



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.

**Statement for the Record
For the
Senate Armed Services Committee, Subcommittee on Personnel
June 20, 2012 Hearing on Department of Defense Programs and Policies to
Support Military Families with Special Needs**

In 2009, the U.S. Marine Corps (USMC) requested that the National Council on Disability (NCD) conduct a study to systematically examine the challenges experienced by Marine Corps Families with disabilities and to identify steps toward ameliorating these challenges. The objectives for the study included: 1) documenting the experiences of USMC Families that have dependents with disabilities in accessing appropriate and effective services in health care, special education and related services, and long-term supports and services; 2) identifying barriers impeding access to appropriate resources and services; and 3) developing recommendations to improve access. While some of the recommendations that were made are directed specifically to the Marine Corps, many more recommendations would require action by other entities such as Congress, Department of Defense (DoD), Tricare, the Department of Education, and individual states, but in the end would benefit military Families in all branches of the military. The complete report is available online at <http://www.ncd.gov/publications/2011/Nov282011>.

The USMC's chief instrument for addressing the needs of USMC Family members with disabilities is the USMC Exceptional Family Member Program (EFMP). EFMP was established by the Marine Corps in 1990. The EFMP provides assignment coordination and Family support.

Focus groups, as well as interviews of caretakers, Family members with disabilities, and service providers were conducted between January 2010 and March 2010 at Marine Corps Base Quantico, Camp Lejeune, and Camp Pendleton—three large USMC bases to which many EFMP Families are assigned.

Findings

EFMs and their Families described a number of barriers that span the domains of healthcare, education, and long-term supports and services. Caretakers stated that 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. EFMP Families who live off base, which describes the majority, are apt to be less Familiar with base services, and to be ineligible to use them.

Access to Health Care

Many Families who were more successful than others at navigating the complex health care service and reimbursement systems attributed their success, in large part, to the assistance of case managers through EFMP, Tricare, and 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. Certain individual healthcare providers were 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 cumbersome Tricare processes and a protracted system for obtaining healthcare referrals, which are particularly burdensome for those that rely heavily on the healthcare system. Many lamented the limitations of Tricare coverage—particularly Tricare coverage of Applied Behavior Analysis (ABA) therapy, offered under the Tricare Extended Care Health Option (ECHO), which falls well short of the recommended standard of care.

Access to Special Education

USMC students frequently attend public schools, because bases with Department of Defense Education Activity (DoDEA) schools are the exception rather than the rule. Parents described DoDEA schools as well-resourced and praised DoDEA's inclusive model for students with disabilities. Similarly positive remarks were made about EDIS (Early Development Intervention Services), 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) and Task.Mil. Despite these resources, EFMP Families encounter a number of 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 (PCS). Several parents and providers observed that schools and other educational facilities (including on- and off-base) 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 healthcare and education, the military is not involved in the delivery of long-term supports and services, and USMC EFM's 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 PCS from state to state. It was also noted that adult EFM's currently lack access to services such as transportation for medical appointments and personal care attendants. Many Families do not live on the same base long enough to qualify for Medicaid waivers, which provide these services for families that meet state residency and other requirements.

Permanent Change of Station and Access to Disability-Related Services

The requirement to move, or PCS, regularly, 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 EFM's, especially if the Families are young and/or the EFM's disability is severe. Every time a Family PCSes, they must re-educate themselves about the resources available to them and the process for accessing them. They must also reassemble their EFM's continuum of care—i.e., 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 where their EFM's needs can be met. 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, e.g., Family Readiness Officers (FROs), Military OneSource, the PCS planning tool on the Military Homefront website, and the Interstate Compact on Educational Opportunity for Military Children.

Permanent Change of Station and Access to Healthcare

The cycle of interrupting and re-establishing healthcare is part and parcel of the PCS experience. The more severe and involved the Family member's condition,

the more challenging the process of re-establishing the continuum of care. Many Families noted that the process of finding new providers is time-consuming and prolongs the lag in healthcare services. The new location may fall under a different Tricare region, necessitating burdensome re-enrollment. EFMs lose momentum and ground in progress toward their treatment goals. There can be problems accessing healthcare, including prescriptions, while in transit and before meeting with the new Primary Care Manager (PCM). Although the obstacles to healthcare 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 healthcare transition. Various medical and non-medical case managers, including EFMP caseworkers, can help Families with the healthcare 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 offer listings of healthcare providers by geographic area, although it was noted that the Tricare lists are not always accurate or easy to navigate.

Permanent Change of Station 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 a lack of continuity 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 both are under-utilized by PCSing EFMP Families due to a lack of awareness of the PCS-related services these programs offer. It also should be noted that EFMP and SL staff couldn't 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. Educational and Developmental Intervention Services (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 there are systems in place to support this.

Permanent Change of Station and Access to Long-Term Supports and Services

Communication among base-level EFM proponents about PCSing Families apparently is inconsistent, and sometimes EFM offices are unaware of incoming Families. Shortfalls in communication between local programs and enrollees also were identified, with many Families saying they do not receive the information from the local EFM office that they should. Many Families voiced

EFM Communications

Several factors potentially interfere with entry of eligible Families into the program. There continues to be a lack of awareness among potential enrollees about EFM, as mentioned earlier, as well as misinformation regarding who is eligible to enroll and what the benefits of enrollment are. A lingering stigma associated with EFM, 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 EFM, which needlessly delays some Families' enrollment and timely receipt of invaluable services (e.g., respite care, services covered by ECHO).

EFM Program Entry

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

EFM and Other Base Programs

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 EFM—i.e., 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 EFM, because there are long waiting lists for the 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, call out the absence of a mechanism to help individuals retain Medicaid benefits. Additionally, although the current study did not target EFM of retirees, it was evident that some currently serving EFM Families are concerned about continuity of care for their EFM upon retirement, e.g., how access to services will be affected by the loss of ECHO.

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 improvement related to quality of service delivery. A large number of enrollees said they were not receiving outreach contact from EFMP. Many participants, including providers, indicated there are too few caseworkers to meet enrollees' needs; some suggested that there are existing EFMP caseworkers who 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 capability of assignment monitors to make appropriate assignment decisions on behalf of Marines and their EFMs. There also was considerable discussion about how enrollment impacts assignment options, deployability, and advancement. As noted previously, there seems to be lingering concern within the USMC community regarding a potential adverse impact of EFMP enrollment on the Marine's career advancement.

Other Base Resources

A number of base entities other than EFMP play an important role in supporting the needs of EFMP Families. Providers and enrollees frequently lauded the EFMP 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 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. Lastly, a number of participants suggested that Families are not sufficiently aware of the base resources available to them.

It should be noted that significant improvements were made to the EFM program during the time this study was being conducted. However, the need for EFMP services still far exceeds program capacity, and many Families remain unaware of program improvements.

NATIONAL COUNCIL ON DISABILITY STUDY RECOMMENDATIONS

Based on the study 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 IV of the report contains a comprehensive list of recommendations, followed by the entity or entities to which each recommendation is targeted (e.g., Congress, DoD, Department of Navy, USMC, Tricare, EFMP). The complete list of recommendations is presented in Appendix H according to which entity or entities each recommendation is directed.

For purposes of this summary statement, ten recommendations, five short-term and five long-term, are being called out for immediate attention, as having the potential to have the greatest impact on Families with members with disabilities.

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, i.e., ADA compliant, if they are not already. Execute plans as appropriate. (USMC)
2. Increase the accuracy and timeliness of information EFMP Families receive from Tricare by assigning Tricare case managers to a larger proportion of the EFMP population and/or establishing a dedicated Tricare telephone hotline (staffed 24/7) for EFMP Families, similar to the Medicare hotline. (Tricare)
3. Disseminate to Local Education Agencies (LEAs) detailed guidance for implementing initiatives included in the Interstate Compact on Educational Opportunity for Military Children. (Interstate Commission, Federal and State DoEs, LEAs, DoDEA)
4. Educate the military and civilian community about EFMP (i.e., base and unit leadership, military and civilian healthcare providers, relevant base and community agencies/providers, including LEAs, and members of the USMC community at large) by designing and implementing a robust, ongoing, multi-faceted 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 healthcare 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 concept, particularly within the military and civilian healthcare communities.
(EFMP, USMC, Department of Navy, Tricare)
5. Ensure EFMP offices systematically gather, maintain, and update contact information from caretaker/EFM spouses and consistently direct all communications—whether by email, telephone, or US mail—to them.
(EFMP)

Long Term Recommendations

1. Address the implications of retirement for continued access to disability-related services, including considering the extension of ECHO coverage.
(DoD, Tricare)
2. For EFMs who are prescribed ABA therapy, continue to work toward full coverage, consistent with the recommended standard of care and healthcare reform. (Congress, Department of Defense, Tricare). (Tricare)
3. Minimize the gaps in healthcare 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 records between bases and between off-base and on-base providers by digitizing EFM medical records.
(EFMP)
 - c. With the help of a Medical Home, establish a mechanism to ensure 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)
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 waitlists each time they PCS:
 - a. Place incoming EFMs on the new state's waitlist based on their position on the previous state's waitlist (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)
5. Increase the flexibility of services covered by ECHO to closely mirror the services available through a Medicaid waiver. (Congress, DoD, Tricare)

NCD appreciates the opportunity to provide this Statement for the Record, and would welcome the opportunity to work collaboratively with others to facilitate implementation of the report recommendations and improve supports and services for military Families with disabilities.