



June 2022

MILITARY PERSONNEL

Opportunities Exist to Improve Access to Services Supporting Caregivers of Dependents with Special Needs

Accessible Version

GAO Highlight

Highlights of [GAO-22-105204](#), a report to congressional committees

Why GAO Did This Study

Caregivers of dependents with special needs can experience negative consequences from their caregiving roles, such as stress and lost wages. Military families with special needs dependents face additional caregiving challenges due to frequent moves to new duty stations. To address the needs of these military families, DOD provides caregiver support services, such as respite care, through its military branches and the TRICARE health care program. Congress included a provision in statute for GAO to review certain caregiving services available to military families. This report (1) describes respite care and other key services for supporting caregivers available to active duty military families through ECHO and other programs, and (2) examines barriers military families may face when seeking to access respite care and actions DOD has taken to address those barriers.

To perform this work, GAO reviewed DOD program policies regarding caregiver benefits. GAO also interviewed DOD officials, TRICARE representatives, state Medicaid officials, and stakeholder organizations representing military families and the special needs community.

What GAO Recommends

GAO is making two recommendations to DOD, including 1) to communicate in writing that there is no TRICARE requirement for another adult to remain in the home during the provision of ECHO respite care, and 2) to collect and analyze data regarding the utilization of ECHO respite care. DOD concurred with both recommendations.

View [GAO-22-105204](#). For more information, contact Sharon M. Silas at (202) 512-7114 or silass@gao.gov.

June 2022

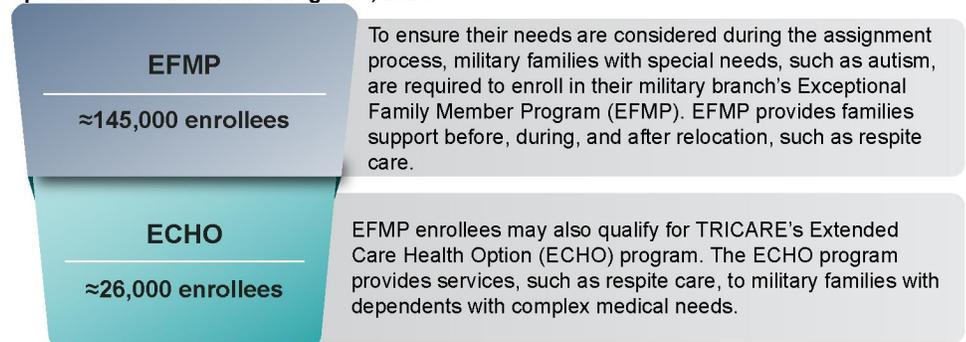
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Opportunities Exist to Improve Access to Services Supporting Caregivers of Dependents with Special Needs

What GAO Found

The Department of Defense (DOD) offers eligible military families several services to support caregivers of special needs dependents. Stakeholder organizations GAO interviewed identified these services as key to supporting caregivers, particularly respite care—in which a provider temporarily cares for the special needs individual. Through the TRICARE Extended Care Health Option (ECHO) program, active duty military families with special needs dependents may obtain respite care, care coordination, training, and some supplemental services. Military families may obtain additional support services through their military branch's Exceptional Family Member Program (EFMP) or state Medicaid programs. However, services available vary by military branch and by state.

Department of Defense (DOD) Programs Supporting Military Members' Dependents with Special Needs and Their Caregivers, 2021



Source: GAO analysis of DOD data and documentation. | [GAO-22-105204](#)

Note: Numbers are rounded to the nearest thousand. For more details, see fig. 1 in [GAO-22-105204](#).

DOD has recently taken steps to address two policy barriers to accessing respite care. In 2021, DOD issued a rule eliminating the requirement for ECHO enrollees to receive a concurrent benefit (e.g., incontinence supplies) to qualify for respite care. DOD is also taking steps to increase the number of respite care hours from 16 to 32 hours per month. DOD officials expect to implement this by 2025.

However, GAO found that Defense Health Agency (DHA) officials miscommunicated requirements for accessing ECHO respite care to EFMP officials, who help refer families to resources like ECHO. Specifically, DHA officials informed EFMP officials of a requirement that another adult remain present during the provision of ECHO respite care. DHA officials told GAO that this is not a TRICARE policy, rather that some home health agencies require this out of concern for the dependent's safety. EFMP officials from one military branch stated that this requirement effectively renders the respite care benefit unusable for eligible families. In addition, GAO found that DOD does not have data on the extent of unmet need for ECHO respite care. TRICARE's two managed care support contractors—the entities responsible for coordinating respite care—collect some data on unmet need for ECHO respite care. However, these data are limited and the contractors are not required to report it to DHA. As

such, DHA cannot assess why, in 2021, only about half of ECHO enrollees authorized to receive respite care (175 out of 341) ultimately utilized this benefit and cannot identify strategies for increasing access to this benefit.

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Abbreviations

CMS	Centers for Medicare & Medicaid Services
DHA	Defense Health Agency
DOD	Department of Defense
ECHO	Extended Care Health Option
EFMP	Exceptional Family Member Program
EHHC	ECHO Home Health Care
HCBS	home- and community-based services
HHA	home health agency
HHS	Department of Health and Human Services
NDAA	National Defense Authorization Act
OSN	Office of Special Needs
PCAFC	Department of Veterans Affairs' Program of Comprehensive Assistance for Family Caregivers
PGCSS	Department of Veterans Affairs' Program of General Caregiver Support Services
VA	Department of Veterans Affairs

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June 29, 2022

The Honorable Jack Reed
Chairman
The Honorable James M. Inhofe
Ranking Member
Committee on Armed Services
United States Senate

The Honorable Adam Smith
Chairman
The Honorable Mike Rogers
Ranking Member
Committee on Armed Services
House of Representatives

Caregivers are often needed to provide long-term services and supports—often in a home or community setting—for special needs individuals with medical, behavioral, or other conditions or disabilities. In 2020, an estimated 53 million individuals served as caregivers for their friends and families, and 14 million of them cared for children.

Due to the demands of their responsibilities, caregivers can experience negative health and financial outcomes, including stress and lost wages.¹ Caregiver support services, such as respite care, can help minimize these negative outcomes and avoid caregiver burnout. Respite care—which provides short-term relief for the caregiver by having another provider temporarily care for the special needs individual—allows the caregiver to rest and to attend to their own financial, social, physical, and emotional well-being.

Caregivers in military families encounter additional challenges with accessing and maintaining consistent support services due to their frequent moves within the United States, or to overseas installations. To address these challenges, military families with special needs dependents may be eligible for services such as home health care and rehabilitative

¹Office of the Assistant Secretary for Planning and Evaluation, *Economic Impacts of Programs to Support Caregivers: Final Report* (Washington, D.C.: Jan. 2020).

services, as well as for caregiver support services such as respite care, through TRICARE's Extended Care Health Option (ECHO) program.² According to the Department of Defense (DOD), as of 2021, approximately 26,000 eligible dependents were enrolled in ECHO, most of them children with intellectual, developmental, or physical disabilities or other significant health needs. Beyond the caregiver support services available through ECHO, caregivers of ECHO enrollees may also be eligible for additional caregiver supports, these include respite care, through DOD's Exceptional Family Member Program (EFMP) or through other programs, such as Medicaid.

Groups representing military families, however, claim that ECHO's caregiver supports are insufficient to address caregiver burden.³ In addition, these groups note that access to Medicaid caregiver supports to supplement ECHO benefits may be limited by wait lists for state Medicaid home- and community-based services (HCBS) programs. In 2015, an independent commission recommended that, due to barriers accessing Medicaid HCBS, ECHO should expand benefits to more closely align with those provided under Medicaid.⁴ The commission specifically cited expanding respite hours and removing a requirement that ECHO enrollees access another ECHO service, such as rehabilitation, to qualify for respite in a given month.

Given the unique challenges faced by military family caregivers, the William M. (Mac) Thornberry National Defense Authorization Act (NDAA) for Fiscal Year 2021 included a provision for GAO to review caregiving

²TRICARE is the Department of Defense's (DOD) regionally structured health care program for eligible military members and their dependents. Generally, TRICARE enrollees include active duty military members and their dependents, medically eligible National Guard and Reserve service members and their dependents, and retirees and their dependents or survivors. Active duty military members include Reserve component members on active duty for more than 30 days. In fiscal year 2020, there were approximately 9.6 million TRICARE enrollees.

³Tricare For Kids Coalition, *Briefing Book: Presented to the Defense Health Board For Consideration in its Review and Recommendations regarding Pediatric Health Care Tasking by the Defense Health Agency* (Washington, D.C.: May 2017).

⁴Military Compensation and Retirement Modernization Commission, *Report of the Military Compensation and Retirement Modernization Commission, Final Report, January 2015* (Washington, D.C.: Jan. 2015).

services available to military families through TRICARE's ECHO program, and other programs such as Medicaid.⁵ This report

1. describes respite care and other key services for supporting caregivers that are available to active duty military families through ECHO and other programs; and
2. examines barriers military families may face when seeking to access respite care through ECHO and other programs, and actions DOD has taken to address those barriers.

To describe respite care and other key services for supporting caregivers that are available to active duty military families through ECHO and other programs, we reviewed ECHO program documentation, and documentation on caregiver support services offered through DOD's EFMP and Medicaid programs in seven selected states.⁶ We also interviewed DOD officials, three groups of TRICARE case managers from each of the two managed care support contractors responsible for coordinating benefits for ECHO enrollees, and officials from the selected state Medicaid offices.⁷ We also reviewed documentation on leading practices for supporting caregivers, including the RAISE Family Caregiving Advisory Council's initial mandated report to Congress on this topic.⁸ We also interviewed representatives from 10 stakeholder

⁵Pub. L. No. 116-283, § 704(d), 134 Stat. 3388, 3688-89 (2020).

⁶To ensure their family member's special needs are considered during the assignment process, active duty military branch members who have family members with special medical or educational needs must enroll in DOD's EFMP, which also provides support to these families before, during and after relocation. Each military branch is responsible for implementing DOD program requirements for its EFMP.

⁷The following states were included in our review: California, Virginia, North Carolina, Texas, Florida, Georgia, and Washington. For additional information about our state selection criteria, see appendix I.

⁸In September 2021, the Council issued its initial report to Congress that (1) identified challenges faced by family caregivers, (2) provided an overview of federally funded efforts to address those challenges, (3) discussed how family caregiving affects the Medicare program, the Medicaid program, and other federal programs, and (4) outlined recommendations to improve and better coordinate federal programs and activities. See RAISE Family Caregiving Advisory Council, *Recognize, Assist, Include, Support, & Engage (RAISE) Family Caregivers Act, Initial Report to Congress*, (Washington, D.C.: Administration for Community Living, Sept. 22, 2021), accessed Mar. 9, 2022, <https://acl.gov/RAISE/report>.

organizations, including four advocacy groups, three provider groups and three national associations of state organizations.

To examine barriers military families may face in accessing caregiver support services through ECHO and other programs, and actions DOD has taken to address those barriers, we reviewed DOD's TRICARE program policy manual and program regulations for current information regarding ECHO program benefits, including respite care. In addition, we interviewed six groups of TRICARE case managers, DOD officials from the Defense Health Agency (DHA) and the Office of Special Needs (OSN), and officials from the EFMP programs for each military branch as well as advocacy groups.⁹ We assessed whether DOD's provision of respite care benefits was consistent with relevant federal internal control standards.¹⁰ Specifically, the information and communication component of internal control was significant to this objective. Finally, we obtained and analyzed DOD data on the ECHO program for fiscal year 2021 (the most recent data available at the time of our review). We conducted interviews with DOD officials responsible for collecting and providing these data and determined these data were reliable for providing a descriptive summary of ECHO program enrollment and utilization of its respite care benefit. See appendix I for a more detailed discussion of our objectives, scope, and methodology.

We conducted this performance audit from May 2021 to June 2022 in accordance with generally accepted government auditing standards. Those standards require that we plan and perform the audit to obtain sufficient, appropriate evidence to provide a reasonable basis for our findings and conclusions based on our audit objectives. We believe that the evidence obtained provides a reasonable basis for our findings and conclusions based on our audit objectives.

Background

The federal government provides services to individuals with special needs as well as support services for their caregivers through several programs, including those specifically for caregivers of military members'

⁹The DHA is responsible for managing the TRICARE health care program, including ECHO. The OSN is responsible for overseeing the DOD's EFMP across all military branches.

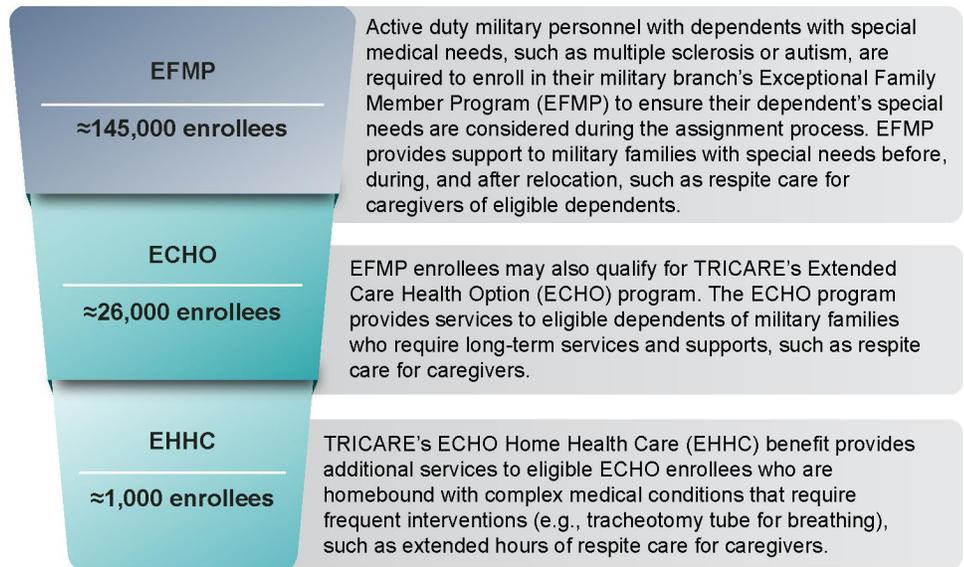
¹⁰See GAO, *Standards for Internal Control in the Federal Government*, [GAO-14-704G](#) (Washington, D.C.: Sept. 10, 2014).

dependents. In addition, caregivers may receive support through other programs, such as those offered by state and local governments. These may include local government programs that provide information and outreach on topics related to providing care and referrals to local resources and services.

Programs for Supporting Military Members' Dependents with Special Needs and Their Caregivers

Active duty military members with dependents who have special needs may obtain services, including caregiver support services, through their military branch or through the TRICARE health care program. (For an overview of DOD programs and enrollment in 2021, see fig. 1).

Figure 1: Department of Defense (DOD) Programs Supporting Military Members' Dependents with Special Needs and Their Caregivers, 2021



Source: GAO analysis of DOD data and documentation. | GAO-22-105204

Note: Numbers are rounded to the nearest thousand. In order to access ECHO program services, active duty military members with an eligible dependent must first enroll in the EFMP program to ensure their family member's special needs are considered during the assignment process. As such, the number of individuals enrolled in the ECHO program (26,000) are a subset of the number of individuals enrolled in the EFMP (145,000). Similarly, only ECHO enrollees who meet certain eligibility criteria may access the EHC benefit. As such, the number of individuals enrolled in the EHC (1,000) is a subset of the number of individuals enrolled in the ECHO program (26,000).

DOD's EFMP. Active duty military members who have dependents with special medical or educational needs must enroll in their military branch's EFMP. These special medical needs include potentially life-threatening or

chronic physical conditions (such as diabetes or multiple sclerosis), current and chronic mental health conditions, asthma, attention deficit disorder, or a chronic condition that requires adaptive equipment or technology devices.

Each military branch is responsible for implementing DOD policy requirements for its EFMP, which are to have three components—identification and enrollment, assignment coordination, and family support.

- **Identification and enrollment.** Once identified by a qualified medical provider, active duty military members are required to enroll dependents with special needs in their service's EFMP to ensure their family member's special needs are considered during the assignment process.¹¹
- **Assignment coordination.** Before finalizing a military member's assignment to a new location, DOD requires each military branch to consider any dependent's special needs, including the availability of required medical and special educational services at a new location.¹²
- **Family support.** DOD requires each military branch's EFMP to help families with special needs identify and gain access to programs and services before, during, and after relocation.¹³ This includes EFMP family support providers who offer information and referral services, non-medical case management, training and other forms of support.

As required by law, DOD established the OSN to monitor each military branch's program to support military families with special needs and

¹¹Dependents of a military member include a spouse and children who are eligible to receive a DOD identification card, medical care in a DOD medical treatment facility, and command sponsorship or DOD-sponsored travel. In certain cases, this may also include other nondependent family members of a military member.

According to DOD officials, special medical or educational needs are identified and updated through the use of DOD's forms DD 2792 and DD 2792-1.

¹²DODI 1315.19, para. 1.2.a,b.

¹³DODI 1315.19, para. 6.1.

ensure the coordination between the military branches programs, among other things.¹⁴

TRICARE's ECHO Program. Through TRICARE, DOD provides enrollees with access to care through military and participating civilian health care providers.

TRICARE's ECHO program provides supplemental services to dependents of active duty military members with qualifying mental, developmental, or physical disabilities. The ECHO program pays for services and supplies designed to reduce the disabling effects of a qualifying condition, which are generally not covered under a TRICARE health plan. It also provides support services for the caregiver of the registered dependent.¹⁵

In order to access TRICARE's ECHO program, the active duty military member must meet certain service-based criteria and the dependent must have one of several qualifying conditions, such as autism, cerebral palsy, or a moderate or severe mental intellectual disability.¹⁶ In addition, the military member must be enrolled in the appropriate military branch's EFMP and can then register for the ECHO program through a TRICARE managed care support contractor.¹⁷ Once registered, an ECHO enrollee must obtain pre-authorization from their managed care support contractor for all ECHO services. The military member also must pay part of the monthly expenses for authorized ECHO benefits through a monthly

¹⁴Section 563 of the NDAA for fiscal year 2010 created the Office of Community Support for Military Families with Special Needs, which was renamed the Office of Special Needs by the NDAA for fiscal year 2017. See Public Law 111-84, 123 Stat. at 2304, as amended by Pub. L. No. 114-328, § 922(a)(4)(B), 130 Stat. 2000, 2364 (2016).

¹⁵The coverage limit for all ECHO program benefits combined, excluding the ECHO Home Health Care (EHC) benefit, is \$36,000 per calendar year, per enrollee.

¹⁶TRICARE-eligible active duty family members include family members of National Guard and Reserve members called or ordered to active duty for more than 30 days for a federal preplanned mission or in support of a contingency operation.

¹⁷In its two TRICARE regions, DOD contracts with private sector companies—referred to as managed care support contractors—to perform customer service functions, such as processing claims and assisting enrollees with finding providers, among other things. TRICARE managed care support contractors have case managers who serve as ECHO program points of contact for caregivers and assist in the development of a care plan to identify short-term and long-term goals with scheduled appointments for the enrolled dependent.

copayment that is based on the service member's pay grade.¹⁸ Within DOD, DHA is responsible for managing the TRICARE health care program, including ECHO.

ECHO Home Health Care (EHC). ECHO enrollees who are homebound with certain complex medical conditions that require skilled nursing care may be eligible for expanded in-home medical services through the EHC benefit. The EHC benefit provides medically necessary skilled services to ECHO enrollees who are homebound and generally require up to 35 hours per week of home health services. It also provides additional supports for the caregivers of these EHC enrollees.¹⁹ In 2021, nearly 1,000 ECHO enrollees were receiving TRICARE's EHC benefit.

Other Caregiver Support Programs

In addition to programs offered through DOD, eligible individuals may obtain caregiver support services through other federal programs—such as Medicaid and VA's caregiver support program for certain veterans—or through state and local programs.

Medicaid HCBS waivers. Medicaid—the joint federal-state financing program for health care services for certain low-income individuals—is the nation's primary payer of long-term services and supports, including HCBS. HCBS cover a wide range of support services to help individuals remain in their homes or live in a community setting, such as personal care services to provide assistance with activities of daily living. In addition, HCBS may include services that support caregivers, such as respite care and case management to coordinate services and supports. While states are required to cover institutional care as part of Medicaid, coverage for most HCBS is optional, and for the most part, individuals who qualify for and receive Medicaid coverage for these services are age 65 or older, disabled, or blind.

¹⁸The monthly copayment is only one fee per service member, not per ECHO enrollee, and is paid only if ECHO benefits are used during that calendar month. In 2021, ECHO copayment amounts ranged from \$25 to \$250 per month.

¹⁹Coverage for the EHC benefit is limited to the maximum fiscal year amount TRICARE would pay if the enrollee resided in a skilled nursing facility. This amount is based on the enrollee's geographic location.

However, states may also cover HCBS for Medicaid beneficiaries through waivers.²⁰ Waivers provide states with flexibility to design their own programs to provide services not otherwise covered by Medicaid to designated populations, such as individuals with intellectual or developmental disabilities, which could include military dependents.

VA's Program of Comprehensive Assistance for Family Caregivers (PCAFC). Since 2011, VA's PCAFC has provided support and services to caregivers of eligible veterans who have a serious injury incurred or aggravated in the line of active duty either on or after September 11, 2001, or on or before May 7, 1975.²¹ As of May 2021, approximately 26,000 veterans are active in VA's PCAFC with at least one designated caregiver. This program is not available to active duty military members, unless undergoing medical discharge from the Armed Forces, and their dependents. For a more detailed overview of VA's PCAFC, see appendix II.

State and local programs. State and local programs may help caregivers find and access support services. For example, Kinship Navigator Programs, funded by the Administration for Children and Families within the Department of Health and Human Services (HHS), provide information and offer referral and follow-up services to grandparents and other relatives raising children, to link them to the benefits and services that they, or the children, need. One such program, SHARE New Mexico, serves as a "first stop" to connect caregivers with existing resources, such as family support, trauma assistance, support groups, legal aid, benefits assistance, and community resources. In

²⁰The Social Security Act authorizes multiple waiver and demonstration authorities to allow states flexibility in operating their Medicaid programs. For example, in 1981, Congress added section 1915(c) to the act enabling states to cover a broad range of services to participants, as long as these services are required to prevent institutionalization. Under section 1915(c), states may offer HCBS without regard to certain Medicaid requirements that HHS may waive under the provision—namely, that benefits be offered statewide and to all Medicaid beneficiaries. Section 1915(c) waivers, referred to as HCBS waivers in this report, are the primary means by which states provide HCBS for Medicaid beneficiaries. States may also provide HCBS in their Medicaid programs through different authorities.

²¹VA's PCAFC is one of two components of the agency's Caregiver Support Program. The other component, namely VA's Program of General Caregiver Support Services (PGCSS), also offers some caregiver support services. Through VA's PGCSS an eligible individual providing personal care services to a covered veteran enrolled in VA's health care system may enroll in VA's PGCSS to access peer support mentoring, skills training, coaching, telephone support, online programs, and referrals to other caregiver resources.

addition, nonprofit organizations may offer information and referral services about local resources and services.

ECHO Offers Care Coordination, Respite Care, Training, and Supplemental Services to Caregivers; Availability of Other Services Varies by Military Branch and State

Our review of TRICARE program and policy documentation found that ECHO’s standard benefit program and its more expansive EHHC benefit offer eligible military families several key caregiver support services—care coordination, respite care, some training, and some supplemental services. These services were identified as key to supporting caregivers by representatives we interviewed from 10 stakeholder organizations. (For an overview of these and other key caregiver support services, see appendix III.) See Table 1 for an overview of the caregiver support services ECHO provides.

Table 1: Caregiver Support Services Available through TRICARE’s ECHO Program

Care Coordination	Case managers develop a care plan to identify enrollee’s short- and long-term goals, and assist the enrollee with accessing care and services.
Respite care ECHO Respite	Respite care provides caregivers with temporary relief from their caregiving responsibilities. Total hours available vary based on the medical needs of the enrollee. Up to 16 hours of respite care in any calendar month. ^a
ECHO Home Health Care (EHHC) Respite	Up to 8 hours of respite care, 5 days per calendar week to allow the primary caregiver time to sleep. This respite care benefit is for the caregivers of those enrollees who need frequent skilled interventions three or more times in the 8-hour respite period.
Limitations	Restrictions and limitations include the following: Only one of the respite care benefits (ECHO respite or EHHC respite) can be used in the same calendar month. Cannot be used for child care services, sibling-care, employment, deployment, or pursuing education. Services must be provided by a TRICARE-authorized home health agency.
Training	Training to assist caregivers in the management of the enrollee’s qualifying condition. For example, training a family member to use the enrollee’s specialized equipment and alternative communication methods.
Supplemental Services	Incontinence supplies or diapers. Transportation to and from institutions or facilities in certain circumstances.

Source: GAO analysis of TRICARE Extended Care Health Option (ECHO) documentation. | GAO-22-105204

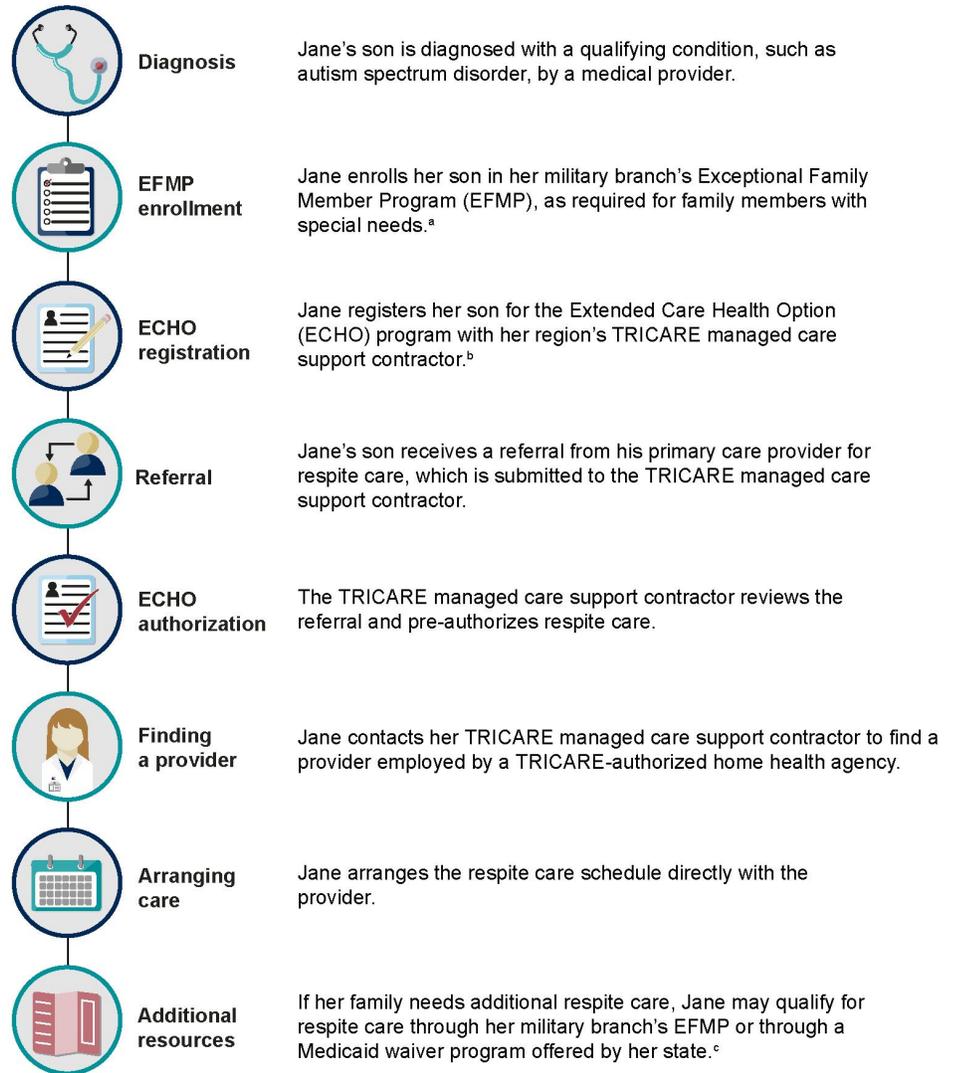
Note: ECHO program benefits are subject to an annual coverage limit that applies to all services offered, including the identified caregiver support services. The coverage limit for all ECHO program benefits combined, excluding the EHHC benefit, is \$36,000 per calendar year, per enrollee. Coverage

for the EHHC benefit is limited to the maximum fiscal year amount TRICARE would pay if the enrollee resided in a skilled nursing facility, based on the enrollee's geographic location.

^aPrior to August 9, 2021, to be eligible for respite care, a beneficiary enrolled in ECHO also needed to receive an authorized non-respite care benefit during the month. 86 Fed. Reg. 36,213 (July 9, 2021). The elimination of the requirement for a concurrent ECHO-authorized benefit was implemented in March 2022.

To access respite care through ECHO, a caregiver of a military member's dependent with special needs is required to follow a series of steps. For information on these steps, see figure 2.

Figure 2: Steps for Accessing Respite Care through TRICARE’s ECHO Program



Source: GAO analysis of Department of Defense documentation. | GAO-22-105204

Note: TRICARE is the Department of Defense's health care program for eligible military members and their dependents. TRICARE's ECHO program provides supplemental services—such as respite care—to dependents of active duty military members with qualifying mental, developmental, or physical disabilities.

^aEFMP provides family support and other services before, during and after the family's relocation. To enroll in EFMP, the active duty family member and their health care provider must complete the required forms. The family member submits the completed forms to the appropriate military hospital or clinic's EFMP special needs program office for eligibility determination.

^bIn the United States, TRICARE is structured into two regions: the TRICARE East Region and the TRICARE West Region. Each region is managed by a private sector company—referred to as a managed care support contractor—to perform customer service functions, such as processing claims

and assisting enrollees with finding providers, among other things. TRICARE's ECHO program is also available to military families living outside of the United States through the TRICARE Overseas Program, but certain ECHO benefits—including respite care—are unavailable.

^cState Medicaid programs may offer home- and community-based services (HCBS), including respite care, through Medicaid “waiver” programs to individuals who would not otherwise qualify for Medicaid because of their income or asset levels. Substantial variation exists across states regarding the eligibility criteria, enrollment caps, and populations served through each HCBS waiver.

Military families may access additional respite care and other support services that stakeholders view as key to supporting caregivers through their respective military branch’s EFMP and through their state’s Medicaid program. However, the availability of services varies by military branch and by state.

EFMP services. Each military branch’s EFMP offers caregiver support services, including non-clinical case management and respite care, but the amount of respite care offered and the eligibility requirements vary.²² For example, according to military branch officials, the Navy and the Air Force offer 40 hours of respite care each month through their respective EFMP, while the Marine Corps offers 20 hours each month, and the Army offers 25 hours each month. In addition, the Army restricts families from using both ECHO and EFMP respite care benefits concurrently, while the other three military branches do not. In terms of eligibility requirements for respite care, each military branch has established the level of need required to qualify for the benefit. According to officials, the Army, Navy, and Marine Corps offer respite care only to families who qualify with the highest levels of need within their EFMP, while the Air Force offers respite care to all families enrolled in its EFMP.

DOD is currently in the process of standardizing the EFMP across the military branches, including respite care benefits in terms of the number of hours and eligibility requirements. The William M. (Mac) Thornberry NDAA for Fiscal Year 2021 directed DOD to standardize the EFMP within 6 months of the act’s enactment.²³ To advance the standardization efforts, DOD’s OSN established an EFMP workgroup—whose members include, among others, representatives from all military branches and from DHA—that assisted OSN in developing the requirements to enhance and standardize support to military families with special needs. According

²²GAO has previously reported on variation in EFMP services in 2012 and 2018. See GAO, *Military Dependent Students: Better Oversight Needed to Improve Services for Children with Special Needs*, [GAO-12-680](#) (Washington, D.C.: Sept. 10, 2012), and *Military Personnel: DOD Should Improve Its Oversight of the Exceptional Family Member Program*, [GAO-18-348](#) (Washington, D.C.: May 8, 2018).

²³Pub. L. No. 116-283, § 582(b), 134 Stat 3388, 3652 (2021). The law was enacted on January 1, 2021.

to OSN officials, OSN also established an EFMP Respite Care Standardization workgroup.

As of November 2021, DOD reported that it had established the standard provision of respite care for eligible families as 32 hours per month of respite care per family with a dependent with profound needs, and as 20 hours per month of respite care per family with a dependent with moderate needs. For the determination of eligibility for respite care, DOD leveraged existing level of need rubrics developed by the Marine Corps for use as the standard rubrics across the branches.²⁴ OSN expects to have fully standardized the number of respite care hours and eligibility process for respite care by the end of fiscal year 2024.²⁵ In addition, as of January 2022, OSN officials stated that the Army's restriction on the concurrent use of ECHO and EFMP respite care is expected to be eliminated, effective summer 2022.

Medicaid HCBS waivers. State Medicaid programs may obtain approval from the Centers for Medicare & Medicaid Services (CMS), the agency within HHS that oversees the Medicaid program, to offer caregiver support services, including respite care, through an HCBS waiver program.²⁶ However, HCBS waivers allow states to choose—and limit—the populations and individuals eligible to receive these services.²⁷ As of Fiscal Year 2018, all states served people with intellectual or developmental disabilities through their Medicaid programs, but not all

²⁴According to officials from the Marine Corps EFMP, dependents with profound needs are those in Level 4 of the level of need rubric, and families with moderate needs are those in Level 3.

²⁵See DOD, *Report on Implementation of Section 582 of the William M. (Mac) Thornberry National Defense Authorization Act for Fiscal Year 2021, Public Law 116-283* (Arlington, VA: Nov. 22, 2021).

According to DOD, the implementation of the standard number of hours and eligibility determination process requires a phased-in approach that is essential to a seamless execution across the military branches, enabling the proper communication of the changes to families.

²⁶State Medicaid HCBS waiver programs may offer a variety of support services such as training, peer support, home modifications, transportation, and payments to unrelated live-in caregivers.

²⁷For states providing HCBS under section 1915(c) waiver authority, the number of waivers averages five per state and ranges from one to 11, depending on the number of populations served and how the state groups those populations. Some states provide these services through other authorities.

states provided services for children who are medically fragile or technology dependent through these programs.²⁸ (See appendix IV for a discussion of HCBS waiver programs and caregiver support services offered in seven selected states with a significant military population.)

Further, states' ability to cap HCBS waiver enrollment can result in wait lists when the number of people seeking services exceeds the number of waiver slots available. For example, a national survey of HCBS waiver programs found that in 2018 the waiting period for waiver services averaged 39 months across all waivers with waiting lists, with substantial variation by target population ranging from 1 month for a waiver targeting people with HIV/AIDS to 71 months for waivers targeting people with intellectual or developmental disabilities.²⁹ Such waiting periods present a unique challenge to military families who are subject to frequent relocations—typically occurring every 2 to 4 years—due to permanent change of station orders. As a result, the availability of caregiver support services through Medicaid varies by the state where the military family lives.

DOD Is Taking Steps to Address Some, but Not All, Barriers to Accessing Respite Care through the ECHO Program and Lacks Data to Identify Other Potential Barriers

DOD is taking steps to address two policy barriers to accessing respite care cited by TRICARE case manager groups and two stakeholder organizations representing military families and their children. Nonetheless, military family caregivers may face a barrier to accessing respite care due to miscommunication about ECHO program requirements. We also found that DOD lacks data on the extent of unmet need for respite care that would help it identify and address other potential barriers to respite care.

²⁸Medically fragile and technology dependent children can be ventilator-dependent, have tracheostomies, or have central IV lines, and require extensive care and services.

²⁹MaryBeth Musumeci, Molly O'Malley Watts, and Priya Chidambaram, *Key State Policy Choices about Medicaid Home and Community-Based Service, Issue Brief: 2018 Data Update* (San Francisco, Calif.: Henry Kaiser J. Kaiser Family Foundation, 2020).

DOD Is Taking Steps to Address Some, but Not All, Barriers to Accessing Respite Care through TRICARE's ECHO Program

Eliminating the requirement for a concurrent ECHO benefit. In August 2018, DOD began taking steps to eliminate the TRICARE requirement that, in order to qualify for respite care benefits, ECHO enrollees had to receive a concurrent benefit, such as incontinence supplies or Applied Behavioral Analysis services that month. According to three groups of TRICARE case managers and two stakeholder organizations we interviewed, this requirement presented a barrier to caregivers receiving respite care. The case manager groups explained this is a barrier because certain enrollees do not qualify for—or do not have a need for—other ECHO benefits. For example, two case manager groups reported ECHO families often use incontinence supplies or autism therapy as concurrent benefits, and when children ages 3 and above no longer need incontinence supplies, the caregiver loses eligibility for the respite care benefit.³⁰ Under a final rule issued in August 2021, DOD eliminated the concurrent benefit requirement.³¹

Increasing ECHO respite care hours. In response to the William M. (Mac) Thornberry NDAA for Fiscal Year 2021, DOD is taking steps to increase the number of allowable hours of respite care to 32 per month.³² DHA officials stated that the department has to study the budgetary effect of this change and plans to issue notice of proposed rulemaking later in 2022, and to complete rulemaking by 2025. As stated previously, DOD policy currently limits ECHO respite care benefits to 16 hours per month.³³ Three TRICARE case manager groups and two stakeholder organizations

³⁰ECHO may cover incontinence supplies or diapers for enrollees age 3 and older who are incontinent as a result of spinal, neurologic and/or mobility issues.

³¹DOD issued a proposed rule to eliminate the concurrent benefit on August 17, 2018 and the final rule eliminating the requirement on July 9, 2021. 83 Fed. Reg. 41026 (2018); 86 Fed. Reg. 36213 (2021) (codified at 32 C.F.R. § 199.5).

³²Pub. L. No. 116-283, § 704, 134 Stat 3388, 3687 (2020).

³³The 16 hours must be used in a single month and cannot be carried over. See 32 C.F.R. § 199.5(c)(7) (2020).

we interviewed told us that the hours available through ECHO's respite care benefit were a challenge, with case manager groups stating that the providers available through TRICARE-authorized home health agencies (HHA) are often not available or interested in such a limited number of hours of care. For example, one case manager group noted that even if they can find a provider to provide respite care, the provider may subsequently stop providing respite services if they are offered a position with more hours.

Miscommunication on the requirements for accessing ECHO respite care. We found DHA officials miscommunicated the requirements for accessing ECHO respite care to EFMP officials, who help families navigate and access available resources, including respite care. This miscommunication creates a potential barrier to accessing ECHO respite care to the extent that eligible caregivers do not seek this care because of the incorrect information. Specifically, during two EFMP standardization meetings that DHA officials attended in 2021, DHA officials informed EFMP officials from all four military branches that having another adult present during the provision of respite care was an ECHO program requirement. EFMP officials from three military branches stated that respite care is not provided as intended when there is a requirement for an adult to be in the home. A 2021 Congressional report stated that respite care should enable caregivers to attend to their own physical and emotional well-being, for example by participating in activities outside the home. Consequently, EFMP officials from one military branch stated that the requirement effectively renders the respite care benefit unusable for eligible families, potentially reducing the likelihood that caregivers will access this important benefit.

When asked about requirements for accessing ECHO respite care, DHA officials who oversee TRICARE's ECHO program told us that requiring another adult to be present during the provision of this care is not a TRICARE requirement. Instead, they noted that some HHAs may impose such a requirement due to liability issues and concern for the dependent's safety during the provision of respite care, but were unsure how big a barrier this is. An official from the National Association for Home Care & Hospice reported that this was not a common practice among its members that provide respite care services. Moreover, none of the six groups of TRICARE case managers we interviewed (who coordinate the ECHO respite care benefit) understood this to be an ECHO requirement or reported encountering this practice.

According to GAO's internal control standard for information and communication, management should communicate quality information throughout the entity and across reporting lines to enable personnel to perform key roles in achieving objectives.³⁴ By addressing the miscommunication of TRICARE's requirements for accessing ECHO respite care, such as by communicating in writing to EFMP officials that there is no TRICARE requirement that another adult remain in the home in order to access this care, DHA could help ensure that EFMP staff have a correct understanding of the access requirements. This, in turn, could help improve access to this important benefit for caregivers.

DOD Lacks Data to Identify Other Potential Barriers to Accessing Respite Care

DOD does not currently collect data on unmet need—that is, data on the number of caregivers who try to obtain respite care but are unable to do so. According to DHA officials, there are no network adequacy requirements for this benefit, and contractors are not required to collect or report any data on unmet need for respite care.³⁵ Even so, TRICARE managed care support contractors voluntarily collect some limited information on unmet need for their own internal purposes. According to contractor data, in 2021, less than 2 percent of caregivers of ECHO enrollees obtained an authorization to receive respite care (341 of out of about 26,000) and only about half of those who obtained an authorization (175 out of 341) ultimately utilized this benefit.³⁶ However, neither contractor was able to report to GAO the reasons why caregivers were not using this benefit. All six groups of TRICARE case managers we interviewed reported that the limited use of respite services is partially driven by difficulty identifying providers who are employed by TRICARE-authorized HHAs, who will provide respite care to ECHO enrollees, but

³⁴See [GAO-14-704G](#).

³⁵Network adequacy requirements specify that contractors have a sufficient number and mix of providers to satisfy the needs of enrollees.

³⁶These data contained some other information about the enrollees authorized to receive ECHO respite care. For example, one contractor collects information on enrollees for whom case managers were unable to identify a respite care provider—including the enrollee's state of residence and qualifying condition—while the other uses an internal spreadsheet to track which HHAs in its region are unable to provide respite care to enrollees.

the extent to which this is the case is unclear as the contractor data do not indicate why caregivers of enrollees did not use the benefit.³⁷

DHA lacks performance measures for TRICARE's ECHO program or a similar source of data that provides information on why eligible beneficiaries are not seeking or utilizing ECHO respite care. Developing such measures—or implementing an alternative means to collect data on the unmet need for ECHO respite care—would be consistent with federal internal control standards for information. Under these standards, agencies should identify and collect the information needed to ensure the agency can meet its program objectives—such as providing respite benefits through the ECHO program to all eligible enrollees in need of the benefit.³⁸

In contrast, DOD is taking steps to collect data on unmet need for respite care delivered through each military branch's EFMP. As part of its EFMP standardization effort, OSN officials stated that they developed performance measures to help them determine why a caregiver is not receiving respite care through the EFMP and to identify the root causes of unmet need. According to OSN officials, the performance measures will allow OSN to determine if, for example, a branch's EFMP may be facing a respite provider shortage because it is competing with other agencies that also hire respite care providers. With data on the extent of unmet need for ECHO respite care, DHA could assess whether, or to what extent, potential barriers to respite care are actual barriers to care.

In addition, TRICARE case managers we interviewed also said one potential barrier to obtaining respite care providers for ECHO enrollees are DOD policies that limit respite care providers to those employed by

³⁷In 2018, we reported on a national workforce shortage of home health and personal care providers, among the providers who may provide respite care. We also reported challenges recruiting and retaining Medicaid providers available to provide home-based care due to low pay and providers traveling far distances, especially in rural or remote areas. See GAO, *Medicaid Home- and Community-based Services: Selected States' Program Structures and Challenges Providing Services*, [GAO-18-628](#) (Washington, D.C.: Aug. 30, 2018). In addition, a national survey in 2021 found that direct care workforce shortages worsened in many states during the pandemic. See Kaiser Family Foundation, *State Medicaid Home & Community-Based Services (HCBS) Programs Respond to COVID-19: Early Findings from a 50-State Survey* (San Francisco, CA: Aug. 10, 2021).

³⁸[GAO-14-704G](#).

TRICARE-authorized HHAs.³⁹ Case manager groups and advocacy groups reported that the providers available through TRICARE-authorized HHAs are often not available or interested in providing a limited number of hours of care from ECHO.⁴⁰ Skilled providers, such as registered nurses and nursing assistants are in high demand in other clinical settings, particularly during the COVID-19 pandemic.

Furthermore, representatives from one group of TRICARE case managers and one advocacy group we interviewed stated that the providers employed by HHAs may not have the appropriate skill set to serve children on the autism spectrum, who comprised at least two-thirds of ECHO enrollees with a known diagnosis in 2021. Advocacy groups and TRICARE case managers noted that working with individuals along the autism spectrum may require special skills, such as training in order to de-escalate behavior or manage sensory overload. Representatives from two case manager groups across both TRICARE managed care support contractors and one advocacy group suggested that other providers, such as behavioral therapists or special education teachers, may be better suited than a registered nurse or certified nursing assistant to provide respite care to children with autism.⁴¹

If DOD had data on the extent of unmet need for ECHO respite care, it could assess the extent to which the requirement for respite care to be provided by TRICARE-authorized HHAs contributes to unmet need for ECHO respite care for dependents with autism. It could also identify strategies for increasing access to this care, if necessary. For example, information on the qualifications and locations of the respite care providers delivering care to ECHO enrollees may inform DOD on the extent to which the TRICARE HHAs are able to meet the needs of this

³⁹According to CMS, an HHA is an agency primarily engaged in providing skilled nursing services and other therapeutic services; has policies established by a group of professionals including one or more physicians and one or more registered professional nurses to govern the services it offers; and provides for supervision of above-mentioned services by a physician or registered professional nurse.

⁴⁰TRICARE policy requires that all ECHO respite care services are provided only by Medicare or Medicaid certified HHAs who have a valid agreement to participate in the TRICARE program in effect at the time of services.

⁴¹TRICARE approves the following providers for applied behavioral therapy for children with autism: Board Certified Behavior Analyst, Board Certified Behavior Analyst Doctorate, or other TRICARE authorized provider who practices within the scope of his or her state licensure or state certification.

population.⁴² Doing so would also enable DHA to track whether the steps the department is already taking, such as expanding the number of allowable monthly respite care hours, will increase caregivers' access to this care in the future.

Conclusions

Support services, such as respite care, are of particular importance to caregivers in military families with special needs. These families encounter challenges with accessing and maintaining consistent support services due to their frequent moves within the United States and to overseas installations. DOD provides caregiver support services—including respite care—through TRICARE's ECHO program as well as through each military branch's EFMP. However, despite recent and ongoing efforts to improve access to respite care, we found an additional barrier caregivers may face to accessing this care. Specifically, we found that DHA officials miscommunicated to EFMP staff a requirement that another adult remain in the home during the provision of ECHO respite care. This may create an access barrier, as EFMP staff from one military branch reported that the requirement effectively renders the respite care benefit unusable for eligible families. DHA could address this incorrect information by communicating in writing to each military branch's EFMP that there is no TRICARE requirement that another adult remain in the home in order to access ECHO respite care. In addition, because DOD does not collect data on unmet need for respite care, it is not able to identify other potential barriers to accessing this care. By establishing a process to collect and analyze data regarding the utilization of respite care among ECHO enrollees, DOD could assess the extent of unmet need and identify strategies for overcoming barriers to increase access to respite care.

Recommendations for Executive Action

We are making two recommendations to DOD.

The Director of the Defense Health Agency should communicate in writing to each military branch's EFMP that there is no TRICARE requirement that another adult remain in the home in order to access

⁴²DHA and the managed care support contractors both reported that there are no specific network adequacy requirements for the ECHO program.

ECHO respite care and determine if additional training is needed to inform EFMP staff on ECHO program requirements. (Recommendation 1)

The Director of the Defense Health Agency should collect and analyze data on the utilization of respite care among ECHO enrollees to include reasons why caregivers do not utilize this benefit, and use these data to help ensure it is providing needed respite care by, for example, helping DHA assess the extent of unmet need and identifying strategies for overcoming barriers to access to respite care. (Recommendation 2)

Agency Comments

We provided a draft of this report to DOD, HHS, and VA for comment. In its written comments, reproduced in appendix V, DOD concurred with both of our recommendations. To address the first recommendation, DHA plans to update the TRICARE Policy Manual to clarify that another adult is not required to remain in the home in order to access ECHO respite care. However to fully address this recommendation, as noted in the report, DHA must communicate this policy manual update to EFMP staff and also determine if additional training is needed on ECHO program requirements. To address our second recommendation, by the end of 2022, DHA plans to evaluate the feasibility of various options for data collection in order to formulate strategies to improve access to ECHO respite care. According to DOD, the timeline for implementing this data collection and analysis will depend on the strategy approved by DHA. DOD, HHS, and VA also provided technical comments that we incorporated as appropriate.

We are sending copies of this report to the Secretaries of Defense, Health and Human Services, and Veterans Affairs, and appropriate congressional committees. In addition, the report will be available at no charge on the GAO website at <http://www.gao.gov>.

If you or your staff have any questions about this report, please contact Sharon M. Silas at (202) 512-7114 or silass@gao.gov. Contact points for our Offices of Congressional Relations and Public Affairs are on the last page of this report. GAO staff who made major contributions to this report are listed in appendix VI.

A handwritten signature in black ink, appearing to read "Sharon Silas". The signature is written in a cursive, flowing style.

Sharon M. Silas
Director, Health Care

Our objectives for this report were to 1) describe respite care and other key services for supporting caregivers that are available to active duty military families through ECHO and other programs; and 2) examine

Appendix I: Objectives, Scope, and Methodology

barriers military families may face when seeking to access respite care through ECHO and other programs, and actions the Department of Defense (DOD) has taken to address those barriers.

To describe respite care and other key services for supporting caregivers, we reviewed documentation on leading practices for supporting caregivers, including for the Department of Veterans Affairs' (VA) caregiver program for veterans, and the RAISE Family Caregiving Advisory Council's initial report to Congress on caregiver supports.¹ We also interviewed representatives from 10 stakeholder organizations offering a range of perspectives on caregiver supports, including four advocacy groups, three provider groups and three national associations of state organizations. In these interviews, we obtained stakeholder perspectives on which services are important to supporting caregivers. (See Table 2.)

Table 2: Stakeholder Organizations Interviewed to Identify and Describe Key Caregiver Support Services

Organization	Type	Description
Access to Respite Care and Help National Respite Network and Resource Center	Advocacy group	Advocates for the development of quality respite programs and helps families locate respite services in their communities through a network of more than 4,000 respite and crisis care providers.
ADvancing States	National association of state organization	Provides support to its members—56 state and territorial agencies on aging and disabilities and long-term services—on policy areas that include caregiver supports.
American Network of Community Options and Resources	Provider group	Represents more than 1,800 organizations employing professionals who serve individuals with intellectual and developmental disabilities.
Autism Society	Advocacy group	Advocates for the autism community and provides education and other resources to its 120,000 members and supporters.

¹See RAISE Family Caregiving Advisory Council, *Recognize, Assist, Include, Support, & Engage (RAISE) Family Caregivers Act, Initial Report to Congress* (Washington, D.C.: Administration for Community Living, Sept. 22, 2021), accessed Mar. 9, 2022, <https://acl.gov/RAISE/report>.

Appendix I: Objectives, Scope, and Methodology

Organization	Type	Description
Easterseals	Provider group	Provides home- and community-based services to more than 1.5 million individuals and families with special needs that enhance their quality of life, such as speech therapy and respite care.
National Association for Home Care & Hospice	Provider group	Represents the nation’s 33,000 home care and hospice organizations and provides information to help its members maintain high quality of care.
National Association of Medicaid Directors	National association of state organizations	Represents and supports Medicaid leaders in 50 states, the District of Columbia and U.S. territories in their efforts to deliver high value services to the people served by Medicaid and the Children’s Health Insurance Program.
National Association of State Directors of Developmental Disability Services	National association of state organizations	Represents the agencies in 50 states, the District of Columbia and Puerto Rico that provide services to children and adults with intellectual and developmental disabilities and their families.
National Military Families Association	Advocacy group	Advocates on behalf of 2.8 million military family members to federal elected officials as well as to the Department of Veterans Affairs, and offers support programs for military families.
TRICARE for Kids Coalition	Advocacy group	Is a coalition of 15 organizations advocating for the health needs of the more than 2 million children of military families covered by TRICARE, including those with special needs.

Source: GAO analysis of information on each organization’s website. | GAO-22-105204

To determine which of the key caregiver support services identified by stakeholder organizations are available to active duty military families through ECHO and other programs, we reviewed ECHO program documentation, including TRICARE program policies and benefits information. We also interviewed officials within the Defense Health Agency (DHA)—the office within DOD responsible for managing the TRICARE health care program, including ECHO—to discuss the ECHO program and the services available to program enrollees. To obtain information about the process for obtaining ECHO services, we interviewed three groups of TRICARE case managers from each of the two managed care support contractors responsible for coordinating benefits for ECHO enrollees.² We also obtained information about the caregiver support services available to military families through DOD’s Exceptional Family Member Program (EFMP) and interviewed officials from each military branch’s EFMP—the Air Force, Army, Navy, and Marine Corps. Moreover, we interviewed officials from DOD’s Office of

²We interviewed TRICARE case managers from Humana Military Healthcare Services and Health Net, who are responsible for coordinating benefits for ECHO enrollees in the United States. The ECHO program is also available to military families living outside of the U.S. through the TRICARE Overseas Program, but certain ECHO benefits—including respite care—are unavailable.

Special Needs (OSN)—the office responsible for overseeing the EFMP across all military branches.³

In addition, we reviewed information on Medicaid programs and also obtained and reviewed documentation from seven selected states regarding the caregiver support services available through each state’s Medicaid program. We selected these seven states based on the number of active duty service members residing there. Together, these seven states accounted for approximately 60 percent of all active duty service members stationed in the United States, and include all states with greater than 50,000 service members, as of December 2020. In addition to obtaining relevant documentation, we interviewed Medicaid officials from these selected states to gather additional information about the caregiver support services available through their Medicaid programs, variation in available services across these states, as well as challenges in meeting demand for respite services. (See Table 3.)

Table 3: States Selected to Discuss Caregiver Support Services Available through Medicaid, by Number of Active Duty Service Members as of December 2020

State	Number of active duty service members
California	166,261
Virginia	130,607
North Carolina	103,260
Texas	119,598
Florida	70,032
Georgia	69,955
Washington	59,534

Source: Department of Defense data. | GAO-22-105204

To examine barriers military families face to accessing caregiver support services and actions DOD has taken to address them, we reviewed DOD’s TRICARE program policy manual and program regulations for current information regarding ECHO program benefits, including respite

³Active duty military personnel who have family members with special medical or educational needs must enroll in DOD’s EFMP, which provides family support and other services to these families before, during and after relocation. Each military branch is responsible for implementing DOD program requirements for its EFMP.

DOD’s OSN is responsible for developing, implementing, and overseeing a uniform policy for supporting military families with special needs. In addition, OSN is responsible for collaborating with the military branches to standardize EFMP components across all military branches and for monitoring the EFMP.

care. In addition, we interviewed case managers from both TRICARE managed care support contractors to discuss any challenges they have encountered when coordinating services for ECHO enrollees. We also interviewed officials from DHA to discuss any barriers military families may face to accessing ECHO benefits and steps that DOD has taken to address them. To determine any barriers military families face when accessing EFMP caregiver support services, we interviewed officials from DOD's OSN and officials from the EFMP programs for the Army, Navy, Marine Corps, and Air Force. We also discussed the extent to which TRICARE and the EFMP programs communicate and coordinate caregiver support services for eligible military families, including respite care, with officials from each of these DOD offices. We assessed whether DOD's provision of respite care benefits was consistent with relevant federal internal control standards. Specifically, the information and communication component of internal control was significant to this objective.

Finally, we obtained and analyzed DOD data on the ECHO program for fiscal years 2019 through 2021. These data included the number of individuals enrolled in ECHO and their primary medical diagnoses, as well as the number of enrollees authorized for the ECHO respite care and the number of authorized enrollees utilizing ECHO respite care. We conducted interviews with DOD officials responsible for collecting and providing these data and determined it was reliable for providing a descriptive summary of ECHO program enrollment and utilization of its respite care benefit. We also requested from DOD any available data on unmet need for the ECHO respite program (e.g., the number of ECHO enrollees authorized to receive respite care who did not receive respite care services); however, DOD did not have such data to provide.

The assistance provided by family caregivers can enable veterans to achieve a better quality of life and contribute to their rehabilitation and recovery. VA's Program of Comprehensive Assistance for Family

Appendix II: The Department of Veterans Affairs' (VA) Program of Comprehensive Assistance for Family Caregivers

Caregivers (PCAFC) offers enhanced clinical support for caregivers of eligible veterans who are seriously injured.¹ For caregivers to be eligible for services, they must be providing in-home care for veterans who have a service-connected qualifying injury either on or after September 11, 2001, or before May 7, 1975.² PCAFC is not available to active duty service members and their dependents, unless the service member is undergoing medical discharge from the Armed Forces.

To be eligible for the program, the veteran must, among other things:

1. Have a single or combined service-connected disability rating of 70 percent or more, and
2. Need in-person personal care services for a minimum of 6 continuous months based on either:
 - a. An inability to perform an activity of daily living, or

¹See 38 U.S.C. § 1720G. For the purposes of our report, the term "caregiver" refers to the individual that VA approved to serve as the veteran's primary caregiver. A veteran may have up to three approved caregivers at a time under the program, see 38 C.F.R. § 71.25(a)(1), but only the primary caregiver is eligible for the full range of services authorized by the statute. 38 U.S.C. § 1720G(a)(3)(A)(ii).

²Section 161 of the VA MISSION Act of 2018 expanded eligibility for the program to family caregivers of eligible veterans who incurred or aggravated a serious injury in the line of duty before September 11, 2001. Pub. L. No. 115- 182, Tit. I, § 161, 132 Stat. 1393, 1438 (2018). VA's final implementing rule — Program of Comprehensive Assistance for Family Caregivers Improvements and Amendments under the VA MISSION Act of 2018 — was effective October 1, 2020. 85 Fed. Reg. 46226 (July 31, 2020) (codified at 39 C.F.R. pt.71). As of October 2022, the program will be open to eligible veterans of all eras.

- b. A need for supervision, protection, or instruction; and
- 3. Be enrolled in the VA health care program.

To be an approved caregiver in the program, the applicant must be, among other things:

- 1. At least 18 years old; and
- 2. Either a spouse, son, daughter, parent, stepfamily member or extended family member of the veteran, or someone who lives full-time with the veteran or is willing to do so if designated as a family caregiver; and
- 3. Free of any determinations of abuse or neglect towards the eligible veteran; and
- 4. Able to meet certain other requirements related to caregiver education and training.

Once eligibility and other requirements are met, the veteran's primary caregiver may receive a monthly financial stipend based on the level of caregiver support the veteran needs. The program also offers other types of assistance to caregivers, including respite care, referral services, peer support, and some mental health services. In addition, primary caregivers may be eligible for health insurance coverage through the Civilian Health and Medical Program of the Department of Veterans Affairs if they have no other coverage.

Caregivers found to be eligible for PCAFC may enroll in the Program of General Caregiver Support Services (PGCSS) that is accessible to caregivers who provide personal care services to covered veterans enrolled in VA healthcare. Through PGCSS, an individual providing personal care services to a covered veteran may access peer support mentoring, skills training, coaching, telephone support, online programs, and referrals to other caregiver resources. Taken together, PCAFC and PGCSS comprise the VA Caregiver Support Program. For a description of selected support services available to caregivers enrolled in the VA Caregiver Support Program, see Table 4.

Appendix II: The Department of Veterans Affairs' (VA) Program of Comprehensive Assistance for Family Caregivers

Table 4: Selected Support Services Available to Caregivers through the Department of Veterans Affairs (VA) Caregiver Support Program

Key caregiver support services^a	Examples
Respite care	Respite care is offered for veterans to help alleviate caregiver burden and may include, among other things, in-home care or short-term institutional stays, such as at a nursing home. Primary family caregivers are eligible for at least 30 days of respite care per year.
Peer support	Peer Support Mentoring is a support program where caregiver mentors are matched with caregivers who are interested in talking with more experienced caregivers. The program was developed to strengthen relationships between caregivers, to provide an opportunity for networking and to empower caregivers to help one another.
Information and referral	VA National Caregiver Support Line is a toll-free information and referral number for caregivers, family members, friends, veterans, and community partners to contact for information related to caregiving and available supports and services.
Training	Building Better Caregivers is an online workshop—with six weekly self-paced lessons, facilitator guidance, group support and access to an alumni community for program graduates—that helps caregivers provide better care to the veteran and learn how to manage their own emotions, stress, and physical health.
Supplemental services	
Resources for caregiver health	Resources for Enhancing All Caregivers Health (REACH) VA provides caregivers support with stress and mood management techniques, understanding the recipient's condition, and care planning. The program provides education, a focus on safety for the patient, and support for the caregiver through individualized sessions over the course of two to three months.
Financial support	VA provides a monthly stipend to a primary family caregiver of an eligible veteran with moderate and severe needs. Stipend payments are based, among other things, on the amount and degree of personal care services provided to the eligible veteran by the primary family caregiver.

Source: GAO review of VA information. | GAO-22-105204

Note: The Caregiver Support Program provides services and support to veterans and caregivers through two programs: the Program of General Caregiver Support Services (PGCSS) and the Program of Comprehensive Assistance for Family Caregivers (PCAFC). The PGCSS is accessible to caregivers who provide personal care services to covered veterans enrolled in VA health care. Caregivers who enroll in PGCSS have access to education and training, including courses at local VA medical centers. In addition, caregivers can participate in support services and take advantage of VA home and community based care, as appropriate. By contrast, PCAFC is a program of enhanced clinical support for caregivers of eligible Veterans who are seriously injured.

^aThese services were among the key caregiver support services identified by the 10 stakeholder organizations we interviewed.

Appendix III: Six Key Caregiver Support Services Identified by Stakeholder Organizations

Representatives from 10 stakeholder organizations that we interviewed identified six key services as necessary, or important, for caregiver support. The table below describes each one and provides examples or

Appendix III: Six Key Caregiver Support Services Identified by Stakeholder Organizations

stakeholder comments.¹

Table 5: Key Caregiver Support Services Identified by Stakeholder Organizations

Caregiver support service	Description	Example or stakeholder comment
Respite care	Planned or emergency care provided to an individual with special needs—through which caregivers can receive temporary relief from their caregiving responsibilities—was identified by all 10 stakeholder organizations. Respite care may be provided in a variety of settings, including homes, adult day care centers, or residential care facilities.	Two stakeholder organizations noted that respite is the benefit that caregivers need the most, while another noted that the need is most acute for families with children with behavioral challenges and autism. Three stakeholder organizations emphasized that respite providers need prior training or experience working with the intellectual and developmental disabilities population.
Information and referral	Services that inform caregivers about, and help connect them with, available programs appropriate to their needs were identified by seven of the 10 stakeholder organizations.	Military OneSource is a Department of Defense-funded program that offers online information and resources, and connects service members to programs, services, and products developed for military life. This includes special needs consultants who can help military members navigate and understand the benefits and resources available to families with special needs.
Training	Training to help caregivers better manage their responsibilities and cope with the stress of caregiving was identified by six of the 10 stakeholder organizations	Easterseals, a service provider for people living with disabilities including autism, offers a 2-week Onsite Parent Training program that teaches the entire family how to best understand and support their child. Under the coaching and direction of an autism training specialist, parents attend daily workshops and conduct therapy sessions with their child.

¹For additional information on the stakeholder organizations interviewed see appendix I.

Appendix III: Six Key Caregiver Support Services Identified by Stakeholder Organizations

Caregiver support service	Description	Example or stakeholder comment
Care coordination	Individuals or groups that help arrange a patient's health care services was identified by six of the 10 stakeholder organizations.	In the Family Support component of its Exceptional Family Member Program (EFMP), the Navy has designated EFMP liaisons who provide system navigation, information and referral services, and non-medical case management. EFMP liaisons link families with available military, national, local, and community resources.
Peer support	Pairing individuals new to a caregiving situation with someone who has previous experience in the role was identified by six of the 10 stakeholder organizations.	Three stakeholder organizations noted that caregivers use peer support to share relevant information or access services. Specifically, two stakeholder organizations stated that the best information is at the grassroots level with families who know the system firsthand and understand what is available. Currently, military families may access such peer support groups as the Military Special Needs Network and Exceptional Families of the Military. Two stakeholder organizations noted the importance of peer support for the caregiver's mental health.
Supplemental services	Supplemental services that support caregivers in caring for dependents at home were identified by five stakeholder organizations.	Examples include home modifications, transportation, and medical or incontinence equipment.

Source: GAO analysis of interviews with 10 stakeholder organizations. | GAO-22-105204

The six key caregiver support services identified by stakeholders largely align with the caregiver support model described in the RAISE Family Caregiving Advisory Council's 2021 initial report to Congress. Specifically, the report advocates a comprehensive direct support model for caregivers that offers multiple, flexible service options that are responsive to caregiver needs as they change over time.

As an example of an existing federal program that shows promise for holistically supporting the needs of family caregivers, the report cites the VA Caregiver Support Program, which includes the Program of Comprehensive Assistance for Family Caregivers. VA offers an array of services to eligible family members and friends who care for veterans, including on-line courses, face-to-face classes, telephone support, and peer support. Every VA medical center has dedicated program staff who assist with information and referrals to these programs.

Medicaid—a joint federal-state financing program for health care services for certain low-income individuals, including individuals with disabilities and administered at the federal level by the Centers for Medicare &

Appendix IV: Caregiver Support Services Available through State Medicaid Home-and Community-based Waivers in Seven States

Medicaid Services (CMS) within the Department of Health and Human Services (HHS)—is the nation’s primary payer of long-term services and supports, including home- and community-based services (HCBS). HCBS cover a wide range of services and supports to help individuals remain in their homes or live in a community setting, including personal care services, day treatment, and home health aide services. In addition, HCBS may cover support services for caregivers, such as respite care, as well as case management services to coordinate services and supports that may be provided from multiple sources.

State Medicaid programs may offer HCBS through Medicaid “waiver” programs to all Medicaid-eligible individuals who meet the state’s eligibility criteria for the waiver including, at the state’s option, individuals who typically would not otherwise qualify for Medicaid because of their income or asset levels.¹ Substantial variation exists across states regarding the eligibility criteria, enrollment caps, and populations served through each HCBS waiver. States also have flexibility in the number of slots available for each waiver, which can influence the wait time before individuals may receive HCBS services.

Military families may qualify for caregiver support services through Medicaid waiver programs depending on the eligibility criteria and types of services each state offers. However, military families may face difficulty

¹States, generally, must offer the same Medicaid benefits throughout the state and to every eligible individual. However, states may obtain approval from CMS under section 1915(c) of the Social Security Act to “waive” these requirements and offer Medicaid-funded services to certain populations and only in specific areas, and to limit the number of people served. Section 1915(c) waivers are the primary means by which states provide HCBS to Medicaid beneficiaries.

**Appendix IV: Caregiver Support Services
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accessing these services in a timely manner for two reasons: the frequency of moves between states, and the variation among the HCBS offered by each state's Medicaid program:

- Service members relocate frequently, generally moving every 3 years if in the Army, Marine Corps, and Navy, and every 4 years if in the Air Force. Medicaid enrollment does not transfer between states, therefore every time a military family relocates to a different state, the family would be required to enroll in the state's Medicaid program. In addition, because Medicaid eligibility is based on residency, enrollment cannot begin until the family has moved into the state and may take between 45 and 90 days, according to Medicaid program officials in two states. States generally require the beneficiary needing services to complete a functional assessment to determine eligibility to access the applicable waiver program.
- To manage costs, state HCBS waiver programs can limit expenditures such as by limiting enrollment. Thus, even if a military family is determined to be eligible for HCBS based on a dependent's qualifying condition, the program may have a waiting list. As of June 2021, of the 36 HCBS waivers in the seven case study states we reviewed, 17 provided respite care for caregivers of dependents with ECHO eligible conditions, and only nine of those had slots available. Of the remaining waiver programs, Medicaid officials reported wait lists for families enrolling in the waiver program in nearly all states with officials from one state reporting a wait of up to 15 years for HCBS.² See Figure 3 for the availability of caregiver support services.

²North Carolina reported reserving five slots specifically for military families. California and Texas reported holding a military family's place on a waiting list for their return to the state, if the beneficiary is still eligible for waiver services.

**Appendix IV: Caregiver Support Services
Available through State Medicaid Home- and
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Figure 3: Medicaid Home- and Community-Based (HCBS) Waiver Programs with Caregiver Support Service Availability as Reported by Selected States, June 2021

	Waiver name ^a	Population served	Maximum enrollment (for one year)	Slots available	Caregiver support services				
 California	HCBS Waiver for Californians with Developmental Disabilities	Autism, Intellectual disability, Developmental disability (IDD)	145,000	2,142	▲	■	●	★	⬡
	HCBS Community Based Alternatives Waiver	Medically fragile, Technology dependent	8,974	2,903	▲	■	●	★	⬡
	California Self-Determination Program Waiver for Individuals with Developmental Disabilities	Autism, IDD	2,500	2,170	▲	■	●	★	⬡
 Florida	Developmental Disabilities Individual Budgeting Waiver	Autism, IDD	37,742	0	▲	■	●	★	⬡
 North Carolina	Community Alternatives Program for Children	Medically fragile children	4,000	861	▲	■	●	★	⬡
	North Carolina Innovations	IDD	13,138	5 ^b	▲	■	●	★	⬡
 Texas	Medically Dependent Children Program	Medically fragile children	5,969	0	▲	■	●	★	⬡
	Home and Community-based Services Program	IDD	27,861	0	▲	■	●	★	⬡
	Deaf Blind with Multiple Disabilities	Developmental disability	355	0	▲	■	●	★	⬡
	Texas Home Living Program	IDD	5,654	0	▲	■	●	★	⬡
	Community Living assistance and Supports	Developmental disability	5,526	0	▲	■	●	★	⬡
 Virginia	Community Living Waiver	Autism, IDD	11,701	0	▲	■	●	★	⬡
	Family and Individual Support Waiver	Autism, IDD	3,593	0	▲	■	●	★	⬡
 Washington	Children's Intensive In-Home Behavioral Support	Autism, IDD	100	4	▲	■	●	★	⬡
	Basic Plus	Autism, IDD	10,274	268	▲	■	●	★	⬡
	Individual and Family Services	Developmental disability	6,500	296	▲	■	●	★	⬡
 Georgia	<i>As of June 30, 2021, none of Georgia's HCBS waiver programs were applicable to the ECHO population. However, eligible military dependents would be able to receive services through Georgia's Medicaid State Plan. Georgia's Medicaid State Plan does not include a caregiver respite benefit.</i>								

Slots available
No slots available
▲ Respite
 ■ Caregiver training
 ● Peer support
 ★ Home modifications
 ⬡ Travel

Source: GAO analysis of State reported Medicaid home- and community-based waiver data. | GAO-22-105204

**Appendix IV: Caregiver Support Services
Available through State Medicaid Home-and
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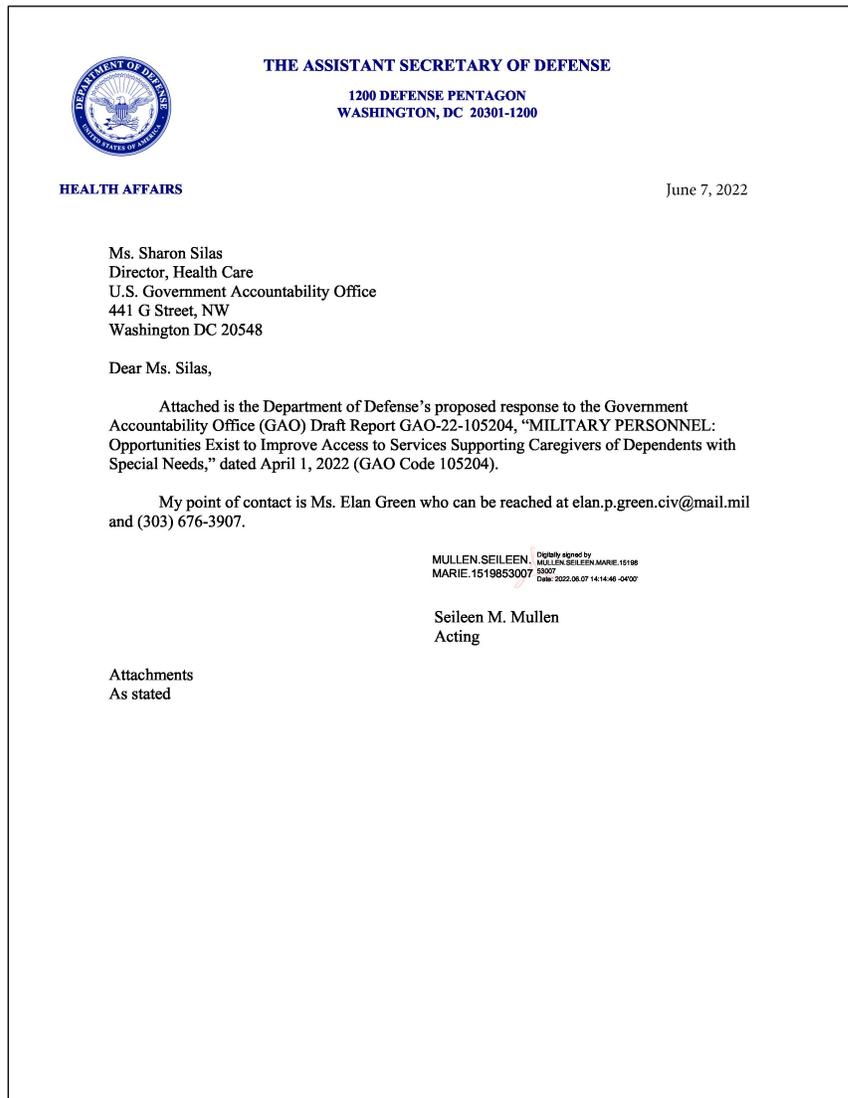
Notes: States were selected based on the highest number of active duty military members stationed in the state as of December 2020. Together, these seven states accounted for approximately 60 percent of all active duty service members stationed in the United States at that time.

^aIncluded are only those HCBS waiver programs approved under section 1915(c) of the Social Security Act that provide coverage for respite care and other support services for which caregivers of eligible Extended Care Health Option (ECHO) enrollees are likely to qualify. Some 1915(c) waiver programs were excluded because they are only available to adults 65 and older or for certain diagnoses, such as traumatic brain injury that generally do not apply to ECHO dependents. HCBS provided through other Medicaid coverage options are excluded.

^bNorth Carolina reserves five slots for qualified military families.

^cThere is no wait list for services under Virginia's Commonwealth Coordinated Care PLUS waiver.

Appendix V: Comments from the Department of Defense



**GAO DRAFT REPORT DATED APRIL 1, 2022
GAO-22-105204 (GAO CODE 105204)**

**“MILITARY PERSONNEL: OPPORTUNITIES EXIST TO IMPROVE ACCESS TO
SERVICES SUPPORTING CAREGIVERS OF DEPENDENTS WITH SPECIAL
NEEDS”**

**THE DEPARTMENT OF DEFENSE RESPONSES
TO THE GOVERNMENT ACCOUNTABILITY OFFICE RECOMMENDATIONS**

RECOMMENDATION 1: The Government Accountability Office (GAO) recommends the Director of the Defense Health Agency (DHA) should communicate in writing to each military branch’s Exceptional Family Member Program (EFMP) that there is no TRICARE requirement that another adult remain in the home in order to access Extended Health Care Option (ECHO) respite care and determine if additional training is needed to inform EFMP staff on ECHO program requirements.

DoD RESPONSE: The Department of Defense (DoD) concurs. The DHA will add language to the TRICARE manuals (i.e., the TRICARE program implementing instructions) clarifying that another adult is not required to remain in the home during the provision of ECHO respite care services.

IMPLEMENTATION DETAILS: DHA will complete a manual change request that adds a paragraph to the ECHO respite care manual language (TRICARE Policy Manual, Chapter 9, Section 12.1) clarifying ECHO respite care requirements. This clarification will provide written instruction to the TRICARE Managed Care Support Contractors that ECHO respite care does not require the presence of an adult (other than the clinician providing services) in order for such care to be covered under the ECHO benefit. We anticipate issuing clarified manual language by the end of Calendar Year 2022.

RECOMMENDATION 2: The GAO recommends that the Director, DHA, collect and analyze data on the utilization of respite care among ECHO enrollees to include reasons why care givers do not utilize this benefit, and use these data to help ensure it is providing needed respite care by, for example, helping DHA assess the extent of unmet need and identifying strategies for overcoming barriers to access to respite care.

DoD RESPONSE: DoD concurs. DHA will evaluate options for data collection, create and implement a plan to collect data, analyze the collected data, and submit recommendations based on the results of the analysis.

IMPLEMENTATION DETAILS: To accomplish this recommendation, DHA will evaluate the feasibility of various options for data collection (such as surveys, claims analyses, and creating requirements for the TRICARE Managed Care Support Contractors to collect specific data and provide detailed reports). The recommended data collection method(s) and

**Appendix V: Comments from the Department
of Defense**

implementation plan will be sent to the Director, DHA, (or designee where applicable) for approval. We estimate that our study of available options (*i.e.*, determining which data collection options are most feasible and practicable and presenting recommendations) will be complete by the end of Calendar Year 2022, with the timeline for data collection depending on the data collection methods that the Director approves. DHA will then analyze the collected data, assess gaps in access to high-quality respite care to the extent feasible, and formulate strategies with the purpose of improving access to ECHO respite care for eligible beneficiaries within the parameters of the TRICARE statute. Further, DHA will continue to work with the Military Services to coordinate EFMP programs with the ECHO program.

Text of Appendix V: Comments from the Department of Defense

Ms. Sharon Silas
Director, Health Care
U.S. Government Accountability Office
441 G Street, NW
Washington DC 20548

Dear Ms. Silas,

Attached is the Department of Defense's proposed response to the Government Accountability Office (GAO) Draft Report GAO-22-105204, "MILITARY PERSONNEL: Opportunities Exist to Improve Access to Services Supporting Caregivers of Dependents with Special Needs," dated April 1, 2022 (GAO Code 105204).

My point of contact is Ms. Elan Green who can be reached at elan.p.green.civ@mail.mil and (303) 676-3907.

Seileen M. Mullen
Acting

Attachments
As stated

GAO DRAFT REPORT DATED APRIL 1, 2022 GAO-22-105204 (GAO CODE 105204)

“MILITARY PERSONNEL: OPPORTUNITIES EXIST TO IMPROVE ACCESS TO SERVICES SUPPORTING CAREGIVERS OF DEPENDENTS WITH SPECIAL NEEDS”

THE DEPARTMENT OF DEFENSE RESPONSES

TO THE GOVERNMENT ACCOUNTABILITY OFFICE RECOMMENDATIONS

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DoD RESPONSE: DoD concurs. DHA will evaluate options for data collection, create and implement a plan to collect data, analyze the collected data, and submit recommendations based on the results of the analysis.

IMPLEMENTATION DETAILS: To accomplish this recommendation, DHA will evaluate the feasibility of various options for data collection (such as surveys, claims analyses, and creating requirements for the TRICARE Managed Care Support Contractors to collect specific data and provide detailed reports). The recommended data collection method(s) and implementation plan will be sent to the Director, DHA, (or designee where applicable) for approval. We estimate that our study of available options (i.e., determining which data collection options are most feasible and practicable and presenting recommendations) will be complete by the end of Calendar Year 2022, with the timeline for data collection depending on the data collection methods that the Director approves. DHA will then analyze the collected data, assess gaps in access to high-quality respite care to the extent feasible, and formulate strategies with the purpose of improving access to ECHO respite care for eligible beneficiaries within the parameters of the TRICARE statute. Further, DHA will continue to work with the Military Services to coordinate EFMP programs with the ECHO program.

GAO Contact:

Appendix VI: GAO Contact and Staff Acknowledgments

Sharon M. Silas (202) 512-7114 or silass@gao.gov

Staff Acknowledgments

In addition to the contact named above, Michael Zose (Assistant Director), Anne Hopewell (Analyst-in-Charge), Nathan Helman, Brienne Tierney, and Heather Tompkins made key contributions to this report. Also contributing were Sam Amrhein, Jacquelyn Hamilton, and Roxanna Sun.

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