



United States Government  
*Progress Report on the Implementation of the Program of  
Action for the Decade of the Americas for the Rights and  
Dignity of Persons with Disabilities  
(2006-2016)*

*Response of the United States Government for the OAS Progress  
Report on the Implementation of the Program of Action for the  
Decade of the Americas for the Rights and Dignity of Persons with  
Disabilities (2006-2016)*

**Annex I** Summary of Inter-American Foundation (IAF) Support to  
People with Disabilities in Latin American and Caribbean

**Annex II** Summary of Activities Supporting the U. N. Convention  
of the Rights of Persons with Disabilities

Responses Prepared by the HHS Office on Disability for the *OAS Progress Report on the Implementation of the Program of Action for the Decade of the Americas for the Rights and Dignity of Persons with Disabilities (2006-2016)*

*Field 2 - Promotion and Health Access*

**Activity 11. Ensure access for people with disabilities to the services of physical and mental health, on equal terms with others, with particular attention to their special needs because of their disabilities, the environment possible.**

**General Laws/Regulations**

- Rehabilitation Act of 1973, as Amended (Particularly Section 504, 508).
- Americans with Disabilities Act of 1990, As Amended (Particularly Titles II & III).
- HIPPA (1995), Health Insurance Portability and Accountability Act, privacy law.
- Mental Health Parity Act of 1996.
- GINA, Genetic Non-Discrimination Act of 2008.
- Assistive Technology Act of 1998.
- Paul Wellstone and Pete Domenici Mental Health Parity and Addiction Equity Act of 2008 (effective January 2010).
- Surgeon General's Call to Health and Wellness for Individuals with Disabilities, 2005.
- Money Follows the Person program (under the Deficit Reduction Act of 2005).
- Medicaid, Early Periodic Screening, Diagnosis, and Treatment (EPSDT), Medicaid Buy In.
- CRIPA - Civil Rights of Institutionalized Persons Act of 1980.

**Centers for Disease Control and Prevention**

- In 1988, the U.S. Congress created the Disability and Health Program within the CDC's National Center for Environmental Health.

- National Center on Birth Defects and Developmental Disabilities (NCBDDD), created in Children's Health Act of 2000, Under special Congressional funding, the CDC Disability and Health Team provides support for the Healthy Athletes Program hosted by Special Olympics to promote the health of athletes with with mental retardation and other disabilities.
- Pending Health Reform Proposals in House & Senate Health Bills would require Access Board to establish standards for accessible medical diagnostic equipment. House bill requires equitable access to programs and services covered under the medical exchange. Senate Bill requires provider training in cultural competency for persons with disabilities.
- Traumatic Brain Injury Act of 1996.

<p><b>Activity 12.</b> Encourage the adoption of preventive measures early detection and intervention in cases of disabling diseases prevention of accidents and preventable risks</p>
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### **General Laws/Regulations**

- Early Periodic Screening, Diagnosis, and Treatment (EPSTD), States Children's Health Insurance Programs (SCHIP), Developmental Disabilities Act, of 1977.
- Public Health Service Act.
- Pilot Programs in Health & Wellness under Medicare Modernization Act of 2003.
- Surgeon General's Call to Health and Wellness for Individuals with Disabilities, 2005.
- Occupational Safety and Health Act of 1970, as amended (2004).
- Pending current health reform proposals include new preventative health measures and early detection.
- Violence Against Women's Act.
- Traumatic Brain Injury Act.

## **Centers for Disease Control and Prevention**

- In 1988, the U.S. Congress created the Disability and Health Program within the CDC's National Center for Environmental Health.
- National Center on Birth Defects and Developmental Disabilities (NCBDDD), created in Children's Health Act of 2000.
- National Institute of Child Health and Human Development. Public Law 87-838 authorizes the establishment of the NICHD (1962).
- National Center for Medical Rehabilitation Research (1990) (P.L. 101-613).
- Early Intervention Program for Infants and Toddlers with Disabilities (Part C of IDEA).

***Activity 13. The Promotion and dissemination of scientific and epidemiological research aimed at discovering the causes of disabilities possible solutions and prevention of disabling diseases and injuries and to improve the quality of life for people with disabilities. Rehabilitation Act of 1973 (NIDRR, RTCs)***

## **General Laws/Regulations**

- Developmental Disabilities Act (Centers of Excellence).
- National Institute of Child Health and Human Development. Public Law 87-838 authorizes the establishment of the NICHD (1962).
- National Center for Medical Rehabilitation Research (1990) (P.L. 101-613).
- VA Rehabilitation Research and Development Service, under the authorizing legislation for the Veterans Administration.

## **Centers for Disease Control and Prevention**

- In 1988, the U.S. Congress created the Disability and Health Program within the CDC's National Center for Environmental Health.
- National Center on Birth Defects and Developmental Disabilities (NCBDDD), created in Children's Health Act of 2000.

- Traumatic Brain Injury Act.

***Activity 14. Promoting preconception care prenatal care and comprehensive health services including information and appropriate nutrition for pregnant women and children less than three years old encouraging breastfeeding given the disabilities that can generate risk prenatal and birth and the inadequate development of early childhood with special emphasis on rural and indigenous areas.***

- Medicaid program.
- States Children's Health Insurance Programs (SCHIP).
- Early Periodic Screening, Diagnosis, and Treatment (EPSDT).
- Food Stamps, Women Infants and Children (WIC) nutrition program, Temporary Assistance for Needy Families (TANF) under 1996 Welfare Reform Legislation/ 2005 Deficit Reduction Act.
- Early Intervention Program for Infants and Toddlers with Disabilities (Part C of IDEA).

***Activity 15. Implementation of plans and free mass vaccination to prevent diseases that causes disability. FDA***

- The Centers for Disease Control and Prevention (CDC) has legislative authority through the Vaccines for Children program.
- Public Health Service Act § 319 (42 U.S.C. § 247d).
- National Emergency Act.
- Stafford Act (as amended in Post Katrina Emergency Management Reform Act of 2006).
- Medicare & Medicaid Act (waivers).
- Early Periodic Screening, Diagnosis, and Treatment (EPSDT).

***Activity 16. Provide people with disabilities with health care and free or affordable the same variety and quality than those provided to others even in the field of sexual and reproductive health and public health programs aimed at the general population***

- Medicaid, Medicare, 2005 Surgeon General's Call for Health and Wellness of People with Disabilities.
- Pending current Health Reform Proposals in House & Senate Health Bills would require Access Board to establish standards for accessible medical diagnostic equipment. House bill requires equitable access to programs and services covered under the medical exchange. Senate Bill requires provider training in cultural competency for persons with disabilities.

***Activity 17. Promote voluntary screening for transmissible diseases diabetes hypertension and transmissible infections including sexually transmitted diseases in order to prevent disability***

- Medicare, Medicaid, Veterans Administration, Early Periodic Screening, Diagnosis, and Treatment (EPSDT), Public Health Service Act.

#### **Centers for Disease Control and Prevention**

- In 1988, the U.S. Congress created the Disability and Health Program within the CDC's National Center for Environmental Health.
- National Center on Birth Defects and Developmental Disabilities (NCBDDD), created in Children's Health Act of 2000.
- Under special Congressional funding, the CDC Disability and Health Team provides support for the Healthy Athletes Program hosted by Special Olympics to promote the health of athletes with with mental retardation and other disabilities.

- U.S. Department of Health and Human Services, National Strategy for Suicide Prevention: Goals and Objectives for Action. (2001).
- Substance Abuse and Mental Health Administration (SAMHSA) Authorization, Garrett Lee Smith Memorial Act.
- 2005 Surgeon General's Call to Health and Wellness for Individuals with Disabilities.

**Activity 18.** Prevent prohibit and punish mistreatment sexual abuse and exploitation especially in the context of the family persons with disabilities particularly children and women.

- Matthew Shepherd Hate Crimes Legislation (recently passed); Disability provisions in the most recent revision of the Violence Against Womens Act (VAWA).
- CRIPA - Civil Rights of Institutionalized Persons Act.
- Older Americans Act.
- Protection and Advocacy Programs (Developmental Disabilities Act).

**Activity 19.** Promote the establishment of health care facilities with equipment to enable access examination and appropriate treatment of persons with disabilities.

- Americans with Disabilities Act & Section 504 & 508 of the Rehabilitation Act.
- Assistive Technology Act.
- 2005 Surgeon General's Call to Health and Wellness for Individuals with Disabilities.
- Pending Health Reform Proposals in House & Senate Health Bills would require Access Board to establish standards for accessible medical diagnostic equipment. House bill requires equitable access to programs and services covered under the medical exchange. Senate Bill requires provider training in cultural competency for persons with disabilities.

- Traumatic Brain Injury Act.

**Activity 20.** Design implement and deliver policies and standards of health and safety in workplaces to prevent or reduce the risk of accidents including adaptation of workplaces to prevent occupational disabilities and diseases.

- Occupational Safety and Health Act of 1970, as amended (2004).
- Proposals to develop Accessible Medical Instrumentation and facilities in health reform legislation to avoid workplace injuries among health workers.
- Federal Mine Safety and Health Act of 1977 (Mine Act).
- Toxic Substances Control Act - TSCA (15 U.S.C. § 2601 et seq.).
  - Title 1 - Control of Toxic Substances - § 2605. Regulation of hazardous chemical substances and mixtures
  - Title 2 - Asbestos Hazard Emergency Response
  - Environmental Protection Agency (EPA) - Commencing in April 2010, contractors who "disturb lead-based paint" during the course of conducting renovation, repair or painting are required to follow specific guidelines.

**Activity 21.** Proceed to the identification and clearance of landmines and other unexploded ordnance in territories where there was armed conflict to prevent disabling accidents.

- The US is a party to the Convention on Conventional Weapons (CCW) and ratified Amended Protocol II on landmines on 24 May 1999.
- US law has prohibited the export of antipersonnel mines since 23 October 1992. This moratorium has been extended several times.
- US Mine Action Funding - According to the Department of State, the US has provided over \$1 billion in mine action funding [for mine removal] since FY 1993.



**Activity 22. Ensure proper and timely medical care physical and mental quality for persons with disabilities taking into consideration the age and provide free or affordable treatments and medicines needed to overcome the disease or health condition control and prevent deterioration of the person or the worsening of disability.**

- Medicare - Medicare Modernization Act, Medicaid / DRA (managed care updates).
- Pending Health Reform Legislative Proposals – Medical Home, Comparative Effectiveness, Community Living Assistance Services and Supports (CLASS) Act (CLASS ACT), Community First Choice (CFC), Health and Wellness proposals.
- Traumatic Brain Injury Act.
- Rehabilitation Act, Americans with Disabilities Act (ADA) could be relevant interacting with other measures.

**Activity 23. Design and implement educational prevention strategies that address all determinants of disabilities and promote healthy lifestyles for people with disabilities at all levels.**

- Public Health Services Act.
- Surgeon General’s Call to Health and Wellness for Individuals with Disabilities.
- Older Americans Act.

#### **Centers for Disease Control and Prevention**

- In 1988, the U.S. Congress created the Disability and Health Program within the CDC’s National Center for Environmental Health.
- National Center on Birth Defects and Developmental Disabilities (NCBDDD), created in Children’s Health Act of 2000.

- Pending Health Reform Proposals in House & Senate Health Bills would support health and wellness programs meeting needs of persons with disabilities.
- National Institute of Child Health and Human Development. (NICHD) Public Law 87-838 authorizes the establishment of the NICHD (1962).
- National Center for Medical Rehabilitation Research- (1990) (P.L. 101-13).
- Rural Training Centers under NIDRR (Rehabilitation Act) are doing a host of health and wellness programs targeting people with disabilities.
- University Centers of Excellence under the Developmental Disabilities Act.

***Activity 24. Implement driver education programs and the consequences of traffic accidents to prevent possible disabilities.***

- National Highway Traffic Safety Administration (NHTSA ), the federal government agency with the authority to regulate the manufacture of automotive adaptive equipment and modified vehicles used by persons with disabilities.

### **Rehabilitation**

***Activity 25. Promote strategies of community based rehabilitation services with emphasis on primary health care integrated health system and tailored to the particularities of each country and with the participation of organizations of persons with disabilities in its design and execution.***

- Inadequate Coordination in this area – most work is only piloted, proposed or in demonstration form with the possible exception of the Veterans Administration.
- Rehabilitation Act –Title VII, Parts B& C Independent Living.

- Medicare (Part D), Medicaid Buy In, Medicaid Rehab Option/ HCBS waivers, Social Security Act (Income Disregards, TWIA, Cash cliff demonstrations, etc).
- Veterans Administration, Updated GI Bill of Rights. The GI bill of Rights, officially known as the Servicemen's Readjustment Act of 1944, was designed to provide greater opportunities to returning war veterans of World War II. The bill, signed by President Roosevelt on June 22, 1944, provided federal aid to help veterans adjust to civilian life in the areas of hospitalization, purchase of homes and businesses, and especially, education. This act provided tuition, subsistence, books and supplies, equipment, and counseling services for veterans to continue their education in school or college.
- Some ideas of this integrated into pending current health reform proposals.
- Pending current Health Reform Proposals in House & Senate Health Bills would require Access Board to establish standards for accessible medical diagnostic equipment, participation of persons with disabilities in setting medical advisory policies. House bill requires equitable access to programs and services covered under the medical exchange. Senate Bill requires provider training in cultural competency for persons with disabilities.
- SAFE-TEA LU New Freedom Transportation Funds (5317).
- Workforce investment Act (WIA) / Disability Program Navigator/ One-Stop Career Center.

***Activity 26. Strengthen existing rehabilitation services so that all people with disabilities have access to rehabilitation services they need as close as possible to their place of residence even in rural areas***

- Inadequate Coordination in this area – most work is only piloted, proposed or in demonstration form with the possible exception of the Veterans Administration.
- Pending current Health Reform Proposals in House & Senate Health Bills would require Access Board to establish standards for accessible medical diagnostic equipment. House bill requires equitable access to programs and services covered under the medical exchange. Senate Bill requires provider training in cultural competency for persons with disabilities.
- SAFE-TEA LU New Freedom Transportation Funds (5317).

- Veterans Administration Authorizing Legislation, Community Health Center legislation.
- Older Americans Act.
- AGRABILITY, a U.S. Department of Agriculture-sponsored program that assists farmers, ranchers, other agricultural workers, and family members impacted by disability.
- Assistive Technology Act.

***Activity 27. Promote the appropriate training of professional and technical staff for the comprehensive care of physical motor disabilities, sensory, intellectual and psychosocial.***

- Inadequate Coordination in this area – most work is only piloted, proposed or in demonstration form with the possible exception of the Veterans Administration & Individuals with Disabilities Education Act (IDEA) training for special education and university centers of excellence for Developmental Disabilities professions.
- Veterans Administration, Medicare Modernization Act, Some resources in Workforce Investment Act (WIA)/ Onestops.
- Pending current Senate Health Reform Bill requires provider training in cultural competency for persons with disabilities.
- NIDRR under the Rehabilitation Act, Rehabilitation Research and Training Centers (RRTC) Disability.
- Developmental Disabilities Act University Centers of Excellence
- Special Education Training under IDEA

***Activity 28. Promote the development of specific training programs and training in production and supply in the national teams of technical and biomechanics and the participation of persons with disabilities in those programs***

- Inadequate Coordination in this area – most work is only piloted, proposed or in demonstration form with the possible exception of the Veterans Administration.
- 2005 Surgeon General’s Call to Health and Wellness for Persons with Disabilities.
- Pending current Health Reform Proposals in House & Senate Health Bills would require Access Board to establish standards for accessible medical diagnostic equipment, participation of PWDs in setting medical advisory policies.

***Activity 29. Promoting in addition to medical rehabilitation vocational rehabilitation and survival strategies in the context of community rehabilitation.***

- Inadequate coordination, but efforts under way.
- Rehabilitation Act of 1973, Workforce Investment Act (1998 Reauthorization), Centers for Independent Living, NIDRR, RTCs, Social Security Act (Ticket to Work, Trial Work Periods).
- Efforts are under way to improve this through the next reauthorization of the Rehabilitation Act and through increased linkages to Office of Disability Employment Policy.
- Money Follows the Person Demonstration under DRA begins to look more holistically at services and supports.
- CLASS Act, Melville Supportive Housing reform legislation and other pending proposals begin to align supportive services with vocational opportunities.
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***Activity 30. Take steps to establish inter-sectoral commitments and programs that link actions to achieve the comprehensive rehabilitation of the disabled since childhood.***

Efforts for coordinated policies are under way but are still extremely disjointed. Hopefully health reform and the next reauthorization of the Rehabilitation Act/ Workforce Investment Act will make significant strides in this arena.

## **Summary of Inter-American Foundation (IAF) Support to People with Disabilities in the Latin American and Caribbean regions:**

### **Travel Grants**

The Technical Secretariat for the Implementation of the Program of Action for the Decade of the Americas for the Rights and Dignity of Persons with Disabilities received IAF funds (approximately \$30,000) to provide airfare for representatives of organizations of persons with disabilities to attend workshops sponsored by the OAS. The IAF entered into an agreement to continue this support for the Secretariat's mission over the next two years.

A representative from Red Latinoamericana de Personas con Discapacidad y sus Familias (RIADIS) and one from Disabled People's International Latin America received travel grants to attend the OAS's General Assembly and the Summit of the Americas. RIADIS and DPI Latin America are the region's largest networks of organizations of people with disabilities.

The IAF organized a panel at the XIV Inter-American Conference of Mayors held in July in Miami where representatives from Federación Nacional de Ecuatorianos con Discapacidad Física spoke of IAF-sponsored Taxi Solidario's successful service for disabled Ecuadorians and Guatemala City representatives showcased their municipality's relationship with organizations of people with disabilities to ensure the accessibility of their recently inaugurated mass-transit system. Over 400 mayors from Latin America and the Caribbean attended this event.

Officers of organizations representing deaf Latin Americans participated in the World Deaf Federation's VI Encuentro Latinoamericano de Sordos e Interpretes, the region's largest meeting of deaf activists, held in Bogota. IAF Fellow Elizabeth Lockwood, who is studying the deaf movement in Uruguay, spoke of her research. The IAF sponsored the participant's airfare.

The General Assembly of Red Latinoamericana de Personas con Discapacidad y sus Familias (RIADIS), held in Cartagena, Colombia in October also received IAF support.

In June, representatives of organizations serving people with disabilities, senior citizens, indigenous peoples, African descendants, youths, women, HIV/AIDS patients and other vulnerable groups addressed employment discrimination and access to health services and education in workshops held in collaboration with the Honduran Congress.

### **The following two program grants funded in previous years received supplemental funding:**

Asociacion Pro Derechos Humanos (APRODEH):

To prepare approximately 520 mentally disabled individuals and their families to advocate for their position with respect to the decentralization process. APRODEH will also assist the trainees in forming a national network to assure the mentally disabled are involved in all public discussions of resources and services. (PU-535)

**Centro de Atención Infantil “Piña Palmera”, A.C. (Piña Palmera)**

**Through a program of community-based rehabilitation, Piña Palmera will work with individuals with disabilities to improve the skills necessary for independent living and community inclusion. The individuals, their family members and community residents will participate in training in life skills, camp programs, sports, rehabilitation activities and a local radio program directed at raising awareness of the challenges and capabilities of persons with disabilities. (ME-485)**



## **Summary of U.S. Department of Health and Human Services' Programs and Activities Supporting the U.N. Convention on the Rights of Persons with Disabilities**

### **Introduction**

The day-to-day work of the United States Department of Health and Human Services (HHS) touches the lives of every American and has special significance for Americans with disabilities. HHS provides funds and oversees critical and significant programs that serve people with disabilities of all ages. HHS has already provided its article-by-article views on the U.N. Convention on the Rights of Persons with Disabilities as part of the initial tri-agency U.S. delegation review of the Convention by the State, Justice, and HHS Departments. What follows is a summary of major HHS laws, regulations, policies, programs, services, and activities that implement articles in the U.N. Convention on the Rights of Persons with Disabilities, noting where there are gaps with requirements in the article. Although the majority of these programs cut across a number of the articles in the Convention, they are included in the article of greatest relevance.

### **Article 3 – General principles**

As the Federal agency responsible for protecting the health of all Americans and providing essential human services, especially for those who are least able to help themselves, HHS administers and funds hundreds of programs and supports research in every aspect of disability that touch upon the underlying principles in the Convention set out in Article 3 to promote the inherent dignity, non-discrimination and equality of opportunity, and full and effective participation and inclusion in society. Total HHS expenditures specifically for persons with disabilities in the major national programs that most directly impact them, such as Medicaid, Medicare, the Social Services Block Grant, Substance Abuse Block Grant, and Older Americans Act, currently total well over \$200 billion. The largest of these expenditures is the Federal share for Medicaid, which is more than \$188.5 billion for the approximately 12 million individuals with disabilities who receive Medicaid services.

### **Article 5 – Equality and non-discrimination**

HHS is an integral part of the Federal Government structure that recognizes and promotes Federal laws and policies to ensure that all persons have equal protection and equal benefits. The HHS Office for Civil Rights (OCR) ensures non-discrimination on the basis of disability and equal access to all HHS funded programs as well as local and state health and human services programs by enforcing Sections 504 and 508 of the Rehabilitation Act of 1973 and Title II of the Americans with Disabilities Act. OCR's jurisdiction under Section 504 includes programs and activities that receive Federal financial assistance from HHS, and programs and activities conducted by HHS. OCR's enforcement authority under Section 508 covers access to electronic and information technology provided by HHS. OCR's jurisdiction under ADA covers all of the healthcare

and social services programs and activities of public entities (state and local governments, departments, and agencies).

### **Article 7 – Children with disabilities; Article 24 - Education**

HHS' Health Resources and Services Administration (HRSA) administers the Maternal and Child Health Block Grant under Title V of the Social Security Act. The Omnibus Budget Reconciliation Act of 1989 substantially broadens the mission of these state programs and explicitly recognizes that all children with a special health care needs should have access to an appropriate, community-based system of care monitored by state Children with Special Health Care Needs (CSHCN) agencies. At least 30% of the Title V Maternal and Child Health Block Grant must be used to improve services for children with special health care needs. In addition, states are now required to conduct needs assessments pertaining to these children, to foster local systems of care and to ensure a high quality of community-based services. Many State CSHCN programs partner with Special Education, Early Intervention, Head Start and Child Care to provide Information and referrals about health guidelines and resources to their programs and families serving CSHCN and provide ongoing monitoring to achieve identified needs for CSHCN. They also assist medical home providers and families to provide health input into development of individualized service plans for these children.

HHS' Administration for Children and Families (ACF) administers Head Start programs, which provide children with disabilities and their families with the full range of comprehensive services available to children and provide individualized services as called for in the Individual Education Program (IEP) under the Individuals with Disabilities Education Act (IDEA). Local arrangements that provide supports to children in Head Start classrooms often include special education teachers and/or therapists employed by the local school system. Head Start is also a leading source of inclusive placements for preschoolers with disabilities. At least 10 percent of Head Start enrollment slots must be made available for children with disabilities. Early Head Start programs provide opportunities for infants and toddlers with disabilities to receive child development services in the program's "natural environment" and are also key collaborators in community efforts to implement Part C of IDEA on Early Intervention. ACF's Child Care Bureau funds child care programs for young and school age children and provides incentives and training programs to develop child care services and providers for children with special needs.

HHS' Substance Abuse and Mental Health Services Administration (SAMHSA) administers the Comprehensive Community Mental Health Services Program for Children and Their Families (<http://mentalhealth.samhsa.gov/publications/allpubs/CA-0013/default.asp>) that promotes systems of care to improve school and other measures of quality of life for children with mental health problems and their families.

HHS' Indian Health Service (IHS) has a number of collaborations with other HHS agencies which focus on children with disabilities, including:

- The Indian Children's Program, which is a service program provided by a consortium of three University Centers for Excellence in Developmental Disabilities with funding by IHS. Most direct services are delivered in the families' homes or the community where the child resides and include speech, hearing and language development, and psycho-educational evaluations.
- The Circles of Care program, which is a partnership between IHS and SAMHSA to (1) support the development of mental health service delivery models that are designed by AI/AN communities to achieve outcomes for their children (with severe emotional behaviors) that they chose for themselves; (2) position tribal and urban Indian organizations advantageously for future service system implementation and development; (3) strengthen Tribal and urban Indian organizations' capacity to evaluate their own service system's effectiveness; and (4) develop a body of knowledge to assist Tribal and urban Indian organizations, and other policy makers and program planners in improving systems of care for AI/AN population overall.

#### **Article 8 – Awareness-raising**

HHS' SAMHSA partners with national, state and local organizations to implement the Campaign for Mental Health Recovery ([www.whatadifference.samhsa.gov](http://www.whatadifference.samhsa.gov)), a public education effort that promotes social inclusion and counters stereotypes, prejudices and harmful practices relating to persons with mental health disabilities. These efforts address all areas of life including employment, education, healthcare, housing, legal, and social participation. Its Voice Awards program works with the media to portray persons with mental health disabilities in a dignified and respectful manner. The ADS Center ([www.promoteacceptance.samhsa.gov](http://www.promoteacceptance.samhsa.gov)) provides technical assistance and supports awareness-training programs for the general public and people with mental health disabilities across the nation.

#### **Article 9 – Accessibility**

HHS' OCR focuses on ensuring physical and programmatic accessibility of all HHS funded programs and services and state and local health and human services programs under Title II of the ADA and Sections 504 and 508. HHS' OCR has taken a number of initiatives that comport with Section 1 of this Article, which calls on States Parties to "take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to ... information and communications, including information and communications technologies and systems." For example, OCR has partnered with the American Hospital Association to give hospitals the tools, information, and other technical assistance they need to ensure equal access to health care by persons with disabilities:

<http://www.hhs.gov/ocr/civilrights/resources/specialtopics/hospitalcommunication/index.html>.

## **Article 11 – Situations of risk and humanitarian emergencies**

HHS has implemented numerous strategies to ensure the health and safety of persons with disabilities in an emergency. For example, HHS has:

- Collaborated with the American Red Cross in the development of a Shelter Intake and Assessment Tool to ensure that individuals with disabilities are referred to the most appropriate shelter setting and that they have access to necessary aids and services. The Tool is now in use at all general population shelters;
- Developed an Evacuation and Transportation Assessment Tool that facilitates the evacuation of individuals with disabilities in appropriate, accessible transportation to evacuation sites that are consistent with their needs. Both HHS and the Federal Emergency Management Agency have agreed to use this Tool in their evacuation activities;
- Established integrated systems to address the availability of durable medical equipment, pharmaceuticals, and support services that people with disabilities and their service animals may need;
- Distributed a matrix of available training opportunities for first responders and health care personnel working with at-risk individuals, including persons with disabilities;
- Developed a toolkit to provide planners with concrete information and guidance on accounting for the needs of at-risk individuals, including persons with disabilities;
- Expanded the cache of equipment and supplies at Federal Medical Stations (FMS) to include accommodations for persons with disabilities, such as bariatric patient lifts, wheelchair and walker accessibility aisles, and toilet seat risers, and a wider range of medications for managing issues for patients with behavioral health disorders. Modified the checklist for site inspection/approval at FMSs to now include accessibility items such as wheelchairs and walker accessible aisles;
- Prepared a workbook to identify at-risk populations, including persons with disabilities, and to develop a communication outreach and information network to reach such persons;
- Developed guidance for health education/communication messages for diverse audiences, including persons with disabilities;

- Developed a web-based tool to help emergency planners make decisions about when health information can be shared in compliance with the Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule; and
- Provides technical assistance to emergency planners, including state and local government agencies, to ensure that issues related to the at-risk population and health information privacy are considered in emergency planning.
- Developed tools for families having children with special health needs in preparing for emergencies, such as portable health records and training materials for first responders.
- In April 2008, *the Newborn Screening Saves Lives Act* became law and directed CDC in consultation with HRSA and the state depts. of health to develop a national contingency plan. The contingency plan contains detailed planning, preparedness and response to NBS during a public health emergency.

In addition, HHS is responsible for implementing key provisions of the Pandemic and All Hazards Preparedness Act (PAHPA). Under PAHPA, the HHS Secretary must establish plans and strategies that address the needs of at-risk individuals, including those with disabilities, so that emergency planners, manager and responders will be better prepared to account for the needs of at-risk individuals prior to and following a catastrophic event. Such strategies include: establishing guidance to ensure that recipients of State and local public health grants include preparedness and response strategies and capabilities that account for the medical and public health needs of at-risk individuals in the event of a public health emergency; overseeing curriculum development for the public health and medical response training program on medical management of casualties, as it concerns at-risk individuals; and disseminating novel and best practices of outreach to and care of at-risk individuals before, during and following public health emergencies.

#### **Article 12 – Equal recognition before the law**

Provision 3 of this Article requires “appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.” HHS administers a series of Federal laws that provide Federal funding to states to create protection and advocacy agencies systems (P & A’s) to empower, protect and advocate on behalf of persons with mental and physical disabilities, and traumatic brain injury. P & A systems are independent of service-providing agencies. Each state and territory, as well as a Native American Consortium, has a P & A to serve individuals with disabilities. These P&As provide information and referral services and exercise legal, administrative and other remedies to resolve problems for individuals and groups of clients. The P&As reach out to members of minority groups that historically have been underserved. Each P&A must provide an annual opportunity for the public to comment on its objectives, priorities, and activities. This gives clients and others in the community an opportunity to voice their concerns and needs to the P&A. In order to safeguard the rights of clients and

prospective clients, each P&A is also required to establish a grievance for individuals who are dissatisfied with the services provided to them by the P&A.

### **Article 13 – Access to justice**

HHS' SAMHSA has made addressing the needs of people with mental health disabilities involved in criminal justice systems a priority. This multi-faceted approach ([http://www.samhsa.gov/Matrix/matrix\\_criminal.aspx](http://www.samhsa.gov/Matrix/matrix_criminal.aspx)) supports many programs such as mental health and addictions drug courts, jail diversion programs, and police training.

### **Article 16 – Freedom from exploitation, violence and abuse**

HHS is responsible for implementing various Federal laws that provide Federal funding to states to protect persons with disabilities from exploitation, violence, and abuse, as required by this article. For example:

HHS funds a comprehensive network of Protection and Advocacy (P & A) programs in each state that are authorized to investigate incidents of abuse and neglect of persons with disabilities and follow up reports of incidents or investigate if there is probably cause to believe that such incidents have occurred.

The Administration on Aging administers a number of Vulnerable Elder Rights Programs that provide important protections against threats to the independence, well being, and financial security of seniors, including those with disabilities.

SAMHSA has initiated efforts to reduce and ultimately eliminate seclusion and restraint procedures in behavioral healthcare settings (<http://ars.samhsa.gov/index.asp>). These activities have included staff training, evaluation of effective reduction practices, planning and implementation grants, and policy development. The Children's Health Act of 2000 (P.L. 106-310) provides legislative requirements regarding seclusion and restraint for all Federally-funded healthcare settings (Part H) and certain non-medical residential programs for children with mental health needs (Part I). One identified potential gap is that HHS has not yet issued mandatory regulations regarding the latter requirement.

SAMHSA has also supported Trauma-Informed Services to assist persons with mental health disabilities who have experienced violence, abuse and other trauma (<http://mentalhealth.samhsa.gov/nctic/>).

### **Article 19 – Living independently and being included in the community**

A number of HHS programs designed specifically around the needs of individuals with disabilities focus on assisting individuals with disabilities to live as independently as possible and to be included in the community. For example:

**The Developmental Disabilities Assistance and Bill of Rights Act** is administered by the Administration on Developmental Disabilities in the HHS Administration for Children and Youth (ACYF). The purpose of this law is to assure that individuals with developmental disabilities and their families participate in the design of and have access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of community life, through culturally competent programs sponsored or conducted through State Councils on Developmental Disabilities in each State; Protection and Advocacy systems in each State to protect the legal and human rights of individuals with developmental disabilities; University Centers for Excellence in Developmental Disabilities Education, Research, and Service; national initiatives to collect necessary data on issues that are directly or indirectly relevant to the lives of individuals with developmental disabilities; and technical assistance.

The law states that it is the policy of the United States that all programs, projects, and activities receiving assistance under this law be carried out in a manner consistent with the principles that individuals with developmental disabilities, including those with the most severe developmental disabilities, and their families --

- *are capable of self-determination, independence, productivity, and integration and inclusion in all facets of community life*, but often require the provision of community services, individualized supports, and other forms of assistance;
- *have competencies, capabilities, and personal goals that should be recognized, supported, and encouraged*, and any assistance to such individuals should be provided in an individualized manner, consistent with the unique strengths, resources, priorities, concerns, abilities, and capabilities of such individuals;
- *are the primary decision makers* regarding the services and supports such individuals and their families receive;
- *have access to opportunities and the necessary support to be included in community life*, have interdependent relationships, live in homes and communities, and make contributions to their families, communities, and States, and the Nation;
- *efforts undertaken to maintain or expand community-based living options for individuals with disabilities should be monitored* in order to determine and report to appropriate individuals and entities the extent of access by individuals with developmental disabilities to those options and the extent of compliance by entities providing those options with quality assurance standards;
- *families of children with developmental disabilities need to have access to and use of safe and appropriate child care and before-school and after-school programs*, in the most integrated settings, in order to enrich the participation of the children in community life;
- *individuals with developmental disabilities need to have access to and use of public transportation*, in order to be independent and directly contribute to and participate in all facets of community life; and

- *need to have access to and use of recreational, leisure, and social opportunities in the most integrated settings, in order to enrich their participation in community life.*

**The Community Mental Health Services Block Grant:** HHS' SAMHSA administers this program to facilitate State efforts to promote the social inclusion and full community participation of persons with mental health disabilities ([www.mhbg.samhsa.gov](http://www.mhbg.samhsa.gov)). This includes a range of supports to facilitate the recovery and resiliency of people with mental health disabilities. Recovery – a holistic, wellness-based approach to enable a person with mental health problems to live a meaningful life in a community of his or her own choice (<http://mentalhealth.samhsa.gov/publications/allpubs/sma05-4129/>) – is a key SAMHSA goal, along with its overall mission of promoting *a life in the community* for all people with mental health disabilities.

**The Medicaid Program:** HHS' Centers for Medicare & Medicaid Services administers the Medicaid program. The Medicaid Program is a joint state and federal program that provides medical and long term care benefits to groups of low-income people, including people with disabilities. Although the Federal government establishes general guidelines for the program, the Medicaid program requirements are actually established by each State. Whether or not a person is eligible for Medicaid will depend on the State where he or she lives and the optional services provided will vary by state. The Medicaid program finances a significant percentage of the resources for home and community based services for people with disabilities in the United States.

**The Omnibus Budget Reconciliation Act of 1981** authorizes the HHS Secretary to grant "home and community-based" waivers in the Medicaid program to enable states to furnish personal assistance and other services to individuals who, without such services, would require institutional care as long as costs under the waiver do not exceed the cost of providing institutional care to the target population. More than 300 of these home and community-based waivers are currently operating in 48 States. As of 2009, more than one-third of these waiver programs offered individuals the opportunity to self direct their services, including hiring staff and making key budget decisions.

**Section 1915(i) of the Social Security Act**, enacted in 2005, now allows states to include home and community-based waivers in their Medicaid State Plans without a waiver, and without requiring that an individual needs institutional placement. Section 1915(j) of the Act was enacted at the same time and allows self-direction in personal assistance and other home and community-based state plan services.

**Money Follows the Person Demonstration Grants:** In 2005, Congress provided an unprecedented \$1.75 billion over a five year period in a grant program known as "Money Follows the Person" to enable individuals who are currently institutionalized or at risk of institutionalization to receive Medicaid funding. These demonstration grants are currently in place in 34 states.



**Community Living Program:** The Administration on Aging (AoA) initiative complements Money Follows the Person by providing flexible, consumer-directed service dollars to assist persons at risk of nursing home placement and spend down to Medicaid to continue to live in their communities. To date, AoA has funded 20 states, reaching a combined federal and non-federal amount of approximately \$20 million.

**HHS and VA Collaboration to support Veterans with Disabilities:** Beginning in 2008, HHS and the U.S. Department of Veterans Affairs (VA) entered into a partnership to help families care for Veterans with disabilities of all ages. HHS and VA this year will make an additional \$10 million available to bring this initiative to 20 states. This partnership will implement the Veteran Directed Home & Community Based Service program through HHS' aging and human services network, in coordination with the AoA's Community Living Program (CLP). Both programs allow participants to direct their own care, including having control over the types of services they receive and the manner in which they are provided. This includes the option of hiring their neighbors, friends and even some family members, to provide needed services.

**Demonstration Grants to Expand Access to Home and Community-based Services for Children with Significant Mental Health Needs:** In 2005, Congress appropriated \$217 million dollars for a 5 year initiative to expand access to home and community-based services for children with significant mental health needs to prevent hospitalization. HHS' CMS has awarded demonstration grants to 10 states to provide HCBS to youth with serious emotional disturbance or mental illness as an alternative to placement in a psychiatric residential treatment facility.

**Medicaid Early & Periodic Screening, Diagnostic, and Treatment (EPSDT) Service:** HHS' Centers for Medicare & Medicaid Services (CMS) administers the Medicaid program which includes EPSDT. The EPSDT service is a comprehensive and preventive child health program for individuals under the age of 21. EPSDT includes periodic screening, vision, dental, and hearing services. In addition, the law requires that any medically necessary health care service in the Medicaid program be provided to an EPSDT recipient even if the service is not available under the State's Medicaid plan to the rest of the Medicaid population. This program enables Medicaid agencies to manage a comprehensive child health program of prevention and treatment, to seek out eligibles and inform them of the benefits of prevention, and to provide services that allow eligible children with disabilities to remain in their homes and communities.

**Medicaid State Options to Serve Children with Disabilities:** The Deficit Reduction Act of 2005 includes legislation to allow states the option to permit parents of children with disabilities to "buy-in" to the Medicaid program for their children if they have family income below 300 percent of the federal poverty level. The Tax Equity Fiscal Responsibility Act allowed states the option of expanding Medical Assistance eligibility to certain disabled children who live at home with their families and would be eligible for Medicaid if they lived in an institution.

**Aging and Disability Resource Centers:** HHS' Centers for Medicare & Medicaid Services, in partnership with the Administration on Aging (AoA) fund state grants to develop Aging and Disability Resource Centers (ADRCs). ADRCs assist consumers with making informed decisions about their long-term care service and support options and serve as the entry point to the long-term service and support system. Aging and Disability Resource Centers serve the elderly and at least one other target population of individuals with disabilities.

**Older Americans Act:** HHS' AoA's statutory mandate under the Older Americans Act is focused on helping older people remain independent in their homes and communities through the provision of supportive services such as meals-on-wheels, in-home support services, transportation services and ombudsmen services. With the passage of the Older Americans Act Amendments of 2000, Congress established the National Family Caregiver Support Program to assist families caring for older persons who are ill or who have disabilities.

**Interagency Collaboration on Community Living for Persons with Mental Health Disorders:** HHS' SAMHSA chairs an inter-agency collaboration in which more than 15 Federal agencies actively participate to transform the nation's mental health system to realize the vision of a "life in the community for everyone."

**State Coalitions to Promote Community-Based Care: Olmstead Initiative:**

In order to assist states in their efforts to respond effectively to the needs of adults with serious mental illnesses and children with serious emotional disturbance, SAMHSA has created an initiative to support local coalitions by providing financial assistance, technical assistance and training to promote community-based care. The overarching goal of the initiative is to assist each state and Territory to develop or expand existing community integration plans that address the service needs of adults with serious mental illnesses and children with serious emotional disturbance who could be served more appropriately in their communities.

Maternal and Child Health State Title V programs are also charged to implement community based services for children and youth with special health care needs and their families. These systems of services are based upon six performance outcomes, where key stakeholders, state level strategies, and community-level strategies are intertwined to achieve these outcomes. These six core components of the system are:

1. Family/professional partnership at all levels of decision-making.
2. Access to comprehensive health and related services through the medical home.
3. Early and continuous screening, evaluation and diagnosis.
4. Adequate public and/or private financing of needed services.
5. Organization of community services so that families can use them easily.
6. Successful transition to all aspects of adult health care, work, and independence.

State Title V programs work in partnership with other HRSA funded grantees and by National Centers.

**Olmstead Enforcement Activities:** In addition to HHS programs that support living independently and being included in the community, HHS' OCR has been working for

the past decade to promote state compliance with the *Olmstead* decision. Shortly after the decision, OCR worked closely with states as they developed *Olmstead* plans. In addition, OCR has investigated over 500 complaints alleging *Olmstead* violations. In every case it investigated, OCR secured corrective action where there was a problem - more than 330 cases, which are highlighted at

<http://www.hhs.gov/ocr/civilrights/resources/specialtopics/community/index.html>

These cases involve both systemic and individual complaints covering a wide range of individuals, including individuals with physical, psychiatric, developmental and cognitive impairments, and individuals of all ages, including children, young and middle-aged adults, and elderly persons. As a result of OCR's efforts, many individuals have been able to move from an institution to the community, and many individuals have avoided unnecessary institutionalization. For example:

- Community services are being provided to individuals who had been institutionalized for decades.
- Community services are being provided or restored to individuals who lost their housing and/or community-based supportive services when they entered institutions due to an acute health care problem.
- Community services are being provided to individuals with disabilities through "waiver" programs.
- Increased hours of personal care and assistance are being provided to individuals who need them to stay in the community.
- Individuals with disabilities are having greater control over their community-based care and services.
- Individuals are provided reasonable accommodations where they reside, rather than having to move to a more restrictive setting.
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## **Article 22 – Respect for privacy**

HHS' OCR is responsible for protecting the privacy of individuals' personal health information under the Privacy Regulation issued pursuant to the Health Insurance Portability and Accountability Act (HIPAA). The Privacy Regulation establishes a foundation of Federal protections and individual rights for the privacy of personal health

information. The Privacy Regulation's standards apply to individually identifiable health information held by the three types of covered entities listed in HIPAA: health plans, health care clearinghouses, and health care providers who conduct certain health care transactions electronically. The Regulation does not replace Federal, State, or other law that grants individuals even greater privacy protections, and covered entities are free to retain or adopt more protective policies or practices.

In the five years since the HIPAA Privacy Regulation has been in effect, OCR has investigated and resolved over 7,230 cases by requiring changes in privacy practices and other corrective actions by health care providers and health insurers. Corrective actions obtained by HHS' OCR from these entities have resulted in change that is systemic and that affects all the individuals they serve. OCR also promotes and protects privacy interests of individuals with disabilities through its comprehensive, national education initiatives about health information privacy rights and responsibilities to both health care providers and consumers: <http://www.hhs.gov/ocr/privacy/index.html> OCR has reached hundreds of thousands of covered entities and consumers through educational conferences, a toll-free call line, and an interactive website with answers to Frequently Asked Questions. HHS has had over 5.5 million visits to its Privacy Web pages and over 4.3 million visits to the frequently asked questions on the Privacy Web pages. OCR regularly distributes announcements and educational information to over 18,000 subscribers to the Privacy list serve.

### **Article 23 – Respect for home and the family**

In support of Provision 3, which requires efforts to “provide early and comprehensive information, services and support to children with disabilities and their families” to “ensure that children with disabilities have equal rights with respect to family life,” HHS' ACF has developed One Stop Family Support 360 Projects. These projects assist a family to stay together as a family in the community. The families helped have a family member with a developmental disability. Through a one-stop a family participates in the development of its individual family plan. The plan is to include the services and supports (e.g., health and/or mental health care, housing, counseling and/or marriage education, parenting skills development, child care, employment, transportation, respite care, personal assistance care, financial assistance and/or management) the family needs that may be provided by multiple funding sources and organizations.

HHS' HRSA has a Division of Services for Children with Special Healthcare Needs within the Maternal and Child Health Bureau whose mission is to promote access to a coordinated, family-centered, culturally competent community-based system of services for children and youth with special health care needs and their families. This mission focuses on six system outcomes:

1. family/professional partnership at all levels,
2. access to coordinated ongoing comprehensive care within a medical home,
3. access to adequate private and/or public insurance to pay for needed services,
4. early and continuous screening for special health needs,
5. organization of community services for easy use, and

## 6. youth transition to adult health care, work, and independence

HRSA implements these outcomes through state grants to develop a comprehensive state wide system of services for children and youth with special healthcare needs. The majority of states currently operate these systems with HRSA support.

HRSA also funds Family-to-Family Health Information Centers support grants to family-staffed organizations to ensure families with children who have special health care needs have access to adequate information about health care, community resources and supports in order to make informed decisions around their children's health care. The currently funded 51 centers are collecting data on the issues facing families regarding services and financing of those services while working with Medicaid, Education, Title V and other agencies to inform them of families needs. Information about health care financing (private and Medicaid), community resources (educational and others), family participation and medical home are the most frequently reported type of assistance requested.

### **Article 25 - Health**

HHS provides national leadership and funds and administers a number of programs, which provide national health care standards and goals, research, technical assistance, and funding that support this Article's premise that "persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability."

#### **National Health Care Standards and Goals:**

The HHS Surgeon General has issued a number of National Calls for Action that provide a roadmap to health care providers and consumers to improve the health and well being of individuals with disabilities, including the "Surgeon General's Call for Action on the Health and Wellness of Persons with Disabilities." The HHS Healthy People 2010, establishes national goals to improve America's health, including specific targets for people with disabilities. Current objectives of Healthy People 2010 include promoting the health of people with disabilities, preventing secondary conditions, and eliminating disparities between people with and without disabilities in the U.S. population. Some specific goals include:

- Increasing the proportion of people with disabilities who report having access to health, wellness, and treatment programs and facilities.
- Reducing the proportion of people with disabilities who report not having the assistive devices and technology they need.
- Reducing the proportion of people with disabilities who report encountering environmental barriers to participating in home, school, work, or community activities.
- Increasing the number of states and tribes that have public health surveillance and health promotion programs for people with disabilities and their

caregivers. Promoting the health of babies, children and adults, and enhancing the potential for full, productive living.

### **Research to Improve the Health of Persons with Disabilities:**

The HHS National Institutes of Health support and conduct research that lays the groundwork for understanding causes of disability and for developing innovative new treatments or assistance for people with disabilities. For example, in the past 10 years NIH-sponsored research has discovered genes related to blindness caused by glaucoma and macular degeneration and has demonstrated the first effective treatment to significantly reduce the disability of patients shortly after a spinal cord injury. In addition, the National Institute on Deafness and Other Communication Disorders is collaborating with the Department of Veterans Affairs and with NASA to support the development of better hearing aids. NIH also funds research related to the growing burden of morbidity and mortality in the developing world due to trauma and injury that may result in disabilities. Moreover, NIH also conducts a research program in low and middle income countries on stigma related to persons with disabilities.

- The Agency for Healthcare Research and Quality (AHRQ) conducts research to help policymakers plan for meeting the health needs of people with disabilities by examining their access to and use of health services, including Medicaid and managed care. AHRQ has used this information to host workshops to educate state health officials and to conduct outreach to people with disabilities to provide them with the information they need to make their own health care coverage decisions.
- The Office of Disability, Aging and Long-Term Care Policy supports and conducts research and analysis of HHS policies and programs that support the independence, health and long-term care of people with disabilities. Over the past 10 years, the office has been responsible for policy coordination and research related to nursing home and community-based services, informal caregiving, the integration of acute and long-term care, Medicare post-acute services and home care, managed care for people with disabilities, long-term rehabilitation services, childhood disability and the link between employment and health policies.

### **Technical Assistance and Grant Programs:**

HHS' Administration on Developmental Disabilities funds a national network of University Centers for Excellence in Developmental Disabilities known as UCEDDs. There is at least one UCEDD in every state and territory in the nation, and all are members of the Association of University Centers on Disabilities (AUCD). AUCD members work to integrate research, training, and information dissemination to achieve positive changes in the lives of persons with developmental disabilities, their families, and their communities.

HHS's Substance Abuse and Mental Health Services Administration (SAMHSA) promotes the delivery of a comprehensive, integrated, public health approach to accessing early intervention and treatment, services and supports for persons with

substance use and mental health disorders, as well as those who are at risk of developing these disorders. Through the various grant programs in SAMHSA, and its training and interface with local behavioral health and primary care partners and physicians, the agency seeks to provide mental health and substance abuse care to communities and encourage the integration of medical and primary services.

In response to research findings documenting excessive rates of early mortality and comorbid chronic primary health conditions for people with mental health disabilities, SAMHSA supports a Wellness Campaign <http://www.bu.edu/cpr/resources/wellness-summit/index.html> to foster improved health and well being for this population. In addition, SAMHSA has initiated Project Launch (<http://projectlaunch.promoteprevent.org>) to promote the wellness of young children ages birth to 8 years of age by addressing the physical, emotional, social, and behavioral aspects of their development. SAMHSA has also initiated efforts to foster Recovery-based Practices by the training of health providers on approaches that include the active participation of people with mental health disabilities. ([http://download.ncadi.samhsa.gov/ken/msword/SDM\\_fact\\_sheet\\_7-23-2008.doc](http://download.ncadi.samhsa.gov/ken/msword/SDM_fact_sheet_7-23-2008.doc)).

While the Paul Wellstone and Pete Domenici Mental Health Parity and Addiction Equity Act of 2008 helped to correct a significant gap regarding discriminatory practices against persons with disabilities in the provision of health insurance, there is still a significant gap with large number of Americans who still do not have access to a range of effective primary health and mental healthcare services.

### **Programs that Finance Health and Long Term Care Services:**

HHS' Centers for Medicare & Medicaid Services administers the Medicare, Medicaid, and CHIP programs. These programs provide health and some long term care benefits to individuals who qualify.

**The Medicaid program** is discussed above.

**The Medicare Program:** Medicare is a health insurance program for people age 65 or older; people under age 65 with certain disabilities; and people of all ages with End-Stage Renal Disease. Medicare Part A (Hospital Insurance) helps cover inpatient care in hospitals, including critical access hospitals, and skilled nursing facilities (not custodial or long-term care). It also helps cover hospice care and some home health care. Beneficiaries must meet certain conditions to get these benefits. Medicare Part B (Medical Insurance) helps cover doctors' services and outpatient care. It also covers some other medical services that Part A doesn't cover, such as some of the services of physical and occupational therapists, and some home health care. Medicare Part D provides prescription drug coverage.

**Children's Health Insurance Program (CHIP):** CMS also administers the CHIP program. The Children's Health Insurance Program Reauthorization Act renewed and expanded coverage of the Children's Health Insurance Program (CHIP) from 7 million

children to 11 million children. Originally created in 1997, CHIP is Title XXI of the Social Security Act and is a state and federal partnership that targets uninsured children, including those with disabilities, and pregnant women in families with incomes too high to qualify for most state Medicaid programs, but often too low to afford private coverage.

Within Federal guidelines, each State determines the design of its individual CHIP program, including eligibility parameters, benefit packages, payment levels for coverage, and administrative procedures.

### **Federally Qualified Health Centers**

HHS' HRSA funds Health Centers, which are community-based and patient-directed organizations that serve populations lacking access to high quality, comprehensive, and cost-effective primary health care. These include low income populations, the uninsured, those with limited English proficiency, migrant and seasonal farmworkers, individuals and families experiencing homelessness, and those living in public housing. For over 40 years, Health Centers have provided a "health care home" through the delivery of comprehensive, culturally competent, quality primary health care that often includes access to pharmacy, mental health, substance abuse, and oral health services regardless of a patient's ability to pay. These Health Centers have a commitment to high quality primary and preventive care. Having a regular source of primary health care has been shown to reduce hospitalization and emergency room use, and prevent more expensive chronic disease and disability among traditionally medically underserved populations. Research indicates that Health Center uninsured patients are far more likely to have a usual and regular source of care than uninsured patients who obtain care elsewhere. In CY 2008, more than 1.7 million people were served at more than 7,500 service delivery sites.

### **Article 26 – Habilitation and rehabilitation**

In support of Provision 1 of Article 26 to take "effective and appropriate measures, including through peer support, to enable persons to attain and maintain maximum independence... and full inclusion and participation in all aspects of life," HHS' SAMHSA promotes peer support to enable people with mental health disabilities to be independent. This includes funding national technical assistance centers on peer-operated approaches (<http://mentalhealth.samhsa.gov/csp/consumers/tacs.asp>), human resources development including educational and training materials development (<http://mentalhealth.samhsa.gov/publications/selfhelp.asp>) and the development of practice guidelines ([http://mentalhealth.samhsa.gov/cmhs/CommunitySupport/evidence\\_based/kits.asp](http://mentalhealth.samhsa.gov/cmhs/CommunitySupport/evidence_based/kits.asp)). In partnership with the Department of Education, SAMHSA supports several Research and Rehabilitation Training Centers on psychiatric disability issues (<http://mentalhealth.samhsa.gov/cmhs/CommunitySupport/rehab.asp>).

### **Article 27 – Work and employment**



HHS administers several major Federal programs that support persons with disabilities to acquire the skills to work and to ensure non-discrimination on the basis of disability in employment opportunities.

HHS' ACF administers the Temporary Assistance for Needy Families (TANF) program to help needy families, including those with disabilities, achieve economic self-sufficiency. HHS' OCR ensures that the TANF program complies with applicable Federal civil rights laws, including those prohibiting discrimination on the basis of disability. To this end, OCR has issued a series of policy guidance, in collaboration with ACF, that provides technical assistance to state TANF agencies to ensure equal access by beneficiaries with disabilities. The series includes a video presentation on OCR Guidance on TANF and Disability and training on screening TANF customers for hidden disabilities to ensure equal opportunity.

HHS helps people with disabilities become self-supporting without losing health coverage through Medicaid. As part of the Ticket to Work and Work Incentives Improvement Act of 1999 by, HHS' Centers for Medicare and Medicaid Services (CMS) works with state Medicaid directors to enable people with disabilities who earn too much money to qualify for Medicaid to buy into the program, or to enable states to extend the income limits of Medicaid programs for people with disabilities.

HHS' HRSA's Maternal and Child Health Bureau funds the "Healthy and Ready to Work" program, designed to help children with special health care needs to successfully make the transition to adult life in the community. Some 6,000 youths with special health needs benefit from \$2.5 million in program grants to help provide training and support in promoting self-determination and leadership skills.

HHS' SAMHSA focuses on improving the employment prospects of those living with psychiatric disabilities, including funding a comprehensive study, Employment Intervention Demonstration Program., to help individuals with mental illness find and keep jobs. In addition, SAMHSA's Campaign for Mental Health Recovery and the ADS Center have efforts to educate employers regarding the employment of people with mental health disabilities  
(<http://www.promoteacceptance.samhsa.gov/topic/employment/>).

#### **Article 28 – Adequate standard of living and social protection**

HHS' SAMHSA supports several efforts to assist people with mental health disabilities who experience homelessness (<http://mentalhealth.samhsa.gov/cmhs/Homelessness/>). This includes providing specialized services via the PATH program, demonstrating effective practices to provide supported housing, and technical assistance to better meet the needs of this population.

#### **Article 29 – Participation in political and public life**

HHS' SAMHSA supports the development of State organizations of people with mental health disabilities to foster their opportunities to effectively and fully participate in political and public life  
(<http://mentalhealth.samhsa.gov/cmhs/CommunitySupport/consumers/grant.asp#grant>).

### **Article 31 - Statistics and data collection**

Several agencies within HHS engage in regular data collection and dissemination that support the mandates within this Article to collect appropriate information, including statistical and research data, in accordance with legally established safeguards to ensure confidentiality, to formulate and implement policies to give effect to the Convention.

Through routine data collections (National Health Interview Survey-NHIS; National Health and Nutrition Examination Survey-NHANES) the HHS National Center for Health Statistics (NCHS) produces timely and relevant analyses of disability and functioning in the US population. Analyses are presented by major demographic background variables (e.g. age, sex, social-economic status, and race/ ethnicity) allowing for an assessment of disparities in terms of employment, education, the performance of specific tasks and participation in social activities according to disability status and these major demographic confounders. NCHS has recently produced a report: Disability and Health in the United States, 2001-2005 (2008); and annually produces a Chartbook on Trends in the Health of Americans (Health US) that includes data on, inter alia, disability and functional status. An area of current and pressing interest is the measurement of child disability. Efforts are ongoing to define and develop better measures that will capture the level of difficulty in functioning among school age children in the US and the impact that may have on children's level of participation in school, sports and play activities. NCHS continues to work to improve the collection of and presentation of disability data and statistics to address health disparities in the US population.

SAMHSA has an array of efforts to collect statistics and data via its Office of Applied Studies and other activities. This includes the National Survey on Drug Use and Health ([www.oas.samhsa.gov/nsduh.htm](http://www.oas.samhsa.gov/nsduh.htm)), partnership with the CDC on the Behavioral Risk Factor Surveillance System (BRFSS), and collaborations with States on a range of data collection efforts.

### **Article 32 - International cooperation**

HHS agencies are active in international cooperation that support the purpose and objectives of the Convention. For example:

The National Center for Health Statistics (NCHS) acts as the Secretariat for the Washington Group on Disability Statistics. The Washington Group on Disability Statistics is a "city group" established by and operating under the aegis of the United Nations Statistical Commission. Acknowledging the scarcity and general poor quality of data on disability, especially in developing countries, the Washington Group was established in June 2001 to meet the need for comparable population-based measures of

disability for individual country use and cross-nationally. It is a cooperative effort among national statistical offices of developed and developing countries, international statistical organizations, and international organizations representing persons with disabilities.

The primary objective of the Washington Group is to promote and coordinate international cooperation in the area of disability statistics, focusing on measures that will provide basic, more comparable information on disability throughout the world. To this end, a short set of questions on disability for use in censuses has been developed and adopted by the Washington Group. The selected purpose in developing these questions was to assess the equalization of opportunity for the population with disabilities. As part of the process of question development, special attention was directed to international comparability of the resulting data which was facilitated by cognitive and field tests conducted in 17 countries. The results of the tests demonstrated that the questions were being interpreted as intended in countries in Africa, South America, North America, and Asia. This short set of questions was developed according to the Fundamental Principles of Official Statistics and is consistent with the International Classification of Functioning, Disability and Health.

The approach to data collection developed by the Washington Group has also been incorporated into the UN Principles and Recommendations for the 2010 Census. The questions cover six core functional domains or basic actions: seeing, hearing, walking, cognition, self care, and communication. <sup>1</sup>

The Convention acknowledges that disability represents a complex process and is not a single, static state. The WG chose to develop questions to address the issue of whether persons with disability participate to the same extent as persons without disabilities in activities such as education, employment or family/civic life, in other words, the equalization of opportunities; which, as mentioned above, is one of the general principles listed in Article 3 of the Convention and the focus of Article 5 (Equality and Non-

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<sup>1</sup> The short question set reads as follows:

The next questions ask about difficulties you may have doing certain activities because of a HEALTH PROBLEM.

1. Do you have difficulty seeing, even if wearing glasses?<sup>1</sup>
2. Do you have difficulty hearing, even if using a hearing aid?<sup>3</sup>
3. Do you have difficulty walking or climbing steps?
4. Do you have difficulty remembering or concentrating?
5. Do you have difficulty (with self-care such as) washing all over or dressing?
6. Using your usual (customary) language, do you have difficulty communicating, (for example understanding or being understood by others)?

Each question has four response categories: (1) No, no difficulty, (2) Yes, some difficulty, (3) Yes, a lot of difficulty and (4) Can not do it at all. The severity scale is used in the response categories in order to capture the full spectrum of difficulty in functioning from mild to severe.

discrimination). It is also particularly relevant to the collection of data for policy purposes outlined in Article 31 (Statistics and data collection) and will facilitate the monitoring of participation in cultural life, leisure, and recreation (Article 30), and work & employment (Article 30).

In order to address the equalization of opportunities for persons with disabilities it is necessary to identify persons who are at greater risk than the general population of experiencing limited participation in society. The recommended short set of questions will identify the majority of the population with difficulties in functioning in basic actions; difficulties that have the potential to limit independent living or social integration if appropriate accommodation is not made.

This indicator, coupled with other information collected through the Census or survey on complex activities, for example, employment, education, or family & social life, can then be used to compare the levels of participation in these complex activities between those with disability (as measured by difficulty in performing basic actions) and those without – and thereby assess equitable access to opportunities as mandated by the Convention. For example, data on difficulty in performing basic actions can be cross-classified with a measure of employment to identify the proportion of persons with and without disability who are employed. This is an assessment of the equality of employment opportunities. If policy interventions are initiated to enhance workplace accommodations, the effect on employment of persons with disability can be determined. In addition to employment, it will be important to collect data on a variety of forms of participation, such as education, housing, transportation, social and health services, in addition to aspects of family, cultural and social life. From a theoretical perspective, if opportunities have been optimized then participation should be equal between persons with and without disability.

Development of an extended set of disability questions for use in surveys is also under way. Cognitive testing has been carried out, with the support of UNESCAP, in 7 countries of the south-east Asian region: Cambodia, Kazakhstan, Maldives, Mongolia, Sri Lanka, Fiji and Philippines. A field test of these questions will follow in these countries over the next 6-12 months. The results of the testing will be presented and discussed at the ninth annual meeting of the Washington Group, scheduled for October 2009 in Dar es Salaam, Tanzania. All papers and products of the Washington Group are available at [www.cdc.gov/nchs/citygroup.htm](http://www.cdc.gov/nchs/citygroup.htm).

HHS also has been supportive of the WHO Alliance for the Global Elimination of Blinding Trachoma and VISION 2020: the Right to Sight. In FY 2008, The National Eye Institute of the National Institutes of Health contributed \$392,695 to the WHO Program for the Prevention of Blindness and in 2009, it will contribute \$403,037.

Moreover, since 1992, HHS has held international conferences to discuss health care of children with special needs. Countries share ideas on how to develop broad national policies as well as specific, practical local programs. In December 2006, the HHS' Office on Disability hosted the 9<sup>th</sup> *International Congress on Community Services for Children, Youth and Families with Special Health Care Needs*.

Finally, the HHS Administration on Developmental Disabilities funds a network of 64 Centers for Excellence in Developmental Disabilities Research, Education and Service to conduct research and provide training and technical assistance. Many collaborate internationally. See, [www.aucd.org](http://www.aucd.org).

**ACRONYMS USED:**

ACF:	HHS Administration for Children and Families
ADRC:	Aging and Disability Resource Centers
AHRQ:	HHS Agency for Healthcare Research and Quality
AoA:	HHS Administration on Aging
AUCD:	Association of University Centers on Disabilities
CDC:	HHS Centers for Disease Control and Prevention
CHIP:	Children's Health Insurance Program
Convention:	U.N. Convention on the Rights of Persons with Disabilities
CSHCN:	State Children with Special Health Care Needs agencies
CMS:	HHS Centers for Medicare and Medicaid Services
EPDST:	Early & Periodic Screening, Diagnostic, and Treatment
FMS:	Federal Medical Stations
HHS:	U.S. Department of Health and Human Services
HIPAA:	Health Insurance Portability and Accountability Act
HRSA:	HHS Health Resources and Services Administration
IDEA:	Individuals with Disabilities Education Act
IHS:	HHS Indian Health Services
NCHS:	HHS National Center for Health Statistics
NIH:	HHS National Institutes for Health
OCR:	HHS Office for Civil Rights
P & A:	Protection and Advocacy Systems
PAPHA:	Pandemic and All Hazards Preparedness Act

SAMHSA: HHS Substance Abuse and Mental Health Services Administration  
TANF: Temporary Assistance for Needy Families  
UCEDD: University Centers for Excellence in Developmental Disabilities  
VA: U.S. Department of Veterans Affairs