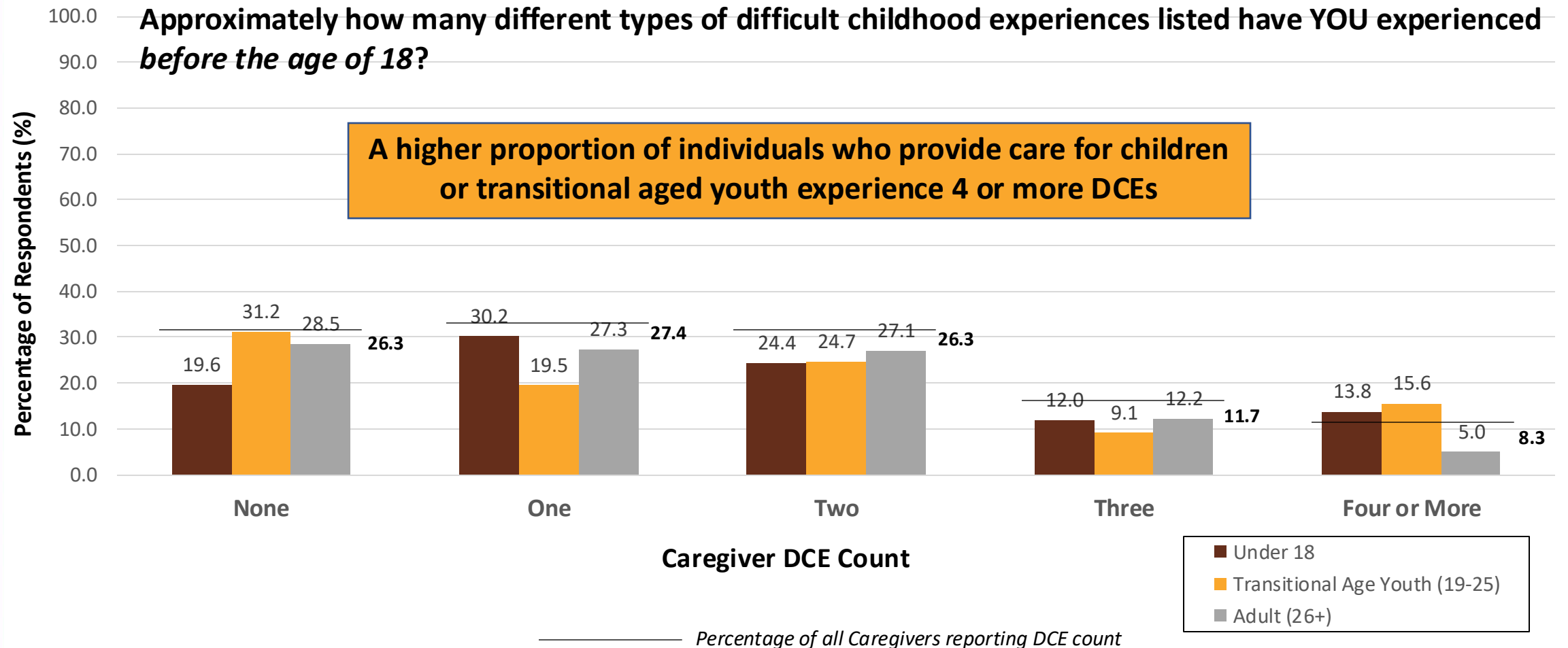
Number of Caregiver DCEs

Percentage of caregivers experiencing DCEs in childhood by the caregiver DCE count (n=635)



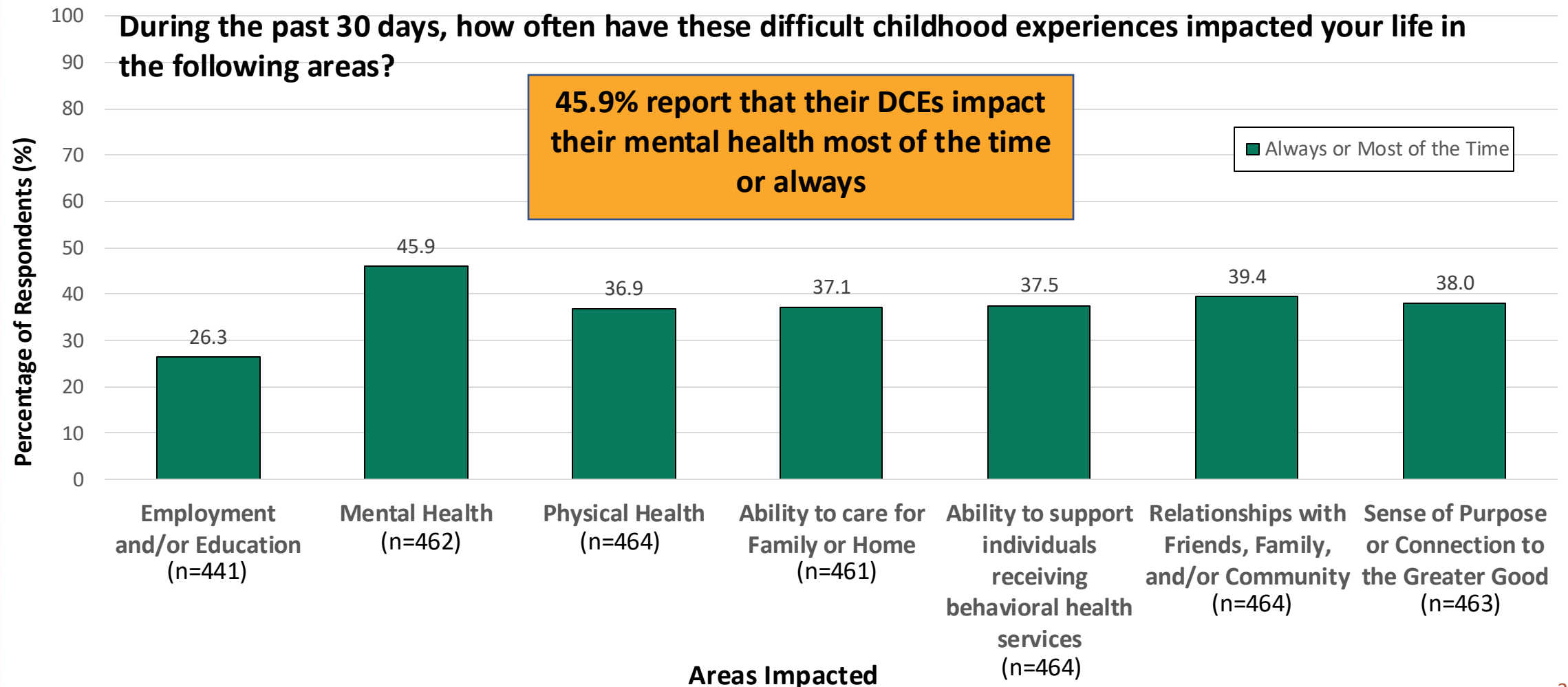
Number of Caregiver DCEs

Percentage of caregivers experiencing DCEs by the caregiver DCE count and the ages of the individuals they support (n=635)



Impact of DCEs on Caregivers

Percentage of caregivers reporting that DCEs impact their life by areas impacted



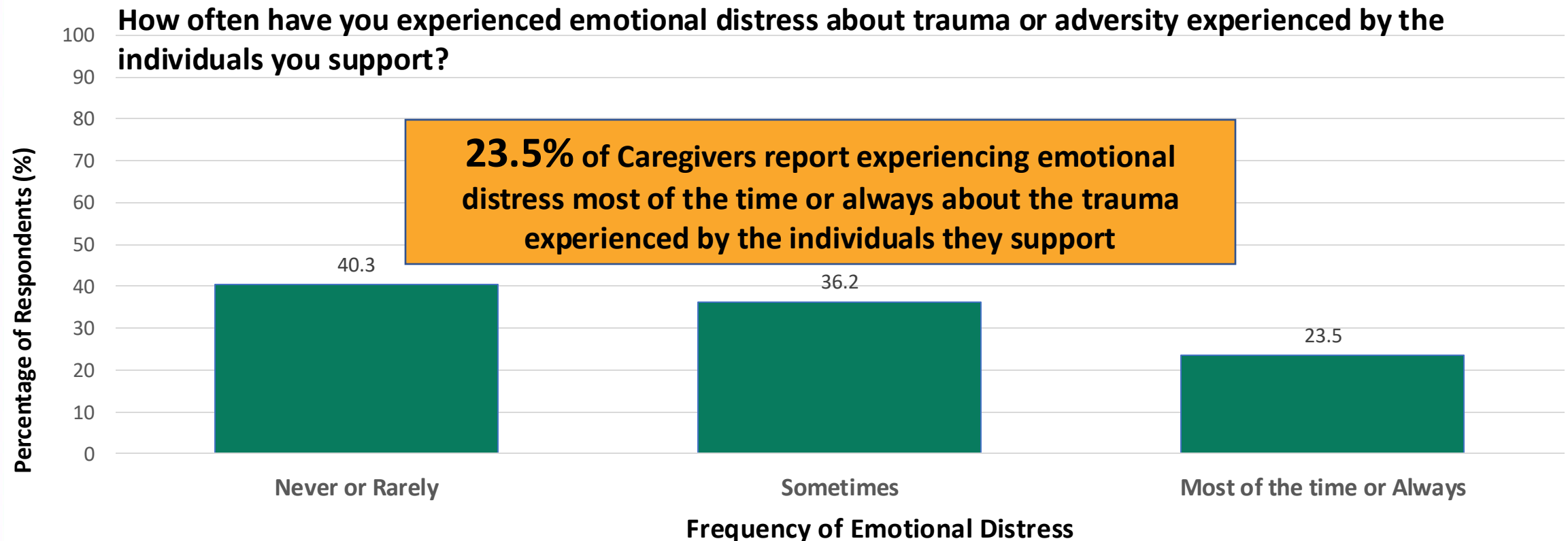
Activities that helped Caregivers with DCEs

Percentage of caregivers reporting that activities in adulthood helped them cope with difficult childhood experiences (n=657)



Emotional Distress in Caregivers

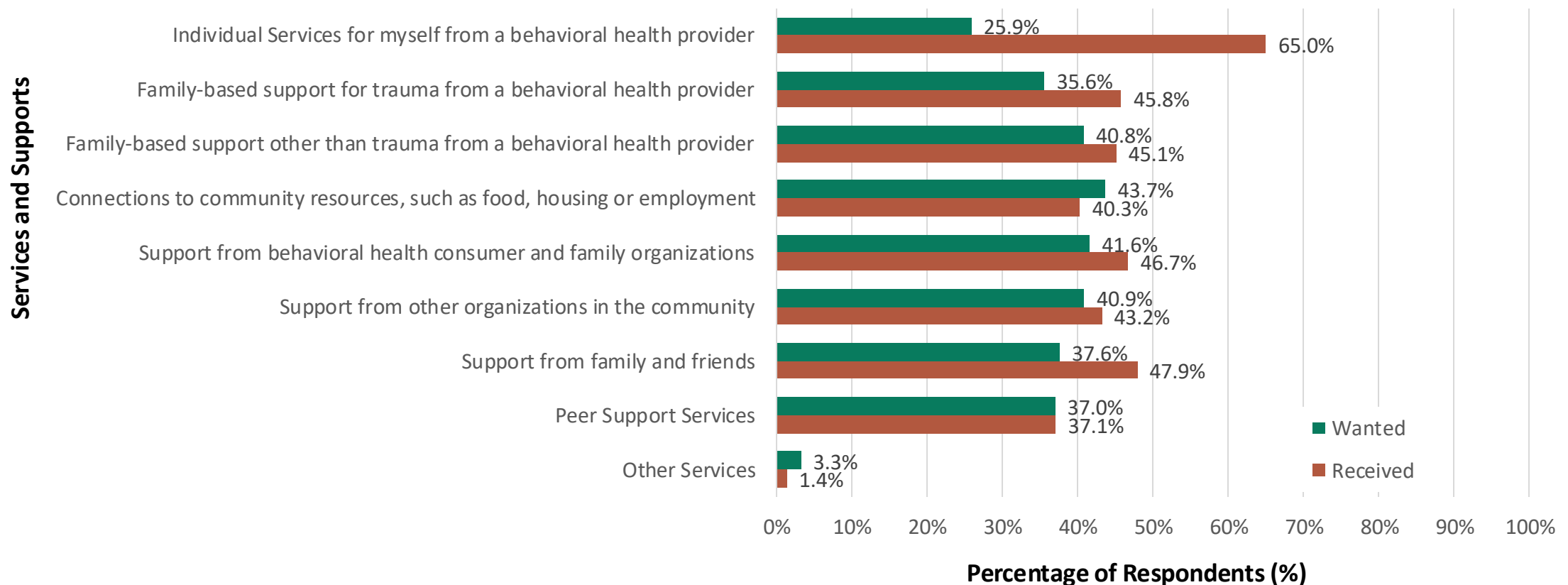
Percentage of caregivers and how often they report experiencing emotional distress about trauma experienced the individuals they support (n=624)



Services and Supports Wanted and Received

Percentage of caregivers who want to receive or have received the services listed below (n=624)

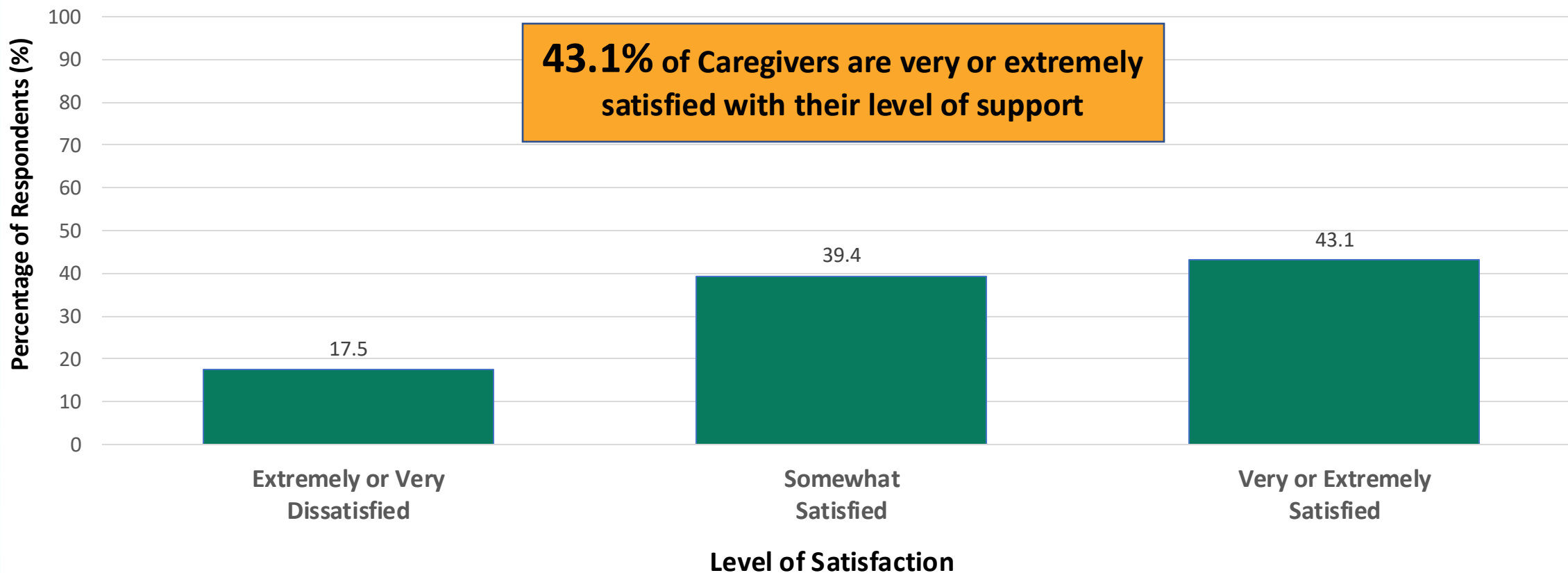
People, especially caregivers, may need services and supports. We'd like to learn more about what types of services and supports you have ever received and would like to receive.



Caregiver Satisfaction with Support

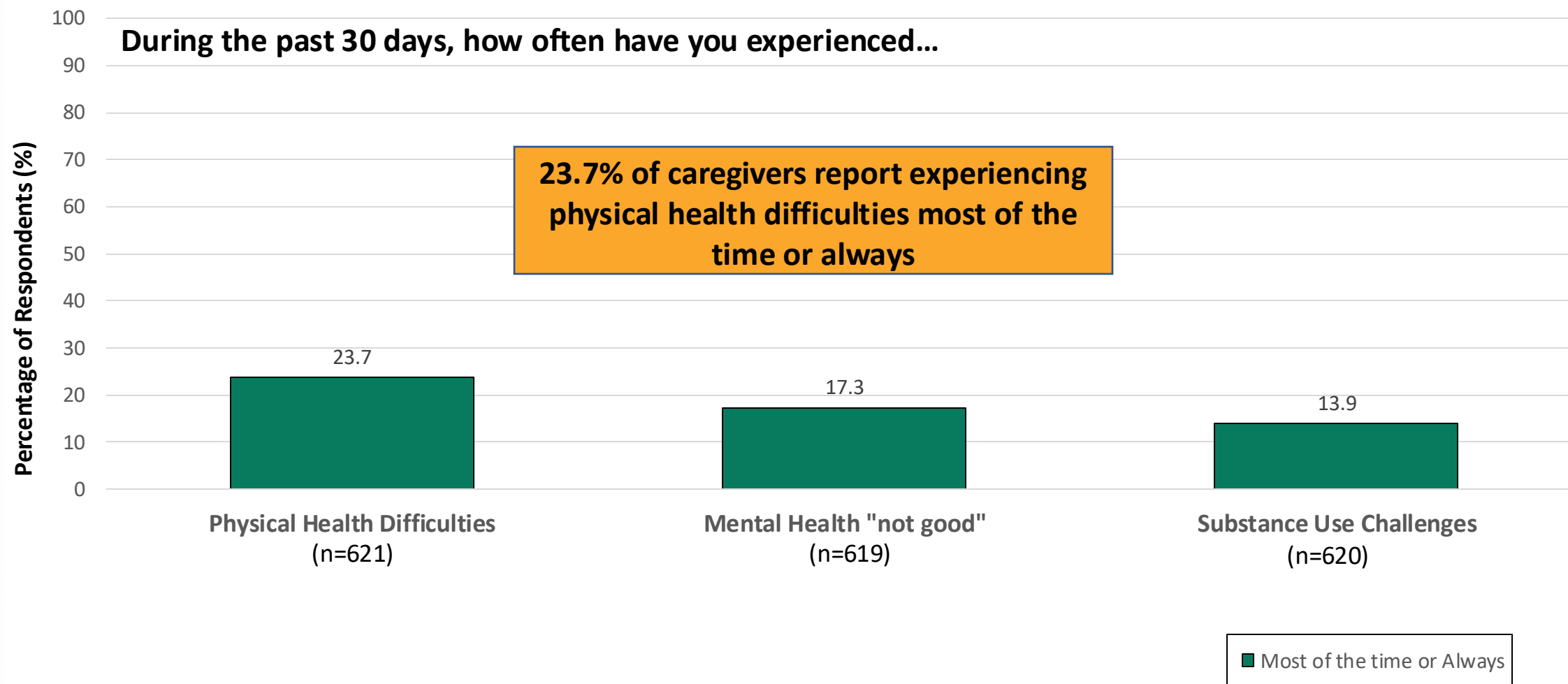
Percentage of caregivers and their satisfaction with the level of support they have for themselves (n=624)

Overall, how satisfied are you with the level of support you have for yourself as you support the individuals you care for who are receiving behavioral health services?



Physical and Behavioral Health in Caregivers

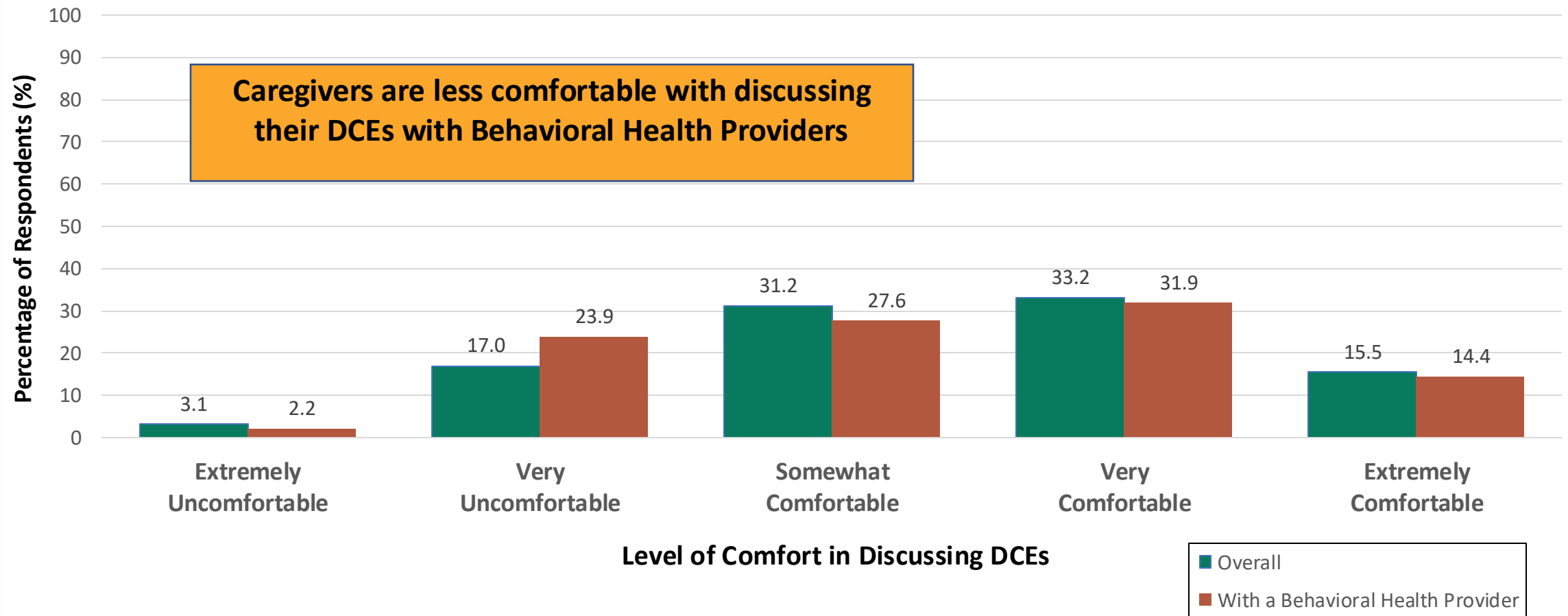
Percentage of caregivers who report challenges with their physical and/or behavioral health



Caregiver comfort in talking about their DCEs

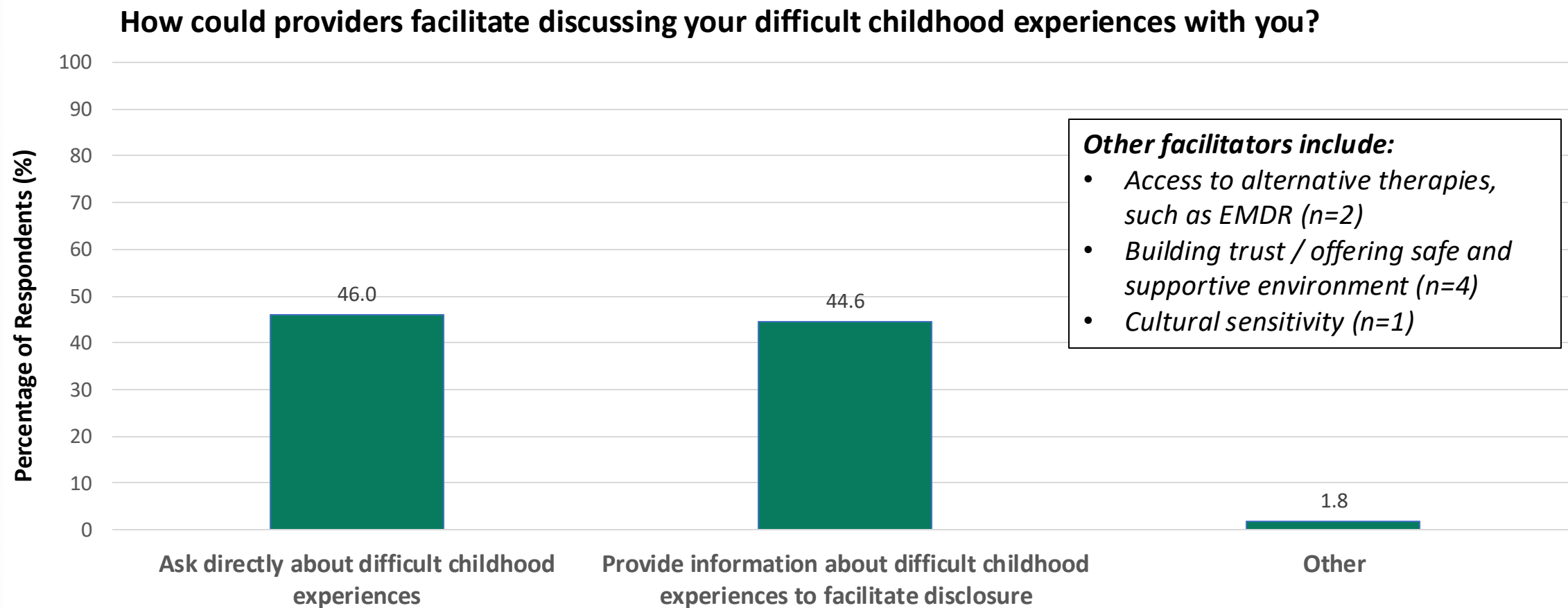
Percentage of caregivers by their comfort level in talking about DCEs overall and with a behavioral health provider (n=458)

How comfortable are you talking about your difficult childhood experiences?



Facilitating DCE discussions with Caregivers

Percentage of caregivers and how providers can facilitate discussing difficult childhood experiences (n=635)





Other Supports from Treatment Providers

Summary of caregiver responses to the open-ended question below: (n=427)

What other things can treatment providers do to better support you as you care for and support individuals who are receiving behavioral health services?



The most caregivers requested Training and Education (n=70) about:

- Behavioral health services, treatment options, their loved ones' mental health, how to support them (n=54)
- Strategies for preventing crisis and assisting their loved ones' when crisis occurs (n=6)
- Self care, coping skills or strategies, and stress management (n=17)

"I feel like I don't know enough to ask the right questions and don't know what supports might be available. I would like to be able to communicate with my loved one's provider to be aware of specific signs of crisis and how to deal with them BEFORE they reach a critical point"

Other Supports from Treatment Providers



Summary of caregiver responses to the open-ended question below: (n=427)

What other things can treatment providers do to better support you as you care for and support individuals who are receiving behavioral health services?



Involve caregivers in treatment planning, inform them about treatment progress, and include them in decision making (n=57)

Individualized treatment plans with re-evaluations for loved ones and providing with ongoing feedback to caregivers (n=27)

Ongoing, open and transparent communication (n=55)

Listen to, understand, and respect caregiver perspectives (n=35)

“Encourage me to participate in the treatment process and make me feel like an important part of the support network.”

“Organize family meetings where I can discuss the best support strategies with my treatment provider and the individual's other support systems.”

Other Supports from Treatment Providers



Summary of caregiver responses to the open-ended question below: (n=427)

What other things can treatment providers do to better support you as you care and support individuals who are receiving behavioral health services?

**Caregiver Support Groups
(n=41)**



Emotional Support (n=39)

“Schedule regular support groups or counseling sessions for me to share experiences and gain support with other caregivers.”

**Caregiver Resources
(n=40)**



“Share useful resources and information, such as relevant books, websites, forums, etc..”

Self Care (n=28)



**Coping Skills
(n=29)**

Stress Management (n=26)

“Provide practical self-care techniques to help me manage stress and anxiety.”

Other Supports from Treatment Providers



Summary of caregiver responses to the open-ended question below: (n=427)

What other things can treatment providers do to better support you as you care and support individuals who are receiving behavioral health services?

***Offer Respite
Care(n=17)***



***Offer a supportive and
non-judgmental
environment (n=13)***



***Collaborate with other
providers for continuity of
care and provide integrated
services (n=15)***



***Provide crisis
intervention resources
and supports (n=15)***



Anything Else from BHA?

Summary of caregiver responses to the open-ended question below: (n=408)

Is there anything else that you think BHA should know about how to provide services or support to caregivers like you?

Fund and provide training for both caregivers and treatment staff (n=71)

Establish caregiver support networks to promote interaction among caregivers with peer mentorship (n=45)



Use technology to provide access to resources and ensure this information is widely publicized (n=26)

Ensure sufficient resources for caregivers and advocate with policymakers for increased resources (n=19)

“Caregiving can be an isolating and challenging experience, and caregivers often feel a sense of isolation and loneliness as they navigate the challenges of supporting their loved ones. By fostering a sense of community and connection among caregivers, BHA can help to reduce this sense of isolation and provide a supportive network for caregivers to turn to.”



Anything Else from BHA?

Summary of caregiver responses to the open-ended question below: (n=408)

Is there anything else that you think BHA should know about how to provide services or support to caregivers like you?

Make mental health supports and services available to caregivers (n=55)

Offer other interventions to carers such as stress management, yoga, meditation, and strategies for dealing with burnout (n=43)

Help caregivers find work/life balance and set healthy boundaries (n=20)



“Our full family suffered from her mental health issues. Her trauma was radiated to the rest of our family affecting our other children and us as parents. We alllll needed to go to counseling/therapy for the secondhand trauma. I feel this is often forgotten - the ripple effect one mental illness can have on those who live with the child.”

Proactively assess caregiver needs and implement personalized caregiver support plans (n=20)

Make respite care available (n=13)



Anything Else from BHA?

Summary of caregiver responses to the open-ended question below: (n=408)

Is there anything else that you think BHA should know about how to provide services or support to caregivers like you?

Encourage healthy work environments with open communication, team building, and adequate staffing and compensation (n=49)

Promote effective communication channels and healthy communication skills to improve transparency and trust between caregivers and practitioners (n=15)



Encourage and promote caregiver participation in treatment planning with ongoing communication between caregivers and treatment providers (n=15)

“Recognize that caregivers' expertise and experience should be respected and valued, and encourage them to speak up in the decision-making process.”



Anything Else from BHA?

Summary of caregiver responses to the open-ended question below: (n=408)

Is there anything else that you think BHA should know about how to provide services or support to caregivers like you?

Acknowledge the importance and emotional impact of caregiving (n=31)

Foster a culture of validation, appreciation and non-judgement for caregivers (n=17)



“Caregiving is a vital and essential role, and it's important for BHA to acknowledge and value the work that caregivers do. This can help caregivers feel appreciated and supported, and can encourage them to continue providing care.”



Anything Else from BHA?

Summary of caregiver responses to the open-ended question below: (n=408)

Is there anything else that you think BHA should know about how to provide services or support to caregivers like you?



Advocate for workplace policies that support caregiving, such as flexible work schedules (n=29)

Collect feedback from and provide feedback to caregivers regularly. Use this information to implement changes (n=24)

Provide resources for handling crisis situations including crisis planning and support, safety protocols and emergency response (n=20)

“... consider offering ongoing evaluation and feedback to caregivers on the effectiveness of the services and support they are receiving. This can help to ensure that caregivers are receiving the support they need and that the services being provided are meeting their needs and goals. By regularly evaluating and adjusting the services and support being provided, BHA can continue to improve the experience for caregivers and ensure that they are receiving the best possible care and support”



Building Healing Systems:

Summary of Findings and
Potential Action Steps



Summary of Findings

- Almost all caregivers (97%) reported experiencing at least one Positive Childhood Experience (PCE), with an average of 4 PCEs per caregiver.
- A majority of caregivers report having experienced one or more Difficult Childhood Experience (DCEs, 74%); 8% with 4+ DCEs
- A higher percentage of caregivers with four or more DCEs support children (14%) or transitional aged youth (16%) compared to adults (5%)
- Caregivers report that their difficult childhood experiences *most of the time* or *always* impacted their mental health (46%), relationships (39%) and the ability to support individuals receiving behavioral health services (38%)
- Caregivers reported several activities that helped them in adulthood including volunteering (39%), supportive relationships (34%) and behavioral health treatment (31%)
- Almost a quarter of caregivers report *most of the time* or *always* experiencing emotional distress about the trauma or adversity experienced by the individuals they support (23.5%)



Summary of Findings

- **Caregivers were satisfied with their level of support (83%)**
 - **Most Wanted:** Connections to community resources, such as food, housing or employment (44%)
 - **Most Received:** individual services for myself from a behavioral health provider (65%)
- **Caregivers reported that they *most of the time* or *always* experienced physical health (24%) mental health (17%) or substance use challenges (14%) in the past 30 days**
- **Caregivers are comfortable with discussing their difficult childhood experiences overall (80%) with fewer feeling comfortable discussing these experiences with behavioral health providers (74%)**
- **Providers can facilitate discussing caregivers' difficult childhood experiences with them by**
 - Asking directly about difficult childhood experiences (46%) or
 - Providing information about difficult childhood experiences to facilitate disclosure (45%)



Summary of Findings

- **Other things that treatment providers can do to better support caregivers**
 - Provide training and education (n=70), most regarding behavioral health services (n=54)
 - Involve caregivers in treatment planning and decision making (n=57)
 - Maintain ongoing, open and transparent communication (n=55)
 - Offer caregiver support groups (n=41)
- **Other things caregivers want BHA to know**
 - Fund and provide training for both caregivers and treatment staff (n=71)
 - Establish caregiver support networks (n=45)
 - Make mental health supports and services available to caregivers (n=55)
 - Encourage healthy work environments with open communication, team building, and adequate staffing and compensation (n=49)



Potential Action Steps

- Understand the needs of each individual caregiver and how their lives are impacted
- Implement processes to facilitate discussing adverse childhood experiences of caregivers
- Develop caregiver specific support plans and link them with resources for themselves as well as the individuals they support
- Implement procedures that include caregivers in treatment planning and decisions about the individuals they support
 - Improve communication between caregivers and treatment providers
 - Foster an environment that engages caregivers
 - Ensure that providers build trustworthiness with individuals receiving services and their caregivers



Potential Action Steps

- **Advocate for workplace policies that support caregiving**
- **Collect feedback from and provide feedback to caregivers regularly**
- **Establish caregiver support networks**
- **Develop a centralized, electronic repository of caregiver resources**
- **Advocate with policy makers to increase funding for caregiver resources**



Appendix - Methods: Eligibility

- **Eligibility: Definition of Caregiver**
 - The survey targeted individuals who provide support (physical, social, emotional or financial) to anyone who has received behavioral health services in Maryland.
 - Behavioral health services included mental health and/or substance use services.
 - The survey did not include professional caregivers unless they are providing unpaid support to someone in their life who is re
 - Individuals who indicated that they did not meet the above definition of “caregiver” were exited from the survey.



Appendix - Methods: Invitation

- **The following methods were used to invite Caregivers to participate in the survey**
 - SEC and/or BHA contacted representatives from organizations that have Caregiver representation,
 - Representatives from Maryland Coalition of Families (MCF) and the National Alliance on Mental Illness (NAMI) reviewed and made recommendation for survey content
 - Each entity distributed the invitation to their Caregiver distribution list. Targeted outreach occurred with caregiver support groups
 - Participants were encouraged to forward the survey to other caregivers who may be interested in completing the survey.



Appendix - Methods: Data Collection and Analysis

- **Data were collected from July 16- October 2, 2024**
 - Approximately 2-4 weeks after the initial survey distribution, a reminder email with the invitation survey was sent with a request to redistribute.
- **Quantitative Data Analysis**
 - General descriptive statistical information were calculated for all quantitative variables
 - Cross-tabulations for relevant variables were used to understand the patterns in the results
- **Qualitative Data Analysis**
 - Qualitative items were analyzed using an emergent theme approach..

References

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