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FAMILY SUPPORT POLICY BRIEF

FAMILY SUPPORT PROGRAMS IN THE U.S. TERRITORIES

Family support is generally defined as doing "whatever it takes" for families and people with disabilities to live as much like other families. This incorporates the use of supports, resources, services, financial assistance and other forms of assistance to families of children with disabilities.

The maintenance and development of family support programs has thus far been largely focused on the U.S. states. All 50 states now offer some form of family support. Program structure and funding levels, however, vary considerably across states and even within states. Still, it is plain that over the past 25 years much has been accomplished to establish family support systems in the states.

By comparison, family support systems in the U.S. Territories have lagged behind and do not appear to be nearly as well developed as in most states. One inescapable reason is that there are fundamental differences in the way families and people with disabilities are able to access federally sponsored and other supports as compared to similar individuals within the fifty (50) states. These differences impede the development of inclusive systems of support in the Territories, including family support.

This Policy Brief provides information to highlight some of the unique barriers faced by those seeking to establish comprehensive family support systems in the U.S. Territories. Emphasis is placed on three of the five Territories due to their involvement with the Administration for Developmental Disabilities' (ADD) family support initiative. These include the U.S. Virgin

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Islands (USVI), the Commonwealth of the Northern Mariana Islands (CNMI) and Guam. Some information, however, is also given for Puerto Rico and American Samoa.

Information for this Brief was gathered from conferences, reports, interviews, responses from jurisdictional ADD leaders, computer research, and other data previously gathered from territorial entities. While this is not an in-depth study of family support programs within each Territory, its purpose is to provide an overview of the five Territories and to inform the reader of existing family support programs and to address the pertinent and overarching issues. Further, we hope to convey the territorial perspective and sentiment from the islands' families and advocates.

In this Brief, these five issues are addressed: (a) Medicaid cap limitations; (b) problems with accessing other federal and local funding mechanisms; (c) lack of local capacity; (d) the relative isolation of the Territories, and (e) the impact of diverse cultures.

Profiles of the Five US Territories

In order of proximity to the U.S. mainland, the five major U.S. Territories are: the Commonwealth of Puerto Rico (Puerto Rico), the U.S. Virgin Islands (USVI), American Samoa, the Commonwealth of the Northern Mariana Islands (CNMI), and Guam.

Puerto Rico lies east of the Dominican Republic between the Caribbean Sea and the North Atlantic Ocean. It became a U.S. Territory in 1898 after the Spanish-American War. Its estimated 1995 population is close to 4,000,000, which is heavily Hispanic. Puerto Rico elected it first governor in 1948 and has been governed by its own constitution since 1952. U.S. firms have invested heavily in Puerto Rico since the 1950's. U.S. minimum wage laws apply. Unemployment rate is 13% (1996-97). [1]

The **US Virgin Islands** (USVI) has been a Territory of the United States since its acquisition from Denmark in 1917. It is located in the eastern Caribbean Sea, approximately 1,000 miles southeast of Miami and forty (40) miles east of Puerto Rico. It consists of the four main islands of St. Croix, St. Thomas, St. John, and Water Island. The year 2000 estimated population of the USVI is 120,000. Racial composition is 77% black (descendants from the African slave population introduced into the islands by the French), 10% white, and 13% other races. Tourism is the primary economic activity, accounting for 70% of employment. The USVI government is the largest single source of the territory's jobs. The unemployment rate is 7% (Dec. 2000). The Territory has had

[1] The Bureau of Labor Statistics of the U.S. Department of Labor reports that the unemployment rate in the U.S. is currently 4.2 percent (Jan. 2001). Recent unemployment statistics for Puerto Rico, however, are not readily available; hence, the latest available unemployment rate acquired from local studies is given.

a democratically elected form of government since 1970. Residents are U.S. citizens but do not vote in presidential elections.

American Samoa lies in Oceania off of the South Pacific Ocean, about one-half way from Hawaii to New Zealand. The islands were acquired by the U.S. in the 1899 Treaty of Berlin with Britain and Germany. Its population (est. 2000) is over 65,446. Ethnicities consist of Samoan, 89%; Caucasian, 2%; Tongan, 4%; others, 5%. Economic activity is strongly linked to the U.S., with which American Samoa conducts 80-90% of its foreign trade. The Territory is administered by the U.S. Department of Interior. American Samoa has been governed by its own constitution since 1966, electing its first governor in 1977.

Traveling west from the mainland, the **Commonwealth of the Northern Mariana Islands** (CNMI) lies east of the Philippines and south of Japan in the Pacific Ocean. The islands were formerly part of the U.S. Trust Territory of the Pacific Islands administered by the U.S. Department of Interior. The CNMI achieved commonwealth status in 1976 and became self-governing in 1978 with its first elected governor. Residents are U.S. citizens but do not vote in presidential elections. The commonwealth comprises fourteen (14) islands in the Marianas chain, four of which are inhabited. The major islands are Saipan, the capital and most densely populated with a large non-resident work force; Rota; and Tinian. The current population is approximately 81,000. Asians comprise the largest group of the inhabitants, along with both the indigenous Chamorros and Carolinians, and other Micronesians. Japanese tourism is a major industry, employing roughly 10% of the workforce. Construction and garment manufacturing are also critical to the commonwealth economy. Federal minimum wage laws do not apply in the CNMI. The unemployment rate is 4.3% (1999).

In close proximity to the CNMI, **Guam** is the largest island in Micronesia, approximately 30 miles in length, with a variable width ranging from 12 miles at its widest point to 4 miles at its narrowest. Guam is located 7,500 miles from California and is the most distant American land from the U.S. With an indigenous culture dating back some 2,600 years, Guam was a Spanish colony in the 16th century and seized by the U.S. in the Spanish-American War. The Japanese took Guam in World War II, and the island was retaken by the U.S. in 1944. Guam became an unincorporated U.S. Territory in 1950. Its first governor was elected through local elections in 1970. Guam's residents are U.S. citizens but do not vote in presidential elections. The population is approximately 149,000, and is a rich blend of many races: the native Chamorros, which are a blend of cultures originating from Asia, Europe and the Americas; along with Filipinos, Caucasians, Japanese, Koreans, Chinese, Indians, and Pacific Islanders. As a result of the Compact of Free Association with the Federated States of Micronesia (FSM), the Marshall Islands, Palau and the federal government, these citizens are allowed unrestricted entrance to Guam for employment and education, adding to the cultural mix. Tourism and outside investment, primarily from Japan, are the driving forces behind Guam's growth. The unemployment rate is 15% (2000).

Five Issues That Hinder Family Support Systems Development

Issue 1: The Medicaid Cap Limitation

While much study, evaluation, and advocacy effort with the fifty (50) states have focused on the use of the Medicaid waiver as the principal avenue to access the kinds of services and assistance to families and people with disabilities, Americans residing in all five Territories have a federally imposed capitation on Medicaid service funds received from the federal government. Territorial governments must provide a 50-50 match for services up to the cap and pay 100% above the cap. The federal capitations for fiscal year 2001 are as follows:

In Guam the federal cap is	$5,620,000
In USVI the federal cap is	$5,810,000
In CNMI the federal cap is	$1,930,000

In 1998, the USVI Medicaid Program estimated that the total cost of the program was $15,562,842. All funds beyond the federal USVI cap of $5,810,000 were paid with territorial funds, which translates to a federal share of 34%, while the USVI share was 66%. The USVI has accumulated a deficit of $25 million in unpaid medical claims over the last seven years.

Both Guam and the USVI have for the past several years exhausted all federal funds available under Medicaid. The Guam Department of Public Health and Social Services reports that the Medicaid cap is generally met in July or August of the fiscal year. When the federal cap and territorial match is met, Guam holds the bills until the next fiscal year, leaving an unfunded shortfall in the current fiscal year.

The Territories have faced great challenges with the Medicaid cap in covering the costs of the basic mandatory set of Medicaid acute/primary care services. As a result, they have not applied for Home and Community Based Waivers (HCBs), which have allowed the states considerable leeway to adopt and develop family support programs for people with disabilities and their families. In the USVI, the Virgin Island Medicaid Task Force (2000) found that the inability of the Territory to apply for community waivers because of the cap on Medicaid service funds has resulted in:

- ✓ No home-based or community-based services;
- ✓ No out-patient therapeutic or psychosocial support services for individuals with mental illness;
- ✓ No residential care for individuals with mental illness (Medicaid will pay for services of a critical nature requiring hospitalization, but only for a period of three (3) days in the hospital);
- ✓ No physical therapy or occupational therapy services in the hospital on St. Croix; and

- ✓ Inability of Special Education programs to bill Medicaid for services and assistive technology devices.

The Task Force offers examples of the impact of such policy on individuals:

- ✓ In the USVI, an 80 year-old father and 74 year-old mother are caring for their adult daughter with cerebral palsy. There is no support in the home to lift, bathe or care for her daily needs.
- ✓ A three year-old child needs a wheel chair. While she can get one for school, she cannot take it home: the wheel chair is for school use only. Medicaid funds cannot pay for the chair because the funds are generally limited to medical emergencies.

Because of the Medicaid cap funding limitations placed upon the Territories and the inequitable federal match ratio in the provision of services to people with disabilities, Congressional Representatives from the Territories have once again introduced a bill to remove the cap on Medicaid payments for Puerto Rico, the Virgin Islands, Guam, the Northern Mariana Islands, and American Samoa, and to adjust the Medicaid statutory matching rate for those Territories. HR 48 sponsored by Rep. Donna Christensen (Virgin Islands) and co-sponsored by Rep. Anibal Acevedo-Vila (Puerto Rico), Rep. Robert Underwood (Guam) and Rep. Eni Faleomavaega (American Samoa), seeks to amend titles XI and XIX of the Social Security Act to remove the cap on Medicaid payments for PR, USVI, Guam, CNMI and American Samoa and to adjust the Medicaid statutory match rate for those Territories. As mentioned, the Medicaid statutory match is currently 50%, whereas under the proposed legislation the Medicaid statutory match is 77%. In his State of the Island address, the Governor of Guam termed this Medicaid reform as “priority”, thereafter proclaiming the year 2001 as “Year of the Family”. While the Territories wholeheartedly support the bill sponsored by their representatives, they are non-voting representatives in Congress and unrepresented in the Senate. Therefore, without support from non-territorial Congress-people or Senators, territorial legislation often goes unconsidered.

Closely related to the Territories’ lack of funding for regular State Plan Medicaid services and waiver services, US Territories also have trouble utilizing the Children’s Health Insurance Program. CHIP gives state legislators a great deal of latitude in expanding health insurance coverage to uninsured children, with some states having opted to specifically address the needs of those with special health care needs.

For example, Connecticut provides children with chronic physical or behavioral conditions with wrap-around benefits to augment its basic benefit package. Florida has a special capitated managed care plan for children with chronic physical, developmental or serious behavioral conditions. North Carolina has wrap-around benefit packages for children with physical or developmental problems. These programs also work to identify a network of service providers, which will streamline the process for the parents in actually accessing services for their children.

All Territories have submitted Title IXX plans to expand Medicaid coverage for their CHIP covering uninsured children under 19. However, because the Territories have a cap on federal expenditures, these children receive services that are unmatched with federal funds through state-only funds once Medicaid federal matching funds have been used. Under current law, the calculation of CHIP funds for U.S. Territories is separate from that used for states, resulting in a lower federal subsidy than is given to states. CHIP financial information for FY '99 is as follows:

	FEDERAL ALLOTMENT	ENHANCED FEDERAL MATCH	STATE SHARE	**TOTAL**
USVI	$1,109,875	.65	$597,625	**$1,707,500**
CNMI	$469,563	.65	$252,842	**$722,405**
GUAM	$1,494,063	.65	$804,495	**$2,298,558**

In the USVI, there is an estimated 11,000 uninsured children. Because the CHIP funding is small when compared to the need, CHIP funding is instead used to pay for hospital bills incurred by Medicaid clients.

Issue 2: Problems With Other Federal and Local Funding Mechanisms

Aside from Medicaid and CHIP, problems persist pertaining to several other funding potential funding mechanisms. For instance, none of the other Territories, with the exception of the CNMI, have a Supplemental Security Income (SSI) Program to provide rehabilitation and supportive services to individuals with disabilities. Moreover, the Medicaid or the local Medically Indigent Program (Guam) does not have any provisions for these services. Despite the participation of all the other Territories in the Aid to the Blind and Aid to the Partially and Totally Disabled programs, payments are low in comparison to those of SSI. In the USVI, the amount of benefit under the Aid to the Aged, Blind or Disabled is $120 per month versus the SSI benefit of $500 in the states (the benefit may be higher in those states which supplement the federal amount). Ironically, a person entitled to SSI but who resides on Guam can move to the nearby island of Rota, which is part of the CNMI, and receive SSI. Thus, the Territorial population best served is left unserved or underserved under these limitations.

Overall, the Territories, as do states, rely heavily on federal funds to operate basic governmental programs and operations. The following table shows what federal programs are in place in the Territories:

	Temporary Assistance for Needy Families	Aid to the Aged, Blind or Disabled	Medi-caid	State Children's Health Insurance Plan	Maternal and Child Health Block Grant	Child Care and Develop-ment Block Grant	Social Services Block Grant	Child nutrition	Special Supplemental Nutrition Program for Women Infants and Children (WIC)	Child welfare services (Title IV-B part 1)	Promoting Safe & Stable Families	Child Abuse Prevention and Treatment Act
Guam	●	●	●	●	●	●	●	●	●	●	●	●
CNMI		●	●	●	●	●	●	●	●	●	●	●
Virgin Islands	●	●	●	●	●	●	●	●	●	●	●	

Under the Temporary Assistance to Needy Families (TANF) Block Grant, the Territories have capped federal funding for public assistance. The USVI, Guam and Puerto Rico were the only jurisdictions in the U.S. that failed to meet work participation standards for all families. America Samoa did not participate in the TANF program, and the CNMI is not eligible for participation.

Aid to the Aged, Blind or Disabled are federal grant programs for the needy, aged, blind, and disabled authorized under four separate titles of the Social Security Act. Each Territory determines its benefit amounts, as compared to the SSI Program available in the CNMI, which has federally determined benefits. SSI may be supplemented by the Territory. The SSI benefit is measurably higher than the benefit received under Aid to the Aged, Blind or Disabled program in the other Territories.

The respective Departments of Public Health, Human Services, Education and Mental Health components in the Territories of USVI, CNMI and Guam administer the Maternal and Child Health Block Grant, Child Care and Development Block Grant, Child Welfare Services, Mental Health Block Grants and Social Services Block Grant. These departments follow the basic structure as those operated in the states. For example, all three (3) Territories have Councils on Developmental Disabilities, University Affiliated Programs or University Centers for Excellence, Protection and Advocacy Systems, Vocational Rehabilitation, and Special Education Services. Guam has a unique one-stop service center for people with disabilities and their families known as the Department of Integrated Services for Individuals with Disabilities (DISID), which is locally funded and under which Vocational Rehabilitation falls.

As in the states, people with disabilities and their families depend greatly upon family support services from non-profit or charitable organizations. Unfortunately, amongst the Territories, the number of voluntary organizations offering family support to people with disabilities and their families is greatly limited. For example, one of the largest charitable organizations, the United Way, does not provide services for families on Guam. Non-profit organizations providing family support are often religiously affiliated or for relatively short-term projects, such as donating toys or other items. The need for

greater inclusion of additional non-profit groups' assistance in family support has been largely untapped.

The USVI, the CNMI and Guam have no comprehensive mental health policy addressing the needs of children and families. While the movement in the states has been to de-institutionalize children and to keep them in their own homes and communities, Guam has within the past ten years opened a 32-bed, acute/urgent care facility which houses a 16-bed children's unit (Guam's first inpatient children's unit) operated by its Department of Mental Health and Substance Abuse. Unlike the states, Guam's relatively young developing government still struggles with development of its infrastructure. Territorial infrastructure is not yet in place.

Issue 3: Lack of Capacity

The Territories face an obvious lack of local capacity to support the needs of people with disabilities and their families. There is no one unified family support organization to address the needs of families, although small volunteer organizations do exist among the Territories. Generally speaking, family support programs in the Territories are not designed for the individual, but programmed to function systematically. For example, when the respite care maximum number of 16 hours per month on Guam is met for an individual, the individual receives no care for the remainder of the month, which is oftentimes inadequate. This results in the majority of parents being unable to participate in outside activities, leaving them frustrated in their attempts to have their needs adequately heard and addressed. Parents who do participate face "burn out', due to serving on multiple committees.

There is also a consistent need for service providers and professionals across the board. The CNMI Early Childhood/Special Education reports that for the '99-'00 school year, both programs lacked an adequate number of service providers, as well as a facility for the pre-school staff. Their Child Care Program currently has 60 children placed on the wait list. The USVI has a tremendous problem with qualified personnel, including special education teachers, psychologists, physical, occupational and speech therapists and other specialized medical disciplines.

On Guam, there are only two private non-profit service providers, Catholic Social Services and Guma Mami, who provide residential care. There are no private, for profit service providers who work with people with disabilities. There is only one child psychiatrist on Guam and one licensed therapist at the Department of Mental Health and Substance Abuse. In the USVI, there are only two out-of-home respite care beds. There are no other mechanisms and no in-home respite services. The CNMI has no nursing facility, and home health services are available only off-island. Thus, unlike the states where the focus has been to address the exploitation of people with disabilities, the Territories are confronted with a sense of neglect due to a basic lack of services and care for these people.

Issue 4: The Relative Isolation of US Territories

Adding to the lack of local capacity, the relative isolation of the Territories from the mainland becomes a major problem. The sheer geographic and cultural differences in the Territories have resulted in a different scheme of supports than can be found in the mainland. For example, the Shriner's Clinic team from Hawaii provides bi-annual orthopedic clinics on Guam for children who may need further evaluation and/or surgery and those requiring fitting for assistive devices.

Because of the lack of services and facilities, individuals are often sent off-island to obtain needed medical services. The Commonwealth Health Center on Saipan, CNMI, sends its patients to Guam, Hawaii or occasionally to the mainland, which is generally to California. The Guam Memorial Hospital, the only hospital on Guam, with the exception of the Navy Hospital for military dependants, sends its patients to Hawaii or California. The USVI, with hospitals in St. Thomas and St. Croix, sends its patients to Puerto Rico or the mainland for care. Patients sent to the mainland often face lack of family support in terms of splitting up the family (no ticket for the parent), plus problems with follow-up services once the patient returns.

Repair is also no easy task when specialized equipment malfunctions. Either parts for repair must be ordered or the equipment itself must be sent off-island. For example, the Guam Memorial Hospital acquired the Distortion Product Otacoustic Emission Equipment to detect hearing difficulties for use on newborns prior to discharge. The testing tool has malfunctioned and it is not known whether replacement parts are available, leaving it inoperational and affecting the efficiency and efficacy of the newborn screening process. Oftentimes weeks or months are required for shipping and repair.

In the past, and still today, Guam has placed children by contract with mainland service providers into residential treatment off-island, upon the recommendation by the Inter-Agency Case Review Committee (IACRC), the Residential Placement Program and order of the Family Court. Once placed off island, these children have limited family contact because of the distance involved and expenses such as flight costs in excess of $1,500.00 per member. The Guam DISID, reports that for FY 2001, seven individuals (two of whom are now adults) reside off-island at a cost to the local government of $781,350, which has resulted in a shortfall of $580,995.17 for the fiscal year. The first child sent off-island some fifteen years ago continues to reside off-island at this time.

Families members with disabilities who have limited financial resources available may be encouraged to send their family members to non-U.S. areas (e.g., the Philippines) which offers "residential care" not available on Guam or the CNMI. In addition to visa issues, these adults are often left in the foreign country without further family contact, facing unmonitored circumstances which could place them at greater peril than if they stayed on island.

The significant distance in travel and difference in time zones adds to the frustration of territorial residents in seeking family supports from the mainland or other areas. Travel costs are most often prohibitive for families and other concerned people, and telephonic communications with stateside providers translate to a very late night-very early morning conversation due to the time difference between locations.

Issue 5: The Impact of Diverse Cultures

Culturally, the Territories present a rich blend of races within significantly small areas. With the influx of a variety of people relocating throughout the Territories, cultural sensitivity to the traditional values of these families is imperative. Communication issues and the limited availability of governmental resources to these families are barriers to accessing services and family supports.

As occurred in the States, travel has greatly affected the meaning of family in the Territories. Economic and political changes have eroded the tradition of extended family, which included aunts, uncles, and cousins. Families have become more mobile and there is less family support for a person with disabilities. Although this tradition still continues, families must now rely on other supports outside of the family circle.

The diversity of cultures brings a wide diversity of family expectations. Every family is an entity unto itself. Successful methods of approaching families and providing services must be within their acceptable cultural boundaries and should address changing needs. Most especially in the Territories, services must “fit” the family.

Looking Forward

Impetus for change has been primarily motivated by family frustration and the advocates and professionals who serve them. New programs funded by the federal government are in the developmental stages in the Territories. The USVI and Guam have had the opportunity to participate in the Wraparound Approach and System of Care conferences. Guam Public Law 25-141 created a System of Care Council for Children with Serious Emotional Disturbance to promote an active partnership between the child, the child=s family and all service providers. The CNMI is currently implementing the “Partners in Policymaking Island-style in the Northern Mariana Islands”, an island-wide effort in innovative leadership training for people who are unserved or underserved and self-advocates. These Territories are in the process under the Family Supports Grant of assessing the population and the needs of families of people with disabilities and bringing forward family support programs.

Given limited funding resources, the Territories realize the need to maximize available funding sources and find creative (traditional and non-traditional) ways of blending resources across families, agencies, and service providers, notwithstanding the heavy reliance upon federal funding. At the federal level, efforts must be coordinated so that participation for the Territories in policy initiatives and programs are more accessible and less burdensome to accomplish.

We in the Territories see the vision. We understand that the “whatever it takes” philosophy requires an unconditional commitment that is family-driven and that crosses cultural and traditional barriers. While significant factors set us apart from the U.S. states in accomplishing our goals, our uniqueness only stands to heighten the awareness of our U.S. counterparts. We have begun the process of developing a family-centered, family-driven, culturally competent and community-centered comprehensive system of family support for people with disabilities and their families.

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