

**United States Marine Corps
Exceptional Family Members:
How to Improve Access to
Health Care, Special Education,
and Long-Term Supports and Services
for Family Members with Disabilities**



National Council on Disability
November 28, 2011

National Council on Disability
1331 F Street, NW, Suite 850
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United States Marine Corps Exceptional Family Members: How to Improve Access to Health Care, Special Education, and Long-Term Supports and Services for Family Members with Disabilities

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National Council on Disability

An independent federal agency making recommendations to the President and Congress to enhance the quality of life for all Americans with disabilities and their families.

Letter of Transmittal

November 28, 2011

The President
The White House
Washington, DC 20500

Dear Mr. President:

The National Council on Disability (NCD) is pleased to submit the enclosed report, “United States Marine Corps Exceptional Family Members: How to Improve Access to Health Care, Special Education, and Long-Term Supports and Services for Family Members with Disabilities.” NCD conducted this study at the request of the Marine Corps, which has a longstanding commitment to providing support for its Families with disabilities. This report is based on a study conducted within the Marine Corps interviewing Marines and Families that have dependents that meet the requirements to qualify for the Exceptional Family Member Program (EFMP).

The lifestyle of the Marine Corps Family is challenging under the best of circumstances. Among the challenges that military Families face are separation from their extended families, Service Member absences, permanent changes of station moves, and the stresses of combat and noncombat deployments. These challenges are compounded for Families with disabilities, referred to in the Marine Corps as “Exceptional Family Members” (EFMs).

The Services have recently passed the marker of 10 plus years of armed conflict across the world, but most specifically in Afghanistan and Iraq. Multiple deployments to these theaters have increased stress on all military Families, but even more on those with EFMs.

The objectives for this study were to:

- 1) Document the experiences of USMC EFMP participants in accessing appropriate and effective services in health care, special education, related services, long-term supports, and services;
- 2) Identify barriers impeding access to appropriate resources and services; and
- 3) Develop recommendations to improve access.

NCD conducted focus groups and interviews of Caregivers, Family Members with disabilities, and service providers between January 2010 and March 2010 at Marine Corps Base Quantico, Camp Lejeune, and Camp Pendleton.

NCD findings indicate that EFMs and their Families face barriers that span the domains of health care, education, and long-term supports and services. Key findings include:

- For Caregivers, navigating the health, education, long-term services systems, and obtaining and maintaining disability-related services require

relentless hard work—a process they have to start over every time the Family moves. For some—particularly young parents, Families with more than one EFM, Families with a dependent with significant disabilities, parents who are themselves EFMs, and Families with a deployed sponsor—it can be an overwhelming prospect and can be so time-consuming that it becomes impossible for the spouse of an active-duty Marine to work outside the home.

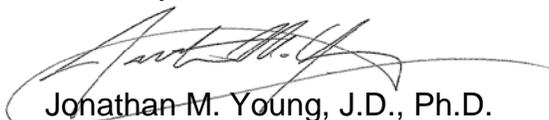
- Many Families lamented the lack of qualified health care specialists near their installations, and they struggle to obtain timely referrals and appointments and make long trips to medical specialists.
- For Family Members in need of special education services, having to make frequent moves to a new school system results in substantial gaps in critical education and therapeutic services.
- The lack of Medicaid portability across states is a significant barrier to obtaining necessary long-term supports and services for Families with EFM dependents. Each time the Family moves, they have to start over on a Medicaid waiver waiting list and often do not live in one place long enough to qualify. Tricare does not cover the same services provided under a Medicaid waiver.
- Many families are dependent on the disability-related services typically covered by ECHO, a Tricare supplemental insurance, and they worry about how they will pay for these services when they retire and ECHO is no longer available to them.

These findings reveal that prompt action must be taken to improve health, education, and long-term services for Marine Corps Families with EFMs. NCD commends the Marine Corps for making significant improvements to their EFM program during the time this study was being conducted (many of which are highlighted in this report). However, many of the changes necessary to improve the supports available to military Families with EFMs are beyond the control of the Marine Corps and may require statutory and regulatory changes to meet these needs.

NCD has concluded that far-reaching systemic changes are needed in our nation's health, education, and long-term service systems to address the significant barriers faced by EFMs. NCD thus seeks support from Congress, the military, and the Administration to build the critical federal partnerships necessary to effect systemic change and ensure that the men and women serving our country can do so knowing their Family Members with disabilities will have the supports and services they need.

NCD commends your Administration for focusing on the needs of military Families, particularly the launch of Joining Forces, and would welcome the opportunity to work with you on behalf of military Families with EFMs.

Sincerely,



Jonathan M. Young, J.D., Ph.D.
Chairman, National Council on Disability

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Executive Summary

U.S. Marine Corps (USMC) family members serve and sacrifice alongside their active-duty service members.

Among the challenges that military families face are separation from extended family, military member absences, permanent changes of station (PCS), and the stresses of deployment. For families that include members with disabilities, the challenges of this lifestyle are compounded. In addition to being a human concern, appropriate access to adequate supports and services for family members with disabilities can have far-reaching implications for force readiness and mission focus. The USMC's chief instrument for addressing the needs of USMC family members with disabilities is the USMC Exceptional Family Member Program (EFMP), established by the Marine Corps in 1990, through which it coordinates assignments and provides family support. Since 2008, at the behest of USMC leadership, EFMP has been expanded and enhanced, and the transformation of EFMP is ongoing.

At the request of the USMC, the National Council on Disability (NCD) conducted a study to systematically examine the challenges experienced by this segment of the USMC community and to identify steps toward ameliorating these challenges. The objectives for this study were to (1) document the experiences of USMC families with members with disabilities in accessing appropriate and effective services in health care, special education and related services, and long-term supports and services; (2) identify barriers impeding access to appropriate resources; and (3) develop recommendations to improve access.

NCD conducted focus groups and interviews of caretakers, family members with disabilities, and service providers between January and March 2010 at Marine Corps Base (MCB) Quantico, Camp Lejeune, and Camp Pendleton—three large USMC bases to which many EFMP families are assigned.

Findings

Exceptional family members (EFMs) and their families described barriers that span the domains of health care, education, and long-term supports and services. For caretakers, navigating the service systems and obtaining and maintaining disability-related services require relentless hard work. For some—particularly young parents, families with more than one EFM, parents who are themselves EFMs, and families with a deployed sponsor—it is an overwhelming prospect. Despite having health insurance, some families experience substantial unreimbursed costs, if not financial hardship, and the demands of caring for the family member with a disability can make it impossible for the caretaker to work outside the home.

Access to Health Care

Families that were successful at navigating the complex health care service and reimbursement systems often attributed their success, in large part, to the assistance of case managers, for example, through EFMP, Tricare, or Tricare Extended Care Health Option (ECHO). Most families, however, reported not having been assigned a case manager, not being able to access their case manager, or not knowing whether they were eligible for case manager services. Others reported that their Tricare case manager withheld information about how to get services covered. Some families benefited from the assistance of health care providers described as exemplary in assisting families to navigate the health care system.

Participants consistently said there is a dearth of nearby specialists (especially in behavioral health), requiring them to routinely travel long distances to obtain specialty care. Some families also described difficulties navigating Tricare processes, particularly for obtaining health care referrals. Many lamented the limitations of Tricare coverage—particularly coverage of applied behavior analysis (ABA) therapy, offered under ECHO, which falls short of the recommended standard of care.

Access to Special Education

Because bases with Department of Defense Education Activity (DoDEA) schools are the exception rather than the rule, USMC students frequently attend public schools. Parents described DoDEA schools as well-resourced and praised DoDEA's inclusive model for students with disabilities. Similarly positive remarks were made about Early Development Intervention Services (EDIS), a base program that feeds into the DoDEA system. Participants also mentioned valuable national-level civilian resources for advocacy and advocacy training within the educational environment—most notably Specialized Training of Military Parents (STOMP). Despite such resources, EFMP families encounter obstacles to special education-related services. With great regularity, parents described feeling that they must fight schools to secure disability-related resources for their children—a lengthy process that may not be resolved before a family has another permanent change of station. This can involve incurring legal fees that the family will not be reimbursed unless they see the case to a successful conclusion. Several parents and providers observed that schools and other educational facilities (including on- and off-base facilities) are not fully accessible to students with disabilities.

Access to Long-Term Supports and Services

Relatively few of the focus group participants had experience in this arena. For the most part, unlike health care and education, other than respite care, the military is not involved in the delivery of long-term supports and services, and USMC EFMs who need such resources must look to the civilian sector. The greatest barrier to long-term services raised by the study participants is the absence of Medicaid portability when USMC families move from state to state. It was also noted that adult EFMs currently lack access to services such as transportation for medical appointments and personal care attendants. These services are provided under Medicaid waivers; however, there can be multiyear waiting lists for waiver eligibility, and many military families do not live in one state long enough to qualify.

PCSing and Access to Disability-Related Services

The requirement to move, or PCS, frequently, often to destinations not of one's choosing, is a constant in military life that entails logistical, emotional, and financial stressors. The focus group results reinforce that PCS challenges can be significantly more arduous for families with EFMs, especially if the families are young or the EFM's disability is severe. Every time family members PCS, they must reeducate themselves about the available resources and the process for accessing them. Then they must reassemble their EFM's continuum of care—that is, request, coordinate, and potentially fight for the services their EFM needs. Families often PCS without knowing exactly where they will be living (e.g., on-base/off-base, school district), which significantly hinders their ability to plan in advance and can result in substantial delays in services. On arrival, there may be a wait for housing (on-base or off-base), necessitating a difficult if not costly stay in temporary lodging. A number of resources can potentially facilitate the PCS move. The EFMP assignment policy, for example, is intended to ensure that families are assigned to locations that meet their EFMs' needs; however, in practice this often is not the case. Priority on-base housing is a significant resource for PCSing EFMP families. Some families were concerned that the current elimination of the EFMP category system, which grades level of need based on disability severity, may jeopardize continued access to priority housing. Families and providers also described EFMP caseworkers as PCS resources, at least for families who are familiar with EFMP services and have an EFMP caseworker. Caretakers mentioned additional resources for all PCSing families, for example, Family Readiness Officers (FROs), Military OneSource, the PCS planning tool on the Military Home front website, and the Interstate Compact on Educational Opportunity for Military Children.

PCSing and Access to Health Care

The cycle of interrupting and reestablishing health care is part and parcel of the PCS experience. The more severe and involved the family member's condition, the more challenging the process of reestablishing the continuum of care. Many families noted that finding new providers is time-consuming and prolongs the lag in health care

services. The new location may fall under a different Tricare region, necessitating burdensome reenrollment. EFMs lose momentum and ground in progress toward their treatment goals. There can be problems accessing health care, including prescriptions, while in transit and before meeting with the new primary care manager (PCM). Although the obstacles to health care during PCS are substantial, there are resources to help families deal with them. Notwithstanding limitations in community awareness, EFMP is available to help coordinate the health care transition. Various medical and nonmedical case managers, including EFMP caseworkers, can help families with the health care transition, although it is not clear which, if any, is specifically assigned this responsibility. Some individual physicians go out of their way to suggest or talk with specialists at the new location, although a “warm handoff” from doctor to doctor is not the norm. Military OneSource and Tricare websites list of health care providers by geographic area, although some study participants reported that the Tricare lists are not always accurate or easy to navigate.

PCSing and Access to Special Education

Many PCSing families are dealing with the public schools, rather than DoDEA schools, on one or both ends of the PCS. The primary difficulty that parents encounter is inconsistency across states and installations in education policies and resources, which often leads to discontinuity and gaps in the special education services offered to their child. The perception of degradation in services, real or otherwise, causes parents great frustration, which both educators and parents said contributes to an adversarial dynamic between parents and the schools. Participants noted that a number of base resources are in place to facilitate EFMs’ educational transition. EFMP and the school liaison (SL) office are two prime examples; however, many suggested that PCSing EFMP families underuse both resources owing to a lack of awareness of the PCS-related services these programs offer. Also notable is that EFMP and SL staff cannot provide families specific school support until the families can tell them where they will be living—information that frequently is unavailable before the family’s departure. EDIS was touted as another reliable base resource for facilitating the educational transition of early intervention clients. Although the participants acknowledged that the public schools, and

public school/DoDEA directors of special education, have the potential to play meaningful roles in the educational transition of military students with disabilities, it does not appear that systems are in place to support this.

PCSing and Access to Long-Term Supports and Services

EFMs must start anew each time they move, learning the services and policies of the new jurisdiction and complying with often-complex application procedures. State-to-state differences in services and eligibility criteria create the risk of privation for PCSing EFMs—that is, gaps in services—and potentially expose the family to financial hardship. The lack of Medicaid waiver portability, specifically, is a significant obstacle to obtaining and keeping long-term supports and services for PCSing EFMs, because there are long waiting lists for these waivers and the EFM's name starts at the bottom of the wait list each time the family moves to a new state. Study participants identified no resources that facilitate access to long-term supports and services during PCS; they did, however, point out the absence of a mechanism to help individuals retain Medicaid benefits. Additionally, although the current study did not target EFMs of retirees, it was evident that some currently serving EFMP families are concerned about continuity of care for their EFM upon retirement, for example, how access to services will be affected by the loss of ECHO.

EFMP and Other Base Programs

The USMC relies on the EFMP as the primary resource for families with special needs. Participants almost unanimously recognized that EFMP, as a program in transition, has grown significantly in the past few years and is continuing to increase its capacity to serve EFMs and their families. Many families and providers affiliated with other base and off-base programs praised the work EFMP is doing, and described a number of EFMP providers as exceptional. EFMs, caretakers, and providers also identified areas for improvement within EFMP.

EFMP Program Entry

Several factors potentially interfere with entry of eligible families into the program. There continues to be a lack of awareness among potential enrollees about EFMP, as mentioned earlier, as well as misinformation regarding eligibility to enroll and the benefits of enrollment. A lingering stigma associated with EFMP, and its impact on a Marine's career, may affect a family's willingness to enroll. Finally, providers—including physicians—do not consistently refer appropriate candidates to EFMP, which needlessly delays some families' enrollment and timely receipt of invaluable services (e.g., respite care, services covered by ECHO).

EFMP Communications

Communication among base-level EFMP proponents about PCSing families apparently is inconsistent, and sometimes EFMP offices are unaware of incoming families with disabilities. Shortfalls in communication between local programs and enrollees also were identified, with many families saying they do not receive the information they should from the local EFMP office. Many families voiced frustration that the EFMP office frequently sends communications only to the Marine, rather than directly to the spouse who typically is the primary caretaker of the EFM or the EFM herself (or himself).

EFMP Service Delivery

Providers and enrollees identified opportunities for improving the quality of service delivery. Many enrollees said they were not receiving outreach contact from EFMP. Many participants, including providers, indicated that there are too few caseworkers to meet enrollees' needs; other participants suggested that some EFMP caseworkers lack the requisite knowledge and background. Additionally, some enrollees characterized EFMP as an assignment program and an information and referral operation, and suggested that EFMP should offer a broader scope of services.

EFMP Assignment Process

Families expressed skepticism about the ability of assignment monitors to make appropriate assignment decisions on behalf of Marines and their EFMs. Also, considerable discussion occurred about how enrollment affects assignment options, deployability, and advancement. As noted previously, there is lingering concern within the USMC community regarding a potential adverse impact of EFMP enrollment on the Marine's career advancement.

Other Base Resources

Base entities other than EFMP play an important role in supporting the needs of EFMP families. Providers and enrollees frequently lauded the National Association of Child Care Resource and Referral Agencies (NACCRRA) respite care program, often describing it as the greatest benefit of EFMP enrollment. Caretakers and providers also mentioned EDIS and the New Parent Support program as other good sources of base-level support for EFMP families. Caretakers expressed concern about the disability-accessibility of base housing, describing it as “adaptable” rather than “accessible”; many indicated that the quarters to which their family was assigned did not adequately accommodate their EFM's disability. In several instances, participants also identified accessibility problems with public spaces on base. A number of participants suggested that families are not sufficiently aware of the base resources available to them.

Note that significant improvements were made to the EFM program while NCD was conducting this study. However, the need for EFMP services still far exceeds program capacity, and many families remain unaware of program improvements.

Recommendations

Based on the findings, and drawing upon decades worth of experience working with people with disabilities, NCD formulated recommendations for improving USMC EFM access to disability-related services. Many of these recommendations echo or build

upon suggestions made by the study participants. Chapter 4 of the report contains a comprehensive list of recommendations, followed by the entities to which each recommendation is targeted (e.g., Congress, Department of Defense, Department of Navy, USMC, Tricare, EFMP). The complete list of recommendations is presented in Appendix H according to the entity or entities to which each recommendation is directed. Ten recommendations, five short term and five long term, are highlighted below for immediate attention, as potentially having the greatest impact on families with members with disabilities. The corresponding recommendation number as it appears in the report follows in parentheses.

Short-Term Recommendations

1. Conduct an accessibility review of human service programs and facilities, including base housing, on USMC bases. Develop plans for each base to make programs and facilities accessible, that is, Americans with Disabilities Act (ADA) compliant, if they are not already. Execute plans as appropriate. (USMC) (1)
2. Increase the accuracy and timeliness of information EFMP families receive from Tricare by instructing case managers to assist families in accessing services, assigning Tricare case managers to a larger proportion of the EFMP population, and establishing multiple communication mechanisms, including a dedicated Tricare telephone hotline (staffed 24/7) for EFMP families, similar to the Medicare hotline. (Tricare) (10)
3. Disseminate to local education agencies (LEAs) and EFM families detailed guidance for implementing initiatives included in the Interstate Compact on Educational Opportunity for Military Children. (Interstate Commission, federal and state departments of education, local education agencies, DoDEA) (13)
4. Educate the military and civilian community (base and unit leadership, military and civilian health care providers, relevant base and community

agencies/providers, including local education agencies, and members of the USMC community at large) about EFMP by designing and implementing a robust, ongoing, multifaceted public relations (PR) campaign to educate stakeholders and the USMC community as a whole to—

- a. Raise their awareness of today's EFMP and sensitivity to EFM issues
 - b. Publicize the specific benefits of enrollment
 - c. Mitigate myths, concerns about stigma, and resulting resistance to enrollment
 - d. Increase the capacity of the entire community (military leaders, military and civilian health care providers, base and community agencies, local education agencies, USMC community members) to inform USMC families about EFMP and to be a supportive presence in the lives of USMC families with members with disabilities
 - e. Promote the Medical Home model, particularly within the military and civilian health care communities (EFMP, USMC, Department of Navy, Tricare) (33)
5. Ensure that EFMP offices systematically gather, maintain, and update contact information from caretaker/EFM spouses and consistently direct all communications—whether by email, telephone, or U.S. mail—to them. (EFMP) (36)

Long-Term Recommendations

1. Address the implications of retirement for continued access to disability-related services, including considering the extension of ECHO coverage. (Congress, Department of Defense, Tricare) (4)

2. For EFMs who are prescribed ABA therapy, continue to work toward full coverage, consistent with the recommended standard of care. (Congress, Department of Defense, Tricare) (11)

3. Minimize the gaps in health care services related to PCS:
 - a. Adjust Tricare procedures to provide EFMs referrals for routine specialty care without needing to be seen by their new primary care manager. (Tricare)

 - b. Facilitate transfer of medical information between bases and between off-base and on-base providers by digitizing EFM medical records and facilitating a warm handoff (direct communications) between providers. (EFMP)

 - c. Establish a mechanism to ensure that EFM families have sufficient prescription medications while in transit between installations, consistent with the Medical Home model. (Tricare, EFMP)

 - d. For recipients of ABA therapy, provide linkage to ABA therapist trainees near the gaining installation (who must complete volunteer hours for their ABA certification) until a longer-term solution can be implemented. (EFMP, Tricare, local health care providers, certifying authorities such as colleges and universities) (24)

4. Implement mechanisms to enable military EFMs to maintain Medicaid waiver services when they move from state to state, rather than requiring them to go to the bottom of the wait lists each time they PCS:
 - a. Place incoming EFMs on the new state's wait list based on their position on the previous state's wait list (i.e., based on "time served"). People who have a Medicaid waiver in the previous state should automatically receive one in the new state. (Congress and state agencies)

- b. Provide EFM's who lose Medicaid waiver services as a result of a PCS the same benefits they received in the previous state until eligibility can be established in the new state. (Congress and state agencies, Department of Defense, Tricare) (31)
- 5. Increase the flexibility of services covered by ECHO to closely mirror the services available through a Medicaid waiver. (Congress, Department of Defense, Tricare) (25)

Statement of the United States Marine Corps

The United States Marine Corps strives to meet the demands of the challenging lifestyle that our families experience every day. The Marine Corps provides numerous programs that support and enhance the lives of our families. Families that care for family members with special needs are of particular priority and warrant greater attention and support. The past two years have been a time of great transition for the Marine Corps Exceptional Family Member Program. General James F. Amos, 35th Commandant of the Marine Corps, is committed to supporting our families. In his 2011 Commandant's Planning Guidance, he states, "We will keep faith with our Marines, our Sailors and our families." The concerns noted by our beloved families, within our ability to control, have been heard and addressed. Our families now report high effectiveness rates and while we are proud of the results, we will continue to improve and respond to help our families support members with special needs. We recognize that many core issues are beyond our scope, but must be addressed. It is our great hope that this research report will bring higher visibility to the challenges faced by those who serve our nation during this critical time in history.

CHAPTER 1. Introduction

U.S. Marine Corps (USMC) family members serve and sacrifice alongside their active duty service members. Among the challenges that military families face are separation from extended family, military member absences, permanent changes of station (PCS), and the stresses of deployment.¹ The challenges of this lifestyle are compounded for families that include members with a disability, potentially compromising those family members' opportunity to reach their potential, if not also degrading the well-being of the family as a whole. In turn, these challenges can influence civilian spouse satisfaction with the military lifestyle. Studies show that family issues and civilian spouse satisfaction can sway service member career intent and diminish mission focus.² Thus, the access of these families to disability-related resources is a force readiness issue as well as a human concern.

At the request of the USMC, the National Council on Disability (NCD) undertook the current study to advise the USMC regarding how to improve access of USMC family members with disabilities to the services and supports they need. The objectives of this study were to (1) document the experiences of USMC families with members with disabilities in accessing appropriate and effective support in health care, special education and related services, and long-term supports and services; (2) identify barriers impeding access to appropriate resources in these domains; and (3) develop recommendations to improve access.³ NCD contracted with ICF International, a professional research consulting firm with an extensive portfolio of military family research as well as experience in the disability arena, to carry out the study.

This report presents the findings and NCD's recommendations. In this introductory chapter, we highlight the substantive and methodological context for the study in three main sections:

- Background
- Prior Studies
- Methodology

At the conclusion of Chapter 1, we provide a brief orientation to the remainder of the report.

1.1. Background

The term “people with disabilities” refers to individuals of all ages with physical, cognitive, psychiatric, sensory, or communication disabilities. More than 34 million people in the United States have limitations in daily activities due to disability or chronic conditions.⁴ According to the Census Bureau, 19 percent of people ages five and older, and 40.5 percent of those ages 65 and older, have a disability.⁵

1.1.1. Federal Policy for People with Disabilities

Four key federal policies protect the rights of people with disabilities. Section 504 of the Rehabilitation Act directs the Department of Defense (DoD) to develop an implementation plan (DoD Directive #1020.1) for ensuring accessibility and nondiscrimination in federally funded activities and programs for qualified exceptional family members (EFMs) and persons with disabilities in the military.⁶ This DoD directive could be considered the central piece of civil rights protection for USMC EFMs. The Americans with Disabilities Act (ADA) was enacted to provide a clear and comprehensive mandate for eliminating discrimination against people with disabilities, provide enforceable standards addressing discrimination and access, and ensure that the federal government plays a central role in enforcing those standards.⁷ ADA applies to all people with disabilities and a broad swath of public and commercial life, for example, access to physical structures, transportation, employment, public services, and services offered by private entities. The Individuals with Disabilities Education Act (IDEA) is a federal law governing special education services and federal funding for eligible infants, toddlers, children, and youth with disabilities.⁸ An important principle of the IDEA is that students with disabilities should receive inclusive free and appropriate public educations (FAPE) of the same quality as students without disabilities, and parents are empowered to protest via lawsuit when they feel their child has been

relegated to an inappropriately segregated environment. IDEA addresses early intervention and assessment measures, the creation of individual education plans (IEPs), and the support of a student's transition from secondary school to postsecondary education or a career. As it pertains to people with disabilities, Medicaid serves dual roles: as the health insurance provision (coupled with Social Security benefits for eligible individuals) and as a partial source of funding for housing and long-term support or care.⁹

A variety of DoD, Department of Navy, and USMC regulations—in addition to DoD Directive #1020.1—mirror federal policy and further protect the rights of Marine Corps community members with disabilities. Since 1997, the authoritative policy for implementing the EFMP within the USMC was Marine Corps Order (MCO) P1754.4A, Marine Exceptional Family Member Program (EFMP SOP).¹⁰ This MCO was superseded as of September 20, 2010, by MCO 1754.4B.¹¹

1.1.2. Services for People with Disabilities

Federally funded programs have been established to serve people with disabilities and their families. For example, although regional differences exist, assistive technology (AT) expertise and loan assistance are available at state AT projects for people with disabilities. Information about housing, transportation, personal assistance options, and other independent living resources are available at independent living centers. In certain instances, legal expertise and advocacy assistance are available at state protection and advocacy organizations. Resources for parents are provided by parent training and information (PTI) centers. Because school and work are equally important to people with and without disabilities, state departments of education and departments of rehabilitation services can be important resources for families of people with disabilities.

Access to disability-related services (related to education, health care, and long-term supports) is a critical concern for people with disabilities.¹² Access issues change over time in response to policy and practice shifts at the federal, state, and local levels. For example, educational practices are affected by reauthorizations and changes in IDEA.

Changes and restrictions in Medicaid, the State Children's Health Insurance Program, and coverage restrictions of private insurance companies affect health care. Medicaid waiting lists and the availability of supports and services in the community affect long-term services.

1.1.3. The Marine Corps Community

The active-duty Marine Corps is a small service branch of 198,415 members, approximately 94 percent of them male. Relative to the other service branches, the Marine Corps has a small family contingent. Approximately 45 percent of active-duty Marines are married and approximately 30 percent have one or more children (minor dependents age 23 or younger or enrolled as full-time students). Thus, the Marine Corps community includes 81,499 civilian spouses and 111,872 children. Children age zero to five years comprise the single largest group of children, which is true of all the service branches.¹³

Seventy-nine percent of Marines are assigned within the Continental U.S. (CONUS), 9 percent to East Asia and 11 percent to North Africa.¹⁴ The largest concentrations of USMC family members (over 30,000 each) are found at Camp Pendleton, Camp Lejeune, Marine Corps Air Station (MCAS) Miramar, MCAS New River, and MCAS Cherry Point.¹⁵ Note that, across DoD, Base Realignment and Closure (BRAC) can have repercussions for military families. That is, troop movements and base closures are expected to affect military children's education opportunities, including children with special needs, by relocating increasing numbers of children to local school districts that may be ill prepared to accommodate them.¹⁶

1.1.4. Services for People with Disabilities within the Marine Corps Community

Established by DoD in 1987 and in the Marine Corps in 1990, the Exceptional Family Member Program (EFMP) offers (1) assignment coordination to ensure that the service member is assigned to locations that can meet the needs of his or her family member

with a disability, and (2) family support through EFMP coordinators and staff at each installation. Until recently, the Marine Corps EFMP used four categories to differentiate the needs of EFMs and determine corresponding military assignment implications.¹⁷

- Category I: sponsor's assignment was not limited by EFM needs
- Category II: EFM needs required specific U.S. or overseas assignments
- Category III: overseas assignments were not appropriate without ensuring availability of needed services
- Category IV: EFM needs could not be met overseas and families received priority housing at U.S. bases

This classification system has been phased out in favor of a more holistic assessment of need and a more customized assignment process. While now obsolete, these categories remain important because they linger in the mind-set and lexicon of many enrolled families.

According to the Marine Corps EFMP consolidated case management system, as of summer 2010, approximately 8,000 Marine Corps families were enrolled in the program. Because many families have more than one EFM, the total number of USMC EFMP enrollees is about 10,000. The majority are families of currently serving (versus retired) Marines. Approximately 20 percent of EFMP families reside on base. Sixteen percent of EFMP families are assigned to remote locations, either domestically or overseas.¹⁸

In 2009, the USMC leadership demonstrated a renewed commitment to Marine Corps EFMs by resourcing a significantly more robust EFMP that is predicated on a continuum-of-care model, emphasizes case management, and offers direct services such as free respite care. Enrollment in the program has burgeoned as a result of these enhancements, and USMC headquarters (HQ USMC) anticipates it may reach 18,000 EFMs if this trend continues.¹⁹ These enhancements and many others are codified in the new Marine Corps Order for EFMP (MCO 1754.4B).

1.2. Prior Studies

This study does not represent the first time the USMC has examined its support of the USMC EFM community. In 2003, HQ USMC assessed the needs, perceptions, and satisfaction of EFMP enrollees via a comprehensive online survey administered to the census of USMC EFMP families, which at the time numbered approximately 4,800. This survey revealed ongoing concerns with health care, education, and long-term services. Nearly 33 percent of respondents reported difficulty finding a school that could meet their child's IEP needs, few reported involvement with or knowledge of various community services, and over one-half indicated that EFMP needed to offer more services and supports. The survey results also indicated that parents of children in DoD schools were more satisfied with special education services than parents of children attending local public schools.²⁰ More recently, EFMP was among the programs included in the Marine Corps Community Services (MCCS) Functionality Assessment (FA), which gathered organizational performance data in August 2007 and September 2009.²¹

Other entities have studied the EFMP as well; results are not available in all cases. In 2007, the Government Accountability Office (GAO) examined access to disability-related services in four communities, each home to two military services and a substantial EFMP population.²² The communities were San Diego, CA; Fayetteville, NC; San Antonio, TX; and Hampton Roads, VA. GAO found that, although medical and family support services existed for the EFMP community, the services could be difficult to obtain, mostly because of understaffing and limited availability. Further, access to state and local resources varied by community, and state laws and policies affected the availability of resources.

In 2008, the Defense Department Advisory Committee on Women in the Services (DACOWITS) studied educational opportunities of military children and youth.²³ Parents of children with special needs were among the study participants. Fewer than half of the participating parents expressed satisfaction with their children's education opportunities,

most frequently citing a lack of choices. Parents also cited disadvantages related to relocation. Parents of gifted children and children with special needs were particularly vocal about their dissatisfaction, noting that the resources their children need are not always available to them, particularly when the family is new to a community.

A Navy audit, focused on special education services for Navy and USMC students with special needs, was conducted in 2009.²⁴ The DoD is studying access to services for military children with autism through a contract with Ohio State University, and, with the support of the Military Child Education Coalition, the Army has recently conducted two comprehensive assessments of the relocation-related challenges faced by EFMP enrollees.^{25,26}

1.3. Methodology

To appropriately evaluate and digest the study results, it is helpful to understand how the results were obtained. This study took place from fall 2009 through summer 2010. The data collection window spanned January 2010 through March 2010. Focus groups, the primary method of data collection, were conducted during site visits to Marine Corps Base (MCB) Quantico, Camp Lejeune, and Camp Pendleton, by a two-person ICF data collection team (moderator and scribe). Three categories of stakeholders comprised the study participants: caretakers of EFMs (e.g., parent, spouse), EFMs (age 18 and above and mentally competent to make decisions on their own behalf), and service providers. The target caretaker and EFM populations were limited to those (1) from active-duty families (versus retired or reserve), (2) living within a 50-mile radius of base, and (3) enrolled in EFMP. These individuals were identified through the EFMP case management database. The target provider population was defined as base and private-sector personnel, including managers and frontline workers, who provide EFMs with disability-related services in health, education, long-term services and supports, and other arenas. EFMP staff, with coaching by ICF, identified these individuals.

The remainder of this summary of the study methodology is presented under the following major headers:

- Data collection methods
- Data collection instruments
- Analysis.

The appendices provide further documentation pertaining to the study methodology.

1.3.1. Data Collection Methods

Focus groups and interviews comprised the primary methods for collecting data from study participants. The research design called for 12 focus groups to be scheduled at each base, including six caretaker focus groups, two EFM focus groups, and four service provider focus groups. ICF employed a three-part email strategy for publicizing the study among these three target populations and recruiting participants. These communications included an introductory letter signed by NCD, an initial invitation, and a follow-up invitation. To protect the personal information of EFMP enrollees and to establish credibility with service providers, local EFMP offices disseminated most of the communications.

Interested individuals self-selected, called ICF on a toll-free line, and were assigned to a focus group. As feasible, providers who work in the health care or education arenas were assigned to specific groups, allowing them to focus primarily on the subjects they know best. Each prospective focus group participant received a reminder email and telephone call prior to his or her scheduled session. The focus groups were augmented with telephone interviews conducted with select individuals who were unable to participate in the on-site focus groups. For copies of key communications employed to advertise and recruit among the target populations, see Appendix A.

1.3.2. Data Collection Instruments

The instrumentation for this study consisted of focus group protocols and demographic sheets. The basis of the focus group protocols, which guided the discussions held with the study participants, was the set of detailed research questions posed by NCD at the outset of the study (see Appendix B for original and matrixed research questions). To ensure comprehensive and systematic coverage of these research questions—that is, to elicit meaningful information that goes beyond superficialities, while at the same time accommodating focus groups about 90 minutes long—it was necessary to divide the research questions among stakeholder groups and subgroups. This ultimately resulted in the creation of five focus group protocols that, while based on a common template and sharing a core set of questions, homed in on different subtopics or stakeholder perspectives. These five protocols, each used to guide the discussion with a different stakeholder group or subgroup, were as follows:

- Generic protocol for use with EFMs
- Generic protocol for use with caretakers
- Generic protocol for use with providers
- Health care protocol for use with health care providers
- Protocol for use with education providers

Copies of the five focus group protocols are in Appendix C. The scripted introduction given at the outset of each focus group, as well as the participant consent form, are in Appendices D and E, respectively. After the focus group introduction and before the start of the discussion, participants were asked to anonymously complete a one-page demographic sheet. Separate demographic sheets were developed for each of the three main stakeholder groups—caretakers, EFMs, and providers. Copies of these instruments are in Appendix F.

1.3.3. Data Analysis

Using a laptop computer, the ICF scribe captured near-verbatim transcripts of each focus group or interview, which became the base document for content analysis. First, each session transcript was cleaned and edited, after which the transcript content was analyzed to identify salient themes. For each session, the salient themes, along with supporting quotations from the transcript, were entered into one of two cross-session databases organized by protocol question—one cross-session database for caretaker and EFM themes and the other cross-session database for provider themes. Salient themes that emerged repeatedly within and across these two databases were identified and form the core of the results summarized in Chapter 3. The analysis process also identified themes that were less consistent but nonetheless noteworthy; these, too, are identified in Chapter 3.

The data gathered by the demographic sheets were aggregated across sessions and sites to generate a description of the study sample as a whole.

1.4. Organization of the Report

The remainder of this report includes four chapters:

- II. Characteristics of Study Participants
- III. Findings
- IV. Recommendations
- V. Recent Improvements Initiated by HQ USMC.

The appendices offer pertinent study documentation and further detail. Appendix I provides a glossary of acronyms used in this report.

CHAPTER 2. Characteristics of the Study Participants

A total of 37 focus groups and telephone interviews were conducted at MCB Quantico, Camp Lejeune, and Camp Pendleton, including 19 sessions with caretakers, 5 sessions with EFMs, and 13 sessions with providers. The study sample, including focus group participants as well as telephone interviewees, totaled 113 individuals, of whom 43 were caretakers, 8 were EFMs, and 62 were providers. This chapter summarizes the key demographic characteristics of the study participants in three sections, as follows:

- Characteristics of Caretaker Participants
- Characteristics of EFM Participants
- Characteristics of Provider Participants

Most of the information presented under these headers is based on the demographic sheet data. For information regarding the characteristics of the EFMP populations at MCB Quantico, Camp Lejeune, and Camp Pendleton, see Appendix G. (Note that several participants belonged to more than one stakeholder group; for example, several caretakers were also adult EFMs or providers. For reporting purposes, each participant is counted only once, based on how they self-identified.)

2.1. Characteristics of Caretaker Participants

We describe the 43 caretakers who participated in the study in terms of characteristics of both the EFM for whom they provide care and their family as a whole. The large majority (39, or 91 percent) of the caretakers were parents of a child with a disability, rather than spouses of an adult with a disability. Typically, the participating parent was the civilian spouse rather than the Marine; in rare instances, both parents participated. The large majority of the caretakers (93 percent) had more than one child, and 40 percent of the caretakers indicated that there was more than one EFM in their household. These were young families—85 percent of them caring for EFMs age 13 or younger.

The 43 caretakers who participated in the focus groups included 39 parents of children with disabilities and four Marines married to adults with disabilities. In all, the parents were caretakers of 60 children with disabilities. The most common condition among these children, by far, was autism (24 children). Exhibit 2-1 identifies the types of conditions represented among these children.

**Exhibit 2-1. Types of Conditions Represented by
Caretakers' Children with Disabilities**
(*N* = 60)*

Types of Conditions	Number of Children
Emotional/Behavioral	35
Autism	24
Psychiatric	5
Attention deficit hyperactivity disorder (ADHD)	4
Other	1
Chronic Health	16
Epilepsy/seizure disorder	4
Asthma	4
Other	8
Cognitive Delays	10
Physical Health	8
Cerebral palsy	4
Neuromuscular or neurodegenerative	3
Other	1
Sensory/Communication	8
Speech disorder/impediment/delay	5
Other	3

*Some children may have more than one condition.

For privacy purposes, the conditions of the spouses with disabilities are summarized with the conditions of adult EFM participants (Section 2.2 below).

Overall, the caretakers came from fairly senior military families. Twenty-two percent were officers or married to officers (including warrant officers), and 60 percent were noncommissioned officers E6 or higher or married to noncommissioned officers E6 or higher. Thus, families of junior enlisted personnel, who are less experienced in the military lifestyle and apt to possess fewer tangible and intangible resources for coping with adversity, were underrepresented in the study sample. This underparticipation by the most junior segment of the military community is common in military family research.

In terms of longevity at their current installation and recent PCS experience, the caretakers spanned the gamut. Just over half (56 percent) had been at their current location less than two years, while 17 percent had been there four to ten years. The caretakers also varied in the length of their association with EFMP. Some were newcomers (16 percent enrolled within the past year and 7 percent within the past two years), but the majority (58 percent) enrolled five or more years ago.

2.2. Characteristics of EFM Participants

All eight EFMs who completed an EFM demographic sheet were female. Two were between the ages of 18 and 25, two between 26 and 30, and four over 30. Seven were spouses of Marines and the eighth the adolescent offspring of a Marine. Four were the only EFM in the household; of the four remaining, three were mothers caring for multiple children with special needs.

Like the caretaker subsample, this group was somewhat “top-heavy” in terms of the ranks represented, including two participants whose Marine sponsor (i.e., spouse or parent) was an officer, three whose sponsor was a gunnery sergeant or staff sergeant (E7 or E6), two whose sponsor was a sergeant (E5), and only one whose sponsor was a corporal (E4).

The following information describes the conditions represented by 11 adult EFM's whose experiences were discussed in the focus groups. These individuals participated in an EFM focus group, participated in a caretaker focus group, or are spouses of Marines who participated in a caretaker focus group. A total of 15 primary conditions were ascribed to these 11 individuals, as depicted in Exhibit 2-2.

Exhibit 2-2. Types of Conditions Represented by Adults with Disabilities
*(N = 11 adults)**

Types of Condition	Number of Adults
Chronic health (e.g., heart condition, asthma, chronic headaches)	10
Physical	4
Psychiatric	1
Sensory/communication	1
Total conditions	16

*Some adults may have more than one condition.

2.3. Characteristics of Provider Participants

The 62 provider participants were a well-educated, professional group overall. Nearly all (87 percent) had bachelor-level degrees, and 61 percent had graduate or professional degrees (e.g., M.S., M.A., Ph.D., J.D.). In addition to formal credentials, the provider participants tended to have substantial experience working in the disability arena and with the military community. Most (82 percent) had been working with people with disabilities more than five years, and more than half (63 percent) had been working in this community for more than ten years. Fifty-seven percent had more than six years of experience working with military families.

More than half of the providers (58 percent) work mostly on base, while one in five (19 percent) work both on and off base. The remaining 23 percent of providers work

mostly off base. Exhibit 2-3 lists the organizations for which the participants indicated they work.

Exhibit 2-3. Types of Organizations for Which Provider Participants Work
(*N = 62 providers*)*

Organizations	Number of Participants
Military Organizations	
Exceptional Family Member Program (EFMP)	7
Naval Hospital or Clinic	6
National Association of Child Care Resource and Referral Agencies (NACCRRA) Respite Care	6
Educational and Developmental Intervention Services (EDIS)	4
New Parent Support Program	3
School Liaison	3
Family Housing	3
Child, Youth, & Teen Program	2
Legal Assistance	1
DoDEA Schools	2
Atlantic MC Communities/HQ USMC Personal & Family Readiness Div.	2
Private Organizations	
May Institute (ABA Therapy)	3
Together We Grow (pediatric day health care)	2
Other Private Providers	4
Other Organizations	
Public Schools	9
Project Pendleton EFM Resource Center (Mil 360 Grant)	2
North Coastal Consortium for Special Education (NCCSE)	2

* Several providers were associated with more than one type of organization.

The participants filled roles at all levels within the organizations listed above, as administrators, managers, and direct service providers. When asked to supply their job titles, some specified their position and others indicated their discipline. Among the more frequent and specific job titles given by providers were: respite care provider (seven), caseworker or case manager (six), school principal (four), director of special education (three), school liaison (three), other liaison (e.g., parent liaison, military counselor liaison, or community liaison) (three), and registered nurse (RN) case manager or RN service coordinator (three). Several providers gave highly generic job titles such as manager, program director or manager, project director, or program specialist. Other job titles cited included behavior analyst (i.e., therapist); training and curriculum specialist or training, education, and outreach specialist; attorney; occupational therapist; speech-language pathologist; family readiness officer; youth activities director; family housing division director; EDIS program manager; children's program administrator; early childhood special education; education manager; education coordinator; personnel support director; EFM suitability coordinator; clinical director; head of pediatrics/EDIS; physician; RN; navigator; and home visitor.

The findings yielded by the responses of the study participants—including caretakers, EFMs, and providers—are summarized in Chapter 3.

CHAPTER 3. Findings

We present here the collective views and perspectives of the study participants—including caretakers of EFMs, service providers, and a small number of adult EFMs—regarding access of USMC EFMs to disability-related services. The findings are organized under four major headings:

- Access of USMC EFMs to Disability-Related Services
- Permanent Change of Station (“PCSing”) and Access of USMC EFMs to Disability-Related Services
- Perceptions of EFMP and Other Base Programs
- Other Topics Related to USMC EFMs and Access to Disability-Related Services

Within the sections, as appropriate, general access issues are discussed first, followed by separate discussions related to health care, education, and long-term supports and services, respectively. The study findings are supplemented by illustrative comments made by the study participants—responses of caretakers, EFMs, and providers that have been excerpted from the focus group transcripts. Illustrative recommendations made by the study participants also are included. The chapter concludes by identifying areas for further research suggested by the study findings.

As noted earlier, this study took place during a period of significant transformation for the USMC EFMP. Accordingly, to its credit, the Marine Corps has already addressed a number of the concerns raised by the study participants. These independent improvements, many well aligned with NCD’s findings, are summarized in Chapter 5.

3.1. Access of USMC EFMs to Disability-Related Services

For reporting purposes, we differentiate between families' steady-state experiences and PCS experiences. This section targets findings that are fairly independent of PCS. In actuality, however, PCSing is a constant in the lifestyle of most military families.²⁷ Both those with and without EFMs spend a significant proportion of each assignment acclimating to the new location and preparing for the next one. Thus, their PCS experiences and steady-state experiences are intertwined.

A core set of focus group protocol questions elicited the preponderance of the study participants' responses:

- What difficulties do EFMs face when seeking services and supports?
- What obstacles prevent EFMs from accessing services and supports (i.e., what are the obstacles that create these difficulties)?
- What services—civilian or military, here or elsewhere—work particularly well?
- What services—civilian or military, here or elsewhere—work less well?
- If you were in charge of improving access to services for Marine Corps EFMs, what additional steps would you take?

All questions were worded to encompass participants' experiences with both the military and the civilian sectors. The findings that emerged from these questions are presented in four sections:

- General access of USMC EFMs to disability-related services
- Access of USMC EFMs to health care services and qualified health care providers

- Access of USMC EFMs to education-related services
- Access of USMC EFMs to long-term supports and services

3.1.1. General Access of USMC EFMs to Disability-Related Services

It was apparent that certain difficulties that EFMs and their families face transcend, or cut across, the domains of health care, education, and long-term supports and services. We describe here these overarching difficulties, which were identified fairly regularly by providers and caretakers at all three study sites.

A Continual Struggle for Parents. Parents of children with special needs spoke of the “full-time job” of getting their children evaluated and referred for services, finding service providers, and maintaining services. Parents feel that the onus for sustaining forward movement is on them, rather than on service providers. Often parents feel they are in a constant battle with service providers of various types. Some parents perceive that civilian agencies take advantage of the fact that military families are transient by deliberately delaying provision of services. Focus group participants said:

“I find a lot of times I’m the one doing the follow-up. If I made an initial call to ask about ECHO, or ABA, it’s always me picking the phone back up to follow up.... I always have to ask all the questions. There’s not a lot of proactivity from the service organizations.... I wish they’d do more follow up.” (Caretaker)

“We’re always battling, that’s the problem.”

“I am constantly in a situation where I’m fighting for my children, where you have to fight all these different organizations....” (Caretakers)

“We are only here for a short period of time, or so they think, so why invest in our kids? If they keep passing the buck long enough, then they won’t have to service our kids.” (Caretaker)

Many families are overwhelmed by the challenge of navigating the service system, particularly young parents, families with more than one EFM, parents who are themselves EFMs, and families with a deployed sponsor. Focus group participants said:

“The families feel very isolated, they are already overwhelmed or maybe so demoralized from this system that they can’t see another specialist, try another route, talk to another person on the phone....” (Provider)

“It’s also so difficult to know where to start. Primary care may send them to a developmental pediatrician who diagnoses them and says ... A, B, and C. Their developmental care physician may be in Bethesda, their primary care physician may be in Fairfax, the path isn’t clear.” (Provider)

“The big difficulty now with so many having a parent deployed is a lot of the time you’re working with a family who has a student with some very unique needs and there’s not a support system there within the internal family. There’s no time out for the mom or dad other than when the student is at school.... With only one parent there to support all those needs, they may not have time to take their autistic son...” (Provider)

In sum, the burden on parents of EFMs can be high and constant, and the way ahead often is not clear to them.

Financial Hardship. Despite coverage by Tricare, if not also ECHO and other forms of public assistance, many EFMP families incur substantial unreimbursed costs. These may range from large expenses such as major equipment to smaller expenses that add up, such as gasoline for frequent trips to nearby or distant health care providers and co-pays for medication. Focus group participants said:

“I don’t care if it’s a \$5 co-pay, some people can’t afford it.”

“When each medication is \$22 and you take three or four at a time and, after filling them, in three weeks you’re changing medication....”

(Caretakers)

“It’s a testament when we have families that can qualify for SSI [Supplemental Security Income]. My husband was an E5. If you’re a typical military family, then you’re living just above the poverty line. There’s a problem with that which is compounded when you add in children with special needs.” (Caretaker)

Military families often do not pass the means test to qualify for public programs, for example, Head Start or SSI. Focus group participants said:

“If they move off base, they lose their Supplemental Social Security Income, which ties to their housing allowance. When you move off base, you’re given a check—when you’re on base, they take it from you. You’d have to be a PFC with three kids to qualify out of town, but on base it’s different.” (Provider)

“Most of the time it’s the income—you say you’re a military wife and they automatically see big pay.... Because we get the Basic Allowance for Housing (BAH) to pay the rent and that counts as an income ... it’s like adding to your income \$1,300 you don’t even see.... When I went to Head Start they told me, ‘Oh, but you’re a military wife, your kids do not qualify for it.’ They didn’t ask me for any income, my husband’s pay grade, even an E1 family can’t go.” (Caretaker)

“We do have families that have three or four children ... with a sergeant they qualify, but a staff sergeant and above won’t.”

“And the BAH is counted against them.”

“When I walked into the SSI in North Carolina, they were like, ‘Oh, you’re military; you make way too much.’” (Caretakers)

Apparently, the hardship of indebtedness can be compounded when it comes to the attention of the Marine’s leadership and potentially jeopardizes the Marine’s security clearances. Focus group participants said:

“Every time something comes up, we have to stand tall to explain why we missed a payment. A red flag comes up on our security clearance.”

“If we declare bankruptcy, we lose our clearance.” (Caretakers)

Barriers associated with living off base and living on base. Military families living off base are not eligible to use certain on-base services, such as DoDEA schools or Early Development Intervention Services (EDIS). Additionally, base services are not as effectively marketed to off-base families as to on-base families, reducing their awareness and use of services available to them. Families with preschool-age children may be particularly isolated. Focus group participants said:

“Each state is totally different. My husband is in the military. We’ve been in the military for 14 years.... You give your life for this and you go to them because that’s who you’re supposed to go to, and they say, ‘You don’t live on base, you can’t get the stuff here.’ I would love for my kids to see the military doctors, if they have it all here, I would love to do all this on base, it’s your home, it’s your family....” (Caretaker)

“But my three-year-old attends the CDC [Child Development Center], and I was given evaluation paperwork for her between two to three years old. My biggest concern is her delayed speech, and they referred me to the public school system. It’s very frustrating to me that, to get her speech, I’d have to take her off base. Because of where I live (off base), certain services aren’t available for me, even though ... my daughter is in the

CDC here. She isn't allowed to get services through EDIS because I live off base.... I am very frustrated that, if I don't live on base, I don't get these services; it isn't fair because I am a military family. I spoke with an EFMP person yesterday, who said that it isn't black and white and maybe we can work something out.” (Caretaker)

“Especially when you live off base, because over here they have EDIS but, since I live off base, I can't use that one. Most of the services on base are just for people that live on base.” (Caretaker)

A few providers at more than one site suggested that, by the same token, living on base also can limit the range of services at a family's disposal. For example, living on base can limit their awareness of services outside the gate, and some families, likely younger ones, may be reluctant to venture from the security of the base. Families may also consider off-base resources too far a drive. Focus group participants said:

“I see families have a hard time getting off base, physically and mind-set-wise, thinking about services off the base.”

“The base is a shelter.”

“They want to be self-contained, we'll hear, ‘Don't make me go downtown.’”

“We're dealing with a younger population that's reluctant to go off base; they're single parenting with husbands deployed.” (Providers)

Barriers Associated with Family Leaving the Duty Station When the Sponsor

Deploys. It is not uncommon for military spouses to move “home” with their children during their partner's deployment to take *advantage* of the support of their extended family. This is a particularly common practice of families with children who have not yet entered school. Unfortunately, neither local providers nor Tricare appear equipped to

easily cover short-term supports. (Access to health care will be discussed further in the next section.) Focus group participants said:

“Our biggest difficulty hasn’t been the base necessarily. It’s been when you have to deal with being out in town without having support. We left to go to X when I was pregnant with my son and my husband deployed. My daughter still needed OT [occupational therapy] and speech, and getting the transition taken care of was hard. I was in X for seven months on bed rest. Getting my daughter services while I was there, finding people who accept Tricare, who understand the military (we only needed services from this month to this month, which no one understood)... It’s hard to explain the nature of the military.” (Caretaker)

“Just the medical, it’s always been the medical. When he deploys and I am back home, Tricare doesn’t want to cover any pediatricians. You have to be always by the ER.... When we came back to 29 Palms, Tricare told us that was wrong, and I said, ‘Every time I call, that’s what they tell me.’ She said, ‘You should call 29 Palms,’ and I said I didn’t know I could call them for that.” (Caretaker)

One educator pointed out that interrupting services can be particularly counterproductive for preschoolers with special needs who may be receiving intensive attention by educators or therapists through the schools or through programs such as EDIS and New Parent Support (NPS). One focus group participant said:

“The interesting part about that is, for those families with special-needs kids who are preschool, it’s so important for those kids to be in school on a regular basis, not to be pulled up and moved around; they need that consistency.... Sometimes families don’t get the importance of consistency for kids.” (Provider)

Although not based on a large number of comments, this finding may be noteworthy in light of the current deployment tempo. The sections that follow address access to health care, education, and long-term services and supports, respectively.

3.1.1.1. Summary

This section has focused on access issues during steady state, as opposed to access issues associated with the transition from one base to another. The first issues discussed were general ones that transcend the specific domains of health care, education, and long-term supports and services. EFM and their families described a number of barriers they grapple with as they endeavor to access disability-related services. For caretakers of EFM, navigating the service systems and obtaining and maintaining disability-related services requires relentless hard work. For some—particularly young parents, families with more than one EFM, parents who are themselves EFM, and families with a deployed sponsor—it is an overwhelming prospect. Despite coverage from Tricare/ECHO and public assistance, families experience substantial unreimbursed costs and, for some, financial hardship. If families live off base, as most USMC families do, they are apt to lack awareness of and access to base services. Finally, many USMC families with preschool-aged children choose to return home to their extended family when their spouse deploys, to take advantage of the support of extended family. In so doing, they risk lack of coverage, discontinuity in health care, and loss of access to important, time-sensitive special educational services for preschoolers.

3.1.2. Access of USMC EFM to Health Care Services and Qualified Health Care Providers

The findings related to access to health care services and providers are organized under the five headings: context, services and circumstances that are working well, difficulties and obstacles, participants' recommendations, and summary. Findings were elicited by the focus group questions listed earlier, unless otherwise specified. Further

findings related to USMC EFM access to health care and qualified health care providers are discussed under Section 3.2, which deals with PCS and access.

3.1.2.1. Context

Marine Corps family members, including Marine Corps EFMs, obtain their health care through the military's health care system, which uses a combination of military hospitals, clinics, and civilian professionals. Because active-duty members have priority at military medical treatment facilities, family members may have to obtain care from civilian providers through Tricare. Tricare Prime is the plan that has the lowest out-of-pocket costs; similar to a health maintenance organization, it requires enrollees to use network providers and coordinate their care through a primary care manager. Tricare also offers the Extended Care Health Option (ECHO), which provides services and supplies not available through Tricare Prime to active-duty family members who are enrolled in EFMP and have qualifying mental or physical conditions.²⁸

With respect to military medical care, the Marine Corps relies on the Navy for medical services. MCB Quantico currently has a Naval Health Clinic on base, but no hospital. Walter Reed Army Medical Center (WRAMC) and Bethesda National Naval Medical Center—with Walter Reed combining with the Bethesda Naval Hospital in 2011—are also located in the National Capital Region. Camp Lejeune and Camp Pendleton each has a Naval Hospital on base. Naval Medical Center San Diego is also in the vicinity of Camp Pendleton.

3.1.2.2. Services and Circumstances That Are Working Well

Following are several positive aspects of the health care experience that were mentioned by some of the study participants. For this subtopic, we focus primarily on the perspective of caretakers and EFMs, that is, the customers.

Coordination and Advocacy by Various Case Managers. Families enrolled in EFMP potentially have access to a variety of case managers. For example, all families should be

assigned an EFMP case manager (also called “caseworker”), some families may be assigned an ECHO case manager or a Tricare case manager, and base clinics may have a pediatric nurse case manager. Families—particularly those dealing with more involved conditions—seem to value the assistance that case managers can provide. (Case managers are discussed further throughout the report.) Focus group participants said:

“Here on base, we have nurse case managers that are assigned for some of the more severe cases. They are assigned through the military pediatricians on base. Then you don’t need to take your child to his or her PCM every time you need a referral, you don’t need to take up the pediatrician’s time, you can just call the nurse case manager and say, ‘This is what I need.’” (Caretaker)

“The pediatric case manager here is phenomenal. I can’t say enough good things about her. She will call me just to follow up, just on a whim.... We need fifty million of her rolling around.” (Caretaker)

“I’ve been very happy with the ECHO case managers. They’ve been exceptionally good about problem solving, getting things negotiated through the system.” (Provider)

“Now we have a pediatric case manager from the clinic who helps us and, between her and our case manager at EFMP, they helped me coordinate that.” (EFM)

“I still think the key in all this is a good case manager through Tricare. We have a Level II case manager, meaning she deals with more of the severe children.... She is the key component in advocating for you. If he needs something, she talks to the vendor or tells me what vendor to use. She’s a key component in maneuvering us around and making sure the vendors deliver. She has a care plan that she updates every three months and sends to us on paper, and she has a grid on there with goals

and the date they were actually met, and she follows up on all of that. I really couldn't do it without her. She's wonderful." (Caretaker)

Most of the families with whom we spoke did not have a Tricare case manager, and there was some confusion among the study participants over who is eligible to be assigned one.

Tricare Extended Care Health Option (ECHO). Qualified EFMP enrollees can obtain supplemental coverage for certain treatment and equipment through ECHO. For example, through ECHO, eligible EFMP enrollees diagnosed with autism can receive ABA, which is the recommended treatment. (Concerns about ECHO and about the ABA coverage it provides, which falls well short of the recommended standard of care, are addressed in the next section.) Focus group participants said:

"You just fill out an application for ECHO and that's it, it provides the medical equipment you may need, the respite care, in-home nursing, and transportation if you're home-bound. Additional respite care above and beyond." (Caretaker)

"ABA therapy—the overall health of our family changed significantly when we started this, especially when my husband was deployed, I don't even know if we could have stayed together because of all the stress." (Caretaker)

Military Health Care Facilities and Providers. Several families at each study site spoke with appreciation about the care they receive through the military health care system. Focus group participants said:

"My neurologist is good. I'm so used to rushing my issue and she's like, 'Go ahead, slow down, and tell me every single thing.' I started crying in the office because I couldn't believe how helpful the doctor was to me." (EFM)

“I’ve never had a problem because I’ve gone to the military hospitals. Everything has worked. This is also our first PCS ever; it’s unusual for a Marine family; we were at X for 10 years and the services I’ve received are straight medical services thus far. Even coming here and finding the cardiologist and being referred to the cardiologist, everything has been fine.” (EFM)

“We have a developmental pediatrician from EDIS and he has been fantastic. This is one of the only times I can think of when I have my doctors’ email addresses.”

“I met the developmental pediatrician from EDIS at one of the EFMP programs they had and I walked up to him and explained to him about my son’s situation, and he said, ‘Bring in everything you have,’ and he reviewed my son’s package. I went back to see him in a week; he had been in touch with specialists for me....” (Caretakers)

3.1.2.3. Difficulties and Obstacles

The findings in this section were elicited by the focus group protocol questions identified earlier as well as the following: To what extent do Marine Corps EFMs have access to qualified health care providers? For this topic, we present the perspectives of all stakeholder groups who participated in the study, including caretakers, EFMs, and providers.

Limited Availability of Specialists. With great regularity, families and providers at all three sites identified the limited availability of specialists as a major problem. Focus group participants said:

“We’re too backlogged, there are too many people trying to get the same services. You might wait two to three months on base trying to get specialty care. You might wait out in town for two to three months. There

just aren't enough providers.... We're a big base; we need more resources." (Caretaker)

"There's a shortage of OTs and speech therapists in this area. I have never seen it this bad. They don't make set schedules. I talk to a family and ask them when they get OT or speech. [They say,] 'I get it every other Friday or Thursday, or sometimes when they call.'" (Provider)

The study participants said there are too few providers at base military treatment facilities. They also said there are too few civilian providers that accept Tricare.

"Depending on where you're located, finding appropriate providers that accept Tricare can be a challenge. We're on the northern end of the base and Orange County is right outside our door. It's a higher income area and providers, even if they take insurance, don't accept Tricare because it's a lower-paying insurance." (Caretaker)

"He told me he was going to commit suicide.... We were jumping through hoops trying to find a Tricare-approved counselor. Nobody was accepting patients. We were footing the bill for \$300 or \$400 an hour for whoever could see him...." (Caretaker)

Participants noted shortages of pediatric specialists, in particular.

"[P]arents call back and say, 'We're having a hard time finding a pediatric PT or OT,' especially finding one that will accept Tricare, [which] is really hard." (Provider)

"There is a deficiency of pediatric specialties in this area. Even when we call to refer them, they go on an eight-month wait list." (Provider)

Participants also noted shortages of behavioral health specialists.

“My other son went to therapy earlier today. He met the counselor but he won’t be seen again for another month because they’re so overbooked. It’s really hard to get into a doctor’s office here.” (Caretaker)

“We have families who are really in need of clinical services, family therapy, clinical psychology, and we look to help them try to find resources that accept Tricare, but it’s a challenge....” (Provider)

It appears that behavioral health specialists who can prescribe medication are in particularly short supply. Focus group participants said:

“Psychiatric services are another area we have trouble with. We had one parent who had a young child who was very aggressive, and she was scared to death of her child.... EDIS couldn’t take her because EDIS was full.”

“There are counselors out there, but psychiatrists specifically can do medication and we need more of them.” (Providers)

“Mental health service availability for children and parents in the area is horrendous. Often that’s what respite care providers are filling in for.”

“The access to child psychiatrists is the absolute worst. The access to medications is the worst.”

“There was more availability before the war, but then all resources shifted to PTSD [post-traumatic stress disorder].” (Providers)

Geographically Inaccessible Health Care. To obtain the care they require, many families, most notably at MCB Quantico and Camp Lejeune, must make frequent road trips, often four to six hours round-trip, to military and civilian major medical centers.

These appointments with geographically distant providers frequently consume an entire day, if not two. Focus group participants said:

“The availability of appointments—we really accommodate EFMP families in the pediatric clinic, but it’s only an ambulatory healthcare center. If they have special needs, they need to go to Walter Reed Medical Center or Bethesda [Naval Medical Hospital] or other specialized facilities, and to do that they need to travel quite a bit. Many of their appointments are frequent and it can be a real hardship on their part.” (Provider)

“The thing I hear the most is there are not as many medical providers and special-needs medical providers in this area. You get a service member who came from a larger area, say Pendleton, and they have a larger field and more resources there. They come here, and they have to go to Duke (three hours), Chapel Hill (three or four hours), Greenville (one and a half hours), or Wilmington (one and a half hours).” (Provider)

The road trips that EFM families must make to obtain needed care introduce significant and varied challenges. Focus group participants said:

“Transportation! They ... have to travel so far, so frequently, and may not have a car.”

“I’m dealing with young parents usually and ... there’s usually only one car. Spouses will say, ‘I don’t want to call and have him miss work again.’”

“We have a couple of moms that don’t drive ... so their husbands have to put in to get the time off of work. It’s one thing to take two hours off to drive them to the clinic and drive them home, but they have to miss the whole day to go to Bethesda.” (Providers)

"I drive to Bethesda almost weekly for all three of us and, if my daughter ends up with a feeding tube, we'll end up there three times a week.... We get speech and OT and a lot there. I had to quit my job last year for this. I know that we did talk to the base commander about that and he said they're trying to get a shuttle that goes from here strictly to Bethesda or WRAMC, but we know we probably won't get it." (Caretaker)

"We have a lot of our kids go there [to Chapel Hill] to see psychiatrists, get genetic testing, etc. Our kids are leaving at 7:30 p.m. to drive to Chapel Hill to be there by 8 a.m. to spend the whole day and then come back. Dad and mom are out of work that whole day. I can't imagine—that's just a lot to have to uproot." (Provider)

"We go once a month to UNC [University of North Carolina], which is two hours away. We get both children in on the same day.... We stay at the Ronald McDonald house the night before, and sometimes the next day. We just found out from X that we could get financial support for transit to these appointments. We've been doing this for five years off and on. In the beginning we didn't even know about the Ronald McDonald ... we paid \$120 a night while my husband was a lance corporal." (Caretaker)

One or both parents may attend these appointments. It is very stressful for the military spouse to navigate them solo, particularly if the family has more than one child. Alternatively, if the Marine attends these appointments or stays home to care for other children, the couple worries about the career implications of repeated absence from place of duty. Focus group participants said:

"I have X other children, so when I have to take my son to UNC, I had to leave at 5 a.m., and my husband had to miss work to take the kids to school and watch the baby. He was penalized at work all the time because he had to miss time to help the family.... We're a career Marine. You're getting bad write-ups and it's affecting your career.... He didn't do

anything wrong. He did what he had to do. I am not the only one that has experienced this—I've talked to other spouses and mothers.” (Caretaker)

“When he says his daughter needs to go to Chapel Hill for an appointment, they say, ‘Your wife can do it,’ but I have three kids and two appointments in one day. They don’t get that my kids need to go three hours away just to see the doctors.” (Caretaker)

“I would say balancing the Marine’s dual world, the needs of the Marine Corps and the needs of their family, that’s hard whether you have an EFM or not, but if you have a dependent with a disability [it’s harder]. You may have a lot of appointments. If a Marine comes here with their wife, they may not have family out here....” (Provider)

EFMP enrollees at MCB Quantico and Camps Lejeune and Pendleton seem to be surprised that they must travel extensively to obtain the care they need since they are under the impression that they were assigned to these locations largely because of the medical resources they offer.

Restrictive Tricare and ECHO Coverage. Many study participants, families as well as providers, expressed deep concern about Tricare coverage, including constraints on therapy dosage and outright denial of coverage. Focus group participants said:

“I think Tricare with speech therapy or OT isn’t working well—they kind of give you 20 to 30 minutes a week when those therapies are usually designed for 60 minutes. When Tricare puts those caps on things, it inhibits us from getting the care because providers say that’s not how we do this.... They will turn down clients and say by the time they get warmed up and have them doing something it’s time to wrap up.” (Caretaker)

“I am in a wheelchair and I need durable medical equipment and Tricare routinely tells me no.”

“Wheelchairs, walkers, canes, anything that helps her be mobile. Her speech device—she practiced with her speech therapist with a great speech device for six months, but then Tricare took it away from her. They literally told her, ‘You don’t need a speech device.’” (Caretakers)

“We got him shatter-proof glasses. Tricare wouldn’t cover it because they wanted a certain type of lens, Medicaid wouldn’t cover it because Tricare denied it, and it was \$300-plus. The special needs bike runs between \$2 and \$3K; I got it for \$1,500, but neither [program] covered it.” (Caretaker)

“Within the autism community, anesthesia for dental work is not covered, helmets for kids with autism are not covered, and I have ECHO. Every now and then you hear of someone who gets it covered, but it seems arbitrary. It’s safety. It’s a medical necessity. It’s medical equipment. It meets the criteria they define, but they refuse.” (Caretaker)

The study participants’ most frequent complaints regarding Tricare coverage pertained to ABA therapy for children with autism. Parents repeatedly observed that military children with autism (one of every 88 military children, they reported) lack optimal access to ABA, which is the treatment recommended by the medical community. They explained that Tricare segregates ABA under ECHO, outside the Tricare basic plan, and suggested that so doing creates several significant barriers to care. Most critically, Tricare ECHO limits coverage of ABA therapy to \$36,000 per year, which pays for considerably less ABA therapy per week than the recommended standard of care. Parents observed that Tricare could not impose this ceiling if ABA therapy were not segregated under ECHO. Parents further observed that, with the recent health care reform, Tricare is now lagging behind other insurers in coverage of ABA, and “military children with autism are suffering.” Focus group participants said:

“Our current enrollment in the ECHO program under the autism services demonstration is 1,600 kids, out of nearly 19,000 Tricare-dependent kids with Autism Spectrum Disorder (ASD). Less than 10 percent are in it... And about the 90 percent receiving care from a provider out in town—do you think that provider is knowledgeable, etc.? ... They absolutely are not; they put a referral into the system and all they know is, it isn’t an authorized Tricare benefit. Parents don’t know what they don’t know, and providers don’t know what they don’t know.” (Caretaker)

“With the dollar cap right now, if you’re lucky enough to get into ECHO and get services, it’s subject to a \$36K cap. That provides roughly 11 to 12 hours a week of services, which is less than half of the minimum outlined medically necessary standard of care...” (Caretaker)

“Recently, with health care reform law, ABA therapy is now recognized as part of the essential benefits package for insurance companies, without dollar limits. So public policy is one thing ... it’s leap-frogged over Tricare, leaving the military family child in the dust ... so public policy has been moving at a quick pace and Tricare has dug in their heels and done nothing, and now we have a federal law that is leaving the military child behind.” (Caretaker)

“Most services simply don’t exist or they exist halfway; for instance, ABA. My son is prescribed 20 hours a week but he only receives 10 hours a week through ECHO. If he were prescribed heart medication, they wouldn’t give him half, they’d give him all of it. The providers are there but the coverage is incomplete.”

“We know the Senate Armed Services Committee has shut down our proposal for the \$36K cap to be raised to \$60K.” (Caretakers)

“Tricare calls it an educational benefit, puts it under ECHO and puts a cap on it. Well, it’s not enough for a full program. The cap is \$36,000 a year, which is roughly 11 hours a week. The American Academy of Pediatrics recommends 25 to 40 hours a week for the complete program. ECHO not covering ABA is my number one issue. It’s like if your kid had cancer and they said we know this treatment works well but we’ll only pay for 25 percent because it’s too expensive.” (Caretaker)

“Would you deny a wounded warrior rehabilitative services because it’s too expensive? The average monthly cost of a comprehensive autism program is \$6,000 per month. The average monthly income for an E5 is \$2,700 a month. I can’t work because I take care of two special-needs children.” (Caretaker)

A few providers observed that Tricare and the schools are not aligned on coverage issues, which creates gaps or delays in services available to EFMP families. For example, Tricare maintains that social skills groups for children with autism are an educational service that the schools should provide, whereas the schools maintain such groups fall in the category of health care and, as such, are Tricare’s responsibility. Focus group participants said:

“There’s a ton of conflict between Tricare and the schools. Social skills groups are a perfect example. Tricare says it’s the schools’ problem, schools say the same thing. Children suffering from autism at any point on the scale all need the social skills component, and everyone keeps saying it’s not my problem, it’s yours.”

“Schools provide, within the realm of the federal regulations, what is required. Sometimes what our children need in therapy is not what’s educationally relevant.... A lot of children need a lot more than what is educationally relevant; a lot of children need to be able to access

therapists in their local community, but they can't because of Tricare.”
(Providers)

Two families with children with autism indicated their children needed to be anesthetized for dental care but Tricare would not pay for the medical component of the procedure.

“United Concordia covers the dental but they wouldn't cover the anesthesia because it's medical, but Tricare wouldn't cover anesthesia for a dental issue.... When you have a child with a diagnosis like my child [autism among other things] that requires the extra bills, someone should cover it.”

“On some installations, like at Balboa, they have a special-needs dentist. They don't have one at every installation.” (Caretakers)

“We had to write senators because he fell and broke out his teeth up front and the dentist said we need to do this procedure in a hospital with anesthesia and Tricare wouldn't cover it because it was a dentist and dental wouldn't cover it because it was in a hospital....” (Caretaker)

The partner of a deaf military spouse who needs sign language interpretation in order to communicate with health care providers indicated Tricare refuses his requests for support.

“The biggest problem that I've had is sign-language [SL] interpreters. We have needed the service of an SL interpreter for family therapy for a long time ... so for four years we've been trying to get family therapy. But every time we try, we hit the same obstacle: the therapist is found by Tricare or OneSource, we see the therapist, I let them know one of the family members is hearing impaired. They say, 'We've done that before,

no problem,' [but] we get to the point of who is going to pay for the SL interpreter and they say, 'It's Tricare or you pay out of pocket.'"

"To have his back, my husband had a Marine, his wife was going deaf and Tricare wouldn't cover SL interpretation." (Caretakers)

Tricare and ECHO Processes. Some study participants reported that access to health care is further constrained by cumbersome Tricare processes and communication failures, which are particularly burdensome for families that require frequent and intensive medical attention. Families do not experience Tricare as customer-friendly, and they find it very difficult to get information from Tricare and to work with Tricare staff. Several families, for example, described how requests for equipment or services were rejected because their claim failed to use precise terminology (e.g., "adaptive car seats" rather than "car seats" or "feeding therapy" rather than "oral motor skills therapy"). Focus group participants said:

"I called in June for a car seat through Tricare [and the request was denied], then I called EFMP to ask how I could do it and they didn't know. So, I called back to my old duty station ... and they told me that it's called an adaptive car seat. And then I called Tricare back and they just gave me each car seat. They were \$1,500 apiece." (EFM)

"Tricare doesn't cover speech therapy, but we were given a prescription for oral motor skills with a speech therapist and finally someone told us it needs to go in as feeding therapy so it will be approved ... [We] finally got someone from there to call our doctor and tell the doctor how to prescribe it." (Caretaker)

"We're having problems trying to communicate with Tricare to see how we can go to a private pediatrician, to see what the process is. Every time we ask them, they say we have to go to the website. Right now we don't have a computer; we are in an odd position with that.... Everybody says

something different about Tricare. Getting information from Tricare has been really hard. I have talked to other military wives. They all have the same problems.” (Caretaker)

“Anyways, when I called Tricare to ask for assistance getting an SL interpreter, they gave me the runaround. They said, ‘We can’t help with that, we can’t pay for it.’ They sent me to ECHO instead, and it took them two weeks to answer my voicemail. Finally they talked to me. They said, ‘Since your wife’s name starts with a G, that’s ECHO West.’ I called ECHO West. Two weeks later I got a call from them, and they said, ‘We understand, but we don’t have any funds for that; that’s Tricare.’” (Caretaker)

In some instances, families give up on Tricare and simply abandon their pursuit of coverage and pay out of pocket.

“Finally, we gave up.... She needed a push wheelchair; I bought it. She needed a speech device, and the school loans us one. We work, she goes to school, we don’t have 10 hours a day to argue with Tricare on the phone about what she needs.” (Caretaker)

It appears that, in some cases, a lack of awareness of ECHO and a lack of clarity regarding ECHO eligibility criteria may limit families’ access to this option.

“I’ve just gotten my denial letters from ECHO that my children’s disabilities don’t rate us getting ECHO.... My son is in a psychiatric hospital because he recently tried to commit suicide.”

“ECHO is something only ‘special people’ get.” (Caretakers)

“They say, ‘Enroll and we’ll get you all this help,’ —for instance, the ECHO program. You have to have two existing conditions.... I was told I

could go into ECHO.... I called them and told them the situation, but then I was told that I don't qualify. I'm like, 'I have these two conditions, how do I not??' This week I got a letter saying that your ECHO POC [point of contact] has changed. How do I even have an ECHO POC?!" (Caretaker)

"Here they have ECHO, but a lot of the families don't even know about it or what it's for." (EFM)

Several providers corroborated that working with Tricare is indeed difficult, if not confusing.

"And just negotiating with Tricare can be difficult. You get a referral, wait 48 hours before you can call them, you try to get an appointment, but if they can't give you one, then you get referred to network, etc." (Provider)

"A lot of times that's hard for them [families] because of all the processes in place, the things you need to do, with Tricare, and that continuous change, it continues to create a lot of inconsistencies for the families who are trying to get the information and it's hard to build a trust relationship with the families. There's been many changes in processes. No one knows the steps on all of those different processes, to get ABA therapy, to go to the clinic at Chapel Hill, etc."

"It's all online, if you can sort through all of the manuals, but sorting through the manuals is beyond my education level [participant with a professional degree]." (Provider)

Protracted health care referral process threatens timely and quality care. Study participants commented regularly on the laborious and lengthy process families must go through under Tricare Prime to see a health care specialist, and how this affects patient well-being. Focus group participants said:

“I’ve been having quite a bit of problem getting her the care she needs in a timely manner. It’s very difficult when you’re in the military because everything has to be done on a protocol basis. It’s been so frustrating that my husband and I have talked about me moving the kids out of state for additional help.... My frustration is that it took three and a half months to help a baby get over something that could have been helped months ago.” (Caretaker/EFM)

“When I first asked for help for my son, we were seeing pediatricians and nurse practitioners here on base. It took me forever to get an appointment. I called and called and called. I just wanted an appointment to know where to go from here. I saw Jenny McCarthy on TV on a morning talk show, and I saw the symptoms that could match my son’s. I came into the Naval Hospital for an appointment. I met with the pediatrician, I told them what I thought, they said, ‘You live off base,’ and they gave me a piece of paper with a phone number on it. They referred me out in town to CDSA [Child Development Services Agency].” (Caretaker)

“Getting the services—it drives me insane that in order to do anything you have to have a referral! If your kid needs to go to a specialist, you can’t call and make that appointment; it has to go through Tricare. Sometimes I don’t even get a response from Tricare to tell me what I’m seeking was approved (or wasn’t). It contributes to a lag in service. Then you still need to make the appointment. That’s a big issue. How available is it really if it takes you a month to get an appointment?.... For people to be in therapy, it needs to be consistent to have any effect.” (Caretaker)

“The hardest part is that today we’re talking about this but I needed it yesterday and I won’t have it until the future. That length is difficult to deal with. Everything is so drawn out.” (Caretaker)

A number of providers concurred that the health care referral process and the pace of referrals are problematic. At one location, this was described as the chief complaint of both EFMP and non-EFMP families. Providers further observed that the path to obtaining health care is not only protracted but at times is not clear or straightforward, particularly when families are dealing with more than one provider (primary care physician, developmental pediatrician, etc.), when families are younger and less experienced, and when families have more than one EFM. Focus group participants said:

“Scheduling has come up in several meetings. It’ll take three months to see the doctor to get the referral.... People are upset because they can’t get in soon enough.” asterisks

“A lot of times they have to go to their primary care manager [PCM] at the hospital and, if they need specialty care, they see their PCM first and then get referred to the subspecialty. That can take months.... Sometimes people get so frustrated trying to get services so they give up.”

(Providers)

“It’s also so difficult to know where to start. Primary care may send them to a developmental pediatrician who diagnoses them and says, you know, A, B, and C. Their developmental care physician may be in Bethesda and their primary care physician may be in Fairfax. The path isn’t clear.”

(Provider)

“Our [ABA] services are difficult to get to. There’s a long process to get them. Our families have to enroll in EFMP, on top of that they need ASD diagnosis, they then need ECHO, then they need a prescription for ABA. There are a lot of steps along the way where these parents are exhausted; they have children with ASD and they need to fill out 100 pages just to be able to see us. Then there’s the other two days they have speech, OT, PT, help with homework. They’re usually not the only

children [in the household]. One thing we found in X was that parents get lost along the way.... I would also say the parents we have now are fierce advocates. They have to be to get to us.” (Provider)

Discontinuity of health care providers threatens quality care. Discontinuity of health care providers goes hand in hand with relocation and is discussed in a subsequent section of this chapter. However, discontinuity is a potential issue in the steady-state environment as well, according to a few family members. Focus group participants said:

“It doesn’t help when there are a lot of doctors that can’t see your children because they’re leaving (deploying, PCSing, etc.). It’s frustrating for me now because her orthopedist has left for Haiti and now she has to see a new person at WRAMC, so now we need to start from scratch. He’s been seeing her since September of last year. He sees her every couple of months, and now he’s gone.” (Caretaker/EFM)

“We’re trying to find a private pediatrician because the Woodbridge Clinic [an off-base military medical facility] is really crowded and we don’t get the same doctor every time we go. We want just one doctor.... They all have different opinions. We don’t ever know what’s going on or who we can trust. We want a steady person so he can know the kids. In the past year, I’ve seen at least 10 pediatricians.” (Caretaker)

3.1.2.4. Summary

The focus of this discussion was access to health care. Study participants expressed that case managers through EFMP [also called “caseworkers”], Tricare, ECHO, and medical facilities can be very effective advocates for EFMs trying to navigate a complex health care system. Some families praised the quality of care they receive at military health care facilities and from military providers. Nevertheless, participants described a plethora of obstacles to accessing health care-related services, such as too few specialists (especially in behavioral health). They noted a particular dearth of specialists

near the installations, amounting to geographically inaccessible health care. Families also noted the protracted health care referral process, a problem that is particularly onerous for families that make intensive use of the health care system, and one that potentially jeopardizes quality of care.

Participants voiced a variety of concerns about Tricare, the civilian component of the military health care system, frequently describing Tricare claims and communication processes as cumbersome and unclear. Some families expressed gratitude for the benefits they receive under Tricare and Tricare ECHO, but more often, families lamented the limitations of Tricare coverage. In particular, participants frequently expressed great frustration that Tricare ECHO's coverage of ABA therapy for ASD falls well short of the recommended standard of care.

3.1.2.5. Study Participants' Recommendations

In this section, we present recommendations offered by the study participants to improve EFM access to health care services and qualified health care providers. These recommendations came from one or more individuals. Recommendations echoed by many participants are so noted.

Study Participants' Recommendations Related to Tricare

- Increase Tricare coverage of ABA therapy for children with ASD, commensurate with the standard of care recommended by the medical community. (A frequent recommendation)
- Extend Tricare coverage of ABA therapy to children with behavioral disorders other than autism.
- Increase the number of providers that accept Tricare.
- Train health care providers in Tricare/ECHO coverage and terminology so prescriptions (e.g., for ABA or specialized car seats) will be honored without dispute.

- Assign Tricare case managers to a larger proportion of the EFMP population.
- Increase Tricare coverage for special-needs family members of retirees.

Study Participants' Recommendations Related to Base Health Care Services

- Establish a dedicated special-needs pediatrician position on base.
- Transport outside health care specialists (e.g., pediatric endocrinologists or neurologists) to base on a regular basis rather than requiring families to travel.

3.1.3. Access of USMC EFM to Education-Related Services

The findings for this topic are presented under six headings: context, services and circumstances that are working well, difficulties and obstacles, other education-related issues, participants' recommendations, and summary. Findings were elicited by the focus group questions listed earlier, unless otherwise specified. Further findings related to USMC EFM access to special education services are discussed under Section 3.2.3, which deals with PCS and access.

3.1.3.1. Context

Children of military families residing in the continental United States may receive their pre-K–12 education from public schools operated by local education agencies (LEAs) in civilian communities, public schools operated by LEAs on base, or DoD schools operated by the DoD Education Activity (DoDEA) on base.²⁹ DoDEA schools serve students with disabilities—beginning with preschool services starting at age three for children enrolled in EFMP. Over the course of their education, military children may move in and out of LEAs and DoD schools. DoDEA operates Domestic Dependent Elementary and Secondary Schools (DDESS) in only seven states (including Puerto

Rico and Cuba), however, and these are intended for the minority of military families that live on base. Likewise, on-base schools operated by LEAs are uncommon. Thus, at any given point in time, the vast majority of military children are attending public schools in the civilian community. A small number of military families send their children to private schools or charter schools, or home-school them.

MCB Quantico has three elementary schools and one middle/high school on base. Quantico children and youth also attend schools in Prince William, Stafford, Spotsylvania, and Frederick Counties. Camp Lejeune has five elementary schools, a middle school, and a high school on base. Lejeune children and youth also attend schools in Onslow and Jones Counties. Two LEAs operate on Camp Pendleton, both of which also operate schools off base. These two LEAs—Fallbrook School District in the northern end of base and Oceanside School District further south—have a total of five schools on base: four K–6 and one K–8. There are no high schools located on Camp Pendleton; however, Oceanside Unified School District high schools and Fallbrook Union High School District high schools are very close to base.

3.1.3.2. Services and Circumstances That Are Working Well

We focus here on the positive observations of caretakers and EFMs, who comprise the customers of special education services. As appropriate, we include provider perspectives on these observations. All services and circumstances noted here were mentioned by at least several study participants.

DoDEA Schools. Consistent with military families at large, many parents of EFMs expressed great satisfaction with the DoDEA schools and a preference for the DoDEA school system over the public school system. Parents tended to perceive that DoDEA schools offer a more inclusive special education environment than most public schools, and providers corroborated this. Focus group participants said:

“I can only speak for Quantico; the school we dealt with there I really loved.... I know a lot of parents aren’t crazy about the DoD school

system, but I really liked it. I liked their inclusion policy.... We had a really great teacher.” (Caretaker)

“She is treated exactly like everyone else in the classroom. We haven’t had any issues as far as her rights. They went on a field trip ... the nurse is great.” (Caretaker)

“Special education out in town is not good. It’s much better within DoDEA and on base, that’s why we’ve stayed here for nine years. I had my fights in South Carolina.... We had to fight for inclusion versus the self-contained approach they use in South Carolina. In South Carolina, their idea of inclusion was seven and a half hours a week at the cafeteria.” (Caretaker)

“When you go the public school, there’s a special education class and the typically developing class; our special education programs are more comingled here. That has proven to be much more successful than just putting a child in a room full of other special-needs children.” (Provider)

Parents perceived, and providers confirmed, that DoDEA schools are well resourced. Focus group participants said:

“The DoD school has been phenomenal.”

“The school on base started off with no accessible playgrounds, and now they’re building one. They went from a blank room and asking us and another couple what we needed for (our severely impaired EFMs) to having everything you can imagine in there now.” (Caretakers)

“My son gets a lot of stuff through the school. Because we’re EFMP, he got into preschool early (we’re on base); he gets a lot of speech, OT, and PT. He gets all that from the school....” (Caretaker)

“Had I known the supports that DoD schools offer for special-needs kids, we would not have bought a house, we would have moved on base.”

“DoDEA has their issues, too, but at least since it’s on base, we can go to the green side and say, ‘Help us.’ At least here we know the Marines are going to take care of their own.” (Caretaker)

“I think compared to the local education agencies—because I’ve worked with both—I think we have incredible resources. We have great reading support programs, math support programs, counseling services, etc. Because we work with only military families, our counselors do amazing support groups....” (Provider)

“The most profound programs have a component for activities of daily living skills. We have a small apartment with a kitchen, washer/dryer, and living room that we link to base.... For students who need community-based instruction, we use the commissary, post exchange, post office, bowling alley, or we send them to “Q Town” [on base] to learn how to go to a restaurant, etc.” (Provider)

Early Development Intervention Services (EDIS). Often, eligible parents expressed great appreciation for the EDIS program. In addition to providing important early intervention services, participation in EDIS qualifies youngsters for enrollment in DoDEA preschool. Of course, EDIS exists only on installations with DoDEA schools, and only families living on base are eligible to participate. (Several providers noted that comparable early intervention programs exist in the civilian community.) Focus group participants said:

“Our case manager at EDIS knows exactly how things need to be put in so we get covered....” (Caretaker)

“Upon diagnosis I turned to EDIS. They gave great information. They were awesome at it.” (Caretaker)

School Liaisons. The USMC recently hired installation-based school liaisons (SLs) to facilitate the educational adjustment of USMC children, including children who are typically developing and those with special needs. There is some recognition among EFMP families, albeit inconsistent, of the help that the school liaisons can provide. Focus group participants said:

“If you can utilize the SL and they’re good, then that’s awesome. He got a copy of my IEP and faxed it directly to the SELPA [Special Education Local Plan Area] director, and this was before we even left 29 Palms, so they had a placement for my child when we got here.” (Caretaker)

“The school liaison is another resource that I used for help. When I wrote my letter requesting evaluation, I sent it to her; she reviewed it, and she made a few minor corrections.... You can tell people, ‘You should call her and do this,’ but until you’re actually going through it you don’t know what a big difference it makes.” (Caretaker)

“SLs are not new, but people are just now finding out about them.... Here, in Norfolk, big Navy, they just got their first SL. She is really great but she gets bogged down, and doesn’t understand EFMP at all. She uses us as a resource to learn about EFMP.” (Caretaker)

In North Carolina only, in recognition of the high concentration of military families in the state, the governor has established a school-based county military liaison officer position to augment the reach of the school liaisons.

Advocacy and Advocacy-Training Organizations. Parents repeatedly mentioned two organizations that have helped them advocate and navigate within school systems.

These organizations were Specialized Training of Military Parents (STOMP) and Task.Mil. Focus group participants said:

“I went to the Task.Mil program and they said, ‘What are you doing?’ So I wrote letters and I kept them [the school] in check. I have huge binders for both of my children now ... and finally in third grade they ran a full psycho-education evaluation on him and they realized he did qualify for special education....” (Caretaker)

“I used TaskMil.Org. They’re government funded; they have lawyers on hand. It’s a team of advocates for special-needs kids. They have a civilian and military division. They helped me to go to bat with the school district....” (Caretaker)

“When I make a phone call to STOMP, they’ll get involved ... to make sure I did everything I needed to, all the ‘I’s are dotted; they come with me and say, ‘We’ll bring our attorneys in if you won’t do this.’” (Caretaker)

“STOMP is EFMP particular. It’s a nationwide initiative paid by federal grant money from the Department of Education with the same goals as a PTI [Parent Training and Information] center to train parents to be knowledgeable and to advocate. They don’t have enough people because there are 300-plus installations for all the services, but you can go on to their listserv and website. STOMP does trainings and they train on all the national laws.”

“The dilemma with STOMP is commands have to provide funding to get STOMP to come.”

“These people are only getting paid \$12–\$14 an hour. They come down to do federal training, but they don’t go into that state’s laws. It’s not state specific; it can’t be.” (Providers)

Free training offered by North Coastal Consortium for Special Education (NCCSE). This resource is unique to NCCSE school districts, which include the school districts serving Camp Pendleton. A California educator noted that parents are welcome to take advantage of NCCSE professional development events and information disseminated at the standing NCCSE parent group meetings. Focus group participants said:

“NCCSE has a huge professional development budget and part of it goes into providing in-services that parents have access to ... [on topics like] good strategies for my child’s behavior or sensory issues. Parents are eligible to attend these trainings.” (Provider)

“Each district sends a parent representative to it [the parent group], a volunteer, and they discuss the issues in the framework of the district, and they usually always have someone who comes and does a special in-service. That’s a regular NCCSE meeting that is mandated in our procedures, part of what we have to do on a yearly basis. It’s an open event; any parent can attend that meeting.... A parent from each district will participate in that and bring back information they get from that meeting to smaller parent groups organized in a district by parents.”
(Provider)

It is unclear whether military families are represented in the NCCSE parent group.

Other Initiatives. Initiatives mentioned by parents included Treatment and Education of Autistic and Communication-related Handicapped Children (TEACCH) (a leading source of autism support in North Carolina), Parent Resource Centers (in most schools in Virginia), and the “School Loop” website (specific to a California school district). Several providers mentioned the conferences and efforts of the Military Child Education Coalition (MCEC).

3.1.3.3. Difficulties and Obstacles

For this topic, we present the perspectives of all stakeholder groups who participated in the study, including caretakers, EFMs, and providers.

Parents feel they are perpetually fighting the school system. With great regularity, parents described how they feel they must constantly push for the educational services their children need and deserve. It appears from parents' comments that lack of knowledge and lack of leverage on their part contribute to the challenge they face. Focus group participants said:

"The school isn't working very well. We're having trouble with getting the school to follow the IEP and personalized education plan (PEP) we have in place. I don't know if it's mandated; I'm being told by my friends that the school has to follow what's in an IEP. I don't know how to force the IEP on the school." (Caretaker)

"It took one and a half years to fight the school system in town to get education for my child. There's no one place to turn to get rights when the school is concerned." (Caretaker)

"[T]hey put my six-year-old in a typical class and I said he couldn't be there, but it took them a month to realize I was right. I asked for an aide, but they wouldn't provide it. I asked for a bus; they said they wouldn't provide them for special-needs kids.... They offered me a school off base, but they wouldn't provide me transportation." (Caretaker)

"I pull out the STOMP paper and I'll come to the meeting with a three-ring binder with STOMP papers on the front and I'm like, "Do you want me to start calling?" Things have to happen, things have to change. I feel like I need to be a bitch to get the help we're supposed to get." (Caretaker)

Providers recognize that there often is an adversarial dynamic in the interactions between parents of special-needs students and the schools. Like parents, providers attribute the problem in part to parents' lack of full understanding of how services are determined. Focus group participants said:

"I hear from parents who have had rough spots and the parents will say, 'I have to fight for everything I get.' I got a call from a parent yesterday with a nine-year-old kid with Downs getting mainstreamed in a kindergarten class in another state, and I assured her that wouldn't happen here...."
(Provider)

"As soon as a parent feels they're having something taken away, or not getting what they got somewhere else, you're already at odds. That's such a negative way to start off with the school...." (Provider)

"Parents have a hard time understanding the district's recommendation for a low-end piece of equipment. The district has to go with the recommendation of their experts. From my understanding (if parents want to obtain more expensive equipment), that becomes a battle between them and Tricare or ECHO. They have to fight with them, too. Parents sometimes feel they're fighting on all fronts." (Provider)

"The IEP services sometimes are not implemented in a way that a parent feels they should be. I'm using my words carefully because the law is clear on this; we don't have to duplicate services; a child can come in from Prince William County with five hours of speech therapy on their IEP, and we could decide to do it in one hour. But the parents do not understand why their child isn't receiving the same amount of time in the resource room in the new place as they were with us...." (Provider)

Some parents perceive that schools take advantage of the fact that military families are transient.

“Because we’re military and we move so much, they don’t feel like they need to provide the services for our kids. By the time they try to help us, we’ll already have left. They say it without saying it.... Administrators will put up a fight, thinking if they do it enough you’ll just take what they give you since you’re so desperate to have something quickly for your child.”
(Caretaker)

“It takes time to make IEPs become compliant. It takes time going through the system. A lot of families move and they count on that.”
(Caretaker)

Parents were less likely to express negative sentiments about DoDEA schools than public schools, and no overarching themes of DoDEA school deficiencies or battling with DoDEA schools emerged from parents’ comments. That said, a parent-advocate suggested that there are significant problems with DoDEA special education at one of the sites visited: “Right now every child with a disability, it doesn’t matter what their needs are, they’re being fully included in a regular classroom without behavioral support.... In addition ... there’s a huge knowledge gap on IDEA and what they need to do to provide appropriate supports.”

Some schools and youth programs are not ADA compliant. Comments about school accessibility or school compliance with ADA were uncommon, possibly because we spoke with few families dealing with students with physical disabilities. The experiences of the few are noteworthy nonetheless.

“Every school she has been to in the past three years ... it’s 2010, not 1963 ... we had to fight with the county to get them to put a lift in the Norfolk County school so she could be in the choir program on stage with other kids. In Onslow County, North Carolina ... there were bathrooms that weren’t handicapped accessible ... buildings without ramps.”

“She is in a school of excellence in Norfolk, Virginia. The elevator is so old it stops working once a week.”

“The main doors aren’t large enough for my wheelchair to get through; the only access I have is through side doors, and the side doors remain locked all day long.”

“There’s no additional handicap parking. There’s two handicap spots, and they’re for teachers.” (Caretaker/EFM)

“Two years ago, the theatre, which holds 1,200 people total, added a wheelchair row in the very back and took out the ramps and said, ‘Too bad, you can sit in the back.’ I brought up fire issues, if there’s a fire in the back, and there’s no ramps going forward, then my child can’t get out unless they go through the fire. They said, ‘There’s 28 seats back there; that’s okay We’re allowed to do that.’” (Caretaker)

One on-base provider identified several instances of failure by base programs to provide appropriate educational and recreational services to children with disabilities. This provider said (1) the Child Development Center places four-year-olds in the two-year-old room if they are not toilet trained, thus depriving them of an age-appropriate education; (2) eligibility to participate in child, youth, and teen after-school programs is denied to children with autism who “don’t behave” or children who use a wheelchair or who wear a diaper; and (3) children who cannot run are disqualified from participating in the summer camp for children with special needs. The provider attributed these shortfalls largely to ignorance of ADA requirements on the part of program providers and base leadership, as well as an absence of oversight.

Public school resourcing is not keeping pace with the influx of military children. At two of the three study sites, participants noted how LEAs (one off base and the other on base) are having difficulty accommodating increasing numbers of military students. The influx includes an inordinately high proportion of students with special needs. In one case, an education professional from a highly military-impacted county indicated that Base

Realignment and Closure (BRAC) and the presence of two nearby installations contribute to a high proportion of military EFMs within her school system and an undue burden on its resources and capacity to meet all children’s educational needs. To this individual’s knowledge, there has been little to no discussion among the bases, DoDEA, and the county about the impact of this influx.

“The X housing office keeps telling families to go down to X County because there are a lot of houses there, whereas X County is congested and full with BRAC.... So we end up with an increasing number of children, and there’s been little to no discussion with the local schools.... I would think it would behoove the military to talk to the local school divisions in terms of impact and how EFMs were to be served but.... I know there’s two kinds of impact aid—the one there has always been ... [and] the other is if a child is over and above.... We can claim a portion of that to get some additional miniscule funding.... By state law, we have eight children in a classroom for children who are more severely impacted by ASD, with a teacher and two aides. We can’t wait for someone to turn around and say, ‘Well, there could be extra funding somewhere down the line.’ We’re experiencing the demand now.” (Provider)

In the second case, the influx was triggered by the construction of additional family housing units on base, which contributed to a growth in the school-age population in that school district.

“I think a big problem is they’ve opened up a new housing area up north, which has allowed a lot of families to come into the school and the classroom sizes have grown.” (Provider)

Ease of Access of On-Base Families to Special Education. This concern is unique to families who elect to live in base housing on the northern end of Camp Pendleton. Due to LEA resource constraints, certain primary-school students with disabilities in grades three and higher must be bused to fairly distant schools in order to obtain

appropriate special-education services. This is an untenable arrangement for many families, and one of which they apparently were unaware at the time they chose their housing. Focus group participants said:

“There’s a lot of housing up around there [San Onofre]. Families want to live there, and there’s access to the beach, but the services there are very limited for families with students from moderate to severe disabilities. We have a preschool class there and a class through second grade.... It’s hard for families to accept, when their house is across the street from an elementary school and their kid can’t go there and has to get bused to another school due to the fact that a limited number of students have that need.... Sometimes in a year we bus one to two students maximum, and then other years we have none.... Especially for a family that has a child with severe disabilities and medical issues, it’s hard for a parent to think about putting their child on a bus 30 minutes away from them versus five minutes up the street, if an emergency occurs. The typical outcome is that families get very upset. It becomes a contentious situation. The district is required to make an offer of FAPE [free appropriate public education] and to provide the least-restrictive environment for that student, which in the district may be in Oceanside [i.e., the southern end of base]. We have no access to the [public school] programs to the north of San Onofre—it’s a totally different district, and they don’t take special-needs students from Pendleton when they’re heavily impacted with special-needs students of their own.” (Provider)

“We’ve been working with families who want to move to San Onofre, but there isn’t the full range of options out there and, if they choose to go there, their family might be on the bus for a while. It’s expensive for the school district. It’s also not good for a kid with special needs to be on the bus for that long.... If you move in with a third-grader or above and you call me and I say, ‘That’s fine, but you’ll have to go to school somewhere

else,' some of them get really upset because they didn't know. So we've been working with Housing.... They need to know ahead of time what they're getting into." (Provider)

3.1.3.4. Other Special Education-Related Issues

The focus group protocol included several special education-related questions. These questions were posed to select focus groups attended by educators, parents, or EFMs with relevant background. The questions, and summaries of the responses they elicited, are presented below.

Oversight of USMC EFM Special Education by the Department of Defense (DoD) and the Department of Education (DoE). Educators were asked,

- In what ways do DoD/DoE monitor and enforce compliance with policy related to the education of USMC students with disabilities?
- How effectively do these DoD/DoE activities address the unique needs of USMC students with disabilities?
- How could DoD/DoE better help to ensure that USMC students receive appropriate, effective education services?

DoD plays a central role in overseeing the quality of special education within DoDEA schools. One focus group participant said:

"We do it in several different levels. The first level is at the district level of oversight; then we have the area service center ... an outside team may come in [from the area service center]. After [that] level it goes up to the DoDEA level, which has headquarters in Arlington, then after that is the DoD level. Every year a school receives at minimum a district visit.... There are 19 standards from the DoD, and DoD flows down from IDEA, that they use to check compliance. We are responsible for 19 standards,

which fall into child find/referral, assessment process, eligibility process, IEPs, least restrictive environment, personnel credentialing, and professional development. We have to meet and show evidence of all of these things.” (Provider)

With respect to oversight of public school special education by DoE, several educators commented about the extensive guidance, resources, and oversight that DoE provides.

“The federal guidelines and regulations for special education are huge. There are timelines and policies and teacher-student ratios, and everything is governed and enforced by federal regulations....”

“There’s a lot of monitoring in the school, and families have to advocate for themselves. It’s not a perfect system by any means, but in this area the monitoring is very on task with making sure they’re abiding by the law....”

“They have a parent liaison in every Title I school. Their job is to help walk every parent in that school through every step as needed.”
(Providers)

“The last time the legislation was reauthorized was 2004. Since that time, the states have developed their own set of regulations governing special education. They may go above and beyond the federal regulations, but they may not go under the federal regulations. The office within DoE for special education services monitors the states and the states monitor the districts. We always have indicator reports. There are a number of indicators looking at compliance issues, like, ‘Have you met 65-day completion of all assessments?’ There are 22 of those. Some apply only to the state... [and] the others we complete and then they are publicly reported, so there’s a tremendous amount of oversight.” (Provider)

No comments were offered regarding DoE oversight of special education services specifically for military or USMC students. A base proponent did observe, however, that LEAs have not yet been provided clear guidance on how to implement initiatives included in the Interstate Compact on Educational Opportunity for Military Children.

“The Interstate Compact on Educational Opportunity for Military Children was recently passed [in this state], but there’s no guidance from the state DoE regarding the implementation of that compact. There’s no guidance to the schools from superintendents down to principals on how to implement that procedure. No one has gone through and said, ‘Here’s this thing, and how does it affect our policy?’ ... They’re really great about it once you say, ‘Okay, you can’t do this anymore; here’s the law.’”

(Provider)

USMC EFM Access to Assistive Equipment. Participants were asked, To what extent does your EFM have access to the technology or equipment (i.e., assistive equipment) that he or she needs to help them do their schoolwork? This question triggered general discussions about access to equipment—for example, mobility devices, eyeglasses, weighted vests, special-needs bicycles, slant-boards, and touch screen computers. The findings were summarized earlier in Section 3.1.2, in relation to health care and Tricare/ECHO coverage. While some families described having to pay out of pocket for such equipment, others indicated the schools [LEAs or DoDEA] or insurance provided it. A DoDEA educator suggested that they are making strides in the use of assistive technology.

“Services in terms of knowing how to access and use assistive technology. I’ve seen that grow [within DoDEA] in the last four years a lot. When our students leave us, we wonder what supports they’ll receive....”

(Provider)

Another educator noted that sometimes the equipment that parents desire for their child is not necessarily the equipment that experts believe would best support the child’s

educational goals. Overall, for analysis purposes, insufficient data were gathered on the topic of assistive equipment.

USMC EFM School-to-Work Transition. Participants were asked the following series of questions pertaining to school-to-work transition:

- How much does PCS impact transition planning for the transition out of high school?
- What kinds of transition-planning services are available to meet your EFM's transition needs?
- How well do these services meet your EFM's needs?
- How could your EFM's transition-planning needs be better supported?

Many of the participating providers and families had little to no direct knowledge or experience related to school-to-work transition. Accordingly, for analysis purposes, the discussions produced insufficient data on this topic. The discussions were fruitful from an exploratory standpoint, however, and they are summarized below. Note that the subject of school-to-work transition pertains to both special education and long-term supports and services. Accordingly, related information is presented in the long-term supports and services discussions under Sections 3.1.4 and 3.2.4.

It became apparent that one must differentiate between school-to-work transition planning and school-to-work transition services. School-to-work transition planning should be a multiyear, multifaceted process that begins as early as middle school and addresses, for example, vocational exploration, college guidance as appropriate, and independent living. Insights about how this works were offered at all three sites. Focus group participants said:

“We have an IEP meeting coming up in a couple of weeks. We’re meeting with voc rehab.... They’re coming to my IEP meeting at the [DoDEA] high

school. It will be a panel discussion as far as what his next steps are. This is the method for transitioning him to what voc rehab can offer.... They've already started the preliminary paperwork to make sure he qualifies for voc rehab services. The school does it for seniors. His special-education teacher contacts voc rehab and tells them who she has that are seniors, and then she sent me the information...." (Caretaker)

"[When students reach]16, we [a DoDEA school] do our transition assessment, and for some students it will mean job exploration during school or even job placement; but for many children it's just support on how to get to college. How do you know what resources you're entitled to and how do you access those? We have a class called 'learning strategies' at the high school, and the midterm and final exam are all about self-advocacy. They have to chair their own IEP meetings by the time they're a senior." (Provider)

"By law, any child who has an IEP, the schools write up a transition plan for those students. It's comparable to a career transition plan. Anybody, military or not, will have access to whatever services the schools recommend for them, which oftentimes includes voc rehab contacts at least. The schools have to look at school to work by law starting at age 16."

"The regional center also has great support for employment and living independently."

"We're working on educating people about knowing what to ask and knowing what to expect. The transition teachers are learning more and more about it." (Providers)

"Schools are responsible for kids up until they're 22. I don't think that looks any different support-wise for military families than it does for the civilian families. Also, we always do the individual transition plan (ITP), which starts when kids are 16.... All students with an IEP get an ITP"

starting at or before 16. But the initial part of ITP at 16 is more exploring courses in school, going on the Internet and looking at job interests.... When kids start college, what junior college will that be? What transcripts will you need? What are your mobility issues going to be? They might start doing mobility training like taking a bus from the high school to the junior college or junior college home. Another part of that might be beginning to explore, through school vocational training, what kinds of jobs do you need or supports do you need while you go to school so you can have a job? What types of adult services can you get when you become 18? Will you go to a junior college and be under their students with disability services?" (Provider)

"Fourteen-year-olds want to be ice princesses or NBA stars. That's a middle-school-to-high-school piece. Looking at the kinds of courses they have to take in order to achieve their ambitions.... That's part of transition planning—it's also working with the family and outside agencies like the Community Services Board.... It really depends on the extent of disability." (Provider)

"I know they have a program called LINKS, which stands for Lifestyle, Insights, Networking, Knowledge, and Skills. LINKS helps any child or young person with a disability to link over into getting jobs, providing resources, and sending them on certain jobs.... It's an MCCS program." (Provider)

School-to-work transition services—including job training, daily living skills training, and employment—may be offered by the schools, departments of vocational rehabilitation and employment, and even USMC bases. It appears that all three bases visited have some form of job training or supportive employment program, including bases with and without DoDEA schools. Focus group participants said:

“We [public school] have a very good transition program ... EMPLOY. [School staff] work with all of the transition specialists, who seek out local employers.... We then have vocational technical people go out and monitor how well the child is performing. We try to tailor those jobs to meet those children’s needs. The aim is to employ the children when they leave school.” (Provider)

“He’s gone to different job sites every year through the [DoDEA] school on base, like the food court or the garden center, videos, the HR office. He learns a different trade each time. This started when he was a freshman, so when he was 15. It’s a program they do about three times a week. They transport him to the sites, they support him, they usually have an aide.... I know through voc rehab that they have services that will put him with a job coach, and work toward helping him get a job. I do know there are several places on base where we think he’d love to work.... The paperwork we’ve filled out so far is just about his disability, not our military status.” (Caretaker)

“For certain students, if the disability is significant enough, they can be in our [public] school system until they’re 22.... At post-22, the state has post-school day services. I think one of the adult programs is actually on base.”

“It’s called ‘solutions’ or something like that—it’s our janitors.” (Providers)

“We also have community-based vocational training as well as our Red Cross office here, which is phenomenal. They help us do job exploration and placement.... Right now we have a young lady working at the relocation office, and every time a Marine comes in she makes them their welcome packet. We’ve used the game warden, the golf club, the commissary, the clinic. Any time a child expresses an interest, we try to hook them up through the base. The partnership on this base is

unbelievable. The monitoring team is always interested in how much we use our installation, our base resources, to address school to work transition.” (Provider)

EFMP’s role in school-to-work transition seems to be limited to information and referral.

“We refer them to agencies that do the transition classes. We’re having a waiver class to talk about this.... These are things you need to consider during transition.... Other than that, we cannot do the transition plan ourselves. We’re in a position to educate families and help them see how to get services. We point them to the people who help you, we do information referral and case management and help transfer them in and out.” (Provider)

Based on the information gathered, it appears that robust programs for school-to-work transition may be lacking. Those who commented suggested that transition planning services, as well as supports for implementing transition plans, are understaffed, weak, and challenged. Focus group participants said:

“Most of your transition stuff comes from schools, but that’s a huge deficit because the schools really need help in doing that.”

“In the county I’m in, we have job coaches and a transition specialist in every high school, but other counties aren’t that lucky. They don’t all get the services.... It’s based on need and we could use one hundred times more.... Once your kids get out of school, there aren’t a lot of services in this area.... We have kids coming out of the school systems and they have transition plans that the school helped them with before they left, but they don’t translate into services once they leave school.” (Providers)

PCS potentially interrupts the high school education and completion of every military high school student, special needs or otherwise. There was agreement, however, that

PCSing while planning or implementing school-to-work transition can place students with disabilities at particular risk. Focus group participants said:

“It would be devastating [for my senior]. When we looked at a house out in town, he was terrified he wouldn’t get to go to X. Plus education: I was like, ‘I cannot change the IEP. I can’t have him move now.’” (Caretaker)

“It’s really kind of challenging. We’re able to link high school students with disabilities with agencies here but, if they’re leaving, that is a challenge, the timing is very difficult. You start that transitional planning in North Carolina at the age of 14. If you know this is a military family that is going to be leaving, that should be central to your transition planning. It’s not easy to do; we do link them up with our voc rehab group and agencies within Onslow County. We can also help facilitate where they’re going and the connection on the other end with EFMP.” (Provider)

“In one way, because it’s a transient population, we link into local rehabilitative services.... But, somehow, impressing upon the family to use those resources doesn’t cover it. The family leaves us and doesn’t access those resources. In the last two instances, we felt they didn’t really know how to go about getting those services. So, for PCS during the delicate time of transition to postsecondary work, we need something tighter.” (Provider)

One educator suggested that continuity of services may be at greater risk if a student with special needs PCSes after graduation than if he or she PCSes during high school.

“We have found it’s better if they move while they’re still in high school because they’re still linked to an LEA. We feel it’s detrimental if they leave right after graduation because then they’re out there and they aren’t hooked to anything, and it requires self-advocacy and it doesn’t happen. If a child is going into their junior year, that’s great.” (Provider)

The transition plan of a young adult with special needs often is location and community specific. The skills and connections they have acquired do not easily transfer to a new environment.

“I think a particular problem a military family might face, for our programs that train 18- to 22-year-olds, it’s always focused on training them to learn to be competent where they live, and since they move so often, the skills they learn that are very specific may not be generalizable. They will have a hard time learning how to transfer those skills to a new job in a new place. That’s an age where the community connections they’ve been able to build come into play. If they’re known in community ... that transition to a nonstructured day is helped, you have people willing to consider you for employment, there’s just more supports.”

“If there are wait lists to get into adult services in other states, then that will be even more of a challenge.” (Providers)

3.1.3.5. Summary

The focus of this discussion was special education services. Because bases with DoDEA schools are the exception rather than the rule, USMC students frequently attend public schools. Participants identified a number of military resources that facilitate EFM access to education-related services. The vast majority of parents described DoDEA schools as well-resourced and praised DoDEA’s inclusive model for students with disabilities. Eligible parents made equally positive remarks about EDIS, an early intervention program that feeds into the DoDEA system. Participants also mentioned valuable national-level civilian resources for advocacy and advocacy training within the educational environment—most notably STOMP and Task.Mil.

In spite of these military and civilian resources, EFMP families encounter a number of obstacles to accessing education-related services. With great regularity, parents described feeling that they must fight schools to secure disability-related resources for

their children. It appears that parents' lack of knowledge about how disability-related services are determined for each child, and their inability to influence this process, contribute to an adversarial dynamic. Several parents and providers observed that schools and other educational facilities (including on and off base) are not fully accessible to students with disabilities. At two locations, it was noted that schools are ill equipped to handle the recent influx of students with disabilities—one influx occasioned by BRAC and the second by the construction of a new housing area on base.

Relatively few providers and parents had direct experience with school-to-work transition. The approach to, and robustness of, school-to-work transition planning seems to vary by location. Several providers suggested it is not well resourced. Providers explained that school-to-work transition planning should be a multiyear process, built into IEPs, that begins early in high school. Both providers and parents noted that PCS during or immediately after high school, when EFMs are engaged in school-to-work transition, may jeopardize EFMs' successful navigation of the school-to-work transition.

3.1.3.6. Study Participants' Recommendations

In this section, we present recommendations offered by the study participants to improve EFM access to special education services. All recommendations were made by one or more individuals; most pertain to DoDEA.

- Assign EFMP families only to bases with DoDEA schools. In other words, allow children with special needs to remain in the DoDEA school system.
- Provide the full continuum of special education services at more installations with DoDEA schools.
- Provide schools detailed guidance for implementing initiatives included in the Interstate Compact on Educational Opportunity for Military Children.

- EDIS exists only on bases with DoDEA schools, and only families living on base are eligible to participate. Ensure that off-base families needing early intervention services are systematically referred to comparable early intervention programs in the civilian community.

3.1.4. Access of USMC EFMs to Long-Term Supports and Services

Early in the data collection phase, we discovered that “long-term supports and services” did not seem to be a commonly used term among the study participants, nor one with a shared definition. For example, several providers assumed it referred to resources that an EFM would need after leaving the current installation or after the EFM’s Marine sponsor leaves active service. In actuality, long-term supports and services are “services that include medical and non-medical care to people with a chronic illness or disability. Long-term care helps meet health or personal needs. Most long-term care assists people with Activities of Daily Living, such as dressing, bathing, and toileting. Long-term care can be provided at home, in the community, or in a facility...”³⁰ We speculate that the term did not resonate with study participants because most of those with whom we spoke did not have personal experience with these kinds of needs. That is, (1) the children of the parents we spoke with had not yet aged out of the special education system; (2) very few of the EFMs we encountered, either directly or through their parents, had conditions requiring long-term services and supports; and (3) the providers who participated in the focus groups came primarily from the education and health care communities. (For further detail about the characteristics of the study participants, see Chapter 2.)

Because most study participants had little to draw upon related to long-term supports and services, the findings yielded on this topic by the focus group discussions are sparse. They are presented under five headings: context, services and circumstances that are working well, difficulties and obstacles, other issues related to long-term supports and services, and summary. The findings were elicited by the focus group questions listed earlier, unless otherwise specified. Further findings regarding long-term supports and services, including recommendations, can be found in the previous

discussion of school-to-work transition (Section 3.1.3) and in Section 3.2.3, which deals with PCS and access.

3.1.4.1. Context

There are military-specific health care and education resources for people with disabilities. For health care, USMC family members with special needs have access to the military health care system, including Tricare. For special education, they have access to DoDEA schools (subject to where they are living). For long-term services and supports, the military and the Marine Corps have no such dedicated programs—EFMs requiring such assistance rely on civilian resources, although EFMP is available for information, referral, advocacy, and related support. The proportion of EFMs across the USMC that rely on long-term supports and services remains unclear.

3.1.4.2. Services and Circumstances That Are Working Well

Following are several positive observations shared by one or more study participants, including families and providers.

Medicaid. Medicaid (in California known as MediCal) is an invaluable resource for families with severely impaired EFMs. Focus group participants said:

“But if your child is on SSI disability and you lose it, you can go to the Regional Center and get a MediCal waiver form, where it’s based on the child and their income, and it’s good because Tricare only covers 35 percent of my son’s needs. MediCal covers diapers for my son, the sprays they give you to help with urine, the creams, the ‘Chux’ pads. Tricare considers cerebral palsy non-rehabilitatable after the first three years, so he can get one PT session every six to eight months.... They see it as a maintenance thing. So MediCal pays for PT three times a week, OT twice a week, our equipment. It’s nine months to a year to get a

wheelchair or walker through Tricare, but I let them deny it, and go through MediCal.” (Caretaker)

“Medicaid pays for all his incontinent items, a hospital bed, the community agency where we hire someone or go through an agency to hire someone to find people to help us with laundry. Also, they get all his co-pays on his medications.”

“We have a lot of costs and we can’t do mail order through Bethesda because if you have 14 medications they come late. So we have to go to the compound, but, with \$9 a med, that adds up, and diapers and pads, etc.” (Caretakers)

EFM Attorney. The EFM attorney provides free legal assistance related to long-term needs, for example, trust planning for special needs. One focus group participant said:

“Estate planning and guardianship are two examples of long-term services that families on the outside don’t have because they don’t have an attorney they can see for free to take care of all those things for them.”
(Provider)

In-Home Supportive Services. A California parent mentioned the home- and community-based care waiver available through Medicaid (MediCal), which pays her to care for her severely disabled child.

“California has in-home supportive services, where parents get paid 280 hours a month to take care of their children. I get paid \$9.50 an hour to stay home, not work, and care for my child. I use that to pay for all the co-pays.” (Caretaker)

Extended Home Health Care (EHHHC). Only one study participant, a provider, mentioned this Tricare program.

“Then there’s another program called EHC—Extended Home Health Care. It’s out of California. It’s part of Tricare. So there’s Tricare, ECHO, and EHC, which provides full time in-home nursing care.” (Provider)

3.1.4.3. Difficulties and Obstacles

The lion’s share of the study participants’ concerns about long-term supports and services pertained to the impact of PCSing, and are discussed under Section 3.2. Several additional difficulties and obstacles are summarized below.

Worry about Long-Term Welfare of Children with Special needs. A number of parents expressed concern over the long-term care of their children with special needs, particularly after retirement from the Marine Corps.

“ECHO is only military active duty. When it comes time for retirement, you lose ECHO, you lose health care, and a lot of those services don’t extend beyond active duty. A lot of families struggle with active duty and deployment because it’s a sacrifice, but when you retire, you’re dropped from that care, and you’re left to start again.” (Caretaker)

Support for Adult EFMs. A provider pointed out that transportation to doctor visits can pose a significant barrier to care for adult EFMs who do not drive, because Tricare does not cover transportation. While Medicaid does cover transportation, some military families do not qualify financially. Focus group participants said:

“There’s the issue of transportation—if they can’t transport themselves to the hospital or doctor, how can we get them treatment? That’s a big issue. They need Medicaid to use civilian transportation resources, but they can’t get that because they have a family member that works. That’s a big conundrum.”

“Transportation falls into the gaps of Tricare.” (Providers)

Another provider observed that, similarly, neither Tricare nor Medicaid covers a personal care attendant for military family members. HQ USMC is keenly aware that there are adult EFMs who need personal care attendants and lack access to them. As of this writing, HQ USMC is pursuing funding for a program that would reimburse families, up to a specified level, for the cost for a nonmedical attendant.³¹ The needs of adult EFMs are discussed further in Sections 3.2.4, and 3.4.3.

3.1.4.4. Other Issues Related to Long-Term Supports and Services

The focus group protocol included three specific questions that were posed to select focus groups attended by providers, caretakers, and EFMs with knowledge of long-term supports and services. These questions shared a common theme, which was the parity of civilian and USMC EFM access to long-term supports and services. The questions were as follows:

- How well do major long-term supports and services available to civilian EFMs also meet the needs of USMC EFMs?
- How well do vocational rehabilitation and employment services available to civilian youth also meet the needs of USMC youth?
- How well do vocational rehabilitation and employment services meet the needs of newly disabled USMC adults?

By and large, the participants indicated that the access of USMC EFMs to these long-term supports and services is comparable to that of their civilian counterparts. They suggested that vocational rehabilitation and employment services tend to be inadequate for both populations, however. Several providers explained that obtaining appropriate vocational rehabilitation and employment services often requires strong advocacy on the part of parents and students, who may not be knowledgeable enough to pursue it. Focus group participants said:

“That’s a subject across the board with civilian and military that’s lacking. The schools are required to start their IEP and transition to the workforce at 16, but there aren’t many states that really provide that. You have to fight to make sure it’s happening. Our job is to train those parents to start the planning and assessments. Teaching them about the work ability programs in the school districts and, as they get ready to graduate, to bring the rehab and social services that provide those job coaches and things like that. It’s about connecting those services with the state so the child has some sort of job prospects or education.”

“It’s very closely connected to the IEP process.”

“It’s only as good as the parents and students that advocate for it. If you know what to ask for, you might be able to get it. It’s not a high priority that I personally have seen the school districts do. It’s not proactive—you must request it.”

“It doesn’t exist unless the parents are following up on it. And whether they’re following up on it depends on their knowledge and where they’re stationed.” (Providers)

The participants identified a few areas in which USMC EFMs are disadvantaged. As discussed in Section 3.1, military families may not qualify financially for certain assistance, and, as discussed in conjunction with PCSing (Section 3.2.2), frequent relocation makes it difficult for USMC EFMs in most states to secure and keep Medicaid waivers. Additionally, in California, the Department of Developmental Services provides disability-related services and supports through nonprofit regional centers that often pay for fewer services (e.g., ABA or respite care) for military families because of the coverage available to them through Tricare or ECHO.

“If we refer a family to the regional center, their interview process is, ‘Are you using ECHO, are you using EFMP respite?’ They try to get a family to use anything the military will give them before they give them any of their

own resources. Not just the regional center—other sources out in the community will try to get the families to rely on Tricare and ECHO rather than on the state, if possible—they encourage them to consider Tricare the primary insurer. When I first got here, the regional center was primary, then after budget cuts it became, ‘No, go to your insurance company first.’ The families are having to go through a lot of frustration. They feel like they’re being shuffled. The ones that still maintain a quality level of service are the ones with severe disabilities.... It’s easier for long-term needs because once they reach 18 they also get the federal funding....” (Provider)

While more an inconvenience than an inequity, it was observed that the government monitors the family income of SSI recipients every six months, which can create a reporting burden owing to significant income fluctuations for Marine families whose sponsors deploy regularly, due to the Marine’s receipt of hazardous-duty pay. By the same token, one parent observed that military families may actually receive more comprehensive support than civilian families.

“Tricare has so much stuff, and covers so many things that other insurance doesn’t cover. When my husband retires, we won’t have the same coverage or access to the same care anymore, and that’s something a lot of civilians never have.... We have families staying in the Marine Corps longer just to keep the care.” (Caretaker)

3.1.4.5. Summary

This discussion addressed long-term supports and services, which assist individuals with disabilities or chronic illnesses with activities of daily living. Relatively few of the focus group participants had experience in this arena. Several providers and families said that programs such as Medicaid provide valuable services to USMC children and adults in need of long-term supports and services; some noted that the EFM attorney, a free resource unique to military families, can assist with securing long-term supports

and services. By far the most frequent and compelling long-term issue raised by the study participants was the absence of Medicaid portability and how this affects access to services when families PCS from state to state (this significant barrier to care is discussed in Section 3.2, which deals with PCS). Participants suggested that access to vocational rehabilitation and employment services is comparable for military family members and civilians with disabilities and, in both cases, inadequate. Conversely, several suggested that access to adult services such as transportation for medical appointments and personal care attendants is not comparable, because these services are normally provided through Medicaid, for which military family members often do not qualify financially. Several parents also expressed concern for the long-term welfare of their children with disabilities, particularly after a parent retires from the Marine Corps.

3.1.4.6. Study Participants' Recommendations

Because recommendations that emerged from these discussions pertained mostly to PCS, they are presented with other long-term supports and services recommendations in Section 3.2.

3.2. PCSing and Access of USMC EFMs to Disability-Related Services

The requirement to move regularly, often to destinations not of one's choosing, is a constant in military life.^{32,33} Moving, or PCSing, entails logistical, emotional, and financial stressors for all military families, whether or not they have members with disabilities. One of NCD's objectives for the current study was to examine how this hallmark of the military lifestyle affects continued access to disability-related services for USMC EFMs. (Note that some USMC EFMP families remain fairly stationary while the military sponsor rotates in and out of a home base.)

As noted earlier, because PCS is so intrinsic to military life, extricating PCS issues from steady-state issues is not necessarily straightforward. For example, do problems with IEPs pertain to steady state or PCS? For the sake of simplicity, we focus our discussion

of IEP problems and several other issues here, in conjunction with PCS, even though they could potentially be discussed also under steady state (Section 3.1.3).

The following core focus group questions elicited responses related to PCS and access:

- When USMC families PCS with their EFMs, what kinds of resources are available to ... help EFMs transition from one school to another (... ensure they get the health care they need at the new location)?
- How well do these resources meet their needs?
- How could EFMs be better supported when they have to switch schools due to PCS? (How could EFM's health care needs be better supported when they PCS?)

The findings that emerged from the participants' responses to these questions (and other questions) are presented under four subsections:

- PCSing and General Access of USMC EFMs to Disability-Related Services
- PCSing and Access of USMC EFMs to Health Care
- PCSing and Access of USMC EFMs to Special Education

PCSing and Access of USMC EFMs to Long-Term Supports and services

3.2.1. PCSing and General Access of USMC EFMs to Disability-Related Services

Many of the comments shared by the study participants about PCSing and access to services cut across the domains of health care, education, and long-term supports and services. (See Section 3.1 for a more general discussion regarding access of USMC EFMs to disability-related services.) The findings from these overarching experiences and observations are the focus of this section, which is organized under four headings:

difficulties encountered, resources and resource effectiveness, participants' recommendations, and summary.

3.2.1.1. Difficulties Encountered

Lack of Uniformity in Services from Base to Base. Because bases—not to mention civilian communities—differ in the range of services they offer, each PCS calls upon families to reeducate themselves about available resources and to reassemble the best possible continuum of care for their EFM, which may or may not match the scope and quality of services at the last location. A number of families commented on this. Focus group participants said:

“When we move, you’re dealing with Pendleton, Lejeune, etc. You think military is military, it doesn’t matter, but they don’t seem to be one. You’re coming to a totally different place....” (Caretaker)

“The differences between what is available to them duty station to duty station—what services a service member received say in Pendleton—those services may not be available here off base or on base.” (Provider)

“If they’re going on to an installation, it’s easier to access the resources. But they could be going somewhere there isn’t an installation; they could be going to an installation with or without DoDEA or LEA schools on the base.” (Provider)

“Things are different in different states; here the young families don’t know where to go. From Quantico to California, things are different. We’ve had young families who have shown up at our door with a four-year-old that has had no intervention.” (Provider)

Delay in Quarters Availability. The longer the family’s period of time in transit—to include movement from one base to the next and time spent in temporary lodging—the

more stressful and costly the PCS. Families can minimize transit time by moving into base housing immediately upon arrival. Sometimes EFMP can proactively facilitate this with the Family Housing Office. Other times, reported a few families, Family Housing is less helpful and does not accept applications in advance or needlessly delays the assignment of quarters. One focus group participant said:

“You can’t do anything ‘til you’re here; you can’t sign up for housing ... and you’re staying in a hotel for two weeks with three kids. Staying in a hotel is a hardship ... as a special-needs family, we have pets for our kids to have some continuity. They’re like therapy dogs, they’re teaching dogs, but they can’t stay with us so we have to pay per dog to keep them out in town.” (Caretaker)

Overwhelming Process, Particularly for Young Families and Those Dealing with Severe Conditions. Providers observed that PCSing is logistically demanding and task-intensive. Arranging for services at the new location is one task of many to which families, often civilian spouses, must attend. In some cases, other tasks may take priority. Focus group participants said:

“The energy level once families transfer ... there is so much on that to-do list; actually being able to access services is a task that doesn’t always get prioritized.”

“The actual move may be difficult but, once you get there, there’s a laundry list of things to deal with: schools, different Tricare region, different state services to get access to care, housing.... There’s the normal stress of the move and then, based on need, it just piles up.”

“We have challenges when we PCS. For a severe case, PCS is a huge challenge, but for less severe cases they’re just doing your average PCS.” (Providers)

Families can partner with base services such as EFMP and SL to facilitate their transition, but sometimes families lack the wherewithal to do their part.

“A lot of times we leave it up to the military members, and they’re typically very young, overstressed, and overwhelmed anyways; even if they knew, I’m not sure they’d have time or energy to reach out.” (Provider)

3.2.1.2. Resources and Resource Effectiveness

The study participants identified a number of resources that they believe facilitate PCSing EFMs’ access to disability-related services. Many of these resources fall under the umbrella of EFMP. We present these resources here, along with any participant comments regarding resource effectiveness.

EFMP Assignment Policy. A few participants characterized the EFMP assignment policy as a resource in that it is supposed to ensure that EFMP families are relocated to locations where their needs can be met. Focus group participants said:

“I understand all they do is make sure that, when you get orders, you only go to a base that has the resources you need based on your category. That’s it.”

“Yeah, they put into consideration your category, and they won’t send you somewhere that your medical needs can’t be met.” (Caretakers)

Some participants noted that, in reality, families often are assigned to locations where their needs cannot be readily met. For example, they pointed out that families assigned to MCB Quantico and Camp Lejeune often cannot access specialty health care on base or in the nearby civilian community.

“A family comes here thinking they’re going to get these medical services at Camp Lejeune, then they find out the hospital isn’t equipped and they have to go elsewhere. That needs to be addressed.” (Provider)

“When you have a family who comes here to this area and they come to us and say, ‘Oh, I’m here and my child needs to have a pediatric neurologist, cardiologist, etc.,’ and they need to see a pediatric developmental specialist, and we say, ‘We don’t have those services here,’ they say, ‘What do you mean? How can that happen?’ We can get you there, but it’s a two-and-a-half-hour drive away....” (Provider)

“Quantico is one of the locations that receives a high number of CAT IV EFMs, people requiring high-specialty care. You come here thinking, ‘I’ll get it here at Quantico’.... We have a brand-new clinic in this area on base that used to be a full hospital, and it has less access to care; it’s just outpatient. It’s a good pediatric clinic, but as an adult with special needs, they send you out in town. If you need medications, they don’t carry them as formulary in the clinic. Even though you’re here, you’re still going to Fort Belvoir, Walter Reed, etc.” (Provider)

Eligibility for Priority Housing through EFMP. Families who qualify for priority housing consider it a resource. That is, being able to move into a house on base immediately upon arrival makes moving somewhat less difficult. One focus group participant said:

“I was CAT IV so I knew we deserved an immediate house. We were able to get a home before we even left North Carolina. They had an address and everything, which was due to me doing the call and checking. I was a high-risk pregnant woman and I was about to go on bed rest, so I knew I couldn’t handle a move there and then a move on base.”
(Caretaker/EFM)

A number of participants expressed concern about how the elimination of the EFMP category system will affect continued access to priority housing. There is fear that families who need priority housing may be at risk of not receiving it.

“Our case manager said she is having to do a lot of appeals for priority housing because people [previous CAT IVs] no longer get that priority housing. She says there’s some families that really need it, and it’s just not really fair.” (Caretaker)

“We go to move now and we need to be near a big city because she has so many specialists that she sees. I used to be able to say to Housing, ‘We’re CAT IV, we need an immediate house,’ but how will Housing help us now? We tell them about her disabilities, and Housing is going to determine if we’re important enough to have that or not? That’s terrible.” (Caretaker/EFM)

“I am very concerned about the categories going away and the availability of housing and not being able to get priority ... a huge concern for us because of my daughter’s medical needs. We’ll have to go to a band-aid school for four months or six months while we’re waiting for housing.” (Caretaker)

3.2.1.3. Services Provided by EFMP Caseworkers.

Study participants identified three direct services that EFMP provides to facilitate a family’s move.

- The PCS needs assessment

“I will also do the PCS needs assessment through my caseworker and fill that out and have that forwarded to our next EFMP office.” (Caretaker)

“The [EFMP] caseworker is supposed to have the family fill out a PCS needs assessment form and then send it to us. When they get here, we contact them directly and give them the resources in the area based on what we found from the assessment.... If their enrollment letter states

that they rate priority housing, then we will contact the Housing Office....”
(Provider)

- Coordination between the losing and gaining installation

“Making sure your case manager comes into play, and the EFMP coordinator. If you’ve got good communication with your current one, they can talk to the other one about your current situation and the current case.... The caseworkers here call caseworkers there, but it is all about the case manager.”

“We need to tell the case manager, ‘We’re leaving, will you be able to help me?’” (Caretakers)

- Facilitation of efficient quarters assignment (as mentioned earlier)

“They already had a house set up for me when I got here. They also helped me get a higher lock for our front door because my children are runaways.” (EFM)

Participants noted that these services are helpful only if both parties—the family and the EFMP office—do their part. They indicated that families often are unaware of how EFMP can assist them or fail to request assistance. EFMP, in turn, does not always follow through. One focus group participant said:

“I filled out a needs assessment form. I said I have a kid with autism. I need priority housing. My caseworker sent my files to Pendleton, to the EFMP office, but we showed up here and they were lost. They didn’t seem to know we were coming. The losing installation did their part, but the gaining installation didn’t pick up the ball.” (Caretaker)

One parent indicated that the EFMP respite care program, which families use regularly during steady state and is discussed further in Section 3.3, can also be helpful during PCS.

Family Readiness Officers (FROs). Several providers suggested the FROs are a potential source of support for PCSing EFMP families, although there seems to be some uncertainty about the purpose of this fairly new position within Marine Corps Community Services. Focus group participants said:

“Aren’t FROs the ones that really help when a family comes into a new area? It’s a family readiness area, so I’m assuming they hit the various points families need to know when they move to a new area.... Wouldn’t he or she be the go-to person for a family?”

“If I’m not mistaken, the main function of the FRO is for deployment readiness; when the sponsor isn’t around the FRO is there. They are the ones that liaison between the spouses and deployed service members.”

“That job has expanded. They are supposed to support the family beyond deployment now; they are supposed to inform families of resources, and various FROs do that, but it’s not consistent across the FROs.”

(Providers)

Providers noted that, in some cases, privacy constraints prevent FROs from proactively supporting EFMP families, both during PCS and steady state. (This will be addressed further in Section 3.3.)

Other Generic PCS Resources. Several participants identified additional PCS resources that, like the FROs, are not specifically for families with special needs. Some of these resources are military-wide, such as the Interstate Compact on Educational Opportunity for Military Children, Military OneSource (e.g., for itineraries and lodging), and the PCS Tool on the Military Homefront website.

“Our caseworker gave us an online calendar for PCSing families. You type in when you’re leaving and where you’re coming from and going to, and it gives you day-by-day [guidance]. It’s a tool on the Military Homefront website. I’m on it every morning it’s so cool. We may not end

up PCSing, but I feel really prepared. My husband told some of the guys from his shop that are leaving, and he told people about the counseling services. He is the platoon sergeant for his shop and he's had to tell people the PCS calendar is for everyone, not just for EFMP.” (Caretaker)

A few providers mentioned base programs or practices such as the Relocation Assistance Program and comprehensive resource information that the Family Housing Office sends to inbound personnel.

3.2.1.4. Summary

The requirement to move regularly, often to destinations not of one's choosing, is a constant in military life. Moving, or PCSing, entails logistical, emotional, and financial stressors for all military families, whether or not they have members with disabilities. The focus group results suggest that PCS challenges can be significantly more arduous for families with EFMs, especially if the families are young or the EFM's disability is severe. Because bases and civilian communities differ in the range of services they offer, every time families PCS they must reeducate themselves about the resources available to them and the process for accessing them. Then they must reassemble their EFM's continuum of care—that is, request, coordinate, and potentially fight for the services their EFM needs. Families often PCS without knowing exactly where they will be living (e.g., on base/off base, school district), which significantly hinders their ability to plan in advance and can result in substantial delays in services. On arrival at the new location, housing (on or off base) may not be available immediately, and the longer the family stays in temporary lodging, the more stressful and costly the PCS.

The study participants were asked to identify resources that support the PCS process and to appraise the effectiveness of these resources. They cited the EFMP assignment policy as such a resource, at least in theory, since it is supposed to ensure that families are assigned to locations where their EFMs' needs can be met. (In reality, they reported, this often is not the case.) They mentioned priority on-base housing as a significant resource for PCSing EFMP families, although there is concern that the

elimination of the EFMP category system (i.e., Category I through IV) may jeopardize this in the future. Families also noted that base Family Housing Offices may not accept housing applications in advance and may not assign available quarters promptly, causing them a longer-than-necessary stay in temporary lodging. Families and providers also described EFMP caseworkers as PCS resources, at least for families who are familiar with EFMP services and who have an EFMP caseworker. For example, the EFMP caseworker can provide a needs assessment, coordinate with a counterpart at the gaining installation, and facilitate quarters assignment. Additionally, caretakers touched on generic resources that can directly or indirectly support all PCSing families, including those enrolled in EFMP, such as Family Readiness Officers, Military OneSource, the PCS planning tool on the Military Homefront website, and the Interstate Compact on Educational Opportunity for Military Children.

3.2.1.5. Study Participants' Recommendations

Following are recommendations made by one or more study participants. Frequent recommendations are annotated. A strong theme throughout many of these recommendations is preparation and planning—by families as well as the gaining command.

Study Participants' Recommendations for Local EFMPs (also see Section 3.3.1)

- Distribute a comprehensive resource packet, resource guide, or directory listing community and base resources (a frequent recommendation). Providers in one focus group discussed creating a web-based resource database, accessible by families, and organized at the installation, state, and USMC levels. Their concept emphasized vetting resources and keeping them current, included online training modules for caregivers, and leveraged existing websites such as Military OneSource, Military Homefront, and National Dissemination Center for Children with Disabilities.

- Provide proactive PCS support for families, including better advertising the services EFMP provides for PCSing families and instructing families on their PCS-related responsibilities. Proactive PCS support also can include facilitating a point of contact or connection at the gaining installation (more on sponsorship below), and reaching out to inbound families—at least those most affected—prior to their arrival.
 - Proactively advertise how EFMP can support PCS
 - Provide “how-to” instructions about PCSing as an EFMP family
 - Facilitate contacts at the gaining installation
 - Reach out to inbound EFMP families
- Help families proactively establish respite care, to minimize delays in this vital service on which so many rely heavily.

Study Participants’ Recommendations for Other Entities

- Resurrect or reenergize the sponsorship system for EFMP families, domestically and outside the Continental United States, at least for families with severely disabled EFMs (a frequent recommendation).
- Cut orders early for EFMP families, at least those with a severely disabled EFM, to allow an early start on the planning process, on the part of both families and the gaining installation. Recognize that the disruption inherent in PCS moves is particularly difficult for children with autism.
- Ensure that gaining commands are alerted when a severely disabled EFM is in-bound.
- Permit families to sign up for housing in advance of arrival, to reduce or eliminate the length of time they must spend in temporary lodging.

- Formalize the coordination process for determining whether an installation can accommodate an EFM, rather than relying on the dedication of individual providers and on well-established working relationships.

Study Participants' Tips for Families

- Play an active role in reaching out to PCS resources and planning for the move.

"We have a sponsor family because we're proactive in our response. Regardless of whether or not you're with EFMP, you prepare well in advance for trips like this, especially when you have a child with ADHD."
(Caretaker)

"I contacted the EFMP office here five months before we were going to move to make sure they knew we were coming and that everything was in place. We moved on base because of what happened to us in Quantico. Since we've been here, I've been very happy with the services we received." (Caretaker)

- Send the service member in advance of the family. The family remains at the losing installation while the service member signs in at the new installation, obtains an appointment with the new primary care manager, and so forth. The disadvantage is that maintaining two households while the family is separated is costly. Also, families residing in quarters may or may not be permitted to stay in them after the departure of the military sponsor.

"If we received orders to another state, I would stay here and have my husband go and sign in so that paperwork can start going before we get there. That's the best way to do it. [All agree] It's the only way to avoid a delay in services.... I've had to do this and have seen other families do it."

P3: [But] to do the two households, it costs about \$6,000 to \$10,000.”
(Caretakers)

“Being at the receiving end, we get their records. Oftentimes we find out ahead of time; sometimes the family will come ahead of time ... to the clinic, saying, ‘My family has this condition, requires these specialists, can you help me?’ So we can get that in place before they physically move here.” (Provider)

3.2.2. PCSing and Access of USMC EFMs to Health Care

The cycle of ending relationships with current health care providers and interrupting current treatment plans, followed by identifying new providers and resuming treatment plans, is part and parcel of the PCS experience. The more severe and involved the family member’s condition, the more challenging the process of reestablishing the continuum of care. USMC EFM experiences in this arena are discussed under four headings: difficulties encountered, resources and resource effectiveness, participants’ recommendations, and summary. (See Section 3.1.2 for a more general discussion regarding access of USMC EFMs to health care.)

3.2.2.1. Difficulties Encountered

Finding new health care providers is laborious, risking delays and gaps in service. With great regularity, families and providers remarked about the laborious and protracted process for reestablishing health care. It is clear that this is particularly problematic when an EFM’s condition is highly involved and his or her care requires multiple providers. Whether highly involved or not, the protracted process often creates delays and gaps in EFMs’ receipt of health care services. Focus group participants said:

“I just was on the phone with a woman who is moving here in August, and Tricare told her she can’t have health care immediately when she gets

here. There will be a break in services for the child ... until they find a new PCM.” (Provider)

“When we got here, she had no doctors. We first had to establish a PCM. That person has to get her referrals to all the services. Inevitably, because she had 11 doctors she had to see, they couldn’t all see her. Back to PCM, more referrals, etc. You need to see the doctor you’re being referred to within 30 days or it expires.... Sometimes they’re in a situation where they can’t fit you in and you’re out of luck. In North Carolina, she went without speech therapy for two and a half years and had no physical therapy for over a year.” (Caretaker)

“You’re on your own to talk to Tricare, and to make all your new appointments. Then you go to your PCM, when you finally get one, and they write you referrals. Then you go to the specialist, then you finally get your ABA prescription. Then you find ECHO and call them and hope you get your caseworker if you’re lucky. Then they need you to fax all this paperwork, etc. Six months later, I still didn’t have ABA.”

“ I had a four-month lag in ABA and my son still isn’t in school. You have a diagnosis; why isn’t that diagnosis on the East Coast any good on the West Coast?” (Caretaker)

Changing Tricare regions exacerbates the challenge of finding new health care providers. Because families must reenroll when they PCS to a new Tricare region, changing regions adds a layer of complexity to the PCS process.

“A huge obstacle for us is Tricare regions and PCS.” (Caretaker)

“I can’t even liaison with the Tricare piece if I’m going from region to region. I can’t call Pendleton, with a Naval Hospital, and say I’ll go ahead and book an appointment in three weeks [i.e., in advance], because I’m

not affiliated with the next hospital and I have to change regions.”
(Caretaker)

“It’s a lot easier if they’re within the same Tricare region; if you’re going from Lejeune to Quantico, it’s easy because one of the resources would be medical case management [through Tricare]. If you’re going from Tricare North to Tricare West, you’re in a different insurance company, so you need to change your medical case manager.” (Provider)

Failing to enroll in the new Tricare region has financial implications as well as health care implications.

“The check-in process is not well enforced. People may not check in and change Tricare regions when they PCS, so then Tricare South bills families like they’re out of network.” (Provider)

When families switch Tricare regions, they must also switch Tricare case managers.

Patients lose forward movement in their health care. We infer from a number of study participant comments that frequent relocation not only creates discontinuity in health care but stymies progress. Some noted that to continue receiving health care services at the new location, they must repeat steps, which strikes them as not only laborious but unproductive. Many feel that they are forced to “start over.” Focus group participants said:

“Moving from one place to another, the doctors always told me I need to start fresh, [I’m] new. I can’t tell you how many times I refill out the paperwork, redo the MRI, redo medications. Why can’t they just read through my medical records? Let’s go from there. Why do we always start from scratch? Why don’t we ever pick up where we left off?” (Caretaker)

“With the transition piece, you’re always starting all over.... Every time I go to the ER, it’s like starting over, and I have to fight to get an IV.”

(Caretaker)

“A lot of it is they check in with the doctor here and they start over.”

(Provider)

Others observed that inconsistencies across locations can force an unwelcome change in treatment plan.

“The one big thing from early intervention is children are coming out of North Carolina, where they don’t have ABA therapy, and they get sensory integration instead. Then they come to Virginia and Tricare only offers ABA here. When your child has been diagnosed and he’s now two and you feel like you know something, and you move and the services change, that’s really hard.” (Provider)

Inconsistencies across locations can put high-risk EFMs in jeopardy. Although we had little exposure to highly involved cases, it was suggested that inconsistencies across locations can have potentially dire consequences for medically fragile EFMs.

“Our son’s Pediasure wasn’t covered at Lejeune through Tricare, and it was going to cost us \$800 a month....” (Caretaker)

Inconsistencies across locations can extend to the ability to fill prescriptions. It was suggested that PCSing families sometimes encounter barriers to filling prescriptions written in a different state, particularly when civilian doctors are involved. Also, the new pharmacy may not carry the prescription.

Health care support for crisis situations in transit is lacking. A few participants told of instances when families were in crisis between duty stations, or before they had connected with a new primary care manager, and lacked recourse.

“We moved from Hawaii to here. We drove cross-country. We took a month. By the time we got here, my son’s medicines weren’t working.... We were told by the Tricare office we couldn’t be seen on base, that base wouldn’t carry his medications... It took me saying, ‘It’s been four weeks in a hotel, what am I supposed to do?’ Because I stood up in front of 100 people [at a town hall meeting], they found a spot for me on base to see a doctor....”

“Most of our problems with medication happen between the day I leave and the day I get there. Like, if he has a seizure, what do I do? There’s nothing there.” (Caretakers)

3.2.2.2. Resources and Resource Effectiveness

The study participants pointed to a variety of resources that they believe facilitate PCSing EFM’s access to health care. Some of these resources also were mentioned earlier. We present these resources here, along with participant comments regarding resource effectiveness.

Case Managers. Various kinds of medical and nonmedical case managers may play a role in facilitating an EFM’s health care transition. Several health care providers indicated that a case manager at the losing installation ensures that records are forwarded and takes the lead, as necessary, in coordinating continuity of care with a counterpart at the gaining installation. Providers suggested that this individual is typically someone from the base medical facility or EFMP. Focus group participants said:

“Frequently it’s coordinated through the clinic. It really is about the family getting engaged with EFMP services.... Then we can communicate with the receiving facility.”

“Records will be sent to the receiving facility.... If they’re just PCSing within CONUS, they do not need to go through suitability screening, but

all their paperwork has to be up-to-date so it can be passed on through their next duty station.”

“Records will be forwarded automatically by their primary care manager, and their case manager will take the lead on coordinating their new services. It really depends on the need of the family.... It could be a medical case manager, Tricare Healthnet case manager, or an EFMP case manager.” (Providers)

It appears that a variety of medical and nonmedical case managers have the ability to help families with their health care transition, but it is not clear whether any have been assigned the responsibility to do so. To the extent that this is an accurate scenario, families may lack a clear go-to person on either side of the move, and some may be overlooked altogether.

The ECHO case manager can be helpful, but is available only to ECHO enrollees, and a subset of them at that. One focus group participant said:

“I’ve used our ECHO case manager—she put me in touch with our new ECHO case manager in our new region; she did a warm handoff. I was able to speak with both of them for up to two months.” (Caretaker)

Tricare Medical Liaison. This position apparently is filled by a nurse located in the Naval Hospital. It is unclear whether all installations have them or what role they play. Few families, if any, specifically mentioned this resource.

EFMP. Study participants indicated, as suggested earlier, that EFMP can support the health care transition in several ways, including arranging for initial medical appointments at the Naval Hospital, ensuring the transfer of medical records, and facilitating transfers to new Tricare regions. Focus group participants said:

“As soon as we knew we were going to Quantico, I think we coordinated through EFMP, and as soon as we checked in they helped facilitate an appointment with a PCM.” (Caretaker)

“Actually the EFMP office helped me. They told me who most kids go to for speech and OT, but I still had to go to their primary care doctor to get referrals. They sent one kid one place and one kid to another, but then EFMP helped me fight to get them to be seen in the same place.”

(Caretaker/EFM)

“From what we found out, EFMP will look into that... EFMP there already knows all about us. We’ll be getting set up with the Naval Hospital there, and they’ll have the records sent right away.” (Caretaker)

Lack of awareness that EFMP can help prevents some families from using EFMP to facilitate their health care transition. Some families stated outright that there are no resources available to support health care transition other than, perhaps, guidance from the current physician.

“Even if I had gone to EFMP, I don’t think EFMP would have had information for me. I don’t think there’s anything they would really do. I knew what to do from my doctor back home and from the whole process I went through over there. I wasn’t as involved with EFMP out there so I knew I wouldn’t need it here; I didn’t have expectations.” (EFM)

Individual Physicians. Some families identified their physician as a resource that facilitates their health care transition. For example, physicians may help families to identify appropriate providers at the next location and even do a “warm handoff.”

“And his PCM here on base, who isn’t even his actual PCM but he’s kind of adopted my child because he handles a lot of the ADHD children, and because he has specific personal experience in Okinawa with ADHD, he

is helping to make sure the overseas screening process goes through smoothly with the medications. We're receiving very good support for the transition." (Caretaker)

One mother continues to obtain referrals from the physician who first diagnosed and treated her child more than a decade earlier. Dedicated physicians who take it upon themselves to provide this level of support are invaluable, but they are not necessarily the norm.

Military OneSource. Military OneSource provides lists of health care specialists by geographic area. One focus group participant said:

"Sometimes I use Military OneSource. I'll call them and say, 'Give me a list of all doctors in this area who do X.' That saves me some time."
(Caretaker)

Tricare Website. Tricare provides lists of participating health care providers, although several providers observed that the Tricare website is not easy to navigate and the information is not organized in a useful manner.

"In advance of moving here I called Tricare to see who the network providers were here." (Caretaker)

"People can go to Tricare and look it up. It's not user-friendly and it's not ped-focused. They get a list of OTs and that OT can be geriatric, etc."
(Provider)

Several family members said that the Tricare lists are not well maintained—for example, the providers listed may not be accepting new patients or may no longer be accepting Tricare.

3.2.2.3. Summary

The cycle of interrupting and reestablishing health care is part and parcel of the PCS experience. The more severe and involved the family member's condition, the more challenging the process of reestablishing the continuum of care, and EFMP families reported facing a number of obstacles. Many cited finding new providers as a major concern because it is time-consuming and contributes to gaps in service—a problem that is exacerbated for EFMs who have involved conditions and see multiple specialists. The new location may fall under a different Tricare region, necessitating burdensome reenrollment, which adds to the difficulty of locating new providers and potentially prolongs the lag in health care. The health care disruption that results from PCS and ensuing challenges can cause EFMs to lose momentum, if not lose ground, in progress toward their treatment goals. For medically fragile individuals, inconsistencies in the caliber and kind of care available state to state can have grave repercussions. Finally, it appears that families can have difficulty accessing health care, including prescriptions, while in transit and before they have met with their new PCM—again, a scenario that can have serious repercussions.

Although the obstacles to health care during PCS are substantial, there are resources to help families deal with them. Study participants noted, for example, that EFMP can help families coordinate the health care transition (e.g., by arranging for initial medical appointments at the Naval Hospital, ensuring transfer of medical records, facilitating transfers to new Tricare region). However, lack of awareness prevents some families from taking advantage of such EFMP support. Families and providers noted that a variety of medical and nonmedical case managers, including EFMP caseworkers, can help families with the health care transition, but it was unclear which, if any, is specifically assigned this responsibility. Some individual physicians go out of their way to suggest or talk with specialists at the new location, although a “warm handoff” from doctor to doctor is not the norm. Participants noted that the Military OneSource and Tricare websites offer lists of health care providers by geographic area. They noted, however, that the Tricare lists are not always accurate or easy to navigate (e.g., the

listed providers may not be accepting new patients or may no longer accept Tricare, or the list may not specify which specialists see children).

3.2.2.4. Study Participants' Recommendations

Presented below are recommendations made by one or more study participants for improving PCS support related to EFM health care. Suggestions offered by many participants are so noted.

Study Participants' Recommendations for Local EFMPs

- Relieve Marines and their spouses of some of the burden of health care transition by playing a proactive role in facilitating the resumption of services at the gaining installation.
- Provide families a checklist detailing the steps to reestablish health care at the gaining installation.
- Help families who are reliant on ABA therapists and respite care providers to resume these services as quickly as possible and to minimize breaks in support.
- Establish a mechanism for families to talk to other parents about local doctors.

Study Participants' Recommendations for Other Entities

- Streamline the steps that families must take to reestablish health care at the new location (a frequent recommendation). For example:
 - Adjust Tricare procedures to minimize the reenrollment burden for families who must change Tricare regions.
 - Adjust Tricare procedures to provide EFMs referrals for routine specialty care without needing to see the new primary care manager.

- Reduce redundant tests and evaluations by encouraging physicians to accept recent results included in patients' medical records rather than requiring that they be repeated. Encourage losing and gaining physicians to communicate.
- Facilitate the transfer of medical records between bases and between off-base and on-base providers.
- Establish a mechanism to ensure that families have sufficient medication while in transit, until they can obtain prescriptions from their new health care providers.

Study Participants' Tips for Families

Study participants noted that families cannot rely solely on health care facilities and providers or EFMP to ensure that their medical records transfer from the losing to the gaining installation, particularly if they are seeing civilian providers. Families should take responsibility for their EFM's medical records, to include maintaining a home copy and hand-carrying a copy for the gaining installation.

3.2.3. PCSing and Access of USMC EFMs to Educational-Related Services

Over the course of their parent's USMC career, school-age children and youth may move in and out of DoDEA and public schools. Because bases with DoDEA schools are the exception rather than the rule, many PCSing families are dealing with the public schools on one or both ends. In this section, we address the impact of PCS moves on students' access to special education. (See Section 3.1.3 for a more general discussion regarding access of USMC EFMs to special education.) USMC EFM experiences in this arena are discussed under four headings: difficulties encountered, resources and resource effectiveness, participants' recommendations, and summary.

3.2.3.1. Difficulties Encountered

The difficulties identified here contribute to an ongoing adversarial dynamic between parents and schools, as described in Section 3.1.3.

Some parents are unaware or perplexed that school resources and policies vary from base to base. Parents may be unprepared for the differences in base educational systems and resources until they encounter them—for example, that bases may differ in the level of schooling available on base, that DoDEA does not run all on-base schools, or that families awaiting base housing may or may not be eligible to attend base schools. Focus group participants said:

“We don’t understand why Pendleton has only elementary schools on base when Lejeune has all the way through high school.” (Caretaker)

“There are bases out in California or in Leavenworth where the schools are located on the installation. The parents naturally assume they’re DoDEA schools and, in fact, they’re not. And parents think they’re going to the same system, and they show up and it’s a surprise.” (Provider)

States’ differing approaches to delivering special education may create a real or perceived degradation in the services students receive when they PCS. A gaining school may not automatically accept IEPs developed in a different state or county. As a result, children may experience a lag in special education services when they PCS. Focus group participants said:

“I was told [by the school], “We can’t do that until your son enrolls on day one,” so no services were in place. DoD schools talk well together—that’s great—but not off-base schools. So there’s a lag in services.” (Caretaker)

“From the legal standpoint, my clients come in thinking their IEP from Virginia or wherever they’re coming from will stay in place, so the families

come to me and they're upset. All the trainings I know EFMP is doing and that I'm trying to get out there, we're all hitting that transition piece."

(Provider)

States' differing approaches to delivering special education can also create substantial discontinuity in the services students receive when they PCS.

"We went ... to a DoD school in Lejeune, where they do not have special day classes, where they integrate everyone. They follow the federal law, which is they need to adapt for the child to be in a regular education classroom as much as possible. So he was in a regular classroom sitting with an aide, following the federal guidelines. We got back here and went to a school here on base and he was put in a class without an aide and his IEP wasn't followed. They went to do a 30-day placement ... they wanted to put him in a special day class, take away his aide, take away his regular classroom. This is totally opposite of what he just had...."

(Caretaker)

"One of the challenges we experience is when they come from a different state; they may be in a special education model that doesn't quite fit ours. There's a struggle from the school end and the parental end. They might have come from a full inclusion program, whereas we had a different model."

"There's almost a translation process that needs to occur, and it's challenging because they come from so many different places. Sometimes there's a need for reassessing the disability, depending on where they came from. One of the larger challenges is to provide a breadth of understanding to answer the questions the parents don't even know that they have...." (Providers)

“When kids come from Hawaii, they have what’s known as wraparound services, meaning all of their services come under the IEPs. We have regional centers here for kids with severe needs—there it’s not separate, it’s all part of the school district. So, they come and expect all these services to be wrapped together, but we have to say, ‘No, call the regional center; they provide respite and those other services.’” (Provider)

“There are different handicapping requirements here ... we don’t have a handicapping condition for oppositional defiance. Here, you won’t qualify for an IEP with that, but in other states you will.... Families have difficulty understanding the differences in services. Overseas they offer PT and we offer adaptive physical education....” (Provider)

Differences in state resources are another potential cause of discontinuity in special education services when EFMs PCS. California, for example, is currently experiencing a budget crisis, and this is affecting the public school system.

“Services also are different. It’s not just translating an IEP. They probably are getting a much better funded program on the East Coast. We’ll do our best to match as best we can from the East Coast, but often times it’s very difficult.” (Provider)

Parents naturally respond with frustration and dissatisfaction to any real or perceived degradation in the services available to their children.

“Sometimes it creates an adversarial role because they feel like we’re trying to take services from them. It makes families suspicious....” (Provider)

“Then families think we’re taking something away from them.” (Provider)

Parents report that gaining schools do not review IEPs and other student records in advance of the student's arrival. Parents feel that these documents contain information that would help school faculty and staff to understand their child and thus would promote a smoother transition.

"I gave the information to the school a month and a half before we got here. They suspended him three days into his being at school in town and in the suspension report noted that they had not read his IEPs."

(Caretaker)

3.2.3.2. Resources and Resource Effectiveness

The study participants identified a number of resources that support the continuity of special education services for PCSing EFMs. We present these resources here, along with participant comments regarding resource effectiveness.

EFMP. EFMP facilitates school transitions for EFMs through one-on-one support as well as through group formats such as trainings. Focus group participants said:

"EFMP is working very hard to provide in-services for families, trainings, conferences, get-togethers, to try to help parents understand the ins and outs of IEP meetings; what it means when they look at their procedural safeguards, their 10- or 12-page document, how that document protects their child and protects them. In reality, we as a school district don't have the resources or time to continually in-service people beyond our staff."

(Provider)

"EFMP caseworkers, they're the second in line after the SL. I just had someone call with three children and three IEPs coming from North Carolina. We do the EFMP piece right away. We tell them to have their current case manager speak to a case manager here." (Provider)

“Generally what we do is, when we receive notice that they have orders, we contact the family, they come in and we do a needs assessment, they come in and do a checkout sheet. We make sure they have their current IEP, and we speak with respite because, if they’re receiving respite here, they’ll probably need it where they are going. We put it all on one neat packet, go over it with the parents. We involve hospitals for transferring medication. The parent gets a copy and then we transfer all that information to the gaining installation’s EFMP to say, “Heads up, this family is coming and the children need X, Y, and Z,” so when they arrive at the gaining command they aren’t shocked and they’re prepared. Ideally, that means less gaps upon arrival.” (Provider)

EFMP also can facilitate school transition by alerting the DoDEA schools of an inbound student.

Several factors can impede the ability of EFMP offices to facilitate school transition for children and youth with special needs. First, not all families are aware that EFMP is available to support school transition.

“The only thing we can do as far as preparing when we PCS is sending the IEP ahead of time.... The services are not uniform across the board in all the different states. The types of services my child may have had in Virginia are different than what he’ll have here.”

“EFMP does not facilitate this transition.” (Caretakers)

“We’re not aware of any resources in place yet to facilitate transition. I don’t want to start with another teacher, to tell another school administration how to do their jobs. I wasn’t told anything that EFMP does.”

“I think there’s somebody on base who helps you do that, but she only knows DoD stuff. We live off base.” (Caretakers)

“We’ve never been with the DoDEA school system. There is no resource in place to help with a school transition....” (Caretaker)

Other factors also inhibit the capacity of EFMP staff to facilitate school transitions. For example, occasionally EFMP is unaware that families are moving or that new families have arrived, and some departing families are reluctant to meet with them to complete the needs assessment. Most significantly, families are often uncertain about where exactly they will be living, which of course will have direct implications for schooling options on and off base.

“We don’t always get the information from EFMP as I feel we should. That’s not a slam on them. I find sometimes I’m calling EFMP and saying, ‘Did you know we have the Smiths coming in with a child with deafness?’ [Then] sometimes I get an incoming notice from them saying, ‘Call us when you can, there’s a family arriving next week.’” (Provider)

“Here it’s a bit more challenging; if you don’t know what housing area you’re getting, you don’t know which of the five different schools you’ll get.” (Caretaker)

School Liaison. The SL facilitates school transitions via one-on-one and group formats. Unlike EFMP, the SL serves typically developing as well as students with disabilities.

“At the conference I was at a couple of weeks ago, there were a few SLs there.... The SLs I spoke with said that 20 percent of the families that call them are in special education, but about 80 percent of the work they do is with those families....” (Provider)

The SLs face challenges similar to those faced by EFMP staff. Awareness of the SL is limited.

“The average 19-year-old mom doesn’t know about the SL. EFMP should be more proactive with new families or younger families. EFMP should be more proactive in educating families not just about their rights but also how to advocate in terms of what resources there are on base.”

(Caretaker)

“I didn’t know about the school liaison until my husband was deploying and the SL happened to be at the predeployment brief.” (Caretaker)

“I didn’t know of it at that time, but now I know there is a military liaison, a school liaison to help get things set up and established. I know now that they offer testing services ... I don’t mean psychological or intellectual. They can just compare your kid’s grade levels.” (Caretaker)

“How come ... the military didn’t tell me about the SL? I found out from the high school.... I could have used that information.

P1: I don’t know about it.” (Caretakers)

As with EFMP, SLs’ usefulness is diminished when families do not know where they will be living.

“I will use the SLs next time since I know they can connect me with the schools in the area that we’ll be going to. Here it’s a bit more challenging ... if you don’t know what housing area you’re getting, you don’t know which of the five different schools you’ll get.” (Caretaker)

“For community school to community school, if a family is changing schools and knows how to do it they contact me and I take care of their needs. The problem is a lot of incoming families don’t know if they’re living on base or not or where their house will be, and location determines services.” (Provider)

“We have a school liaison, and she is phenomenal. But as far as transferring, there isn’t anything you can do without knowing where you’re going....” (Caretaker)

Participants also noted that the SL is a relatively new initiative within Marine Corps community services. A few expressed skepticism regarding the SL mission and capabilities.

“The problem with the SL is that it’s still evolving.... A lot of the information they pass on really doesn’t fit because every family has different needs.... I don’t think they have enough experience or knowledge. I see the SLs as a political type of entity ... the ones that keep everything on the down-low and make nice with everyone. They don’t hone in on what the families really need.” (Provider)

“They hire someone and put them in that position and it’s a train as you go. They’ve never worked with special education before....” (Caretaker)

“Here in X ... they just got their first SL. She is really great, but she gets bogged down, and doesn’t understand EFMP at all. She uses us as a resource to learn about EFMP.” (Caretaker)

Directors of Special Education. These individuals are potential linchpins in the transition of students with special needs from one school system to the next.

“I can make a call to the next special education director, whether it’s at a civilian or DoDEA school.... Even if they don’t call me, especially if they’re going to a non-DoDEA school and the child is on the severe or profound end of the spectrum of impairments, I call the board of education in the community where the family is moving and then I ask to speak to the special-education director and tell them about the family coming ... we don’t do this for all children ... we just call ahead for moderate, severe,

and profound children. We try to do it more so for a parent that is not as resourceful and organized in coordinating services for their child. This doesn't necessarily correspond to rank.” (Provider)

It was suggested that DoDEA directors of special education tend to recognize the importance of providing this warm handoff for outgoing families, although the prevalence of this practice is unclear. While DoDEA may reach out to LEAs on families' behalf, LEAs do not necessarily reciprocate by reaching out when a family is inbound to DoDEA. Our source suggested that military-impacted public school systems may be more inclined than others to support military EFMs in this way: “It really just depends on the personal relationships you establish.... It's generally more prevalent in the local area.”

Public School Systems. In theory, the public schools are a resource to inbound and outbound EFMP families. A public school educator indicated that, when informed that a student is leaving, the school gathers pertinent documentation, makes copies, and instructs parents where to send it. The public school educator noted, however, that many parents do not inform the school that they are leaving. Another public school educator stated that, in her experience, schools are not notified of inbound EFMs either.

“We don't know that they're coming; someone shows up in one of the 89 schools wearing a uniform and comes to register their child. If they mark on the registration form that the child has a 504 or an IEP, then the person registering them asks for a copy, the same as any other parent coming in, but we don't know they're coming, unless they contact me in advance.” (Provider)

From this admittedly very limited sample, we infer that public schools, including those that are military-impacted, may not have systems in place for facilitating the transitions of military students with special needs. By the same token, it is also unclear to what extent base proponents have reached out to surrounding school systems. A local educator reported an absence of communication between her office and the local base:

“As far as knowledge of what we do, no one [from the base] has ever asked me. (I was also in X County, in a similar position. No one asked me from the military there ... either.) They have one SL, but she has not established a relationship with me or my underlings. The only communication we have had has been completing forms at the end of the school year and looking at the children who have had very exceptional needs. This latter work comes from DoD or DoDEA.” (Provider)

Early Development Intervention Services (EDIS). An early intervention program located on bases with DoDEA schools, EDIS apparently is equipped to help families identify early intervention (EI) programs at the gaining location (either an EDIS program on base or an EI program in the civilian community). Furthermore, as a federal EI program, EDIS is mandated by federal law to contact the gaining service provider and send them a copy of the individualized family service plan (IFSP).

“With our program, if it’s done correctly, we go on the National Early Childhood Technical Assistance Center (NECTAC) website—it has all 50 programs and the state contact. Every state has an EI program. It’s just that EDIS is only in a few locations.... We help them find an agency....” (Provider)

“Families aren’t necessarily told what their rights are with respect to IEP for children ages 3 to 21. In contrast, for children ages zero to three, IFSP requires a warm handoff by federal law.” (Provider)

EDIS proponents noted that they are unable to identify an agency if families cannot pinpoint where they will be living.

Military OneSource. Military OneSource coordinates a “buddy” program for students and can help with identifying local schools at the new location.

“Military OneSource was the best source where you could set up a buddy program at the new base. We just had them help us find out what schools were here, we had them chart out my drive to get my EFMP kids from X to here, and we had them help us find a hotel that’s kid friendly. They also helped me with some of the surrounding schools that weren’t here on base.” (Caretaker/EFM)

Student Online Achievement Resources (SOAR). SOAR is a web-based tool for military families and school districts. It offers at-home learning resources, state-specific resources, assessments, tutorials, remediation tools, and professional development tools for educators. SOAR is sponsored by the Military Impacted Schools Association (MISA), the Princeton Review, Skills Tutor, and the University of Northern Iowa.

3.2.3.3. Summary

Over the course of their parent’s USMC career, school-age children and youth may move in and out of DoDEA and public schools. Because bases with DoDEA schools are the exception rather than the rule, many PCSing families are dealing with the public schools on one of the PCS or both. Parents’ primary difficulty with PCSing and special education is the inconsistency they encounter across states and installations in terms of education policies, resources, and services. Parents tend to be caught unawares by this inconsistency, and it often leads to discontinuity and gaps in services for their special education students. Parents frequently perceive that schools are not doing their part to prepare for incoming students with disabilities—for example, parents described many instances of IEPs not being read in advance. Perhaps more troubling, parents often perceive upon arrival that the special education services offered their child at the new school are not only different but of lesser quality than those at the prior school. The perceived degradation in services, real or not, causes parents great frustration, which educators and parents said contributes to an adversarial dynamic with the school.

Parents noted that a number of base resources are in place to facilitate EFMs’ educational transition. Participants cited EFMP—for example, for providing parent

training, case management support, and communication with gaining DoDEA schools—and SLs. However, many parents suggested that PCSing EFMP families underuse both EFMP and SLs due to a lack of awareness of the PCS-related services these programs offer. Note also that EFMP and SL staff cannot provide families specific school support until the families can tell them where they will be living—information that frequently is unavailable before the family’s departure. EDIS was touted as a reliable base resource for facilitating the educational transition of EI clients, to include the transitions from one base EDIS program to another as well as from a base EDIS program to a community-based EI program. Although the participants acknowledge that the public schools, and public school/DoDEA directors of special education, have the potential to play a meaningful role in the educational transition of military students with disabilities, it does not appear that there are systems in place to support this.

3.2.3.4. Study Participants’ Recommendations

Below are recommendations made by one or more study participants for improving PCS support related to EFM special education. Suggestions offered by many participants are so noted.

Study Participants’ Recommendations for Local EFMPs

- Prepare parents of students with special needs to expect and navigate a very different educational environment when they PCS. (A frequent recommendation)
- Proactively send families of students with disabilities customized school information prior to arrival.

Study Participants’ Recommendations for SLs

- Market SL services more actively, for example, include a flyer about the SL in newcomer materials at check-in.

- Initiate a more systematic and robust program of base outreach to highly impacted LEAs, to ensure that they understand the challenges USMC students with special needs face and to work with the LEAs to provide these students the best support possible.

Study Participants' Recommendations for Other Military Entities

- Allow children with special needs to attend the DoD school regardless of the expected wait for base housing.
- Facilitate rapid assignment to base quarters for families who are eligible for them so they can identify, and begin dialoging with, schools as early as possible.

Study Participants' Other Recommendations

- Establish standards related to the transfer, review, and use of IEPs and other information related to the PCSing students:
 - Incentivize gaining schools to read and assimilate IEPs and other pertinent information from the losing school in advance of student arrival.
 - Require losing schools to send IEPs to gaining schools well before the student's arrival so the new school will have ample time to review and assimilate student information.
 - Create standard criteria for IEPs and other programs that would be accepted across counties and states.
- Encourage LEAs to communicate with the gaining schools of their departing special-needs students. (Possibly begin with LEAs that are receiving DoDEA partnership.)

Study Participants' Tips for Parents

- When possible, talk with EFMP, the SL, and the new school in advance of arrival.

"I came down here about two months before we moved and met with the principal and talked about what her needs might be and what was expected for the school to take care of her."

"We try to be as proactive as we can. We liaison with the EFMP to say, 'Heads up, we're coming.'" (Caretakers)

- Maintain contact with the gaining school district and school in advance of arrival.

"If you know you're coming, call me six months ahead of time, send me the IEP, the last psych report, call me again a month before you're coming, remind me so I'll know you're coming. It makes the transition for military families smoother, I think."

"I think 99 percent of [my counterparts around the country would be receptive to this kind of contact with families]. The other program specialists I work with would much rather have that kind of information up front. I look at class numbers now. Knowing what kinds of kids are coming in lets me share that information with the teachers now, and the teachers can make preparations for next year ... maybe they need to get training on a particular disability, for example." (Providers)

- Hand-carry IEPs and school records in addition to sending them in advance.

"[W]e moved from X to Quantico. I learned about bringing a copy of my IEP with me and having all my records in hand when I reach the school. I learned that lesson the hard way, going from the public school to the DoD school [because] it was a couple of weeks before the DoD school got my

children's IEP and it was very difficult to have the lag in service.”
(Caretaker)

“We recommend families use Family Educational Rights Privacy Act (FERPA) to get their file [the child's educational records] and take it with them.” (Provider)

3.2.4. PCSing and Access of USMC EFMs to Long-Term Supports and Services

For the most part, USMC EFMs are reliant on civilian resources for long-term supports and services. We examine here EFMs' continuing access to these resources when they PCS. (See Section 3.1.4 for a more general discussion regarding access of USMC EFMs to long-term supports and services.) Our discussion is presented under four headings: difficulties encountered, resources and resource effectiveness, participants' recommendations, and summary.

3.2.4.1. Difficulties Encountered

Frequent relocation decreases USMC EFM access to long-term supports and services. Providers and families who had experience with these resources repeatedly echoed this perspective. Focus group participants said:

“The more problematic thing is those [families] with the most severe needs. If they're settled in a state, they do everything they can not to leave the state if they're getting services from the state, whereas in the military, families don't get the choice not to move.” (Provider)

“This problem is even worse because your military families move three times more often than your average family.” (Provider)

“They start all over again.”

“To me, that’s heartbreaking; I’d sit there and throw my hands in the air and cry.”

“Makes it easy to understand why people won’t go with their Marine or they leave the military.” (Providers)

Eligible EFMs have difficulty obtaining and keeping Medicaid waivers because their name goes to the bottom of the waiting list each time they PCS. This was a frequent observation among providers and family members who were familiar with long-term supports and services. (EFMs seem to have easier access to Medicaid in California than in other states.)

“Even if you have coverage in California, for example, say a family gets 11 hours of ABA via Tricare and 10 at the regional center and Mom and Dad supplement four hours, they leave California and go to Quantico or Lejeune and they go to the bottom of a 10-year waiting list. I was there for several years and I never moved up one notch on the wait list. They leave California and go to Quantico and they lose a huge segment of their child’s treatment program.” (Caretaker)

“This is an issue whether you are military or not. You can get Medicaid waivers for your child with special needs, you can get an MR waiver if you have some intellectual disability, DD waiver, Elderly and Disabled waiver. You can get on the waiting list for an MR waiver in Virginia and that waiting list is at least 10 years long.... If you have an MR waiver in Virginia and you move to Texas, you lose it. Then you have a DD waiver ... it’s a bit easier to get, but we get so many people on that list, with fewer funds it’s hard to get. It’s the same thing with the Elderly and Disabled waiver. We saw a lot of our kids qualifying with this for attendant care, and all of a sudden we’re seeing them turned down, kids who are in wheelchairs or can’t be left on their own after school and can’t be

independent, but they're turned down because they don't have a medical need." (Provider)

"I feel like people coming into the state are discriminated against. If you're very severe and you need that personal care attendant, that piece is there. But for a ... family member with an intellectual disability, those families have to go on waiver lists that are seven to ten years long. Those families transferring in have to go on a wait list. By the time they [local children] are seven to ten years old, they get those services, whereas our families are not here long enough to get those services." (Provider)

"You don't automatically get Medicaid in this state just because you get SSI. You get it to a point, but when you need severe services you have to access them through waivers, and Virginia has about six waivers. If we had lived here forever, my son would have been able to have the full support, whereas moving here later means we only have partial support." (Caretaker)

Differing long-term supports and eligibility criteria create the risk of privation for PCSing EFMs, and the risk of financial hardship for their families. Participants also noted that, with each PCS, families must learn the services and policies of the new jurisdiction and comply with often-complex application procedures.

"Each state interprets federal laws so differently and spends the money differently, so it creates inconsistency." (Provider)

"You may qualify for certain entities and programs here that you don't qualify for when you move to a different state—like Medicare, Medicaid, SSI—and that puts a hardship on a family.... Let's say you're being covered for diapers over here, but you may not be over there. Military families operate on a very tight budget—this needs to be taken into consideration." (Caretaker)

Differing state requirements for special-needs trusts can adversely affect PCSing families. An attorney observed that special-needs trusts established in one state are not necessarily as effective under the laws of another state. Consequently, when EFMs PCS, their access to trust funds, and the services those funds can buy, may be reduced.

“Families who may have a need to have a special-needs trust, they have done that in one state based on the laws of that state. Then, when they move to a different state, that trust may not be as effective based on the laws of that new state. The trust can be used for the extra services like personal care or custodial care. And the funds may not be as available when families have to move.” (Provider)

3.2.4.2. Resources and Resource Effectiveness

Study participants identified no resources that facilitate access to long-term supports and services during PCS. They did, however, identify the absence of a mechanism to help individuals retain Medicaid benefits when they move state to state.

“If we move out of state we lose Medicaid; that’s a huge chunk of it. It would be great if you could see Medicaid portability. Sometimes we can’t take the chance of moving, but you don’t always have the control. We think it might be Georgia we’re going to; their wait list is three years long. He would only get ECHO therapy there. It would be great to see Medicaid portability, especially for military family members who are constantly relocating.”

“My situation is, as long as he’s in the group home, I have to keep an address in this state with Medicaid. I’ve basically made that choice. I’ve been here since X and I have X more years ... to retire. It probably shoots my chances down of getting promoted anymore....” (Caretakers)

3.2.4.3. Summary

Participants reported that the civilian sector, rather than the military, is the primary source of long-term supports and services for those USMC family members who use them. Because most of these civilian resources are state-based, EFMs must seek them out from scratch each time they move, learning the services and policies of the new jurisdiction and complying with often-complex application procedures. State-to-state differences in services and eligibility criteria create the risk of privation for PCSing EFMs—that is, gaps in services—and potentially expose the family to financial hardship. EFMs, caretakers, and providers cited the lack of Medicaid waiver portability, specifically, as a huge obstacle to obtaining and keeping long-term supports and services for PCSing EFMs, because there are long waiting lists for these waivers and the EFM's name starts at the bottom of the wait list each time they move. Study participants identified no resources that facilitate access to long-term supports and services during PCS; they did, however, identify the absence of a mechanism to help individuals retain Medicaid benefits.

3.2.4.4. Study Participants' Recommendations

- Establish Medicaid waiver portability for military families.
- Award Medicaid waivers based on the child's date of diagnosis rather than the date of application.
- Extend Tricare coverage to services that Medicaid covers for civilians.

3.3. EFMP and Other Base Programs

Because the USMC relies on the EFMP as the primary resource for families with special needs, NCD sought to tap family and provider perspectives on this important program. Because other on-base and off-base providers and organizations also serve this population, NCD was interested in stakeholders' views about these entities as well. Although findings related to EFMP and other base entities (e.g., SL, EDIS, DoDEA) are

included in previous sections of this chapter, it is in this section that we present the most concentrated and detailed feedback about these programs.

The findings in this section did not result from targeted focus group protocol questions. Rather, the findings emerged spontaneously from the general questions that also elicited earlier findings (listed previously) and from follow-up questions. The section is divided into two parts, the first addressing EFMP and the second addressing other base entities.

3.3.1. EFMP

This study took place during a period of transition for the USMC EFMP, which has been undergoing a transformation since 2008. The program has grown significantly in terms of budget (the baseline budget increased by \$11 million) and number of enrolled families (currently 7,500 and projected to 18,000).³⁴ As of this writing, the USMC is in the final phase of this multiyear transformation. Indeed, the responses of the study participants clearly conveyed that this is an evolving—and improving—program. The findings regarding EFMP are presented under four familiar headings: services and circumstances that are working well, difficulties and obstacles, participants' recommendations, and summary.

3.3.1.1. Services and Circumstances That Are Working Well

Unsolicited positive remarks about EFMP were made with great regularity, in almost every focus group held at each of the three study sites. Families, EFMP providers, and providers affiliated with other base and off-base programs spoke of how EFMP is improving, praised the work EFMP is doing, and described a number of EFMP providers as exceptional.

Families said:

“They’re beefing up the EFMP staff. They’re better trained than they were.” (Caretaker)

“We got a new caseworker and I’ve heard more from him in the past four weeks than my other caseworker in the past six months.” (Caretaker)

“Until recently, until the program had been overhauled, we were kind of dropped off the map from EFMP. We’d make phone calls and get no contact back. I tried to get information once when my daughter started kindergarten because she needed severe speech help at times. In recent months my husband has been waiting for an order to leave. Our case manager got in touch with us recently to tell us the program changed. Previously we were told we weren’t exceptional enough to be included. Our son had asthma but until recently hadn’t been diagnosed with X. We assumed they weren’t contacting us because we didn’t have enough need. We started the process to disenroll our kids because we were so frustrated. My husband got orders and then EFMP called us and he said, ‘Honestly, we’ve been trying to disenroll; no one has tried to help us in the last couple of years.’ Recently my case manager, X, is amazing. He put us in touch with NACCRA; we get 40 hours of in-home daycare for the kids. We can call our home care provider 24 hours a day, and he is on call for us. That’s been on for the past few months. In addition to the respite care, they gave us all kinds of help for our son, like EDIS. He needed a developmental screening. We didn’t know where to turn. Our case manager said, ‘Call them [EDIS]—they’ll come to your home.’ He also helped us with the paperwork to do for our daughter’s IEP. This changed literally in the last six months.” (Caretaker)

“Recently, EFMP started providing more. When I first came on board, there was nothing really out there....”

“They changed staffing, and since then we’ve seen some positive changes and I feel like now they’re doing a lot to be resourceful and provide the support families need.”

“When I saw the change in EFMP was when the commandant’s wife came down and did the big open forum. I think she was really surprised by how many people were really disgruntled by the EFMP. After that, there were many more meetings like with Tricare, just more town hall meetings, etc. That meeting was about two and a half years ago. They’ve done some more teachings and stuff. There’s been more about education, IEPs, what your rights are as a parent, more forums where they have different people from the community come in and tell you what their organization is about, more town hall meetings with directors from Tricare, the Naval Hospital, etc., giving people a chance to speak up and voice their opinions.” (Caretakers)

“I was here before three years ago. The program is growing; the program is much bigger and better now. Last time I was here it was one person, now there’s several of them and we have some of the key players coming into place. But they need better ways of getting the word out about different activities or different trainings. We were telling them to get the spouses’ email when they do the application. They’re trying to figure all that out.” (EFM)

“EFMP is kind of a start-up right now. They’ve been here for about a year; they’re doing a great job now, but there wasn’t much over a year ago.”

“Our case manager had to take a lot of time helping us and that took away from her ability to help others.... The people they had in EFMP were temporary; they helped us as much as they could. There’s always been this high turnover and now they have a good group in there that I think will do a lot.” (Caretakers)

"I feel like the caseworker at EFMP was able to give me some information, but she's brand new and they're reworking their caseworker qualifications ... now they're really trying to make sure they have additional qualifications." (Caretaker)

"The EFMP case management needs to be fine-tuned and ramped up more but it's something we didn't have five years ago...." (Caretaker)

Providers (other than EFMP staff) said:

"It's gotten a lot better, EFMP has; there are thousands on base receiving care...."

"I do believe that we see that parents with newly identified children are getting more support ... because they are expected by the Marine Corps to sign up for EFMP."

"There's been a huge difference, there's more involved parents, they have more meetings, they have support groups, they're good about getting information, and I get emails from them when they have different things going on. I think EFMP is connecting people, and it's the best thing that can happen to families. They come with them to IEPs if they're uncomfortable, and the attorney has worked really well with us (P4 agrees); that's helped a lot with a family who isn't knowledgeable." (Providers)

"They're working on it. It's changed a lot since I've been here six years ago." (Provider)

"[B]ecause I was a liaison with the EFMP program here on the base, years ago, they were part of our mayor's committee for people with disabilities. They were active then, but there's no comparison between what it was 10 years ago and what they are now." (Provider)

3.3.1.2. Appreciation for EFMP

Families said:

“Their EFMP program is really helpful. Just in the short time we’ve been with them, they’ve made a big difference. There are a lot of programs in the area I didn’t know were available, including civilian programs. They [EFMP] didn’t just put me in touch with civilian providers, but with different resources—they have a library at EFMP about issues you might have. They also put us in touch with support agencies, and they have support groups. The EFMP respite care has been a lifesaver, and I get 40 hours per child.” (Caretaker)

“I deployed to Iraq. I have an awesome husband who stayed behind and took care of my children, and the only way he was able to do that was through amazing support from the EFMP program and the local community.” (Caretaker)

Providers (other than EFMP staff) said:

“I think the EFMP program here on base is working very well.” (Provider)

“The EFMP partnership with the local school system is working particularly well.” (Provider)

“EFMP does an excellent job. The case managers take them under their wing and help them.” (Provider)

“The Marine Corps has it right. They have a very good process where a nonmedical case manager in the EFMP office, wherever they are, calls the nonmedical case manager at the EFMP office wherever they’re going

and they say, 'This child will need help.' They do this for off- and on-base schools." (Provider)

"Those fierce parents come from reinforcement by EFMP people. They are just a group of people who provide the consistency and continuity for these families. They are the ones who are able to do it ... who can say, 'I can give you this name for who to call when you get there.' Our EFMP office is like a rock."

"I totally agree—the EFMP here is amazing. They're great for our families. I had a question about a parent advocate for one of the kids in the school district. I called the EFMP and they could find a parent advocate. If you say there is a child in this school district or in this county who needs something, they can tell you who to contact or get back to you right away." (Providers)

"They're such a constant for me. I can get a call in my office and get an EFMP person right away. Say there's a new family here and they are out of medicine, EFMP will call me and say, 'Can you help them?' EFMP will call me to let me know they [a family who needs me] are here. They'll call me from an EFMP office away from here and say, 'We have a child with this diagnosis and this need and I want to know, if they're going to come to Camp Lejeune, will this resource be there for them?'" (Provider)

"We identified crisis managers at EFMP that we use all the time. A typical example is for a family that comes to the area and knows nothing about the area. We had a family that needed daycare services but had all these special needs. Dad had to start work the next day, parents were anxious, and I called EFMP and, as soon as I did, EFMP said, 'We already got it taken care of; we'll meet with the mom tomorrow.' Everybody else was freaking out, but EFMP had it and knew what to do and how to do it." (Provider)

“They’ve done a great job in the last couple of years for the staff of defining what their role is as far as supports go, helping staff to understand what the district can and can’t do, working outside of the IEP. Sometimes an EFMP staff person will call me and say, ‘I have a family and this is what’s going on, what do you think? Can you help me?’ That’s been a big help.” (Provider)

3.3.1.3. Select EFMP Staff are Outstanding

Families said:

“I love the outreach specialist. She’s responsive to families, and she runs the autism support group on base. X is another one who really gets it.”

“There are some super caseworkers.”

“I have a wonderful caseworker, too.” (Caretakers)

“My EFMP caseworker got back in touch with me (after it was determined that my son needs more services). She has been very responsive.”

(Caretaker)

“Ever since I’ve been involved in the EFMP program, my caseworker emails me constantly. He is sure to send an email out. He’ll just check in on me to see how we’re doing.” (Caretaker)

“My caseworkers and SL were phenomenal in my support for my child.”

(Caretaker)

“My EFMP caseworker helps me prepare for the IEPs when I know it’s time. I can brainstorm or bounce things off of her. She helps me take my emotional hat off. She helped me when I was getting frustrated with

ECHO and I wasn't getting replies from them. She contacted them and got a swift response.” (Caretaker)

Providers (other than EFMP staff) said:

“X is the first EFMP coordinator who ever called us and introduced herself and told us what the program was. We'd have no idea what that was, and I've been working with special needs for a long time. Now, when we have a family come in, especially ones with little kids, we always ask if they're military and now we refer them to all of the military services.” (Provider)

“The outreach liaison from EFMP comes over to the hospital at least once a month, if not more often, for being available to pediatrics, for anyone else who needs to talk with her. She proactively appears. In fact, we have her do an in-service for all of the [hospital] case managers.” (Provider)

Miscellaneous services and circumstances that are working well. A number of study participants praised the EFMP summer and overnight camps and the support for EFMP demonstrated by senior USMC leaders. A couple of family members singled out the Okinawa EFMP as particularly effective.

3.3.1.4. Difficulties and Obstacles

Extensive findings emerged from the focus group discussions on the difficulties and obstacles that the participants observed and experienced with EFMP. These findings clustered under five main topic areas:

- Awareness of, Referral to, and Application for EFMP
- Communication Processes within EFMP
- Quality of EFMP Service Delivery

- The EFMP Assignment Process
- Elimination of EFMP Categories

In combination, the results of these five topics provide detailed feedback regarding USMC EFMP program implementation.

3.3.1.5. Awareness of, Referral to, and Application for EFMP

These issues deal with entry into the program. That is, awareness of EFMP, referral to EFMP, and the EFMP application process are prerequisites to enrollment in EFMP. They are also prerequisites to accessing various disability-related services that are contingent upon EFMP enrollment.

Insufficient Awareness of EFMP. With regularity, study participants observed that many eligible families continue to lack awareness of EFMP's existence.

“One of the people in my husband’s shop, his daughter lives with her mom and is moving down here and she’s in a wheelchair. He didn’t even know EFMP existed.... He is a sergeant.... His wife and daughter were living with her parents because their house was equipped for her.”

(Caretaker)

“Here in X, I talked to a man whose daughter is on a g-tube. I said, ‘Did you contact Quantico and let them know about your daughter to ask about respite care?’ They didn’t know about EFMP. He had been in the Marine Corps almost four years and he was about to reenlist. This shows a lack of care from the leadership.” (Caretaker)

“It takes months and years to find out about services. My experience was 10 years ago, but it hasn’t changed. One parent I know, the baby is eight or nine months old; they owe probably close to \$25K for co-pays for medical stuff because they didn’t know they could get the MediCal

waiver. They're not registered in EFMP. They don't know about the early intervention services out there." (Caretaker)

"Knowledge is a difficulty for families. They don't know the resources are there. They don't know about the EFMP program. That's what EFMP is working to do, that should be the main go-to for the Marines—the caseworkers." (Provider)

"We have received some families from other places where a child went almost six months without services because the family wasn't aware of services, like they got here, and didn't know EDIS was available. They moved from off base to on base, so she just knew her child needed speech, OT, and PT, came here and told her PCM what she needed, and her PCM referred her out in town." (Provider)

Misinformation about EFMP. Study participants observed in large numbers that many families continue to misunderstand who is eligible to enroll in EFMP and what the benefits of enrollment are.

"They never told us that he was eligible or automatically qualified because he was born prematurely. I always thought that it was for kids with really, really big disabilities, not just asthma or being premature." (Caretaker)

"It took a year for us to figure out that having educational disabilities qualified us for EFMP. Other parents with similar situations and my friends told me that we were EFMP eligible. I found out from a friend of mine and called the EFMP office and said, 'I heard a rumor, my son has an educational issue, [and] I heard that qualifies him for EFMP,' and they said, 'Yeah,' and I'm [thinking], 'Like why am I calling you?' [as opposed to EFMP calling her]." (Caretaker)

“There’s a lot of people who may not even know they qualify for EFMP. We had a neighbor who has a child with severe asthma and she had no idea she could be in it. People don’t realize you can be in it for educational disabilities, speech, IEPs, learning disabilities, etc.”
(Caretaker)

It was apparent that people do not necessarily share a common definition of “disability.” By way of example, the researchers frequently encountered prospective focus group participants who questioned whether certain medical diagnoses, including mental health diagnoses, qualified as disabilities. It appears such conceptual ambiguity is yet another form of misinformation that can discourage families from enrolling in EFMP.

“Some people aren’t aware of what a disability may consist of; people assume it’s inability to walk, or blindness. People aren’t aware of psychological disabilities.” (Provider)

The focus group discussions revealed that many Marines and spouses apparently continue to believe that enrollment in EFMP will adversely influence a Marine’s career and opportunity for advancement. This “stigma” associated with enrollment is discussed further under EFMP Assignment Process.³⁵

Unreliable Referral Process. Study participants spoke with regularity about eligible Marine families that are “falling through the cracks” and not getting referred to EFMP. Delays in referral to EFMP can result in delays in critical services for EFMs or significant financial hardship for their families.

“When I found out he was autistic, I had no idea we even qualified for EMP—he was enrolled in the school and nobody told us....”

“My husband sends a lot of Marines my way.... They are not being referred and getting the help. When the command gets involved is when people find out, when the finances hit the floor.” (Caretakers)

“For us, a lot of it is identifying the families that are undiagnosed and getting them the support, because we deal with such a young age group. We get children who are three and a half to four years old, whose parents want them to be in preschool. Somehow they’ve fallen through the cracks of NPS and EI.”

“If the child isn’t diagnosed at birth, and they’ve moved three times in different environments, or they go home when their husbands deploy, and they come back, etc. That’s one way the system loses track of kids.”

(Providers)

Physicians can and should refer families to EFMP. However, many study participants, including enrollee families and providers, reported that physicians do not consistently refer eligible families to EFMP. It appears many physicians lack sufficient knowledge of EFMP to function in this capacity (or to supply needed documentation). This seems to be particularly true for civilian physicians.

“I’ve had civilian doctors say, ‘I don’t know what this is. I won’t do it’ [regarding EFMP paperwork].”

“[W]ith military doctors, it’s about 50-50 ... they’re just not trained.”

(Caretakers)

“My neurologist is unfamiliar with EFMP and he won’t fill out the update paperwork.... I try to explain EFMP to him, but it’s hard for me and I want the EFMP office to explain it to him. He doesn’t want to sign his name to a piece of paper without knowing what it is.” (Caretaker)

“Tricare has primary care providers in the town who often don’t know about EFMP and they don’t enroll these children. There’s no training. There are a lot of children out there who move on base but their families don’t know about EFMP, which is because the primary care providers in town don’t know about this and don’t do it. Providers say, ‘Yes, we know

how to do that' [help enroll families in EFMP], but somewhere it's breaking down." (Provider)

"Communication between civilian and military providers [is not working well]. The more we could do to facilitate that, the better it would be. It may be on the provider in the community to do more outreach, on military providers, on EFMP, etc." (Provider)

This referral problem does not apply only to civilian physicians; a number of families cited instances in which military physicians were resistant or lax about referring eligible family members to EFMP. For example, a military pediatrician actively resisted a mother's requests for referral for more than a year. In another case, a premature baby was referred to the New Parent Support Program on base but not to EFMP. In both cases, the delay between diagnosis and enrollment in EFMP created unnecessary financial burden and stress. Focus group participants said:

"[The military pediatrician told the mother], 'Oh, she doesn't need to be enrolled in EFMP,' even though I asked a year ago if we should enroll her.... Finally, after some crises, he went ahead and filled out her EFMP forms.... My physicians' view for EFMP was that it's only if you can't go certain places, and your daughter can go wherever, so you don't need to enroll." (Caretaker)

"I heard about EFMP through a friend, same with ECHO. We'd been paying out of pocket for a private school and out of the \$30K we paid a year for the school, \$25K would have been covered through ECHO. He was originally diagnosed here with an on-base doctor.... [H]e was diagnosed by a military doctor who didn't refer a child with autism to EFMP." (Caretaker)

"I have a hard time with that because we in education don't know where those families are ... if pediatricians would become ... more

knowledgeable of the process of referring a family, that would be better. Physicians are the front line and they should be the first referral source.... They should be held responsible, particularly in the military medical system; they should be responsible for identifying kids who need support earlier.” (Provider)

Laborious Application Process. The process for getting enrolled in EFMP, once referred, was described by several as complicated, even from a provider standpoint.

“From the New Parent Support standpoint, our social workers and nurses go into homes and make referrals for families, I had a question from a new nurse saying, ‘This mother is a candidate for EFMP, so we downloaded all the paperwork ... it’s 10 pages ... I don’t know where to start!’” (Provider)

“The EFMP paperwork is hard for families ... not understanding the wording of paperwork and needing someone to walk through it ... it’s not just that there’s a lot of paperwork, but that it’s hard.” (Provider)

3.3.1.6. Communication Processes within EFMP

We address here communication among base EFMPs as well as base EFMPs’ communication with their customers, the enrollees.

Unsystematic Communications among Base-Level EFMP Proponents. Providers, including EFMP staff, noted that the system for notifying EFMP about inbound families is unreliable, and sometimes EFMP is unaware of inbound families. One focus group participant said:

“A lot of the time, Housing will know because the people fill out a housing application, but we won’t always know people are coming, are going, or that they’re already here.” (Provider)

Unsystematic EFMP Communications with Enrollees. Study participants spoke frequently on the topic of EFMP communication with families. Many families expressed the view that they do not receive the information from the local EFMP office that they should. As a result, it was not uncommon to hear that some families were ignorant of the services available to them. As one provider put it, “Sometimes I think it’s the luck of the draw for parents, that is, who they get hooked up with in terms of access to resources, to shared knowledge of resources.” Based on participants’ comments, it appears that the breakdown in communications when one “draws the short straw” can lead to unnecessary stress and expense.

“I had been enrolled since the beginning of June. This was the middle of October. I just went through a summer by myself with my two kids, one of which was EFM. I was ready to scream and cry I could have used the respite so much. This was summer of 2009. I had to fork out money every time I wanted a break from my son ... I don’t get emails or telephone calls. I accidentally found out about a free movie night they had a few months ago ... I heard about this focus group from friends.” (Caretaker)

“I went home and cried the first day that we met with the [current] EFMP case manager. He was so open and helpful. I said, ‘How did we not know about this, this whole time? How did we not know about all of these services?’ Some of these services were there all along, like meet-and-greet groups, being able to call the EFMP office to work on IEPs, or respite. We’re not seasoned 40-year-old parents ... and our children have had a lot of special needs. When we realized that our child was sick ... it would have been helpful to find out we aren’t alone. Now to discover that we have two children with special needs, that’s devastating and we could have used emotional support. When our son was diagnosed ... I was nine months pregnant and he was in Iraq. Why couldn’t I have known about EFMP support when I needed it?” (Caretaker)

Ineffective Information Dissemination. The participants discussed shortcomings associated with the methods EFMP uses to communicate information to enrollee families. In many regards, their concerns echoed common challenges associated with communicating with all military families.³⁶ For example, the base newspaper is not an effective or reliable means of reaching the large segment of the military community that lives off base, and briefings (e.g., the “Welcome Aboard” brief for newcomers) are frequently attended by the Marine only, who cannot be relied upon as a conduit for information.

“The problem is that some people live off base, so how are they getting those resources to them? How could they find out if they don’t read the base newspaper? ... But now they’re getting a little bit better about putting the base activities on the marquee.” (EFM)

“I know the base commander has a ‘Welcome Aboard’ brief and the spouse is offered to attend but, if she doesn’t, how much does the Marine tell the wife? ... If the wife can’t attend, a lot of information doesn’t get to her.” (Caretaker)

“This base is very good about briefs before people PCS. I tend to think the young ones go through lots of briefs (pre-deployment, post-deployment, all kinds of them). The wives are not required to attend, and I think a lot of the information isn’t getting home.” (Provider)

“And for spouses, the information may not get from the Marine to the family member regarding what services are available for EFMs ... during official check-in, information is given to the Marine. If the Marine doesn’t go home and say, ‘Hey honey, there’s an EFMP program we should sign up for,’ she may not know, and that happens a fair amount of the time, even with the New Parent Support Program.” (Provider)

According to some family members, there are EFMP staff who routinely direct families to websites for information. Not all military spouses are computer savvy or view the Internet as their preferred source of information, however.

“Some of our families are having trouble just knowing how to look through the website if you aren’t computer savvy.” (EFM)

“They always say, ‘Go to the Internet.’ I always say, ‘I don’t have time to do that.’”

“I didn’t know they have a website.”

“Everything changes like night and day here. They used to do respite care, where you would come in and give them your receipts and get reimbursed. I came in to ask about how it changed and to ask for information about ABA therapy, and they say, ‘Well, it’s all on the website.’ They make me feel degraded, like I should have known this stuff.” (Caretakers)

Email is a particularly flawed method of communicating information to EFMP families, according to many study participants. Participants noted that the poor quality of the family contact information in the program databases prevents the programs from communicating effectively with many of their customers. Most problematic seems to be the fact that the databases frequently have contact information only for the Marines, and typically it is their duty email address. The Marines may or may not forward communications from EFMP to their adult EFMs or spouses—particularly when the Marine happens to be deployed.

3.3.1.7. Quality of EFMP Service Delivery

We discuss here the success of EFMP caseworkers’ outreach efforts, the qualifications and availability of caseworkers to meet customers’ needs, and the scope of EFMP

services. The subsection concludes by examining participants' experiences with EFMPs of other service branches.

Inconsistent Outreach. Based on the comments of many of the family members, outreach—which most participants agree is a critical component of EFMP service delivery—is not yet a strength of the program. Focus group participants said:

“At times I feel like I’m in this alone.... There is some responsibility for me that I need to go search EFMP and knock down their door, but they should have been in touch more.” (Caretaker)

“X hasn’t checked up on me by calling or anything. I haven’t attended their events because I don’t know about them. I have called them just when I have questions. My EDIS caseworker calls me to check up on my daughter.” (Caretaker/EFM)

“I don’t even get emails from them. EFMP contacts me, but it’s never my caseworker. It’s another caseworker ... who always contacts us. I get publicity about support groups, etc., but it’s not outreach from my assigned caseworker.” (Caretaker)

Many enrollees do not know who their EFMP caseworker is or haven't heard from him or her, which seems to speak directly to the effectiveness of current outreach efforts.

“I don’t know my EFMP caseworker. I know we’ve changed caseworkers because the person that emailed me about this [focus group] was a new person.” (Caretaker)

“I never knew I had a caseworker. I used to get emails all the time. The only reason I got this email was that my husband happened to be back and they emailed my husband.... They used to email me, but I haven’t

gotten an email from them in about four months.... I don't even know who my caseworker is now." (Caretaker)

"I have a caseworker assigned to me, but I'm not sure who it is."
(Caretaker)

"When we first enrolled at the X office, the lady bent over backwards to help us enroll. She was great—then, all of a sudden, it was just nothing. We got a letter in the mail saying we're CAT II. Now I don't know who my caseworker is. One hasn't been assigned to me as far as I know." (EFM)

"Parents often don't know who their caseworker is. I see families all the time who don't know their caseworker.... Or they have the name of their old caseworker, because EFMP had a major staff change.... I love EFMP. They're fabulous, but I am wondering if the caseworker needs to make more of an outreach effort to introduce themselves. One of my tasks is to help my moms find their caseworkers through EFMP."
(Pediatric nurse case manager)

"We found, even when the family is enrolled in the EFMP program, they don't know their caseworker and they haven't been contacted, and they're not sure what they should be doing...." (Providers)

"In EDIS, we have 75 families right now and maybe 10 of them would know who their EFMP coordinator is." (Provider)

An EFMP provider noted that there are instances when caseworkers are unable to reach families despite their best efforts, such as when the contact information is incorrect or when enrollees do not return calls or emails.

Inconsistent Qualifications of Caseworkers. A fair number of families indicated that they had encountered caseworkers who lacked the requisite knowledge and background to assist them.

“EFMP is there if they answer the phone.”

“If they know what they’re talking about.” (Caretakers)

In this past fall we lost six people; two got rehired back. They just keep turning over. They’re reassigning their caseloads. This group got nothing and has not been educated. They’re learning on the fly at the cost of families. (Caretaker)

“EFMP should be in touch with the schools and they should know what’s out there in the public schools as well. EFMP coordinators need to be more familiar with what’s going on out in the community.”

“I’ve needed education information, and I feel like the caseworker at EFMP was able to give me some information, but she’s brand new and they’re reworking their caseworker qualifications....” (Caretakers)

Insufficient Availability of Program Staff. A large number of study participants—including EFMP providers, other providers, and families—stated that there are too few caseworkers to meet the demand. Some families who described receiving less than adequate support from their caseworker attributed this to the size of the caseworker’s caseload.

“The amount of cases that each case manager has is amazing. Trying to touch base with each of these families and take care of what’s in the works is probably too much.” (Provider)

In a few cases, families indicated the EFMP office sometimes was not open during normal business hours or that EFMP staffers, if present, were not responsive to their questions.

Limited Scope of Services. Some participants expressed the view that EFMP is primarily an assignment program and an information and referral program, and many indicated that they want and need more.

"[EFMP is] ... kind of like a portal, a centralized clearinghouse, so we can refer them out...." (Provider)

"Our case manager suggested the NPS program. I have changed tens of thousands of diapers.... All of the resources here are support groups.... We're that family falling through the cracks.... They need to do more than just assign us to a CAT IV base. But to command they say, 'Okay, they're in the right installation, their needs are covered, that's it.'" (Caretaker)

"But there's a high emotional need and toll going on in our family."

"The system is reactive."

"It's like our house is on fire and the whole neighborhood is standing around and doing nothing. They stand by and watch it or tell you it's your fault it's happening." (Caretakers)

A few study participants identified a void in the area of advocacy and advocacy training.

Experiences with Other Service Branches. USMC families may serve with, and receive their EFMP support from, other service branches. Providers participating in one focus group observed that families encounter differing or unexpected circumstances when they receive services from other service branches, which they suggested can jeopardize the support that EFMs receive.

“The regulations make parents get fewer services or delayed services. There’s a maze of services, and there’s poor coordination or collaboration between the branches of service, and then there’s fallout for the families.”
(Provider)

“Something that we discussed is that we all work off of a Marine Corps order, but sometimes the Marine Corps order doesn’t marry with the Navy order. For example, the Navy order says, ‘Go straight, turn left,’ but the Marine Corps order says, ‘Go backwards, turn right.’ So they’re working with one family with two different orders.”

“There’s an interservice issue, a medical and nonmedical issue, and HIPAA [Health Insurance Portability and Accountability Act] causes problems. We fall under Navy and we send information to the suitability screener, who works for EFMP. Now, the Navy is using a different coding system for EFMPs from the Marine Corps, so a big issue is who you give the EFMP enrollment package to.” (Providers)

A provider offered this real-world example, albeit perhaps an extreme one, of how working with more than one service branch can affect a family:

“Families get lost in the paperwork. You have a family that’s Army stationed here, but you’ve got orders to Okinawa through the Navy, and your child has some psychotropic medication they aren’t legally allowed to take there. Then they show up there and EFMP sends them back.”

More often than not, families suggested that other service branches offered superior or more extensive resources for EFM families.

“I don’t want to slam EFMP completely because EFMP coordinators in Okinawa went above and beyond to help us, to try and advocate as much as they could, but I expected the same advocacy when we got here and

we didn't get it. I'm not sure why but we didn't get it... But Okinawa isn't even an EFMP area and we had all those services and here we don't and it is an EFMP area. I believe it is a service difference, not a location difference. It took me three months to check in with my command because I didn't have care for my son, and that's wrong.... EFMP caseworkers worked with doctors in Okinawa. That was a big difference. There were only two of them, but they did a fantastic job. They were great at helping transition; they continued to follow up once we were here. Even in Okinawa they knew that in X the care wouldn't be as good, so they set up the appointments for my family before we moved...." (Caretaker)

"I go to X to get a lot of my resources.... They gave me a current 2009 book that had all the diagnoses and the direct contact numbers, and they gave me a book of all the EFMP offices so I know who to contact when I transfer." (EFM)

At least one family entered EFMP while serving with another service branch. They discovered upon returning to a USMC base that they were not enrolled in the USMC EFMP. In other words, it appears, based on this family's experience, that enrollment may not be coordinated across service branches.

"The speech therapist who evaluated my daughter at base A [an Army installation] told us they were going to enroll her in EFMP, but she wasn't actually enrolled when we arrived to base B [a USMC installation]. It wasn't communicated from base A. So, in the A system, she was an EFMP, but it didn't cross over anywhere else, because it had to be with your service branch, and it wasn't explained it to me." (Caretaker)

3.3.1.8. EFMP Assignment Process

This subsection encompasses a set of study participants' concerns that are beyond the control of base-level EFMPs. These concerns pertain to assignment monitors, the

implications of enrollment on Marine career and advancement, and the elimination of the EFMP category system.

Families Question Monitor Capabilities. Monitors determine Marines' assignments and thus wield a great deal of power over both a Marine's military career and the family's well-being. Given the importance of the monitor's job, and the very real and lasting human ramifications of the decisions he or she makes, a number of families questioned whether the monitors have the appropriate information and sensitivity.

"The man who had approved our orders was going off of an EDIS report from two years before. They didn't have my son's IEP.... It was a very big communication breakdown; the process didn't work for us." (Caretaker)

"The career planners are not considerate to EFMP. My husband was on a ship and they cut him orders to Okinawa and they refused to listen to us. We were like, 'We're EFMP CAT III.' My child's teacher contacted the special education teacher in Okinawa and asked about post-high school education services, and they're like, 'There are none.' We sent that information to my husband, who sent it to the career planner, who said, 'I'm sorry, you're going.' They're like, 'You need to talk to the overseas screener,' but he wouldn't see me until the overseas screener from Okinawa told him they don't have the resources we need. We were just lost in this giant loophole because this one career planner was being so inconsiderate as to needs." (Caretaker)

Several spouses shared anecdotal perspectives regarding the assignment monitors and the assignment process. Each anecdote is different but, as a group, they help us to understand families' skepticism and discomfort with the current process.

"The monitors don't know what to do with the new system. I talked to my husband's monitor and he has no idea what to do. The monitor said, 'You're not CAT IV anymore, so I can put you anywhere?' No! EFMP

doesn't [even] know what the new system means ... what the implications of it are." (Caretaker)

"When you talk about categories and where you can PCS to, you can't get a straight answer." (Caretaker)

"EFMP status doesn't affect rank or your career, but it does if you have to stop orders or get out of orders if you're in the wrong location. It's like humanitarian moves, it's not supposed to hurt you [your rank or career], but it does. It's frowned upon. If the monitors knew where to put us to begin with, if they understood how hard it is to move a child with a disability, it would be better." (Caretaker)

Perceived Adverse Career Implications. There was considerable discussion among the study participants about how enrollment affects assignment options, deployability, and advancement. It was apparent that some members of the USMC community are still reluctant to enroll, or to acknowledge enrollment, for fear of adverse impact.

"My husband doesn't like his command to know about our EFMP status. He's afraid it will mess up his career."

"It's not supposed to."

"But he's afraid it will. We try to fly under the radar. He doesn't like anyone to know about this. My husband deploys once every three months for two to six months."

"I understand. My husband likes to fly under the radar, too." (Caretaker)

"Even with EFMP, there's a big cloud over it. A lot of people think that your husband is never going to get deployed.... There's a lot of people who think their husbands will get in trouble if they join, they'll get outcast, our personal lives will be made public." (Caretaker)

“If I run into someone who isn’t enrolled, I really encourage them to sign up. A lot of people don’t know.... Fix the misrepresentation that people have that they won’t get to deploy, they’ll know our business, etc. We’ve had a couple of people we’ve pushed to do it that needed it really bad, that would have benefited from getting on it a lot earlier.” (Caretaker)

Providers concurred that there is a continuing stigma attached to enrollment in EFMP.

“The concern that it might affect the Marine’s career in the military, that stigma is very much there.” (Provider)

“There are some that don’t inform their commands, just that whole stigma piece.” (Provider)

“I had a Marine father tell me recently that his superior said to him, ‘You know, these EFMs, they just get in this program so they can choose where they want to go.’ You can imagine the impact that had on him, and he has a child with involved disabilities....” (Provider)

“The marketing is important because there is stigma out there, too. The EFMP program started as an overseas screening tool. It still does that, but now it’s so much more. There’s a lot of Marines that think you’re going to get flagged and won’t be able to go where you want.” (Provider)

Several providers suggested the stigma of enrollment and disability in general is exacerbated when the special need involves mental health.

“For the stigma question, for our children with social and emotional disabilities, the stigma is still alive and well. For parents, clearly the child presents a challenge that’s more complex for the parents to see. I’m really encouraging parents to get support for themselves as they deal with the children, and I am getting a lot of resistance. I am talking

exclusively about military families. Support for parents with children that have socio-emotional disabilities is a huge challenge.” (Provider)

There was sentiment from some providers that any lingering stigma associated with EFMP enrollment is subsiding.

“I think at one time service members would try to hide the fact that they had family members with special needs [several agree] because they thought it would affect where their next duty station would be, because certain duty stations affect their career opportunity.... That’s changed a lot now; that’s not still the case. In the new EFMP order, if I remember the draft properly, it specifically states that you cannot use that against a member.”

“We can help them go unaccompanied for not as long; we can work with a liaison between them and the military, so they can go for one year unaccompanied, instead of two years. It used to be we sent the family and the resources weren’t there, so they’d send the family back. Then nobody from the family can go, now the Marine can go and the family can stay. It takes education. It takes communication.” (Providers)

“Many families who should be enrolled don’t enroll because they don’t want to disclose to HQ....”

“They think it will injure their career if they report that information.”

“People have less fear now as far as going to the command.... I see it as being addressed here on base.” (Providers)

“She [EFMP outreach coordinator] gives a massive presentation on all of the resources here to FROs, but there is still that stigma.”

“They don’t want their transfer being controlled. They’re concerned about the impact on their career.”

“A few years ago, less so now, I’d get calls saying, “We get dinged by our command if we give the schools too much trouble.” I would say that fear has been reduced over time.” (Providers)

Several Marines observed that the Marine Corps may permit a family to stay in place in order to ensure continuity of services for the EFM. The Marine, in turn, may also stay in place or may be sent on an unaccompanied (a “dependent-restricted”) assignment. Both of these alternatives are problematic, however. Staying in place, it was suggested, damages opportunity for further advancement. Changing duty stations, on the other hand, creates a financial hardship for the family, since they must support two households. Changing duty stations can also create a potentially untenable burden on the civilian spouse, who then becomes the sole caretaker of the EFM.

“I’ll tell you this right now. It took me a long time to become an EFMP-identified Marine, because now you’re landlocked to a geographical area. Unless you know somebody on the promotion board ... unless they actually know about Category IV, my gut feeling tells me they’ll never understand. How does that make us feel that we’re getting passed over because of that?”

“I totally agree. That stigma is alive.”

“So now we have somebody who hasn’t gotten a B billet and hasn’t gone to combat, so how can he compare to his peers when it comes up for promotion?” (Caretakers)

“It’s tough.... I’m homesteaded, but ... it affects your career. They’re going to tell you it doesn’t, but it does. I haven’t got promoted since X because I’ve been here. They tell me it’s a choice I make—I could choose to go Lejeune for two years or go to Iraq or Okinawa, but the first time he’s in the hospital and they’re in Bethesda, but my other child is down here ... she [my wife] can’t do it.” (Caretaker)

3.3.1.9. Elimination of EFMP Categories

Elimination of category system jeopardizes access to services. The four-category system that the USMC historically has used to differentiate level of EFM need and to determine assignments was recently eliminated, to the consternation of many.

Families consistently expressed deep worry that the loss of their category designation will compromise access to needed resources. They were especially worried about how it will affect their eligibility for priority base housing, which is important because it provides access to DoDEA schools and other base services.

“Now they’re ditching categories, which I don’t understand.”

“I think it’ll be a bigger problem because when you go to Housing, certain people need priority housing.”

“Our case manager said she is having to do a lot of appeals for priority housing because people no longer get that. She says there’s some families that really need it, and it’s just not really fair.” (Caretakers)

“I’m upset about the Marine Corps ending categories. The last time we saw her orthopedist, he was literally shocked that she didn’t have a category, and that was November of 2009. He said, ‘How is that going to help her be able to navigate the system when everyone asks, when they’re EFMP, what category are you?’ We look like idiots when we go in there and they say, ‘What category is she?’ and we don’t have one anymore. We go to move now, and we need to be near a big city because she has so many specialists that she sees. I used to be able to say to Housing we’re CAT IV, we need an immediate house, but how will Housing help us now? We tell them about her disabilities and Housing is going to determine if we’re important enough to have that or not? That’s terrible.” (Caretaker/EFM)

“If we aren’t in a position to get priority housing ... then my kid may end up in some crummy school biding time to end up in a DoD school. I want kids to have access to DoD schools if they really need it, regardless of the availability of housing.”

“I am very concerned about the categories going away and the availability of housing and not being able to get priority ... a huge concern for us because of my daughter’s medical needs. We’ll have to go to a band-aid school for four months or six months while we’re waiting for housing.”

(Caretakers)

3.3.1.10. Summary

The USMC relies on the EFMP as the primary USMC resource for families with special needs. Participants almost unanimously recognized that EFMP is a program in transition that has grown significantly in the past few years and is continuing to increase its capacity to serve EFMs and their families. Many families and providers affiliated with other base and off-base programs praised the work EFMP is doing, and described a number of EFMP providers as exceptional. EFMs, caretakers, and providers also identified areas for improvement within EFMP.

Several factors may interfere with entry of eligible families into the program. Participants noted that there continues to be a lack of awareness among potential enrollees about EFMP, as well as misinformation regarding who is eligible to enroll and what the benefits of enrollment are. A lingering stigma associated with EFMP, and its impact on a Marine’s career, may affect a family’s willingness to enroll. Finally, providers—including physicians—do not consistently refer appropriate candidates to EFMP, which can needlessly delay their enrollment and their timely receipt of invaluable services (e.g., respite care, services covered by ECHO).

Communications is a second area in which difficulties were identified. Communication among base-level EFMP proponents about PCSing families seems to be inconsistent,

and sometimes EFMP offices are unaware of incoming families. Shortfalls in communication between local programs and enrollees also were identified. Many families indicated that they do not receive the information from the local EFMP office that they should—indeed, some of the focus group participants were unaware of services available to them. The participants also discussed concerns regarding the effectiveness of the methods that EFMP uses to communicate information to enrollee families. For example, many voiced frustration that the EFMP office does not send communications directly to the spouse—typically the primary caretaker, or the EFM—and instead sends them to the Marine, who may or may not forward them, particularly if deployed.

Providers and enrollees identified opportunities for improvement related to quality of service delivery. Outreach is not yet a strength of the program—indeed, many enrollees said they were not receiving outreach contact from EFMP. With respect to EFMP staff, a number of families expressed concerns about the qualifications of EFMP caseworkers, suggesting that some lacked the requisite knowledge and background, and many participants indicated that there are too few caseworkers to meet enrollees' needs. Additionally, some enrollees characterized EFMP as an assignment program and an information and referral operation, and suggested that EFMP should offer a broader scope of services.

Finally, there was discussion regarding the EFMP assignment process and the elimination of EFMP categories—two headquarters-level responsibilities about which EFMP families have strong feelings. Families expressed skepticism about the capability of assignment monitors to make appropriate assignment decisions on behalf of Marines and their EFMs. Also on the subject of assignments, there was considerable discussion about how enrollment affects assignment options, deployability, and advancement; as mentioned earlier, some members of the USMC community are still concerned about the adverse impact of EFMP enrollment. With respect to the elimination of the EFMP categories, families voiced concern that it will jeopardize their continued access to resources, to include eligibility for priority base housing.

3.3.1.11. Study Participants' Recommendations

The study participants offered extensive constructive feedback. These suggestions for EFMP are grouped below under the following headings:

- Study Participants' Recommendations about EFMP Personnel and Services
- Study Participants' Recommendations about Awareness of, and Referral to, EFMP
- Study Participants' Recommendations for Other EFMP Processes

Those made frequently are so noted.

Study Participants' Recommendations about EFMP Personnel and Services

- Cap caseworkers' caseloads, and increase the number of caseworkers, to allow them to provide more comprehensive services to base EFMP families.
- Establish new programs:
 - A sponsorship program through which each incoming EFMP family is paired, well prior to arrival, with an EFMP family at the gaining installation, for information and other informal support. (A frequent recommendation—see Section 3.2)
 - A peer mentoring program. (A frequent recommendation) Find ways to help parents share support, lessons learned, and information. This may already exist in some form in some locations.
 - A support group for siblings.

- Expand the scope of the EFMP mission beyond information and referral (a frequent recommendation):
 - Provide regular outreach to enrollee families. (A frequent recommendation)
 - Proactively push information and resources to families, to include immediately upon enrollment, so they will know what to expect and how to derive maximum benefit. (A frequent recommendation)
 - Provide more advocacy training for parents.
 - Provide more advocacy. Some suggested hiring certified advocates or more EFM attorneys.
 - Provide a mechanism for families to learn from one another about local schools, classrooms, teachers, and so forth.
 - Provide supplemental outreach and programming for families with deployed members.
 - Extend services to children of retirees.

Study Participants' Recommendations about Awareness of, and Referral to, EFMP

- Increase the USMC community's awareness of EFMP, including families and command. (A frequent recommendation) Recognizing that new families are continually joining the military community, and families move regularly, establish an ongoing and multifaceted system to communicate comprehensive and accurate information about EFMP to command, Marines, and families.
- Publicize the specific benefits of enrollment, and mitigate resistance and concerns about stigma.

- Educate command. Ensure that commands and leadership have sufficient knowledge of EFMP and associated processes and issues to deal with families' concerns appropriately and with sensitivity. (A frequent recommendation)
- Educate civilian and military physicians about EFMP and their role so they can make timely referrals and be more supportive of special-needs families and EFMP processes. (A frequent recommendation)

Study Participants' Recommendations for Other EFMP Processes

- Establish more effective methods of communicating with EFMP families, targeting civilian spouses rather than service members. (A frequent recommendation)
- Where possible, reduce time and effort required to obtain EFMP services; streamline the renewal process, adjust the required frequency of EFMP application updates on a case-by-case basis, and notify families when their renewal date is approaching.
- Leverage command support for special cases that may merit extra attention or exceptions to policy by proactively apprising the leadership element before the arrival of severely disabled family members.

3.3.2. Other Base Programs

A number of base entities play an integral role, along with EFMP, in supporting the needs of USMC EFMs. Several of these entities, such as the military health care system and DoDEA schools, have already been discussed in depth (in Sections 3.1 and 3.2). In this section we present findings regarding other notable base entities and resources. These findings are presented under four headings: services and circumstances that are working well, difficulties and obstacles, participants' recommendations, and summary.

3.3.2.1. Services and Circumstances That Are Working Well

Respite Care. EFMP families have access to their choice of two respite care programs, one through a National Association of Child Care Referral and Resource Agencies (NACCRRRA) contractor and another, “installation respite care,” that allows families to select their own provider, typically a friend or neighbor. Most of the families who participated in the focus groups used NACCRRRA respite care. Respite received extremely high praise from families and providers alike as a significant new service and possibly EFMP’s greatest draw.

“For me it’s respite care, it’s phenomenal, that’s who is watching my child right now, because there wasn’t child care. My husband and I can actually go out on a date night without needing to worry about finding a new babysitter at the end of the night. They’re highly qualified, they bring things for the kids, they make it so I can do what I need to do as a mom, wife, and an advocate. I can’t speak highly enough about the respite providers.” (Caretaker)

“[W]ith NACCRRRA, we get 40 hours of in-home daycare for the kids. We can call our home care provider 24 hours a day, and he is on call for us; that’s been on for the past few months. We can’t believe how amazing they are now.” (Caretaker)

“My husband is deployed so I very much depend on respite.”

“Respite is a godsend for us, to have some breathing time or to spend time with one of our other children without some of the attention being on the EFM.”

“There’s the respite care; it’s so good. She comes and she not only watches my son but she watches the other two.... She also runs a daycare out of her house. If for some reason I need to go to the hospital, I

can just drop a child off there; she's 10 minutes from my house."

(Caretakers)

"This is such a huge program, physically being there as a caretaker. My husband deployed out seven times. When the respite program came in I was so excited about it because I knew it was a really important piece that kept our family glued together." (Caretaker)

"I have heard absolutely wonderful things about it. "Respite care is it for us." The parent is finally sleeping; the baby is sleeping through the night. One of the biggest benefits is that if they have to go to Bethesda for an appointment, the respite care provider can receive the second child home from school, or what have you. The impact has been tremendous. I haven't seen anything like that in years."

"I think it's probably one of the biggest selling points to get family members enrolled—look at what you'll get! It's the best way to get families what they need." (Providers)

"The respite care program has been a gift, at every opportunity. I cannot tell you how many families' lives have been changed; they are able to balance their own personal care and better care for their children."

(Provider)

(While this report was being written, we learned that USMC is no longer contracting with NACCRRRA for respite care, due to "ongoing inconsistencies.")

Early Development Intervention Services (EDIS). Mentioned previously, EDIS is the military version of the federal Early Intervention program for ages zero to three and exists only on installations with DoDEA schools. (See Section 3.1.)

New Parent Support Program. Also mentioned previously, New Parent Support is for families with children ages zero to five in the Marine Corps (zero to three in the other branches of service). Focus group participants said:

“And NPS, without them we couldn’t have made it. I was getting depressed and feeling guilty that he came early, and they were the ones that always kept me on track. Every week the social worker came to my home and helped me if I was having a doubt about why he is not doing this yet or they’re doing this and he’s not supposed to or the pediatrician says he’s underweight and I’m concerned, etc. She always talked to me. If I needed her before she was coming again, I could call her or the nurse. If I needed something, they were there. She introduced me to WIC [Women, Infants, and Children], being there for me, not letting me by myself since I didn’t have family at all....” (Caretaker)

“Our role at NPS is to work with young children but we do a lot of work with parents as well, since parents have to be functioning to be able to take care of those children, so it’s very often that we’re helping parents to understand that they must follow up with EFMP and go to their appointments. We do a lot of that screening initially to figure out what’s going on with the family. Oftentimes the parent has a lot of physical or mental needs that might be suited for EFMP.” (Provider)

Formal and Ad Hoc Coordination among Key Base Entities. Educators, health care providers, EFMP staff, and other providers at all three bases remarked on the importance and effectiveness of teamwork on behalf of special-needs families. Examples of standing events include a monthly meeting of EFMP and Housing to review new needs among existing EFMP families and needs of newly arrived and inbound EFMP families, Special Needs Evaluation Resource Team (SNERT), Quantico Inter-Agency Coordinating Council (QUICC), and Grand Rounds. Examples of less formal collaboration include a close working relationship between the base pediatric clinic and the DoDEA schools, or between New Parent Support and EFMP.

“At EFMP we do exactly what we do with Housing, but we also do it with the CDCs through SNERT and the hospital and the Grand Rounds, so I do feel like that’s working really well.... There’s a variety of monthly meetings with other organizations, so we can all be a team approach.”
(Provider)

“I think the way we collaborate, like New Parent Support and EFMP with EDIS, all of us working together.... I think the people in this room, we sort of know each other and work together.”

“One thing I like and have noticed is the ease and quickness of being able to put your hands on appropriate information that you need to tell families when they come to ask you for help. They’re in your office and you know who to call, depending on what it is and what you need; it’s quick.” (Providers)

“There’s a monthly forum at the hospital and EFMP attends and providers, primary care managers, etc., attend. EFMP and providers at the hospital get together and talk about certain cases. The forum is called Grand Rounds. It’s a monthly meeting of military medical, community service, and civilian players who are involved in EFM well-being.”
(Provider)

“Once every six weeks or so, we have a meeting at the hospital where the OB case manager and myself and our social worker ... gather up and invite people from the community, people from New Parent Support, and ... we do a little show-and-tell ... to make sure we all know what everyone does (not like Grand Rounds, when cases are discussed).... You can hear about an agency and what they do forever, but until you attach a name and a face together, it’s hard to reach out.” (Provider)

“[E]very quarter I send [EFMP] an electronic roster of every child in our [DoDEA] school with an IEP... I do that so they can identify any child that isn’t enrolled.” (Provider)

Navy Marine Federal Relief Society. Although financial hardship was a recurrent theme throughout the focusgroup discussions, only one study participant mentioned the Navy Marine Federal Relief Society (NMFERS).

“The Navy Marine Federal Relief Society ... they were awesome. When the babies were born, we were maybe two hours away from home and we had to go back and forth every day. It got to a point that we were tired... And then NMFERS paid for a hotel for us to stay in until the babies got out of the hospital. We stayed in the hotel for a month or so. It was a lot of help. We are really grateful for that. Because for me I couldn’t get away, and every time I was leaving the hospital to go back to X, I was devastated. They helped a lot.” (Caretaker)

Unit/Command. Two military spouses identified their Marine’s unit as a source of support. As it happens, these spouses were both adult EFMs with no children.

“His command is wonderful. If anything happens to me, if I have a migraine, they let him come home right away. If I have an appointment I need to be driven to, they let him help me. For the command to work with family members like this, I think it’s noteworthy.” (Caretaker)

Project Pendleton. Project Pendleton is a nonprofit EFM Resource Center through the San Diego State University Foundation that offers area families resources and referrals. It is made possible by a Military 360 Grant through the Department of Developmental Services (DDS) (part of the California Health and Human Services Agency) and the California Department of Education. Project Pendleton, unique to California, was mentioned by only two providers associated with this organization, who indicated that

their focus has been to develop networking for the Pendleton EFM community and provide training.

3.3.2.2. Difficulties and Obstacles

Concerns Regarding Base Housing for Special-Needs Families. Independent of concerns about eligibility, issues related to base housing were frequently raised by the study participants. Many focus group participants, at all three sites, indicated that the quarters to which their family was assigned did not adequately accommodate their EFM's disability.

"They put me in two-level housing in spite of a letter from my doctor.... I'm still in two-level housing." (Caretaker/EFM)

"I'm in a two-story house and I'm not supposed to be.... The steps in our house are too steep, even according to state regulations. I'm basically sleeping downstairs because I don't do the stairs. The bedroom is up there, the clothes are there, and if I keep anything downstairs, it looks like someone else is living there...." (Caretaker/EFM)

"They have these one-level homes that are great homes for accessibility. The doors are widened and the countertops are different heights.... They knew our situation, but they moved us into a home that didn't have it..."

"It's a big problem on this base. There's another family with a wheelchair and they tried to get a reserved handicap parking spot up front. They had to jump through hoops to try and get it. These are handicap-adaptable homes, but not accessible. Handicap accessible is fully accessible, like walk-in showers. Out of our front door there would be a ramp to the home, whereas adaptable can be adapted, you can make it work. A lot of the homes for people with wheelchairs don't have a ramp up front. They'll say, 'You have a garage, use that' but in our case we have a ton of equipment in our garage...." (Caretakers)

“They gave me a physical house before I got here, but the accommodations within the house had to be certain things, and they weren’t willing to give it to me because it wasn’t an EFMP house—they didn’t want to make changes to the house. But EFMP helped me get that.” (Caretaker/EFM)

“Our house was 106 degrees during the day.... I was passing out, and I was having trouble with the heat, and my autistic child was doing terribly. I went to doctor after doctor to try to get a medical note, so we took another financial hit and moved off base to get central air.” (Caretaker/EFM)

At two of the participating sites, representatives from the Housing Office spoke to the high demand for base quarters.

“[T]hat’s an issue when we have a need for single-story ADA homes. Single-story homes are 10 percent of total inventory (4,327) on base. There’s a need for them, but at any point in time they might be all full.”

“We had six in a day who all needed them.”

“The average wait time for housing in general is six to eight months; the ADA housing wait is even longer.” (Providers)

“Now, they can pick any area that is rank appropriate for them. There’s about 22,000 families that come to Pendleton and there’s 6,500 homes, so there’s not a home for everyone.... We don’t know of every EFMP family. We know about the families that identify themselves to us.... I would say we house 99 percent of those that identify themselves.” (Provider)

The parents of a severely disabled and medically fragile child shared further concerns about access to accommodations for families with profound needs. Although these

observations were not echoed by others—indeed, we spoke with few parents in such extreme situations—they deserve mention.

“They’ve really let us down. We tried to communicate along the way. They just don’t get it.”

“We had how much snow and the only guy that would help us was a maintenance guy. We needed a place for our nurse to be able to park, but Housing wouldn’t help us [plow]. They did the whole front of our street, clear a place for our nurse to park! Housing just says, ‘We’re doing our best.’”

“Having signed forms for a year and a half saying you can move and then they gave away a house to someone who didn’t need it and they admitted they didn’t need it.” (Caretakers)

“Simple things like with the severest kids on base, if power goes out and the base is cold, there’s no prioritizing of generators from the Fire Department among EFMP families. My son needs the generators for his ventilator....” (Caretaker)

Several participants addressed the subject of an EFMP family’s continuing eligibility to reside in quarters when the Marine is residing elsewhere. For example, can families stay in quarters when a Marine takes an assignment elsewhere? Can outbound families stay in quarters until the Marine has secured housing at the gaining installation? Based on the few comments made by study participants, including Housing proponents and others, it appears the answers to such questions may vary.

“My husband does his PCSing, but as a family they leave us. We just need permission from the base commander and Housing to be able to stay, and sometimes they won’t give us permission and we lived out in town for a while. We had to rent a house out in town for nine months. It affected schooling ... and my son lost his SSI because we started getting

BAH [Base Allowance for Housing], so we lost about \$10K worth of services because Tricare won't pay for any of those therapies."

(Caretaker)

Several participants expressed concern regarding the accessibility of base facilities.

"It took five years for the base to get the base training facility ADA accessible (they have graduations there, deployment ceremonies, movies on weekends, etc.)" (Caretaker)

"[I]f they have a movie night, we can't go because the theatre isn't accessible [isn't wheel chair accessible] or the bowling alley." (Caretaker)

"School on base started off with no accessible playgrounds, and now they're building one." (Caretaker)

Concerns about Base Responsiveness to Needs of Profoundly Disabled EFMs.

The parents of a severely disabled and medically fragile child shared the perspective that the base is not geared to support families with severe needs and is more focused on the needs of family members with less severe disabilities. Again, we are uncertain that others share these perspectives, but they are important nonetheless.

"It's almost the most severe your kid is, the less help you get. The autistic kids, they have everything, all sorts of resources on base; they have classes, they have everything for the parents, like movies, etc. For us, if they have a movie night, we can't go because the theatre isn't accessible [for wheelchairs] or the bowling alley. They were going to do a movie night for everyone outside; two-thirds of the severe kids, our kids, can't hang out outside in the fall because of their allergies. They think about the less severe kids, but if your kid is really severe, there's not much there for you." (Caretaker)

“I don’t know if some people on the base don’t realize how severe the kids are. There are some handicapped kids who can walk and talk and you don’t even know they’re handicapped, and there are some like my child. The whole base doesn’t realize and the base commander doesn’t realize how many sick kids are on base. I’m pretty sure base command doesn’t realize how many people actually have really handicapped kids. He says, ‘Oh, I have over 400 EFMPs, but out of how many of them really need care?’ Somebody has to tell him!” (Caretaker)

More than one family suggested that the absence of nurses, for example, at the Child Development Center or at EFMP events, prevents certain families from taking advantage of these supports.

Limited Awareness of Base Programs. Consistent with the findings regarding EFMP, study participants suggested that many families with special needs lack knowledge of the resources available to them.

“New Parent Support helps children up to age six. My husband says a lot of Marines need to go to the group meetings or classes that NPS offers, but the young Marines don’t know about them.” (EFM)

“There was a woman that had no idea that equipment was covered for her child and she was working at McDonalds at night for extra money.” (Caretaker)

Family Readiness Officers (FROs) Are Insufficiently Involved with EFMP Families.

A number of family members expressed concern that FROs are not actively supporting or representing EFMP families. Apparently, privacy considerations prevent FROs from learning that an incoming family has an EFM, which limits the opportunity of FROs to reach out to EFMP families on arrival.

Privacy Constraints Hinder Collaboration by Base Agencies. The FROs are not the only entity whose opportunity to support EFMs is inhibited by privacy rules. In fact, many of the base entities that participate in ad hoc and formal coordination on behalf of EFMP families indicated that they could work even more effectively if they could share information with one another.

Respite Care Shortcomings. While families are very appreciative of the respite care they receive, several highlighted ways in which the NACCRRRA respite care program falls short of their needs. For example, respite care coverage is less adequate for families with multiple EFMs, and families that include both a parent and a child with special needs.

“These families with one child and the mom needs a break and the mom gets her hair done and her nails done, that’s not us. I use my respite hours throwing up so someone can watch my children. Because I’m sick, my respite hours are used to supervise my children while I’m sick. There’s nothing for me, there’s no respite care for me, there’s no resource for me ... to have time when I’m feeling well, to have a break.”

“A family with one child can use their 40 hours for a luxury.”

“For us it’s how we live, it’s a support network.” (Caretakers)

At more than one location, study participants indicated there are insufficient numbers of qualified respite care providers to meet the demand—particularly for children requiring specialized attention (e.g., children with autism, with g-tubes, and who are nonverbal).

3.3.2.3. Summary

A number of base entities other than EFMP play an important role in supporting the needs of EFMP families. Both providers and enrollees frequently sang the praises of respite care, particularly the NACCRRRA respite care program, often describing it as the greatest benefit accrued by EFMP enrollees. Caretakers and providers also mentioned

EDIS and NPS as good sources of base-level support for EFMP families. Additionally, providers frequently mentioned formal and ad hoc coordination among these and other key base entities (e.g., medical providers, Housing Office) as an effective strategy for providing integrated and proactive support for EFMP families. Examples of formal coordination include SNERT and QUICC. Providers did mention that privacy constraints hinder their ability to collaborate as effectively with one another as they might like.

Most caretakers expressed concern about the disability-accessibility of base housing. Caretakers described base housing as adaptable rather than accessible, and some indicated that the quarters to which their family was assigned did not adequately accommodate their EFM's disability. In several instances, participants also identified accessibility problems with public spaces on base. The parents of a severely disabled child shared the perspective that the base is more attuned to, and equipped for, families with mild to moderate needs. Some suggested that the family readiness officers, unit-based positions created only recently, are not actively supporting or representing EFMP families. A number of participants suggested that, as with EFMP, families are not sufficiently aware of base resources available to them.

3.3.2.4. Study Participants' Recommendations

The focus of these recommendations is on entities other than local EFMP programs, such as base leadership, the base Housing Office, Headquarters USMC, and the NACCRRRA respite care program. That said, because EFMP plays such an influential role in supporting EFMs and interfaces so extensively with base-level and headquarters-level entities, many of these recommendations cannot be implemented without EFMP involvement. The recommendations pertain to five areas:

- Recommendations regarding base housing
- Recommendations regarding respite care
- Recommendations regarding inter-program coordination

- Recommendations regarding assignment monitors
- Other recommendations

Housing

- Ensure that housing is available for EFMP families that need it and make it truly accessible, rather than offering makeshift accommodations.
- Allow families to remain in quarters at the losing installation until the gaining installation has the resources to support them (e.g., housing, doctors).

Respite Care

- Adjust the 40-hour-per-month allocation. (A frequent recommendation) For example, suggestions were made to determine the allocation on a case-by-case basis (as the Army apparently does) and to allow unused hours to roll over into the next month.
- Explore variations on the current respite care program, such as offering it to caregivers of adult EFMs; offering additional hours for families with multiple EFMs, families who are PCSing, and families with a deployed sponsor; and allowing families to use their hours to pay for care at the Child Development Center.

Inter-program Coordination

- Continue to support coalitions of community-based EFM providers.
- Establish systematic notification and referral processes between NPS, EDIS, and EFMP.
- Legally and logistically facilitate providers' (e.g., EDIS, EFMP, military treatment facility) and service branches' ability to share EFMP enrollee

information so they can support EFMP families more seamlessly and efficiently.

Assignment Monitors

- Educate monitors to ensure that assignment outcomes are determined by policy rather than personality or personal background.
- Train and assign a group of monitors to specialize in assignments for Marines enrolled in EFMP.

Other

- Provide EFM families living off base access to all base services, including DoDEA schools. (A frequent recommendation)

3.4. Other Topics Related to USMC EFMs and Access to Disability-Related Services

The data collection effort for this study yielded limited information on several additional topics related to USMC EFM access to disability-related services. This information is summarized under the following topics:

- USMC EFMP Enrollee Sources of Information
- USMC EFMP Enrollee Knowledge of Rights and Self-Advocacy
- Adult USMC EFMP Enrollees and Access to Disability-Related Services
- USMC EFMP Families and Wounded Warriors

The first two topics were addressed in the focus group protocol, whereas the third and fourth topics were byproducts of more general discussions.

3.4.1. USMC EFMP Enrollee Sources of Information

The focus group protocol posed to participants the following questions: Where do you turn for information about getting the services and supports your EFM needs (civilian and military)? How do you know where to turn for this information?

The most common response from families, expressed by nearly all who participated, was that they rely on one another—other parents and word of mouth—for information. Many families said they use the Internet to find the information they need; they also mentioned EFMP, EFMP caseworker, and Military OneSource with some regularity. The participants noted that families' sources of information vary with the point in time and the type of information that is needed. For example, at the time of diagnosis, many tend to look to the medical community for information. This may include guidance by the diagnosing physician, as well as training and clinics offered at the Military Training Facilities (e.g., caring for a child with juvenile diabetes and clinics on ADHD or autism). Families with youngsters turn to their contacts at New Parent Support and EDIS, if they are participating in these programs. Additional sources of information mentioned by more than one parent include STOMP and support groups on base or in the civilian community. While some providers acknowledged that families frequently turn to one another for information, providers were more apt than family members to respond to this question by identifying the methods through which the base disseminates information to families, such as the "Welcome Aboard" newcomers brief and program brochures.

3.4.2. USMC EFMP Enrollee Knowledge of Rights and Self-Advocacy

The focus group protocol posed the following questions to families: What are your EFM's rights as far as disability-related services and how are those rights protected? How do you learn to speak up for your EFM and get what you need from the service system?

Most families were hard-pressed to articulate their or their EFM's rights. Focus group participants said:

“I don’t know anything about my rights.” (EFM)

“I don’t understand what you mean by rights. She has a right to health care—my husband serves our country.... She’s a baby, so what rights does she have? Her mother has to fight for what she believes are her baby’s rights....” (Caretaker/EFM)

Interspersed among the groups were a handful of families that mentioned or alluded to IDEA or FAPE. Some of these individuals had deeper knowledge than others.

“She is entitled to a free and appropriate public education. Under IDEA, if her needs and disabilities and diagnoses are adversely affecting her education, then she is also entitled to either be evaluated and/or receive an IEP through the public school system....” (Caretaker)

“I do know about my child’s rights, and it’s all thanks to EDIS.... They really taught me how to navigate the system.... Then STOMP seconded everything that was said initially from EDIS about what it means when you have someone with a disability, what they’re entitled to, what the law says.... It worries me for other parents who know less.”

“I don’t know.”

“I don’t know, either.” (Caretakers)

“I took STOMP training in Okinawa and it opened my eyes to our rights.... I learned about IDEA.”

“I don’t know about IDEA.” (Caretakers)

“I’m learning as we go.... I know about IDEA. You get the handbook whenever there’s an IEP meeting ... other than that, I don’t know too much about what their rights are.” (Caretaker)

“Up until the sit-down with our EFMP case manager, we didn’t know anything. He sat with us with papers and explained different laws and things we can do and groups that meet.” (Caretaker)

“I don’t know.”

“Isn’t everything supposed to be open to them? They’re not supposed to be denied anything? They’re supposed to be in a classroom with kids who are normal, so everything is integrated.”

“Any kind of devices or services are supposed to be offered to them to help assist them in the classroom.” (Caretakers)

The identified sources of advocacy training, for those who have been fortunate enough to obtain it, included STOMP, EDIS, and EFMP.

3.4.3. Adult USMC EFMP Enrollees and Access to Disability-Related Services

Because of the characteristics of the study participants, including the demographics of the families and the backgrounds of the providers, the focus group discussions were somewhat child-centric. Following are adult-specific observations made by a few providers and families during the focus group discussions. Although this information also appears elsewhere in the report, it is consolidated below for the reader’s convenience.

Although adult EFMs represent a minority of the EFMP population (see Appendix G for the sizes of these populations at MCB Quantico, Camp Lejeune, and Camp Pendleton), several providers suggested that it is particularly important to address adults’ needs. In the absence of adequate external supports, caregiver responsibility is likely to fall to dependent children in the household or to the Marine—both of which can be difficult scenarios. Focus group participants said:

“The adult EFM is very important. They may not be able to care for the other children. Sometimes the active duty member is the primary care provider for the adult EFM and may not have the ability for custodial care, so that family member affects their service member’s ability to do their mission.” (Provider)

“Unless you bring in a family member or you have a teenager taking care of Mom or Dad (it’s family, but it’s not what we really want; it’s a huge responsibility on a child) ... without a care attendant there for the severe needs, it affects that family in a big way financially and the teenager developmentally.” (Provider)

Providers noted that there are two long-term services for adult EFMs that are not covered by Tricare and which military EFMs are ineligible to receive through Medicaid, due to the military member’s income—transportation to medical appointments and a personal care attendant.

“There’s the issue of transportation—if they can’t transport themselves to the hospital or doctor, how can we get them treatment? That’s a big issue. They need Medicaid to use civilian transportation resources, but they can’t get that because they have a family member that works. That’s a big conundrum.”

“Transportation falls into the gaps of Tricare. Transportation and a care attendant are part of that.” (Providers)

“As Tricare implements their policies, stand-alone custodial care is not a benefit. If there’s a health aid in the home, they can provide custodial-care-type duties, like helping to feed or bathe the EFM if they’re already in a home performing other services. But there are some situations where the home health aide is only there for an hour each day and an individual needs personal care for the rest of the day....” (Provider)

As noted earlier, HQ USMC recognizes that adult EFMs lack access to personal care attendants, and it is pursuing funding for a reimbursement program.

The concurrent strains of being away from extended family, having medical issues of one's own, and managing the needs of one's children—including those with and without disabilities—can be overwhelming for an adult EFM.

“As a mother I’m just overwhelmed. It’s very hard to be away from family since you move around so much. It’s hard to take care of a special-needs baby and to throw in the mix an 11-year-old who needs attention too and yourself when you’re an EFMP.” (Caretaker/EFM)

“When he needs to deploy I have no one to move in with me and help with the children. In my physical condition I can’t care for my children, especially one that is screaming, scratching their skin, and punching holes in the walls. For them to say he’s going to deploy anyways and, if you can’t deal with it, put your kids in foster care, that’s totally unacceptable. We fall between the lines.”

“In order to get care for her she’d have to be bedridden, and it would be a nurse.” (EFM)

“For years, I did it, I had a three-year-old with autism, but I took care of my children, I was healthy. My husband went to Iraq two times in a row, it was stressful but I was able to do it, and I didn’t need the outside support. We didn’t have respite, we had no resources, it was just me taking care of everything, taking care of those children, but once I became sick, that’s when our life fell apart.” (EFM)

Adult EFMs encounter the additional challenge of finding child care during their own medical appointments.

“[A]nd then if there is a mother who would be the EFMP client and they have one car and she’s got little ones, there’s the issue of coordinating child care ... she may not make the appointment. I’ve got a mother with an appointment at 1 p.m. tomorrow with no one to watch her kids. There are a lot of young families that are needy and new to the area and there are problems with coordination of care. Then if there’s an older child who is a “normal child,” the older one feels neglected because of all the focus on the younger EFM. So, the issue is how to make it easy for parents to make their own appointments and appointments for others.” (Provider)

Adult enrollees with certain medical issues may encounter fewer difficulties, particularly if they are not also dealing with children who have special needs.

“I’ve never had a problem because I’ve gone to the military hospitals. Everything has worked. This is also our first PCS ever; it’s unusual for a Marine family. We were at Pendleton for 10 years and the services I’ve received are straight medical services thus far. Even coming here and finding the specialist and being referred to the specialist, everything has been fine.” (EFM)

Adult enrollees may perceive that EFMP is primarily for families’ children with special needs.

“I think my only thing with EFMP is I don’t get a lot of information pertaining to the program. I don’t really know what EFMP does. I hear things from P2, but if I went to EFMP, how would they help me?... I am not getting the information, but I haven’t asked them for it ... I haven’t reached out to them because I feel honestly that a lot of the EFMP activities are catered more for children....” (EFM)

3.4.4. USMC EFMP Families and Wounded Warriors

The USMC Wounded Warrior Battalions are located at Camp Lejeune (Battalion East) and Camp Pendleton (Battalion West). Recognizing that access issues may be compounded for an EFMP family with a wounded warrior, we attempted to identify and recruit any EFMP enrollees who may have been assigned to the wounded warrior battalions. As far as we are aware, no wounded warriors attended our focus groups. However, we did have participation from providers with insights into the needs of this population, and from spouses of at least two wounded warriors. Their responses— anecdotal yet compelling—are presented here.

Families who have young children with disabilities face a unique set of challenges when their wounded warriors return.

“To take into consideration the wounded warriors coming back and the issue with respite. We have a dad who returned, the mom was working, and the child was at home. The dad didn’t want anybody in the house—he had a lot of cognitive-related issues. He said he was taking care of the child, but he scared mom to death. The child was not in a safe environment. The dad was not aware that his attitude isn’t appropriate.... They need to look at a system-level at the impact of wounded warriors on accessing these barriers. These families will say we don’t want anyone in the home, but they’re the ones who need it the most.” (Provider)

“I have to drive my wounded warrior husband to all his medical appointments. I was told by Wounded Warrior [the Wounded Warrior Battalion] to make sure to use my respite care when I take him to his medical appointments.... WW or Tricare should have something to supplement the care for your husband it shouldn’t come away from your husband’s respite.” (Caretaker)

3.5. Conclusion

A rich data set resulted from NCD's focus groups and interviews with caretakers, EFMs, and service providers regarding USMC EFM access to disability-related services in the domains of health care, education, and long-term supports and services, allowing NCD to document the experiences of EFMs and their families, identify barriers to access, and gather stakeholder suggestions. The results that emerged from this data set are presented in this chapter in four sections focusing on access in general (Section 3.1), access in conjunction with PCSing (Section 3.2), EFMP and other base programs (Section 3.3), and other related topics (Section 3.4). Sections 3.1, 3.2, and 3.3 include detailed summaries.

Of the many challenges that USMC EFMP families face that are documented in this chapter, PCSing seems to stand out as the major obstacle to EFM access to services. The process of moving and transitioning the continuum of care can be an overwhelming one for families with EFMs, particularly when families are young or their EFM's condition severe. Even for seasoned military families, reestablishing services tends to be a laborious if not contentious process that frequently results in discontinuity and gaps in health care, education, or long-term services. Although USMC EFMs have comparable access to civilian services as their civilian counterparts by and large, Medicaid waivers are a significant exception. Because these waivers have years-long waiting lists and are not portable from state to state, PCSing can create privation and financial hardship for USMC families who need them.

The USMC EFMP, a program that the USMC is growing and refining as we write, is charged with providing family support and assignment coordination for enrolled USMC families. Along with other base programs, such as the School Liaison Office, New Parent Support, the base Naval Hospital or Clinic, DoD schools and EDIS (on select installations), and the base Housing Office, a strong and often integrated network of services and supports exists for USMC EFMs and their families. Lack of awareness about EFMP and other base resources remains an obstacle to full use by eligible

families, however. Families living off base—which applies to the majority—are particularly apt to lack awareness of base resources and, in some cases, to be ineligible to use them.

Further research can support USMC's ongoing expansion and refinement of the Exceptional Family Member Program. For example, documenting the challenges faced by remotely located EFMP families would inform efforts to shape targeted services for this population. The needs of other subgroups within the EFMP community may merit similar scrutiny, such as families of reservists, families of wounded warriors, and eligible families who are not enrolled in EFMP. Finally, given that the current study was undertaken during a period of transformation for EFMP, it would be instructive to reassess USMC EFM access to services after the transformation is complete.

Based on the extensive study findings, NCD formulated evidence-based recommendations to address the barriers to service encountered by USMC EFMs and their families. These recommendations, several of which entail further research, are presented in Chapter 4. Improvements that HQ USMC EFMP has already initiated, independent of the NCD study, are presented in Chapter 5.

CHAPTER 4. NCD Recommendations

This chapter presents NCD's recommendations for improving USMC EFM access to disability-related services. These are evidence-based recommendations informed by the study results; in many cases, they mirror or build upon suggestions made by the study participants. The chapter comprises three main sections:

- Recommendations Regarding USMC EFM Access to Disability-Related Services
- Recommendations Regarding PCSing and USMC EFM Access to Disability-Related Services
- Recommendations Regarding EFMP and Other Base Services

Because the Exceptional Family Member Program is a linchpin in USMC support for EFM's, recommendations involving EFMP are integral to this chapter and appear in each of the three sections.

Following each recommendation, we identify in parentheses the entities to which it is directed (e.g., Congress, DoD, USMC, EFMP). In Appendix H, the recommendations are listed by entity.

4.1. Recommendations Regarding USMC EFM Access to Disability-Related Services

4.1.1. General Access of USMC EFM's to Disability Related Services

1. Conduct an accessibility review of human service programs and facilities, including base housing, on USMC bases. Develop plans for each base to make programs and facilities accessible, that is, ADA compliant, if they are not already. Execute plans as appropriate. (USMC)

2. Provide EFMP families living off base, which includes most EFMP families, access to disability-related services offered on base. Most notable among these services is special education through DoDEA schools, at installations where they are available. Other services might include, for example, speech therapy and early intervention services. (Tricare, DoDEA, EDIS)
3. Undertake a study of access to disability-related services among remotely located USMC EFM's. (USMC) Upon ascertaining the needs of this population and gaps in services, determine the baseline support USMC should provide remote EFMP families, and resource and train caseworkers accordingly. (EFMP)
4. Address the implications of retirement for continued access to disability-related services, including considering the extension of ECHO coverage. (Congress, DoD, Tricare)

4.1.2. Access to Health Care Services and Qualified Health Care Providers

5. Promote the implementation of the "Medical Home" model among military and civilian providers of health care for EFMP families. Medical Home is a patient-centered "approach to providing comprehensive primary care ... that facilitates partnerships between individual patients, and their personal providers, and when appropriate, the patient's family." Components of this model may include comprehensive case management, care coordination and health promotion, transitional care, patient and family support, referral to community and social services, and use of health information. (Department of Navy, Tricare)
6. At geographically isolated installations where there is a dearth of both military and civilian health care specialists and many families must travel for hours on a recurring basis to obtain specialty health care—

- A. Create a program to bring medical specialists to the installation on a regular and reliable basis. (Department of Navy, Tricare)
 - B. Provide free disability-accessible transportation to major medical centers within the region. (Department of Navy)
 - C. Establish financial incentives, such as scholarships and loan forgiveness programs, to train and recruit specialists to serve military families with special health care needs, and to locate practices near military installations. (Congress, DoD, Department of Health and Human Services)
7. Currently, families are paid mileage for travel to medical appointments 100 or more miles away. Modify the existing policy to include reimbursement for frequent visits to more proximate medical appointments, which can pose a comparable financial burden. (USMC)
8. Establish and staff a dedicated developmental pediatrician position on all USMC installations to which Marines with families are assigned. (Department of Navy)
9. In military-impacted areas where there is a dearth of civilian health care providers who accept Tricare (particularly specialists), gather information from the civilian providers regarding (a) their reasons for accepting or declining Tricare and (b) how the number of Tricare providers in these areas might be expanded. (Tricare, Congress)
10. Increase the accuracy and timeliness of information EFMP families receive from Tricare by instructing case managers to assist families in accessing services, assigning Tricare case managers to a larger proportion of the EFMP population, and establishing multiple communication mechanisms, including a dedicated Tricare telephone hotline (staffed 24/7) for EFMP families, similar to the Medicare hotline. (Tricare)

11. For EFMs who are prescribed ABA therapy, continue to work toward full coverage, consistent with the recommended standard of care. (Congress, DoD, Tricare)
12. Ensure that USMC EFMs who use sign language are aware of their right to the services of an interpreter for medical appointments, including behavioral health sessions, and ensure that this service is available to them at no charge. (Tricare, EFMP)

4.1.3. Access to Education-Related Services

13. Disseminate to local education agencies (LEAs) and EFM families detailed guidance for implementing initiatives included in the Interstate Compact on Educational Opportunity for Military Children. (Interstate Commission, Federal and State DoEs, LEAs, DoDEA)
14. Urge states to establish interstate compact commissions and to take action to train LEA staff. (State DoEs, DoD-State Liaison Office)
15. Ensure that off-base families needing early intervention services for their children are systematically referred to comparable early intervention programs in the civilian community. (EFMP, EDIS, Department of Navy medical, Tricare, civilian medical providers)

4.1.4. Access to Long-Term Supports and Services

See Section 4.2.4, PCSing and Access to Long-Term Supports and Services.

4.2. Recommendations Regarding PCSing and USMC EFM Access to Disability-Related Services

4.2.1. PCSing and General Access to Disability-Related Services

16. In order to eradicate lingering myths about the assignment process, which can discourage enrollment or foster negativity about EFMP, actively promote awareness about the current EFMP “informed assignment process” among EFMP families and the USMC community at large. (USMC, EFMP)
17. Establish a sponsorship program for PCSing EFMP families. (EFMP)
18. Distribute a comprehensive resource packet, resource guide, or directory listing base and community resources for EFMs. Produce this tool both electronically and in hard copy and update the information regularly. Proactively distribute it to new arrivals and new enrollees. Through an ongoing strategic marketing campaign, ensure that all families with EFMs know about the tool and have ready access to it either online or in hard copy. (EFMP—also see Chapter 5 regarding the resource that USMC EFMP is currently developing.)
19. Proactively offer to help families sign up for base housing or to get assigned quarters, in advance of their arrival. (EFMP)
20. Proactively offer families resource lists for respite care providers so they can arrange for respite care in advance of their arrival and thus minimize gaps in service, particularly during the stressful transition period. (EFMP)
21. Augment the PCS Planning Tool on the Military Homefront website to provide EFMP families access to online relocation guidance that is interactive and disability-focused. (DoD Military Community and Family Policy)

4.2.2. PCSing and Access to Health Care Services and Qualified Health Care Providers

22. Promote the implementation of the “Medical Home” model among military and civilian providers of health care for EFMP families. (See recommendation #5.) With an emphasis on medical case management and coordination, Medical Home will facilitate communication between losing and gaining health care providers and health care systems, reduce unnecessary redundancy, and streamline access to specialists. (Department of the Navy, Tricare)
23. Adjust Tricare procedures to minimize the reenrollment burden for families who change Tricare regions. (Tricare)
24. Minimize the gaps in health care services related to PCS:
 - A. Adjust Tricare procedures to provide EFMs referrals for routine specialty care without needing to be seen by their new primary care manager. (Tricare)
 - B. Facilitate transfer of medical information between bases and between off-base and on-base providers by digitizing EFM medical records and facilitating a warm handoff (direct communication) between providers. (EFMP)
 - C. Consistent with the Medical Home model, establish a mechanism to ensure that EFM families have sufficient prescription medications while in transit between installations. (Tricare, EFMP)
 - D. For recipients of ABA therapy, provide linkage to ABA therapist trainees in the vicinity of the gaining installation (who must complete volunteer hours for their ABA certification) until a longer-term solution can be implemented. (EFMP, Tricare, local health care providers, certifying authorities such as colleges and universities)

25. Increase the flexibility of services covered by ECHO to closely mirror the services available through a Medicaid waiver. (Congress, DoD, Tricare)

4.2.3. PCSing and Access to Education-Related Services

26. Promulgate and enforce rules for schools receiving new students to ensure advanced preparation for these students' special education needs.
(Interstate Commission)
27. Prepare parents of students with disabilities to expect and navigate a very different educational environment when they PCS by mitigating parental distrust. Specifically, preemptively educate parents, via one-on-one and group formats, about the ways that different school districts may meet IEP goals. (DoDEA, EFMP, SL, LEAs, federal and state DoEs, education associations, parent-teacher organizations/associations)
28. Increase the capacity of school liaisons to support EFMP enrollees by ensuring that (1) school liaisons are sufficiently familiar with EFMP, EFM needs, and special education resources on and off base (USMC, EFMP), and (2) proactively marketing school liaison services, for example, include a flyer in newcomer materials. (SL)
29. Proactively send inbound EFMP families who have students with disabilities customized school information prior to arrival. Of necessity, this information will be less customized if families do not yet know where they will be living.
(EFMP)
30. Develop and provide to military-impacted schools succinct guidance on steps to facilitate a military student's transition out of their system. Start with military-impacted schools that are beneficiaries of DoDEA partnership grants. (DoDEA, LEAs)

4.2.4. PCSing and Access to Long-Term Supports and Services

31. Implement mechanisms to enable military EFMs to maintain Medicaid waiver services when they move from state to state, rather than requiring them to go to the bottom of the wait lists each time they PCS:
 - A. Place incoming EFMs on the new state's wait list based on their position on the previous state's wait list (i.e., based on "time served"). If individuals have a Medicaid waiver in the previous state, they should automatically receive one in the new state. (Congress and state agencies)
 - B. For EFMs who lose Medicaid waiver services as a result of a PCS, provide the same benefits the EFM received in the previous state until eligibility can be established in the new state. (Congress and state agencies, DoD, Tricare)

4.3. Recommendations regarding EFMP and Other Base Programs

4.3.1. EFMP

32. Determine the validity of continuing concerns about the impact of EFMP enrollment on a Marine's career. Assess whether or not this lingering stigma is deserved by comparing rates of advancement among enrolled and non-enrolled Marines in comparable occupational specialties and year-groups. If no differences are observed, use this information to quell remaining concerns about enrollment within the USMC. Alternatively, if differences are observed, and enrollment does indeed impact advancement, take corrective action as appropriate. (USMC)
33. Educate the military and civilian community about EFMP (i.e., base and unit leadership, military and civilian health care providers, relevant base and community agencies/providers, including LEAs, and members of the USMC)

community at large) by designing and implementing a robust, ongoing, multifaceted public relations (PR) campaign to educate stakeholders and the USMC community as a whole to—

- A. Raise their awareness of today's EFMP and sensitivity to EFM issues
 - B. Publicize the specific benefits of enrollment
 - C. Mitigate myths, concerns about stigma, and resulting resistance to enrollment
 - D. Increase the capacity of the entire community (i.e., military leaders, military and civilian health care providers, base and community agencies, LEAs, USMC community members) to inform USMC families about EFMP and to be a supportive presence in the lives of USMC families with members with disabilities.
 - E. Promote the Medical Home model, particularly within the military and civilian health care communities. (EFMP, USMC, Department of Navy, Tricare)
34. Explore to what extent ambiguity surrounding the definition of “disability” may prevent eligible USMC families from looking to EFMP for support. As appropriate, incorporate findings into the PR campaign addressed in the previous recommendation. (EFMP)
35. Expand the scope of the support provided EFMP families beyond information and referral. For example,
- A. Deliver regular, proactive outreach to enrollee families (EFMP)
 - B. Proactively push information and resources to EFM families immediately upon enrollment and on an ongoing basis, so they will know:

- i. What to expect from enrollment
 - ii. How to derive maximum benefit from enrollment
 - iii. Who their “go-to” people are—including their position, purpose, and contact information (EFMP)
- C. Establish a mentoring program to facilitate opportunities for EFMP families to share information and lessons learned with one another. This may be as simple as maintaining a roster of interested currently enrolled families who consent to their contact information being shared with newly enrolled or newly arrived families as appropriate. (EFMP)
- D. Develop and offer more advocacy and more advocacy training opportunities. Leverage partners in policy-making such as the Office of Protection and Advocacy (OPA) and the Council on Developmental Disabilities. (EFMP)
- E. Develop and offer supplemental outreach and programming for families with deployed members. (EFMP)
- F. Create a support group for EFM siblings, or help EFMP families link into civilian support groups for EFM siblings. Offer transition-planning support aimed at facilitating continuity of care for EFMs of Marines who are retiring or separating from the military. (USMC Relocation Program with assistance from EFMP)
36. Ensure that EFMP offices systematically gather, maintain, and update contact information from caretaker/EFM spouses and consistently direct all communications—whether by email, telephone, or U.S. mail—to them. (EFMP)
37. Continue to grow the number of EFMP caseworkers, to allow them to provide more comprehensive services to EFMP families. (USMC)

4.3.2. Other Base Programs

38. Clarify the intended role of the FROs with regard to EFMP families, both during steady state and during PCS. If appropriate, address privacy constraints (e.g., HIPAA) that prevent FROs from learning of, and proactively reaching out to, incoming EFMP families. (USMC)
39. Explore how base providers can share pertinent information with one another regarding EFM needs without violating privacy rules. (USMC)
40. Continue to encourage coalitions of base providers serving EFMs, and regular meetings of coalition members, to promote coordinated and proactive service delivery. (USMC)
41. Explore how the much-appreciated respite benefit could be made more flexible in order to better respond to individual family needs. (USMC, EFMP)

CHAPTER 5. **Recent Improvements Initiated by HQ USMC**

HQ USMC EFMP has already put into motion solutions for a number of the access issues that NCD has identified in this report. These solutions, many of which are captured by the new Marine Corps Order for EFMP (MCO 1754.4B), are listed below. It is clear that the intent of USMC Headquarters and the findings of NCD are well aligned. That said, EFMP families are not yet consistently reaping the benefits of these good intentions. We are reminded by the many issues identified by families and providers at installation level—but apparently already addressed by headquarters—that it takes time for policy to be translated into practice and that the litmus tests of effective policy are implementation at the installation level and stakeholder awareness. NCD encourages the USMC to continue to monitor the implementation of these and future initiatives and to remain attuned to how they are affecting EFMP families.

5.1. USMC Improvements Regarding PCSing and Access to Disability-Related Services

- In the previous chapter, NCD recommended that EFMP distribute a comprehensive resource packet, resource guide, or directory listing base and community resources for EFM's (see recommendation #18). USMC EFMP has contracted to have a comparable resource developed, to include training modules for staff and families, a resource guide, and promotional materials. These products were to be distributed mid-October 2010.
- NCD initially recommended substantial refinements to the assignment process for Marines enrolled in EFMP, and to the training of assignment monitors. However, the new MCO mandates an "informed assignment process" that USMC EFMP proponents indicate should assuage Marines' and families' concerns about the impact of the assignment process on Marines' careers and families' and EFM's well-being.

- NCD initially recommended allowing eligible EFMP families to sign up for housing at the gaining installation upon receipt of orders (subject to housing inventory), in order to increase the likelihood that they will be assigned quarters in a timely manner, and to give families the geographic information they need to assess their schooling options and begin addressing the logistics of school transition. According to USMC EFMP proponents, however, current policy already allows families with PCS orders to sign up for housing at the gaining installation. Furthermore, they indicate that, to the extent that this policy may not be consistently followed, the new MCO should ensure compliance.
- NCD initially recommended allowing EFMP families to remain in quarters at the losing installation until the gaining installation has the resources to support them (e.g., housing, doctors). USMC EFMP proponents report that this option is already in place via “Continuation on Location” policy outlined in MARADMIN 068/09 and the new MCO.
- NCD initially recommended several methods for EFMP to proactively support the moves of EFMP families (including their navigation of health care and school transitions) and relieve families of some of the logistical burden associated with these moves. For example, we would have recommended strategically advertising to EFMP families exactly how EFMP can support PCS moves, and disseminating detailed guidance about PCSing as an EFMP family (to include step-by-step instructions/checklists for closing out and reestablishing health care and switching schools). USMC EFMP proponents observe, however, that the DoD Military Homefront website, which is used by both EFMP staff and EFMP families, already accomplishes these objectives.
- NCD initially recommended that EFMP proactively support PCS moves by digitizing EFMs’ civilian medical records, but USMC EFMP proponents

indicate that the new MCO and the informed assignment process it mandates will negate the need for such support.

- NCD initially recommended leveraging command support by proactively alerting installation command when an EFM with a severe disability is inbound. USMC EFMP proponents indicate that the intent of this recommendation is covered through the informed assignment process.

5.2. USMC Improvements Regarding PCSing and Access to Education-Related Services

- NCD initially recommended the creation of handouts to illustrate differences in how special education services may be delivered, for example, a cross-walk of comparable services or a glossary of services/terminology that may vary by location. USMC EFMP proponents indicate, however, that glossaries of services and terms are readily available and the intent of this suggestion is met through such vehicles as parent training, HQ's quarterly newsletter, and "Parents as Advocates."
- NCD initially recommended digitizing EFMs' IEPs to allow the losing EFMP office to transmit them electronically to the gaining EFMP office. USMC EFMP proponents report that this practice has been in place since November 2007.
- NCD initially recommended allowing families who are waiting for base housing, and living off-base in the interim, to send their school-aged students with disabilities to DoDEA schools regardless of the expected wait for base housing. USMC EFMP proponents state that DoDEA regulations already allow this option.

5.3. USMC Improvements Regarding EFMP and Other Base Programs

- In the previous chapter (see recommendation #35), NCD recommended that the scope of the EFMP missions be expanded beyond information and referral, and identified strategies for doing so. USMC EFMP proponents concur with this recommendation.
 - USMC EFMP proponents observe that many of these strategies reflect the intent of the new Marine Corps, for example, delivering regular, proactive outreach, and proactively pushing information and resources so families will know what to expect from enrollment, how to derive maximum benefit, and who their “go-to” people are.
 - USMC EFMP proponents note that some of these strategies are in place in certain locations, for example, some installations have established mentoring programs and offer support groups for EFM siblings.
- NCD initially recommended less burdensome EFMP documentation renewal requirements for EFMs with permanent disabilities that are unlikely to improve over time. USMC EFMP proponents indicate that the new MCO extended the update requirement from every two years to every three years.

In closing, NCD commends the USMC for the command emphasis, resources, and expertise it has dedicated to addressing the needs of individuals with disabilities within the Marine Corps community. We underscore the importance, going forward, of educating families about the new and existing policies created on their behalf (e.g., informed assignment policy, continuation on location, access to DoDEA schools while awaiting on-base housing, and so forth) and ensuring that these policies are enforced—and programs implemented—as intended.

APPENDIX A. **Communications for Recruiting Study Participants**

A1. INITIAL EMAIL FROM LOCAL EFMP TRANSMITTING INTRODUCTORY LETTER FROM NCD

Subject: National Council on Disability (NCD) Study of USMC Exceptional Family Member Access to Disability-Related Services

Dear EFMP Enrollee,

The National Council on Disability (NCD) is collaborating with USMC Headquarters on a study aimed at better understanding, and improving, USMC exceptional family members' experiences with access to disability-related services. Please read the attached letter describing the study and how you may be able to participate. This is an opportunity for us all—enrollees and service providers—to meaningfully contribute to improvements in available support for exceptional family members across the USMC.

Don't hesitate to contact the EFMP office if you have any questions,

Monique O'Neal, Manager
MCB Quantico Exceptional Family Member Program
Telephone: (571) 931-0525

A2. INTRODUCTORY LETTER FROM NCD (ATTACHMENT TO EMAIL TRANSMITTAL BY LOCAL EFMP)

Subject: National Council on Disability (NCD) Study of USMC Exceptional Family Member Access to Disability-Related Services

Dear Exceptional Family Member Program Family or Service Provider,

The National Council on Disability (NCD) is an independent federal agency that is dedicated to promoting equal opportunity, independence, and inclusion for all individuals with disabilities. NCD is supporting U.S. Marine Corps (USMC) efforts to provide the best possible service to its exceptional family members by collaborating with the USMC on an assessment of exceptional family members' access to disability-related services and how access can be improved. To carry out this study, NCD has contracted ICF International (ICF), a professional research firm with a long track record of conducting research for and about the military community.

From January through March 2010, ICF will hold focus groups (structured discussions) with groups of caretakers of exceptional family members (e.g., parents and spouses), exceptional family members age 18 and over, and service providers at Marine Corps Base (MCB), Quantico Camp Lejeune, and Camp Pendleton. Each study participant will be asked to attend one focus group lasting approximately 90 minutes. The ICF research team will be at MCB Quantico during the week of January 25, 2010.

USMC, NCD, and ICF are committed to preserving the rights and privacy of study participants. Participation in the study is voluntary—no one is required to participate. The USMC will not be told who does or does not participate. Participants' responses will be summarized, and responses of individual participants will not be disclosed. (To protect EFMP enrollee personal information such as name and email address, initial communications about the study, such as this letter, are being transmitted by the local EFMP.)

In a few days, a second email inviting participation in the upcoming focus groups will be sent to caretakers, exceptional family members age 18 and over, and service providers. If you receive one of these emails, we urge you to accept. Please support this important and impartial effort to improve exceptional family members' access to disability-related services across the USMC!

Sincerely yours,

Michael Collins, Executive Director
National Council on Disability

A3. INITIAL CARETAKER INVITATION—EMAILED BY LOCAL EFMP AND SIGNED BY ICF

Subject: National Council on Disability (NCD) Study of USMC Exceptional Family Member Access to Disability-Related Services—Invitation to Participate

Dear Caretaker of an Exceptional Family Member,

A few days ago, we emailed you a letter introducing the upcoming focus groups (structured group discussions) that will be taking place at MCB Quantico. These sessions are part of a joint U.S. Marine Corps (USMC) and National Council on Disability (NCD) study that will gather information from caretakers, exceptional family members age 18 and over, and service providers, regarding access to disability-related services and how it can be improved. ICF International (ICF), a professional research firm with extensive military community research experience, has been contracted to conduct the study.

During the week of January 25, ICF will hold six focus groups at MCB Quantico, with a total of approximately 50 caretakers of exceptional family members (e.g., a parent, spouse, etc.). The purpose of this email is to notify you that ICF has randomly selected your family to be invited to one of these focus groups. This will involve participating in an approximately 90-minute structured group discussion and filling out a one-page questionnaire.

This is a rare opportunity to share your perspective and experiences regarding access to disability-related services, and to have a voice in how these services will be delivered in the future. Participation is completely voluntary. The USMC will not be told who does or does not participate. If you choose to participate, we will report what you say but we will not disclose that it was you who said it. In this way, we will keep your input confidential. (To protect personal information such as name and email address, initial communications about the study, such as this email, are being sent to you by your local EFMP.)

These focus groups will be held both during the daytime and the evening. If you are interested in participating, please contact ICF by calling toll-free 1 (877) 221-7179.

Thank you in advance for your participation. With your help, the USMC will gain an unfiltered and impartial understanding of the access issues that USMC exceptional family members face and how to address them. Let your voice be heard!

Sincerely yours,

The ICF Research Team

A4. INITIAL EFM INVITATION—EMAILED BY LOCAL EFMP AND SIGNED BY ICF

Subject: National Council on Disability (NCD) Study of USMC Exceptional Family Member Access to Disability-Related Services—Invitation to Participate

Please share the following message with your Exceptional Family Member (age 18 or older).

Dear Exceptional Family Member,

A few days ago, we emailed your family a letter introducing the upcoming focus groups (structured group discussions) that will be taking place at MCB Quantico. These sessions are part of a joint U.S. Marine Corps (USMC) and National Council on Disability (NCD) study that will gather information from caretakers, exceptional family members age 18 and over, and service providers, regarding access to disability-related services and how it can be improved. ICF International (ICF), a professional research firm with extensive military community research experience, has been contracted to conduct the study.

During the week of January 25, ICF will hold two focus groups at MCB Quantico, with a total of no more than 16 exceptional family members who are at least 18 years old and legally competent to consent to participate. These focus groups, which typically last approximately 90 minutes, are small group discussions led by a trained discussion moderator. The purpose of this email is to invite you participate in one of these focus groups, if you are able and interested.

This is a rare opportunity to share your perspective and experiences regarding access to disability-related services and to have a voice in how these services will be delivered in the future. Participation is completely voluntary. The USMC will not be told who does or does not participate. If you choose to participate, we will report what you say but we will not disclose that it was you who said it. In this way, we will keep your input confidential. (To protect personal information such as name and email address, initial communications about the study, such as this email, are being transmitted to you by your local EFMP.)

If you are interested in participating in one of these two focus groups, please contact ICF by calling toll-free 1 (877) 221-7179.

Thank you in advance for your participation. With your help, the USMC will gain an unfiltered and impartial understanding of the access issues that USMC exceptional family members face and how to address them. Let your voice be heard!

Sincerely yours,

The ICF Research Team

A5. INITIAL PROVIDER INVITATION—EMAILED BY ICF

Subject: National Council on Disability (NCD) Study of USMC Exceptional Family Member Access to Disability-Related Services—Invitation to Participate

Dear Service Provider,

A few days ago, we emailed you a letter introducing the upcoming focus groups (structured group discussions) that will be taking place at MCB Quantico. These sessions are part of a joint U.S. Marine Corps (USMC) and National Council on Disability (NCD) study that will gather information from caretakers, exceptional family members age 18 and over, and service providers, regarding access to disability-related services and how it can be improved. ICF International (ICF), a professional research firm with extensive military community research experience, has been contracted to conduct the study.

During the week of January 25, ICF will hold four focus groups at MCB Quantico with people who play a role in the provision of disability-related services to exceptional family members. These focus groups will address all types of services—including services related to education, health care, and long-term supports—for exceptional family members of all ages. The purpose of this email is to request your participation in one of these 90-minute focus groups.

This is a rare opportunity to share your perspective and experiences regarding access to disability-related services, and to have a voice in how these services will be delivered in the future. Participation is voluntary. The USMC will not be told who does or does not participate. If you choose to participate, your individual responses will be kept confidential—i.e., they will not be reported or disclosed in a way that can be linked to you individually.

The provider perspective will be critical to obtaining a balanced understanding of both the challenges and the potential solutions regarding USMC exceptional family members' access to disability-related services. We hope you can make time to talk with us. To sign up for a focus group or to obtain further information, please contact ICF by calling toll-free 1 (877) 221-7179.

Thank you in advance for your participation. With your help, the USMC will gain an unfiltered and impartial understanding of the access issues that USMC exceptional family members face and how to address them. Let your voice be heard!

Sincerely yours,

The ICF Research Team

A6. CARETAKER FOLLOW-UP—EMAILED BY LOCAL EFMP AND SIGNED BY ICF

Subject: National Council on Disability (NCD) Study of USMC Exceptional Family Member Access to Disability-Related Services—Follow-up

Dear Caretaker of an Exceptional Family Member,

Recently, we emailed you about the upcoming focus groups (structured group discussions) that will be taking place at MCB Quantico during the week of January 25. These sessions are part of a joint U.S. Marine Corps (USMC) and National Council on Disability (NCD) study that will gather information from caretakers, exceptional family members age 18 and over, and service providers, regarding access to disability-related services and how it can be improved. Focus groups also will take place at Camps Lejeune and Pendleton. ICF International (ICF), a professional research firm with extensive military community research experience, has been contracted to conduct the study.

During the week of January 25, we will be holding six focus groups at MCB Quantico, with a total of approximately 50 caretakers of exceptional family members (e.g., a parent, spouse, etc.). ICF randomly selected your family to be invited to participate in one of these focus groups. This involves participating in a 90-minute group discussion and filling out a one-page questionnaire. This is a rare opportunity to share your perspective and experiences regarding access to disability-related services and to influence how these services will be delivered in the future.

WE HAVE NOT YET HEARD FROM YOU! To reserve your spot in one of these daytime or evening focus groups and obtain further information, please contact ICF by calling toll-free 1 (877) 221-7179

USMC, NCD, and ICF are committed to preserving the rights and privacy of study participants. Participation in the study is voluntary—no one is required to participate. The USMC will not be told who does or does not participate. The responses of individual participants will not be disclosed. (To protect personal information such as name and email address, initial communications about the study are being transmitted to you by your local EFMP.)

Thank you in advance for your participation. With your help, the USMC will gain an unfiltered and impartial understanding of the access issues that USMC exceptional family members face and how to address them. Let your voice be heard!

Sincerely yours,

The ICF Research Team

A7. EFM FOLLOW-UP—EMAILED BY LOCAL EFMP AND SIGNED BY ICF

Subject: National Council on Disability (NCD) Study of USMC Exceptional Family Member Access to Disability-Related Services—Follow-Up

Please share the following message with your Exceptional Family Member (age 18 or older).

Dear Exceptional Family Member,

Recently, we emailed you about participating in the upcoming focus groups (structured group discussions) that will be taking place at MCB Quantico during the week of January 25. These sessions are part of a joint U.S. Marine Corps (USMC) and National Council on Disability (NCD) study that will gather information from caretakers, exceptional family members age 18 and over, and service providers, regarding access to disability-related services and how it can be improved. Focus groups also will take place at Camps Lejeune and Pendleton. ICF International (ICF), a professional research firm with extensive military community research experience, has been contracted to conduct the study.

During the week of January 25, we will be holding two focus groups at MCB Quantico, with a total of no more than 16 exceptional family members (age 18 and over). These focus groups, which typically last about 90 minutes, are small group discussions led by a trained discussion moderator. The purpose of this email is to invite you participate in one of these focus groups, if you are able and interested. This is a rare opportunity to share your perspective and experiences, as an exceptional family member, regarding access to disability-related services and to influence how these services will be delivered in the future.

WE HAVE NOT YET HEARD FROM YOU! If able and interested, please reserve your spot in one of these two focus groups and obtain further information by contacting ICF toll-free at 1 (877) 221-7179.

USMC, NCD, and ICF are committed to preserving the rights and privacy of study participants. Participation in the study is voluntary—no one is required to participate. The USMC will not be told who does or does not participate. The responses of individual participants will not be disclosed. (To protect personal information such as name and email address, initial communications about the study are being transmitted to you by your local EFMP.)

Thank you in advance for your participation. With your help, the USMC will gain an unfiltered and impartial understanding of the access issues that USMC exceptional family members face and how to address them. Let your voice be heard!

Sincerely yours,

The ICF Research Team

A8. PROVIDER FOLLOW-UP—EMAILED BY ICF

Subject: National Council on Disability (NCD) Study of USMC Exceptional Family Member Access to Disability-Related Services—Follow-up

Dear Service Provider,

Recently, we emailed you about the upcoming focus groups that will take place at MCB Quantico during the week of January 25. These sessions are part of a joint U.S. Marine Corps (USMC) and National Council on Disability (NCD) study that will gather information from caretakers, exceptional family members age 18 and over, and service providers, regarding access to disability-related services and how it can be improved. Focus groups also will take place at Camps Lejeune and Pendleton. ICF International (ICF), a professional research firm with extensive military community research experience, has been contracted to conduct the study.

During the week of January 25, ICF will hold four focus groups at MCB Quantico with people who play a role in the provision of disability-related services to exceptional family members. These focus groups will address all types of services—including services related to education, health care, and long-term supports—for exceptional family members of all ages. The provider perspective will be critical to obtaining a balanced understanding of both the challenges and the potential solutions regarding USMC exceptional family members' access to disability-related services.

WE HAVE NOT YET HEARD FROM YOU! To reserve your spot in one of these focus groups and obtain further information, please contact ICF by calling toll-free 1 (877) 221-7179

USMC, NCD, and ICF are committed to preserving the rights and privacy of study participants. Participation in the study is voluntary. The USMC will not be told who does or does not participate, and the responses of individual participants will not be disclosed.

Thank you in advance for your participation. With your help, the USMC will gain an unfiltered and impartial understanding of the access issues that USMC exceptional family members face and how to address them.

Sincerely yours,

The ICF Research Team

APPENDIX B. Research Questions

Research Questions from Solicitation

1. What are the unique challenges encountered by Marine Corps families in accessing appropriate and effective supports and services for dependent family members with disabilities? In the education setting? Healthcare services? Long-term supports and services?
2. Do Marine Corps families have knowledge of, and access to, civilian and military information sources about disability-specific education services, disability-specific health services, tools for self-advocacy, understanding their rights, and navigating the service systems and enforcement mechanisms? What barriers impede use of these resources?
3. Do Marine Corps families with dependent members with disabilities have access to adequate resources to facilitate transitions to new schools and healthcare providers when they relocate? How could transition be facilitated?
4. Do the young adults with disabilities of Marine Corps families receive adequate and effective transition planning services to ensure transition to productive pursuits after high school?
5. Are civilian supports and services for families with disabilities, such as the network of Independent Living Centers, state Assistive Technology Projects, state Protection and Advocacy Services, and the Parent Training and Information Centers able to meet the unique needs of Marine Corps families with disabilities, and are there recommendations to be considered to improve these resources for Marine Corps families?
6. Do youth and newly disabled family members receive adequate and effective vocational rehabilitation and employment services?
7. Do students with disabilities have access to:
 - Accessible information, e.g., accessible electronic materials, accessible textbooks, Braille instructional materials, etc.?
 - Technology, e.g. speech-adapted computers, speech-adapted calculators, note-taking devices, closed-circuit TVs, speech communication devices, etc.?
 - Effective communications, e.g. Sign Language interpreters, assistive listening devices, CARTT, captioned education videos, etc.?

- Appropriate and effective rehabilitation services for maximizing and maintaining functional abilities, preventing secondary health conditions, and maximizing full participation in their family, school, and community lives?
8. Do Marine Corps family members with disabilities have access to appropriate and effective health screenings, qualified health care providers, disability-specific assistive technology and mobility devices, and long-term supports and services?
 9. Do federal compliance, monitoring, and enforcement activities by the U.S. Department of Education adequately address the unique needs of Marine Corps families' students with disabilities? Are there recommendations to consider for improving participation by the Department of Education in ensuring the students receive appropriate, effective education services?
 10. Do compliance, monitoring, and enforcement activities of the Department of Defense adequately address the unique needs of Marine Corps families' students with disabilities? Are there recommendations to consider for improving participation by the DoD in ensuring that the students receive appropriate, effective education services?

Research Questions by Target Subpopulation and Support Domain*

Domains in Which Support Is Needed	Subpopulations of Marine Corps Family Members with Disabilities		
	About Children & Youth	About Young Adults	About Adults
Education Setting	Unique challenges ⁽¹⁾	Unique challenges ⁽¹⁾	Unique challenges ⁽¹⁾
	Knowledge of/access to civilian and military info sources ⁽²⁾	Knowledge of/access to civilian and military info sources ⁽²⁾	Knowledge of/access to civilian and military info sources ⁽²⁾
	Effect of relocation ⁽³⁾	transition planning ⁽⁴⁾	Adequacy of civilian supports and services ⁽⁵⁾
	Adequacy of civilian supports and services ⁽⁵⁾	Adequacy of civilian supports and services ⁽⁵⁾	
	Access to accessible info, technology, assisted communications ⁽⁷⁾		
	DOE compliance, monitoring, enforcement ⁽⁹⁾ DoD compliance, monitoring, enforcement ⁽¹⁰⁾		
Health Care Services	Unique challenges ⁽¹⁾	Unique challenges ⁽¹⁾	Unique challenges ⁽¹⁾
	Knowledge of/access to civilian and military info sources ⁽²⁾	Knowledge of/access to civilian and military info sources ⁽²⁾	Knowledge of/access to civilian and military info sources ⁽²⁾
	Effect of relocation ⁽³⁾	Effect of relocation ⁽³⁾	Effect of relocation ⁽³⁾
	Adequacy of civilian supports and services ⁽⁵⁾	Adequacy of civilian supports and services ⁽⁵⁾	Adequacy of civilian supports and services ⁽⁵⁾
	Access to healthcare ⁽⁸⁾	Access to healthcare ⁽⁸⁾	Access to healthcare ⁽⁸⁾
Long-Term Supports and Services	Unique challenges ⁽¹⁾	Unique challenges ⁽¹⁾	Unique challenges ⁽¹⁾
	Knowledge of/access to civilian and military info sources ⁽²⁾	Knowledge of/access to civilian and military info sources ⁽²⁾	Knowledge of/access to civilian and military info sources ⁽²⁾
	Adequacy of civilian supports and services ⁽⁵⁾	Adequacy of civilian supports and services ⁽⁵⁾	Adequacy of civilian supports and services ⁽⁵⁾
	Access to adequate rehab services ⁽⁷⁾	Adequacy of voc rehab and employment services (newly disabled adults) ⁽⁶⁾	Adequacy of voc rehab and employment services (newly disabled adults) ⁽⁶⁾

* Numbers in parentheses correspond to how the research questions are numbered in the announcement.

** “Adequate” is short for adequate, appropriate, effective.

APPENDIX C. Focus Group Protocols

C1. EFM Focus Group Protocol

Focus Group Session Information

Location:
Date:
Time:
Facilitator:
Recorder:
Number of participants present for entire session:
Number of participants excused:

Focus Group Questions

1. Where do you turn for information about getting the services and supports you need?
 - a. Where do you turn for information regarding civilian services and supports?
 - b. Where do you turn for information regarding military services and supports?
2. How do you know where to turn for this information?
3. What difficulties do you face when seeking services and supports?
4. What obstacles prevent you from accessing the services and supports you need?
 - a. Barriers that prevent you from accessing civilian services and supports?
 - b. Barriers that prevent you from accessing military services and supports?
5. How do you learn to speak up for yourself and get what you need from the service system?

To succeed educationally, students with disabilities may need **ASSISTIVE EQUIPMENT**.

6. To what extent do you have access to the technology or equipment you need to help you do your schoolwork (also called assistive equipment)? Please be specific about your disability and the required technology or equipment (e.g., accessible information via electronic or Braille instructional materials and textbooks; speech-adapted computers, speech-adapted calculators, note-taking

devices, closed-circuit TVs, speech communication devices; sign language interpreters, assistive listening devices, CARTT, captioned education videos.)

We'd like to explore the topic of **EDUCATIONAL TRANSITION** with you. As we all know, PCSing is a fact of life in the military and, when families PCS, dependent children and youth must switch schools. We know that changing schools can be a hardship, even in the best of circumstances.

7. When you PCS, what kinds of resources are available to help you transition from one school to another? (Please specify the level of schooling: preschool, primary, secondary, postsecondary.)
8. How well do these resources meet your needs? Please be specific about the ways in which the resources do or do not meet your needs. (Please specify the level of schooling.)
9. How could you be better supported when you have to switch schools due to PCS? (Please specify the level of schooling.)

If applicable:

We recognize that young adults with disabilities need support as they transition out of high school. This is often called school-to-work transition.

10. How much does PCS impact transition planning for the transition out of high school?
11. What kinds of transition planning services are available to meet your transition needs?
12. How well do these services meet your needs? Please be specific about the ways in which the services do or do not meet your needs.
13. How could your transition planning needs be better supported?

Now we'd like to talk with you about the **IMPLICATIONS OF PCSING FOR EFMS' ACCESS TO HEALTH CARE.**

14. When you PCS, what kinds of resources are available to ensure you get the health care you need at your new location? (If applicable, please specify age group, gender, nature of disability, or other relevant characteristics.)
15. How well do these resources meet your needs? Please be specific about the ways in which the resources do or do not meet your needs. (If applicable, please include relevant personal characteristics.)
16. How could your health care needs be better supported when you PCS? (If applicable, please include relevant personal characteristics.)

Adequacy of civilian resources for MC families:

17. How well do the major long-term services and supports for families with disabilities that are available to civilian families also meet the needs of MC families? Please be specific about the ways in which particular resources do or do not meet MC family needs.
 - a. Independent living centers
 - b. State assistive technology projects
 - c. State protection and advocacy services
 - d. Parent training and information centers
18. How well do vocational rehabilitation and employment services that are available to civilian youth also meet the needs of MC youth? Please be specific about the ways in which these services do or do not meet the need.
19. How well do available vocational rehabilitation and employment services meet the needs of newly disabled adult MC family members? Please be specific about the ways in which these services do or do not meet the need.
20. How could these civilian resources we have been discussing better meet the needs of MC families? Please specify whether your recommendations apply across the board or to specific resources (e.g., Independent Living Centers, State Assistive Technology Projects, State Protection and Advocacy Services, Parent Training and Information Centers, voc rehab and employment services).

Wrap-Up

These wrap-up questions apply to all the areas we have been discussing, education, health care, long-term supports and services, and so on.

21. What services—civilian or military, here or elsewhere—work particularly well?
22. What obstacles—civilian or military, here or elsewhere—work less well?
23. If you were in charge of improving access to services for Marine Corps EFMs, what additional steps would you take (that we haven't already discussed)?

This concludes our discussion. Please remember that any personal information shared during this discussion should stay in this room. Thank you for taking the time to share your experiences and perspectives with us. Your input will be very valuable to efforts to improve access to services for Marine Corps EFMs. Once again, thank you very much. And we thank you for your service.

C2. Caretaker Focus Group Protocol

Focus Group Session Information

Location:

Date:

Time:

Facilitator:

Recorder:

Number of participants present for entire session:

Number of participants excused:

Focus Group Questions

1. Where do you turn for information about getting the services and supports your EFM needs?
 - a. Where do you turn for information regarding civilian services and supports?
 - b. Where do you turn for information regarding military services and supports?
2. How do you know where to turn for this information?
3. What difficulties do you face when seeking services and supports?
4. What obstacles prevent you from accessing services and supports?
 - a. Barriers that prevent you from accessing civilian services and supports?
 - b. Barriers that prevent you from accessing military services and supports?
5. How do you learn to speak up for your EFM and get what you need from the service system?

To succeed educationally, students with disabilities may need **ASSISTIVE EQUIPMENT**.

6. To what extent does your EFM have access to the technology or equipment your EFM needs to help them do their schoolwork (also called assistive equipment)? Please be specific about your EFM's disability and the required technology or equipment (e.g., accessible information via electronic or Braille instructional materials and textbooks; speech-adapted computers, speech-adapted calculators, note-taking devices, closed-circuit TVs, speech communication devices; sign language interpreters, assistive listening devices, CARTT, captioned education videos.)

We'd like to explore the topic of **EDUCATIONAL TRANSITION** with you. As we all know, PCSing is a fact of life in the military and, when families PCS, dependent children and youth must switch schools. We know that changing schools can be a hardship, even in the best of circumstances.

7. When you PCS, what kinds of resources are available to help your EFM transition from one school to another? (Please specify the level of schooling: preschool, primary, secondary, postsecondary.)
8. How well do these resources meet your EFM's needs? Please be specific about the ways in which the resources do or do not meet your EFM's needs. (Please specify the level of schooling.)
9. How could your EFM be better supported when your EFM has to switch schools due to PCS? (Please specify the level of schooling.)

If applicable:

We recognize that young adults with disabilities need support as they transition out of high school. This is often called school-to-work transition.

10. How much does PCS impact transition planning for the transition out of high school?
11. What kinds of transition planning services are available to meet your EFM's transition needs?
12. How well do these services meet your EFM's needs? Please be specific about the ways in which the services do or do not meet your needs.
13. How could your EFM's transition planning needs be better supported?

Now we'd like to talk with you about the **IMPLICATIONS OF PCSING FOR EFMS' ACCESS TO HEALTH CARE.**

14. When you PCS, what kinds of resources are available to ensure your EFM gets the health care your EFM needs at your new location? (If applicable, please specify age group, gender, nature of disability, or other relevant characteristics.)
15. How well do these resources meet your EFM's needs? Please be specific about the ways in which the resources do or do not meet your EFM's needs. (If applicable, please include relevant personal characteristics.)
16. How could your EFM's health care needs be better supported when you PCS? (If applicable, please include relevant personal characteristics.)

Adequacy of civilian resources for MC families:

17. How well do the major long-term services and supports for families with disabilities that are available to civilian families also meet the needs of MC families? Please be specific about the ways in which particular resources do or do not meet MC family needs.
 - a. Independent living centers
 - b. State assistive technology projects
 - c. State protection and advocacy services
 - d. Parent training and information centers
18. How well do vocational rehabilitation and employment services that are available to civilian youth also meet the needs of MC youth? Please be specific about the ways in which these services do or do not meet the need.
19. How well do available vocational rehabilitation and employment services meet the needs of newly disabled adult MC family members? Please be specific about the ways in which these services do or do not meet the need.
20. How could these civilian resources we have been discussing better meet the needs of MC families? Please specify whether your recommendations apply across the board or to specific resources (e.g., Independent Living Centers, State Assistive Technology Projects, State Protection and Advocacy Services, Parent Training and Information Centers, voc rehab and employment services).

Wrap-Up

These wrap-up questions apply to all of the areas we have discussed, education, health care, long-term supports and services and so on.

21. What services—civilian or military, here or elsewhere—work particularly well?
22. What obstacles—civilian or military, here or elsewhere—work less well?
23. If you were in charge of improving access to services for Marine Corps EFM, what additional steps would you take (that we haven't already discussed)?

This concludes our discussion. Please remember that any personal information shared during this discussion should stay in this room. Thank you for taking the time to share your experiences and perspectives with us. Your input will be very valuable to efforts to improve access to services for Marine Corps EFM. Once again, thank you very much. And we thank you for your service.

C3. Generic Provider Focus Group Protocol

Focus Group Session Information

Location:

Date:

Time:

Facilitator:

Recorder:

Number of participants present for entire session:

Number of participants excused:

Focus Group Questions

1. Where do MC families turn for information about getting the services and supports they need?
 - a. Where do they turn for information regarding civilian services and supports?
 - b. Where do they turn for information regarding military services and supports?
2. How do MC families know where to turn for this information?
3. What difficulties do MC families face when they try to access services and supports?
4. What obstacles prevent MC families with EFMs from using or accessing services and supports?
 - a. Barriers that prevent them from accessing civilian services and supports?
 - b. Barriers that prevent them from accessing military services and supports?
5. How do MC families with EFMs learn to speak up for themselves and their EFM, and get what they need from the service system? (Sometimes called advocating for the EFM.)

To succeed educationally, students with disabilities may need **ASSISTIVE EQUIPMENT**.

6. To what extent do students have access to the technology or equipment they need to help them do their schoolwork? (Also called assistive equipment.) Please be specific about your disability and the required technology or equipment (e.g., accessible information via electronic or Braille instructional materials and textbooks; speech-adapted computers, speech-adapted calculators, note-taking

devices, closed-circuit TVs, speech communication devices; sign language interpreters, assistive listening devices, CARTT, captioned education videos.)

We'd like to explore the topic of **EDUCATIONAL TRANSITION** with you. As we all know, PCSing is a fact of life in the military and, when families PCS, dependent children and youth must switch schools. We know that changing schools can be a hardship, even in the best of circumstances.

7. When MC families PCS with their EFMs, what kinds of resources are available to help EFMs transition from one school to another? (Please specify the level of schooling: preschool, primary, secondary, postsecondary.)
8. How well do these resources meet their needs? Please be specific about the ways in which the resources do or do not meet their needs. (Please specify the level of schooling.)
9. How could EFMs be better supported when they have to switch schools due to PCS? (Please specify the level of schooling.)

If applicable:

We recognize that young adults with disabilities need support as they transition out of high school. This is often called school-to-work transition.

10. How much does PCS impact transition planning for the transition out of high school?
11. What kinds of transition planning services are available to meet your transition needs?
12. How well do these services meet your needs? Please be specific about the ways in which the services do or do not meet your needs.
13. How could your transition planning needs be better supported?

Now we'd like to talk with you about the **IMPLICATIONS OF PCSING FOR EFMS' ACCESS TO HEALTH CARE.**

14. When MC families PCS with their EFMs, what kinds of resources are available to ensure EFMs get the health care they need at their new location? (If applicable, please specify age group, gender, nature of disability, or other relevant characteristics of EFM.)
15. How well do these resources meet EFMs' needs? Please be specific about the ways in which the resources do or do not meet their needs. (If applicable, please include relevant characteristics of EFM.)

16. How could EFM's health care needs be better supported when they PCS? (If applicable, please include relevant characteristics of EFM.)

We turn now to the topic of long-term services and supports.

Adequacy of civilian resources for MC families:

17. How well do the major long-term services and supports for families with disabilities that are available to civilian families also meet the needs of MC families? Please be specific about the ways in which particular resources do or do not meet MC family needs.
- a. Independent living centers
 - b. State assistive technology projects
 - c. State protection and advocacy services
 - d. Parent training and information centers
18. How well do vocational rehabilitation and employment services that are available to civilian youth also meet the needs of MC youth? Please be specific about the ways in which these services do or do not meet the need.
19. How well do available vocational rehabilitation and employment services meet the needs of newly disabled adult MC family members? Please be specific about the ways in which these services do or do not meet the need.
20. How could these civilian resources we have been discussing better meet the needs of MC families? Please specify whether your recommendations apply across the board or to specific resources (e.g., Independent Living Centers, State Assistive Technology Projects, State Protection and Advocacy Services, Parent Training and Information Centers, voc rehab and employment services).

Wrap-Up

These questions apply to all of the areas we have been discussing: education, health care, long-term supports and services, and so forth.

21. What services—civilian or military, here or elsewhere—work particularly well?
22. What obstacles—civilian or military, here or elsewhere—work less well?
23. If you were in charge of improving access to services for Marine Corps EFM's, what additional steps would you take (that we haven't already discussed)?

This concludes our discussion. Please remember that any personal information shared during this discussion should stay in this room. Thank you for taking the time to share your experiences and perspectives with us. Your input will be very valuable to efforts to improve access to services for Marine Corps EFM's. Once again, thank you very much. And we thank you for your service.

C4. Provider Healthcare-Related Services Focus Group Protocol

Focus Group Session Information

Location:
Date:
Time:
Facilitator:
Recorder:
Number of participants present for entire session:
Number of participants excused:

Focus Group Questions

Information:

1. What are the MC families' main sources of information about healthcare-related services?
 - a. Sources of information on health care services provided by the military
 - b. Sources of information on health care services provided by nonmilitary sources
2. How do MC families know to where to turn for this information?
 - a. For information on health care services provided by the military
 - b. For information on health care services provided by nonmilitary sources

Access to services:

3. What difficulties do MC families face when they try to access services and supports related to health care?
4. What obstacles prevent MC families with EFMs from using or accessing health care-related services and supports?
5. How do MC families' experiences accessing health care services from the military differ from their experiences accessing health care services from nonmilitary sources?

Let's discuss some specific **HEALTH CARE ISSUES**.

6. To what extent do MC EFMs have access to the health screenings they need? Please be specific.
7. To what extent do MC EFMs have access to qualified health care providers? Please be specific.

As we noted earlier, PCSing is a fact of life in the military. We'd like to talk with you about the **IMPLICATIONS OF PCSING FOR EFMS' ACCESS TO HEALTH CARE**.

8. When MC families PCS with their EFMs, what kinds of resources are available to ensure EFMs get the health care they need at their new location? (If applicable, please specify age group, gender, nature of disability, or other relevant characteristics of EFM.)
9. How well do these resources meet EFMs' needs? Please be specific about the ways in which the resources do or do not meet their needs. (If applicable, please include relevant characteristics of EFM.)
10. How could EFMs' health care needs be better supported when they PCS? (If applicable, please include relevant characteristics of EFM.)

Wrap-Up

11. What services—civilian or military, here or elsewhere—work particularly well?
12. What obstacles—civilian or military, here or elsewhere—work less well?
13. If you were in charge of improving access to services for Marine Corps EFMs, what additional steps would you take (that we haven't already discussed)?

This concludes our discussion. Please remember that any personal information shared during this discussion should stay in this room. Thank you for taking the time to share your experiences and perspectives with us. Your input will be very valuable to efforts to improve access to services for Marine Corps EFMs. Once again, thank you very much. And we thank you for your service.

C5. Provider Education-Related Services Focus Group Protocol

Focus Group Session Information

Location:

Date:

Time:

Facilitator:

Recorder:

Number of participants present for entire session:

Number of participants excused:

Focus Group Questions

Information:

1. What are MC families' main sources of information about education-related services?
 - a. Sources of information for education-related services provided by the military
 - b. Sources of information for education-related services provided by nonmilitary sources
2. How do MC families know where to turn for this information?
 - a. For information on education-related services provided by the military
 - b. For information on education-related services provided by nonmilitary sources

Access to services:

3. What difficulties do MC families face when they try to access services and supports related to education?
4. What obstacles prevent MC families with EFMs from accessing education-related services and supports?
5. How do MC families' experiences accessing education-related services from the military differ from their experiences accessing education-related services from nonmilitary sources?

DoD oversight:

6. In what ways does DoD monitor and enforce compliance with policy related to the education of MC students with disabilities?
7. How effectively do these DoD activities address the unique needs of MC students with disabilities?
8. How could DoD better help to ensure that MC students receive appropriate, effective education services?

Federal (Department of Education) oversight:

9. In what ways does the Department of Education monitor and enforce compliance with policy related to the education of MC students with disabilities?
10. How effectively do these Department of Education activities address the unique needs of MC students with disabilities?
11. How could the Department of Education better help to ensure that MC students receive appropriate, effective education services?

We'd like to explore the topic of **EDUCATIONAL TRANSITIONS** with you.

As we all know, PCSing is a fact of life in the military and, when families PCS, dependent children and youth must switch schools. We know that changing schools can be a hardship, even in the best of circumstances.

12. When MC families PCS with their EFMs, what kinds of resources are available to help EFMs transition from one school to another? (Please specify the level of schooling: preschool, primary, secondary, postsecondary.)
13. How well do these resources meet their needs? Please be specific about the ways in which the resources do or do not meet their needs. (Please specify the level of schooling.)
14. How could EFMs be better supported when they have to switch schools due to PCS? (Please specify the level of schooling.)

If applicable:

We recognize that young adults with disabilities need support as they transition out of high school. This is often called school-to-work transition.

15. How much does PCS impact transition planning for an EFM's transition out of high school?
16. What kinds of transition planning services are available to meet the transition needs of young adults enrolled in the USMC EFMP?

17. How well do these services meet their needs? Please be specific about the ways in which the services do or do not meet the needs.

18. How could these young adults' transition planning needs be better supported?

Wrap-Up

19. What services—civilian or military, here or elsewhere—work particularly well?

20. What obstacles—civilian or military, here or elsewhere—work less well?

21. If you were in charge of improving access to services for Marine Corps EFMs, what additional steps would you take (that we haven't already discussed)?

This concludes our discussion. Please remember that any personal information shared during this discussion should stay in this room. Thank you for taking the time to share your experiences and perspectives with us. Your input will be very valuable to efforts to improve access to services for Marine Corps EFMs. Once again, thank you very much. And we thank you for your service.

APPENDIX D. Focus Group Introduction

Focus Group Kick-Off: Key Points

- Distribute name tents and markers
- Welcome attendees
 - Thank you for taking the time to join our discussion today.
 - My name is Suzanne Lederer. I am a researcher with ICF International and the wife of an Army retiree. With me is Alex Conlon, also of ICF, and Julie Carroll with the National Council on Disability (NCD). (More on our roles in a moment.)
- Introduce study
 - Marine Corps Headquarters has asked NCD to examine the access of Marine Corps exceptional family members to services in three areas: education, healthcare, and long-term supports. The Marine Corps and NCD are looking at the experiences of exceptional family members of all ages.
 - NCD is an independent federal agency and a leader in disability policy.
 - NCD has hired ICF, including our National Organization on Disability partner, to conduct this study. They came to us because of our extensive experience conducting research within the military community and our knowledge of disability issues.
 - The purpose of this study is to talk to people such as yourselves—who know the most about Marine Corps exceptional family members' access to services—in order to generate relevant and realistic recommendations for improving them.
- Explain study process
 - This study involves gathering information from three categories of people—caretakers of EFMs, EFMs, and service providers—at Marine Corps Base Quantico, Camp Lejeune, and Camp Pendleton.
 - We will gather this information by holding structured discussions (or focus groups) such as this one at each base.
 - After each site visit, we also will conduct telephone interviews with other service providers, such as staff from independent living centers and the

Department of Vocational Rehabilitation, and school system administrators.

- We will combine the information we gather from these focus groups and interviews and, based on the results, develop recommendations.
- The final report of this study, including the recommendations, should be complete by September 2010.
- Describe how the focus group session will work
 - This session is intended for xxx (this will vary).
 - I have scripted questions formulated to address specific topics.
 - The session will last approximately 90 minutes, and we will not take a formal break. (Restrooms are located xxx, if you need to excuse yourself.)
 - Before we begin our voluntary discussion, we will pass around a short questionnaire to gather some basic background information from you. The questionnaire is voluntary and should be completed anonymously—no names please.
 - Each of us has a role to play.
 - I serve as an impartial data gatherer and discussion regulator.
 - Our scribe serves as note-taker—she is taking no names and we are not audiotaping or videotaping the session.
 - Our other colleagues are with NCD are here as observers
- Emphasize that participation is voluntary
 - Your participation in this session is voluntary.
 - While we would like to hear from everyone, feel free to answer as many or as few questions as you prefer.
 - If you would prefer to excuse yourself from the focus group at this time, you are free to do so.
 - You may also excuse yourself at any point during the focus group and, if you wish, return.

- Address confidentiality
 - Information you share is confidential. The research team will protect your confidentiality to the extent allowable by law and no information will be reported that can identify you or your family. We will not report the names of study participants or the responses they share.
 - In fact, my colleagues and I have signed confidentiality agreements pledging to safeguard the confidentiality of the information we gather in these sessions.
 - However, if we learn that you are being hurt or planning on hurting yourself or others, or others are being hurt or planning on hurting themselves or others, the law requires that we share this information with someone who can help.
 - Also, because this is a group meeting, it is important that each of you agree to respect and protect each other's privacy. We expect you to keep any information you hear today in the strictest of confidence, and not discuss it with anyone outside of this group. Please be aware, however, that we cannot guarantee that other participants will honor this expectation.
 - If this concerns you, you should limit your participation to what you are comfortable discussing, or not participate in the focus group at all.
 - We will shortly distribute an informed consent form for you to read and sign.
- Distribute forms for participants to fill out, collect, and clearly place in separate piles
 - Short demographic sheet to be completed anonymously.
 - Informed consent form to be read and signed.
- Explain ground rules
 - Speak as clearly as possible and one at a time.
 - There are no right or wrong answers.
 - We want to hear the good and the bad.
 - We respect and value differences of opinion.
 - Please avoid sidebar conversations.

- Please note that we will use the language used by the Marine Corps: exceptional family member (EFM), exceptional family member program (EFMP). We apologize if this language is not your preference.
- Conduct introductions
 - To begin, I'd like to go around the room and ask each of you to introduce yourselves.
 - Caretakers: First name, how long family has been enrolled in EFMP, and number of EFMs in family.
 - EFMs: First name, how long family has been enrolled in EFMP, and number of EFMs in family.
 - Providers: How we should refer to you, position title, and how long you have worked with people with disabilities.
- Reminder: Provide overarching structure of focus group.
 - We'll be talking about these key topics: sources of information, access to services, oversight, transition, and then some wrap-up questions.

APPENDIX E. Focus Group Participant Consent Form

How to Improve Access to Health Care, Special Education, and Long-Term Supports and Services for USMC Exceptional Family Members

Thank you for participating in this important study conducted by ICF International for the National Council on Disability and the U.S. Marine Corps (USMC). Our goal is to better understand USMC exceptional family members' experiences accessing disability-related services and, based on what we learn, to recommend ways that access to services could be improved.

To participate in this study, we are asking you to join in today's discussion and give basic background information about yourself by anonymously completing a short form. The group discussion takes about 90 minutes.

Your participation is voluntary. You do not have to answer any question you don't want to answer, and you are free to leave this discussion at any time. Your answers are confidential. They will not be shared with anyone outside the ICF research team, and your name will never be linked to your answers or to any comments you make during the discussion. The discussion will not be videotaped or recorded.

Note that the ICF team includes several individuals who will be observing today's session, including representatives from the National Organization on Disability and the National Council on Disability.

You are expected to respect and protect the privacy of other group participants and to not discuss anything you hear today with anyone outside of this group. We cannot guarantee, however, that other participants will honor this expectation.

If you have questions about this study, please contact Ms. Julie Carroll, of the National Council on Disability, at (202) 272-2019. If you have questions about privacy and confidentiality, please contact Dr. Laurie May, of ICF International, at (703) 934-3273.

If you agree to participate, please print and sign your name below and write in the date.

I agree to participate in the USMC Exceptional Family Member Study

(Print) _____
First Name M.I. Last Name

(Signature) _____
First Name M.I. Last Name

Date: ____/____/2010

APPENDIX F. Demographic Sheets

USMC Exceptional Family Member(EFM) Access to Disability-Related Services: Caretaker Questionnaire

(NOTE: Questions #8-11, under “About Your EFM,” may be difficult to answer if you have more than one exceptional family member in your family. To avoid confusion, please answer those questions for your EFM whose birthday is closest to today’s date.)

ABOUT YOU:

1. **How are you related to your EFM?**
 - I am the parent of my EFM
 - I am the spouse of my EFM
 - I am the guardian of my EFM
 - I have another relationship with my EFM (specify:_____)
2. **Are you a Marine or a family member?**
 - I am a Marine
 - I am a family member

ABOUT YOUR FAMILY:

3. **What is the total number of children under the age of 18 in your household?**
 - One child
 - Two children
 - Three children
 - Four or more children
4. **How many EFMs are in your household?**
 - One EFM
 - Two EFMs
 - More than two EFMs
5. **How long has your family been enrolled in the EFM Program (EFMP)?**
 - Less than 1 year
 - 1 – 2 years
 - 2 – 3 years
 - 3 – 4 years
 - 4 – 5 years
 - 5 – 10 years
 - More than 10 years
6. **How long has your family been at your current station?**
 - Less than 1 year
 - 1 – 2 years
 - 2 – 3 years
 - 3 – 4 years
 - 4 – 5 years
 - 5 – 10 years
 - More than 10 years

7. **What is your Marine’s (or your) rank?**

<input type="radio"/> Private	<input type="radio"/> Warrant Officer
<input type="radio"/> Private First Class	<input type="radio"/> Chief Warrant Officer 2
<input type="radio"/> Lance Corporal	<input type="radio"/> Chief Warrant Officer 3
<input type="radio"/> Corporal	<input type="radio"/> Chief Warrant Officer 4
<input type="radio"/> Sergeant	<input type="radio"/> Chief Warrant Officer 5
<input type="radio"/> Staff Sergeant	<input type="radio"/> Second Lieutenant
<input type="radio"/> Gunnery Sergeant	<input type="radio"/> First Lieutenant
<input type="radio"/> Master Sergeant	<input type="radio"/> Captain
<input type="radio"/> First Sergeant	<input type="radio"/> Major
<input type="radio"/> Master Gunnery Sergeant	<input type="radio"/> Lieutenant Colonel
<input type="radio"/> Sergeant Major	<input type="radio"/> Colonel or above
<input type="radio"/> Sergeant Major of the Marine Corps	

ABOUT YOUR EFM:

8. **What is your EFM’s gender?**
 - Female
 - Male
9. **To which age group does your EFM belong?**
 - Newborn to 2 years old
 - More than 2 years to 5 years old
 - More than 5 years to 10 years old
 - More than 10 years to 13 years old
 - More than 13 years to 17 years old
 - More than 17 years to 21 years old
 - More than 21 years to 25 years old
 - More than 25 years old
10. **In which functional area(s) does your EFM have a disability? (Mark all that apply)**
 - Physical/mobility
 - Cognitive
 - Sensory/communication
 - Psychiatric
 - Other:_____
11. **Please check the EFMP category to which your EFM is currently assigned:**
 - Category I
 - Category II
 - Category III
 - Category IV
 - Other:_____
 - Don’t know

USMC Exceptional Family Member Access to Disability-Related Services: Provider Questionnaire

1. **Which statement below best describes your current position? (Mark one only)**
 - I am a Marine
 - I work as a civilian for the Marine Corps
 - I work as a contractor
 - I work as a civilian for another governmental agency (e.g., federal, DoD, state, county, school district) (specify: _____)
 - I work in the private sector
 - Other (specify: _____)

2. **Please check your primary place of work:**
 - I work mostly on base
 - I work mostly off base
 - I work about the same amount of time on base and off base

3. **For what organization do you work? (e.g., name of program, social service agency, hospital, school)**

4. **Which best describes what *type* of organization this is? (Mark one only)**
 - Installation office or program
 - Installation school
 - Installation hospital
 - Local school
 - Local school district
 - Local hospital
 - Governmental organization: federal
 - Governmental organization: state
 - Governmental organization: county
 - Other governmental organization (specify: _____)
 - Non-governmental organization: national
 - Non-governmental organization: state
 - Non-governmental organization: regional
 - Non-governmental organization: local
 - Other non-governmental organization: other (specify: _____)
 - Other (specify: _____)

5. **In which domain(s) do you work? (Mark all that apply)**
 - Education
 - Health care
 - Long-term supports and services
 - Other (specify: _____)
 - No specific domain

6. **What is your job title?**

7. **How long have you worked with this organization?**
 - Less than 1 year
 - 1 – 2 years
 - 2 – 3 years
 - 3 – 4 years
 - 4 – 5 years
 - 5 – 10 years
 - More than 10 years

8. **How long have you worked with *people with disabilities*?**
 - Less than 1 year
 - 1 – 2 years
 - 2 – 3 years
 - 3 – 4 years
 - 4 – 5 years
 - 5 – 10 years
 - More than 10 years

9. **How long have you worked with *the military community*?**
 - Less than 12 months
 - More than 12 months but less than 2 years
 - More than 2 years but less than 4 years
 - More than 4 years but less than 6 years
 - More than 6 years

10. **What is the highest level of education you have completed?**
 - High school diploma or GED
 - Some college, but no degree
 - Technical or vocational degree
 - Associate's degree
 - Bachelor's degree
 - A year or more of graduate credit, but no graduate degree
 - Master's degree
 - Doctorate degree
 - Professional degree (e.g., MD, DDS, or JD)

11. **If you are in the military, what is your pay grade?**

<input type="radio"/> E1	<input type="radio"/> E6	<input type="radio"/> WO1	<input type="radio"/> O1
<input type="radio"/> E2	<input type="radio"/> E7	<input type="radio"/> CW2	<input type="radio"/> O2
<input type="radio"/> E3	<input type="radio"/> E8	<input type="radio"/> CW3	<input type="radio"/> O3
<input type="radio"/> E4	<input type="radio"/> E9	<input type="radio"/> CW4	<input type="radio"/> O4
<input type="radio"/> E5		<input type="radio"/> CW5	<input type="radio"/> O5
			<input type="radio"/> O6

Check here if you are not in the military:

USMC Exceptional Family Member (EFM) Access to Disability-Related Services:
Questionnaire for Exceptional Family Member

ABOUT YOU:

1. **What is your gender?**
 - Female
 - Male
2. **To which age group do you belong?**
 - More than 18 years to 21 years old
 - More than 21 years to 25 years old
 - More than 25 years to 30 years old
 - More than 30 years old
3. In which functional area(s) do you have a disability? (Mark all that apply)
 - Physical/mobility
 - Cognitive
 - Sensory/communication
 - Psychiatric
 - Other: _____
 - Don't know
4. **Please check the EFMP category to which you are currently assigned:**
 - Category I
 - Category II
 - Category III
 - Category IV
 - Other: _____
 - Don't know
5. **How are you related to your Marine?**
 - I am the child of my Marine
 - I am the spouse of my Marine
 - I have another relationship with my Marine (specify: _____)
7. **How many EFMs are in your household in addition to you?**
 - No other EFMs
 - One other EFM
 - More than one other EFM
8. **How long has your family been enrolled in the EFM Program (EFMP)?**
 - Less than 1 year
 - 1 – 2 years
 - 2 – 3 years
 - 3 – 4 years
 - 4 – 5 years
 - 5 – 10 years
 - More than 10 years
9. **How long has your family been at your current station?**
 - Less than 1 year
 - 1 – 2 years
 - 2 – 3 years
 - 3 – 4 years
 - 4 – 5 years
 - 5 – 10 years
 - More than 10 years
10. **What is your Marine's rank?**

<input type="radio"/> Private	<input type="radio"/> Warrant Officer
<input type="radio"/> Private First Class	<input type="radio"/> Chief Warrant Officer 2
<input type="radio"/> Lance Corporal	<input type="radio"/> Chief Warrant Officer 3
<input type="radio"/> Corporal	<input type="radio"/> Chief Warrant Officer 4
<input type="radio"/> Sergeant	<input type="radio"/> Chief Warrant Officer 5
<input type="radio"/> Staff Sergeant	<input type="radio"/> Second Lieutenant
<input type="radio"/> Gunnery Sergeant	<input type="radio"/> First Lieutenant
<input type="radio"/> Master Sergeant	<input type="radio"/> Captain
<input type="radio"/> First Sergeant	<input type="radio"/> Major
<input type="radio"/> Master Gunnery Sergeant	<input type="radio"/> Lieutenant Colonel
<input type="radio"/> Sergeant Major	<input type="radio"/> Colonel or above
<input type="radio"/> Sergeant Major of the Marine Corps	

ABOUT YOUR FAMILY:

6. **What is the total number of children under the age of 18 in your household?**
 - One child
 - Two children
 - Three children
 - Four or more children

APPENDIX G. Characteristics of EFMP Population by Installation

Installations	MCB Quantico	Camp Lejeune (N=1,501 EFMs)	Camp Pendleton (N=2,125 EFMs)
	N (%)	N (%)	N (%)
EFM Relationship to Marine Sponsor			
Spouse	166 (24%)	401 (27%)	608 (29%)
Child	515 (75%)	1,092 (73%)	1,508 (71%)
Other	8 (1.0%)	8 (0.5%)	9 (0%)
Sponsor Grade			
E1–E5	89 (13%)	396 (26%)	575 (27%)
E6–E9	283 (41%)	826 (55%)	1,134 (53%)
WO1–CW5	28 (4.0%)	100 (7.0%)	119 (6.0%)
O1–O6	241 (35%)	178 (12%)	296 (14%)
O7+	47 (6.8%)	0 (0%)	1 (.05%)
EFM Age			
0–18	487 (71%)	1,048 (70%)	1,453 (68%)
19–21	25 (5.0%)	52 (3.0%)	87 (4.0%)
22–25	21 (4.0%)	60 (4.0%)	88 (4.0%)
26–30	33 (7.0%)	88 (6.0%)	138 (6.0%)
31+	131 (19%)	248 (17%)	386 (18%)
Number of Families vs. Enrollees (EFMs)			
Families	594	1,203	1,963
Enrollees	689	1,501	2,125

* MCB Quantico and Camp Lejeune characteristics apply to enrollees living within a 50-mile radius of the installation.

APPENDIX H. **Recommendations by Entity to Which They Are Directed**

The numbers in parentheses correspond to the order in which each recommendation appears in Chapter 4. Note that many recommendations are directed to more than one entity.

Recommendations for Congress

- Address the implications of retirement for continued access to disability-related services, including considering the extension of ECHO coverage. (1)
- At geographically isolated installations where there is a dearth of both military and civilian health care specialists, and many families must travel for hours on a recurring basis to obtain specialty health care:
 - Establish financial incentives, such as scholarships and loan forgiveness programs, to train and recruit specialists to serve military families with special health care needs, and to locate practices near military installations. (6c)
- In military-impacted areas where there is a dearth of civilian health care providers who accept Tricare (particularly specialists), gather information from the civilian providers regarding (a) their reasons for accepting or declining Tricare and (b) how the number of Tricare providers in these areas might be expanded. (9)
- For EFMs who are prescribed ABA therapy, continue to work toward full coverage, consistent with the recommended standard of care. (11)
- Increase the flexibility of services covered by ECHO to closely mirror the services available through a Medicaid waiver. (25)
- Implement mechanisms to enable military EFMs to maintain Medicaid waiver services when they move from state to state, rather than requiring them to go to the bottom of the wait lists each time they PCS:
 - Place incoming EFMs on the new state's wait list based on their position on the previous state's wait list (i.e., based on "time served"). If individuals have a Medicaid waiver in the previous state, they should automatically receive one in the new state.
 - For EFMs who lose Medicaid waiver services as a result of a PCS, provide the same benefits the EFM received in the previous state until eligibility can be established in the new state. (31)

Recommendations for State Agencies

- Implement mechanisms to enable military EFMs to maintain Medicaid waiver services when they move from state to state, rather than requiring them to go to the bottom of the wait lists each time they PCS:
 - Place incoming EFMs on the new state's wait list based on their position on the previous state's wait list (i.e., based on "time served"). If individuals have a Medicaid waiver in the previous state, they should automatically receive one in the new state.
 - For EFMs who lose Medicaid waiver services as a result of a PCS, provide the same benefits the EFM received in the previous state until eligibility can be established in the new state. (31)

Recommendations for Tricare

- Provide EFMP families living off base, which includes most EFMP families, access to disability-related services offered on base. Most notable among these services is special education through DoDEA schools, at installations where they are available. Other services might include, for example, speech therapy and early intervention services. (2)
- Address the implications of retirement for continued access to disability-related services, including considering the extension of ECHO coverage. (4)
- Promote the implementation of the "Medical Home" model among military and civilian providers of health care for EFMP families. Medical Home is a patient-centered "approach to providing comprehensive primary care ... that facilitates partnerships between individual patients, and their personal providers, and when appropriate, the patient's family." Components of this model may include comprehensive case management, care coordination and health promotion, transitional care, patient and family support, referral to community and social services, and use of health information. (5)
- At geographically isolated installations where there is a dearth of both military and civilian health care specialists, and many families must travel for hours on a recurring basis to obtain specialty health care, create a program to bring medical specialists to the installation on a regular and reliable basis. (6a)
- In military-impacted areas where there is a dearth of civilian health care providers who accept Tricare (particularly specialists), gather information from the civilian providers regarding (a) their reasons for accepting or declining Tricare and (b) how the number of Tricare providers in these areas might be expanded. (9)

- Increase the accuracy and timeliness of information EFMP families receive from Tricare by instructing case managers to assist families in accessing services, assigning Tricare case managers to a larger proportion of the EFMP population, and establishing multiple communication mechanisms, including a dedicated Tricare telephone hotline (staffed 24/7) for EFMP families, similar to the Medicare hotline. (10)
- For EFMs who are prescribed ABA therapy, continue to work toward full coverage, consistent with the recommended standard of care. (11)
- Ensure that USMC EFMs who use sign language are aware of their right to the services of an interpreter for medical appointments, including behavioral health sessions, and ensure that this service is available to them at no charge. (12)
- Ensure that off-base families needing early intervention services for their children are systematically referred to comparable early intervention programs in the civilian community. (15)
- Promote the implementation of the “Medical Home” model among military and civilian providers of health care for EFMP families. (See recommendation #5.) With an emphasis on medical case management and coordination, Medical Home will facilitate communication between losing and gaining health care providers and health care systems, reduce unnecessary redundancy, and streamline access to specialists. (22)
- Adjust Tricare procedures to minimize the reenrollment burden for families who change Tricare regions. (23)
- Notwithstanding HIPAA limitations, minimize gaps or discontinuity in health care services related to PCS:
 - Adjust Tricare procedures to provide EFMs referrals for routine specialty care without needing to be seen by their new primary care manager (24a)
 - Consistent with the Medical Home model, establish a mechanism to ensure that EFM families have sufficient prescription medications while in transit between installations. (24c)
 - For recipients of ABA therapy, provide linkage to ABA therapist trainees in the vicinity of the gaining installation (who must complete volunteer hours for their ABA certification) until a longer-term solution can be implemented. (24d)
- Implement mechanisms to enable military EFMs to maintain Medicaid waiver services when they move from state to state, rather than requiring them to go to the bottom of the wait lists each time they PCS:

- Place incoming EFMs on the new state’s wait list based on their position on the previous state’s wait list (i.e., based on “time served”). If individuals have a Medicaid waiver in the previous state, they should automatically receive one in the new state. (Congress and state agencies)
- For EFMs who lose Medicaid waiver services as a result of a PCS, provide the same benefits the EFM received in the previous state until eligibility can be established in the new state. (31)
- Educate the military and civilian community (i.e., base and unit leadership, military and civilian health care providers, relevant base and community agencies and providers, including LEAs, and members of the USMC community at large) about EFMP by designing and implementing a robust, ongoing, multifaceted PR campaign to educate stakeholders and the USMC community as a whole to—
 - Raise their awareness of today’s EFMP and sensitivity to EFM issues.
 - Publicize the specific benefits of enrollment.
 - Mitigate myths, concerns about stigma, and resulting resistance to enrollment.
 - Increase the capacity of the entire community (i.e., military leaders, military and civilian health care providers, base and community agencies, LEAs, USMC community members) to inform USMC families about EFMP and to be a supportive presence in the lives of USMC families with members with disabilities.
 - Promote the Medical Home model, particularly within the military and civilian health care communities. (33)

Recommendations for Department of Education

- Disseminate to local education agencies (LEAs) and EFM families detailed guidance for implementing initiatives included in the Interstate Compact on Educational Opportunity for Military Children. (13)
- Prepare parents of students with disabilities to expect and navigate a very different educational environment when they PCS by mitigating parental distrust. Specifically, preemptively educate parents, via one-on-one and group formats, about the ways that different school districts may meet IEP goals. (27)

Recommendations for DoD

- Address the implications of retirement for continued access to disability-related services, including considering the extension of ECHO coverage. (4)
- At geographically isolated installations where there is a dearth of both military and civilian health care specialists, and many families must travel for hours on a recurring basis to obtain specialty health care, establish financial incentives, such as scholarships and loan forgiveness programs, to train and recruit specialists to serve military families with special health care needs, and to locate practices near military installations. (6c)
- For EFMs with autism who are prescribed ABA therapy, continue to work toward full coverage, consistent with the recommended standard of care. (11)
- Implement mechanisms to enable military EFMs to maintain Medicaid waiver services when they move from state to state, rather than requiring them to go to the bottom of the wait lists each time they PCS:
 - Place incoming EFMs on the new state's wait list based on their position on the previous state's wait list (i.e., based on "time served"). If individuals have a Medicaid waiver in the previous state, they should automatically receive one in the new state. (Congress and state agencies)
 - For EFMs who lose Medicaid waiver services as a result of a PCS, provide the same benefits the EFM received in the previous state until eligibility can be established in the new state. (31)
- Provide EFMP families living off base, which includes most EFMP families, access to disability-related services offered on base. Most notable among these services is special education through DoDEA schools, at installations where they are available. Other services might include, for example, speech therapy and early intervention services. (2)
- Disseminate to LEAs and EFM families detailed guidance for implementing initiatives included in the Interstate Compact on Educational Opportunity for Military Children. (13)
- Increase the flexibility of services covered by ECHO to closely mirror the services available through a Medicaid waiver. (25)
- Prepare parents of students with disabilities to expect and navigate a very different educational environment when they PCS by mitigating parental distrust. Specifically, preemptively educate parents, via one-on-one and group formats, about the ways that different school districts may meet IEP goals. (27)

- Develop and provide to military-impacted schools succinct guidance on steps to facilitate a military student's transition out of their system. Start with military-impacted schools who are beneficiaries of DoDEA partnership grants. (30)

Recommendations for the Office of the Secretary of Defense (OSD) Military Community & Family Policy (MC&FP)

- Augment the PCS Planning Tool on the Military Homefront website to provide EFMP families access to online relocation guidance that is interactive and disability-focused. (21)

Recommendations for DoD-State Liaison Office

- Urge states to establish interstate compact commissions and to take action to train LEA staff. (14)

Recommendations for Department of Navy

- Promote the implementation of the “Medical Home” model among military and civilian providers of health care for EFMP families. Medical Home is a patient-centered “approach to providing comprehensive primary care ... that facilitates partnerships between individual patients, and their personal providers, and when appropriate, the patient’s family.” Components of this model may include comprehensive case management, care coordination and health promotion, transitional care, patient and family support, referral to community and social services, and use of health information. (5)
- At geographically isolated installations where there is a dearth of both military and civilian health care specialists, and many families must travel for hours on a recurring basis to obtain specialty health care—
 - Create a program to bring medical specialists to the installation on a regular and reliable basis. (6a)
 - Provide free disability-accessible transportation to major medical centers within the region. (6b)
- Establish and staff a dedicated developmental pediatrician position on all USMC installations to which Marines with families are assigned. (8)
- Ensure that off-base families needing early intervention services for their children are systematically referred to comparable early intervention programs in the civilian community. (15)

- Promote the implementation of the “Medical Home” model among military and civilian providers of health care for EFMP families. (See recommendation #5.) With an emphasis on medical case management and coordination, Medical Home will facilitate communication between losing and gaining health care providers and health care systems, reduce unnecessary redundancy, and streamline access to specialists. (22)
- Educate the military and civilian community about EFMP (i.e., base and unit leadership, military and civilian health care providers, relevant base and community agencies and providers, including LEAs, and members of the USMC community at large) by designing and implementing a robust, ongoing, multifaceted public relations (PR) campaign to educate stakeholders and the USMC community as a whole to:
 - Raise their awareness of today’s EFMP and sensitivity to EFM issues.
 - Publicize the specific benefits of enrollment.
 - Mitigate myths, concerns about stigma, and resulting resistance to enrollment.
 - Increase the capacity of the entire community (i.e., military leaders, military and civilian health care providers, base and community agencies, LEAs, USMC community members) to inform USMC families about EFMP and to be a supportive presence in the lives of USMC families with members with disabilities.
 - Promote the Medical Home model, particularly within the military and civilian health care communities. (33)

Recommendations for USMC

- Conduct an accessibility review of human service programs and facilities, including base housing, on USMC bases. Develop plans for each base to make programs and facilities accessible, that is, ADA compliant, if they are not already. Execute plans as appropriate. (1)
- Currently families are paid mileage for travel to medical appointments 100 or more miles away. Modify the existing policy to include reimbursement for frequent visits to more proximate medical appointments, which can pose a comparable financial burden. (7)
- In order to eradicate lingering myths about the assignment process, which can discourage enrollment or foster negativity about EFMP, actively promote awareness about the current EFMP “informed assignment process” among EFMP families and the USMC community at large. (16)

- Determine the validity of continuing concerns about the impact of EFMP enrollment on a Marine's career. Assess whether or not this lingering stigma is deserved by comparing rates of advancement among enrolled and nonenrolled Marines in comparable occupational specialties and year-groups. If no differences are observed, use this information to quell remaining concerns about enrollment within the USMC. Alternatively, if differences are observed, and enrollment does indeed affect advancement, take corrective action as appropriate. (32)
- Educate the military and civilian community about EFMP (i.e., base and unit leadership, military and civilian health care providers, relevant base and community agencies and providers, including LEAs, and members of the USMC community at large) by designing and implementing a robust, ongoing, multifaceted PR campaign to educate stakeholders and the USMC community as a whole to—
 - Raise their awareness of today's EFMP and sensitivity to EFM issues.
 - Publicize the specific benefits of enrollment.
 - Mitigate myths, concerns about stigma, and resulting resistance to enrollment.
 - Increase the capacity of the entire community (i.e., military leaders, military and civilian health care providers, base and community agencies, LEAs, USMC community members) to inform USMC families about EFMP and to be a supportive presence in the lives of USMC families with members with disabilities.
 - Promote the Medical Home model, particularly within the military and civilian health care communities. (33)
- Continue to grow the number of EFMP caseworkers, to allow them to provide more comprehensive services to EFMP families. (37)
- Clarify the intended role of the FROs with regard to EFMP families, both during steady state and during PCS. If appropriate, address privacy constraints (e.g., HIPAA) preventing FROs from learning of, and proactively reaching out to, incoming EFMP families. (38)
- Explore how base providers can share pertinent information with one another regarding EFM needs without violating privacy rules. (39)
- Continue to encourage coalitions of base providers serving EFMs, and regular meetings of coalition members, to promote coordinated and proactive service delivery. (40)

- Explore how the much-appreciated respite benefit could be made more flexible in order to better respond to individual family needs. (41)

Recommendations for USMC EFMP

- Undertake a study of access to disability-related services among remotely located USMC EFMs. (USMC) Upon ascertaining the needs of this population and gaps in services, determine the baseline support USMC should provide remote EFMP families, and resource/train caseworkers accordingly. (3)
- Ensure that USMC EFMs who use sign language are aware of their right to the services of an interpreter for medical appointments, including behavioral health sessions, and ensure that this service is available to them at no charge. (12)
- Ensure that off-base families needing early intervention services for their children are systematically referred to comparable early intervention programs in the civilian community. (15)
- In order to eradicate lingering myths about the assignment process, which can discourage enrollment or foster negativity about EFMP, actively promote awareness about the current EFMP “informed assignment process” among EFMP families and the USMC community at large. (16)
- Establish a sponsorship program for PCSing EFMP families. (17)
- Distribute a comprehensive resource packet, resource guide, or directory listing base and community resources for EFMs. Produce this tool both electronically and in hard copy and update the information regularly. Proactively distribute it to new arrivals and new enrollees. Through an ongoing strategic marketing campaign, ensure that all families with EFMs know about the tool and have ready access to it either online or in hard copy. (18)
- Proactively offer to help families sign up for base housing, if not get assigned quarters, in advance of their arrival. (20)
- Proactively offer families resource lists for respite care providers so they can arrange for respite care in advance of their arrival and thus minimize gaps in service, particularly during the stressful transition period. (20)
- Notwithstanding HIPAA limitations, minimize gaps or discontinuity in health care services related to PCS:
 - Facilitate transfer of medical information between bases and between off-base and on-base providers by digitizing EFM medical records and

facilitating a warm handoff (direct communications) between providers. (24b)

- Consistent with the Medical Home model, establish a mechanism to ensure that EFM families have sufficient prescription medications while in transit between installations. (24c)
- For recipients of ABA therapy, provide linkage to ABA therapist trainees in the vicinity of the gaining installation (who must complete volunteer hours for their ABA certification) until a longer-term solution can be implemented. (24d)
- Prepare parents of students with disabilities to expect and navigate a very different educational environment when they PCS by mitigating parental distrust. Specifically, preemptively educate parents, via one-on-one and group formats, about the ways that different school districts may meet IEP goals. (27)
- Proactively send inbound EFMP families with students with disabilities customized school information prior to arrival. Of necessity, this information will be less customized if families do not yet know where they will be living. (29)
- Educate the military and civilian community (i.e., base and unit leadership, military and civilian health care providers, relevant base and community agencies and providers, including LEAs, and members of the USMC community at large) about EFMP by designing and implementing a robust, ongoing, multifaceted PR campaign to educate stakeholders and the USMC community as a whole to—
 - Raise their awareness of today's EFMP and sensitivity to EFM issues.
 - Publicize the specific benefits of enrollment .
 - Mitigate myths, concerns about stigma, and resulting resistance to enrollment
 - Increase the capacity of the entire community (i.e., military leaders, military and civilian health care providers, base and community agencies, LEAs, USMC community members) to inform USMC families about EFMP and to be a supportive presence in the lives of USMC families with members with disabilities.
 - Promote the Medical Home model, particularly within the military and civilian health care communities. (33)
- Explore to what extent ambiguity surrounding the definition of “disability” may prevent eligible USMC families from looking to EFMP for support. As

appropriate, incorporate findings into the PR campaign addressed in the previous recommendation. (34)

- Expand the scope of the support provided EFMP families beyond information and referral. For example,
 - Deliver regular, proactive outreach to enrollee families.
 - Proactively push information and resources to EFM families immediately upon enrollment and on an ongoing basis, so they will know—
 - What to expect from enrollment
 - How to derive maximum benefit from enrollment
 - Who their “go-to” people are—including their position, purpose, and contact information
 - Establish a mentoring program to facilitate opportunities for EFMP families to share information and lessons learned with one another. This may be as simple as maintaining a roster of interested currently enrolled families who consent to their contact information being shared with newly enrolled or newly arrived families as appropriate.
 - Develop and offer more advocacy and more advocacy training opportunities. Leverage partners in policymaking, such as the Office of Protection and Advocacy (OPA) and the Council on Developmental Disabilities.
 - Develop and offer supplemental outreach and programming for families with deployed members.
 - Create a support group for EFM siblings, or help EFMP families link into civilian support groups for EFM siblings.
 - Offer transition-planning support aimed at facilitating continuity of care for EFMs of Marines who are retiring or separating from the military. (35)
- Ensure that EFMP offices systematically gather, maintain, and update contact information from caretaker/EFM spouses and consistently direct all communications—whether by email, telephone, or U.S. mail—to them. (36)
- Explore how the much-appreciated respite benefit could be made more flexible in order to better respond to individual family needs. (41)

Recommendations for USMC School Liaison

- Prepare parents of students with disabilities to expect and navigate a very different educational environment when they PCS by mitigating parental distrust. Specifically, preemptively educate parents, via one-on-one and group formats, about the ways that different school districts may meet IEP goals. (27)
- Increase the capacity of school liaisons to support EFMP enrollees by ensuring that (1) school liaisons are sufficiently familiar with EFMP, EFM needs, and special education resources on and off base (USMC, EFMP), and (2) proactively marketing school liaison services, for example, by including a flyer in newcomer materials. (28)

Recommendations for USMC Early Development Intervention Services (EDIS)

- Provide EFMP families living off base, which includes most EFMP families, access to disability-related services offered on base. Most notable among these services is special education through DoDEA schools, at installations where they are available. Other services might include, for example, speech therapy and early intervention services. (2)
- Ensure that off-base families needing early intervention services for their children are systematically referred to comparable early intervention programs in the civilian community. (15)
- Recommendations for USMC Relocation Program
- Expand the scope of the support provided EFMP families beyond information and referral. For example, offer transition-planning support aimed at facilitating continuity of care for EFMs of Marines who are retiring or separating from the military. (USMC Relocation Program with assistance from EFMP) (35)

Recommendations for Other Entities

Department of Health and Human Services

- At geographically isolated installations where there is a dearth of both military and civilian health care specialists and many families must travel for hours on a recurring basis to obtain specialty health care, establish financial incentives, such as scholarships and loan forgiveness programs, to train and recruit specialists to serve military families with special health care needs, and to locate practices near military installations. (6c)

Civilian or Local Medical Providers

- Ensure that off-base families needing early intervention services for their children are systematically referred to comparable early intervention programs in the civilian community. (15)
- For recipients of ABA therapy, provide linkage to ABA therapist trainees in the vicinity of the gaining installation (who must complete volunteer hours for their ABA certification) until a longer-term solution can be implemented. (24d)

ABA Certifying Authorities (e.g., colleges and universities)

- For recipients of ABA therapy, provide linkage to ABA therapist trainees in the vicinity of the gaining installation (who must complete volunteer hours for their ABA certification) until a longer-term solution can be implemented. (24d)

State DoEs

- Disseminate to local education agencies (LEAs) and EFM families detailed guidance for implementing initiatives included in the Interstate Compact on Educational Opportunity for Military Children. (13)
- Urge states to establish interstate compact commissions and to take action to train LEA staff. (14)
- Prepare parents of students with disabilities to expect and navigate a very different educational environment when they PCS by mitigating parental distrust. Specifically, preemptively educate parents, via one-on-one and group formats, about the ways that different school districts may meet IEP goals. (27)

LEAs

- Disseminate to LEAs and EFM families detailed guidance for implementing initiatives included in the Interstate Compact on Educational Opportunity for Military Children. (13)
- Prepare parents of students with disabilities to expect and navigate a very different educational environment when they PCS by mitigating parental distrust. Specifically, preemptively educate parents, via one-on-one and group formats, about the ways that different school districts may meet IEP goals. (27)
- Develop and provide to military-impacted schools succinct guidance on steps to facilitate a military student's transition out of their system. Start with

military-impacted schools who are beneficiaries of DoDEA partnership grants. (30)

Interstate Commission

- Disseminate to local education agencies (LEAs) and EFM families detailed guidance for implementing initiatives included in the Interstate Compact on Educational Opportunity for Military Children. (13)
- Promulgate and enforce rules for schools receiving new students to ensure advanced preparation for these students' special education needs. (26)

Education Associations

- Prepare parents of students with disabilities to expect and navigate a very different educational environment when they PCS by mitigating parental distrust. Specifically, preemptively educate parents, via one-on-one and group formats, about the ways that different school districts may meet IEP goals. (27)

Parent-Teacher Organizations and Associations

- Prepare parents of students with disabilities to expect and navigate a very different educational environment when they PCS by mitigating parental distrust. Specifically, preemptively educate parents, via one-on-one and group formats, about the ways that different school districts may meet IEP goals. (27)

APPENDIX I. **Glossary**

ABA	Applied Behavior Analysis
ADA	Americans with Disabilities Act
ADHD	Attention Deficit Hyperactive Disorder
ASD	Autism Spectrum Disorder
AT	Assistive Technology
BAH	Basic Allowance for Housing
BRAC	Base Realignment and Closure
CARTT	Computer Assisted Real Time Translation
CDC	Child Development Center
CDSA	Child Development Services Agency
CONUS	Continental United States
DD	Developmental Disability
DDS	Department of Developmental Services
DDESS	Domestic Dependents Elementary and Secondary Schools
DoD	Department of Defense
DoDEA	Department of Defense Education Activity
DoE	Department of Education
ECHO	Extended Care Health Option
EDIS	Early Development Intervention Services
EFM	Exceptional Family Member
EFMP	Exceptional Family Member Program
EHHC	Extended Home Health Care
EI	Early Intervention
FA	Functionality Assessment
FAPE	Free and Appropriate Public Education
FERPA	Family Educational Rights Privacy Act
FRO	Family Readiness Officer
GAO	Government Accountability Office
HIPAA	Health Insurance Portability and Accountability Act
IDEA	Individuals with Disabilities Education Act
IEP	Individual Educational Plan
IFSP	Individualized Family Service Plan
ITP	Individual Transition Plan
LEA	Local Education Agency
LINKS	Lifestyle, Insights, Networking, Knowledge and Skills
MCEC	Military Child Education Coalition
MCCS	USMC Marine Corps Community Services
MISA	Military Impacted Schools Association
MR	Mentally Retarded
NACCRRRA	National Association of Child Care and Resource and Referral Agencies
NCCSE	North Coastal Consortium for Special Education
NCD	National Council on Disability
NECTAC	National Early Childhood Technical Assistance Center
NMFRS	Navy Marine Federal Relief Society

NPSP	New Parent Support Program
OPA	Office of Protection Advocacy
OT	Occupational Therapy
PCM	Primary Care Manager
PCS	Permanent Change of Station
PEP	Personalized Education Plan
PFC	Private First Class
PT	Physical Therapy
PTI	Parent Training and Information Center
QUICC	Quantico Inter-Agency Coordinating Council
SELPA	Special Educational Local Plan Area
SL	Sign Language
SL	School Liaison
SNERT	Special Needs Evaluation Resource Team
SOAR	Student Online Achievement Resources
SSI	Supplemental Security Income
STOMP	Specialized Training of Military Parents
UNC	University of North Carolina
USMC	U.S. Marine Corps
WRAMC	Walter Reed Army Medical Center

Endnotes

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⁷ Americans with Disabilities Act of 1990, 42 U.S.C. §12101 (1990).

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⁹ Centers for Medicare & Medicaid Services, *Overview Medicaid Program*, <https://www.cms.gov/home/medicaid.asp> (March 20, 2009).

¹⁰ MCO P1754.4A, Marine Exceptional Family Program (EFMP SOP) (April 1997).

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