Department of Defense Exceptional Family Member Program Benchmark Study

Final Project Report

Submitted to:
Office of Community Support
for Military Families with Special Needs

Department of Defense

Military Community and Family Policy

Submitted by:

Bronfenbrenner Center for Translational Research,

Cornell University
And
Beach Center on Disability,
The University of Kansas

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EXECUTIVE SUMMARY

The Bronfenbrenner Center for Translational Research, Cornell University, and the Beach Center on Disability, University of Kansas, have completed the Department of Defense (DoD) Exceptional Family Member Program (EFMP) Benchmark Study. The study was funded by the National Institute for Food and Agriculture (NIFA), United States Department of Agriculture (USDA) and the Department of Defense, Military Community and Family Policy, Office of Community Support for Military Families with Special Needs (OSN), Agreement No. 2010-39562-21770. The University of Kansas prepared the literature review and conducted a series of interviews with family support programs for families with special needs within the military and civilian sectors. Cornell University conducted a broad based needs assessment with Service members and their families, EFMP family support staff and other service providers through a series of focus groups and interviews at military installations throughout the continental United States (CONUS).

Literature Review and Military and Civilian Sector Program Reviews

The literature review was conducted from the fall of 2010 through the spring of 2011 and included a broad range of healthcare, social work, and special education databases as well as a review of relevant DoD and Service policy and protocol documents. The contents of each document were coded into four categories: staff guidelines, service provision, personnel training, and evaluation metrics. Staff from nine family support programs was interviewed and the information collected was coded into the same four categories that were used for the literature review findings.

1. **Staff Guidelines:** While the selected civilian and military family support programs had very similar caseload ratios, in general the civilian caseloads tended to be smaller than military caseloads. Programs with lighter caseloads provided more intensive, one on one services, such as offering a "mentoring process" for the family and tailoring support to the family needs; whereas, programs with heavier caseloads tended to only offer group training and information and referral services. Large caseload sizes negatively impact the ability of *case managers* to assist clients to achieve better outcomes. With large caseload sizes, contacts become less frequent while approach to family support becomes more reactive.
2. **Service Provision:** Services provided covered a wide continuum of supports ranging in intensity from least intensive (e.g., information and referral) to most intensive (e.g., "whatever it takes" level of support). Information and referral is a service in which the most appropriate services are identified to meet a family's needs and the family is linked to the agencies providing the services. The most intensive approach includes any level or intensity of support necessary to meet a family's needs, in accessing medical, social, vocational, rehabilitative and other services, such as making initial contact with other resources on the family's behalf, scheduling appointments and accompanying the family as needed, and developing, implementing, and monitoring an individualized family service plan.

3. **Personnel Training:** The most common training that family support case managers received was identified as initial orientation training and/or annual conferences to update or expand staff knowledge. Other professional training included: (a) military and civilian workshops, (b) one-on-one training, (c) engagement in a community of practice, (d) tiered system of training and technical assistance, (e) independent study course, and (f) a train-the-trainer model. The knowledge required for case managers included information on the nature and scope of local community resources both within and across settings. Program interviews also indicated that additional specific knowledge was required for EFMP *case managers*, including knowledge of: (a) military structure and protocol; (b) existing rules, regulations, and policies; (c) program eligibility requirements; (d) funding sources for services; (e) principles of family-centered practice; and (f) interpersonal and problem solving skills. The literature also recommended that professional knowledge include an understanding of the development of children with special needs and team-building skills.

4. **Evaluation Metrics**: The evaluation metrics identified in the literature review and program interviews addressed both process and outcome measures as well as evaluation of staff and professional training. Typically, programs were able to provide a detailed accounting of the broad diversity of individuals they serve and the services they provide. In some cases, formal and informal assessments of the impact of those activities were completed using a number of standardized assessment tools that measured family well-being and self-efficacy. Program staff was evaluated using a number of work related performance measures and by tracking completion of training and certifications. The literature also discussed supervisor observation, fidelity checklists, and quality assurance calls. Training evaluation was accomplished mainly by using post-training measures of satisfaction.

Needs Assessment

Site visits were made to eight CONUS military installations, two in each branch, between April 2011 and October 2011, during which time focus groups and individual interviews were conducted with 301 Service members, family members, and service providers. Two of the sites were joint base installations. The sites were identified by the Service points of contact (POC's) in each EFMP as locations where many families with special needs were assigned because of proximity to multiple resources and services, particularly medical services. This selection of sites was efficient for providing a large pool of participants but did tend to focus on those families with the most challenging medical, educational and behavioral issues and was heavily weighted toward children and teens. Participants in the study were recruited by the local installation EFMP family support providers. This needs assessment also overlapped with the infusion of additional funds allocated to each military branch to expand their family center support and reflects the progress of this expansion. Despite these caveats, the information is remarkably consistent with previously identified concerns and recommendations that other studies have made for improvement.

1. Resources: Availability and Comparability

Installation, medical, educational, state and federal resources varied widely from location to location both in terms of what was actually available as well as how eligibility was determined by different providers depending on their professional responsibilities and organizational guidelines. Services were described as rarely equivalent or comparable primarily due to differing installation procedures and guidelines; different state and federal reimbursement schedules, eligibility rules and waiting lists; large versus small school district resources; availability of licensed therapists, physician specialists, and availability of legal guidance/counsel.

2. Paperwork: Redundancy

Families were expected to provide different information at different sites (civilian and military) on different forms and for multiple providers. The process is not streamlined; records and forms are only partially digitalized; and tracking paperwork for both service providers and families is labor intensive. From the families' point of view, the most critical issue is that the paperwork controls how quickly family members with special needs actually get services such as an educational evaluation, prescription recertification; placement on the waiting list for therapists, appointments with specialists, and respite care or housing priorities. A consistent, strong recommendation from participants was to bring this process into the electronic age and institute an online tracking system.

3. Lack of Transparency: Enrollment and Assignment Process

There is frustration among Service members about the assignment process and among Families with the enrollment process. The paperwork for both is complex, not streamlined as noted above, and from the family's perspective, lacks transparency. For assignments, many of the Service member participants were unclear as to what is considered when assignments are made (i.e., "they" [Personnel] don't ask for our input). There is a general feeling that despite statements to the contrary (*having an exceptional family member does not affect your career*) the career impact on the Service member can be experienced as a "career stopper".

Enrollment challenges for many families included misinformation and confusion about the basis for the severity categories and levels that not only determine eligibility for services but also may restrict them from moving since it impacts the assignment process. The requirements for getting all the correct paperwork is time consuming, difficult and in some situations – expensive (e.g., civilian medical providers sometimes require a fee to fill out the military forms or schools charge for multiple copies of documents). Since there are multiple entry points to the program with different timelines for identification and enrollment, families may not get the coordination they need to effectively manage their specific family situation. Referrals to the program may come from different sources (through command, by unit member or spouse, private pediatrician, military medical clinic diagnosis, schools, etc.) Depending on where (and when in the life course of the family member with special needs),

the Service member and family go to follow up on that initial referral can influence what information they get about what is available to them and how quickly they can move through the system.

4. People Make Good Outcomes Happen

Among all the participants from every branch (Service members, family members, and service providers) at every location there were frequent "*good news*" stories about things that had worked well for families with special needs as well as gratitude for the many military services that were often seen to be more responsive than civilian resources. A consistent theme was that when things did work well, it was usually because individuals in the family, in the service provider community, or at the command level made it happen by being persistent advocates, understanding the needs of the family, and most importantly, knowing how to work effectively within the system.

A common recommendation from the groups was to have better communication about all the different steps in the process and the range of available resources in one place, preferably online so it could be updated and revised as needed. Many families use electronic communications: email, websites (local, state, federal, and organizational), chat groups, and online support groups to seek information.

Participants in this needs assessment report noted that in the past few years they have seen numerous positive changes for military families with special needs, but many challenges remain in balancing the demands of both military life and the most intense special needs that some military families face. Despite the enormity of these challenges in some situations, these families remain highly motivated to find ways to continue their service in the military while assuring the special needs of their family member are met.

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1. INTRODUCTION

The Exceptional Family Member Program (EFMP) is a mandatory enrollment program for active duty personnel who have family members with on-going medical or special educational needs. Over 120,000 military families are currently enrolled in the EFMP. Under the provisions of 10 U.S.C. § 1781c, Section 563(National Defense Authorization Act (NDAA) of 2010 the Department of Defense (DoD) was required to establish a policy requiring the Military Services to provide and/or expand community support to military families with special needs. As of 2010, all of the Military Services provide family support through the EFMP.
EFMP has three components: identification/enrollment, assignment coordination, and the provision of family support services. Each of the Military Services offers support through their respective medical services to provide the means for identification and enrollment into EFMP. Once enrolled, assignments (particularly those overseas) are coordinated to ensure special medical and educational needs are considered.

For family support services, installation family centers have EFMP personnel to assist families in identifying and accessing a variety of programs and needed services on and off the military installation. They also provide information and referral services on topics such as local education opportunities, respite care and an array of public benefits. In addition, family support services personnel offer a "warm handoff" to families moving to a new location in an effort to maintain a continuum of care. The level of family support and assistance varies significantly by Service.

In addition to the requirements noted above, 10 U.S.C. § 1781c, Section 563 requires DOD to establish a comprehensive policy requiring the Military Services to provide community support to military families with special needs. The Office of the Secretary of Defense (OSD) Military Community and Family Policy, Office of Community Support for Military Families with Special Needs (OSN) commissioned the Bronfenbrenner Center for Translational Research at Cornell University to carry out the '*DOD EFMP Benchmark Study*'. This study was designed to provide additional information through a policy review, practice review (literature analysis and interviews), and a current needs assessment as part of the foundation for developing an effective family support policy across OSN and the four Military Services. Cornell University entered into an agreement with the Beach Center on Disability at the University of Kansas, and the two universities conducted the study jointly, with the University of Kansas completing the policy and practice reviews and Cornell University completing the needs assessment.

The literature analysis includes an examination of peer-reviewed and other professional literature as well as the findings and policy/practice recommendations from two recent National Symposia on Family Support. The interviews were conducted with top-tier family support programs within military and civilian sectors to identify best practices related to intake, evaluation, and provision of services and supports. The needs assessment was intended to gather input from Service members, family members and family support providers concerning

the challenges they face, what programs and policies are meeting needs, and how gaps in existing services might be filled.

Findings are presented in the following chapters:

- Literature Analysis and Interviews
- Family Needs Assessment
- Conclusions and Recommendations

Additional information about the literature review and technical documents related to the focus groups and interviews can be found in the appendices.

There are two contextual points that should be mentioned prior to presenting the study findings. First, this study is not the first to look at the challenges of military families with special needs. Many of the findings in this report corroborate the findings of other studies. Second, this study began a year into substantial changes that are continuing to be made in each of the four Military Services' EFMPs. Although many of the same needs, gaps, and inconsistencies continue to exist, there is unanimity among all those involved in the study that significant effort has been made to address these concerns and progress is being made toward reducing or eliminating the negative effects they have on families. This report should be viewed as an update on the steps the military is taking to support families with special needs as well as providing recommendations for next steps to ensure progress continues.

2. LITERATURE ANALYSIS AND INTERVIEWS

In this chapter, (a) the analysis of family support literature and (b) findings from a series of interviews conducted with family support programs within military and civilian sectors are discussed. The chapter begins with a brief description of the methodology for each research activity followed by a combined literature analysis and interviews findings section.

Throughout this chapter, all terms, such as case manager/management, systems navigation, and family service plan, are **generic** to family support, whether civilian or military. These terms **are not** proper nouns or terms specifically used by programs found in the literature or specifically related to programs interviewed or specific terms used in the military (e.g., EFMP medical case management).

The terms *case manager* and *case management* are used throughout this chapter to be consistent with terminology used in Section 563 of the National Defense Authorization Act (NDAA) for FY 2010. The term case management refers generically to a collaborative process of assessment, planning, facilitation, care coordination, evaluation, and/or advocacy for options and services to meet an individual's and family's comprehensive needs. TRICARE and Regional Contractors provide medical case management to individuals with significant chronic or high-risk health issues. Therefore, the terms *case manager/management* are italicized throughout Chapter 2 to denote the generic use of the term and to delineate it from specific EFMP medical case manager/case management usage.

PART ONE: Methodology

I. Literature Analysis Methodology

Family support is defined as "consisting of cash assistance, professionally provided services, in-kind support from other individuals or entities, goods or products, or any combination of them, that are provided to families who have minor or adult members with special needs living in the family's home." This definition was derived from the definition of family support in the *Consensus statement on family support: Beyond support to control of one's life*, which was created following the first National Symposia on Family Support hosted by the Beach Center on Disability in 2006. The goals of family support are to: (a) assist families to stay intact; (b) enable families to provide needed supports at home to their family member; (c) assist families to enhance their family quality of life and be included in their communities; and (d) assist them as they guide the member toward achievement of the nation's goals for people with disabilities, namely, equal opportunities, economic self-sufficiency, independent living, and full participation.

A. Criteria for and Methods of Collection

Literature for analysis was selected by (a) gathering relevant documents at DOD or Service sponsored events; (b) searching healthcare, social work, and special education databases with 20 different terms related to family support, Military Service, special education, and *case management*; (c) conducting ancestral searches by identifying documents of interest through reviewing bibliographies of relevant

documents; and (d) making contacts with knowledgeable professionals and requesting recommendations for key documents in the disciplines of healthcare, social work, and special education. See Appendix A for a reference list of documents reviewed. See Appendix B for specific information concerning number and types of documents reviewed.

B. Criteria for and Methods of Analysis

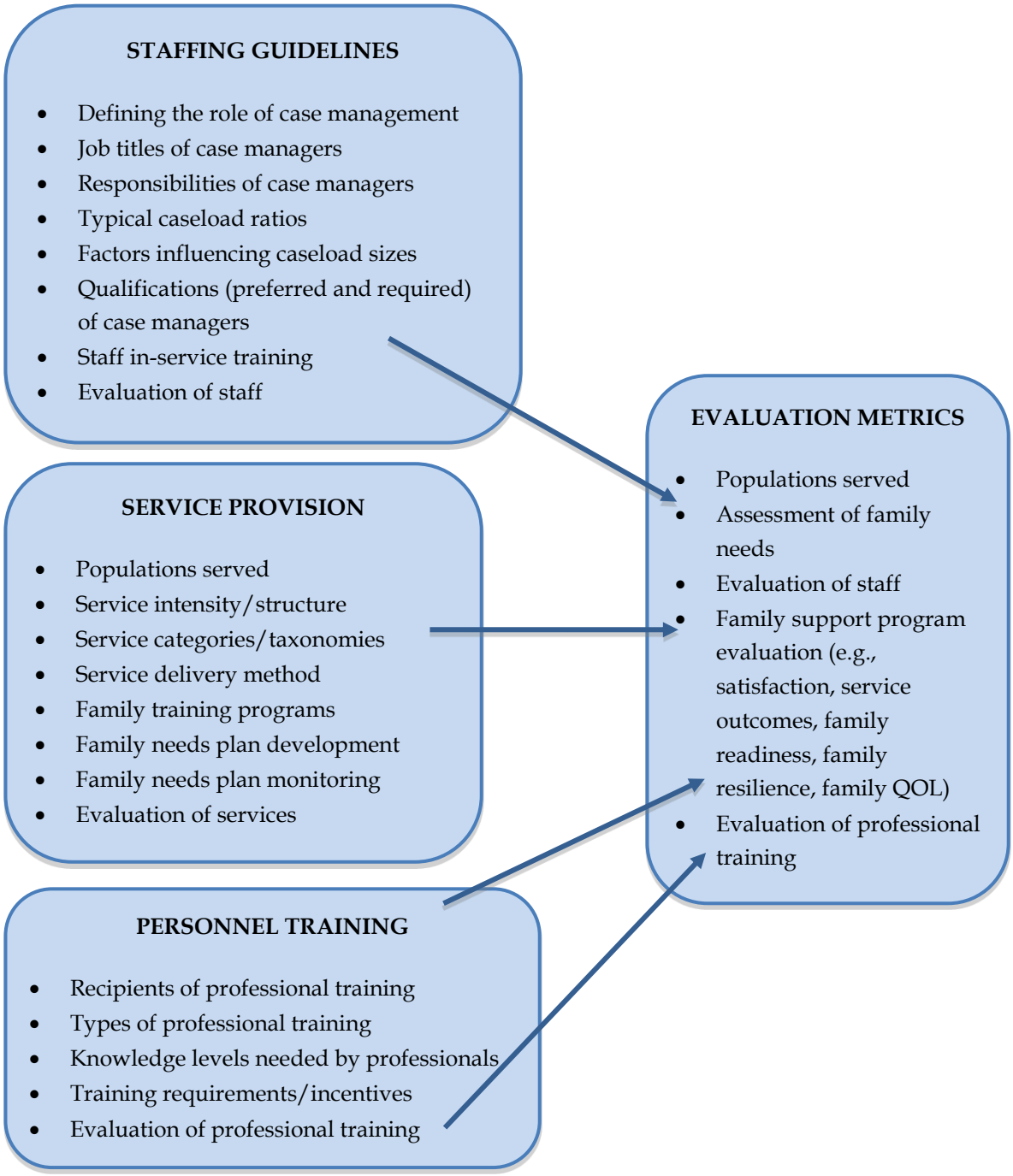
An analysis of documentary data was conducted. This involved coding each document for content relevant to four major categories identified in the conceptual map (see description below and Figure 1) with regard to development and implementation of family support programs. The documents reviewed were developed for multiple purposes unrelated to the Benchmark Study; therefore, it was highly unusual for any one document to address all areas of interest for inquiry. Appendix C includes definitions for the coding categories.

C. Conceptual Map

A Conceptual Map was developed as part of the literature review to inform and guide the analysis for the EFMP Benchmark Study (see Figure 1). The Conceptual Map emerged following an initial analysis of the literature on family support and *case management*. Through an iterative process of document analysis and categorization, the Conceptual Map was revised and the findings distilled into essential elements of family support programs, ensuring to include areas of specific concern or interest to the Office of Special Needs (OSN). Findings are organized according to the following four categories: (a) staffing guidelines, (b) service provision, (c) personnel training, and (d) evaluation metrics.

No single category was a silo; each category had at least one element that crossed over into another category. Wherever there was a crossover, an arrow was drawn in the Conceptual Map (see Figure 1) to connect the presence of the element across both categories in which it is represented and to indicate under which major category its findings will be presented.

Figure 1. EFMP Benchmark Study Conceptual Map



Staffing guidelines: Program staffing related to *case management*, program development, operation, and evaluation.
Service provision: Service provision related to service identification, delivery, and evaluation.
Personnel training: Personnel training related to recipients, scope, delivery and evaluation.
Evaluation metrics: Evaluation aspects of previous categories, in addition to populations served and family needs assessment.

II. Family Support Program Interview Methodology

Nine interviews were conducted: four Military Service branch family support EFMPs, four civilian family support programs, and one federal program. The following describes the sampling, data collection and analysis methods.

Civilian program sample. Established national leaders in the field of family support were contacted and asked to nominate family support programs that they considered to be top-tier and to provide the name and contact information of the program director. Top-tier was characterized as the top 10% of programs that would actualize at least a majority of the following elements: use evidence-based practices, have a systematic way of identifying and prioritizing family needs and priorities, implement partnership practices characterized by dignity and respect, individualize services and supports, assist families in navigating multiple service systems, assist families in connecting with informal supports, and document outcomes.

A rubric was developed to ensure greater diversity in selecting four programs to interview out of the group of programs nominated. The rubric included, but was not limited to: (a) type of program (e.g., Parent to Parent, University Centers for Excellence in Developmental Disabilities Education--UCEDD, Family Support 360 programs, Parent Training and Information Center), (b) state/local vs. federal focus, (c) the region served (e.g., national, state), (d) geographic focus (e.g., rural, urban), and (e) the population served (e.g., disability, military branch).

Military program sample. The headquarters staff of each branch family support EFMP was contacted and asked to nominate an installation EFMP for their service that exemplified excellent family support, based on criteria similar to those identified for civilian family support programs. The name and contact information was provided for the nominated installation program manager/director.

Participant contact. The nominated civilian and military family support program directors were contacted by email, followed up by a phone call, inviting them to participate in this study. All invited program directors consented to participate in the phone interviews and to have the interviews audio recorded. Interviews were conducted on a date and at a time identified as convenient for each interviewee.

Interview process. The Conceptual Map, iteratively developed as a result of the literature review (see Figure 1), served as a framework in creating the interview protocol (see Appendix D). Multiple researchers conducted the interviews, using the interview protocol, field notes, and audio recording to increase dependability. The interview questions were sent to each interviewee in advance of the interview.

Qualitative data collection and analysis. Audio recordings and detailed notes were taken for each interview. Following the interviews, recordings were reviewed and notes were enhanced, including direct quotes. The data was analyzed, using a qualitative data analysis

process that involved (a) managing raw data, (b) data reduction, and (c) interpretation/conclusion drawing. Important and salient data was sorted according to the topic under investigation. The data was organized and categorized while searching for emerging patterns, themes, and relationships

PART TWO: Literature Analysis and Interviews Combined Findings

The findings of the literature review and interviews with model family support programs are combined in order to give a full and rich report on the various elements of family support.[1] The combined findings are organized according to the four major categories of the conceptual map related to family support programs: (a) staffing guidelines, (b) service provision, (c) personnel training, and (d) evaluation (see Figure 1,). The categories and associated elements of the combined findings from the literature analysis and interviews are described below.

Staffing guidelines. Staffing guidelines encompassed the findings descriptive of *case management* (i.e., definitions, job titles, roles and responsibilities), caseload ratios and the factors influencing caseload sizes, and qualifications of *case managers*. Evaluation of staff is a crossover element whose findings will be presented in the evaluation metrics category. Staff in-service training is also a crossover and will be represented in the category of training for personnel.

Service provision. Service provision encompassed the findings descriptive of service intensity/structure, service categories, service delivery methods, family training programs, and family plan development and monitoring. The populations served and how the services are evaluated are crossover elements whose findings will be presented in the evaluation metrics category.

Training for personnel. Training for personnel encompassed the findings descriptive of the recipients of training, types of trainings offered or available to family support *case managers*, the knowledge levels needed by various professionals, and any incentives or requirements for training. Evaluation of professional training is a crossover element whose findings will be presented in the evaluation metrics category.

Evaluation metrics. Evaluation metrics encompassed the findings of the crossover elements previously mentioned (i.e., demographics of the populations served, evaluation of staff, evaluation of services, evaluation of professional training) as well as the element of family needs assessment.

I. Staffing Guidelines

Under *Staffing Guidelines*, content was identified as it related to the following elements in the Conceptual Map: (a) definition of *case management*, (b) job titles of *case managers* in family

[1] To increase readability of this chapter, all citations are omitted except those referencing a direct quote. References can be found in Appendices E and F.

support programs, (c) common responsibilities of *case managers*, (d) typical caseload ratios, (e) factors influencing caseload sizes, and (f) qualifications of *case managers*.

A. Definition of *Case Management*

Throughout this report, the term *case manager* is used to refer to the role of individuals designated to provide support to families with special needs family members. Comparable terms were used in both the literature and the interviews to refer to professionals who fulfill that role, such as service coordinator, care coordinator, and systems navigator. These terms are briefly discussed in the following paragraphs.

Literature was gathered on the topic of family support in early intervention as well as across the lifespan in the fields of developmental disabilities and healthcare. The terms and definitions used in the literature differed depending on the field from which they were derived. The disability field used the term *case management,* and the Centers for Medicaid and Medicare Services defined it as an activity that "assists individuals to gain access to needed care and services appropriate to the needs of an individual" (Cooper, 2006 as quoted in Research and Training Center for Community Living, 2008, p. 3).

The medical field used the term *care coordination* to refer to a "process of linking children with special health care needs and their families to needed resources and services to maximize a child's potential and optimize health care" (O'Neil, Ideishi, Nixon-Cave, & Kohrt, 2008, p. 120).

The early intervention field used the term *service coordination* and defined it as a process that includes "coordinating the provision of needed services, facilitating timely delivery of services, and continuously seeking services and supports for the benefit of the child and family" (MEDCOM-CSPD, 2010, p. 2). Service coordinators act as the "point of contact in helping parents obtain services and assistance they need".

All of these definitions have three common elements. These elements identify the primary responsibilities of a *case manager*: (a) assisting the individual or family to access and/or coordinate needed services or care, (b) linking the individual or family to resources, and (c) focusing on the outcomes for the individual or family.

B. Job Titles of *Case Managers* in Family Support Programs

Job titles, identified by interviewees, for those who functioned in role of *case manager* included the following: (a) Liaison, (b) Coordinator, (c) Navigator, (d) Outreach Specialist, and (e) Manager. Coordinator was the most common job title.

C. Common Responsibilities of *Case Managers*

The bulleted list below synthesizes the responsibilities of family support *case managers* as identified both in the literature and interviews.

- Working with a multi-disciplinary team
- Coordinating medical services
- Making contacts with individual and family
- Coordinating different types of supports and services
- Handling paperwork – completing necessary forms and tracking systems
- Integrating both medical care and long-term care supports and services for persons with disabilities
- Conducting intake interviews and collecting personal information
- Acting as an advocate (i.e., attending Individualized Education Program (IEP) meetings, assisting with communications with school or other service providers)
- Identifying family needs – conducting a family needs assessment
- Coordinating evaluations/assessments
- Coordinating family plan development
- Collecting, maintaining, and analyzing data for planning and reporting purposes
- Coordinating and monitoring family plan implementation
- Conducting marketing of the program's services
- Providing information and referral and connecting families with resources
- Evaluation of services and outcomes for families' quality assurance activities
- Providing intensive services to address any family support needs
- Collaborating with families
- Coordinating the transition plan (e.g., when a Service member transfers from one installation to another, when a family member with special needs moves from one service system to another)

D. Typical Caseload Ratios

Caseload ratios refer to the number of individuals or families to whom one staff member provides support at any one time. Literature on caseload ratios spanned the range of disability fields: early intervention, developmental disabilities, mental health, social work, and healthcare. See Appendix E for a table with detailed caseload ratio literature organized by field. The data from Appendix E is summarized below.

Early intervention caseloads tended to range from 9 to 70, averaging approximately 38. Early intervention *case managers* fulfill a service coordination role and may provide direct services as well.

Developmental disabilities caseloads commonly ranged from 30 to 99, with outliers of extremely heavy caseloads at 300 and 500. Depending on the level of service/support provided, the most common caseload ratio range was 1:30-39 individuals.

Mental health* and *social work caseloads were often much lighter due to the intensity of service needs of the individual being served. Caseloads typically ranged from 10 to 30, with intensive needs caseloads hovering around 10-12 and less intensive community mental health caseloads around 40-50. One outlier reported an unusually high caseload of 365 for a social work clinic model.

Healthcare caseloads seem to be more moderate, typically ranging from 20 to 50, with an outlier reporting acute inpatient intensive care setting caseloads at 1-2. Another way to conceive of caseload ratios data is to categorize the data into caseload weights (i.e., light, moderate, and heavy) using caseload numbers and intensity of service. Table 1 below displays this categorization of the data. Interviews with both model civilian and military family support programs revealed very similar numbers. As with the literature, caseload weight numbers ranged from light (serving 17 families per *case manager* per year) to heavy (serving over 300 families per *case manager* per year). Civilian family support programs tended to have lighter caseload ratios (17–82 families per *case manager*) than military family support programs (30–300 families per *case manager*). Similar to the literature findings in Table 1 regarding caseload weight and intensity of services provided, programs with lighter caseloads provided more intensive services, such as offering a "mentoring process" for the family and/or supporting the families by doing "whatever the family needs;" whereas, programs with heavier caseloads tended to offer solely information and referral services.

Caseload weight	**Service intensity**	**Caseload Size**	**Common fields**
Light	Intensive services and support – may include direct service provision	Less than 20	Mental Health Social Work Early Intervention
Moderate	Coordination of service programs with established oversight	20-50	Mental Health (community) Early Intervention Developmental Disabilities Healthcare
Heavy	Information and referral only – commonly for individuals with no direct paid services	50+ (up to 500)	Developmental Disabilities

Table 1. Categorization of Caseload Ratios by Weight.

Three civilian family support programs reported caseload ratios. Two of the three programs reported caseloads with a maximum of 20 per *case manager*. One civilian

family support program served significantly higher numbers, providing one-on-one assistance, with approximately 82 families per *case manager* per year. Similarly, another civilian program reported approximately 140 parents per *case manager*, with 8% accounting for military families. All civilian family support programs also reported providing training to hundreds of parents in addition to the one-on-one support reported in the caseload ratios.

Three military family support programs reported caseload ratios. Two of the three were EFMPs, each with caseloads ranging from 225 to over 300 families per *case manager*. The third military family support program reporting caseload ratios focused on serving injured Service members as well as their families. This program focused its efforts on meeting both medical and non-medical needs of the individual and family. Caseloads were 30-40 recovering Service members and their families per *case manager*.

E. Factors Influencing Caseload Sizes

Several factors influenced the caseload size maintained by a *case manager* or other service professional in a family support program. These factors include: (a) intensity of services provided; (b) frequency of contacts with the individual with a disability or family seeking support; (c) scope of responsibilities of the service professional; (d) fiscal limitations; (e) state or local policies governing caseload size; (f) weights of activities (e.g., time associated with completion of each activity) engaged in by the service professional; (g) interventions used; (h) "acuity of the Service member's medical condition and complexity of nonmedical needs" (DOD, 2008, p. 16); (i) program staffing numbers; (j) funding requirements for service to families; and (k) level of needs of the family.

The Case Management Society of America and the National Association of Social Workers (2008) determined that "large caseload sizes negatively impact the ability of *case managers* to assist patients and clients to achieve better outcomes" (p. 16). Similarly, King et al. (2004) addressed the impact of high caseloads saying that "as caseload increases, contacts become less frequent and approach to work becomes more reactive. … Not only is general *case manager* self-efficacy a function of caseload, it is clear that *case managers* report specific roles as being sensitive to caseload," (p. 15) such as responsiveness to client needs, contacts made, and advocacy.

F. Qualifications of *Case Managers*

Numerous qualifications of *case managers* were identified in both the literature and the interviews. There appeared to be no standard required or preferred qualifications among either military or civilian programs. The analysis identified multiple qualifications, including: (a) high school diploma with two-years of experience; (b) bachelor's degree in a human service/social service; (c) master's degree in a human service/social service field; (d) nurse licensure; (e) licensed

professional with experience in Applied Behavior Analysis supervision; (f) personal or professional experience with the military and/or families and family members with special needs; (g) a combination of education and experience, or a number of years of appropriate experience; (h) strong capacity to develop positive relationships with clients; (i) bilingual; (j) no conflicts of interest; and (k) familiarity with available health, developmental, behavioral, and family support services.

II. Service Provision

Under *Service Provision*, content was identified as it related to the following elements in the Conceptual Map: (a) service intensity/structure, (b) service categories, (d) service delivery methods, (e) family training programs, (f) family needs plan development, and (g) family needs plan monitoring.

A. Service Intensity/Structure

A complete list of services was compiled from the literature and interview data. The vast majority of services were professionally provided as formal supports; however, several interview respondents discussed the importance of informal supports and how their family support programs assisted families in accessing those supports. The literature that was analyzed and all but one civilian family support program indicated that family support services were *not* provided using a system of tiers of increasingly intensive interventions/support. Formal support services, however, covered a wide continuum of support intensity from information and referral (I & R) to a "whatever it takes" level of support. Family support programs providing *case management* operated "on a variety of levels with a range of intensity that was dependent upon the needs...and the preferences" of the families they served, resulting in wide variations in program designs.

I & R is a service in which the professional identifies the most appropriate services to meet a family's needs and then links the family to the agencies providing the needed services.

By contrast, a "whatever it takes" approach to family support included any level of service or intensity of support necessary to meet a family's needs in accessing needed medical, social, vocational, rehabilitative and other services. This type of service often includes developing a comprehensive individualized family service plan, ongoing monitoring of the family service plan, making initial contact with other resources on the family's behalf, scheduling appointments, and attending IEP meetings.

B. Service Categories

The complete list of services was analyzed using the ten categories of the Family Support Services Taxonomy (see Appendix F): (a) respite services; (b) financial support; (c) in-home support, education, and training; (d) assistive and medical technology; (e) health and related professional services; (f) family training/counseling; (g) transportation; (h) *case management*/service coordination; (i) recreation/leisure; and (i) other family support. I & R was the most commonly provided service and was present in each of the ten categories. See Appendix F for a table containing the specific services identified for each family support category.

C. Service Delivery Method

The methods of service delivery varied depending on where the particular family support program fell on the formal support service continuum. The most common service delivery method was in written form via listserv, online information, newsletters and e-newsletters, and email or phone consultation.

These services typically provided information and referral. Other, more "hands-on" support services delivery methods included systems navigation, workshops, one-on-one/face-to-face provider to family support, and peer-to peer support.
Parent and family-centered education/training warrants particular note. Workshops were, by far, the most common type of parent and family education/ training method. Family workshops were scheduled several times a year and covered many topics, including learning about available resources, disability and military policies, goal setting, teamwork, making informed decisions, futures planning, communicating health needs, peer support and relationships, self-management and care, social support and relationships, health care issues, infant care, public school education (e.g., Individuals with Disabilities Education Act/IDEA including early intervention, Section 504), parent/professional communication, negotiations and conflict resolution, Department of Defense Education Activity **(**DODEA) system overseas and within CONUS**.**

Other types of parent and family education/training were one-on-one information provision, including coaching, mentoring, and at-home support sessions for the family member with special needs and siblings.

D. Family Training Programs

Two primary themes emerged regarding family training programs (a) family-centered workshops and (b) trainings provided to families in their homes.

Workshops are discussed in the paragraph above. In-home trainings occurred throughout the year, and were provided one-on-one (typically by a *case manager*) to the entire family, including parents, individuals with a disability, and siblings.

One-on-one trainings covered various strategies and activities designed to help the family understand their family member's disability and how to best support their family member. One-on-one trainings also provided coaching, information, and encouragement to families.

E. Family Needs Plan Development

Typically, family needs plans were developed by local program staff, either face-to-face (e.g., in an office or family's home) or over the phone. Tools such as program-specific checklists, forms, or worksheets were commonly used as methods for gathering information about families to create individualized family plans that reflected the needs, priorities, and goals of the family. Family needs plans reflected the needs of both the individual with special needs and the family as a whole. Some programs even extended participation in family plan development to anyone involved in the family circle.

Program staff typically completed tools to facilitate conversations and plan development in collaboration with families. Some family support programs included tools in their program manual to assist *case managers* in learning more about how families operate and any resources or supports families need or already have in place. These tools also ensured that families received adequate support and assistance and developed feasible goals and action steps. Some programs did not have system-wide tools to facilitate family plan development; so individual *case managers* employed and/or developed tools they found useful for learning more about families.

Interviews and conversations provided additional methods for gaining information from families. While interviewing families about their needs, *case managers* frequently asked open-ended questions to uncover additional support needs that the family might not have initially identified. Interviews typically inquired about family needs related to healthcare, education, support groups, recreation, and housing. Interviews allowed program staff the opportunity to explain how other programs, organizations, and processes worked so that families gained a better understanding of various supports and services.

Some programs included family needs unrelated to disability (e.g., unemployment) on family plans. Two programs created plans only for the 10-20% of families that required intensive support to meet their needs. Such needs included geographic isolation, language barriers, need for respite care, or other "crisis" situations. Still other programs did not develop family plans for any families served, but rather responded to family requests for support on an incident-by-incident basis.

F. Family Needs Plan Monitoring

The program interviews and literature described multiple methods for monitoring family plans. Making contact with families was one method for monitoring family plans. For instance, *case managers* may have contacted a family following plan development anywhere from one to two times a month, to once a day, depending on the level of family need. *Case managers* may also have contacted families on a prescribed basis (such as at quarterly intervals) to review the family plan and determine if any changes were necessary. Another method for monitoring family plans included employing an evaluation team to fulfill several responsibilities, such as (a) checking that plans are complete and appropriate, (b) verifying that data were recorded, (c) ensuring that data reflected progress, and (d) adjusting plans based on data and/or family transitions. A final method for monitoring plans involved the use of written protocols.

III. Personnel Training

Under *Personnel Training*, content was identified as it related to the following elements in the Conceptual Map: (a) recipients of professional training, (b) types of professional training, (c) knowledge levels needed by professionals, and (d) training incentives/requirements.

A. Recipients of Professional Training

Recipients of professional training primarily included *case managers* in family support programs. However, the literature and interviews also indicated additional recipients of professional training, including: (a) medical professionals such as nurses and physicians, (b) parent-professional teams, (c) behavior analysts, (d) program managers and coordinators, and (e) counselors and social workers.

B. Types of Professional Training

"Professional training" was defined as additional ongoing professional development or training (in-service training) required by or provided by the family support program that was above and beyond the required and preferred qualifications for hire. Training of family support program *case managers* varied widely. Only three documents and interviewees addressed the length of the trainings, with duration varying from 2-12 days.

A combination of group and individual learning experiences was identified in the literature and interviews. The most common methods of training professional staff included providing initial orientation training and/or annual conferences to update or expand staff knowledge. Other formats of professional training included using: (a) installation workshops, (b) one-on-one training, (c) community of practice, (d) tiered system of training and technical assistance, (e) independent study course, and (f) a train-the-trainer model. Instructional activities identified included the use of video, case study, panel discussions, role-play, and modeling.

The literature and the interviews typically did not identify who conducted these trainings. However, among those that did specify, a national center with topic area expertise was the most commonly cited. Three interviewees identified a military organization or service level that was responsible for conducting trainings. Additionally, two of those also cited civilian sources of expertise in their local communities (i.e., state and local agencies, state university).

C. Knowledge Levels Needed by Professionals

The literature and program interviews revealed several elements of knowledge required for *case managers*, including knowledge of local community resources and knowledge about the nature and scope of services available within and across settings. In a related finding, program interviewees discussed the importance of keeping program personnel (e.g., coordinators, managers, case managers) stable because it enables newcomers in a community to "borrow" from the social capital of the program personnel who have developed collaborative social connections and networks over time based on trust and mutual reciprocity. Program interviews also indicated specific knowledge required for EFMP *case managers*, including: (a) knowledge of military structure and protocol; (b) knowledge of rules, regulations, and policies; (c) knowledge of program eligibility; (d) knowledge of funding sources for services; (e) knowledge of family-centered practice; and (f) interpersonal and problem solving skills. The literature also recommended that professional knowledge include an understanding of the development of children with special needs and team-building skills.

D. Training Requirements/Incentives

"Training requirements" were defined as compulsory professional training programs or activities. "Incentives" for training were defined as any form of encouragement offered by a program or agency to reinforce professionals who attend trainings.

The literature search and interviews revealed little about requirements or incentives for training. Program interviews revealed few incentives for required trainings, outside of stipends for travel, which one may consider a form of compensation, not an incentive.

IV. Evaluation Metrics

Under *Evaluation Metrics*, content was identified as it related to the following elements in the Conceptual Map: (a) populations served, (b) assessment of family need, (c) family support program evaluation, (d) evaluation of staff, and (e) evaluation of professional training.

A. Populations Served

The literature reviewed included programs that served such a diverse population of individuals with special needs (e.g., chronic illness, disabilities) and their families that it was not possible to succinctly describe the collective demographics. The diversity of individuals served spanned the continuum of: (a) age of individual with special needs (i.e., birth through adulthood), (b) socioeconomic status, (c) ethnicity, (d) types/categories of special needs, and (e) race.

Similarly, the military family support programs served an equally diverse population. The civilian family support programs had comparable population demographics except that several of the programs served only individuals with disabilities, aged birth through 22, and their families.

B. Family Need Assessment

"Assessment of family needs" was defined as specific instruments, methods, or techniques used to determine family need relative to family members' special needs. These included formal tools such as validated scales or questionnaires, or informal methods such interviews or observations.

Program interviews and the literature revealed three major areas regarding assessment of family needs. These areas were (a) assessing family needs using a variety of methods and tools, (b) assessing family needs for eligibility/placement, and (c) assessing family needs during transition.

Assessing family needs using a variety of methods and tools. Many methods for assessing family needs involved standardized instruments. Examples of these instruments included Routine-Based Interviews, the Modified Johnson Support Tool, and the Family Readiness Assessment Tool.

Non-standardized assessment techniques included: (a) formal and informal in-home assessments with individuals and their primary caregivers; (b) "family friendly information collection process" (U.S. Department of Health & Human Services, 2010, p.6); (c) a family needs matrix; (d) enrollment, intake, and evaluation forms; (e) questionnaires and assessments; (f) multidisciplinary evaluations by a professional; (g) phone calls to caregivers questioning caregiver well-being, concerns, and problems; (h) interviews or conversations in the family home or program office that may involve a series of open-ended questions directed to parents or the family member with special needs or the completion of an intake sheet developed by a program manager; and (i) family and caregiver self-reports.

Assessing family needs for eligibility/placement. Only one family support program interviewed assessed family needs to determine the eligibility and placement of individuals with disabilities into specific categories or tiers within a program. Intake

staff used tools such as decision trees to assess the intensity of family needs and determine in which tier to place families.

Assessing family needs during transition. Family support services personnel[2] used transition checklists to assess the needs of military families before they relocated to new installations. Such checklists included a list of possible needs (e.g., identifying new schools, finding new physicians, locating housing, and identifying support resources) that the family may experience at a new installation. Family support services personnel used this information to assist families and locate available resources at their new installation. Installation family support services personnel also sent transition information to family support services personnel at other installations to alert receiving installations of an incoming family's need.

C. Family Support Program Evaluation

Family support program evaluation included using instruments or techniques that assessed programs and services provided, including the impact of programs on the family or family member with special needs. These methods included formal (standardized surveys or scales) or informal (interviews or observations) instruments/methods, and measured a variety of outcomes (e.g., family satisfaction, quality of life, stress, and depression).

Furthermore, program evaluations used a variety of methods to determine outcomes, such as pre- and post-tests or weekly/quarterly/annual follow-ups. They also included family, professional, and/or staff input.

Program interviews and the literature revealed many methods for evaluating family support programs. The major methods of program evaluation were sorted into two categories: (a) informal and (b) formal evaluations.

***Informal evaluations*.** Informal and non-standardized program assessment tools included (a) author-created surveys, scales, and checklists; (b) parent input, parent and staff satisfaction tools, staff focus groups; (c) interviews or focus groups with families; (d) administrative data; (e) quarterly "town hall" meetings with families and the garrison staff; (f) monthly reports from program liaisons; and (g) using specific criteria/outcomes to determine the effectiveness of a program.

***Formal evaluations*.** Standardized assessment tools included the Medical Home Family Index, the Caregiver Strain Index, the Family Empowerment Scale and the Family-Centered Behavior Scale, the Family Readiness Assessment Tool, and the Modified Johnson Support Tool. Examples of formal tools given to individuals who required healthcare support or services included the Consumer

[2] The specific term "family support services personnel" is used here rather than the generic term "*case managers*" as this paragraph reflects responses from military family support program respondents only.

Assessment of Health Plans and Systems, the Patient Assessment of Chronic Illness Care, and the Primary Care Assessment Survey. Examples of formal tools administered to program staff included the Stages of Concern Questionnaire and the Service Coordination Scale.

D. Staff Evaluation

Evaluation of staff included any instrument, method, or technique used to assess staff performance. In this section, interview findings are reported first, followed by findings from the literature review.

Several methods were used to assess staff performance such as tracking staff contacts and using evaluation forms, and checklists. This included analyzing quarterly reports that examined how many appointments staff made per month, number of walk-ins they processed, how many IEPs they participated in, and the number of contacts they made. Additionally, program managers worked directly with program staff to monitor caseloads and staff performance. Program certification after training was another method identified in the interviews for evaluating staff. One program required staff to become certified through a process, which included a pre- and post-test, a full training program, and demonstration of competency by producing and completing an action plan to gain certification.

The analysis of the literature also identified a variety of staff evaluation methods, including direct observation by a superior staff member, fidelity checklists, and quality assurance calls. The literature also noted a number of formal methods for evaluating staff performance.

E. Professional Training Evaluation

Evaluation of trainings included any instrument, method, or technique used to assess trainings (e.g., professional development, workshops, or staff training). Post-training evaluations developed by specific programs were often used to assess the quality of trainings and improve future trainings. For instance, one document described a post-survey used to determine if training participants perceived workshops as useful.

3. FAMILY NEEDS ASSESSMENT

This chapter of the report discusses the findings from the family needs assessment. Cornell University project staff conducted a targeted needs assessment using a combination of key informant interviews and focus groups with Service members, family members and EFMP family support services personnel between April and October 2011. This needs assessment overlapped with the infusion of additional funds allocated to each Military Service to expand their family center support. Information from this study's target audiences reflects some of the evolving changes as the Military Services have expanded family support services by augmenting existing programs with additional personnel, increasing resources and technology or initiating new family support services personnel

There have been numerous surveys, interview and focus group reports, and multiple government reports[3] outlining the challenges and issues that led up to the NDAA 2010 legislation. This report confirms many of the previously identified concerns and emphasizes some of the same recommendations for improvement. While there have been many positive changes as a result of additional funding and focus on the families enrolled in the EFMP, these studies form a compelling argument for continued efforts for change.

PART ONE: Evaluation Scope

The Benchmark Study's needs assessment was designed to gather information about the 2010-11 comprehensiveness of the military EFMP services that support Service members (Soldiers, Sailors, Marines, or Airmen) and their family members with special needs.

This needs assessment:

- Identified the needs of those military families with special needs members as well as how current policies, programming options and best practices are addressing those needs;
- Identified the challenges that military families with special needs members face;
- Identified any gaps or inconsistencies in EFMP services;

[3] The Military Family Needs Assessment: Final Report 2010; The National Leadership Summit on Military Families 2010; The DOD 2011 Report to Congress; 4-NDAA-586 Report to Congress, 9.27.2011, Enhancing Benefits Available for Military Dependent Children with Special Education Needs; the Military Child Education Coalition Report Phases I and II (2005 and 2009); the Army Exceptional Family Member Program Focus Group Report (2010), March 2007 GAO -7-317A- DOD Exceptional Family Member Program; NCD (USMC) How to Improve Access to Health Care, Special Education and Long-term Supports and Services for Family Members with Disabilities; Education Services for Military Dependent Children with Autism (2011), The Ohio State University. Although conducted independently of each other and with different subpopulations within the military community, all of these reports have outlined similar issues.

- Gathered EFMP family support service provider perspectives on the successes and challenges in providing services to families with special needs in the EFMP.

I. Study Limitations

This study was designed to collect a qualitative sample from EFMP family support services personnel, other military and civilian service providers, and Service members and family members in each Military Service. With eight sites, two per Service, this report cannot be considered fully representative of the total population nor can it detail every issue facing military families with members who have special needs. It does, however, present an in depth snapshot of the major themes that were identified across all sites and was remarkably consistent in terms of the issues across the Services. The sites chosen were identified by the EFMP family support headquarters staff for each Military Service as being locations where many families with special needs were assigned because of proximity to multiple resources and services, particularly medical services. This selection of sites was efficient for providing a large pool of participants but did tend to focus on those families with the most challenging medical, educational and behavioral issues. Additionally, variations among the selected sites, in terms of the infrastructure, organization and longevity of each EFMP family support program; differences in number of staff, their years of experience and range of responsibilities along with the uniqueness of family situations provided a broad range of perspectives. However, even with this variability, the information from this study is remarkably consistent with information gathered from the other studies referenced as well as from the policy review conducted by the University of Kansas.

Service providers, Service members and family members were asked to volunteer for interviews or focus groups. For most site visits, all available EFMP family support services personnel at a location were interviewed so there was little selection bias. For Service members and family members there was the possibility of some selection bias as those who volunteered tended to be those already involved with the local EFMP staff that extended the invitation and were more likely to be participants whose family members had the most complex medical and educational needs. In this sample, the majority of the Service member and family member participants were older, more likely but not exclusively midgrade and above in pay grade and had often been associated with the EFMP for several years. Approximately one quarter of the respondents focused on the needs of adult family members with the vast majority relating experiences with finding support for children and youth with special needs.

II. Methodology

As part of the research protocol, permission to contact human subjects was requested and received from the Department of Defense and Cornell University's Institutional Review Boards (IRB). All Cornell staff conducting the interviews and focus groups for the needs assessment and subsequent analysis of data were trained in human subjects' research protocols through the Collaborative Institutional Training Initiative (CITI). At each site, the

study team reviewed the steps to be taken to mitigate any potential risks to human subjects, including any related to a) recruitment, b) sharing of personal information, beliefs, and opinions in a group setting, c) storage of data and personal information, opinions, and beliefs, and d) reporting of family needs and preferences for assistance.

III. Recruitment of Subjects and Subject Description

The logistics for each site visit was coordinated through the DOD Office of Community Support for Military Families with Special Needs, the EFMP family support headquarters staff of each Service, and the installation chain of command including both the EFMP family support services personnel and staff at the medical treatment facility. Once approval of the sites by each Service was confirmed, the Cornell team provided the protocols to the local installation POCs (point of contact) for the focus groups and interviews and sampling plan options. *(See Appendix G for additional details on the protocol format, informed consent process and sampling plan options and questionnaire topics).* The study team worked directly with the installation level intermediaries to arrange conference calls in which the local POC and Cornell staff discussed the project, and the purpose of soliciting the input of Service members, family members, and EFMP family services support personnel.

Local installation, base, and station contacts then proceeded to recruit Service members, family members, EFMP family support services personnel and other service providers to explain the purpose of the study and provide information about informed consent and the voluntary nature of their participation. Installation level POCs arranged times and provided meeting places for the interviews and focus groups and notified the Service point of contact (POC) and Cornell staff of the schedule and number of participants to expect. Arrangements were made individually as needed, if child care, interpreters, or other assistance was required. Service members and family members represented in this study had spouses, children and/or other family members with a variety of special needs that included physical, developmental, mental health, and medical needs over a wide spectrum of diseases and conditions such as but not limited to autism, hearing loss, depression, speech /educational/developmental challenges, cerebral palsy, cancer, and chronic medical conditions such as asthma, sickle cell anemia and diabetes. Some family members were or had been EFMP clients themselves and also had children in the program. A few of the EFMP family support services personnel were also current adult EFMP clients. In some locations, participants also included active duty Service members who had a command assignment with responsibility for EFMP within their unit.

As a group, the participants in the needs assessment had significant experience in navigating the various military and civilian school, state and federal systems. Their experiences made them valuable sources of information because their historical perspective enabled them to talk about how much things had changed. Although the Benchmark Study team only visited eight sites, many of the participants had lived and worked at many other locations in each Military Service and were able to compare and contrast both current and

historical resources and services. Along with the Service members and family members, family support services personnel and other service providers were equally forthcoming on differences from one location to the next and changes over time.

IV. Interview and Focus Group Protocol

The research team used a semi-structured questionnaire based on Cornell's prior work with military families with special needs, a literature search on existing reports and focus group studies, as well as consultation with the University of Kansas research team who had researched family needs in the civilian population. This process was intended to minimize site to site variations but also allow for any additional concerns and issues presented by the respondents. The questions were designed to cover the following topics:

- knowledge and awareness of the EFMP enrollment and recertification process,
- the availability and usefulness of military and civilian medical and educational programs,
- school enrollment and the IEP process,
- respite care,
- medical and behavioral health services,
- relocations and Permanent Change of Station (PCS) assignment procedures,
- child and youth services (CYS),
- housing accommodations, and
- case management, including coordination of resources.

V. Interview/ Focus Group Process

After welcoming the group with brief introductions and prior to any discussion, the purpose of the meeting and its voluntary nature was explained. Due to the group setting, participants were also asked to respect the privacy of others and keep other participant comments in confidence. The Cornell facilitators offered their contact information so participants could provide information privately that they did not wish to discuss in the group. Participants were also encouraged to ask any other questions about the interview/focus group process and raise any issue or concern they deemed appropriate.

Individual interviews were arranged to accommodate schedule conflicts and for those who wanted to speak in private. Every attempt was made to include as many participants as possible including offering early morning and evening hours, and when requested, onsite child care arrangements provided by approved installation staff. With three to four Cornell team members at each visit, concurrent groups and individual interviews were often held. In-briefs and out-briefs were conducted with each command and/or program director as requested. (See Appendix G, page 92).

VI. Data Collection, Analysis and Storage

Data collection for this qualitative study was documented with detailed written notes of the focus group sessions and individual interviews (i.e., interview location, date, number of

participants and basic de-identified demographics, the team's observations of the process as well as quotations, key phrases and major points made by participants) Team members met to debrief after each site visit. One team member compiled the data and then summarized for each Military Service. These documents were then reviewed by the whole team to identify recurring cross cutting themes which are highlighted in the findings section of the report. All documented notes and interim summaries were typed and stored in a password-protected format on computers in a locked location under the sole control of the study team. Only the installation name, participant description [family member (FM), Service member (SM) and service provider (SP)], and date of the contact was included to identify the data source. Information revealed during the focus groups or interviews such as the nature of a family member's disability, the family history of moves, and their utilization of services at various locations was noted without reference to identifying demographics such as site location, pay grade, or family status.

VII. Privacy and Confidentiality

This report does not refer to any of the visited sites by name in order to ensure confidentiality. Quotations used to illustrate examples are provided without attribution other than to identify the source and provide the context of the quotation. Sessions were not audio taped; written notes were taken by designated members of the team and then summarized for the final report. Interviewees and focus group participants were asked not to provide names but only to identify whether they were Service members, family members or family support personnel.

Descriptions of family circumstances that occurred in the conversations which were extraordinary, such as an extremely large family or a unique low incidence diagnosis are omitted or referred to in the report as "exceptional" or "other than typical" circumstances.

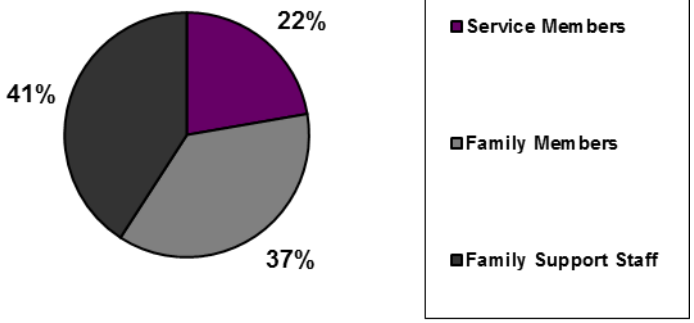
VIII. Interview and Focus Group Participants

The total number of participants in this study was 301.

- Service members = 67 (22% of total)
- Family members = 111 (37% of total)
- Family support staff = 123 (41% of total)*

*Family support staff who were EFMP clients themselves were counted in the staff group.

Active Duty Service members and family members were from the Army, Navy, Marine Corps, Air Force, and Coast Guard



The **Family Support Staff** participants include:

Military and Civilian Service Providers/Staff
Professionals in both the military and civilian communities were invited by the installation POC to participate in order to gather information about protocols, policies, and practices associated with their duties in helping families caring for individuals with disabilities navigate the military and civilian support systems. These service personnel also offered recommendations about additional services or organizational changes to existing services needed to better support families. Their subject matter expertise and local perspective enabled the research team to place the individual family experiences within the context of the local communities. Below are several groupings of service personnel/staff who participated in the study.

Family Center and other Military Representatives: OSD Program Staff / Regional Managers or Representatives / Command Representatives / Family Program Directors or Representatives / EFMP Program Managers / EFMP Family Support Services Personnel, System Navigators or Liaisons / School Liaison Officers / Respite Care Coordinators / Outreach Specialists / Child and Youth Services Providers / Family Advocacy Program Managers / New Parent Support Home Visitors / Military Family Life Consultants

Medical and Behavioral Health Personnel: Hospital or Clinic Chiefs/ Pediatric Case Managers and Certified Nurse Case Managers /Primary Care Physician Specialists / Developmental Pediatricians / Pediatric or Resident Fellows / Behavioral Health Representatives / Early Intervention Specialists / Administrative Technicians / Speech Pathologists/Pediatric Physical and Occupational Therapists

Civilian Community Professionals: School Psychologists / School Counselors / Principals / Maternal Child Health Community Providers / Division of Developmental Disabilities Providers (State Dept. Social and Health Services) / STOMP (Specialized Training for Military Parents) and PAVE (Partners for Action, Voices for Empowerment)

PART TWO: Findings

Needs and Support

The following sections summarize the most commonly reported needs, successes, and continuing challenges identified by the study participants. While many topics were discussed, these are the ones that were the most consistently reported across all Military Services and were the highest priority for this sample of Service members, family members and family support personnel.

I. Information

A. Needs

Families reported that they needed accurate, consistent and time sensitive information as well as support in interpreting, coordinating and prioritizing multiple streams of

information. This information should be provided in a variety of ways (electronic; print; media, personal contact).

Families need information on:

- eligibility and enrollment requirements,
- available family support services,
- medical and health related services,
- educational resources and services,
- state and federal system requirements and available resources,
- local community/installation resources (formal and informal).

B. Current Support

DOD and the different Service EFMPs have partially addressed this need by standardizing some forms. Service specific information is also increasingly being provided online. Most importantly, the recent addition of EFMP family support services personnel is addressing the interpretation, communication, and coordination issues.

A single POC, on-going collaboration among professionals, and timely communication is essential. (SM commenting on need for coordination among family support services personnel and medical case managers)

We are totally dependent upon the EFMP program and on the good folks (staff) here. ***(FM expressing gratitude for emotional support as well as connection to services)***

I am a single special needs parent who is entirely dependent on EFMP information for the resources, the insurance, and the TRICARE coordinator. If I had to research resources as a civilian, I do not think I would have made it. I am dependent upon the resources in this area. ***(SM commenting on how many resources are available through the military)***

My children, upon diagnosis, were able to get all the services they needed… they have made tremendous progress. ***(FM commenting on result of getting connected to services)***

When we got diagnosed, it was the hardest thing to navigate the system. We shouldn't have to dig for everything. (FM commenting on how hard it is to sort through information)

II. Advocacy

A. Needs

Families need advocates as well as help learning how to be their own advocates. Most of the families who participated were clear that they had the primary responsibility to

advocate for themselves and their own family members, but they also explained that they needed assistance learning how to do this more effectively. This was especially true for those families needing to enroll and access services for the first time or when finding resources and services because of relocation and school transitions. More experienced family members also endorsed the need for advocacy support since their perception is that the system requirements and guidelines are constantly changing. Both EFMP medical case managers and family support services personnel were frequently mentioned as "*making things happen.*"

B. Current Support

Families have noticed and appreciate the current EFMP support in the form of increased funding and new positions in all four Services for this advocacy role. Families described their need for individualized and personal contact to learn about EFMP and view the additional family support services personnel as fulfilling that need. This personal touch is viewed as a key strategy to motivate families to enroll in EFMP and is required to fully assess the needs, priorities, and services for each family situation. Many participants related how a medical case manager or family support services personnel provided both effective and empathic help. The family support services personnel also reiterated that this was one of their primary roles and that families viewed this as an effective way to help reduce their stress.

Families need to have an advocate in order to learn how to be an advocate. (FM commenting on the way to build EFMP family strength)

Advocates make things happen. (FM commenting on how having an advocate helps them get connected to services)

You have to learn to be the advocate for your child/spouse/family member and you don't know what you don't know. (Experienced SM commenting on the importance of outreach to new and young EFMP families)

III. Access to Specialized Treatment and Intervention Services

A. Need

Many families with special needs require access to highly specialized medical, therapeutic, and educational services. This need for availability and access is critical for all families, but especially for those with the most medically fragile members or with individuals with significant behavioral and developmental disabilities. Respondents told the study team that at the larger military installations with major medical centers in more urban environments, both civilian and military specialized

medical care was rated as good to excellent, although actual availability due to scheduling difficulties and waiting list restrictions was increasingly a problem. On the other hand, at the smaller locations with fewer specialized medical resources, lower case loads sometimes made available care easier to access because there were many fewer individuals with similar needs.

B. Current Support

Each Military Service:

- identifies specific locations where families are able to have their needs met due to the existence of major military medical facilities and equivalent civilian hospitals and clinics,
- makes a valiant effort to locate those families with high intensity special needs in or close to highly resourced locations, and
- has developed policies and guidelines on assignment to provide as much stabilization as possible to assure high quality continuity of care.

> ***EFMP has been good to me. I've had good results. I feel hugely blessed by the care my son has received from his military doctors. We have had a direct line to medical care and I fear getting out of military care.*** **(SM who is a single mom)**

IV. Consistent Guidelines for Access to Services and for Reimbursement

A. Need

Relevant to their access to medical services and other specialized treatment intervention, families want more consistent guidelines for reimbursement across the TRICARE regions, across the different locations within each Military Service, and especially at joint bases where different Services appear to provide different levels of services.

B. Current Support

This is a complicated problem with some changes out of the control of the Department of Defense but families report that current support from the expanded EFMP family support services personnel has helped them better understand what the military can and cannot do and also how to address some of these inconsistencies.

V. Respite Care

A. Need

Families need respite care and access to child care for a variety of reasons:

- medical and educational appointments,
- additional support while the Service member is deployed,
- compassionate stress relief for primary caregivers, and
- opportunities for socialization and inclusion of children and youth in the life of the community

B. Current Support

Expanded EFMP family support program funding has increased both availability of respite hours in each Service as well as expanded flexibility in how respite care can be used. Although specific respite care options have previously been available through the TRICARE Extended Care Health Option (ECHO) and ECHO Home Health Care (EHHC) programs, these new resources are greatly appreciated and highly utilized.

These additional funds provide options to augment existing respite resources. Family support service personnel, Service members, and family members agree that the new respite care support is the "most useful" additional service for eligible families. Several of the families who were using respite care also wanted to go on record as saying that all families with special needs members get stressed regardless of the severity of the disability and that some level of respite care should be available for everyone with family members with special needs.

There is a huge need for respite care. Respite care is important for all EFMP families and all five categories should be able to qualify. (FM commenting on the necessity of relief to those with family members having special needs)

Respite care has been a huge relief for our family. (FM)

Respite care through the NACRA program was a Godsend. (FM)

The Respite care assessment process was very smooth and the number of hours we received was very generous. (FM)

VI. Child Care and CYS Resources

A. Need

Where child and youth services have been able to provide specialized support, they have worked well for families that have been able to gain access to these programs. However, not all of these programs are staffed to accommodate a full range of medical or behavioral needs.

B. Current Support

When child and youth services have been unable to provide specialized support, EFMP family support has advocated on behalf of families with children who have special needs and helped families identify alternative resources.

VII. Educational and School Support

A. Need:

- support in identifying and understanding local, state, and federal education regulations and requirements,
- assistance to connect with appropriate schools and educational therapy services,
- support in preparing for and attending IEP meetings,
- realistic expectations about what can and cannot be done with IEPs particularly when moving between different states and school districts, and
- access to free or inexpensive legal assistance to secure the necessary accommodations in those cases where conflicts occur.

This information and tangible support is especially important for those with newly enrolled family members entering into the school system.

B. Current Support

Current support with the recent addition of family support services personnel in the EFMPs as well as the increased support of the military school liaison officers is highly valued by families.

> ***Military wives talk purple; sharing on listserves what is the best in the area. (FM commenting on their bond with other EFMP families sharing information about the best schools for children with special needs in their area)***
>
> ***Whenever we PCS we prefer to live on base because the schools are better on post than off post. (FM)***
>
> ***The system navigator taught me how to be an advocate for my daughter's school needs and not be intimidated by the school. (FM)***

VIII. Command Support

A. Need

Families need command support if they are going to manage the challenge of providing for the needs of their family members while fulfilling their military mission. A supportive, knowledgeable command, especially at the unit level, was regarded as a major positive influence. Family members and Service members said that these command representatives often provided additional referral points of

contact and were often helpful in facilitating informal connections between other EFMP families within the unit.

B. Current Support

All of the Military Services provide command EFMP briefings pursuant to their own regulations and DOD instructions. The recent addition of the new EFMP family support services personnel appears to have increased the frequency and comprehensiveness of these educational briefings. Additionally, some but not all Services have assigned specific active duty command POCs, usually as collateral duty.

Increased emphasis throughout DOD on families with special needs and the expanded role of family support personnel in EFMP was noted by many participants. Service members and family members reported that this change has made it somewhat easier for families to come forward to access services and feel less isolated. Study participants also indicated that the stigma of being a family with special needs is on the decline because of the proactive recruitment of families for the program through effective marketing. This new marketing focus has also made command much more aware of the issues. Several command representatives who participated in the focus groups and interviews said while they were always aware of the EFMP program, the new emphasis gave it a much higher priority.

> ***Command has to be on board to support EFMP families. (SM commenting on having, then not having good command support)***
>
> ***In the best cases, a well-informed and sensitive command makes all the difference. (SM commenting on being a Service member with a supportive commander in the unit)***
>
> My command allowed me to go home, when needed, to care for my family when my wife was hospitalized. (SM with a spouse with special needs)

IX. Continuity of Care

A. Need

Families need continuity of care for their family members given the many transitions they experience throughout their military careers. For military families with special needs, the frequency of relocations as well as combat deployments and other family separations due to Military Service become especially challenging. Maintaining continuity of care is difficult whether the transition is the birth or new diagnosis of a child with a disability; the onset of a chronic or acute illness in a child or adult family member; children aging out of the educational system into adulthood, or the family transitioning out of the military to the civilian world. For families about to transition

out of the Service there were also many concerns raised about losing military benefits and services that families felt would not be available in the civilian communities.

B. Current Support

DoD and EFMP policies that support various stabilization arrangements and compassionate reassignments for active duty families are viewed as very helpful. The EFMP family support services personnel are also viewed as playing a primary role in coordinating PCS moves between reassignments. One innovative example of current support was a transition care clinic established within the medical center to provide coordination and outreach for young adult family members with disabilities as they aged out of the school system.

The problems going to new state agencies were very difficult. It's a service resource morass here.

(FM talking about relocating to a state with many more resources and finding it hard to figure out which ones to approach and taking 8 months to find the right services.)

You have to repeat your story over and over again. I should just make a tape and play it. Why do we have to reinvent the wheel? I have to "gold mine" for resources and information. (FM talking about what happens every time they move and how they have to keep redoing everything every time.)

When a Service member detaches or retires, the services for the EFM should not be severed, especially the services for children. Some children will require special needs and assisted living for their entire life. (SM and FM approaching retirement and speaking about their child with significant special needs).

We waited 2 years to see a development pediatrician after relocating. There are not enough doctors to do the diagnoses. (FM commenting on how hard it is to get into to see the doctors who are the gatekeepers for entry to many services.)

For those Service members and families who have served, benefits should continue for as long as needed. Provide Service members and their families with a continuation of TRICARE and ECHO benefits upon the sponsor's retirement. (SM and FM speaking about their child's lifetime needs)

X. Streamlined and Transparent Enrollment Process

A. Need

Families want a transparent, standardized, and streamlined documentation process for enrollment. Depending on where and when the family with a child or adult with special needs enrolls in the EFMP can influence what information they get about what is available and how quickly they can become eligible for services. At least initially, many families need a lot of support to get through the enrollment process.

B. Current Support

The currently expanded family support services personnel are viewed as supporting families by assisting them with the intricacies of the enrollment and recertification process.

Streamline the enrollment forms. (From several experienced FMs and SMs)

The paperwork is cumbersome. (SP commenting on two packets for special education and 13 pages for the pediatrician)

Walking families through the enrollment process "step-by-step" and conferencing between all parties, especially during the initial enrollment and soon thereafter is really helpful and 'Tele-medicine' conferencing between the family and the primary care physician/pediatrician works well. (SM speaking about needing help with TRICARE)

The enrollment process needs to be managed in a timely and consistent manner. (SM speaking about lost enrollment forms, the need for transparency, and the time it takes to process the application)

XI. Support in Assignment Coordination and Enrollment

A. Need

Families want access to personnel involvement in the assignment process so that information unique to the family situation can be included in the decision process. In addition to the EFMP identifier, personnel officers and others who make the assignments need to know about the specifics of the family member who has special needs. According to the respondents in this sample, ideally the assignment officer could then match the needs of the exceptional family member with what is available before sending the family to the next location. The families pointed out that the family's responsibility is to check to be sure that the services are actually available and accessible at the proposed location. To do this most effectively, families need assistance to prepare for this, as well as the opportunity to be part of the decision process to provide additional relevant information for better informed assignments.

B. Current Support for Assignment Coordination and Enrollment

The currently expanded family support services personnel in each Military Service are viewed as supporting families by facilitating more effective coordination related to assignment.

Challenges

I. Maintaining Continuity of Care

There are many challenges facing military families with special needs, but clearly the greatest is maintaining continuity of care throughout the many transitions that are routine for military families. These transitions starting with the inherently mobile nature of military life also include the normal developmental transitions all children and youth face, especially transitioning into adulthood, unexpected changes in the nature and severity of various medical and developmental problems for both adults and children and finally transitioning from military life back to civilian life. Even the most proactive Service members and family members who receive timely support during transitions encounter continuity of care issues that must be continually addressed. These include:

- Finding new health care providers,
- Securing appropriate housing,
- Changing TRICARE regions,
- Enrolling in state and district educational services,
- Finding new respite care providers,
- Reestablishing informal support groups,
- Negotiating different enrollment, eligibility, and financial reimbursement requirements for federal, state, and local community services,
- Finding appropriate continuity of care from childhood to adolescence and young adulthood and
- Transitioning to civilian life upon retirement/separation from Service.

II. Early Intervention Services (EIS) Boosts Continuity of Care

One excellent example of how to maintain continuity of care was mentioned by both EFMP family support service personnel and several participants. Both groups described how helpful the early intervention services (EIS), which are part of the Individuals with Disabilities Education Act (IDEA), are for working with young children and also helping in the transition to school and other services. For families with children with special needs who get an early diagnosis, EIS seems to make a big difference in continuity of services with more efficient enrollment and was cited as a model for working with families.

III. Continuity of Care and the Coordinated Assignment Process

Military Service members are expected to be mobile. In addition to relocating between locations as needed for mission requirements and to continue to advance their military career, they also need flexibility to work longer hours at times of higher operations tempo in the same location. This is in stark contrast to the critical need for some families with special needs members to be stabilized in order to maintain a consistent routine and continuity of treatment and support services. The frequency of both routine and unexpected transitions and relocations become especially problematic for those military families enrolled in the

EFMP. Balancing the needs of the entire family with the needs of the military is complicated given the limited places some families can be stationed and still receive appropriate services. Aligning everyone's expectations with the reality of these complex situations is very labor intensive and can be challenging for the military, the family and the Military Service providers.

For families with members who have special needs, the ability to set up at least some services prior to moving is critical. While some services and resources can be arranged in advance, depending on the location, others may require a physical presence or proof of residency in order to begin the process. Although this may not always be the case, there were enough examples provided to suggest this is an ongoing struggle. The whole point, as one participant said, of using the PCS coordination services in the EFMP "*is to get things organized before we arrive*". One family member's comment emphasized the attitude of others: "*Every time you change station, if you were on a wait list for resources, you now have to start all over again*". This is especially problematic if the resources in the new geographic area are limited and families have to drive long distances for appointments.

Depending on the assignment location, families have to navigate through the TRICARE region, state agencies, and local school districts, arrange for prescription transfers and new medical providers, and secure placement on housing and respite care waiting lists. Some of these requirements are installation specific such as housing assignments while others are dictated by state and federal guidelines. School assessment meetings for appropriate educational placement are further complicated by the timing of most military family moves which take place during the summer months when many school staff and IEP committee members are not available to complete new assessments and assign special services.

Understanding and negotiating the varying eligibility and enrollment requirements for services for children and youth with special needs is another challenge for military families as they move around the globe. Every time any military family relocates, they have to find appropriate housing, enroll in new schools, find medical services and locate a wide array of military and community services. This would be challenging enough without the additional burden of finding and connecting to the extensive services frequently required for a family member with special needs. Additionally, all of these "usual" changes typically require completing new paperwork. For a family enrolled in the EFMP, paper work is extensive and according to the families, highly redundant. Although EFMP enrollment requirements within the Military Services are more standardized, among civilian providers there appear to be different EFMP identifiers for similar conditions as well as different interpretations depending on the provider or agency. Since both the EFMP identifier and its interpretation governs the eligibility and reimbursement rates for services, when there are discrepancies from agency to agency and location to location, families are understandably confused and frustrated.

Outside the military system, medical, state, and federal eligibility requirements, reimbursement schedules and waiting list guidelines also vary widely across states and regions. Depending on state budgets, resources for special needs are markedly different. Some communities have larger and more specialized medical facilities, and not all schools are in resource-rich districts. The size and budget of the school district often constrains how Individualized Education Programs (IEP) are formulated and executed. School budgets and public resources may also impact the availability of licensed speech, occupational and physical therapists. This variability is not only a function of what resources are actually at the location, but also a function of how eligibility is interpreted by the different providers — sometimes within the same organization — depending on their professional responsibilities and organizational guidelines. As many families pointed out, there are no guarantees that the quality and level of care the family may have had in the current location will be matched in the new location.

Other transitions that challenge families with special needs are those that result from a child aging out of school programs and transitions into adulthood. Another challenge that families encounter is when the family leaves Military Service and returns to the civilian sector. At the very least, the transition commonly results in changes in benefits which sometimes mean a loss in coverage for care and services that continue to be needed. Similarly when the family separates from the military many needed health care benefits are lost. This not only affects children and youth, but adults with special needs can also find themselves without coverage for services or care that was provided by military benefits. Many Service members and family members nearing the end of their military career voiced concern about how to continue needed care and services for their family when they left the military.

Stabilization is a huge concern. (SM and FM commenting on stabilization helping to ease the burden on their family)

Family should be moved when their needs cannot be met. (SP commenting on school resources unable to handle a child's behavior and family want to return to an area that can assist him)

My son has 15 physicians - moving has made that more difficult. (FM reporting that they are currently in a good medical environment but will be relocating soon and are anxious about the transition.)

Most children with ADD need consistency. Changing schools was detrimental to his educational progress. (FM speaking about the educational and social regressions with each move)

The hardest thing is to give up good medical care when going to a new location. (FM commenting on not wanting to leave the current location with medical services that she is very satisfied with and emphasizing that not all medical care in the new location is nearby causing added time and expense)

Wait lists cause further delay in care. By the time they receive the service the family will have disintegrated. (SM stating it was difficult to get resources even when located in the category 5 catchment areas)

Why do I have to do the paperwork all over again for PCSing when my medical diagnosis will never change (FM suggests a short form for situations like this)

IV. Deployment

Combat deployments present additional challenges. Most military families, whether or not they have special needs, have to cope with many disruptions and additional stress during deployment. For families with special needs, developing a family care plan and establishing a 24/7 formal and informal support network to back up the primary care provider can be overwhelming depending on the severity level of the disability, how many family members with special needs they have, and the proximity of the family to appropriate resources.

We were on respite before deployment and it was great until respite was dropped- now it's hard to get back on. (FM who is now on a wait list for respite care)

V. Stigma and Career Advancement

Concerns about stigma and career advancement emerged in nearly every site visit. Regardless of Military Service, pay grade or location, many study participants report that

stigma remains high regarding involvement in EFMP. Some participants reported disassociating from EFMP services as much as possible "*to avoid social embarrassment*". Others feared that the stigma of having their family identified as an "*exceptional needs*" family would hinder assignments necessary for future promotions or compromise reenlistment opportunities. For some families, an assignment (ideally close to the best resources) can often conflict with the best assignment for the Service member's career. A few families were pretty explicit in discussing how they initially refused to enroll in the program. They said they intentionally hid their family member's needs because they were convinced that public knowledge or command knowledge of these needs would compromise overseas assignments or assignments they deemed critical to their Service member's career advancement. Service members said that orders are a "*balancing act for promotions and career advancements*" and when the Service member goes in front of their respective promotion board, the record does not document that assignment orders have changed to accommodate a family member with special needs. Instead, the board observes a lack of advancement, ultimately affecting the Service member's career.

Being EFMP they have wrapped me in cotton and put me in a box- EFMP makes me non- promotable. (SM who believes the stigma attached to EFMP is the biggest obstacle with Leaders)

Homesteading is a stigma to promotions. (SM)

Being EFM hinders and influences your career. (SM commenting on what younger members say about being denied some assignments that would make them promotable)

Identify Gaps and Inconsistencies in Services

The major gaps and inconsistencies identified by the Benchmark study participants could be broadly categorized as gaps in resources for varying reasons, such as supply and demand, inconsistent application of requirements and guidelines between locations and Services, or a lack of coordination and communication among service providers in different helping organizations who are typically involved in helping families find services. Often these factors overlap and when they co-occur in any given situation, it creates a "perfect storm" of challenges.

The major gaps and inconsistencies highlighted in this section are:

I. Varying Enrollment Circumstances and Timelines
II. Multiple POCs and Effort of Coordination
III. Inconsistent Opportunity to Participate in Assignment Process
IV. Uncertainty about Services and Resources
V. Respite Care Challenges
VI. Limited Command EFMP Awareness
VII. Complicated, Redundant, and Inefficient Paperwork
VIII. Gaps in Health Care Availability and Support
IX. Continuity of Medical Care Coverage
X. Child and Youth Services (CYS)Access and Suitability Issues
XI. Shortage of Educational Resources and IEP Inconsistencies

I. Varying Enrollment Circumstances and Timelines

Enrollment occurs for varying circumstances and at different times for families in the EFMP which contributes to the confusion about the enrollment process. A significant number of the participants indicated that the EFMP enrollment process, depending on location, is somewhat "*broken*" and needs to be "*streamlined.*" Where the Service member and family enter the system influences what information they receive about what resources are available. It also influences how many places they have to go to complete the process and how many points of contact (POC) they have for different aspects of the process. According to some of the study participants, not all of these POCs are aware of all the resources and/or applicable protocols. Some Service members and family members also indicated that they do not necessarily know what they are eligible for or how to access that support.

> ***You don't know what you don't know.*** **(SM and FM commenting about the process of getting a diagnosis and finding out about EFMP)**

II. Multiple POCS and Coordination of Effort

As families engage with multiple systems and enter the EFMP at different referral points, there are often several points of contact (POCs) with varying degrees of experience. During the enrollment and recertification process there can be many contacts and for the personnel

assignment process, there is another set of POCs. One of the most frequent communication gaps mentioned by family members was the lack of coordination and communication between all the different case managers and family support service personnel. The positive side of multiple referral points and POCs is that many different people with different knowledge about resources and requirements are available to help. The downside is that each of those providers needs to coordinate with each other and stay connected with the family for the best outcomes. This kind of case management takes a lot of time and effort and communication gaps exist not only within the system, but also within the family. Sometimes the sponsor, who is not usually the primary caregiver, may not communicate all of the information he or she receives to the civilian spouse or primary caregiver. Recognizing that this is the structure of the system and proactively helping the family work out a clear communication system would reduce overload on the service providers and support families in becoming more skilled advocates. This assumes a sufficient number of trained staff and a reasonable caseload.

III. Inconsistent Opportunity to Participate in Assignment Process

Another identified inconsistency is the opportunity to be part of the decision making process for personnel assignment. Service members and family members, who are the "experts" concerning their own situation, want a face-to-face or at least a teleconferencing opportunity to discuss their circumstances with the assignment officer. Service members and family members want the chance to explain that the "category" or EFMP identifier does not necessarily reflect the specifics of their situation. Participants pointed out that the same classification may be experienced differently for families with varying internal resources and extended family resources. These families feel that if they could be part of the discussion, this would result in a more informed decision that supported the military mission and the family quality of life in a wider variety of locations, and would provide more options for career advancement. In the best examples given - either when the Service member or family member did have a chance to talk with the assignment officer or when a well-informed and supportive command knew the specifics of the family situation and could advocate on their behalf - it made a positive difference. On the other hand, without input from the Service member or advocacy by command, the chances are greater that the sponsor and family will receive a "cookie cutter decision" for relocation.

IV. Uncertainty about Services and Resources

Family uncertainty about what they can reasonably expect from the military, local, state, and federal agencies in terms of resources and services creates additional issues when:

- eligibility rules change or are misinterpreted,
- eligibility differs from one place to the next,
- there are fluctuations in the funding for similar services, or
- there are significant qualitative differences between available providers

Weaving the military and civilian (local, state, federal) resources into a comprehensive support system is the preferred outcome for all families. Experienced families usually have figured most of this out. Well trained case managers also know how to help those new to the system accomplish this coordination. However, even with experience and regardless of broad knowledge; the process is time and labor intensive for all parties.

> ***Communication about the program is a big issue. Do not solely rely on the Service member to educate the family.*** **(FM indicating using the Internet to find out information)**

V. Respite Care Challenges

Families identified the following respite care gaps and inconsistencies:

- Non-equitable allocation of respite care,
- Inadequate training, experience, and availability of respite care givers, and
- Waiting list constraints often related to funding.

As the preponderance of families that participated in the Benchmark study had family members with moderate to severe developmental disabilities, many of the participant families were using or trying to use the recently funded respite care hours (i.e. hours in addition to those provided by TRICARE/ECHO). There was general agreement that respite care managed by each Service's EFMP family support program is greatly appreciated despite the fact that many participants perception is that there are often not enough hours, that some families are not able to get any hours and in many cases regardless of eligibility, there are often lengthy waiting lists. Families understood that there were many funding constraints for respite care but were hopeful that the enhanced respite care dollars could be maintained and if possible, increased, to resolve at least some of the waiting list delays.

There was considerable discussion about discrepancies in how many hours were available for the same levels of need in different locations and across Services. Additional stress exists about the changing guidelines regarding when respite caregivers can be used. Respite care benefits parents in multiple ways - by giving them the opportunity to complete simple chores such as grocery shopping, attending important EFMP trainings and meetings, spending quality time with a spouse or other children and generally helping to reduce the 24/7 stress of caring for family members with special needs. In this sample, some of the families who participated had multiple special needs family members. Since the different (TRICARE/ECHO and Service specific EFMP family support) respite care programs have different eligibility requirements and guidelines, this may have contributed to the belief that decisions are not made in a transparent or equitable manner as families may not distinguish between different sources of respite.

Families were also concerned about the inconsistencies in training for respite caregivers for family members with complicated and multiple handicapping conditions. It became clear in a few of the focus groups that some families did not know that it was possible for them to arrange for an already identified caregiver to become qualified, or that they had the option to continue using a qualified caregiver already within the system even if the agency contract changed. It was not unusual for some of the families to find out about how to access available resources (new EFMP staff, different respite providers, a "good" babysitter/physical/speech /occupational therapist in the area) through their participation in the focus groups either from other Service member and family participants or from the EFMP staff.

There is a huge need for respite care. Respite care is important for all EFMP families and all five categories should be able to qualify. Waiting lists can be as much as one and a half years. (FM)

There is a lack of transparency of the entire respite care system, especially around eligibility and the associated records with respite care. There are different standards for respite among the military branches. (FM)

Respite care providers are often unable to meet the care needs of individuals with severe autistic behaviors or children and adults with multiple handicapping conditions. (FM)

Changes in local agency contracts, resulting in involuntary changes in caregivers, impede continuity of care for our family. (FM)

VI. Limited Command EFMP Awareness

The need to provide more consistent trainings and briefings for all levels of command was a frequently identified gap. While acknowledging that there are many informed and supportive commanders, many participants requested more training so command at all levels:

- Understand special needs and what families are dealing with on a day to day basis
- Understand what the EFMP can and cannot provide for those who are enrolled
- Understand leadership's role – when and how they can support Service members in their command who have family members with special needs
- Understand how to refer families to the appropriate EFMP resource person

Command has to be on board to support EFMP families. Start by training from the top down. Include command, other services, schools, medical providers, community organizations and families in training about EFMP and what resources and related services are available to families. **(SM and FM)**

VII. Complicated, Redundant and Inefficient Paperwork

Complicated paperwork in multiple systems was identified repeatedly as a major frustration. Families understand that completing the paperwork is their responsibility but would like the system to be less complicated and barring that, at least available in an electronic/web-based format. There was almost unanimous agreement for modernizing the military process for enrollment, recertification and assignment processes by creating online systems to reduce "lost" paperwork and to enable both family support services personnel and family members to track the flow through the system. Several participants indicated that if the medical records and accompanying forms were online, they would not have to redo paperwork for every medical appointment.

At all sites, at least one, if not more, families came to the focus groups and interviews bearing large binders with multiple copies of required forms. The experienced families indicated that they had learned the "*hard way*" that they could not trust that previously submitted (mailed, faxed) paperwork "*would be where it needed to be when it needed to be there*." Additionally, even if paperwork (state and federal benefits, EFMP enrollment, medical history, etc.) is not lost, military and civilian providers use different forms and have documentation requirements which are not interchangeable.

One unanticipated effect of the lengthy paperwork that needs to be completed by medical providers is related to scheduling insufficient appointment time to allow for completing EFMP paperwork in order to avoid a second appointment. This was primarily a concern for the military medical appointments. On the civilian side, participants indicated that they often have to pay extra for copies and records from civilian providers and are not reimbursed for these expenses. Additional appointments and travel time are also not usually reimbursable.

A recurring theme from families was that paperwork should be standardized and streamlined. Families and Service members indicated that the lack of easy access to digitalized (i.e. interactive not static) forms increases the burden of coordination and communication. Instituting a tracking system for enrollment and assignment packets that could be accessed by all parties could also dramatically lower the uncertainty associated with these different decision processes that the family and that Service members perceive as critical for everything from continuity and quality of care to career advancement.

Enrollment packages take so long to process because of the increased volume of applicants, fewer staff, the complexity of the diagnoses, and the external needs of the system. Often it is a collateral duty for several of the positions processing the applications. (SP speaking about the current situation at their location)

VIII. Gaps in Health Care Availability and Support

Both military and civilian physicians were often described by the families and the staff as overwhelmed with the expanding caseloads due to the increasing number of EFMP families relocating to the area. Even at the larger military medical facilities, a common concern was the lack of medical specialists. It was not unusual to hear of up to 18-month delays just to get a pediatric developmental assessment following a preliminary visit with the primary care physician. This can be very problematic since these specialized assessments govern eligibility and provision of services, which in turn affects continuity of care and placement on waiting lists. In addition to a shortage of medical specialists at some locations, families also talked about the decreased availability of other health and service providers, such as individuals trained in ABA (Applied Behavioral Analysis) and occupational, physical, and speech therapists. These shortages are usually associated with less resource rich locations, but they were also related to a trend of overloading families with special needs at some locations where demand for resources exceeds supply.

IX. Continuity of Medical Care Coverage

The lack of continuity of medical care coverage across the different Military Services (as well as within the civilian sector) is also a concern for families. Families are very aware of what they perceive as different levels of coverage that is increasingly obvious with joint basing and when they change TRICARE regions. Families in the program, moving from one location to another, reported losing necessary services because the benefits and services approved by one TRICARE region were either not approved or approved but not reimbursed at the same level by another TRICARE region. This is not dissimilar to issues of losing educational services due to availability and differential funding state to state or within states across school districts. Continuity of care issues were described as becoming even more challenging as children age out of the system and/or as families leave the Service. Many families reported scrambling to figure out how to maintain necessary services. Families also freely acknowledged that many of the Services are hard to duplicate outside the gate and worry that they will be unable to replicate services in the civilian sector.

TRICARE is a complex program and has ill-defined policy and regulation for current services and resources. Dealing with TRICARE is like a full time job for a stay at home **spouse. (FM talking about the inability to have a job outside of the home)**

With TRICARE, there's no guidebook. It's like having an opponent who tells you the rules as you go and changes them all along the line. Some prescriptions/referrals are good for 6 months, some for a year, and some for 18 months. When prescriptions expire your only feedback is that your claim is rejected. There is a lack of awareness of TRICARE/ECHO benefits being able to pay for special needs. **(SM and FM)**

The doctor that your child sees for their actual condition cannot prescribe equipment, because TRICARE makes families go through their primary care provider for all medical equipment. If I go to a specialist with a referral TRICARE won't recognize it. All referrals must come from the primary care physician who may not even know what I'm talking about. **(FM)**

ECHO's approval of Applied Behavioral Analysis (ABA therapy) is extremely useful for families, but not reimbursable for ADHD diagnosis. **(SP)**

X. Child and Youth Services (CYS) Access and Suitability Issues

Families were often disappointed about the inability of their children and teens to access CYS recreational and socialization activities especially since they felt that the marketing of the programs was inviting them to participate. Families reported that many of the military child care and youth centers are not equipped to provide appropriate supervision for children and youth with challenging medical and behavioral conditions. The issue of appropriately trained caregivers in these settings was frequently raised. Families indicated that mild to moderate developmental and/or medical conditions could often be handled within the structure of these programs, but more severe or multiple handicapping conditions could not and typically exclude or drastically limited participation for their children or youth with special needs.

XI. Shortage of Educational Resources and IEP Inconsistencies

Families indicated shortages of special educational services as well as private therapy services such as speech, occupational and physical therapists at many of the designated locations containing large concentrations of the most seriously challenged children and youth. It is not only an over saturation issue; sometimes there are additional resources but the local decisions made to provide these services are different from a family's prior experience.

Another identified concern is the varying language and terms on IEPs from state to state, as well as across school districts within a state. Just switching to a school across town can restart the whole IEP process to reassess for services and class placement. Many state's school regulations require the completion of a new IEP evaluation before services are given, causing further delays. Allowing for the IEP transferred from the last location to the new location to remain in effect until another IEP can be arranged would prevent a break in service. While some families knew this was possible, many did not. Families are not always aware of the DoD guidelines and the other federal regulations that apply.

It is not surprising that families may have difficulty understanding inconsistencies in the provision (and quality) of IEP services when comparing different school districts and different states. This seems to be especially critical for the increasing number of students diagnosed with Attention Deficit Hyperactivity Disorder (ADHD) or Autism Spectrum Disorders (ASDs). Families indicated that some schools and/or teachers will not permit approved ABA therapists in the classroom. In locations where the EFMP family support services personnel coordinate closely with the schools and the school liaison officers work well with the local schools, these kinds of issues are more easily resolved. However, both families and EFMP family support personnel described differences in local policy regarding permission for school liaison officers and/or EFMP family support services personnel to attend the IEP meetings. Sometimes the school's policy excluded them; in other examples, it appeared to be a local restriction on the military side. Obviously families would like a standardized IEP process. Realistically, however, many state and educational regulations and civilian school district practices and guidelines are out of the military's control.

> ***It is not going to help me now but if I can help another EFM go through the process without as many struggles, we can all help each other do the "best" for our family.*** **(FM speaking about the trials and tribulations with getting the schools to assist her son)**

EFMP support service personnel perspectives on successes and challenges

In addition to hearing from Service members and their families about their experiences, the Benchmark team interviewed 123 different service providers about the protocols, policies, and practices associated with their duties in helping families navigate the military and civilian support systems.

This section summarizes the perspectives of the 89 branch EFMP family support services personnel (72% of the total provider sample). It is important to remember that while some Services had existing family support personnel and were in the process of adding additional staff; other Services were instituting these positions for the first time and most of their EFMP family support services personnel were new to the program.

Overall the subject matter expertise and local perspective of the EFMP family support services personnel was extremely helpful in answering questions about Services' guidelines and clarifying local implementation policies and practices; confirming the accuracy of Service and family member understanding and perceptions of the program; corroborating what they saw as the successes and challenges for the program; and offering their own recommendations about additional services or changes to existing services that they felt were needed to better support families.

With few exceptions and despite some specific concerns and frustrations with the system, the vast majority of the Service EFMP family support services personnel confirmed that most families had "*good news stories*" to tell about what worked well for them. Personnel also commented on how grateful many families were for Military Services that they perceived to be more responsive and comprehensive than civilian resources.

Personnel working in the program, especially those who had themselves been enrolled in the program, agree that the program has continued to expand and improve in many ways. In the situations where expectations are not being met and where people are disappointed or frustrated, there are two major themes. In some locations and for some conditions, there is either a lack of specific resources and/or very long waiting lists to access existing resources.

When there is far greater demand for services than supply, eligibility criteria tend to become stricter, procedural compliance tighter, in-kind requirements on the part of the service recipient increase, and diversion efforts may increase; all of which lead to less satisfaction on the part of the family dealing with a special need as well as frustration for the EFMP staff working with them. Secondly, for some families who do not have an accurate understanding about EFMP services, there is often confusion about what can or cannot be provided and who provides what service. This creates misunderstandings and elevates the level of frustration.

I. Multiple POCs Continue to Benefit Families

Due to both an increased emphasis on the availability of services and increased funding for the EFMP, the EFMP family support personnel agreed with the families that there are more points of contact and that these additional points of contact are able to identify and refer families for help earlier as well as assist families in navigating the system. The EFMP family support service personnel also pointed to an additional benefit - families are less likely to feel isolated when more people in the military community are aware of the resources available to Service members whose family members have special needs.

> ***This is our primary job – to help them be their own advocate to navigate the system.*** **(EFMP SP)**

II. Personal Touch and Warm Handoffs – Essential to Engage Families

Personal touch is critical. This was a repeated comment from both Service staff and families. Both groups agreed that service delivery is impeded and support seems uncaring when families are handed print materials, referred to a web site(s), and expected to complete confusing paperwork on their own. Moreover, families new to a diagnosis or to the program are often in denial and overwhelmed dealing with an urgent medical crisis or difficult diagnosis. According to the EFMP family support services personnel, personal touch is a key strategy to get families to enroll in EFMP and allow staff to effectively assess the needs, priorities, and services for each family situation.

A "*warm handoff*" between the different service personnel is also a high priority given the many transitions experienced by these families and the importance of continuity of services. EFMP staff concurs with the families that good communication and coordination can resolve a lot of problems and misunderstandings. EFMP staff also agree that on-going collaboration among professionals is essential even though it is often time consuming. Formal advocates within the medical and family support side were often mentioned as **"***making things happen***".** It is telling that Service members and family members frequently referred to their EFMP family support services provider or medical case manager by name rather than function. Family support staff who were clients themselves or had a family member with special needs who had benefited from the programs and services were also seen as especially helpful and credible.

> ***Person to Person handoff is the best way to help EFM families. Whether it is to another professional or to an empathetic local family member, the personal touch makes all the difference in how people feel they are being treated.*** **(EFMP SP)**

III. Strained Resources Due to Influx of Families

At installations where many families with special needs with moderate to severe disabilities were stationed, EFMP family support services personnel confirmed that the influx of additional families has often strained both their family support resources and the medical and educational resources in their geographic area to the limit. They echoed what families reported, that this is frequently reflected in long waiting lists, limited or overwhelmed educational services in the local school districts, and difficulty in getting seen by physician specialists and therapists.

IV. Varying Reimbursement and Billing Obstacles

Family support services personnel also confirmed the financial difficulties that many families experienced with the varying reimbursement and billing structures across states, TRICARE regions, and sometimes within branches. A typical example was Supplemental Security Income (SSI): one state counts Basic Allowance for Housing, another state does not and that in turn affects the amount of SSI benefits. Providers also reported on the additional costs families incurred such as

- lodging and transportation costs when family members needed to be treated/hospitalized away from home
- costs for multiple appointments, the copying of records, or costs for the time it takes for filling out extensive paperwork, and
- prescription costs or medical devices that were authorized but not reimbursed

V. Assignment Process Issues

EFMP service providers reported that family involvement in the assignment process was highly dependent on at least three conditions:

- Adequate command support;
- Service member and family member knowledge about the process and their ability to provide additional information; and perhaps most importantly
- Service member confidence that the request for communication would not be held against them.

The EFMP personnel also corroborated family reports that the PCS assignment decision is often not individualized and there are inconsistencies in the family being able to contact and communicate with the assignment officer. They agreed that families do not always have the opportunity to communicate what is actually needed for stabilization options. If the assignment officer does not communicate with families or does not obtain additional information from EFMP medical or family support services personnel, the focus is perceived to be on the EFMP identifier. Using the identifier alone does not always adequately represent a holistic view of the family member's requirements nor does it take into account what internal and external resources exist in the family that could change or mitigate assignment decisions. In some locations, Service members and family members are told

specifically that they are not allowed to contact the assignment officers. In other locations they are actively encouraged to provide additional information if they want to do that.

> *….families do have to be very proactive regarding their special needs family member … … many seem to be unaware that they can update their package to have the codes changed.* **(SP)**

VI. Command Support Is Essential

Family support service personnel agreed with the families' perception that command support for assignment coordination makes a big difference. When command is knowledgeable about the program and supports the Service member and family, and if the family is diligent in keeping all their paperwork up to date, most assignment situations were able to be worked out. Family support service personnel also talked about how some commands are much more flexible than others if the Service member needs to adjust a work schedule. However, they also pointed out that this flexibility is not necessarily related to a lack of command support but can be because of the military occupational specialty of the Service member or the type of mission.

VII. Stigma and Career Advancement

Despite stated policy that enrollment does not have an adverse impact on the Service member's military career; families remain very concerned about the lack of career options if they are enrolled in the EFMP. The EFMP family support service personnel agreed with the family reports that there is often tension trying to balance the requirements for program enrollment, career advancement options, mission readiness, and family needs. They also acknowledged Service member and family member perceptions that there can still be stigma attached to EFMP enrollment. Families also see this stigma as currently exacerbated with the draw down in forces related to retention and relocation decisions. Family support service personnel also said that if Service members and families do not trust the system, they will sometimes delay enrolling or refuse to enroll, often sabotaging the help that could be given.

VIII. Respite Care Availability and Transparent Eligibility Requirements

EFMP personnel from both the family support side and the medical side reported that while families really do appreciate the additional respite care that has been made available because so many families need respite care and additional funding is still in question; the waiting lists remain a frustration for them. The EFMP family support services personnel also agree with families that sometimes there is a second issue besides that of adequate supply: a lack of transparency around eligibility requirements. EFMP personnel indicated that the issue is about how the guidelines are interpreted and implemented at different locations. Even when the guidelines appear clear, they are not always consistently applied.

The disparity becomes very obvious to the family when they move from location to location or when they are at a joint base with families from different Services in the same location.

The service personnel also concur with families that changes in respite care agency contracts can disrupt the relationship with the family and reported that families are not always aware that they can request that a preferred provider be qualified under the respite program. This is another way that EFMP support staff can assist the family.

IX. Access to Child Youth Services (CYS) Programs and Services

Families report that rarely are they able to access these programs and services if their child or teen has any significant medical, educational or behavioral issues. They are disappointed and frustrated since the marketing of the program seems to invite participation but the reality is that access is extremely limited. The EFMP family support personnel agree that this perception is accurate but are more aware than many families that CYS staff in these programs are not hired with this kind of special expertise; may not have opportunities for training in the area, and most importantly, the staff to child/teen ratios do not support this kind of supervision and assistance under the current CYS organizational structure. Multiple service providers at the visited sites seem to be aware of this situation and many are trying to figure out ways to improve access. The study team did hear from some families and from some program staff about some amazingly creative ways that some CYS directors and staff were able to surmount all of these obstacles and provide these opportunities.

> ***CYS here are much better with the new director. Leadership from the top makes all the difference.*** **(SP)**

X. Documentation

The EFMP staff confirmed that the paperwork many families find confusing is a realistic concern. EFMP family support service personnel are sympathetic to the families' desire for simplification but generally think that is not realistic given all the different medical, educational, and insurance requirements. They do, however, agree that the process of moving the paperwork through the system, automating some of the updating and recertification requirements, and instituting a tracking mechanism would benefit the service providers as well as the families. On the positive side, EFMP family support personnel indicated that there are several Service initiatives coming in 2011or already started to streamline some of the paperwork transfer if not the actual volume of paperwork.

XI. Housing

EFMP personnel also indicated that priority housing with appropriate accommodations is often very limited at the locations where many families with special needs are assigned. In

addition, at some locations, a family cannot get on the housing list until they physically arrive. This seems to vary less by Service guidelines and more by local protocol.

XII. Educational and School Concerns

One of the most frequent requests for help that EFMP family support service personnel receives is for the families' need for information and advocacy for school related problems. A major concern is the IEP process which governs the provision of appropriate services. EFMP family support personnel acknowledged considerable variability in how schools handle this, which can be very frustrating for families trying to maintain continuity of services. While some school districts will honor an existing IEP until a new assessment and a new IEP is authorized, others require that new assessments be completed and a new IEP established before services can start. Since many military families move during the summer months when assessments and school IEP teams do not meet, these assessments are often postponed until the school year starts. This can affect how quickly the families are assigned to waiting lists for any additional school services such as speech therapy or aides in the classroom.

Many of the EFMP family support services personnel pointed out that mediation and due process for educational services is Federal law and while states are supposed to accept out-going states' IEP until the incoming state can reauthorize the IEP, this is not always done. Several staff indicated that many families do not understand all of these rules and requirements and really count on both them and the school liaison officers to help advocate with the schools. To complicate the situation, the study team heard that in some locations, EFMP guidelines do not allow EFMP staff to attend school meetings or conversely the schools will not allow "outside" persons to attend with the families.

4. BENCHMARK RECOMMENDATIONS

Recommendations for the EFMP family support services are based on findings from the literature analysis, family support program interviews, and family needs assessment. Many of the recommendations received while conducting the family needs assessment concerned non-family support aspects of EFMP, namely enrollment, assignment coordination, information management, and ways to strengthen and improve non-EFMP services and programs such as respite care, TRICARE, the Medicaid Waiver system, DoD Schools, childcare, recreational programs, and legal assistance. While enrollment, assignment coordination, and information management were not the main focus of this study and the non-EFMP programs are outside the authority and responsibility of the Office of Community Support for Military Families with Special Need, these programs and services may have a significant impact on the families OSN serves and the family support EFMP provides. As a result, the families' main concerns and recommendations about the enrollment, assignment coordination, and information management processes have been included here as well as those for family support. Family and Service member concerns related to non-EFMP programs and services are also included. Since these are beyond the authority and responsibility of OSN they are included as advocacy recommendations. The recommendations are organized into three tables, those concerning EFMP family support, those concerning EFMP enrollment, assignment coordination, and information management, and those concerning advocacy.

Family support recommendations focus primarily on ways to standardize EFMP across the four Military Services so that families receive the same high quality responses to their needs regardless of Military Service or duty assignment. Families were generally very satisfied with the family support they received from EFMP. Nonetheless, they did have suggestions as to how those services could be better and their ideas along with those from the literature and family support programs are presented here. Practices in all areas of the Exceptional Family Member Program vary from one Military Service to the next. It is recommended that roles and responsibilities for family support staff be standardized, including the training they receive. There should be greater standardization of caseload sizes with a sufficient number of trained staff to adequately respond to families in a timely fashion and in a tiered support response based on family need. It is also recommended that marketing resources be increased to educate the military community about what can be expected from the program as well as educating the military community about special needs in general and the role Service members, family members, professionals, and command could play. This could be accomplished via multiple media formats. Reduction of the stigma associated with families with special needs and the programs that support them will only be achieved through greater awareness and understanding. Many parents indicated they would like to see more opportunities for peer-to-peer support. Sometimes having the perspectives of other families dealing with similar special needs at the same location can be more helpful than information from professional staff. Finally,

for joint base installations it is recommended that a single family support capability be established.

Table 1. Family Support

Area	Family Support Recommendation
Staffing	• Continue to fund the 2011 family support case managers/system navigators/ liaisons as Military Service members and family members reported that these EFMP family support personnel provide valuable support while they learn how to be advocates for their family member with special needs. • Develop standard job descriptions that establish expectations across all Military Services concerning staff roles and responsibilities. • Provide standards and guidelines for EFMP caseloads as they impact personnel requirements. • Develop standardized training detailing the essential skills and tasks of EFMP family support service providers. • Provide standardized training for EFMP family support services on EFMP policies and practices, Federal and state legislation, educational guidelines, and TRICARE. • Facilitate EFMP key staff stability at each installation. • Consider personal or professional experience with the military and/or families and family members with special needs as an optional staff job qualification.
Services	• Establish a single integrated EFMP installation support capability for joint based installations. • Establish consistent practices across all Military Services to facilitate the needs of families related to family support. • Establish tiered levels of support based on intensity of need. • Facilitate the establishment of peer-to-peer support programs for parents as well as other family members (e.g., Parent–2–Parent, parent/sibling support groups, peer mentorships/networks). • Focus the family plan on family's strengths to meet the needs of all family members. • Include the family member with special needs in the planning process whenever possible. • Identify and map the civilian and installation service networks, including electronic resources and established groups. • Assist families in navigating and coordinating civilian and military medical, educational, and family support services. • Connect families to resources inside and outside the gate by providing a warm handoff, making initial phone calls, or arranging a joint meeting when needed.

Area	Family Support Recommendation
	• Provide family support services through multiple means (e.g., e-mail, telephone, in-office consultation, workshops/trainings).
Marketing/ Education/ Advocacy	• Provide EFMP strategic communications (marketing) using multiple formats to Service members, families, commanders, and community service providers. • Continue to train/brief all community members to help reduce stigma regarding program enrollment, in particular because it is perceived as being a barrier to relocation options and career advancement. • Identify any EFMP systemic needs and advocate for improvements. • Interface with command regularly and discuss issues pertaining to EFMP and families with special needs. • Provide family members and Family Programs staff with ongoing training and education, e.g., use Subject Matter Experts on advocacy, coping, local/state policies and guidelines.

Enrollment, information management, and assignment coordination recommendations focus on streamlining and automating the enrollment and recertification system and making the assignment coordination process more transparent. This was something that family members, Service members and family support providers in every location of every branch strongly endorsed. Some Services have already begun to move toward automated online systems that are trackable by family members and family support personnel in much the same way as shipping information can be tracked online. This would greatly reduce paperwork by putting more of the enrollment process online, and creating more transparency, and could be tied to an automated case management system that would track standard information about how many individuals are enrolled in each Military Service program with some minimum demographic descriptors. This would also allow each Military Service to collect data the same way, (e.g., EFMP coding category/severity) so that what was reported would have the same meaning across the military. Similar standardized practices could be put in place for procedures to include better communication between Service members, family members, and personnel officers and other representatives during assignment coordination.

Table 2. Enrollment, Information Management, and Assignment Coordination

Area	Recommendations
Enrollment/ Information Management/ Assignment Coordination	• Streamline the enrollment process and create more transparency making it digital, interactive, and trackable, reducing redundancy. • Create an online interactive flow chart so families can chart their progress, identify issues causing delays, know what the next steps are, and know exactly how close they are to completion of each phase of the enrollment and assignment process. • Standardize data collection and reporting across the Military Services. • Include the Service member, family, and family member with a special need to the extent possible, when making decisions about coding for severity/categories. • Enhance communication and feedback opportunities, between Service members and personnel offices during assignment coordination whenever possible. • Create consistent EFMP forms to facilitate smooth transitions from installation to installation as well as to reduce the paperwork burden.

Non-EFMP service recommendations include standardizing eligibility guidelines for respite care and establishing a consistent number of hours of care based on need. Although large amounts of resources have already been devoted to respite care, the importance of respite care to family well-being cannot be overstated. This is especially true for families dealing with severe disabilities where respite care can mean the difference between a special needs family member being able to remain at home or having to be placed in a more specialized care setting. Having a standard baseline level of respite care available as a minimum in the four Military Services would help to ensure the same resource regardless of Military Service or duty assignment. Other programs and services that families, Service members, and service providers would like to see standardized to a greater extent are TRICARE and the Medicaid Waiver system. Families reported that when relocating from one TRICARE region to another their medical needs that were previously cover were no longer covered or had different coverage limits. Availability of services through the Medicaid Waiver system varies greatly from state to state with most having waiting lists that the family is placed at the bottom of each time they relocate to a new state. Finally, families expressed a need for availability of legal support in their efforts to have agencies follow the federal and state guidelines, particularly around the provision of educational programs and services.

Table 3. Other Services/Advocacy

Area	Recommendations Regarding Other Services/Advocacy
Non-EFMP Service Providers	• Standardize decisions concerning covered services and coverage limits across TRICARE regions. • Standardize the respite care guidelines across the Military Services for family members with special needs to include the purpose, parameters and hours associated with care. • Increase training for respite care providers in general and through training increase the availability of qualified respite care providers for family members with severe disabilities. • Explore solutions to the current state and federal program system which penalizes mobile families by putting them at the bottom of the waiting list for services each time they relocate. • Explore options for legal support and advocacy for families when dealing with schools and state agencies to assure they provide appropriate resources. • Explore options for supporting families throughout the IEP process and helping parents advocate on behalf of their child.

Conclusion

Families and Service members are generally very satisfied with the family support they receive from EFMP. The most predominant theme is the need for greater standardization and consistency across Services and geographically. Not only would families like to see greater standardization in the family support they receive from EFMP, but they would like simplification and automation of the EFMP enrollment and assignment coordination processes so that accessing, updating, correcting, and sharing records is made easier. Additionally, standardizing and streamlining non-EFMP programs would help reduce the burden on families with special needs and make the services they receive from EFMP more effective. By providing more consistent and congruent resources and responses within a system that is more consistent and congruent, the Exceptional Family Member Program will be able to build on the many positive changes that have occurred over the past two years and be in a better position to support special needs families.

APPENDICES

Appendix A: Reference list for literature analysis

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Appendix B: Definitions of types of literature

The literature search resulted in 56 documents with publication dates ranging from 2000-2010 (with the exception of one 1998 article with substantial data on caseload sizes). Refer to Appendix A for a reference list. We included eight different types of documents in our analysis: (a) forum, (b) informative non peer-reviewed, (c) informative peer-reviewed, (d) literature review, (e) mixed methods peer-reviewed, (f) qualitative research peer-reviewed, (g) quantitative research peer-reviewed, and (h) report. The definitions of these document types are below.

Forum

What: opinions, editorials, personal stories, or recommendations for policy change; typically state or program specific

Who: parent, service provider, academic, individual with a disability, or advocate

Why: to inform general population (including consumers, family members, service providers, advocates)

Where: published in a journal, magazine, or agency newsletter

Informative, Non Peer-Reviewed

What: facts and information about program(s)/agency; reports trends; may be state or program specific

Who: researchers, academics, or agencies

Why: to inform consumers, family members, service providers, advocates, and academics

Where: published by a public service agency, advocacy organization, or university-affiliated center

Informative, Peer-Reviewed

What: facts, information about a program(s)/agency, reports trends; may be state or program specific

Who: researchers, academics, or agencies

Why: to inform consumers, family members, service providers, advocates, and academics

Where: published in a peer-reviewed journal

Literature Review

What: reviews a body of literature, synthesizing the critical points of current knowledge; does not report any new or original experimental work

Who: researcher(s) affiliated with an agency or university, federal agency or advocacy agency

Why: to inform service providers, academics, researchers, and policy makers

Where: published in peer-reviewed journal available through library databases; found on the website of the authoring body and/or funding agency

Mixed Methods Research, Peer-Reviewed

What: research study including literature review, an analysis of both qualitative and quantitative data from interviews or surveys, and a discussion, typically with policy recommendations

Who: researcher(s) affiliated with an agency or university

Why: to inform service providers, academics, researchers and policy makers

Where: published in peer-reviewed journal

Qualitative Research, Peer-Reviewed

What: research study including literature review, an analysis of qualitative data from interviews or surveys, and a discussion, typically with policy recommendations

Who: researcher(s) affiliated with an agency or university

Why: to inform service providers, academics, researchers and policy makers

Where: published in peer-reviewed journal

Quantitative Research, Peer-Reviewed

What: research study including literature review, an analysis of quantitative data from surveys or other measures, and a discussion, typically with policy recommendations

Who: researcher(s) affiliated with an agency or university

Why: to inform service providers, academics, researchers, and policy makers

Where: published in peer-reviewed journal

Report

What: digests of current policy, research, trends and/or current practices and programs; may include independent literature review, non-peer reviewed qualitative or quantitative research;

typically includes policy recommendations; may be an overview of multiple programs or be state program specific

Who: individual or team affiliated with a university, federal agency or advocacy agency; typically funded by a grant

Why: to inform academics and policy makers and make recommendations

Where: found on the website of the authoring body and/or funding agency; freely available for download as PDF

Appendix C: Definitions of coding categories

Type of Document: categorize the document according the characteristics of What (general description of the document content), Who (role of the author), Why (for what purpose it was developed), and Where (location the document may be found)

Discipline/Field: identify the discipline or field that the document stems from or takes its perspective from (e.g., early intervention, school services, healthcare, case management/care coordination, social work)

Population Served: identify the population served/targeted in the document: (a) Early Childhood (0-5), (b) School-Age (K-21), (c) Adult (18+), (d) Any Age, (e) Not Specified

Organizational Structure: identify the administrative structure of the program, the unit in which the services are embedded (e.g., standalone case management agency, combined case management and direct service agency, program is part of a university unit, part of the state's PTI organization)

Staffing/Case Ratios: identify the staff/service provider caseloads – to how many individuals with disabilities and/or their families does one staff member/service provider provides supports

Assessment of Family Need: any specific instruments used to determine family need relative to the exceptional family member; any additional assessment methods including interview, informal professional assessments, observation

Eligibility Criteria: criteria may include assessment results, exceptional family member age, support needs, disability, and financial criteria

Name and Nature of Supports and Services: name and description of specific services (could be discipline specific like OT or PT or program specific such as care coordination or workshop trainings) available to families and/or the exceptional family member; included services identified as the responsibility of the service provider

Profession of Provider: the provider's field-based professional title (e.g., doctor, nurse, general educator, special educator, occupational therapist, social worker)

Required Qualifications: qualifications such as professional degrees, experience of the service provider, specialized training, certifications, organization affiliations that are required of the professional/service provider providing family support

Preferred Qualifications: qualifications that the program would like you have but are not required of the professional/service provider for hiring purposes (e.g., bilingual, being from the same region, professional qualifications or certifications)

Job Performance Criteria: any instrument used to assess the performance of the service provider in the delivery of family supports (e.g., surveys, evaluations, interviews)

Professional Training Program: additional ongoing professional development or training (in-service training – after hire) above and beyond the required or preferred qualifications

Cost of Services: any out-of-pocket expenses to the family for the receipt of services – may be specific or generalized (e.g., "may be costly to the family")

Family Training: training provided by the service provider or organization associated with the family supports program (e.g., workshops, online modules, webinars, teleconferences)

Program Evaluation: any instrument used to assess the family support program and the services provided (e.g., surveys, evaluations, interviews) or the impact of the program on the family or exceptional family member (e.g., family satisfaction, quality of life, stress, depression)

Recommendations: recommendations the author makes relevant to the development of services, programs, supports, or the evaluation of supports

Other Possibly Useful Information: relevant information or quotes that seem important but it is unclear of where to categorize it; data in this field may be used to identify additional relevant fields to be added to the database

Appendix D: Protocol for interviews with family support program leaders

A. Please describe your program demographically (this can be provided via email or during the interview).

A1. Number of families served

A2. Age range of individual with a disability

A3. Types of disability

A4. Approximate proportionality in terms of race/ethnicity

A5. Number of staff and staff/family ratio (caseload ratios/sizes)

- What are your programs staffing guidelines concerning caseload ratios/sizes?
- What factors influence caseload sizes?

A6. Job titles and descriptions/roles/responsibilities of staff positions

A7. Staff/personnel training

- Who gets training?
- When is training held - orientation and in-service?
- What kind of training is provided (topics and format)?
- What is the cost of providing training annually?
- What are incentives/requirements for training?

A8. What are staff members' credentials (required/preferred qualifications, education requirements)?

B. Identifying Family Needs

B1. What is/are the process/procedures used for identifying family needs?

- What assessment tools are used?
- Does your program have assessment tools that could be shared with us?

C. Developing Family Plan

C1. What is/are the process/procedures used for developing a family plan?

- Does your program have forms related to family plan development that could be shared with us?

D. Providing Services

D1. What types (categories/taxonomy) of services are provided by your program?

D2. What is/are the process/procedures for providing services?

D3. Do you have a tiered-level of services that provides differing levels of support intensity based on the family's needs? If yes, how do you determine the level of need?

D4. Does your program have any resources/documents concerning the services provided by your program that could be shared with us?

E. Monitoring of Program Implementation

E1. What is/are the process/procedures for program monitoring (e.g., staff evaluation, staff/personnel training evaluation, documentation of services provided and to whom)?

E2. Does your program have any tools/documents concerning monitoring tools that could be shared with us?

F. Evaluating Outcomes

F1. How does your program evaluate generic outcomes across families particularly as related to resilience, quality of life, readiness?

F2. How does your program evaluate specific outcomes for individual families based on the family plan and service satisfaction?

- Does your program evaluate resiliency and quality of life outcomes for individual families? If yes, what tools are used for evaluation?

F3. Does your program have evaluation tools that could be shared with us?

G. Outreach Programs/Recruiting Families

G1. What is/are the process/procedures for marketing/recruiting—how does your program get the word out about services?

G3. Does your program have marketing/recruiting tools that could be shared with us?

H. Areas of Greatest Strength

H1. What are the greatest strengths of your program?

I. Areas of Greatest Need

I1. What are this program's greatest challenges?

I2. What would be helpful in taking next steps for program improvement?

I3. What are the greatest challenges *addressed* by the program (e.g., family mobility, large or rural region to serve, lack of adequate resources)?

J. Identifying Model Programs

J1. What other family support programs have particularly impressed you?

K. Identifying Lessons Learned

K1. Knowing what you know now, in starting a new program, what 2-3 things would you do differently than you did initially?

K2. What advice or recommendations do you have for the Department of Defense in starting case management programs for military families?

Appendix E: Associated literature for case ratios categorized by field

Field	Ratio	Reference
Early Intervention	from 1:11 to 1:57	(Roberts, 2005)
	average 38 cases (9 to 70)	(Harbin, Bruder, Adams, Mazzarella, Whitebread, Gabbard, & Staff, 2004)
Developmental Disabilities	Each family support center is "required to work with at least 50 families a year" (¶ 6).	(U.S. Department of Health and Human Services, Administration for Children & Families, Administration on Developmental Disabilities, 2010)
	"Program Case Management" for people enrolled in structured service programs that have some kind of regular oversight; caseload is approximately 1:90; and "Primary Case Management" for people who are the most vulnerable with caseloads limited to 1:35 to encourage monthly contact.	(Research and Training Center on Community Living, 2008)
	One state reported a ratio of 1:50 as an average caseload ratio for TCM under the HCBS waiver program, but said caseload ratios for children can be as high as 1:300; another state reported a ratio of 1:72 for HCBS program, 1:99 for people receiving state-only funded services or Medicaid; and 1:500 for people receiving no paid services. Most common caseload ratios fell in the range of 1:30-39 individuals.	(Cooper, 2006)

Field	Ratio	Reference
Mental Health	Maximum caseload of 10 families with youth with persistent mental health disorder and functional impairment and at-risk	(Stambaugh, Mustillo, Burns, Stephens, Baxter, Edwards, & DeKraai, 2007)
Social Work	Small caseloads (1:10) intensive, including provision of direct services, beyond info and referral Less intensive and typically has a client ratio of 1:20-30 1:10 in ACT model; 1:12 in Strengths model; no study with ratio higher than 1:20 has positive client outcomes	(Goscha, Rapp, Bond, & Drake, 2010) (Rapp, 1998)
Healthcare	"… with an average active caseload of 50 children" (p. 635) with significant chronic medical problems "The maximum number of recovering Service members in CAT number 2 that the DOD Recovery Care Coordinators and Nonmedical Care Managers will be assigned to serve will be 40. The actual number will depend on the acuity of the member's medical condition and complexity of the nonmedical needs.…The actual number of cases assigned to each recovery care coordinator will be closely monitored."	(Kelly, Golnik, & Cady, 2008) (Department of Defense, 2008)
Behavioral Healthcare, Healthcare, Social Work	"The size of caseloads crosses a large span of numbers of cases, which are considered ratios of clients-to-case manager. Caseloads ranged widely over six delivery examples contained in the literature reviewed by the CLWG. Specifically, caseloads ranged from a high in a social work clinic model of 365 clients to 1 case manager (365:1) (Wilson,	(Case Management Society of America, & National Association of Social Workers, 2008)

Field	Ratio	Reference
	Curtis, Lipke, Bachenski, & Gillian, 2005) to 50:1 or 40:1 in community mental health (Hromco, Moore, & Nikkel, 2003) to 26:1 or 32:1 in acute inpatient units considered less intense (Underwood, McKagen, Thomas, & Cesta, 2007) to 20:1 in a maternity ambulatory outpatient clinic (Kane & Issel, 2005) to 12:1 or 10:1 in the intensive Mental Health (MH) CM model (Dewa et al., 2003) to 2:1 or 1:1 in acute inpatient intensive care settings (Underwood et al., 2007)" (p. 12).	

Appendix F: Associated literature for family support services

NOTE: G.3, G.13, G.14. etc. refer to documents obtained from programs interviewed. For purposes of anonymity, an alphabetical letter was assigned to each program and, subsequently, a number was assigned to each document received from each program.

Family Support Services Categories (Braddock & Hemp, 2008)	**Service Type**	**References**
Respite services	Respite Care	(Documents G.3, G.13, G.14, G.17; Interviews B, D, F, G; Kelly, Golnik, & Cady, 2008; Lopatin, 2010; Neff & The Health Net Federal Services ECHO Team, 2007; Specialized Training of Military Parents, 2006)
	TRICARE/ECHO	(Documents G.1, G.2; Specialized Training of Military Parents, 2006)
Financial Support	Financial assistance for medical needs supplemental to TRICARE/ECHO	(Document E.4; Lopatin, 2010; Neff & The Health Net Federal Services ECHO Team, 2007; Specialized Training of Military Parents, 2006)
	Accessing funding for services/equipment	(Interviews A, D, E; Krauss, Wells, Gulley, & Anderson, 2001)
	Obtaining tangible items (e.g., bus tickets, infant formula	(Cooper, 2006; Interview D)

In-home support, Education and Training	Integrated preschool program Early Intervention/Early Childhood Services-Routine-Based ABA therapy Social skills classes Feeding therapy Personal care	(Dunst & Bruder, 2006; Greenwald, Siegel, & Greenwald, 2006; Interview F; McWilliam, 2009) (Document E.3; DOD, 2007; Russo & Pollack, 2007) (Nickel, Cooley, McAllister, & Samson-Fang, 2003)
Assistive and Medical Technology	Accessing funding for services/equipment	(Interviews A, B, C, D, E; Krauss, Wells, Gulley, & Anderson, 2001)
Health and Related Professional Services	Primary medical care Therapy (physical, speech, occupational) Home Health NICU family education TRICARE	(Kelly, 2003-2004; McWilliam, 2009) (Greenwald, Siegel, & Greenwald, 2006; Krauss, Wells, Gulley, & Anderson (2001) (Lopatin, 2010) (Cooper et al, 2007) (Document E.1; Lopatin, 2010; Specialized Training of Military Parents, 2006)

	TRICARE ECHO	(Document E.2; Ladew & Chevalier, 2009; Lopatin, 2010; Neff & The Health Net Federal Services ECHO Team, 2007; Specialized Training of Military Parents, 2006; U.S. Gov't Accountability Office, 2007)
		(Girard, 2007)
	Medical consultation via VTC or web	(Krauss, Wells, Gulley, & Anderson, 2001)
		(Dave, Foster, Milton, & Duncan, 2009)
	Health insurance	(Capitman, 2003)
	Nutrition counseling	(Capitman, 2003; Nickel, Cooley, McAllister, & Samson-Fang, 2003)
	Specialty medical care Preventive healthcare	(Backer, 2007; Capitman, 2003; Cooley, McAllister, Sherrieb, & Kuhlthau, 2009; Hwang et al, 2009; Interviews B & D; Krauss, Wells, Gulley, & Anderson, 2001; Nolan, Orlando, & Liptak, 2007)
	Coordinated medical care	(Davey, Foster, Milton, & Duncan, 2009; Greenwald, Siegel, & Greenwald, 2006)

		(Davey, Foster, Milton, & Duncan, 2009)
	Mental Health Services	(Case Management Society of America & National Association of Social Workers, 2008; Interviews, A, C, D; Walsh, Estrada, & Hogan, 2004)
	Assertive community Treatment (ACT) & Strengths models	(Kelly, Golnik, & Cady, 2008)
	Psychotherapy	(Stambaugh et al, (2007)
	Family therapy	
	Emotional support	(Sanders, Turner, & Markie-Dadds, 2002)
	Behavioral issues	
	Multisystemic Therapy (MST) behavioral support	
	Behavioral family intervention	

Family Training/Counseling	Obtaining waiver services	(Kelly, Golnik, & Cady, 2008)
	Help accessing services	(Interviews A, D, E; Krauss, Wells, Gulley, & Anderson, 2001)
	Parent education	(Greenwald, Siegel, & Greenwald, 2006; Interviews A, B, C, D, E, F, G, I; Russo & Pollack, 2007; Sanders, Turner, & Markie-Dadds, 2002; Specialized Training of Military Parents, 2009; Wolff et al, 2009)
		(Greenwald, Siegel, & Greenwald, 2006; Interview C)
	Peer support (e.g., fathers' network, sibling support)	(Stambaugh et al, 2007)
	Multisystemic Therapy (MST) behavioral support	(Sanders, Turner, & Markie-Dadds, 2002)
	Behavioral family intervention	(Greenwald, Siegel, & Greenwald, 2006)
	Parent support groups	(Interviews A, B, C, D, G; Specialized Training of Military Parents, 2009)
	Informational Workshops are parent rights & responsibilities	(Interviews A, C, D, E; Research and

	Individual and systems advocacy) Military Child Education Coalition (MCEC) Caregiver support groups	Training Center on Community Living, 2008) (Hill, 2009) (Grabel, Trilling, Donath, & Lutenberger, 2010; Greenwald, Siegel, & Greenwald, 2006; Interview C ; Kelly, 2003-2004; Krauss, Wells, Gulley, & Anderson, 2001; Milberg, Rydstrand, Helander, & Friedrichsen, 2005; Walsh, Estrada, & Hogan, 2004)
Transportation	Transportation	(Interview F; Kelly, Golnik, & Cady, 2008)
Case Management/Service Coordination	Information and Referral Family/ Collaborative Support Plan (CSP)	(Williams, 2004), Nicel, Cooley, McAllister, & Samson-Fang, 2003), (Dunst & Bruder, 2006), (Walsh, Estrada, & Hogan, 2004), (MEDCOM-CSPD, 2010), (Hebdon, 2007), (Winter, 2007), (Cooper et al, 2007), (Kelly, 2003-2004), (Case Management Society of America, & National Association of Social Workers, 2008), (U.S. Gov't Accountability Office, 2007), (Williams, 2004), (Interviews A, B, C, D, E, F, G, H, & I) (Case Management Society of America, & National Association of Social Workers, 2008; Interviews A, B, C, D, F, G, I; MEDCOM-CSPD, 2010) (Interviews B & D; Kelly, Golnik, &

		Cady, 2008; Rapp, 1998; Roberts, 2005)
	Care coordination	(Greenwald, Siegel, & Greenwald, 2006; Interviews A, B, C; MEDCOM-CSPD, 2010; Stambaugh et al., 2007; Suter & Bruns, 2009; Walker & Bruns, 2008; Williams, 2004)
	Systems/Service Navigation	
Recreation/Leisure	Community participation	(Interviews A & D; Nolan, Orlando, & Liptak, 2007)
Other Family Support	Social support	(Capitman, 2003; Interview C)
	Housing	(Interviews B & D; Kelly, Golnik, & Cady, 2008)
	Household maintenance	(Greenwald, Siegel, & Greenwald, 2006)

Appendix G: Needs Assessment Protocol

Invitation to Participate in the DoD EFMP Benchmark Study – Cornell Site Visit

You are invited to provide your input into a Department of Defense (DoD) wide study of the challenges faced by military families who have special needs members. Cornell University, in partnership with the University of Kansas, is conducting a study of Exceptional Family Member Programs (EFMP) and services throughout the Department of Defense to collect information that will provide the foundation for an effective Family support policy across the four Services.

About the Study. This study is being carried out under the auspices of Section 563 of the National Defense Authorization Act (NDAA) which requires the DoD to establish a policy requiring the Military Services to provide community support to military families with special needs. This study is being done in two phases, a program and policy review and a needs assessment. The needs assessment will entail site visits to gather input from Service Members, family members, and family support providers on what supports families currently use, what additional support they need, and any other **information** they can share to inform recommendations to the Office of the Secretary of Defense for policy and programming decisions.

Participation. As subject matter experts, we would like you to spend 60 minutes sharing your experiences, concerns, and recommendations with the Cornell group who will be leading the small group discussions. The small groups will be composed of approximately eight to twelve Service members or family members who share some key circumstances, such as pay grade, responsibilities for the special needs family member, and type of exceptional need. The discussion will focus on how needs and resources are identified, how connections are made to resources, and what related supports are needed that are not generally available. Another important part of the discussion will focus on balancing the care of an individual with disabilities, with the demands of military life. The Cornell staff will take notes during the discussion, but there will be no recording device used during the session.

Confidentiality. Participation is completely voluntary and by agreeing to participate you do not give up your right to withdraw from the study at any time for any reason. Cornell will take all reasonable precautions to safeguard your privacy and maintain the confidentially of the information you provide. Others who participate in the group with you will be asked by the Cornell staff to keep the information that each participant contributes confidential. You should be aware that Cornell cannot guarantee everyone's cooperation with this request. Cornell staff will make their contact information available so participants can provide information privately that they do not wish to discuss in the group.

Benefits. Other than the confidentiality risk stated above, no other risks are envisioned as a result of participation in these small group discussions. The potential immediate benefits for those who participate will be that you will be able to hear how others have dealt with

similar issues. The potential long term benefits are that the information will be used to inform decision making within the Department of Defense about services for military families with special needs which might benefit you in the future or others experiencing similar needs. Discussion leaders will be happy to answer any questions you have about the process or the intended use of the information being gathered.

Local Information. [provide site specific information such as date/time/place etc.]

Discussion topics for Service Member and Family Member focus groups

- Who helps the Families of individuals with special needs identify their needs and determines which of those needs can be met by the Family, which can be met by the military program, and which will require other civilian resources?
- Who helps Families identify/find/locate the resources they need?
- Who helps Families get connected to resources and assists with eligibility determination, transportation, childcare, etc. and who follows-up to monitor fit between the family and the resource?
- What makes it easier to be connected with needed resources, what makes it harder, and what would you recommend about making 'connection' easier?
- Who provides advocacy for the Family? – someone to go to bat for the Family
- Who provides support for the Family? – someone the Family can talk to
- What other Disability-Related Supports are needed to enhance Family Interaction, Parenting, Emotional Well-Being, and Physical/Material Well-Being?
  In other words, what key issues do families with special needs need help with?
  (Examples: Benefits and Entitlements, Parenting Challenges, Single Parenting Issues, Relationship Issues, Depression or Mental Health related).
- Were those who provided support, helpful, knowledgeable, supportive?
- What recommendations do you have to change or improve EFMP services?

Discussion topics for staff interviews

- The same topics listed above plus the person's position, educational background, training, and experience prior to coming to the position, and what in-service opportunities they have had in the position.

DoD Benchmark Study – Cornell Site Visit Description

Cornell University in partnership with the University of Kansas is conducting a study of Exceptional Family Member Programs and services throughout the Department of Defense to collect information that will provide the foundation for an effective family support policy across the four Services. This study is being carried out under the auspices of Section 563 of the National Defense Authorization Act (NDAA) which requires the Department of Defense to establish a policy requiring the Military Services to provide community support to military families with special needs. This study is being done in two phases, a program and policy review and a needs assessment. The needs assessment will entail site visits to gather input from

Service members, family members, and family support providers on what they currently use in terms of support, what they need in terms of additional support, and any other information they can share to inform recommendations to the Office of the Secretary of Defense for policy and programming decisions.

The primary method for conducting the needs assessment will be site visits to local installations within each Service. We plan small group discussions or focus groups with family members and Service members but could do individual interviews for some participants if that would be preferable. We also need to speak with the primary service providers, and can do that in individual interviews or meet with them in small groups if that is more convenient. Ideally the Service member and family member focus groups will consist of 8-12 participants who share some key circumstances, such as pay grade, responsibilities for the special needs family member, type and/or severity of the disability, and in any other way that makes discussing their family situation safer and less threatening for them.

Participation of Service members and family members must be completely voluntary. It is important that participants understand their rights including the voluntary nature of their participation, their right to withdraw from the study at any time for any reason, what they can expect regarding confidentially and privacy, any potential risks and benefits they might experience, how the information they provide will be used, and answers to any questions they may have. We will provide you greater detail in writing about the rights of participants which can be shared when recruiting them for participation in the study.

The Cornell team will work with the host site to determine the number and composition of the groups; provide a meeting place or places if groups will be run concurrently and help facilitate access for the team to the installation. The Cornell team can provide an in-briefing with command of the nature and purpose of the study, how it will be conducted, and what will be done with findings, as well as answer any questions that command might have. An out-briefing can also be provided if desired. All expenses of the Cornell team, travel, per diem, etc., will be covered by an agreement with DoD and USDA/NIFA.

Scheduling Suggestions:

Sample schedules are provided below. They are based on what we expect to find at a medium to large installation with many family members wanting to express their views on the programs and services available to their special needs family member. The schedule will need to be modified to fit local circumstances, and are only meant to serve as a starting point, e.g. groups can be arranged in any order, etc. We are very flexible on timelines and can begin earlier, or host evening sessions. Please keep in mind that the room should be able to accommodate up to 15 people. We do not need to know what is planned with this level of specificity before we arrive, but it would be helpful to know if groups/interviews will be scheduled concurrently so we have sufficient staff to cover multiple locations if required.

EFMP Benchmark Study Schedule –Sample 1

Time	Day One	Day Two
	Conference Room	
0730-0830	*In-briefing or Interviews*	
0900-1000	Staff Interview	Autism Group
1030-1130	Staff Interview	Cerebral Palsy Group
1130-1330		
1330-1430	Staff Interview	Down Syndrome Group
1500-1600	Staff Interview	Epilepsy Group
	Class Room	
0900-1000	Junior Enlisted SM	Junior Enlisted FM
1030-1130	Mid-Grade Enlisted FM	Mid-Grade Enlisted SM
1130-1330		
1330-1430	Senior Enlisted FM	Senior Enlisted SM
1500-1600	Officers SM	Officers FM
*We can also be available evenings or start earlier. if this works better at your installation		

Source: This schedule is for illustration purposes only

EFMP Benchmark Study Schedule – Sample 2

Time	Day One	Day Two
	Class Room	
0830-0930	Staff Group	Group
1000-1100	Junior Enlisted I	Group
1130-1230	Mid-Grade Enlisted I	Group
1230-1330		
1330-1430	Senior Enlisted I	
1500-1600	Officers I	
	Class Room	
0830-0930	Junior Enlisted II	
1000-1100	Mid-Grade Enlisted II	
1130-1230		
1230-1330	Senior Enlisted II	
1400-1500	Officers II	
1530-1630	Autism Group	
*We can also be available evenings or start earlier if this works better at your installation		

Source: This schedule is for illustration purposes only

EFMP Benchmark Study Schedule – Sample 3

Time	Day One
	Conference Room
0800-0900	Junior Enlisted I
0930-1030	Mid-Grade Enlisted I
1100-1200	Senior Enlisted I
1230-1330	
1330-1430	Officers I
1500-1600	Junior Enlisted II
1630-1730	Epilepsy Group
	Class Room
0800-0900	Mid-Grade Enlisted II
0930-1030	Senior Enlisted II
1100-1200	Officers II
1230-1330	
1330-1430	Autism Group
1500-1600	Down Syndrome Group
1630-1730	Cerebral Palsy Group
0800-1330	*Office Space for interviews* Conduct individual staff interviews

*We can also be available evenings or start earlier if this works better at your installation.

Source: This schedule is for illustration purposes only

EFMP Benchmark Study Schedule – Sample 4

Time	Day One	Day Two
	Class Room	*Class Room*
0800-0900	Staff Group	Junior Enlisted II
0930-1030	Junior Enlisted I	Mid-Grade Enlisted II
1100-1200	Mid-Grade Enlisted I	Senior Enlisted II
1200-1300		
1300-1400	Senior Enlisted I	Officers II
1430-1530	Officers I	Cerebral Palsy Group
1600-1700	Autism Group	Down Syndrome Group
1730-1830		Epilepsy Group

*We can also be available evenings or start earlier if this works better at your installation

Source: This schedule is for illustration purposes only