

**Summary of the
The West Virginia University Project Team's Reports on**

***Medicaid and Military Families with Children with Special Healthcare
Needs: Accessing Medicaid and Waivered Services***

**Final Project Report
Submitted to the Office of Community Support
for Military Families with Special Needs
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Military Community and Family Policy**

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EXECUTIVE SUMMARY

One of the priorities of the Department of Defense (DoD) is the provision of adequate access to quality healthcare for military personnel and their family members through the TRICARE program. Some military families seek to supplement TRICARE benefits with Medicaid coverage. The extent to which military families with special needs access Medicaid and their experiences is difficult to assess.

Military families face multiple challenges in accessing Medicaid. These include:

1. State residency eligibility requirements that may create barriers to enrollment, especially as families move across state lines.
2. The demand for Medicaid services outstrip funding and availability.
3. Many home and community based services (HCBS), which are especially crucial to families with special needs, are often provided under Medicaid “waiver programs.” While these programs help in expanding potential eligibility to new groups of individuals, enrollment is often capped or limited due to constrained funding and service availability. As a result, even those eligible for Medicaid may have to wait for long periods before accessing services provided under HCBS “waiver” programs.

In response to the need for more study, and to address concerns that are being expressed in the military community, the DoD’s Office of Community Support for Military Families with Special Needs (OSN) commissioned West Virginia University (WVU) to examine Medicaid and its relationship to military families with special needs. Specifically, the WVU research team focused on *active duty* military families with special needs and their relationship with HCBS waivers.

This research involved a three phase study consisting of:

1. Field research conducted at six military installations in the United States,
2. Review and analysis of existing survey data, and
3. Analysis of Medicaid regulations across the states.

This report summarizes major findings of the West Virginia studies submitted to OSN and was compiled by OSN staff with the assistance of the WVU research team. By design this research is primarily exploratory and seeks to identify factors, issues, and concerns that might be further considered by OSN and other DoD principals in addressing well-being issues associated with accessing services for families with special needs.

The major findings of this research include:

1. Military families with special needs use Medicaid as a resource to obtain specific supplementary services and coverage, such as respite care, transportation, supplies like diapers for older children, durable medical equipment and nutritional products like formulas, that are either not provided or not fully covered by TRICARE.
2. Military families are more likely to access Medicaid due to the family member’s health condition rather than qualification under eligibility related to low income status. There is the perception

that children with physical disabilities more readily access Medicaid than those with intellectual development conditions.

3. The Medicaid system is structurally incompatible with the needs of active duty military families. There is too much variation across state Medicaid systems to ensure that active duty military families moving across state lines will have access to needed services. There is a perception among families that it is not worth applying for Medicaid waived services because the waiting period will likely exceed the duration of the assignment to a duty station within that state.
4. There is a lack of capacity within military family support and medical case management to effectively assist families in their efforts to understand and access Medicaid. There are nodes of expertise within the military health and family support systems, but these are neither coordinated nor systematic.

Consideration of further action includes:

1. Training and education for base level staff to help them take a more active role in providing assistance to families that might need Medicaid where TRICARE does not cover needed services.
2. At the state and federal level, closer liaison work between the DoD and civilian agencies (CMS or providers such as nonprofits and managed care contractors) may facilitate increased access to Medicaid for military families.
3. The DoD should consider establishing a clear liaison relationship with the Centers for Medicare and Medicaid Services (CMS). State and local offices responsible for Medicaid administration need to heighten awareness of the special circumstances of military families.
4. Both the field and statistical research suggest that the military health system is very robust and responsive. Findings indicate that readily accessible resources for active duty military families are not being fully utilized. TRICARE Extended Care Health Option (ECHO) program managers may need to increase communication and outreach to those families that are both eligible and in most in need of its services.
5. The DoD should establish reliable estimates of current needs and projected estimates of qualified active duty family members who should be enrolled in ECHO, based on special needs health conditions. Considerable differences between the qualified population and those enrolled should trigger planning activities focusing on outreach, education, and enrollment. This may call for clearer coordination of ECHO and EFMP enrollment, outreach, and navigation activities. It may also necessary for TRICARE to evaluate the adequacy of service delivery capacity and coverage limits to meet needs.

This study provided an opportunity to learn more about the context and depth of issues surrounding active duty military families with members with special needs. Despite the barriers and challenges identified, the WVU team was especially heartened by what it saw and learned from the field. At each of the military installations visited, for example, the team encountered resilient families and dedicated personnel joined in common purpose to provide for families with special needs. While at times the site visits revealed gaps and problems, the team recognized a sincere commitment on the part of command and front-line personnel in serving those with special needs. One can never overlook the complexities and

unique attributes of each family with a special needs member. An enduring challenge for the military is to balance established and competent systems of support with a need for flexibility and adaptability to new situations and circumstances. Given that this has traditionally been the operating environment of the military, the project team is confident in the DoD's ability to meet this challenge.

PURPOSE OF THE STUDY

Providing adequate access to quality healthcare for military personnel and their family members is a priority for the Department of Defense (DoD). Healthcare for military personnel and their family members is provided through the TRICARE military insurance program. However, some families seek to supplement TRICARE benefits with Medicaid coverage. Services covered by Medicaid can be especially important to military families with members with special needs (hereinafter referred to as ADFMSN). This study, conducted by researchers affiliated with West Virginia University (WVU), reviews and assesses access to Medicaid services by military families with special needs. The study:

- 1) Quantifies the scope of ADFMSN population by analyzing various existing data sets that provide information on enrollment, population demographics, and service utilization,
- 2) Examines Medicaid coverage in the fifty states and the District of Columbia through a regulatory analysis that takes into account variation in program practices and the delivery of mandated and optional services for disabled and special needs populations in this state-federal program, and
- 3) Provides perspective from ADFMSN sponsors and spouses and others involved in providing health care to these families.

Considering military families have to negotiate an often complex network of health coverage options and services, the DoD has dedicated resources to care management and referral services. However, there are times when ADFMSNs may seek additional resources provided by Medicaid. Over the past two decades, this state-federal program has increased the number of services and types of treatments and delivery models for special needs populations. Many of these are provided through “waiver” programs which states operate under federal approval. Such programs allow for new treatment paradigms – such as home-based rather than institutional care. As promising as these developments may be, funding constraints, limits on available services, and variations in state Medicaid systems can make accessing and receiving these services challenging to military families.

State Medicaid systems have traditionally been structured with “static” populations in mind. In other words, they have created systems that tie eligibility to proof of residency and to the health delivery systems found within a particular state. The federal system has mandated certain covered services, but has allowed states considerable discretion in the design and delivery of Medicaid services. As a result the current Medicaid system has common elements but also varies in terms of eligibility requirements, the types of services provided, and the means in which programs are managed and services are delivered. For ADFMSNs moving from installation to installation across state lines, negotiating the Medicaid system can be a daunting process.

This study sought to provide needed information to OSN to aid in efforts to assess and address programming and services for active duty military families with special needs. The interface between Medicaid and military health systems is of special priority – especially in context of what barriers and conduits exist for families accessing those Medicaid services for which they are eligible.

The study focused on *active duty personnel* and how support structures in the military help families learn about and negotiate access to resources that can assist their family members with special needs as they relocate with frequency. More specifically, focus was on the extent to which Medicaid provides coverage

and services for these families and how the Medicaid system interacts with the military. When utilized, it is seen as another venue to access very specific needed services, such as respite care and transportation services. Of special concern is whether the unique residency situations of military families are being taken into account and accommodated by state Medicaid systems. Of additional concern is whether military families and the military system is maximizing access to services and resources that are provided within the military health and insurance systems, such as Medicaid.

MAJOR STUDY COMPONENTS

This study was established through a cooperative arrangement between the OSN, the United States Department of Agriculture's National Institute for Food and Agriculture, and WVU. At WVU, a team of researchers led by the project's principal investigator, David Snively, (Associate Director for the WVU Extension Service) carried out a multi-faceted study of the topic. The study includes three components: 1) analysis of existing survey and enrollment data, 2) regulatory analysis, and 3) field research.

Analysis of Existing Survey and Enrollment Data

This analysis was conducted to understand the scope of the population of military families that may interact with state Medicaid systems for special needs health services. Due to the limits in available data, the research focused on children with special needs in active duty military families. Key guiding questions included: What numbers of children have problems receiving health services? What factors are associated with problems receiving health services? Data from various public and DoD sources were analyzed to understand population trends and demands including the National Survey of Children with Special Healthcare Needs, the Health Care Survey of DoD Beneficiaries, and the Defense Manpower Data Center (DMDC). Dr. Tami Gurley-Calvez of the University of Kansas (and formerly with the WVU Bureau for Business and Economic Research) led this component of the project. She was assisted in her efforts by Adam Pellillo, then a graduate student attached to the WVU Bureau for Business and Economic Research. Quantitative analysis of existing national and military-specific data sets, surveys, and other resources helps to identify the prevalence and character of populations with special needs and their utilization of health services and health insurance coverage. Such analysis can also reveal gaps in data and point out the need for more robust and refined approaches to data gathering and analysis by principal agencies involved.

Regulatory Analysis

The regulatory analysis of Medicaid policies and practices in the various states (Appendix A) allows for insight on how well this system interfaces with military health care coverage and services. The focus here is on Medicaid and the manner in which states have established such policies and procedures for eligibility determination and redetermination; the provision of, and access to, waived services that are often designed for special needs services; and the identification of potential barriers for military families seeking Medicaid services in the states. Professor Shelley Cavalieri now of the University of Toledo Law School (and formerly of the West Virginia College of Law) led this component of the project. Regulatory analyses can help to understand the governmental landscape in which military families must navigate in accessing services for their family members with special needs. Our complex intergovernmental system shapes and constrains the manner in which publically funded supports, such as Medicaid and other programs aimed at populations with special needs can be delivered.

Field Research Overview

The Field Research project incorporated analyses from regulatory and data analyses projects and supplements these with additional research focusing specifically on special needs populations and Medicaid policy. Through field work, a deeper understanding was gained of the specific policy issues and political cultures relating to Medicaid services as they relate to active duty military families.

The center piece of the field research project involved site visits to six military installations across the United States. These were conducted in the fall of 2011 and were carried out by teams of WVU-affiliated researchers to include faculty members, extension agents, and graduate students. At each installation, the researchers met with senior base leadership as well as personnel involved in medical and family services. In addition, focus group interviews were held with parents of family members with special needs to gain their perspective on experiences involving Medicaid access and services. Through our research, we sought to understand ADFMSN concerns in families with both children with special needs and adult dependents, such as adult children.

The field research component of the study was led by Dr. Christopher Plein (WVU Department of Public Administration), with the considerable assistance of John Kincaid and Andrea Bowman (both graduate students at the time in WVU's Department of Public Administration). Additional assistance was provided by Quinn Kratovil (a Master of Social Work student at WVU). Members of the field research teams included; Andrea Bowman (MPA Graduate Student and now WVU Extension Agent), Alicia Cassels (WVU Extension Specialist), Professor Shelly Cavalieri (formerly of the WVU College of Law), Louise Donato (Extension Agent), John Kincaid (WVU MPA Student) Rebecca Mowbray, (WVU Extension Agent), Jennifer Murray (WVU Extension Agent), Terrill Peck (WVU Extension Agent), Gina Taylor (WVU Extension Agent), and Lucinda Vasofski (WVU Extension Program Specialist).

FIELD RESEARCH METHODOLOGY AND APPROACH

While an analysis of data sources and regulatory policies provided some context and background for challenges facing families, the WVU evaluation team recognized that the most crucial information would come from interviews with base-level personnel responsible for assisting families in accessing needed medical and family support services; base command representatives who were knowledgeable about the overall needs of active duty personnel and their family members ; and the active duty personnel and their representatives who were familiar with the needs of ADFMSNs. In the fall of 2011, eleven WVU-affiliated researchers visited six military installations in three member teams. The military installations were chosen in coordination with the OSN personnel and with the permission of representatives of the respective service branches.

The evaluation team visited two installations in each of the three TRICARE regions. The team worked closely with DoD project sponsors in reviewing the criteria necessary for such visits – namely that each installation have significant Military Treatment Facility (MTF) and family support capacity. The team also worked closely with DoD principals in identifying the key base-level personnel, or “intermediaries,” who could provide information and perspectives associated with Medicaid related issues. The team was especially interested in understanding: the profile of special needs challenges at bases; experiences in accessing Medicaid, especially waived services; and the role of various base intermediaries in connecting families to Medicaid and other public or community-based support services and programs. More

specifically the team examined: 1) how each intermediary interacts with families regarding referral, eligibility, and enrollment in Medicaid, and/or 2) how they contribute directly and indirectly to helping families access Medicaid. Through the base visits, the teams were to learn about the obstacles families encounter in handling: eligibility criteria; enrollment processes; waiver lists; and the receipt of services from Medicaid. The teams also sought to learn about best practices and innovations that have emerged in military and civilian systems to assist families. These visits were not intended to be evaluations of specific base operations, but rather to provide a ground-level perspective on ADFMSN access to Medicaid.

Intermediaries identified who could best speak to military health and family support needs at the base level included Base Commanding Officers, MTF Commanding Officers, Family Center Managers, Exceptional Family Member Program (EFMP) Managers and Program Representatives, Beneficiary Counseling and Assistance Coordinators (BCACs), Medical Case Managers, School Liaison Officers, Personal Finance Managers, New Parent Support Program Visiting Nurses, Developmental Pediatricians, Family Support Group representatives and Ombudspersons. Interviews with each were approximately one hour long. In order to gain further perspective on military family experiences with Medicaid, each visit also included a focus group meeting with up to eight parents. The purpose of the focus groups was to gain the perspective of parents of children with special needs and an understanding of what services they need but cannot access through Medicaid.

In order to conduct the field research, the team developed a detailed field interview protocol that was vetted by OSD personnel and other DoD principals. In response to multiple teams of researchers being used in the field research, a detailed protocol was developed to ensure consistency in application in the various site visits that were conducted (Appendix B). The field research methodology adopted an approach commonly used in the study of health and human services programs in the United States that relies not only on structured interviews with key informants, but also analysis of relevant documents, reflections on settings and environments, and other context factors (Nathan 1982). In addition to recruiting focus group participants, the team relied on key points of contact at each base to identify and schedule interviews with intermediaries. Over 85 individuals were interviewed in their roles as support staff, base command, family support, and as parents of family members with special needs.

SCOPE OF NEED: FAMILIES WITH SPECIAL NEEDS IN THE ACTIVE DUTY MILITARY

The profile of military families, like that of the general population, reflects varying degrees of healthcare needs. As defined by the Centers for Disease Control and Prevention and as utilized in the National Survey of Children with Special Health Care Needs (CSHCN), “children with special health care needs are those who have a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.” It is important to remember, however, that these family members may also include adults – including adult children of active duty or retired military personnel.

It is important to have an adequate profile of military families in order to better anticipate and respond to special needs circumstances. Williams et al. (2004) examined CSHCN data, as well as the military’s own Health Care Survey of DoD Beneficiaries (HCSDB), to develop a profile of special needs in the military. They noted that of the 8 million active duty, retired, and family members of military families covered through the military health system that approximately two million children received health coverage from

the military system. Looking more closely at the TRICARE system, they found that 23 percent of those enrolled in TRICARE Prime were children with special needs. While concentrating on a subset of the military population (those enrolled exclusively in TRICARE Prime), Williams et al. were able to provide a more detailed profile of military families with special health needs. Their study focused on both family members of active duty and retired military personnel. Foremost in their findings is that the incidence of children with special needs was higher than previously estimated and is higher than the national average for the civilian population. Using the HCSDB survey, they also found that less than one percent (.67) of families with children with special needs enrolled in Medicaid when on TRICARE Prime. At the same time, within the military health system, “a disproportionate amount of health care is provided to enrolled CSHCN.” Implicit in the Williams et al. study is that the military health system may be especially responsive to military families with special health care needs. As they note, “the high proportion of CSHCN identified in our population may be attributable to entry or reentry of people with CSHCN or to programs, such as those described earlier, that promote recognition and treatment of special health care needs.” These and other factors have important implications for serving children with special needs and their families. As Williams et al. (2004, p. 392) conclude:

“[O]ur study clearly indicates the magnitude of systemic efforts required to measure, plan for, and meet the health care needs of families with CSHCN. The MHS [military health system] will require a coordinated effort across the medical departments of all 3 armed services to bring together the staff and resources to ensure that these children get the care that they require when and where they need it.”

To better understand how military families interact with the Medicaid system, Shin et al. (2005) conducted an in-depth study of the topic. Utilizing CSHCN data they found that approximately 14 percent of children in the general population could be designated as having special health care needs in the 2000-2002 time period. Building on previous research by Williams et al. (2004) and using additional data sources from the CSHCN, Shin et al. estimated that 150,476 of these or about 8 percent of the military population received Medicaid benefits in addition to their TRICARE coverage. They found that “Medicaid covered more than one in 12 military children.” They also found a high level of military families on Medicaid were low-income status, noting “53 percent of military children with Medicaid had incomes less than 200 percent of the Federal Poverty Level.” (Shin et al. 2005, p. 14).

It is important to note that the both the Shin et al. and Williams et al. analyses were conducted prior to the implementation of the TRICARE Extended Care Health Option (ECHO) program which was intended to address some of the needs of active duty military families with members with special needs. In addition, these studies examined the general military population that is served through the military health service (i.e. TRICARE). The Williams et al. study examined only those enrolled in TRICARE Prime -- the managed care coverage option for TRICARE beneficiaries. The data used in both the Williams et al. and the Shin et al. studies do not appear to differentiate between active duty and retired or reserve military. Non-active duty personnel are outside of the primary population enrolled in the EFMP.

One of the main purposes of the current study was to gain a better sense of the prevalence and profile of family members with special needs in the military. Building on both the Williams and Shin studies, two of the WVU researchers (Calvez and Pellillo) conducted an analysis of existing data of the general special needs population and the military special needs population utilizing more recent CSHCN and HCSDB data. As they note, these data sets have certain limitations. For instance, they were not able to differentiate

between active and non-active duty family members in the military health system or on Medicaid. Sample sizes and other data limitations restricted analysis of specific state-level phenomena. Nonetheless, their analyses helps to build on the foundations established by previous studies and expands our understanding of military family members with special needs and their access to Medicaid.

The CSHCN survey data and subsequent analysis of HCSDb data of what constitutes “special needs” may not correlate to an individual receiving specific special needs programs, benefits, or services from military or civilian sources. The criteria include whether children have prescriptions, whether medical needs are greater than normal for those of their age, whether the child needs special therapy or has behavioral, emotional or developmental problems. The scope and degree of the conditions can vary considerably among families. In addition, these conditions are self-reported by the children’s parent or guardian in the survey. As a result, self-reported special needs status or the determination of special needs status through the survey criteria will not necessarily equate to a family being eligible for special needs services under Medicaid or other programs.

Calvez and Pellillo estimate that from 2008 to 2010, approximately 30% of children in the HCSDb had a special health care need (CSHCN) following the methodology in Williams et al., 2004. They estimate that about 4% of CSHCN are enrolled in Medicaid (for supplemental general health services with a specifically), representing just under 20,000 children in 2010. Significantly smaller numbers of military CSHCN who are eligible for Medicaid are estimated to successfully access HCBS waivers, specifically. Parents of CSHCN enrolled in Medicaid reported a much greater need for services, particularly specialist and mental health services. They found some tentative evidence that parents have fewer problems accessing services in states providing more home based and personal care services through their Medicaid programs, but the sample size was too small to get precise estimates.

The accumulated evidence of the Williams, Shin and the WVU analyses suggest that the incidence of children with special needs is substantial. These needs are recognized by the military and are perhaps most clearly reflected in the adoption and evolution of the TRICARE ECHO program and the EFMP family support.

BACKGROUND: THE MEDICAID PROGRAM

The Medicaid program was established in 1965. Over the course of almost half a century it has grown from a program aimed at serving primarily those receiving public cash assistance (e.g. welfare) to one that now serves many above the poverty line (low income recipients), as well as those who qualify for care due to disability and medical needs. The implementation of the Affordable Care Act marks a further expansion of Medicaid coverage to a broader class of low income individuals. Throughout its history, and including the potential for Medicaid expansion, states have always maintained options in the design and implementation of their programs. They have even had the ability to decline to participate in Medicaid. As a result, states’ administration and partial funding of Medicaid have led to a high degree of variation among the Medicaid programs of the various states. Because each state administers its own Medicaid program, each state has likewise had considerable discretion to shape its Medicaid system according to internal state politics, pressures, culture, and preferences, provided that the individual state’s Medicaid program satisfies the federal mandates on which federal funding is contingent. This is not to say that states have complete autonomy in the operation and design of their Medicaid programs. To participate in

the Medicaid program, which is funded by matching grant system of federal and state dollars, states must provide a set of mandatory services.

The array of services that the federal government requires states to offer as part of their Medicaid program includes physician services, laboratory and x-ray services, inpatient hospital care, early and periodic screening, diagnostic, and treatment services for individuals under 21, family planning, rural and federally qualified health center services, nurse midwife services, nursing facility services for individuals 21 and over, home health care services for individuals entitled to nursing facility care, smoking cessation services for pregnant women, and free-standing birth center services (Kaiser Commission 2011). States are permitted to provide additional services to supplement these services, including prescription drugs, clinic services, dental services, dentures, physical therapy, rehabilitative services, prosthetic devices, eyeglasses, primary care case management, intermediate care facilities for the intellectually disabled, , inpatient psychiatric care for individuals under age 21, home health care under home and community-based waivers, personal care services, hospice services, health home for those with chronic conditions, and home and community based attendant services and supports.

Likewise, states must provide services to a certain core group of low-income persons. Today, pregnant women and preschool and younger children up to 133 % of the federal poverty level, school-aged children up to 100% of the federal poverty level, and elderly persons and persons with disabilities up to 75% of the federal poverty level are categorically eligible for Medicaid. States must provide Medicaid to persons within these groups. Additionally, working parents up to a minimum income level that depends on certain state welfare rules in effect in 1996, in all instances less than 50% of the federal poverty level, are likewise eligible for Medicaid. Elderly and disabled persons receiving Social Security Income, with incomes up to 75% of the federal poverty level, are also eligible. Historically, Medicaid has not covered non-disabled, non-elderly adults who do not have children (Kaiser Commission 2013).

Provided each state satisfies the federal standards for Medicaid, each is free to build additional layers of coverage to provide services to additional groups of individuals. Some states tend to build fairly substantial superstructures on top of the federal floor that Medicaid establishes. Other states tend to maintain a much leaner approach to the provision of social services such as Medicaid and do not provide significant additional services beyond those that are federally required. State additions and expansions of Medicaid coverage are subject to federal approval.

One of the key additional forms of coverage that states offer beyond the categorically eligible groups described above is coverage for what are termed “medically needy” citizens, which are individuals with substantial medical bills who would be eligible for Medicaid, but for income that exceeds the maximum threshold. Such individuals face serious and substantial financial hardship as a result of significant liability for medical bills. Where enacted, Medicaid programs for the medically needy operate by reducing the state’s assessment of household income by the value of incurred medical costs, thus allowing individuals to spend their income down to the threshold of Medicaid eligibility, after which their medical care will be covered by Medicaid. Thirty-four states provide Medicaid to medically needy populations (Kaiser Commission 2012).

For families that use Medicaid, the patchwork that results from the decentralized administration of the Medicaid system can be particularly challenging in times of relocation from one state to another. Medicaid dependence can tie families to a particular location for fear of loss of Medicaid benefits. This is

especially problematic for military families, whose military service requires frequent transfer from one military installation to another. Because a family may become reliant on and accustomed to a particular set of Medicaid services in one state, they may find themselves surprised with a far more limited menu of services in a new locale. Yet it is of central importance to note that this kind of outcome based on variation among states is predictable, and indeed expected, with the Medicaid system as it was initially constituted and continues to be operated today. The potential benefits of this model include the responsiveness of localities or states to specific local needs, as well as the notion that fifty-one different approaches allows for experimentation through novel programs that other states could adopt if they are successful. The downside, of course, is that some individuals will be disadvantaged when moving from one state to another under this kind of model.

Beyond this degree of variation, even within a state, changing priorities can cause dramatic and sudden alterations to the state's Medicaid program based on changes in the tax base, a shift in partisan control of a governor's office or legislature, or other kinds of local pressures. Any report on Medicaid, therefore, is purely a snapshot in time, as changes can occur at any time and for any reason, provided states maintain their basic compliance with the federal Medicaid program's requirements.

MEDICAID AFTER THE AFFORDABLE CARE ACT

The state of affairs described above is in great flux. The Affordable Care Act ("ACA") provides to states the option of expanding Medicaid eligibility to all persons under 138% of the Federal Poverty Line.¹ This will include, for the first time, non-disabled adults without dependent children at home. Under the ACA, the federal government will cover the full cost of the expansion at its initiation, with the federal contribution eventually dropping to 90%. An open question is whether states will elect to participate in the Medicaid expansion or not. While numerous states have indicated that they are not planning to be involved in the expansion, most health care experts and commentators believe that states are unlikely to give up large sums of federal money that would help their citizens as a form of political protest against the ACA. Although states have recently indicated interest in partially expanding their Medicaid programs under the ACA, the Department of Health and Human Services has ruled that at least through 2017, partial expansions will not receive complete federal funding. As a result, states must expand Medicaid access to all individuals at or below 138% of the Federal Poverty Line if they wish to obtain the full amount of funding available under the ACA. States may apply for a waiver permitting partial expansion in 2017, when federal levels of support drop to 90% of the cost of the expansion, as long as they can demonstrate that they will be providing similar coverage and benefits as mandated by the ACA (Galewitz and Carey 2012).²

Because states have been required to announce their ultimate decisions regarding participation in the Medicaid expansion, the present interplay of evolving Medicaid law in each state and the interests of

¹ While the Affordable Care Act specifies 133% of the Federal Poverty Line, due to other income that will be excluded from this calculation, the net effect is that the Medicaid expansion will be available to persons under 138% of the Federal Poverty Line. Phil Galewitz, Kaiser Health News Changes How It Describes Medicaid Eligibility Level Under Health Law, Kaiser Health News Blog, December 5, 2012, *available at* <http://capsules.kaiserhealthnews.org/index.php/2012/12/khn-changes-how-it-describes-medicaid-eligibility-level-under-health-law/>.

² Phil Galewitz & Mary Agnes Carey, HHS Tells States It Will Not Fund Partial Medicaid Expansion, Kaiser Health News, Dec. 10, 2012, *available at* <http://www.kaiserhealthnews.org/Stories/2012/December/10/hhs-states-medicaid-expansion.aspx>.

military families cannot be fully assessed at this time; much depends on whether states decide to participate in the Medicaid expansion -- a decision that will lead to changes in the models and levels of services provided under Medicaid in each state. However, as the Medicaid expansion itself primarily affects low-income adults, the individuals with disabilities who are the target of this study are largely, though not completely, outside the scope of the expansion.

MILITARY FAMILIES, SPECIAL NEEDS, THE MILITARY HEALTH SYSTEM AND MEDICAID

In recent decades, the DoD has relied on combination of health services delivered by military and civilian providers to service members and their families. Today's current TRICARE program for coordinating and providing healthcare coverage is an outgrowth of earlier efforts in the 1980s to meet healthcare and health coverage needs through the Civilian Health and Medical Program for the Uniformed Services (CHAMPUS). The contemporary military health system has followed practices adopted in the civilian health care sector. Most notably, the TRICARE program has provided different coverage options to families, has embraced managed care and provider network models to coordinate cost and control access, and has adopted co-payments and premiums for some of its options and services in order to encourage responsible care utilization by beneficiaries.

Since 2005, TRICARE has provided an additional health coverage option for active duty military families with special needs; the Extended Health Care Option or ECHO program. Like its precursor, TRICARE's Program for Persons with Disabilities (PFPWD), ECHO provides coverage for various medical services, rehabilitative services, and therapies associated with the treatment of developmental disabilities, like applied behavioral analysis (ABA) for children with autism. It also provides various assistive services that can be delivered in the home or community based setting. One of the most important services is respite and in-home care for families with members with special needs. In many ways ECHO provides services similar to that provided by states under the various home and community based services that are provided through public programs, such as Medicaid. As one support group publication notes:

"Congress created the ECHO program to make services accessible to active duty service members in one state that are not accessible in another state because they are required to move frequently and are normally not in one area long enough to wait to become eligible for services through Medicaid waivers in most states" (Stanier 2008).

Ideally, the coverage provided by TRICARE, especially under ECHO for those with special needs can render the receipt of Medicaid moot. As noted by a developmental pediatrician in an interview, "Medicaid is a hollow benefit for our families." In large part this is because of the robust coverage offered by TRICARE. Nonetheless, the Department of Defense is aware that families seek Medicaid coverage for their special needs members as well. Specifically, families often seek home and community-based services that are provided through Medicaid programs. Many of these are provided through what are called "Medicaid waivers."

MEDICAID WAIVERS

Throughout its nearly 50 year history, Medicaid has provided a platform to expand and extend health coverage to vulnerable and at-risk populations. Populations served by Medicaid today are much broader than anticipated when the program was enacted in 1965. The program serves not only low-income

individuals attached to public cash assistance programs (e.g. welfare), it also serves medically needy populations, the disabled, the elderly, as well as various “at-risk” populations like lower income women and children. In addition to extending Medicaid to new populations, over time the program has also expanded the types of services and benefits available. These include medical treatments, prescription drug coverage, as well as institutional, community-based and in-home care. Both physical and behavioral health therapies and services have been expanded over the course of program evolution as well. The expansion of services reflects both federal mandates for program change as well as state options to adopt and expand new services.

One method by which states develop new services and extend benefits to new populations is through Medicaid “waivers.” Broadly speaking, these are referred to as Section 1115 or 1915 waivers. The section numbers relate to relevant sections of the Social Security Act under which the Medicaid program is established. The 1115 waivers tend to focus on state-wide demonstration projects aimed at converting or changing health system delivery arrangements for Medicaid. More simply put, this might include a state Medicaid system adopting managed care or health maintenance organization (HMO) arrangements as the preferred method of service delivery of Medicaid to low-income populations (Fossett et al. 2000). The 1915 waivers tend to focus on specific populations, medical conditions and care needs, and geographic areas within a state.

Thus there are many different types of Medicaid “waivers” that provide for a variety of services to different groups or populations of Medicaid beneficiaries. Waivers often expand eligibility to families because of different criteria for determining income eligibility. The best example of this relates to HCBS waivers. Under these waivers, the individual – such as a minor dependent – is determined for eligibility based solely on that person’s income and not that of his or her parent(s). This is the formula used for institutionalized care and can be applied in circumstances where an individual can receive home or community based care instead. The receipt of the home and community based care also signifies a different delivery system for care (Zaharia and Moseley 2008, Braddock et al. 2011, Larson et al. 2012).

In considering the needs of active duty military families with members with special needs, HCBS (Home and Community Based Services) waivers are the most important and relevant to the purposes of this study. The types of services that families often stress that they need – such as respite care, transportation support, in-home skilled nursing care, day-care facilities for those with intellectual or developmental disabilities – are often provided by the broad category of HCBS waivers which vary across and within states by the types of populations that are targeted (e.g. by age), the comprehensiveness or specificity of services provided, and the conditions that are eligible for care (e.g the severity of an intellectual or developmental disability).

In general HCBS waivers serve the aged and disabled, as well as the intellectually disabled and developmentally disabled. For the aged and disabled, receipt of an HCBS waiver means that the individual can stay in their home or with family rather than having to reside in a long-term care facility. As of 2009, the elderly and disabled made up 47 percent of the population receiving HCBS waived services. Those with intellectual disabilities or developmental disabilities (primarily children and young adults) made up 42 percent of the HCBS waiver service population (Ng, Harrington and Howard 2011, p. 6). Waivers can be used for different purposes and targeted to different populations, so it is not at all unusual for states to

operate more than one HCBS waiver program. As of 2007, there were 270 HCBS waiver programs in operation across the United States (Ng, Harrington and Howard 2011, p. 9).

Medicaid waivers for home and community based care can be traced back to legislation enacted in 1981, which allowed the federal government to grant permission to states to modify their Medicaid state plans to allow HCBS in addition to institution-based care for the aged, disabled, those with mental retardation (now referred to as intellectual disabilities), and those with developmental disabilities. A state could petition the federal government to rely on community-based or in-home based care rather than institutional care for qualified individuals needing such services as: case management, personal care services, home health aide assistance, homemaker assistance, adult day care, and habilitation services (Duckett and Guy 2000, p. 123). The HCBS waiver program was developed as an alternative to long-term care for the aged and disabled and especially for intermediate facility care for the mentally retarded (ICF-MR) and developmentally disabled (referred to as the MR/DD population). As noted by Larson et al. (2012) “the Medicaid Home and Community Based Services (HCBS) program serves persons who, but for services available through the Medicaid HCBS program, would be at risk of placement in an ICF-MR.” By decoupling eligibility from institutional care, it also helped to expand eligibility for coverage to those who might be reluctant to seek care in long-term care facilities and other institutionalized settings. By the early 2000s, Medicaid spending for HCBS surpassed that of Medicaid reimbursement for institutional-based ICF/MR care (Braddock et al. 2011, p.23).

Considering military family members already receive TRICARE, their needs for services under waivers can be very specific. Most commonly, families were in need of home health, respite care, and even diapers. As noted by one developmental pediatrician interviewed in the field research:

“We have a considerable number of families that possess the waiver. However, what the waiver will provide to them monetarily tends to be quite limited. It is limited especially by their medical need. If it is a cognitive disability or an autistic disorder, their benefits from the waiver might be limited to incontinence supplies for children who are not toilet trained. This might be the only care provided.”

States have an interest in promoting home and community based care. Most ID-DD (Intellectual Disabilities -Developmental Disabilities) HCBS recipients live with their families. This in turn holds down costs for long-term care and allows other supports to be provided that are not paid by the state or Medicaid programs, such as community services and uncompensated family care (Larson et al. 2012, p. 114). Since its beginnings in 1981, the HCBS waiver program has provided much of the funding and catalyst for transforming care for the intellectually disabled and developmentally disabled from care in institutionalized settings to care at home and in the community (Braddock et al. 2011).

For ADFMSNs, it is important to recognize that eligibility criteria and practices vary across the state. This is a function not only of state policy preferences, but also a function of the target or focus of the HCBS waiver(s) in operation. The issue of qualifying for and receiving “waivered services” under Medicaid is of ongoing concern in both the civilian and military world. States utilize “Medicaid waivers” for a variety of reasons, such as demonstration projects that extend coverage to populations that would otherwise be ineligible due to economic reasons or to provide a new modality of treatment. Home and community based service or HCBS waived services are often restricted as demand outstrips funding and supply. States limit access to waived services due to economic, regulatory, and political reasons. It is important to note that the waiver process is highly dynamic for the following reasons:

- 1) States are allowed to develop their own demonstration or waiver programs, state systems are not interlocked with each other so we cannot expect a seamless system across the nation,
- 2) Eligibility criteria may vary and that the types of services under a waiver may vary across states,
- 3) Court decisions can disrupt waiver programs (as has been the case in a number of states with large military installations) leading to changes in how they are administered,
- 4) State fiscal issues can create uncertainties about availability of services,
- 5) Being on a “waiting list” is not simply a matter of one’s place in “the line” – other factors may be taken into account in granting waived services, including the severity of a condition and the appropriateness of services, and
- 6) Future of waived services is subject to uncertainty pending implementation of the ACA and future rulemaking by the Centers for Medicare & Medicaid Services.³

MEDICAID ELIGIBILITY

This study concentrated primarily on military family’s perceptions of access to waived Medicaid services for ADFMSNs. This study also considered and examined how various DoD support services, such as medical case managers and EFMP staff, perceive and interact with the Medicaid system – as well as other community and public support services. It is important to note that while the “waiver” system is often the focus of attention, military families may access other services if they are deemed eligible for Medicaid. A military family member will most likely be eligible for Medicaid if they are deemed “categorically eligible” due to a disability or medical need. While most Medicaid enrollment, in general, is based on low-income status, federal law and state policy also allow individuals to qualify for Medicaid coverage using criteria that establishes eligibility in the case of disability, chronic disease or other medical need. These criteria can be quite stringent and restrictive.

Medicaid serves primarily low-income families. It also serves special-needs populations who have health conditions that make them “medically needy” or otherwise qualified for Medicaid. In addition, Medicaid serves many seniors, who may be “dual eligible”- that is receiving both Medicare and Medicaid benefits. Both active duty and non-active duty military families may also be dually eligible for Medicaid and TRICARE. This is a unique design feature of the TRICARE program in that qualified families will have “wrap-around” coverage provided by Medicaid for services that are not provided by TRICARE or are limited in terms of coverage.

For military families moving across state lines, applying for Medicaid can be a daunting experience. Eligibility does not convey from state to state, but must be determined by a new eligibility review process. It is a state-federal program, so each state enjoys considerable discretion in structuring application and enrollment processes. Given the DoD’s emphasis on providing adequate pay and benefits to active duty military families, it is unlikely that service personnel above E-5 and their dependents will qualify for Medicaid due to low income status. Instead, they will more often qualify because of a disability or medical

³ See for example, Centers for Medicare and Medicaid Services. Medicaid Program; State Plan Home and Community-Based Services, 5-Year Period for Waivers, Provider Payment Reassignment, and Setting Requirements for Community First Choice, *Federal Register*. <https://www.federalregister.gov/agencies/centers-for-medicare-medicare-services>, May 3, 2012.

condition. To qualify on such a basis can be more complex than on an income basis alone. While military families most often access Medicaid because of medical conditions, income must still be taken into account for verifying eligibility for certain benefits, such as Medicaid and Medicaid HCBS waived services. Income determination processes can be more complex for active duty military personnel than for their civilian counterparts. It is difficult for families to navigate the means and asset tests used in Medicaid, SSI, and other public assistance programs because income and asset determination is complicated by surges and changes in income due to per diem, combat, and related pay. Housing allowances may also be counted as income.

In the field research study, a family support expert noted that for military families the eligibility process can be seen as being long and complex. She noted that there is a sense that by the time someone gets approved for Medicaid that they will have already been reassigned to a different duty station. At another military installation, a focus group member responded similarly noting, “I don’t even bother looking for Medicaid because you are likely to move before you get the service.” The paper work is not going to make sense to pursue if a family is stationed at a base for only 12 months or 18 months which is often the case at her base which is primarily a training site, “the process can be overwhelming” when applying for services such as Medicaid. The process differs from state to state. Even the covered Medicaid services can differ from state to state. “What you get in terms of services in one state is not the same that they get in another.” When a family moves, “they have to start all over again” if they want to receive Medicaid in their new state. Echoing this sentiment, another intermediary noted that military families get “frustrated” when having to move from one base to another and reapply for Medicaid.

Customarily, Medicaid serves as a gateway to a set of services and coverage that can vary significantly among the states. For most on Medicaid it is their only source of insurance coverage. For the dually-eligible, the program serves a different purpose. The aim is primarily to provide supplementary coverage. Active duty military families with special needs are most likely to turn to Medicaid for supplemental services that cannot be, or are not being, accessed through the military health and insurance systems. The supplemental services that these families seek to access through Medicaid are generally associated with HCBS. For over three decades, the federal government in partnership with state governments has used the Medicaid program to encourage a transition away from institutional-based care for the aged, disabled, intellectually disabled, and developmentally disabled to home and community based care and services. As noted by (Smith 2007, p. 1):

“Medicaid home and community services include home healthcare, personal care/assistance provided as Medicaid state plan benefit, and home and community-based services (HCBS) furnished under federal waivers. All states must cover home health in their Medicaid programs. States may elect to provide personal care/assistance and/or operate HCBS waivers. As provided by the Deficit Reduction Act of 2005, effective January 2007, states may provide home and community-based services as Medicaid state plan benefits in addition to operating HCBS waivers.”

While HCBS waivers garner significant attention, they are not the exclusive means of providing home and community-based services. The HCBS waivers allow states to be exempted from specific federal policies and procedures in order to develop demonstration programs aimed at innovations in care and cost management. There are other HCBS options and alternatives offered by Medicaid as well. Some of these include requirements in state Medicaid plans and others are offered as options for state Medicaid

programs. How a state implements federal requirements and whether a state elects to operate one or more HCBS related waivers or state plan options is very much a function of state politics, economics, and other circumstances. The Affordable Health Care Act has provided further options to states to increase and expand HCBS through new and revised amendments to federal legislation. This includes Community First Choice 1915(k) state option plans that provide more state level flexibility in the design of HCBS services and enhances federal funding (Centers for Medicare and Medicaid Services 2012a). One theme is very clear from a review of the literature, and that is that there is substantial variation and differences among the states (see Duckett and Guy 2000, Kitchner et al. 2004, Smith et al. 2007, Zaharia and Moseley 2008, Ng. et al. 2011). This is common in Medicaid program implementation in general (see Fossett et al. 2000, Brown and Sparer 2003).

Once a family is deemed eligible for Medicaid, they have available to them a range of services and coverage. For those interested in securing in-home care for their family members with special needs, there are other programs besides those offered under HCBS waivers. For example, offering home health services for those who would otherwise be eligible for institutional care under Medicaid. Over 30 states offer “personal care” services under a state plan option through Medicaid. These are targeted services that can provide families with specific benefits and supports (Ng, Harrington and Howard 2011, p. 2). In addition, once an individual is deemed qualified for Medicaid they are able to access a wide array of services beyond the immediate waiver or specialized program in which they are participating. This might include durable medical equipment, nutritional supplements, and other products and services that are needed to provide care at home and in the community.

In the field research, a senior EFMP program staffer noted that it is difficult to coordinate Medicaid at a national level, “you talk about standardization, but you just can’t do it” when there are so many states involved. “We have to play by each state’s rules,” she said. When asked what words of advice would they give to someone moving to another state when they were already receiving Medicaid at their “losing” installation, a focus group participant said, “stay where you are and don’t move here.” “You can’t transition Medicaid; you’ve got to start over.” As noted below, there are some paths to Medicaid eligibility that are smooth but do not entirely erase the friction that is involved when families move from state to state. This involves qualifying for Supplemental Security Income.

One of the primary pathways to gain Medicaid access is through the Supplemental Security Income (SSI) program which is administered by the U.S. Social Security Administration. For families with children with special needs, this can be an important option. While a primary benefit of SSI is to provide cash transfers to families with children who are disabled, one of its most important aspects is that it often makes it easier to qualify for Medicaid programs at the state level. Considering SSI eligibility includes both a means and a needs test (based on income eligibility and determinations of disability), the program is not accessible to all. Higher income families are not likely to qualify for SSI. In addition, low-income working families may qualify, but because they work, the cash assistance payment will be reduced (Centers for Budget and Policy Priorities 2011). A number of families reported that they “made too much” to qualify for SSI. Others said that because the cash payment would be low, applying for SSI would not “be worth it.” However, such priorities may be misplaced since the most crucial benefit is the medical services that are covered through Medicaid. One of the most disconcerting accounts emerging from the WVU field study was from a family that gave up their SSI benefit, because the cash assistance payment was so low, with

little regard for their future health coverage under Medicaid – and their long-term future once they separated or retired from the military.

As one of the family members explained to a WVU field research team, “Our daughter was enrolled in SSI and she started off receiving a fair amount of money, but somewhere along the line they decided that my husband was making too much money and they started withholding money.” They kept sending this message and “finally it was not worth the effort to continue using SSI.” “So we voluntary ended our SSI and Medicaid benefits because it was too much hassle for zero dollars.” In their case TRICARE ECHO was providing the coverage. She also realizes that, “maybe when we get out of the Army and we don’t have the insurance that we have now, because my husband wants to get out next year when our contract is up, maybe we will look into it again, because we’ll probably need it.”

As of December 2009, children under the age of 18 comprised 15.6 percent of all SSI recipients. The overall number of children recipients has been growing steadily in recent decades. Between 2000 and 2010, the caseload grew from approximately 844,000 to 1.2 million (Centers for Budget and Policy Priorities 2011, p. 1). While eligibility criteria have been adjusted to allow easier access to the program, being deemed eligible is still a complex and stringent process. According to Haskins (2012, p. 4), “the approval rate of applications has remained stable at about 40 percent for more than a decade.” One of the complicating factors in making eligibility determinations and one of the main controversies associated with the SSI program is how disability is defined, especially for children. Enrollment growth has occurred among those “hard-to-measure mental disability categories such as speech and language disabilities and attention-deficit/hyperactivity disorder” (Haskins 2012, p.5). Haskins also notes that as fiscal constraints create pressures to scale back or limit SSI benefits, debates over what constitutes disability are expected to continue and intensify.

WAIVER APPLICATION PROCESS

With federal encouragement, states have sought to increase the enrollment of those qualified for Medicaid. The importance of this “take-up” rate has meant that many states have simplified enrollment procedures, are relying on electronic or web-based eligibility and re-eligibility determination procedures, and are conducting outreach efforts to publicize and connect families to Medicaid. These efforts have relied largely on broadcasting information to, and engaging with, a relatively large and undifferentiated audience of current and potential beneficiaries who would qualify for Medicaid primarily on economic grounds.

Applying for waived services is a more complex process. While taking into account the applicant’s income and financial resources, Medicaid eligibility will be determined primarily based on a medical or developmental disability condition, its severity, and the appropriateness of the treatment services provided under the HCBS waiver. In terms of income eligibility, the waivers allow the states to “disallow” various sources of income to enable eligibility. It is common for the income of a child’s parents to be disregarded if it is determined that the child would require an institutionalized level of care in the absence of the community and home-based services offered under the waiver. However, there is considerable variation in the application of income guidelines and eligibility thresholds among the states. Considerable medical documentation is required to establish eligibility as well. This might include letters of medical

necessity provided by primary care physicians and specialists. The process of arranging such documentation can be complex.

In the most simple of terms, gaining waiver services is a two-step process. The first is to establish eligibility for Medicaid based on health status, income, or other criteria. The second is to gain access to the waived service, which depends on the availability of the service (a “slot”) and the appropriateness of the service to the need. States are not consistent in their approaches to placing individuals on waiting lists. It is entirely possible that an individual will be on a waiting list before their Medicaid eligibility is determined.

In determining the eligibility of children with special needs for Medicaid, states rely on a number of mechanisms. Some states consider receipt of SSI as satisfying eligibility. While this can greatly simplify the eligibility and enrollment process, some children will not qualify due to their parents’ income being too high. States may relax some of these restrictions through what is called “Katie Beckett” or the “deeming” waiver to enroll children in Medicaid. The Katie Beckett “waiver” (not an HCBS waiver, but instead a waiver of income eligibility requirements) was established under the Federal Tax and Fiscal Responsibility Act of 1982. Only the child’s income is considered in making eligibility determinations, parental and guardian income is disregarded. In addition, the child must meet all of the following criteria: 1) be 18 years or younger, 2) meet federal criteria for childhood disability, 3) meet an institutional level of care need, 4) meet determination that it is appropriate to provide for care of the child in the home, and 5) the costs of care to Medicaid would not exceed that of care provided in an institutional setting (Georgia Department of Community Health 2011, p. 3). Negotiating this process is complex and can be time consuming.

Since many states offer more than one HCBS waiver program, the eligibility and assignment process may be further complicated by determining the appropriate program for care. It is not unusual for families to be encouraged to apply for two or more waivers at once. Often service providers or non-profits contracted by state government can provide essential support to families as they seek to navigate the waiver system. EFMP arrangements, especially in context of family support services, may need additional training to become more proactive in assisting families navigate to the Medicaid eligibility and Medicaid waiver application process.

Waiting List Issue

The literature shows that, the number of individuals served by HCBS waivers has grown tremendously over time. For those receiving waived services because they have an intellectual disability or a developmental disability, the numbers served in the United States have grown from 291,225 in 2000 to 592,070 in 2010 (Larson et al. 212, p. 109). Over time, the demand for waived services has often outstripped state capacity to respond and provide services. As a result, waiting lists have developed. These increases have been rapid and have taxed state capacity to provide services due to fiscal constraints, regulatory restraints, and the availability of providers to meet demands.

Those with ID/DD needs are a substantial subset of an even larger population that has sought HCBS waived services but have not been able to enroll. Ng, Harrington, and Howard (2011) found that in 2009 nationwide there were 365,553 individuals on waiting lists, of which 221,898 represented the ID/DD population. It was estimated that the total number of waiver “slots” in the United States totaled 1,345,855. The study also found that among the states with the longest waiting lists were Texas (129,518)

and Florida (32,432). The average wait time for receiving a waiver slot was 19 months in Texas and 33 months in Florida. Some states, like Louisiana and Oklahoma had even longer waiting periods, averaging approximately five years.

Military families moving from one state to another may find that waiting lists are longer and demand is greater where their new duty station is located. States with large military populations, such as Texas, California, and Virginia also have years-long waiting lists for HCBS related waived services. There is concern that military families are disadvantaged in the waiting list process. As noted in an article posted to a military-related website "Operation Home" in 2010:

"As waiting lists for Medicaid benefits grow, the disabled children in military families are being left behind, their parents say. Their families move where the military tells them to, forcing them to start at the bottom of a new state waiting list with each reassignment" ("Stuck at the Bottom of the List," 2010).

Unfortunately, the phrase "waiting list" is a term of art. There is no standard definition or practice for wait lists as they vary across the states. Not even the nomenclature is standardized, wait lists are also called planning lists, registries and interest lists. In some states, getting on the list may be the result of a simple contact with the agency responsible for waiver administration. One of the focus group respondents understood this implicitly as she recounted that it was easy to get on the list but that getting approved was difficult because of state financial woes. As she commented:

"It doesn't take much to be eligible, it is the funding." "I know people who have been on the list for six or seven years." "So what's the sense of being eligible, why are you doing all of the paper work?"

In other states, eligibility for the waived service must first be determined. In some states waivers are coordinated and allocated at the state level, in other states waiver slots are allocated to and determined at the local level. While a "first-come, first-served" approach is often used to prioritize those on the wait list, many states also make exceptions based on the severity of a condition and need (Auerbach and Reinhard 2006, p. 1). At least one state, Tennessee, has utilized three tiers of need. Crisis cases are the highest priority, followed by urgent cases, followed by deferred. In our analysis, we reviewed a number of HCBS waiver applications submitted by the states to the federal Center for Medicare and Medicaid Services (CMS). A common feature of these applications is that states will also hold-back waiver slots to assign to families in need or to assign to those who are currently institutionalized and may be candidates for transition to home and community-based care and services (also see Auerbach and Reinhard 2006, p. 2). The process of getting on the waiting list can be quite complex, as procedures in the state of Tennessee illustrate. According to the state agency responsible for enrollment:

"Individuals who request services from DIDD will be assigned a case manager to assist them in the Intake process. Individuals on the DIDD waiting list must meet eligibility criteria for Medicaid Waiver Home and Community Based Services. During the Intake process, individuals seeking services will be asked to provide legitimate documents to show eligibility. In Tennessee, individuals seeking our services must have primary diagnosis of intellectual disabilities with the onset prior to age 18. While there are financial eligibility criteria for Medicaid Services, the DIDD does not typically seek this eligibility until the person is approved to begin the enrollment process." (Tennessee Department of Intellectual and Developmental Disabilities, n.d).

It is important to remember that individuals receive waived services only when they meet certain eligibility criteria. In the case of intellectual and developmental disabilities, states use differing criteria to determine eligibility for HCBS services. As noted by Zaharia and Moseley (2008, p. 2), states may use categorical or functional criteria. The former will “reference specific related conditions by medical diagnoses or type, such as mental retardation, spina bifida, autism, etc.” The latter establishes criteria “based on a person’s adaptive abilities or capacity to perform tasks at a specific level.” States will also use a combination of categorical and functional criteria in determining eligibility.

Pressing demands for HCBS waived services that have resulted in waiting lists has prompted at least two major political and policy developments. First, and most significantly, waiting lists have prompted controversy, which has resulted in litigation and political debate. Various individuals and advocacy groups have brought suit against state governments on the grounds that they were being denied services for which they were otherwise eligible or entitled. Plaintiffs use protections afforded under the Civil Rights Act of 1871 to seek “prospective relief from alleged state violations of federal law and show that federal law conveys an *individually enforceable right*” in order to side-step the administrative appeals process that might otherwise result in a sanction against the state by the federal government, but not necessarily a remedy for the plaintiff (Smith 2007, p. 2). Many cases involve the developmentally disabled who claim that as a result of being placed on waiting lists that state Medicaid programs fail to provide prompt and comparable services as required under federal statute governing the Medicaid Program. By May 2007, such lawsuits had been filed in 25 states (Smith 2007, p. 4). A review of more recent sources demonstrates that these lawsuits continue. For example, in 2011 a lawsuit was filed in Florida requesting immediate action to move 19,000 individuals into waived services (Support Disability Rights Florida 2011).

These lawsuits and resulting court decisions help to shape the climate and context of waiver program administration and services in the states. In Kentucky the resulting settlement of a lawsuit resulted in 3,000 new waiver slots being opened under the “Michelle P. waiver” agreement (Braddock et al 2011, p. 69). In Virginia, a recent settlement brokered by the U.S. Department of Justice, will result in the expansion of 4,000 waiver slots in the next decade. News reports suggest that this will still not be sufficient to meet demands (Wild 2012).

At both the state and federal level, actions have been taken to provide additional services and supports relating to HCBS. In part these new waivers are aimed at relieving some of the pressures on established waiver programs that provide a broad range of services. These include additional waiver programs that provide “supportive” rather than “comprehensive” services that are targeted to specific needs, such as respite care and transportation support. The federal government has allowed adjustments in the manner in which waivers are designed to allow these supportive services waivers (Smith 2007) and also provided states with the option of amending their Medicaid state plans to develop what are called 1915(i) home and community based supports. Unlike 1915(c) provisions that limit eligibility to those who would otherwise have to seek services in an ICF/MR or long-term care facility, under this state plan amendment, the eligibility threshold is lowered to allow those “at-risk” of such level of care to qualify for services. Among the services that these plans offer are respite care, skilled nursing services, dental services, case management, and environmental modifications to housing (Centers for Medicare and Medicaid Services 2012b). Considering this is a state plan option, states are not required to adopt these provisions.

Concerns about military families being disadvantaged by waiting list practices in the states has gained substantial national attention and was one of the catalysts for this study. Some have advocated that active duty military families be given the benefit of having their waiting line status be transferable from one state to another so that they do not have to start at “the bottom” or “at the end of the line” when moving to a new state as part of the PCS process. This concept has been advocated for by national groups representing military families (Rupe 2009, “Stuck at the Bottom...,” 2010). The field research study found evidence that this concept has been widely embraced by senior level commanders and others at the military bases that we visited. In addition, many of those who participated in the focus group discussions would like to see this practiced as well.

The WVU field research teams received many comments from families about the difficulties encountered with waiting lists. One focus group participant noted “we came from Kansas where there is a 7 year waiver waiting list”. Another participant added that they were receiving services on a waiver in Pennsylvania and now were in Virginia and that the criteria for selection differ. As she commented, “we are now on a “non-urgent list” waiting to qualify for ID services. Who knows when she will be able to get that ID waiver.” One of the most telling illustrations of these challenges came from a parent who was wrestling with whether to take her child with her to a new duty station or have her remain in her home state where she was receiving Medicaid waiver services and could be cared for by other family members, as the focus group member said: “I am torn.” “You’ve got to plan long term,” she said, adding that “I have already been doing my homework. I got to find a place to live, a school.” She went on to explain:

“If I decide to take my children with me, my daughter automatically loses her Medicaid.” I already went through the agony of waiting seven years until she got the waiver, now I would have to face eight years. I might have to leave my family behind. It’s a ‘Catch 22’ situation. My daughter gets 24 hour care, and fortunately Medicaid pays that.”

Waiting list problems can also occur among waiver programs within a specific state. In the field research visits to military installations, an active duty soldier recounted how her daughter had been terminated from Medicaid due to a class action lawsuit which changed program operations. As she noted, TRICARE ECHO stepped in to address her daughter’s need. At the same time, she was placed on a waiting list for another program in the state. However, she has little optimism about receiving this Medicaid waiver service. As she said,

“I will probably be on this for the next ten years. The list is longer than my arm. In the mean time I still have the same issues with my daughter, what makes them think that things are going to change?”

Unfortunately, waiting lists are amorphous and non-standardized across the state, so too are the waiver programs which have different purposes, target populations, eligibility criteria, and treatment and service provisions. As one expert in Virginia explained to a field research team, the transferability of a guaranteed waiver slot may not be the solution for families moving from state to state. For example, while Virginia has a DD (developmental disability) waiver, Massachusetts does not. Thus, this would not be a solution because the program would simply not be there “because the states have the flexibility to design their own programs, and they don’t match.” The differences in state approaches may also have an effect on waiting lists, as explained by a developmental pediatrician:

“One thing that is different in California is that it didn’t put all of its disability services under MediCal [the state’s Medicaid program]. And so there are not those enormous waiting lists for Medicaid based services, because the state pulled that out and put that under a different funding hat to their Developmental Disabilities Divisions which are then managed by their regional centers.” So families are better off here, then say Virginia, where there are very long waiting lists for ABA funded therapy.”

A developmental pediatrician noted that transferable waiting list status from state to state would be very difficult to implement and manage. As he noted the problem is that there “is a line” for the waived service. He recognized the need to not “disenfranchise someone because they are moving from Texas to Virginia” and added that there should be some respect for someone’s place on the list. “People don’t even fool with waivers because unless they know they are going to retire here they know that they will never be here long enough to get the benefit.” He added that while waiver waiting lists affect all – both civilian and military families – the burden is disproportionately on military families.

In the tables below, the estimated waiting list numbers are presented for the ten states that have the highest active duty military populations in the nation. These ten states account for 69.9 percent of the active duty military members located in the United States (U.S. Department of Defense 2011, p. 27). The waiting list figures represent estimates of the total waiting lists in each state for each waiver offered. These figures reflect the total number of individuals on waiting lists – *they do not differentiate between active duty and civilian applicants*. In addition, the waiting lists do not reflect the total potential need for these services. There may be some who are unaware of services and others who have opted not to apply for waived services. These waiting lists estimates are from a 2009 national study conducted by the Kaiser Family Foundation by Ng et al (2011). States vary in the manner in which they define waiting lists and not all fifty states are able to provide data on waiting lists.

TABLE 1
2009 Waiting List Data

<i>State</i>	<i>Waiting List Estimate</i>	<i>State</i>	<i>Waiting List Estimate</i>
California	2,030	Washington	829
Virginia	11,114	Florida	32,432
Texas	129,518	Hawaii	100
North Carolina	6,509	Kentucky	0
Georgia	11,242	Colorado	4,307

Source: Waiting list estimates are from Ng, Harrington and Howard (2011). The top ten active military states were derived from U.S. Department of Defense (2011).

In 2012 Ng et al. provided an update using data for 2011 to provide a portrait of HCBS waivers across the nation. Like their earlier report that drew data from 2009, Ng and associates reveal the complex landscape of waiver programs. As the authors summarize in their report, overall waiting lists continue to grow across the nation. They found that “In 2011, the average waiting times to receive waiver services were more than two years, and the number of persons on waiver waiting lists increased by 19 percent over the previous year.” The total estimated number of individuals on waiting lists in 2011 was 511,174 – over a half a million individuals (Ng et al. 2012, p. 3). Table 2 below illustrates both the cumulative demand of waivers and the volatility of the waiting list issue for the top ten states with active duty military personnel.

TABLE 2
2011 Waiting List Data

<i>State</i>	<i>Waiting List Estimate</i>	<i>State</i>	<i>Waiting List Estimate</i>
California	2,132	Washington	829
Virginia	7,188	Florida	44,596
Texas	157,202	Hawaii	0
North Carolina	10,722	Kentucky	0
Georgia	11,242	Colorado	4,307

Source: Waiting list estimates are from Ng, Harrington, Musumeci, and Reaves (2012). The top ten active military states were derived from U.S. Department of Defense (2011).

The wide variations in numbers among these states, both across time and space, tell us something about the distinctive state policy, legal, and political cultures that surround each state. For example, in California the state's waiver system tends to be permissive in granting individuals waiver slots. From our field research, we found that being deemed eligible for a waived service was less of a challenge in that state than was accessing services that were limited in availability. The fact that Kentucky has no reported waiting list is likely the product of the lawsuit, which brought about the "Michelle P." settlement mandating that waiting lists be eliminated. The decline in the waiting list in Virginia may also be attributable to recent court actions mandating that more "slots" be opened. The high numbers, which continue to grow, for both Texas and Florida suggest that approved waiver slots are much lower than apparent demand for these services.

Medicaid and the Waiver Administration: Role of State Agencies and Local Intermediaries

The administration of Medicaid varies across the nation. In some states, Medicaid is administered centrally by the state government and is often implemented through state field offices based in communities. In other states, this function is delegated to local governments with ultimate state control over program operations. The primary Medicaid administrative functions involve eligibility determination and redetermination, enrollment management, claims and billing management, quality assurance and fiscal oversight of the program. Since its beginnings in the 1960s, state Medicaid agencies have relied significantly on state and local welfare offices to manage the eligibility and enrollment process.

With the adoption of waiver options, the state and local administration of Medicaid has undergone significant changes. While the basic eligibility determination and redetermination processes remain in the hands of the public Medicaid agency, along with program oversight and fiscal responsibilities, much of the administration of Medicaid has been delegated to non-governmental actors. Since the 1980s, many states have contracted with HMOs and other managed care organizations to provide Medicaid services, especially to low-income families. Medicaid managed care arrangements have been allowed under what are called Section 1115 waivers and now is a common practice across the United States. Outreach and enrollment functions are often contracted with and carried out by "enrollment brokers" that conduct public relations, case management, and related services for the general low-income Medicaid population.

The utilization of HCBS waivers has also led to changes in the manner in which Medicaid is implemented. At the state level, program administration has often been delegated to departments or divisions of disability services or their equivalent, rather than the state Medicaid agency (Zaharia and Moseley 2008).

In turn, some states sub-delegate program management to non-profit community-based organizations that manage the waivers at the local or regional level. These organizations may actually be allocated a set number of waiver slots which further complicates waiting list practices. In some states, there are questions around the transferability of waiting list status if a family moves intrastate from one region to another (Auerbach and Reinhard 2006). Such concerns were raised by families as part of this study focus group interviews at a military installation in California. This unsettled situation within some states further complicates the interstate dynamics of the waiver issue.

Regional or community-based non-governmental intermediaries appear to play a more proactive role in outreach and support than traditional state bureaucracies. Not only do they implement waiver programs, as non-governmental entities they have more leeway to advocate for policy change and improvement by mobilizing stakeholder groups. In two of the states visited (California and Virginia), military family members and base intermediaries, such as EFMP staff and medical case managers, tended to give these community centers high marks in their outreach efforts. Indeed, in one visit a representative of one of these groups was brought into a panel interview by an EFMP staff member.

In a field visit, one EFMP specialist noted that the intermediary was a key community resource that families were referred to and that it served as a valued partner in connecting families to waived services and other programs. It was also noted that while the state Medicaid agency was “inconsistent” and lacked compassion, the local non-profit intermediary was responsive.

In Virginia, the field research found that one intermediary group works closely with families to determine whether they will qualify for waived services because of the severity of the disability facing the child. Most military families will not be financially eligible for Medicaid, but may be eligible for waived service through disability and special income disregard provisions that exclude the parent’s income in eligibility determinations. This organization helps families work through their options and offers workshops, webinars, and other activities to help families understand the waiver process. The Center seeks to work with families on a step-by-step basis. As a representative noted, “families can get overwhelmed, so it’s easier to give them one step at a time.”

In California, twenty-one regional non-profit disability service centers help to coordinate the state’s various waiver programs. The San Diego Regional Center was cited by many of our informants as being especially valuable in connecting families to disability services, such as those provided through the state’s Medicaid program, called MediCal, and the various waiver programs operated by the state.

While base level visits revealed some positive perspectives on the role of non-profit intermediaries, the same was not often the case for some state Medicaid agencies and their local state offices. A senior family support staff member at a major installation noted:

“The worst story that I personally encountered was a family member whose husband was deployed and she was suffering, in addition to a couple of other mental illnesses, from social anxiety disorder. And not only did she have to talk to all of these strangers herself in the Exceptional Family Member Program, she then had to turn around and deal with all of these people that work for the continuation of her medical care. Since she was only 19 it was difficult to release her records and negotiate the process. Medicaid needs to be aware that it is not only children who are special needs, but parents and adults as well”.

There were concerns also expressed that state Medicaid programs may not be fully cognizant of the circumstances of active duty personnel who are deployed. One soldier spoke of her daughter who was on waiver when state legal action forced the cancellation of the program. She was in theatre at the time and received a terse notice from the state Medicaid office. As she recounts:

“I was serving my country. And I am over there fighting a war – and I get that? [notice of termination of services] That’s undue stress. That should have never have happened. And trust me, I went all the way to Congress with that.”

At one base, a medical case manager likened negotiating the Medicaid system to learning “a secret handshake and password” that will get you into the system. Most of what she learned was from word-of-mouth. She realizes that she can help others now in negotiating the process. She noted that things were much more difficult until she “broke the code” of Medicaid. She learned a lot from “a savvy mother” and a home health nurse about the Medicaid program. As she noted:

“If they are trying to discourage people from applying for these [Medicaid] waiver programs, they are doing a really good job.”

A similar concern was raised by a senior level family support administrator, who noted

“I don’t think that Medicaid has any incentive to market itself to military families or how to enroll. So I’ve had families come to me and say so what is Supplemental Security Income and what is Medicaid and can I qualify? A lot of families don’t realize that there are income waivers and these are programs that are available to them. Unless we touch them first, they have no idea of what they can access from the state.”

The literature clearly illustrates the complexity of the waiver system. Many states operate more than one waiver that might be applicable to a family with a child with special needs facing intellectual development or development disabilities challenges. These programs are often supervised by different state agencies adding further complexity to the enrollment process, each may have different criteria and differing waiting lists. As noted by another source, in Virginia families might seek services through one of any number of waivers gaining access to one while awaiting more robust services that might be provided by another (Cann and Ogburn 2007). Similarly, the state of Texas offers an array of comprehensive and supportive service waivers aimed at those with disabilities that families could seek out (Imagine Enterprises 2007). Many of these supportive services waivers have been adopted to meet more specific needs of families who would otherwise receive services under a comprehensive waiver. According to Smith et al. (2007), states have adopted supportive services waivers – which provide for respite care, transportation and other distinct services – in response to growing waiting lists for comprehensive waivers and to hold down state budgetary costs.

Numerous waiver programs were in operation in each of the study states. The field research teams heard from families and from base personnel of experiences of seeking one or another waived service. Thus not only across states, but within states the application and eligibility process for waived services can be seen as complex. While multiple waivers have their advantages in tailoring services to those in need:

“The downside is the increased complexity for users and potential users of the services, as well as providers of services, in navigating the various waivers in systems that are already founded on complex bureaucratic structures and processes. State policy makers should consider monitoring the expanded use of

waivers and the integration of existing waiver programs to ensure the most effective use of state resources given the needs and preferences of individuals receiving support.” (Zaharia and Mosely 2008, p. 11)

MEDICAID, AUTISM SPECTRUM DISORDER (ASD), AND WAIVER SERVICES

Research conducted for the U.S. Centers for Medicare and Medicaid Services has noted that as the prevalence and visibility of ASD has increased and as existing programs and supports have been found to have shortcomings, there has been a movement toward new federal and state programs to address ASD needs specifically. As the research notes:

“This picture is now beginning to change, as more states pass legislation establishing governmental bureaus or offices dedicated to autism, apply for Medicaid home and community-based services (HCBS) targeted to persons with autism or ASD, and move to adopt and implement on a broader scale evidence-based/promising practices targeted directly on ASD” (Abt Associates 2011, p. 9).

Medicaid has been one of the platforms used to address ASD needs. In some circumstances those with ASD will qualify for Medicaid home and community based services. However, it has been noted that “although people with autism can potentially receive services under these waivers, many do not because they do not meet eligibility rules or because the states limit enrollment” (Spigel 2007). Eligibility criteria based on severity of condition varies across the states. A 2007 legislative analysis conducted in Connecticut suggested that among the states with the most stringent eligibility criteria were Virginia, Mississippi, and Alabama. Over the past decade, some states have begun to develop HCBS waivers aimed specifically at children with ASD. These include Colorado, Connecticut, Indiana, Maryland, Missouri, Pennsylvania, and Wisconsin (Spigel 2007, Abt and Associates 2011).

Just as Medicaid served as a mechanism to encourage changes in the intellectual disabilities and developmental disabilities treatment paradigm, by encouraging home and community-based services rather than institutional-based care, it now appears that Medicaid is playing a similar role in directing resources toward ASD care. However, it is essential to remember that as in past iterations of Medicaid reform, variation is the essential element among the states. As Abt and Associates found in their study for the U.S. Centers for Medicare and Medicaid Services (2011), state approaches to serving the ASD population, both through Medicaid and other tools, varies in terms of methods and criteria for diagnosis, funding of programs, treatment and services, outcomes assessments and the basic administration of programs.

Autism services vary across states, even those that are funded through Medicaid and operate under HCBS or related-waiver programs. It may be that those with children with medical conditions find it easier to negotiate the process than those with behavioral issues. Military families moving across states are likely to encounter differing services and arrangements among those states that have targeted ASD through public services, programs and supports. Complaints about Medicaid waivers may be misplaced for ASD families. They may want to be on waived services but would never qualify whether in the civilian or the military system. The severity of their autism may not reach a level that would trigger the institutional based component required of HCBS coverage. The answers to autism issues may be found within the military health system, rather than in the patchwork of services provided to families through state Medicaid systems and waiver programs. This may help to explain why advocates for autism services and

coverage have been pressing steadily at the national level for TRICARE to provide more services for family members with autism.

In the view of some of the base level personnel interviewed for this research, access to Medicaid is especially difficult for those with developmental disabilities – such as ASD – who have no concurrent physical disabilities or severe medical conditions. As one developmental pediatric staff member noted, those with intellectual disabilities or autism will have to wait a long time for Medicaid. Some of those with profound physical needs that are qualified for services are not wait listed. Similar observations were offered at other installations visited. A medical case manager at one base noted that the Medicaid system appears to be more accessible for those with physical disabilities. In addition, for those children with autism who are able to access a Medicaid waiver, they may only qualify for limited services under supportive rather than comprehensive waiver programs. As noted by one developmental pediatrician at another base in a state that does not have major wait list challenges:

“We have a considerable number of families that possess the waiver. However, what the waiver will provide to them monetarily tends to be quite limited. It is limited especially by their medical need. If it is a cognitive disability or an autistic disorder, their benefits from the waiver might be limited to incontinence supplies for children who are not toilet trained. This might be the only care provided.”

MILITARY FAMILIES WITH OLDER CHILDREN AND THE MEDICAID SYSTEM

Research on military families with special needs tends to focus on children with special needs. In conducting the research, the WVU team sought further perspectives on the needs of older children and adult dependents. Among this latter group, the research team was particularly interested in adult children who continued to live with their parents. Due to the increased prevalence of autism and the continued need to serve those with disabilities as they mature, there is considerable strain being placed on health systems to respond to the needs of these individuals. As families explained in focus groups, it is not impossible to get Medicaid coverage as a child ages, but there is a constant struggle to maintain eligibility over time. For example, eligibility for services is subject to periodic redeterminations of the child's income and health status. One focus group member talked about his son who is 19 years old. He recounted that as you advance in rank and the child advances in age, it is more difficult to qualify for Medicaid services. It is difficult for military health systems to provide all the services that you need. With the eligibility redetermination process, “you have to go through all of the ropes to get services downtown.”

For those families moving out of active duty status, an important consideration involves making arrangements for older and adult children to qualify for public assistance and health services in the civilian world. Success in negotiating this system is highly contingent. For example, in one focus group session, a parent recounted how a local social service agency staff member was extremely helpful in the family's successful efforts to have their daughter deemed eligible for SSI benefits. The parent credited success to establishing a good one-on-one relationship with the agency representative. At the same focus group, another parent admitted that she was not aware of the scope of benefits, such as Medicaid coverage, that were available to her older child now that she was receiving SSI. Community agencies can provide an important intermediary function in helping families qualify for, and access, publically-funded services such as SSI and Medicaid.

CONTINUING AND EMERGING CHALLENGES: MILITARY HEALTH SYSTEM, MEDICAID, AND SUPPORTS

Through field and ancillary research the findings suggest some continuing and emerging challenges that should be taken into account in assessing active duty military family access to special need services, programs and treatment. These involve 1) relationships between the military health system and Medicaid, 2) the need to promote and understand ECHO utilization, 3) the need for the EFMP providers to be trained on more effective referral processes to Medicaid and/or ECHO to assist families in accessing needed levels of care and service 4) the need to work with, improve, but not overly rely on informal networks of knowledge and expertise in the military community, and 5) the need to increase consistency in programs and coordinate practices across the military service branches. As a result of these continuing challenges, there is already evidence of some best practices and formal responses in meeting some of these concerns. This section of the report examines these issues.

Military Health Care and Medicaid: An Unclear Relationship

Medicaid can provide secondary or wrap-around coverage for services that TRICARE does not cover or does not fully cover in terms of expense or need. This is a distinct arrangement in the American health care system, analogous only to similar arrangements found between Medicare and Medicaid. Shin et al (2005) analyzed the relationship between Medicaid and TRICARE through their examination of children with special needs in the military population. As part of their analysis, they conducted telephone interviews with four TRICARE Beneficiary Counseling and Assistance Coordinators (BCACs) at four separate military installations. Though their findings are limited to the very few intermediaries they talked to, Shin et al. offer findings relevant to the interface of the military health system with Medicaid. While their conclusions are somewhat optimistic that “military personnel at all sites are equipped to assist families with Medicaid enrollment as well as to identify other federal state, and community services” (Shin et al. 2005, 24-25), the authors also note some key concerns were further explored in the present analysis. This includes that knowledge is at best anecdotal at the base level regarding the number of families accessing Medicaid at the installation; that it is not unusual for families to have difficulties accessing specialty providers due to lack of supply and increased demand; and that there is not an active Medicaid presence on installations in the form of out-stationed agency Medicaid personnel conducting outreach and enrollment. At the time of the Shin et al. analysis, the ECHO program was on the threshold of adoption. The authors speculated that ECHO coverage would supplant much of the needs-based demand for Medicaid waived services, but that a connection between the two programs would continue in those situations where families exceeded coverage caps provided by the ECHO program.

From our research we found instances where the interface between TRICARE and Medicaid is not always smooth. In a number of instances, we were told that these systems interact effectively or efficiently in terms of provider reimbursement or billing procedures. As a medical case manager at one major MTF told us, in order to be reimbursed for services provided, TRICARE must first review and deny claims before Medicaid coverage will “kick in” and such reviews can take a long time to complete. This friction can serve as a disincentive to providers to accept TRICARE beneficiaries as patients and clients.

A number of remedies for improving Medicaid assistance to families were suggested by base command, MTF personnel, and family support personnel. A common theme was “out-stationing” state or local Medicaid representatives assigned to large military treatment facilities that would have sizable populations of potentially eligible beneficiaries. Said one medical case manager, this would be “huge.”

These arrangements are used in a number of states at civilian hospitals. At another base a senior family support administrator, also suggested that there could be a closer working relationship between state Medicaid agencies and the EFMP office, such as helping with case management. She cited precedent for this by noting that the WIC (the Women, Infant and Children nutrition program) program conducts outreach and enrollment at her base in cooperation with family support services.

A senior level MTF commander suggested that an exchange program between military health administrators and Medicaid administrators might also be helpful in getting both systems to understand each other's worlds. Through these arrangements military personnel could work in state Medicaid offices to learn more about the program and the processes, in turn state and local administrators could work with MTFs and other base entities involved in health care and family support.

The lack of interface between Medicaid and TRICARE also creates frustration for health care providers and other personnel involved in serving families in the military health system. One developmental pediatrician recounted the difficulties involved in determining which services might be covered by Medicaid and which would be covered by TRICARE. As he said:

"It gets to be a little like the tax code for us, trying to figure that out for families." "Once their eligibilities are determined we do not try to take Medicaid's job from them, to advise the families in the specific of the benefit." "We certainly make families aware of their possible Medicaid-SSI eligibility and that a waiver program does exist for kids with severe disabilities."

Both the military health system and state Medicaid systems, and other public programs, face serious constraints. Medicaid does not work seamlessly with the military health system due, in part, to the variability allowed to states in program design. Resource constraints further complicate these relationships. For example, at the local level, community based organizations responsible for implementing public programs may be reluctant to expend scarce resources for military families who are seeking to augment benefits that they are already receiving from the military and local communities may not have the resources to meet the demands of military families. As noted in previous evaluations, local communities may not have the resources to meet the demands of military families (U.S. Government Accountability Office 2007, p. 9). The issue of respite care is a good illustration of this, where funded supports are strictly allocated since demand far outstrips available funding. At one site, field researchers heard the following from a focus group respondent:

"That happens with a lot of services. They won't piggyback. Regional Center [a non-profit community-based agency that administers Medicaid waivers under state contract] won't provide service if you already getting them through somewhere else – even if there is a gap in those services. Your service is only covered up to this point, you need additional, well you are receiving it so we are not going to give it to you."

The WVU study suggests that some of the strongest actions can be taken by forging clearer relationships between the DoD and the CMS. These sentiments were expressed as well by key informants at the base level – such as senior commanders, physicians, and family support providers. As a senior level commander explained, "we try to do what we can at a local level" but at the national and international level, there needs to be resources, and there is a need to agree on what standard of care and services are provided in an equitable manner. Medicaid has a role to play in helping military families, "but it is one resource, not the only." He noted that it would desirable for Medicaid to be more responsive to military family needs

and he cited the desirability of having eligibility follow families along the model of the interstate compact for education.

The field research suggests that among military personnel – especially at the supervisory or command level – there is a recognition that the waiver “wait list” problem exists and that DoD and Medicaid could work more effectively in serving the needs of active duty military families. These leaders express concern about the situation and support for the families. It was very common for senior leadership to advocate for new policies that would allow a military family member’s “place in line” to be transferred to another state. However, beyond this general level of cognizance about the issue – there seems to be very little understanding of what Medicaid waiver programs are, how the wait lists are comprised, or what type of services – beyond respite care – are offered by Medicaid waived services. This is not a criticism of base level leadership, but rather an encouragement for these commanders to have accessible to them clear guidance on the realities of Medicaid program operations. In our opinion, both CMS and DoD could play a stronger role in helping base commanders and other key stakeholders understand the complexity of the waiver issue.

While states exercise considerable discretion in the operation of their Medicaid programs, they are subject to federal oversight and mandates. States take policy direction and cues from the Centers for Medicare and Medicaid Services. Field research interviews with base commanders suggested that it is difficult to establish relationships between installations and state government. Sometimes it is a matter of distance from the state capital. There are other organizational and practical matters at stake as well. As one senior base administrator noted,

“[The state capital] is pretty far away from most military family issues. It doesn’t seem that they are very responsive to them unless a lot of pressure is placed. And military leaders are not politicians, they are not into that, and very rarely try to exert pressure.” “The states are permanent, the admirals and the base commanders are in here for two or three years.”

Relationships between bases and government agencies, where they exist, tend to be at the local level and involve specific matters of service provision, enrollment procedures, and other immediate matters. These relationships do not involve matters of policy, program review or strategic planning. In our opinion national-level guidance is required.

In sum, there is a widely shared belief that the military health system is not well connected with the Medicaid system. While many in the military health and family systems are generally unfamiliar with Medicaid, those who are familiar with the program often offered suggestions of how improvements could be made in facilitating Medicaid access. However, the WVU study found that there also needs to be a better understanding of *why* the Medicaid system needs to be accessed. As noted throughout this report, reiterated here, and further discussed in the remainder of this report, Medicaid should be seen as a fallback option to be pursued only after all available resources in the military health and family support systems have been exhausted. While beyond the scope and purpose of this report, it should be emphasized that the most important linkages between the Medicaid and the military may be for non-active duty military members and their families rather than those on active duty status.

Enhancing Awareness and Understanding of the ECHO Program

It is our impression that ECHO can provide a safe harbor for military families from the uncertainty of Medicaid coverage – especially through HCBS waivers. These waivers occupy a policy niche that can be highly politicized. There is any number of stress or tension points in waiver arrangements. This leads to overall instability within and among the states regarding waiver services in terms of their breadth of coverage and availability. This volatility is a function, of part of the following:

- 1) There can be inherent tensions between long-term care providers and in-home care providers over waiver programs. Long-term care providers may perceive HCBS waivers as taking business away from them. They may see a HCBS waiver program as “skimming” or “creaming” lower-cost patients from the long-term care market thus raising the overall cost of care,
- 2) With a limited number of slots, there may be tensions among those who might utilize the services. Determinations for who receives waived services are not simply a function of who is “next in line” – waivers may be designed to address specific populations or the severity of a condition within a targeted population,
- 3) There can be state-level concerns over the fiscal impacts of providing waived services – especially if there are expansions to newly eligible populations due to health status and new ways of determining eligibility based on income, and
- 4) There may be state and federal tensions regarding reporting requirements and other regulatory issues associated with the development and operation of a waiver program.

As a result, while intended to provide a platform for service innovation and expansion, the waiver programs also reflect the patchwork nature of Medicaid program design and delivery that is inherent in this joint state-federal program. Military families moving across state jurisdictions are likely to find many barriers to accessing Medicaid and waived services.

The contingency of state programming and variation across states is well understood in the military health and family support system. For example, in the 1960s, the DoD established the Program for the Handicapped, later renamed the Program for Persons with Disabilities. These programs were designed to provide consistent services and health coverage for families with special needs members through the military health systems. The need for this was recognized because of the difficulties of achieving eligibility in states due to various residency requirements. This program was established at a time when programs for the disabled were a patchwork of services across the states. The need to more formally coordinate these services would eventually lead to the Social Security Administration assuming responsibilities for what had been the responsibilities of the states. From this the Supplemental Security Insurance (SSI) and Supplemental Security Disability Insurance (SSDI) programs were established.

ECHO can serve very much the same purpose of its predecessor DoD programs by anticipating the distinctions between state Medicaid programs, and perhaps by anticipating the difficulties encountered by families seeking to gain eligibility with the federal SSI program. However, in order to be effective ECHO needs to reach its qualified target population. This requires actuarial estimation of the potential population served and requires assessment of the enrollment or “take-up” rate within this population. Both of these crucial matters are beyond the immediate scope of this analysis. However, from the field research there are indications that ECHO should be given more prominence and visibility at the installation level and that base-level support systems might better coordinate and integrate communications and

guidance to families relating to this important TRICARE coverage option. This linkage is especially important since all ECHO beneficiaries are required to be enrolled in the EFMP.

Base level intermediaries seem to have relatively little knowledge of TRICARE's ECHO program, beyond some of the services that are provided to families. Closer connections might be made between ECHO case managers, Beneficiary Counseling and Assistance Coordinators (BCACs), and EFMP personnel at the installation level. The BCACs are an essential component to a family's process for navigating this system. BCACs and other important personnel should have familiarity with provider and service capacities of the region, how TRICARE and Medicaid work together on claims, and how the referral and application process is handled for individual cases. They should also be familiar with broader trends in Medicaid eligibility systems and most importantly, the availability of waiver services. However, these personnel often appeared to be disconnected from the EFMP and family support service programs. While the field research teams were able to meet with BCACs at some of the bases visited, they were not able to meet with them at all of the sites. Indeed this can be considered a limitation of the WVU study. However, because the researchers had to rely on base level points of contact to arrange interviews for us, there was little that could be done to control this. The BCACs absence in some of the field level interviews suggests that relationships may not always be well formed between BCACs and EFMP personnel. These connections should be robust to ensure that ADFMSNs are properly accessing needed health services, insurance coverage and supports.

While some expressed concerns about coverage limitations and financial caps on benefits, for the most part those interviewed through the field research who had ECHO coverage were positive about the program. A number of active duty personnel complimented the case managers who work in the ECHO program. They mentioned that they provided help in the PCS or transfer process and provided assistance in trouble shooting. As one focus group member reported, the ECHO representative is important and, "they will stay with you in your TRICARE region no matter where you are transferred." "If you move to another region, you will be assigned another and when this happens there may be some disruption."

The ECHO benefit provides substantial coverage to families for services and benefits that would not otherwise be provided under TRICARE basic. ECHO is limited only to active duty family members, so some military families may face a dilemma as to when to exit from the service. As one developmental pediatrician noted, "the TRICARE benefit is robust enough so that Medicaid is the payer of last resort." He noted that Medicaid is most relevant to providing supplies, like diapers. He added that retired families are having more difficulties due to the lack of coverage from ECHO and their inability to get on Medicaid: "There are decisions where families and sponsors delay their transition to the civilian community."

FAMILY SUPPORT SERVICES: THE EXCEPTIONAL FAMILY MEMBER PROGRAM (EFMP)

In response to growing concerns about the welfare of military families, the DoD has developed or enhanced its systems of family support. In providing the family support function, "state and local medical, family support, and educational services in these communities may also serve the military's exceptional family members as part of providing services to local residents" (U.S. Government Accountability Office 2007). Effective EFMP family support implementation relies on program personnel and practices being tightly networked with resources and services offered both on base and in the community. Such networks can be facilitated by program staff knowledgeable of key community and public-based supports, such as

Medicaid, and their relationship with the MTF and TRICARE. The EFMP should play an important role in helping families access and negotiate Medicaid.

The field research found that base intermediaries are not well connected to Medicaid, either in terms of familiarity with the system or with contacts to local or state agencies. When it comes to Medicaid we found significant deficiencies in the level of knowledge, familiarity, and guidance by EFMP personnel and other base level intermediaries who should serve as key reference points and resources for military families. There were some important exceptions to this, but this reinforces the point that the most effective personnel are those who are plugged into informal networks or have personal knowledge and experience with children and other family members with special needs. However, these cannot be considered best practices because they are not replicable.

A review of relevant documents, government reports, and field research illustrate, 21st century military family support functions are still a work in progress. There are clear organizational differences across the Services in the approach to working with families and local base cultures and local civilian communities. In this regard, the report's findings are similar to those offered in previous assessments of the EFMP process across the Services (U.S. Government Accountability Office 2007, Heubner 2010, National Disabilities Council 2011). There is also a growing recognition that family support systems need to be more proactive in helping families navigate complex healthcare and community support systems both on and off the military installation. In our research we found acknowledgement that systems need to be assessed and improved, we also found frustrations being expressed by some families and others who expressed appreciation for what the military is trying to do to help families with members with special needs.

EFMP Family Support Services

The essential components of the EFMP are: 1) to identify and enroll family members with special educational or medical needs, 2) to consider these special needs in coordinating the sponsor's assignments, and 3) to provide family support services. The field research found that the EFMP family support has developed information systems and practices that can lend to the "warm handoff" that is the goal of every PCS experience. We realize that to be effective EFMP family support needs to be fully integrated with the web of support services that are available to all families, not just those with special needs. At the base level, medical and family support services have a continuing obligation to assist families in accessing needed services. They also have a role to play in helping identify families with newly emergent special needs concerns.

Both the nature of the military health system and the needs of family support systems require interaction with the programs and services that are offered "outside of the gate." At a number of installations, we found significant engagement with community-based resources aimed at providing help and assistance to families. This included annual events for children with special needs, like fairs and outings; liaison work with family support groups, engagement with local school systems, and relationships with various community-based service organizations, like Easter Seals and other agencies.

The field research found significant variation among family support staff regarding their knowledge of Medicaid and the strength of the relationships that they had formed with key intermediaries both on-base and in the community who could serve as a resource to families with special needs. In its family support function, the EFMP should act as a hub in a network of on-base and off-base community services,

programs, and resources for active duty military families with special needs. This includes those children and adults who might qualify for services provided by TRICARE ECHO and Home and Community Based Services provided by Medicaid programs.

The field research suggests the strengths of these networks can vary widely. In some cases, it appears that other personnel who should have a key role in helping connect families to Medicaid and other needed services may not be fully aware of the services that might be available. It was disconcerting to find that many of the base level intermediaries who were interviewed had very limited knowledge of Medicaid and even less engagement with Medicaid program staff. The only exception to this was at military installations that worked with local non-profits that were hired by states to implement various Medicaid Home and Community Based Service waiver programs.

The field research interview protocol (Appendix B) identified Personal Finance Managers (PFMs) as an important contact. They are in a position to understand the general economic situation of families at the installation and to provide guidance. It was anticipated that PFMs would also be effective reference points for connecting families with public programs and services such as Medicaid, SSI, and specialized programs. However, this does not appear to be the case. In interviews, the PFMs noted that they dealt primarily with families' consumer and housing debt issues, rather than with health care and cost issues. There was little interaction with Medicaid. As one PFM said:

"I've never had anyone ask me about Medicaid. If that need arises, you know, I go to Google first and then to my site director and my program director and find out what tools and resources we have out there."

Given that health care costs and support service costs can be a significant financial burden on families, further attention may want to be given to encouraging stronger liaison between EFMP family support staff and these staff members.

During one base visit, a family support specialist mentioned that she does not deal with Medicaid or waiver issues, leaving these matters instead to the TRICARE system. This was not uncommon across the base visits. The field research teams found that intermediaries are not always well connected with the Medicaid system. This is especially the case with family support services, and EFMP family support staff assigned to or located with family support. Even in the MTF setting, we found a lack of systematic Medicaid program knowledge. For example, when asked how patients are dealt with when they make inquiries about Medicaid, a patient relations manager responded, "we can give the number to Medicaid" but beyond that they do not help. "We rely on the internet and look at the local services," "as for talking to a Medicaid representative – no we don't." He does not have any contact with Medicaid and had no opinion on the enrollment process, challenges, or difficulties. "We look at Medicaid from the TRICARE plan view" and "depending on what has precedence over TRICARE," "we look at the supplementals, like Medicaid. Unless they are not happy with TRICARE, we don't mention Medicaid." He noted that there are instances when those on TRICARE also have Medicaid, "we see this on DEERS (Defense Enrollment Eligibility Reporting System), because sometimes we see that they have another coverage, thinking it is another carrier, and then we find out that have Medicaid eligibility."

The field research suggests that in many instances Medicaid appears to be viewed as a low-income public assistance program rather than a publicly-supported health insurance program that can provide wrap-

around coverage for qualified military families. There is a wide-spread assumption that families will not qualify for Medicaid due to income factors. It is important for military families to understand their options under the more relaxed income determination procedures enabled by the Katie Beckett Waiver programs used in many states and the various HCBS waiver programs that factor comparative eligibility for institutional care. Familiarity with these policy arrangements is important for those both on the medical and family support side of the EFMP process.

Those in family support services, including at times EFMP staff, were forthright in acknowledging their lack of familiarity with Medicaid systems and processes. In some cases, they deferred to the expertise of counterparts in the MTF. This sentiment was expressed by one staff member who noted, “I don’t know a whole lot about Medicaid waivers” but “our case managers at the hospital” do know about the program.

This study suggests that the locus of Medicaid expertise on bases is with MTF personnel, including staff in the EFMP office at the MTF, medical case managers, and developmental pediatricians. These personnel work closely with families and have often become key intermediaries. Many of these children have severe physical needs and conditions, such as the need for feeding tubes and ventilators, and these conditions are more apparent for diagnosis, so they appear to be more quickly referred to and enrolled in Medicaid when they qualify for services. In general, families with members with intellectual and developmental disabilities may not have as ready access to the Medicaid system. At a number of installations visited we saw optimism that the military can provide more effective care through the medical home concept and active case management. One senior MTF commander took the perspective of the parent when explaining the need for a proactive approach when he commented:

“If you are telling me that there is something wrong with my child, I am not focusing on much else. That is another reason why it is helpful to have a consult coordinator to aide families in making appointments, making sure that appointments are followed up on by providers, and providing general guidance. We want to make sure that those are hands are held” as necessary to get them where they need to be.”

Informal Networks

In their study of support services for military families with special needs, Huebner et al. (2010) commented on the importance of informal supports and relationships that provide assistance to military families. Families are increasingly relying on social networking sites to get information for their families. They tend to navigate the system on their own, sometimes with the assistance of other base resources. The question that needs to be asked is whether these institutional sources of base support are now acting as an adjunct rather than as a lead for families seeking to access resources and services for the family members with special needs. As one developmental pediatric staff member noted, “our families are more knowledgeable.” “They network more,” but they might not recognize that what’s available in one state is not available in another – and that can be frustrating.

Best practices can be rare practice. The informal networks and dedication of individuals that help families negotiate the complex processes associated with accessing medical and other care through TRICARE and through Medicaid should be lauded, but these are not a sufficient foundation from which to build effective systems. It is true that informal network have many advantages in allowing peer-to-peer and lateral sharing of knowledge and information, but they may also have their drawbacks. Most significantly,

obsolete or inaccurate information may become embedded in these networks. Too much deference may be given to those with status and stature based on their past experiences or reputation. Health insurance policy in general, and Medicaid policy in specific, is complex and ever changing. Those who are “in the know” now may not actually have up-to-date knowledge as policies and practices change. In a number of interviews with base personnel, we found instances when these intermediaries noted that they relied on informal authorities as sources of assistance, knowledge, and expertise.

We caution that these arrangements should not be a substitute for more systematic and institutionalized knowledge of Medicaid and other related health insurance matters. The management literature has long recognized that informal communication networks have both benefits and drawbacks. Among these drawbacks are information distortion, either by purpose or accident, and a lack of full dissemination of information because not all affected parties are guaranteed access to information (see Hall 1996, Jaffee 2001). Clearly, the importance of established institutional memory and capacity to understand and disseminate information relating to health care coverage, insurance, and assistance cannot be over emphasized.

SUMMARY MEDICAID AND MILITARY FAMILIES

This study provided an opportunity to learn more about the context and depth of issues surrounding active duty military families with members with special needs. It explored in detail the various organizational services and programs offered to these and other families that make up the military community. Field researchers had the opportunity to witness the context in which services are offered by visiting bases and their military treatment facilities and their family support and related services offices. Perhaps most importantly, researchers were able to meet with parents – both active duty sponsors and their spouses.

Medicaid is best seen as part of a loosely woven fabric of supports and services for active duty military families with members with special need. The WVU study finds:

- Military families with children and other family members with special needs turn to Medicaid to rely on specific services and coverage that are either not provided or are in short supply in the military health system. This includes respite care, transportation, supplies like diapers for older children, durable medical equipment, and nutritional products like formula. Medicaid provides supplemental services to the military health system.
- Military families are most likely to access the Medicaid system because of the health status of their child or family member, rather than qualifying due to low income economic circumstances. Those children with physical disabilities more readily access the Medicaid system than those with intellectual development conditions.
- The pathway to Medicaid eligibility for medically needy or disability-related reasons is not necessarily smooth. The process for determining SSI eligibility, which often, but not always confers Medicaid eligibility, as well as monetary benefits can be daunting. When income and asset tests are used for military families to determine eligibility for various services and programs, the process is complicated by surges and changes in income due to per diem, combat, and related pay. Housing allowances are also counted as income when a family resides off base. The age of the child may also affect eligibility.

- There is a widespread perception among families that it is not worth applying for a waived Medicaid service because the waiting period will likely exceed the duration that a family is assigned to a duty station.
- There are cases where military family members face decisions about leaving a child in one state to live with relatives and receive a waived service while the service member PCSs and is assigned to a new base in a different state. This situation occurs when the child is receiving waived services in the current state of residence.
- Among those families that have children with intellectual developmental disabilities and autism, one of the greatest needs is respite care. Home and community based waiver programs are seen as a lifeline to supplement the respite care benefits provided by the military health system or by the respite care programs of the various Services. It is not clear whether other alternatives provided by the DoD, such as TRICARE ECHO, are being fully utilized by families in need.

As the foregoing suggests, there is a need to be attentive to the overall policy and practice landscape relating to special needs services and programming – especially in the civilian sector. A major “take away” of the research is that Medicaid is not a reliable alternative for active duty military families seeking assistance in health care and support services. The following should be kept in mind regarding Medicaid and Medicaid waivers:

- Medicaid is not a reliable alternative to the services provided by the military health system. Eligibility hurdles are set high. Enrollment procedures are complicated and take too long. Services and coverage differs across states. At any time, waiver services may be disrupted due to budget cut backs, lawsuits, and other contingencies.
- By design, waivers constitute a patchwork of demonstration projects and exemptions from federal regulation across the United States. While there are many similarities across state systems, these waiver programs are not intended to be coordinated or integrated with each other. Indeed, waiver programs further reinforce the ad-hoc and patchwork nature of Medicaid programs across the states.
- Even within a state there may be more than one waiver program – relating to home and community based services in operation. Some of these may be comprehensive waivers which offer a full range of services: others may be supportive service waivers that target specific benefits and supports, such as transportation and respite care.
- Eligibility for one waiver program in a state does not guarantee eligibility for other waiver programs offered by a state – waiver programs are often targeted to specific populations.
- Considering waiver services are in such high demand, the lack of availability of “slots” authorizing an individual to enroll in these waived services may be limited. As a result, there are “waiting lists” in many states for waived services. There is no standardized procedure in constructing waiting lists. Some states have more formalized procedures than others in which they only place an individual on a waiting list once they have been deemed eligible for Medicaid, while others allow individuals to be on a waiting list and then have their eligibility determined. “First come, first served” practices are common in waiver programs, but states also utilize prioritization practices that take into account the severity of need for a service.

- The lack of standardization among the states in how they structure waiver programs and how they control access to them (such as through waiting lists), makes any proposal to transfer one's status "in line" from one state to another impractical.
- Even in the best of all worlds, where there were no waiting lists and where Medicaid eligibility and enrollment systems were to mesh well and responsively for military families, relying on waived services is problematic for active duty military families who are subject to PCS or transfer. The reasons are simple: 1) standards vary across states in terms of income and categorical eligibility criteria, 2) similar waivers from state to state, such as HCBS waivers, may vary in content and approach, 3) states operate waivers within fiscal constraints which may limit the amount of services or coverage that a qualified family will receive.

For the DoD to be able to fully grapple with the waiver wait list issue, there is a need to breakdown and more carefully study the underlying problem that has been presented for response and action. With this said, the following general points should be considered:

- There needs to be a clear delineation of the problem as it exists for active duty and non-active duty military (including non-activated reservists and retired personnel covered under TRICARE with family members with special needs).
- The gateway to Medicaid is very limited for active duty military families, and, in many cases, perhaps should not be necessary. The DoD has long anticipated the needs of active duty families facing residency challenges to state program eligibility through its Persons with Disabilities Program and later through the ECHO program. Greater emphasis might be given to assessing the efficacy of ECHO in terms of accessibility, benefits, and enrollment.
- For active duty personnel with children with special needs, the Medicaid system is likely too difficult to navigate to satisfy coverage needs of these families. This report has sought to illustrate and explain the lack of consistency in how waiting lists are managed across the states; the variety of waiver programs that are implemented and the contingency of these programs availability due to funding and political reasons contribute to the challenges associated with the Medicaid application process. Ideally, the ECHO program was developed and can be further enhanced to off-set the need for supplemental insurance from Medicaid for these active duty families with members with special needs.
- For non-active duty personnel who maintain health coverage through TRICARE, the issue becomes one of degree of assistance that the military health system provides to families seeking to access supplementary benefits and coverage through Medicaid – and other appropriate publically-funded programs. Offering recommendations regarding this is beyond the immediate scope of this study, but should be considered.
- While these two populations can be separated for purposes of analysis and response, in the political and policy arena relating to family members with special needs that the distinctions between active and non-active duty personnel are not being made. Instead, both populations are being combined and considered as a whole.

The OSN is charged with providing oversight, education, outreach and training for systems aimed at serving military families with special needs. It has at its disposal many sources of information for analysis, planning and action. With this said the study offers the following recommendations:

- It is necessary to analyze the types of services and treatments that are being utilized by active duty family members. DMDC data and other data available to the DoD are important sources of information that can be analyzed. DoD should establish reliable estimates of current and project estimates of qualified active duty family members who should be enrolled in ECHO, based on special needs health conditions. This should be followed by an analysis of “take up” rates in the ECHO program among this identified population.
- Considerable differences between the qualified population and those enrolled should trigger planning activities focusing on outreach, education, and enrollment. Both intermediaries (e.g. BCACs, EFMP personnel) and affected families should be targeted.
- In providing supportive services to active duty personnel, EFMP staff and other support staff and programs need to be more proactive in providing assistance. This may call for clearer coordination of ECHO and EFMP enrollment, outreach, and navigation activities.
- Just as state systems must anticipate that more and more children with special needs will be transitioning to adulthood and may require continuing long term care, so too should the military health system.

Federal and state Medicaid authorities also have a role to play in helping families understand and access Medicaid services as appropriate. The following should be considered:

- DoD should work to establish liaison relationships between TRICARE and the Center for Medicare and Medicaid Services (CMS).
- Through collaborative and joint action, the DoD may request that CMS consider providing policy guidance to state Medicaid systems regarding the needs of military families.
- DoD may request that Medicaid consider out-stationing personnel upon request at PCS orientations, at major MTFs, or at designated events.
- The DoD and Medicaid should be especially attentive to the needs of non-active duty military families and those active duty military families that will soon be transitioning from active duty status. There is likely a need for education and outreach to help these families once they reenter the civilian world.

The WVU team was impressed by the resiliency of the military families that they met. These families face many challenges and navigate a complex system the best they can. The team was also impressed by the sincere interest expressed by base personnel (from command, to MTF personnel, to EFMP and related support services) in providing assistance to military families. To enhance family connections to Medicaid and other services, the study observed that:

- The special needs military population is by design concentrated in a number of hub areas in the United States due to the need for many family members to be stationed near a major medical facility or civilian medical center. The DOD should be attentive to any unintended consequences associated with this practice. These hub areas may also be in areas with high civilian demand on the same “beyond the gates” service providers in the community. Staffing ratios of EFMP family support, medical case

managers, and other support staff should be regularly assessed to ensure that they are proportionate to the special needs population at a specific base.

- In areas of high concentrations of active and retired military personnel – such as compassionate reassignment sites, homestead sites, and those bases with significant MTF capacity – special attention should be given to cultivating relationships with state and local Medicaid administrators to better develop lines of communication and understanding of the needs of military families. The EFMP process should be particularly sensitive to the needs of active duty sponsors and their families in these locations.
- Medicaid and other related support programs (such as Supplemental Security Income) can be complex in terms of eligibility guidelines, benefits, coverage, etc. Military support staff, such as EFMP personnel, may need to be more proactive in guiding families through the application process. More training and education for staff might be helpful.
- Brochures, handouts, and flyers that are distributed at the base level should be up to date. To assist in this, various publications should be dated so that it can quickly be determined whether they are obsolete.
- State and local offices responsible for Medicaid administration might benefit from being further aware of the special circumstances of military families. On more than one occasion, those interviewed suggested more interaction – perhaps through the out-stationing of state Medicaid personnel at major MTFs to assist families in the application and enrollment process.
- Through our interviews and focus groups, we found frustration about state residency requirements that mandate that a family be in a state before applying for Medicaid. With a three to six month window of transition in a typical PCS, it might be helpful for a family to have presumptive or advance qualification to apply for Medicaid in the state to which they are transferring.

CONCLUSION

This study sought to explore and reveal issues relating to active duty military families with special needs access to health care and allied support services. Research was carried out with the primary purpose of examining these families' experiences in accessing Medicaid services. In doing so the study focused on evaluating the military's health and family support systems and their capacity to assist families in their efforts to gain Medicaid coverage. Of central concern was access to services provided primarily through Medicaid's HCBS waivers and plans. As often happens in field research, which is an inductive process that relies on the perspectives and insights provided by those interviewed, these efforts revealed new dimensions and issues that were not originally anticipated when this study was designed. By working closely with OSN and with the families and base level personnel, the WVU team was able to discover and reveal a number of issues that may assist the DoD in better serving active duty military families with special needs.

The Medicaid system is structurally incompatible with the needs of active duty military families. There is simply too much variation across state Medicaid systems to ensure that military families moving across state lines will have access to needed services and programs. We also found a lack of capacity within military family support and medical case management to effectively assist families in their efforts to access

Medicaid. There are nodes of expertise within the military health and family support systems, but these are neither coordinated nor systematic. True organizational capacity and institutional memory is lacking.

The shortcomings of state Medicaid systems and of military health and family supports beg a larger question that needs to be considered. The field research, supplemented by statistical research, suggests that the military health system is very robust and responsive. While acknowledging some of the controversies surrounding some special needs areas, the analysis suggests that there are many resources available to families. In many circumstances, the flexibility and innovation commonly associated with military operations and administration result in genuine efforts to identify resources and services for families both on-base and beyond the gates of the military installation. However, it is possible that readily accessible resources for active military families are not being fully utilized. Specifically, there is a concern that the TRICARE ECHO may be falling short in reaching those families that are both eligible for the option and are in most in need of its services.

There remains a need for the military health system to provide effective and coordinated assistance to families with special needs who are seeking access to health care and allied family support services. Doing so requires a command of knowledge, clear communications and coordination with the DoD, and effective cooperation and liaison efforts with other federal agencies as well as state agencies. The foundation of knowledge depends on mining deeply the rich data resources already available to the DOD through Tricare Management Activity (TMA) administration and other department sources. There is a need for a better understanding of the population characteristics of active duty military families with special needs and their utilization of health services within the military health system. This need for knowledge extends as well to those personnel assisting families navigate the military health and family support systems. Clear communication and coordination may require a number of steps, including better cross-Services interaction and the need for active rather than passive approaches to providing assistance to families with special needs. Finally, we perceive a need for effective inter-agency cooperation so that unique needs and expectations can be better matched. Specifically, closer liaison work between the DoD and the CMS might be beneficial. The CMS might prove an effective ally in communicating to state Medicaid directors the needs of those military families who cannot otherwise be served through the military health system.

Many of these steps are being taken. At the national level, efforts to conduct a “functional analysis” and other efforts aimed at better coordinating individual Service branch data management and standardized business processes for EFMP have been undertaken. There are also efforts to create medical homes for military families which should ensure better case management and continuity of care. Inroads have been made in examining DOD beneficiary data to better understand the characteristics of families with special needs and that the lines of communication have been strengthened with CMS and other Department of Health and Human Services agencies.

The WVU research team was especially heartened by what they saw and learned from the field. At each of the military installations visited the team encountered resilient families and dedicated personnel joined in common purpose to provide for those with special needs. While at times the visits revealed gaps and problems, they also demonstrated a sincere commitment on the part of command and front-line personnel in serving those with special needs. One can never overlook the complexities and unique attributes of each family with a special needs member. An enduring challenge for the military is to balance established and competent systems of support with a need for flexibility and adaptability to new situations

and circumstances. Given that this has traditionally been the operating environment of the military, there should be confidence in the DoD's ability to meet this challenge.

BIBLIOGRAPHY

- Abt and Associates. (2011). *Report on State Services to Individuals with Autism Spectrum Disorders (ASD), Centers for Medicare and Medicaid Services (CMS), ADS Services Project*. Final Report. Cambridge, MA (April).
- Auerbach, R., & Reinhard, S. C. (2006). *Challenges Posed by Waiver Waiting Lists*. Rutgers Center for State Health Policy. New Brunswick: Rutgers Center for State Health Policy. Retrieved from www.cshp.rutgers.edu/cle.
- Autism Speaks. (2012a, May). *This Month in Review*. Retrieved from www.autismspeaks.org:
- Autism Speaks. (2012b, August 28). *TRICARE Update: Military Families & Autism*. Retrieved from Autism Votes: www.autismspeaks.org
- Braddock, D., Hemp, R., Rizzolo, M. C., Haffer, L., Tanis, E. S., & Wu, J. (2011). *The State of the States in Developmental Disabilities 2011*. Department of Psychiatry and Coleman Institute for Cognitive Disabilities, University of Colorado. Retrieved from www.cu.edu/ColemanInstitute/stateofthestates.
- Brown, L., & Sparer, M. (2003). Poor Program's Progress: The Unanticipated Consequences of Medicaid Policy. *Health Affairs*, 22;32-44.
- Cann, J., & Ogburn, E. (2007). *Virginia's Medicaid Waivers for Persons with Disabilities, Their Parents, and Caregivers*. Richmond: Partnership for People with Disabilities.
- Center on Budget and Policy Priorities. (2011). *Introduction to the Supplemental Security Income (SSI) Program*. Washington DC.
- Centers for Medicare and Medicaid Services. (2012a). *Community First Choice 1915(k)*. Retrieved from www.medicaid.gov: http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Support/Home-and-Community-Based-Services/Community-First-Choice-1915-k.html
- Centers for Medicare and Medicaid Services. (2012b). *Home & Community – Based Services 1915 (i)*. Retrieved from www.medicaid.gov: http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Support/Home-and-Community-Based-Services/Home-and-Community-Based-Services-1915-i.html
- Duckett, M. J., & Guy, M. R. (2000). Home and Community-Based Services Waivers. *Health Care Financing Review*, 123-125.
- Federal Register. (2011, Dec 29). Tricare: Extended Health Care Option. *Federal Register*, 81897-81899.

- Federal Register. (2012, May 3). Centers for Medicare and Medicaid Services, Medicaid Program; State Plan Home and Community-Based Services, 5-Year Period for Waivers, Provider Payment Reassignment, and Setting Requirements for Community First Choice. *Federal Register*.
- Florida Agency for Health Care Administration. (2012, September). *Health Care Alerts and Provider Alerts Messages*. Retrieved from <http://www.fdhc.state.fl/us/Medicaid>
- Fossett, J., Goggin, M., Hall, J. S., Johnston, J., Plein, L. C., Roper, R., & Weissart, C. (2000). Managing Medicaid Managed Care: Are States Becoming Prudent Purchasers? *Health Affairs*, 36-49.
- Georgia Department of Community Health, Division of Medical Assistance. (2011, October). Part II: Information Manual TEFRA/Katie Beckett Deeming Waiver. Georgia, United States of America: Georgia Department of Community Health.
- Tennessee Government. (n.d.). *Case Management*. Retrieved from Tennessee Dept. of Intellectual and Developmental Disabilities DIDD: Retrieved From http://www.tn.gov/did/case_manage/waiting_lists.html.
- Granger, E., Boyer, J., Weiss, R., Linton, A., & William, T. V. (2010). Historical Evolution of Medical Quality Assurance in the Department of Defense. *Military Medicine*, 581-586.
- Groysberg, B., Hill, A., & Johnson, T. (2010). Which of These People is Your Future CEO: The Different Ways Military Experience Prepares Managers for Leadership. *Harvard Business Review*, 80-85.
- Guice, Karen & Posante, Rebecca. (2012, June 20). Prepared Statement of Dr. Karen Guice, Principal Deputy Secretary of Defense (Health Affairs) and Dr. Rebecca Posante, Deputy Director, Office of Community Support for Military Families with Special Needs before the Senate Armed Services Committee Subcommittee on Military Personnel.
- Gurley-Calvez, T., & Pellillo, A. (2011). *Military Children with Special Health Care Needs: The Role of Medicaid/SSI*. Draft Background Report WVU DOD Medicaid Project.
- Gurley-Calvez, T., & Pellillo, A. (2012a). *Medicaid and Military Families with Children with Special Health Needs*. Draft Report. WVU-DOD Medicaid Report.
- Gurley-Calvez, T., & Pellillo, A. (2012b). *TRICARE Children with Special Health Care Needs and the Role of Medicaid: Insights from the Health Care Survey of DOD Beneficiaries(HCSDB)*. Draft Background Report, WVU-DOD Medicaid Project.
- Hall, R. H. (1996). *Organizations: Structures, Processes, and Outcomes*. Englewood Cliffs: Prentice Hall.
- Haskins, R. (2012). *The SSI Program for Children: Time for Change?* Princeton: The Future of Children.
- Huebner, A., Babak, A., Brickel, M., & Wade, K. (2010). *Summary of Findings: Military Family Needs Assessment*. US Department of Defense Military Community; Family Policy Office; Virginia Polytechnic Institute; State University. (August)

- Imagine Enterprise. (2007). *Which Waiver Does What? An Unofficial Quick Reference*. Seabrook: Self Determination for Texas. Retrieved from www.imagineenterprises.com/waiver_chart.pdf.
- Jaffee, D. (2001). *Organization Theory: Tension and Change*. Boston: McGraw-Hill.
- Kime, P. (2012). Lawmakers Seek to Expand TRICARE Autism Therapy Benefit. *Navy Times*. (June 12).
- Kitchener, M., Ng, T., & Harrington, C. (2004). Medicaid 1915 c Home and Community-Based Services Waivers: A National Survey of Eligibility Criteria, Caps, and Waiting Lists. *Home Health Care Services Quarterly*, 55-69
- Kliff, S. (2012, July 10). Medicaid Expansion Poses a Familiar Face-Off with States. *Washington Post*, A5.
- Larson, S., Ryan, A., Salmi, P., Smith, D., & Wuorio, A. (2012). *Residential Services for Persons with Developmental Disabilities: Status and Trends through 2010*. Minneapolis: University of Minnesota; Research and Training Center on Community Living; Institute on Community Integration.
- Nathan, R. P. (1982). *The Methodology for Field Network Evaluation Studies*. Albany, United States of America: Nelson a. Rockefeller Institute of Government.
- National Council on Disability. (2011). *United States Marine Corps Exceptional Family Members: How to Improve Access to Healthcare, Special Education, and Long-Term Supports and Services to Family Members with Disabilities*. Washington DC: National Council on Disability.
- Ng, T., Harrington, C., & Howard, J.(2011). *Medicaid and Home and Community Based Services Programs: Data Update*. Kaiser Commission on Medicaid and the Uninsured. Retrieved from www.kf.org.
- Ng, T., Harrington, C., Musumeci, M., & Reaves, E. (2012). *Medicaid and Home and Community Based Services Programs: 2009 Data Update*. Washington DC: Kaiser Commision on Medicaid and the Uninsured. Retrieved from www.kf.org.
- O'Brien, J. (2012, June 20). Testimony of John O'Brien, Director of Healthcare and Insurance, Office of Personnel Management before the United States Senate Committee on Armed Services. Subcommittee on Personnel on Department of Defense Programs and Policies to Support Military Families with Special Needs.
- Pincus, W. (2012, Dec 3). The Fine Print: A Question of What Tricare Should Cover. *The Washington Post*.
- Quadagno, J. (1988). From Old-Age Assistance to Supplemental Security Income: The Political Economy of Relief in the South, 1935-1972. In M. Weir, A. S. Orloff, & T. Skocpol, *The Politics of Social Policy in the United States* (pp. 235-264). Princeton: Princeton University Press.
- Rupe, L. (2009). Autism and the Military Family. *The Autism File*(33), 102-105.

- Shin, P., Rosenbaum, S., & Mauery, R. D. (2005). *Medicaid's Role in Treating Children in Military Families*. George Washington University Center for Health Services Research and Policy (October). Retrieved from www.gwumc.edu/sphhs.
- Smith, G. (2007). *Home and Community Services Litigation Status Report*. Human Services Research Institute . Retrieved from www.hsri.org.
- Smith, G., Agost, J., Fortune, J., & O'Keefe, J. (2007). *Gauging the Use of HCBS Support Waivers for People with Intellectual and Developmental Disabilities: Final Project Report*. Prepared for the Office of Disability, Aging, and Long-Term Care Policy, Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services. Human Services Research Institute; RTI International.
- Spigel, S. (2007). *Medicaid Autism Waivers and State Agencies Serving People with Autism*. Connecticut Office of Legislative Research. Retrieved from www.cga.ct.
- Stainer, P. (2008). *Resource Guide for Military* . Autism Society of North Carolina.
- Stobbe, M. (2012, March 30). Autism Reports Rise, Likely from Better Tests. *Charleston Gazette*, p. 9A.
- Stuck at the Bottom of the List: Roadblocks to Care. (2010). *Operation Home: The Web Community*. Retrieved from www.homefrontonline.com/article.asp?articleid=1523
- Sunstein, C., & Thaler, R. (2003). Libertarian Paternalism is not an Oxymoron. *The University of Chicago Law Review* 70 (4), pp. 1159-1202.
- Support Disability Rights Florida. (2011, March 24). *Lawsuits Asks Federal Court to Help Move DD Waiver List*. Retrieved from Support Disability Rights Florida: Retrieved from <http://www.disabilityrightsflorida.org/>
- TRICARE. (2010, November). TRICARE Extended Health Care Option Brochure. TRICARE.
- TRICARE. (2012a). *Applied Behavior Analysis Therapy*. TRICARE. Retrieved from www.tricare.mil/abatherapy
- TRICARE. (2012b). *Report to Congress: Evaluation of the TRICARE Program, Fiscal Year 2012*. TRICARE.
- US Department of Defense. (2003). *Proposed Rule, 32 CFR Part 199: RIN 0720: TRICARE: Individual Case Management Program; Program for Persons with Disabilities, Extended Benefits for Disabled Family Members of Active Duty Service Members; Custodial Care*. US Department of Defense.
- US Department of Defense. (2007). *Department of Defense Report and Plan on Services to Military Dependent Children with Autism*. US Department of Defense.
- US Department of Defense. (2011). *Demographics 2010: Profile of the Military of Community*. Office of the Deputy Under Secretary of Defense.

- US Department of Defense. (2012). *Annual Report to Congress on Plans for the Department of Defense for the Support of Military Family Readiness, Fiscal Year 2011*. US Department of Defense.
- US Government Accountability Office. (2007). *DOD Exceptional Family Member Program*. US Government Accountability Office.
- US Navy. (2011, March). Navy Exceptional Family (EFM) Program. Briefing Materials of Vice Admiral Mark Ferguson III, Chief of Naval Personnel and Deputy CNO (N1).
- US Navy. (n.d.). Navy Exceptional Family Member Program (flyer) Navy EFM Program Manager; Chief of Naval Personnel. Milington, Tennessee.
- Wild, W. (2012). *Virginia Medicaid Waiver List Continues to Grow*. Retrieved from WJLA: www.WJLA.com
- Williams, T., Shone, E. M., Archibald, N. D., & Thompson, J. (2004). A National Assessment of Children with Special Health Care Needs: Prevalence of Special Needs and Use of Health Care Services Among Children in the Military System. *Pediatrics*, pp. 384-393.
- Zaharia, R., & Moseley, C. (2008). *State Strategies for Determining Eligibility and Level of Care for ICF/MR and Waiver Program Participants*. Rutgers Center for State Health Policy.

APPENDIX A: Availability of Medicaid to Military Families with Special Needs: Legal and Regulatory Analysis

INTRODUCTION

Medicaid began in 1965 as a federal program designed and implemented to operate as a federal-state partnership for the provision of health care to low-income Americans. Medicaid also serves as supplemental, wrap-around insurance for those with other forms of health insurance but who are otherwise eligible for the program. For military family members with special needs, Medicaid can in some instances supplement the medical services provided through TRICARE and TRICARE ECHO. This segment of the Medicaid study offers an analysis of the legal and regulatory framework in which Medicaid operates so that the Department of Defense can better understand the shifting, patchwork nature of the Medicaid services available to military families with Medicaid-eligible family members with special needs. This report focuses particular attention on how recent changes to Medicaid due to the Affordable Care Act will affect military family members with special needs. It also provides data on Medicaid drawn from the fifty states and the District of Columbia, detailing the nature of the Medicaid provisions available to all citizens without regard to their affiliation with the military.

STUDY METHODOLOGY

This report details the regulatory and legal research and analysis that was conducted as one of the three components of West Virginia University's Medicaid study. This portion of the research involved a state-by-state review of each state's legislative and administrative laws, as well as other policy documents and secondary sources, in order to gather data regarding Medicaid characteristics, rules, and provisions in each state. This segment of the study did not involve interviews with Medicaid officials or nonprofit organizations related to services to individuals with disabilities in each state. Background literature was reviewed for purposes of providing context of the legal framework in which Medicaid laws and regulations exist.

In conjunction with the econometric research team, the regulatory team drafted a research checklist to guide the process of gathering data from the individual states. This checklist identified the specific data to be collected regarding each state's Medicaid program. Prior to using this checklist for each state, the team first tested it on a small initial number of states and refined the checklist before implementing it for all states.

Under faculty supervision, law students at West Virginia University College of Law reviewed state regulations, legislation, and other policy guidance documents to gather the specific data about the design of each state's Medicaid program. Faculty and student team leaders trained the student researchers on Medicaid background information and standardized practices for conducting the research.

The data was gathered from July 2010 through March 2012. Through this analysis, the team completed a careful review and survey of state law, state regulation, and additional materials relevant to the provision of Medicaid services to military family members with special needs. Following the collection of this data, two members of the regulatory analysis research team focused on reducing this complex data into a series of variables to offer a more simplified vision of how Medicaid looks in each state. The period of this study coincided with an era of significant change in the nation's Medicaid programs due to the passage and

implementation of the Affordable Care Act. Because this study's timeframe extended over a period of multiple years, the legislative and administrative regulatory data represents no single fixed date of the status of state Medicaid law. As a result, states throughout the country began a process of dramatic change to their Medicaid programs, both as required and in response to the ACA. These changes continue to the present day and rendered some data obsolete.

In order to update the data and provide as current of a vision of Medicaid as possible, the collected data was supplemented with additional data from the Kaiser Family Foundation. The data presented in the appendices represent the original data collected by the study team, as updated with the most current available information, cited to the Kaiser Family Foundation.

STUDY FINDINGS

The findings from this segment of the study are presented in two primary forms. First, the collected data has been collated into spreadsheets. Second, the report also analyzes the data contained within the spreadsheets.

Discussion of Tabular Data

The first spreadsheet found in Table 1 provides a tabular presentation of a series of variables that together, offer a snapshot of Medicaid in the various jurisdictions. They primarily provide a broad view of the nature of the Medicaid program in each state as pertains to the provision of services to military family members with disabilities. The second spreadsheet, Table 2, details additional information from the seven states of residence for the service members at the study's six site visits—California, Georgia, Kentucky, Tennessee, Texas, Virginia, and Washington.⁴ In addition to the site visit states, data from Florida and North Carolina have also been included in Table 2 as other states in which there is a high concentration of military families such that more detailed information would be particularly useful to the Department of Defense. This additional information offers a more complex look at how the Medicaid programs in each of these featured states functions. In particular, while this study did not call for research regarding the scope of waiver waiting lists, Table 2 provides data from the Kaiser Family Foundation detailing the length of waiting lists in these selected states.⁵

Discussion and Analysis of Trends

Variation is the Key Finding: These data demonstrate some clear developments in the provision of Medicaid. Wide variation remains the case in terms of the level of poverty at which Medicaid coverage will be extended to low-income Americans. However, some of this variation has less impact on the majority of children than would otherwise be anticipated since the Child Health Insurance Program ("CHIP") has assumed responsibility for providing medical insurance to low-income children.⁶ As a result,

⁴ Numerical data in Table 2 regarding waiver numbers of participants and persons on waiver waiting lists comes from Kaiser Commission on Medicaid and the Uninsured, Medicaid 1915(c) Home and Community-Based Service Programs, *available at* <http://www.kff.org/medicaid/upload/7720-05.pdf>.

⁵ Kaiser Commission on Medicaid and the Uninsured and The University of California at San Francisco, Medicaid 1915(c) Home and Community-Based Service Programs: Data Update, *available at* <http://www.kff.org/medicaid/upload/7720-05.pdf>.

⁶ The Child Health Insurance Program, known as CHIP, was signed into law in 1997. It is designed to provide health insurance coverage to children who are uninsured but ineligible for Medicaid. Kaiser Commission on Medicaid and the Uninsured, Health

Medicaid is offering a relatively smaller share of publicly supported insurance to children, since many states have moved children off of their Medicaid rolls and into their CHIP enrollment. One additional effect of the ACA will be to move some fraction of CHIP-recipient children back to Medicaid, since under the ACA's Medicaid expansion, Medicaid must be provided for all persons under 138% of poverty. Children under 138% of poverty who currently are enrolled in CHIP will eventually be covered by Medicaid instead, as long as they live in an opt-in state. Yet above 138% of poverty, even states that opt into the Medicaid expansion will continue to offer widely varying levels of Medicaid coverage to their citizens. In essence, the ACA has raised the floor of poverty under which all children are eligible for Medicaid coverage, as long as their state of residence opts into the new expansion. Above that floor, children may receive health insurance through a state decision to increase the poverty line of Medicaid coverage even further, through CHIP, or through the new subsidies and exchanges to help individuals' access insurance on the private market provided by the ACA.

Changes in Service Delivery: Service delivery models are also reflected in the data in Table 1. While Alaska, New Hampshire, and Wyoming continue to provide care under the auspices of Medicaid through fee- for-service models, all of the remaining states have moved toward managed care, and Idaho, South Carolina, and Tennessee now provide Medicaid only through managed care models. This is a dramatic change over the last decade. In 2002, 57.58% of Medicaid recipients received Medicaid through a managed care program; in 2011, fully 74.22% of recipients were enrolled in a managed care program.⁷ Managed care programs typically pay provider groups on a per capita basis per enrollee in the insurance program and do not pay providers individually for the specific services, treatments, and procedures they provide. This shift toward managed care is reflective of a more generalized effort toward cost-containment measures in health care; managed care is expected to shift the incentives in medicine away from providing expensive procedures and toward preventative medicine and other low-cost care options. While managed care's effectiveness in reducing health care costs remains open for debate, the trend is clearly away from fee-for-service models of health care provision and toward managed care.

Enrollment Process Standardization: The impact of the ACA can also be perceived in the context of enrollment processes. The ACA has shifted focus to online enrollment, while still requiring states to permit paper- based enrollment for those lacking access to computers for enrollment purposes.⁸ Similarly, under the ACA, starting in 2014, states can no longer require in-person interviews or asset tests for Medicaid enrollment. What is most clear from these data is that while the ACA is leading to some nationwide standardization of processes related to Medicaid, Medicaid itself varies widely from state to state, and that the level of confusion and frustration experienced by relocating members of the armed forces with family members with special needs who rely on Medicaid is based in no small part on the essential and varied nature of the Medicaid program itself. Medicaid's design as a federal-state partnership created a

Coverage of Children: The Role of Medicaid and CHIP, *available at* <http://www.kff.org/uninsured/upload/7698-06.pdf>. As military family members all have health insurance through TRICARE, CHIP is largely irrelevant to the target population of the study.

⁷ Centers for Medicare and Medicaid Services, U.S. Department of Health and Human Services Medicaid Managed Care Enrollment Report, November 2012, *available at* <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Data-and-Systems/Downloads/2011-Medicaid-MC-Enrollment-Report.pdf>.

⁸ Kaiser Commission on Medicaid and the Uninsured, *Getting into Gear for 2014: Findings from a 50-State Survey of Eligibility, Enrollment, Renewal, and Cost-Sharing Policies in Medicaid and CHIP, 2012-2013*, *available at* <http://www.kff.org/medicaid/upload/8401.pdf>.

situation of purposeful wide variation in the kinds of programs and the methods of implementation in each state. Yet this variability, intended to create a laboratory for experimentation and creative provision of services, offers difficulty and exasperation to families that must move from state to state due to the requirements of service in the nation's armed forces. The ACA will help reduce some of this variation by increasing uniformity in the service of improved access to Medicaid, but variations in waivers and services provided will remain.

WAIVER PROGRAMS

As waiver programs are a topic of great interest to the target population, Table 2 includes information on the length of the waiver waiting lists in the selected, high-military- concentration states. These data should not be misinterpreted as an indictment of the states with longer waiting lists, as the number of persons on a waiting list does not necessarily demonstrate the general availability of waivers in the state. It is possible for states to keep their waiting lists short while offering relatively few waivers due to barriers in the eligibility process. On the other hand, a state might have a fairly robust waiver program for which many individuals are eligible, but still maintain a lengthy waiting list. Thus, the mere existence of a waiting list does little to demonstrate whether waivers are accessible or not in a particular state; the number of persons receiving waivers is likely a better proxy for this aspect of a state's Medicaid program. However, the waiting lists provide one straightforward measure of how many individuals eligible for a waiver under a specific state's criteria remain without the waiver they seek.

The final column of Table 2 is a percentage calculated by dividing the total number of persons on the waitlist for waivers by the total number of waiver recipients in a particular state. While this number is not a precise apples-to-apples comparison since the figures draw on data from different years, it provides a rough estimate of how effectively states are moving those eligible for waivers in the jurisdiction from the waitlist into access to a waiver and the services it provides.

State	Persons on the waiver waitlist as a percentage of total waiver recipients
Kentucky	No waitlist
Washington	2.0%
California	2.2%
North Carolina	14.8%
Tennessee	25.8%
Virginia	27.5%
Georgia	42.2%
Florida	50.3%
Texas	194.9%

As this figure above indicates, the ratio ranges from Kentucky, where a percentage cannot be calculated as there was no waitlist for waivers in 2010, to Texas, which had approximately twice as many people on the waitlist in 2010 as being served by a waiver in 2008.

In addition to the spreadsheet data, this section of the report also provides textual descriptions of the Medicaid waiver programs in the states where site visits were conducted, as well as Florida and North Carolina. Unless otherwise specified, these waiver programs require individuals to prove that they are eligible for Medicaid prior to receiving waiver services. These descriptions offer an example of the wide level of variation in waiver programs that exists among states. For military families with Exceptional Family Members, it is these waiver programs that are typically the aspect of Medicaid of the greatest interest, which is the reason why they are the focus of this discussion.

While this discussion lists the specific waivers available in each included state, this treatment is brief due to the actual dearth of clear, helpful information about waivers. Researchers of waiver programs struggle to find publicly available information, which further highlights the difficulties that families in need of waivers experience in their efforts to determine what waivers will best meet their families' needs. In practice, families seeking waivers rely on local networks with experienced individuals to decide which waivers to seek; as will be noted in the conclusion and recommendations section, this lack of transparency makes waivers even more inaccessible and opaque for military families with special needs.

California: California offers nine different waivers that are relevant for the target population of the study. The AIDS Waiver provides home and community based services to Medicaid beneficiaries with AIDS, to help them avoid institutional care during the end stages of AIDS. For 2011, this waiver was capped at 4250 recipients. The Assisted Living Waiver is available to senior citizens and persons with disabilities in particular California communities, and provides assisted living services as an alternative for individuals who require the care of a nursing facility. The Home and Community-Based Services Waiver for the Developmentally Disabled offers recipients the option of avoiding placement in an intermediate care facility for the intellectually disabled,, instead providing services to permit recipients to stay at home. For 2011, this waiver was capped at 95,000 recipients. The Nursing Facility/Acute Hospital Waiver is available to physically disabled persons and provides at home nursing facility level care. For 2011, this waiver was capped at 3032 recipients. The In-Home Operations Waiver likewise serves physically disabled persons and provides them care either from a licensed nurse or at a level of care more intensive than that available under the NF/AH waiver. In 2009, 210 of these waivers were available. The Developmentally Disabled-Continuous Nursing Care Program Waiver provides 24-hour nursing care for persons who are medically fragile and developmentally disabled in seven small, home-like facilities throughout the state. The Multipurpose Senior Services Program provides home and community-based services to recipients over 65 who are disabled and living in their own homes; 16,335 waivers are available. The Specialty Mental Health Consolidation Program offers mental health services to recipients with certain mental health diagnoses. For children with severe illnesses, the Pediatric Palliative Care Waiver provides palliative care services.⁹

Florida: Florida provides twelve different Medicaid waivers: Adult Cystic Fibrosis, Aged/Disabled Adult Services, Adult Day Health Care, Assisted Living for the Elderly, iBudget, Channeling Services for the Frail

⁹ List of waivers and links to relevant information about them is available at <http://www.dhcs.ca.gov/services/med-cal/Pages/Medi-CalWaiversList.aspx> (last accessed April 30, 2013).

Elderly, Developmental Disabilities, Familial Dysautonomia, Model, Nursing Home Diversion, Project AIDS Care, and Traumatic Brain Injury and Spinal Cord Injury Waivers. Of particular relevance to the target population of the Medicaid study are the Developmental Disabilities Waiver, which provides in-home services to disabled individuals who meet the Intermediate Care Facility level of need, the Aged/Disabled Waiver, which allows adults with physical disabilities to receive care at home, and the Model Waiver, which permits those under 21 who have a degenerative spinocerebellar disease to remain at home under the services of skilled care.¹⁰

Georgia: Georgia offers several waiver programs.¹¹ The Elderly and Disabled Waiver, including the Community Care Services Program and the Service Options Using Resources in Community Environment Program, is available to elderly and/or individuals with functional impairments, or individuals with disabilities. The Independent Care Waiver Program provides adults with physical disabilities with services to live in their communities. The New Options Waiver Program and Comprehensive Supports Waiver Program provide community-based services for people with developmental disabilities. Georgia Pediatric Program offers skilled nursing in medically licensed day care facilities to medically fragile children through three years of age through its Medical Day Care and in-home care to those under 21 through its In-Home Nursing Program. The Money Follows the Person Demonstration Program helps those with physical disabilities, traumatic brain injuries, and developmental disabilities who have lived in nursing homes and Intermediate Care Facilities-Mental Retardation make the transition to a community setting.

Kentucky: Kentucky provides six waiver programs.¹² The Acquired Brain Injury Waiver Services helps adults with brain injuries to live in the community by providing services in that setting. The Acquired Brain Injury Long Term Care Waiver provides individuals whose condition has stabilized the opportunity to remain in the community and avoid institutionalization. The Home and Community Based Waiver program helps elderly people or persons with disabilities avoid institutionalization by providing services in their homes. The Michelle P. Waiver provides in-home services for individuals with intellectual or developmental disabilities. The Model II Waiver offers in-home services for persons dependent on ventilators who would otherwise need to live in a hospital-based nursing facility. The Supports for Community Living Waiver provides community-based services for persons with intellectual or developmental disabilities.¹³

North Carolina: Residents of North Carolina can access a number of different waivers.¹⁴ The Community Alternatives Program Developmental Disabilities Waiver is available to adults with developmental disabilities to receive services outside of institutions. The Elderly and Disabled Waiver permits elderly individuals and those with disabilities to receive community-based nursing care. The Community

¹⁰ A list of all waivers available in Florida can be found at http://ahca.myflorida.com/medicaid/hcbs_waivers/index.shtml (last accessed April 28, 2013).

¹¹ Information on Georgia's waivers can be found at http://dch.georgia.gov/sites/dch.georgia.gov/files/imported/vgn/images/portal/cit_1210/28/23/31945394homencommbooklet27-12-2010.pdf (last accessed April 30, 2013).

¹² Information on Kentucky's waivers can be found at <http://chfs.ky.gov/dms/mws.htm> (last accessed April 30, 2013).

¹³ <http://chfs.ky.gov/dms/mws.htm> (last accessed April 30, 2013).

¹⁴ A list of waivers in North Carolina can be found at <http://www.thedesk.info/states-and-territories/north-carolina-hcbs-waiver-programs/> (last accessed April 30, 2013), with some additional information about the waivers available on the North Carolina Department of Health and Human Services.

Alternatives Program Choice Waiver offers disabled individuals over 21 nursing care in the community to avoid relocation into residential facilities. The Children's Waiver is available to children who are medically fragile and in need of long-term care. Individuals with developmental disabilities of all ages can receive a wide variety of medical and social services assistance through the Comprehensive Waiver or the Supports Waiver, at varying levels of service intensity.

Tennessee: Tennessee's waiver programs are less narrowly tailored than those offered by many other states, with three broad options.¹⁵ Its Developmental Disabilities Waiver, also known as the Arlington Waiver, is available to persons with developmental disabilities and provides community-based services of various kinds.¹⁶ Tennessee's HCBS Elderly and Disabled Waiver is available to persons with physical disabilities who need community-based nursing care at a higher level of intensity than the Developmental Disabilities Waiver in order to remain outside of an institution. Finally, the Self-Determination Waiver Program for people with intellectual and developmental disabilities permits the recipient to be more actively involved in self-directed care.¹⁷

Texas: Texas provides six different waiver programs to its residents.¹⁸ The Community Based Alternatives Waiver offers elderly and disabled Texans over 21 with services to avoid entering a nursing home. The Community Living and Support Services Waiver provides home and community-based services to individuals with intellectual disabilities who would otherwise be treated in an intermediate care facility for individuals with intellectual disabilities. The Deaf- Blind with Multiple Disabilities Waiver is available to those who are deaf-blind and multiply disabled to avoid institutionalization, with particular focus on improving communication opportunities. The Home and Community-Based Services Waiver gives individualized services to individuals with intellectual disabilities outside of institutions. The Medically Dependent Children Program helps families with medically dependent children and young adults to care for their children at home. The Texas Home Living Program offers a limited array of services to individuals with intellectual disabilities. Because choosing among waiver programs is a difficult decision for families and individuals who may not appreciate subtle differences in the kind of services available pursuant to a particular waiver, Texas provides a useful website designed to help individuals and their families decide which waiver would best meet their particular medical and social service needs. Texas also offers a consumer directed services option for some of the services provided through some of its waivers. This option is designed to provide individuals and their families with more control over how services are provided, if they would like to take authority to determine who would be care providers, what salary to pay, or what agency to contract with for care and services.¹⁹

Virginia: Five of the waivers currently available in Virginia provide services that make them potentially useful to the study's target population; two others for persons with HIV/AIDS and Alzheimers Disease are of limited value for this study.²⁰ The Intellectual Disabilities Waiver provides a variety of medical and

¹⁵ http://www.tn.gov/didd/consumer_services/fgmwb.pdf (last accessed April 30, 2013).

¹⁶ http://www.tn.gov/tenncare/long_arlington.shtml (last accessed April 30, 2013).

¹⁷ http://www.tn.gov/tenncare/long_self.shtml.

¹⁸ Information on Texas's waivers can be found at http://www.dads.state.tx.us/providers/waiver_comparisons/index.html (last accessed April 30, 2013).

¹⁹ <http://www.dads.state.tx.us/services/faqs-fact/cds.html>

²⁰ A list of Virginia's waivers can be found at http://www.dmas.virginia.gov/Content_pgs/ltc-wvr.aspx (last accessed April 30, 2013).

social support services; it is available to persons diagnosed as intellectually disabled aged 6 and older or under age 6 and at developmental risk instead of placement in an intermediate care facility for persons with intellectual disabilities. The Day Support Waiver offers social services focused on employment and vocational training for individuals on the waiting lists for a Mental Retardation/Intellectual Disabilities Waiver. The Individual and Family Developmental Disabilities Support Waiver provides a wide variety of services for developmentally disabled individuals age 6 and older as an alternative to placement in an intermediate care facility for persons with intellectual disabilities. The Elderly or Disabled with Consumer Direction Waiver offers a variety of community-based services to disabled people and elderly people to avoid placement in nursing facilities. Finally, the Technology-Assisted Waiver provides a limited menu of services, including assistive technology, to children and adults who require skilled nursing care. Virginia has a useful, though somewhat dated, publication from 2007 detailing the various waivers available in the commonwealth.²¹

Washington: Washington State offers a variety of Medicaid waivers to families with disabled family members.²² The COPES (Community Options Program Entry System) Waiver provides a variety of services to children and adults with disabilities to enable them to stay in their homes or communities. The New Freedom Waiver permits elderly adults and individuals with disabilities in a limited geographic area to avoid institutionalization by receiving a variety of health and social services in a self-directed manner. The Children's Intensive In-Home Behavior Support Waiver provides case management, behavior support, and wraparound services to 100 children with Autism Spectrum Disorder or other developmental disabilities who at high risk of institutional placement due to behavioral problems. The Basic Plus Waiver and Core Waivers are available to developmentally disabled individuals age 18 and over and provide services to prevent them from being institutionalized in an intermediate care facility for the intellectually disabled. The Community Protection Waiver provides services to disabled individuals who have committed serious crimes in order to keep the community safe.

STUDY LIMITATIONS

The simple fact that Medicaid is a constantly evolving program is the primary limitation of this study. Given the volume of data collected and the timespan of this project, it is imperative to note that the data does not represent a single snapshot of the parameters of Medicaid coverage and services on a specific day, but rather reflects evolutions in state law that occurred broadly over the period of the study. The regulatory team has therefore supplemented the original data gathered in the study with additional, recent data reported by the Kaiser Family Foundation and the Centers for Medicare and Medicaid Services.²³ This data is the most recent data that is publicly available and provides the Department of

²¹ http://www.dmas.virginia.gov/Content_atchs/ltc/ltc_md_waiver.pdf

²² <http://www.dshs.wa.gov/ddd/waivers.shtml> (last accessed April 30, 2012).

²³ Kaiser Commission on Medicaid and the Uninsured, *Getting into Gear for 2014: Findings from a 50-State Survey of Eligibility, Enrollment, Renewal, and Cost-Sharing Policies in Medicaid and CHIP, 2012-2013*, available at <http://www.kff.org/medicaid/8401.cfm>; Kaiser Commission on Medicaid and the Uninsured, *The Medicaid Medically Needy Program: Spending and Enrollment Update*, at 1, available at <http://www.kff.org/medicaid/upload/4096.pdf>; Centers for Medicare and Medicaid Services, U.S. Department of Health and Human Services Medicaid Managed Care Enrollment Report, November 2012, available at <http://www.medicare.gov/Medicare-CHIP-Program-Information/By-Topics/Data-and-Systems/Downloads/2011-Medicaid-MC-Enrollment-Report.pdf>.

Defense with the most up-to-date information available. However, it is important to note that even this data is changing rapidly and may well be out of date at the time of publication of this study.

Similarly, there are serious difficulties in assessing distinctions among states and the services they provide as part of Medicaid, as state autonomy means that programs may not always be comparable. This is particularly the case in regard to waiver programs, where criteria for each waiver are unique to the individual state. The nature of Medicaid, in which individual states can alter their coverage and services with autonomy, presupposes this outcome since Medicaid has always been a program subject to alteration by states. However, in light of the Affordable Care Act, any momentary representation about the status of Medicaid in individual states is likely to be partial, contingent, and temporary, and even more in flux in the coming years than it was during the timespan of this study.

Indeed, the most important limitation on the study is the fact that states have been adjusting to the Affordable Care Act since its passage in 2010. Additionally, given that many states were waiting for the U.S. Supreme Court to rule on the ACA, it is also appropriate to note that the speed of change within each state is only likely to accelerate. The reality that the portion of the ACA most relevant to this study, which is the expansion of Medicaid, will be implemented within the next year prior to the 2014 implementation date of the expansion suggests that it would be inappropriate to draw any broad conclusions about the permanent nature of Medicaid in an individual state based on the presented data. Rather, in light of this current historical milieu, what this report represents is a set of general trends reflective of the moment in time in which the study was conducted. This is not a limitation of the study design itself, but rather a reality based primarily on the nature of Medicaid and its constant, state-by-state revision, which is simply symptomatic of the legislative design of the program, and secondarily by the current rate of change in Medicaid, which is higher than the historical average due to the effects of the Affordable Care Act.

CONCLUSIONS AND RECOMMENDATIONS: *Possible Resolutions to the Waiver Problems Confronting Military Families*

In particular, changes to the waiver programs that are the target population's most desired component of the Medicaid program would be especially difficult to implement. At the present time, when a military family obtains a waiver for a dependent with a disability, moving to a new installation in another state means that the family will lose the benefit of that waiver. In its new installation, the family may need to wait a lengthy period of time to obtain a new waiver, or may not even satisfy eligibility criteria to be a candidate for a waiver in the new state.

Under current federal law, waiver programs are created by individual states through grants of authority from the Centers for Medicare and Medicaid Services. In theory, the federal government could standardize these waiver programs to simplify matters for military families with special needs. However, to do so would belie the essence of the waiver programs, which is to permit states to try various methods of service delivery outside of the typical strictures of Medicaid regulation. To standardize waivers through federal fiat would undermine the entire purpose and design of the waiver programs. Waivers vary across states in terms of scope, scale, eligibility criteria, target groups, and services offered based upon each state's assessment of the needs of its residents. However, it is worth exploring what this standardization might look like and why this approach is ill-advised.

Federal intervention in existing waiver programs could render them more accessible or available to military families. One could envision altering this system based on a federal regulation in order to provide waivers more promptly to military family members who have previously lost a waiver due to a service-related move from one state to an installation in another state. For example, the Department of Health and Human Services could mandate the portability of waivers from one state to another for military family members with special needs whose loss of a waiver was predicated by move based upon a military readiness decision. Such a change would likely result in serious public discontent among civilian and military families already present in that state who have spent months or years waiting for a waiver, who might perceive that they lost their waiver to recent arrivals who unfairly received a preference in receiving a waiver. As a result, this kind of regulation would likely be politically unpalatable, both within individual states and at a federal level.

Even if such a program for waiver portability were to be created by agreement between the Departments of Defense and Health and Human Services, implementation of this kind of portability program would be nearly impossible due to the wide variation in the kinds of waivers available and the services offered pursuant to each one. As demonstrated above, each state has established its own varieties of waivers consistent with the federal scheme by which waiver permits are granted. Transporting a waiver from one state where it exists to another state lacking that type of waiver would raise substantial administrative hurdles and problems. Given that each state establishes its own waivers in conjunction with the federal government, it is entirely possible under such a policy change that a military family member with special needs could move to a state lacking a waiver of the type that was previously available in the prior state of residency. Whether previously holding a waiver would create a vested right to those waiver services in perpetuity, available only to individuals with disabilities who are affiliated with the armed forces, raises serious questions of justice in the treatment of all persons with disabilities. Furthermore, even if two states appeared to have similar, but not identical waivers, this raises the question of which state's level of services would prevail, how long the recipient would be entitled to those services, which state would manage the care for the recipient, and most importantly, which state's budget would cover the cost of such waiver services. In a time of across-the-board tightening of state budgets, and especially tightening social services provisions, waiver portability from state to state is probably a political impossibility. As concluded in other components of this study, the most practical point of intervention for the Department of Defense in providing the kind of wraparound services sought by the target population of military families with special needs who lack waivers is through the military health insurance programs of TRICARE and TRICARE ECHO.

However, the regulatory research also demonstrates that the kind of nationwide reform that waiver portability would require is not the only way that the Department of Defense could assist its military families with special needs in accessing existing Medicaid waiver services. Exceptional Family Member Program offices on individual military installations could partner with local nonprofit organizations to provide support services and information regarding Medicaid and Medicaid waivers for military families with disabled family members. Such written resources, published by nonprofit organizations specializing in assistance to persons with disabilities and their families, already exist in some states. A particularly good one comes from South Carolina's Protection and Advocacy for People with Disabilities, which publishes a handbook entitled "South Carolina Medicaid Waiver Programs: A Guide

for Self-Advocates.”²⁴ This booklet, made available on their website, offers specific descriptions of each waiver available, including the application process, who should apply, what services are available pursuant to each waiver, and how to appeal a denial, as well as relevant contact information for the various agencies involved in granting and managing each waiver. The work of the regulatory team demonstrates that this kind of information is rarely available to the public in a centralized location. Rather, obtaining waiver information too often requires families to network with other, similarly situated families or to develop personal relationships with Medicaid staff in their state to help them navigate the system.

Were such partnerships with nonprofit organizations considered unfeasible by the Department of Defense, the Department of Health and Human Services could implement a halfway step by regulatory action requiring each state to publish its own guide to waivers. Some states, such as Georgia, already publish these types of user-friendly materials for Medicaid recipients to help them understand what waivers are available and what services these waivers offer. In Virginia, this kind of publication has been assembled through cooperative efforts of the state Department of Medical Assistance Services and nonprofit organizations.²⁵

Yet the option of partnering with nonprofit organizations would likely prove even more beneficial to families enrolled in EFMP than official state publications in two key ways. First, offering specific advice regarding appeals processes and successful application procedures as do publications from nonprofit organizations may be an inappropriate function for a government agency. Though this information would prove invaluable to families trying to navigate the complex bureaucracy of a state and its particular waiver regime, especially immediately following a move to that state, official publications may not be able to provide the same level of insider information on how to master a bureaucratic system. Second, fostering meaningful connections with local nonprofit resources would help recently relocated military families to identify support services on which they could rely outside of the military structures. Since civilian families with children with disabilities face the same kinds of needs as do similarly situated military families, but may have a longer history in a particular community, this may well help families with special needs build a support network more rapidly after transferring to a new installation.

In lieu of, or perhaps in addition to, either of these options for generating specific information regarding waivers for families with special needs, the Department of Defense might also consider offering additional kinds of know-your-rights information regarding Medicaid to this target population. Confusion about what Medicaid provides is widespread throughout communities in this country, including among members of the armed forces. For example, while military families have expressed frustration regarding the differences between services provided in the various states, most individuals, civilian or military, are not aware that it is perfectly legal for one state to provide dramatically different services than another state, or to offer services to more people than another state might opt to provide coverage.

²⁴ Home and Community Services: A Guide to Medicaid Waiver Programs in Georgia, *available at* http://dch.georgia.gov/sites/dch.georgia.gov/files/imported/vgn/images/portal/cit_1210/28/23/31945394homencombooklet27-12-2010.pdf.

²⁵ Virginia’s Medicaid Waivers for Persons with Disabilities, Their Parents, and Caregivers, *available at* http://www.dmas.virginia.gov/Content_atchs/ltc/ltc_md_waiver.pdf.

Further frustrating to families with children having special needs is the simple fact that there is no straightforward appellate process to broaden the menu of services offered to those enrolled in Medicaid or to gain access to Medicaid if one is ineligible in a particular state, which can be very troubling for families whose prior Medicaid experience differed in another state. The only options for individuals in these categories who wish to increase the level of service provision or broaden the categories of people covered are advocacy efforts before state legislators or administrative agencies, focused on growing the menu of services or the covered population under Medicaid law within the state. This variation is a source of endless frustration for families that are the target population of this study, who appear to be unaware that this is the designed legal landscape of the Medicaid program.

Using the Exceptional Family Member Program as a clearinghouse for information about the distinctions between basic Medicaid services that are federally required and optional add-on services with which states can choose to augment their Medicaid programs may reduce the amount of exasperation that families experience, as they may be able to accept variation in Medicaid coverage if they are taught that this is the legal norm rather than an unacceptable injustice that is particularly grievous in its harmful effects on military families. The constantly evolving information about Medicaid resources and provisions necessary could come from one of the methods described above, such as direct provision by the states themselves or EFMP partnerships with non-profits in each state, or through some other means, such as in-house data collection methods, through developing and maintaining relationships with each state's Medicaid Director, as well as other key Medicaid players in the various states.

SOURCES CITED

Centers for Medicare and Medicaid Services, U.S. Department of Health and Human Services Medicaid Managed Care Enrollment Report, November 2012, *available at* <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Data-and-Systems/Downloads/2011-Medicaid-MC-Enrollment-Report.pdf>.

Phil Galewitz, Kaiser Health News Changes How It Describes Medicaid Eligibility Level Under Health Law, Kaiser Health News Blog, December 5, 2012, *available at* <http://capsules.kaiserhealthnews.org/index.php/2012/12/khn-changes-how-it-describes-medicaid-eligibility-level-under-health-law/>.

Home and Community Services: A Guide to Medicaid Waiver Programs in Georgia, *available at* http://dch.georgia.gov/sites/dch.georgia.gov/files/imported/vgn/images/portal/cit_1210/28/23/31945394homencommbooklet27-12-2010.pdf.

Phil Galewitz & Mary Agnes Carey, HHS Tells States It Will Not Fund Partial Medicaid Expansion, Kaiser Health News, Dec. 10, 2012, *available at* <http://www.kaiserhealthnews.org/Stories/2012/December/10/hhs-states-medicaid-expansion.aspx>.

Kaiser Commission on Medicaid and the Uninsured, Federal Core Requirements and State Options in Medicaid: Current Policies and Key Issues, April 2011 *available at* <http://www.kff.org/medicaid/upload/8174.pdf>.

Kaiser Commission on Medicaid and the Uninsured, Getting into Gear for 2014: Findings from a 50-State Survey of Eligibility, Enrollment, Renewal, and Cost-Sharing Policies in Medicaid and CHIP, 2012-2013, *available at* <http://www.kff.org/medicaid/upload/8401.pdf>.

Kaiser Commission on Medicaid and the Uninsured, Health Coverage of Children: The Role of Medicaid and CHIP, *available at* <http://www.kff.org/uninsured/upload/7698-06.pdf>.

Kaiser Commission on Medicaid and the Uninsured, Medicaid 1915(c) Home and Community- Based Service Programs, *available at* <http://www.kff.org/medicaid/upload/7720-05.pdf>.

Kaiser Commission on Medicaid and the Uninsured and The University of California at San Francisco, Medicaid 1915(c) Home and Community-Based Service Programs: Data Update, *available at* <http://www.kff.org/medicaid/upload/7720-05.pdf>.

Kaiser Commission on Medicaid and the Uninsured, Medicaid: A Primer, Key Information on the Nation's Health Coverage Program for Low-Income People, at 7, 2013. *available at* <http://www.kff.org/medicaid/upload/7334-05.pdf>.

Kaiser Commission on Medicaid and the Uninsured, The Medicaid Medically Needy Program: Spending and Enrollment Update, at 1, December 2012. *available at* <http://www.kff.org/medicaid/upload/4096.pdf>.

Anita Kumar, McDonnell Considers Opting out of Medicaid Expansion, Virginia Politics Blog, WASHINGTON POST, *available at* http://www.washingtonpost.com/blogs/virginia-politics/post/mcdonnell-considers-opting-out-of-medicaid-expansion/2012/07/10/gJQAfzOGbW_blog.html.

Michael Martz, Medicaid Expansion Battle Continues, RICHMOND TIMES-DISPATCH, March 24, 2013, *available at* http://www.timesdispatch.com/news/medicaid-expansion-battle-continues/article_86e3cdab-f7d7-54af-bf6d-2a1203e2a26f.html.

National Federation of Independent Business v. Sebelius, 567 U.S. _____ (2012).

Protection and Advocacy for People with Disabilities, South Carolina Medicaid Waiver Programs: A Guide for Self-Advocates, *available at* <http://pandasc.org/wp-content/uploads/2011/12/Medicaid-Manual-10-3-122-1.pdf>.

Virginia's Medicaid Waivers for Persons with Disabilities, Their Parents, and Caregivers, *available at* http://www.dmas.virginia.gov/Content_atchs/ltc/ltc_md_waiver.pdf.

Table 1: State-by-State Regulatory Data

State	Medicaid eligibility (age <1, percent of Federal Poverty Level)¹	Medicaid eligibility (ages 1-5, percent of Federal Poverty Level)¹	Medicaid eligibility (ages 6-19, percent of Federal Poverty Level)¹
Alabama	133%	133%	100%
Alaska	150	150	150
Arizona	140	133	100
Arkansas	133	133	100
California	200	133	100
Colorado	133	133	100
Connecticut	185	185	185
Delaware	185	133	100
District of Columbia	185	133	100
Florida	185	133	100
Georgia	185	133	100
Hawaii	185	133	100
Idaho	133	133	100
Illinois	133	133	100
Indiana	200	133	100
Iowa	133	133	100
Kansas	150	133	100
Kentucky	185	133	100
Louisiana	133	133	100
Maine	185	133	125
Maryland	185	133	100
Massachusetts	185	133	114
Michigan	185	150	150
Minnesota	275	275	275
Mississippi	185	133	100
Missouri	185	133	100
Montana	133	133	100
Nebraska	150	133	100
Nevada	133	133	100
New Hampshire	185	185	185
New Jersey	185	133	100
New Mexico	185	185	185
New York	200	133	100
North Carolina	185	133	100
North Dakota	133	133	100
Ohio	150	150	150
Oklahoma	133	133	100
Oregon	133	133	100
Pennsylvania	185	133	100
Rhode Island	185	133	100
South Carolina	150	150	150
South Dakota	133	133	100
Tennessee	185	133	100

Table 1: State-by-State Regulatory Data, continued

State	Medicaid eligibility (age <1, percent of Federal Poverty Level)¹	Medicaid eligibility (ages 1-5, percent of Federal Poverty Level)¹	Medicaid eligibility (ages 6-19, percent of Federal Poverty Level)¹
Texas	185	133	100
Utah	133	133	100
Vermont	225	225	225
Virginia	133	133	100
Washington	200	200	200
West Virginia	150	133	100
Wisconsin	300	185	100
Wyoming	133	133	100

Table 1: State-by-State Regulatory Data, continued

State	Interview required for enrollment ¹	Online enrollment ¹	Asset test required for children's coverage ²
Alabama	No	Yes	No
Alaska	No	No	No
Arizona	No	Yes	No
Arkansas	No	Yes	No
California	No	Yes	No
Colorado	No	Yes	No
Connecticut	No	No	No
Delaware	No	Yes	No
District of Columbia	No	No	No
Florida	No	Yes	No
Georgia	No	No	No
Hawaii	No	No	No
Idaho	No	No	No
Illinois	No	Yes	No
Indiana	No	Yes	No
Iowa	No	Yes	No
Kansas	No	Yes	No
Kentucky	No	No	No
Louisiana	No	Yes	No
Maine	No	Yes	No
Maryland	No	Yes	No
Massachusetts	No	No	No
Michigan	No	Yes	No
Minnesota	No	Yes	No
Mississippi	Yes	No	No
Missouri	No	Yes	No
Montana	No	Yes	No
Nebraska	No	Yes	No
Nevada	No	Yes	No
New Hampshire	No	Yes	No
New Jersey	No	Yes	No
New Mexico	No	No	No
New York	No	No	No
North Carolina	No	No	No
North Dakota	No	Yes	No
Ohio	No	Yes	No
Oklahoma	No	Yes	No
Oregon	No	Yes	No
Pennsylvania	No	Yes	No
Rhode Island	No	No	No
South Carolina	No	No	Yes
South Dakota	No	No	No
Tennessee	Yes	Yes	No

Table 1: State-by-State Regulatory Data, continued

State	Interview required for enrollment¹	Online enrollment¹	Asset test required for children's coverage²
Texas	No	Yes	Yes
Utah	No	Yes	Yes
Vermont	No	Yes	No
Virginia	No	Yes	No
Washington	No	Yes	No
West Virginia	No	Yes	No
Wisconsin	No	Yes	No
Wyoming	No	Yes	No

Table 1: State-by-State Regulatory Data, continued

State	Medicaid program for the medically needy ^{3, 5}	Presumptive eligibility ^{1, 6}	Fee for service or managed care ⁴
Alabama	No	No	both
Alaska	No	No	Fee for service
Arizona	Yes	No	both
Arkansas	Yes	No	both
California	Yes	Yes	both
Colorado	No	Yes	both
Connecticut	Yes	Yes	both
Delaware	No	No	both
District of Columbia	Yes	No	both
Florida	Yes	No	both
Georgia	Yes	No	both
Hawaii	Yes	No	both
Idaho	No	No	Managed care
Illinois	Yes	Yes	both
Indiana	No	No	both
Iowa	Yes	Yes	both
Kansas	Yes	Yes	both
Kentucky	Yes	No	both
Louisiana	Yes	No	both
Maine	Yes	No	both
Maryland	Yes	No	both
Massachusetts	Yes	Yes	both
Michigan	Yes	Yes	both
Minnesota	Yes	No	both
Mississippi	No	No	both
Missouri	No	Yes	both
Montana	Yes	Yes	both
Nebraska	Yes	No	both
Nevada	No	No	both
New Hampshire	Yes	Yes	Fee for service
New Jersey	Yes	Yes	both
New Mexico	No	Yes	both
New York	Yes	Yes	both
North Carolina	Yes	No	both
North Dakota	Yes	No	both
Ohio	No	Yes	both
Oklahoma	No	No	both
Oregon	No	No	both
Pennsylvania	Yes	No	both
Rhode Island	Yes	No	both
South Carolina	No	No	Managed care
South Dakota	No	No	both
Tennessee	Yes	No	Managed care

Table 1: State-by-State Regulatory Data, continued

State	Medicaid program for the medically needy^{3, 5}	Presumptive eligibility^{1, 6}	Fee for service or managed care⁴
Texas	Yes (pregnant women and children)	No	both
Utah	Yes	No	both
Vermont	Yes	No	both
Virginia	Yes	No	both
Washington	Yes	No	both
West Virginia	Yes	No	both
Wisconsin	Yes	Yes	both
Wyoming	No	No	Fee for service

Table 1: State-by-State Regulatory Data, continued

State	Medicaid premium for children¹	Medicaid copay for children¹
Alabama	No	No
Alaska	No	No
Arizona	No	No
Arkansas	No	Yes
California	No	No
Colorado	No	No
Connecticut	No	No
Delaware	No	No
District of Columbia	No	No
Florida	No	No
Georgia	No	No
Hawaii	No	No
Idaho	No	No
Illinois	No	No
Indiana	No	No
Iowa	No	No
Kansas	No	No
Kentucky	No	No
Louisiana	No	No
Maine	No	No
Maryland	Yes	No
Massachusetts	No	No
Michigan	No	No
Minnesota	Yes	No
Mississippi	No	No
Missouri	No	No
Montana	No	No
Nebraska	No	No
Nevada	No	No
New Hampshire	No	No
New Jersey	No	No
New Mexico	No	Yes
New York	No	No
North Carolina	No	No
North Dakota	No	No
Ohio	No	No
Oklahoma	No	No
Oregon	No	No
Pennsylvania	No	No
Rhode Island	Yes	No
South Carolina	No	No
South Dakota	No	No
Tennessee	No	No

Table 1: State-by-State Regulatory Data, continued

State	Medicaid premium for children¹	Medicaid copay for children¹
Texas	No	No
Utah	No	No
Vermont	Yes	No
Virginia	No	No
Washington	No	No
West Virginia	No	No
Wisconsin	Yes	Yes
Wyoming	No	No

Notes to Table 1

¹ Data original to study, updated by reference to Kaiser Commission on Medicaid and the Uninsured, Getting into Gear for 2014: Findings from a 50-State Survey of Eligibility, Enrollment, Renewal, and Cost-Sharing Policies in Medicaid and CHIP, 2012-2013, *available at* <http://www.kff.org/medicaid/8401.cfm>.

² Kaiser Commission on Medicaid and the Uninsured, Getting into Gear for 2014: Findings from a 50-State Survey of Eligibility, Enrollment, Renewal, and Cost-Sharing Policies in Medicaid and CHIP, 2012-2013, *available at* <http://www.kff.org/medicaid/8401.cfm>.

³ Data original to study, updated by reference to Kaiser Commission on Medicaid and the Uninsured, The Medicaid Medically Needy Program: Spending and Enrollment Update, at 1, *available at* <http://www.kff.org/medicaid/upload/4096.pdf>.

⁴ Data original to study, updated by reference to Centers for Medicare and Medicaid Services, U.S. Department of Health and Human Services, Medicaid Managed Care Enrollment Report, November 2012, *available at* <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Data-and-Systems/Downloads/2011-Medicaid-MC-Enrollment-Report.pdf>.

⁵ Medically needy individuals are those with substantial medical bills who would be eligible for Medicaid, but for income that exceeds the maximum threshold.

⁶ Presumptive eligibility allows providers to make an initial eligibility decision while an application is still pending.

Table 2: Enrollment and Waiver Data for Selected States

State	Medicaid enrollment process	12 month continuous eligibility ¹	Relevant waivers	Waiver waitlist (2010) ²	Waiver participants (2008) ²	Waitlist as percent of recipients
California	Paper or online	Yes	AIDS, Assisted Living, HCBS for Developmentally Disabled, Nursing Facility/Acute Hospital, In Home Operations, Developmentally Disabled-Continuous Nursing Care Program, Multipurpose Senior Services Program, Specialty Mental Health Consolidation Program, Pediatric Palliative Care	2030	91006	2.2%
Florida	Paper or online	Under age 5; over 5, six month continuous eligibility	Adult Cystic Fibrosis, Aged/Disabled Adult Services, Adult Day Health Care, Assisted Living for the Elderly, iBudget, Channeling Services for the Frail Elderly, Developmental Disabilities, Familial Dysautonomia, Model, Nursing Home Diversion, Project AIDS Care, Traumatic Brain Injury and Spinal Cord Injury	32753	65152	50.3%
Georgia	Paper	No	Service Options Using Resources in a Community Environment (SOURCE) Program, Community Care Services Program, Independent Care Waiver Program, New Options Waiver Program (NOW), Comprehensive Supports Waiver Program (COMP), Georgia Pediatric Program (GAPP), Money Follows the Person Demonstration Program, Katie Beckett	11242	26647	42.2%
Kentucky	Interview required for families, not children	No	Acquired Brain Injury, Acquired Brain Injury Long Term Care, Home and Community Based (1915), Michelle P., Model II, Support for Community Living	0	13471	N/A
North Carolina	Paper	Yes	Community Alternatives Program Developmental Disabilities, Elderly and Disabled, Community Alternatives Program Choice, Children's, Comprehensive, Supports	3753	25389	14.8%

Table 2: Enrollment and Waiver Information for Selected States, continued

State	Medicaid enrollment process	12 month continuous eligibility ¹	Relevant waivers	Waiver waitlist (2010) ²	Waiver participants (2008) ²	Waitlist as percent of recipients
Tennessee	Paper, online, or fax	No	Developmental Disabilities, HCBS Elderly and Disabled, Self-determination	2666	10318	25.8%
Texas	Paper, online, or fax	No	Community Based Alternatives, Community Living and Support Services, Deaf-Blind with Multiple Disabilities, Home and Community-Based Services, Medically Dependent Children Program, Texas Home Living Program	125385	64329	194.9%
Virginia	Paper or online	No	Mental Retardation/Intellectual Disabilities, Day Support for Individuals with MR/ID, Individual and Family Developmental Disabilities Support, Elderly or Disabled with Consumer Direction, Technology Assisted	6798	24760	27.5%
Washington	Paper or online	Yes	Community Options Program Entry System (COPES), New Freedom, Children's Intensive In-Home Behavior Support, MR/DD Basic Plus; Core Waiver, Community Protection Waiver	829	41451	2.0%
¹ See Kaiser Commission on Medicaid and the Uninsured, Getting into Gear for 2014: Findings from a 50-State Survey of Eligibility, Enrollment, and Cost-Sharing Policies in Medicaid and CHIP, 2012-2013, <i>available at</i> http://www.kff.org/medicaid/8401.cfm .						
² See Kaiser Commission on Medicaid and the Uninsured, Medicaid 1915(c) Home and Community-Based Service Programs, <i>available at</i> http://www.kff.org/medicaid/upload/7720-05.pdf .						

WEST VIRGINIA UNIVERSITY

Intermediary Interviews

9/7/11



Overview

Because military families have to negotiate an often complex network of health coverage options and services, the Department of Defense has dedicated resources to care management and referral services. In addition to these military systems like TRICARE, the Exceptional Family Member Program (EFMP), and Military Treatment Facilities, families must also negotiate the eligibility determination, enrollment, and case management functions of state Medicaid systems. There are a number of intermediaries that perform a crucial function in connecting families to these services. The performance and role of these intermediaries require attention in an evaluation and assessment of Medicaid services for military dependents with special health needs.

"Special Needs" is an umbrella underneath which a staggering array of diagnoses can be wedged. People with special needs may have mild learning disabilities or profound intellectual disability; food allergies or terminal illness; developmental delays that catch up quickly or remain entrenched; occasional panic attacks or serious psychiatric problems. The designation is useful for getting needed services, setting appropriate goals, and gaining understanding for a person with special needs and their stressed family.

Special Needs, for this study will be defined as a person that has a minor to severe impediment to their cognitive abilities, behavior, physical abilities, or development that hinders their learning and/or assimilation into their peer group. It is also defined as a person with chronic medical, mental, emotional, behavioral, or educational needs that could require extra on-going care.

INTERMEDIARY INTERVIEW SCHEDULE

Base Commanding Officer (BCO)

Family Center Director

Exceptional Family Member Program (EFMP) Manager

Personal Financial Management Program Manager

New Parent Support Program-Visiting Nurse

School Liaison

Military Treatment Facility (MTF) Commanding Officer

Medical Case Manager (MTF)

Beneficiary Counseling & Assistance Coordinator (BCAC)

Developmental Pediatrician

Family Support Group (FSG) Leader

General Notes

- At each interview our ultimate goal is to find out what happens, with whom, and in what order. This includes people at the installation, in the community, and at other installations.
- Make sure to get copies of print materials from all people you interview. This includes forms, applications, brochures, etc. These are meant to be blank forms- not something that would have personal information on it.
- Be familiar with the questions. It isn't important to ask them word-for-word.
- At places that say "HCBS waivers" it is perfectly acceptable to just use "waivers."
- Make it personal. At places that talk about "the installation" use the installation name or "here".
- Try to make the tone of the interview conversational rather than a "quiz" of someone's knowledge of Medicaid, referrals, waivers, etc.

Base Commanding Officer

Introduction

Thank you for agreeing to meet with us today. Our study will provide needed information about supports and barriers that exist for families accessing Medicaid services for which they are eligible.

Your participation in this discussion is completely **voluntary** and you can choose not to answer any question. I will be **taping** the session because I don't want to miss any of your comments. Although I will be taking some notes during the session, I can't possibly write fast enough to get it all down. You should also know that this conversation will be kept **confidential**. Your name will not be in the transcripts and notes that we make, and we will not associate your name with any of your comments. Additionally, we will ensure that any information we include in our report does not identify you as the respondent.

Questions

1. What resources/supports are available to military families with special needs family members at this installation?
2. How does your command structure aid families seeking to access special needs services? (Prompt: Key personnel and their roles)
 - a. Interviewer note: We want to find out what happens, with whom and in what order.
3. What do you consider strengths of your command or at the installation in general, when assisting special needs families seeking services?
4. What types of command activities take place that would help identify families with special needs and get them connected to information and beneficial resources, e.g. disability resource fair at the community center?
5. When you receive an exceptional family member to your command, what do personnel do to assist families in accessing needed services?
6. What is the process for addressing systemic issues affecting military families with special needs? Is there an installation family readiness or EFMP committee that elevates the issue up the chain of command to you? If it involved access to community-based services, such as HCBS waivers, how would you proceed?
7. How do families with special needs affect unit readiness?
8. What changes have you observed in special needs concerns over time, especially in terms of number of families with special needs and issues involving access to Medicaid covered services and HCBS waivers?

9. Through our research at the national level, we are aware that some families have had difficulties accessing services provided by HCBS waivers. Do you know if this concern has been raised at your installation?
10. How does your installation collaborate with state agencies that provide services to military families with special needs? How would you characterize these relationships?
11. If you had the ability to improve access to health care for military families with special needs, how would you change the military health system, Medicaid, and/or the HCBS waiver system to accomplish this goal?

FAMILY CENTER DIRECTOR

Introduction

Thank you for agreeing to meet with us today. Our study will provide needed information about supports and barriers that exist for families accessing Medicaid services for which they are eligible.

Your participation in this discussion is completely **voluntary** and you can choose not to answer any question. I will be **taping** the session because I don't want to miss any of your comments. Although I will be taking some notes during the session, I can't possibly write fast enough to get it all down. You should also know that this conversation will be kept **confidential**. Your name will not be in the transcripts and notes that we make, and we will not associate your name with any of your comments. Additionally, we will ensure that any information we include in our report does not identify you as the respondent.

Questions

1. What resources/supports are available to military families with special needs family members at this installation?
2. How does the family center aid families seeking to access special needs services? (Prompt: Key personnel and their roles)
 - a. Interviewer note: We want to find out what happens, with whom and in what order.
3. How does the center provide outreach and service connection to service members with special needs family members?
4. How do you communicate with the Base Commanding Officer's staff?
5. How do you communicate with Military Treatment Facility (MTF) supervisors/staff?
6. Describe your command's relationship with state and local support services and agencies (Prompt: Medicaid, social services, schools). How would you characterize your relationship (e.g., collaborative)?
7. How does your installation collaborate with state agencies that provide services to military families with special needs? How would you characterize these relationships?
8. What is your assessment of the Medicaid application and eligibility determination process in this state?
9. What are the biggest challenges families face concerning access to Medicaid and HCBS waivers?
10. Through our research at the national level, we are aware that some families have had difficulties accessing services provided by HCBS waivers. Do you know if this concern has been raised at your installation?

11. How have you sought to resolve these concerns or problems accessing HCBS services?
12. What changes have you observed in special needs concerns over time, especially in terms of number of families with special needs and issues involving access to Medicaid covered services and HBCS waivers?
13. Has the HCBS waiver issue been identified as a systems issue for families and elevated to the installation Commanding Officer's level or higher?
14. **If** you had the ability to improve access to health care for military families with special needs, how would you change the military health system, Medicaid, and/or the HCBS waiver system to accomplish this goal?

EXCEPTIONAL FAMILY MEMBER PROGRAM MANAGER

Introduction

Thank you for agreeing to meet with us today. Our study will provide needed information about supports and barriers that exist for families accessing Medicaid services for which they are eligible.

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Questions

1. What resources/supports are available to military families with special needs family members at this installation?
2. How does the EFMP operate to aid families seeking to access special needs services? (Prompt: Key personnel and their roles)
 - a. Interviewer note: We want to find out what happens, with whom and in what order.
3. In general, how do you communicate information and resources about your EFMP program and other beneficial programs various stakeholders (Prompt: installation command, service members, families of service members, other support groups on installation, outside agencies)?
4. How do you work with your counterparts at other installations to facilitate the relocation of a family member?
5. Describe how service members and/or their family members are referred to your office. What happens once they are here?
6. Describe your office's relationship with state and local support services and agencies (Prompt: Medicaid, social services, schools).
7. How does your office collaborate with state agencies that are providing services to military families with special needs? How would you characterize these relationships?
8. Who are the key personnel or organizations in your area (military, state, other) that have been the most helpful to military families with special needs?
9. How do you work with military families to help them access Medicaid and/or HCBS waivers? (Prompt: help with the process, with the application, with trouble-shooting,

problem-solving, and advocating for families in the Medicaid eligibility or claims process, with making needed contacts (state/local *off* installation)?

10. What is your assessment of the Medicaid application and eligibility determination process in this state?
11. If you have a question about Medicaid where do you go for answers?
12. What are the most common services that families at your installation receive from state HCBS waivers?
13. Through our research at the national level, we are aware that some families have had difficulties accessing services provided by HCBS waivers. Do you know if this concern has been raised at your installation?
14. How have you sought to resolve these concerns or problems?
15. What changes have you observed in special needs concerns over time, especially in terms of number of families with special needs and issues involving access to Medicaid covered services and HCBS waivers?
16. Are state implemented programs such as Medicaid providing acceptable coverage for special needs families in your area?
17. If you had the ability to improve access to health care for military families with special needs, how would you change the military health system, Medicaid, and/or the HCBS waiver system to accomplish this goal?

PERSONAL FINANCIAL MANAGEMENT PROGRAM MANAGER

Introduction

Thank you for agreeing to meet with us today. Our study will provide needed information about supports and barriers that exist for families accessing Medicaid services for which they are eligible.

Your participation in this discussion is completely **voluntary** and you can choose not to answer any question. I will be **taping** the session because I don't want to miss any of your comments. Although I will be taking some notes during the session, I can't possibly write fast enough to get it all down. You should also know that this conversation will be kept **confidential**. Your name will not be in the transcripts and notes that we make, and we will not associate your name with any of your comments. Additionally, we will ensure that any information we include in our report does not identify you as the respondent.

Questions

1. What resources/supports are available to military families with special needs family members at this installation?
2. How does your office aid families seeking to access special needs services? (Prompt: Key personnel and their roles)
 - a. Interviewer note: We want to find out what happens, with whom and in what order.
3. In general, how do you communicate information and resources about your program and other beneficial programs various stakeholders (Prompt: installation command, service members, families of service members, other support groups on installation, outside agencies)?
4. How do you work with your counterparts at other installations to facilitate the relocation of a family member?
5. Describe your interaction with the EFMP Manager and other key support services and personnel for special needs families.
6. Describe how service members and/or their family members are referred to your office. What happens once they are here?
 - a. Interviewer note: We want to find out what happens, with whom and in what order.
7. Describe your office's relationship with state and local support services and agencies (Prompt: Medicaid, social services, schools).
8. How do you work with military families to help them access Medicaid and/or HCBS waivers? (Prompt: help with the process, with the application, with trouble-shooting, problem-solving, and advocating for families in the Medicaid eligibility or claims process, with making needed contacts (state/local) off installation)?

9. What is your level of understanding about HCBS waivers in your state? If you have a question, where do you go for answers?
10. What is your assessment of the Medicaid application and eligibility determination process in this state?
11. If you have a question about Medicaid where do you go for answers?
12. Are you familiar with military families with special needs that are having financial problems due to out-of-pocket medical expenses? If so, please describe.
13. Do you refer families to the TRICARE Debt Collections Assistance Officer at the MTF to have any debt issues resolved? Have families been successful in having some, if not all, of their (medical) debt resolved?
14. Have you seen any change in special needs concerns over time (Prompt: number of military families identified with special needs and issues involving access to Medicaid, including HCBS waivers)?
15. If you had the ability to improve access to health care for military families with special needs, how would you change the military health system, Medicaid, and/or the HCBS waiver system to accomplish this goal?

NEW PARENT SUPPORT PROGRAM-VISITING NURSE

Introduction

Thank you for agreeing to meet with us today. Our study will provide needed information about supports and barriers that exist for families accessing Medicaid services for which they are eligible.

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Questions

1. What resources/supports are available to military families with special needs family members at this installation?
2. How does your program aid families seeking to access special needs services? (Prompt: Key personnel and their roles)
 - a. Interviewer note: We want to find out what happens, with whom and in what order.
3. In general, how do you communicate information and resources about your EFMP program and other beneficial programs various stakeholders (Prompt: base command, service members, families of service members, other support groups on installation, outside agencies)?
4. Describe how service members and/or their family members are referred to your office. What happens while they are here?
 - a. Interviewer note: We want to find out what happens, with whom and in what order.
5. Describe your interaction with the EFMP Manager and other key support services and personnel, such as medical case management at the **MTF**, for families with children with special needs.
6. Do you develop goals for families to work on behalf of their children? If yes, what are typical goals for your families with children who have special needs?
7. Are you aware of the services available to military families with special needs via Home Community Based Services waivers? What services are most commonly used?
8. What information do you provide to families about services provided by Medicaid and/or HCBS waivers?

9. Describe the referral process you engage in after a special needs child is over 3 years old. Where does the child go next?
10. What changes have you observed in special needs concerns over time, especially in terms of number of families with special needs and issues involving access to Medicaid covered services and HBCS waivers?
11. If you had the ability to improve access to health care for military families with special needs, how would you change the military health system, Medicaid, and/or the HCBS waiver system to accomplish this goal?

SCHOOL LIAISON

Introduction

Thank you for agreeing to meet with us today. Our study will provide needed information about supports and barriers that exist for families accessing Medicaid services for which they are eligible.

Your participation in this discussion is completely **voluntary** and you can choose not to answer any question. I will be **taping** the session because I don't want to miss any of your comments. Although I will be taking some notes during the session, I can't possibly write fast enough to get it all down. You should also know that this conversation will be kept **confidential**. Your name will not be in the transcripts and notes that we make, and we will not associate your name with any of your comments. Additionally, we will ensure that any information we include in our report does not identify you as the respondent.

Questions

1. Can you give us an overview of what resources/supports are available to military families with special needs family members at this installation?
2. How does your *office* operate to aid families seeking to access special needs services? (Prompt: Key personnel and their roles)
 - a. Interviewer note: We want to find out what happens, with whom and in what order.
3. In general, how do you communicate information and resources about your EFMP program and other beneficial programs various stakeholders (Prompt: installation command, service members, families of service members, other support groups on installation, outside agencies)?
4. How do you work with your counterparts at other installations to facilitate the relocation of a family member?
5. How do you work with local schools?
6. Describe your interaction with the EFMP Manager and other key support services and personnel for special needs families.
7. Describe how service members and/or their family members are referred to your office. What happens once they are here?
8. What is your level of understanding about Medicaid and/or HCBS waivers in your state? If you have a question where do you go for answers?
9. If you had the ability to improve access to health care for military families with special needs, how would you change the military health system, Medicaid, and/or the HCBS waiver system to accomplish this goal?

MEDICAL CASE MANAGER (MTF)

Introduction

Thank you for agreeing to meet with us today. Our study will provide needed information about supports and barriers that exist for families accessing Medicaid services for which they are eligible.

Your participation in this discussion is completely **voluntary** and you can choose not to answer any question. I will be **taping** the session because I don't want to miss any of your comments. Although I will be taking some notes during the session, I can't possibly write fast enough to get it all down. You should also know that this conversation will be kept **confidential**. Your name will not be in the transcripts and notes that we make, and we will not associate your name with any of your comments. Additionally, we will ensure that any information we include in our report does not identify you as the respondent.

Questions

1. Can you give us an overview of what resources/supports are available to military families with special needs family members at this installation?
2. How does your office operate to aid families seeking to access special needs services? (Prompt: Key personnel and their roles)
 - a. Interviewer note: We want to find out what happens, with whom and in what order.
3. How do you work with your counterparts at other installations to facilitate the relocation of a family member?
4. Describe how special needs families are referred to your office. What happens once they are here?
 - a. Interviewer note: We want to find out what happens, with whom and in what order.
5. Would you say the individuals or families you are serving that have disabilities are paying out of pocket for services, etc. that TRICARE does not provide?
6. How do you work with military families to help them access Medicaid and/or HCBS waivers? (Prompt: help with the process, with the application, with trouble-shooting, problem-solving, and advocating for families in the Medicaid eligibility or claims process, with making needed contacts (state/local) off installation)?
7. What are the services available to military families with special needs via HCBS waivers? What services are most commonly used?
8. Do you have families that are currently receiving Medicaid or the HCBS waiver? Do families have challenges accessing these services due to eligibility requirements or waiting lists?

9. Where do you refer families who are paying out of pocket for services that TRJCARE does not provide?
10. Through our research at the national level, we are aware that some families have had difficulties accessing services provided by HCBS waivers. Do you know if this concern has been raised at your installation?
11. How have you sought to resolve these concerns or problems?
12. What services are currently unavailable and needed in your area?
13. What is your assessment of the Medicaid application and eligibility determination process in this state?
14. Describe your office's relationship with state and local support services and agencies (Prompt: Medicaid, social services, schools).
15. What changes have you observed in special needs concerns over time, especially in terms of number of families with special needs and issues involving access to Medicaid covered services and HCBS waivers?
16. If you had the ability to improve access to health care for military families with special needs, how would you change the military health system, Medicaid, and/or the HCBS waiver system to accomplish this goal?

BENEFICIARY COUNSELING & ASSISTANCE COORDINATOR

Introduction

Thank you for agreeing to meet with us today. Our study will provide needed information about supports and barriers that exist for families accessing Medicaid services for which they are eligible.

Your participation in this discussion is completely **voluntary** and you can choose not to answer any question. I will be **taping** the session because I don't want to miss any of your comments. Although I will be taking some notes during the session, I can't possibly write fast enough to get it all down. You should also know that this conversation will be kept **confidential**. Your name will not be in the transcripts and notes that we make, and we will not associate your name with any of your comments. Additionally, we will ensure that any information we include in our report does not identify you as the respondent.

Questions

1. Can you give us an overview of what resources/supports are available to military families with special needs family members at this installation?
2. How does your office operate to aid families seeking to access special needs services? (Prompt: Key personnel and their roles)
 - a. Interviewer note: We want to find out what happens, with whom and in what order.
3. How do you work with your counterparts at other installations to facilitate the relocation of a family member?
4. Describe how special needs families are referred to your office. What happens once they are here?
 - a. Interviewer note: We want to find out what happens, with whom and in what order.
5. How do you work with military families to help them access Medicaid and/or HCBS waivers? (Prompt: help with the process, with the application, with trouble-shooting, problem-solving, and advocating for families in the Medicaid eligibility or claims process, with making needed contacts (state/local) off installation)?
6. Describe the functional relationship between Medicaid and TRICARE in your area. How do they work together? Are there gaps in wraparound? How important is Medicaid for supplemental coverage in services for special needs families?
7. What is your assessment of the Medicaid application and eligibility determination process in this state?
8. Describe your office's relationship with state and local support services and agencies (Prompt: Medicaid, social services, schools).

9. Through our research at the national level, we are aware that some families have had difficulties accessing services provided by HCBS waivers. Do you know if this concern has been raised at your installation?
10. How have you sought to resolve these concerns or problems?
11. What changes have you observed in special needs concerns over time, especially in terms of number of families with special needs and issues involving access to Medicaid covered services and HCBS waivers?
12. If you had the ability to improve access to health care for military families with special needs, how would you change the military health system, Medicaid, and/or the HCBS waiver system to accomplish this goal?

DEVELOPMENTAL PEDIATRICIAN (OR EMFP PHYSICIAN)

Introduction

Thank you for agreeing to meet with us today. Our study will provide needed information about supports and barriers that exist for families accessing Medicaid services for which they are eligible.

Your participation in this discussion is completely **voluntary** and you can choose not to answer any question. I will be **taping** the session because I don't want to miss any of your comments. Although I will be taking some notes during the session, I can't possibly write fast enough to get it all down. You should also know that this conversation will be kept **confidential**. Your name will not be in the transcripts and notes that we make, and we will not associate your name with any of your comments. Additionally, we will ensure that any information we include in our report does not identify you as the respondent.

Questions

1. Can you give us an overview of what resources/supports are available to military families with special needs family members at this installation?
2. Describe the process of how newly referred children are directed to your office.
3. Where do you refer patients with special needs when the MTF cannot accommodate their needs?
4. What role does Medicaid play in providing coverage for services needed by patients with special needs?
5. What role do HCBS waivers and services play in providing services needed by patients with special needs?
6. Are you aware of any challenges families have with accessing Medicaid or the HCBS waivers?
7. Has a lack of access to specialty and medical services created challenges to your ability to provide care? If so, what are these challenges?
8. What changes have you observed in special needs concerns over time, especially in terms of number of families with special needs and issues involving access to Medicaid covered services and HCBS waivers?
9. If you had the ability to improve access to health care for military families with special needs, how would you change the military health system, Medicaid, and/or the HCBS waiver system to accomplish this goal?

FAMILY SUPPORT GROUP LEADER/ FAMILY READINESS ASSISTANT

Introduction

Thank you for agreeing to meet with us today. Our study will provide needed information about supports and barriers that exist for families accessing Medicaid services for which they are eligible.

Your participation in this discussion is completely **voluntary** and you can choose not to answer any question. I will be **taping** the session because I don't want to miss any of your comments. Although I will be taking some notes during the session, I can't possibly write fast enough to get it all down. You should also know that this conversation will be kept **confidential**. Your name will not be in the transcripts and notes that we make, and we will not associate your name with any of your comments. Additionally, we will ensure that any information we include in our report does not identify you as the respondent.

Questions

1. Can you give us an overview of what resources/supports are available to military families with special needs family members at this installation?
2. How much of a role does the family support group have for families with an exceptional family member?
3. Describe the installation's climate of assistance for special needs families.
4. What processes are currently working for special needs families?
5. What barriers to special needs services do families most frequently encounter in your area?
6. Which intermediaries are you interacting with most frequently for assistance (Prompt: EFMP, Med Case Manager, BCAC, etc.)?
7. What additional support would be most beneficial for your families?
8. Through our research at the national level, we are aware that some families have had difficulties accessing services provided by HCBS waivers. Do you know if this concern has been raised at your installation?
8. How have you sought to resolve these concerns or problems?
9. What changes have you observed in special needs concerns over time, especially in terms of number of families with special needs and issues involving access to Medicaid covered services and HBCS waivers?

10. If you had the ability to improve access to health care for military families with special needs, how would you change the military health system, Medicaid, and/or the HCBS waiver system to accomplish this goal?

POST INTERVIEW QUESTIONS

Interviewer

After you have completed the interview process, please draft answers to the following questions for greater clarity and further discussion. They are intended to help synthesize the overall experience from your perspective. Record the discussion as you debrief with your team.

1. What was your overall sense of the coordination of installation services and resources that are designed to assist families with special needs members?
2. Overall, what was your impression of the physical location, accessibility, and environment of key facilities that special needs families would utilize on this installation (**MTF**, family centers, etc.)?
3. Do you see particular connects or disconnects among key intermediaries?
 - a. What might a "service map" look like, reflecting services on post?
4. Did the responses from various intermediaries depict a consistent picture of what's happening at the installation level for special needs families, or do you note significant differences of opinion or perspective?
5. Are there any overarching concerns or issues that have been raised about Medicaid administration, quality of service, eligibility, and availability of waived services?
 - a. What does your visit tell you about the Medicaid and waiver situation in this state?
 - b. Is this situation problematic throughout the Tricare region?
6. Please identify some best practices that the installation is using to help serve military families with special needs members.
7. From your installation visit, what is your evaluation of how well integrated Tricare and Medicaid services are in providing health coverage to eligible military families?
8. What surprised you about this installation visit? What did you find most interesting, compelling, novel, or memorable regarding the provision of care to special needs dependents?
9. Are there ways in which the dog did not bark-i.e., can you identify any gaps or omissions that struck you as problematic or interesting during your visit?

GLOSSARY, TERMS AND DEFINITIONS

Section 1915 (c) Home and Community-Based Services Waiver Program: This section provides the U.S. DHHR Secretary the authority to waive Medicaid provisions in order to allow long-term care services to be delivered in community settings. This program is the Medicaid alternative to providing comprehensive long-term services in institutional settings.

Possible range of services includes:

1. **Adult day care-** Daytime, community-based program for functionally impaired adults that provides a variety of health, nutrition, social, and related services in a protective setting to those who are otherwise being cared for by family members. Its purpose is to enable individuals to remain at home and in the community and to encourage family members to care for them by providing relief from the burden of constant care.
2. **Adult day habilitation services-** Day program usually serving individuals with MR/DD, teach skills such as cooking, recreation, and work skills. The individual may work part of the day with other individuals with disabilities in assembly and production work for piece rate wages or below minimum wages (Work Activities Center). In some sites, the recipient attends a center with peers learning non-vocational or pre-vocational skills.
3. **Adult day health services** -Adult day care setting which provides more health-related services.
4. **Assistive technology-** A range of equipment, machinery and devices that share the purpose of assisting or augmenting the capabilities of individuals with disabilities in almost every area of daily community life, including mobility, independence in activities of daily life, communication, employment learning and so forth. Specialized examples include wheelchairs and ramps, and electronic and printed picture/icon communication devices, but also can include tape recorders and tapes for messages, materials, instructions and so forth normally presented on paper, special large or punch switches available at a local electronics store, level door handles (as opposed to knobs) that are available at any hardware store, and telephones with single function keys for dialing certain numbers that are available at most department stores.
5. **Adaptive equipment-** Physical and/or mechanical modifications to the home, vehicle or the recipient's personal environment.
6. **Case management** -Services which assist individuals' access to needed medical, social, educational, and other services.
7. **Personal care attendant** – Services such as, help balancing a checkbook, grocery shopping, developing a budget, paying bills, etc.
8. **Habilitation services** - Services designed to assist individuals in acquiring, retaining, and improving the self-help, socialization, and adaptive skills necessary to reside successfully in home and community based settings; and includes prevocational, educational, and supported employment.

9. **Homemaker services** - Assistance with general household activities and ongoing monitoring of the well-being of the individual.
10. **Home health aide** - Health care professional who assists with specific health problems.
11. **Nursing care services**- Services provided by or under the direction of a registered nurse.
12. **Personal care services** - Direct supervision and assistance in daily living skills and activities (e.g., assisting the individual with bathing and grooming).
13. **Respite care** - Short-term supervision, assistance, and care provided due to the temporary absence or need for relief of recipient's primary caregivers. This may include overnight, in-home or out-of-home services. Training for the family in managing the individual. Day treatment or other partial hospitalization, psycho-social rehabilitation services and clinical services for people with a mental illness.
14. **Vocational services** - Supported employment, pre-vocational education, and other services not covered by other sources.

Focus Group Moderator's Guide

Facilitator Instructions

Provide the introduction at the start of the focus group.

Facilitator prompts have been included for each section in case participants have a hard time getting warmed up. When prompting participants, don't give specific suggestions of people/services-it will bias their answers. Ask them to go with what they remember and whatever comes to their mind.

Instructions for each activity are included in the box under each section. The purpose of each activity is to encourage interaction and discussion among the participants. Encourage this as much as you can.

Before the Session

1. Set-up snacks.
2. Set-up room with participants in a circle, if possible.
3. Post flip-chart paper on wall ready for service mapping. Will probably need one 4-page map and two or three 2-page maps ready to go.
4. As participants arrive, handout demographics form and cover letter.
5. Also, make sure participants all have a pen, marker, and pack of sticky notes.
6. Provide participants with nametags. Have them only give their first name.
7. Start two digital recorders before session starts. Record date and time at the beginning of the session.
8. Supplies: 8 packets of sticky notes, markers, pens, blank paper, clear tape, intermediary cards, 2-3 digital recorders, sticky flip-chart, camera.

After the Session

1. Turn off digital recorders.
2. Photograph the flip chart notes, especially the service map with the sticky notes. Tape down the sticky notes to help them stay in place. This will help in case something gets misplaced, or the sticky notes come loose. Take a picture of the maps in case they are lost.
3. Roll up the flip chart notes so they can be captured later in session notes.

Focus Group Moderator's Guide

Introduction

I want to thank you for taking the time to meet with me today. My name is . Please continue to help yourself to snacks and beverages as we move on this evening. Please note that the restrooms **are-----'**

Today we would like to discuss your experiences with accessing services for your exceptional family member. Specifically we want to hear about your experiences with accessing Medicaid services, including Home and Community Based Services waivers, both here and in other states where you may have lived.

Here are a couple of things you should know.

This discussion should take about an hour and a half. During this time we will have some open discussion questions and we will also have a time where you will use your sticky notes to write information we will use to map some processes on these flip charts posted on the wall.

I will be taping the session because I don't want to miss any of your comments. Although I will be taking some notes during the session, I can't possibly write fast enough to get it all down. Because we're on tape, please be sure to speak up so that we don't miss your comments. Also, try to speak one at a time.

All responses will be kept confidential. This means your name will not be in the transcripts and notes that we make, and will not associate your name with any of your comments. Additionally, we will ensure that any information we include in our report does not identify you as the respondent. Remember, you don't have to talk about anything you don't want to.

Let me set up a few ground rules so that tonight goes smoothly.

First, each of you should feel free to speak your mind. I plan to maintain a positive atmosphere in which all answers are acceptable. I'm interested in your honest responses to this very important issue among military families.

Second, make sure that you speak up and that you allow others to finish their thoughts before you chime in. If you have a thought that you don't want to forget, we have provided paper and a pen for you to take notes.

The goal is that the results of this study will be used to help make decisions about how to work with military families with exceptional family members.

Part 1 (Time: 15 minutes)

Question: What are some specific things that have gone well for you in receiving health coverage options and other services for your family member with special needs?

Facilitator prompts: Think about all of the people you connect with in providing care for your family member. Who were helpful contacts? If you have been transferred, what resources did you have before that you still have access to? What do you have now that you didn't have before?

Also keep in mind the following:

- Eligibility criteria
- Enrollment processes
- Receipt of services
- Waiver list

1. Ask participants the question.
2. Give them a minute to think about and maybe write down their responses.
3. Ask participants to provide a list, "shout-out", things they would add to the list.
4. Probe these items with questions like...
 - a. Can you give me an example of a time this was a good experience?
 - b. Do others have similar or different experiences to share?

Part 2 (Time: 15 minutes)

Question: What are the challenges you face in receiving health coverage options and other services for your family member with special needs?

Facilitator prompts: Think about all of the people you connect with in providing care for your family member. What is missing from your interaction with these services? What are the barriers to receiving services you need?

Also keep in mind the following:

- Eligibility criteria
- Enrollment processes
- Receipt of services
- Waiver list

1. Ask participants the question.
2. Give them a minute to think about and maybe write down their responses.
3. Ask participants to provide a list, "shout-out", things they would add to the list.
4. Probe these items with questions like...
 - a. Can you give me a specific example of these challenges?
 - b. Do others have similar or different experiences to share?

Part 3 (Time: 30 minutes)

Hypothetical situation: Suppose a family with an exceptional family member is making a transition (i.e.-PCS) to a new state. What things should this family do to make sure they receive needed medical services at their new station?

Facilitator prompts: Who are the contacts they should make? Focus on transferring medical benefits, especially Medicaid and Home and Community Based Services waivers.

Also keep in mind the following:

- Eligibility criteria
- Enrollment processes
- Receipt of services
- Waiver list

1. Give the hypothetical situation.
2. **Say:** The purpose of this activity is to start a "map" of the process a family would go through to get the services they need. Let's take a moment to make our "to-do" list for this family.
 - a. What are the things you would do in this situation?
 - i. Ask participants to "shout-out" things they would add to the list. Write each response on a sticky note and add it to the flip chart paper.
 - b. Is there a certain order to the steps you should take?
 - c. Now, what do you see or get at each of these?
 - d. Who do you talk to at each step
3. Let's discuss this list...
 - a. What is important about each step?
 - b. Are there any services we missed?

Service Mapping Continued:

1. Give each participant a stack of "*intermediary cards*." Ask the participants to rank the positions from most to least helpful.
2. Discuss...
 - a. What did you rank as some of the most helpful positions?
 - b. Where are the differences? Where do we disagree?
 - c. What are some specific experiences?
 - d. Are there any services we missed?
3. Have participants' paperclip stack in order with the top card being "most helpful."
4. Collect cards and place in envelope.

Facilitator Note: It is possible that there will be disagreement in this discussion based on various experiences. It's ok if the map gets "messy," but try to capture as much of the alternative service maps as possible.

Part 4 (Time: 15 minutes)

Question: If you were in charge for a day, what would you do to help military families like yours in terms of programs/services/contacts?

Facilitator prompt: What goals would you have for providing Medicaid and related services to military families?

1. Ask participants the question.
2. Ask participants to provide a list, "shout-out", things they would add to the list.
3. Additional discussion
 - a. How would these items change your experience and the experiences of other families?

Part 5 (Time: 15 minutes)

We want to make sure we get information on some specific topics during these sessions. Could you tell me more about...?

☐ Your experience with the Medicaid eligibility process. Specifically...

_____Resources/contacts on base that help with the process

_____Medicaid waiver programs

☐ When making a transfer, is there any assistance between locations during the process? (i.e.-contacts at old base helping you make contacts with new base before transfer)

☐ How do you make contact with _____?

___ ___ Local Medicaid office

_____Exceptional Family Member Program

_____TRICARE

☐ Who do you go to for advice?

Part 6 (Time: with part 5)

Is there anything else we need to know about?

Conclusion

Thank you for participating in our focus group today! Your input into this very important issue facing military families will help us provide recommendations for change.

Background Questions

These questions are not meant to be asked of participants, but rather they are a guide for you, the facilitator, on the kind of information we are hoping to gain from the discussions.

Part 1

- When you need information or help outside of your friends/family where do you go?
- What programs/services are you and your exceptional family member currently using? Are they provided by the military? Community? Online?
- Which of these programs are most valuable?
- How did you learn about these services?

Part 2

- What services do you need that you are not receiving?
- Why aren't you receiving these services?
- Have you received these services before, but not anymore?
- What is missing from the services you are using? What do you need that you are not receiving?
- If you are on a waiver waiting list, how is that affecting your situation?
- What barriers exist to accessing resources?
- What limits your ability to access resources in the community? In the military?

Part 3

- Are you aware of resources that can help, either in your community or in the military?
- Where do you go for advice or information on resources and support for you and your child with special needs, especially regarding Medicaid?
- Who do you turn to? On base? Off base?
- Which programs/services provide assistance in accessing Medicaid?
- Which programs provide assistance to you in the Medicaid claims process?
- How does the "hand-off" happen when you move to a new base that is in a different state?
- Who gave you assistance during your transition at your previous duty assignment?
- Did you have contact with anyone here before the transfer?
- How did you go about contacting Medicaid when you and your family arrived at the new assignment?

Part 4

- How can things change to improve access to Medicaid and related services to military families?
- Would change be necessary at the state level? With what the military offers? With how Tricare works with dual eligibility cases?
- What is the culture like for military families with exceptional family members?