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 DoD 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 ACA 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 ACA. 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 DoD. This additional information offers a more complex look at how the Medicaid programs in each of these featured states function. 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,

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[4] Numerical data in Table 2regarding 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

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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 who 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/medi-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

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[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

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[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 are 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 DoD with the most

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[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.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Data-and-Systems/Downloads/2011- Medicaid-MC-Enrollment-Report.pdf.

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 ACA, 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 ACA 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 ACA.

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. At 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 DoD 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 DoD 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 DoD 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 DoD, 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 DoD 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.

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[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_1210/28/23/31945394homencom mbooklet27-12-2010.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 who 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.

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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 enrollment[1]	Online enrollment[1]	Asset test required for children's coverage[2]
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 care[4]
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 children[1]	Medicaid copay for children[1]
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 children[1]	Medicaid copay for children[1]
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.

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[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, *available at* 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, *available at* 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 (DoD) 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 (MTF), 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 Staff
- 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 HBCS 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.

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 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 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 HBCS 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 who 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 STAFF

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 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 HBCS 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 HBCS 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 HBCS 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 waivered services?
    a. What does you 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?

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 grounds 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.

GLOSSARY, TERMSAND 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.

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?