
**SERVICES FOR PEOPLE
WITH INTELLECTUAL
AND/OR
DEVELOPMENTAL
DISABILITIES IN THE
U.S. TERRITORIES**



Institute for Community Inclusion, University of Massachusetts Boston,
Access to Integrated Employment Project



UNIVERSITY OF MINNESOTA

Driven to DiscoverSM

RTC on Community Living, University of Minnesota
Supporting Individuals and Families Information Systems Project



**STATE OF THE STATES
IN DEVELOPMENTAL DISABILITIES
UNIVERSITY OF COLORADO**

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The following report represents an expansion of the data collection activities mandated by a 2012 Administration of Intellectual and Developmental Disabilities (AIDD) Funding Opportunity Announcement (FOA). Prior to 2012, the AIDD funded data projects, Access to Integrated Employment, Family and Individual Information Systems project (FISP), Residential Information Systems Project (RISP) and the State of the States in Developmental Disabilities only collected data from the 50 states and the District of Columbia. The 2012 FOA requested that three of the AIDD data projects work together to include the five U.S. Territories (American Samoa and the Commonwealth of the Northern Marianas Islands, Guam, Puerto Rico and the Virgin Islands) in their data collection and analysis efforts. This summary represents the first step to describe the services for people with intellectual and developmental disabilities and their families in the territories. While the information may have limitations in the comparability to the rest of the nation, AIDD believes that it is important to begin data collection, tracking and analysis to increase opportunities to improve self-determination, independence, productivity, integration and inclusion of people with IDD into their communities in the U.S. Territories. The three AIDD funded projects are summarized below:

- **Access to Integrated Employment (AIE)**, housed at the University of Massachusetts Boston collects, analyzes, and reports on data describing employment services and supports for people with intellectual and developmental disabilities (I/DD). AIE examines and reports on the employment status of people with I/DD and related outcomes as a result of policies and programs that support their education and employment. You can read more about employment outcomes for people with I/DD at <http://www.statedata.info/>
- **Family Information Systems Project (FISP) and Residential Information Systems Project (RISP)**, both of which are housed at the University of Minnesota, analyze and describe the settings where people with ID/DD in the United States live, who they live with and the services provided. The project includes analyses of the funding for supports and services from a variety of sources, including public and non-public, Medicaid-funded, and state-funded residential and supportive services. <https://risp.umn.edu/>, <https://fisp.umn.edu/>
- **The State of the States in Developmental Disabilities**, a collaboration between the University of Colorado and the University of Illinois at Chicago, is a comparative

nationwide longitudinal study of public financial commitments and programmatic trends in services and supports for people with ID/DD in the United States, with data encompassing the past 37 years. The project examines trends in community living, public and private residential institutions, individual and family support, Medicaid HCBS Waivers, demographics and related areas. www.stateofthestates.org

Beginning in spring 2013 staff from each of the data projects began working together to identify experts in disability policy and outcomes in each of the 5 territories. Experts were identified through the territories' Developmental Disabilities Councils, University Centers for Excellence in Developmental Disabilities (UCEDDs), Departments of Education, and Departments of Health. Data was collected through semi-structured interviews, document and policy review, and data provided directly by the territories. The report was developed as a collaborative activity across the three data projects, the collection of data would not been possible without the extraordinary assistance of disability leaders living in the Territories. These people are both experts in disability services and the Territory where they live. For some territories local level experts are co-authors of their summary. This combination proved to be invaluable in describing the services in the Territories. We would like to acknowledge:

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American Samoa

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I. Geography

American Samoa, an unincorporated and unorganized territory of the United States, is located in Oceania which is comprised of a group of islands in the South Pacific Ocean halfway between Hawaii and New Zealand. It has a land area of approximately 77 square miles, which is slightly larger than Washington, D.C. (Central Intelligence Agency [CIA], 2013). After ceding to the United States in 1900, the U.S. Navy oversaw it until 1951 when authority was transferred to the Office of Insular Affairs, U.S. Department of the Interior (U.S. Department of the Interior, 2013). The capital of American Samoa is Pago Pago.

II. Industry

American Samoa conducts the majority of its commerce with the United States, and canned tuna is the primary export (CIA, 2013). Tuna fishing and tuna canneries are the main private sector industry, accounting for 80% of private sector employment. The American Samoan government employs 28% of the labor force who work in public education, health and telecom. The private sector employs 64% (U.S. Department of the Interior, 2013).

III. Population

According to the CIA, the population of American Samoa was 54,517 in July 2014 (CIA, 2014). The vast majority (91.6%) of American Samoans claim native Hawaiian or other Pacific Island as their race (CIA, 2014). The unemployment rate was 29.8% in 2005 (CIA, 2014). In 2008, 27% of Samoans were living below the basic needs poverty level (Pacific Islands Forum Secretariat, 2012). Disability-specific population data is not available in the Behavioral Risk Factor Surveillance System through the Centers for Disease Control and Prevention (CDC) nor through Kids Count. The World Health Organization, however, lists significant increases in the prevalence of obesity, while chronic diseases such as hypertension, cardiovascular and cerebrovascular diseases, type II diabetes mellitus, arthritis, gout and some cancers are also prevalent (2011).

Residents of American Samoa are citizens of the United States, however, they do not vote in U.S. presidential elections. They elect a governor, currently Lolo Matalasi Moliga, a 39-member bicameral legislature, as well as one non-voting delegate to the U.S. House of Representatives. The current delegate, Congressman Eni F.H. Faleomavaega, serves on the House Committee on Foreign Affairs and is Ranking Member of the Subcommittee on Asia and the Pacific. Additionally, he serves on the Committee on Natural Resources Subcommittee on Fisheries, Wildlife, Oceans and Insular Affairs as well as the Subcommittee on Indian and Alaska Native Affairs (House of Representatives, 2013).

American Samoa does participate in Social Security (Retirement, Survivors and Disability Insurance), Medicare and Medicaid. In FY2011, total Medicaid funding was approximately \$25.4 million (Coleman Institute, unpublished data). American Samoa is not eligible to participate in the Supplemental Security Income program. Although American Samoa is eligible for Temporary Assistance for Needy Families (TANF) they do not participate in the program (U.S. House of Representatives, 2014). Though it does not participate in the Supplemental Nutrition Assistance Program (SNAP), American Samoa does receive an indexed nutrition assistance grant which benefits low-income, aged and disabled individuals (House Committee on Ways & Means, 2012). This aid has a ceiling of \$1,000,000 under Section 1109 of the Social Security Act (U.S. House of Representatives, 2014).

IV. Medicaid Program

American Samoa's Medicaid program, called the Medical Assistance Program (MAP) is administered by the Medicaid Office in the Office of the Governor. Prior to the establishment of a State Medicaid Office, Medicaid authority was by the American Samoa Medical Center (Office of the Governor, 2011). The Medicaid Director is appointed by the Governor. A Medicaid Coordinating Council consists of the following standing members: Secretary of American Samoa, Attorney General, and Director of the Department of Commerce. To qualify for Medicaid, an individual's income must be below 200% of the federal poverty level (FPL), which was \$21,660 in 2009. Unlike the states and other four territories, there is no specific categorical membership required. In FY2011, the estimated MAP enrollment was 57,982, which is an estimated 88% of

the population (HHS Office of Intergovernmental Affairs, 2011). Since January of 1983, the MAP program has operated under a Section 1902(j) waiver.

Unlike the states, territory Federal Medical Assistance Percentage (FMAP) is set by statute (GAO, 2005). In FY2014, it was 55% (U.S. Department of Health & Human Services, 2014) and is subject to annual caps. Like the other U.S. Territories, American Samoa typically exhausts this Medicaid cap prior to the end of the fiscal year. Once the cap has been met, territories are responsible for the remainder of Medicaid costs. In some cases, territories suspend services or cease provider payments until the beginning of the subsequent fiscal year (GAO, 2005).

Congressman Faleomavaega, in collaboration with the other five Territory Delegates, introduced H.R. 5566, Medicaid Payment Fairness to the Territories Act of 2012 in May of 2012. This bill would increase the Territory FMAPS to “the highest such [FMAP] applicable to any of the 50 States for the fiscal year involved.” The bill never made it past the House Committee on Energy and Commerce (Library of Congress, 2013). Faleomavaega also co-sponsored H.R. 79 Medicaid Payment Fairness to the Territories Act of 2013, which was introduced to the House in January 3, 2013. This bill has made no movement through the House.

V. Services

All residents of American Samoa are entitled to free medical care under their legislative code. American Samoa has one general acute care hospital, the 128-bed L.B. Johnson Tropical Medical Center, located in Pago Pago, along with five primary health centers. Sixteen percent of the medical center’s funding comes from the \$3M annually provided by the U.S. Centers for Medicare and Medicaid Services (CMS). The majority of these monies purchase medicine and medical supplies. In 2003, its health workforce included 49 physicians, 15 dentists, 127 nurses and 2 pharmacists (World Health Organization, 2011).

Unlike the states, American Samoa is not required to cover federally mandated Medicaid services. American Samoa provides the following services: inpatient/outpatient hospital, physician’s services, laboratory and x-ray, Early Periodic Screening, Diagnostic and Treatment (EPSDT), family planning and transportation; home health is covered with limitations. Additionally, there

are a few services that are only covered off island: nursing facility services, private duty nursing, podiatry, optometry, and occupational and speech therapies. These services are generally provided in Hawaii, although may be provided in other states as funds are available. Off-island services must be pre-approved by the admitting physician as a medical necessity and then pre-approved by physician-members of the Off-Island Medical Referral Committee (House Committee on Ways & Means, 2012). American Samoa does not operate any home and community based waiver services, nor does it have any intermediate care facilities for people with intellectual disabilities (ICF/ID). People who have intellectual and/or developmental disabilities are typically cared for by a family member in their family home. This caretaking responsibility is considered a “blessing” and out of home care is rarely considered. Should a family not be able to care for an individual with a disability, there is a convalescent home that is run by the Catholic Sisters which supports 22 adults and children (Tupuola, 2013).

References

- Central Intelligence Agency (2013). The World Factbook: American Samoa. Retrieved December 5, 2013 from: <https://www.cia.gov/library/publications/the-world-factbook/geos/aq.html>.
- Department of Commerce (2011). American Samoa Statistical Yearbook. Retrieved December 5, 2013 from: <http://americansamoa.gov/index.php/2012-04-25-19-44-32/2012-04-25-19-52-04/departments/commerce>.
- Government Accountability Office (2005). U.S. Insular Areas: Multiple Factors Affect federal health care funding. Retrieved November 11, 2013 from: <http://www.gao.gov/new.items/d0675.pdf>.
- HHS Office of Intergovernmental Affairs (2011, February 2). Medicaid in the Territories – Current Law Including those in Health Reform. Retrieved December 17, 2013 from: http://www.doi.gov/oia/igia/2011/upload/14-Medicaid_in_the_Territories-HHS.pdf.
- House Committee on Ways & Means (2012). Green Book: Background Material and Data on the Programs within the Jurisdiction of the Committee on Ways and Means, Appendix B: Social Welfare Programs in the Territories. Retrieved November 13, 2013 from: http://greenbook.waysandmeans.house.gov/2012-green-book/appendix-b-social-welfare-programs-in-the-territories#_ftn1.
- House of Representatives (2013). Congressman Eni F. H. Faleomavaega: Committees and Caucuses. Retrieved December 4, 2013 from: <http://faleomavaega.house.gov/legislation/committees-and-caucuses>.
- Library of Congress (2013). H.R. 5566 Medicaid Payment Fairness to the Territories Act of 2012. Retrieved November 11, 2013 from: <http://thomas.loc.gov>.
- Office of the Governor (2011). Executive Order No. 006-2011: An order locating the state Medicaid office from the American Samoa Medical Center authority to the Office of the Governor and providing for the overall functions, duties, and responsibilities of the office.
- Pacific Islands Forum Secretariat (2012). 2012 Pacific Regional MDGs Tracking Report. Retrieved December 11, 2014 from: <http://www.forumsec.org.fj/resources/uploads/attachments/documents/MDG%20Track%20Rpt%20web%202012.pdf>
- Tupuola, R. (2013). Personal correspondence, April 15, 2013.
- U.S. Census Bureau (2011). U.S. Census Bureau Releases 2010 Census Population Counts for American Samoa. Retrieved December 4, 2013 from: http://www.census.gov/newsroom/releases/archives/2010_census/cb11-cn177.html.
- U.S. Department of the Interior (2013). American Samoa, Insular Area Summary for American Samoa. Retrieved December 17, 2013 from: <http://www.doi.gov/oia/islands/american-samoa.cfm#>.

U.S. Department of Health and Human Services (2014). ASPE FMAP 2014 REPORT. Retrieved December 11, 2014 from:
<http://aspe.hhs.gov/health/reports/2014/FMAP2014/fmap2014.cfm>

U.S. House of Representatives. (2014). Appendix B: Social Welfare Programs in the Territories. Retrieved December 15, 2014 from:
<http://greenbook.waysandmeans.house.gov/2014-green-book/appendix-b-social-welfare-programs-in-the-territories>

World Health Organization (2011). American Samoa Country profile. Retrieved December 17, 2013 from: http://www.wpro.who.int/countries/asm/1FAMSPro2011_finaldraft.pdf.

The Commonwealth of the Northern Mariana Islands

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I. Geography

The Commonwealth of the Northern Mariana Islands (CNMI) is a U.S. island territory (the others are Guam, Puerto Rico, the U.S. Virgin Islands, and American Samoa). It is located in Oceania, a group of islands in the North Pacific Ocean, about three-quarters of the way from Hawaii to the Philippines and about 1000 miles north of the Equator. The United States Census Bureau reports the total land area of all islands as 183.5 square miles; about 2.5 times the size of Washington, DC (Central Intelligence Agency [CIA], 2014). CNMI is often called “America’s best kept secret” based on its natural beauty and its remote location.

CNMI’s center of government is in the village of Capitol Hill on Saipan. As the island is governed as a single municipality, most publications name Saipan as the capital. CNMI is self-governing with a locally elected governor, lieutenant governor, and legislature (CIA, 2014).

II. Industry

CNMI’s gross domestic product comes mainly from tourism, banking, construction, fishing, handicrafts, and other services. The tourist industry employs approximately a quarter of the work force and accounts for roughly one-fourth of GDP. Annual tourist arrivals are around 400,000—a majority comes from Japan and South Korea. The small agriculture sector is made up of cattle ranches and small farms producing coconuts, breadfruit, tomatoes, and melons (CIA, 2014).

As of May, 2014, the minimum wage in CNMI is 5.55 per hour. Until 2007, the minimum wage was not covered by U.S. wage laws and average pay for workers was lower than in the states. After an act of Congress, the rate was supposed to be raised each year by .50 but recent legislation has suspended this until 2016 (Swift, 2013). The suspension is related to trying to make CNMI competitive with neighboring countries.

Because of regulations and wage issues, CNMI, once a leading producer of apparel for export, has closed all its garment factories—they had 32 as recently as 2007, and CNMI lost 30% of its

economy in four years (Commonwealth Economic Development Strategic Planning Commission, 2009).

III. Population

As of the 2010 census, CNMI had a population of 53,883—90% live on the island of Saipan. Of the 14 other islands, only two, Tinian and Rota, are permanently inhabited (US Census Bureau, 2013). The population once approached 78,000 people but economic conditions have led to the emigration of over 20,000 in recent years (Commonwealth Economic Development Strategic Planning Commission, 2009).

Approximately half of the citizens of CNMI have Asian origins and another two-fifths have a Native Hawaiian or Pacific Islander background. Forty percent of the population is under 24 years of age and 85% are under age 54.

IV. Medicaid Program

According to information found in the CNMI State Medicaid Health Information Technology Plan (2013), CNMI has very few Medicaid providers—it has one eligible hospital, one federally qualified health center, two rural health clinics, approximately twenty other potential eligible providers, and ten potential eligible dentists in four major clinics.

The plan noted that the number of Medicaid clients is approximately 17,200, about 32% of the population. A number of people also fall into the category of “Medically Indigent population” or “MIP.” The majority of Medicaid patients are of Northern Marianas descent.

The plan describes how health care mainly comes through the CNMI Commonwealth Healthcare Corporation which operates the government hospital, clinics, and public health programs. There are a few small numbers of private providers, insurers, private pharmacies, and other service providers.

The CNMI Medicaid Program is administered by the Office of the Governor. The CNMI Medicaid Program’s mission is to assure that federal Medicaid funds are utilized in a manner which provides

the greatest possible benefits for the CNMI Medicaid population, and to do so in a manner consistent with the federal guidelines.

The plan describes how CNMI is the “only U.S. territory which has Supplemental Security Income (SSI), and its entire Medicaid program is based on SSI requirements”. Anyone on SSI can become eligible for Medicaid by completing an application. Others are eligible if their income is below 150 percent of the SSI Federal benefit rate. CNMI pays Medicare premiums (i.e., buy-in) for dually entitled individuals. Mandated services, (except for rural health clinics) are provided by the Commonwealth Health Center on Saipan. Other covered services, such as nursing facility services, are available off-island—in Guam, Hawaii, Philippines or occasionally the continental U.S., generally to California.

The plan described some difficulties with the financing of the program. Although CNMI Medicaid operates under a cap of about \$18 million a year, but with a match of about \$15 million based on the 55%-45% Federal-State program formula most of the money is inaccessible. In 2012, the CNMI Legislature appropriated only \$2.4 million for the Medicaid program and thus the islands could only expend \$5.3 million in a year. This is an annual issue.

V. Services

Health Care. The Department of Public Health comprises three divisions: the Division of Public Health, which provides preventive and community health programs; the Hospital Division; and the Community Guidance Center (CGC), which delivers mental health and substance-abuse programs. The Department also oversees the Medicaid and Medical Referral programs. The Department of Public Health is the sole provider of comprehensive health care services and, through its primary health care facility, the Commonwealth Health Center (CHC) on the island of Saipan, provides a wide range of preventive (public health) and curative health services aimed at protecting and improving the health and quality of life of the population (Commonwealth Healthcare Corporation, 2014).

CHC is an 86-bed, Medicare-certified hospital that opened in 1986 and was expanded in 2007. The hospital’s scope of services includes emergency medicine, obstetrics, postpartum care, adult and

neonatal intensive care, surgery, general medicine, pediatrics, physical therapy, dialysis, mental health and various outpatient services. It is a busy community hospital, with more than 60,000 outpatient visits each year. The hospital is also very full, with a daily census nearing 90% of capacity (Commonwealth Healthcare Corporation, 2014).

The U.S. Department of Health and Human Services routinely gives each geographic area a Health Professional Shortage Area (HPSA) score. This HPSA score is based on the number of doctors available for the population, travel time to the nearest available source of care, and other factors. A score of “1” is excellent with the worst at “25.” The CNMI has an HPSA score of 18. In contrast, Guam has a score of 8 and the Federated States of Micronesia has a score of 25 (CNMI Medicaid Program, 2013).

Disability Culture. There are very few segregated settings for individuals with disabilities (or for the elderly). Families generally care for their loved ones in their homes. Some individuals with significant chronic behavior issues may leave the island and receive services in Hawaii or other western states. CNMI does have a few vocational rehabilitation counselors and some Veteran Affairs staff that support individuals with disabilities.

Policy and Advocacy. CNMI has a Council on Developmental Disabilities that meets regularly in support of its mission to “promote systems change to ensure that individuals with developmental disabilities and their families have the same opportunities as others in the community.” Its 25 members are appointed by the governor and focus on issues “related to self-determination, education, employment, transportation, housing, recreation, healthcare and overall quality of life of people with developmental disabilities and their families.” The council’s members include people with developmental disabilities, family members, and representatives of agencies and groups that provide services. (Council on Developmental Disabilities, n.d.)

Protection and Advocacy. NMPASI, a local non-profit organization, administers grant programs from the U.S. Department of Health and Human Services’ Center for Mental Health Services, the Substance Abuse and Mental Health Services Administration, the Administration on

Developmental Disabilities, the Human Resources Services Administration, the U.S. Department of Education/Rehabilitation Services Administration, and the Social Security Administration.

NMPASI's overriding goal is to ensure that individuals with disabilities in institutional and/or community settings (1) are not subject to abuse/neglect, (2) are free from discrimination, (3) are provided with an appropriate education, (4) are provided appropriate health care services, and (5) are provided with opportunities to make informed decisions about their lives as independent, contributing members of the community (NMPASI, 2014).

Technical Assistance. Northern Marianas College is the site of the CNMI University Center of Excellence in Developmental Disabilities (UCEDD); it is “committed to the development of culturally complimentary outcomes while promoting equal opportunity, independence, productivity, promoting self-determination, and supporting an improved quality of life for people with developmental disabilities...” The UCEDD provides “training, technical assistance, and information-sharing with the focus on building the capacity of the CNMI to fully include persons with developmental disabilities.” The UCEDD does not provide direct services but collaborates and coordinates with other agencies like NMPASI, the Development Disabilities Council, and the Office of Vocational Rehabilitation.

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References

- Central Intelligence Agency (CIA) (2014). Northern Mariana Islands. *World Factbook*. Retrieved from <https://www.cia.gov/library/publications/the-world-factbook/geos/cq.html>.
- CNMI Medicaid Program (2013). *CNMI State Medicaid Health Information Technology Plan*. Retrieved from <http://cnmi-hit.mp/attachments/article/42/CNMI%20SMHP-Final%20Submitted%20to%20CMS.pdf>.
- Commonwealth Economic Development Strategic Planning Commission (2009). *Comprehensive Economic Development Strategic Plan, 2009-2014, for the U.S. Commonwealth of the Northern Mariana Islands*. Retrieved from http://www.doi.gov/oia/reports/upload/CNMI_CEDS_Report-2009-2014-3.pdf.
- Commonwealth Health Care Corporation (2014). *Division of hospital services*. Retrieved from <http://chcc.gov.mp/>
- Council on Developmental Disabilities, (n.d). *Our mission*. Retrieved from <http://www.cnmicdd.org/>.
- NMPASI (2014). *Statement of goals and priorities*. Retrieved from <http://www.nmpasi.org/>.
- Swift, J. (2013). Obama delays minimum wage increase. *Weekly Standard* (on line) Retrieved from http://www.weeklystandard.com/blogs/obama-delays-minimum-wage-increase_756381.html.

Guam

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I. Geography

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. It is located 7,500 miles from California and is the most distant American land from the mainland United States. Located within the Mariana Island chain, it is the most southern of the islands and is located in the western Pacific Ocean, about three fourths of the way between Hawaii and the Philippines (Sommerfleck & Renacia, n.d.). Due to its strategic location in the Pacific Ocean, the military installations on the island are some of the most strategically important US bases (CIA, 2014).

II. Economy

Tourism, the military, and outside investment (primarily from Japan) are the driving forces behind Guam's economic growth. The unemployment rate in Guam for September 2013 was 10% (U.S. DOL, Feb. 2014). In 2010 the estimated per capita income was \$28,700 and the unemployment rate was 8.2% (CIA, 2014).

III. Population

Guam participates in the decennial United States Census. The population of Guam in 2010 was 159,358 (U.S. Department of Commerce, 2014a). Residents of the island are citizens of the United States and represent a wide variety of ethnicities, including Chamorro (37.3%), Filipino (26.3%), white (7.1%), Chuukese (7%), Korean (2.2%), other Pacific Islander (2%), other Asian (2%), Chinese (1.6%), Palauan (1.6%), Japanese (1.5%), Pohnpeian (1.4%), mixed (9.4%), and other (0.6%) (CIA, 2014). Data collected in the 2010 Census found that 19,775 individuals over the age of five identified as having a cognitive disability (U.S. Department of Commerce, 2014b).¹

¹ The Census describes a cognitive disability as follows: "Because of a physical, mental, or emotional problem, having difficulty remembering, concentrating, or making decisions (DREM)."

IV. Government

With an indigenous culture dating back more than 2,600 years, Guam became a Spanish colony in the 16th century and was seized by the U.S. during the Spanish-American War. The Japanese occupied Guam during World War II, and the island was retaken by the U.S. in 1944. Guam became an unincorporated U.S. Territory in 1950, and citizens of Guam are U.S. citizens.

Residents have a popularly elected governor, Eddie Calvo. Additionally, there is a unicameral legislature with 15 seats whose members are elected by popular vote to serve two-year terms. Relations between Guam and the U.S. fall under the jurisdiction of the Office of Insular Affairs, U.S. Department of the Interior. Guam does not have voting representation in either house of the U.S. Congress (Senate and House of Representatives) and is ineligible to vote in presidential elections (CIA, 2014). The commonwealth has a non-voting member of Congress, Madeleine Z. Bordallo.

Residents pay Social Security taxes and, depending on residency status, pay income taxes to the U.S. government, the government of Guam, or both (IRS, 2014). Despite the payment of federal taxes, residents of Guam are not eligible to receive Supplemental Security Income (SSI) from the Social Security Administration (U.S. House of Representatives, 2012).

V. Health Insurance and Medicaid Program

Citizens' access to health insurance is an important measure of public health. According to analysis of 2010 Census data reported by the National Association of Insurance Commissioners (2011), 21.1% of Guamanians are uninsured. Insurance coverage is a mix of private and public insurance options (NAIC, 2011), and the total number of Guam residents covered by the Medicaid Program in fiscal year 2013 was 43,603, or 27% of the total population based on the 2010 Census.

In Guam, the Medicaid State Plan is administered as a block grant for all health services. The Medicaid Authority is the Guam Department of Public Health and Social Services. The original published Federal Medical Assistance Percentage (FMAP) for Guam for FY2015 is 55%, and the enhanced percentage is 68.5% (HHS, 2014a). However, Guam has secured an increase in that percentage for calendar years 2014 and 2015 (personal communication, 2014).

Traditionally, territory residents have a federally imposed capitation on Medicaid service funds received from the Federal Government. This cap was temporarily removed when Guam was allocated additional funding under the Affordable Care Act (ACA). The Guam Medicaid program was given an additional \$268 million to be spent beginning July 1, 2011 thru FY2019. Also, beginning January 1, 2014 the Guam Medicaid State Plan Amendment was approved to include childless adults with income above 100% to 133% of the federal poverty level with an FMAP of 78.6%.

Like most states, Guam's Medicaid Authority offers federally mandated services and a number of optional services, including dental, optical, pharmacy, off-island medical services, and roundtrip airfare for patients referred off-island. Additionally, the program pays for skilled nursing services for 180 days per year. Guam does not have access to Medicaid Home and Community Based Waivers.

Despite the temporary lifting of the Medicaid capitation due to additional funds provided by the ACA, the long-term impact of the ACA on Guam is expected to be limited. According the U.S. Department of Health and Human Services, "U.S. territories can decide whether to create their own Health Insurance Marketplace or expand Medicaid coverage. Residents of a U.S. territory are not eligible to apply for health coverage using the federal or state Marketplace unless they also qualify as a resident within the service area of a Marketplace, nor do the individual and employer mandates apply" (HHS, 2014).

VI. Services for People with Intellectual and Developmental Disabilities²

The Department of Integrated Services for Individuals with Disabilities (DISID) was established under Guam P.L 24-16 on March 26, 1997. It is the designated single point of entry agency that provides, promotes and ensures a full continuum of programs and services for people with disabilities. The department is comprised of two divisions: the Division of Vocational

² This section contains information excerpted and/or adapted from Department of Integrated Services for Individuals with Disabilities: A report to the citizens of Guam (2011). Retrieved from <http://disid.guam.gov/wp-content/uploads/2013/09/CCR-FY2011.pdf>

Rehabilitation (DVR) and the Division of Support Services (DSS). Additionally, Guam was recently awarded a “No Wrong Door” planning grant from the federal Administration on Community Living. The grant is located within the Department of Public Health and Social Services, Division for Senior Citizens.

DVR provides vocational rehabilitation and supported employment services to eligible individuals with disabilities, and serves as the designated entity to administer the State Plan for Vocational Rehabilitation Services, Independent Living Services and Independent Living for the Older Blind. DVR provides administrative support and works collaboratively with the State Rehabilitation Council (SRC) and the State Independent Living Council (SILC) in implementing these state plans.

Guam’s VR program receives approximately \$1.9 million per year in federal funding, and, as required by individual student transition plans, VR transition services are provided in schools. A few people with intellectual and/or developmental disabilities (IDD) work in their community without any formal supports, and typically DVR closes fewer than five individuals with IDD into employment annually (Winsor & Domin, 2014). One significant barrier to employment is that there is limited public transportation for people with disabilities.

DSS is responsible for the development of a community service delivery system which includes the design, implementation, administration, coordination, monitoring and evaluation of programs and services for persons with disabilities. The Guam Behavioral Health and Wellness Center is responsible for the establishment of a continuum of comprehensive services and residential alternatives in the community so as to allow individuals with dual diagnosis to live in the least restrictive, most individually appropriate environment.

The island has approximately eight group homes, funded by the government through contracts with providers. There are two main service providers on the island. Most people with disabilities live at home with their families. Guam has one formal Community Habilitation Program that is offered by Catholic Social Services, and group home (residential) providers support individuals to engage in daytime activities. One example of how providers are leveraging available resources for

individuals with IDD is one service provider's art program, which was established with funds from the National Council for the Arts. The service provider is supporting some of these individuals to sell the art they create.

DISID serves as the state Americans with Disabilities Act (ADA) coordinating agency, and includes liaison representatives from each of the government of Guam agencies that ensure ADA awareness and compliance. DISID coordinates accessible parking enforcement and education, and provides training and technical support regarding the ADA. The University of Guam Center for Excellence in Developmental Disabilities Education, Research and Service (CEDDERS) is the designated assistive technology state agency and operates the Guam System for Assistive Technology (GSAT). CEDDERS has been serving as the State Assistive Technology Lead Agency for 20 years.

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References

- Central Intelligence Agency (CIA) (2014). *The world factbook: Guam*. Retrieved from <https://www.cia.gov/library/publications/the-world-factbook/geos/gq.html>
- Department of Integrated Services for Individuals with Disabilities. (2011). *A report to the citizens of Guam*. Retrieved from <http://disid.guam.gov/wp-content/uploads/2013/09/CCR-FY2011.pdf>
- National Association of Insurance Commissioners. (2011). *Implementation of the Affordable Care Act in the U.S. territories*. Retrieved from http://www.naic.org/documents/committees_b_exchanges_hcr_reg_alt_wg_130819_draft_territories_sg_discussion_paper.pdf
- Somerfleck, D., & Renacia, V.M. (n.d). *Family support policy brief: Family support in the U.S. territories*. National Center for Family Support, Human Services Research Institute.
- U.S. Department of Commerce. (2014). *United States Census Bureau: American fact finder*. Retrieved from http://factfinder2.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=DEC_10_DPGU_GUDP1&prodType=table
- U.S. Internal Revenue Service. (2014). *Filing information for individuals in certain U.S. possessions*. Retrieved from http://www.irs.gov/publications/p570/ch03.html#en_US_2013_publink1000221315
- U.S. House of Representatives. (2012). *Greenbook: Appendix B: Social welfare programs in the territories*. Retrieved from <http://greenbook.waysandmeans.house.gov/2012-greenbook/appendix-b-social-welfare-programs-in-the-territories>
- U.S. Department of Health and Human Services. (2014a). *ASPE FMAP 2015 report*. Retrieved from <http://aspe.hhs.gov/health/reports/2014/FMAP2015/fmap15.cfm>
- U.S. Department of Health and Human Services. (2014b). *Am I eligible for coverage in the marketplace?* Retrieved from <https://www.healthcare.gov/am-i-eligible-for-coverage-in-the-marketplace/#question=what-if-im-a-resident-of-a-territor>

Winsor, J. E., & Domin, D. (2014). *Vocational rehabilitation closure trends for individuals with intellectual disabilities: A snapshot of five U.S. territories*. DataNote series, No. 48. Boston, MA: University of Massachusetts Boston, Institute for Community Inclusion.

Puerto Rico

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I. Geography

Puerto Rico is an archipelago located between the Caribbean Sea and the North Atlantic Ocean. The main island is 3,515 square miles, which is less than three times the size of Rhode Island. There are also three small islands included in the commonwealth: Vieques and Culebra to the East, and Mona to the West. The location of these islands places them within a key shipping route to the Panama Canal. The capital, San Juan, is recognized as one of the best natural harbors in the Caribbean (Central Intelligence Agency CIA, 2014).

II. Economy

Puerto Rico has one of the most dynamic economies in the Caribbean region. Plantation sugar production dominated Puerto Rico's economy until the 1940s. Industry has surpassed agriculture as the primary sector of economic activity and income, and economic opportunities have shifted from rural to urban and coastal areas. Encouraged by duty-free access to the U.S. and by tax incentives, U.S. firms have invested heavily in Puerto Rico since the 1950s (U.S. minimum wage laws apply). As a result, Puerto Rico's export and import industries have prospered and the primary industries are pharmaceuticals, electronics, apparel, food products, and tourism.

Like much of the United States, Puerto Rico experienced a decline in economic activity as a result of the 2008 recession. The per capita income in Puerto Rico in 2012 was \$16,300, and the 2011 unemployment rate was 16% (CIA, 2014). It should be noted that Puerto Ricans who reside on the island experience a higher rate of poverty (44%) compared with individuals who identify as of Puerto Rican origin in the 50 states and D.C. (24%) (Lopez & Valesco, 2011). A key difference between Puerto Rico and the other U.S. territories is that United States federal minimum wage laws are applicable within the commonwealth.

III. Population

Puerto Rico participates in the decennial United States Census, as well as the annual Puerto Rican Community Survey, a version of the Census Bureau's American Community Survey, customized for Puerto Rico. The 2010 population of Puerto Rico was 3,725,789, and the median

age was 36.9 years (U.S. Department of Commerce, 2014a). Seventy-six percent of residents of Puerto Rico identified their race as white and 12.4% identified as black. Regardless of race, 99% identified their ethnicity as Hispanic or Latino (U.S. Department of Commerce, 2014b). It is interesting to note that the Hispanic population of Puerto Rican origin in the 50 states and D.C. grew by more than one million between 2000 and 2010, and there are more people of Puerto Rican origin who live in the 50 states and D.C. than on the island of Puerto Rico (Lopez & Valesco, 2011).

According to the 2012 Puerto Rican Community Survey, 8.3% of the non-institutionalized population between five and 17 years of age indicated having a cognitive disability, and 8.7% between the ages of 18 and 64 years reported having a cognitive disability (U.S. Department of Commerce, 2014b). According to the Behavioral Risk Factor Surveillance System (BRFSS, 2012a), 19% of adults indicated that they are “limited in any activities because of physical, mental or emotional problems,” while 9.7% indicated that they have health problems requiring the use of special equipment (BRFSS, 2012b). In 2011 the prevalence of autism on the island was one in 62 for children between four and 17 years of age (Cordero, Alonso, Mattei, & Torres, 2012).

IV. Government

Puerto Rico has been a territory of the United States since 1898, when it was ceded to the United States as a result of the Spanish-American War (CIA, 2014). Residents of Puerto Rico were granted United States citizenship in 1917. Puerto Rico is a self-governing commonwealth with a constitution enacted in 1952 (CIA, 2014). The official language of the commonwealth is Spanish. Residents have a popularly elected governor, Alejandro Garcia Padilla. Additionally there is a bicameral legislature and 78 municipalities.

Puerto Rico has authority over its internal affairs unless a U.S. law is involved, such as in areas of public health and Social Security (Rivera, 2014). Residents pay Social Security taxes but do not pay federal income taxes on income earned from sources within Puerto Rico (IRS, 2014). Puerto Rico does not have voting representation in either house of the U.S. Congress (Senate and

House of Representatives) and is ineligible to vote in presidential elections (Rivera, 2014). The commonwealth does have a non-voting member of Congress, Pedro R. Pierluisi.

V. Health Insurance and Medicaid

Citizens' access to health insurance is an important measure of public health. Across all five territories, Puerto Rico has the lowest rate of uninsured residents. This is the third-lowest rate of uninsured in the United States, behind only Massachusetts and Hawaii (personal communication, 2014). According to analysis of 2010 Census data reported by the National Association of Insurance Commissioners (2011), fewer than 8% of Puerto Ricans are uninsured.

Insurance coverage is a mix of private and public insurance options, with 58.2% enrolled in public insurance programs such as Medicaid and Mi Salud (NAIC, 2011). The percentage of those with coverage is highest for those not in the labor force at 93.1%, followed by the employed labor force (88.4%) and the unemployed members of the labor force (84.3%) (IMPACTIVO, 2014). Mi Salud is a locally funded health coverage program that provides insurance coverage for individuals whose incomes exceed the threshold for Medicaid eligibility (NAIC, 2014).

In Puerto Rico, the Medicaid State Plan is administered as a block grant for all health services, and there are not specific funds allocated towards disability services (personal communication, 2013). The Medicaid Authority in Puerto Rico is the Administration of Health Services, and they contract to private providers for health care services (personal communication, 2013). The Medicaid Spending Cap for Puerto Rico in FY2010 was \$364 million (HHS, 2010). The Federal Medical Assistance Percentage (FMAP) for the commonwealth for FY2015 is 55%, and the enhanced percentage is 68.5% (HHS, 2014). Puerto Rico does not have access to Medicaid Home and Community Based Waivers.

The Affordable Care Act's (ACA) impact on Puerto Rico is expected to be limited. According to the U.S. Department of Health and Human Services (2014a), "U.S. territories can decide whether to create their own Health Insurance Marketplace or expand Medicaid coverage. Residents of a U.S. territory are not eligible to apply for health coverage using the federal or state Marketplace

unless they also qualify as a resident within the service area of a Marketplace, nor do the individual and employer mandates apply” (HHS, 2014b). In July 2013, the Legislative Assembly authorized its Insurance Department authority to guarantee issue and open special enrollment periods for the individual plan to its health insurance code. Puerto Rico’s Department of Health has not ruled out establishing a health care exchange or partnering with a state that has established one (NAIC, 2011).

VI. Services for People with Intellectual and Developmental Disabilities

The Puerto Rico Department of Health coordinates services for individuals with disabilities between the ages of birth and three years. The Department of Education coordinates services for individuals with disabilities between the ages of four and 21 years. Once an individual is 21 years old, he or she can seek services from the Vocational Rehabilitation Administration. However, most adults are not in government funded services during the day and most people remain with their families.

Medicaid Home and Community Based Waiver Services are not available in the commonwealth. Many services are funded by the government of Puerto Rico as Special Projects (personal communication, 2013). While there are many service organizations, because most of their services are not funded by the government there is no standard method for collecting data about the services they provide. The long-term goal is for the Puerto Rico Institute of Statistics to collect this type of information (personal communication, 2013).

There is a limited mix of government-supported and private services for adults who do not have family members who are able to provide care. The Center for Habilitation within the Department of Health serves a limited amount of people, and there is often a wait list (personal communication, 2013). Some people with disabilities are also living in public housing (personal communication, 2013).

The Developmental Disabilities Council has provided funds to support special demonstration projects of independent living homes. These homes can house between six and eight adults. The Department of Health is another source of government support, and for adults offers the Program

for Persons with Intellectual Disabilities, a community-based service. Also, the Department of Health has regional centers where children (birth to 21 years) can receive services, but this department has experienced funding challenges and this limits the number of people they can serve (personal communication, 2013). Since 2012 there is an autism center for diagnostic and short-term intervention for children birth to three years of age that was developed by the Institute on Developmental Disabilities and is sponsored mainly by the Department of Health. This is also part of the Puerto Rico Autism Public Policy Act (personal communication, 2014).

Some private nursing facilities provide care for individuals with disabilities who are able to pay for services with their own funds (personal communication, 2013). On the west side of the island there is a residential service provider that runs three supported living homes, and on the northern part of the island there are two other residential programs run by non-profit organizations. Similar to government-provided services, non-profit agencies also struggle with funding issues and this limits the number of people they can support (personal communication, 2013).

References

- Behavioral Risk Factor Surveillance System (2012a). *Prevalence and trends data: Puerto Rico – 2012 disability*. Retrieved from <http://apps.nccd.cdc.gov/brfss/display.asp?cat=DL&yr=2012&qkey=8301&state=PR>
- Behavioral Risk Factor Surveillance System (2012b). *Prevalence and trends data: Puerto Rico – 2012 disability*. Retrieved from <http://apps.nccd.cdc.gov/brfss/display.asp?cat=DL&yr=2012&qkey=8311&state=PR>
- Central Intelligence Agency (CIA) (2014). *The world factbook: Puerto Rico*. Retrieved from <https://www.cia.gov/library/publications/the-world-factbook/geos/rq.html>
- Cordero, J., Alonso, A., Mattei, H., & Torres, I. (2012) *Prevalence of ASD in Puerto Rico*. Report to the Department of Health, Puerto Rico.
- IMPACTVO. (2014). *Baseline assessment of the Puerto Rico public health system*. Association of State and Territorial Health Officials.
- López, M.H., & Valesco, G. (2011). *A demographic portrait of Puerto Ricans: Statistical profile*. Pew Research Hispanic Trends Project. Retrieved from <http://www.pewhispanic.org/2011/06/13/a-demographic-portrait-of-puerto-ricans/>
- National Association of Insurance Commissioners. (2011). *Implementation of the Affordable Care Act in the U.S. territories*. Retrieved from http://www.naic.org/documents/committees_b_exchanges_hcr_reg_alt_wg_130819_draft_territories_sg_discussion_paper.pdf
- Personal communication. (2013). Discussion with Miss Aimar E. Cagigas; Mrs. Carmen M. Rodriguez; Mr. Carlos Molina Román; and Mr. Pablo Ramos at the April 2013 AUCD Conference.
- Personal communication. (2014). Email Dr. Annie Alonso Amador, Directora Instituto de Deficiencias en el Desarrollo.
- Rivera, M. (2014). *Welcome to Puerto Rico*. Retrieved from <http://welcome.topuertorico.org/government.shtml>
- U.S. Department of Commerce. (2014). United States Census Bureau. Retrieved from https://www.census.gov/history/www/faqs/demographic_faqs/when_was_puerto_rico_first_included_in_the_us_census.html
- U.S. Department of Commerce. (2014a). *United States Census Bureau: American fact finder*. Retrieved from http://factfinder2.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=DEC_10_DP_DPDP1

- U.S. Department of Commerce. (2014b). *United States Census Bureau: American fact finder*. Retrieved from http://factfinder2.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=ACS_12_1YR_S1810&prodType=table
- U.S. Department of Health and Human Services. (2010). *Medicaid in the territories: Current law and changes proposed in health reform*.
- U.S. Department of Health and Human Services. (2014a). *ASPE FMAP 2015 report*. Retrieved from <http://aspe.hhs.gov/health/reports/2014/FMAP2015/fmap15.cfm>
- U.S. Department of Health and Human Services. (2014b). *Am I eligible for coverage in the marketplace?* <https://www.healthcare.gov/am-i-eligible-for-coverage-in-the-marketplace/#question=what-if-im-a-resident-of-a-territor>
- U.S. Internal Revenue Service. (2014). *Topic 901 - Is a person with income from Puerto Rican sources required to file a U.S. federal income tax return?* Retrieved from <http://www.irs.gov/taxtopics/tc901.html>

U.S. Virgin Islands

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I. Geography

The U.S. Virgin Islands (USVI), an unincorporated U.S. Territory located between the Caribbean Sea and the North Atlantic Ocean, and double the size of Washington, D.C, is a collection of four main islands: St. Croix, St. Thomas, St. John, and Water Island as well as additional smaller uninhabited islands. The USVI have been a U.S. Territory since being purchased from Denmark in 1917 (Central Intelligence Agency [CIA], 2013). According to the U.S. Central Intelligence Agency, the population of the USVI was 104,170 in 2014 (CIA, 2014). Charlotte Amalie, its capitol, located on St. Thomas, is the USVI's largest city with a population of over 18,000.

II. Industry

The USVI economy is largely dependent upon tourism (CIA, 2013). The closure of the Hovensa oil refinery in February of 2012, which contributed 20% of the USVI's gross domestic product, resulted in the loss of approximately 2,000 jobs and had a devastating impact on the territory's economy (Shea, 2012). Rum distilleries remain major manufacturers (CIA, 2013). The average annual wage in 2013 was \$34,780 (U.S. Census Bureau, 2014). The unemployment rate was 13.4% in August of 2014 (U.S. Virgin Islands Department of Labor, 2014), more than double the US unemployment rate of 6.1% (U.S. Bureau of Labor Statistics, 2014). The USVI is one of two territories eligible for the Unemployment Compensation program (U.S. House of Representatives, 2014).

III. Population

Residents of the USVI are United States citizens although they do not vote in U.S. presidential elections or pay federal income taxes. They do, however, contribute to Social Security and are eligible to serve in the U.S. Military. They elect a governor and a 15-member unicameral

legislature as well as one non-voting delegate to the U.S. House of Representatives. The current delegate, Congresswoman Donna Christensen, M.D., has been in office since 1996 and is the first delegate to serve as a member of the House Energy & Commerce Subcommittees on Health, Energy and Power, and on Commerce, Manufacturing and Trade. She was the first female elected to represent an off-shore territory. Until taking office in 1996, Dr. Christensen was a family physician (Office of Congresswoman Christensen, 2013).

The majority of the population (76%) identified as Black or African American in the 2000 Census. Thirty-three percent of the population is foreign born. Sixteen percent of the non-institutionalized population five years of age and over indicated having a disability, of which 3.1% had a sensory disability, 5.7% a physical disability, 3.1% a mental disability. In 2010, 2.8% of children between the ages of 5 and 19 had a disability, while 1,416 children 18 and under were enrolled in Special Education (Kids Count, 2013). According to the Behavioral Risk Factor Surveillance System (BRFSS, 2010a), 11.4% of adults indicated that they are “limited in any activities because of physical, mental or emotional problems” while 4.3% indicated that they have health problems requiring the use of special equipment (BRFSS,2010b).

The cost of living in the USVI is 30% higher than that of the District of Columbia (House Committee on Ways & Means, 2012). Thirty-two percent of the population had an income below the 1999 poverty level (U.S. Census Bureau, 2003). In 2007, 24% of families lived below the poverty level. Virgin Islanders are not eligible to participate in the Supplemental Security Income Program. They instead participate in the Aid to the Aged, Blind or Disabled Program, Temporary Assistance for Needy Families (TANF) and the Supplemental Nutrition Assistance Program (SNAP) (House Committee on Ways and Means, 2012). Section 1108 of the Social Security Act caps this Aid at \$3,554,000 (U.S. House of Representatives, 2014).

IV. Medicaid Program

The USVI Medicaid program, known as the Medical Assistance Program (MAP), is administered by the Virgin Islands’ Department of Health (DOH). The DOH serves both as a local and state health department through two major divisions: Public Health Services and Health Promotion and Statistics (USVI, 2013). The Bureau of Health Insurance and Medical Assistance administers

USVI's MAP (USVI, 2013). In 2010, 8,993 Virgin Islanders were enrolled in Medicaid (CMS, 2012). In order to be eligible for MAP, residents must meet asset limits or be determined to be medically needy. These locally established asset limits are more restrictive than Federal guidelines (GAO, 2005).

Unlike states, the territory Federal Medical Assistance Percentage (FMAP) is statutorily set (GAO, 2005). It is 55% for FY2015 (U.S. Department of Health & Human Services, 2014), however, the amount was capped at \$43 million in 2012. Congresswoman Christensen has actively pursued legislation that would increase the Territory FMAPs to be on par with that of the 50 states and the District of Columbia. In 2012, she, along with the other five Territory Delegates introduced H.R. 5566, Medicaid Payment Fairness to the Territories Act of 2012. This bill, if enacted, would increase the Territory FMAPS to "the highest such [FMAP] applicable to any of the 50 States for the fiscal year involved." The bill was referred to the House Committee on Energy and Commerce the same day it was introduced, May 8, 2012, but was not enacted (Library of Congress, 2013). On January 3, 2013 she and four co-sponsors introduced a new bill H.R. 79 Medicaid Payment Fairness to the Territories Act of 2013. The bill was referred to the House subcommittee on Health on January 4, 2013 but progressed no further (Library of Congress, 2014).

Other efforts to increase Medicaid parity between the USVI and the US Mainland are being explored. In response to the 2010 Affordable Care Act, the USVI has opted to expand its Medicaid program in lieu of establishing an Exchange.

In FY2003, the Federal contribution to the USVI Medicaid program was \$60 per capita and ranged from \$33 – 65 per capita in the Territories. The average Federal Medicaid spending in the states during that same time period was \$565 per capita.

V. Services

The system of health care service delivery in the USVI includes two semi- autonomous hospitals (the Roy Lester Schneider Hospital and Medical Center on St. Thomas and Juan F. Luis Hospital and Medical Center on St. Croix), nursing homes, clinics, home health services, hospice, health

care providers (HRSA).

Unlike the states, territories are not required to cover federally mandated Medicaid services. The USVI fully covers the following mandatory Medicaid services: inpatient and outpatient hospital services; physician services, laboratory and x-ray services (with prior approval), early and periodic screening, diagnostic, and treatment (EPSDT) services for individuals under 21, family planning services and supplies, home health and Federally Qualified Health Center (FQHC) services. On-island transportation services are not covered; however, off-island services may be covered with prior approval. Services from a certified nurse practitioner are covered if delivered in a Medicaid-certified facility or program. There is one 80-bed nursing facility, 20 of which are Medicaid certified, in the USVI. The USVI MAP does not cover services from nurse midwives or rural health clinics. Optional Medicaid services covered by MAP include outpatient prescription medications and optometry services (GAO, 2005). The USVI does not participate in the Intermediate Care Facility for Persons with Intellectual Disabilities (ICF/ID) program, nor do they have a Home and Community Based Services (HCBS) Waiver program.

Currently, the USVI does not have the resources available to track Medicaid spending on services for people with I/DD or their families; however, university colleagues have indicated this type of information is critical to advocacy efforts (Habtes, 2012).

References

- Behavioral Risk Factor Surveillance System (2010a). Prevalence and trends data: Virgin Islands – 2010 Disability. Retrieved November 5, 2013 from: <http://apps.nccd.cdc.gov/brfss/display.asp?cat=DL&yr=2010&qkey=4000&state=VI>.
- Behavioral Risk Factor Surveillance System (2010b). Prevalence and trends data: Virgin Islands – 2010 Disability. Retrieved November 5, 2013 from: <http://apps.nccd.cdc.gov/brfss/display.asp?cat=DL&yr=2010&qkey=4001&state=VI>.
- Central Intelligence Agency (CIA) (2013). The World Factbook, Central America and the Caribbean: Virgin Islands. Retrieved November 6, 2013 from: <https://www.cia.gov/library/publications/the-world-factbook/geos/vq.html>
- Central Intelligence Agency (2014). The World Factbook, Central America and the Caribbean: Virgin Islands. Retrieved December 11, 2014 from: <https://www.cia.gov/library/publications/the-world-factbook/geos/vq.html>
- Centers for Medicare and Medicaid (2012). Retrieved November 7, 2013 from: <http://www.medicare.gov/Medicare-CHIP-Program-Information/By-Topics/Data-and-Systems/Downloads/2011-Medicare-MC-Enrollment-Report.pdf>
- Government Accountability Office (2005). U.S. Insular Areas: Multiple Factors Affect federal health care funding. Retrieved November 11, 2013 from: <http://www.gao.gov/new.items/d0675.pdf>.
- Habtes, Y. (2012) Personal communication.
- House Committee on Ways & Means (2012). Green Book: Background Material and Data on the Programs within the Jurisdiction of the Committee on Ways and Means, Appendix B: Social Welfare Programs in the Territories. Retrieved November 13, 2013 from: http://greenbook.waysandmeans.house.gov/2012-green-book/appendix-b-social-welfare-programs-in-the-territories#_ftn1.
- Kids Count Data Center (2013). Children enrolled in special education. Retrieved November 6, 2013 from: <http://datacenter.kidscount.org/data#VI/4/0>.
- Kids Count Data Center (2013). Children with a disability. Retrieved November 6, 2013 from: <http://datacenter.kidscount.org/data/tables/5486-children-with-a-disability?loc=54&loct=4#detailed/4/any/false/133,38,35,18,17/any/12056,12057>.
- Library of Congress (2013). H.R. 5566 Medicaid Payment Fairness to the Territories Act of 2012. Retrieved November 11, 2013 from: <http://thomas.loc.gov>.
- Library of Congress (2014). H.R. 79 Medicaid Payment Fairness to the Territories Act of 2013. Retrieved December 11, 2014 from: www.congress.gov.

- Office of Congresswoman Christensen (2013). Full biography. Retrieved November 11, 2013 from: <http://donnachristensen.house.gov/about-me/full-biography>.
- Shea, D. (January 19, 2012). Hovensa closing. Virgin Islands Daily News. Retrieved November 6, 2013 from: <http://virginislandsdailynews.com/news/hovensa-closing-1.1259790#axzz1nXpo7wFr>.
- U.S. Bureau of Labor Statistics (2014). Labor Force Statistics from the Current Population Survey. Retrieved December 11, 2014 from: <http://data.bls.gov/timeseries/LNS14000000>.
- U.S. Census Bureau (2014, April 1). May 2013 State Occupational Employment and Wage Estimates: Virgin Islands. Retrieved December 11, 2014 from: http://www.bls.gov/oes/current/oes_vi.htm#00-0000.
- U.S. Census Bureau, 2010 Census of Population and Housing, U.S. Virgin Islands Demographic Profile Summary File: Technical Documentation, 2013 (RV).
- U.S. Census Bureau (2011). U.S. Census Bureau Releases 2010 Census Population Counts for the U.S. Virgin Islands. Retrieved November 6, 2013 from: <http://www.census.gov/2010census/news/releases/operations/cb11-cn180.html>.
- U.S. Census Bureau (2003). U.S. Virgin Islands: 2000, Social, economic, and housing characteristics. Retrieved November 6, 2013 from: <http://www.census.gov/prod/cen2000/phc-4-vi.pdf>.
- U.S. Department of Health & Human Services (2014, February 5). ASPE FMAP 2015 Report. Retrieved December 11, 2014 from: <http://aspe.hhs.gov/health/reports/2014/FMAP2015/fmap15.cfm>.
- U.S. House of Representatives. (2014). Appendix B: Social Welfare Programs in the Territories. Retrieved December 15, 2014 from: <http://greenbook.waysandmeans.house.gov/2014-green-book/appendix-b-social-welfare-programs-in-the-territories>
- U.S. Virgin Islands (2013). Title V Block Grant FY 2012 Annual Report and FY 2014 Application; Narrative. Retrieved November 13, 2013 from: <https://mchdata.hrsa.gov/TVISReports/StateMchApps/StateNarrativeMenu.aspx>.
- U.S. Virgin Islands Department of Labor (2014). Employment Situation: August 2014. Retrieved December 11, 2014 from: <https://www.vidolviews.org/gsipub/index.asp?docid=430>.

Appendix A

GEOGRAPHY

	American Samoa (AS)	Commonwealth of the Northern Mariana Islands (CNMI)	Guam	Puerto Rico	Virgin Islands
Size	77 square miles	183.5 square miles	212 square miles	3,515 square miles (main island); 3 smaller islands: Vieques, Culebra, and Mona.	134 square miles
Nearest State/Country	Hawaii and New Zealand	Hawaii and the Philippines	Hawaii and the Philippines	The British Virgin Islands and the Dominican Republic	The British Virgin Islands and the Dominican Republic
Population	54,517	53,883	159, 358 (yr 2010)	3,725,789 (yr 2010)	104,170
Ethnic groups	Native Hawaiian or Pacific Islanders (91.6%)	Asian (50%) heritage, Native Hawaiian or Pacific Islander heritage (40%).	Chamorro (37.3%), Filipino (26.3%), white (7.1%), Chuukese (7%), Korean (2.2%), other Pacific Islander (2%), other Asian (2%), Chinese (1.6%), Palauan (1.6%), Japanese (1.5%), Pohnpeian (1.4%), mixed (9.4%), and other (0.6%)	Hispanic or Latino (99%)	Black or African American (76%)

ECONOMY

	American Samoa (AS)	Commonwealth of the Northern Mariana Islands (CNMI)	Guam	Puerto Rico	Virgin Islands
Industry	Tuna canaries, the AS government	Tourism, banking, construction, fishing, and handicrafts	Tourism, the military, and outside investment (primarily from Japan)	Pharmaceuticals, electronics, apparel, food products, and tourism	Largest island is dependent on tourism, rum distilleries also major manufacturers
Percent of residents below the poverty line	27%	Not available but 32% of all residents qualify for Medicaid	19.9% (2010)	45.1% (yr 2013)	24%
Unemployment rate	29.8% (2005)	25%	10% (2014)	16% (2011)	13.4% (2014)

PUBLIC ASSISTANCE

	American Samoa (AS)	Commonwealth of the Northern Mariana Islands (CNMI)	Guam	Puerto Rico	Virgin Islands
Inpatient/outpatient hospital	One hospital on the island	One Health Center (86 bed)	One civilian hospital, and one center for military, veterans, and dependents	Several hospitals, including a children's hospital	Two hospitals
Physician's services	Provided in the territory	Provided in the territory	Provided in the territory	Provided in the territory	Provided in the territory
Medicaid	All residents are entitled to free medical care. To qualify for Medicaid, an individual's income must be below 200% of the federal poverty level (FPL), which was \$21,660 in 2009.	To qualify for Medicaid, an individual's income must be less than 150% of FPL.	Medical Assistance (Medicaid and Medically Indigent Program) is available through the Bureau of Economic Security. In fiscal year 2013 43,603, people or 27% of the total population received services	58.2% enrolled in Medicaid and Mi Salud public insurance programs. Mi Salud is a locally funded insurance coverage for those whose incomes exceeding the threshold for Medicaid eligibility.	MAP (Medicaid) is administered by the VI Department of Health (DOH). To be eligible for MAP, residents must meet asset limits or be determined to be medically needy. 8,993 Virgin Islanders were enrolled in 2010.
Social Security	Participates in Social Security (Retirement, Survivors and Disability Insurance), Medicare and Medicaid	Participates in Social Security (Retirement, Survivors and Disability Insurance), Medicare and Medicaid	Participates in Social Security (Retirement, Survivors and Disability Insurance), Medicare and Medicaid	Participates in Social Security (Retirement, Survivors and Disability Insurance), Medicare and Medicaid	Participates in Social Security (Retirement, Survivors and Disability Insurance), Medicare and Medicaid

	American Samoa (AS)	Commonwealth of the Northern Mariana Islands (CNMI)	Guam	Puerto Rico	Virgin Islands
Supplemental Security Income program	Not eligible to participate	Has Supplemental Security Income (SSI)	Not eligible to participate	Not eligible to participate	Not eligible to participate
Temporary Assistance for Needy Families (TANF)	Eligible for TANF, but they do not participate in the program	No	Yes	Yes	Yes, Blind or Disabled Program, TANF
Supplemental Nutrition Assistance Program (SNAP)	Does not participate in SNAP but it receives an indexed nutrition assistance grant which benefits low-income, aged and disabled individuals	CNMI has been considering SNAP participation and is completing a proposal to do a pilot project in October. CNMI does have a Nutrition Assistance Grant	Yes	Yes	Yes
Federal Medical Assistance Percentage (FMAP)	For FY2015 it was 55%, and the enhanced percentage is 68.5%.	For FY2015 it was 55%, and the enhanced percentage is 68.5%.	For FY2015 it was 55%, and the enhanced percentage is 68.5%. Guam has secured an increase in that percentage for calendar years 2014 and 2015. Medicaid spending is capped. This cap was temporarily removed when Guam was allocated additional funding (\$268 million to be spent beginning July 1, 2011 thru FY2019) under the Affordable Care Act (ACA). Also, beginning January 1, 2014 the Guam Medicaid State Plan Amendment was approved to include childless adults with income above 100% to 133% of the federal poverty level with an FMAP of 78.6%	For FY2015 it was 55%, and the enhanced percentage is 68.5%. Medicaid spending cap was \$364 million in 2010.	For FY2015 it was 55%, and the enhanced percentage is 68.5%. Medicaid spending cap was \$43 million in 2012. Congresswoman Christensen has actively pursued legislation that would increase the Territory FMAPs to be on par with that of the 50 states and DC.

SERVICES FOR PEOPLE WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

	American Samoa (AS)	Commonwealth of the Northern Mariana Islands (CNMI)	Guam	Puerto Rico	Virgin Islands
Laboratory and x-ray, Early Periodic Screening, Diagnostic and Treatment (EPSDT)	Yes	Yes	Yes	Yes	Yes
Nursing facility services, private duty nursing, podiatry, optometry and occupational and speech therapies	<p>These services are provided, but they are off the island.</p> <p>Off-island services must be pre-approved by the admitting physician as a medical necessity and then pre-approved by physician-members of the Off-Island Medical Referral Committee</p>	<p>Some. Other services are provided off the island.</p>	<p>Guam Memorial Hospital Authority Skilled Nursing Unit (40 Medicaid beds) is an off hospital site that provides long term rehabilitative care.</p> <p>Guam Memorial Hospital Authority also provides rehabilitation services.</p> <p>Medicaid Services for Speech, Hearing and Language Disorders are reimbursed as fee for service using Medicare fee schedule.</p>	<p>Allowable Medicaid services include physical therapy, occupational therapy, and speech therapy and are included in the capitated rate paid to managed care plans.</p>	<p>Services from a certified nurse practitioner are covered if delivered in a Medicaid-certified facility or program. There is one 80-bed nursing facility (20 Medicaid certified). The USVI MAP does not cover services from nurse midwives or rural health clinics. Optional Medicaid services covered by MAP include outpatient prescription medications and optometry services</p>

	American Samoa (AS)	Commonwealth of the Northern Mariana Islands (CNMI)	Guam	Puerto Rico	Virgin Islands
ICF-ID	<p>There are no intermediate care facilities for people with intellectual disabilities (ICF/ID).</p> <p>There is a convalescent home that is run by the Catholic Sisters which supports 22 adults and children</p>	<p>There are very few segregated or specialized settings for individuals with disabilities (or for the elderly). Some individuals with significant chronic behavior issues may leave the island and receive services in Hawaii or other western states.</p>	<p>There are no intermediate care facilities for people with intellectual disabilities (ICF/ID).</p> <p>The Guam Behavioral Health and Wellness Center coordinates comprehensive services and residential alternatives in the community for individuals with dual diagnosis.</p> <p>The island has approximately eight group homes, funded by the government through contracts with providers. There are two main service providers on the island. Most people with disabilities live at home with their families. Guam has one formal Community Habilitation Program that is offered by Catholic Social Services, and group home (residential) providers support individuals to engage in daytime activities.</p>	<p>There are no intermediate care facilities for people with intellectual disabilities (ICF/ID).</p> <p>Individuals over 21 years old, can seek services from the Vocational Rehabilitation Administration. Most adults are not in government funded services during the day and most people remain with their families.</p> <p>Limited mix of government-supported and private services for adults who do not have family members who are able to provide care. The Center for Habilitation within the Department of Health serves a limited amount of people, and there is often a wait list. Some people with disabilities are also living in public housing.</p> <p>The Developmental Disabilities Council has provided funds to support special demonstration projects of independent living homes. These homes can house between six and eight adults. Some private nursing facilities provide care for individuals with disabilities who are able to pay for services with their own funds.</p>	<p>There are no intermediate care facilities for people with intellectual disabilities (ICF/ID).</p>

	American Samoa (AS)	Commonwealth of the Northern Mariana Islands (CNMI)	Guam	Puerto Rico	Virgin Islands
HCBS Waivers	Does not operate Medicaid HCBS Waivers	Does not operate Medicaid HCBS Waivers	Does not operate Medicaid HCBS Waivers	Does not operate Medicaid HCBS Waivers	Does not operate Medicaid HCBS Waivers
Vocational Rehabilitation Services	Division of Vocational Rehabilitation Phone: (684) 699-1371 Fax: (684) 699-1376	Office of Vocational Rehabilitation Phone: (670) 322-6537 Fax: (670) 322-6536 TTY: (670) 322-6449	Division of Vocational Rehabilitation Phone: (671) 475-4200 Fax: (671) 475-4661 TTY: (671) 477-8642	Vocational Rehabilitation Administration Phone: (787) 729-0160 Fax: (787) 728-8070 TTY: (787) 268-3735	Division of Disabilities and Rehabilitation Services Phone: (340) 774-0930 x4190 Fax: (340) 774-7773 TTY: (340) 776-2043

ADMINISTRATION OF DEVELOPMENTAL AND INTELLECTUAL DISABILITIES GRANTEES

	American Samoa (AS)	Commonwealth of the Northern Mariana Islands (CNMI)	Guam	Puerto Rico	Virgin Islands
Developmental Disabilities Council	American Samoa Developmental Disabilities Council E-Mail: council@samoatelco.com Executive Director: Norma L. Smith, nlsmith@dhss.as	Executive Director Pamela Sablan http://www.cnmicdd.org/	Guam Developmental Disabilities Council, Email: guamddc@gddc.guam.gov Executive Director: Rosanne S. Ada, rosanne.ada@gddc.guam.gov	Puerto Rico DD Council, President: Vincente Sanabria Acevedo, prced@prtc.net	Virgin Islands DD Council Yvonne D. Petersen Executive Director VI Developmental Disabilities Council E-mail: viddcouncil@gmail.com Phone: (340) 773-2323 Ext. 2137
Protection and Advocacy System	Client Assistance Program and Protection & Advocacy Executive Director: Dr. Uta Laloulu Tagoilelagi, utalaloulu@yahoo.com	James Rayphand Executive Director http://www.nmpasi.org/	Guam Client Assistance Program	Office of the Governor/Ombudsman for Persons with Disabilities http://www.oppi.gobierno.pr/	Disability Rights Center of the Virgin Islands http://www.drcvi.org/home
University Center on Developmental Disabilities	Pacific Basin Program American Samoa Community College Executive Director: Seth Galeai, Ph.D., s.galeai@ascc.as	Northern Marianas College http://www.marianas.edu/content.php?id=146&cat=151&mnu=148	Guam Center for Excellence in Developmental Disabilities Education, Research and Service (CEDDERS); Heidi E. San Nicolas, Ph.D. heidi.sannicolas@guamcedders.org	Puerto Rico University Center for Excellence on Developmental Disabilities/IDD; Annie Alonso Amador, Psy.D. MSW. annie.alonso@upr.edu	Virgin Islands University Center for Excellence in Developmental Disabilities Yegin Habtes, Ph.D., yhabtes@uvi.edu Charles Beady, Ph.D., cbeadyj@live.uvi.edu
Help America Vote Act	Yes		Yes	Yes	Yes

