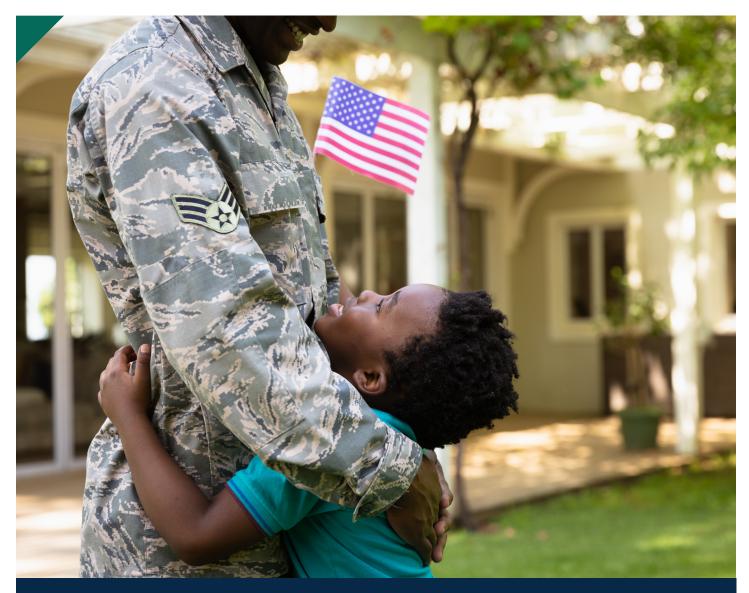


WOUNDED WARRIOR PROJECT







Hidden Helpers at the Frontlines of Caregiving: Supporting the Healthy Development of Children from Military and Veteran Caregiving Homes

Final Report

November 2021

Steven Malick, Mayra Sandoval, Tatiana Santiago, Cleo Jacobs Johnson, Amy Gehrke, and Emily Metallic

Acknowledgments

This study would not have been possible without the contributions of many individuals and organizations. The most important ones were those of the Hidden Heroes and Hidden Helpers—America's military and veteran caregivers and caregiving children—who shared their time, experiences, wisdom, and insights with our team. The families we interviewed have already given so much to our country and to their families, and we are especially grateful for them. This report was made possible with support from the Wounded Warrior Project, the Lilly Foundation, and the Elizabeth Dole Foundation. We also thank the staff from the Elizabeth Dole Foundation, particularly Rashi Romanoff and Rachael Barrett, for their unwavering partnership to shape and complete the study. We also appreciate the input from subject matter experts which guided our early efforts as this study started. And we were buoyed by the enthusiasm the broader military and veteran caregiving community showed as we conducted and shared this research.

This study also benefited from the contributions of many people at Mathematica. The report's authors were supported by a team of dedicated staff: Joe Zickafoose, Irna May Connor, and Morgan Woods. We benefited from the support of our in-house library staff, Jazmine Faherty and William Rafferty, and expert editing and production support from Dorothy Bellow, Colleen Fitts, Donovan Griffin, John Kennedy, Effie Metropoulos, and Anuja Pandit. We also relied on support from our communications team, including Demetrius Goosbey, Deric Joyner, Gwyneth Olson, and Sarah Vienneau. Finally, we thank Phyllis Barker, Patricia Guroff, and Raquel af Ursin for helping us ensure we could cast the widest possible net to reach military caregiving families for focus groups and interviews.

We thank the Elizabeth Dole Foundation and the military caregiving community for several of the images of families in this report. The use of these images does not imply participation in the study.

Contents

| Acknowledgmentsii | IV. Recommendations23 |
|---|--|
| Contents iii | Create and scale. Quality programs and |
| Executive Summaryiv | interventions that support children in caregiving families and focus on peer support, mental |
| I. Introduction1 | health, and age-appropriate developmental opportunities 26 |
| Overview of study and research questions3 | Invest. Fund, promote, and create |
| II. Exploring the literature on the potential impact of caregiving on children from military caregiving homes6 | supports targeted to the entire family unit28 Raise awareness. Amplify national campaigns and coalitions to improve understanding of care recipients' visible and invisible wounds |
| Short- and long-term outcomes for children growing up in military caregiving homes 7 | and the needs of caregivers and children in military caregiving homes |
| Exploring the possible impacts of caregiving through related literature on military children who take on adult responsibilities | Increase access. Partner with federal and local agencies, including private organizations, to reduce barriers to health care and provide centralized comprehensive services focused |
| Emerging evidence on effective supports for children from military caregiving homes9 | on supporting caregiving families |
| III. Understanding the experiences of | VI. References |
| children in military caregiving homes through their own words, the eyes of caregivers and experts, and nationally | Appendix A: Literature review methods and description of studies identified |
| representative surveys | How we conducted the literature review and what types of studies we found 38 |
| struggle to identify responsive sources of support for children | Appendix B: Data analysis of nationally representative surveys42 |
| Caregiving demands can interfere with family dynamics that support the development of all | How we used survey data to learn about children in military caregiving homes |
| family members, and caregivers need support to ensure children's needs are addressed 15 | Exhibits |
| Fears of stigma and being misunderstood by friends, family, and the greater community | Exhibit I.1. Characteristics of children and caregivers participating in focus groups 5 |
| contribute to feelings of isolation for children and caregivers 17 | Exhibit III.1. The relationship between children's well-being and their care |
| National and local barriers limiting access to timely and quality care for care recipients | recipient's injury or illness22 |
| and their families negatively impact the entire family's well-being, but families have ideas about how to overcome the barriers | Exhibit IV.1 Improving the well-being of children in military caregiving families requires action at all levels of society 25 |
| A family ecological model to guide improvements for child well-being 21 | Exhibit A.1. Eligible studies identified during the literature review 39 |
| | Exhibit A.2. Interventions focused on improving outcomes for military children 41 |

Executive Summary

"Far too often, the veteran is the only one who is made to be the primary person in need of support. If you're not talking about the other people in their life, you are missing a giant piece of the puzzle."

- Adult caregiver

Why this study?

Empowering, supporting, and honoring the informal caregivers who care for America's wounded, injured, or ill service members and veterans is the mission of the Elizabeth Dole Foundation (the Foundation). These informal caregivers are usually the service members' or veterans' family members or friends. The Foundation led some of the earliest research on these caregivers, also known as "Hidden Heroes," and identified the challenges military and veteran caregivers (hereafter military caregivers) encountered in helping their service member or veteran manage the adversities that stem from their visible and invisible wounds (Ramchand et al. 2014; Tanielian et al. 2017). This effort resulted in a research blueprint which revealed that attending to the well-being of children, the "Hidden Helpers" living in these homes, was a critical next step to enhance support for military caregiving families (Tanielian et al. 2017). The Foundation partnered with Mathematica to examine the impact of caregiving on children growing up in military caregiving homes to help address the national challenge of providing effective support to caregivers of all ages and backgrounds.

"People would ask how our dad was. Nobody would ask how we were."

- Young adult who grew up in a military caregiving home

Whom do we hope to help with this study?

Approximately 2.3 million children under age 18 live with a veteran who is disabled, according to our analyses of data from American Community Survey (ACS) for 2015–2019. Prior research suggests negative outcomes for children growing up in military caregiving homes (Briggs et al. 2020; DeVoe et al. 2018; Glenn et al. 2002). The return of service members who sustained or developed an illness or injury because of their military service can be disruptive for families as they learn to support them and establish new norms for operating as a family. In the midst of this disruption, families are often left wanting help. Caregiving consumes the time and energy of the adult caregiver, and children in many military caregiving homes consequently take on additional responsibilities—ranging from additional household chores to caregiving responsibilities for their injured or ill service member or veteran and responsibilities for siblings who would otherwise have been cared for by the adults in the home. Ultimately, children in military caregiving homes can get lost in their family's response to the needs of the care recipient.



What did our study find?

"There are not enough programs, and there is not enough attention for people with problems."

- Child caregiver

Children want more support to navigate their experiences as Hidden Helpers, and caregivers struggle to identify responsive sources of support tailored for caregiving children. Children need help not only managing the stresses and the demands of caregiving; they need child-centered information on their servicemember's or veteran's injury and its long-term implications. Adult caregivers face challenges identifying and accessing supports and attending to children's needs can become crowded out by the demands of caregiving.

"The responsibility of everything is really my responsibility. I just try to delegate where I can."

- Adult caregiver

Caregivers fight to make the most of their situation and to foster well-functioning families by emphasizing cohesion, communication, and flexibility. They also work hard to keep the demands of caregiving from dominating all aspects of family life. Addressing the expressed needs of caregivers could help families function better.

" I do not want my children to feel that they need to hide dad's injuries." – Adult caregiver

Fears of stigma and being misunderstood by friends, family, and the larger community can engender feelings of isolation for children and caregivers. Children and caregivers report that their non-caregiving peers struggle to understand the experience of caregiving. At worst, misunderstanding and stigma about injured and ill care recipients can keep military caregiving families from seeking healthcare and other supports. Some families avoid looking for support altogether out of fear.

" I'd like a program that gets the veterans and caregivers and families what they need. I want to be able to come home and not see my mom doing a bunch of paperwork... I want to see that my dad gets the correct care, and it doesn't take him a week to get permission to go to the ER for a broken bone. I want my mom to get the help she needs."

- Child caregiver

National and local barriers limiting access to speedy, high quality care for care recipients and their families negatively impact the entire family's well-being, but families have ideas about how to overcome the barriers. Navigating the federal system to access quality care is a significant source of anxiety and distress for military caregiving families. Caregivers offered solutions that they believed could help improve family functioning and support the well-being of children from military caregiving homes, like providing affordable and accessible child care and cultivating schools' understanding of the needs and impacts of caregiving.



"We've been married for 20-something years, and I've seen how my husband was prior and then after... It's two different men... The Army does not brief you on this." – Adult caregiver

What can be done about it?

We identified four key recommendations to help improve the well-being and healthy development of children in military caregiving homes:

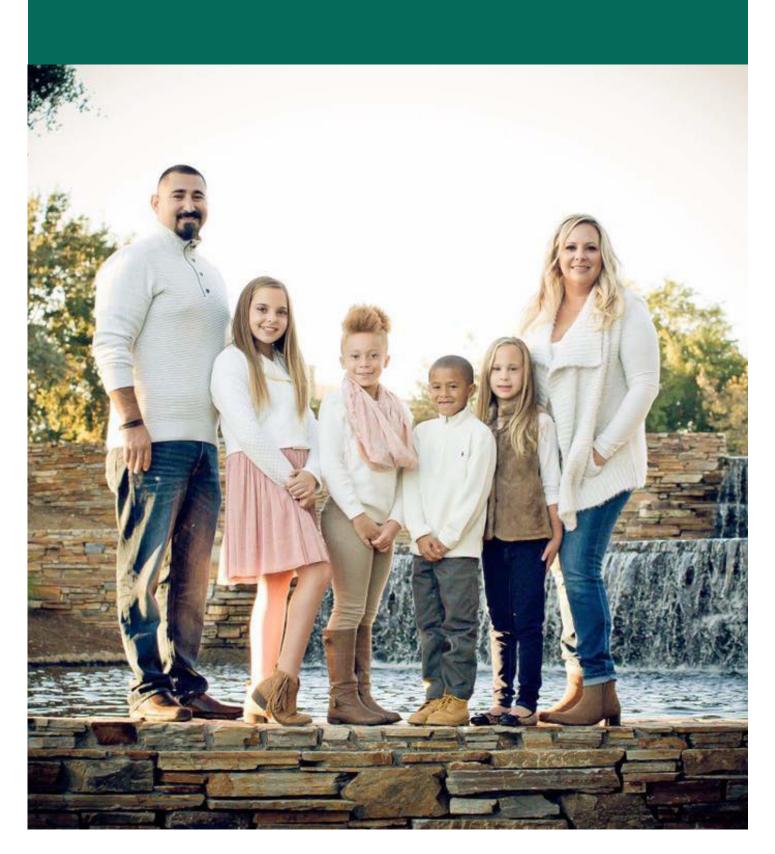
| ୁଲି Create | Invest | Raise | (규) Increase |
|---|--|--|---|
| ରୁଦିର and scale | | awareness | 이 이 이 이 이 이 이 이 이 이 이 이 이 이 이 이 이 이 이 |
| Develop quality programs and interventions that support children in caregiving families and focus on peer support, mental health, and age-appropriate developmental opportunities. | Fund, promote, and create supports for the entire family unit. | Amplify national campaigns and coalitions to improve understanding of care recipients' visible and invisible wounds and the needs of caregivers and children in military caregiving homes. | Partner with federal and local agencies, including private organizations, to reduce barriers to health care and provide centralized comprehensive services focused on supporting caregiving families. |

Hidden Helpers take pride in the ways they help their families, but they need more support, both to navigate their role in their families and foster their own healthy development. Acting on these recommendations requires active collaboration and partnership among federal agencies, community and nonprofit organizations, policymakers, researchers, and philanthropic organizations. To this end, steps these entities could take to improve the well-being of military caregiving children include:

- / Identifying, researching, and scaling programs and strategies likely to improve outcomes for children and caregivers in military caregiving families;
- / Identifying and removing barriers or disincentives to obtaining timely and effective care;
- / Improving data collection about military caregiving families to more comprehensively understand their needs and monitor progress toward improving their outcomes;
- / Building on existing and create new efforts to build awareness and understanding of the needs of those in military caregiving families;
- / Providing trainings for those most likely to interact with individuals in military caregiving families so that they are better equipped to support their needs; and
- / Centralizing and sharing resources that help military caregiving families better identify and navigate programs and supports.

Hidden Helpers at the Frontlines of Caregiving: Supporting the Healthy Development of Children from Military and Veteran Caregiving Homes

I. Introduction



After two decades of war in the aftermath of the September 11, 2001 terrorist attacks, the federal government, national organizations, and community organizations increasingly prioritized supporting service members, veterans, and the families of those who sustained injuries or became ill because of their service in the ensuing conflicts in Afghanistan, Iraq, and elsewhere. The professional medical care provided to many wounded, injured, or ill service members and veterans is augmented by care from informal and unpaid caregivers. These informal caregivers are most often the service members' and veterans' family members and friends and the value of this care exceeds \$14 billion annually (Tanielian et al. 2017).

The mission of the Elizabeth Dole Foundation is to empower, support, and honor the informal caregivers who care for America's wounded, injured, or ill service members and veterans. The Foundation spearheaded some of the earliest research on these caregivers (for example, Ramchand et al. 2014). This early work identified challenges military and veteran caregivers (hereafter military caregivers) encountered while helping their service member or veteran manage challenges related to their visible

wounds, such as physical disability, or invisible wounds, non-physical wounds such as post-traumatic stress disorder. The research provided a road map, which is an ongoing effort to document the military caregiver journey and its impact on caregivers' physical, psychological, financial, and social well-being. See the <u>Foundation's</u> <u>Military and Veteran Caregiver Experience Map</u>. Much of that early work focused on adult caregivers, also known as "Hidden Heroes." The research revealed that attending to the well-being of "Hidden Helpers," that is the children and youth living in homes with wounded, injured, or ill service members and veterans, was a critical next step to enhance supports for military caregiving families.

"There's always a high level of anxiety in children going through the things military caregiving families experience. Children are often the silent heroes in this military journey. They are part of the caregiving; when deployments and homecomings happen, they are there."

– Program provider

In 2020, the Foundation partnered with Mathematica to:

- Examine the impact of caregiving on children growing up in military caregiving homes.
- 2. Identify promising activities that could support the well-being of children in these homes.

To address these goals, the Mathematica team documented the opportunities and challenges facing children growing up in military caregiving families by:

- / Conducting a literature review to summarize what is known about the impact of caregiving on military children.
- / Analyzing data from the 2015–2019 American Community Survey.
- / Analyzing data from the 2016–2018 National Health Interview Surveys.
- / Interviewing researchers and practitioners who understand the dynamics of military caregiving in families.
- / Listening directly to the people who care for injured or ill service members or veterans and to the children of these care recipients.

We found dynamic families that are working hard to support the care recipients' needs and the individual needs of other family members in the face of caregiving demands. Yet, these demands also created important and meaningful challenges that could influence the healthy development of children and impact their life outcomes.

Overview of study and research questions.

Research questions

The study was designed to deepen understanding of the experiences of children from military caregiving homes to identify promising practices to support their well-being. To this end, this report presents findings and recommendations based on an exploration of the following research questions:

- **1.** How are military children affected in the short- and long-term when a parent or family member returns home from combat with an injury or illness?
- 2. What is known about children that have taken on caregiving duties for ill, injured, or wounded service members and veterans?
- **3.** How can we best support children in caregiving households?
- **4.** What interventions and programs have demonstrated the potential to be the most supportive to military children from caregiving families?
- **5.** What policy recommendations should we consider in the area?

Data sources and analysis methods

To develop a holistic picture of the experiences of and outcomes for children from military caregiving homes, the study used a mixed-methods approach. We used the following data sources:

Literature review

We conducted a literature review to summarize what is known about how caregiving in military homes can affect children. We first identified studies that examined outcomes for children from military families broadly. We then reviewed the articles focused on military-connected children, their caregiving duties, or their responses to their parents' chronic deployment-related injuries or illnesses. This search also revealed rigorous studies on certain programs or supports for military children. Details are in <u>Appendix A</u>.

Data analysis of the 2015–2019 American Community Survey results

The American Community Survey (ACS), administered each year by the U.S. Census Bureau to about 3.5 million households, collects detailed information on the U.S. population. The ACS collects information on all members of a household, including their age, current and past military service, and disability. We analyzed data from the 2015–2019 ACS to estimate the number of children under the age of 18 who were living with a disabled veteran. We defined a disabled veteran as anyone who had served in the military and had been recognized by the U.S. Department of Veterans Affairs (VA) to have either a service-connected disability rating or had difficulties with self-care, independent living, walking, cognitive function, hearing, or vision. Self-care difficulties included physical, mental, and emotional challenges and challenges with concentration, memory, decision making, personal care and hygiene, and completing errands. Details are in Appendix B.

Data analysis of the 2016–2018 National Health Interview Survey

The National Health Interview Survey (NHIS) is a nationally representative survey that monitors the health of the noninstitutionalized United States population. The NHIS collects information on all members of a household, including age, current and past military service, and disability. It also includes one child age 17 or younger from each household in the sample (if any children live in the household) and collects more detailed information on the health and well-being of the child. Previous research has found that less than 3 percent of the U.S. adult population are military caregivers (Ramchand et al. 2014);

3

therefore, we did not expect to find many veterans in the NHIS data. To obtain a large enough sample size to produce reliable estimates and acceptable standard errors, we combined data from the 2016, 2017, and 2018 NHIS to compare outcomes for children who lived in different kinds of households: those from households with military and veteran care recipients, current military households without caregiving needs, households with civilian care recipients, and households with civilians and no caregiving needs. The combined 2016, 2017, and 2018 NHIS sample included 28,221 children. Details are in <u>Appendix B</u>.

Because the NHIS does not identify caregivers directly, we identified households with care recipients through the presence of households with an adult age 18 or older who requires help with personal care or routine needs because of physical, mental, or emotional injuries and illnesses, in which children are living. We identified current military service members as those who were serving full-time active duty with the Armed Forces at the time of the survey, and veterans as those who had ever served on active duty in the Armed Forces, Reserves, or National Guard. Their needs included support with activities of daily living, such as eating, bathing, dressing, or getting around inside the home, or instrumental activities of daily living, such as completing household chores, doing necessary business, shopping, or getting around for other purposes. Because we wanted to understand outcomes for children who were not the primary caregiver in military caregiving homes, we limited our analysis to households in which there were at least two adults present under the assumption that one of these individuals was the care recipient, and the other was the adult caregiver. Of the 28,221 children in the sample, 23,728 lived in multiple-adult households. Of those, we identified 94 children who lived in a military or veteran caregiving household, 470 children who lived in a current military non-caregiving household, 960 children who lived in a civilian caregiving household, and 22,204 children who lived in a civilian non-caregiving household.

Interviews with subject matter experts

We reached out to 16 subject matter experts who had varying experience with military families in general and caregiving families in particular. Foundation staff provided recommendations and contact information for individuals to participate in the interviews. We completed 15 one-hour semistructured virtual interviews (and in one instance, an email correspondence) from August 2020 through August 2021. The subject matter experts included representatives from 13 different organizations. These organizations included programs that provide services to military-connected children, government agencies or military-focused initiatives, and research or academic institutions. We received approval from Health Media Lab's (HML) Institutional Review Board (IRB) before conducting the interviews with subject matter experts.

Interviewers recorded and produced written summaries of each interview and used a codebook in Microsoft Excel to manually code each transcript. We conducted an analysis by identifying emerging themes from the data covered in the interviews, which included the following three main topics:

- **1.** Roles, responsibilities, and relationships within military caregiver families.
- 2. The impacts of caregiving on children from military caregiving homes.
- **3.** Supports and interventions for children in these homes. To ensure confidentiality, we destroyed all recordings after verifying the accuracy of our notes.

Focus groups with children and caregivers in military caregiving families

We held virtual focus groups with 24 caregivers, 23 children, and 7 young adults who grew up in military caregiving homes. We used a nonrepresentative snowball sample to recruit adult caregivers with children through social media platforms and word of mouth between October 2020 and January 2021. The posts were primarily delivered through social media platforms, including the Foundation's Hidden Heroes Caregiver Community. The recruitment posts included information about the study and a SurveyMonkey link to learn key information about prospective participants to determine their eligibility. Participants were eligible to take part if they indicated:

- 1. They care for a military service member or veteran who developed a chronic injury or illness as a result of their military service.
- 2. They care for child(ren) who live in the household of the care recipient.
- **3.** The timing of the injury or illness occured during or after Operation Enduring Freedom or Operation Iraqi Freedom.

We obtained IRB approval from HML before conducting the focus groups.

We contacted eligible caregivers by email and obtained their verbal consent by phone. In total, we contacted 52 caregivers, and 35 of these (67 percent) agreed to participate. Of these 35 caregivers, 24 caregivers attended the focus groups (69 percent). These caregivers also agreed to have their child(ren) participate in focus groups with other children. A total of 24 children ages 10 to 17 and 7 young adults ages 18 to 25 participated in focus groups. The children under the age of 10 were not included in part because of our desire to learn about the experiences of older children. When unavailable for focus groups, we conducted individual interviews. Due to the COVID-19 pandemic, all focus groups were conducted virtually. Exhibit I.1 presents more on the characteristics of children and caregivers in the study. We followed the same process we used for interviews with subject matter experts in recording, summarizing, and analyzing the focus group data. We destroyed the recordings of our conversations after verifying the accuracy of our notes.

Exhibit I.1. Characteristics of children and caregivers participating in focus groups

| Family participants | | |
|---|--------------------------|----------------------|
| | Numberª | Percent ^b |
| Caregiver characteristics | | |
| Region where caregiver wa of participation | as living at t | ime |
| Midwest | 4 | 17% |
| Northeast | 1 | 4% |
| Southeast | 8 | 33% |
| Southwest | 4 | 17% |
| West | 7 | 29% |
| Injury or illness type of care | e recipient ^c | |
| Only visible | 0 | 0% |
| Only invisible | 8 | 33% |
| Both visible and invisible | 13 | 54% |
| Other combination | 3 | 12% |
| Time of injury | | |
| After OEF/OIF | 24 | 100% |
| Before OEF/OIF | 0 | 0% |
| Characteristics of childre | n and youn | g adults |
| Age of children or young a | dults | |
| 10-14 | 15 | 50% |
| 15-17 | 8 | 27% |
| 18–25 | 7 | 23% |

^a 54 individuals participated in focus groups.

- ^b Percentages may not sum to 100% due to rounding.
- ^c Visible injury or illness includes any type of physical disability. Invisible injury or illness includes PTSD, depression, or other mental health issues.
- OEF = Operation Enduring Freedom OIF = Operation Iraqi Freedom

II. Exploring the literature on the potential impact of caregiving on children from military caregiving homes



As a first step to understanding the experiences of children from military caregiving homes, we sought to document what research has found about military children who live with a parent or caregiver who has sustained a chronic injury or illness during their military service.

To develop a holistic understanding of the experiences of children in these homes, we set out to explore the literature to deepen our understanding of:

- Short- and long-term outcomes for children from military caregiving homes.
- 2. The consequences for these children of taking on caregiving duties.
- **3.** The evidence base for effective interventions and supports.

We focused our review on research of children younger than age 18 and defined injury or illness broadly to include both visible wounds and invisible wounds. Our search reaffirmed that children of military caregivers are fittingly called Hidden Helpers because their caregiving efforts are largely unacknowledged in research. Our literature search identified 133 studies focused on outcomes for children of U.S. military service members regardless of their caregiving status. However, only 18 of these studies focused on military children's responses to parental chronic injuries or illnesses due to deployment or their caregiving duties during a parent's deployment, and none focused on the impacts of caregiving itself.

Short- and long-term outcomes for children growing up in military caregiving homes.

We found limited research describing the outcomes of caregiving for children, but findings in the literature pointed to several themes related to children's well-being.



Research on children whose parent or family member returns from military service with an injury or illness points to worrisome outcomes, particularly related to psychological or behavioral well-being.

We found 13 studies that examined the impact of a parent returning from deployment with an injury or illness. Eight studies described behavioral outcomes of children. Three studies found increased rates of child behavioral problems, violence, or hostility in children whose parents had combat-related injuries or illnesses (Briggs et al. 2020; DeVoe et al. 2018; Glenn et al. 2002). For example, Briggs et al. (2020) found higher rates of injury-related stressors (such as combat and noncombat injuries or caring for an injured spouse) reported by the caregiver was associated with higher rates of child conduct problems (such as persistent challenges following rules and respecting others). Similarly, DeVoe et al. (2018) found that parental reports of child behavior problems were associated with the severity of the parent's PTSD symptoms. Two studies found that parental combat-related injury or illness was related to increased rates of child maltreatment (Hisle-Gorman et al. 2015; Glen et al. 2002).

Three of these studies described outcomes related to internalizing behaviors (inwardly focused negative behaviors such as social withdrawal, nervousness, or fearfulness) and externalizing behaviors (outwardly focused negative behaviors such as physical aggression or destructive behaviors) (Briggs et al. 2020; Herzog et al. 2011; Yager et al. 2016). Briggs et al. (2020) found that the presence of parental chronic injury or illness was associated with an increase in internalizing and externalizing symptoms in their children. Herzog et al. (2011) found an association between children's secondary traumatic stress resulting from their caregiver's traumatic stress and increases in children's internalizing behaviors. This study did not, however, find an association between a child's secondary traumatic stress and externalizing behaviors. Yager et al. (2016) found differences based on the gender identity of the children they studied. They found that boys whose parents experienced PTSD were more likely to exhibit internalizing and externalizing behaviors. Although it found no association for girls generally, this study found increases in girls' externalizing behaviors when their mothers had been "demoralized" by their fathers experiencing PTSD.

Six studies reported psychological outcomes of children, such as depression or anxiety. Only three used primary data, and they all examined outcomes related to mental health and child distress. Briggs et al. (2020) found no association between injury-related stressors and diagnoses of attention-deficit disorder and attention-deficit/hyperactivity disorder in children. Cozza et al. (2010) noted that families that experienced high levels of disruption as a result of injury were more likely to report high levels of child distress. There is also evidence of adverse psychological impacts on caregiving children in general.

In a review of 21 studies of child caregivers, Marote et al. (2012) found that caregiving children were more likely to:

- **1.** Experience isolation and have fewer opportunities to interact with their peers and develop friendships.
- 2. Have increased feelings of stigmatization.
- **3.** Have difficulties expressing emotion and learning in school.
- **4.** Have more health problems such as stress, burnout, and fatigue.



Despite the challenges faced by children from military caregiving homes, a few potential bright spots also emerged.

Relatively few studies of the general population identified possible positive consequences of caregiving on children. Two studies reported that children of caregivers with disabilities (visible or invisible) can have positive disability-related experiences—that is, positive reactions to the daily events that make up a person's experience with disability (Mazur 2011; Marote et al. 2012). Specifically, Mazur (2011) found that adolescents of disabled parents with less anxiety were more likely to report positive disability-related experiences in caring for their parent. This suggests that the mental health of disabled parents could factor into their caregiving child's experience.

"Children in military caregiving families can gain a heightened level of proactive empathy and a greater sense of community support. One caregiving mother told me that she sees her young child caring profoundly for people in a way his peers don't. He wants to help strangers struggling to reach something in the grocery store, and she doesn't see other kids his age doing that."

-Researcher

Exploring the possible impacts of caregiving through related literature on military children who take on adult responsibilities.

While we uncovered no studies exploring outcomes for children who have assumed caregiving duties for parents *after their return* from military service, we found related research examining the impacts of children taking on adult responsibilities to support their family *during* a parent's deployment that could reveal insight into outcomes for military caregiving children.



Many studies paint a nuanced and at times problematic picture about the impact of children taking on adult responsibilities during their parent's deployment.

We found eight studies of military children taking on adult caregiving responsibilities for their families during a deployment. The caregiving responsibilities children assumed could vary, with some children taking on extra vigilance to "protect" the family, providing care for younger siblings, or emotionally supporting the non-deployed parent (Baptist et al. 2015). An experience often described as parentification takes place when adult caregivers transfer child-rearing responsibilities to a child (such as having a young child taking on caregiving responsibilities for a younger sibling) or expects emotional support from the child that would typically be expected from a spouse or other adult.

Several studies suggested negative impacts of parentification for children, including heightened family tension, worsened mental health outcomes, increased sense of stress and worry, and decreased sense of safety (Baptist et al. 2015; Cramm et al. 2019; De Pedro et al. 2011; Hathaway et al. 2018; Huebner et al. 2007). Two studies noted the challenges faced by children as deployed service members return home, including developmental regression (Hathaway et al. 2018; Huebner et al. 2007). Truhan (2015) found that although military families with deployed parents had higher rates of parentification than non-deployed military families did (about 7 percent compared with about 4 percent), rates of parentification were higher among children with non-deployed, divorced or alcoholic parents than they were for children with deployed parents. The study authors hypothesized that existing supports for military families, such as family readiness groups, might contribute to relatively lower rates of parentification among children with deployed parents.

Some studies suggest some parentified children may develop an increased sense of personal strength and self-efficacy (Cramm et al. 2019). Some children even found pride in taking on adult responsibilities, including taking on more chores and taking care of younger siblings (De Pedro et al. 2011). For many children across the studies, their self-parentification could be perceived as a strength in that they took initiative to support the family unit. Potential evidence for this might be research showing that some children are frustrated over relinquishing previously acquired responsibilities when their deployed parent returns (Huebner et al. 2007).

Although the context of a parent or caregiver's deployment is uniquely different from the context of supporting a parent or caregiver with a military service related injury or illness, both may necessitate children taking on additional responsibilities that might not otherwise have been expected of them. The consequences of parentification and the outcomes associated with it may remain a concern for children from military caregiving homes.

Emerging evidence on effective supports for children from military caregiving homes.

The picture painted by research on children from military caregiving homes is not encouraging. We set out to understand what could be done to mitigate these detrimental outcomes. We found an emerging body of research starting to point to interventions that might support military children broadly, but only one intervention focused on helping children adapt to returning service members who were injured during deployment (Walker et al. 2014).



Most interventions identified aimed to improve mental health and coping outcomes for children.

The studies we reviewed examined different features of interventions. Two interventions focused on improving family relationships or resiliency for military children and their parents (Chawla and Wadsworth 2012; Lester et al. 2012, 2013, 2016). One intervention focused on military children's parents and their parenting skills (Gewirtz et al. 2018; Piehler et al. 2018; Zhang et al. 2020). Three interventions focused on military children in particular, but the setting varied. One was implemented in classrooms over the course of one school year (Ohye et al. 2019), one was a one-time program implemented during Yellow Ribbon reintegration programming for returning service members (Wilson et al. 2011), and the final intervention helped children cope with their parent's deployment-related injury through homebased multimedia programming (Walker et al. 2014).

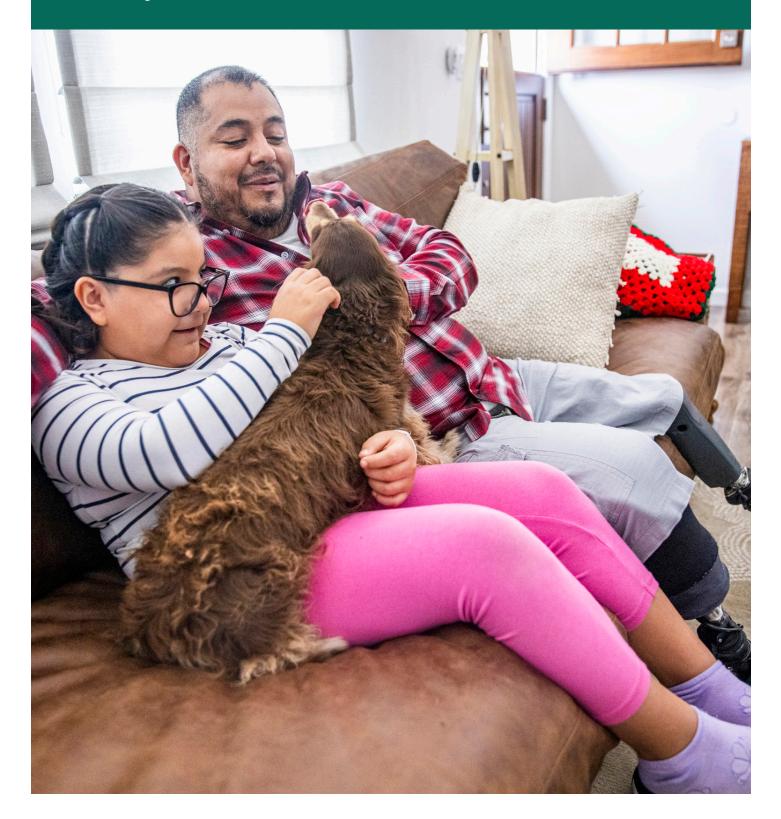
These studies collectively found improved outcomes in military children's:

- 1. Perceptions of self, their social support, and their happiness with their life.
- 2. Levels of adjustment and pro-social behavior.
- 3. Internalizing and externalizing behaviors.
- 4. Psychological, emotional, and behavioral health.

Five of the studies documented here used a randomized controlled trial, which increases our level of confidence about the impact of these interventions. The other studies used relatively weaker designs, such as a pre-post design and a correlational design, so we are less confident in the impacts of these interventions.



III. Understanding the experiences of children in military caregiving homes through their own words, the eyes of caregivers and experts, and nationally representative surveys



Approximately 2.3 million children under age 18 live with a disabled veteran, based on our analyses of 2015-2019 ACS data. To start understanding the experiences of children in military caregiving homes, we explore four key findings we identified from our data analyses of nationally representative surveys, interviews with subject matter experts, and focus group conversations with children and caregivers from military caregiving homes. We found a robust picture of strong and adaptable families who work hard to support the individual needs of all their members in the face of caregiving demands. Yet, these demands also created important and meaningful challenges that could influence the healthy development of children and impact their life outcomes. We have organized our findings to focus first on those most relevant to individual children moving outward from there to findings focused on families, then to the community and national levels.

Children want more support to navigate their experiences as Hidden Helpers, and caregivers struggle to identify responsive sources of support for children.



Attention to children's needs can become crowded out by caregiving needs, which accelerates or inhibits aspects of their development.

Many of the children we spoke to saw themselves as no different from their non-caregiving peers, and their families as generally no different from other families. Children from military caregiving homes often responded positively to the challenges posed by caregiving with increased empathy, maturity, and adaptability. However, children, caregivers, and subject matter experts consistently expressed concerns about the ways that caregiving can take over life at home. This can cause some children to avoid seeking out support or to deprioritize their own needs because of the needs of their care recipient.

"[My daughter] seems more grown-up. She is very nurturing. She's a caretaker. She's more resilient in some ways because she had to focus on herself, doing things herself that I normally would have helped the other kids with, but I didn't have that opportunity with her because of doctor appointments and therapies. She's doing everything she can to make my life easier now, which in some ways is wonderful, but in other ways, I feel sad that she didn't get the same childhood experience. She thinks about things that she shouldn't have to like doctors, anger problems, why our house is so different than others. She didn't get to be the child I wish she would have gotten to be sometimes."

-Adult caregiver

For example, children from military caregiving homes often talked about how they prioritized the health and wellness of their care recipient over their own. One military caregiving child said he is "constantly worried" about his care recipient. One young adult also reflected on his experiences growing up in a military caregiving home. He believed his family's necessary focus on their care recipient prevented his parents from noticing and responding to his own mental health challenges in a meaningful way, and his challenges later escalated into a substance use issue.

For children from military caregiving families, caregiving can take the form of assuming important duties that the adult caregiver might not otherwise expect of them at their age, and many of these caregivers were concerned about the central attention caregiving took for the entire family. One caregiver shared that her child was responsible for tasks she did not consider ageappropriate, like buying groceries for the family and ensuring their home was safe for their care recipient (such as making sure cooking appliances were shut off when not in use). Children were also called on to support their care recipient's emotional regulation. This could take a variety of forms, including helping the care recipient avoid triggering situations and, if they were triggered, using de-escalation strategies. The exact ways that these responsibilities manifest in families can vary depending on the type of injury or illness, but the outcome for children is the same: the identity of the child is crowded out by the demands of caregiving. Often, caregivers refer to their children as "secondary caregivers" or "caretakers." Others become de facto guardians for their siblings so the primary caregiver can respond to the care recipient's needs. Caregivers often express guilt over this arrangement. For example, one shared that her child's "opportunities have been hindered" by the demands of caregiving. Although some caregivers talked about their attempts to avoid assigning adult responsibilities to their children or overburdening them with adult responsibilities, some caregivers could not avoid it. Instead a "creeping parentification" occured in which their children gradually took on more and more responsibilities to support the care recipient and the family unit.

Differences in outcomes for children from military caregiving homes may be explained in part by the limits caregiving places on the bandwidth of caregivers to respond to the needs of children. Specifically, children from military caregiving homes are more likely to experience negative outcomes related to their healthy development, with mental health issues rising to the top. This is also reflected in NHIS data, which reveal that children from military caregiving homes are more likely to have many worries (45 percent) than children living in either current military or civilian non-caregiving households (24 percent).

Moreover, the same data indicated that children from military caregiving homes are more likely than children living in non-caregiving homes to be unhappy or depressed often (22 percent of children living in military caregiving homes versus 7 percent of children living in current military non-caregiving households and 10 percent of children living in civilian non-caregiving households). According to National Health Interview Survey data, children from military caregiving homes are more likely than children in non-caregiving homes to have many worries or be unhappy or depressed.



Children expressed a need for more support to navigate their experiences as Hidden Helpers, and caregivers are looking for the right kinds of support.

Many of the caregivers we interviewed described a variety of programs and supports they used to help their children manage the demands of caregiving. The most common form of support they sought was therapy or counseling. Caregivers also accessed one-time getaway or overnight camp programs, some of which focused on the stresses of growing up in a military-connected family. Although there are camp programs specifically for caregiving families, none of our study participants attended those camps. In addition, none of the supports referenced by children and caregivers were explicitly focused on children from military caregiving homes. For example, one child lamented: "There are not enough programs, and there is not enough attention for people with problems" from military caregiving homes. The lack of supports specific to children from military caregiving homes is consistent with our findings from the literature review and conversations with subject matter experts. The lack of formal support specifically designed for children from military caregiving homes sharply contrasts with families' strong interest in finding this support.

"I went to the mental health services on campus when I was in college. It helped to an extent, but they are not trained in what is going on with a military child."

-Young adult who grew up in a military caregiving home

Children and young adults who grew up in military caregiving homes, as well as caregivers, noted a set of distinct needs:

- Deepening their understanding of their care recipient's chronic injury or illness so they could have more meaningful interactions with their care recipient.
- 2. Developing personal perseverance while maintaining physical health, mental health, and wellness.
- **3.** Building social connectedness and interpersonal relationships with other children with similar caregiving backgrounds.

Understanding the nature of their care recipient's

injuries. Many children said they wanted a stronger relationship with their care recipient, but their care recipient's injury often made building relationships challenging. As one child put it, "It would be better if we spent a little more time together." When they do spend time with their care recipients, many children struggle to engage authentically for fear of upsetting the care recipient. One child noted that it took time to understand "what's fine to say around [care recipient] and what's not," and that he learned through "trial and error." Two other children said they would like to see a program that helps children "have fun with the person who is wounded," such as one that works on "helping kids get more bonding time" with the care recipient. Yet lack of understanding about their care recipient's injury or illness caused children to feel like they were walking on eggshells. This is prevalent especially for those whose care recipients have invisible wounds as otherwise typical interactions with their parents can turn into an emotional minefield that children struggle to navigate.

Moreover, several children and caregivers noted how the nature of their care recipient's injuries or illnesses evolved over time (as some care recipients learned to manage old wounds better and uncovered new, often invisible wounds), and children felt ill equipped to manage these changes. Children, caregivers, and subject matter experts discussed the need for supports that empower children with information about their care recipient's illness and injuries. This could develop their awareness of environmental triggers for their care recipients, give them the skills to de-escalate situations as needed or know when to seek help, and support building stronger, healthier relationships with their care recipient.

"I can talk to him about some things, but others I shouldn't because I might trigger something, or I don't feel comfortable talking to him about it." -Child caregiver

Fostering social connectedness and interpersonal relationships with other military caregiving children.

One of the most common needs expressed by children and caregivers was a desire to connect with other children from military caregiving families. One child expressed a sentiment shared by many: "It's important to let your feelings out to someone that's not in your family that you can trust. That's a lot of stress off of you." They also talked about how important it was to have the person they were connecting with understand their experiences. Some children said that they had friends who were not connected to the military, but the friendships they valued most were those with other military-connected children, because they understood the culture of a military caregiving family. As one young adult who grew up in a military caregiving household reflected, "It would've been beneficial to have friends to hang out with that were my age and who had that understanding [of the demands of caregiving]." Another remarked, "If there was a program that offered the kids who needed it someone to talk to just about anything, even if it doesn't include their parents, I think that would be very nice, especially for older kids."

"I want to make sure [children like me] have therapy and someone to talk to. Maybe extra help in school." -*Child caregiver*

14

Caregiving demands can interfere with family dynamics that support the development of all family members, and caregivers need support to ensure children's needs are addressed.



Caregivers sought to foster wellfunctioning families by emphasizing cohesion, communication, and flexibility while working to keep the demands of caregiving from dominating all aspects of family life.

Most children and caregivers said they spent time together as a family in activities that promote communication—sharing meals, engaging in the same hobbies and activities, talking about their interests or life goals, or "just doing fun things." This was true for almost every caregiver and child even though many live in a stressful home environment. One caregiver said that pushing her family to do things together, such as biking or hiking, has helped break her family away from the "constant state of turmoil" in their home. Families tackle the challenges of caregiving in various ways, but nearly every caregiver we talked to was responsible for coordinating family activities, delegating responsibilities, and managing the schedules of everyone in the home.

Caregivers are sandwiched between the demands of caregiving for both children and the care recipient while also serving as a "buffer" or "filter" between the care recipient and the children in the household. Critically, subject matter experts and caregivers affirmed the importance of both the caregiver and the care recipient in fostering family functioning. Our subject matter experts also described the importance of effective communication with children about the needs of the care recipient, and we observed through our conversations with children and caregivers that families who prioritized honest and age-appropriate communication about the challenges of their care recipient's injury or illness appeared to manage the demands of caregiving more smoothly than those who struggled with this communication. Caregivers who felt confident about communicating the needs of the care recipient noted the importance of this transparency. They cited the value of helping their children understand that negative interactions with their care recipient are primarily about the care recipient's challenges, not the children themselves. This approach may empower children to manage negative interactions more productively so that they do not take the interaction personally. Conversely, some caregivers said they avoided direct conversations with their children about the needs of their care recipients and the nature of their injury or illness because they feared the conversation could cause more disruption. These same caregivers often reported challenges related to raising their children. For example, one caregiver acknowledged that her "sweeping it under the rug" was not a healthy strategy and shared her frustration and belief that her children "hated her" because she shielded them from understanding the full nature of her care recipient's injury or illness.

"A lot of caregivers indicated that [their caregiver's return home with an injury or illness] was like getting a divorce but still living with the person you [were] divorced from. The caregiver is not just working with the partner, but also to help care for the partner. This affects the kids with added anxiety and stress and additional duties. Often kids can become secondary caregivers and often have secondary PTSD effects." -Researcher



Caregivers, too, can find themselves occupied by the demands of caregiving, which can also adversely impact children.

The caregivers we met were all spouses or longterm romantic partners of their care recipients, and many lamented the impact that caregiving has on their relationships with the care recipient. Caregiving has changed routines, careers, and friendships. One caregiver said she "manages everyone's schedule," and has secondary PTSD because of how hard she has tried to hide their home life from people outside their household. Another caregiver was planning on quitting her job so she could dedicate more time to caregiving.

The demands of caregiving led some caregivers to consider ending their romantic relationships with their care recipient.

Others expressed frustration over their ability to process and adapt to the demands of caregiving, with several sharing that they were contemplating ending their relationship with their care recipient. The demands of caregiving also limited caregivers' availability to their children, which can have a negative impact on children.

Yet the caregivers themselves believed the stakes of their support were too high, with a subset of caregivers sharing their belief that their care recipients would end up homeless if not for their support.



Addressing the needs expressed by caregivers could help improve family functioning.

Most caregivers felt deeply unprepared to manage their needs of their care recipient. When one caregiver was asked whether she ever expected she would need to provide care, she replied "I got thrown this hat". We've been married for 20-something years, and I've seen how my husband was prior and then after [his deployment and development of injury]. It's two different men. The Army does not brief you on this." But caregivers were clear about the challenges they faced that impeded family functioning:

- Their need to better understand the evolving needs of their care recipient's injury or illness.
- 2. Access to affordable child care so caregivers can respond to the demands of caregiving while also pursuing their own interests.
- Access to better transportation options or better access to local services so the care recipient's appointments consume less travel time for all family members.
- **4.** Fewer barriers to finding supports and navigating the federal benefits process.

To emphasize the need for holistic supports for children and caregivers, one caregiver noted that, "Far too often, the veteran is the only one who is made to be the primary person in need of support. If you're not talking about the other people in their life, you are missing a giant piece of the puzzle."

Fears of stigma and being misunderstood by friends, family, and the greater community contribute to feelings of isolation for children and caregivers.



Children and caregivers report that peers who do not have care recipients struggle to understand the experience of caregiving.

Children and caregivers shared that their extended family members and friends struggled to understand their lived experience. For some of these families, this lack of understanding led to estrangement from family and friends. One caregiver lost a lot of family support after the injury, and her family "chose not to be a part of [their] lives ... because they don't understand why [she is still with her care recipient]." Another caregiver shared that they lost a lot of friends because they "couldn't handle how [her] husband was acting ... [they] walked off on us." Others chose to move away to avoid the stigma. For example, one family moved to a rural location so the care recipient "doesn't have to worry about being loud or neighbors being nosy."

Many children and caregivers worried about how others perceived their care recipient's injury or illness. For example, one caregiver shared, "As soon as someone finds out that a parent in the house is suffering from PTSD from military service, they automatically assume they are going to go hurt people." She laments the feelings generated by these perceptions: "I do not want my children to feel that they need to hide dad's injuries." Another caregiver shared that their child "has to keep the way his dad is a secret" because they do not live in a community with a large military-connected population.

Due to civilian lack of understanding of military life, she added that her child "expressed that he doesn't have any peers who understand." Some children reiterated this, saying they do not talk with friends about what is happening at home. As one child put it, "It's a private thing," and for another child, it's a "heavy topic," so she does not talk to her friends about her dad. Some children spoke specifically about friends not understanding PTSD or not having dads with PTSD. One child shared, "I don't have very many friends who understand the PTSD veteran life," and because of this she keeps things to herself. She shared that her friends also do not understand her caregiving responsibilities: "One of my friends doesn't have many chores or tasks to do. When she sees me doing more than she does, she doesn't get it. I do it because I want to, but they just don't understand." Because their peers do not understand their lived experiences, children and caregivers often believe they are misunderstood and isolated from their friends, family, and the greater community.

"I lost a lot of family support [as a result of the illness] because they don't understand why I am still here [with him]. They chose to not be a part of our lives."

-Adult caregiver

"I don't have a lot of friends who have dads with PTSD and anxiety. I'll talk to my sister about it sometimes, or I won't say anything. Most of the time, I keep it inside."

-Child caregiver





••••••••••••••••••

At worst, misunderstanding and stigma about injured and ill care recipients can keep military caregiving families from seeking certain kinds of support, with some of them avoiding looking for support altogether out of fear.

Instead of feeling encouraged to seek support and care, some caregivers were reluctant to deal with the possibility of negative outcomes. For example, one caregiver said her care recipient is hesitant to seek care at his local Veterans Administration (VA) hospital because VA staff reported their family to child protective services after he had a public outburst there.

She expected more understanding from staff at the VA, "[The VA worker], of all people, should've had an understanding." The caregiver was incredulous that the VA worker "[did not] understand what a traumatic brain injury or PTSD outburst looks like." The caregiver now believes she needs to "carry the weight" of caregiving without professional support.

"As we sought to get feedback from military caregiving families, caregivers posted about their feelings of hesitation of asking for help and their sense of isolation and stigma."

-Researcher

For some caregiving families, reluctance to seek mental health treatment extends beyond the care recipient to their children. Some raised concerns that military caregiving families may forgo seeking mental health support for their children if their child is insured through TRICARE. One subject matter expert reported that the U.S. Department of Defense (DoD) examines young people's TRICARE health records as part of reviewing their application to join the military, which can result in automatic disqualification from service because of common disorders like anxiety or attention-deficit hyperactivity disorder. Young people who receive mental health services outside of TRICARE do not receive this scrutiny. The result of this automatic review of young people's military health records is that it may discourage families from using military health services for common mental health challenges out of fear that doing so may prevent their children from joining the military.

In addition, some children may not receive the support they need from school because of lack of disclosure about their care recipient's injury or illness. Many children and caregivers said they did not talk about their home lives with schools, or schools were not aware of their caregiving status at home. When asked whether schools provided specific support for their caregiving demands, one child said their school does not accommodate for "those types of issues." However, caregivers who were open about their caregiving homes with their children's school expressed frustration with the lack of understanding and support from school staff, especially from "civilian schools." This included lack of flexibility on issues related to attendance (when, for example, children accompanied their care recipient to appointments) or distractedness at school because of a recent caregiving-related incident. One child said when her father goes through a "rough patch" it makes her "more stressed" and "very distracted at school." One caregiver emphasized the lack of education about PTSD: "I don't know how you can teach the kids living in those situations if you have no idea [about] their reality." The lack of awareness by schools may be preventing school staff from providing support to children whether families ask for it or not. One child shared that his school did not provide him with extra help, and in particular, "No one really comes up to [him] and asks, 'How are you feeling?'"

Law enforcement is another community support that caregivers find challenging to deal with. One caregiver expressed fear over how local law enforcement might respond to her care recipient, who experienced severe PTSD-related flashbacks. To prevent a potentially violent misunderstanding, she "intentionally befriended the authorities" and convinced officers to take her care recipient out for a meal so he would know them better. She also pushed her local police department to train its officers on PTSD. She concluded, "There is no help ... it was the most frustrating thing to find help." This example, although extreme, point to a persistent stigma and lack of awareness that military caregivers face, especially from officials who respond to health crises.

National and local barriers limiting access to timely and quality care for care recipients and their families negatively impact the entire family's well-being, but families have ideas about how to overcome the barriers.



Navigating the federal system to access quality care was a significant source of anxiety and distress for military caregiving families.

Chronically injured or ill care recipients are only as strong as the families that care for them, yet a significant source of anxiety and distress for both children and caregivers was navigating the federal system to access care.

Caregivers commonly identified four significant barriers to accessing care:

- 1. Long wait times.
- 2. Inaccessible health care offices (due to factors including distance or travel time to offices and wait times).
- 3. Complex paperwork.
- 4. Delays in receiving referrals. Children and caregivers worry about the physical and mental health of their care recipient and when care is neither timely nor quality, it increases the anxiety and distress felt by the family.

One child reported that his father had to wait a week to get an appointment at the VA for a torn Achilles tendon. Similarly, another mentioned she did not like her care recipient having to wait "a week to get permission to go to the ER for a broken bone." She added, "We've already got enough stress, give us something that we don't need to worry about." One caregiver reported that their child becomes anxious whenever the family receives mail from the VA because "no mail from the VA is ever good mail." Children from military caregiving homes feel acutely the stress inflicted on families as their care recipient struggles to receive quality and timely care.

One caregiver shared that accessing mental health support for her care recipient through the VA was "draining." At one point, she heard it would take three months before her care recipient could get treatment for his deteriorating mental health.

"When finding mental health support, [the] VA told us it was going to be three months before they could see him, even though I physically made him walk in, and he told them how he was feeling; it included suicidal thoughts. I had to find somewhere that would see him without insurance."

-Adult caregiver

Exasperated, she forced her care recipient to go to the local VA office so the staff could hear his suicidal thoughts firsthand. Ultimately, her care recipient did not receive the support he needed, and she obtained outside care; these costs were not covered by her insurance. In addition to the challenges of even being seen by a doctor in moments of crisis, children and caregivers described long wait times and questioned the quality of care they received when they did receive it.

Some caregivers shared their own challenges accessing care for themselves. One caregiver said her care recipient "could have eight appointments in a day, no problem," but it took her a year to get counseling because the VA kept referring her to a provider who was far away from her home, and she could not leave her care recipient alone or with their children. Given the demands of caregiving, these caregivers often opt out of receiving care, which can have both short- and long-term impacts on the functioning of families and, ultimately, the well-being of children from military caregiving homes.



Caregivers offered solutions they believed could help improve family functioning and support the well-being of children from military caregiving homes.

Despite the complexity of the challenges they faced, many caregivers had clear recommendations for how to support families and children. Many caregivers emphasized the importance of providing support for the entire family. As one noted, "We have to elevate the caregiver and the children to the same playing field" as the care recipient in terms of focus and importance. Echoing comments from children, several caregivers wanted their children to interact with other children from military caregiving homes. This could take the form of a support group or engaging in hands-on and fun activities. Another caregiver shared, "I would love some sort of group similar to caregiver support groups for the kids. Just them having an outlet of somebody in a similar boat as them would be an immeasurable asset."

Multiple caregivers described the critical importance of affordable child care. One caregiver reported that her children's free child care through YMCA ended once their care recipient's appointments lost active duty status as a result of an injury. This loss of child care occurred the moment he was discharged. Another caregiver said that "daycare would have been lifesaving" to aid in juggling caring for their care recipient and children. This has implications for military caregiving families, specifically caregivers who are balancing caring for their care recipient and their children. Caregivers noted that quality, affordable daycare for young children from military caregiving homes can reduce the burden on caregivers and their care recipients because it helps caregivers focus on the care recipient.

Caregivers also reported needing to take children out of school for care recipient's appointments if they were either far away or if schools would not allow the caregiver to pick up their children after the school day had ended. Schools, particularly those with fewer children from military families, often failed to accommodate their military caregiving families. Caregivers cited these schools' lack of understanding of their lived experiences and constraints and ultimately, they had to constantly explain their situation to the school. One frustrated caregiver shared, "Look, my oldest is in high school, he's on a different schedule. My daughter would be at home alone, by herself [if I didn't take her with me to her care recipient's appointment]. I would get in trouble with [child protective services]. I am going to pick taking my kid to the VA." The lack of understanding from schools puts a heavy stress on caregivers to coordinate care and leaves children exposed to struggling systems, which may contribute to their experiences of anxiety and distress.

Caregivers reported that finding supports for their children and care recipient is difficult, even in the age of the Internet and social media.

Finally, many caregivers would like a simple and easy-to-use place to get the information and resources they need to provide care and navigate the federal system. They suggested a centralized location where they could easily access these resources. One caregiver said, "Having a one-stop shop would be helpful ... having an organization where you can dial in saying that we're in crisis."

Caregivers noted that the onus is on them to do research to find support networks and organizations for their family, and this is difficult even in the age of the Internet and social media. This is especially true in rural areas because many programs are in more populated areas. Some caregivers suggested receiving information early in the care recipients' journey to better prepare them for what they can expect and tell them which support services they can easily access, such as specific caregiver support and mental health treatment.

Caregivers frequently cited the efforts of actors such as the Elizabeth Dole Foundation's social media groups, its caregivers' fellowship program, and its advocacy, but they also wanted more comprehensive services. This is especially critical because many caregivers reported that their own and their children's health challenges could be exacerbated by caregiving (for example, secondary PTSD and existing health conditions). Ultimately, one of the many impacts of the lack of a centralized location for resources is time lost that could have otherwise been spent with children in the family.

"Children need to be able to relate to peers similar to themselves, and I haven't found a program that can do it."

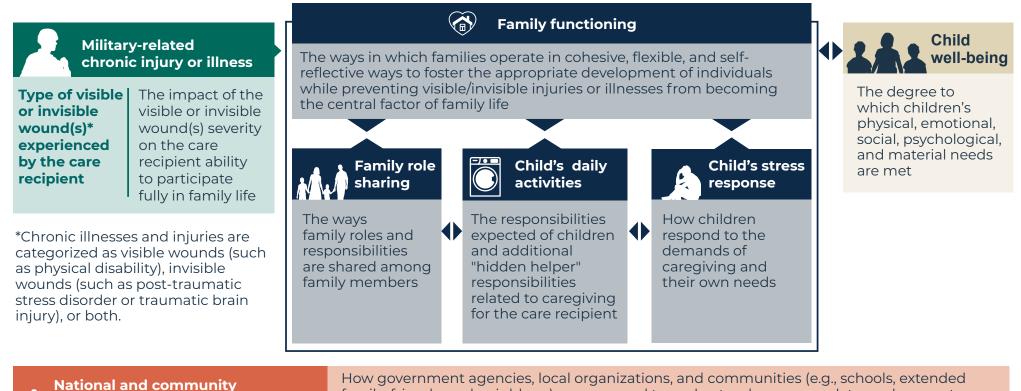
-Adult caregiver

A family ecological model to guide improvements for child well-being.

Given the diversity of experiences that children from military caregiving homes have, we set out to illustrate the key factors that influence children's well-being when their loved one returns from military service with an injury or illness. Shining a much needed light on the relationship between the development of the injury or illness and children's well-being could help practitioners and policymakers develop a theory of action for improving the well-being of children in military caregiving families. Informed by our findings and exploration of the empirical research, particularly Pedersen and Revenson (2005), we developed the ecological model (<u>Exhibit III.1</u>) to describe the relationships between factors that may advance or inhibit child development as a result of the recipient's injury or illness and children well-being. These factors include:

- / The type(s) and severity of injury or illness
 sustained by the care recipient;
- / How the family functioned before the injury or illness, and how family functioning changes because of the injury or illness;
- / How roles are distributed to individual family members to adapt to the demands of caregiving;
- / The types of activities and responsibilities children engage in to accommodate the demands of caregiving;
- / How children respond to and manage the stresses that emerge from changes in the family and the demands on their time; and
- / The broader readiness and response of national and local community agencies and organizations, community members, and neighbors to respond to the needs of military caregiving families.

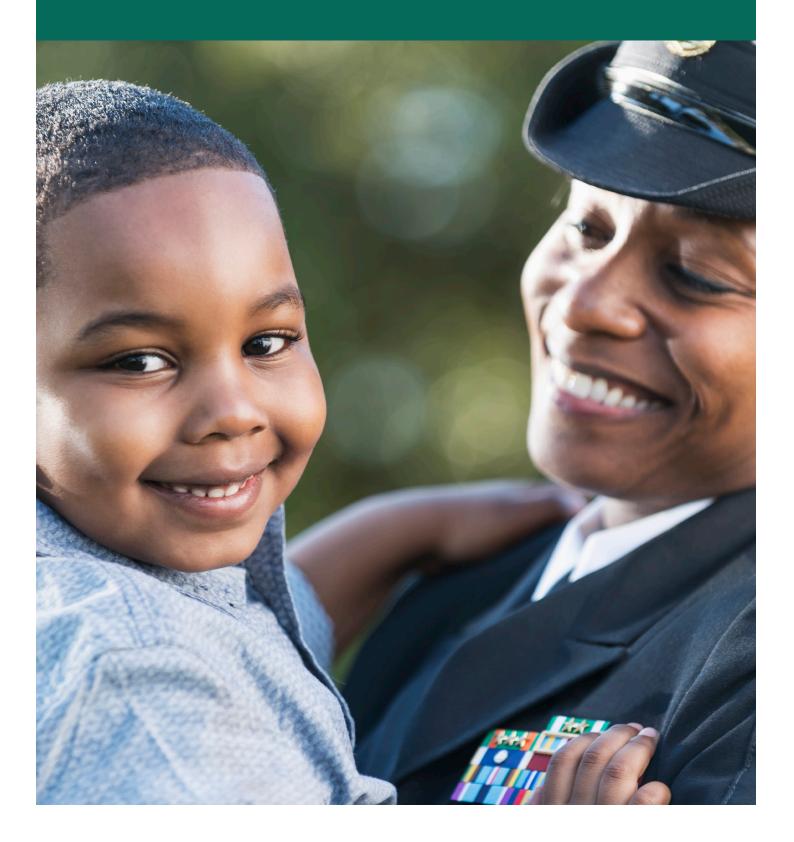
Exhibit III.1. The relationship between children's well-being and their care recipient's injury or illness



readiness and response to military caregiving children and their family How government agencies, local organizations, and communities (e.g., schools, extended family, friends, and neighbors) are prepared to understand, accommodate, and support military caregiving families in all aspects of life, inclusive of health, education, employment and other needs

Hidden Helpers at the Frontlines of Caregiving: Supporting the Healthy Development of Children from Military and Veteran Caregiving Homes

IV. Recommendations



All children must experience conditions that support their healthy development in their home, their communities, and the broader society. This study led to four key recommendations that could improve the well-being of children from military caregiving homes (Exhibit IV.1). These recommendations are grounded in what the general public, who are less familiar with the experiences of military caregiving families might expect to be true for those children, given their unique challenges. They stem from and take into consideration the reality that many families face. These recommendations can help equip nonprofits, program leaders and practitioners, policymakers, researchers, employers, schools, and other stakeholders with concrete next steps they can take to help better support military caregiving families and, in turn, the well-being of children in these families.

The challenges faced by children and caregivers in military caregiving families should be approached from a systems perspective.

No individual action in any level of the system will have a full impact on children's well-being unless it supported by other actions at other levels of the system. There are consequently four primary cross-cutting themes:

- 1. The need to develop new or expand high quality evidence-based existing programs and interventions.
- **2.** The need to develop cross-sector partnerships and foster collaboration.
- **3.** The need to build awareness about the lived experience of children in military caregiving families.
- **4.** The need to continue to build evidence about what works in support of these aims.



Exhibit IV.1 Improving the well-being of children in military caregiving families requires action at all levels of society

| | What is expected | What often happens | What can be done about it |
|-----------|--|---|---|
| Children | Children help with care for the injured or ill care recipient while being supported in their own appropriate development. | Children's lives become consumed by caregiving needs, which inhibits or accelerates their development. | Create and Scale: Quality programs and interventions that support children from caregiving families, focus on peer support, mental health and age-appropriate developmental opportunities. |
| Families | Families are well-equipped to manage the demands of caregiving. | Families fall through persistent gaps in supports and services while managing caregiving demands. | Invest: Fund, promote, and create supports targeted for children and their families. Raise Awareness: Amplify national campaigns and |
| Community | Communities, neighbors, and local organizations are prepared to understand, accept, and support caregiving families in all aspects of community life. | Communities and local organizations attempt to support military caregiving families, but these supports incompletely meet their needs. | coalitions to improve understanding of care recipients' visible and invisible wounds and the needs of caregivers and children in military caregiving homes. |
| National | Federal agencies provide health care services to injured and ill care recipient and their dependents. | Federal agencies and other national organizations provide inconsistent and fragmented supports to care recipient and their dependents. | federal and local agencies, including private organizations, to enhance the social safety net of comprehensive services focused on supporting children and their families. |

Create and scale. Quality programs and interventions that support children in caregiving families and focus on peer support, mental health, and age-appropriate developmental opportunities.

Our findings suggest that children need interventions to support their healthy development. Quality programming that could help children in military caregiving homes overcome challenges related to caregiving would

- 1. Facilitate peer relationships between military caregiving children.
- 2. Have schools focus on mental wellness through curricula and after-school programming.
- **3.** Focus on the mental health of children from military caregiving homes.
- Use grant funding to generate evidence about "what works."

These programs could be implemented by various federal, philanthropic, and community organizations focused on improving outcomes for military-connected children.

The research is limited on which interventions could best support children from military caregiving homes. Our literature review identified six named programs designed to improve outcomes for military-connected children. Although one focused on helping young children adapt to their returning injured or ill service member, none of the programs were designed with a focus on children ages 10 to 17 from military caregiving homes (Walker et al. 2014; details in <u>Appendix A</u>). Our subject matter experts were unable to identify a single program focused on improving outcomes for these same children. Furthermore, of the 24 individual programs, interventions, or support types that participating children and caregivers identified, none had any published research that used a comparison group design to examine its impact (Malick, Sandoval, Woods, and Jacobs

Johnson 2020). The lack of rigorous evidence about what works for children from military caregiving homes makes the identification and scaling of effective programs particularly difficult. However, based on the interviews done with military caregiving children and caregivers, there are several avenues to take.

Virtual platforms for connectedness. Many military caregiving families shared that they felt socially isolated, in part because many of them are geographically isolated from similar families. During the COVID-19 pandemic, families and children have increased their use of and comfort with virtual platforms for delivery of essential services. Moreover, many military caregiving families are already familiar with virtual platforms for connecting to health supports. Military caregiving children could connect with each other virtually. This is an opportunity to develop interactive programming, whether counseling (such as through tele-behavioral health sessions) or virtual "play dates" for children of all ages. In our interviews with children, young adults who grew up in military caregiving families, and caregivers, many expressed interest in receiving support through virtual platforms.

Schools. Children and caregivers both shared that schools struggled to accommodate the needs of military caregiving families. School is, however, an opportunity to reach a large number of children in military caregiving families. Support could be integrated into existing school courses or programs. For example, supplemental units that address the physical and mental health and wellness needs of children from military caregiving homes could be developed for implementation in health classes or after-school clubs. With these curricular resources in place, schools could identify eligible children and train staff to support them by delivering the supplemental material. Importantly, there are school districts that collect information on military status for children's families, but do not capture families' veteran status.

One key step schools across the country must take to succeed in this effort is to proactively identify which children are military-connected to include families currently serving and veteran families and, of those, which have a family member with a visible or invisible injury or illness.

Targeted mental health support. Mental health professionals can be a listening ear for children and help them with developing healthy coping mechanisms. Providing mental health support earlier in life can help children cope better with the stressors of living in a military caregiving household. Caregiving families and experts shared some barriers to seeking mental health treatment, including long wait times, distance, and the DoD policy of reviewing children's TRICARE records when those individuals seek to join the military. Removing these and other barriers will go a long way toward improving access to care.

Grant programs. Programs that have been tested with military families already could give some ideas about how to adapt their programs to support the specific needs of military caregiving families. Those adaptations could themselves be tested, and the ones determined to be effective could be scaled to reach more military caregiving families. A grant program funded by the federal government, philanthropy, or other sectors also could be used to identify programs that are viewed as successful in improving outcomes for children but have not yet been rigorously tested. The grant program could help these programs refine their underlying theories of change and action and then evaluate their core program components to identify effective practices for children from military caregiving families.

Models for such programs exist, such as the U.S. Department of Education's Education Innovation and Research grant program and the Robert Wood Johnson Foundation's Equity-Focus Policy Research effort.

Potentially promising practices for supporting children from military caregiving homes based on rigorous studies are found in the research literature, and these practices are ripe for further testing with the goal of scaling. They could include:

- Those focused on improving parenting practices or family functioning such as the After Deployment Adaptive Parenting Tools Intervention and the Families OverComing Under Stress (FOCUS) program.
- 2. Those focused on addressing the behavioral health needs of children (such as the Staying Strong with Schools program).

These programs supported military-connected children in general, including children who were not living in military caregiving homes. A grants program would have to consider how it could prompt programs to respond to the developmental needs of children at different ages while tailoring themselves to the needs of children from military caregiving families. Other programs perceived as effective by children and caregivers from military caregiving homes may be interested in building or applying more rigorous research methods to strengthen the evidence for their efficacy and could be spurred to do so through a competitive grants program. This could also prompt them to simultaneously develop specific supports that might be helpful for military-connected children from caregiving homes.



Invest. Fund, promote, and create supports targeted to the entire family unit.

Our findings point to the need to provide better supports for the entire family unit to foster family functioning and support the caregiver in their central role responding to the needs of the family. Support for military caregiving families to manage the needs of their care recipient come in two broad forms:

- Those that foster positive interpersonal relationships between family members while nurturing the appropriate development of all individuals.
- 2. Those that help remove barriers to care for military caregiving families.

Supports for fostering interpersonal relationships and the appropriate development of individuals.

Programming that helps families develop better communication strategies and systems for managing their care recipient's needs while simultaneously supporting the development of all family members could have the power to improve family functioning and, ultimately, children's well-being. Subject matter experts and many caregivers noted the importance of transparent communication between adults and children about the care recipient's illness and injury. Moreover, in families that appeared to manage the demands of caregiving more smoothly, children are empowered with information about the evolving and ongoing needs of their care recipient, information that is delivered in honest yet developmentally appropriate ways.

Caregiving families also need support to foster the interpersonal relationship between the adults in the household. Caregivers and experts shared that romantic relationships between care recipients and caregivers can become strained by caregiving. Caregiving families would also benefit from supports designed to strengthen interpersonal relationships with extended family members and non-romantic relationships between adult caregivers and care recipients. **Supports that remove obstacles to more easily access care.** Factors external to the family can create barriers to daily life and can negatively influence family functioning. The process of obtaining appropriate care for the care recipient and their family can be a significant source of anxiety and distress. For example, caregivers said they would benefit from access to affordable child care so they can respond to the demands of caregiving while pursuing their own interests.

They also wanted access to better transportation options or increased access to local services so the care recipient's appointments would consume less travel time. Caregivers discussed the equal importance of removing barriers to finding supports and navigating the process of obtaining federal benefits. To accomplish this, policymakers may consider the feasibility of extending benefits received by active duty status families to those in military caregiving families. Policymakers should also closely examine policies and procedures that may disincentivize military caregiving families using TRICARE from seeking care, for their children, particularly mental health care. Given that children in military families often view the military as a viable future career option, policies which automatically disqualify otherwise acceptable candidates from joining the military because of relatively minor and at times developmentally normal mental health challenges may fundamentally weaken force readiness.

Military caregiving families need easier access to information about support. The creation of a one-stop shop for information about resources, programs, and forms of support available to care recipients and their families could make a big difference for those families. Moreover, as discussed in an earlier recommendation, the modality of these services should be considered. Virtual supports to enhance families' ability to manage the stresses of caregiving could dramatically increase access. Ultimately, families equipped to manage the demands of caregiving better have more time and capacity to support the healthy development of the children raised in these homes. **Raise awareness.** Amplify national campaigns and coalitions to improve understanding of care recipients' visible and invisible wounds and the needs of caregivers and children in military caregiving homes.

To raise awareness, we first need better data about military caregiving families. The current lack of comprehensive, systematic data collection about caregivers and military caregiving children weakens the ability of program leaders and practitioners, policymakers, and researchers to identify the highest leverage opportunities to improve child well-being and family functioning. Federal agencies such as the DoD or the VA should consider expanding their data collection efforts to include the family members of care recipients. Longitudinal surveys could help the nation monitor its progress toward improving outcomes for military caregiving families.

With this data, national campaigns, such as the Foundation's Hidden Helper Campaign and the Campaign for Inclusive Care can more effectively raise awareness of the needs of those from military caregiving families and can help elevate their needs and destigmatize their lived experience by breaking the silence around the demands of caregiving. Moreover, a national campaign could be focused to build awareness and provide resources for those who are in the most contact with military caregiving families. For example, several caregivers noted that health care professionals and civil servants within the VA system responded negatively to the demands of caregiving, which made some families feel more isolated and less likely to reach out to obtain needed supports.

Efforts by the Foundation's Campaign for Inclusive Care as well as trainings for these staff who are likely to interact with military caregiving families could help them understand how to better identify and support families' needs in a positive, sensitive, and inclusive way. This in turn could help military caregiving families find more value in the support they receive and increase the likelihood that they reach out to get that support.

Children also reported that their teachers and other adults in their school building were unlikely to know about their families' unique circumstances. Caregivers who were open about this with their children's school expressed frustration with the lack of understanding and support from school staff. Trainings geared for educators to understand how to make reasonable accommodations for their students from military caregiving homes could help them provide better academic and social support to their students and build more positive relationships between caregivers and school staff.

One last audience for a national campaign to improve understanding of military caregiving officials is law enforcement officers. In extreme cases, some families expressed fear about interacting with law enforcement, especially when care recipients were experiencing mental health crises. Law enforcement officers could become better equipped to understand signs of these sorts of crises and employ strategies to help de-escalate them.



Increase access. Partner with federal and local agencies, including private organizations, to reduce barriers to health care and provide centralized comprehensive services focused on supporting caregiving families.

Military caregiving families would benefit from partnerships between federal and local agencies, including private organizations, to address barriers to care. Federal agencies, policymakers, nonprofit organizations, and philanthropies can collaborate and share resources to better support military caregiving children, care recipients, and caregivers. Where possible, federal agencies can provide funding to public and private organizations to create a robust network of resources in communities across the country. Communities surrounding military bases are strong candidates for such a coordinated system, as are communities with a strong presence of caregiving families. The Foundation's carefully designed Military and Veteran Caregiver Experience Map is a good starting point for identifying where caregiving families live and zeroing on local needs.

Caregivers noted that despite the advances made with the availability of the Internet, time-consuming online searches for care limited their availability to be present for their families. A system that is easy to navigate and provides a robust set of resources would make a significant difference for caregiving families. This system could be modeled on Military OneSource, a central repository of information on a wide range of topics for care recipients and their families. The resources housed in such a system could allow caregivers to search for resources related to the areas of unmet needs identified in this study in their local area as well as nationwide. This centralized hub could document therapy and peer support resources for caregiving children, including virtual offerings, and have Hidden Helper educational content that is tailored to both children and adults to facilitate exploration of children's caregiving role.



V. Conclusion

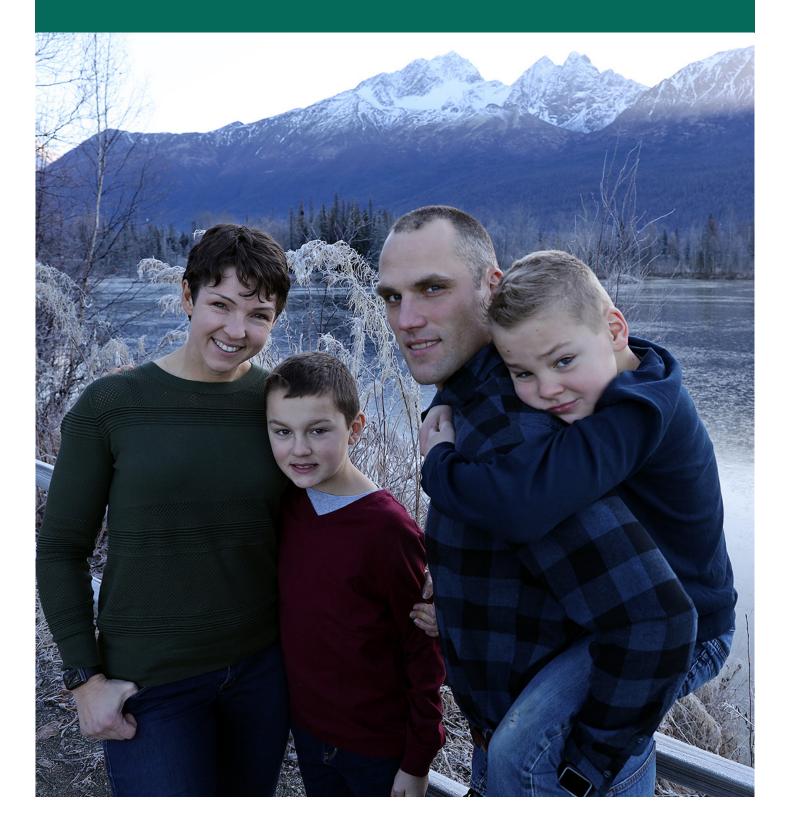


Over the last several decades, advances in science, technology, and medicine have dramatically reduced casualties from military conflicts but also have increased the likelihood that service members may return from their service with a chronic illness or injury. Simultaneously, shifts in the model of care has increasingly emphasized the role of family members in helping service members and veterans recover and reacclimate to life back home. For many care recipients, the home is now the frontline of care. The Hidden Helpers and Hidden Heroes who provide this care are responding to a clear and compelling mission: ensure that their care recipient experiences a rewarding and fulfilling family and community life. Yet these Hidden Helpers and Hidden Heroes rarely viewed themselves as caregivers. They were not in denial about their role in their care recipient's recovery and wellness. Instead they saw their caregiving duties primarily through the lens of family and wanting to do the best they could for their loved ones.

Those from military caregiving families did not seek pity, nor did they expect anyone to solve all their challenges. But they did want to be recognized for the sacrifices they made in service to their county, and many wished that their lives were a little easier. We saw that children needed more support to navigate their place in military caregiving homes. Although they often took pride in the ways they could help their family, they also deserved better mental health support, peer support, and guidance to better understand their care recipient's injury or illness. Likewise, we saw caregivers who often selflessly dove right into the challenges of caregiving and child-rearing. Faced with these responsibilities, caregivers often made hard and, at times, seemingly impossible decisions about the distribution of time, resources, and responsibilities among members of the family. And caregivers were often unhappy with the choices they were forced to make in order to help their care recipient get what they deserved and while also trying to make sure their children's needs were met. But in the drive to ensure their family survives, the developmental needs of children can become overlooked. We do not yet know the long-term impact caregiving has on children—there is a lack of longitudinal research on military caregiving children—but our findings show that children at different stages of development, from youth through early adulthood, are grappling with significant challenges to their healthy development. Their challenges at home were further exacerbated by local and national barriers to quality care and resources. The lack of local and national awareness about the experiences of military caregiving homes has contributed to fears of stigma and misunderstandings, isolating them from their family, friends, and the greater community.

We recognize that the needs of children in military caregiving homes are one piece of a broader, complicated puzzle. However, the support that children, caregivers, and care recipients in military caregiving families receive ought to reflect the sacrifices they have made together. Improving the well-being of children from military caregiving families requires action and support at all levels of society, and we encourage those committed to improving the well-being of children and families to partner and collaborate to ensure Hidden Helpers experience healthy development. Hidden Helpers at the Frontlines of Caregiving: Supporting the Healthy Development of Children from Military and Veteran Caregiving Homes

VI. References



Baptist, Joyce, Patricia Barros, Bryan Cafferky, and Elaine Johannes. "Resilience Building Among Adolescents from National Guard Families: Applying a Developmental Contextual Model." *Journal of Adolescent Research*, vol. 30, no. 3, 2015, pp. 306–334.

Briggs, Ernestine C., John A. Fairbank, Angela M. Tunno, Robert C. Lee, Nida H. Corry, Jacqueline C. Pflieger, Valerie A. Stander, and Robert A. Murphy. "Military Life Stressors, Family Communication and Satisfaction: Associations with Children's Psychosocial Outcomes." Journal of Child & Adolescent Trauma, vol. 13, no. 1, 2020, pp. 75-87.

Centers for Disease Control and Prevention. "2018 National Health Interview Survey (NHIS) Public Use Data Release: Survey Description." Centers for Disease Control and Prevention. June 2019. Available at https://ftp.cdc.gov/pub/Health_Statistics/NCHS/ Dataset_Documentation/NHIS/2018/srvydesc.pdf.

Chawla, Neelu, and Shelley M. MacDermid Wadsworth. "The Impact of an Operation Purple Camp Intervention on Military Children and Adolescents' Self-Perception of Social Acceptance, Athletic Competence, and Global Self-Worth." American Journal of Family Therapy, vol. 40, no. 3, 2012, pp. 267–278.

Chen, Cliff Yung-Chi. "Educational Functioning of Children of Parents with Chronic Physical Illness: A Systematic Review." *School Psychology International*, vol. 37, no. 6, 2016, pp. 606–626.

Cozza, S. J., J.M. Guimond, J. B.A. McKibben, R.S. Chun, T.L. Arata-Maiers, B. Schneider, A. Maiers, C.S. Fullerton., and R.J. Ursano. "Combat-Injured Service Members and Their Families: The Relationship of Child Distress and Spouse-Perceived Family Distress and Disruption." *Journal of Traumatic Stress*, vol. 23, no. 1, 2010, pp. 112–115.

Cramm, Heidi, Mary A. McColl, Alice B. Aiken, and Ashley Williams. "The Mental Health of Military-Connected Children: A Scoping Review." *Journal of Child & Family Studies*, vol. 28, no. 7, 2019, pp. 1725–1735. De Pedro, Kris M. Tunac, Ron A. Astor, Rami Benbenishty, Jose Estrada, Gabrielle R. D. Smith, and Monica C. Esqueda. "The Children of Military Service Members: Challenges, Supports, and Future Educational Research." *Review of Educational Research*, vol. 81, no. 4, 2011, pp. 566–618.

Dekel, R., and H. Goldblatt. "Is There Intergenerational Transmission of Trauma? The Case of Combat Veterans' Children." American Journal of Orthopsychiatry, vol. 78, no. 3, 2008, pp. 281–289.

DeVoe, Ellen R., Tessa M. Kritikos, Ben Emmert-Aronson, Glenda K. Kantor, and Ruth Paris. "Very Young Child Well-Being in Military Families: A Snapshot." *Journal of Child & Family Studies*, vol. 27, no. 7, 2018, pp. 2138-2148.

Fekadu, W., A. Mihiretu, T.K.J. Craig, and A. Fekadu. "Multidimensional Impact of Severe Mental Illness on Family Members: Systematic Review." *BMJ Open*, vol. 9, no. 12, 2019.

Gentile, Salvatore, and Maria L. Fusco. "Untreated Perinatal Paternal Depression: Effects on Offspring." Psychiatry Research, vol. 252, 2017, pp. 325–332.

Gewirtz, Abigail H., David S. DeGarmo, and Osnat Zamir. "After Deployment, Adaptive Parenting Tools: 1-Year Outcomes of an Evidence-Based Parenting Program for Military Families Following Deployment." *Prevention Science*, vol. 19, no. 4, 2018, pp. 600–601.

Glenn, D. M., J.C. Beckham, M.E. Feldman, A.C. Kirby, M.A. Hertzberg, and S.D. Moore. "Violence and Hostility Among Families of Vietnam Veterans with Combat-Related Posttraumatic Stress Disorder." *Violence and Victims*, vol. 17, no. 4, 2002, pp. 473–489.

Hathaway, Alisa, Justin Russotti, Jed Metzger, and Catherine Cerulli. "Meeting Military Children's Biopsychosocial Needs: Exploring Evidence-Based Interventions." *Best Practice in Mental Health*, vol. 14, no. 1, 2018, pp. 54–77. Hisle-Gorman, Elizabeth, Donna Harrington, Cade M. Nylund, Kenneth P. Tercyak, Bruno J. Anthony, and Gregory H. Gorman. "Impact of Parents' Wartime Military Deployment and Injury on Young Children's Safety and Mental Health." Journal of the American Academy of Child & Adolescent Psychiatry, vol. 54, no. 4, 2015, pp. 294–301.

Huebner, Angela J., Jay A. Mancini, Ryan M. Wilcox, Saralyn R. Grass, and Gabriel A. Grass. "Parental Deployment and Youth in Military Families: Exploring Uncertainty and Ambiguous Loss." *Family Relations*, vol. 56, no. 2, 2007, pp. 112–122.

King, Natalie, and Alison Smith. "Exploring the Impact of Parental Post-Traumatic Stress Disorder on Military Family Children: A Review of the Literature." Nurse Education Today, vol. 47, 2016, pp. 29–36.

Lester, Patricia, Judith A. Stein, William Saltzman, Kirsten Woodward, Shelley W. Macdermid, Norweeta Milburn, Catherine Mogil, and William Beardslee. "Psychological Health of Military Children: Longitudinal Evaluation of a Family-Centered Prevention Program to Enhance Family Resilience." *Military Medicine*, vol. 178, no. 8, 2013, pp. 838–845.

Lester, Patricia, Li-Jung Liang, Norweeta Milburn, Catherine Mogil, Kirsten Woodward, William Nash, Hilary Aralis, Maegan Sinclair, Alan Semaan, Lee Klosinski, William Beardslee, and William Saltzman. "Evaluation of a Family-Centered Preventive Intervention for Military Families: Parent and Child Longitudinal Outcomes." Journal of the American Academy of Child & Adolescent Psychiatry, vol. 55, no. 1, 2016, pp. 14–24.

Lester, Patricia, William R. Saltzman, Kirsten Woodward, Dorie Glover, Gregory A. Leskin, Brenda Bursch, Robert Pynoos, and William Beardslee. "Evaluation of a Family-Centered Prevention Intervention for Military Children and Families Facing Wartime Deployments." American Journal of Public Health, vol. 102, 2012, pp. S48–S54. Malick, S., M. Sandoval, M. Woods, and C. Jacobs Johnson. "Literature Review on the Impact of Caregiving on Military Children." *Elizabeth Dole Foundation*, unpublished, May 2020.

Marote, A.S.F., C.A. Pinto, M.dR. Vieira, M.dC.A. Barbiéri-Figueiredo, and P.M.N. Pedrosa. "Children as Carers: An Integrative Review." *Revista Latino-Americana de Enfermagem*, vol. 20, no. 6, 2012, pp. 1196–1205.

Mazur, E. "Parent and Adolescent Positive and Negative Disability-Related Events and Their Relation to Adjustment." In *Risk and Resilience in U.S. Military Families*, edited by S.M. Wadsworth and D. Riggs. Berlin, Germany: Springer Science + Business Media, 2011.

Ohye, Bonnie Y., Rafaella J. Jakubovic, Rebecca Zakarian, and Eric Bui. "Staying Strong with Schools: Testing an Elementary School-Based Intervention for Military-Connected Children." Journal of Clinical Child and Adolescent Psychology, 2019.

Pederson, S., and T. Revenson. "Parental Illness, Family Functioning, and Adolescent Well-Being: A Family Ecology Framework to Guide Research." *Journal of Family Psychology*, vol. 19, no. 3, 2005, pp. 404-419.

Piehler, Timothy F., Kadie Ausherbauer, Abigail Gewirtz, and Kate Gliske. "Improving Child Peer Adjustment in Military Families Through Parent Training: The Mediational Role of Parental Locus of Control." *Journal of Early Adolescence*, vol. 38, no. 9, 2018, pp. 1322–1343.

Ramchand, Rajeev, Terri Tanielian, Michael P. Fisher, Christine A. Vaughan, Thomas E. Trail, Carolyn Epley, Phoenix Voorhies, Michael W. Robbins, Eric Robinson, and Bonnie Ghosh-Dastidar. "Hidden Heroes: America's Military Caregivers." 2014. Available at http://www.rand.org/pubs/research_ reports/RR499.html. Sherman, M.D., J.L. Gress Smith, K. Straits-Troster, J.L. Larsen, and A. Gewirtz. "Veterans' Perceptions of the Impact of PTSD on Their Parenting and Children." *Psychological Services*, vol. 13, no. 4, 2016, pp. 401–410.

Tanielian, T.T., K.E. Bouskill, R. Ramchand, E.M. Friedman, T.E. Trail, A. Clague. "Improving Support for America's Hidden Heroes: A Research Blueprint." 2017. Available at <u>https://www.rand.org/pubs/</u> <u>research_reports/RR1873.html</u>.

Thompson, David E., Joyce Baptist, Bryant Miller, and Una Henry. "Children of the U.S. National Guard: Making Meaning and Responding to Parental Deployment." Youth & Society, vol. 49, no. 8, 2017, pp. 1040–1056.

Truhan, Tayler. "Parentification in Deployed and Non-Deployed Military Families: A Preliminary Assessment." University of Central Florida Undergraduate Research Journal, vol. 8, no. 1, 2015, pp. 1–11.

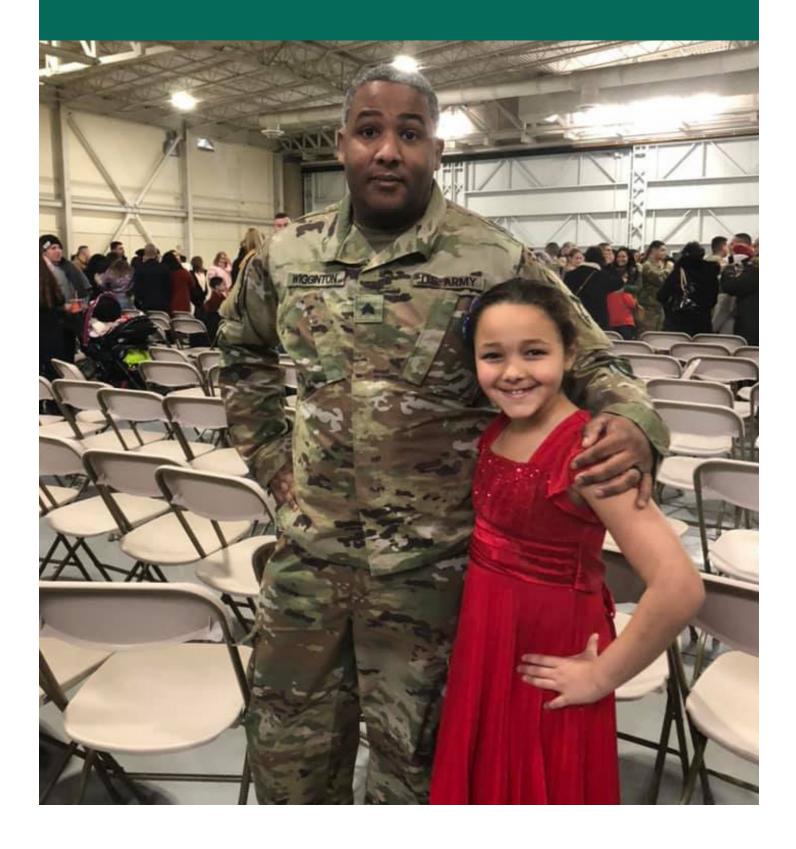
United States Census Bureau. "American Community Survey Design and Methodology: Chapter 12: Variance Estimation." United States Census Bureau. January 30, 2014. Available at https://www2.census.gov/programs-surveys/ acs/methodology/design_and_methodology/ acs_design_methodology_ch12_2014.pdf Walker, David I., Jean-François Cardin, Neelu Chawla, David Topp, Thomaseo Burton, and Shelley MacDermid Wadsworth. "Effectiveness of a Multimedia Outreach Kit for Families of Wounded Veterans." Disability and Health Journal, vol. 7, no. 2, 2014, pp. 216–225.

Wilson, Steven R., Kristi Wilkum, Skye M. Chernichky, Shelley M. MacDermid Wadsworth, and Kathy M. Broniarczyk. "Passport Toward Success: Description and Evaluation of a Program Designed to Help Children and Families Reconnect After a Military Deployment." Journal of Applied Communication Research, vol. 39, no. 3, 2011, pp. 223–249.

Zhang, Na, Sun-Kyung Lee, Jingchen Zhang, Timothy Piehler, and Abigail Gewirtz. "Growth Trajectories of Parental Emotion Socialization and Child Adjustment Following a Military Parenting Intervention: A Randomized Controlled Trial." *Developmental Psychology*, vol. 56, no. 3, 2020, pp. 652–663.



Appendix A: Literature review methods and description of studies identified



How we conducted the literature review and what types of studies we found.

We conducted two separate searches to find the studies this report explored. The first was on the core population of military-connected children, and the second was on similar populations of civilian children who are caregivers for a parent with a chronic injury or illness. We identified nine databases (Academic Search Premier, CINAHL Complete, Cochrane Database of Systematic Reviews, Education Research Complete, SocINDEX, APA PsycInfo, Education Resources Information Center, SAGE Journals Online, and Scopus) to search that contained research related to children, families, health, education, and human development. We also searched the Harvard Kennedy School Think Tank Search, which uses a Google custom search engine to review the websites of over 1,200 think tanks, research centers, and other institutions that generate public policy research and analysis.

/ In our first search, we focused on children of U.S. military service members. We looked for qualitative and quantitative studies of any design, such as ethnographic research or randomized controlled trial, that focused on caregiving military children or their caregivers and were published from 2000 to 2020.

- / In our second search, we focused on similar populations in related topics. We looked for literature reviews and meta-analyses published from 2010 to 2020 that focused on children who care for those with chronic injuries or illnesses. To keep this second search manageable, we used a more narrowly focused search plan because we expected the number of studies examining caregiving children to greatly exceed the number of studies focused on military caregiving children.
- / For all searches, we initially screened by reviewing study abstracts to ascertain whether they met our eligibility criteria. For those that seemed eligible, we conducted a second, closer review of these studies and their full text to extract relevant information that formed the basis of our findings from this literature review.
- / In the end, our search on military children identified 133 studies that examined outcomes for children from military families. We narrowed in further to focus on 18 eligible studies that described the impacts of caregiving—broadly defined to include children taking on adult responsibilities normally conducted by adult caregivers—and the impacts of having a parent who experienced a chronic injury or illness as a result of their deployment.
- / Our second search on similar populations identified six eligible studies.



Description of eligible studies focused on military children, their caregiving duties, or responses to parental chronic injuries or illnesses as a result of deployment.

Exhibit A.1. has details on eligible studies identified by the literature review.

| Exhibit A.1 Eligible studies identified durin | ng the literature review |
|---|--------------------------|
|---|--------------------------|

| | | | Examines outcomes related to: | |
|--------------------------------|---|--------------------------|-----------------------------------|--|
| Citation | Focus of study | Study design | Caregiving and adult duties | Parent with chronic injury or illnessª |
| Baptist et al. 2015 | Explores factors that helped resiliency among children with deployed parents | Descriptive ^b | × | |
| Briggs et al. 2020 | Examines facets of military life and family factors that could impact child psychosocial and mental health functioning | Correlational | | × |
| Cozza et al. 2010 | Examines the relationship of child distress pre-injury to post-injury, deployment-related family distress, injury severity, and family disruption post-injury | Correlational | | × |
| Cramm et al. 2019 | Describes the mental health of children growing up in military-connected families | Literature review | × | × |
| Creech et al. 2014 | Examines prior study findings to describe the impact of deployment separation on parenting and children's emotional, behavioral, and health outcomes; the impact of parental mental health symptoms during and after reintegration; and current treatment approaches in veteran and military families | Literature review | | × |
| De Pedro et al. 2011 | Reviews studies on military children and their families that examined links between special circumstances and stressors and outcomes known to impact students' school experiences | Literature review | × | × |
| Dekel and Goldblatt 2008 | Reviews literature on intergenerational transmission of PTSD from fathers to sons in families of war veterans | Literature review | | × |
| DeVoe et al. 2018 | Seeks to understand the relationships between parental mental health status, parenting stress, couple functioning, and young children's well-being | Correlational | | × |
| Glenn et al. 2002 | Provides a portrait of emotional-behavioral functioning within a small sample of Vietnam veterans with combat-related PTSD, their partners, and older adolescent and adult children | Correlational | | × |
| Hathaway et at. 2018 | Seeks to better understand the mental health needs of military-involved children | Descriptive | × | |
| Herzog et al. 2011 | Explores the effects of combat exposure on soldier's spouses and children, including combat exposure with trauma symptoms, substance abuse, domestic violence, and secondary trauma symptoms among family members | Correlational | | × |

| | | | Examines outcomes related to: | |
|---------------------------------|---|---------------------|-----------------------------------|--|
| Citation | Focus of study | Study design | Caregiving and adult duties | Parent with chronic injury or illnessª |
| Hisle- Gorman et al. 2015 | Determines the impact of parental deployment and combat injury on young children's post-deployment mental health, injuries, and maltreatment | Correlational | | × |
| Huebner et al. 2007 | Explores uncertainty, loss, resilience, and adjustment among children who had a parent deployed | Descriptive | × | |
| Sherman et al. 2016 | Explores the impact of PTSD on parenting, children, and the parent-child relationship | Descriptive | × | × |
| Thompson et al. 2017 | Explored how children's behaviors during deployment were influenced by their perceptions of their non deployed parents | Descriptive | × | |
| Truhan 2015 | Investigates the differences in parentification in military families with a deployed parent and without a deployed parent | Comparison group | × | |
| Walker et al. 2014 | Evaluates a Sesame Workshop multimedia kit that aimed to help caregivers assist young children as they adjusted to their parent's injury | Comparison group | | × |
| Yager et al. 2016 | Focuses on secondary traumatization of wives and offspring of Vietnam veterans | Correlational | | × |

^a Parents or caregivers in these studies generally developed their chronic injury or illness as a result of their deployment.

^b Descriptive studies can refer to qualitative studies such as ethnographies or quantitative studies such as those without advanced statistical analyses like correlations or regressions.

Details on interventions focused on improving military children's outcomes.

We provide additional detail about studies of interventions aimed at improving military children's outcomes examined in the literature review.

Exhibit A.2. Interventions focused on improving outcomes for military children

| Intervention | Finding | Citation(s) |
|---|---|---|
| Operation Purple Camp, a summer camp for military children and their families to develop and maintain healthy relationships during deployments | Using a pre-post analysis, Operation Purple Camp might have improved participants' (1) perceptions of their acceptance by peers, (2) sense of athletic competence and ability, and (3) level of happiness with their life. | 1. Chawla and Wadsworth 2012 |
| After Deployment Adaptive Parenting Tools Intervention (ADAPT), a 14-week parenting program to address core parenting skills | In a study using a randomized controlled trial, ADAPT showed significantly improved parenting practices in observations. These improvements in parenting practices were associated with improvements in children's adjustment. In a study using a randomized controlled trial, ADAPT showed improvements in parental locus of control. Increases in mother's locus of control was associated with improvements in children's peer adjustment. In a study using a randomized controlled trial, mothers and fathers completing ADAPT had reductions in non-supportive parental emotional socialization over two years, which was associated with decreases in children's internalizing behaviors. Improvements in mothers were associated with decreases in children's externalizing behaviors. | Cewirtz et al. 2018 Piehler et al. 2018 Zhang et al. 2020 |
| Families OverComing Under Stress (FOCUS), a family resiliency training | In a study using a pre-post analysis, FOCUS might have improved emotional and behavioral adjustment in parents and children. Children's pro-social behaviors and positive coping skills increased, and psychological distress for service members and their spouses decreased. In a study using structural equation modeling, parental participation in FOCUS was associated with improved family functioning and reductions in child distress. In a study using a linear mixed-effects longitudinal regression model, parental participation in FOCUS was associated with a reduction in anxiety and depression in parents. It was also associated with emotional, behavioral, mental health, and pro-social improvements in children. | Lester et al. 2012 Lester et al. 2013 Lester et al. 2016 |
| Staying Strong with Schools (SWSS), a school-based intervention addressing behavioral health needs of military-connected children | In a study using a randomized controlled trial, parents reported that military-connected children participating in SWSS exhibited fewer internalizing behaviors. Children participating in SWSS reported greater perceived social support. | 1. Ohye et al. 2019 |
| Talk, Listen, Connect: Changes (TLC-II), a multimedia kit from Sesame Workshop designed to help young children adjust to parental deployment- related injury | In a study using a randomized controlled trial, TLC-II led to statistically significant declines in caregivers' social isolation, children's aggression, and household disruption among children with a caregiver with physical or psychological injuries as a result of deployment. | 1. Walker et al. 2014 |
| Passport Toward Success (PTS), a program for military children to practice skills related to coping with reintegration | In a study using a pre-post analysis, PTS might have helped children learn about skills that facilitate resiliency, but the study did not find any other potential impacts. | 1. Wilson et al. 2011 |

Appendix B: Data analysis of nationally representative surveys



How we used survey data to learn about children in military caregiving homes.

This appendix details how we developed our estimates for each survey we analyzed.

American Community Survey (ACS)

Because the ACS does not identify caregivers directly, we identified households with a disabled veteran, then counted the number of children under the age of 18 who lived in the same household. Of the 15,947,624 individuals included in the 2015–2019 ACS, we identified 451,302 disabled veterans. We identified 109,116 children under the age of 18 who lived in the same household as these disabled veterans. We identified 28 individuals age 17 who were disabled veterans.

Because they were themselves the disabled veteran, we did not include them as children under the age of 18 living with a disabled veteran, but any additional children living in the same household were included. We applied person-level weights to estimate the number of children living with a disabled veteran. We used replicate weights to calculate standard errors, as outlined in the American Community Survey Design and Methodology Report (Centers for Disease Control and Prevention 2019).

This produced the following 95 percent confidence intervals:

- / Children ages 0–11 living with disabled veterans (1,426,139–1,470,173)
- / Children ages 12–17 living with disabled veterans (846,375–873,117)

National Health Interview Survey

The National Health Interview Survey (NHIS) collects data on the non-institutionalized United States population. Active duty armed forces personnel are excluded from the survey, unless at least one other family member (for example, a spouse or child of the active duty service member) is an eligible civilian. Although data on these current active duty service members are collected, including whether the individual requires help with personal care and routine needs, their weight is zero, and therefore they are not included in any population estimates. Because our population of interest was the children living with these service members, we were able to use unweighted data on current military service and caregiving needs to classify households as military and veteran caregiving or current military non-caregiving. We used sample weights for children to estimate the percentage of children with each outcome of interest. We specified survey design characteristics (that is, strata and cluster), as outlined in the NHIS Description, to calculate standard errors and 95 percent confidence intervals for each outcome of interest (United States Census Bureau 2014).

Hidden Helpers at the Frontlines of Caregiving: Supporting the Healthy Development of Children from Military and Veteran Caregiving Homes



Thank you!

For more information

Mathematica

Princeton, NJ • Ann Arbor, MI • Cambridge, MA • Chicago, IL • Oakland, CA • Seattle, WA • Tucson, AZ • Woodlawn, MD • Washington, DC

EDI Global, a Mathematica Company

Bukoba, Tanzania • High Wycombe, United Kingdom

